Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland
Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland

Dr Kathy Murphy, Prof. Eamon O’Shea, Ms Adeline Cooney, Prof. Agnes Shiel and Dr Margaret Hodgins

National Council on Ageing and Older People

Report No. 93
As Chairperson of the National Council on Ageing and Older People, it gives me great pleasure to introduce this report, *Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland*. The quality of life of older people in all care settings is a primary concern of the Council and it believes that this study, which seeks to explore the objective and subjective dimensions of quality of life of older people living in long-stay care, is of critical importance in this regard.

The study identifies, for the first time, the factors that contribute to quality of life in public, private and voluntary long-stay facilities in Ireland while also providing up-to-date information regarding the demographics of long-stay care services in Ireland.

The Council acknowledges the focus in health policy documents on quality of care as a desired outcome of long-stay care service delivery, however it also believes that long-stay care services should enable residents to achieve their fullest possible potential. Therefore, the Council advocates that any measures designed to promote the quality of long-stay care services must place a central focus on promoting the quality of life of residents. This report is timely in this regard and the Council believes that the challenge now is for policy-makers and service providers to respond to the stated needs of residents.

Furthermore, the research demonstrates the critical importance of the quality of the interaction between staff and resident in enhancing quality of life outcomes. The Council is aware that current training programmes for long-stay care staff tend to be task-oriented with little emphasis on the non-clinical aspects of long-stay care. In this regard, the Council strongly advocates that education and training dedicated to enhancing quality of life be developed and proposes that it will endeavour to support such education and training in partnership with other agencies.
On behalf of the Council, I would like to thank the residents and staff who were interviewed for this study, as well as all the staff who kindly completed and returned postal questionnaires to the research team.

I would like to thank sincerely the excellent research team and authors: Dr Kathy Murphy, Prof. Eamon O’Shea, Adeline Cooney, Prof. Agnes Shiel and Dr Margaret Hodgins.

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Cllr Éibhlin Byrne
Chairperson
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Chapter Seven: Description of Study Sites and Resident and Staff Demographics

7.1 Geriatric Homes/Hospitals
   7.1.1 Physical Environment
   7.1.2 Staffing
   7.1.3 Life in the Facility
   7.1.4 Resident Profile/Dependency

7.2 Private Nursing Homes
   7.2.1 Physical Environment
   7.2.2 Staffing
   7.2.3 Life in the Facility
   7.2.4 Resident Profile/Dependency

7.3 Welfare Home
   7.3.1 Physical Environment
   7.3.2 Staffing
   7.3.3 Life in the Facility
   7.3.4 Resident Profile/Dependency

7.4 Voluntary Home/Hospital
   7.4.1 Physical Environment
   7.4.2 Staffing
   7.4.3 Life in the Facility
   7.4.4 Resident Profile/Dependency

7.5 Community/District Hospitals
   7.5.1 Physical Environment
   7.5.2 Staffing
   7.5.3 Life in the Facility
   7.5.4 Resident Profile/Dependency

7.6 Resident Demographics
7.7 Staff Demographics

Chapter Eight: Care Environment and Ethos of Care

8.1 Introduction

8.2 Promoting Autonomy
   8.2.1 Involvement in Decision-Making
   8.2.2 Exercising Choice

8.3 Promoting and Maintaining Independence
### Chapter Nine: Personal Identity

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.1 Introduction</td>
<td>168</td>
</tr>
<tr>
<td>9.2 Self-Expression</td>
<td>168</td>
</tr>
<tr>
<td>9.3 Personal Appearance and Grooming</td>
<td>172</td>
</tr>
<tr>
<td>9.4 Individuality</td>
<td>174</td>
</tr>
<tr>
<td>9.5 Privacy</td>
<td>177</td>
</tr>
<tr>
<td>9.6 Self-Respect</td>
<td>179</td>
</tr>
<tr>
<td>9.7 Conclusions</td>
<td>181</td>
</tr>
</tbody>
</table>

### Chapter Ten: Connectedness, Social Relationships and Networks

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.1 Introduction</td>
<td>184</td>
</tr>
<tr>
<td>10.2 Connectedness, Involvement and Interest</td>
<td>185</td>
</tr>
<tr>
<td>10.3 Resident/Staff Relationships</td>
<td>187</td>
</tr>
<tr>
<td>10.4 Resident/Resident Relationships</td>
<td>190</td>
</tr>
<tr>
<td>10.5 Family and Community Connections</td>
<td>194</td>
</tr>
<tr>
<td>10.6 Conclusions</td>
<td>198</td>
</tr>
</tbody>
</table>

### Chapter Eleven: Activities and Therapies

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.1 Introduction</td>
<td>200</td>
</tr>
<tr>
<td>11.2 Purposeful Activity</td>
<td>200</td>
</tr>
<tr>
<td>11.3 Therapeutic Activity</td>
<td>203</td>
</tr>
<tr>
<td>11.4 Outdoor Activities</td>
<td>205</td>
</tr>
<tr>
<td>11.5 Making Activities Work</td>
<td>207</td>
</tr>
<tr>
<td>11.6 Conclusions</td>
<td>209</td>
</tr>
</tbody>
</table>

### Chapter Twelve: Conclusions and Recommendations

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.1 Introduction</td>
<td>212</td>
</tr>
<tr>
<td>12.2 Methodology and Model</td>
<td>213</td>
</tr>
<tr>
<td>12.3 Key Findings</td>
<td>216</td>
</tr>
<tr>
<td>12.4 Staffing Levels and Skill Mix</td>
<td>216</td>
</tr>
<tr>
<td>12.5 Physical Environment and Ethos of Care</td>
<td>218</td>
</tr>
<tr>
<td>12.6 Activities and Therapies</td>
<td>222</td>
</tr>
<tr>
<td>12.7 Policy and Practice Issues</td>
<td>224</td>
</tr>
</tbody>
</table>

### References

231

### Appendices

243

### Terms of Reference

273
List of Tables

Table 4.1: Distribution of focus group participants 82
Table 4.2: Distribution of questionnaires to pilot sites 85
Table 4.3: Questionnaires returned by category of facility 86
Table 4.4: Study sites 89
Table 6.1: Type of facility 113
Table 6.2: Total number of beds (including long-stay, respite, convalescent, etc.) by facility type 113
Table 6.3: Ratio of registered nurses (RNs) to non-nursing care staff and (all) residents by facility type and size 120
Table 6.4: Ratio of non-nursing care staff to (all) residents by facility type and size 121
Table 6.5: Ratio of RNs on the morning shift to (all) residents by facility type and size 122
Table 6.6: Ratio of RNs on the evening shift to (all) residents by facility type and size 123
Table 6.7: Ratio of RNs on the night shift to (all) residents by facility type and size 123
Table 6.8: RN overtime hours in the previous week by facility type and size 124
Table 6.9: Staff turnover of nursing and non-nursing staff in the previous six months by facility type 125
Table 6.10: Therapeutic and other services available free of charge by facility type 127
Table 6.11: Availability of organised activities by facility type 128
Table 6.12: Availability of communal facilities by facility type 129
Table 6.13: Number of facilities in which residents participate in various household tasks 131
Table 6.14: Choice of time to get up and go to bed for residents by facility type 132
Table 6.15: Provision of various facilities and space by facility type 135
Table 6.16: Ratio of WCs/special baths to (all) residents by facility type 136
Table 6.17: Call bell facilities by location and by type of facility 137
Table 7.1: Number of resident respondents in each facility type 148
Table 7.2: Age profile of resident respondents 148
Table 7.3: Length of stay 148
Table 7.4: Number of staff respondents in each facility type 149
Table 7.5: Age profile of staff respondents 149
Table 7.6: Number of years working with older people 150
Table 8.1: Involvement of residents in decision-making 155
Table 8.2: Maintaining independence 157
Table 8.3: Staffing resources and physical environment 160
Table 8.4: Individualised care and routine care 164
Table 9.1: Identity and personalised environment 169
Table 9.2: A life in pictures 170
Table 9.3: Opportunity to observe their faith 172
Table 9.4: Clothes and washing and grooming 173
Table 9.5: Freedom and constraints 175
Table 9.6: Perspectives on privacy 178
Table 9.7: Self-respect through involvement and recognition 179
Table 10.1: Connectedness 186
Table 10.2: Resident/staff relationships 188
Table 10.3: Relationships among residents 193
Table 10.4: Family and community connections 196
Table 11.1: Meaningful activity 202
Table 11.2: Therapeutic activities 204
Table 11.3: Activities outside the facility 206
Table 11.4: Making activities work 208
Table 12.1: Main recommendations for enhancing quality of life in long-stay care settings 228

List of Figures

Figure 6.1: Percentage of male/female long-stay residents by facility type 114
Figure 6.2: Age profile of long-stay residents by facility type 115
Figure 6.3: Percentage of long-stay residents admitted for predominantly social reasons by facility type 115
Figure 6.4: Percentage of long-stay residents within dependency category by facility type 116
Figure 6.5: Long-stay resident dependence in personal care by facility type 117
Figure 6.6: Long-stay residents’ level of confusion by facility type 118
Figure 6.7: Long-stay residents’ level of mobility by facility type 119
Figure 6.8: Percentage of facilities in which residents participate in household tasks 130
Figure 6.9: Process and organisational issues by facility type 133
Figure 6.10: Facility purpose-built as a long-stay residential facility 134
Figure 12.1: Model of factors determining residents’ quality of life in long-term care 215
Council Comments and Recommendations
The quality of life of older people in all care settings is a primary concern of the National Council on Ageing and Older People (NCAOP); a concern echoed by the National Economic and Social Forum (NESF) in its recent report Care for Older People in which it stated that ‘enhancing quality of life of older people in different settings should be a key policy priority’ (NESF, 2005).

In recent years, the Council has been at pains to establish older people’s views and preferences on a range of issues central to their well-being and their quality of life. Given the relative absence of a definitive description of the factors that enhance quality of life in long-stay care in an Irish context (O’Shea et al., 1991), the Council believes that the present study which seeks to explore the objective and subjective dimensions of quality of life of older people living in long-stay care is of critical importance. The study identifies, for the first time, the factors that contribute to good quality of life in public, private and voluntary long-stay facilities in Ireland from the perspectives of residents, their relatives and staff. Furthermore, the research presents up-to-date data regarding the demographics of long-stay care services in Ireland and, as such, is a useful tool for service planning and development.

The Council believes that while ‘quality of care is a key determinant of quality of life’ (NESF, 2005), long-stay care services should also enable residents to achieve their fullest possible physical, mental, emotional and social potential. A core objective of long-stay care service delivery must, therefore, be rehabilitation and the enhancement of quality of life. In this regard, the Council recommends that all future legislation, policy documents and service statements relating to long-stay care services for older people, whether public, private or voluntary, at a local, regional and national level, assert that a core objective of these services is promotion of quality of life and rehabilitation.
Quality of Life Domains

The research highlighted four broad domains of quality of life in long-stay care:

- independence and autonomy of the resident
- a resident’s ability to maintain his/her personal identity and sense of self
- a resident’s ability to maintain connectedness, social relationships and networks within and outside of the care setting
- a resident’s engagement in meaningful activities.

The Council recommends that the development of all future initiatives designed to improve quality of life in long-stay care take account of and promote these quality of life domains.

Promoting Independence and Autonomy

In order to promote residents’ quality of life, the research advocates that long-stay care facilities should adopt an ethos of care that:

- views residents as equal partners in their own care
- facilitates residents to exercise choice
- encourages self-sufficiency
- places a focus on person-centred care
- enables residents to live insofar as possible in a manner akin to in their own homes.

The Council recommends that this ethos be fostered in all long-stay care facilities for older people. It further recommends that each facility should describe this ethos in all documentation, and, in particular, in any brochures that are made available to prospective residents and their families or carers.

Personal Identity and Sense of Self

The research found that long-stay care facilities enhance the quality of life of residents when each resident is treated as a unique individual whose ‘life has been shaped by a variety of events, experiences and circumstances’ (NCAOP, 2005). Examples of ways in which this can be facilitated include:
actively providing residents with opportunities for self-expression
providing private space and private rooms for residents
fostering positive staff attitudes towards ageing and older people, e.g. encouraging residents to assist with tasks in the facility as appropriate
preserving residents’ self-respect and self-esteem through enhanced staff engagement.

The Council recommends that these and other age friendly and independence-enhancing practices form part of any future initiatives aimed at enhancing quality of life in long-stay care facilities.

Connectedness, Social Relationships and Networks

As endorsed in Care for Older People (NESF, 2005), the research found that quality of life in long-stay care is enhanced if:
- residents are encouraged and facilitated to retain previous interests
- residents are enabled to maintain contact links to the community, their social networks and family
- residents have meaningful relationships with those around them
- continuity of staff is developed and maintained.

In this regard, the Council recommends that:
- meaningful and respectful engagement with residents is encouraged
- residents are treated with kindness, respect and consideration
- good relationships between residents and family and community are encouraged wherever residents wish it
- resident/resident relationships are encouraged and facilitated, but respect for individual preferences always guides this facilitation
- family and community contributions, where appropriate, are recognised as an important part of the residents’ care
- the facility is located within the community in which the resident formerly resided and continuing contacts are encouraged and fostered.
Meaningful Activities

The research noted that the quality of life experienced by residents in long-stay care facilities is enhanced by:

- the inclusion of the widest possible range of purposeful activities
- the inclusion of activities with which residents have been familiar and interested in the past
- consultation with residents to identify their preferences for activities.
- provision of opportunities to ‘get out’ of the facility in order to take part in activities.

The Council recommends that priority be accorded to the provision of meaningful activities in long-stay care and built into the ethos of the facility to ensure staff and space availability. A positive development in this regard has been the introduction of activity nurses and the Council recommends that this practice be further developed so that all long-stay facilities have access to the services of these health and social care professionals.

Quality of Life Enablers

Staffing: Staffing Levels and Skills Mix

The research findings highlight that appropriate staffing levels and skill mix in long-stay care facilities are critical to the quality of life of residents. The survey data revealed the wide diversity of staff/resident ratios in public, private and voluntary facilities. Focus group participants also stressed the need for an appropriate skill mix among staff. The research found that, in general, while the ratio of non-registered care staff to residents was broadly the same across all categories of facility, the ratio of registered nurses (RNs) to residents in private facilities was significantly higher than in all other facility types, across all shifts and by size of facility.

Currently, no legislation or guidelines stipulating staff/resident ratios or skill mix for all long-stay care facilities exist apart from the Health (Nursing Homes) Act, 1990, which requires only one RN to be on duty at any one time in private and voluntary facilities. **While it may not be appropriate to specify a staff/resident ratio for**
all long-stay facilities, the Council recommends the development of guidelines to ensure that adequate and appropriate staffing is provided in all facilities in keeping with the numbers, dependency levels and needs of residents.\(^1\) The Council further recommends the development of national guidelines on skill mix requirements, taking into account assessed levels of disability of residents together with quality of life and rehabilitation objectives.

**Staffing: Recruitment and Retention**

The focus groups highlighted particular difficulties with regard to recruitment and retention of staff in services for older people, as older people’s nursing is often perceived as being particularly strenuous and maintenance-focused. In this regard, the Council recommends that a more concerted effort be made to enhance the image of older people’s nursing, as has been done with palliative care, and believes that the rehabilitation and quality of life development potential of the work should be promoted, fostered, encouraged and rewarded. Furthermore, the focus groups noted that there is a perceived lack of value placed on older people’s nursing as a nurse-led opportunity. The Council recommends that clinical career pathways be developed to attract nurses to this specialism and retain them.

Therapeutic activities are critical to quality of life and rehabilitation objectives in long-stay care services; therapies such as physiotherapy, occupational therapy and chiropody are particularly important in this regard. However, the study found that some or all of these therapies were often unavailable or available on a very limited basis. The Council, therefore, reiterates recommendations that it has made previously that these services be defined as core services available to all residents on the basis of need and that this is underpinned by legislation and funding (Garavan et al., 2001; Delaney et al., 2001; Haslett, 2003).

**Physical Environment**

Though long-stay facilities should satisfy the requirements of staff and enable them to carry out their duties effectively and safely, they should also provide a ‘homely atmosphere’ for residents (NESF, 2005). Site visits conducted during the course of

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\(^1\) An interesting example in this regard is the development by the health authorities in Scotland of a model for measuring the relative needs of older people in long-stay care settings, which places older people in care resource utilisation groups according to their level of dependency and need for care. There are eight groups in all, ranging from ‘residents of low dependency with no behavioural problems or needs for special care’ to ‘residents of high dependency with both behavioural problems and needs for special care’ (NHS National Services Scotland, 2005).
the research revealed that, in general, public units were older, poorly designed for the purpose of person-centred care delivery (particularly for people with dementia), and rarely provided private rooms for residents. In contrast, private facilities were, for the most part, newer, more spacious and more likely to be designed for the purposes of promoting individual privacy. With regard to these existing facilities (particularly larger, public units), the Council recommends:

- phasing out all large shared rooms in favour of smaller units
- adding en suite facilities to rooms where possible
- personalising spaces in partnership with residents
- improving access within and outside the buildings.

With regard to the construction of new facilities, the Council recommends that such facilities be purpose-built and provide separate units (or units to accommodate spouses/friends) with en suite toilet and washing facilities. The Council further recommends that planning guidelines and standards be developed to inform the construction and physical requirements of all new long-stay care facilities and suggests that registration should be based on adherence to these guidelines. In this regard, the Council endorses the guidelines provided by the National Disability Authority (NDA) in Building for Everyone (NDA, 2002) and recommends, where reasonable and practicable, their utilisation when constructing new facilities.

The Council also advises that careful consideration be paid to the location of facilities, particularly new ones, and recommends that the Health Service Executive (HSE) conduct analyses to assist the strategic planning of long-stay care services in Ireland. This should enable it to ascertain the number of long-stay care places that will be required in the future and where they will be needed. The Council proposes that its recent report on population projections (Connell and Pringle, 2004) would assist with this planning process as it provides details of the number of people aged eighty years and over in each county for future years to 2021.

Finally, the Council recommends that the location of new facilities should be determined by reference to other community services in light of the research findings on the importance of connectedness to the community.
While this research and the Council’s recommendations focus particularly on quality of life in long-stay care, the Council always has been, and remains, concerned with the need for minimum standards, clinical standards, practice guidelines and uniform inspection processes that apply to all long-stay care facilities (NCAOP, 2000; NCAOP, 2005).

However, the Council is concerned that, of themselves, standards, practice guidelines and inspection will be insufficient for guaranteeing quality of life in long-stay facilities and proposes that other separate measures are required in this regard. Given the findings of this research, the Council believes that a new focus on improving the quality of life of residents will require a change of mindset and a new vision for long-stay care, which, among other things, challenges stereotypical assumptions about old age and promotes quality of life and rehabilitation objectives. In *An Age Friendly Society: A Position Statement* (NCAOP, 2005), the Council proposed that an age friendly society is one which is receptive to positive constructs of ageing, rejects negative ones and is informed by ideas of active ageing, healthy ageing, positive ageing and successful ageing. The Council asserts that the policies of an age friendly society should address health and well-being concerns over the life-course and, included in this is the provision of age friendly long-stay care services.

Consistent with the values of an age friendly society, the Council believes that age friendly long-stay care services should:

- promote an anti-ageist philosophy
- be integrated
- be needs-focused
- be person focused
- be holistic
- be flexible
- build self-esteem and self respect
- facilitate choice
- facilitate empowerment
- promote partnership
- aim to maximise the well-being of residents (NCAOP, 2005).
The Council accepts that the cultural shift necessary to translate these values into action is, by no means, insignificant and it recognises that such a shift requires the sustained provision of dedicated assistance, guidance, encouragement and support to long-stay care staff.

**Education and Training for Age Friendly Long-Stay Care Services**

Participants in the nurse manager focus groups concluded that a programme of education and training is required to facilitate the development of an ethos of care that focuses on quality of life and addresses the attitudinal and organisational changes required in this regard. They also highlighted that training opportunities are limited for those working in the sector and noted that the traditional focus of training for long-stay care staff has been on the process of nursing care delivery only.

The Council has previously asserted its concern to promote education and training for an age friendly society, leading to a better understanding of ageing and older people in all walks of life and particularly where decisions affecting older people are being taken (Delaney *et al.*, 2005). The Council will, therefore, endeavour to support the development of education and training for age friendly long-stay care services in partnership with other agencies and recommends that together with a focus on the quality of life domains outlined previously, a number of further strands be incorporated including:

- age awareness training
- quality assurance training
- training for consultation.

The Council recommends that standards for training and development plans that have a specific quality of life focus be drawn up for all staff working in long-stay care facilities, and advocates that staff should be provided with opportunities to avail of such education and training.
Age Awareness Training

Many stereotypical assumptions about old age as being a time of disease, decline and passivity are fuelled by an absence of information about our older population. Through its programme of research, over a number of years, the Council has drawn together a large volume of information about older people in Ireland. This information highlights the heterogeneity of the older population, in addition to dispelling some of the myths of ageing. The Council recommends that its research findings, and in particular, the findings detailed in this report be incorporated into any age awareness training programme that is developed for long-stay care staff.

Quality Assurance Training

Quality assurance is a process through which service providers and recipients can assess services to ascertain whether acceptable practices are being adopted, and devise adjustments and improvements where deficiencies are identified. As such, quality assurance mechanisms are viewed as a way of continuous improvement. In this regard, the Council notes the Code of Practice for Nursing Homes (Department of Health, 1995), which was developed as a quality assurance guidance document to encourage long-stay care service providers to promote quality of life for residents.

Another form of quality assurance is accreditation. In this regard, the Council notes the recent development of draft Residential Care Accreditation Standards (RCAS) by the Irish Health Services Accreditation Board (IHSAB). The Council reiterates its recommendation for the development of quality assurance mechanisms for the long-stay care sector. Specifically, it reiterates its recommendation that all long-stay facilities be required to produce a quality assurance policy statement and a quality assurance service plan (NCAOP, 2000). In order to foster and enhance quality of life in particular, the Council advises that all quality assurance mechanisms should take account of the findings of this research.

An example of good practice with regard to quality assurance is the Healthy Ageing Initiative for Residential Care (HAIRC), which has been developed jointly by the NCAOP and the Irish National Health Promoting Hospitals Network (INHPHN). The initiative proposes ten steps to promote person-centred care and quality of life, the creation of a positive working environment for those involved in care provision, and the development of family friendly environments. Launched in 2005, the initiative is being evaluated with a view to its further development as a tool to promote quality of life in the facilities that opt to implement the programme. It is critical to note that experience from the facilities to date highlights the need for support and training in
this regard. The Council believes that specific guidance and training is necessary to enable long-stay care staff to develop and produce quality assurance statements and policies, and would be pleased to assist in this regard as appropriate.

Training for Consultation

The research has demonstrated the importance of consulting with residents in order to ensure that their physical, mental, social, spiritual and emotional needs are being met. The Council believes that residents are in the most appropriate position to inform service planning and development that improve their quality of life. In addition, the effectiveness of these services should be judged by how well they meet the stated needs of the residents; consultation is, therefore, a key requirement of any quality assurance mechanism.

Many service providers rely on patient satisfaction assessments as a means of fostering resident involvement in the development and evaluation of services. However, there are limitations to this approach. It has been reported that older people, in particular, are reluctant to criticise care provision and such assessments provide little information about a older person’s role in decision-making and involvement. The Council reiterates its recommendation for the adoption of a democratic approach to consumer consultation in which older people take an active role in all decision-making processes, including how services are planned, structured or provided (Garavan et al., 2001; NCAOP, 2005). The development of standards relating to the establishment of resident committees and family committees in all long-stay care services would be welcome in this regard. Furthermore, in the absence of relatives who can act as advocates on behalf of more dependent residents, advocacy groups should be encouraged to offer their services to long-stay care residents.

However, other research has noted that a lack of training may also mitigate against effective consultation irrespective of the model chosen (Delaney et al., 2002). Therefore, the Council recommends that training for age friendly long-stay care services should include training in effective consultation. The Council believes that the research findings are a valuable tool in this regard as they provide key pointers regarding the subject matter for any consultation exercises and, as such, should form an integral component of such training.
Finally, the Council recommends that clear complaint procedures be established in all facilities and believes that effective consultation between staff and residents should form the basis of such procedures. Such procedures should not be so bureaucratic as to dissuade older people from availing of them and very importantly, they should be available to residents, their families and their advocates, as appropriate.

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Executive Summary

Introduction

Quality of life has become an increasingly popular term and is now spoken of in a diversity of contexts. Its usage has become widespread covering almost all facets of daily living. Quality of life is especially relevant for residents in long-term care facilities, who may be considered as one of the most vulnerable groups in society given their increasing age and levels of dependency. While quality of life is a useful expression, its apparent simplicity masks the complexity and ambiguity surrounding the concept and there remains much debate and confusion over what elements should be included. This research contributes to this debate and presents a model of factors determining residents’ quality of life in long-stay care in Ireland. This model was built from the analysis of data which was collected from a survey of long-stay units and interviews with managers, residents, relatives and staff with the aim of exploring the quality of life of older people living in long-stay care from a number of perspectives.

Quality of Life

While the literature on quality of life is complex, several areas of agreement are evident. It is clear that quality of life is a multidimensional concept, which cannot be explained in medical terms alone. Quality of life only makes sense if considered in a holistic context. It also contains both subjective and objective elements, therefore there is a need to take account of both when measuring the concept. There is also an emerging consensus on quality of life domains for older people. These include objective domains such as the physical and care environment, physical and mental health, level of functioning and socioeconomic status; and subjective domains such as psychological well-being, autonomy/independence, purposeful activity, social relationships, spirituality and identity/sense of self. The emergence of these domains confirms the complex, interrelated and multidimensional nature of quality of life for older people.
Methodology

A mixed method research design was selected for this study as the aim was to explore the quality of life of older people living in long-stay care from a number of perspectives. Three methods were employed within this study: focus groups with managers; quantitative survey of long-stay facilities; and qualitative interviews with residents, relatives and staff.

Focus group interviews and analysis were undertaken prior to other data collection as they informed the development of the survey instruments and provided, alongside the literature review, contextual information on factors that influence residents’ quality of life and care provision in general. Focus groups enabled important background information on quality issues in long-stay care to be gathered. Seven focus groups were held with managers/proprietors of long-stay facilities. A purposeful, stratified sampling strategy was employed to ensure that representatives from five types of facilities (geriatric hospital/home, health board district hospital/community hospital, health board welfare home, voluntary geriatric home/hospital, and private nursing home), three sectors (public, voluntary and private) and a mix of facilities (large, small and geographical setting) were invited to participate. In all, 67 managers participated in focus groups held in Donegal, Dublin, Cork and Galway.

The survey of all long-stay facilities extends and develops previous work by the then National Council for the Aged (now the NCAOP) on quality of life in private and voluntary nursing homes in Ireland (O’Connor and Thompstone, 1986). All 556 long-stay facilities in Ireland were surveyed. The final response rate was 332 giving a response rate of 62 per cent. The response varied across facility type; the highest rate was achieved in welfare homes (95 per cent) and the lowest in private nursing homes (56 per cent). The quantitative survey of long-stay facilities was designed to provide an insight into the likely impact of physical, environmental and staffing issues on older people’s quality of life.

The qualitative interview data provided information on resident and staff perceptions of quality of life in long-stay care.² The focus was on environmentally-related quality of life issues (both physical and social) rather than on the individual health and functional capacity of respondents, although some data was collected on the latter.

² Long-stay care is provided to those who reside permanently within a facility.
The interviews with residents, staff and relatives were gathered in 12 long-stay care study sites. This approach yielded a rich contextualised data set and was resource efficient as it allowed a large number of residents and staff to be interviewed in the same setting over a period of a few days.

In all, 101 resident interviews were gathered with between eight and ten undertaken in each study site. The sample comprised of residents who were newly admitted, residents who had lived in the facility for longer than three months and residents who had some cognitive impairment but were able to understand questions and respond. Both male and female residents were included. Forty-eight interviews were conducted with staff across facilities, four within each study site. All categories of staff were included: registered nurses, directors of nursing, health care assistants, care attendants, cooks, cleaning staff, physiotherapists and occupational therapists. Interviews with relatives were conducted by phone; in all, 13 interviews were conducted with relatives who agreed to participate.

Focus Group Findings

The findings from focus groups revealed that low staffing levels and inappropriate skill mix were considered to be major barriers to the provision of quality care. The relatively low ratios of registered nurses to care assistants in some private nursing homes was also raised as an issue of concern. Participants also reported that it was increasingly difficult to recruit and retain staff. Participants considered the physical and social environment of the facility to be key determinants of residents’ quality of life. The major negative impacts on quality of life were identified as a lack of privacy and an institutionalised approach to care. A shift to individualised and person-centred care was viewed as central to improving quality of life and well-being of people in long-stay care. Focus group participants made a number of recommendations for change. Chief among these were the need for stronger regulation and legislation and an independent inspectorate for both public and private facilities.
Long-Stay Facility Survey Findings

This quantitative survey focused on the size and number of facilities, residents, dependency levels, staffing levels, provision of therapies and activities and the physical environment. Key differences in staffing provision and physical environment emerged between private and public facilities. Dependency levels were highest in the public sector, with the exception of welfare homes which tended to cater for less dependent residents. Staffing ratios were higher in public facilities than in private facilities and there was more evidence of therapeutic activity. However, physical environment and infrastructure were generally better in the private sector than in the public sector. Residents in the private sector were also more likely to be given choice over when to get up and go to bed. The survey also found that there were a significant amount of activities going on for residents in both public and private long-stay facilities, though it was impossible to tell from the survey what value residents placed on these activities.

It was evident from the findings of the survey that there were differences in resident quality of life both within and across sectors. Some were related to the care environment, others to the dependency and personality of the resident. What was clear from the data was that management and organisational structures within long-stay care facilities matter for quality of life and can compensate for poor physical environment in certain circumstances. The issue was less whether care was delivered publicly or privately, more whether care was resident-centred and quality driven.

Qualitative Interview Findings

The findings from qualitative interviews revealed four thematic domains of quality of life: care environment and ethos of care, personal identity, connectedness to family and community, and activities and therapies. The study found that there were significant differences in resident experiences across care study sites and some differences between public and private study sites. The ethos of care in many facilities did not facilitate resident inclusion in decision-making and routine continued to prevail in some facilities. This was more evident in the public sector than the private sector. The findings suggested that physical environment was important as it constrained resident choice and, therefore, impacted greatly on quality of life. The physical environment was poor in some facilities, but more so in the public sector than the private sector.
The findings also revealed that staffing levels and skill mix were major issues in the provision of quality of care and, therefore, quality of life. Concern was expressed about registered nurse staffing levels and skill mix within the private sector, particularly as there was a reliance on non-qualified care staff in the provision of resident care. The public long-stay facilities were better staffed which impacted positively on the overall quality of life of residents.

Residents highlighted the importance of identity and maintaining a sense of self in long-term care facilities. The ease with which they achieved this varied across sites, with residents living in old, large public facilities having greatest difficulty. A number of enabling or inhibiting factors were identified in relation to this theme. Chief among these was whether residents had a room of their own or a choice to share if that was their preference. A private room was the norm within the private sector but rare within the public sector. Residents with a room of their own had greater privacy, more scope to live their life as they liked, and opportunities to adapt their environment to suit themselves. In contrast, residents living in open-plan wards had little privacy and limited opportunity to do as they pleased.

Residents who felt empowered perceived that they could shape their day and had the potential to make choices. Residents who felt disempowered felt constrained by rules and routine. They perceived themselves as ‘one of a number’ rather than an individual and this impacted negatively on their sense of self and personal identity. This could happen equally in public and private facilities but could be avoided by a willingness on the part of staff to personalise the life experience of residents in the facility, making it a home away from home. The attitude of staff to the care process and their access to, and participation in, person-centred training contribute to maintaining quality of life for residents.

The majority of residents interviewed wanted to be more connected to the outside world. Visits from family and friends were very important to residents. Visits helped to maintain family bonds and kept the older person in touch with what was happening at home and in the local community. Proximity to family and community was seen as important in maintaining relationships. A number of factors were found that either enhanced or diminished residents’ potential to retain their connections and relationships with people and place; an open visiting policy, a feeling of welcome, a homely atmosphere and strong links with the local community were the main enhancing factors. Perceptions that children were unwelcome, lack of privacy, having to talk to visitors in public and poor links with the local community inhibited residents’ connectedness. In general, relationships between staff and residents were good with the majority of residents describing staff as caring, kind and helpful.
Residents were most positive about staff who chatted and showed an interest in them. Overall, interaction amongst residents was good, although people wanted more choice in relation to how these relationships were negotiated and mediated.

There were widespread differences in the provision of activities across study sites. Some sites had an extensive range of activities while others provided little in the way of activities. Some residents, therefore, had good opportunities to pursue meaningful activities while others did not. It was evident that some residents’ days were long and boring; consequently, these residents were often frustrated and disengaged. Residents were most likely to participate in activities which were designed to take into account their own particular interests. The absence of occupational therapy and physiotherapy were highlighted as particular concerns by residents and staff in both public and private facilities.

Conclusion

It was evident that much work remains to be done in ensuring a good quality of life for older people in long-stay care. Any new legislation will have to acknowledge that residential care is the permanent home of the majority of its residents. Long-stay facilities must, therefore, be encouraged, through regulation and sanctions, to produce a more home-like environment and reduce the institutional feel of these facilities. Residents must be able to continue living as they did in their former homes taking into account their limitations and capabilities. Finding out what people like and dislike is the first step to giving residents a more home-like environment. Giving people more choice will help to develop residents’ independence and autonomy, thus contributing to their dignity and self-respect. Dignity can also be upheld by respecting residents’ need for privacy, through, for example, the provision of an adequate number of single rooms.

To date, not enough attention has been paid by policy-makers and regulators to quality of life, who have instead focused their attention on ensuring a good quality of care. While this can be justified by the central role played by these facilities as providers of care and the more tangible nature of quality of care indicators, the prominence given to quality of care, while necessary, is not sufficient and it is imperative that quality of life in long-stay care is also given the due recognition it deserves. Older people in long-stay care are more than just patients, they are individuals who deserve to live the remainder of their days with dignity and
respect in an environment that is empowering and enabling, not belittling. It is not only policy-makers that have to change; management and staff also need to change and see their roles in terms of developing and enhancing quality of life as much as quality of care. Long-stay care settings are not places to die, they are places to live and live well. The impetus is now on regulators, policy-makers and practitioners to ensure that residents of long-stay care are guaranteed the best quality of life possible in these settings as well as the best possible quality of care.

**Authors’ Recommendations**

1. Develop a person-centred ethos of care within residential settings through education and training of management and staff.

2. Ensure that registered nurse to resident staffing ratios are high enough to allow the direct participation of nurses in the planning, delivery and supervision of care.

3. Develop uniform national care standards for all types of residential care settings in Ireland.

4. Establish an independent social services inspectorate for the regulation, inspection and monitoring of quality of care and quality of life in residential care.

5. Ask residents and their families directly about their experiences of long-stay care as part of the regulatory and inspection process.

6. Publish regular information on the results of inspection which includes reference to, and monitoring of, quality of life in the following domains: care environment and ethos of care, sense of self and identity, connectedness, and meaningful activities and therapies.

7. Develop appropriate consultation structures within long-stay settings to give older people a greater voice in how services are structured and delivered.

8. Review the appropriateness of current care environments and the overall management of residents with dementia, with particular reference to the care of people with challenging behaviours.

9. Replace existing, inappropriately designed public long-stay facilities with new buildings designed to provide accommodation that recognises the individuality of all residents and allows them to choose their desired mix of private and public space.

10. Develop an appropriate reward structure for residential care settings that deliver good quality care and good quality of life for residents and penalties for those that provide poor quality of care and diminished quality of life for residents.
Chapter One
Introduction
Chapter One

Introduction

Quality of life has become an increasingly popular term and is now spoken of in a diversity of contexts. Its usage has become widespread covering almost all facets of daily living, although the concept remains complex and mostly ill-defined. Quality of life is especially relevant for residents in long-stay care facilities, who may be considered as one of the most vulnerable groups in society given their increasing age and levels of dependency. For this group, a poor quality of care provision will have a significant impact on their quality of life. Furthermore, older people in residential settings may be unable or unwilling to complain about substandard care or conditions due to cognitive and/or communication impairments, or because of low expectations about quality of life in long-stay care. Older people living in residential care cannot always exercise their usual consumer sovereignty and the power relationship between the providers of long-stay care and residents is an unequal one. Residents in long-stay care may be afraid to criticise the services provided to them due to a concern that such action might have negative repercussions. In addition, many residents may have little or no support outside the residential care setting and, therefore, have no alternative but to accept the treatment given to them. While regulations have been put in place in most countries, including Ireland, to ensure that minimum acceptable standards are adhered to in residential care and that the rights and entitlements of residents are recognised and respected, this has not always been enough to ensure good quality of life. There is evidence, for instance, that the quality of long-stay care services for older people is variable in many countries and does not always meet the expectations of the public, the users of services or their families (OECD, 2005). Quality of life for people with dementia may be a particular problem in residential care settings (Moise et al., 2004).

While quality of life is a useful and widely used expression, its apparent simplicity masks the complexity and ambiguity surrounding the concept. There is much debate and confusion over what elements should be included in quality of life, how these various elements should be measured and who should do the measuring.
There is no single definition describing this concept, which makes it more difficult to think about domains of quality of life. It is important, however, to provide a framework for the exploration and measurement of quality of life for residents in long-stay residential care settings. While an objective assessment of quality of life is important, the subjective experiences of residents also matter; these must be communicated if we are to move towards an understanding of the ‘good life’ within residential care. It is only then that policy-makers will be able to develop quality of life indicators and implement meaningful regulatory structures to improve quality of life in long-stay care.

Despite the complex and subjective nature of quality of life and the various measurement difficulties it poses, quality of life is being increasingly recognised as a key outcome of the care of older people. Sander and Walden (1985) describe the ideal nursing home as a place where people live their lives with as little physical or psychosocial discomfort as possible, ‘with dignity and a good quality of life’. The life of the nursing home resident, they suggest, should be as similar as possible to the life he or she would choose to live at home. The Royal College of Physicians (1992) insists that good quality of life should be the goal of long-stay care. Recent Irish health policy espouses similar goals, although plans are weak on definitions, measurement instruments and implementation strategies (Department of Health and Children [DoHC], 2001; Department of Health, 1994; Department of Health, 1988). There is an evolving literature on quality of life for people in long-stay care, which has identified a number of important key domains including: identity, autonomy, physical environment, social environment, connectedness, and meaningful activity (Age & Opportunity, 2003; Standing Nursing and Midwifery Advisory Committee, 2001; Nolan et al., 2001; National Council on Ageing and Older People (NCAOP), 2000; Davies et al., 1999; Royal College of Nursing, 1991). Notwithstanding an increased emphasis on quality of life, we must now develop regulatory frameworks to bring about genuine improvements in quality of life for older people in residential care settings. This is particularly so in Ireland, where we have been much better at providing beds and financial support for older people, albeit sometimes controversially, than considering the many and varied issues that affect quality of life.
Traditionally, the quality focus in residential care settings in Ireland has been on quality of care rather than quality of life. The Health (Nursing Homes) Act, 1990, provides a regulatory framework that emphasises structural and process dimensions of quality of care. The main areas covered by the regulations include the care and welfare of residents, staffing, accommodation, facilities, hygiene, inspections and complaints – all of which contribute to quality of life, but none of which, even in combination, determine quality of life. Several quality initiatives have been developed and implemented in recent years in an effort to improve the quality of long-stay care for older people, but the dominant concern in most of these has been on enhancing standards of care rather than quality of life. These initiatives include the establishment of the interim Health Information and Quality Authority (iHIQA), the Irish Health Services Accreditation Board (IHSAB), the Healthy Ageing Initiative for Residential Care (HAIRC) (which directly covers quality of life dimensions) and various Health Services Executive (HSE) programmes, based mainly on Essence of Care frameworks for older people in long-stay care.

Long-stay care units are more than just providers of healthcare; they are also the permanent dwelling place of residents – home for the people that live there. They have the potential, therefore, to influence and affect many aspects of residents’ daily lives beyond health and functional ability. It is important, therefore, that policy-makers and other interested parties recognise and understand the important elements that constitute a good quality of life in long-stay care in order to put in place mechanisms that will ensure that this objective is achieved.

The origin of this research report lies in the concern of the NCAOP about the quality and effectiveness of long-stay care services in Ireland and its desire to develop quality assurance mechanisms for long-stay care that emphasise quality of life as much as quality of care. The purpose of the report is to explore quality of life issues as perceived by residents and staff in long-stay care settings in Ireland.

The report begins with an examination of quality of care and quality of life issues for older people in Ireland. Existing measurement instruments and regulatory frameworks for quality of care and quality of life are described. A cross-country comparative review of public policy relating to quality of life in long-stay care is also provided. Chapter Two examines various approaches to understanding quality of life before going on to explore quality of life for older people. A number of quality of life frameworks for older people in long-stay care are examined with a view to ascertaining their usefulness in exploring quality of life in an Irish context in Chapter Three. The methodology used in the study is outlined in Chapter Four.
This chapter provides justification for both the quantitative and qualitative approaches used in the study, as well as for the quality of life frameworks used to organise the collection of data from the survey and interviews. Chapter Five reports on policy and practice issues with regard to quality issues in long-stay care from the viewpoint of nurse managers. The focus groups of nurse managers provided a valuable insight into current thinking on quality of life among staff in residential care settings and helped to inform subsequent data collection in these settings. The findings from the survey questionnaire are presented in Chapter Six. A number of different dimensions are covered including: beds, residents, dependency, staffing, services, facilities, activities, care environment and physical environment. Wherever possible, a comparison is made with previous work by O’Connor et al. (1986) on the quality of life in private and voluntary nursing homes.

Chapter Seven provides detailed descriptions of the study sites used to collect qualitative information from residents and staff on their perceptions of factors that contribute to older people’s quality of life in long-stay care. This is followed in Chapter Eight by the first of four chapters on qualitative aspects of quality of life in long-stay care. This chapter examines the care environment and the ethos of care, both of which have a huge influence on the ability of residents to live life to the full within an institutional setting. A number of interrelated issues are explored including: autonomy and freedom, choice, and the opportunity to shape the pattern of daily living. Chapter Nine examines the extent to which personal identity can be maintained in long-stay care. Identity emerges as a leading issue in respect of quality of life in long-stay care in Ireland; particularly whether the resident’s own sense of self remains intact following admission and prolonged stay in a long-stay facility. Identity is, of course, multifaceted and incorporates many dimensions, the most important of which will be considered in this chapter including: a sense of well-being, attitude and outlook, self-expression, spirituality, appearance and privacy.

Connectedness issues are explored in Chapter Ten; relationships are important in determining quality of life in long-stay settings and moving into a long-stay facility may enhance or diminish the potential set of connections and relationships with other people, including family and friends. The chapter explores internal resident interactions, companionship, family relationships, intergenerational contacts, and general links between the community and the residential facility. Meaningful and purposeful activities are also important for quality of life in long-stay settings and these are examined in Chapter Eleven. People’s preferences are unlikely to alter once they enter long-stay care, given that they have been formed and shaped over a lifetime. It is important, therefore, that residents are given the opportunity to pursue interests and activities that they have enjoyed all of their life, as well as the opportunity to participate (voluntarily) in new activities offered by the facility.
Chapter Twelve provides a model for understanding quality of life in long-stay care services in Ireland; this includes the full range of factors likely to influence the health and well-being of residents. The key findings in terms of facilitating and constraining factors are also summarised in this chapter; these relate to staffing levels and skills mix, physical environment and ethos of care, and activities and therapies. The policy implications of the research and its conclusions are also considered, based on an analysis of the quantitative and qualitative findings of previous chapters. A ten-point action plan to enhance quality of life in residential care derived from the conclusions is provided as a guide to policy-makers in this important field.
Chapter Two

Quality of Care and Quality of Life for Older People
Concerns surrounding the quality of long-stay care are not unique to Ireland. Evidence has emerged in many Organisation for Economic Co-operation and Development (OECD) countries of quality shortfalls in nursing homes, ranging from inappropriate and substandard care to the more serious problem of neglect and abuse of residents (OECD, 2005). Problems contributing to unsatisfactory care in nursing homes tend to be similar across OECD countries. These problems include insufficient numbers of trained staff, substandard buildings and facilities, inadequate quality assessment and poor monitoring systems. Lack of consumer satisfaction with institutional care is often contrasted with the higher levels of satisfaction expressed by recipients of home care services. This has resulted in a demand for more comprehensive quality regulations for residential care across Europe, including in Ireland. Reform, where it has occurred, has, however, concentrated more on quality of care than on quality of life, which continues to be seen as secondary to concerns about care. This chapter examines both quality of care and quality of life issues for older people in residential care in Ireland, beginning with an attempt to distinguish between the two.
2.2 Separating Quality of Care and Quality of Life

The move to residential care is a huge transition and period of upheaval for older dependent people. Residents have altered the conditions of their lives for long periods of time, often forever (Kane, 2003a). Therefore, institutional care has the potential to influence residents’ lives either positively or negatively on outcomes that include more than just health status. The long-stay care facility shapes where people live, how they live, whom they see, what they do, and the relationships transpiring within families and communities (Kane, 2001). Outcomes of residential care include elements of living as well as care. Kane (2003a) notes that quality of life is often treated as a luxury in relation to care outcomes. While health-related quality of life has been the most common measure of quality of life in nursing homes, it is also important to take account of a wider concept of quality of life. Concepts such as self-esteem, sense of self and identity, sense of control and spiritual well-being have been largely ignored in the measurement of quality of life of older people in healthcare settings, which have tended to focus on narrow, medically orientated definitions of health (Bond and Corner, 2004).

The emphasis in discourse and policy developments relating to quality in long-stay care internationally and in Ireland has been on ensuring adequate standards of care for residents in long-stay care. The concentration on care standards is necessary but not sufficient to ensure a good quality of life for residents in long-stay care. Many researchers have emphasised the distinction between quality of care and quality of life and the need to separate the two in policy discussions (Kane et al., 2003b; Kane, 2003c; Birren and Dieckmann, 1991). While the quality of care provided in long-stay facilities is an important contributor to a resident’s quality of life, there must be recognition of other important factors that play a role in quality of life in residential care. Gentile (1991) makes this distinction explicit:

*Whereas quality of care is measured by the cleanliness of the environment, compliance with regulations, and the type of nursing and medical care provided, quality of life focuses on the attitudinal and affective atmosphere of the facility in addition to quality of care as one component.*

The unique nature of long-stay care settings poses a challenge to the measurement and analysis of quality in these institutions. Long-stay care facilities are both a healthcare setting and a person’s residence (Phillips, 2001; Katz and Gurland, 1991).
While residents may have a range of physical and mental limitations, they cannot be viewed merely as patients. They are also members of a community and have needs and wants that go beyond health and physical functioning. Some commentators have proposed that the limited abilities and freedom of residents along with the institutional nature of long-stay care settings means these facilities impact on every aspect of a resident’s life (Kane et al., 2004). It is important that managers and staff in long-stay care settings provide a service that is mindful of its full impact.

There have been more attempts to conceptualise and measure quality of care than quality of life in long-stay care (Noelker and Harel, 2001). The concentration on quality of care by policy-makers and regulators has occurred mainly because long-stay care settings are seen primarily as healthcare institutions and also because measuring quality of care has proved to be a less difficult task than measuring quality of life. Measurement of quality of care has been guided by a framework put forward by Donabedian which emphasises the components of structure, process and outcomes. Structure is concerned mainly with the physical environment and staffing; process refers to ‘what is done (appropriateness of care), when it is done (its timeliness), and how well it is done (technical efficiency)’ (Donabedian, 1980). Examples of process include mechanisms to protect residents’ rights, well-functioning transfer and discharge management, procedures of resident assessments used for care planning, availability of services needed to attain and maintain residents’ highest practicable level of functioning, and availability of sufficiently qualified staff around the clock, seven days a week (OECD, 2005). Care outcomes have received the most attention for monitoring the quality of long-stay care, mainly because they are the easiest to measure and are regarded as being central to quality assurance and regulation (Noelker and Harel, 2001). Some examples of quality outcomes include the prevalence of pressure sores, the prevalence of malnutrition and adequacy of tube feeding, use of restraints, number of falls, infections, and poorly managed pain (OECD, 2005).

However, interpretations and developments arising from Donabedian’s framework for quality of care do not recognise or incorporate the full range of factors influencing the quality of life of residents. The focus on the physical structure of the residential care setting, the facilities and care provided, and the health and safety of residents means that important aspects of a resident’s quality of life such as privacy, social interaction, activities, independence and autonomy are ignored and neglected. Therefore, the prominence given to quality of care is inadequate and the onus is now on policy-makers to address the important issue of quality of life in long-stay care services. The next section examines how quality issues in long-stay care have been handled in respect of public policy for long-stay care in Ireland.
The Health (Homes for Incapacitated Persons) Act, 1964, was the first formal recognition by the State of private nursing homes. This Act provided for the 1966 Regulations which set minimum standards for care, accommodation and food, as well as inspections in private nursing homes. The report by the Inter-Departmental Committee on the Care of the Aged, published in 1968, was the first explicit report outlining a policy for older people in Ireland. The report made several recommendations concerning long-stay care for older people. One of the main recommendations of the committee was the replacement of the old county home structure by geriatric hospitals and welfare homes. The former would cater specifically for older people in need of constant nursing care while the latter would meet the needs of older people requiring residential care for other reasons, for example frailty or the inability to live alone at home.

The Care of the Aged report was concerned primarily with the provision of care for older people in public long-stay care and makes no reference to quality of life in relation to older people in Ireland. The emphasis on care was probably due to the underdeveloped nature of care services for older people in Ireland at the time. It appears that the lack of reference to quality of life was due to the fact that the term ‘quality of life’ was not yet in common usage by health professionals or by policy-makers working in the area of health and social care.

The next major benchmark for policy on older people was the report of the Working Party on Services for the Elderly, The Years Ahead: A Policy for the Elderly (Department of Health, 1988). This document remains the official policy framework on services for older people (Mangan, 2003). The main recommendations of The Years Ahead report were as follows:

- Existing geriatric hospitals/homes, long-stay district hospitals and welfare homes should be developed, where appropriate, as community hospitals. The proposed community hospitals should provide a wide range of services for older people and their carers including assessment and rehabilitation, convalescent care, respite care, facilities for nursing older people who cannot be cared for at home, and information, advice and support for carers of older people at home.

- The Health (Homes for Incapacitated Persons) Act, 1964, should be amended to include nursing homes run by voluntary bodies and to provide for a licensing system for all nursing homes.
The Health Act, 1970, should be amended to allow the subvention of residents in voluntary and private homes by health boards, with the level of subvention varying according to a resident’s needs.

In order to be eligible for a nursing home licence, a nursing home must make a brochure available to prospective residents and their families providing details of the services provided, the charges, the qualifications of nursing home staff and other relevant information.

The establishment of an independent inspectorate of care facilities for older people.

The creation and implementation of a ‘code of good practice’ for nursing homes.

The report pointed to the fact that maintaining high standards of care for older people who are in residential settings is essential to ensuring a good quality of life for this vulnerable sector of the population. There was explicit recognition that the quality of residents’ lives is dependent upon the nature and quality of the care provided by those who work in the institutions catering for older people. However, while the report recognised the importance of the quality of life of older people, it did not provide a clear definition of the concept of quality of life. It appears that the assumption was that people had an implicit understanding of the term ‘quality of life’ that did not require further elaboration.

The 2001 health strategy, *Quality and Fairness: A Health System for You* (DoHC, 2001) recognised the need to develop a comprehensive approach to meeting the needs of ageing and older people if problems in the care and quality of life of older people were to be addressed. The strategy highlighted quality of life as one of its central objectives and stated that ‘actions to improve social gain and quality of life should form part of a coherent health strategy’. However, despite numerous references to the quality of life of older people and how this may be improved, the strategy failed to provide a clear or definitive explanation of quality of life or a coherent strategy to enhance quality of life for older people.

Therefore, like *The Years Ahead* report, the strategy seems to take it for granted that people understand the term ‘quality of life’ and the mechanisms through which care can transform quality of life in residential settings. The strategy made two main recommendations that, if implemented, would serve to enhance quality in long-stay care: the widening of the remit of the Social Services Inspectorate to include residential care for older people; and the preparation of national standards for community and long-term residential care of older people – both are primarily focused on care rather than quality of life. The strategy made no explicit statement with regard to quality of life domains within long-stay care or on the measures that might enhance quality of life for older people living in residential settings.
There are no regulations governing care within public long-stay settings in Ireland. The private and voluntary nursing home sector in Ireland is subject to regulations through the Nursing Homes (Care and Welfare) Regulations, 1993, which were made under Section 6 of the Health (Nursing Homes) Act, 1990. The regulations cover the following areas:

- Standards of care – nursing homes must provide ‘suitable and sufficient care to maintain the person’s welfare and well-being’. This is achieved by ensuring a high standard of nursing care and medical care by a medical practitioner of the resident’s choice.

- Welfare and well-being – a wide range of suitable activities for the resident must be provided along with facilities for occupation and recreation. The resident must be able to carry out personal affairs in private and to exercise choice as long as it does not infringe on the rights of other residents. The nursing home must provide adequate arrangements to allow religious observance by residents. Residents must also be kept informed of current affairs and local and community news and events.

- Contract of care – a contract of care outlining details of the services to be provided and the fees to be charged should be provided to the resident by the nursing home within two months of the person’s admission to the home.

- Personal possessions – residents must have sufficient space for personal possessions. Provision must be made for the safe-keeping of personal possessions.

- Discharge – a nursing home proprietor must give a resident 14 days notice prior to discharging that resident.

- Staffing – the person in charge of a nursing home must be a nurse with at least three years experience, unless the proprietor is a medical practitioner. A nurse must be on duty at all times. Staff must be adequate in number and sufficiently trained. Training facilities for staff may be provided by health boards.

- Accommodation and facilities – suitable and sufficient accommodation must be provided. The number of residents in the nursing home must not exceed the number for which the nursing home is registered. Standards regarding sleeping, living and dining areas, lighting and heating, and facilities and equipment are provided. A visitor’s reception area and a staff office must be provided. Doorways and corridors must be wide enough to accommodate wheelchairs, walking aids and access ramps where appropriate. There must be a separate kitchen with suitable cooking facilities, equipment and tableware.
Design – the design of the nursing home must protect residents from the risk of accidents. Floors must have a safe covering. Handrails must be provided on both sides of staircases and in circulation areas, and grab rails must be provided in bath, shower and toilet areas. If residents use more than two floors, a lift must be provided if the health board in question deems it necessary.

Hygiene – the nursing home must be kept in a clean and hygienic condition and adequate sanitary facilities provided. Food must be stored in hygienic conditions.

Sanitary facilities – there must be sufficient piped hot and cold water and wash-hand basins provided in each bedroom. There must also be a sufficient number of toilets, commodes, baths and showers. An adequate number of toilets should have wheelchair access. Bed linen, disposable sheets and incontinence sheets should be in sufficient supply and changed as frequently as required. Adequate arrangements for the disposal of such items must be in place.

Nutrition – suitable, nutritious and varied food must be served in a sufficient amount bearing in mind dietary requirements of residents. Fresh drinking water must also be available on every floor of the nursing home.

Information – a brochure with information about the nursing home must be provided outlining issues such as the admissions policy, accommodation provided and special facilities and services.

Records – adequate records concerning information on residents and staff should be kept in a confidential and safe manner.

Death and dying – upon the death of a dependent person the nursing home proprietor must inform the medical officer of health for the area in which the nursing home is located not later than 48 hours after the death.

Inspections – inspections of nursing homes should be made at least every six months. Inspectors are permitted to conduct interviews in private with persons in the home, including staff, and to examine any resident believed to be in receipt of substandard care. Inspections may also be carried out in premises believed to be nursing homes but which are not registered as such.

Complaints – any nursing home resident or a person acting on his or her behalf may make a complaint in writing to the health board concerning any matter pertinent to the nursing home in general or the maintenance, care, welfare and well-being of a resident. The CEO of the health board will then assign an officer to investigate the nursing home in question.
Medical preparations – medication should be stored safely and properly administered and recorded.

Treatment – where medical treatment is required and agreed to by the resident it must be carried out. A person’s right to refuse treatment must be respected. If physiotherapy, occupational therapy or chiropody is required it must be made available by the nursing home proprietor or by arrangement with the health board.

Services – a nursing home proprietor may make arrangements with the health board for the provision of services by that health board.

Registration certificate – the current registration certificate must be displayed in a prominent place in the nursing home at all times.

Insurance – residents must be adequately insured against injury.

These regulations were supplemented in 1995 by the voluntary Code of Practice for Nursing Homes agreed by experts including the health boards, owners of nursing homes, the NCAOP, carers and other people experienced in the care of older people (Mangan, 1998). The Code of Practice is designed to complement the 1993 regulations and guides nursing homes in the operation of best standards of care beyond the minimum standards outlined in the regulations. In particular, the ‘aim of the Code of Practice is to promote a good quality of life for residents in nursing homes’ (DoHC, 1995).

The Code of Practice proposes that nursing homes should create an environment that imitates home life as closely as possible. In particular, it proposes that the lifestyle of residents should be as non-institutionalised as possible. The code recommends that:

- residents must be involved in decision-making regarding the routines of the home to the extent that this is feasible
- rigid routines should not be imposed on residents, who should be able to exercise a degree of choice regarding daily activities such as bedtimes and mealtimes, and selecting food and clothing
- the facility should seek to develop the full potential of the individual and promote his or her independence
- residents should be able to avail of introductory visits to the nursing home
- residents should be able to access their personal records
- residents should be given a choice regarding the gender of the care giver
restraint should only be used in cases where residents pose a threat of injury to themselves or other residents

a complete nursing review of each resident should be undertaken at least every six months

a wide range of normal activities should be made available to residents and competent residents should be free to judge the risk to them posed by certain activities

visiting arrangements by families and friends of residents to the nursing home should be flexible

visits from volunteers and members of the local community should be facilitated

there should be a mechanism within nursing homes to deal with in-house complaints.

The Code of Practice was an interesting and welcome quality initiative intended to broaden the scope of existing regulatory structures for nursing homes in Ireland. It focused on quality of care and quality of life of residents. It recognised the importance of choice and autonomy for older people, their empowerment through consultation, their connectedness to the outside world and their involvement in meaningful activities. The main difficulty with the code was, and is, that it remains voluntary and the actions recommended are not subject to monitoring or evaluation. Moreover, like the regulations, the code is confined to private and voluntary nursing homes and does not cover public long-stay institutions.

2.5 Problems with Current Regulatory Structures

The problems of the current regulatory structures for long-stay care in Ireland are well known and have been articulated in many reports and commentaries (O’Shea, 1991; Ruddle et al., 1997; NCAOP, 2000; Women’s Health Council, 2001; Mangan, 2003). Some of the main concerns in this area are that:

there are no national standards of care

existing regulations are confined to nursing homes and voluntary homes

the lack of tangible outcome measures means that standards of care are largely dependent on the personal interpretation of different inspectors
inspections are mainly concerned with physical conditions and health and safety. There is little reference to quality of life or social gain issues

the regulations do not provide a framework to monitor residents’ care plans. There are no mechanisms to identify how much long-stay care is required, how it is to be provided and whether the individual needs of residents have been met

it is difficult to prosecute nursing homes that violate existing regulations and it is rare that a nursing home will be closed down even if a breach of the regulation is proven

there is no published analysis of the inspection reports of private facilities

the recommendation of *The Years Ahead* report and the 2001 health strategy, *Quality and Fairness: A Health System for You*, that an independent inspectorate be established has still not been implemented. It is planned that the Bill establishing the Social Services Inspectorate on a statutory basis covering both public and private long-stay facilities will be published in the near future. The forthcoming Bill will also include a specific provision to allow easy access by the public to inspectors’ reports on nursing homes (DoHC press release, 2005).

there is no common, standardised approach to nursing home inspections which leads to an inconsistent application of standards throughout the country. The training of inspectors is neither comprehensive nor uniform

there is no statutory independent complaints and appeals system within the health service. Nor is there an organised advocacy service for vulnerable older people in residential care

the *Code of Practice for Nursing Homes* is not legally enforceable and there is no means of assuring the standards outlined in it are respected and adhered to by nursing homes

the remit of the Ombudsman only extends to public long-stay care facilities and not to private or voluntary nursing homes, although public policy for private homes is covered

the system of linking the amount of subvention paid to the dependency level of residents in private nursing homes has encouraged ‘dependency creep’, with some older people being placed in the highest dependency category in order to qualify for the maximum subvention payment
public patients in private nursing homes do not get the same access to assessment and rehabilitation that they would receive in public facilities. More services are available in public residential care, for example occupational therapy and physiotherapy, and the ratio of nursing staff to care staff is likely to be higher in public facilities.

2.6 Evidence of Quality Deficits in Residential Care

Quality deficits in long-stay care have been reported throughout OECD countries, though most of the evidence relates to poor care outcomes rather than poor quality of life of residents. The most commonly reported problems for older people in long-stay care include: pressure sores, malnutrition, inappropriate use of physical and pharmaceutical restraints, unsatisfactory pain management, neglect and abuse (OECD, 2005). In 2002, for example, 9 per cent of nursing home residents in the USA were found to have pressure sores, while in Australia 28 per cent of residents had insufficient pain relief. Other shortfalls reported by the OECD include the insufficient use of anti-psychotic drugs and unsatisfactory practices concerning the tube feeding of residents.

Research has found that many of the reported quality problems appear to be interrelated and the presence of one problem may lead to, or signal, the presence of one or more quality deficits; for example, the risk of a resident developing pressure sores is increased by malnutrition and dehydration, incontinence and the use of physical restraint. The prevalence of pressure sores can, in turn, highlight neglect or mistreatment of residents. Problems with the structure and process of care delivery are most likely to contribute to the quality deficits outlined above. For example, poor infrastructure and design, and inadequate numbers of trained and experienced staff are the most common impediments to good quality care (OECD, 2005; Noelker and Harel, 2001).

Research on the quality of care delivery and the quality of life of residents in Irish long-stay care settings is limited. In 1986, the National Council for the Aged published two studies, one quantitative the other qualitative, on quality of life in private and voluntary nursing homes in the Republic of Ireland (O’Connor and Walsh, 1986; O’Connor and Thompstone, 1986). The quantitative study revealed that most of the facilities were in a good physical condition. Most of them, however, were not purpose built as nursing homes, therefore facilities were
often not designed to meet the specific needs of residents. For example, although all of the homes surveyed had beds on more than one floor, only one third of the buildings had lifts. In addition, handrails were rarely fitted in sitting or dining rooms and ramps were provided as an alternative to stairs in less than half of all homes surveyed. Therefore, the physical design of the nursing homes tended to engender increased dependence rather than to facilitate or promote greater independence of residents. In relation to staffing, the results revealed that the ratio of full-time equivalent nurses to residents was higher in private nursing homes than voluntary homes. The study also noted the high number of nursing aides employed by both types of home.

The qualitative study (O’Connor and Thompstone, 1986) was undertaken in a representative random sample of twenty nursing homes. Almost three quarters of residents reported that they were contented living in a nursing home while just over a quarter were unhappy or felt isolated. More women than men reported feelings of happiness or contentment. The residents reported that the best features of living in a home were the security and protection it provided and that the residents’ day-to-day needs were looked after leaving residents free to enjoy their retirement. Negative aspects of living in a nursing home cited by residents included a lack of ‘real home life’, loss of friendships and loss of control over daily aspects of their lives.

In 2003, Age & Opportunity commissioned a small-scale, yet pioneering study to elicit the views of residents on social gain and quality of life in three long-stay care settings – two were run by a health board and the third by a religious order. The institutions were selected to reflect the variety in type and geographical setting rather than being representative of all Irish long-term residential care settings. The research identified ten quality of life domains:

- Companionship and loneliness – many residents had experienced loneliness prior to moving to residential care and the availability of companionship in residential care significantly contributed to the quality of life of residents. However, some residents still experienced loneliness, in particular residents who suffered from a hearing or communication impairment, or individuals who had no shared interests with other residents.

- Personal identity and privacy – residents’ personal identity was commonly expressed in their personal space and the ability to have their personal possessions near them. Private rooms were important in order to maintain personal identity and, thus, significantly contributed to quality of life. The absence of privacy and space for personal belongings undermined the quality of life of residents.
Group identity and being part of the community – residents’ identity extended beyond the person to incorporate the group and local community. Therefore, maintaining links with the local community and with current affairs helped to strengthen residents’ identity.

Being active or bored – being involved in the activities on offer was important to residents and a lack of meaningful activity impacted negatively on quality of life.

Family and friends – regular contact with family and friends was a key contributor to the quality of life of residents and many residents felt that not being able to have their family around them detracted from the quality of their lives.

Safety and security – the sense of safety and security of living in residential care was a major contributor to quality of life for residents and the routine of the facility brought a feeling of comfort and familiarity. However, for some residents the routine was a negative aspect of life in long-stay care.

Being cared for – having their needs and wants attended to contributed to the quality of life of residents. An important element of this was a good relationship with staff and the absence of warm staff relationships detracted from quality of life.

Religion – the availability of religious services in the residential care settings significantly contributed to residents’ quality of life.

Physical functioning – difficulties with the basic elements of physical functioning (walking, hearing and seeing) were frequently mentioned as impacting negatively on quality of life.

Control and choice – autonomy in terms of making choices and controlling aspects of their lives was cited by many residents as impacting substantially on their quality of life.

In 2004, a joint research initiative by the former Western Health Board (WHB) and a selection of private nursing homes, was established to investigate quality of life in three different types of long-stay care setting in the region – long-stay hospitals, community nursing units and private nursing homes. A sample of 25 of these institutions representing 30 per cent of all such facilities in the region was selected to take part in the study. The results of the study revealed that 67 per cent of residents rated their quality of life in residential care as being either ‘very good’ or ‘fairly good’, while 13 per cent felt their quality of life was ‘bad’ or ‘fairly bad’. Differences emerged between the three types of institution with respect to residents’ reports on quality of life. Eighty-four per cent of community nursing home residents reported a ‘good’ or ‘very good’ quality of life, compared to 65 per cent of private nursing home residents and 52 per cent of long-stay hospital residents.
Residents who did not want to be in residential care and residents who suffered from depression were more likely to report a poor quality of life. In relation to the general living accommodation provided, over two thirds of residents were happy with the accommodation offered while close to one third reported dissatisfaction with the available accommodation. The absence of facilities and equipment such as lifts, wheelchairs, walking frames and hoists detracted from the quality of life of residents. The study showed that understaffing and large staff workloads posed an obstacle to the provision of a high standard of care to residents.

The conclusions with regard to factors in long-stay care that promoted a good quality of life for residents were very similar in all three reports, particularly in relation to the importance of greater autonomy for residents in long-stay facilities. The need to identify areas where residents can exercise greater choice in relation to day-to-day life was seen as critical to improved well-being. Each report emphasised the importance of the person being cared for rather than staff routine or the system of care. Identity and connectedness for residents were mentioned in equal measure. Connectedness to the local community was seen as necessary for a good quality of life in residential care. The importance of involving older people in the decision to enter residential care was advocated as a means of ensuring a smooth transition to residential care. Residents must also have the choice of participation in activities within residential settings and these activities must be meaningful and geared towards the interests of residents.

2.7 Current Initiatives on Quality of Care and Quality of Life in Ireland

A major impetus for the developing interest in quality in long-stay care in Ireland was the Framework for Quality in Long-Term Residential Care developed by the NCAOP (2000). This framework addressed a number of different areas including: setting of standards, an independent inspectorate and quality assurance mechanisms.

There are currently a number of different initiatives designed to improve quality of care and quality of life in long-stay care in Ireland which include some of the elements outlined in the NCAOP framework. While these initiatives are in an early construction phase, they do provide an insight into current thinking on required reform in this area. Some have their origins at central government level, while others are direct local responses to local needs and local quality issues.
The establishment of the Health Information and Quality Authority (HIQA) was proposed in the 2001 health strategy in order ‘to promote quality care throughout the health system’. It is envisaged that HIQA will enable the Government to achieve its aim of delivering high quality health services based on evidence-supported best practice. HIQA will achieve this by ensuring that services provided in the health system meet nationally agreed standards, and by assessing whether health and personal social services are managed and delivered to ensure the best possible outcomes given the resources available. The main functions of HIQA will be:

- the national promotion of quality
- the development of health information
- the development of an annual programme of service reviews
- the overseeing of health technology assessment
- to publish a report assessing the national performance of each service area examined in relation to specified national standards.

In March 2005, an interim authority was established to prepare for the establishment of the HIQA under legislation. The HIQA, once established on a statutory footing, will amalgamate the information functions of the National Cancer Registry Board and the National Disease Surveillance Centre (NDSC), and the quality functions of the IHSAB.

The IHSAB was established by the Minister for Health and Children in 2002. The main aim of the board is to be ‘a key driver for the continuous quality improvement of the Irish health system (IHSAB, 2005). The board plans to achieve this objective through ‘the provision of healthcare accreditation, related quality improvement activities and the highest international standards of service delivery to our clients’. While initially the operation of accreditation programmes was confined mainly to hospitals and other providers of health services, the board has recently expanded its remit to long-stay residential services for older people. Accreditation involves self-assessment by a healthcare organisation in order to evaluate their level of performance against established standards. The IHSAB Acute Care Accreditation Scheme (ACAS) Standards are grouped into five categories which are:

- Care/service standards – these concern provision of healthcare and/or services to patients/clients.
- Environment and facilities management standards – these cover the management of the organisation’s physical surroundings and equipment.
- Human resources management standards – these focus on issues such as selection and recruitment of personnel, enhancing personal performance and the provision of a healthy work environment.
- Information management standards – these enable the organisation to assess and evaluate the planning, obtaining, management and security of data and information provisions.
- Leadership and partnership standards – these relate to an organisation’s governance, management and collaborative performance.

Four quality dimensions (responsiveness, system competency, patient/client/community focus, and work environment) provide the basis for the structure of the standards. The accreditation process provides a framework to enable organisations to identify, prioritise and implement ways to continuously improve the quality of their services.

The HAIRC is a joint programme by the NCAOP and the Irish National Health Promoting Hospitals Network (INHPH) and was launched in January 2005. This initiative enables older people in residential care facilities to become actively involved in their own care and to have a say in how their quality of life may be improved. The initiative is designed to encourage the involvement of residents in decision-making by establishing patient interest groups in residential care facilities in order to give residents a voice. The objective of the initiative is to achieve person-centred care, a positive work environment for care workers and a family friendly atmosphere in care facilities. A list of Ten Steps to Healthy Ageing have been designed in order to realise these objectives. The Ten Steps to Healthy Ageing are:

1. Consultation – consult with residents to ensure that health promotion policy reflects their needs and preferences.
2. Health promotion policy – develop and implement personalised practices that support healthy ageing.
3. Policy to practice – initiate structures that will enable and support best practice towards healthy ageing.
4. Choice – facilitate full resident involvement in decision-making and daily activity choices.
5. Information practices – establish effective communication and information processes that best meet the needs of residents, carers, staff and community.
6. Personal space and belongings – ensure the development of practices that recognise the individuality of all residents.
7. Independence – develop support systems that enable and protect the autonomy of all residents.

8. Lifestyle – facilitate the development of procedures that promote healthy lifestyle choices among residents.

9. Healthy staff – establish practices and procedures that acknowledge and meet staff development and training requirements.

10. Family friendly – create an organisational environment that encourages the continued involvement and participation of the resident in family and community activities.

The Ten Steps provide a framework for care facilities to realise and act upon their health promoting capacity and, thus, improve the quality of life of residents. Since the initiative has been launched, a wide range of innovative projects and activities have been undertaken in order to improve the quality of life of residents. Such projects include: arts in residential care settings; holiday schemes; music; dancing and physical exercise; and reminiscence therapy.

Essence of Care is a patient-focused quality initiative that is now used at local and regional levels as a way of improving quality of care for older people through providing a supportive environment for carers. It achieves this by benchmarking best practice in nine areas of care: privacy and dignity; food and nutrition; recordkeeping; continence; personal and oral hygiene; pressure ulcers; principles of self-care; safety; and communication. Essence of Care is particularly appropriate for residential care settings as it provides a more holistic, person-centred, social and collaborative model of care.

Essence of Care was first implemented in the North Western Health Board (NWHB). It has been successfully implemented by the HSE in the Southern Area. A seven-member steering group was established and 27 implementation sites dealing with the care of older people were identified. These sites included community, voluntary and acute hospitals, welfare homes and mental health areas. An implementation strategy was developed based on an excellence model using an emancipatory practice development approach. A facilitator training programme, road shows and roll-over sessions were put in place. The benchmarking cycle was then implemented at all 27 sites. Evaluation of the Essence of Care programme at all of these sites was carried out using semi-structured interviews, progress questionnaires, focus groups and feedback from facilitators.
The Mid-West Standards for Residential Hospitals and Nursing Units originated in Essence of Care but developed specifically for the Mid-West; they operated in nine public community hospitals/nursing units across Clare, Limerick and North Tipperary. The standards were developed following a process of consultation involving staff, patients, informal carers, consumer panels, a regional advisory committee on older people’s services and the public. The following principles guided the development of the standards: respect; privacy; dignity; health and well-being; social and emotional well-being; security and safety; participation; and culture and belief. Once a standard is agreed upon (there are 55 in total), comparison groups are established and a baseline audit of practice against the standard is performed. This initial audit provides information on best practice in order to change the implementation plan if necessary. Another audit is then carried out and the results are disseminated to other care units and a new standard can be recommenced.

Finally, a large group of private nursing homes in counties Meath, Kildare, Dublin and Wicklow have developed evidence-based standards of care for clinical nursing practice which could have universal application to residential care facilities for older people. It is proposed that these standards will have in-built audit tools to allow individual facilities to continually monitor their own compliance with the standards and identify areas for improvement. The specific objectives of this project are:

- to identify areas of clinical nursing practice in older person care that could be standardised based on best practice information, e.g. falls prevention, continence promotion etc.
- to develop standards of care for these areas
- to ensure that standards identified are realistic and achievable within the context of the facilities involved
- to identify audit criteria for each standard to allow continuous monitoring of standard compliance
- to supplement individual standards with nursing policies, procedures and protocols where appropriate. (For example, where a standard of care is developed for pressure sore prevention, this standard would be supplemented with a protocol that nurses could use to make decisions about mattresses and other pressure relieving devices for patients; or a standard for medication management would include a procedure for administration of medications.)
- to write the standards in a format that will allow them to be used for standardised care plans/care pathways for older people
to identify and liaise with other relevant stakeholders, including the IHSAB, representatives from the HSE inspectorate, residents and carers, nursing and midwifery planning and development units etc. when developing these standards so that standards reflect overall health policy and strategies.

While all of these initiatives are to be welcomed, particularly the HAIRC initiative with its focus on quality of life, it is essential that there is greater integration of these separate initiatives in order to avoid overlap and duplication. Coordination of the setting and measurement of quality standards is necessary at a national level in order to ensure consistency and a comprehensive uniform approach to quality in long-stay care. The overall goal must be the development of national care standards that cover quality of life as well as quality of care, for application in all care settings. It is imperative that any national initiative recognises the importance of quality of life of older people in long-stay care and develops policies accordingly.

### 2.8 International Developments

The increased awareness by governments of the need to monitor and improve the quality of long-stay care is reflected in the numerous policy initiatives developed and implemented in many OECD countries. Three broad approaches have been used to monitor and guarantee better quality in long-stay care. Firstly, there has been increased monitoring by regulators and purchasers; secondly, the commitment to quality improvement on the part of providers of care has been enhanced; and thirdly, market competition and consumer information have been strengthened (OECD, 2005).

It has been accepted in most OECD countries that providers of long-stay care should be more accountable and should conform to a set of external standards. These standards are often a precondition for the licensing of institutions and the failure to adhere to such standards and regulations may lead to a nursing home licence being revoked. Traditionally, standards have focused on care rather than on quality of life, but this has begun to change in recent years, albeit slowly. Examples of various government initiatives to improve the quality of long-term care include the Care Standards Act 2000 in the UK, the Nursing Home Reform Act of 1987 in the USA, the Aged Care Act 1997 in Australia and the Health and Disability Services (Safety) Act 2001 in New Zealand. The care standards outlined in these Acts are quite complex as they tend to cover a wide range of criteria in respect of structure,
process and outcomes of the services provided.\textsuperscript{3} For example, the UK's Care Standards Act 2000 outlines 38 standards grouped under seven main headings: choice of home; health and personal care; daily life and social activities; complaints and protection; environment; staffing and management; and administration. Similarly, the Australian Aged Care Act of 1997 compels an accreditation assessment by providers against 44 criteria covering: management systems, staffing and organisational development; health and personal care; resident lifestyle; and physical environment and safe systems.

The Nursing Home Reform Act of 1987 in the USA outlines standards relating to five major elements: residents’ rights; quality of life and quality of care; staffing services and resident assessment; federal survey procedures; and enforcement procedures. In addition to government standards, a number of self-regulatory approaches involving voluntary standards have been put in place by professional societies, trade associations and other organisations in various countries (OECD, 2005). For example, in the Netherlands, the major care service association requires all its member organisations to act in accordance with a formal system of internal quality management. An independent agency ensures compliance and upon approval an organisation is certified.

In order to ensure compliance with standards, many countries have established independent agencies to monitor long-stay care institutions (OECD, 2005). In the UK, the Care Standards Act 2000 created the National Care Standards Commission (NCSC), which is an independent non-governmental public body responsible for regulating social and healthcare services. The national minimum care standards provide the basis for decisions made by the NCSC regarding whether or not a care facility should be registered or have its registration cancelled, or whether to take action for breach of regulations. A similar agency, the Aged Care Standards and Accreditation Agency (ACSAA), has been established in Australia. In the USA, the Centers for Medicare and Medicaid Services rely on the ‘mandatory use of a standardised, comprehensive system, known as the Resident Assessment Instrument (RAI), to assist in assessment and care planning (Hawes \textit{et al.}, 1997). The RAI provides a means of assessing each resident in order to develop a care plan specifically designed to meet the individual’s needs. Residents are assessed upon entering a nursing home and at regular intervals thereafter (Mozley \textit{et al.} 2004).

\textsuperscript{3} See OECD (2005) for an overview of efforts to monitor and improve quality long-stay care in OECD countries.
The introduction of the RAI entailed a shift in focus away from physical facilities and features of care towards aspects of quality of life. The RAI is required to include observation and communication with residents as well as communication with staff. The main functional assessment instrument in the RAI is the Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS) (Hawes, 1997). The MDS forms the basis for the development of quality indicators for the following domains: accidents; behaviour/emotional patterns; clinical management; cognitive patterns; continence nutrition; physical functioning; psychotropic drug use; skin care and quality of life. These domains can help to identify facilities performing below the minimum standards and are also used to compare and rank institutions according to their performance (Mor, 2001).

Reform has also sought to ensure conformity with minimum standards by the imposition of sanctions in cases of non-compliance. For example, the Nursing Home Reform Act of 1987 in the USA permits ‘the imposition of civil money penalties, denial of payment for new admissions, temporary management, immediate termination, and other remedies or sanctions’ (OECD, 2005). Australia’s Aged Care Act of 1997 outlines several sanctions that may be enforced including restricting, revoking or suspending an institution’s approval as a provider of care services for older people, revoking or suspending all or some of the places already allocated to the care provider or prohibiting the further allocation of places, and the repayment of some or any grants paid to the care provider. Legislation has also provided mechanisms for the increased empowerment of nursing home residents. For example, the Aged Care Complaints Resolution Scheme (ACCRS) was established in Australia in 1997 to deal with complaints about care services funded by the government. Funds are also provided for independent support and information to recipients of care services or other interested parties. In the USA the Nursing Home Quality Initiative (NHQI) was established in 2002 to allow publication of information about the quality of care in nursing homes in all fifty states.
Quality of life for older people should be of concern to all citizens. Regulations dealing with standards of care in long-stay facilities are necessary but they are not enough. We must think about maximising the potential of dependent older people wherever they live. This report is concerned with quality of life in residential care, but quality of life is equally important for dependent older people living at home. Important initiatives have been undertaken to raise awareness about quality of life within long-stay facilities, including a voluntary Code of Practice for Nursing Homes and the HAIRC. As a result, more attention is now being paid to quality deficits and the need to develop and strengthen quality assurance mechanisms. However, the measurement of quality of life in residential care settings remains overshadowed by the importance placed on care structures and health outcomes as indicators of quality. While these are, of course, important, they do not tell the whole story about life in an institutional care setting. Although quality of care poses less of a challenge to measure and assess than quality of life, the focus of attention in long-stay care must now shift to a holistic interpretation of the ‘good life’ for dependent older people, of which quality of care is but one dimension.
Chapter Three
The Interpretation and Exploration of Quality of Life for Older People
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3.1 Introduction

Quality of life is difficult to define and to measure. It is made up of a collection of interacting objective and subjective dimensions, which may change over time in response to life and health events and experiences (Bowling et al., 2003). It is a multi-disciplinary term and has been examined and used in areas as diverse as economics, sociology, psychology, philosophy, medicine, nursing, social history and geography (Farquhar, 1995b; Bowling and Brazier, 1995). Each discipline approaches the concept with different concerns and this means that the expression has various interpretations according to which perspective is taken (Farquhar, 1995b; Anderson and Burckhardt, 1999; Haas, 1999b). Some authors have avoided giving any definition of quality of life or associated concepts, thus adding to the confusion and ambiguity surrounding the term (Farquhar, 1995a; 1995b, Haas, 1999a; 1999b). Others provide precise definitions, such as Lawton (1991) who defines quality of life as:

*the multidimensional evaluation, by both intra-personal and social-normative criteria, of the person-environment system of an individual in time past, current and anticipated.*

These definitions are often difficult to interpret and to operationalise.
The difficulty of defining such an abstract concept has led to the equally complicated task of measurement. Without a clear definition of quality of life it is hard to assess if quality of life tools are successful in measuring what they intend to measure (Bond and Corner, 2004). In relation to long-stay care, collective agreement on what constitutes a good or even an acceptable quality of life is essential for policy-makers and other interested parties to perform programme evaluations and to ensure that a satisfactory standard is being achieved (Kane, 2001). Getting agreement, however, on the constituent parts of quality of life is very difficult. Researchers must ensure that all relevant domains are included and must take account of subjective as well as objective measures. Evidence suggests that individual and expert or proxy assessments of quality of life frequently diverge, partly due to the dynamic nature of quality of life and the individual strategies of adaptation, expectation and ‘response shift’ (Bowling and Gabriel, 2004; Bond and Corner, 2004). The perspective of the individual matters for quality of life, particularly their psychological adaptation to the ageing process (O’Boyle, 1997).

3.2 Origins of Quality of Life

Interest in quality of life has existed for centuries across different cultures. Early references can be traced back to Aristotle’s writings on ‘the good life’ and the idea that this can be achieved by man leading a life of virtue and fulfilling his capacity for rational action (Megone, 1990; Smith, 2000; Zhan, 1992; Anderson and Burckhardt, 1999). George and Bearon (1980) deem quality of life to be the modern counterpart of ‘the good life’. Traditional Chinese culture and thinking maintained that a good quality of life would result from a harmony of Yin and Yang (Zhan, 1992). A Scottish philosopher, John Seth, referred to quality of life in his article ‘The Evolution of Morality’ in the 19th century (Seth, 1889). Seth stressed the importance of considering the quality of the life as well as the quantity, and viewed this as a moral end towards which mankind could aim (Smith, 2000).

The term ‘quality of life’ only came into popular usage in the 1950s and 60s following World War Two and the consequent post-war economic boom (Farquhar, 1995b; Smith, 2000; Meeberg, 1993; Zhan, 1992; Haas, 1999a; 1999b; Bond and Corner, 2004). While measurement initially focused on objective indicators such as material possessions, it was soon realised that these were inadequate for fully understanding and explaining the concept. Therefore, subjective measures such as the individual’s sense of well-being, happiness and satisfaction with life began
to be taken into account (Farquhar, 1995b; Smith, 2000; Haas, 1999b). The fact that
the term ‘quality of life’ did not appear in the *International Encyclopaedia of Social
Sciences* until 1968 highlights the relatively recent interest in the concept among
academics and researchers (Bond and Corner, 2004). Quality of life became a
concern in the medical and nursing professions from the 1970s onwards with a
shift in emphasis away from mere survival following the realisation that a prolonged
life may not necessarily be a desirable life (Farquhar, 1995b; Smith, 2000; Sarvimäki
and Stenbock-Hult, 2000; Haas, 1999a). More recently, quality of life has been used
as an output measure for comparing the effectiveness of health interventions and
allocating scarce resources (Smith, 2000; Williams, 1985; Birren and Dieckmann,
Therefore, the evolution of quality of life as a concept can be traced from the
general philosophical teachings of Aristotle through to an efficiency outcome
in health and social care.

### 3.3 Frameworks for Understanding Quality of Life

Given the diversity and ambiguity surrounding definitions of quality of life, it is
helpful to attempt to classify existing definitions into a framework in order to identify
shared elements. Farquhar (1995a) provides a taxonomy of definitions of quality of
life according to their origin, distinguishing between expert or professional definitions
and lay definitions. Expert definitions comprise global, component, focused and
combination definitions. Global definitions are the most common type of definition
and provide a general account of quality of life. They incorporate ideas such as the
degree of satisfaction, happiness or well-being that a person experiences. However,
due to their general and all-encompassing nature they fail to give a full description
of all the possible components of quality of life or its operationalisation (Farquhar,
1995a). Moreover, life satisfaction is not the same as quality of life (Gentile, 1991;
George and Bearon, 1980; Haas, 1999b). Component definitions emphasise the
multidimensional nature of quality of life and divide the concept into its component
parts or dimensions (Bond and Corner, 2004; Farquhar 1995a). They are more
useful for empirical work than global definitions as they come closer to measuring
or operationalising the concept, although they may still lack specificity. There may
also be some overlap among domains (Haas, 1999b). Focused definitions concentrate
on one or a limited number of components of quality of life, for example health-
related quality of life. Focused definitions can be either explicit or implicit.
Implicit definitions use the broad term ‘quality of life’ even though they only focus on one or a small number of its component parts. Explicit definitions, on the other hand, make the distinction between the broader concept of quality of life and the more limited perspective they are considering (Farquhar, 1995a). Combination definitions include elements of both global and component definitions.

Lay definitions of quality of life reflect the opinion and perspective of older people and are, therefore, essentially subjective measures. Lay definitions of quality of life can serve to inform expert definitions. Bond and Corner (2004) make the assertion that population surveys of older people tend to employ expert definitions and concepts, rather than focus on lay definitions. Bowling et al. (2003) also believe that the majority of research into the quality of life of older people consists of the opinions of experts. Nevertheless, studies have shown that older people are willing to talk about the quality of their lives and several insights about quality of life have emerged from these studies. These domains include family, social interaction and support, health and functional ability, psychological well-being, activities, independence, living environment and material circumstances (Farquhar, 1995b; Bowling et al., 2003; Bowling and Gabriel, 2004). Yet, lay definitions or subjective evaluations of quality of life are often dismissed as lacking the scientific ‘reality’ or validity of objective indicators (Bond and Corner, 2004; Meeberg, 1993; Farquhar, 1995a). They are liable to change over time as people’s circumstances and expectations change and, hence, do not constitute a stable or reliable concept. However, Farquhar (1995a) questions if it is people’s assessments of the quality of their life rather than the definition of quality of life that changes.

Most quality of life research now incorporates both subjective and objective dimensions; both measures have advantages. Objective measures allow extensive research from multiple disciplines to be employed. They also allow community standards to be included in quality of life assessments. Objective indicators can aid the implementation of social policies and programmes as it may be easier to identify the effect of such policies and programmes on objective rather than subjective quality indicators (Raphael, 1996). On the other hand, subjective measures allow those who benefit most from goods or services to contribute to research designed to improve those goods or services. In this way, subjective indicators focus attention on the aspects of quality of life that are of primary concern to the recipient, not the provider, of the goods or services (Raphael, 1996). Subjective indicators also reflect the heterogeneity of people and the fact that ‘different people value different things’ (George and Bearon, 1980).
In a study of quality of life in nursing homes in the USA, Kane treated residents’ own reports as the gold standard for quality of life because, in her view, quality of life is inherently subjective (Kane, 2003b). However, she does not advocate the exclusive use of subjective measures as they may be subject to bias (Kane, 2003c). Self-report measures of quality of life may have to be treated with some degree of caution for a number of reasons: residents may be reluctant to criticise nursing home facilities or staff upon which they are dependent (Kane, 2003c; Raphael, 1996; Clark and Bowling, 1990; Bowling et al., 1991; Bowling and Formby, 1992; Cohn and Sugar, 1991); they may not wish to appear ungrateful or unappreciative of the service offered; residents who have been in the home for some period of time may become desensitised to their conditions or lack knowledge about what constitutes an acceptable standard of quality of life and view their conditions as adequate (Kane, 2003c); and Lawton (1983) points to the fact that the tendency of people to assert their satisfaction may be accentuated in older people. Therefore, objective views on a resident’s quality of life may also need to be garnered from staff, family or the direct observation of researchers.

A discrepancy between appraisals of quality of life may occur due to differing agendas and perspectives. Cohn and Sugar (1991) found clear differences in the ways in which nursing home residents, staff and families defined quality of life. They suggest that groups tended to define quality of life in terms of domains that validated their roles (Cohn and Sugar, 1991). It may be that salience is also a factor, with groups emphasising those areas for which they hold responsibility or with which they are most familiar. While medical experts judge quality of life based on physical and functional impediments of a person, the individual concerned will consider other aspects of life when evaluating their quality of life (Bond and Corner, 2004; Gentile, 1991).

Berglund and Ericsson (2003) conducted a study to compare meanings of quality of life as defined by older people and geriatric staff. Their results revealed a variation between what the two groups judged to be important for quality of life. Geriatric staff over-emphasised two of the categories – health and social network. The older people placed more emphasis on subjective factors such as ‘being appreciated’ and ‘living a good life’. The authors feel that this evidence underscores the importance of including the views and opinions of older people in care planning. This is a view supported by Kane (2003b; 2003c) and Tester et al. (2004). Therefore, subjective indicators are needed in the setting of policy goals, based on what people need and want. Objective indicators alone do not provide sufficient information. Haas (1999b) recognises the importance of objective indicators of quality of life but believes that they should be used to complement subjective indicators which are a more direct measure.
Human needs may also provide part of the foundation for quality of life and this can be an important influence on the theory and practice of measurement (Bowling, 2004; Raphael, 1996; Sirgy, 1986; Browne et al., 1997). A.H. Maslow’s *A Theory of Human Motivation* (1970) outlines a needs-based approach to measuring quality of life that adopts a hierarchical stance. At the bottom of the hierarchy are basic needs which are physiological, followed by safety and security needs. These needs are deemed to be essential for human survival and it is not until they have been fully satisfied that an individual will seek to fulfil higher level needs. When the physiological and safety needs have been gratified, then love, affection and belongingness needs will emerge. These include the need for affectionate relationships, for example with family and friends. When this need is satisfied, the individual will strive to fulfil esteem needs which include a feeling of self-respect and self-confidence and the gaining of the respect of others. Finally, Maslow maintains that even if all of these are met, an individual will not be at peace until they have fulfilled the need for self-actualisation, i.e. ‘the individual is doing what h/she, individually, is fitted for’ (Maslow, 1970). In other words, the individual must be able to realise and express his full potential, whatever the circumstances; what Sen (1993) might describe as maximising capabilities.

The consideration of quality of life in terms of human needs provides a useful framework for understanding the interplay of objective and subjective components of quality of life and why people’s perceptions of quality of life may change over time. Bowling (2004) believes that the objective approach to measuring quality of life is fundamentally a needs-based approach (which assumes that individuals have basic needs) and the satisfaction of these needs determines an individual’s well-being. Therefore, as a society becomes more affluent and basic needs (e.g. physiological, comfort, safety and security) are met, subjective indicators of quality of life may grow in importance (Gentile, 2001). Therefore, quality of life may be more accurately measured or defined as an individual’s evaluation of their perceived well-being or satisfaction with life.

### 3.4 Assessing Quality of Life for People with Dementia

A particular challenge arises in the measurement of the quality of life of people with dementia. Any framework adopted for measuring the quality of life of residents must take account of the needs and limitations of people suffering from dementia (Lawton, 2001). It is often assumed that dementia patients are incapable of
Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland

expressing their preferences or views on the quality of their lives. Cognitive impairment, memory loss and the inability to communicate do pose difficulties in obtaining self-report measures of quality of life (Lawton, 1997; Bond, 1999). Therefore, relying on self-reported measures of quality of life alone poses the risk of excluding the perspective of a sizeable proportion of the nursing home population (Kane, 2003a; 2003c). Strategies adopted to assess the quality of life of people with dementia must be extended to include direct observation and proxy reports, as well as self-reporting (Lawton, 1991; Hubbard et al., 2003; Kane, 2003a; 2003c). Lawton (1997) believes that proxy measures of quality of life can be obtained for objective quality of life domains such as activities of daily living, behaviour, social interaction, affect states and environmental quality. Proxy measures include direct observation and attribute ratings. Direct observation entails directly monitoring behaviour in order to capture occurrences of particular events. Attribute ratings are single ratings of quality of life based on observations of a resident over an extended time period. While direct observation may be more time consuming, it may be more reliable than attribute ratings which can be subject to observer bias.

Hubbard et al. (2003) utilised interview and observational methods to elicit the perceptions of nursing home residents suffering from dementia. The researchers found that the observation technique provided a more spontaneous and less constrained means of ascertaining what influenced a resident’s quality of life. The observational method also granted more control to the participant. Although the participants were unable to thoroughly articulate their feelings and perceptions regarding quality of life, the researchers were able to establish specific domains by observing and analysing the resident’s behaviour and casual conversation. The study also highlighted the importance of flexibility in measuring quality of life of dementia sufferers. The unpredictable and volatile nature of the disease means that the lucidity and ability of sufferers to communicate will vary from day to day and, indeed, from hour to hour (Hubbard et al., 2003). According to Lawton et al. (1999), while residents suffering from moderate to severe dementia may no longer be able to verbally communicate their opinions on quality of life, they may still be able to express their preferences through their emotions. By observing and interpreting residents’ displays of emotions, nursing home staff and care givers can adapt the nature of their care giving in order to influence and improve the quality of life of the patient (Lawton et al., 1999).

Kane (2003c) found that significant numbers of residents who scored poorly on a cognitive score were able to answer a long quality of life interview. This finding has been supported by other researchers (Brod et al., 1999; Logsdon et al., 1999). In a study by Coen et al. (1993), patients suffering from mild dementia were able to
successfully complete a self-report measure of quality of life, the Schedule for the Evaluation of Individual Quality of Life (SEIQoL). Therefore, it should not be taken for granted that dementia sufferers are unable to report on their own quality of life. Indeed, encouraging dementia sufferers to activate and use any retained abilities to communicate can serve to improve the quality of life of people with dementia (O’Shea and O’Reilly, 1999). Through increased communication, dementia patients can make their needs and feelings better understood and have improved interactions with other people and the environment.

In cases where dementia patients are incapable of reporting their own quality of life, proxy assessments may be utilised. Family members are usually the best proxies but staff members may also be trained to be reliable proxies. Proxy rating, however, poses a difficult undertaking as proxies must attempt to rate the quality of life of the resident from the resident’s perspective, not from the perspective of the rater themselves (Coen, 1999). This means that a degree of objectivity and impartiality is needed. Addington-Hall and Kalra (2001) found that proxy assessments may be influenced by the feelings and experiences of caring for the patient. As a group, proxies tend to rate a patient’s quality of life worse than the patient themselves would rate it. Kane (2003c) found that proxy reports correlated poorly with those of residents thereby raising concern about the validity of such measures.

### 3.5 Quality of Life Domains for Older People

In recent decades there has been an increasing acknowledgment of the importance of the measurement and enhancement of quality of life of older people in particular. Increases in life expectancy in the twentieth century have resulted in an increased older population in Western developed countries. Accompanying this has been an emergence of a more positive view of old age as a period when people are freed from formal social responsibilities such as employment and parenting and are free to enjoy an active and fulfilled retirement. This means that older people will strive to maintain and enhance the quality of their lives in order to fully enjoy this stage of the life-cycle. In a study carried out by Gabriel and Bowling (2004) on the quality of life of older people living in private households in Britain, the main quality of life themes that were revealed included: having good social relationships, help and support; living in a home and neighbourhood that is perceived to give pleasure, feels safe, is neighbourly and has access to local facilities and services including transport; engaging in hobbies and leisure activities (solo) as well as maintaining
social activities and retaining a role in society; and having enough money to meet basic needs, participate in society, enjoy life and retain one’s independence and control over life. Many of these themes are relevant to people in all age categories, while some are particular to people in their later years.

However, older people do not comprise a homogeneous group; it is not possible to generalise about the concept of quality of life for older people, given the variety of circumstances in which older people may live their lives. Quality of life will differ for able older people and for older people who may suffer from a physical or mental disability. Old age is often accompanied by increasing ill-health and declining physical and mental ability. The goal of health interventions for older people may be to minimise the negative affects of infirmity and improve the person’s quality of daily life rather than effect a cure. Some older people are unable to remain in their own home due to increased frailty and difficulty coping with activities of daily living, and so require residential care. A further distinction may, therefore, have to be made between dependent older people who live at home and dependent older people living in residential care, as quality of life domains may differ between the two settings. It is important to recognise this heterogeneity when consulting older people about the quality of their lives. As Kane (2003c) notes, older people who do not require long-term care may have different and higher expectations for their quality of life than recipients of long-term care.

A universal quality of life measurement instrument, the World Health Organisation Quality of Life Survey (WHOQOL-100) has been developed by the World Health Organisation (WHO). This instrument is applicable to quality of life among all age groups and in all settings. In order to ascertain the factors that contributed to quality of life, the WHO consulted focus groups comprised of health professionals, and members of the general population who were ‘healthy’ and those who were in receipt of health services. Six quality of life domains emerged from the consultation process. The domains ranged from health-related factors such as physical, psychological and level of independence factors, which include aspects such as pain and discomfort, mobility and self-esteem, to social factors such as social relationships and spirituality. The environment also emerged as an important contributor to quality of life. The domains reflect the multidimensional and all-encompassing nature of quality of life. They also reflect the difficulty of measuring the concept of quality of life. While it may be relatively easy to observe and measure physical or environmental features, it proves more difficult to measure self-esteem or the level of social support of an individual. An abbreviated version of this instrument – the WHOQOL-BREF (The WHOQOL Group, 1998) has also been developed which includes just four domains as follows: physical health, psychological health, social relationships and environment.
In relation to older people specifically, Lawton (1983) and Hughes (1990) utilised a conceptual framework in order to establish quality of life domains for older people. According to Lawton (1983), the central aspects of quality of life are behavioural competence and domain-specific perceived quality of life (Lawton, 1991). Behavioural competence refers to an individual’s functioning with respect to health, cognition, time use and social behaviour. Domain-specific perceived quality of life represents an individual’s satisfaction with four domains: family, housing and neighbourhood, friends, and the use of time. Psychological well-being and the objective environment are not central sectors but rather ‘essential components of a loose causal model’. Psychological well-being is ‘the ultimate outcome in a causal model of the open type’ (Lawton, 1991). Objective environment refers to both the physical environment and an individual’s interpersonal environment and can influence both behavioural competence and domain-specific quality of life (Gerritsen et al., 2004).

Hughes (1990) produced ‘a multidimensional model which encompasses all major elements or components in its definition of quality of life’ (Hughes, 1990). The model is based on two basic principles: firstly, it must reflect the multidimensional nature of the concept of quality of life; secondly, no single definition of quality of life exists that can be applied universally. Social gerontology forms the theoretical base for the proposed quality of life model. A set of propositions can be derived from social gerontology which aids the understanding of quality of life for older people. These propositions presume that quality of life for older people can be defined in a similar way to that of younger people; that quality of life must include both subjective and objective elements and that the heterogeneity of older people must be recognised (Hughes, 1990). Hughes describes her model as a network as its component parts interact in order to define and assess quality of life. The relevant domains included in this model are:

- personal autonomy – choice, decision-making, control, privacy
- expressed satisfaction – life satisfaction, affect balance, psychological well-being, positive self-image, consumer views
- physical and mental well-being – physical health, handicap, functional abilities, dependency
- socioeconomic status – income, former occupation, material status, housing, standard of living, nutrition
- quality of environment – warmth, comfort, security, personal space, décor, amenities, routine and rules
- purposeful activity – activities of daily living, recreation, work, interests
- social integration – social contacts, family contacts, social roles, citizenship
- cultural factors – age, gender, class, race, religion.
Many researchers believe that the best way to investigate what factors contribute to the quality of life of older people is to ask older people themselves. Bowling et al. (2002), for example, developed quality of life domains through a national survey of the quality of life of people in Britain aged 65 or over who lived at home. Focus groups of older people were used to advise on the questionnaire content. The final quality of life survey questionnaire consisted of mainly structured questions and scales but open-ended questions were also used to obtain descriptions of respondents’ quality of life and how it could be improved. The results showed that the main domains of quality of life and their components were:

- social comparisons and expectations
- personality and psychological characteristics – self-efficacy, optimism/pessimism bias, depression/anxiety, self-assessed risks of negative life events
- health and functional status – physical functioning, health status, longstanding illness
- social capital (personal and external) – social activities, social contacts, social support, pets, frequency of loneliness, increase in loneliness, quality of area, safety of area, problem of area.

These domains reflect the subjective and social nature of quality of life domains. Quality of life is as much affected by the individual’s personality and attitude (as well as social support) as it is by their health status.

A study by Leung et al. (2004) into the quality of life of older people living in either residential care or their communities utilised focus groups in order to elicit the perspectives of older people on the quality of their lives. The participants were asked open-ended questions such as ‘What are the most important things in your life?’ and ‘What things give elderly people life quality?’. Six quality of life dimensions were identified:

- physical health
- psychological health
- social function
- living environment
- economic status
- religion and death.
The results of this particular study place a lot of weight on more objective quality of life measures such as physical health, living environment and economic status. However, psychological health also emerged as being important, as did social function. The presence of religion and death reflects the importance of the metaphysical in influencing the quality of life of older people.

Quality of life domains for residents in long-stay care have also been investigated. Kane (2003a; 2003b; 2003c) carried out a study to identify factors influencing nursing home residents’ quality of life that were not considered in existing quality of care measures. The study focused primarily on the psychological and social aspects of quality of life. In order to identify relevant quality of life domains, a literature review was carried out and then important stakeholders including care providers, regulators, professionals and family members were consulted in order to ascertain their views. Eleven quality of life domains were identified through this research: autonomy, individuality, dignity, privacy, enjoyment, meaningful activity, relationships, security, comfort, spiritual well-being and functional competence.

Similar research was undertaken by Tester et al. (2004) who interviewed 52 residents in institutional care suffering from severe physical and/or mental disabilities in order to ascertain how they perceived the quality of their lives. The study utilised a range of qualitative interviews and observational methods in order to accommodate the mental and physical capacities of the participants. The researchers initially used focus groups of older people and carers in order to identify the areas of quality of life that are most important to older people, followed by interviews and observations of residents. The process identified four main components of quality of life which are interrelated:

- sense of self – perceptions of own and others’ frailties and strengths, appearance, personal possessions, and privacy
- care environment – autonomy, control, choice, independence and staff/resident relationships.
- relationships – social interaction, relationships with other residents and relationships with family
- activities – meaningful activities, organised activities and religious activity.

Establishing the validity of these various quality of life measures can be problematic, particularly for self-reported or subjective measures (Farquhar 1995a; 1995b; Mozley et al., 2004). The validity of a measurement instrument can be defined as ‘the degree to which a particular instrument measures the variable or phenomenon it is intended to measure’ (George and Bearon, 1980). While there is no direct and
certain test of validity, there are a number of different measures of validity (Arnold, 1991; George and Bearon, 1980), of which content validity is the most important measure in respect of domains. Content validity refers to the extent to which a quality of life measure incorporates all the relevant domains. Content validity may be particularly difficult to assess due to the large number of scales and measures developed to measure quality of life. These scales vary widely in their content and interpretation and often cannot be easily compared to one another (Farquhar, 1995b). The task of determining if a quality of life measure is valid proves more challenging for subjective measures as the importance of a quality of life domain varies from person to person and cannot be compared (Mozley et al., 2004). This means that results gained from self-reported measures are often criticised for their validity (Farquhar, 1995a; 1995b).

3.6 Influences on the Quality of Life of Older People

A person’s physical and social environment has an important role to play in the quality of their life. This is particularly true for residents of long-stay care. Residential care settings can directly influence certain domains, e.g. functional competence, comfort, meaningful activities and security etc. They may also have an indirect influence on other domains. For example, the facility provides the environment or milieu that can either encourage or discourage the resident from maintaining existing relationships or forming new ones. Residents may also depend on the physical design and layout of the residential care setting to compensate for impaired mobility, sensory losses or cognitive impairments (Parker et al., 2004). Therefore, it could be argued that the residential care setting influences all aspects of residents’ quality of life. A study carried out by Kane et al. (2004) using resident reports of quality of life to distinguish between nursing homes found that while resident characteristics explained a substantial amount of the variance, there was a small but significant facility effect. The study findings revealed that nursing homes can influence many different aspects of quality of life including comfort, privacy, meaningful activity, food enjoyment, relationships, security, spiritual well-being, autonomy and independence. Mor (2001) also cites evidence of particular attributes of nursing home environment that influence quality of care and quality of life.
The design of a residential care setting is especially important for residents suffering from dementia. In particular, dementia sufferers benefit from home-like environments, small-scale units, stimulation, easy access and safe outside and/or conservatory space (O’Shea and O’Reilly, 1999). Other important design principles identified by Pynoos and Regnier (1991) that are particularly relevant for residents of long-stay care with dementia include aesthetics/appearance, orientation/wayfinding, safety/security, accessibility and functioning, and stimulation/challenge. Sensory stimulation in the form of sight, smell, hearing and touch can also improve the quality of life of dementia sufferers. A garden is an important part of the physical environment of a long-stay care facility as it offers a change of scenery for the residents and can provide ‘diverse sensory stimulation, including sound, colour and fragrance’ (Barnes and the Design in Caring Environments Study Group, 2002). However, residents may be constrained from accessing the therapeutic effects of a garden space due to concerns about safety. This raises more general issues about the relationship between health and safety and acceptable risk, and the need to balance concerns for health and safety with risk (Parker et al., 2004; Age & Opportunity, 2003; Kane, 2001).

Kane (2001; 2003b; 2003c; 2004) points to the need to identify how resident factors outside the control of the nursing home affect quality of life, for example personal attributes of residents. Certain domains of quality of life will be influenced by personality more than others. Kane (2003c) found that spiritual well-being, security and individuality had a strong relationship with personality, while personality had little effect on factors such as functional competency, autonomy or enjoyment. When specific personality traits such as agreeableness and neuroticism were examined, the results showed that high levels of agreeableness were correlated with a high quality of life. On the other hand, a lower quality of life in domains such as comfort, meaningful activity and autonomy was linked to neuroticism. It has also been shown that social comparison and an optimistic attitude play important roles in quality of life evaluations. Individuals who make downward comparisons with people who are worse off than themselves in some way report a better quality of life (Beaumont and Kenealy, 2004; Browne et al., 1997). This is a view supported by Bowling et al. (2002) who found that individuals who were more optimistic, who made downward social comparisons, had higher self-efficacy and who rated themselves at a lower risk of negative health and life events were more likely to report a good quality of life. The mood and emotional temperament of the participant at the time of interview may also influence the assessment of quality of life reported (Browne et al., 1997). Lawton (1996) infers that as people grow older they moderate and control their emotions more and this serves to optimise quality of life. The disposition of an individual is a stable contributor to quality of life evaluations (Lawton, 1996; Browne et al., 1997).
3.7 Conclusion

While the literature on quality of life is complex, several areas of agreement have been highlighted in this chapter. It is now clear that quality of life is a multidimensional concept, which cannot be explained only in medical terms. Quality of life only makes sense if presented in a holistic context. Quality of life also contains both subjective and objective elements, therefore there is a need to take account of both when measuring the concept. Specifically, the views of older people need to be incorporated into any measure of quality of life. This is so even for people with dementia and related cognitive impairments. There is also an emerging consensus on quality of life domains for older people. These include objective domains such as the physical and care environment, physical and mental health, level of functioning and socioeconomic status; and subjective domains such as psychological well-being, autonomy and independence, purposeful activity, social relationships, spirituality and identity/sense of self. The emergence of these domains confirms the complex, interrelated and multidimensional nature of quality of life for older people. Notwithstanding these points of agreement, much debate and division still surrounds the concept of quality of life and a definitive framework for its definition and measurement has yet to be agreed.
Chapter Four
Methodology
Chapter Four
Methodology

4.1 Introduction

This chapter outlines the research design employed in this study and the methodological approach used for the various component parts of the work. The methodological approach chosen was informed by the literature review relating to quality of life studies in particular. The purpose of this study was to explore quality of life issues as perceived by residents, relatives and staff and to contribute to the overall understanding of quality of life domains among older people in long-stay care in Ireland. Given the lack of agreement on both definition and components of quality of life, the approach taken in this study is a mixed method design incorporating both qualitative and quantitative elements. The qualitative element of the study was informed by a phenomenological approach as the aim was to allow older people to talk about their experience and interpretation of quality of life within the context and culture of their care environment. Quality of life is taken to encompass in a broad sense the social, psychological and physical aspects of living in residential care, as interpreted by residents and staff. Although health and functional status are recognised as important for quality of life in residential care settings, the emphasis in this study is mainly on social and psychological domains as these have not yet featured in any regulatory frameworks for analysing and measuring quality in residential care in Ireland.

4.2 Research Design

A mixed method research design was selected for this study as the aim was to explore the quality of life of older people living in long-stay care from a number of perspectives. Mixed method research is defined as the use of two or more research methods within a single study (Boyd, 2001). Mixed method studies ask complementary questions using different methods and data can be collected from
There are two types of mixed method research: within method and across method (Denzin, 1989). Within method research involves the use of two or more methods within a research paradigm, while across method research involves the use of two or more methods across research paradigms. As this study used qualitative and quantitative methods and part of the qualitative data collection and analysis preceded the quantitative data collection and analysis, the study is categorised as an across method sequential exploratory design. This design was chosen because it gave the best means of exploring the research problems.

Three methods were employed within this study: focus groups; quantitative survey of long-stay facilities and qualitative interviews with residents and staff.

### 4.3 Focus Groups with Managers/Proprietors

Focus group interviews and analysis were undertaken prior to other data collection as they informed the development of the survey instrument and provided, alongside literature review, contextual information on factors that influence residents’ quality of life and care provision in general. Focus groups enabled important background information on quality issues in long-stay care to be gathered. Seven focus groups were held with managers/proprietors of long-stay facilities. A purposeful, stratified sampling strategy was employed to ensure that representatives from the five types of facilities (geriatric hospital/home, health board district hospital/community hospital, health board welfare home, voluntary geriatric home/hospital and private nursing home), the three sectors (public, voluntary and private) and a mix of facilities (large, small and geographical setting) were invited to participate. Managers in these settings were contacted by telephone and invited to attend a focus group; 35 nurse managers were invited to each focus group with the assumption that 10-15 managers would attend. Letters outlining the purpose of the study and the goals of the focus group were sent to nurse managers/proprietors who expressed an interest in attending. The purpose of the focus groups was to identify quality of life issues within long-stay facilities, as perceived by managers/proprietors, and to use this information to inform the data collection process through the survey instruments. In all, seven focus groups were held: three in Dublin, two in Galway and one in Cork and in Donegal. The distribution of participants is detailed in Table 4.1 below.
### Table 4.1: Distribution of focus group participants

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<th>Private</th>
<th>Voluntary</th>
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<td>13</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Dublin (2)</td>
<td>7</td>
<td>2</td>
<td>5</td>
<td>–</td>
</tr>
<tr>
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</tr>
<tr>
<td>Galway (1)</td>
<td>16</td>
<td>8</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Galway (2)</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>Cork</td>
<td>11</td>
<td>4</td>
<td>7</td>
<td>–</td>
</tr>
<tr>
<td>Donegal</td>
<td>$4^4$</td>
<td>3</td>
<td>1</td>
<td>–</td>
</tr>
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<td><strong>37</strong></td>
<td><strong>28</strong></td>
<td><strong>2</strong></td>
</tr>
</tbody>
</table>

### 4.3.1 Development of Focus Group Interview Schedule

A semistructured interview schedule was developed from an analysis of the literature for use in all focus groups. The guide addressed five key areas: dependency measurement, staffing, quality of care, quality of life and future policy. All focus groups were tape recorded with the permission of participants and transcribed verbatim.

### 4.3.2 Conduct of Focus Groups

Careful attention was given to setting up the environment so that participants could be as relaxed as possible. Two members of the research team attended each focus group. One acted as facilitator, the other as moderator. The facilitator’s role was to ask the questions on the interview schedule, clarify issues with the group and explore the extent to which views expressed by a group member were shared by all the group. The moderator’s role was to listen to focus group participant perspectives, gather demographic details from participants, take notes and ensure that the recording equipment was working. Each group was asked questions in the same order and questions and responses were displayed to aid clarity.

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$^4$ Participants representing the public sector in Donegal indicated that two nurse managers had been selected to represent the ten nurse managers in the region.
4.3.3 Data Analysis

The transcripts were coded initially using open codes; a coding guide of interpretive codes was then developed and transcripts were recoded using this guide. Codes were then compared, clustered and collapsed. Analysis revealed six themes: measuring dependency, issues in staffing, recruiting and retaining staff, education and training, maintaining quality of life and policy issues.

4.4 Survey of Long-Stay Facilities

The quantitative survey of long-stay facilities provided an insight into the likely impact of physical, environmental and staffing issues on older people’s quality of life. This national survey of all long-stay facilities extends and develops previous work by the then National Council for the Aged (now the NCAOP) on quality of life in private and voluntary nursing homes in Ireland. The total population of 556 long-stay facilities in Ireland were included in the study. The thirty facilities included in the pilot study were excluded leaving 526 long-stay facilities in the main survey. For the purpose of the study, the DoHC (2003) five categories of long-stay care were used to define the categories of long-stay facilities.\(^5\) These were:

- health board geriatric homes/hospitals
- health board welfare homes
- health board district/community hospitals
- voluntary geriatric homes/hospitals
- private nursing homes.

Two sources of data were used to develop a comprehensive list of facilities under each of these headings: the long-stay care statistics produced by the DOHC and health board lists of all public, private and voluntary long-stay facilities within each region. A comparison of these lists revealed a number of discrepancies. Not all lists distinguished between public geriatric hospitals, welfare homes and district/community nursing units. Voluntary facilities were categorised differently across lists.

\(^5\) The DoHC has made some changes to the categorisation of long-stay facilities for 2004 but previous practice in regard to categorisation was followed.
A small number of private nursing homes listed had closed. There were also differences between how facilities were categorised on the lists received from the health boards and how the facilities categorised themselves. Most discrepancies occurred where a facility categorised as voluntary in the list from the health board categorised itself as private. Also, some facilities listed as welfare homes in the health board data categorised themselves as public geriatric homes. There were, therefore, considerable difficulties in categorising facilities. Pragmatic decisions were made in light of these discrepancies; lists were modified to ensure consistency and some facilities were recategorised. In addition, a web search for new facilities was also undertaken and new facilities added, where appropriate.

4.4.1 Questionnaire Design

The questionnaire used in the survey was developed from that used in the O’Connor and Walsh (1986) study as one of the aims of this study was to allow some comparison between the two studies. The survey instrument, therefore, had to be broadly comparable to the instrument used in 1986. This prior study, however, only focused on the private and voluntary long-stay sector. Following a review of the literature and examination of data from focus groups, a number of changes to the survey instrument were made to reflect changes in the health and social care system in the interim and the need for the questionnaire to be equally applicable to public and private facilities (Appendix One). Questionnaires were coded according to type of facility, health board region and number of facilities in that region.

4.4.2 Pilot Survey

Prior to the main survey, a pilot questionnaire was sent to thirty long-stay facilities across the country (Table 4.2). The pilot sample was stratified to mirror the characteristics of the population as a whole using the following criteria:

- representation from the five categories of long-stay facilities
- inclusion of at least one facility in each category from each health board area (where possible)
- appropriate urban/rural mix
- the total number of facilities used as pilot sites reflected the percentage of total long-stay beds in each of the categories.
Table 4.2: Distribution of questionnaires to pilot sites

<table>
<thead>
<tr>
<th>Region</th>
<th>Geriatric homes/ hospitals</th>
<th>Welfare homes</th>
<th>District/community hospitals</th>
<th>Voluntary geriatric homes/hospitals</th>
<th>Private nursing homes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of total beds</td>
<td>24</td>
<td>4</td>
<td>12</td>
<td>12</td>
<td>48</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>ERHA</td>
<td>1 – – 2 3 6</td>
</tr>
<tr>
<td>Midland</td>
<td>1 – – – 1 2</td>
</tr>
<tr>
<td>Mid-West</td>
<td>1 – 1 1 1 2</td>
</tr>
<tr>
<td>North-East</td>
<td>1 – – – 2 3</td>
</tr>
<tr>
<td>North-West</td>
<td>1 – 1 – 1 3</td>
</tr>
<tr>
<td>South-East</td>
<td>1 1 – 1 2 5</td>
</tr>
<tr>
<td>South</td>
<td>1 – 1 – 2 4</td>
</tr>
<tr>
<td>West</td>
<td>1 – – – 2 3</td>
</tr>
<tr>
<td>Total</td>
<td>8 1 3 4 14 30</td>
</tr>
</tbody>
</table>

Each pilot site was allocated a code and data was entered into SPSS using this code. In addition, feedback was gathered from respondents by telephone with respect to question clarity, time to complete and any other issues. Non-responders were contacted by telephone to encourage them to complete the questionnaire. The final response rate to the pilot questionnaire was 60 per cent (18 questionnaires).

Having analysed the returned pilot questionnaires and respondents’ comments, the basic structure of the questionnaire remained the same but some minor changes were made to the wording of questions and to the layout of some questions. The topics covered in the final questionnaire were as follows: profile of the long-stay facility, including beds, residents and dependency; staff resources, including nursing and other staff and information on shifts; services and facilities, covering therapeutic services, activities and communal provision; care process, measuring choice and autonomy for residents within the facility; and physical resources, detailing the nature of the physical care environment.

Originally, it was proposed that the main survey could be run as a census exercise. It was proposed that a date for return of all data be set and a mechanism for collection of questionnaires put in place, including the physical collection of questionnaires from respondents. It was evident from the pilot work that this would not be possible for two reasons. Firstly, the resources required to physically collect questionnaires from all long-stay facilities in the country were not available
Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland

to the research team; secondly, it was evident from the pilot study that a single date for return would impact negatively on overall response rate as the manager/proprietor would not necessarily be on duty on the specified date. It was decided, therefore, that the questionnaire should be collected by post only and that a longer time span for return be given.

4.4.3 Main Survey

A questionnaire was sent to all facilities (n = 526). Responses were tracked and those who had not returned the questionnaire by a specified date were followed up and telephoned individually. The purpose of this was to encourage participants to return the questionnaire and to clarify with participants any issues they had in filling in the questionnaire. The questionnaire was reissued to all participants who had not returned the questionnaire by a specified date. These strategies helped maximise the response rate. The final response rate was 332 (62 per cent), which is excellent for a postal questionnaire of this type. The response rate varied across facility type; the highest rate was achieved in welfare homes (95 per cent) and lowest in private nursing homes (56 per cent).

An examination of non-response was undertaken to identify if there was any pattern underlying non-response. None was evident; there were responses from all types of facilities and locations. Table 4.3 below outlines the response rate by facility type.

Table 4.3: Questionnaires returned by category of facility

<table>
<thead>
<tr>
<th>Number of questionnaires sent</th>
<th>Geriatric homes/hospitals</th>
<th>Welfare homes</th>
<th>District/community hospitals</th>
<th>Voluntary geriatric homes/hospitals</th>
<th>Private nursing homes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of questionnaires sent</td>
<td>53</td>
<td>19</td>
<td>48</td>
<td>61</td>
<td>345</td>
<td>526</td>
</tr>
<tr>
<td>Number of questionnaires returned</td>
<td>37</td>
<td>18</td>
<td>34</td>
<td>43</td>
<td>193</td>
<td>325</td>
</tr>
<tr>
<td>Response rate</td>
<td>70%</td>
<td>95%</td>
<td>71%</td>
<td>70%</td>
<td>56%</td>
<td>62%</td>
</tr>
</tbody>
</table>

6 The response rate identified above refers to the classification of facilities used at the start of the study. Some survey respondents had recategorised themselves when the survey was returned.
4.4.4 Quantitative Data Analysis

The data from the questionnaires was entered into SPSS Version 12, using double data entry, which was then validated. A comparison of data sets was made using EpilInfo in order to verify that data entry was correct. Three questionnaires had to be excluded from the overall analysis because they did not report their facility type; this left 322 questionnaires for analysis.

Descriptive statistics were used to determine means and create tables of results. F-tests were used to establish if there were significant differences across facility types in the mean ratios of registered nurses to care assistants or residents. Cross tabulations of key variables were used to examine potential relationships. Where appropriate, the existence of relationships between variables were tested for using Pearson’s chi-squared ($\chi^2$) test, the Mann-Whitney test (U) and the Kruskal-Wallis test (H).\footnote{The Mann-Whitney (U) and Kruskal-Wallis (H) tests are non-parametric equivalents of the t- and F-tests respectively; they are used when a normal distribution of the groups cannot be assumed.} Caution must be exercised when interpreting these results since they are simply testing the bivariate relationship between two variables and introducing a third variable or more could fundamentally alter the relationship.

4.5 Resident, Staff and Relative Interviews

The qualitative interview data provided information on perceptions of residents and staff of quality of life in long-stay care. Interviews with residents, staff and relatives were held in 12 study sites and provided rich in-depth data. Using study sites enabled the researchers to gather contextual data which informed data analysis and to include a larger number of resident and staff interviews within the study as it was resource efficient.

4.5.1 Study Sites

The generation of the qualitative data from residents and staff occurs within residential sites and consequently contains elements of case study methodology in that the data collection process captures ‘holistic and meaningful characteristics of real life events’ (Yin, 1994; 1999; 2003). The focus on study sites provides an understanding of the ‘processes and context’, allowing constraints experienced
by participants to be taken into account (Glen and Waddington, 1998). However, the methodology cannot be described as one of case study, mainly because the emphasis throughout the work is on the identification of quality of life domains rather than on providing a holistic, integrated and comparative account of the 12 study sites. Although comprehensive data was collected, case study material will not be presented primarily because access to residents and staff for the qualitative study was predicated on guaranteeing owners, managers and respondents of the 12 facilities a high level of anonymity; this would not be possible using a case study methodology.

To provide contextual data and facilitate data collection 12 study sites were selected in line with criteria that ensured that they were reflective of the five types of long-stay facilities. Geriatric hospitals (n = 2) and the welfare home (n = 1) were selected on the basis of age of the establishment and number of residents. Voluntary facilities (n = 2) were selected on the basis of governance and number of residents. Health board district hospitals (n = 2) were selected on the basis of type and age of establishment. Private nursing homes (n = 5) were selected on the basis of size, governance/ownership and original purpose of the facility. The number of study sites chosen within each facility type was also determined by the percentage of beds that facility type had of the total number of long-stay beds. These inclusion criteria were agreed by the Quality of Life in Long-Stay Care Consultative Committee set up by the NCAOP. Following this agreement, a list of all eligible sites was drawn up and study sites were selected at random from that list.

4.5.2 Number of Study Sites

The number of study sites to be included in this study was agreed in advance with the NCAOP Consultative Committee. The location of sites was confined to the East and West of the country in order to minimise travel and data collection costs. For the purposes of the study, East was defined as the counties of Dublin, Kildare, Wicklow and Meath. The West included the counties of Mayo, Roscommon, Galway and Clare. Facilities were also divided into urban and rural in the two regions. Urban was defined as Dublin and Galway cities while rural was all other areas. A minimum of one urban and one rural facility in each category was included, except for community/district hospitals, and a proportionally higher number of private facilities were included to reflect the current ratio of private to public facilities in the country. As there were no community or district hospitals in the two urban areas included, two rural study sites were chosen in this category – one a community hospital and one a district hospital.
Anonymity and confidentiality are important in all studies, but because of the size of Ireland there was a particular concern that sites could be identified if each site was reported on individually. It was essential, therefore, that the report was written in a way that minimised the likelihood of site identification. It was decided, therefore, not to portray any single one of the sites; the report synthesises the findings from each facility type and the results are presented under the four themes that emerged from an analysis of the qualitative data. The four themes are: care environment and ethos of care; personal identity; connectedness; and community, activities and therapies. Under each theme appropriate examples are drawn from the 12 study sites, thereby providing context and lived experience for the results that emerge.

4.5.3 Gaining Consent for Interview

Each selected study site was contacted by phone and invited to take part in the study. They were given assurances that their facility would not be named or be recognisable in the final publication. Permission to gather data within the study site was granted in 8 out of the 12 facilities initially approached. Permission was refused for a variety of reasons, including one facility no longer functioning. Where permission was refused, the next facility on the list was approached. Following agreement to participate, an information pack was sent to the facility detailing what participation involved. Each facility was asked to sign a consent form and was contacted again by telephone to confirm participation. Table 4.4 shows the breakdown of the study sites following the stratified random selection on the basis of the criteria set out above.

Table 4.4: Study sites

<table>
<thead>
<tr>
<th>Facility type</th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary hospital</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Community/district hospital</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td>Private nursing home</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Welfare home</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Geriatric hospital/home</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
4.5.4 Profile of Study Sites

A comprehensive profile of each facility was completed by research assistants (Appendix Two). A template for this profile was developed by the research team and used by each research assistant so that there was consistency of data gathered from each study site. The research assistant remained on site for one week and was responsible for identifying residents, staff and relatives for interview, for establishing a rapport with residents and staff, gathering demographic data from interviewees, obtaining consent and completing the quantitative instruments with residents. Interviews with residents and staff were conducted by experienced interviewers. Interviewers used an interview schedule to guide interviews.

A list of residents for interview was supplied by the director of nursing in each of the chosen facilities. The list excluded residents who, for either physical or mental health reasons, could not participate. Residents were then selected at random and invited to participate. If they refused, or were not deemed suitable, another resident was chosen at random from the list. Staff were also selected randomly from the duty rotas. All staff involved in direct care had the potential to be included. Residents selected for interview were asked to nominate a relative who may wish to participate in an interview. Telephone interviews were conducted with relatives.

4.5.5 Research Instruments

The Middlesex Elderly Assessment of Mental State (MEAMS) (Golding et al., 1989) was used to ensure that residents were cognitively able to participate in the study. The MEAMS was chosen, firstly, because it has the capacity to differentiate between dementia and depression (Golding et al., 1989) and, secondly, because amended norms for participants who have had a stroke are available (Shiel and Wilson, 1992). Only residents with a score of three or higher on the MEAMS were included for interview. Residents’ overall level of dependency was measured by the Collin and Wade version of the Barthel Index (Collin et al., 1997). This was administered by interview with residents where possible or when not with staff on residents’ behalf.

4.5.6 Interview Schedules

Following an analysis of the literature, two resident interview schedules were developed – one for residents who could communicate without difficulty and one for residents who could only answer ‘yes’ or ‘no’ (Appendix Three). The schedules were based around the domains of quality of life identified within the literature and
from stakeholders who attended the focus groups. A total of 12 domains were presented to residents: ethos of care; choice and control; privacy; feeling cared for/feeling secure; sense of self; meaningful activity; companionship; relationships; continuity with life/community; independence; spirituality and a general category. All interviews addressed the 12 domains but the schedule was used flexibly in order to allow a conversational interview style. The schedule included prompts which were used only if resident participants required further guidance. Two pilot interviews were undertaken in order to test the interview schedules. Following analysis of the pilot data, some minor modifications to the schedules were made. A similar schedule was prepared for staff (Appendix Four) and relatives (Appendix Five). In the staff interview schedule specific questions on resident quality of life and staff educational needs were added.

4.5.7 Sampling Strategy

A purposive sampling strategy was employed which is typical of qualitative research. Purposive sampling entails making a ‘calculated decision to sample a specific locale according to a preconceived but reasonable initial set of dimensions’ (Cutcliffe, 2000). In this study the following sampling decisions were taken:

- to sample across the five care facility types, including rural and urban settings
- to ensure the views of both men and women were represented
- to include residents who were new to the facility (there for less than three months) and those who had resided in the facility for longer periods
- to include residents who had significant communication difficulties
- to include staff with different roles, for example cooks, physiotherapists, nurses and activity therapists; and at different levels, for example directors of nursing, registered nurses and care assistants.

There are no firm criteria or rules regarding sampling size in qualitative research. A small sample size permitting full, in-depth study of the chosen topic is typical of qualitative studies (Tuckett, 2004; Miles and Huberman, 1994; Patton, 1990). Factors such as the quality of information, type of interview and available time may determine what is possible (Polit and Beck, 2004). The goal in this study was to include the perspectives of as many residents, staff and relatives as possible. A pragmatic decision was taken, therefore, to interview as many residents as possible within the available time.
4.6 Interviews

4.6.1 Residents

In all, 120 residents were identified for interview, 10 from each study site. However, some residents were unable to be interviewed on the day due to ill health. The sample was comprised of residents who were newly admitted, residents who had lived in the facility for longer than three months and residents who had some cognitive impairment but were able to understand questions and respond. Both male and female residents were included. In all, 101 resident interviews were conducted. Interviews lasted between 15 and 45 minutes.

4.6.2 Staff

An interview schedule to guide staff interviews was developed following an analysis of the literature. Forty-eight interviews were conducted with staff across facilities, 4 within each study site. All categories of staff were included. Interviewees included registered nurses, directors of nursing, health care assistants, care attendants, cooks, cleaning staff, physiotherapists and occupational therapists. Interviews lasted between twenty and forty minutes.

4.6.3 Relatives

Relative interviews were conducted by phone. Again, an interview schedule was developed to guide these interviews. Twenty-four relatives were identified for interview, two within each study site. However, a number did not agree to participate. In all, 13 interviews were conducted with relatives. Interviews lasted between 15 and 20 minutes.

4.6.4 Qualitative Data Analysis

All resident and staff interviews were recorded with the permission of the resident or staff member. Interviews were then transcribed verbatim. Relative interviews were gathered by phone. Recording of these interviews over the phone was found to be unsatisfactory so extensive notes were taken. The constant comparative technique was used to analyse this data (Strauss and Corbin, 1990). This involved reading each transcript and assigning preliminary codes. Similar codes were then grouped to form tentative categories. A coding guide was formulated at this stage and used to reanalyse the data. A process of continuous comparison enabled the collapse of category domains and the identification of overarching themes.
4.7 Ethical Clearance

Ethical clearance was sought prior to data collection from the National University of Ireland (NUI) Galway Research Ethics Committee. Informed consent was obtained from all residents, staff and relatives prior to interview. Given that the resident sample group was defined as a vulnerable group (Polit and Beck, 2004), special consideration was given to ways of obtaining informed consent. The research assistant described the study in detail a minimum of 24 hours before the interview was scheduled. This gave residents an opportunity to consider if they wished to participate. They were assured that they had a right to withdraw at any point without consequences. Once consent was obtained, participants were allocated a study number and all interview data collected was identifiable by this study number only. Questionnaires were also given a study number and all identifying data were removed. Data were entered into the statistical programme by study number only. Anonymity, privacy and confidentiality were maintained at all times.

4.8 Conclusion

This chapter provides an overview of the research approach adopted. A mixed method research design was used. In total, 7 focus group, 101 resident, 48 staff and 13 relative interviews were conducted over 12 study sites. In all, 526 long-term care facilities were surveyed with an overall response rate of 62 per cent. The combination of data sources has resulted in rich, in-depth data. It is beyond the scope of the current report to include all of this data and further output can be expected. The objective of this report is to identify the key domains of quality of life in long-stay care and to explore the policy implications for standard setting and regulatory frameworks that arise from consideration of these domains.
Chapter Five

Quality of Life in Long-Stay Care Facilities: Focus Group Findings
Chapter Five
Quality of Life in Long-Stay Care Facilities: Focus Group Findings

5.1 Introduction
In this chapter the findings of the focus group interviews are reported. Focus groups were conducted with a sample of nurse managers representative of the five facility types. A total of seven focus groups were held: three in Dublin, two in Galway and one each in Cork and Donegal. Participants were encouraged to talk about the broad topics of quality of life, quality of care, dependency, staffing and future policy. Focus groups proved to be a valuable method for collecting data from service providers across facility types that differed geographically, organisationally and in approach to delivering care to older people. The data provided rich contextual information and helped to inform the development of the survey tool. Analysis of the data revealed six key themes: measuring dependency, issues in staffing, recruiting and retaining staff, education and training, maintaining quality of life, and policy issues.

5.2 Measuring Dependency
This theme focused on participants’ experiences of dependency measurement, their perception of its purpose and the issues they encountered in measuring resident dependency. The majority of participants considered measuring resident dependency to be useful. They identified three main uses: identifying residents’ care needs, making a case for staffing, and determining appropriate subvention levels.
All participants reported that there had been a dramatic change in resident dependency level over the last ten years as most residents admitted to long-term care were now high or maximum dependency. They reported that measures put in place to enable older people to stay at home for longer resulted in higher dependency levels when residents were finally admitted. In addition, some participants felt that the current DoHC categories (low, medium, high and maximum) were too broad. They reported that the majority of residents fell into the high or maximum category despite having very different needs. Some participants, therefore, felt that current measurements were insensitive to the varied needs of residents, lacked specificity and were open to interpretation.

**Measuring dependency: comments from focus group participants**

*Where you are trying to increase the level of staffing, you would certainly need some documentary evidence to support that.* (FG1D)

*Because of the rate of subvention you’re sometimes trying to bring them up to max in order for them to qualify for the subvention.* (FG2G)

*Sometimes you can’t assess someone’s dependency level accurately until you’ve cared for them for a little while.* (FG3D)

*Some of what would be described by the health board as maximum dependency would be some of our least troublesome residents. The person that is lying in the bed all day and doesn’t look for much to someone that maybe has a psychiatric disorder that’s very depressed and it’s every day you’re having to watch them.* (FG2G)

*Most older people in long-stay care are at very high dependency and even if you were to scientifically measure it there would be very small numbers that would move out of dependency levels four (maximum) or three (high).* (FG1D)

### 5.3 Staffing Levels and Skill Mix

Focus group participants reported that there was a great variation in staffing levels across long-term care facilities in Ireland. They suggested that staffing levels in the public sector had been set some time ago and have remained largely unchanged. They described staffing levels as historical and suggested that current levels did not meet the needs of their service. While the ‘historical’ setting of staffing levels was mostly an issue for those working in the public sector it was not exclusively so. Some participants working in the private sector reported similar problems.

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8 Whilst a key to interpreting codes can not be supplied for reasons of confidentiality, codes are included to illustrate the spread of responses across focus groups and study sites.
Participants from welfare homes reported a particular problem as they perceived staffing levels within these facilities to be very low and not reflective of current resident dependency. They explained that residents’ profiles have changed over time and these facilities now have large numbers of residents of high or maximum dependency but staffing levels which assume residents to be low dependency. There were difficulties with both the staffing numbers and the number of registered nurses. In contrast, participants who worked in facilities which had previously been designated ‘acute’ described their staffing levels as adequate or generous.

In the private sector, staffing was set with residents’ needs and economic viability in mind. While the legislation required just one registered nurse on duty per shift, some facilities had increased staffing over and above this level, as recommended by the Inspectorate. In contrast, other participants suggested that staffing levels remain an issue within some private nursing facilities. They reported that the issue was related more to the mix of registered nurses to care assistants rather than numbers per se and that some facilities did not have an appropriate number of registered nurses. The inspectors who attended focus groups highlighted the need for review of the Health (Nursing Homes) Act, 1990, which currently only requires one registered nurse to be on duty at any one time. When resident numbers were high they found that this level of registered nurse cover was totally inadequate.

Coupled with the issue of staffing was the issue of skill mix. All participants stressed the need for an appropriate skill mix. They argued that there was a need to ensure that registered nurses’ expertise was maximised; this could only be done if nurses were supported by appropriately trained health care assistants and/or care attendants, and nurses embraced change. Some participants reported they did not have an appropriate mix of staff. For some the problem was a lack of registered nurses but for others it was not enough care assistants.

Participants suggested that there should be national policy guidelines in relation to skill mix and the determination of what is an appropriate skill mix. Participants explained that an appropriate skill mix also required nurses to delegate some of their tasks and duties to others. Participants suggested that it was difficult for some nurses to do this. They believed that some nurses were comfortable with a role which included many non-nursing duties, for example general administrative and clerical work, and did not wish to redefine their role if it meant increased responsibility or autonomy.
5.4 Recruiting and Retaining Staff

Many participants reported difficulties in recruiting and retaining staff within services for older people. They suggested that this was because of the increased opportunities available to registered nurses elsewhere in the health services. They perceived that gerontological nursing was not the first preference of younger nurses. This had two effects: firstly, some services had to recruit high numbers of overseas nurses; and secondly, investing in staff appeared less worthwhile if they were in post for a short time only. This was a particular problem for many of the private nursing homes who suggested that the nurses they recruited to their facilities saw working in a private nursing home a stepping stone to moving to working in the public and acute sector.
Participants also reported that there were fewer younger nurses working in older people’s services. They were concerned about this as they believed that older peoples’ services needed to attract and retain younger nurses. However, participants also believed that working with older people required maturity and experience and, therefore, was most appropriately suited to those who had some years of experience in clinical settings other than older people’s services.

The other group of nurses most likely to be transient were overseas nurses who were attracted to higher pay differentials in the public sector and perceived work within the acute sector as having more potential career opportunities for them. Participants in Dublin reported that up to 85 per cent of their registered nurses were from overseas.

In addition, participants expressed concern about the age profile of their staff. For many, the failure to recruit younger people into their services meant that many of their staff were over fifty years old and some were close to retirement. While they acknowledged the experience and quality of these staff, they were concerned about their ability to continue to participate in heavy physical work into their sixties and to remain enthused and motivated.

Participants also reported that they were heavily dependent on longer-term staff for continuity of care and their knowledge of local policies and procedures. The transient nature of younger and overseas care staff posed real challenges in providing continuity of care. Continuity was also identified as an issue for participants who had put in place flexible working options for staff. While family friendly policies were key to retaining staff, participants suggested that full-time permanent staff were required to cover antisocial duties and holiday times.

All participants highlighted the need to positively promote the nursing of older people. They suggested that ageism coloured perceptions of this work but also that the nursing profession itself did not sufficiently value the potential of nursing older people as a nurse-led opportunity. Some participants articulated the complexity of caring for older people and suggested that clinical career pathways needed to be developed in order to attract people into this specialism and retain them.
Recruiting and retaining staff: comments from focus group participants

A lot of nurses see a nursing home as a stepping stone to get back into nursing and then move on once they are back into the system. That is where I have been burnt. (FGC)

The nurse I would like to see is a nurse who has spent at least three or four years in the acute sector, who comes to you with total confidence in her abilities, and it is very difficult for them to develop a lot of skills in the care of the elderly. ... She needs to develop (these skills) in the wider setting, and maybe in the bigger hospital. (FG1D)

In the private nursing home sector, I think there’s about 80-85 per cent of staff from overseas. ... Older people sometimes have difficulty in trying to communicate, but trying to communicate with somebody who doesn’t understand (is difficult). (FG2D)

It’s hard. ... It’s a physical job, they’re tired, they haven’t the same energy, some of them may have back problems or whatever, they don’t have the same interest in education either, you know, and they just want to come in, do a day’s work and go home, and that’s it. (FG1G) (Referring to older nurses)

It (flexible working options) means that the person who’s there all the time – a bigger burden falls on them, because they have to be the lynchpin ... the burden of responsibility seems to fall on them. (FGDO)

5.5 Education and Training

Participants suggested that education and training of staff within older people’s services was an essential prerequisite to staff motivation and organisational change. They were concerned, however, about staff access to educational opportunities as releasing staff was a problem and suitable courses which were geographically convenient were not always available.

Many participants reported that some care attendants in their facility were undertaking the training programme for health care assistants and suggested that this course had made an enormous difference to both the skills of staff and their approach to practice. Care attendants who had either completed or were undertaking the programme were described as more questioning, assertive and better able to contribute to individualised care. However, many participants across focus groups highlighted the difficulties they had in implementing the evolving health care assistant role as there was a lack of clarity in relation to job description, national issues in negotiating new contracts, and issues related to pay and cover for domestic tasks.
Education and training: comments from focus group participants

It’s one of the most difficult things to initiate – is organisational change. At the end of the day, it’s the hardest job. … And I think the only way you will deal with it is through education and training. It’s the only tool that you will break it down with. (FG3D)

I think sometimes on the fringes you do lose out (on educational opportunities) and it’s vital to keep in touch now. Everything is changing so rapidly … and I know practice is important too, but in order to practise, you have to have the knowledge. (FG1G)

I’ve seen a difference in their actions and their behaviours on the ward. … Much more careful and much more precise. … They’re asking more questions … taking more individual attention to the patient. (FGC) (Referring to care assistants who are undertaking the health care assistants training programme)

5.6 Maintaining Quality of Life

Participants considered a focus on quality of life to be important. They perceived that residents’ quality of life is affected by the physical and social environments in which they live. Opportunity to keep in touch with their community was also identified as a dimension of good quality of life.

5.6.1 Physical Environment

Participants believed that the physical environment of the facility significantly impacted on residents’ quality of life. Participants described the negative impact of the structure of older facilities on residents’ independence, privacy and dignity. Participants working in older facilities indicated that in these facilities, large open wards and cramped space was the norm. In some cases, the lack of day rooms meant residents had little option but to remain by their bed for the duration of the day. Participants believed that poor building structure and lack of amenities could decrease older people’s independence and ability to self-care. There was unanimous agreement across focus groups that communal living, particularly when coupled with an institutionalised approach, impacted negatively on residents’ quality of life.
Impact of physical environment on residents’ quality of life: comments from focus group participants

New buildings should (have) single rooms, like ... the criteria that are used to build nursing homes ... that should be exactly the same for the public. There should be no difference. (FGDO)

Patients get up in the morning and they’re sitting on their chair which is beside their bed, and the next bed is literally a couple of inches from them. Now the person on the other side of the curtain could be using a commode while this person is actually eating, because we don’t have day rooms, so therefore everything is done in the one space. (FG1G)

I would hate to think that when I’m eighty years of age that my future life would be in a six-bedded ward with the toilet beside the bed, having to watch what the other five want and having to eat what's put in front of me, request something, having to get up when I’m told to and go back when I’m told to. When you put it like that, what you would want for yourself? (FGDO)

One patient if he wants to go to the bathroom has to walk one hundred steps to the nearest bathroom. The chances are that he will become dependent on nursing intervention much more easily than say, if he had an en suite facility that he has to walk four steps to get to the toilet. ... The environment (should enhance) their movement and maintenance of function. (FG1D)

Participants saw the opposite to institutionalised care as individualised care. They believed a resident should be treated as an individual and a person, not a patient. However, participants suggested that individualised did not necessarily mean no routine. They believed that some degree of routine was important and necessary but the goal should be to have as ‘few rules as possible’.

Participants believed creating a home-like environment was an important determinant of residents’ quality of life. They equated ‘homely’ with giving residents control and choice over their day-to-day activities. All groups agreed that the goal of care should be that the life of residents is as similar as possible to the life that they would choose to live at home. They believed residents should be given choices about their day, including the time they got up, when they went to bed and what they did during their day. They argued residents should not be expected to fit into the routine, rather the routine should be sufficiently flexible to allow residents choice. Participants believed that greater choice was possible but that staff attitudes inhibited residents’ choice as much as staffing levels. They suggested staff were sometimes too immersed in the routine to see beyond it and reported that choice was not a reality in some care settings because routine continued to dominate care organisation.
Participants maintained that a key factor in residents feeling at home was whether they were involved in the decision to move into the facility. Participants’ comments suggested that the decision was sometimes a forced choice with the older person being excluded from decision-making. They also commented that it was important that families were included in decisions about ongoing care and/or care provision. They reported that staff sometimes excluded family and suggested this was a habit acquired when they worked in the acute care sector. Participants believed that an important dimension of quality of life for older people was close links with their family. They recommended that a family-centred approach to care should be adopted where possible, where care is shared and jointly planned.

**Importance of individualised and home-like care: comments from focus group participants**

*Being treated as individuals (is important for quality of life), that they don’t just become … like they very quickly become a patient. And really within the care settings, they’re not. They’re not patients.* (FG3D)

*I suppose a home from home environment (is important). I mean if you ask any of the patients where they’d like to be, they all want to be at home, and I think (it is important) to keep it homely.* (FG3D)

*The philosophy should be about making their (residents) pattern of life as close to as what they would experience at home. Sometimes I think that our … there’s this thing called ‘institutional efficiency’ – like we’ve to try and get the patients into the routine as quickly … and I think it should be the opposite way. Even our assessment, do we sit down and ask them well, ‘What time did you go to bed when you were at home?’ Things like that, rather than … the whole emphasis is on getting them into the routine. It’s about patterns of life as close to what they were used to at home.* (FGDO)

*I think the big quality of life issue is that they still have their rights, human rights that they had when they were living in their home, to say that ‘no, I don’t want you to come in and give me a shower today, thank you very much’, and that should be respected, rather than fitting into our routine.* (FG1G)

*We’re so task-orientated. People have to go back to bed at a certain time because you’re going to have less people on in the afternoon or the evening time and people don’t get the choice at all. … I don’t honestly think that it’s all about staffing.* (FG3D)
5.6.2 Social Environment

Participants considered it important that residents had opportunities to participate in recreational activities. They highlighted the importance of planned provision, variety and a choice as to whether to participate or not. Participants suggested that recreational activities were an important indicator of the quality of the social environment.

However, participants reported that it was very hard to meet everybody’s needs, particularly in the larger facilities. Despite recognising its importance, participants found financing activities and trips problematic as it was not budgeted for for.

### Activities: comments from focus group participants

*Well, I think it’s very important (having activities), it keeps them very motivated – activity, and it keeps their mindset from becoming very … looking inwards. And they love activity, and they … it cheers them up a lot, I find. (FG2G)*

*And I think a lot of residents probably would find that (boredom is) a problem initially when they go into long-term care, and then they get so used to the fact that there is nothing happening and they sit there all day. I think that needs to be addressed. (FG1G)*

*Activities, they should be led by the residents really, by their needs, or requirements. (FG2D)*

*They all have their own personality and they have different expectations, and you know, the one that will play a game of cards, the other one never played cards in their life, and won’t do it. It’s difficult trying to cater for everybody. (FG1G)*

*It’s very difficult to achieve in a residential setting, and you don’t have a budget for it either, which is a problem. (FG1D)*

5.6.3 Keeping in Touch with Their Community

Participants considered it important that older people maintained contact with their community and equally that people from the community were involved in some of the activities in the facility. They believed that it was particularly important that the older person was placed somewhere near their home if they were to retain links with their community. Participants also highlighted the importance of volunteers although they made no reference as to whether volunteers should come from younger or older age groups. They were somebody different, somebody residents could chat to and helped to retain a link with the community. Some participants reported that it was difficult to recruit volunteers and that there were issues over insurance under the present Clinical Indemnity Scheme (CIS). A further suggestion was that consideration should be given to integrating day care centres into long-stay facilities as this would increase the potential of residents to retain their local links.
Keeping in touch with the community: comments from focus group participants

*I would have said that being part of the community (is important for quality of life), feeling like they are part of the community, and not being removed from it, or isolated from it. (FG3D)*

*I think having services located as close to home as possible is important. (FGDO)* (referring to making it easier for families to visit)

*With the day care centre, it’s a wonderful facility for the residents of a long-stay unit, whether it be private or public, because when the people come in from the villages around, to the day care unit, the residents look forward to them coming in, because they’re coming from their home areas, and they bring in the news, they chat, they meet. It’s a lovely social outing for the day care, but also for the residents, who look forward to them coming in, and meeting their friends. (FG1G)*

*(Volunteers) enhance the quality of life of people, don’t they? They do the little things that no-one (does). … They develop personal relationships with individuals, as opposed to just going around to everyone. (FG2D)*

5.7 Policy Issues

Participants raised many policy issues. Analysis of this data revealed four main themes: shaping future care provision; increasing the visibility of older people in the system; providing the resources required for care and changing the approach to inspection.

5.7.1 Shaping Future Care Provision

Many participants felt that a new national strategy for older people was required. They were of the opinion that prior policies had not been fully operationalised and stressed the need for a national policy for older people which had full government commitment and appropriate resources allocated for implementation. Participants also reported that the current options for frail older people were too limited. Their vision was one which gave older people a range of care options and rapid access to care. They expressed the need for services to be joined up and based within the local community.

Participants also reported that many older people had difficulty at present in accessing a place in long-stay care. They suggested that some older people waiting for a public bed were waiting for long periods of time before a bed became available.
They believed that this problem was compounded by the fact that some older people who had the resources to pay for private healthcare were not doing so. Beds were, therefore, unavailable to those who were in real need but did not have the resources to pay for them. Participants suggested that there should be a new way of determining the financial resources of older people entering long-term care which would be applied across the sectors and administered by the social work services.

Many participants reported that once a resident was admitted to long-term care, services such as physiotherapy and occupational therapy, which had been freely available in acute care, were no longer available to them. In addition, private nursing homes also reported that some residents had difficulties in accessing services because residents had to pay. While some residents had the resources to pay for services others did not. Participants suggested that it was an unfair burden on residents as they would be entitled to these services free of charge if they had remained in acute care or were in the public sector. A policy which stated the rights of older people to the range of services was, therefore, required.

Some participants suggested that there should be special facilities for people with dementia as their needs were different to other residents and specialised facilities and staff skills were required.

Looking to the future: comments from focus group participants

Well I would say (we need) a national strategy. But not a slow one, not a glossy document! We have the information. (FG1D)

A lot … (of older people) don’t want to move out of their own homes, where they’ve lived all their life. … An out of hours service, a twilight service, whereby they have contact with someone before they actually go to bed, and perhaps early morning calls, because … their level of dependency doesn’t actually warrant somebody to be actually with them, or … (to be in) care. But they’re lonely, and loneliness is one of the greatest problems. (FGDO)

Patients moving into residential care, they’ve had their assessment, there’s nothing after they get there. There’s no such thing as an integrated care pathway. (FG1D)

There should be something legislatively that the health boards can make some claim on an estate – I never thought I’d see myself saying that, but I’ve actually got to believe it now. A nephew or niece that has never visited them, or never had an input into their care, suddenly benefits hugely. I think the reality is in years to come, where people are living longer, pensions have to last longer, you haven’t the same amount of people working, there’s going to be some radical shift in how to fund it, and that’s one clawback. (FGDO)

(You) cannot nurse both types of patients in the one unit; staff need different skills to look after them. (FGC)
5.7.2 Increasing the Visibility of Older People

Participants suggested that there was a need to lobby others to ensure that older people’s services were given the same emphasis and recognition as other vulnerable groups in society such as people with disabilities. Some participants felt the lack of emphasis on older people arose from apathy and ageist attitudes. They suggested that ageism was a major issue both in society and in nursing. They felt that this had a significant effect on quality of life and that a Bill of Rights for older people should be developed.

Participants stated that there were also particular issues related to the ethics of care for older people and the lack of inclusion of older people in the decision-making process. They were concerned that family members may try to limit the freedom of an ageing relative to choose. They suggested that taking informed risks was part of living and that older people should have the right to take calculated risks if they so choose. Participants argued that any new policy related to older people should ensure that older people had the right of self-determination.

Attitudes to older people: comments from focus group participants

Ageism operates right through society and into our institutions! (FG1D)

There was a very interesting comment made by a group of elderly people and they came up with this, not professionals. … They said that, when you’re in your forties or fifties and you want to join a gym, you don’t see on the headline ‘if you don’t join the gym, you’ll get a heart attack’ or ‘you’ll get old quickly’. So why should you say to me, as an old person, if you do this, you’ll fall and you’ll break your hip, and you’ll end up in casualty. So I think we’ve got to kind of … let them take the risks. (FG1D)

5.7.3 Resources

Participants raised two important issues in relation to resources: the need for resources to be channelled into older people’s services and issues related to the implementation of subvention regulations. Participants reported that there was a lack of resources within their services to fund innovative initiatives or new approaches to care provision. They suggested that older people’s services had not been allocated sufficient funding over a number of years and facilities and staffing had, therefore, suffered. They suggested that there needed to be a new emphasis within healthcare policy and that the resources required to implement new approaches to care provision should be allocated. They stated that communal living without a private space was no longer acceptable and purpose-built units which gave older people a room of their own were important and should be part of policy.
Participants also discussed at length the issues related to subvention. Two problems were evident: firstly, that the standard rate of subvention was not enough to provide for the needs of older people; secondly, that the rates of enhanced subvention varied widely across the country. Participants suggested, therefore, that the agreed rate should reflect the actual costs of care. They also agreed that there should be a national approach to enhanced subvention which ensured consistency across the country.

Resources: comments from focus group participants

Communal living! I hate it! The only people who are used to living in a community setting were nuns and priests and even that’s changed; the convents have all been sold off and the nuns put into houses and yet we persist and continue to build institutions that have, you know. … I don’t want to be stuck in a corner with a screen around me, you know. So we have to get away to look at a different approach. (FG1D)

It’s a question of resources. There’s no shortage of ideas and plans and ways to solve it. (FGD0)

5.7.4 Changing the Approach to Inspection

All participants raised the issue of inspections of private nursing homes. The consensus from all focus groups was that there needed to be a change in inspection regulations. Participants suggested that both public and private facilities should be inspected.

Some participants also reported that there was a need to change the focus of inspection. They were concerned that the current focus was more on the physical facilities than on quality of care or quality of life. While they agreed that the standard of the facility was important, they felt the emphasis should be more on standards of care. They suggested that there should be national standards for quality of care which would be used to direct inspections and that the inspectorate should be independent.

Inspection: comments from focus group participants

I think the health board facilities should be inspected too, and brought up to a certain standard. They’re not. It’s one rule for one … (FG2G)

The inspection teams are looking at the switch on the wall and the light on the bulb, or whatever! (FG2D)
This chapter presented the findings of the focus group interviews. Low staffing levels and inappropriate skill mix were considered to be major barriers to the provision of quality care. The relatively low numbers of registered nurses to care assistants in some private nursing homes was also raised as an issue of concern. Participants also reported that it was increasingly difficult to recruit and retain staff.

Participants considered the physical and social environment of the facility to be key determinants of residents’ quality of life. The major negative impacts on quality of life were identified as communal living and an institutionalised approach to care. A shift to individualised and person-centred care was viewed as desirable. Participants made a number of recommendations for change. Chief among these was the need for stronger legislation, an independent inspectorate and the introduction of inspection of both public and private facilities. The need to resource more innovative approaches to supporting people in their homes was highlighted including, for example, rapid access to care, assisted care and joined up care.
Chapter Six

Quality of Life in Long-Stay Care Settings: Survey Findings
Chapter Six
Quality of Life in Long-Stay Care Settings: Survey Findings

6.1 Introduction

This chapter is based on an analysis of the questionnaires that were returned following the postal survey of all known residential care facilities in the country. Of these, the majority of respondents (63 per cent) were from private nursing homes with approximately equal numbers of respondents from public geriatric homes/hospitals, voluntary geriatric homes/hospitals and district/community hospitals (Table 6.1). Welfare homes make up 4 per cent of the total returns. Facilities are categorised ex post according to respondents’ own labelling of their facility rather than on the basis of the ex ante categorisation which determined the postal survey. The main changes occurred in the welfare home category where a small number of welfare homes categorised themselves as public geriatric homes and in the private nursing home sector where some facilities classified themselves as voluntary homes. Responses vary by question, which is why total N values are given for each question, and may be different from the total number of questionnaires returned. As units range in size from 10 to 379 residents, they are divided into categories based on size for some data analysis, particularly for staffing comparisons. Where appropriate, comparison is made with the 1986 survey of private and voluntary facilities carried out by O’Connor and Thompstone (1986) for the National Council of the Aged.
Table 6.1: Type of facility

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private nursing homes</td>
<td>203</td>
<td>63</td>
</tr>
<tr>
<td>Public geriatric homes/hospitals</td>
<td>38</td>
<td>12</td>
</tr>
<tr>
<td>Voluntary geriatric homes/hospitals</td>
<td>34</td>
<td>11</td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>33</td>
<td>10</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>All facilities</td>
<td>322</td>
<td>100</td>
</tr>
</tbody>
</table>

6.1.2 Beds

Table 6.2 shows the minimum and maximum numbers of residents, the mean number of residents and the total number of beds in each facility type. The size of the facilities responding to the survey varied considerably, ranging from 10 to 316 beds. The largest units are the public geriatric hospitals/homes which have a mean capacity of 92 beds. Nursing homes have the lowest mean number of beds at 39. The total bed numbers represented in the survey are 15,223. These beds represent the capacity of facilities rather than actual resident numbers as not all beds were occupied at the time of the survey. This leads to an overall occupancy rate of 92 per cent, highest in the public sector. In keeping with national trends, private nursing home beds in the survey comprise over half of all beds. The majority of facilities provide long-stay accommodation with provision of other types of accommodation amounting to less than 10 per cent of all beds. Some facilities have short-stay, respite, convalescent and palliative care beds, but overall these are largely confined to the public sector. Similarly, the number of rehabilitation beds was low overall and these were most likely to be available in the public geriatric hospitals and homes.

Table 6.2: Total number of beds (including long-stay, respite, convalescent etc.) by facility type

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>N</th>
<th>Min.</th>
<th>Max.</th>
<th>Mean</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private nursing homes</td>
<td>199</td>
<td>11</td>
<td>200</td>
<td>39.1</td>
<td>7,785 (51.1)</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>33</td>
<td>10</td>
<td>316</td>
<td>91.5</td>
<td>3,019 (19.8)</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>32</td>
<td>12</td>
<td>203</td>
<td>60.0</td>
<td>1,920 (12.6)</td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>31</td>
<td>21</td>
<td>155</td>
<td>60.6</td>
<td>1,880 (12.3)</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>13</td>
<td>20</td>
<td>192</td>
<td>47.6</td>
<td>619 (4.1)</td>
</tr>
<tr>
<td>All facilities</td>
<td>308</td>
<td>10</td>
<td>316</td>
<td>50.4</td>
<td>15,223 (100.0)</td>
</tr>
</tbody>
</table>
The total number of residents in the survey is 14,266, of which 12,696 or 89 per cent are classified as long-stay residents. The proportion of long-stay residents was highest in the private sector (95 per cent) and lowest in district/community hospitals (68 per cent). Just under 70 per cent of all residents in long-stay beds are female with the highest ratio of females to males in private nursing homes (Figure 6.1). The vast majority of residents in long-stay facilities are aged 75 years or over, with a significant number (just over 40 per cent) aged 85 years or over (Figure 6.2). This proportion is lowest in district/community hospitals and highest in voluntary homes/hospitals at more than 50 per cent. About 5 per cent of residents are aged 95 years and over. There is a small proportion of people aged less than 65 years of age in each facility type. However, the age of residents does not differ significantly among the various facilities. The percentage of people in the oldest age category (85+) in voluntary and private facilities has increased significantly since 1986, from 29 and 28 per cent respectively (O’Connor and Thompstone, 1986) to 54 and 44 per cent respectively in 2005.

Figure 6.1: Percentage of male/female long-stay residents by facility type
Just under 10 per cent of all residents can be described as being in long-stay care for predominantly social reasons (Figure 6.3). This is a similar result to that generated by the DoHC and published as part of the national *Long-Stay Activity Statistics*. The numbers admitted for social reasons\(^9\) vary considerably among types of facility with welfare homes having by far the highest proportion of residents (24 per cent) in this category. This is not surprising given the role of welfare homes in catering for less physically dependent older people who may have nobody to look after them in the community. Public geriatric hospitals and district/community hospitals contain the lowest proportion of older people admitted for predominantly social reasons. This is again not surprising given the more interventionist nature of care in these two types of facility and their overall higher dependency levels.

\(^9\) A social admission is admission for reasons other than physical disability. The reasons for admission are numerous but are related to a person’s personal circumstances, for example fear for personal safety, isolation or loneliness.
Dependency levels were assessed on a four-point scale from low dependency, through medium and high to maximum dependency.\textsuperscript{10} In addition, levels of confusion, mobility and reliance on personal care, all of which contribute to levels of dependence, were recorded for each long-stay facility. Just under 40 per cent of all residents are in the maximum dependency category which means they require a high degree of nursing care and assistance (Figure 6.4). District/community hospitals and public geriatric homes/hospitals contain the highest proportion of maximum dependency residents. About two thirds of all residents in private nursing homes are either high or maximum dependency compared to 80 per cent in the same categories in public geriatric homes/hospitals. Welfare homes contain the highest number of low dependency residents, although over 50 per cent of residents are either high or maximum dependency despite a policy of admitting residents within the low to medium categories only. Clearly, either admissions policy to welfare homes has changed or residents have become more dependent over time, which is more likely.

Differences in levels of dependency between facilities were tested statistically using non-parametric analysis (Kruskall-Wallis and Mann-Whitney tests). Results show that public geriatric hospitals/homes have significantly greater numbers of residents assessed as being in the high and maximum dependency categories than any of the other facilities. Welfare homes have significantly higher numbers of low dependency residents compared to other types of facilities.

Figure 6.4: Percentage of long-stay residents within dependency category by facility type

\textsuperscript{10} The DoHC four dependency levels were used as this data was already complied by facilities for the annual report of long-stay statistics.
Figure 6.5 shows the percentages of residents in long-stay facilities in each of the three categories of personal care. Overall, just under 10 per cent are classified as independent, 40 per cent need help with some tasks, while the remainder, over 50 per cent, are completely dependent in respect of personal care. Approximately two thirds of residents in both district/community hospitals and public geriatric homes/hospitals are classified as fully dependent with respect to personal care. The corresponding proportion for private nursing homes is less than 50 per cent. Welfare homes contain the highest proportion of fully independent residents at 20 per cent. In 1986, 27 per cent of residents in private nursing homes and 46 per cent in voluntary homes were classified as self-reliant (O’Connor and Thompstone, 1986). In 2005, the corresponding percentages of independent residents were 8 per cent and 9 per cent respectively. This again provides evidence that nursing home populations have become more dependent in the past twenty years.

![Figure 6.5: Long-stay resident dependence in personal care by facility type](image)

Figure 6.6 shows the number of residents pertaining to level of confusion, in long-stay facilities in each of the three categories. Overall, about one third of residents are in each category of mental awareness: mentally alert, confused some of the time, and severely confused all of the time. Again, welfare homes contain the highest proportion of mentally alert residents (55 per cent) while district/community hospitals contain the highest proportion of severely confused residents (38 per cent). However, the remaining facilities, with the exception of welfare homes, all have 30 per cent or more residents severely confused all of the time. In 1986, approximately two thirds of residents in private nursing homes and voluntary facilities were classified as mentally alert (O’Connor and Thompstone, 1986) compared to one third in 2005; this suggests an increase over the 20-year period in residents who are confused in these two sectors.
Figure 6.6: Long-stay residents’ level of confusion, by facility type

Figure 6.7 provides details of the number of residents in long-stay facilities in respect of mobility. Overall, 17 per cent of residents in long-stay facilities in Ireland are fully mobile, 24 per cent are mobile with the use of a walking aid or stick, 18 per cent are mobile with the help of another person, and 40 per cent are immobile, meaning that they are confined to bed or a chair. Over 50 per cent of people in public geriatric hospitals/homes are immobile compared to 25 per cent of people in welfare homes. The latter also contain the highest proportion of residents who are fully mobile (approximately one third of residents). One in three people in private nursing homes are immobile. In 1986, only 20 per cent of residents in private nursing homes were classified as bedfast or chairfast (O’Connor and Thompstone, 1986); this again suggests that dependency in private nursing homes has increased in recent decades. The same picture of increased dependency is true for voluntary nursing homes. While levels of immobility have increased in the private and voluntary sectors, they are still significantly below those observed in the public geriatric homes/hospitals and in district/community hospitals.
6.4 Staffing

The majority of long-stay units (93 per cent) provide access to local GPs for residents, ranging from 76 per cent of district/community hospitals to 97 per cent of private nursing homes. Access to consultant geriatrician services is available in 22 per cent of units responding to the survey, with access more likely in public geriatric homes/hospitals than in private nursing homes. The vast majority of care for older people in long-stay units is, however, provided by nurses and other care staff. Nurse staffing levels are influenced by numbers of residents and by dependency. Consequently, data relating to the mix and level of staff is presented by size of facility, specifically for facilities with forty residents or less, and for facilities with more than forty residents. Staffing ratios are also correlated with dependency levels. Care staff are characterised in terms of whole time equivalents (WTE)\(^{11}\) employed by the different facilities.

Differences in staffing with regard to ratios of qualified staff (i.e. registered nursing staff) to non-nursing care staff (i.e. health care assistants or care attendants) between facilities of different sizes are evident across facilities (Table 6.3). The average ratio of registered nursing staff to non-nursing staff across all facilities with fewer than or equal to forty beds is 1:1.6, ranging from 1:0.7 in district/community hospitals to 1:2.0 in private nursing homes. The average ratio of registered nursing staff to non-nursing staff across all facilities with more than forty beds is 1:1.2, ranging from 1:0.7 in district/community hospitals to 1:2.7 in private nursing homes.

\(^{11}\) Each whole time equivalent (WTE) equals one full-time staff member.
The differences between public geriatric hospitals/homes, welfare homes and district hospitals, for both large and small facilities, were not significant when tested using category by size interaction effects. However, significant differences emerged in respect of nursing/non-nursing staffing ratios between public facilities and voluntary and private nursing homes. Public facilities tend to have higher ratios of registered nurses to non-nursing care staff, with the pattern reversed in voluntary and private homes.

### Table 6.3: Ratio of registered nurses (RNs) to non-nursing care staff and (all) residents by facility type and size

<table>
<thead>
<tr>
<th></th>
<th>≤40 residents</th>
<th></th>
<th>&gt;40 residents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>RNs</td>
<td>Non-nursing care staff</td>
<td>Residents</td>
</tr>
<tr>
<td>All facilities</td>
<td>196</td>
<td>1</td>
<td>1.6</td>
<td>3.9</td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>142</td>
<td>1</td>
<td>2.0</td>
<td>4.7</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>13</td>
<td>1</td>
<td>0.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>14</td>
<td>1</td>
<td>1.9</td>
<td>3.7</td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>15</td>
<td>1</td>
<td>0.7</td>
<td>2.1</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>12</td>
<td>1</td>
<td>1.3</td>
<td>4.4</td>
</tr>
</tbody>
</table>

With regard to staffing ratios of registered nurses to residents, there is significant variation at the 5 per cent level across the various facility types in both small and large institutions (Table 6.3). Overall, staffing ratios are 1:3.9 in facilities with forty beds or less and 1:3.4 in facilities with more than forty beds. In public geriatric hospitals/homes, the average ratio of registered nurses to residents lies between 1:2.0 and 1:2.5 depending on size. A similar ratio exists in district/community hospitals with the range between 1:2.1 and 1:2.2. In welfare homes, where the trend is for the resident population to be less dependent, the ratio is 1:4.4 for homes with forty residents or less and 1:2.8 for homes with more than forty residents.
In private and voluntary facilities, where dependency is, as observed earlier, lower than in public facilities excluding welfare homes, the ratio of registered nurses to residents is highest. For facilities with forty residents or less the ratio is 1:4.7, while for homes with more than forty residents the ratio rises to 1:6.5. Overall, there is a statistically significant relationship between the level of dependency among residents and the ratio of RNs to residents. However, that relationship is strongest within public facilities. Table 6.4 shows the ratio of non-registered nursing care staff to residents. The ratio of non-registered nursing care staff in public facilities is broadly similar to private and voluntary facilities, except for welfare homes which have a slightly higher ratio.

Table 6.4: Ratio of non-nursing care staff to (all) residents by facility type and size

<table>
<thead>
<tr>
<th></th>
<th>≤40 residents</th>
<th>&gt;40 residents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Non-nursing</td>
</tr>
<tr>
<td></td>
<td>Residents</td>
<td>care staff</td>
</tr>
<tr>
<td>All facilities</td>
<td>196</td>
<td>1</td>
</tr>
<tr>
<td>Private nursing</td>
<td>142</td>
<td>1</td>
</tr>
<tr>
<td>homes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public homes/</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>hospitals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary homes/</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>hospitals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>District/</td>
<td>15</td>
<td>1</td>
</tr>
<tr>
<td>community hospitals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Welfare homes</td>
<td>12</td>
<td>1</td>
</tr>
</tbody>
</table>

These ratios are only general indicators of staffing as they do not represent staff on duty at any particular time, given holidays, sick leave and other types of leave. Tables 6.5, 6.6 and 6.7 examine the ratio of registered nurses to residents on the morning, evening and night shift in each type of facility by size of facility. In all facilities, there are significantly more registered nurses on the morning shift than there are on the evening or night shifts. For facilities of forty beds or less the ratio
in the morning for all facilities is 1:14.7. That ratio rises to 1:20.7 in the afternoon and 1:24.6 at night. A similar pattern is evident in facilities with more than forty beds. In the private sector, the ratio of registered nurses to residents in the morning shift is almost three times greater than in public homes/hospitals. The difference between these two facility types is not as pronounced for the evening or night shifts. The ratio of registered nurses to residents is highest across all facilities at night but is particularly so in private homes with an average ratio of 1:40 residents. In general, the ratio of registered nurses to residents in private facilities is significantly higher than in all other facility types, across all shifts and facility sizes.

Table 6.5: Ratio of RNs on the morning shift to (all) residents by facility type and size

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>≤40 residents</th>
<th></th>
<th>&gt;40 residents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N RNs</td>
<td>Residents</td>
<td>N RNs</td>
<td>Residents</td>
</tr>
<tr>
<td>All facilities</td>
<td>202 1 14.7</td>
<td>109 1 12.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>144 1 19.5</td>
<td>53 1 21.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>13 1 6.9</td>
<td>24 1 8.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>17 1 13.3</td>
<td>17 1 15.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>16 1 7.1</td>
<td>14 1 8.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Welfare homes</td>
<td>12 1 13.6</td>
<td>1 1 23.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6.6: Ratio of RNs on the evening shift to (all) residents by facility type and size

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>N</th>
<th>RNs (evening shift)</th>
<th>Residents</th>
<th>N</th>
<th>RNs (evening shift)</th>
<th>Residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>All facilities</td>
<td>185</td>
<td>1</td>
<td>20.7</td>
<td>99</td>
<td>1</td>
<td>21.1</td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>130</td>
<td>1</td>
<td>24.3</td>
<td>48</td>
<td>1</td>
<td>30.6</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>13</td>
<td>1</td>
<td>11.9</td>
<td>23</td>
<td>1</td>
<td>18.3</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>15</td>
<td>1</td>
<td>18.2</td>
<td>14</td>
<td>1</td>
<td>24.5</td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>16</td>
<td>1</td>
<td>14.8</td>
<td>13</td>
<td>1</td>
<td>13.9</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>11</td>
<td>1</td>
<td>18.8</td>
<td>1</td>
<td>1</td>
<td>46.0</td>
</tr>
</tbody>
</table>

Table 6.7: Ratio of RNs on the night shift to (all) residents by facility type and size

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>N</th>
<th>RNs (night shift)</th>
<th>Residents</th>
<th>N</th>
<th>RNs (night shift)</th>
<th>Residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>All facilities</td>
<td>199</td>
<td>1</td>
<td>24.6</td>
<td>108</td>
<td>1</td>
<td>29.6</td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>143</td>
<td>1</td>
<td>27.0</td>
<td>53</td>
<td>1</td>
<td>40.0</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>13</td>
<td>1</td>
<td>17.6</td>
<td>24</td>
<td>1</td>
<td>27.2</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>17</td>
<td>1</td>
<td>23.6</td>
<td>17</td>
<td>1</td>
<td>29.1</td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>16</td>
<td>1</td>
<td>16.4</td>
<td>13</td>
<td>1</td>
<td>19.8</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>10</td>
<td>1</td>
<td>27.1</td>
<td>1</td>
<td>1</td>
<td>46.0</td>
</tr>
</tbody>
</table>
It is also of interest to document the number of overtime hours worked as an indicator of the care needs within a facility. Table 6.8 documents overtime activity by registered nurse by facility type in the week prior to the survey. The expectation is that long-stay units with relatively poor staffing ratios should have higher overtime activity. However, mean hours of overtime worked is highest in public homes/hospitals, where staffing ratios are high, and relatively low in private facilities, where staffing ratios are poor. There is a fivefold difference in mean overtime hours worked between public geriatric homes/hospitals and private nursing homes in units of forty beds or less, rising to an eightfold difference in units of more than forty beds. There is, however, no way of knowing why there was a need for overtime as no data was gathered on staff sickness or special leave. It is also possible that the higher overtime rates in the public sector may be due to the current staffing embargo (each facility in the public services has a ceiling on the number of staff that can employed). Irrespective of this, the expectation that private nursing homes would have higher overtime rates is not borne out by the data.

Table 6.8: RN overtime hours in the previous week by facility type and size

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Min. hours</th>
<th>Max. hours</th>
<th>Mean hours</th>
<th>Std. dev.</th>
<th>Total hours</th>
<th>Number of hours per RN (WTE)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>≤40 Residents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All facilities</td>
<td>173</td>
<td>0</td>
<td>57.3</td>
<td>3.7</td>
<td>8.8</td>
<td>641.7</td>
<td>0.53</td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>127</td>
<td>0</td>
<td>40</td>
<td>3.0</td>
<td>7.4</td>
<td>383.4</td>
<td>0.52</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>10</td>
<td>0</td>
<td>57.3</td>
<td>17.6</td>
<td>19.3</td>
<td>176.3</td>
<td>1.13</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>14</td>
<td>0</td>
<td>8</td>
<td>0.9</td>
<td>2.4</td>
<td>13.0</td>
<td>0.15</td>
</tr>
<tr>
<td>District/Community hospitals</td>
<td>11</td>
<td>0</td>
<td>9</td>
<td>0.8</td>
<td>2.7</td>
<td>9.0</td>
<td>0.06</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>11</td>
<td>0</td>
<td>27</td>
<td>5.5</td>
<td>8.5</td>
<td>60.0</td>
<td>0.78</td>
</tr>
<tr>
<td><strong>&gt;40 Residents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All facilities</td>
<td>97</td>
<td>0</td>
<td>794.0</td>
<td>29.1</td>
<td>91.7</td>
<td>2,822.7</td>
<td>1.26</td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>48</td>
<td>0</td>
<td>270</td>
<td>9.6</td>
<td>40.1</td>
<td>461.0</td>
<td>1.13</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>21</td>
<td>0</td>
<td>794</td>
<td>76.0</td>
<td>174.3</td>
<td>1,596.7</td>
<td>1.58</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>14</td>
<td>0</td>
<td>71</td>
<td>17.9</td>
<td>24.3</td>
<td>251.0</td>
<td>1.02</td>
</tr>
<tr>
<td>District/Community hospitals</td>
<td>13</td>
<td>0</td>
<td>220</td>
<td>39.5</td>
<td>63.6</td>
<td>514.0</td>
<td>0.90</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.00</td>
</tr>
</tbody>
</table>
Staff turnover investigates the number of staff who have left or joined the facility in the six months prior to the survey. Over 1,000 people joined the staff of all facilities in the past six months, with 715 people leaving in the same period. Overall, more people joined the staff in the past six months than left. The mean turnover does not vary by facility type, when corrected for size, but the range of turnover varies greatly with one long-stay unit in the private sector having 24 staff leave over the six months prior to the study. However, there is no evidence of differences between the public and private sectors in their ability to recruit or keep new staff. Details of turnover are shown in Table 6.9.

Table 6.9: Staff turnover of nursing and non-nursing staff in the previous six months by facility type

<table>
<thead>
<tr>
<th></th>
<th>Joined in the last 6 months</th>
<th>Left in the last 6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Sum</td>
</tr>
<tr>
<td>All facilities</td>
<td>303</td>
<td>1,043</td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>189</td>
<td>620</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>37</td>
<td>179</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>33</td>
<td>145</td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>32</td>
<td>88</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>12</td>
<td>11</td>
</tr>
</tbody>
</table>
Table 6.10 provides details of the availability of various therapeutic services free of charge in the five facility types. Physiotherapy is available free of charge in over three quarters of public geriatric hospitals, in 88 per cent of district/community hospitals and in 71 per cent of welfare homes. Forty-seven per cent of voluntary homes and 23 per cent of private nursing homes provide physiotherapy free of charge, although it is not known if the cost of physiotherapy is built into fee schedules in the latter. Occupational therapy provision is generally poorer than physiotherapy provision across all facility types. Occupational therapy is available free of charge in 66 per cent of public geriatric hospitals, 50 per cent of district/community hospitals and 43 per cent of welfare homes. Provision of speech and language is the least available of all therapies, at 20 per cent overall. Provision of speech therapy is lowest in the voluntary and private sectors. Each of the above therapies are, at least in theory, available privately in the majority of private nursing homes (and from some voluntary homes), but not from public geriatric hospitals, district hospitals or welfare homes. However, the data supports the commonly held perception that public residents in public facilities have a much higher probability of accessing therapeutic services than publicly subvented residents in private and voluntary facilities. A limitation of the data is the absence of information on the number of therapists relative to the number of residents. The data, therefore, does not provide a full picture of the adequacy of provision, even where it exists.

Publicly provided social work provision was uniformly low across all facilities and, in contrast to therapy provision, was also less likely to be available for a fee in either private or voluntary facilities. Provision of public psychology services was low and again was rarely available in any facility for a fee. In addition, where psychology services are provided, there is no indication as to the type of service (e.g. counselling, clinical psychology and neuropsychology) available to residents. This may be important as the type of service available may mean that provision is restricted to a subgroup of residents in the facility. The provision of publicly provided chiropody services is uniformly good across most facilities with the majority of public facilities providing chiropody free of charge, and voluntary and private facilities providing a mixture of free of charge and fee-based services. Hairdressing services are not generally available free of charge even in public facilities, which is interesting given the weight that most people, old and young, place on personal appearance as an indicator of their own general well-being.
Table 6.10: Therapeutic and other services available free of charge by facility type

<table>
<thead>
<tr>
<th>Service Type</th>
<th>All facilities</th>
<th>Private nursing homes</th>
<th>Public homes/hospitals</th>
<th>Voluntary homes/hospitals</th>
<th>District/community hospitals</th>
<th>Welfare homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapist</td>
<td>131 (40.7)</td>
<td>47 (23.2)</td>
<td>29 (76.3)</td>
<td>16 (47.1)</td>
<td>29 (87.9)</td>
<td>10 (71.4)</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>100 (31.1)</td>
<td>44 (21.7)</td>
<td>25 (65.8)</td>
<td>10 (29.4)</td>
<td>15 (45.5)</td>
<td>6 (42.9)</td>
</tr>
<tr>
<td>Speech therapist</td>
<td>64 (19.9)</td>
<td>26 (12.8)</td>
<td>18 (47.4)</td>
<td>4 (11.8)</td>
<td>13 (39.4)</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Social worker</td>
<td>79 (24.5)</td>
<td>47 (23.2)</td>
<td>8 (21.1)</td>
<td>8 (23.5)</td>
<td>12 (36.4)</td>
<td>4 (28.6)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>54 (16.8)</td>
<td>37 (18.2)</td>
<td>1 (2.6)</td>
<td>7 (20.6)</td>
<td>7 (21.2)</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Chiropodist</td>
<td>141 (43.8)</td>
<td>54 (26.6)</td>
<td>34 (89.5)</td>
<td>18 (52.9)</td>
<td>23 (69.7)</td>
<td>12 (85.7)</td>
</tr>
<tr>
<td>Dentist</td>
<td>149 (46.3)</td>
<td>77 (37.9)</td>
<td>24 (63.2)</td>
<td>16 (47.1)</td>
<td>22 (66.7)</td>
<td>10 (71.4)</td>
</tr>
<tr>
<td>Optician</td>
<td>149 (46.3)</td>
<td>85 (41.9)</td>
<td>22 (57.9)</td>
<td>17 (50.0)</td>
<td>17 (51.5)</td>
<td>8 (57.1)</td>
</tr>
<tr>
<td>Hairdresser</td>
<td>76 (23.6)</td>
<td>33 (16.3)</td>
<td>24 (63.2)</td>
<td>7 (20.6)</td>
<td>11 (33.3)</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Other</td>
<td>22 (6.8)</td>
<td>16 (7.9)</td>
<td>3 (7.9)</td>
<td>3 (8.8)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>N</td>
<td>322</td>
<td>203</td>
<td>38</td>
<td>34</td>
<td>33</td>
<td>14</td>
</tr>
</tbody>
</table>

6.6 Activities and Communal Facilities

The activities offered to residents varied by facility type (Table 6.11). The vast majority of facilities received visits from schools as part of both formal and informal intergenerational programmes that mostly had their origins in the schools. Music, bingo, card games and physical exercise are also important activities in all types of facility. Almost two thirds of respondents reported that arts activities or programmes are available in their facility, with availability more likely in public facilities than private and voluntary facilities. The Sonas Programme is also popular, especially in public homes/hospitals. Snoezlan activities are not generally provided, but when they are provided it is more likely to be in public geriatric hospitals/homes. The opportunity to engage in gardening was less available, although, somewhat surprisingly, when it was available, it was more likely to be in public geriatric hospitals/homes. Complementary therapies are available in many units. While the data does not reveal the frequency of provision of these services, the quality of provision,
or how many residents avail of the activities on offer, the picture is somewhat encouraging in respect of the breadth of the activities available. Whether these are the activities that residents would choose themselves is unclear; this issue is discussed in later chapters.

Table 6.11: Availability of organised activities by facility type

<table>
<thead>
<tr>
<th>Activity Type</th>
<th>All facilities</th>
<th>Private nursing homes</th>
<th>Public homes/hospitals</th>
<th>Voluntary homes/hospitals</th>
<th>District/community hospitals</th>
<th>Welfare homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sonas</td>
<td>139 (43.2)</td>
<td>73 (36.0)</td>
<td>29 (76.3)</td>
<td>14 (41.2)</td>
<td>15 (45.5)</td>
<td>8 (57.1)</td>
</tr>
<tr>
<td>Snoezelan</td>
<td>24 (7.5)</td>
<td>5 (2.5)</td>
<td>7 (18.4)</td>
<td>5 (14.7)</td>
<td>5 (15.2)</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Arts</td>
<td>209 (64.9)</td>
<td>120 (59.1)</td>
<td>34 (89.5)</td>
<td>19 (55.9)</td>
<td>24 (72.7)</td>
<td>12 (85.7)</td>
</tr>
<tr>
<td>Music</td>
<td>264 (82.0)</td>
<td>173 (85.2)</td>
<td>31 (81.6)</td>
<td>27 (79.4)</td>
<td>2 (72.7)</td>
<td>9 (64.3)</td>
</tr>
<tr>
<td>Dancing</td>
<td>128 (39.8)</td>
<td>80 (39.4)</td>
<td>22 (57.9)</td>
<td>10 (29.4)</td>
<td>13 (39.4)</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Gardening</td>
<td>104 (32.3)</td>
<td>66 (32.5)</td>
<td>17 (44.7)</td>
<td>8 (23.5)</td>
<td>10 (30.3)</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Physical exercise</td>
<td>261 (81.1)</td>
<td>161 (79.3)</td>
<td>34 (89.5)</td>
<td>25 (73.5)</td>
<td>28 (84.8)</td>
<td>13 (92.9)</td>
</tr>
<tr>
<td>Bingo/cards/board games</td>
<td>261 (81.1)</td>
<td>160 (78.8)</td>
<td>34 (89.5)</td>
<td>28 (82.4)</td>
<td>25 (75.8)</td>
<td>14 (100.0)</td>
</tr>
<tr>
<td>Complementary therapies</td>
<td>164 (50.9)</td>
<td>101 (49.8)</td>
<td>22 (57.9)</td>
<td>19 (55.9)</td>
<td>14 (42.4)</td>
<td>8 (57.1)</td>
</tr>
<tr>
<td>Visits from schools</td>
<td>269 (83.5)</td>
<td>170 (83.7)</td>
<td>34 (89.5)</td>
<td>28 (82.4)</td>
<td>27 (81.8)</td>
<td>10 (71.4)</td>
</tr>
<tr>
<td>Other</td>
<td>88 (27.3)</td>
<td>47 (23.2)</td>
<td>16 (42.1)</td>
<td>15 (44.1)</td>
<td>7 (21.2)</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>N</td>
<td>322</td>
<td>203</td>
<td>38</td>
<td>34</td>
<td>33</td>
<td>14</td>
</tr>
</tbody>
</table>

Table 6.12 provides information on the availability of communal facilities in long-stay units across the country. Almost all long-stay units had TV, video/DVD players and newspapers available to residents. Similarly, most had games and telephones available for communal use. The majority of units also had libraries, although less so in district/community hospitals. It is noteworthy that a quarter of all long-stay units had a shop of some kind with availability highest in voluntary homes/hospitals. Tea/coffee-making facilities are generally scarce, with only 29 per cent of long-stay units in public geriatric hospitals/homes and 18 per cent of district/community hospitals having facilities for residents to make a cup of tea or coffee either for themselves or for a visitor. The availability of tea-making facilities is higher in private and voluntary homes but still only reaches 44 per cent in the private
sector and 50 per cent in the voluntary sector. Nearly one quarter of units in district/community hospital facilities have no personal laundry arrangement which means that residents have to arrange for relatives to do their laundry or, in some cases, cannot choose to wear their own clothes.

Table 6.12: Availability of communal facilities by facility type

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>All facilities</th>
<th>Private nursing homes</th>
<th>Public homes/hospitals</th>
<th>Voluntary homes/hospitals</th>
<th>District/community hospitals</th>
<th>Welfare homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Television</td>
<td>320 (99.4)</td>
<td>203 (100.0)</td>
<td>38 (100.0)</td>
<td>34 (100.0)</td>
<td>31 (93.9)</td>
<td>14 (100.0)</td>
</tr>
<tr>
<td>Newspapers</td>
<td>300 (93.2)</td>
<td>194 (95.6)</td>
<td>36 (94.7)</td>
<td>32 (94.1)</td>
<td>28 (84.8)</td>
<td>10 (71.4)</td>
</tr>
<tr>
<td>Video/DVD players</td>
<td>293 (91.0)</td>
<td>180 (88.7)</td>
<td>38 (100.0)</td>
<td>32 (94.1)</td>
<td>30 (90.9)</td>
<td>13 (92.9)</td>
</tr>
<tr>
<td>Library</td>
<td>262 (81.4)</td>
<td>168 (82.8)</td>
<td>27 (71.1)</td>
<td>32 (94.1)</td>
<td>22 (66.7)</td>
<td>13 (92.9)</td>
</tr>
<tr>
<td>Games</td>
<td>279 (86.6)</td>
<td>178 (87.7)</td>
<td>35 (92.1)</td>
<td>29 (85.3)</td>
<td>26 (78.8)</td>
<td>11 (78.6)</td>
</tr>
<tr>
<td>Musical instruments</td>
<td>163 (50.6)</td>
<td>101 (49.8)</td>
<td>18 (47.4)</td>
<td>24 (70.6)</td>
<td>11 (33.3)</td>
<td>9 (64.3)</td>
</tr>
<tr>
<td>Shop</td>
<td>78 (24.2)</td>
<td>36 (17.7)</td>
<td>15 (39.5)</td>
<td>17 (50.0)</td>
<td>8 (24.2)</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Public telephone</td>
<td>272 (84.5)</td>
<td>161 (79.3)</td>
<td>35 (92.1)</td>
<td>33 (97.1)</td>
<td>29 (87.9)</td>
<td>14 (100.0)</td>
</tr>
<tr>
<td>Tea/coffee making facilities</td>
<td>128 (39.8)</td>
<td>89 (43.8)</td>
<td>11 (28.9)</td>
<td>17 (50.0)</td>
<td>6 (18.2)</td>
<td>5 (35.7)</td>
</tr>
<tr>
<td>Personal laundry facilities</td>
<td>271 (84.2)</td>
<td>169 (83.3)</td>
<td>33 (86.8)</td>
<td>30 (88.2)</td>
<td>26 (78.8)</td>
<td>13 (92.9)</td>
</tr>
<tr>
<td><strong>N</strong></td>
<td><strong>322</strong></td>
<td><strong>203</strong></td>
<td><strong>38</strong></td>
<td><strong>34</strong></td>
<td><strong>33</strong></td>
<td><strong>14</strong></td>
</tr>
</tbody>
</table>

6.7 Meaningful Occupation

In recent years, there has been a growing recognition that activity programmes designed to fill the time should be differentiated from meaningful or purposeful activity in long-stay facilities. Meaningful occupation is likely to incorporate daily activities that promote enjoyment and fulfil individual needs in relation to purpose, self-care and participation. Respondents in our survey were first asked if they permitted residents to engage in household tasks followed by a question on the type of activities that residents could pursue. Two thirds of all facilities offered
residents the opportunity to participate in household tasks within the residential setting. Almost four fifths of private nursing homes offered residents the opportunity to engage in purposeful activity (Figure 6.8). In contrast, only one third of district/community hospitals allowed such participation. Generally, the opportunity for participation is higher in welfare homes than in other public facilities, reflecting the lower levels of dependency in the former compared to public geriatric homes/hospitals and district/community hospitals.

Having the opportunity to participate does not indicate actual participation. Table 6.13 shows that while residents may generally have the opportunity to engage in household tasks, participation levels are quite low. Laying tables and gardening tend to be the activities that residents do most, with gardening most likely to occur within private nursing home settings. The lower level of dependency in welfare homes is reflected in the relatively high level of resident involvement in activities such as laying tables and making beds. Resident participation in serving food, cleaning rooms and cooking occurs in only a handful of facilities reflecting the general commodification of these activities in all settings.

Figure 6.8: Percentage of facilities in which residents participate in household tasks
Table 6.13: Number of facilities in which residents participate in various household tasks

<table>
<thead>
<tr>
<th>Task</th>
<th>All facilities</th>
<th>Private nursing homes</th>
<th>Public homes/hospitals</th>
<th>Voluntary homes/hospitals</th>
<th>District/community hospitals</th>
<th>Welfare homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Washing/drying dishes</td>
<td>53 (16.7)</td>
<td>45 (22.7)</td>
<td>1 (2.6)</td>
<td>2 (5.9)</td>
<td>3 (9.1)</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Laying tables</td>
<td>114 (36.0)</td>
<td>80 (40.4)</td>
<td>10 (26.3)</td>
<td>8 (23.5)</td>
<td>9 (27.3)</td>
<td>7 (50.0)</td>
</tr>
<tr>
<td>Serving food</td>
<td>6 (1.9)</td>
<td>3 (1.5)</td>
<td>1 (2.6)</td>
<td>1 (2.9)</td>
<td>0 (0.0)</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Cooking</td>
<td>5 (1.6)</td>
<td>4 (2.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>1 (3.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Cleaning rooms</td>
<td>12 (3.8)</td>
<td>7 (3.5)</td>
<td>2 (5.3)</td>
<td>1 (2.9)</td>
<td>2 (6.1)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Making beds</td>
<td>57 (18.0)</td>
<td>33 (16.7)</td>
<td>5 (13.2)</td>
<td>7 (20.6)</td>
<td>6 (18.2)</td>
<td>6 (42.9)</td>
</tr>
<tr>
<td>Gardening</td>
<td>115 (36.3)</td>
<td>90 (45.5)</td>
<td>10 (26.3)</td>
<td>9 (26.5)</td>
<td>5 (15.2)</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Other</td>
<td>57 (18.0)</td>
<td>43 (21.7)</td>
<td>5 (13.2)</td>
<td>4 (11.8)</td>
<td>2 (6.1)</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>N</td>
<td>317</td>
<td>198</td>
<td>38</td>
<td>34</td>
<td>33</td>
<td>14</td>
</tr>
</tbody>
</table>

6.8 Choice and Autonomy

Choice and autonomy are examined in respect of whether residents can choose the times at which to get up in the morning and go back to bed (Table 6.14). Residents in private nursing homes are most likely to be able to exercise choice in these areas and this difference is significant at the 1 per cent level, relative to public facilities. More than half of private long-stay units allow all residents to choose what time to get up and go to bed. The corresponding figure for public geriatric homes/hospitals is less than 25 per cent for both getting up and going to bed. Choice in public facilities is most likely to be restricted to those who do not require help to get up and/or go to bed. Voluntary facilities also offer low levels of choice to residents in respect of rising and retiring.
Table 6.14: Choice of time to get up and go to bed for residents by facility type

<table>
<thead>
<tr>
<th>Time to get up</th>
<th>All facilities</th>
<th>Private nursing homes</th>
<th>Public homes/hospitals</th>
<th>Voluntary homes/hospitals</th>
<th>District/community hospitals</th>
<th>Welfare homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>All residents can choose</td>
<td>135 (44.7)</td>
<td>107 (55.7)</td>
<td>8 (22.9)</td>
<td>7 (20.6)</td>
<td>9 (33.3)</td>
<td>4 (28.6)</td>
</tr>
<tr>
<td>Independent residents only can choose</td>
<td>123 (40.7)</td>
<td>73 (38.0)</td>
<td>16 (45.7)</td>
<td>21 (61.8)</td>
<td>8 (29.6)</td>
<td>5 (35.7)</td>
</tr>
<tr>
<td>Nursing staff decide</td>
<td>24 (7.9)</td>
<td>7 (3.6)</td>
<td>6 (17.1)</td>
<td>3 (8.8)</td>
<td>5 (18.5)</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Other</td>
<td>20 (6.6)</td>
<td>5 (2.6)</td>
<td>5 (14.3)</td>
<td>3 (8.8)</td>
<td>5 (18.5)</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Total</td>
<td>302 (100.0)</td>
<td>192 (100.0)</td>
<td>35 (100.0)</td>
<td>34 (100.0)</td>
<td>27 (100.0)</td>
<td>14 (100.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time to go to bed</th>
<th>All facilities</th>
<th>Private nursing homes</th>
<th>Public homes/hospitals</th>
<th>Voluntary homes/hospitals</th>
<th>District/community hospitals</th>
<th>Welfare homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>All residents can choose</td>
<td>128 (43.8)</td>
<td>96 (50.8)</td>
<td>8 (24.2)</td>
<td>9 (27.3)</td>
<td>9 (37.5)</td>
<td>6 (46.2)</td>
</tr>
<tr>
<td>Independent residents only can choose</td>
<td>142 (48.6)</td>
<td>84 (44.4)</td>
<td>19 (57.6)</td>
<td>20 (60.6)</td>
<td>12 (50.0)</td>
<td>7 (53.8)</td>
</tr>
<tr>
<td>Nursing staff decide</td>
<td>9 (3.1)</td>
<td>5 (2.6)</td>
<td>1 (3.0)</td>
<td>2 (6.1)</td>
<td>1 (4.2)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Other</td>
<td>13 (4.5)</td>
<td>4 (2.1)</td>
<td>5 (15.2)</td>
<td>2 (6.1)</td>
<td>2 (8.3)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Total</td>
<td>292 (100.0)</td>
<td>189 (100.0)</td>
<td>33 (100.0)</td>
<td>33 (100.0)</td>
<td>24 (100.0)</td>
<td>13 (100.0)</td>
</tr>
</tbody>
</table>

6.9 Care Process and Organisational Issues

Respondents were asked a number of questions about care process and organisational issues within long-stay units (Figure 6.9). Just over 10 per cent of all units have a residents’ committee. While one third of welfare homes have a residents’ committee, less than 5 per cent of private nursing homes have a formal committee in place. However, the majority of long-stay units across all facility types have procedures in place to deal with residents’ complaints. The majority of long-
stay units also allow ambulant, mentally alert residents to leave the facility unaccompanied. All facilities had visits from the clergy and the vast majority also had oratory facilities. Access to a private phone was best in private nursing homes and voluntary homes and worst in public geriatric facilities. Only 7 per cent of district/community hospitals offered residents the facility to lock away possessions. Voluntary homes performed best in this area with 70 per cent of units offering residents the facility to lock their own cupboard or drawer. Provision for married couples was variable ranging from just over 10 per cent in welfare homes to 70 per cent in private nursing homes.

Figure 6.9: Process and organisational issues by facility type
Figure 6.10 shows the percentage of long-stay units in each facility type which are purpose-built for the care of dependent older people. The results reveal that just over 50 per cent of all facilities are purpose-built for the care of dependent older people. Welfare homes are most likely to be purpose built and district/community hospitals are least likely to be designed specifically for the care of dependent older people. Of those public long-stay units which are not purpose-built for long-stay care, more than half are former acute hospitals. Approximately 60 per cent of private nursing homes are purpose-built for long-stay care. The majority of private nursing homes that are not purpose-built had formerly been private residences.

![Figure 6.10: Facility purpose-built as a long-stay residential facility](image)

Private nursing homes are more likely to provide accommodation in single or double rooms, and public facilities more likely to offer ward accommodation (defined as rooms of three or more beds). Almost all facilities have a garden. However, in public geriatric hospitals and district/community hospitals resident access to the garden is not possible in up to 20 per cent of units responding to the questionnaire. When care is provided in multistorey buildings, between 40 per cent and 60 per cent of units have rooms or other resources for long-stay residents on upper floors. However, almost all units providing care on upper floors have lift facilities for residents. With the exception of welfare homes, the majority of facilities had a specially designed sluice room. Within welfare homes, only three quarters of facilities have sluice rooms.
The majority of private and voluntary facilities have separate sitting and dining rooms (Table 6.15). However, the proportion is significantly lower in public geriatric home/hospitals and district/community hospitals. Public geriatric hospitals/homes and district/community hospitals mostly have combined dining and sitting rooms. A separate room or rooms for meeting/entertaining visitors is available in 70 per cent of all facilities, with the figure much higher in the private and voluntary sectors than in the public sector. Less than half of public geriatric homes/hospitals and only 39 per cent of district/community hospitals have separate visiting rooms. As these public facilities are more likely to have communal wards, this lack of provision is likely to significantly impact on the ability of residents to maintain social relationships and/or develop new friendships. Provision for children visiting long-stay facilities is poorly provided for, especially in public facilities. The availability of child friendly areas is highest in private nursing homes, with 18 per cent of facilities having a designated space for children.

Table 6.15: Provision of various facilities and space by facility type

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>All facilities</th>
<th>Private nursing homes</th>
<th>Public homes/hospitals</th>
<th>Voluntary homes/hospitals</th>
<th>District/community hospitals</th>
<th>Welfare homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Separate dining room</td>
<td>267 (82.9)</td>
<td>195 (96.1)</td>
<td>20 (52.6)</td>
<td>30 (88.2)</td>
<td>11 (33.3)</td>
<td>11 (78.6)</td>
</tr>
<tr>
<td>Separate sitting room</td>
<td>270 (83.9)</td>
<td>194 (95.6)</td>
<td>22 (57.9)</td>
<td>32 (94.1)</td>
<td>13 (39.4)</td>
<td>9 (64.3)</td>
</tr>
<tr>
<td>Combined sitting/dining</td>
<td>81 (25.2)</td>
<td>26 (12.8)</td>
<td>20 (52.6)</td>
<td>7 (20.6)</td>
<td>25 (75.8)</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Combined sitting/reception</td>
<td>36 (11.2)</td>
<td>26 (12.8)</td>
<td>4 (10.5)</td>
<td>3 (8.8)</td>
<td>3 (9.1)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Separate reception</td>
<td>240 (74.5)</td>
<td>173 (85.2)</td>
<td>20 (52.6)</td>
<td>26 (76.5)</td>
<td>13 (39.4)</td>
<td>8 (57.1)</td>
</tr>
<tr>
<td>Separate visiting room</td>
<td>224 (69.6)</td>
<td>162 (79.8)</td>
<td>18 (47.4)</td>
<td>26 (76.5)</td>
<td>13 (39.4)</td>
<td>5 (35.7)</td>
</tr>
<tr>
<td>Child friendly area</td>
<td>43 (13.4)</td>
<td>37 (18.2)</td>
<td>3 (7.9)</td>
<td>3 (8.8)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Activities room</td>
<td>91 (28.3)</td>
<td>52 (25.6)</td>
<td>10 (26.3)</td>
<td>19 (55.9)</td>
<td>6 (18.2)</td>
<td>4 (28.6)</td>
</tr>
<tr>
<td>Other</td>
<td>54 (16.8)</td>
<td>40 (19.7)</td>
<td>3 (7.9)</td>
<td>7 (20.6)</td>
<td>3 (9.1)</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>N</td>
<td>322</td>
<td>203</td>
<td>38</td>
<td>34</td>
<td>33</td>
<td>14</td>
</tr>
</tbody>
</table>
Bathroom facilities varied considerably between and within each facility type (Table 6.16). In general, the private nursing home sector provides better bathroom facilities than the public sector. After correction for numbers of residents, these differences are significant for numbers of en suite rooms and for WCs with fixed grab rails. Differences are not so evident in respect of WCs separate from bathrooms or showers, or for special baths. Call bells are provided in the majority of rooms, bathrooms and WCs, but not generally in corridors (Table 6.17). However, in public geriatric hospitals, 25 per cent of residents’ rooms and 25 per cent of WCs do not have call bells.

Table 6.16: Ratio of WCs/special baths to (all) residents by facility type

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>En-suite rooms</th>
<th>Resi- dents</th>
<th>Fixed grab rails in WCs</th>
<th>Resi- dents</th>
<th>Sep- arate WC</th>
<th>Resi- dents</th>
<th>Special baths</th>
<th>Resi- dents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All facilities</strong></td>
<td>300</td>
<td>1</td>
<td>3.9</td>
<td>1</td>
<td>3.8</td>
<td>1</td>
<td>9.4</td>
<td>1</td>
<td>34.8</td>
</tr>
<tr>
<td><strong>Private nursing homes</strong></td>
<td>190</td>
<td>1</td>
<td>2.2</td>
<td>1</td>
<td>2.6</td>
<td>1</td>
<td>8.9</td>
<td>1</td>
<td>32.3</td>
</tr>
<tr>
<td><strong>Public homes/ hospitals</strong></td>
<td>36</td>
<td>1</td>
<td>43.9</td>
<td>1</td>
<td>9.1</td>
<td>1</td>
<td>10.3</td>
<td>1</td>
<td>50.6</td>
</tr>
<tr>
<td><strong>Voluntary homes/ hospitals</strong></td>
<td>33</td>
<td>1</td>
<td>4.8</td>
<td>1</td>
<td>4.9</td>
<td>1</td>
<td>8.5</td>
<td>1</td>
<td>25.4</td>
</tr>
<tr>
<td><strong>District/ community hospitals</strong></td>
<td>28</td>
<td>1</td>
<td>26.3</td>
<td>1</td>
<td>7.7</td>
<td>1</td>
<td>16.4</td>
<td>1</td>
<td>39.4</td>
</tr>
<tr>
<td><strong>Welfare homes</strong></td>
<td>13</td>
<td>1</td>
<td>25.2</td>
<td>1</td>
<td>8.5</td>
<td>1</td>
<td>5.8</td>
<td>1</td>
<td>37.9</td>
</tr>
</tbody>
</table>
Table 6.17: Call bell facilities by location and by type of facility

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Residents’ rooms %</th>
<th>Bathrooms %</th>
<th>WCs %</th>
<th>Corridors %</th>
<th>Other %</th>
</tr>
</thead>
<tbody>
<tr>
<td>All facilities</td>
<td>322</td>
<td>302 (93.8)</td>
<td>289 (89.8)</td>
<td>276 (85.7)</td>
<td>79 (24.5)</td>
<td>133 (41.3)</td>
</tr>
<tr>
<td>Private nursing homes</td>
<td>203</td>
<td>200 (98.5)</td>
<td>189 (93.1)</td>
<td>179 (88.2)</td>
<td>60 (29.6)</td>
<td>89 (43.8)</td>
</tr>
<tr>
<td>Public homes/hospitals</td>
<td>38</td>
<td>29 (76.3)</td>
<td>33 (86.8)</td>
<td>29 (76.3)</td>
<td>5 (13.2)</td>
<td>14 (36.8)</td>
</tr>
<tr>
<td>Voluntary homes/hospitals</td>
<td>34</td>
<td>32 (94.1)</td>
<td>31 (91.2)</td>
<td>30 (88.2)</td>
<td>10 (29.4)</td>
<td>16 (47.1)</td>
</tr>
<tr>
<td>District/community hospitals</td>
<td>33</td>
<td>29 (87.9)</td>
<td>27 (81.8)</td>
<td>28 (84.8)</td>
<td>4 (12.1)</td>
<td>10 (30.3)</td>
</tr>
<tr>
<td>Welfare homes</td>
<td>14</td>
<td>12 (85.7)</td>
<td>9 (64.3)</td>
<td>10 (71.4)</td>
<td>0 (0.0)</td>
<td>4 (28.6)</td>
</tr>
</tbody>
</table>

6.11 Conclusion

This chapter presented the results from the survey of long-term care facilities in Ireland. Results focused on the size and number of facilities, residents, dependency levels, staffing levels, provision of therapies and activities, and the physical environment. Key differences in staffing provision and physical environment emerged between private and public facilities, although it is impossible to tell from the data the effects of these differences on the quality of life of residents. Dependency levels are highest in the public sector, with the exception of welfare homes which tend to cater for less dependent residents. Staffing ratios are higher in public facilities than in private facilities, no doubt reflecting higher levels of dependency but also cost containment imperatives for private providers. Physical environment and infrastructure is generally better in the private sector than in the public sector. Residents are also likely to be given more choice in the private sector over when to get up and go to bed.
Overall, there is a significant amount of activity taking place in long-stay facilities, though it is impossible to tell from the survey what value residents place on this activity. The opportunity to participate in meaningful activity within long-stay settings is much more circumspect. In terms of comparisons with earlier work for the National Council for the Aged on private nursing homes and voluntary nursing homes in Ireland (O’Connor and Thompstone, 1986), it is clear that dependency has increased in long-stay units in these two sectors in the past twenty years.
Chapter Seven
Description of Study Sites and Resident and Staff Demographics
Chapter Seven
Description of Study Sites and Resident and Staff Demographics

Twelve study sites were included in the study. These sites were divided into five types: geriatric hospitals (2); private nursing homes (5); voluntary hospitals (2); welfare homes (1); and health board district/community hospitals (2). The descriptions provided below have been derived from observation and data collection within the study sites and are included here to provide care contexts for the analysis to follow in subsequent chapters. This section will describe the key characteristics of each type of facility and identify observed similarities and differences amongst them. These descriptions, however, only paint a general picture as there were not only differences between types of facilities but also within facility types. The descriptions focus on four key areas: the physical environment; staffing; life in the facility; and resident profile/dependency. The chapter ends with a profile of the residents and staff interviewed.

7.1 Geriatric Homes/Hospitals

7.1.1 Physical Environment

The geriatric hospital study sites were built in the last century as care centres or workhouses and were adapted in the 1950s and 1960s to provide care for older people living in long-term care. The hospitals, which were surrounded by large grounds with beautiful gardens, had between two and three hundred beds. There was a chapel within the grounds of the hospital or within the hospital. Although there were some single rooms in these facilities, most residents were accommodated in shared wards. These had originally been large hospital style open wards but had been adapted to create four to six bed units. Some of these units had doors while
others were open and residents’ beds were visible from the corridor. The common feature of this type of facility was that space was very limited. There was a lack of space between beds and there was little space for residents’ personal belongings, wardrobes or care giving. Some facilities had very limited sitting room or dining room space and this resulted in some residents spending the day by their bed. There was no call bell system visible in any of these facilities. A feature of many shared wards was a large communal television kept on at a loud volume for most of the day. Bathrooms in these facilities had been adapted to meet current needs and special baths had been added for residents with physical disabilities. Despite these modifications, however, the ratio of bathrooms to residents often did not facilitate daily bathing of residents, if that was what they desired.

7.1.2 Staffing

Registered nurses and care assistants\textsuperscript{12} provided care for residents. While the ratio of registered nurses to care assistants varied between the two facilities, there were more registered nurses than care assistants in both sites. In general, the care assistant role was a combination of patient care and domestic/house duties. This impacted significantly on the routine of the day as there was a need to complete physical care early so that care assistants could help nurses with this before they attended to their domestic duties.

7.1.3 Life in the Facility

For some residents living in geriatric hospitals there was good companionship, the day was varied and staff tried hard to meet residents’ needs. In one unit the day was structured to facilitate resident choice, residents had key workers and there was a real attempt to move away from routine. However, for many residents life was mundane and difficult with very little choice in respect of the structure of the day. Routine rather than residents’ preferences determined the time they got up or went back to bed. While more able residents were often able to make some choices about their day, those requiring significant levels of physical help were less likely to have choice. Some residents were woken early and put back to bed in the middle of the afternoon because this was the routine. The lack of a call bell system resulted in some residents waiting for long periods to get help from staff for toileting or physical care. Both facilities had tried to provide activities for residents. Gardening, card games, music, Sonas Programmes and bingo were common in both sites.

\textsuperscript{12} The term care assistant is used as a generic term; some facilities had health care assistants who had received training for the role, and others had care attendants.
7.1.4 Resident Profile/Dependency

While there were some residents in each of these facilities who were under the age of 65, the majority of residents were between 75 and 94 years old. Most residents living in these facilities were categorised as high or maximum dependency. The majority needed help with activities of daily living, some required wheelchair assistance, while a number had significant cognitive impairment. Some residents had complex nursing needs which required high levels of registered nursing expertise. Few residents were independently mobile or able to leave the facility on their own.

7.2 Private Nursing Homes

7.2.1 Physical Environment

All of the private nursing home study sites had been custom built. The oldest was established 17 years ago, while the most recent was four years old. The size varied from 22 to 61 beds with an average of 40. The layout varied from facility to facility but they were either circular or square in shape. One facility had a garden in the centre of the square, another had a courtyard. The corridors or resident rooms looked out onto these. One of the circular facilities had wide corridors to accommodate residents who were wheelchair users and those residents who wandered persistently. The majority of rooms in each of these facilities were single or double rooms; a few facilities also had some three bedded areas. Some rooms were en suite while others had their own toilet, wash-hand basin or both. In all facilities residents had a call bell system to summon staff. All facilities had a sitting area for residents, which ranged from cramped to spacious; and some facilities had a number of smaller sitting areas dotted around the facility. Many of the facilities had a small oratory. Dining facilities varied but most facilities had a separate dining room with tables to seat four to six people. Some facilities had a very homely feel with photographs of the residents, small sitting areas (some with a fire), tasteful, bright colour schemes and good access into and out of the home for visitors. In contrast, some facilities appeared to have few pictures of residents, dark colour schemes, sparse furnishings and access to the facility was controlled by staff. Most residents living in these facilities were categorised as high or maximum dependency.
7.2.2 Staffing

Registered nurses and care assistants provided care for residents. The ratio of registered nurses to care assistants varied across facilities and shift times. At worst, the ratio was 1:4, at best 1:3. Where ratios of care assistants were highest, the registered nurse(s) focused on specific tasks such as administering medication and activities such as wound dressings rather than direct care. Consequently, care assistants were responsible for most of the fundamental care of residents. In some facilities the ratio of registered nurses to care assistants left little capacity for supervision of care assistants’ work.

7.2.3 Life in the Facility

In all facilities residents generally appeared to be able to choose the time they got up or went back to bed. While there was usually a routine shaped around meal times residents did have some choices about their day. The range of choices was greater in some facilities than others. One facility staggered lunch times to facilitate resident preferences for late or early lunch. In another, the routine of the day was much more fixed with little resident choice. In some facilities residents appeared to have a good rapport with staff who seemed to know them well.

Most facilities had a range of activities for residents including painting, card games, music, Sonas and bingo. One facility had a tai chi class for residents and staff and their own transport system which helped to facilitate resident outings. In another facility the only activity offered was singing.

7.2.4 Resident Profile/Dependency

The majority of residents living in these facilities were between 75 and 94 years old. One facility, however, had a unit for younger people with disabilities, which meant that 40 per cent of their residents were under the age of 65. Most residents living in these facilities were categorised as high or maximum dependency. Many residents needed help with some activities of daily living, but there were a significant number of residents who were mobile without the help of staff. A few residents were independently mobile enough to be able to leave the facility on their own. In all facilities there were some residents who qualified for subvention from the HSE. In one facility over half of the beds had been allocated for public patients but not all of these beds were utilised.
7.3 Welfare Home

7.3.1 Physical Environment

This facility was purpose built as a welfare home in the 1970s. Welfare homes were set up to provide care for older people who needed support but were reasonably self-caring and independent in their activities of living. The facility has beds for 39 residents but some were not occupied. The building was in the shape of an H and was surrounded by a small garden. The corridors were long and nursing offices were at some distance from residents’ rooms. There was a mix of single and three bedded rooms. The single rooms were small, had a wash-hand basin, few furnishings, a small built in wardrobe and few electric sockets. The three bedded wards shared an en suite bathroom with an adjoining three bedded ward. The building was in poor repair but there was a good atmosphere. Pictures of residents and paintings by residents helped to make the facility feel warm and welcoming. The day room was large but homely and most of the day activities took place there. There was a separate dining area for residents. The bathrooms and toilet facilities were so small that the use of aids such as a hoist would not have been possible. Residents could not bring walking aids into the toilet and staff assistance was difficult because of the lack of space. There was no call bell system in residents’ rooms.

7.3.2 Staffing

Registered nurses and care assistants provided care for residents. The ratio of registered nurses to care assistants was 1:2 or 1:1 on most shifts. At night, one registered nurse and a care assistant were on duty.

7.3.3 Life in the Facility

Residents appeared to be able to choose the time they got up or went back to bed. The day seemed varied and there was a real buzz of activity in the air. Residents talked and chatted amongst themselves and with staff. Meal times were good humoured, lively events with good rapport between staff and residents. Many residents had an interest in the world around them and were up to date in current events. There was a good range of activities including cards, Sonas, reading the news to residents, singsongs and dancing. Members of the local community came in to participate in some of the activities and this was very popular with residents.
Some residents were able to leave the facility unassisted and visit the local shops. Outings for residents were arranged during the year. Residents, but particularly those on the edges of the corridors at the bottom of the H shape, had considerable difficulty in calling the nurse as they could not be heard from the nurses’ station.

7.3.4 Resident Profile/Dependency

The majority of residents living in this facility were between 75 and 94 years old. Half of the residents were categorised as low dependency and the other half as medium dependency. Resident dependency was, however, increasing as long-term residents of the facility aged. Some residents had severe confusion and one resident had severe behavioural problems. Most residents needed some help with activities of living.

7.4 Voluntary Home/Hospital

7.4.1 Physical Environment

One of the facilities was purpose built in the 1970s as a nursing home, while the other was a private house which was refurbished as a nursing home in the late 1980s. The size of these facilities varied from 40 to 152 beds. Both facilities were surrounded by beautiful gardens. There were single and double rooms in each of the facilities with a chair, wash-hand basin and toilet. The larger facility also had some four bedded units and some self-contained chalets which provided assisted-living support. The chalets had a kitchen, sitting room, bathroom and bedroom. Within these facilities, there were large sitting room areas and separate dining areas with tables for four to six residents. There was also an oratory or chapel incorporated into these facilities.

7.4.2 Staffing

Registered nurses and care attendants provided direct care for residents within these facilities. The ratio of registered nurses to care attendants varied from a ratio of 1:3 in the larger units to 1:2.5 in smaller units.
7.4.3 Life in the Facility

Most residents appeared to have a choice about their day and care across these facilities was predominantly person-centred. The facilities were warm and welcoming and independent residents and visitors had good access into and out of the facility. Paintings by residents were exhibited on the walls and there was a buzz of activity. One facility had a library for residents and a small shop which sold toiletries, sweets and drinks. The facilities had tried to provide activities for residents and had good links with the local community in the provision of these. There was a good sense of community within these facilities with residents stating that they felt they had a lot in common with other residents. Companionship was very evident. There was a focus on residents’ needs and a caring ethos. Card games, music, art classes, singing and bingo were activities commonly offered. Residents who were independent had a lot of freedom and could leave the facilities if they so wished. Those living in chalets organised their day as they wished.

7.4.4 Resident Profile/Dependency

The majority of residents living in these facilities were between 75 and 94 years old. There were mixed dependency levels. While the majority of residents were categorised as high or maximum dependency, 30-40 per cent were in the low or medium category. Those living in assisted living chalets were virtually self-caring but had 24-hour support if required, as well as access to cooked meals and activities.

7.5 Community/District Hospitals

7.5.1 Physical Environment

The community/district hospital study sites were built in the early or mid 1900s; one had been a former workhouse and the other an acute hospital. One building had been renovated and extended during the 1990s. One facility was in a scenic area and the other was surrounded by an extensive garden. Most residents in these facilities were accommodated in seven to eight bay units, although there were a few single/double rooms. Each unit had a T.V. and a radio. Space appeared very constrained in these study sites, leading to an absence of basic amenities like wash-hand basins within units or dining or sitting rooms. In one facility there was a small day room but it was so small that it was difficult to accommodate many residents within it. The space constraints meant that some residents had to spend
the day by their bed. In addition, toilets were located at a distance from some of the bays. Despite these physical constraints imposed by the buildings, great effort had been made to try and make the facilities more homely with plants and bright colour schemes. Each resident had their own locker/wardrobe, bed-table and chair. One of these facilities also had palliative care beds.

7.5.2 Staffing

Registered nurses worked with care attendants to provide care. Within this sector as a whole, there were more registered nurses than care attendants. Some care attendants had a mixed care giving and domestic role.

7.5.3 Life in the Facility

The atmosphere in these study sites was relaxed, warm and friendly. The more able residents were often able to make some choices about their day. However, those requiring significant levels of physical help were less likely to have choice. Dependent residents’ days were more likely to be shaped by routine and many were put back to bed by the late afternoon. Many residents sat in comfortable chairs by their bed and listened to the radio or watched television. Several residents spent some periods dozing in their chairs during the day. In one facility there were students on work experience who were involved in running activities for residents; bingo, arts and crafts, and cards games were offered.

7.5.4 Resident Profile/Dependency

Most residents were highly dependent and needed significant levels of help with physical care. While full data on resident dependency was not available, in one study site, 24 out of 29 long-stay residents were deemed to be high or maximum dependency.

7.6 Resident Demographics

A total of 101 residents were interviewed. Residents’ age, gender, duration of stay, type of facility and dependency rating was gathered. More women (n = 65) than men (n = 31) were included in the sample. Below is a series of tables which outline resident demographics.
Table 7.1: Number of resident respondents in each facility type

<table>
<thead>
<tr>
<th>Facility type</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public geriatric hospital/home</td>
<td>19</td>
</tr>
<tr>
<td>Welfare home</td>
<td>12</td>
</tr>
<tr>
<td>District/community hospital</td>
<td>14</td>
</tr>
<tr>
<td>Voluntary</td>
<td>14</td>
</tr>
<tr>
<td>Private</td>
<td>42</td>
</tr>
<tr>
<td>Total</td>
<td>101</td>
</tr>
</tbody>
</table>

Table 7.2: Age profile of resident respondents

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-74 years</td>
<td>16</td>
</tr>
<tr>
<td>75-84 years</td>
<td>46</td>
</tr>
<tr>
<td>85-89 years</td>
<td>23</td>
</tr>
<tr>
<td>90+ years</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>101</td>
</tr>
</tbody>
</table>

Table 7.3: Length of stay

<table>
<thead>
<tr>
<th>Duration of stay</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3 months</td>
<td>7</td>
</tr>
<tr>
<td>3 months-1 year</td>
<td>24</td>
</tr>
<tr>
<td>2-&lt;4 years</td>
<td>38</td>
</tr>
<tr>
<td>4-&lt;6 years</td>
<td>21</td>
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<tr>
<td>6-&lt;10 years</td>
<td>3</td>
</tr>
<tr>
<td>10+ years</td>
<td>6</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>101</td>
</tr>
</tbody>
</table>

Resident respondents’ scores on the Barthel Index, which is a measure of the individual’s dependency/independency, were gathered in nine domains: feeding, grooming, dressing, bathing, bowels, bladder, toilet use, mobility, and use of stairs. Residents’ scores reflect a range of abilities with some resident respondents scoring 10 or 15 (maximum points for independence) while others scored 0 (fully dependent on care staff). Of particular note was bathing where 71.3 per cent of respondents were dependent. Approximately one third of resident respondents
required full assistance with dressing. With respect to feeding, 5.9 per cent of respondents were totally dependent on staff, while 71.3 per cent were independent. In relation to transferring from bed to chair, 10.9 per cent were totally dependent on staff while 40.6 per cent were classified as fully independent. The sample, therefore, was comprised of residents with all ranges of abilities. Some residents had difficulty communicating verbally and the yes/no version of the interview schedule was used in order to capture their views.

7.7 Staff Demographics

A total of 48 staff were interviewed. Age, gender, type of facility, job title, qualifications and number of years of experience of working with older people were gathered. The sample reflects the predominately female presence within the workforce – women (n = 43); men (n = 5). Below is a series of tables which outline staff demographics.

Table 7.4: Number of staff respondents in each facility type

<table>
<thead>
<tr>
<th>Facility type</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public geriatric hospital/home</td>
<td>8</td>
</tr>
<tr>
<td>Welfare home</td>
<td>4</td>
</tr>
<tr>
<td>District/community hospital</td>
<td>10</td>
</tr>
<tr>
<td>Voluntary</td>
<td>6</td>
</tr>
<tr>
<td>Private</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
</tr>
</tbody>
</table>

Table 7.5: Age profile of staff respondents

<table>
<thead>
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<th>Age range</th>
<th>Number</th>
</tr>
</thead>
<tbody>
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<td>1</td>
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<td>21-30 years</td>
<td>7</td>
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<tr>
<td>31-40 years</td>
<td>14</td>
</tr>
<tr>
<td>41-50 years</td>
<td>10</td>
</tr>
<tr>
<td>50+</td>
<td>15</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
</tr>
</tbody>
</table>
Table 7.6: Number of years working with older people

<table>
<thead>
<tr>
<th>Duration of stay</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 year</td>
<td>3</td>
</tr>
<tr>
<td>1-10 years</td>
<td>30</td>
</tr>
<tr>
<td>11-20 years</td>
<td>9</td>
</tr>
<tr>
<td>21-30 years</td>
<td>2</td>
</tr>
<tr>
<td>31-40 years</td>
<td>2</td>
</tr>
<tr>
<td>41-50 years</td>
<td>0</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
</tr>
</tbody>
</table>

Of the 48 respondents, the majority were registered nurses (20); there were 7 health care assistants, 14 care attendants, 2 physiotherapists, 2 household staff and 2 cooks. Within nursing, while the majority of respondents were staff nurses (15), 5 nurses were in a management role – one was a clinical nurse manager, 3 were directors of nursing and one was an assistant director of nursing.
Chapter Eight
Care Environment and Ethos of Care
Chapter Eight
Care Environment and Ethos of Care

8.1 Introduction

This chapter examines the impact of care environment and ethos of care on the quality of life of long-stay residents in Ireland. This was one of the four themes that emerged from the qualitative research undertaken with residents and staff in the twelve study sites. The value of the study site material is that it allows the voice of residents and staff to be heard directly. It is not possible, however, to extrapolate from the study site material, particularly in respect of comparative care. One of the messages from the research is that there is evidence of good and bad practice in all types of long-stay facility. Consequently, we cannot say that one type of care regime is unambiguously better than another for quality of life. Thus, pronouncements on sectoral quality of life are not made in a comparative sense; rather, the experiences of residents and staff are reported to assist the reader to make sense of general quality of life in long-stay care.

In this chapter, the emphasis is on care environment and the underlying ethos of care in the study site. As part of the qualitative research, residents described their day-to-day experiences, from the time they woke up until the time they went to sleep for the night. They also spoke about their capacity to make choices in the long-stay facility and the extent to which they were included in decisions about their care. They spoke about the attitudes of staff to caring. Staff also described the ethos of care in the facility and identified factors which impacted on day-to-day care. Four categories were identified as important: promoting autonomy; promoting and maintaining independence; staffing and physical resources; and the care philosophy.
8.2 Promoting Autonomy

This category brought together the elements of the care environment which determined the extent to which residents could exercise choice and autonomy in their daily life. Aspects of autonomy were discussed in the previous chapter, particularly in relation to getting up in the morning and going to bed at night. Within the study site data, this was explored through focusing on two key aspects of autonomy: involvement in decision-making and exercising choice.

8.2.1 Involvement in Decision-Making

Staff respondents identified the inclusion of residents in decision-making as an important aspect of quality care for older people and some described ways in which residents were included. They suggested that residents’ opinions about care were sought and their care was based on these. Resident respondents also described situations when their opinion had been sought. Most relatives were not sure if their relative was consulted about their care or not. Some suggested that the illness of their relative made consultation difficult.

In many sites resident inclusion in decision-making appeared to be ad hoc rather than part of the ethos. Some staff respondents, because they had worked in the facility for some time, felt that they knew a resident’s likes and dislikes and could, therefore, make appropriate choices for them. In some facilities, residents felt the need to fit in and do what they were told; some of them suggested that there might be consequences for them if they did not.

A few facilities had formal resident committees and sought residents’ views in relation to many aspects of day-to-day life within the facility. Others had suggestion boxes for residents to use. One public facility had set up an activities committee which was chaired by a resident and was charged with organising and planning outings.

Some resident respondents differentiated between residents who had been included in the decision to enter into long-term care and those who had not. They had noticed that residents, whose families had made the decision for them to enter long-term care, were less likely to feel settled, did not really participate in life within the facility and generally appeared more unhappy.
8.2.2 Exercising Choice

Resident and staff respondents emphasised the importance of having choice within the day. Choices about the time residents were woken, had breakfast, went back to bed, had meals and what they did during the day were identified by respondents as important. It was also evident from respondent accounts that choice could only be facilitated when there was flexibility in care giving routines. Care was demonstrably more routine in some sites than others, and this had an important affect on residents’ ability to make choices. In the more flexible regimes, residents had more choice and this contributed significantly to their overall quality of life.

The quotes in Table 8.1 from residents, staff and relatives demonstrate the extent to which choice is allowed in their care setting. For many resident respondents, choice over their day was possible, they were able to request changes to their daily pattern if they so wished, and they had been fully involved in the decision about the time they got up or went back to bed. Other respondents, however, felt they had little control over their day and for them choice was very constrained. Some resident respondents described being woken at around 6 a.m. to have breakfast and stated that they would not wake so early if the choice were theirs. It appeared from the accounts of these residents that breakfast was traditionally given by the night staff and the early start was to ensure that this task was completed prior to the day staff arriving on duty. Going back to bed in the early afternoon was also an experience of some residents. While this was described as a choice by some residents because they were tired, for others it was part of the routine and just something that happened. Some staff respondents suggested that choice about when to go back to bed was only possible when staffing levels in the evening allowed it or if residents could return to bed without staff help.

Relatives were divided in the extent to which they perceived that the residents had choice. While the majority suggested that residents did, four stated that they did not. However, two of these respondents perceived that the lack of choice was because of the resident’s disability rather than practices within the care environment.

Meal-times for most were set at fixed times and often the day was shaped around these. In some facilities, however, meal-times were staggered to give residents some choice of eating time and this was highlighted by resident respondents as something they greatly appreciated and contributed positively to their quality of life.
Table 8.1: Involvement of residents in decision-making

<table>
<thead>
<tr>
<th>Involvement in decision-making</th>
<th>No involvement in decision-making</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>We have an activities committee. I am the chairman.</em> (GR1 Resident 6, Public)</td>
<td><em>Since they (residents) are here every day and we are here every day, it is mostly known, the long-stay patients we know what they want and what they don’t like.</em> (YW2 Nurse 01, Private)</td>
</tr>
<tr>
<td><em>It’s the one thing that struck me when I am in, all the people I was friendly and chatting with, I found they were all the people who had made the decision … they made up their own minds and they are happy. … I don’t say the other ones are all miserable but it’s often to do with the family.</em> (LC1 Resident 01, Voluntary)</td>
<td><em>They keep saying like, ‘oh well now, I’ll be going home, I’m not in here, I won’t be staying, I’ll be going home’ and that seems to go on. … They never accept it, never, never.</em> (LC1, Resident 06, Voluntary)</td>
</tr>
<tr>
<td><em>I’m on the committee. I go (to the garden) a bit more. I’m more on the administration end.</em> (GN1 Resident 01, Public)</td>
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<table>
<thead>
<tr>
<th>Have choice</th>
<th>Little choice</th>
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<tbody>
<tr>
<td><em>I don’t go to bed until around ten. I can go to bed anytime that I like but after ten suits me. I come in and look at my own television.</em> (YW3 Resident 09, Private)</td>
<td><em>I love my bath. I look forward to it. It’s once a fortnight but I think we could have it weekly.</em> (PK3 Resident 02, Public)</td>
</tr>
<tr>
<td><em>You can stay in bed to 11 o’clock if you like, they come to make your bed. You can suit yourself. You are your own boss kind of thing now.</em> (YW1 Resident 02, Private)</td>
<td><em>There is one nurse and she has a positive craze for this cardigan and I hate it but she insists on my wearing it.</em> (YW4 Resident 05, Private)</td>
</tr>
<tr>
<td></td>
<td><em>As you can see around, it’s a very open ward area. It’s a very small space in terms of the environment. There is nothing of the notion of privacy, there’s nothing of the notion really of a sense of choice either and that worries me a lot.</em> (PK1 Nurse 01, Public)</td>
</tr>
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<td></td>
<td><em>Some choices are not allowed if they can avoid it. … They avoid changing the routine.</em> (Relative)</td>
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<tr>
<td></td>
<td><em>You can’t (give a choice) – you have to have everybody up by a certain time because if you don’t then the dinner is there and then you can’t be coming into, we do not have the staffing levels to do that.</em> (YW1 Nurse 01, Private)</td>
</tr>
<tr>
<td></td>
<td><em>At my age I don’t bother. I do whatever the girls tell me to do.</em> (YW4 Resident 01, Private)</td>
</tr>
<tr>
<td></td>
<td><em>You have breakfast at 6.30 because the night staff have to do it and they have forty-something people to deal with.</em> (LC1 Resident 07 Private)</td>
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</table>
8.3 Promoting and Maintaining Independence

Many residents expressed the desire to maintain or improve their current level of independence (Table 8.2). This involved doing what they could do for themselves, participating in exercise classes if possible, keeping mobile and trying to maintain their physical abilities. Residents suggested that it was important to do the things they could for themselves and described what they did for themselves and what they needed help with. Some residents felt they were given the time they needed to participate in their care while others felt rushed. Residents across all facility types felt that care staff were very rushed and busy which resulted in residents feeling concerned about slowing things down.

Some residents had been admitted to long-term care from acute settings and had had an active programme of physiotherapy; they found, however, that this had stopped since their admission to long-term care (Table 8.2). One resident who had had a stroke described her struggle to try to regain her mobility and felt she had gone backwards since her admission. Another resident described the lack of physiotherapy as a terrible loss. Residents were equally likely to talk about loss of independence in public and private settings; this reinforces the view of long-stay care as static and terminal, rather than dynamic and rehabilitative. It is not automatic that one should lose one’s independence upon admission to long-stay care. Where efforts are made to maintain independence for residents, the gains are enormous and quality of life is enhanced.
<table>
<thead>
<tr>
<th>Maintaining independence</th>
<th>Becoming more dependent</th>
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<tbody>
<tr>
<td><strong>When you learn, you are able to do it on your own.</strong> (PK2 Resident 01, Public)</td>
<td><strong>I have lost out on the physiotherapy and the exercises and I am not doing any exercises now, which is a terrible loss.</strong> (YW3 Resident 02, Private)</td>
</tr>
<tr>
<td><strong>They let me try and help myself as much as I can, you know.</strong> (PK3 Resident 09, Public)</td>
<td><strong>I did get a lot of physio (in an acute hospital). I got it for an hour a day but when I went to long-stay care, no physio. That’s not right. ... I was beginning to pick up and it would have made a lot of difference.</strong> (LC1 Resident 7, Private)</td>
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<td><strong>I think that it’s most important that you don’t take any piece of independence that they have away from them and just kind of stand behind them.</strong> (YW1 Care Assistant 01, Private)</td>
<td><strong>They are not taken to the toilet when they need to go.</strong> (PK2 Resident 7, Public)</td>
</tr>
<tr>
<td><strong>I think to have a quality of life they have to be able to do as much as they can for themselves. We must, you know like sometimes, I remember this from being on wards, sometimes it was easier to feed someone than to try and help them to feed themselves. Now I know that there are people that will always have to be fed but to give them as much independence as they can and what they need too is they need a little bit of time.</strong> (GN2, Activity Therapist 01, Public)</td>
<td><strong>The problem in terms of independence is that very few would be considered independently mobile, which is why they are here so there would not be a huge demand on maintaining independence.</strong> (PK2 Resident 01, Public)</td>
</tr>
<tr>
<td><strong>So we try to keep their independence, we don’t take it away from them. There’s some patients there now, and they barely feed themselves, but I’d have a spoon, and they’d have a spoon, and let them work around the plate. I work with them. They still have their independence, I wouldn’t take it from them.</strong> (YW1, Care Assistant 01, Private)</td>
<td><strong>But you know as nurses we tend to be just busy doing for you, whether you want it or not sometimes, you know. And being afraid of letting people have their independence.</strong> (PK1 Nurse 01, Public)</td>
</tr>
<tr>
<td><strong>What I like about (living here) is my independence. I can go for a walk or go out.</strong> (YW3. R10, Private)</td>
<td><strong>I’d like to be able to go out, to be more independent, to be able to go to the toilet myself. I’d like to be able eventually to go out to the shop. That’s the one thing you miss terribly. It’s exercise that you get there. ... After I’d been sick, the first thing, to go into a shop to buy a box of matches and it was a joy, you know, just to do it yourself. People say ‘oh, I’ll do it for you’. You hear this, that’s not the same. I’m the kind of person I like to see results of what I buy you know, but we miss a shop. We used to have one. Haven’t had one in the last year, so I have to depend on people to bring in stuff.</strong> (GN2 Resident 01, Public)</td>
</tr>
<tr>
<td><strong>You know when they first come in we’re not too invasive. We’ll hold back. Our aim is to let them hold on to their independence. That’s fine but we have to be in the wings.</strong> (YW5 Nurse 01, Private)</td>
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8.4 Staffing Issues

Staffing resources were discussed by staff and resident respondents in the study sites and in the focus groups. Two aspects of staffing were evident: the need for adequate staff to meet the needs of residents; and the right skill mix amongst staff to deliver skilled care. Staff described how staffing levels could dictate the focus of care and the extent to which residents were able to have choices about their day. Some suggested that when staffing levels were low, the best that could be done was to get through the work. They suggested that this was easiest when staff knew the facility and residents well and was most difficult when there were large numbers of new or agency staff.

Residents across all facilities perceived staff as extremely busy with limited time to complete their care tasks (Table 8.3). In all types of settings, many were very impressed by the dedicated, friendly and caring staff that looked after them on a day-to-day basis. Some considered staff as friends who shared information about their families and activities. Many resident respondents highlighted that great staff were the best aspect of the facility in which they lived. Relatives also identified staff as the most important determinant of quality care.

While the majority of comments on staff were positive, residents in a few study sites described situations where they had not been able to get the attention of staff and had to wait for substantial periods of time for assistance. This was particularly distressing to them when it involved waiting to be taken to the toilet in the morning or waiting for staff to attend to their personal care. Sometimes this was due to low staff numbers or the absence of call bells; other times it was due to the insensitivity of staff to the needs of residents.
Focus group participants reported that there was great variation in staffing levels across long-term care facilities in Ireland. They suggested that staffing levels in the public sector were ‘historical’ and suggested that current levels did not meet the needs of their service. Some focus group participants reported that staffing levels were also an issue within some private nursing facilities. They suggested that the issue was related more to the ratio of registered nurses to care assistants rather than numbers per se and that some facilities did not have an appropriate number of registered nurses. They suggested that the lack of registered nurses could lead to inadequate supervision of care staff and lower standards of care. The inspectors who attended focus groups highlighted the need for review of the Health (Nursing Homes) Act, 1990, which requires that only one registered nurse be on duty at any time. This legislation, which governs care in private homes, was, in their view, outdated. They described how the dependency and numbers of residents in many facilities had increased as the trend was to build larger nursing homes or extend existing ones. They suggested that the increasing numbers of residents were not always matched by a commensurate increase in the number of registered nurses. They had, therefore, found the level of registered nurse cover totally inadequate in some nursing homes.

Focus group participants also stressed the need for an appropriate skill mix amongst staff. They indicated that there was a need to review the role of registered nurses and health care assistants providing care for older people. They argued that there was a need to ensure that registered nurses’ expertise was maximised and suggested that this could only be done if nurses were supported by appropriately trained health care assistants and care attendants, and if nurses themselves embraced change. Some participants reported that they did not have an appropriate mix of staff in their facility. For some, the problem was a lack of registered nurses, and for others, not enough care assistants.
<table>
<thead>
<tr>
<th>Staffing resources</th>
<th>Physical environment</th>
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<tr>
<td>It’s in their (proprietors) interests to keep staffing levels low and if you are in a public nursing home it is probably higher. … I would not think they work half as hard as we do. (YW1 Nurse 01, Private)</td>
<td>(Space) it is very limited. You bring them to the day room when everyone is in this little space with the table in front of them. Then you have to move three tables before you get to the patient you want. (PK1 Nurse 02, Public)</td>
</tr>
<tr>
<td>Because of our staffing levels, things are done according to routine. (PK1, Nurse 02, Public)</td>
<td>The television goes on at six and it goes on until midnight; it is noisy. (PK2 Resident 07, Public)</td>
</tr>
<tr>
<td>When you get your breakfast and you might want to go to the toilet and you call the nurse and she would not come, … then you wait and wait and then you call the nurse again, that nurse will say ‘wait a minute’. Well, that minute could be an hour. (GN1 Resident 06, Public)</td>
<td>Sharing is not as good as a private room. I’d prefer a private room. (GN2 resident 08, Public)</td>
</tr>
<tr>
<td>This morning a lady turned on me because I wet the floor while I was waiting for her to come along and she was slow in coming and she thinks I should not have wet the floor. (GN2 Resident 08, Public)</td>
<td>They could be more considerate. As a visitor you pass the other rooms and very often the doors are open. (Relative)</td>
</tr>
<tr>
<td>We are blessed here because they have great programmes going on in education. We have to pay and that’s another issue. The staff have every opportunity to up-skill their competence. (YW3 Nurse 01, Private)</td>
<td>There is no call system and the nurses are very far away. … I think it’s terrible. You would be wanting to go to the toilet and you can’t get a nurse. (GN 01 Resident 06, Public)</td>
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<td></td>
<td>There’s a lot of Alzheimer’s patients here and some of them, they’re lost really. It’s the wrong place for them, you know. There’s no facilities at all for them, you know. … They wander up and down the corridor, that’s it. There’s nothing for them to do or to get them interested, you know. Can’t sit and chat. (PK3 Health Care Assistant 01, Public)</td>
</tr>
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</table>
Staff respondents also highlighted their educational needs; they suggested that training was important in order to give informed care. Some staff respondents highlighted the difficulties of participating in educational opportunities; low staffing levels and lack of availability were cited as the major issues. Nursing staff identified a need for clinical updating and for courses which focused on the needs of older people. One staff respondent in a senior managerial position described how she had set up an educational network with other facilities in order to maximise educational opportunities for staff. Care attendants also discussed their educational needs. In some facilities care attendants who had undertaken the health care assistant course highlighted the difference this had made to their capacity to care for residents. They were concerned, however, that they had not been able to take up a new role on return from the course. In the focus groups, participants also raised the issue of the health care assistant training course. They were extremely positive about this course and felt that it had really made a difference to client care. Many, however, had also experienced difficulties in implementing the new role within their facilities.

8.5 Physical Environment

The issue of physical environment was raised by a number of respondents (Table 8.3). Staff and resident respondents and relatives highlighted the importance of homely environments which were structured to give residents a choice of their own room if desired. For some resident respondents, the lack of a private room was a real problem, particularly in public facilities. Communal facilities were much more a feature of public facilities than private ones. Residents found life in a communal ward difficult and highlighted issues of privacy and the lack of choice in listening to the television or radio. Relatives also shared this concern. It was evident from resident interviews that the quality of the physical environment made a difference to resident quality of life. Poor physical facilities meant that some residents, mainly in public facilities, spent substantial time each day by their bed.

It was also evident from observation within the study sites that living in a communal ward impacted on the capacity of a resident to exercise choice about the time they got up in the morning. The general noise of others getting up was likely to disturb all residents in a ward which made later waking impossible. An additional problem highlighted by a number of resident respondents within a few public care study
sites was the lack of a central call bell system to get staff attention. Residents in these sites either got someone else to go and get the nurse or hoped they would be heard when they shouted for attention. Some resident respondents highlighted situations when they were waiting for attention for a considerable length of time.

The question of the number of bathrooms and toilets was also raised by some staff and resident respondents as a concern. When the ratio of bathrooms to residents was low, residents were often bathed or showered in rotation, resulting in residents only having the opportunity of being bathed or showered every few weeks. Another issue raised was that some bathrooms and toilets were too small. This was a problem because hoists could not be used in these small spaces. In one facility the toilets were so small that it was difficult for a staff member to enter with a resident to give help when required. Staff respondents were extremely concerned about health and safety issues for residents and staff.

In many facilities, particularly in the public sector, staff raised concerns about the suitability of the physical environment for residents with Alzheimer’s disease. They suggested that buildings were sometimes unsuitable for people with dementia and impacted negatively on their quality of life. Design issues were highlighted, including choices of colour and lighting for people with dementia. A few resident respondents voiced concern for their physical safety as some people with dementia could be physically violent occasionally. Some residents could not lock away possessions or lock their rooms at night which led some of them to fear for their safety.

**8.6 Care Philosophy**

Staff respondents were asked to describe the focus of care. Some respondents, when describing what was important to a resident's quality of life, stressed the need for care to be individualised. Many described care within their facility as individualised and tailored to the residents’ needs. In these facilities, many residents could dictate the pattern of care for the day (Table 8.4). While staffing constraints were an issue for many of these facilities, care was organised to try and give residents maximum flexibility. For management, this meant that off-duty rotas for all staff had to be organised in a way which facilitated resident choice.
Therefore, the practice of rostering most nursing staff in the morning and minimum
nursing staff in the evening was discarded and new staff rotas implemented
to enable residents to get up and go back to bed at their desired time. In some
facilities, mealtimes were staggered and activities were at different times of the
day to meet residents’ preferences.

In some facilities, both public and private, resident and staff respondents
commented on the caring ethos and how this shaped care within the facility.
In some facilities this ethos was based on resident inclusion in decision-making,
maximising resident capacity, facilitating choice and keeping residents involved.
The manager’s role in shaping this ethos was commented on by staff and residents.
One manager described the difficult and challenging path of implementing a new
ethos of care and the time, commitment and support needed to see it through.
Another manager described how the ethos pervaded all aspects of management
of the facility. She described how this ethos involved caring for staff and investing
in training and induction so that the best care could be delivered for residents.

In other facilities, again both public and private, care was described as routinised
and focused on tasks. In these facilities care was perceived as focusing mostly
on the physical aspects. Some staff were concerned that the social and emotional
needs of residents were not being met. In some of these facilities, it was evident
that there was a real desire to change care practices but that many constraining
factors had held back the pace of change (Table 8.4). In these facilities staff
expressed the need for change in the routine of care and their frustration that little
progress had been made. In other facilities the focus on routine had become so
embedded, staff could not see how it could change. They explained that current
staffing levels and resources made change impossible. A few staff respondents
questioned the commitment of some staff to change and suggested that a few
staff were not motivated to care for older people.
### Table 8.4: Individualised care and routine care

<table>
<thead>
<tr>
<th>Individualised care</th>
<th>Routine care</th>
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<tbody>
<tr>
<td>We are trying to look at people as individuals. The respect and dignity and sense of humour, that's so important because people do not want to be a number in a bed. (LC2 Director of Nursing, Private)</td>
<td>You’d have your breakfast in bed. You have a little bowl of porridge in the morning about six o’clock. (PK2 Resident 03, Public)</td>
</tr>
<tr>
<td>I think the first thing that struck me about the place when I came, that the ethos of care was very person-centred and holistic before those words were ever coined. (LC2 Nurse 01, Private)</td>
<td>You’re told to get up at seven and I think that is too early. (YW3 Resident 05, Private)</td>
</tr>
<tr>
<td>If I go in and they say ‘look, I don’t want to get up’, I say ‘fine I’ll come back in an hour to you’. (YW3 Health Care Assistant 01, Private)</td>
<td>It’s very hard (to treat residents as individuals) because we have so many patients; we try to but it is very difficult. … We have a work schedule and you must get your round done. (PK2 Nurse 03, Public)</td>
</tr>
<tr>
<td>Each person has their own individual care plan and they are drawn up by a staff nurse, and it usually involves, we try as far as possible to involve the patient and their family, in devising the care plan. (YW1, Assistant Director Nursing 01, Private)</td>
<td>I would feel it’s very task orientated. You know, that the routine, ritualistic, we are doing this and that. (PK2, Nurse 04, Public)</td>
</tr>
<tr>
<td>I do know that there was an older school of thought here in this facility where some of the patients were put into bed really early in the day due to staffing sort of … that the staff rotated eight to four I think was one shift and some of the patients would be put back to bed before the four o’clock shift ends because I think there’s a lighter … the four to midnight shift is smaller and I know that there’s a push on for that not to happen. So that’s a definite quality of care issue that people are being put back into bed just for management of workload, but I think that that’s something that they’re … that they’re trying not to do. (PK2, Nurse 01, Public)</td>
<td>It’s not too bad on this ward. The last ward I worked on I had to ask to come off it because there was this big mad rush and the last matron here stopped that rush. She said you’re here for 24 hours and she’s right. The patient gets up when they want to get up and back to bed when they want to go back and you should be able to judge a patient when she’s tired in the afternoon and she’d like to go in. On this particular ward, (the residents) they’re up at half eight, go back (to bed) at quarter past one, they’re in bed for 19 hours. Far too much, far too much. (GN1, Care Assistant 2, Public)</td>
</tr>
<tr>
<td>Because of our system and because of our staffing levels, and it is a huge issue our staffing levels, things are done according to a routine. (PK1 Director of Nursing, Public)</td>
<td>You’re woken up quite early in the morning. … So you’re woken at six and breakfast isn’t until ten past eight. It’s a long day. The nurses change at six o’clock and it wakes you up. So is there a routine here, there is, yeah ok, and is every day the same then, every day is the same, absolutely the same. … The day is very long, yeah boring. (GN2, Resident 02, Public)</td>
</tr>
<tr>
<td>A lot of (the care) is routine, but on the other hand they all seem, the majority or all of them seem to be happy. (YW4, Care Assistant 01, Private)</td>
<td>It’s not very patient-centred and I’m not criticising anybody individually but it’s not and a lot of people who work here, I don’t know, I’m very compassionate about people but a lot of people who work here, it’s really not about the patients, it’s about their pay cheque or whatever. I find anyway and it’s not any group in particular, it’s everybody. It’s probably us sometimes as well you know. (GN2, Physiotherapist, Public)</td>
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It is very open for them. Like even in the morning, you’d go in and say to some of them ‘did you want to get up yet, or are you going to stay there for another while?’ ‘Ah, no, sure I’ll get up now’, or ‘come back to me in ten minutes’, but they could say ‘come back to me in 15 minutes’. (YW1, Care Assistant 01, Private)
This chapter presented findings related to the care environment and ethos of care. The findings revealed that there were significant differences in resident experiences across care study sites and some public/private differences among the sites. The findings suggest that physical environment constrained resident choice and, therefore, impacted greatly on quality of life. The physical environment was poor in some facilities, more so in the public than the private sector. The ethos of care in many facilities did not facilitate resident inclusion in decision-making and routine continued to prevail in some facilities. This was also more evident in the public sector than the private sector. That said, there was awareness among staff, even in routine-based systems, that more flexibility was required to enhance the quality of life of residents. The problem was that they could not see a way to effect change from routine-based care to individualised care. The findings also revealed that staffing levels and skill mix were major issues in the provision of quality of care. Concern was expressed about registered nurse staffing levels and skill mix within the private sector, particularly as there was a reliance on non-qualified care staff in the provision of resident care. It was evident from the data that the care environment, staffing and ethos of care have a very significant impact on a resident’s quality of life.
Chapter Nine
Personal Identity
Chapter Nine
Personal Identity

9.1 Introduction

This chapter examines whether residents are able to maintain their personal identity when living in long-term care settings. People express their personal identity in many different ways that are unique to each individual. Four interrelated categories were identified through the qualitative interviews as impacting on, and reflecting, identity: self-expression, individuality, privacy and self-respect. In general, people need to feel at home in residential care in order to express their identity. They were more likely to feel at home if they could express their identity through their personal appearance, memory, personal possessions, spirituality and preferences for personal space. These issues are discussed in this chapter as they were articulated in various ways by residents and staff. Again, the emphasis in the chapter is on hearing the voice of residents and staff rather than generalising about quality of life in the various settings or comparing regimes of care.

9.2 Self-Expression

Resident respondents maintained a sense of self by various means. Some personalised their private space or room by putting personal possessions on show (Table 9.1). Opportunities for resident respondents to personalise their environment varied across sites. Respondents who had a room of their own had an opportunity to create a personal space. Some respondents had put up pictures or brought a favourite piece of furniture with them. They also organised their room to make it more comfortable, for example, by positioning a chair near the window for the light or having a wardrobe specially built to house all their belongings. These respondents tended to be the happiest and considered the facility a ‘home from home’. It would appear that having the opportunity to organise their space helped them to feel at home.
Table 9.1: Identity and personalised environment

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<th>Capacity to personalise their environment</th>
<th>Limited capacity to personalise their environment</th>
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<tr>
<td>I am very happy, like at home. That is my room, and this is my own furniture, and this all, yes, this was from my home when I sold, and this table is my one, small one. (LC1 Resident 12, Private)</td>
<td>Although I have a computer of my own, I haven’t got it here because I can’t you know. That is the difficulty with me here. (GN1 Resident 04 Public)</td>
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<td><strong>Int:</strong> And this is your own … duvet? Ah yes, my friend gave it to me, she moved house and she gave me that, and I love, I love my room and she gave me pictures. … That one up there, I think that’s the best.</td>
<td>Sister said I will have to put them (books) down in the day room. … Well, she said we will have to get rid of them. So I am slipping (them) out to me son every week … because some of them came from my own home.</td>
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<tr>
<td><strong>Int:</strong> You’ve managed to make it homely in here. Oh I do yes, I do yes, yes. (PK3 Resident 02, Public)</td>
<td><strong>Int:</strong> But … you would like them to stay here? Yeah, yeah. (GN1 Resident 06 Public)</td>
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<tr>
<td>I have my Sacred Heart picture up there, and I have a, em, perpetual lamp since back in the sixties, but of course, I couldn’t have it when I came. (PK3 Resident 10, Public) (Referring to having only one electric socket in her room)</td>
<td>I have my Sacred Heart picture up there, and I have a, em, perpetual lamp since back in the sixties, but of course, I couldn’t have it when I came. (PK3 Resident 10, Public) (Referring to having only one electric socket in her room)</td>
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Other resident respondents brought very little with them. They saw little need as ‘everything you’d need is here’. Their rooms were less personal and more functional. Some of these respondents frequently spoke about ‘going home’, may have seen their stay as short-term and so felt it was not worthwhile to personalise their room. In contrast to resident respondents who organised their space, these respondents had not fully settled. Their ‘home’ remained their old home.
In contrast to residents who had their own rooms, resident respondents living in large open-plan wards were very restricted in what they could bring with them. Large open-plan wards were a feature of public rather than private facilities. Typically, respondents’ space comprised of a small locker and a single wardrobe. Despite space restrictions, many respondents had a few personal items on display – usually photographs, ornaments or religious statues. Some respondents, however, would have chosen to bring other items with them if there had been sufficient space.

Photographs were greatly treasured by resident respondents (Table 9.2). They loved to talk around their photographs, speaking at length about the people or events depicted. Photographs provided a connection to respondents’ past lives, prompted memories and seemed to help maintain their sense of identity and uniqueness. Respondents also used photographs to illustrate their story, referring interviewers to photographs so they could see what they looked like when their hair was brown or know what their sons or daughters looked like. Photographs had a particular significance for resident respondents living in large open-plan wards. In sites where routine dominated, respondents seemed to view photographs of themselves as their ‘true’ selves.

Table 9.2: A life in pictures

<table>
<thead>
<tr>
<th>And that is my picture, my relations, you know. And that is ... and that was (naming people and describing events). And that’s my wife and meself, and that’s my son, ... that’s my sister, ... that’s my son and his wife. ... And that’s my life story. (LC1 Resident 12, Private)</th>
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<tbody>
<tr>
<td>Those are the two sisters. There should be one of the three of us somewhere, where it is now?</td>
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<tr>
<td>Int: Oh, there’s pictures there. Did you find it?</td>
</tr>
<tr>
<td>Int: I’m just looking now for it. I don’t know where it is, it’s not behind any of them?</td>
</tr>
<tr>
<td>Int: Oh, I see a picture of, yeah, there’s a picture of ... with an umbrella. The three of us?</td>
</tr>
<tr>
<td>Int: Oh, there’s one. There’s one of you three. I can see, you’re in your home. I’m in me home. Now that’s a while took of course. (YW2 Resident 04, Private)</td>
</tr>
</tbody>
</table>
The real me

I’m there in a photograph where I’m lovely in it.

Int: Well, I’ll have to have a look at that.
You can see it there … I’d lovely black hair. (GN2 Resident 03, Public)

I had brown hair when I come in. So you can imagine it. And I never got it done and I went snow white … and when the neighbours come in they go ‘Oh my God, you are white’ (laugh) … because they saw me when I was brown. I have photographs there of me when I was brown. Am I there anywhere? (GN1 Resident 05, Public)

There appeared to be two contrasting perspectives on the importance of having belongings around. Some resident respondents found it a comfort; their possessions evoked happy memories and helped them feel at home. Others appeared not to want such reminders. Anxiety about the security of their belongings may also have inhibited them. Some resident respondents, in both public and private facilities, expressed concern about the security of their belongings. Similarly, staff respondents were divided as to whether it was good or not for residents to have their possessions around them. Many acknowledged that it was important that residents had their ‘bits and pieces’. However, a few commented that possessions from home had the potential to create a longing to be back home.

Another way in which residents expressed their individuality was through their observance of their faith. Many resident respondents spoke about the strength and comfort they derived from their faith. Opportunities to attend mass were particularly important to these residents (Table 9.3). In some facilities, residents had an opportunity to attend daily mass, which they valued highly. However, some resident respondents reported that they had less opportunity to attend mass than they would have liked. Resident respondents and staff reported that the decline in the number of priests made it more difficult to find a priest able to visit to say mass, particularly on Sundays. Many facilities offered alternatives, for example meeting to say the rosary or for a prayer service. Resident respondents who were not Catholic had greater difficulty in finding ways to express their faith.
Table 9.3: Opportunity to observe their faith

<table>
<thead>
<tr>
<th>Opportunity to observe their faith</th>
<th>Limited opportunity to observe their faith</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s great to have the mass in the morning. (LC2 Resident 01)</td>
<td>I go to mass here any time there is mass. ... Of course, I have to be pushed. And then they find that an effort.</td>
</tr>
<tr>
<td>(The priest) comes in on a Monday. ... We have a nun and she comes in on the Sunday. ... We all sit down in the room down below and we listen to the mass and Sister gives communion. Father can’t come up on a Sunday because he has the parishes, and the priests are very slack, no priest. (PK3 Resident 02 Public)</td>
<td>Int: Is it the staff that bring you?</td>
</tr>
<tr>
<td></td>
<td>No, there is men (volunteers) that comes in. ... About three Sundays ago no one came and the three of us were ready waiting and we missed mass. And we were annoyed like. (GN1 Resident 06, Private)</td>
</tr>
<tr>
<td></td>
<td>I’d like to have mass here oftener. We only have mass every month. The first Friday that’s all and I’d love to (be able to attend mass more frequently). (YW4 Resident 06 Private)</td>
</tr>
<tr>
<td></td>
<td>We’ve got two patients ... that are protestants, and if they don’t want to sit in mass with the other residents, we’ll take them down. ... I’ve never seen a reverend coming in. I’ve seen the Catholic priests coming in and the mission priests coming in and nuns. (YW1 Care Assistant 04, Private)</td>
</tr>
</tbody>
</table>

9.3 Personal Appearance and Grooming

For women resident respondents, how they presented themselves to the world appeared to be closely linked to their self-expression and positive self-esteem. This did not appear to be as great an issue for men. Female respondents liked to wear their own clothes and tended to have strong opinions as to what they wanted to wear. They were equally concerned that their clothes were cared for properly. Many had very exacting standards and occasionally the laundry failed to meet their requirements. Some respondents complained about the laundry losing their clothes or shrinking them. Many opted to send their clothes home for laundering (Table 9.4). Female respondents also enjoyed having their hair or nails done. The hairdresser’s visit was a big event, creating a buzz of conversation about appointment times, hair colour, etc. In contrast, male respondents rarely mentioned clothes or their personal appearance. Across all study sites, residents had their own clothes. Only one man reported wearing the facility’s clothes. Staff respondents also believed that it was important that residents looked their best and described
how important it was that residents’ clothes were appropriate and matched. Staff respondents described how they personally bought clothes or toiletries for residents who had little.

Table 9.4: Clothes and washing and grooming

<table>
<thead>
<tr>
<th>Clothes and laundry</th>
<th>Washing and grooming</th>
</tr>
</thead>
<tbody>
<tr>
<td>The girls brings all my clothes home and washes them and brings me in whatever I want. I just tell them and they get it for me. (GN2 Resident 02, Public)</td>
<td>Oh yeah, the hairdresser comes in, hairdresser comes in whenever I want you know, get a perm whenever I want it. It would want to be done again. I like a good shape on my hair; that’s the way I like it. (PK3 Resident 11, Public)</td>
</tr>
<tr>
<td>Int: And what about your clothes and things? They’re washed. They’ve a washeteria here and I have to sort out my clothes because I don’t like letting my good things go. (YW5 Resident 02, Private)</td>
<td>I love my bath. Int: You love your bath? Yes, I love my bath, yes, look forward to it.</td>
</tr>
<tr>
<td>Int: So sometimes they lose the clothes, do they? No, they shrink them. (YW5 Resident 02, Private)</td>
<td>Int: Is that once a day, or once a week? Fortnight, but I think we could have it weekly.</td>
</tr>
<tr>
<td></td>
<td>Int: That would be your preference. Yes, weekly. (PK3 Resident 02, Public)</td>
</tr>
<tr>
<td></td>
<td>Int: Are there enough bathrooms? We need more. … Most people who want to do their showers, that is, in the mornings, and you see queues, actually for the bathrooms. We have two shower rooms and a bathroom. That is all, it’s not enough. … And we are rushing in and out and you might stay a little bit but before you go someone else is there (laugh). Sometimes it’s upsetting. You get so upset. (GN1 Registered Nurse 01, Public)</td>
</tr>
<tr>
<td>They have nice clothes and if they haven’t we kind of all, you know, if we have the odd patient that just wouldn’t have that much clothes, we personally bring in things to them, like blouses and tops and that. (YW4 Registered Nurse 02, Private)</td>
<td>When I came in here, the second day, no, the second day I was here, I was in me room … and this young fella was standing in the corner and, and eh, and the nurse came in and she says ‘take off your’, she says ‘you have a shower today’. … I said I’m not taking off my clothes, he has to leave’. She said, ‘you don’t have to bother about him’, she says ‘you have got to take off your clothes and get washed, get your shower’. So I done it and I threw all the clothes up in the corner. (YW5 Resident 03, Private)</td>
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<td></td>
<td>A funny little man was in here a while ago and I had a sore bottom … (the sister recommended some cream). … Next day the cream came and the funny little man who looked after me, about five foot nothing, bald, just a funny little man, he said ‘what was it’, so I showed it to him … and he said … ‘you bring your bum and put it on the bed there and I will use it (the cream) for you’. Well now, I felt mortified, but on the other hand, how mortified does he feel? (YW2 Resident 01, Private)</td>
</tr>
</tbody>
</table>
Opportunities to have a wash differed across sites. In private nursing homes, resident respondents usually had a room with an en suite. Consequently, they could have a bath or shower when they liked if they were able to wash independently, or when staff were available if they needed help. In contrast, the lack of bathrooms in public facilities meant that resident respondents were frequently on a rota for a bath. Many respondents in public facilities expressed a desire for more frequent baths. This reinforces the data from the survey reported in Chapter Six, which showed a much greater availability of washing facilities in private nursing homes.

One issue raised by residents was who assisted them with washing. Some female resident respondents were shocked when a male carer helped them with washing or other intimate care. It would appear that on occasions, women’s preference for a same-sex carer could not be accommodated. The female respondents who described this experience were clearly upset by the experience but ‘got on with it’. However, most respondents shared that it was how kind and caring someone was that was more important than gender. None of the men interviewed raised a similar concern.

9.4 Individuality

The extent to which long-term care facilities met or responded to resident respondents’ individual preferences and needs varied greatly (Table 9.5). At one end of the spectrum, respondents were able to live their life as normal and did not feel constrained by rules or regulations. They could ‘be themselves’ and felt they had the freedom to come and go as they pleased. At the other end of the spectrum, the routine dominated to such an extent that respondents felt they had little autonomy. There was a sense that they had to fit their lives around the routine and obey the ‘rules’. What the rules were was not always clear, but they reported mirroring what the other residents did. They described their life as monotonous and unchanging. One resident respondent likened it to ‘living in a prison’, another to ‘being in school. Respondents coped with this in different ways. The majority spoke about ‘putting up with it’ or ‘getting on with it’. A few actively rebelled and did what they wanted irrespective of the consequences. Others worried about being viewed as a troublemaker or getting on the ‘wrong side’ of the staff.
### Table 9.5: Freedom and constraints

<table>
<thead>
<tr>
<th>A feeling of freedom</th>
<th>Feeling constrained</th>
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</thead>
<tbody>
<tr>
<td>Mealtimes are fixed, but otherwise I’m a free agent and that appeals to me like. … There’s a sense of freedom or something. There’s no rules, like you get your meals and that sort of stuff, but I can go out for a walk. I mean you can come and go. (YW3 Resident 10, Private)</td>
<td>Ah sure, you’d have to get out, you couldn’t be stuck in here the whole time.</td>
</tr>
<tr>
<td>It is just right, I couldn’t fault, unless I told a lie, I couldn’t find fault with, if I want something done, I find them perfect really. Because if I want something done they’ll get it done for me, and there’s an atmosphere of home about it. That you don’t feel you’re in a strange place at all. (YW3 Resident 11, Private)</td>
<td>Int: Why? Oh God, you wouldn’t, never stick it. You might as well be in Mountjoy.</td>
</tr>
<tr>
<td>Knowing the individual the priority</td>
<td>Int: And why is it like Mountjoy?</td>
</tr>
<tr>
<td>They understand a lot about me. … And then as we grew, as (the Director) and I grew together she understood me. … There are things that you don’t do, naturally, and there are things that you can; she’s very broadminded. So it took a while to settle in but it was a matter of getting used to. … It was a matter of getting used to know, them to know me. (YW3 Resident 03, Private)</td>
<td>Well, I mean to say, you’re confined. … That’s why I call it, I mean, you’re confined here and you’re not one of the people or anything, you’re not mixing with people or anything like that. You only see the patients here, and the nurses and whatever men is here. (GN2 Resident 09, Public)</td>
</tr>
<tr>
<td>Knowing the individual not a priority</td>
<td>It’s just that it’s like a school. It’s very, how shall I say, regimented, you know. You do a thing now if it’s handy for the hospital to do but if you want a cup of tea you couldn’t get it. … In a democracy you have to do the best for everyone you know. (GN1 Resident 01, Public)</td>
</tr>
<tr>
<td>Int: Do you feel that they know you, your likes and your dislikes, the staff here. Would they know you well?</td>
<td>Some choices are not allowed if they (can) avoid it. … They avoid changing the routine. (Relative)</td>
</tr>
</tbody>
</table>
Ways of coping

There are days I decide I’m not getting up. She comes around and asks me ‘are you getting up today?’ No. A simple answer like that. No.

**Int:** So when you say no is that a problem?
No, it’s not a problem with me.

**Int:** You just stay there and that’s it?
I just stay put and that’s it. And, and to be, to be honest about it … I defy anyone to move me when I make up my mind.

**Int:** And do you know the staff? Do you know their names?
I don’t know the staff. One thing I don’t do, I don’t inquire about the staff’s names or anything like that because I don’t like to get involved where any of the staff are concerned.

**Int:** Why is that?
Well, I have a twofold purpose you know; you become immune to anything they might say against you, that would be the same for something they might say for you at the same time. … It makes you immune to any criticism.

**Int:** Not getting to know them.
Not getting to know them. (GN2 Resident 10, Public)

**Int:** Each day being the same, is that boring?
Oh yes, that’s the word, boring, that’s the word … but I don’t like saying anything because, you’re, if you say anything you’re in the bad books altogether.

**Int:** Would you?
I’d say that I wouldn’t.

**Int:** What would happen if you were in the bad books?
Oh, I don’t know, they, they ignore you and everything else, isolate you and everything.

**Int:** Do they?
Ah they would, they would, so I say nothing.

**Int:** So that’s your policy, say nothing?
That’s it now. I seen it a couple of occasions with others, and it’s, I don’t like it. I’ve nothing to say about the nurses and that, cos they’re alright, but it’s em, it’s not a nice place to be in, and that’s to tell you the truth. (GN2 Resident 09, Public)

The difference between facilities centred on whether residents felt empowered or powerless in the system. Some facilities empowered resident respondents by making them feel ‘in charge’, while others made resident respondents feel powerless and vulnerable. The ability to make respondents feel empowered related to how well staff knew residents as individuals and showed interest in them as people. Some respondents reported that staff spent time getting to know them and were willing to meet their individual needs. This was more evident in the smaller facilities than the larger, older facilities. Staff attitude to residents was also a factor; for example, viewing residents as patients may result in a focus on physical rather than emotional care. This may be the legacy of the experience of some staff working in a general hospital. Focus group participants considered a move away from this orientation to be key to good quality of life for residents.
The degree of privacy enjoyed by resident respondents largely depended on whether they had a room of their own or not (Table 9.6). Respondents who lived in large open-plan wards in public facilities experienced the greatest lack of privacy. Many reported that it was a struggle to have any kind of private life. The curtains around their bed were the only means they had of shutting out the rest of the ward. However, curtains provided visual privacy only and many commented that even when they were closed, ‘everybody knows what’s going on’. Staff respondents working in these facilities also reported that they found it difficult to maintain residents’ privacy. For example, the cramped space made it difficult to keep the curtains closed when using bulky equipment. The lack of a day room in some facilities exacerbated the problem. Reality for residents living in these facilities is that their world shrinks to the space around their bed. All activities – eating, sleeping and socialising, are carried out in or beside their bed against the backdrop of a large, noisy ward. Residents who were fit and active had the option of taking a walk outdoors or going ‘down town’. Those who were physically dependent had little option but to ‘put up with it’. Many respondents longed for a private room but believed that there was little hope of getting one. Residents who lived in two or three bedded rooms had fewer issues. They tended to be positive about sharing and liked the company. Many of the private study sites had a few two or three bedded wards. In these facilities, resident respondents who shared usually had opted to share rather than have a room of their own; it was their choice, unlike resident respondents in large open plan wards who had no other option.

Respondents who had a room of their own had a degree of privacy and control not open to residents living in multiple occupancy rooms. Having a room gave them choices. They could choose to join other residents or had the option of retreating to their room if they wanted to be alone. Having a door literally meant that they could shut out the rest of the world if that was what they chose. A room of their own also freed them from the worry of disturbing others. They could choose to watch television or turn up their radio if they wished.

There were some differences between staff and resident respondents’ perceptions of privacy and what was important. Staff respondents focused on physical privacy more so than resident respondents. They tended to highlight the importance of ensuring that curtains and doors were closed when providing intimate care. Relatives raised similar concerns. However, resident respondents rarely raised this as an issue. The issue for them was that staff rarely knocked and tended to ‘barge’ in. In contrast to staff, resident respondents prioritised social and psychological privacy rather than physical privacy. More problematic for them was the lack of ‘peace
and quiet’ and having nowhere private to talk to their visitors. In the context of protecting residents’ privacy and dignity, there was consensus across resident, staff and relative respondents that residents should have the option of a single room. Focus group participants agreed and suggested that single occupancy rooms with en suite facilities should be the norm. They recommended that this should be the minimum standard for newly-built facilities in the future and believed this standard should apply across both public and private facilities.

Table 9.6: Perspectives on privacy

<table>
<thead>
<tr>
<th>Resident perspectives on privacy</th>
<th>Staff and relative perspectives on privacy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I’ve a very nice little room, comfortable bed.</strong> … I have privacy if I wanted to go down and sit there or go down and listen to the radio or lie on the bed or whatever I like. And then if I want to mix with some of the other people I can come up and mix with them. (GN2 Resident 07, Public)</td>
<td><strong>The beds are so close to one another – there is no privacy. How can there be. It’s terrible really. People should have their own space – own room and that. (PK1 Care Assistant 02, Public)</strong></td>
</tr>
<tr>
<td><strong>You only have a curtain separating you … (sometimes). It usually doesn’t matter that much but there are private things that you need to talk about, no matter how poor you are you need to get these things sorted out.</strong> (GN1 Resident 04, Public)</td>
<td><strong>We have these curtains and we pull them … so I think from that way, there could be more privacy, yes. But on the other side, I think again they don’t care really if there is a person next to them. I think it would be worse for them if everyone had a single room, you know. (PK2 Registered Nurse 01, Public)</strong> (This nurse believes residents do not want to be alone)</td>
</tr>
<tr>
<td><strong>I was brought up with knocking on the door. Here nobody has time to knock. They just barge in. … Most of the staff don’t knock, they just come in.</strong> (YW5 Resident 05, Private)</td>
<td><strong>Patients get up in the morning and they’re sitting on their chair which is beside their bed, and the next bed is literally a couple of inches from them. Now, the person on the other side of the curtain could be using a commode while this person is actually eating, because we don’t have day rooms, so, therefore, everything is done in the one space.</strong> (FG1G Focus Group Participant)</td>
</tr>
<tr>
<td><strong>I always had me own room till I came here. There’s nowhere to get away on your own.</strong> (PK1 Resident 04, Public)</td>
<td><strong>They could be more considerate. As a visitor you pass other rooms and very often the door is open.</strong> (Relative)</td>
</tr>
</tbody>
</table>
| **I was in a ward with a number of other men you know, but I wanted to be on me own.** | **Int: What was hard about living with a group of people?**
Ah, just fellows there all the time. Somebody might want to sing.
**Int: So having your own room gives you a bit of peace?**
Oh absolutely, yes. … I hate to be with somebody who is rabbiting on all the time. (GN1 Resident 10, Public) (This resident now has a room of his own) |
Acknowledging residents’ value was key to their self-respect. Staff drawing on residents’ expertise or life experience in some way, for example asking them to help out or sit on a committee, gave the message that they still had something to offer. Recognition of achievement was also important to residents. Acknowledgement could be either formal or informal including, for example, a piece in the hospital newsletter or simply thanking or praising them for their help. Some facilities facilitated resident respondents to help with the running of the facility in some way, for example helping with the garden or setting up the altar. Resident respondents derived great satisfaction from this. Some facilities deliberately involved residents in the running of the facility; it was part of their approach to care. Others, however, did not seem to see this as important. It was noticeable that resident respondents living in facilities where no formal opportunities to help were provided created ways to help. This could be helping out a room-mate with greater disabilities than they had, or fetching and carrying for someone in a wheelchair. In interviews these respondents proudly described how they ‘helped out’. Clearly, helping in some way was important for residents’ self-identity and self-esteem (Table 9.7).

Table 9.7: Self-respect through involvement and recognition

<table>
<thead>
<tr>
<th>Self-respect gained through opportunities to help</th>
<th>Limited opportunities to help</th>
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<tbody>
<tr>
<td>I’m now on the committee (responsible for setting up the garden). … I’m more on the administration end. I did a lot of gardening before I came and I won prizes. … That’s why I do that here and once they got it going here I’m helping them, so they’re still getting it going. (GN1 Resident 01, Public)</td>
<td>It was a big, big change when I came here because in (where the resident previously lived) after each meal we’d all go out to the kitchen, we’d help with the washing-up and all that sort of thing … and we’d have great fun there washing up. Of course here you’re not allowed in the kitchen. I went in to the kitchen after I came here to help. I said ‘I’ll give a bit of a hand’, they said ‘what are you doing in here … you’re not allowed in the kitchen because if anything happened to you the insurance wouldn’t cover (you)’. … I miss all that. (LC1 Resident 01, Private)</td>
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</table>

Int: And you set up the altar.
I do all that. … I keep an eye that I’m not running out of things and as I say make sure there are candles and … count out hosts and all that for. … I do a list then anyone wants masses said for anybody or people die in the house, we have a list ready for the priest, people who are sick and all that you know, there are all little things like that. (LC1 Resident 01, Private)
Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland

Self-respect gained through acknowledgement of achievements

We have a local artist and she has … helped with the art and I mean we’ve people who never painted, and I’ve seen progression you know from just a daub to actually beautiful paintings, you know.

Int: I’ve seen some of them down on the wall.

Yeah, yeah, and they’ve all been done by individuals and it kind of increases their self-worth as well, you know, and it’s involvement and we had an exhibition once and it was so great because they were so proud of it really and they love to see them on the walls, and they bring their families to see them. (LC2 Director of Nursing O1, Private)

Informal acknowledgement of resident achievements

I like to get out there and do a bit of gardening, and when I’m doing my garden I sit down on a little stool, cos I’m not, well I am mobile alright, but em, my feet, like you know, at my age, eighty, I feel a bit of a cripple (laugh). … I love flowers and when I do my garden, everybody tells me its looks lovely. (PK3 Resident 02, Public)

During the summer they’re taken out on little field trips and have parties. When their birthday comes up, they have a big party, their pictures are taken, and they’re put up on the noticeboard. (YW1 Care Assistant 04, Private)

Visiting study sites revealed distinct differences in attitudes to the contribution and achievements of residents. Some facilities made great efforts to acknowledge residents’ accomplishments. Staff had put their artwork on display or had put up photographs of residents when on trips or at parties. Indeed, some residents in the photographs had since died but there was a sense that they were remembered and the other residents still talked about them. These facilities managed to generate an atmosphere that the older people living there were important, mattered and were respected. Other facilities, while bright and cheerful, had bare walls or hung formal pictures instead of contemporaneous records of residents’ lives or achievements. There was a feeling of a hotel rather than a home – a sense that residents were transitory. The essential difference was that some facilities managed to make residents feel valued and this was linked to a sense of feeling comfortable and at home.
The findings suggest that most residents are able to maintain a sense of self in long-term care facilities. The ease with which they can achieve this varied across sites, however, with residents living in old, large public facilities having greatest difficulty. A number of enabling or inhibiting factors were identified. Chief among these was whether residents had a room of their own or a choice to share if that is their preference. A private room was the norm within the private sector but rare within the public sector. Residents with a room of their own had greater privacy, more scope to live their life as they liked and opportunities to adapt their environment to suit themselves. In contrast, residents living in open-plan wards had little privacy and limited opportunity to do as they pleased.

The key difference between facilities was the extent to which residents were empowered or disempowered. Residents who felt empowered perceived that they could shape their day and had the potential to make choices. Residents who felt disempowered felt constrained by the rules and routine. They perceived themselves as ‘one of a number’ rather than an individual and this impacted negatively on their sense of self and personal identity. This could happen equally in public and private facilities, but it did not need to happen; it depended on the willingness of staff to personalise the life experience of residents in the facility, making it a home away from home.
Chapter Ten
Connectedness, Social Relationships and Networks
10.1 Introduction

This chapter explores residents’ relationships within and outside the residential setting. In particular, it focuses on internal resident interactions, companionship, family relationships, intergenerational contacts, and general links between the community and the residential facility. An analysis of the data revealed four interrelated categories: connectedness; involvement and interest; resident/staff relationships; resident/resident relationships; and family and community connections.
This category focused on the extent to which residents maintained an interest in external events and current affairs. Some respondents were either too frail or ill for this to be a priority; their physical comfort was their major concern. Among the fitter residents there were noticeable differences across sites in their general interest in and connectedness to the world outside the facility (Table 10.1). In general, the degree of resident connectedness was directly related to the extent to which staff actively promoted residents’ interest in current affairs. Staff in some facilities worked to keep residents in touch, interested and involved. In one facility, for example, staff read sections out of the newspaper and asked residents for their comments and opinions. Resident respondents in these facilities retained an interest in what was going on in the wider world and had what could be termed an ‘outward’ perspective. They were informed on current events, were animated when talking, and held strong opinions which they enjoyed debating. In contrast, residents in facilities where this ethos was not strong adopted an ‘inward’ perspective. They appeared disconnected from the outside world and had little interest in what was happening. They offered few opinions and in some cases their conversation was limited. Their lives appeared to revolve around the facility and its routine – the wider world had lost significance for them.
### Table 8.3: Staffing resources and physical environment

<table>
<thead>
<tr>
<th>Connected</th>
<th></th>
<th>Disconnected</th>
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<tbody>
<tr>
<td><strong>I’m able to keep in touch with the outside world with the paper.</strong> <em>(Name) gets the paper and we pass it around from one to the other, so I read all the paper and the Tribune. I get my Tribune and then we have the radio. So we keep in touch all the time, follow the Government, see how they’re going!</em> [Laughter]</td>
<td></td>
<td></td>
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<tr>
<td><strong>Int:</strong> And does it make you feel good to be able to do that?</td>
<td></td>
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<tr>
<td><strong>Int:</strong> You were saying you read the newspaper <em>(to residents)</em> and it’s important to keep them, I think you said, mentally alert.</td>
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<tr>
<td><strong>Yeah.</strong></td>
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<tr>
<td><strong>Int:</strong> How do you try and do that?</td>
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<td></td>
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<tr>
<td><strong>Well, sometimes we ask them when they’re looking at the telly, what did you see in the news?</strong> <em>(PK3 Care Assistant 02, Public)</em></td>
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</tr>
<tr>
<td>**(We have) twelve residents who would have their own newspapers, and they would … they would be watching … if they were an hour late, they would really have a barney. And then we’d leave one on each side for general use. … And I heard one <em>(resident)</em> the other day, and it was so funny, she was reading the newspaper, and she called me and she said ‘did you hear the story, the condoms that somebody put holes in?’ She’s well in her eighties, and she had such a laugh about it. If you heard what she said! And this was a very, very … what would you say, a very strait-laced lady! She thought it was so funny, and I thought well ‘fair dos, she’s taking it all in’. <em>(YW3 Director of Nursing 01, Private)</em></td>
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</tr>
<tr>
<td><strong>Disconnected</strong></td>
<td></td>
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</tr>
<tr>
<td><strong>Int:</strong> Does the time hang heavily on your hands?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Well, sometimes I don’t know what time, what day it is. I couldn’t tell you what day it is here each day. What day is today?</strong></td>
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<td></td>
</tr>
<tr>
<td><strong>Int:</strong> It’s Thursday. Thursday is it, I wouldn’t know. I wouldn’t know what day it was.</td>
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<tr>
<td><strong>Int:</strong> Do all the days kind of blur for you?</td>
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<tr>
<td>**Yeah … we were to go to a meeting Tuesday and I knew it was Tuesday and I thought the day was Tuesday and I went and I was the only one sitting there <em>(laugh)</em> until they came in and they said this is only Monday. <em>(GN1 Resident 05, Public)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Int:</strong> If you could change something here what would you change?</td>
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<td></td>
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<tr>
<td>**I think the fact that people have, seem to be so vacant in their minds. … I would encourage them, because what <em>(happens)</em> … we’ll say eleven people are together and five or six of those have no interest in life or anything and the other five have. If they’re left together long enough they will become eleven people with no interest in anything. At least that’s my way of looking at things and that scares me. <em>(GN1 Care Assistant 02, Public)</em></td>
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<td></td>
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<tr>
<td><strong>Oh, it’s always boring. Every day is the same, it’s literally like seven days of the week. I have a calendar up and I watch the calendar or if I can get a newspaper, it’s only a few times a week Sister buys it for me. I’m terribly lost without a newspaper every day you know.</strong> <em>(GN1 Resident 01, Public)</em></td>
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</table>
A concrete example of the priority given by the facility to keeping residents connected was whether the facility made newspapers available to residents or not. Many facilities had one or two newspapers delivered, some had none and a few had individual newspapers delivered to residents. The facilities which bought individual newspapers had an explicit ethos of enabling residents to continue to live a normal life. There was a clear focus on keeping residents involved and staff respondents prioritised talking to residents about the news and other events. Some staff respondents working in facilities that did not make newspapers available recognised this as an omission and responded by bringing newspapers in to some residents. However, in effect, this meant that most residents had no access to a newspaper. Relatives also brought newspapers and favourite magazines in to residents. The choice of newspaper delivered was also an issue. Facilities which bought one or two newspapers tended to buy the most popular papers. A resident who had always read a particular paper might be unlucky in not having access to his or her favourite newspaper.

10.3 Resident/Staff Relationships

This category explored resident/staff relationships, focusing on what residents considered important for good relationships (Table 10.2). Resident respondents described staff they liked as ‘friendly’ and ‘interested in them’. They valued opportunities to chat with staff and were particularly pleased when staff shared personal information as opposed to care-related information only. This could be as trivial as what they did last night but to resident respondents this was a sign that they had forged a ‘special’ relationship. It is possible that sharing this kind of information helped equalise the relationship as it mirrors the give and take of ‘normal’ interaction and friendship. Continuity of staff made it easier for resident respondents to build a relationship with staff as it provided greater opportunity for chatting and sharing information. Resident respondents found it difficult when staff, although efficient, were cold and unfriendly. Relatives also identified staff relationships with residents as an important determinant of quality of life. The staff characteristics relatives identified as important closely matched those identified by resident respondents: kindness, being caring and being good humoured. Treating residents well, being respectful and being ‘nice’ were also valued highly by relatives.
Resident respondents indicated that staff were generally kind and helpful. They emphasised how hard they worked and that ‘nothing was too much trouble’ for them. Not surprisingly, residents had favourite staff members but they also indicated that there were some staff they did not like. When staff were not liked, it appeared to relate to either their manner or general approach to their work. A clash of personalities could account for some of these differences, but in some instances residents’ comments would suggest that to some degree they were frightened of some staff members. A few residents described being handled roughly on occasions. Some reported that certain staff did not provide care in a caring way, making them feel a nuisance if they sought help. In such instances, residents reported not asking for help unless they had to.

Table 10.2: Resident/staff relationships

<table>
<thead>
<tr>
<th>Building a relationship</th>
<th>Relationship with residents not a priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’ve visited nursing homes before we came in you know, visiting neighbours and there was nobody talking to anybody.</td>
<td>They’re (staff) very, very busy here. You feel that you can’t make more friendship with them. (YW5 Resident 07, Private)</td>
</tr>
<tr>
<td>Int: But it’s different here?</td>
<td>Some people (staff) are very strict and maybe it depends about the personalities and expectations. Maybe some people here only treat the job as a job because they need money. They don’t need to build some relationship but anyways it’s always easier to work you know … if you have good relationship with your patients. (YW5 Registered Nurse 01, Private)</td>
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<tr>
<td>It’s different here, the nurses come up there, they just come up for a bit of slag.</td>
<td>They (staff) are very good at providing physical care but they do not cater well for emotional side of things. … Emotional well-being plays second fiddle. (Relative)</td>
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<tr>
<td>(LCI Resident 15, Private)</td>
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<tr>
<td>I’ll always speak to them (residents), have a little chat … and we talk about gardens.</td>
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<tr>
<td>… Sometimes the patients will ask me ‘are you married?’, and that’s the way I like it, as if you were visiting them at home. That’s the way I look at it. (YW2 Care Assistant 01, Private)</td>
<td></td>
</tr>
<tr>
<td>GENTLE AND CARING</td>
<td>Rough handling</td>
</tr>
<tr>
<td>You’ve no idea how good they (staff) are! It’s like your own now.</td>
<td>Int: Are they (staff) gentle when they’re washing you?</td>
</tr>
<tr>
<td>Int: And they’re gentle with you now are they, when they’re handling you?</td>
<td>Ah, they are, very gentle, but some of them is tough like, you know.</td>
</tr>
<tr>
<td>Oh, you couldn’t imagine it. They hug you and love you, and all that.</td>
<td>Int: How are they tough?</td>
</tr>
<tr>
<td>(YW1 Resident 02, Private)</td>
<td>Well, they wouldn’t mind throwing you around. (GN2 Resident 06, Public)</td>
</tr>
</tbody>
</table>
More generally, some respondents prided themselves on their independence and being able to care for themselves. Not asking for help was a point of principle for them. However, others were concerned that they would be considered a burden by staff and would not ask for help even when they needed it. Some residents also described feeling rushed and hurried. They indicated that they liked to do things at their pace and wanted to do as much as possible for themselves. This incompatibility in pace frustrated residents. They did not appreciate being rushed but accepted it, putting it down to staff being busy or the consequence of staff shortages.
A few resident respondents commented on cultural differences with staff. In the main, their comments were positive. They enjoyed learning about another culture and had great sympathy for staff who were a long way from home and missing their family. However, on occasion, residents reported misunderstandings with care staff from overseas. In the main, these related to language difficulties but sometimes they resulted from a lack of a shared cultural understanding. Focus group participants also highlighted different cultural understandings as potentially problematic, highlighting the importance of orientation for staff from overseas. Care staff from overseas that were interviewed commented that while, in general, it was not a problem, some of the residents were racist and responded negatively to them.

10.4 Resident/Resident Relationships

This category focused on resident relationships and the factors that influenced the level of interaction (Table 10.3). In some facilities, residents were friendly, tolerant of one another and there was a strong sense of collegiality. They clearly enjoyed one another’s company, made the most of what was on offer by joining in the activities, laughed at one another’s jokes and viewed a ‘falling out’ as a normal part of life. Several factors appeared to contribute to this. Staff in these facilities actively created opportunities for residents to get to know one another and also demonstrated acceptance of residents who were frail or confused. Resident respondents in their interactions with cognitively impaired residents appeared to mirror this behaviour and were tolerant of ‘odd’ behaviour. These facilities also tended to have several comfortable spaces where residents could congregate to chat or play card games etc. The availability of separate spaces allowed like-minded residents to get together. In other facilities, there was a tendency for residents to form cliques and there was a general lack of tolerance among residents for those with dementia. There was not the same spirit of community and general friendliness in these facilities.

Residents differed in the extent to which they enjoyed the company of others. Some saw themselves as ‘loners’ and preferred to be on their own, while others enjoyed socialising and the company of others. The latter group frequently spoke about being lonely at home; they enjoyed the companionship of the other residents and welcomed the opportunity to make new friends. Some resident respondents were discriminating in their use of the term ‘friend’. They distinguished between ‘friend’ and ‘being friendly’. They described themselves as ‘friendly’ with all
residents but reserved the title of friend for close, long-term acquaintances. When resident respondents did make friends, it was normally because they knew one another before they moved to the facility or had some other connection or shared interest. Residents who had lived in the facility for longer spoke about the loss they experienced when a friend died. They were more cautious about making friends as a result of their loss.

The potential for residents to form friendships was determined by several factors; staff facilitating residents with similar interests to get together was key. This was not always recognised by staff who, on occasion, neglected to introduce new residents to the others. Respondents new to a facility felt overwhelmed by the ‘newness’ of it all. Getting to know other residents was an enormous challenge for them. The help and support of staff at this stage was crucial in helping them settle in. Whether the older person was involved in the final decision to move into the facility, however, was the determining factor in how easy they found it to settle. Respondents reported that older people who had either made or been involved in the decision made their minds up to ‘make the best of it’ and worked hard to settle. They joined in the activities and sought to make friends with staff and other residents. Those who had not been involved in the decision to enter responded very differently. They tended to withdraw into themselves and described themselves as lonely and unhappy. This group often spoke about going home and appeared to cope by considering their stay as short-term.

A further factor determining resident/resident interaction was proximity. Residents reported that they tended to form relationships with those with whom they had most contact – usually those they sat with for meals or those with rooms near them. It was observed that residents sat in the same place every day. In conversation, residents referred to ‘everybody at my table thinks’ and it was evident that the group who sat together discussed and debated issues of concern ranging from the food to staff. To a large degree, therefore, the people they sit with shape residents’ perspectives and are a powerful determinant in their initial and ongoing experience of life in the facility. In some facilities, staff made the decision as to where residents sat and it may be that they did not always recognise the significance of this decision.

Another key relationship for residents was the relationship with their room-mate(s). This relationship could be either positive or negative. Positive relationships seemed to evolve when the room-mate(s) provided companionship or opportunities for them to help; as previously noted, some respondents derived great satisfaction from being able to help others. Occasionally, however, room-mates did not get on.
This was more an issue when only a small number of residents shared a room, for example in two bedded rooms. Sharing with somebody they did not get on with was very distressing for resident respondents.

Some resident respondents described keeping apart from the others, not because they were ‘loners’, but because they saw themselves as ‘different’. These respondents deliberately distanced themselves from the others. Two factors tended to contribute to this, a sense of being from a different social class and therefore ‘better’ than the others, or not sharing similar interests. In addition, resident respondents who were mentally competent tended to avoid those who were confused. Several issues seemed to impact on this behaviour. Some respondents were frustrated by having to answer the same questions or hear the same story over and over, or were annoyed by the repetitive behaviour of those with dementia. Others seemed to believe that their own mental health could be compromised by too much contact. Others saw themselves as ‘lucky’ because there were others worse off than themselves. At its most extreme, some respondents were not merely irritated by other residents with dementia but were frightened of them. There were instances where respondents had been attacked and hit. In one case, a woman described sleeping with a chair against her door for fear that she would be attacked while she slept. The majority of focus group participants agreed that residents with dementia should not be mixed with residents who were mentally competent. They believed that neither group benefited from this mixing and recommended that residents with dementia should be cared for separately.

The group of resident respondents who had greatest difficulty forming relationships were those with communication difficulties and, as a consequence, this group of residents were likely to be isolated within the larger group. Respondents with hearing impairment had difficulty following what was said and consequently could not join in. Those with aphasia had even greater difficulty. Some communicated using a ‘magic slate’ but their opportunities to ‘talk’ to others were very limited. Another group with the potential to be marginalised within the larger group were men. In all study sites, there were fewer male than female residents. In mixed units, men were very much in the minority. They tended to cluster together and rarely mixed with the women. Occasionally, a relationship developed between a male and female resident. These friendships were rarely discussed but were significant in the companionship they provided. A number of facilities had separate male and female wards only. Consequently, there was limited opportunity for men and women to mix. None of the resident respondents in these wards commented on this. In facilities with mixed units, those who participated in the interviews liked the mix. They felt it gave greater balance and increased the possibility of discussing different topics apart from ‘aches and pains’.
Table 10.3: Relationships among residents

<table>
<thead>
<tr>
<th>General interaction good</th>
<th>General interaction poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have a laugh you know, we have a joke. … I mean we have a good rapport with each other. … It’s not like your own family but you make them your family. Sure what else, you’ve no other family at the moment when you’re here. Only them and we’re nice to each other. (PK3 Resident 05, Public)</td>
<td>I try and make friends with them all you know. That’s the only hope you have.</td>
</tr>
<tr>
<td>I try and make friends with them all you know. That’s the only hope you have. Ah it’s not, em, it’s not a place like that. Everyone is an individual here themselves. (GN2 Resident 09, Public)</td>
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<tr>
<td>(PK3 Resident 05, Public)</td>
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</table>

<table>
<thead>
<tr>
<th>Friendly but not friends</th>
<th>Keeping your distance</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have no deep friendship with anybody, but I talk.</td>
<td>Int: Have you made friends here at all?</td>
</tr>
<tr>
<td>Int: You’re friendly with them? Friendly, yes, but not a good friend. (YW3 Resident 11, Private)</td>
<td>Some. … Not a whole lot because this place is really for the poorer class and I don’t like being stuck in with them because they think I’m too, I’m too swanky altogether for them. (YW5 Resident 02, Private)</td>
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<tr>
<td>I had a friend and she died, but I don’t really stick to the one person. (PK3 Resident 02, Public)</td>
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<table>
<thead>
<tr>
<th>Good room-mates</th>
<th>Bad room-mates</th>
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</thead>
<tbody>
<tr>
<td>There was only one woman in my room … and we got on famously, we still do. I love that woman … we get on great, absolutely great, she is a first class lady, lovely woman. (PK3 Resident 03, Public)</td>
<td>(I) … had to share a room and I had a demon of a woman, she was dreadful. … I was nearly mental before I got out of it. (LCI Resident 07, Private)</td>
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<table>
<thead>
<tr>
<th>Tolerant of residents with dementia</th>
<th>Problems living with residents with dementia</th>
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</thead>
<tbody>
<tr>
<td>Well, you get to know them (people with dementia) and you feel sorry for them now, and well you do your best, you know, and they’ll always say did I tell you this before and rather than annoy them you say ‘no, what was it?’ … It might annoy some people but I don’t think it annoys anyone here. (YW3 Resident 01, Private)</td>
<td>There’s about four or five really bad mental cases here and its very hard. They attack the nurses. I’ve to put that chair against the door that one of them won’t come in here because she’s already attacked and she’s very violent. She’s Alzheimer’s. Not her fault, but the language of her and the carry-on. … Oh, it’s frightening. (PK3 Resident 05, Public)</td>
</tr>
</tbody>
</table>
Men and women

* Tis all aged women that’s here mostly now like. Do you know, there’s only four or five men. *(YW4 Resident 02, Private)*

* And I stay (in the smoking area) with (man’s name) all the time; he’s my best friend. And we have a chat and we read the paper. *(YW2 Resident 03, Private)*

Communication difficulties

* Well, as I say, it’s not easy on anyone because I do feel awkward even someone talking to me this side (because of the deafness). They are saying something and I say ‘I don’t know what you are saying really’. They might think I don’t want to talk to them, you know. *(GN1 Resident 07, Public)*

Involvement in the decision to move into long-term care

* Because at least the people who know they’re coming, they’ve made the decision. They know they have to stay, and they get on with it. Whereas other people who are just brought in, they say you have to stay here for two weeks … they’re on edge, they want to go home. They never give themselves the chance to settle down, whereas the other people do and they decide to just get on. *(YW2 Resident 06, Private)*

Problems living with residents with dementia

* If the choice isn’t their own, then there’s hostility and then the little pebbles or water wave start spreading out – the negativity. *(FG2D Focus Group Participant)*

10.5 Family and Community Connections

This category focused on the extent to which residents can maintain contact with home and people from the local community (Table 10.4). Resident respondents particularly enjoyed visits from their family and friends. Visitors kept them updated on what was happening at home, brought them gifts or other things that they needed and helped out, for example, by doing their laundry. More importantly, visits from relatives made resident respondents feel that they were still an integral part of their family. Being consulted and included in family outings and events was viewed by respondents as an indicator that they were still at the heart of the family.

Opportunities for resident respondents and their visitors to have a private chat varied across sites. Those who had a room of their own were able to meet their visitors in private. Alternatively, they could meet their visitors in the sitting room. A few facilities had tea or coffee-making facilities in the sitting room, enabling them to offer their visitors a cup of tea. This helped normalise the visit and make
it feel more like visiting somebody in their home. In other facilities, household staff checked if visitors would like a cup of tea. However, in the large public facilities the only option was to visit in the open ward. Visiting in these facilities was reminiscent of visiting in a general hospital – visitors gathered around the resident’s bed or in a corner of the day room and all interaction was in the public domain. A phenomenon within these facilities was the ‘generic’ visitor. Generic visitors visited everybody in the room and not just their own relative or friend. Residents who had few or no visitors benefited, as a ‘generic’ visitor ensured that they had a chat with somebody. All facilities had an open visitor policy but some were more tolerant than others of people visiting with young children or pets.

As indicated above, some resident respondents rarely had visitors. Of this group, some respondents stated they had nobody left ‘belonging to them’. Some accepted this as a feature of ageing, others a sign that they had lived too long. For others, families lived too far away to visit often with many respondents having sons and daughters who lived overseas. A small cohort of resident respondents had no visitors because they were placed in facilities at some distance from their home. It was, therefore, more difficult for their relatives and friends to visit. They missed their friends and family acutely and wished they could move nearer home. Geographical distance was not the only factor. Poor or awkward transport was also a feature in limiting visits. It was likely that friends who visited were older themselves and a difficult journey made it unlikely that they would be able to visit often.

On a positive note, the advent of the mobile phone has made a tremendous difference in enabling resident respondents to keep in touch with loved ones. Many of the respondents had mobile phones and they were in constant touch with their family and friends. Having a phone also gave them independence in that they could contact their friends or family whenever they wanted rather than relying on staff to bring them the telephone.

Facilities varied in the degree of their links with the local community. Some facilities had forged strong links and either individual volunteers or groups of volunteers visited regularly. Resident respondents enjoyed these visits and felt special if somebody came to visit only them. Other facilities did not have well-established links and visits were either sporadic or non-existent. In addition, some facilities worked with local schools and invited transition year students to read to residents or play scrabble with them. Facilities differed in how they structured these visits.
In some facilities, it seemed that the students themselves were expected to find ways of helping. These visits were less successful than those where there was a structure in place. It was striking that some of the staff respondents saw volunteers as helpful but of limited use as they could not help with the ‘real’ work. They considered physical care, for example changing, washing and feeding, as the priority. This would suggest that some staff respondents put little value on interacting with clients beyond that which was necessary when giving physical care. In contrast, focus group participants viewed keeping residents in touch with their community as key to good quality of life. They acknowledged, however, that this was an area that had to be ‘worked at’.

Table 10.4: Family and community connections

<table>
<thead>
<tr>
<th>Easy to keep in touch</th>
<th>Finding it hard to keep in touch</th>
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<tbody>
<tr>
<td>I make all the inquiries about what’s happening, who dies and who lives. And what happens, and who’s getting married. Oh, I keep in touch with everybody! (YW1 Resident 02, Private)</td>
<td>You’re confined here and … you’re not mixing with people or anything like that. You only see the patients here, and the nurses and whatever men is here. (My nephew) took me out for an hour, only for him I’d never stick it at all. (GN2 Resident 09, Public)</td>
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</table>

<table>
<thead>
<tr>
<th>Still part of a family</th>
<th>No one belonging to me</th>
</tr>
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<tbody>
<tr>
<td>I’m going to a big wedding. My nephew’s daughter is getting married … so I’m going to a big do. That’s how I got that perm. … I’ll be looking all the best, all glammed up (laugh). All I want now is a fella (laugh). (PK3 Resident 01, Public)</td>
<td>I am the last of the billy goats. I am all alone in the world. … I have no family. Int: So you are the longest living of them all are you? Plenty of bad news. (GN1 Resident 08, Public)</td>
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<table>
<thead>
<tr>
<th>Open visiting</th>
<th>Restricted visiting</th>
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<tbody>
<tr>
<td>I have a lovely dog; at least my son has a lovely dog. … Oh, he’s a dote, his name’s (name). … He’s a lovely dog. We’re all very fond of him, and he’s brought in here occasionally. (YW3 Resident 09, Private)</td>
<td>I would like if I was allowed bring my youngest children in (referring to grandchildren). … Because one is a bit noisy but like I’ll sit her on my knee and she’ll stay quiet, but they don’t seem to want that, and I’d like for all the children to be together, you know. (YW5 Resident 02, Private)</td>
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</table>
Near home

(I) was living up the road and have a lot of friends around. It’s far better than what other people have … because their visitors have to maybe come a long way in the day. My sister comes three times a day which is very handy. (YW4 Resident 04, Private)

When I do go home every Wednesday …

Int: (That helps to) keep you in touch?

Oh Lord, it does, very much. … I would need that or else I’d be institutionalised and I don’t want to get that way. I’d hate to be that way. (PK2 Resident 06, Public)

Placed at a distance

I’m cut off (resident placed at a distance from her community). I feel cut off, you know, from all my friends. You see all the people here, they’re very nice, they’re very good, but they’re all strangers to me. Do you know what I mean? … I’m not happy here.

Int: Have you made friends with the others?

Oh yes, more or less, with them. I don’t know, it’s not the same. As I said they’re very good and very nice and very helpful, but it’s the fact of, you know, losing all your friends that you had for twenty years, it’s a big break. … I was very depressed when I first came, you know.

Int: Have you settled a little now?

Well, I’m tryin, I’m still, still em, pining after (area name).

Int: Four years on you’re still pining?

Yeah, I’m still pining. (PK3 Resident 10, Public)

Somewhere to meet

Being on your own is great (resident has a room of her own). You have your visitors there. It’s very awkward when you’re with the three people now. (PK3 Resident 01, Public)

Meeting in public

Int: When your visitors come in there is nowhere that you can go with them to have a chat if you wanted?

They, just like yourself, sit there (beside the bed) and talk to me. (GN1 Resident 06, Public)

Volunteers – recognised as making an important contribution

The volunteers, they come in on a Friday night.

Int: And what do they do when they come in?

Eh, there’s a gentleman who plays the accordion, lovely music, country, real, all those songs kind of, you know. … Sometimes (the residents) sing … and the staff get involved. (PK3 Care Assistant 02, Public)

(Volunteers) enhance the quality of life of people, don’t they? They do the little things that no one (does). … They develop personal relationships with individuals as opposed to just going around to everyone. (FG2D Focus Group Participant)

Volunteers – not recognised or not organised

The transitions (transition year students) comes in here. They’re fine, they’re good, they’re okay. They’ll talk to them and that, maybe wheel a wheelchair around but they can’t, you can’t give them any tasks, no feeding or no changing. Totally superficial, maybe read to them or something. (LCI Registered Nurse 01, Private)
A number of factors were found that either enhanced or diminished residents’ potential to retain their connections and relationships with other people. An open visiting policy, a feeling of welcome, a homely atmosphere and strong links with the local community were the main enhancing factors. Perceptions that children were unwelcome, lack of privacy, having to visit in public and poor links with the local community inhibited residents’ connectedness. In general, staff/resident relationships were good with the majority of residents describing staff as caring, kind and helpful. Residents were most positive about staff who chatted and showed an interest in them. When residents were not positive about staff, it related to either their manner or their general approach to work. A few residents described some staff as rough. Overall, resident/resident interaction was good. Visits from family and friends were very important to residents. Visits helped maintain family bonds and kept the older person in touch with what was happening at home and in the local community. Proximity to family and community was important in maintaining relationships.
Chapter Eleven
Activities and Therapies
Chapter Eleven
Activities and Therapies

11.1 Introduction

This chapter examines the opportunities within the long-stay care sector for residents to pursue meaningful and purposeful activities. It explores residents’ perceptions of the opportunities available within long-stay care. Respondents described the activities, if any, which were offered in their facility, the extent to which they participated in these and reasons they did or did not participate. Some also discussed activities they would like to pursue which were not currently on offer. Staff described the activities within their facilities, their participation in running these and their perception of resident participation. Four categories were identified within this theme: purposeful activity, therapeutic activity, outdoor activities, and making activities work.

11.2 Purposeful Activity

This category focused on the way in which activities were structured, the extent to which residents were consulted in determining appropriate activities and the issues which impacted on residents’ participation (Table 11.1). Staff described the activities that were offered within their facility each day. In some study sites there was a planned provision of activities which changed on a daily basis. Activities on offer included painting, bingo, dancing, singing, exercise classes, tai chi, watching television, cards, scrabble and gardening. These activities were often offered to all residents as a group regardless of interest or capacity to participate. Most of the time activities were offered within the main sitting area, although a few facilities
had a special activities/therapies room. In some facilities activities were available in the daytime (9-5 p.m.) only. This was most likely when activities were managed by an activities person or department. This was raised by some residents as a problem because they found the evenings long and dull.

Residents were mixed in their view of activities. Some were very enthusiastic and described in detail the satisfaction they got from activities such as painting, dancing, gardening or playing cards. Two aspects were evident from these resident accounts: the residents had a personal interest in the activity; and the activities were offered in small groups of like-minded people. An example of this was a card group in one facility. The card group included a person from the local community and five residents from the facility. These residents perceived that the card group members were of equal ability and had the capacity to learn new games. The outside person brought news from the community and residents particularly valued this. Card games were changed regularly to maintain interest.

Some resident respondents, while describing the day as boring, long or tedious, did not wish to participate in any activity. Sometimes this was because they perceived themselves as different from other residents and having little in common with them. Other respondents perceived that residents within the facility had different capacities and levels of cognitive functioning to themselves. They reported that grouping all residents together made activities less interesting for them personally. Sometimes residents did not participate because they had significant hearing or vision problems and they had found that little provision or allowance was made for this. Many respondents were not aware of where they could get large print or talking books, or of adaptations that could be made to the television to compensate for hearing loss. A few facilities had an internal library with borrowing facilities. Relatives highlighted residents’ past interests and activities their relations might like to do but they had little expectation that these could be provided. In general, there was not enough emphasis placed on residents’ personal interests when decisions were being made about activities for the facility. Residents were not always consulted and little effort was put into finding out about residents’ past interests when deciding on new programmes.
### Purposeful activity

*Now that’s the thing; I have things in common with them all. I can discuss the things that are happening.* (LC1 Resident 01, Private)

*My best hobby of all is playing cards. I play four times a week with four other ladies.* (PK3 Resident 02, Public)

*A member of staff is after teaching us a new card game and it’s brilliant – knock out. … It took us a long time to learn it but we are getting to be experts now.* (PK3 Resident 01, Public)

*The patients have decided that bingo is their number one at the minute so there’s a lot of focus on it but that’s because that’s what the patients want, and that is working really well. So, in other words, I’m demonstrating to the staff that it isn’t another nurse necessarily is what we need to improve the quality. It might just be somebody who can take some of the burden off nurses so that they can focus maybe on more nursing issues and people who actually might be more, more interested in sort of doing social skills, social activities and that is working well.* (PK1 Nurse 02, Public)

*Some of them play cards; a lot of them now in their nineties that are more with it as, true as God, you would be left. And they play cards. They go into the little room across here now, a couple of times a week and then they have the rosary another day. This lady comes in with this most beautiful statue, fabulous. Then another day they have mass, they have the piano lady, they get their nails done, they get their hair done by a hairdresser – you name it they have it.* (PK3 Care Assistant 01, Public)

*I do drama on a Monday. I’m doing a play, we’re doing a play, Searching for a Husband. Well I’m Missus O’Brien in the play.* (GN1 Resident 09, Public)

### Lack of purposeful activity

*Just the same thing, the same day in and day out. … It’s boring … but I don’t like to say anything because if you say anything you are in the bad books altogether.* (GN2 Resident 09, Public)

*Well, one of them was the activity where it was for the whole hospital. It was in a lecture room. When I went to it I realised it was them and us. There was a crowd up in the corner, wheelchair people; full of wheelchair people and I was down the bottom on my own.* (GN1 Resident 04, Public)

*The activities, there aren’t any. … In the States, I think it’s mandated that every nursing facility has a recreation department. I suppose here they kind of term it ‘diversional’ activity. So that’s something that I think is lacking at the moment.* (PK2 Resident 01, Public)

*There’s a piano there. I don’t go to it, it’s too noisy and I’m too tired at that stage to enjoy it.* (PK3 Resident 08, Public)

*It’s a long day for me. Well, yes it’s long because there’s not much to do.* (GN2 Resident 07, Public)

*It’s boring, the sameness of it. I’m afraid I’m not a very good mixer and because I’m not I don’t involve myself with, you know, with any activities. So it’s my own fault it’s boring, you know.* (YW1 Resident 01, Private)

*There are activities here, eh, but I don’t bother really. I like to sing. And maybe I am selfish in as much as I don’t want to sit in the common room looking at people, looking at one another.* (YW1 Resident 05, Private)

*No, nothing here, they are too old. They all exercise, you know, but sitting down. You can’t exercise sitting down. It’s no good for me.* (LCI Resident 12, Private)

*I don’t go out to bingo because me hearing is very bad. The others, they go to bowling. That woman over there in the corner won a thing for bowling, but I can’t bend down.* (GN1 Resident 06, Public)

*The time can be a bit long. On the whole there is plenty of activities, but I don’t join in a lot because I can’t hear. And then the eyes are so bad I can’t see things.* (GN1 Resident 07, Public)
This category focused on activities which were designed to contribute to the residents’ well-being, independence and health. Such activities included physiotherapy, occupational therapy, art therapy, Sonas and massage. Three therapies: physiotherapy, occupational therapy, and speech and language therapy were deemed by staff as essential to maintaining resident independence. Staff suggested that these therapies enabled residents to regain or maintain optimal functioning. Staff and residents described the availability of these therapies within their facilities (Table 11.2). Many staff respondents were concerned that they could not access services for residents when they perceived that a resident could benefit from them. There was some suggestion that a lack of these therapists had a detrimental effect on residents’ cognitive abilities.

It was evident from residents’ accounts that there were widespread differences in the availability of physiotherapy. In some public facilities there was a physiotherapist but in others there was not. Sometimes there was a very limited service because there were not enough physiotherapists to meet the needs of residents. Some residents were very concerned that they could not get physiotherapy when they clearly perceived that they would benefit from it. Concern was expressed that residents in private facilities lost access to physiotherapy unless they had the capacity to pay for it themselves. Staff also highlighted the problems that they had in trying to access physiotherapy for residents. Many working in private facilities raised the question of payment for this service and suggested that it was inequitable that a person living in a private facility had to pay but would have received this service free if they were living in a public facility. The difficulty of accessing these services and the equity issues were also raised by focus group participants.
Table 11.2: Therapeutic activities

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<tr>
<th>Therapeutic activities</th>
<th>Lack of therapeutic activities</th>
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<td>It is extremely important. From the client’s perspective it’s extremely important, and, therefore, I take that as being the most important thing. At this particular moment we don’t have a physiotherapist, but that’s just a transition; one left and another is being recruited. (PK1 Nurse 02, Public)</td>
<td>They want to incorporate an exercise class, and that would be something that I would be teaching, once it gets set up. ... I will be planning an exercise class with her, that would probably be your walking group. ... Then again, most of the long-term residents wouldn’t be that ambulatory, so you’re limited enough in what you can do, because of their medical background. The extent of it would be providing an exercise class or showing somebody how to do the exercise regime. (PK2 Physiotherapist 01, Public)</td>
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<td>The occupational therapy is very good. She has them singing and, like I said, the art, the knitting, dominoes, bingo, you know, they love this. The majority of them go for these. Some would like the knitting, some would rather the bingo, but they have their own days for it. (YW3, Nurse 02, Private)</td>
<td>I used to go to physiotherapy but I don’t see that girl here now at all. But I will go back to her again if I find out where she is. (GN2 Resident 9, Public)</td>
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<td>Well, we do hand massage and this would be for people on a one to one who would be in the bed, wouldn’t be getting much in the line of anything else. And we do crosswords, we do reminiscent therapy. Sonas, do you know Sonas? Well, we do Sonas individual as well and other than that it’s just quizzes, games, arts and crafts, a little bit of painting. We don’t do so much of that now because we just don’t have the people and we don’t have the room. That’s basically it, it’s just activities all day. (GN2 Activity Therapist 01, Public)</td>
<td>Well, there’s one thing – (the lack of) physiotherapy. There’s one woman in this unit, she’s had a stroke. I often say, ‘do you go for physiotherapy?’ and she said ‘no’. I didn’t say any more to her because I thought, well, this is for her family, like, to decide. But if there was physiotherapy available here, you know, if they had the option of going, or whatever, if it was needed. (YW Nurse 02, Private)</td>
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<tr>
<td>Well, we do hand massage and this would be for people on a one to one who would be in the bed, wouldn’t be getting much in the line of anything else. And we do crosswords, we do reminiscent therapy. Sonas, do you know Sonas? Well, we do Sonas individual as well and other than that it’s just quizzes, games, arts and crafts, a little bit of painting. We don’t do so much of that now because we just don’t have the people and we don’t have the room. That’s basically it, it’s just activities all day. (GN2 Activity Therapist 01, Public)</td>
<td>We have no physiotherapy or occupational therapy here, you see. (PK3 Care Assistant 02, Public)</td>
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<td>You need to have access to physiotherapy. Particularly stroke patients. Now it’s very, very sad. They spend two weeks in rehab and they come to us, but you know that’s only the beginning of their recovery. And I mean, I have sent requests for speech therapy again and again for people and it’s a no-no. ... We try to be as up to date as possible, like, and we have a falls policy, but, like, you haven’t got a physiotherapist. (LC2 Director of Nursing 01, Voluntary).</td>
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<td>There’s only one thing that worries me is the physiotherapy now because I had a great girl coming in. Now, I had to pay her and I don’t think that old people should have to pay for those facilities. (LC1 Resident 07, Voluntary)</td>
<td>There’s only one thing that worries me is the physiotherapy now because I had a great girl coming in. Now, I had to pay her and I don’t think that old people should have to pay for those facilities. (LC1 Resident 07, Voluntary)</td>
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<td>Well, I haven’t got physiotherapy for a long, long time. I do feel I need it. To straighten down my legs because you can’t straighten them down. Well, I mean the physiotherapy I was getting, and it just stopped, you know. (PK2 Resident 06, Public)</td>
<td>Well, I haven’t got physiotherapy for a long, long time. I do feel I need it. To straighten down my legs because you can’t straighten them down. Well, I mean the physiotherapy I was getting, and it just stopped, you know. (PK2 Resident 06, Public)</td>
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<td>The funding isn’t there … so we have no O.T. ... We have our own private physiotherapist, that would attend to the patients for a charge. (YW1 Assistant Director of Nursing, Private)</td>
<td>The funding isn’t there … so we have no O.T. ... We have our own private physiotherapist, that would attend to the patients for a charge. (YW1 Assistant Director of Nursing, Private)</td>
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A few facilities had incorporated other therapeutic activities such as massage, Sonas and tai chi into the activities offered to residents. Resident respondents were very enthusiastic about these as they found them relaxing and stimulating. Staff highlighted the benefits of these activities for residents as they had found they encouraged social participation and communication among residents. One facility offered a tai chi class for staff and residents which they suggested helped foster good staff/resident relationships.

11.4 Outdoor Activities

Resident respondents who were ambulatory described the importance of ‘getting out’ of the facility (Table 11.3). ‘Getting out’ included such things as going for a walk or shopping, visiting friends or family, outdoor events such as a barbecue, and day trips to places of interest. These activities enabled residents to mix with people outside the facility and were perceived by them as important for knowing what was going on. It was the more able residents in most facilities that appeared to have the choice to leave the facility if they so wished. This was made easier or more difficult by the security system used within the facility. Facilities had to ensure the safety of residents as in all facilities there were some residents who were confused and had a tendency to wander. Facilities, therefore, had to have a mechanism to ensure residents who were a concern could not leave the facility unnoticed. Many facilities had a key pad system which could only be operated by staff. This meant that the more able residents who wished to leave the facility for a walk could not do so without a staff member facilitating their exit and re-entry. Considerable planning had, therefore, to be done before leaving. One facility had, with the permission of resident relatives, initiated an electronic tagging system. This meant that able residents had open access into or out of the facility but residents who were a concern would set off an alarm if they tried to leave. Residents living in this facility liked the freedom this gave them.
Table 11.3: Activities outside the facility

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<tr>
<th>The importance of outdoor activities</th>
<th>The lack of outdoor activities</th>
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<td><em>My day is brilliant. I’ve got something to do all the time. … If the weather is fine now, if it is warm I’ll walk away up the road, away up past the swimming pool for about an hour, an hour and a half. … You can go in and out (of the facility) as much as you feel like; no one to stop you. It’s your time. You can do what you like with it.</em> (PK3 Resident 01, Public)</td>
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<td><em>That is very important; the body must be used. Your legs and your whole body, you must be used. That is very important. I love walking. I walk, I’ll keep walking. Oh yes, and I’m even planning now to go to walk so.</em> (LCI Resident 12, Public)</td>
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<td><em>Oh yeah, I go out. Sometimes in the summertime I go down to the shops but I’m not allowed out on my own. I have to get a nurse to come with me and she goes with me down to do the shopping and then we come back home again.</em> (PK3 Resident 04, Public)</td>
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<td><em>We go to the races twice a year and we will go to the panto at Christmas. We don’t go to the one in Dublin. We did at one stage but it’s hard sometimes, it depends on how well our clients are. And we might have a picnic out in the summer. Different things, if we get invited and we’re able to go, we’ll take somebody. We’ve often took maybe six or seven men down to the pub in the afternoon. You know, bring a guitar and have some sandwiches and things like that.</em> (GN2 Activity Therapist 01, Public)</td>
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<td><em>We have also trips out in our minibus now that we have it. Tuesdays, Thursday and sometimes Friday mornings, you know, and five or six clients would go out. During the wintertime it’s not great, we usually go to a shopping centre, but during the summer it’s fantastic. They get a chance then to go (place) and they go for a ramble around, might go for a coffee or they go for a drop of sherry, pint or whatever it is and then come back again.</em> (YW5 Assistant Director of Nursing 01, Private)</td>
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<td><em>I used to love to get out but not now. You see, it’s alright if any of my cousins came up from Cork. They might, they’d have a car and they might take me out for a drive or a thing but I don’t expect any of the locals to take me out. … I feel that I’d be holding them up. They’d have to walk slowly and you know, in fact, I’ve come to the conclusion that I shouldn’t be bothering anyone. It’s alright if they have a car and take me on a drive but to walk.</em> (LCI Resident 08, Private)</td>
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<td><em>No. (I don’t get out on trips). It’s very awkward, you see. They’d have to bring a chair and me as well, like, you know. If there were trips to Knock or anything like that, it isn’t just me they’d have to load on to the bus, I’d have to bring the chair as well and take that out and then put me into it.</em> (YW4 Resident 05, Private)</td>
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<td><em>Well, I suppose going around farmers’ yards and that, I’d love that.</em> (YW5 Resident 02, Private)</td>
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<td><em>Int: So you’d love some trips out? Yes, yes I’d love that. And they haven’t done that yet.</em></td>
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<td><em>Int: And do you think that’s possible? Yes, it is possible. I mean, why shouldn’t it be when you’re a farmer’s daughter and there’s several of us here. They should surely be able to get a couple of farms that they could bring us to.</em> (YW5 Resident 02, Private)</td>
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<td><em>She was a carer herself … and always liked to feel needed … and out of doors. Liked to be outdoors and walking. … She is confined a lot.</em> (Relative)</td>
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Some facilities organised special trips for residents to places of interest. Sometimes the residents participated in deciding where these trips should be to. One facility had set up a residents’ outdoor activities group, chaired by one of the residents. There were, however, widespread differences in the capacity of facilities to take residents on outdoor trips. Some facilities had specialised transport; others did not. Some residents, therefore, found that they could not go on trips because it was difficult to accommodate their special needs or wheelchair. Some facilities had fundraising activities to pay for trips, or had other sources of funding, while others had none. In the circumstances where no outside funding was available, a resident’s capacity to pay for trips was a limiting factor in the organisation of such trips.

Staff respondents highlighted the importance of outdoor trips and how much these were enjoyed by residents, but also stressed that a prerequisite for such trips was adequate staffing levels. A few staff suggested that trips for residents had been organised in the past but were not possible with current staffing levels. One relative suggested that it was not possible to take his relative out of the facility because of insurance issues.

11.5 Making Activities Work

In some study sites activities were part of the everyday life of the facility, while in others there was little evidence of any activities at all. In the absence of activities, residents often described the day as tedious and boring. Some spent long periods dozing by their bed. Resident respondents were very specific about the kinds of activities they were interested in and who could best facilitate these activities. Many residents described the importance of people from outside coming into the facility to bring news of the outside community and a fresh perspective. Some staff respondents also described the inclusion of outside groups in activities as important; however, a few staff were unsure about allowing ‘outsiders’ into the facility. Some facilities had transition year students coming in regularly to participate in activities; others involved local voluntary groups. Some had activity departments, while others relied on the staff to provide activities. Staff suggested that activities were important; indeed, some noted recreational activities to be a key quality of life issue for older people. However, in general, staff felt that time and work constraints meant that providing activities for residents was not a priority. A few staff felt the expectation that they provide activities for residents was not reasonable and suggested that there should be specific people delegated to carry out this role (Table 11.4).
Table 11.4: Making activities work

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<tr>
<th>Making activities work</th>
<th>The difficulties of making activities work</th>
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<td>I have two girls that come in to help us. They’re in doing a work experience course for a year, on-the-job training, which is very useful to us. And what they do is they come in in the mornings and they make the beds. That frees up time for the nursing staff to do other things and they have felt the benefit of that. Then in the afternoon the two girls, and they are wonderful girls, they do some social activities with the patients. (PK1 RN02, Public)</td>
<td>There’s not enough activity. There is an activities unit here in the last couple of years and there’s care attendants, a nurse and a ward sister. We’d have a few patients who love singing and you arrange for the activities but they never turn up. There should be activities on every ward. Today we had Sonas. I’d never seen Sonas up here before. (GN1 CA2, Public)</td>
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<td>Two days a week we have schoolboys to come up from transition year and they do activities on the men’s wards in the afternoons with us from two to four; that’s Wednesday and Thursday. (GN2 AT01, Public)</td>
<td>They’ll come into the ward and have some activities. They mostly sing songs. They have their exercise which is the hands. Int: And do most of the residents participate in that? No, it’s difficult because our patients who are immobile cannot, they can’t really participate. Only those who are with it enough who can actually join in. So for patients now, some of them would also refuse as well. So for this morning, for 28 patients there was only, I think eight of them joined. (GN RN02, Public)</td>
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<td></td>
<td>No, they don’t (have enough activities). We do the exercises over there every day, you know, and they all just sit like that. Sometimes, then, they have a bad mix of maybe too much dementia and then there is a resident who is dying of cancer. We’re kind of expected to amuse them all. We’re like, we really should be carers and have other people for amusing them, but we do everything. (YW5 RN1, Private)</td>
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<td></td>
<td>I think there could be more done. I think games and activities – it’s just that we’re very busy and if there was extra people on, they could come in and do just activities or whatever with them. (PK2 H CA01, Public)</td>
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Many resident respondents stated that they did not participate in the activities offered because they were not interested in large group activities, in the activities offered, or felt they were mentally at a different level to others. In many facilities an activities schedule for the week was in place but it was evident that in some facilities the activities were not focused on the residents’ particular interests.
For residents, what appeared to be important was that activities were structured to meet their interests and capacities, and that they were integrated into the everyday life of the facility. It was also important that activities were changed regularly. Those who did participate in activities often demonstrated personal interest in the activity and appeared to prefer activities which were structured into small groups of like-minded people. The success of activities appeared to hinge on two factors: firstly, that the residents’ interests were known and taken into account in the determining of activities; secondly, that residents perceived that there were other residents who had similar interests and capacities who also participated in that activity. It was important, therefore, that those organising activities knew the residents’ interests and capacities. In some large facilities, when activities were provided by an activities department, it was less likely that residents were known well.

Staff respondents also highlighted that activities were mostly for those residents who were mobile enough to go to the day or activities room. Residents who were bedbound or who spent long periods in bed, therefore, rarely had the opportunity to participate in activities.

11.6 Conclusions

This chapter presented findings related to activities and therapies within long-stay care. It was evident that there were widespread differences in the provision of activities across study sites. Some sites had an extensive range of activities while others provided little by way of activities. Some residents, therefore, had good opportunities to pursue meaningful activities while others did not. It was evident that some residents’ days were long and boring. Consequently, these residents were often frustrated and disengaged. Residents were most likely to participate in activities which were designed to take into account their own particular interests. The absence of occupational therapy and physiotherapy were highlighted as particular concerns by both residents and staff.
Chapter Twelve
Conclusions and Recommendations
Chapter Twelve
Conclusions and Recommendations

12.1 Introduction

Quality in long-stay care is important due to the distinctive nature of these places of residence for older people. The majority of inhabitants of residential care settings suffer from a physical and/or mental disability and require much care and attention. While residential care settings are correctly seen as places of care for older people, they also serve the dual role of being the permanent dwelling place of the majority of their residents. Therefore, long-stay care institutions should influence aspects of residents’ lives in far more extensive areas than just health or functioning; long-stay care facilities must be seen as providing the resident with the best possible quality of care and quality of life.

As a society, we have been much better at regulating quality of care in residential care than quality of life. This is because society has tended to define ageing as a biomedical problem, focusing on pathologies and physical dependency rather than on general quality of life. While quality of care is very important, a satisfactory quality of life in residential care depends on much more than quality of care. Policy-makers and regulators are now beginning to recognise the importance of quality of life in long-stay care and important initiatives in this regard have been outlined earlier in the report. One of the most important developments has been the HAIRC jointly sponsored by the NCAOP and the INPH. This initiative promotes autonomy, independence and choice for residents within residential care facilities and emphasises the importance of health promotion for both residents and staff in long-stay settings. The problem is that there is no consensus about what the term ‘quality of life’ means and, even among researchers, no agreement about what domains should be included in its assessment within long-stay settings (Walker, 2004).
The prevalence of quality deficits in residential care across OECD countries has led to international concern about the quality of care and quality of life in long-stay institutions. In general, governments have focused on developing and enforcing basic regulatory frameworks for minimally acceptable quality of care standards in residential care. In addition, most countries have developed and implemented a second layer of quality initiatives in order to ensure that standards of care exceed minimum requirements and positively enhance the health and well-being of residents. The development of a third layer of initiatives designed to enhance quality of life in residential care has not always been forthcoming, either voluntarily or through regulation. Even allowing for definitional and measurement difficulties, more needs to be done to increase the regulatory and policy focus on quality of life, in addition to quality of care, in residential settings. Such an approach would focus on both the physical and social environment within long-stay settings and their impact on the quality of life of residents. It would challenge ageist attitudes among providers, place the focus firmly on the rights and needs of residents, and ensure person-centred training for all staff providing care for older people. Quality of life for older people is an issue for everyone, both within residential care settings and outside. As such, any initiatives designed to enhance quality of life for dependent people in residential care settings should apply equally to older dependent people living at home.

12.2 Methodology and Model

As a concept, quality of life can mean anything to anybody and there is no consensus on the meaning of quality of life, especially with respect to older people in long-stay care. The measurement of quality of life is a difficult and complex exercise. For this study, objective data was collected on dimensions of residential care that previous research indicated were likely to impact on the quality of life of residents. This was conducted through a postal questionnaire to all known long-stay facilities in the country. The overall response rate to the survey was 62 per cent. The subjective views on quality of life of both residents and staff in residential care were also explored, through study site work in 12 sites across the country. The rationale for the study site work was the belief that an individual’s own sense of the ongoing narrative of life is more meaningful than an outside expert’s construction of objective reality. Hearing the voice of older people was central to this study and the phenomenological nature of the study site interviews facilitated this, thus ensuring an authentic account of quality of life as older people
themselves experience it. The approach was not to homogenise quality of life but to represent its complex and varied nature. For that reason, what gave meaning to the lives of older people within residential care was of greater interest than their health and functional capacity.

The methodology employed in this study, therefore, took a more holistic approach, including social, psychological, philosophical, emotional, spiritual and environmental dimensions. To establish domains of quality of life for older people in long-stay care, the following steps were taken:

- review of the literature on quality of life for older people, especially for people in residential care
- review of existing summary measures of psychosocial quality of life for older people in residential care
- discussion with stakeholders through focus groups in the early stages of the research process
- organisation of a one-day seminar with stakeholder groups on quality of life issues
- analysis of the interview data taken from residents, staff and relatives in the 12 study sites.

Four core themes emerged as important for older people in long-stay residential care in Ireland: care environment and ethos of care; personal identity; connectedness to family and community; and activities and therapies. These factors were found to be the ‘constants’ which determined residents’ overall quality of life. Within the theme of care environment and ethos of care, four categories emerged: autonomy; independence; staff and physical resources; and care philosophy. Identity incorporated four categories: self-expression; individuality; privacy and self-respect. Connectedness included relationships with fellow residents, staff, family and communities. The activities domain covered purposeful activity, therapeutic activity, activities outside the long-stay facility and making activities work.

To claim that all dimensions of quality of life of older people in residential care are captured in this typology would do an injustice to the vast array of literature on quality of life and the exhaustive search for overarching domains that continues to be pursued in the literature (as evident from Chapter Three). Residents’ experience of these domains is mediated by factors individual to him or her, for example their health status, personality, past experiences or expectations of care and their own adaptive response. This explains why individual residents’ quality of life may differ within the same facility. The results of this study show residents’ morale and
attitude to their institutionalisation to be important to their own interpretation of quality of life. This may explain why it is so difficult to compare facilities; subjective experiences within institutions can vary so much. In addition, quality of life is enhanced or constrained by the wider environment, including the physical environment of the care setting and wider community and social factors. Figure 12.1 represents quality of life in Ireland in respect of the four key determinants of this study as expressed by residents, and the mediating and constraining factors that influence and inform these determinants.

Figure 12.1: Model of factors determining residents’ quality of life in long-term care
12.3 Key Findings

Analysis of the key findings will focus on understanding the dynamic aspects of the relationship between care provision and environment in residential settings, and residents’ quality of life. There are differences in resident quality of life both within sectors and across sectors, some of which relate to the care environment, others of which relate to the dependency and personality of the resident themselves. What is clear from the data is that management and organisational structures within long-stay care facilities matter for quality of life and can compensate for poor physical environment in certain circumstances. The issue is less whether care is delivered publicly or privately, more whether care is resident-centred and quality driven. The focus of the final chapter is to explore what can be done to bring about an improvement in quality of life for residents on the basis of the findings of the research. Notwithstanding the complexity associated with the meaning and measurement of quality of life, there are underlying issues that need to be resolved to effect an improvement in the lives of older people in residential care. An examination of the four key quality of life determinants revealed three interconnected issues that had a significant impact on all determinants: staffing and skill mix; physical environment and ethos of care; and the provision of meaningful activities and therapies.

12.4 Staffing Levels and Skill Mix

A survey of 19 OECD countries, including Ireland, found that staff shortages and staff qualifications are the primary concerns of long-stay care policy-makers in these countries (OECD, 2005). This finding was confirmed by survey and interview data in the present study. It was evident from the study sites that there were significant differences in staffing levels and staff mix across facility types. Within the private sector, the ratio of registered nurses to care assistants was significantly lower than that in the public sector. In addition, the survey found that the ratio of registered nurses to residents was significantly lower in the private sector than in the public sector. While dependency levels in public geriatric hospitals were highest, this alone could not account for the variance in staffing levels. Three issues are apparent: the ratio of registered nurses to care assistants impacts directly on the capacity of registered nurses to supervise the work of care assistants; care assistants who are providing a very high percentage of residents’ care in the private sector must be fully trained for this role in order to provide an acceptable standard of care; and the
higher the proportion of care given by unqualified staff, the less capacity there is for
the identification of potential resident problems, client education or skilled nursing
support of residents. Therefore, when the ratio of registered nurses is low, the
quality of care may be compromised.

Stanton and Rutherford (2004) reporting on a number of studies undertaken in the
USA found that there was strong evidence of an association between registered
nurse staffing levels and adverse patient outcomes. Level of infection, pressure
ulcer occurrence and rate of falls were identified as some of the outcomes which
were likely to be affected by staffing levels. He, therefore, concluded that there
was an association between hospital nurse staffing and the quality of care.

Adams and Bond (2003) examined the relationship between nursing staffing
resources, the ward organisational practice and nurses’ perceptions of the ward
environment. They found that fewer nurses were associated with both hierarchical
attitudes to care and task approaches to the organisation of care. They found that
when there were more staff, nurses perceived that they were better able to cope
with the workload and had higher levels of job satisfaction. Interestingly, however,
they did not establish a link between higher staffing levels and higher standards
of nursing practice.

Currently, there is no legislation to guide staffing in the public sector while the
current legislation which guides the private sector simply specifies that there
should be one registered nurse per shift. This is inadequate, particularly in larger
facilities. The current legislation clearly requires urgent review and reform. It is
essential that registered nurse to resident staffing ratios are high enough to allow
the direct participation of nurses in the planning, delivery and supervision of care.
Further work needs to be undertaken in relation to determining appropriate staffing
levels and skill mix.

The current role of care assistants in public facilities is under review. This is welcome
as the current care attendant role had a major impact on ward organisation. The
requirement to complete physical care during the early morning to enable care
attendants to undertake their domestic duties constrained the organisation of work
in some areas to such an extent that patients were often woken early and given
rushed care. It is important that the direct care role of care assistants is divided
from their domestic role in all facilities.
It was evident across all data sets that the number of nursing staff from overseas has grown significantly. Many staff commented on the crucial role these staff had in maintaining services for older people. The findings of this study would suggest that some facilities have been more successful than others in facilitating integration of staff from overseas. These facilities had invested heavily in induction and support and reported that they were able to retain care staff from overseas for a number of years. Other facilities reported difficulty in recruitment and retention, leading to concern about an impending skills crisis within their services. The survey revealed that there were little overall differences in staff turnover across facility types. However, there were very significant differences in the range of staff turnover across facilities with one facility reporting 24 staff leaving in the last six months.

Focus group participants reported that overseas nurses were difficult to retain, as they were attracted to higher pay differentials in the public sector and perceived work within the acute sector as having more potential career opportunities for them. Focus group participants, particularly in Dublin, reported that up to 85 per cent of their registered nurses were from overseas. They were very appreciative of being able to recruit these nurses as covering the service would have been impossible without them, but they also highlighted the need to review salary levels, support and training.

Interview and focus group data revealed that the age profile of staff working with older people was different to that of those working in acute services. They reported that nurses working with older people were older and many were nearing retirement. Many nurses, therefore, trained some time ago and this may be significant in relation to continuing education needs. In addition, if many staff working in long-stay care are near to retirement as reported, succession planning for long-stay care services is vital.

12.5 Physical Environment and Ethos of Care

Observation within study sites revealed that a resident’s capacity to make choices about their day varied across facilities. Staff and resident interviews and survey data also revealed significant differences in the capacity of residents to exercise choice. On the whole, residents were more likely to have choice about the time they got up or went back to bed if they lived in a private rather than public facility. However, overall, the survey found that the more dependent someone was, the less likely it
was that they had a choice. In some study sites staff were able to facilitate resident choice while others, which appeared to have similar staff resources and facilities, could not. Observation within the sites indicated that some sites were fully committed to the organisational change required to facilitate choice and others were not. In some places, what Kane (2001) refers to as the ‘unshakable routines of the organisation’ militates against the expression of personal autonomy. The tension between routine and personalised care was evident in all of the study sites.

Some residents reported that they felt at ‘home’ in residential care and that they were able to continue to live their life as normal. The experience of residents who lived in facilities where routine dominated was very different. They felt constrained by the ‘rules’ and feared being considered a ‘troublemaker’. Best practice would suggest that residents’ lives should be as similar as possible to the lives they would choose to live at home. Quality care requires the collection of prior information on residents’ normal routines and preferences. Residents need to be asked about their likes and dislikes. Collecting this information is mere tokenism, however, unless greater flexibility is built into the routine to enable residents’ choices to be met. This should include extending dining times, meeting bathing preferences and accommodating preferred times of rising and going to bed.

It would seem, therefore, that one of the most significant factors to impact on a resident’s quality of life is the care philosophy of the unit in which they live. This dictates the general approach to care, staff attitudes, care priorities and resident autonomy. It, therefore, has a tangible impact on residents’ quality of life. In some facilities residents felt empowered, whereas in others residents appeared powerless and constrained. The current trend in gerontological nursing is a move to a more person-centred service. A person-centred service is one which is based on consultation, autonomy, choice, individual care and resident involvement in decision-making (McCormack, 2003; Clarke et al., 2003; Davies et al., 1999). If the services are to become more person-centred, it is important that these concepts drive the philosophy of facilities and steps are taken to embed these concepts into the way in which care is delivered. The findings of this research would suggest that a move to person-centred care will require a fundamental shift in the way in which services are managed and delivered. The international literature would suggest that the nurse manager is key to making this shift; many studies have found that the nurse manager has a powerful role in shaping the philosophy of the facility/unit and in leading change (Wright and McCormack, 2001; Redfern et al., 2002; Kitson, 1991). Management training and continuing education for staff should focus on developing an understanding of quality of life issues and putting in place person-centred models of care within facilities. All staff need to prioritise quality of life objectives if they are to provide good quality of care for residents.
The importance of continuing education opportunities for staff has been identified as an essential prerequisite of quality care. However, the cost and difficulty of releasing staff to avail of the opportunities were highlighted by staff respondents and focus group participants. The survey revealed that the ratio of registered nurses to residents was particularly low within large private facilities. Given these ratios, it could be very difficult for such units to release staff to attend continuing education opportunities, particularly in relation to quality of life. However, given the crucial role that continuing education plays in updating staff in best practice and new philosophies of care, it is important that ways of releasing staff are found.

Observations within study sites revealed great differences in the physical environments across facility types. Public hospital sites are older and are generally poorly designed for the purpose of caring for dependent older people. They are often extremely constrained in terms of space and physical infrastructure. In contrast, private study sites are relatively new and spacious, and have generally been designed for the purpose of caring for dependent older people. The absence of sitting rooms or homely social spaces resulted in some public residents spending the day by their bed. This also limited opportunity for communication and contacts with other residents, and participation in communal and/or physical activities. The poor physical environment in public facilities also impacted on toilet and bathroom provision, which in turn impacted on quality of life. In addition, the distance a resident has to walk to the toilet impacts on the extent to which it is possible for a resident to get to the toilet unaided. It was evident from all of the data that large, older public hospitals need to be replaced with facilities designed for the purpose of caring for older dependent people. These findings were confirmed in the survey of facilities and from observation, interview and focus group data. The physical environment, while not a sole determinant of quality of life, does make a difference and generally tends to be better in private facilities.

In some facilities bathroom and shower facilities were limited and residents reported that they were on a rota for a bath or a shower. The survey revealed that public facilities had fewer bathroom facilities per resident than private facilities. Residents in public facilities were less likely than residents in private homes to have en suite facilities, and generally had fewer toilets and special baths. Many residents living in public facilities, therefore, did not have the choice of regular bathing, if they so wished. There is an urgent need to increase the number and quality of bathrooms and toilets in public facilities.
The physical environment in some facilities was less suitable for residents with dementia than others. Lack of space to wander and constrained physical space in general exacerbated resident agitation. In addition, many staff reported that they felt they did not have the skills to manage residents with dementia. It is important that residents with dementia are cared for in appropriate facilities and managed by staff that are skilled in the care of people with dementia. There also needs to be a mechanism to transfer residents whose challenging behaviour is problematic to facilities that are structured to support their particular needs.

Privacy is an important issue for residents in long-stay care. Many residents living in public facilities are accommodated in communal units. While many of these units have been adapted from large open wards to smaller units, residents in these facilities have little opportunities for privacy or personalising their environment. Sharing a room with others may be a choice that a resident would make, but many public facilities could not offer such a choice to residents because they have a very limited number of single rooms. Residents who expressed greatest satisfaction with their environment generally had a room of their own. A room of their own gave residents control over their environment, greater choice in how they spent their time and more privacy. Residents who lived in large open-plan wards were least satisfied. They described their struggle to live a private life in a public space and many expressed a desire for a room of their own. A single room was the norm across private facilities (apart from residents who choose to share) but the exception in public facilities. The authors recommend that single occupancy rooms with en suite facilities should be the norm in all future buildings. This standard should apply across both public and private facilities. Clearly, the time has come to modernise public long-stay facilities and invest in new, appropriately designed, buildings for the care of older dependent people.

It was evident from the interview data that the perspectives of residents and staff differed in what they considered important for privacy. Staff equated privacy to physical privacy. Residents, in contrast, perceived privacy to include social and psychological privacy in addition to physical privacy. Many residents living in communal spaces wanted a private visiting area and a quiet place away from the general noise of the ward. The survey demonstrated, however, that you were less likely to have access to a private visiting space if you were living in a public facility. Another issue raised by residents was staff failing to knock prior to entering their rooms. It is important that residents’ rooms are considered to be their private spaces and sensitivity should be demonstrated.
The physical environment and attitudes of staff can also enhance the connectedness of residents both inside and outside the facility. Good social relationships are fundamental to quality of life and have consistently been mentioned by older people as fundamental to health and well-being (Bowling et al., 2003). A fundamental aspect of quality of life in residential care is being able to develop new relationships and maintain existing relationships. Connectedness requires residential care settings to be part of local communities rather than seen as places of exile that older people retreat to when they cannot be cared for in their own homes. Some facilities are better than others in facilitating greater connectivity among residents, between residents and their families, and between the facility and the wider community. But much more can be done in this regard. Firstly, design issues need to be resolved to encourage family and social relationships to grow and develop, including the provision of meeting rooms and play areas for young children visiting the facility. Secondly, the attitudes of staff need to change regarding the balance between the private and the social within long-stay care. Thirdly, connectedness extends beyond families to incorporate local communities through visiting and other forms of communication. Fourthly, the balance between risk and safety may need to be recalibrated in favour of the former, with residents encouraged to remain part of their own local communities. It is clear from the data in this study that when social relationships are strong and attachments to people and places are maintained, quality of life is enhanced.

12.6 Activities and Therapies

Another key finding from the study is that quality of life is enhanced when residents have plenty to do, particularly if what they have to do is meaningful and, to some extent at least, is freely chosen. The findings revealed that most facilities are expending significant effort and resources to provide daily activities for residents. Some facilities had even set up a specific activities department dedicated to the provision of activities. Unfortunately, some residents did not participate in activities because they did not perceive them to be of personal interest or did not like the way in which they were structured. Two important issues emerge in respect of activities within long-stay care. Firstly, residents’ interests should drive the provision of activities. For this to happen, there should be an assessment of residents’ interests and capacities on admission and a review of these on a regular basis. The schedule of activities should be driven by residents and their inclusion in drawing up a schedule would be of great benefit. To maintain resident interest,
activities need to be dynamic and relevant. Secondly, many residents found large undifferentiated group activities uninteresting. It was evident from resident accounts that small group activities with like-minded people were what residents wanted and enjoyed most. While this undoubtedly takes more organisation and planning, structuring activities in this way may result in greater inclusiveness.

Some facilities were innovative in their use of pictures, photographs and information boards. This served two purposes; their usage added change and variety to the environment, and also helped orientate residents to date, time and activities. The use of pictures, bright colours, furniture and open fireplaces created a homely ambience in some facilities. Others, however, were more hospital-like or impersonal. It was evident from resident interviews that feeling at home was closely bound to their overall quality of life. Facilities should consider ways of creating a homely atmosphere through the use of displays of photographs of residents, activities and outings, comfortable homely furniture and a focal point for resident interaction.

The role of care staff in the provision of activities is an important issue. The move of activities by some facilities from individual units to an activities department has resulted in ward staff perceiving activities as another person’s responsibility. This raises an important issue about the focus of care for older people. If the focus of care is mostly on physical care, then dividing the responsibility for activities and care could be justified. However, if the social dimensions of care are integral to care giving, it would seem sensible that those involved in direct care should also take the main responsibility for activities. Knowing the person is an important element in the provision of relevant activities and keeping someone ‘connected’ is as much about the way you work with someone as it is about activities. If nurses and care assistants are to retain a social dimension to their role, this needs to be an explicit expectation embedded into the philosophy of the unit. In addition, the role of activities departments should be evaluated.

The need to contribute, to feel useful and to have their skills and abilities recognised was closely bound to residents’ self-worth and self-respect. Some facilities were innovative in involving residents and drew on their past experience or skills. They also celebrated residents’ achievements through art exhibitions etc. The survey revealed that some facilities offered residents opportunities to participate in everyday household tasks and some had resident committees. These, however, were in the minority. Many facilities did little to involve residents. The authors of this study recommend that all facilities should introduce mechanisms to involve residents in decision-making. Possible strategies include; introducing resident committees, facilitating residents with shared interests to
meet and work on a joint project or introducing resident/staff committees to work on an agreed project. The introduction of biographical interviewing would enable staff to get to know the resident, his/her past experience and interests.

The provision of physiotherapy, occupational therapy and speech and language therapy was identified by this study as a key concern. In the public sector, while physiotherapy services were available free of charge in most facilities, the resources were often spread very thinly and resulted in many residents not receiving adequate attention. Occupational therapy was generally less available in public facilities and where it was available it was also likely to be thinly spread. Speech therapists, psychologists and social workers were even less available.

If the focus of long-stay care is on maintaining and promoting a resident’s independence, these services are crucial to quality of life. While the survey data revealed that these services could be accessed at market rates in most private facilities, the ability to pay may be an issue for residents, especially for those in receipt of public subventions. This gives rise to the anomaly that older people in public long-stay facilities tend to have greater access to public therapeutic facilities than publicly supported residents living in private nursing homes, even allowing for issues of availability in the public sector. A key finding of this research is the need to see all long-stay facilities in dynamic rather than static terms, as places of rehabilitation and recovery for the people who live there rather than places of dependency and decline.

12.7 Policy and Practice Issues

At the heart of any reform with respect to policy and practice is the need to embrace a new philosophy that places older people at the centre of decision-making in long-stay care. The central principles that should underpin any new legislation include: personhood, autonomy, empowerment and capabilities. Personhood offers an opportunity to personalise care that will enhance the dignity and self-respect of residents. Self-respect incorporates both self-worth and self-confidence and individuals require these attributes in order to believe that their actions in everyday life are worthwhile and are appreciated by others. The move to residential care can lead to an erosion of people’s independence, autonomy and sense of self. Therefore, it is particularly important that the ethos of the residential care facility is one of encouraging autonomy and empowerment and that there are structures in place to encourage and promote the self-determination of residents.
Older people in residential care must be recognised as individuals in their own right, not just patients. Residents of long-stay care have the same needs and rights as all other people and, in fact, their needs are greater because of the prevalence of physical and mental frailty. Capabilities refer to the ability of an individual to maximise performance and achievement in terms of doing and being in life. The capability of a person is dependent on the resources available to them as well as their personal characteristics. Thus, the residential care environment, both physical and social, plays an important role in influencing the capabilities of its residents.

The current legislation and regulations governing residential care have many limitations, not least of which is their focus on quality of care rather than quality of life. In addition, the regulations outlined under the Health (Nursing Homes) Act, 1990, apply only to the private sector and are not relevant to public facilities. The legislation is weak on sanctions for facilities providing inferior quality of care. There is no independent inspectorate of nursing homes which means that it is left up to the HSE to inspect private nursing homes while those facilities run by the HSE are not subject to any inspection at all. Inspections are rarely carried out at night and unannounced inspections are uncommon. While inspection reports are available under the Freedom of Information Act, 1997, this is a cumbersome and time-consuming process, making exposure of poor facilities less likely. Information is the key to a transparent and quality-driven service and to competition within the sector. Residents are poorly served at the moment with respect to information on quality of care and quality of life.

There is no statutory or independent complaints or appeals mechanism. It is rare that private nursing homes are closed down following complaints or inspection. While the HSE can move to shut down a private or voluntary nursing home or put in place its own management team if it believes the proprietors fail to meet minimum standards, it can only do this with the compliance of the proprietors; otherwise, it must go to the District Court in order to carry out these actions. In the case where a nursing home is closed down, alternative accommodation must be found for the residents, which can be traumatic for residents and their families.

Many countries, including Ireland, are becoming increasingly aware of the importance of quality in long-stay care institutions. This has resulted in the development and implementation of quality mechanisms both nationally and internationally, mainly in relation to physical environment and care process. In Ireland, the Government has realised the need to foster and promote high-quality health and care services and have established the HIQA and the IHSAB to achieve this goal. In addition, quality of care initiatives have been developed at local and
Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland

Regional levels. Examples of independent quality initiatives include the HAIRC, which includes quality of life dimensions, as well as quality of care elements. Internationally, many countries have moved to put in place mechanisms to guarantee better monitoring and assessment of quality in long-stay care. The UK and Australia have established independent agencies to regulate social and healthcare services. The USA has developed an RAI and MDS in order to identify and develop quality indicators for nursing home residents, which include some quality of life domains. However, quality of life is still in its infancy and remains underdeveloped in most countries. This is why the policy focus in Ireland in the coming years must be on quality of life as much as on quality of care if real improvements in the lives of older people in long-stay care are to be realised.

The emphasis on quality of care at the expense of quality of life in long-stay care has been due to the fact that quality of care has proved easier to measure and assess due to its more tangible nature. Difficulties in measuring quality of life arise due to its complex, multidimensional and subjective nature. Quality of life covers many domains and the relevance and importance of these domains remain contentious. Nevertheless, while quality of life will depend on people’s individual circumstances, personality and life history, there are many things that an institution can do to enhance quality of life. For this reason, asking people directly about their quality of life must be built into any new legislation and regulations dealing with quality in residential care. It is acknowledged that there are considerable challenges to measuring the quality of life of older people in long-stay care, particularly for residents suffering from dementia. Cognitive and/or communication impairments mean that dementia sufferers may find it more difficult to report on their quality of life. Yet, if dementia sufferers are not consulted about quality of life, this leaves out a considerable proportion of long-stay residents. Measuring quality of life in dementia patients is not impossible and a number of researchers have successfully identified person-centred quality of life domains for residents suffering from dementia.

Any new legislation must acknowledge that residential care is the permanent home of the majority of its residents. Therefore, long-stay facilities must be encouraged through regulation and sanctions to produce a more home-like environment and reduce the institutional feel of facilities. Residents must be able to continue living as they did in their former homes, taking into account their limitations and capabilities. Finding out what people like and dislike is the first step to giving residents a more home-like environment. Giving people more choice will help to develop residents’ independence and autonomy, thus contributing to their dignity and self-respect. For example, dignity can be ensured by giving the resident the
choice regarding the gender of a care giver administering intimate care. Dignity can also be upheld by respecting residents’ need for privacy through, for example, the provision of an adequate number of single rooms.

Similarly, new regulatory structures must take account of the social world of residents. Personal and group identity can be sustained by maintaining and developing contact with families and local communities. Residential care units should be at the centre of communities, drawing in people from the outside through family contacts and intergenerational programmes of activities. Contacts with active retirement associations, schools and voluntary groups should be developed and maintained to foster relationships at all levels. Connectedness can be improved by ensuring that the physical layout of the facility encourages visiting and social interaction. Tables that residents can sit around and chat or interact would be an improvement on chairs lined around the walls facing the television. Residents should also be grouped together according to mental, not physical, capability. Flexible visiting hours and the provision of private space to entertain visitors, including child friendly areas, will also contribute to greater social interaction and connectedness with family and friends.

Any new regulatory structure must also ensure that the autonomy and capabilities of residents are recognised and understood. For example, with respect to activities it is essential that those on offer should be meaningful and provide the resident with interest and stimulation. Therefore, residents should be consulted about what activities to offer in the care setting. Residents should also be given the choice of participation in available activities. Residential care staff face a common dilemma regarding the health and safety of residents and the degree of acceptable risk. Residents must be allowed to decide on the level of risk they are willing to take. Balancing risk with health and safety and allowing residents to take greater risks would enable residents to have a greater involvement in the running of the nursing home. Enabling those residents who wish to become more involved in the running of the care facility and participate in activities lends a sense of empowerment to residents and makes them feel useful, thereby contributing to their sense of self. It also makes the care establishment seem more of a home and less of an institution. On the other hand, many residents are happy to be freed of these responsibilities so they can relax and enjoy their retirement more fully. If that is the case, then they should not be pressurised into doing things they do not want to do.
Table 12.1 provides a summary of the main recommendations of the authors arising from this report. It is clear that improving the quality of life of older people in long-stay care will require action in respect of all of the domains identified in this report. Changing the ethos of care and mindset of management and staff within institutions will be fundamental to making progress in improving quality of life for residents. A sustained education and training programme will be necessary to facilitate a move away from care models based on routine towards person-centred models of care. It is also clear that nurse staffing ratios will have to increase, particularly in the private sector. Guidelines on staffing ratios for all types of residential care need to be agreed by stakeholders as part of the standard setting process and be related directly to overall dependency levels. Staffing guidelines should be reviewed regularly as part of the overall evaluation process of quality of life in long-stay care.

Table 12.1: Main recommendations for enhancing quality of life in long-stay care settings

1. Develop a person-centred ethos of care within residential settings through education and training of management and staff.
2. Ensure that registered nurse to resident staffing ratios are high enough to allow the direct participation of nurses in the planning, delivery and supervision of care.
3. Develop uniform national care standards for all types of residential care settings in Ireland.
4. Establish an independent Social Services Inspectorate for the regulation, inspection and monitoring of quality of care and quality of life in residential care.
5. Ask residents and their families directly about their experiences of long-stay care as part of the regulatory and inspection process.
6. Publish regular information on the results of inspection which includes reference to, and monitoring of, quality of life in the following domains: care environment and ethos of care, sense of self and identity, connectedness, and meaningful activities and therapies.
7. Develop appropriate consultation structures within long-stay settings to give older people a greater voice in how services are structured and delivered.
8. Review the appropriateness of current care environments and the overall management of residents with dementia, with particular reference to the care of people with challenging behaviours.
9. Replace existing, inappropriately designed public long-stay facilities with new buildings designed to provide accommodation that recognises the individuality of all residents and allows them to choose their desired mix of private and public space.
10. Develop an appropriate reward structure for residential care settings that deliver good quality care and good quality of life for residents and penalties for those that provide poor quality of care and diminished quality of life for residents.
Residents and their families should be asked directly about their experiences of quality of care and quality of life in residential care as part of the inspection and regulatory process and procedures carried out by a newly established Social Services Inspectorate for long-stay care. Information should be published regularly on the results of inspections, including specific information on care environment and ethos of care, sense of self and identity among residents, social connectedness and meaningful activities and therapies. As part of the new emphasis on quality of life, all long-stay facilities should be mandated to develop appropriate consultation structures designed to give older people a voice in how the facility is run, including what services are provided to residents.

New investment is also required in respect of public long-stay facilities to replace an ageing capital stock that, for the most part, was not designed to cater for the needs of dependent older people. Unfortunately, regulations on the design of care buildings have accumulated over time with little knowledge of their impact on the quality of life of building users. This must change and any new investment must be small-scale and facilitate the independence of residents. Building features that maximise choice and control, privacy, social connectedness, physical support, cognitive support, comfort and personalisation will enhance the quality of life of residents. The physical care environment and overall design of the buildings are particularly important for people with dementia. Finally, good quality facilities should be rewarded with extra resources and residents, while poor quality providers, whatever their origins, should be named, shamed and prosecuted.

In conclusion, it is evident that much work remains to be done in ensuring a good quality of life for older people resident in long-stay care. To date, not enough attention has been paid by policy-makers and regulators to quality of life and they have instead chosen to focus their attention on ensuring a good quality of care is made available in long-stay residential care. While this can be justified by the central role played by these facilities as providers of care and the more tangible nature of quality of care indicators, the prominence given to quality of care, while necessary, is not sufficient and it is imperative that quality of life in long-stay care is given the due recognition it deserves. Older people in long-stay care are more than just patients; they are individuals who deserve to live the remainder of their days with dignity and respect in an environment that is empowering and enabling, not belittling. It is not only policy-makers that have to change; management and staff also need to change and see their roles in terms of developing quality of life as much as quality of care. Long-stay care settings are not places to die; they are places to live and live well. The impetus is now on regulators, policy-makers and practitioners to ensure that residents of long-stay care are guaranteed the best quality of life possible in these settings as well as the best possible care.
References
References


Appendices
Appendix One

Census Questionnaire

The National University of Ireland, Galway has been asked by the National Council on Ageing and Older People to conduct a survey of public, private and voluntary long-stay facilities for older people in Ireland. This national project seeks to explore quality of care and quality of life from the perspectives of residents and staff in all long-stay facilities in Ireland. This information will be used to guide policy for future development in this sector and your views are critical to this process.

We are asking you to fill in this questionnaire at any stage during the week beginning 4 April and to return it in the stamp-addressed envelope provided by 11 April 2005. Your response matters in getting a detailed picture of quality of life and quality of care for older people. The information you provide will be treated in strict confidence and it will not be possible to identify your specific response or your facility in the final report.

The study has the support of all public, private and voluntary agencies involved in long-stay care of older people in the country. The Consultative Committee for the study includes representation from the following groupings: private nursing homes, voluntary nursing homes, the Health Services Executive, the National Council on Ageing and Older People, the Alzheimer Society of Ireland and the Department of Health and Children.

While we recognise that some people may use your facilities for respite care, rehabilitation and so on, the focus of this study is on people living permanently in long-stay facilities. Therefore, we would appreciate if, for the questions about residents, you could provide us with information on those long-stay residents only when completing this questionnaire.

Most questions can be answered by ticking one or more boxes or entering brief data. The questionnaire should be completed by the owner or by the Director of Nursing or by the person in charge in your long-stay facility.

Thank you very much for your time in filling in this questionnaire. The results of the study will be made available when the study is complete.
1. Please tick the category which best describes your facility (please tick one box only):

- Public (Health Board) geriatric home
- Public (Health Board) geriatric hospital
- Public (Health Board) welfare home
- Public (Health Board) district hospital
- Public (Health Board) community hospital
- Voluntary geriatric hospital
- Voluntary geriatric home
- Private nursing home

2. What is the total number of beds (include long-stay, respite, convalescent etc.) in the facility?

3. Please indicate the number of residents who fall into each of the following categories:

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Long-stay/permanent</td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Short-term respite</td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Short-term for winter period</td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>Short-term convalescence</td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>Palliative care</td>
<td></td>
</tr>
<tr>
<td>f</td>
<td>Rehabilitation</td>
<td></td>
</tr>
<tr>
<td>g</td>
<td>Other (please specify):</td>
<td></td>
</tr>
<tr>
<td>h</td>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>
4. For long-stay/permanent residents only, please indicate the number of residents in each of the following age groups (if none, enter zero):

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of long-stay residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 65 years</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td></td>
</tr>
<tr>
<td>75-84</td>
<td></td>
</tr>
<tr>
<td>85-94</td>
<td></td>
</tr>
<tr>
<td>95+</td>
<td></td>
</tr>
</tbody>
</table>

5. What is the average weekly charge for residents in your facility? While we are aware that you may charge different rates, please estimate the average charge (please tick one box only; if there is no charge, please tick No charge).

<table>
<thead>
<tr>
<th>€ per week</th>
<th>€ per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>No charge</td>
<td>a</td>
</tr>
<tr>
<td>1-100</td>
<td>b</td>
</tr>
<tr>
<td>101-200</td>
<td>c</td>
</tr>
<tr>
<td>201-300</td>
<td>d</td>
</tr>
<tr>
<td>301-400</td>
<td>e</td>
</tr>
<tr>
<td>401-500</td>
<td>f</td>
</tr>
<tr>
<td>501-600</td>
<td>g</td>
</tr>
<tr>
<td>601-700</td>
<td>h</td>
</tr>
<tr>
<td>701-800</td>
<td>i</td>
</tr>
<tr>
<td>801-900</td>
<td>j</td>
</tr>
<tr>
<td>901-1000</td>
<td>k</td>
</tr>
</tbody>
</table>
6a. Are there any reasons why you would not accept a person for long-stay admission to your facility?

Yes [ ] No [ ]

6b. If Yes, please specify why not (please tick more than one box if appropriate):

Severe behavioural problems [ ]
Tracheostomy [ ]
Wandering [ ]
Mental illness [ ]
Intellectual disability [ ]
Specialist equipment to provide appropriate level of care not available in facility [ ]
Needing a high degree of medical care [ ]
Others (please specify): [ ]

7. Please indicate the number of long-stay residents who are in your facility for predominantly social reasons (if none, enter zero).

8. Please indicate the number of long-stay residents in this facility who fall into each of the following dependency categories (if none, enter zero):

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of long-stay residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>a  Low dependency</td>
<td></td>
</tr>
<tr>
<td>b  Medium dependency</td>
<td></td>
</tr>
<tr>
<td>c  High dependency</td>
<td></td>
</tr>
<tr>
<td>d  Maximum dependency</td>
<td></td>
</tr>
</tbody>
</table>
9. Please indicate the number of long-stay residents in this facility who fall into each of the following categories (if none, enter zero):

<table>
<thead>
<tr>
<th>Personal care (for example, washing, feeding and continence)</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Fully independent</td>
<td></td>
</tr>
<tr>
<td>b Needs help with some tasks</td>
<td></td>
</tr>
<tr>
<td>c Fully dependent (for example, incapable of washing hands and face, or of feeding self)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mental state</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Mentally alert</td>
<td></td>
</tr>
<tr>
<td>b Confused some of the time</td>
<td></td>
</tr>
<tr>
<td>c Severe confusion all of the time</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mobility</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Fully mobile (without walking aid or stick or assistance from another person)</td>
<td></td>
</tr>
<tr>
<td>b Mobile with the use of a walking aid or stick</td>
<td></td>
</tr>
<tr>
<td>c Mobile with the help of another person</td>
<td></td>
</tr>
<tr>
<td>d Immobile (confined to bed or chair)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Persistent wandering only</td>
<td></td>
</tr>
<tr>
<td>b Severe behavioural problems only</td>
<td></td>
</tr>
<tr>
<td>c Physical aggression only</td>
<td></td>
</tr>
<tr>
<td>d Some combination of the above behaviours</td>
<td></td>
</tr>
</tbody>
</table>
10. How many whole-time equivalents, in each of the following categories, work in your facility?

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of whole-time equivalents</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Registered nurses (RN)</td>
<td></td>
</tr>
<tr>
<td>b Care attendants</td>
<td></td>
</tr>
<tr>
<td>c Healthcare assistants</td>
<td></td>
</tr>
<tr>
<td>d Porters</td>
<td></td>
</tr>
<tr>
<td>e Cleaners/housekeepers</td>
<td></td>
</tr>
<tr>
<td>f Cooks</td>
<td></td>
</tr>
<tr>
<td>g Administrators</td>
<td></td>
</tr>
<tr>
<td>h Other (please specify)</td>
<td></td>
</tr>
<tr>
<td>i Total</td>
<td></td>
</tr>
</tbody>
</table>

11. How many healthcare staff (in each of the categories below) are employed in your facility? Please indicate the actual numbers of people in each category.

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of actual people employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Registered nurses (RN)</td>
<td></td>
</tr>
<tr>
<td>b Care attendants</td>
<td></td>
</tr>
<tr>
<td>c Healthcare assistants</td>
<td></td>
</tr>
<tr>
<td>d Total</td>
<td></td>
</tr>
</tbody>
</table>
12. How many registered nurses and healthcare staff are normally on duty during each of the following shifts, where applicable?

<table>
<thead>
<tr>
<th>Shifts</th>
<th>No. of RNs on duty</th>
<th>No. of care attendants on duty</th>
<th>No. of healthcare assistants</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Morning shift</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b Afternoon shift</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c Evening shift</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d Night shift</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e Other (e.g. twilight shift – please specify):</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

13. How many healthcare staff (RNs, care attendants, healthcare assistants) either joined or left your facility in the last six months?

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Joined in the last 6 months</td>
<td></td>
</tr>
<tr>
<td>b Left in the last 6 months</td>
<td></td>
</tr>
</tbody>
</table>

14. What was the total amount of overtime hours worked by registered nurses in your facility in the past week?

15. What is the nature of medical cover provided for long-stay residents in your facility (please tick more than one box if appropriate)?

- Local GP
- Consultant geriatrician
- Other (please specify):

16. Can long-stay residents who wish to remain under the care of their own GP do so?

Yes  No
17. Are any of the following services available in your facility (please tick the appropriate box for each service):

<table>
<thead>
<tr>
<th>Service</th>
<th>Available free of charge</th>
<th>Available privately for a fee</th>
<th>Not available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapist</td>
<td></td>
<td>1a</td>
<td>1b</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td></td>
<td>2a</td>
<td>2b</td>
</tr>
<tr>
<td>Speech therapist</td>
<td></td>
<td>3a</td>
<td>3b</td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
<td>4a</td>
<td>4b</td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
<td>5a</td>
<td>5b</td>
</tr>
<tr>
<td>Chiropodist</td>
<td></td>
<td>6a</td>
<td>6b</td>
</tr>
<tr>
<td>Dentist</td>
<td></td>
<td>7a</td>
<td>7b</td>
</tr>
<tr>
<td>Optician</td>
<td></td>
<td>8a</td>
<td>8b</td>
</tr>
<tr>
<td>Hairdresser</td>
<td></td>
<td>9a</td>
<td>9b</td>
</tr>
<tr>
<td>Others (please specify):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

18. Are any of the following communal facilities available for long-stay residents in your facility (please tick more than one box if appropriate):

<table>
<thead>
<tr>
<th>Facility</th>
<th>Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>Television</td>
<td>a</td>
</tr>
<tr>
<td>Newspapers</td>
<td>b</td>
</tr>
<tr>
<td>Video/DVD</td>
<td>c</td>
</tr>
<tr>
<td>Library/book lending</td>
<td>d</td>
</tr>
<tr>
<td>Games</td>
<td>e</td>
</tr>
<tr>
<td>Musical instruments (e.g. piano)</td>
<td>f</td>
</tr>
<tr>
<td>Shop (sale of general sundries)</td>
<td>g</td>
</tr>
<tr>
<td>Public telephone</td>
<td>h</td>
</tr>
<tr>
<td>Tea/coffee making facilities</td>
<td>i</td>
</tr>
<tr>
<td>Personal laundry facilities</td>
<td>j</td>
</tr>
</tbody>
</table>
19. Does your facility have any of the following activities available on a regular basis (please tick more than one box if appropriate):

- Sonas programme
- Snoezelan
- Arts activities
- Organised music
- Organised dancing
- Gardening
- Activity/physical exercise programme
- Organised bingo/cards/board games
- Complementary therapies (e.g. reflexology, massage)
- Visits from school students e.g. Transition Year
- Other (please specify):

20. Is there a residents’ committee in your facility?

- Yes
- No

21. Is there a complaints procedure for residents and relatives in your facility?

- Yes
- No

22. Have residents access to a phone which they can use uninterrupted in a private room?

- Yes
- No

23a. Do long-stay residents in your facility have regular scheduled visits from clergy/Eucharistic ministers/other religious?

- Yes
- No

23b. Does your facility have a quiet room/place of reflection/oratory?

- Yes
- No
24a. Can long-stay residents choose to undertake household or garden tasks in your facility if they wish?

Yes [ ] No [ ]

24b. If yes, how many residents help regularly?

[ ]

24c. Which activities do residents help with (please tick more than one box if appropriate)?

- [ ] Washing/drying dishes
- [ ] Laying tables
- [ ] Serving food
- [ ] Cooking
- [ ] Cleaning rooms
- [ ] Making beds
- [ ] Gardening
- [ ] Others (please specify): [ ]

25. Do long-stay residents have the facility for locking their own cupboard or drawer?

Yes [ ] No [ ]

26. Are any provisions made for residence of married couples in this facility?

Yes [ ] No [ ]

27. Are ambulant, mentally-alert long-stay residents allowed to leave the facility (to go for a walk, visit a relative etc.) unaccompanied?

Yes [ ] No [ ]
28. Can long-stay residents decide at what time they get up in the morning? Please tick one box only.

- All residents can decide the time they get up [a]
- Only residents who are independent can decide the time they get up [b]
- Nursing/care staff decide the time residents get up [c]
- Other (please specify):  

29. Can long-stay residents decide at what time they go to bed? Please tick one box only.

- All residents can decide the time they go to bed [a]
- Only residents who are independent can decide the time they go to bed [b]
- Nursing/care staff decide the time residents go to bed [c]
- Other (please specify):  

30. In which of the following areas/activities do long-stay residents have a personal choice (please tick more than one box if appropriate):

- Wearing their own clothes [a]
- Participation in religious services [b]
- Food and drink menus [c]
- Times of meals [d]
- Participation in organised activities [e]
- Choice of newspapers [f]

31. How are visiting hours organised? Are they:

- Restricted to certain times [a]
- Flexible [b]

32a. Are residents allowed to smoke in your facility?

- Yes [ ]  
- No [ ]
32b. If Yes, when can residents smoke (please tick one box only)?

Whenever they wish  a
At designated times only  b
Other (please specify):

33a. Are long-stay residents allowed to keep their own drink (alcohol) in the facility?

Yes  a  No  b

33b. If Yes, when can residents drink (please tick one box only)?

Whenever they wish  a
At designated times only  b
Other (please specify):

34a. Are there circumstances whereby existing long-stay residents can no longer reside in this facility?

Yes  a  No  b

34b. If Yes, please indicate what circumstances apply (please tick more than one box if appropriate).

Severe behavioural problems  a
Physical aggression  b
Wandering  c
Dementia  d
Permanent deterioration of medical condition  e
Multiple and complex disability  f
Financial  g
Other (please specify):  h
35. Are any of the following processes/arrangements in place to help residents make the transition from living at home in the community (or other circumstances) to your facility (please tick more than one box if appropriate):

- Resident visit prior to admission
- Family visit prior to admission
- Brochure/web site/other information available about facility
- Resident allocated a named nurse on admission
- Life history of resident gathered on admission
- Other (please specify):

36. Please indicate in which of the following places there is a call system installed (please tick more than one box if appropriate).

- Residents’ rooms
- Bathrooms
- WCs
- Corridors
- Other (please specify):

Physical resources

In this section, please refer to accommodation and facilities used by long-stay residents only.

37. How many of the following are in your facility?

<table>
<thead>
<tr>
<th>Type of room</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Single rooms</td>
<td></td>
</tr>
<tr>
<td>b Double rooms</td>
<td></td>
</tr>
<tr>
<td>c Wards (defined as rooms with 3 or more people)</td>
<td></td>
</tr>
</tbody>
</table>
38a. Was this facility purpose-built as a long-stay residential facility?
Yes [ ] No [ ]

38b. If No, what was the building previously used for (please tick the appropriate box)?

- Private residence [ ]
- Former hospital [ ]
- Hotel [ ]
- Guest house/B&B [ ]
- Other (please specify): [ ]

39a. Is there a garden or outside recreational area attached to the facility?
Yes [ ] No [ ]

39b. If yes, can all residents access the garden or outside recreational area?
Yes [ ] No [ ]

40a. If the facility is a multi-storey building, are there rooms or other resources for long-stay residents on upper floors?
Yes [ ] No [ ] Not applicable [ ]

40b. If yes, is there a lift to the upper floors?
Yes [ ] No [ ]

41. Is there a specially-designed sluice room in the facility?
Yes [ ] No [ ]

42. Can long-stay residents adjust heating levels in their own rooms?
Yes [ ] No [ ]
43. Which of the following types of rooms are in your facility (tick more than one box if appropriate)?

- Separate dining room
- Sitting room(s) separate from residents dining room
- Sitting room(s) combined with residents dining room
- Sitting room(s) combined with reception area
- Reception area separate from residents’ sitting room(s)
- Private room/space for entertaining visitors
- Child-friendly area (e.g. with a toy box) for children while visiting relatives?
- Separate activities room
- Other (please specify):

44. Please provide information about the bathroom facilities, indicating the number of each of the following:

<table>
<thead>
<tr>
<th>Bathroom facilities</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>a  En suite rooms</td>
<td></td>
</tr>
<tr>
<td>b  WCs with fixed grab rails</td>
<td></td>
</tr>
<tr>
<td>c  WCs that are separate from bathrooms and showers</td>
<td></td>
</tr>
<tr>
<td>d  Special baths</td>
<td></td>
</tr>
<tr>
<td>e  Wheelchair accessible showers</td>
<td></td>
</tr>
<tr>
<td>f  Bath aids and appliances</td>
<td></td>
</tr>
</tbody>
</table>
45. Are any of the following provided in this facility (please tick more than one box if appropriate)?

- Walking aids  
- Manual wheelchairs  
- Electric wheelchairs  
- Handrails along corridors  
- Handrails along dining room/sitting room walls  
- Ramps  
- Automatic doors  
- Special eating utensils  
- Special writing utensils  
- Colour-cueing e.g. toilet doors painted the same colour

46. Is there occupational therapy advice available regarding the provision of the above?

- Yes  
- No

Conclusion

If you have any other comments that you would like to make about quality of life issues in long-stay facilities, we invite you to add these comments here:

Thank you for your time and help!
Appendix Two

Description of Study Sites: Guidelines

- Brief history of building, e.g. custom-built in 1980 or an old workhouse.
- General description of building and grounds.

Physical environment

- Produce a detailed floor plan of ward/unit/home showing the use of each room.
- General comments on first impressions, e.g. décor, bright, access to garden etc.
- Describe where residents sleep, e.g. private room or 6-bedded unit, each bed has curtains around it, each resident has a chair, locker etc.
- Describe where residents eat, e.g. at bedside or separate dining area.
- Describe the day room, e.g. décor, typically where residents sit etc.
- Describe the bathroom facilities, e.g. number accessibility to residents.
- Identify off-ward/unit/home facilities available to residents, e.g. chapel, garden etc.
- Do residents wear their own clothes? Have they access to locker/press where they can store their own things?
- Do residents have their own belongings, e.g. photos etc. around them?

Life in the ward/unit/home

- Describe a typical day.
- Identify the types of social/recreational activities available to residents; how often do they happen?
- Identify additional services, e.g. physiotherapy, hairdressing etc. How often do they come?
General atmosphere

- Comment on the general atmosphere, e.g. relationship between residents, relationship between staff and residents.
- Do many visitors come in each day? Where do residents and relatives talk? Is there a visitor policy?
- Do volunteers come into the facility? What do they get involved in?

Ethos of care

- Collect a copy of any relevant documents, e.g. mission statement etc.
- What approach to care is adopted e.g. patient allocation, task allocation etc.
- Comment on the extent to which care is individualised or routinised. Give examples where possible.
- Any other comments you think are important in painting a picture of the setting.
Appendix Three

Resident Interview Schedules

The interview guides were used flexibly. The researcher followed the lead of the resident participants rather than imposing his/her agenda on the interview; questions were asked where appropriate in the conversation. Two versions of Resident Interview Schedules were employed: the first was used when resident participants were articulate and fluent while the second was used if the resident participant had difficulty communicating and comprised of closed questions which facilitated resident participants to answer yes/no only. A series of cards were printed with yes/no, very satisfied/satisfied/not satisfied etc. This allowed participants to point to an answer if that was easier for them. Normally it was possible to glean more than yes/no through the participant’s non-verbal communication. This allowed the researcher to explore some issues in greater depth.

Table 1: Resident Interview Schedule 1

<table>
<thead>
<tr>
<th>Domain</th>
<th>Cue question/prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethos of care</td>
<td>Describe your typical day? Can you tell me what happens each day from the time you wake to the time you go to bed?</td>
</tr>
<tr>
<td></td>
<td>Is every day the same?</td>
</tr>
<tr>
<td></td>
<td>Would you say there is a routine? Good/bad, rules.</td>
</tr>
<tr>
<td>Choice and control</td>
<td>Do you have a choice about what you do every day?</td>
</tr>
<tr>
<td></td>
<td>Time: get up/go to bed.</td>
</tr>
<tr>
<td></td>
<td>Meals: choice/timing.</td>
</tr>
<tr>
<td>Privacy</td>
<td>Do you have enough privacy?</td>
</tr>
<tr>
<td></td>
<td>Do you have your own room or share with others?</td>
</tr>
<tr>
<td></td>
<td>Issues in sharing?</td>
</tr>
<tr>
<td></td>
<td>It there someplace that you can go to be private?</td>
</tr>
<tr>
<td></td>
<td>If you have a visitor is there someplace you can go to talk in private?</td>
</tr>
<tr>
<td>Domain</td>
<td>Cue question/prompts</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Feeling cared for/feeling secure</td>
<td>What is it like for you living here? Has life changed for the better for you since you moved here? Has life changed for the worst since moving here?</td>
</tr>
<tr>
<td></td>
<td>What kinds of services are available to you here? Therapeutic: physiotherapy etc. General: hairdresser etc.</td>
</tr>
<tr>
<td></td>
<td>Is there anything else you think should be available to you?</td>
</tr>
<tr>
<td></td>
<td>Is this a good place to live? Comfortable, temperature, noise.</td>
</tr>
<tr>
<td></td>
<td>Do you feel cared for here? Staff polite, staff gentle, staff respectful.</td>
</tr>
<tr>
<td></td>
<td>Do you feel safe here? Personal safety, safety of possessions.</td>
</tr>
<tr>
<td></td>
<td>Can you get help quickly if you need it? Call bell/other.</td>
</tr>
<tr>
<td></td>
<td>In general would you say there is a friendly atmosphere?</td>
</tr>
<tr>
<td>Sense of self</td>
<td>Would you say staff know you well? Known as an individual?</td>
</tr>
<tr>
<td></td>
<td>Likes and dislikes.</td>
</tr>
<tr>
<td></td>
<td>Do staff take time to listen to you? Friendly, have a chat.</td>
</tr>
<tr>
<td></td>
<td>Do staff take on board your opinion/wishes?</td>
</tr>
<tr>
<td></td>
<td>In general would you say that people are treated as individuals? Examples.</td>
</tr>
<tr>
<td></td>
<td>Were you able to bring your own belongings with you?</td>
</tr>
<tr>
<td></td>
<td>Are you able to do the things that are important to you? The things that make you feel good? Examples: favourite TV programme, newspaper of choice.</td>
</tr>
<tr>
<td></td>
<td>Are you able to dress as you like?</td>
</tr>
<tr>
<td></td>
<td>Can you do what you’d do if you were at home?</td>
</tr>
<tr>
<td></td>
<td>Do you feel at home here?</td>
</tr>
<tr>
<td>Meaningful activity</td>
<td>What kind of activities are available for people to take part in? Examples: painting, activity programme etc.</td>
</tr>
<tr>
<td></td>
<td>Do you get involved?</td>
</tr>
<tr>
<td></td>
<td>Do you get outdoors as much as you want?</td>
</tr>
<tr>
<td></td>
<td>Visits/trips: where, how often, who with?</td>
</tr>
<tr>
<td></td>
<td>Garden/outdoor recreational area?</td>
</tr>
<tr>
<td></td>
<td>Do you get bored?</td>
</tr>
<tr>
<td>Companionship</td>
<td>Have you made friends here? If no: is it hard to make friends here?</td>
</tr>
<tr>
<td></td>
<td>Do you enjoy the others company?</td>
</tr>
<tr>
<td></td>
<td>Is it sometimes difficult living with some of the other residents? Why?</td>
</tr>
<tr>
<td></td>
<td>Are you near your home here?</td>
</tr>
<tr>
<td>Domain</td>
<td>Cue question/prompts</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Relationships</strong></td>
<td>Do you still have contact with your family and friends from home?</td>
</tr>
<tr>
<td></td>
<td>How do you keep in touch?</td>
</tr>
<tr>
<td><strong>Continuity with old life/ community</strong></td>
<td>Are you able to keep in touch with what’s happening at home?</td>
</tr>
<tr>
<td><strong>Independence</strong></td>
<td>Do the nurses let you do the things you can do for yourself? Washing, feeding, walking.</td>
</tr>
<tr>
<td></td>
<td>Are you able to do things at your own speed? Do you feel rushed?</td>
</tr>
<tr>
<td></td>
<td>Is it easy to get around? Grab rails, ramps.</td>
</tr>
<tr>
<td></td>
<td>Can you get to the bathroom quickly?</td>
</tr>
<tr>
<td><strong>Spirituality</strong></td>
<td>Are there any religious services held here? Mass, service.</td>
</tr>
<tr>
<td></td>
<td>Does this meet your needs? Phrase in line with whatever wording the resident uses.</td>
</tr>
<tr>
<td><strong>General</strong></td>
<td>What do you like most about living here?</td>
</tr>
<tr>
<td></td>
<td>What do you like least about living here?</td>
</tr>
<tr>
<td></td>
<td>What would you like to change?</td>
</tr>
<tr>
<td></td>
<td>Are you happy here?</td>
</tr>
<tr>
<td></td>
<td>Is there anything else that I haven’t asked you that you think is important for your quality of life?</td>
</tr>
</tbody>
</table>

**Table 2: Resident Interview Schedule 2 (yes/no)**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Cue question/prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethos of care</strong></td>
<td>I’m interested in what your day is like here. Is every day the same?</td>
</tr>
<tr>
<td></td>
<td>Would you say that there is a routine here?</td>
</tr>
<tr>
<td></td>
<td>If yes: is it good to have a routine?</td>
</tr>
<tr>
<td></td>
<td>Are there things about the routine that annoy or bother you?</td>
</tr>
<tr>
<td><strong>Choice and control</strong></td>
<td>Do you have a choice about what you do every day? Examples: say the time you get up? What you eat? When you eat?</td>
</tr>
<tr>
<td></td>
<td>If no: would you like to have more choice?</td>
</tr>
<tr>
<td></td>
<td>Try to elicit what aspects of care the participant would like choice in: time s/he gets up, time s/he goes to bed, meals, timing of meals.</td>
</tr>
<tr>
<td><strong>Privacy</strong></td>
<td>Do you have a room of your own?</td>
</tr>
<tr>
<td></td>
<td>If no: do you mind sharing?</td>
</tr>
<tr>
<td></td>
<td>Do you have enough privacy?</td>
</tr>
<tr>
<td></td>
<td>If no: is there some place you can go to be private?</td>
</tr>
<tr>
<td>Domain</td>
<td>Cue question/prompts</td>
</tr>
<tr>
<td>------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Feeling cared for/feeling secure | Is it comfortable here? Noise, temperature, food.  
Do you feel cared for here?  
Do you feel safe here?  
Can you get help (nurse) quickly if you need it?  
Are you ever afraid?  
If yes, try to elicit what frightens him/her: getting sick and not being able to tell anyone, falling or slipping and not being able to get help, other residents e.g. residents with dementia.  
How staff treat him/her or others.  
Do staff treat you with respect?  
Are staff gentle, for example, when lifting you?  
Do staff protect your modesty? Examples: close the curtains, knock on the door before entering.  
Are staff friendly?  
Overall, are you satisfied with the care provided? |
| Sense of self           | Do you feel the staff know you well?  
Do staff know your likes and dislikes?  
Do staff respect your wishes? Examples: respect choices, respond to likes and dislikes.  
Are you able to/helped to do the things that are important to you? Examples: favourite TV programme, read newspapers etc.  
Do staff take time to listen to you?  
Do staff take time to chat to you?  
Have you opportunities to influence your care?  
Do you feel you can say no? When you say no does it count?  
Do you feel at home here? |
| Meaningful activity     | Do you take part in the social/recreational activities available here? Examples.  
If yes: do you enjoy them?  
Is it important to you to get outdoors?  
Do you get outdoors as much as you’d like? Examples: visits/trips, the garden.  
If yes: who takes you? Family, friend, staff, volunteers.  
Are there things you’d like to do that are not available to you here?  
Do you get bored? |
<table>
<thead>
<tr>
<th>Domain</th>
<th>Cue question/prompts</th>
</tr>
</thead>
</table>
| **Companionship**          | Have you made friends here?  
Do you enjoy the others (residents) company?  
Are you near your own home here?  
If yes: are some of the other (residents) neighbours or from your parish?  
Does that make it easier to make friends?  
Is it sometimes difficult living with some of the other residents?  
If yes: what makes it difficult? Try to elicit what makes it difficult possible: e.g. some are confused and they don’t make much senses or do odd things, some are aggressive and they frighten me, they don’t include me, they don’t talk to me. |
| **Relationships**          | Do you still have contact with your family and friends from home?  
Do you have visitors from home?                                                                                                                                                                                   |
| **Continuity with old life/community** | Is it important to you that you keep in touch with what’s happening at home?  
If yes: are you able to keep in touch with what’s happening in your old home (community) or (if more appropriate) current affairs in general?  
If yes, try to elicit how the person keeps in touch: my family/friends keep me up to date, the staff keep me up to date, I read the newspaper, I look at the news on the television, I listen to the news on the radio.  
If no, try to elicit what the cause is: would like to hear/see the news but doesn’t get a chance to, the staff are too busy to talk, doesn’t get to see family/friends very often, not able to read the newspaper. |
| **Independence**           | If appropriate: I’m interested in how the building affects your care.  
Is it easy to get around? (in your wheelchair, on your frame etc.)  
If no: what would make it easier? Examples: more ramps, more grab rails, a better wheelchair e.g. an electric wheelchair.  
Is it easy to take a bath/shower?  
Is it easy to use the toilet?                                                                                                                                                                      |
| **Spirituality**           | Are there religious services held here?  
Do you get an opportunity to attend?  
Does this meet your needs?                                                                                                                                                                                       |
<table>
<thead>
<tr>
<th>Domain</th>
<th>Cue question/prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>Has your life changed for the better since moving here?</td>
</tr>
<tr>
<td></td>
<td>Has your life changed for the worst since moving here?</td>
</tr>
<tr>
<td></td>
<td>Overall, are you satisfied with your care?</td>
</tr>
<tr>
<td></td>
<td>Overall, are you satisfied with the accommodation?</td>
</tr>
</tbody>
</table>
Appendix Four

Staff Interview Schedule

The interview guides were used flexibly. The researcher followed the lead of the staff member. Questions were not asked in the order listed below.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Cue questions</th>
</tr>
</thead>
</table>
| **Quality of life**             | What do you think is important for good quality of life for residents?  
How would you rate residents’ quality of life here? Why?  
What would make it better (if appropriate)? |
| **Ethos of care**               | What would you describe as the focus of care?  
How would you describe care, e.g. task-centred, individualised,  
person-centred, routinised?  
Is there an individualised plan of care for each patient?  
Can you provide the level of care that you would wish within current staffing levels? |
| **Choice and control**          | To what extent is it possible to give residents a choice with respect to their care?  
Do residents have opportunities to influence their care?  
Are their opinions sought, e.g. resident forum etc.?  
When they express an opinion about their care does it count?  
Could you give me an example? |
| **Privacy**                     | Do you think residents have enough privacy?                                                                                                                                                                 |
| **Feeling cared for/feeling secure** | What are the issues for you in providing quality of care for residents?  
Would you say that residents feel safe and secure here?  
In general, how would you describe the relationship between staff and residents? Examples. |
| **Sense of self**               | Do you think residents are treated as individuals here? Examples.  
Do you think it is homely here? Is that important for residents?  
What helps with that/what would help? |
| **Meaningful activity**         | What kinds of recreational activities are available for residents to take part in?  
Is there anything else you think should be made available? |
<table>
<thead>
<tr>
<th>Domain</th>
<th>Cue questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Companionship/relationship</td>
<td>How would you describe the relationships between residents? Are residents able to maintain contact with family and friends from home?</td>
</tr>
<tr>
<td>Continuity with old life/community</td>
<td>In general, are residents from the immediate area? Do people from the community, e.g. volunteers, come in to visit? How often? What do they do?</td>
</tr>
<tr>
<td></td>
<td>Do residents go out on visits/trips? How often? Where do they go? Who takes them? Are residents able to keep in touch with what’s happening in their community/the wider community? How?</td>
</tr>
<tr>
<td>Independence</td>
<td>Is there a focus on keeping residents as independent as possible? Are the support services to help with that available, e.g. physiotherapy, occupational therapy?</td>
</tr>
<tr>
<td></td>
<td>Have you access to the aids etc. that you need? What do you think of the building itself in terms of promoting older people’s independence?</td>
</tr>
<tr>
<td>Spirituality</td>
<td>Is it possible to meet clients’ spiritual needs?</td>
</tr>
<tr>
<td>Educational needs</td>
<td>Have you had an opportunity to attend a course/study day etc. recently? In the context of your work with older people, would you say your educational needs are met? What would you suggest or recommend?</td>
</tr>
<tr>
<td>General</td>
<td>Is there anything else I should have asked you? Or that you’d like to comment on?</td>
</tr>
</tbody>
</table>
Appendix Five
Relative Interview Schedule

This element explored the perspective of relatives or family members on quality of life generally for people in long-stay residential care.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Questions</th>
</tr>
</thead>
</table>
| **Transition to LTC: decision-making framework** | When it was evident that _____ needed a place in LTC, how easy or difficult was it for you to access a place?  
Were you directly involved in the decision of _____ to enter this facility? If yes: did you and _____ have enough support, information and time to make the right decision?  
To what extent was it possible to include _____ in the decision to enter LTC? |
| **Quality of care**                              | What do you think is good about the care given in this facility?  
Overall, what, in your view, is the most important factor determining the quality of care for residents in long-stay facilities?  
On a scale of 1 to 5, with 1 as ‘poor’ and 5 as ‘excellent’, how would you rate the care within this facility? |
| **Responsiveness to residents’ needs and wishes** | Knowing your relative and knowing what they enjoyed/what was important to them, to what extent has this facility been able to meet their needs/preferences? On a scale of 1 to 5, with 5 as ‘totally’ and 1 as not ‘at all’. |
| **Autonomy**                                     | To what extent are you consulted/included in decisions about _____ care?  
To what extent has _____ been able to be included in decisions about his/her care?  
Have you found that _____ has been able to make choices about their day to day care and activities? |
<table>
<thead>
<tr>
<th>Domain</th>
<th>Questions</th>
</tr>
</thead>
</table>
| Relationship to family/friends | Are your able to visit at any time you wish?  
Do you feel welcome by the staff when you visit?  
Would you describe the atmosphere as warm and friendly.  
Are small children welcome within the facility?  
Is it easy to for you to remain in contact with _____ in here?  
What, if anything, would make it easier for _____ to keep in contact with family and friends? |
| Quality of life               | Having seen _____ in residential care, have you any thoughts about quality of life for people in LTC? For example, some people have identified the following as important for quality of life in long-stay care. How would you rank these from 1 (the highest) to 6 (the lowest):  
- maintaining health and independence  
- maintaining own identity  
- being able to make own choices about things  
- being safe and secure  
- keeping a relationship with family and friends |
| Developments in care provision| Looking into the future and with the experience of having seen _____ in LTC, have you any views on the way in which care for older people needs to be developed to meet your needs in the future? |
| General                       | Is there anything else I should have asked you? Or that you’d like to comment on?                                                                                                                             |
Terms of Reference
Terms of Reference

The National Council on Ageing and Older People was established on 19th March 1997 in succession to the National Council for the Elderly (January 1990 to March 1997) and the National Council for the Aged (June 1981 to January 1990).

The functions of the Council are as follows:

1. To advise the Minister for Health on all aspects of ageing and the welfare of older people, either at its own initiative or at the request of the Minister and in particular on:
   a) measures to promote the health of older people;
   b) measures to promote the social inclusion of older people;
   c) the implementation of the recommendations contained in policy reports commissioned by the Minister for Health;
   d) methods of ensuring co-ordination between public bodies at national and local level in the planning and provision of services for older people;
   e) methods of encouraging greater partnership between statutory and voluntary bodies in providing services for older people;
   f) meeting the needs of the most vulnerable older people;
   g) means of encouraging positive attitudes to life after 65 years and the process of ageing;
   h) means of encouraging greater participation by older people;
   i) whatever action, based on research, is required to plan and develop services for older people.

2. To assist the development of national and regional policies and strategies designed to produce health gain and social gain for older people by:
   a) undertaking research on the lifestyle and the needs of older people in Ireland;
   b) identifying and promoting models of good practice in the care of older people and service delivery to them;
c) providing information and advice based on research findings to those involved in the development and/or implementation of policies and services pertaining to the health, well-being and autonomy of older people;
d) liaising with statutory, voluntary and professional bodies involved in the development and/or implementation of national and regional policies which have as their object health gain or social gain for older people.

3. To promote the health, welfare and autonomy of older people.

4. To promote a better understanding of ageing and older people in Ireland.

5. To liaise with international bodies which have functions similar to the functions of the Council.

The Council may also advise other Ministers, at their request, on aspects of ageing and the welfare of older people which are within the functions of the Council.
# Membership

**Chairperson** Cllr Éibhlín Byrne

<table>
<thead>
<tr>
<th>Mr Bernard Thompson</th>
<th>Ms Mary O’Neill</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr Eddie Wade</td>
<td>Cllr Jim Cousins</td>
</tr>
<tr>
<td>Mr Michael Dineen</td>
<td>Dr Ciaran Donegan</td>
</tr>
<tr>
<td>Fr Peter Finnerty</td>
<td>Mr James Flanagan</td>
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<tr>
<td>Mr Eamon Kane</td>
<td>Dr Michael Loftus</td>
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<tr>
<td>Mr Michael Murphy</td>
<td>Ms Mary Nally</td>
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<tr>
<td>Mr Pat O’Toole</td>
<td>Mr John Brady</td>
</tr>
<tr>
<td>Ms Pauline Clancy-Seymour</td>
<td>Ms Kit Carolan</td>
</tr>
<tr>
<td>Mr Noel Byrne</td>
<td>Mr John Grant</td>
</tr>
<tr>
<td>Dr Davida de la Harpe</td>
<td>Ms Sylvia Meehan</td>
</tr>
<tr>
<td>Dr Ruth Loane</td>
<td>Ms Martina Queally</td>
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<tr>
<td>Mr Paddy O’Brien</td>
<td>Mr Oliver R Cleary</td>
</tr>
<tr>
<td>Ms Eileen O’Dolan</td>
<td>Ms Annette Kelly</td>
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<tr>
<td>Mr Paul O’Donoghue</td>
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</tbody>
</table>

**Director** Bob Carroll
Improving Quality of Life for Older People in Long-Stay Settings in Ireland

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