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

Conference Proceedings
Foreword

As Chairperson of the National Council on Ageing and Older People (NCAOP), it gives me great pleasure to present the proceedings from the conference, *Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland*.

The conference took place on 8 May 2006 in the Tullamore Court Hotel, Tullamore, Co. Offaly. It attracted almost 250 delegates from across the statutory, voluntary and private sectors.

The report launched at the conference, *Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland*, is, I believe, a very important report. It reflects the views and aspirations of older people and their right to achieve their potential in the most holistic manner possible, wherever it is that they call home.

The message from this conference is that quality of care should not be the sole concern of policy-makers and practitioners. This discussion should broaden to include important matters relating to quality of life.

Whether in the community or in long-stay care, what is essential is that the rights and dignity of the individual are respected. I was struck by the fact that only 25 per cent of older people had discussed their preferences for long-term care. It is a decision that is often not made independently and for some people it is a decision made by circumstances. From the moment a decision is made, independence, dignity and respect are all in danger of being lost if quality of life is not given the same priority as quality of care.

I do not like the term ‘retirement homes’, the association with the word ‘retire’ implying a withdrawal. Long-stay care settings are not places to hide away – they should reach out and draw in the rest of the world.

Dr Bill Thomas, writing about the long-term care environment for older people, concluded that residents suffer from three plagues:

- **Loneliness** – a result of being uprooted from family, friends and even pets
- **Helplessness** caused by losing control of their lives – eating, sleeping and going to bed according to the schedule of an institution
- **Boredom** – the absence of meaningful occupation.

Care for older people is not just about healthcare, medicine or technology concluded Dr Thomas; it is about creating the right environment for caring relationships that sustain an older person in later years. Whether in the community or in long-stay care the issues remain the same.

Ageing is a natural and ongoing life experience; a gradual process that is unique for each of us.
George Bernard Shaw said that the only man who behaved sensibly was his tailor because he took his measurements every time he saw him while everybody else went on believing that the old measurements would do for life. Life is about constantly measuring and ensuring that the fit is right and perfectly adapted to the wearer, thereby ensuring the quality of that life. I hope that the report and the proceedings of this conference will contribute significantly to a worldwide discussion on the importance of improving the quality of life for older people.

I would like to thank Minister Sean Power TD, for his Opening Address, Dr Kathy Murphy, NUI Galway, for her presentation of the study findings and Bob Carroll, Director, NCAOP, for presenting the Council’s comments and recommendations. Thanks are also due to Eithne Ní Domhnnaill, Dr Robyn Stone and Dr Suzanne Cahill for their papers on staff support and the quality of life of older people in long-stay care.

I would like to thank the chairpersons of each of the sessions, the speakers in the parallel exchanges, panel members and conference delegates for their valuable contribution to the conference discussions.

On behalf of the Council I would like to thank the conference rapporteur and report editor, Ms Yvonne McGivern, for summing up the work done in the parallel group sessions and preparing the conference proceedings. A special thanks is due to the Council’s staff for their invaluable assistance in organising and running the conference. Finally, thanks to Helen Bradley who prepared the proceedings for publication and to West Cork Arts Centre for providing the cover image.

Cllr Éibhlin Byrne
Chairperson
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Introduction
Introduction

The structure of these proceedings follows the format of the conference:

- **Opening Session: NCAOP Study Findings on Quality of Life for Older People in Long-Stay Care Settings in Ireland**
  
  Three papers were presented in this session:
  
  - Opening Address
  - Study Findings
  - Comments and Recommendations Arising from the Study Findings.

- **Second Session: Parallel Group Exchanges**
  
  A discussion followed the papers in each of the four parallel group sessions:
  
  - Group 1: Initiatives in private nursing homes
  - Group 2: Initiatives in public long-stay facilities
  - Group 3: Initiatives in dementia services
  - Group 4: Structured approaches to the promotion of quality of life in long-stay care.

- **Third Session: Exploring the Relationship Between Staff Support and the Quality of Life of Older People in Long-Stay Care**
  
  Three papers were presented in this session:
  
  - Valuing Staff in Long-Stay Facilities for Older People
  - International Long-Term Care Workforce Issues
  - Workforce Support and Development: Priorities in Long-Stay Dementia Care Settings in Ireland.

- **Final Session: Lessons of the Day for Future Legislation, Regulation, Inspection, Accreditation, Standard Setting and Quality of Life Improvement Measures**
  
  In this session the closing contributions of each of the six panel members were given.
Opening Session

NCAOP Study Findings on Quality of Life for Older People in Long-Stay Care Settings in Ireland

Chair: Cllr Íéibhlin Byrne
Opening Address

Sean Power TD
Minister of State, Department of Health and Children

Introduction

I am delighted to give the Opening Address at this conference, the theme of which is most topical in today’s political and social climate.

Older people are no different from any other age group; we all need a sense of control over our lives and a means to participate in society in a meaningful way. It is right that older people should seek to be empowered and to influence decision-making in the areas that affect them. This is particularly important when it comes to decisions about their care, present and future, whether at home, in a long-stay care unit or a nursing home. It is not just a question of care; older people, including those who are vulnerable and in need of care, must be able to participate to the maximum extent possible in all aspects of life that contribute to their well-being.

My priority as Minister of State with responsibility for Services for Older People is to ensure that the issues facing older people are addressed with a view to providing improved services befitting an older population.

Policy

We know that most of our older population are healthy and living actively and independently. There are, however, those who will require some degree of intervention to maintain their independence and dignity. I am glad to say that the cornerstone of policy in relation to the care of older people is care in the community. The overall aim of care in the community is to support older people to live in dignity in their own communities for as long as possible by helping them to stay in their own homes. Research has shown this is what older people want; they are much happier living in their own homes amongst family and friends. We also know that they recover more quickly from illness in this environment.
Funding

We, as a government, are committed to the development of a comprehensive health service that is capable of responding quickly, fully and effectively to the needs of older people. In the budget of December 2005, we received additional funding amounting to €150 million for services for older people. This provides for a number of initiatives including home care packages (by the end of 2006 we will have increased the number of home care packages from 1,100 to 3,000). These packages, in many cases, mean that a person is able to stay at home rather than having to go into hospital, or that a person can leave hospital earlier than might normally be the case. Home help, day respite centres and further development of the nursing home subvention scheme are among other areas that we will target with the additional funding.

I would be the first to say that services for older people were under-funded in the past and, while I was delighted with the extra €150 million, we must ensure that that investment is the start of continued investment in services for older people.

Regulation

It is the intention of the Department of Health and Children (DoHC) to put in place a more robust regulatory system as quickly as possible to protect vulnerable, older people and to provide for the highest possible standards of care for older people in long-stay facilities.

It is intended that the Health Bill 2006 will establish both the Health Information and Quality Authority (HIQA) and the Social Services Inspectorate (SSI) on a statutory basis. It will contain provision to underpin a more robust inspectorial system. The Health Service Executive (HSE) currently carries out inspections in private nursing homes under the Nursing Homes Regulations, 1993. In the context of the Health Bill 2006, the process is going to be reviewed with a view to strengthening the powers available to those involved in inspecting facilities and to extending the inspection system to public facilities.

It is also intended that the Bill will provide for the setting and monitoring of standards for residential facilities for older people. To this end the DoHC has begun the review of the Nursing Homes (Care and Welfare) Regulations, 1993. It is working in conjunction with the HSE, the SSI and other relevant bodies to develop a new set of standards that would apply to all residential services for older people. Up to now we have not been applying the standards we have set and required of the private sector to public sector institutions. This will change.
The DoHC has set up a working group to develop standards for residential care settings for older people which will consult with appropriate and interested parties. The group is chaired by the DoHC and members include representatives of the Department, the HSE, the SSI and the Irish Health Services Accreditation Board (IHSAB). We have begun a wide-ranging public consultation process on the legislative proposals in the draft general scheme prior to finalising the legislation.

Conclusion

We are aiming to ensure that we are in a position to provide the best quality of care in the best possible environment. We must bring about a situation in Ireland that when someone goes into long-stay care the person and their family can feel confident, knowing that they will receive the best possible care and that the people looking after them will have received the best possible training. No matter how long they are in long-stay care it must be a positive experience, not something to fear or worry about.

We have a huge job to do and it is our intention to work with other organisations to bring about the change needed. The older population of Ireland has made an invaluable contribution to all aspects of Irish life. We acknowledge this. We are committed to improving all aspects of the lives of older people by focusing not only on health but on quality of accommodation, security, welfare and all other issues which affect older people. These improvements will only be achieved through partnership between government, service providers (both public and private), voluntary organisations and older people.

I would like to thank Cllr Byrne and the rest of the NCAOP’s Committee for inviting me to deliver this Opening Address. I wish you every success with your deliberations.
Introduction

The aim of the study was to explore the quality of life of older people living in long-stay care from a number of perspectives. More specifically, our objectives were to:

- undertake a survey of long-stay institutions in relation to facilities, staffing levels, types of accommodation, involvement of the community and types of care offered
- identify resident:staff ratios in public, private and voluntary sectors
- explore residents’ experiences of residential care
- explore residents’ perspectives of quality of life and resident/staff relationships within long-term care settings
- explore staff perspectives of quality of life within long-term care settings; adequacy of resident:staff ratios; continuing professional development requirements; and staff/resident relationships
- compare the findings from the 1986 study (O’Connor and Thompstone) to current study findings
- examine any differences between sectors – public, private and voluntary.

The purpose of this paper is to present an overview of the study findings. Before setting out the findings we first look at what we mean by quality of life and then present a summary of how the research was conducted.

Quality of Life

Quality of life has become a popular term. Its usage is widespread, covering almost all facets of daily living. It is especially relevant for residents in long-term care facilities. But what exactly do we mean by ‘quality of life’? It is an apparently simple expression for what is a complex, multidimensional concept. There is much debate over what elements it should include. There are several areas of agreement, however. It is clear that it cannot be explained in medical terms alone; it only makes sense if considered in a holistic context. It contains both subjective and objective elements.
There is 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.

Research Approach

We used a mixed method approach with three methods of data collection: qualitative focus groups (or group discussions) with managers; a quantitative survey of long-stay facilities; and qualitative interviews with residents, relatives and staff.

The Focus Groups

We first conducted a series of focus groups with managers/proprietors of long-stay facilities and analysed the findings from these groups. We used these findings to develop the survey questions and to give us, alongside the literature review, contextual information on factors that influence residents’ quality of life and care provision in general.

We held seven focus groups with managers/proprietors. Participants were chosen purposively to ensure that we had 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 by geographical setting. In total, 67 managers took part in focus groups in Donegal, Dublin, Cork and Galway.

The Survey

The aim of the quantitative survey of long-stay facilities was to provide an insight into the likely impact of physical, environmental and staffing issues on older people’s quality of life. The survey 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). Questionnaires were sent to all 556 long-stay facilities in Ireland. A total of 332 replied – a response rate of 62 per cent. The response rate varied by facility type; the highest rate was achieved in welfare homes (95 per cent) and the lowest in private nursing homes (56 per cent).

Qualitative Interviews

The aim of the qualitative interviews was to gather information on resident and staff perceptions of quality of life in long-stay care. We interviewed residents, staff and relatives in 12 long-stay care homes. This qualitative approach allowed us to interview a large number of people in the same home over a period of a few days.
We completed interviews with 101 residents – men and women. 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. We completed 48 interviews with staff – four within each home in the sample. 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 (a total of 13) were conducted by phone.

The Findings

Focus Group Findings

The findings from the 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.

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 was a significant amount of activities going on for residents in both public and private long-stay facilities, although 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 domains of quality of life:

- care environment and ethos of care
- personal identity
- connectedness to family and community
- 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 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 and this had a positive impact 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 issue. 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, no private space to receive visitors 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 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 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 is 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 residents more choice will help to develop their 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; attention has, instead, been focused 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. 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.

**Recommendations**

We recommend the following ten actions:

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 of 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.
Comments and Recommendations Arising from the Study Findings

Bob Carroll
Director, National Council on Ageing and Older People

Enhancing the Quality of Life of Older People – A Key Long-Stay Services Policy Objective

The quality of life of older people in all care settings is a primary concern of the NCAOP. It is a concern echoed by the National Economic and Social Forum (NESF) in its recent report, Care for Older People, in which it states that ‘enhancing quality of life of older people in different settings should be a key policy priority’ (NESF, 2005).

The NCAOP 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 local, regional and national level, assert that a core objective of these services is the promotion of quality of life and rehabilitation.

Quality of Life Domains

The research highlighted four 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

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, in so far 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’ (Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland, 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

The research also 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 with 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.

Staff

People’s personalities and personal resources determine greatly how they adjust to their circumstances and, therefore, the quality of life that they enjoy. The measure of control they have over their circumstances is also critical. This is equally true for older people in long-stay care, which is why maximising autonomy and independence remains so important to them.

The measure of independence and autonomy enjoyed by residents, however, together with the realisation of the other determinants of quality of life discussed above, may ultimately be in the hands of residential care staff. Staff are the key to the quality of life enjoyed by residents in any facility. Much more public attention needs to be paid to this truth: without adequate, appropriately selected and trained staff, the quality of life of older people in long-stay care cannot be maximised.
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 (RN) 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. 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.

Valuing and Promoting a Positive Image of Those Who Work in Long-Stay Facilities for Older People

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 it believes that the rehabilitation and quality of life development potential of the work should be promoted, fostered, encouraged and rewarded.

Furthermore, the findings from the focus groups showed 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 and retain nurses to this specialism.

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. The study found, however, 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.
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).

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 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.

The Council also advises that careful consideration be paid to the location of facilities, particularly new ones, and recommends that the 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.

*Older people may prefer the best health and safety outcomes possible that are consistent with meaningful quality of life rather than the best quality of life that is consistent with health and safety.*

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. While it is conscious that many excellent person-centred long-stay care services for older people exist, it is equally mindful that limited and substandard services also exist, as attested in the report of the Working Group on Elder Abuse.

The Council accepts that the cultural shift necessary to translate age friendly values into action in all long-stay care settings is by no means insignificant. It believes that such a shift requires the sustained provision of dedicated assistance, guidance, encouragement and support to long-stay care staff. The value of their work to individual older people, and for our society, needs to be constantly adverted to and affirmed.

The cultural shift cannot be achieved by and within long-stay facilities on their own, particularly in an ageist climate, or one of disinterest or unconcern about those in long-stay residential care. It is not helped by those who wish to see no evil or hear no evil, or by those who see and hear only evil about residential care. Nor is it helped by those who see older people in residential care only in terms of increasing numbers and increasing costs. It is not helped either by those who see long-stay care only in terms of tax incentives or maximising profits, or who think only in terms of reducing overheads and achieving economies of scale at the expense of the quality of life of residents.

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 lifecourse and included in this is the provision of age friendly long-stay care services. A new vision for long-stay care will challenge stereotypical assumptions about old age in long-stay care and prioritise quality of life and rehabilitation objectives.

**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 needed 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 will, therefore, endeavour to support the development of education and training for age friendly long-stay care services in partnership with other agencies. It 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.

Postscript

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 (INHPH). Ann O’Riordan gives an outline of HAIRC in her paper later in these proceedings. It is critical to note that experience from HAIRC to date highlights the need for support and training.

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.
Introduction

Our mission statement at Marymount, a private nursing home, is:

… to achieve and sustain quality care in a secure and homely environment. We respect the dignity and individuality of human life in all its stages, remembering … [that] to nurse is to nourish.

We set out to do this in several ways:

- by seeing the whole person
- by creating the right environment
- by helping our residents to stay active
- by helping our residents to maintain their independence
- by encouraging intergenerational sharing.

Seeing the Whole Person

We encourage residents and their families on admission to give us a detailed account of the resident’s life events. This includes family names, where he or she lived, where family members live, the person’s hobbies and interests, their likes and dislikes, and so on. This enables us to see a broad picture of the whole person, not only the person’s disability or health crisis.
Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland

Creating the Right Environment: Involving the Residents

We aim to keep the atmosphere and environment at Marymount as non-clinical as possible whilst providing good nursing and social care. Our residents are encouraged to become involved in the day-to-day activities of the home. Kathleen, for example, looks after the altar clothes and preparation for Mass, Ger displays an art exhibition at regular intervals, Agnes reads the newspaper headlines to friends and discussions ensue and others make tea or coffee for themselves whenever they like in our coffee room. Residents are also involved in baking and gardening – growing tomatoes and herbs in the greenhouse, growing and harvesting blackcurrants from the garden and fruit from our orchard (and using it to make jam). We also have music sessions with singing and piano playing. Indeed, the variety of activities that residents are involved in is increasing as a result of having a multicultural team.

Residents also take part in activities (writing their life stories, playing cards, reading) organised by voluntary groups including Age Action.

Helping to Maintain Independence

We have our own shuttle bus service which takes people to the local garden centre, shopping centre and coffee shop as well as to hospital appointments.

Intergenerational Sharing

We encourage and support students from local second level schools on social work experience programmes. We find the intergenerational sharing that happens as a result very worthwhile – it is amazing how young at heart our residents can be. Young children and babies are always welcome at Marymount.

Other Initiatives: Essence of Care

We are in the process of developing Essence of Care (see Margaret Buckley’s paper in these proceedings) in Marymount. The first project will focus on privacy and dignity. We have a steering group comprised of residents, families and staff.
We feel that quality of life in Marymount is enhanced by our welcoming attitude and openness to all who live, work and visit us. We treat and respect everyone as equals. We promote an approach to safety that takes account of the fact that we all need to take risks from time to time. We believe that keeping a balance is important. In the years ahead we hope that we will always remain true to our mission statement that ‘to nurse is to nourish’.
How we do it at Montenotte Care Centre

Geraldine Keohane
Director of Nursing, Montenotte Care Centre

Introduction

The aim of this short paper is to tell you about the experience of Montenotte Care Centre on the pilot programme for the Quality of Care Standard for Nursing Homes.

Staff and Facilities

Montenotte Care Centre has a total of 111 residents and 102 staff. Eighty staff members are involved directly in the care of our residents and 22 work in support services – administration, the canteen, the laundry and housekeeping. We also have a dedicated pastoral care team.

We have 56 private en suite rooms and 29 semiprivate en suite rooms (all of which have telephones and televisions). We have a dedicated reception and administration office, an oratory, private gardens, a sensory room, electric Parker baths, a hairdressing salon, smoking and non-smoking day rooms, kitchenettes, dining rooms and a visitors’ canteen. The centre is monitored by CCTV and security systems.

Quality of Care Standard Initiative

The Quality of Care Standard for Nursing Homes is a comprehensive approach to assessing nursing homes. The initiative was developed by Excellence Ireland Quality Association (EIQA) in collaboration with the Irish Nursing Homes Organisation (INHO) and the Irish Society for Quality and Safety in Healthcare (ISQSH). It uses a holistic organisation assessment that covers all aspects of the nursing home business and a quality framework to provide an integrated approach to measuring service levels. It also checks compliance with all legal and regulatory requirements.

1 Following a pilot phase, the programme was launched on 25 May 2006 by An Tánaiste, Mary Harney TD. Nursing homes which successfully complete the programme will be certified with the new standard.
We were involved in the pilot programme of the Quality of Care Standard for Nursing Homes initiative. We found it challenging but believe that it raises the standards and profile of the care centre. We would encourage nursing homes that aim to raise the standard of service they provide to residents to apply for the Quality of Care Standard for Nursing Homes.

Person-Centred Approach

Taking a person-centred approach is key. When a patient is admitted we get a description that focuses on their disability and tells us nothing about them as a person. It is important that we move away from this sort of description and get to know the whole person. Here are two contrasting descriptions of a fictional patient that illustrate the difference:

Hannah, from her admission notes – 88-year-old woman transferred from hospital X for rehabilitation following a fractured neck of femur. Reluctant to do things for herself so needs a ‘bit of encouragement’. Main problems – not eating very much, incontinent, needs help with walking.

Hannah, from her obituary – Maguire, Hannah, died peacefully in her sleep on Sunday morning, 17 May at Frostfields, Skibbereen, in her 88th year. Beloved sister, aunt, great aunt, friend, colleague. Doctor of Philosophy, economist, athlete, colonel, teacher, pioneer, giver, friend. Christ’s faithful soldier and servant to her life’s end.

McCormack (2001 and 2004) writes about person-centred practice as ‘humanistic caring’. He notes that this involves the following:

- deep respect for the autonomy of the patient as a person
- acceptance of the person’s way of life
- transformation of experience through therapeutic relationships
- healing of the body and a restoration of individual self-worth
- consistency of care (more important than continuity of care)
- acknowledgment of individual biography and working with narrative identity.

Conclusion

We have found that when people who are not used to speaking are heard by people who are not used to listening, real change occurs.


*Ageing and Society*, 21.


Discussion

Rapporteur
John Heuston

Participants agreed that the layout or environment and the activities of residents in long-stay facilities should not be overly constrained or dominated by health and safety regulations. It was noted that the duty of care that managers have to residents supersedes the demands of health and safety regulations. It was agreed, however, that management and staff should ensure that all procedures are documented and that the necessary insurance cover is in place.

It was noted that management and staff must feel free at all times to speak up for residents. It was agreed that a culture change is needed, with a move away from a blame culture.

Participants agreed that long-stay care managers should put in place a holistic approach to care, moving away from the medical model of care.

It was pointed out that since the 1990s there has been greater growth in the provision of private long-stay care than there has been in provision of public places. There was a feeling that ensuring that a private long-stay care facility was profitable may affect, in some cases, the quality of care provided. In addition, some participants felt that the choice of a long-stay care place was becoming limited.

Paying for long-stay care was raised as a key issue – paying for care as an individual and the related issue of subvention, and funding of long-stay care by the state.

Some participants mentioned the need to establish an insurance-based system of funding care. Participants agreed that the state must guarantee support for long-stay care and that it must ensure that a choice of long-stay options is available. It was agreed that the question of how to finance long-stay care is a critical one and one that must be raised during the political campaign leading to the next general election.

Participants agreed that a ‘tool’ is urgently needed that would allow long-stay care managers and others to work out what constitutes an adequate staffing level. Participants also agreed that help was needed to determine what is the optimal skills mix in a long-stay facility. It was felt that these tools should be developed from the bottom up (via those working in long-term care), rather than being imposed from the top down via the HSE. It was also noted that the many demands on key members of staff, including nurses, must be taken into account in putting in place and developing a team with the optimal mix of skills.

Given the demands on nurses’ time, it makes their work more manageable if they can have all residents in a day room – a common feature of life in long-stay care. It was agreed, however, that this should be balanced by the wishes of the residents. While all agreed that there is a need to offer privacy to residents and that the need for privacy is to be respected, it was also noted that this should be done in such a way as not to isolate people from their fellow residents.

Participants agreed that there is a pressing need for greater access to community-based services, particularly community home care packages.
The group Chair summarised the key messages from the discussion as:

1. The need to change several aspects of the culture of long-stay care in Ireland.
2. The need to achieve clarity about payment for long-stay care.
3. The need to get the right skills mix within long-stay care facilities.
Group 2: Initiatives in Public Long-Stay Facilities

Chair: Julie Ling

St Mary’s Hospital, Dublin

Breda Hayes
Director of Nursing

Introduction

To improve quality of life of our residents at St Mary’s Hospital we looked at five things:

- advocacy
- care planning
- nutrition
- environment
- residents’ satisfaction.

Advocacy

Working with Age Action Ireland we set up an advocacy project. It was a success and as a result we set up residents’ councils to continue the work.

Care Planning

We devised an ‘Individualised Care Planning’ project and put together ‘care pairs’ – a registered nurse and a care assistant – to share the care of one resident on a fifty:fifty basis. We found through a survey that this approach was a success.
**Nutrition**

We set up a project to examine nutrition and food issues. The aim was to improve the nutritional value of the food we give our residents and to increase the range of food available to them.

**Environment**

We set out to improve the physical environment of the hospital. We found this to be the most challenging issue. We were constrained by the lack of space and by limitations on our ability to reorganise this space. We have made some improvements and have plans for a major expansion project starting in 2007.

**Satisfaction**

To give our residents a sense of empowerment we consulted with them to find out how satisfied they were with different aspects of their care and to identify ways in which we could improve the care we give. As a result of the consultation we have made several changes: staff, for example, now wear name badges and we have set up a gardening club and residents sell the plants they grow to the public. Residents also told us that spirituality was a particularly important contributor to their quality of life.
Hazelwood Unit, St John’s Community Hospital, Sligo

Mary Kilfeather and Jacinta Gallagher

Introduction

The aim of this short paper is to look at two initiatives we have implemented which we believe have helped to foster good quality of life among older people in our hospital unit: the CHOICE approach; and the Practice Development approach.

The Hazelwood Unit

St John’s Community Hospital, Sligo, has 95 beds and is made up of a rehabilitation unit, a day hospital and four extended care units. One of these extended care units is the Hazelwood Unit. The unit has 35 beds and offers a range of services tailored to the individual needs of its male residents. These include the following:

- assessment
- convalescence
- respite
- palliative care
- extended care
- occupational therapy and physiotherapy.

Clients come from Sligo General Hospital for convalescence, respite or extended care as well as via GP and day hospital referral for assessment and respite care.

The CHOICE Approach

In 2000 the North Western Health Board, as it was then, examined how it delivered services to the older person in the community. A survey of 113 older people in the Sligo/Leitrim area found that 97 per cent of them wanted to stay at home. As a result the CHOICE programme was developed.
The CHOICE approach to care is based on respecting the wishes and choices of the older person and responding to their lifetime opportunities and needs. It is about:

- listening to the older person
- promoting a sense of independence
- putting older people first
- making older people matter.

Use of the CHOICE approach started in the community and has now been extended to all units within our hospital. Each unit has a CHOICE ‘link person’.

As a result of the CHOICE programme, together with Home Support and Discharge Planning, we have found that the type of person admitted to our unit has changed; we get fewer people admitted for extended care and more for a combination of assessment, convalescence, respite and palliative care. The age profile is also now much higher than it was in the past.

**Practice Development**

We have always endeavoured to achieve a person-centred approach. We aimed to do this by listening to the needs of residents and carers in the unit. We found, however, that there were no criteria for measuring these needs. We were not aware of this until we became involved in Practice Development.

A Practice Development Unit (PDU) is a clinical area accredited by a university as a centre of excellence. It has the following characteristics: it aims to deliver person-centred care; it is committed to the development of individuals and teams as well as advancing practice; it combines the activities and theories of quality improvement, evidence-based practice, workplace creativity and innovation; it is an ongoing process rather than a project and only succeeds when all staff engage in the process.

The PDU process has two stages and takes about two years to set up. The university accrediting the process sets out 15 criteria against which we are measured. The first step in the process is to determine the needs of residents, families and staff. To do this we held focus groups, conducted a survey and held one-to-one meetings. From these we identified key areas which needed to be addressed. Issues that were addressed included:

- changing the name of the ward
- creating a more homely environment
- creating better working conditions
- renovating and refurbishing the unit
- creating extra dining and sitting room areas
increasing and upgrading office space
enlarging and upgrading the treatment room
running more structured social activities.

We introduced two exercise groups: a falls prevention programme for mobile residents; and a social activity for chair-based residents. We also set up a reminiscence group which helped enhance residents’ self esteem and sense of identity.

We encourage residents and families to become more involved with the unit. To do this we published an information booklet and newsletter; invited them to our launch day and held an open night. We also held quality of life and choice initiatives meetings with residents and families. At the end of their stay with us we asked people to fill in a questionnaire.

We found that it is important to maintain the motivation and commitment of staff. To achieve this we set up a group comprised of staff from all grades who work directly with residents. We now hold more frequent ward meetings.

In terms of evidence-based practice, we researched and introduced a ‘change’ framework to develop best practice. This allows change to be thought through before it is implemented.

We have started to use the Essence of Care benchmark tool (see Margaret Buckley’s paper for more detail) for continence and for food and nutrition.

Conclusion

We have found that both the CHOICE and Practice Development approaches foster good quality of life among the older people who are admitted to our unit.
Discussion

Rapporteur: Liza Costello

Participants discussed the challenges faced by long-stay care facilities housed in old buildings. They noted that these buildings are not suitable for long-stay care. Some expressed concern that the buildings, the environment in which the residents live and the staff work, limit the effect of quality of life improvement initiatives. One participant gave as an example a facility that has no day or dining area. It was noted that funding sources for renovation were very limited. Sheltered housing was noted as a way of providing residential care in a homely setting.

Participants identified personal autonomy as a significant factor in achieving quality of life and noted that current health and safety regulations for long-stay care settings often work against this with residents being barred from kitchens. For this reason participants noted that it was important for representatives from residential care homes to become involved in the development of regulations. It was felt that there is a need to strike a balance between providing a homely environment and meeting health and safety standards.

It was noted that few long-stay care facilities are currently involved in any quality of life initiatives. It was agreed that there is a need to raise the level of awareness of ongoing initiatives such as the HAIRC Ten Steps initiative. Participants pointed out that the lack of awareness and of information (and the lack of information sharing) has meant that there is no infrastructure or framework for setting up and running initiatives and no mechanism for integrating services.

Participants noted the division that exists between private and public sectors (and the voluntary sector) in discussing long-stay care. They argued that this division should be removed and that all sectors should work together to achieve quality of life for residents.

Key Messages

The group Chair summarised the key messages from the discussion as follows:

- Regulation and its effects – the difficulty in providing a 'home from home' within current health and safety regulations.
- Buildings – the difficulty of improving care and quality of life of residents within the limiting constraints of old, unsuitable buildings and the lack of funding available for renovation.
- Awareness, evaluation, coordination and integration of initiatives – the need to increase awareness of initiatives currently in place; to evaluate them and to build an evidence base for best practice; and to coordinate and integrate best practice into the fabric of long-stay care.
Sonas is a therapeutic communication activity for older people. It focuses on sensory stimulation in the belief that the senses are the gateways to communication. Specifically, it is for older people whose communication is impaired as a result of, for example, dementia, Alzheimer's Disease or intellectual disability. These people are often isolated and marginalised; because their verbal communication can be limited it is often assumed they have nothing to say.

In a residential care setting where staff are busy and preoccupied and where the priority is on meeting the physical needs of residents, those whose behaviour is regarded as difficult or uncooperative are fighting a losing battle. Our aim is to enhance the quality of life of this most vulnerable group.

In our training we emphasise the importance of non-verbal communication. The nurses, care assistants, speech and language therapists and family carers who attend our workshops leave with an appreciation of the many ways in which people can communicate. We give them tools and skills and urge them to use Sonas to reach out to their clients and enhance their quality of life.

The approach was developed in 1991 by Sr Mary Threadgold, a speech and language therapist and Sister of Charity who set up Sonas aPc to deliver her training. To date we have held several hundred workshops in Ireland and the UK. Research supports the large amount of anecdotal evidence of the benefits of Sonas. We receive annual funding from the DoHC in Ireland, which enables us to subsidise the cost of workshop attendance. The Department’s policy, as articulated in NCAOP’s An Action Plan for Dementia, has recommended that Sonas be implemented in nursing homes.

As an organisation, Sonas aPc aims to:

- activate the potential for communication (the aPc in our title) that the individual has retained
- encourage and promote a communicative environment
- have activation of a person’s potential for communication recognised as essential in planning his or her care.
Essential Features of the Sonas Approach

Sonas is delivered through group and individual sessions. These are recorded on CD or cassette to enable those carrying out the sessions to completely focus on participants. The group sessions provide cognitive, sensory and social stimulation involving gentle exercise, massage, relaxing music, singalongs, memory-focused exercises and personal contributions by participants. The individual one-to-one sessions are based on music and touch. The essential features of the approach are:

- multisensory stimulation
- a focus on communication
- use of structure and repetition
- a focus on abilities.

All five senses (sight, hearing, taste, touch and smell) are incorporated into the group sessions to increase the participants’ opportunities to communicate through all their sensory channels. Exercises encourage participants to become more alert and, as a result, more inclined to communicate.

The defined structure of the session and its repetition over time brings familiarity and creates a secure environment in which people feel more confident and relaxed. There is an emphasis on the participants’ abilities rather than their disabilities. They are encouraged to take part but only in so far as they are able and if they want to do so. We have found that some decide to be observers only. It is important that no one feels under pressure to perform or take part in something that they would prefer to avoid or is beyond their level of ability. For this reason it is important that the group leader and helper know the participants.

Our ethical framework states that Sonas sessions are never imposed on anyone. The option to participate rests with the person and this choice is always respected. When touch is used the privacy of the individual is never invaded.

Other Work: Spiritual Care and Ciúnas

In addition to our Sonas programmes, we have recorded a selection of hymns and prayers, called Ciúnas, which can be used as an aid to prayer. Traditional prayers are meaningful to many older people and it is often a loss to them when, because of failing memory or concentration, they find it difficult to pray independently. We are also developing knowledge, expertise and a network of contacts in the broader area of spiritual care of older people, an area that is now gaining increasing recognition.
Brú Chaoimhin Advocacy Group: The Unifying Voice of Residents With and Without Dementia

Sarah Marsh
Senior Social Worker, Brú Chaoimhin Nursing Home

Introduction

The aim of this short paper is to explain why we ran an advocacy programme for people with dementia and to share what we learned in running it. The programme was evaluated by an independent researcher and the findings presented to the HSE.

Why Did We Do It?

There were several reasons why we ran this programme:
- we see all the residents of Brú Chaoimhin as belonging to the Brú Chaoimhin community
- we believed that advocacy could help us enhance the sense of inclusion and belonging within this community
- we wanted to build the confidence of our residents, increase their independence and ‘enable’ them or give them a sense of empowerment
- we wanted to challenge ageism and discrimination and the myth that dementia is a death that leaves the body behind
- we wanted to find out if people with dementia could contribute to and benefit from being involved in advocacy groups
- we believed that advocacy would help us evaluate the service we provide and so help us improve practice development and inform staff
- we wanted to move away from a ‘caring for carers’ approach.

How Did We Do It?

We recruited residents to take part in the advocacy groups in two ways: we asked all staff to refer residents to us; and we put up posters inviting people to attend. We then gathered residents together in small groups of no more than ten people. We aimed to get a balance of personality
types to ensure that they could work together as a group. (We found, however, that it is also important to take up individual cases as needed since not everyone wants to talk in a group). Carers were not involved in the groups – the aim was to find out the needs of residents.

We found that it is important to get the environment right – an accessible room with no unwanted stimuli, of the right temperature and with the right seating. To run a group effectively the group facilitator must have both a sound knowledge of dementia and of the principles and practice of advocacy. We found that getting the group running effectively is a slow process. In order to communicate and understand meaning, the advocate/facilitator must get to know each person and trust needs to be built. Explanations need to be clear, short and repeated as necessary. We found cue cards, written information (for example on flip charts) and body language to be very useful. We also found it necessary to go over the same issues many times. We found that there were days when residents did not have any particular issues but this did not mean that they did not have something to say.

What We Learned

We found that group advocacy is possible for people with dementia. Residents helped themselves and the group was largely self-directing. Without prompting, for example, one group member made notes during each session to support her memory and to enable her to bring ideas to the next meeting. We found that group members created a supportive environment – one of mutual respect, goodwill, interest and consensus.

There were benefits to all: to the group members, to other residents, to the facilitator and to Brú Chaoimhín. Residents got much of what they requested and the cost of delivering what was requested was minimal. There were also challenges. We found that our approach did not suit everyone; one size does not fit all. We needed to adapt the techniques we used to suit the group and take account of and work with the group dynamics.

Recommendations

We recommend that you try it but be prepared that it may not be a success. From our experience we recommend a combination of peer and professional advocacy. Those facilitating advocacy groups with people with dementia must have sound knowledge of dementia and a clear understanding of advocacy and the theory that underpins it. We would also recommend that further work be done to develop advocacy models for people with dementia.
Discussion

Rapporteur: Sinead Quill

Participants agreed that there is a real need to consult with older people in order to find out what it is they want and need. Without asking them, we can often make the wrong assumptions about their preferences. Participants agreed that one of the aims of any consultation is to break stereotypes and eliminate the habit of making assumptions about older people.

It was noted that enabling people with dementia to speak for themselves allowed them a measure of choice in long-stay care. Participants acknowledged the importance of taking into account the non-verbal behaviour of those with communication difficulties in order to ascertain what the person is communicating.

Participants agreed that it is crucial to disseminate the deliberations of the advocacy group and to encourage residents to do this themselves. An independent researcher, Ms Emer Begley, evaluated the Brú Chaoimhin advocacy project on behalf of the HSE. The evaluation showed that the cost of delivering what residents requested was minimal.

Participants agreed that training of staff is important; the need to have an understanding of advocacy and dementia in advance of setting up an advocacy group for people with dementia was emphasised. Participants agreed that it is important to have the right ratio of staff to residents in order to be able to set up and run an advocacy group. It was noted that while there is a shortage of social workers working with older people, public facilities are more likely than private ones to be able to avail of their services. As a result opportunities to set up advocacy programmes in private facilities may be limited.

Participants agreed that the focus of nursing home inspections should shift from ‘bricks and mortar’ issues to quality of life. It was suggested that providing activities for residents in long-stay facilities should be compulsory and included in regulations. It was noted that due to constraints on resources it is difficult to provide residents with choices and the focus tends to be on getting the work done. It was observed that in private nursing homes, where the individual or the family is paying for services, a greater amount of choice is expected. Participants identified a need to clarify which therapies residents in private nursing homes are entitled to receive.
The Chair summarised the key messages from the discussion as follows:

- The person should always be placed at the centre of the care process.
- In order to attend to quality of life issues for people with dementia there is a need for:
  - adequate staffing
  - the training and education of staff
  - an understanding of difficult or challenging behaviour and non-verbal communication
  - standards that cover more than just ‘bricks and mortar’ issues
  - provision of a homely environment
  - the same rights to services when in long stay-care as one has when living at home.
Introduction

Essence of Care (EOC) is a quality framework for clinical governance that involves setting benchmarks for best practice in areas of care considered crucial to the patient/client experience. It addresses quality of life as well as quality of care and centres on the person, seeking to ‘see through the patient’s eyes’. It involves clients, carers and the whole healthcare team. Users of the service identify the standards. It empowers people who have had little say in decision-making about care planning and giving in the past.

In summary it aims to:
- improve the patient/client experience and quality of life
- improve patient/client care
- involve the client, carer, family and whole healthcare team
- take a structured approach to sharing and comparing best practice
- improve working lives.

Over the last two years, we have started the EOC benchmarking process in 27 long-stay care units in the Cork/Kerry region. Each of the nine EOC benchmarks is allocated to three sites for comparison and sharing.
What Is New About It?

We have found that what distinguishes it from other initiatives is that it:

- is person-centred
- involves the whole healthcare team
- encourages the sharing and comparing of best practice
- operates across all services
- uses a bottom-up approach
- fosters openness and honesty
- changes the culture and context of care.

Implementing Best Practice

The first step in implementing best practice is to address the following questions:

- What is best practice?
- What is the standard we want to achieve?
- How does our current practice rate in relation to that standard?
- If current practice does not reflect best practice, how do we implement change to achieve best practice?
- How do we measure achievement of the best practice standard?

This is done by asking the patient or resident and carer. Once this is addressed you are ready to embark on the EOC process. There are five stages:

1. Agree best practice.
2. Assess clinical area against best practice.
3. Action plan.
5. Disseminate improvements and/or review action plan.
Stage 1: Agree Best Practice

To do this you must:
- include the residents and carers in the decisions about what represents best practice
- engage relevant members of the team – value everyone’s experience
- use all available evidence – empirical and experiential
- reach agreement about the evidence necessary to demonstrate best practice.

Stage 2: Assess the Clinical Area Against Best Practice

To do this you must:
- consider the patients’ or carers’ experiences and how current care is delivered
- consider barriers that prevent achievement of best practice
- compare and share practice.

Stage 3: Action Plan

In devising an action plan you must address the following questions:
- Where are we at this moment?
- Where do we want to be?
- How are we going to get there?
- What do we need to do to help us to get there?
- When are we going to get there?
- Who can we get to help us?

Stage 4: Review Achievement Towards Best Practice

It is important to review progress and to do this effectively you need to document what you have done, observe what is happening, and note any improvements and problems. You also need to evaluate outcomes. Ask:
- Did patients’ experience improve?
- Did service delivery benefit from changes?
Stage 5: Disseminate Improvements and/or Review Action Plan

To embed the process it is important to share what you have learnt and to use that knowledge to review and revise the action plan, if necessary. You should share your findings with:

- your comparison group
- all colleagues in the unit
- the wider organisation and community.

Conclusion

In our experience Essence of Care does deliver under the domains of quality of life identified in the NCAOP’s report, *Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland* (see Dr Kathy Murphy’s paper in these proceedings).

In terms of independence and autonomy we have been told the following:

- *Patients are empowered, it is person-centred, the patient is number one.*
- *Patients are given choice – this is a huge thing – they are being asked and they feel that they matter.*
- *They like to be consulted, like to feel in control.*

Regarding personal identity we have found that the privacy and dignity benchmarks mean that:

- patients benefit from care that is focused upon respect for the individual
- patients feel that they matter all of the time
- patients experience care in an environment that actively encompasses individual values, beliefs and personal relationships
- patients’ personal space is actively promoted by all staff
- patients and/or carers can access an area that safely provides privacy.

In terms of connectedness and engagement in meaningful activities we have seen a greater amount of participation in comparison EOC group meetings. Patient and carer participation is crucial.
The Health Promoting Hospitals’ Healthy Ageing Initiative for Residential Care

Ann O’Riordan
Director, Irish Health Promoting Hospitals Network

Introduction

The HAIRC was developed in 2004 in response to:

- the NCAOP’s recommendation in 2003 that its Healthy Ageing Programme focus on residential care
- the desire of the INHPH Network (which has a growing membership from the residential care sector) to develop a way of giving greater support and direction to those in the residential care sector for their health promoting activities, as well as acknowledging and crediting existing activities
- the Health Promotion Strategy for Older People, which identified lifestyle and physical and social environments as important in healthy ageing.

Aim

The aim of the initiative is to encourage and support residential care facilities to:

- realise and act on their health promoting capacity
- integrate a health promotion aspect into their daily work.

The HAIRC initiative was developed to fit in with and complement other service development and improvement initiatives while bringing a focus to and support for improvements for older people in the social and well-being aspects of living within a residential setting.

Approach to Development

A partnership approach was used to develop the initiative, which included all relevant stakeholders in the delivery, planning and provision of residential services for older people as well as consultation with and involvement of residents. We designed a ten steps self-assessment framework that would help users implement the healthy ageing initiative.
The Ten Steps

The ten steps are as follows:

- consultation
- healthy ageing policy development
- policy to practice
- choice
- information practices
- personal space and belongings
- independence
- lifestyle
- healthy staff
- family friendly.

Discussion

**Rapporteur: Olga McDaid**

Participants agreed that there is a need to change the culture of long-stay care in Ireland. It was agreed that there is a need to focus on valuing people’s differences, recognising the need for choice and standardising clinical practice. It was suggested that a systems theory approach be adopted in order to change the culture of long-stay care.

Participants acknowledged the need for awareness building, education and training in achieving a culture change. Some advocated a practice development approach and the introduction of accreditation programmes. Participants agreed that it is important to acknowledge and value those working with older people. They noted the importance of promoting positive images of long-stay care to the wider public.

Participants noted the importance of taking the environment (as a place where people live and work) into account in developing and implementing quality of life initiatives.

Participants agreed that it is important to get the balance right between a bottom-up approach, (empowering older people and giving them the necessary skills) and a top-down, policy approach. They noted that older people should have a greater say about their own situation. The issue of rights in the home versus rights in long-stay care was raised. Participants identified the need to balance risk and autonomy or choice; for example a person wanting to make a cup of tea may risk burning themselves with the boiling water and a member of staff may wish to make the tea because they see it as their professional responsibility.
The question was raised as to how to incorporate quality of life initiatives into the current system. Participants suggested that there is a need for a national plan for older people, one that sets targets and identifies resources, as there is a belief that the current system is disjointed. Participants identified a need to develop an overarching framework to help long-stay care facilities implement the various quality of life initiatives. Participants also identified the need for facilities seeking accreditation of quality of life initiatives to take an evidence-based practice approach. They agreed that there is a need to promote best practice examples.

Participants noted that it is important, if the culture of long-stay care is to be changed for the better, that facilities share their learning – their evidence-based practice – and support each other in promoting quality of life. Participants called for the setting up of a central database that would allow for consultation of best practice initiatives. (Healthdata was proposed as an example of one such database enabling the sharing of projects.) It was envisaged that each organisation would upload its own projects to this central database and that each organisation could access details of the projects run by others. It was suggested that access to this database might be available through the NCAOP website www.ncaop.ie or at www.healthdata.ie.

Key Messages

The group Chair identified the key messages from the discussion as:

1. The need to change the culture of long-stay care in Ireland.
2. The need to develop a framework or an approach that allows quality of life initiatives to be embedded in the current system.
3. The need to take an evidence-based approach and to set up a mechanism to enable organisations to share best practice.
Third Session

Exploring the Relationship Between Staff Support and the Quality of Life of Older People in Long-Stay Care

Chair: Dr John Browne
Valuing Staff in Long-Stay Facilities for Older People

Eithne Ni Dhomhnaill

Nursing Matters

Introduction

The aim of this paper is to look briefly at the perceptions held by nurses and other staff to working in long-stay care and to suggest ways in which these perceptions might be overturned in order to encourage people to work and stay working in long-term care.

Perceptions

Care in long-term facilities in Ireland is primarily provided by nurses and health care assistants. We know from the findings set out in the NCAOP report, *Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland*, that managers and owners of residential care facilities find it difficult to recruit and retain staff. We know that gerontological nursing is not the first preference of many younger nurses. Many of the nurses recruited to work in private residential care facilities see working there as a stepping stone to a job in the public acute care sector. Overseas nurses are attracted to the higher pay levels available in the public sector; they also see work in the acute care sector as offering greater opportunities for career development.

There is no doubt that ageism colours people’s perception of long-term care work. The nursing profession does not value the potential of nursing older people. Wells *et al.* noted in 2004 that:

> The attitudes of nurses regarding ageing and working with older adults are likely to influence both their career choices and the quality of care that older adults experience.

According to Ford and McCormack (1999), services for older people, including residential care services, have continually been stifled by under-funding, inferior care environments, low levels of staffing, poor educational preparation of staff, low priority and a general ageist attitude among society.
Nurses’ Perceptions of Working in Long-Term Care

Research shows that nurses working in residential care are more likely than nurses in other settings to agree that low esteem is associated with working with older adults (Wells et al., 2004). Moreover, the Australian Department of Education, Science and Training (DEST), in its 2000 review of education, recruitment and retention in this sector, identified a number of difficulties in attracting skilled nurses to the care of older people. These included a negative bias towards nurses who work in residential care settings; a lack of collegiality due to the relative absence of other health care professionals and a perceived lack of professional autonomy.

Paraprofessional Staff Perceptions of Working in Long-Stay Care

In a report by Harris-Kojetin et al. (including Dr Robyn Stone) at the Institute for the Future of Aging Services (IFAS) (2004), paraprofessional staff, such as licensed and unlicensed care assistants, identified the following as barriers to working in long-term care:

- inadequate training
- the poor public image of the long-term direct care workforce
- the low level of pay and insufficient benefits
- inadequate job orientation and lack of mentoring
- lack of opportunity to take part in continuing education and development
- poor supervision
- emotional and physical hard work
- workplace stress and burnout
- personal life stressors, e.g. problems with housing, childcare and transportation
- lack of respect from residents’ families
- poor staffing levels.

A number of authors (Munley Gallagher, 1999; Mueller, 2000; Seago, 2002; and the American Nurses Association, 1998) highlight the fact that appropriate staffing is a complex issue and that estimating staffing requirements should be based on the following:

- patient needs (also known as patient acuity)
- experience, education and competency of care givers
- architecture and geography of the care setting
- philosophy and care standards
the purpose of the unit, e.g. for respite, rehabilitation or dementia care

- quality care indicators

- availability of resources, e.g. technical support, front line and management support staff, medical and multidisciplinary support staff, clerical and auxiliary support staff.

Ways of Valuing Staff Working in Long-Term Care

The following are ways in which this can be done:

- Raise the profile of working in long-term care: increased and improved training and exposure to older people has been shown to do much to raise the status of work in geriatrics (Lothian and Philp, 2001).

- Second undergraduate nursing students to nursing home facilities and expose medical students and junior doctors to the sector. A study in Sweden showed that after a year of special education, medical trainees came to see older people with dementia as unique human beings rather than as a homogeneous group (Skog et al., 1999).

- Introduce and support structured career pathways.

- Allocate a preceptor (someone with expert knowledge who gives guidance and practical experience and training) to all new staff members.

- Make available continuing education and training – the DEST research (noted above) shows that the more continuing education nurses have, the higher the level of job satisfaction.

- Improve autonomy.

In addition, there are several initiatives from which we can learn, including the following:

- The Wellsprings Model, US

- Magnet Facilities, US and UK

- Essence of Care, UK and Ireland

- The Nursing Homes’ Nursing Projects, Ireland.


International Long-Term Care Workforce Issues

Dr Robyn Stone
Executive Director, Institute for the Future of Aging Services (IFAS)

Introduction

Without a quality workforce it is not possible to develop quality of life for people living in residential facilities. Yet it has been almost impossible to get this issue onto the policy radar screen. It appeared eventually in the US in the late 1990s when the booming US economy meant that we could not find people to fill jobs in long-term care. We have managed since then to begin to acknowledge that this is not a short-term problem; rather it is a long-term, systemic problem for all the industrialised world, where we have ageing societies.

In Ireland about 11 per cent of the population is aged 65 and over; in the US it is about 14 per cent. We have relatively young populations compared to Italy, Sweden and Japan, for example, where over 20 per cent are aged 65 and over. As such we have an opportunity to do something. In Ireland there is a great opportunity to do something different as it is small enough to bring all the relevant people to the table. In the US, with a population of 260 million people and a fragmented system with many different providers, this is much harder to do. Nevertheless, there are some things that we have learnt in the US that might be useful to you here in deciding how to do things.

The aim of this paper is to look briefly at:

- the importance of the long-term care (LTC) workforce issue
- the Better Jobs Better Care (BJBC) study and some key findings from it
- issues arising from the IAHSA 2005 LTC Workforce Summit.

The Importance of the Workforce Issue

Staff-Centred

The workforce issue should be at the top of everyone’s list of priorities for improving the quality of life for older people in long-term care. You cannot achieve person-centred care without being staff-centred. Key to this is thinking about a place where people live and, at the same time, where people work. Residential care is very different from acute care – people in acute care do not live in a hospital; people live in residential facilities and work in residential facilities.
Direct Care Workers

In 2002 the direct care workforce in the US numbered around 2.6 million people. This included around 1.4 million nurse aides, orderlies and attendants in nursing homes and about 600,000 home health aides and another 600,000 or so personal care aides (US Bureau of Labor Statistics, 2002). The size of this workforce is expected to grow by about 34 per cent by 2012.

In the US these workers provide 60 per cent of all formal care – care that is intimate, personal and physically and emotionally challenging. They are the eyes and ears as well as the hearts and minds of our system. The typical worker is a middle-aged single mother with a low level of educational attainment. The workforce includes a relatively high proportion of minorities: 25 per cent are African American; 15 per cent are either Asian or Hispanic; and 16 per cent of homecare aides are non-US citizens.2

According to figures from the Bureau of Labor Statistics (2002), the hourly median wage for home health aides in the US was $8.71; for nursing aides it was $9.59 (for a receptionist it was $9.93). The poverty level in 2002 for a family of two was about $12,000 a year. The annual median wage for a nursing aide was $13,000 – right at the poverty level. This is our struggle in the US – the direct care workforce is a low wage workforce that is undervalued financially as well as emotionally and socially. If we are going to bring about quality of life and better quality of care for older people, we have to change that.

In 2002, 35 out of 44 states that responded to a national survey reported recruitment and retention problems. In addition to relatively high job vacancy rates we have significantly high staff turnover rates: for example the US national average among certified nursing assistants in nursing homes is about 70 per cent. This is a serious and costly problem. Average direct costs to the provider are about $2,500 for each direct care worker; the indirect costs are $1,000. On average, every time someone leaves a job the cost to the provider is about $3,500 to $4,000 per worker. If we want to make the case financially for why we should do something different we should think about this 70 per cent turnover – forget about the altruistic reasons why we should do something. Put simply, we cannot afford to do nothing. The estimated cost is $2.5 billion a year.

By presenting the argument in this way we have managed to make this a national issue in the US. Providers understand that the cost of turnover affects their bottom line, and the federal and state governments – the major payers of long-term care through our Medicare and Medicaid programs – have begun to recognise the lost resources associated with an unstable workforce.

Turnover of direct care staff also has other effects: it leads to reduced access to care and it puts more pressure on family care givers. We have empirical evidence to support this. We have seen studies that show the relationship between turnover and high worker stress and increased injury and illness; these lead to substantial work compensation costs and have implications for quality and safety of care.

2 In Ireland you are perhaps just beginning to deal with some of the issues that an immigrant workforce raises. We can help you with this. At IFAS we are currently involved in two projects that address cultural competence. The findings will be available on our website.
Strategies and Solutions

We have focused on three areas in relation to workforce development:

- Extrinsic rewards
  - wages
  - job benefits (healthcare coverage for direct care workers, sick and annual leave)
  - training
  - career paths
- Expansion of the labour pool
  - non-traditional workers (older workers and family members)
- Organisational culture change
  - self-managed teams
  - empowering workers
  - management training for supervisors
  - consumer-directed home care

**Extrinsic Rewards**

Many of those working in healthcare and long-term care in the US are not covered by health insurance. We are attempting to address this problem at the federal and state levels.

**Expanding the Labour Pool**

In the US we know that we are going to have a shortage of workers in the future, despite high levels of immigration. We are, therefore, looking at ways of bringing non-traditional workers into the labour market. We have targeted two groups: older workers; and family members.

We have found that older people in their fifties and sixties, particularly older women, need to stay in the labour force and/or are interested in and attracted to care-giving jobs if we can deal with some of the physical demands (and we can). We have found, too, that some family members, many of whom were care givers in the community, become formal care givers when they are exposed to formal care giving (and we have programmes with which to do this).

**Organisational Culture Change**

When it comes to bringing about a change of culture, the challenges are implementation and sustainability. We know that there are things that are necessary for supporting a quality workforce, for example self-managed work teams, empowering the workforce and management training for supervisors.
We need to know, however, what works and at present there are gaps in our knowledge. We need an empirical evidence base that focuses less on analysis of the problem and more on the empirical and analytical study of solutions. While there are many studies on nursing homes we need more to be carried out in residential care, assisted living environments and in home care. There is a lot of work that is anecdotal and a lot that claims to identify best practice but with little rigorous evaluation. We have very little information on costs or cost-effectiveness.

Empirical work in the US, Australia and elsewhere identifies a lack of management skills and training of supervisors as major issues. I would suggest that if you are going to invest in one thing in Ireland, it should be to train nurses and other managers in residential facilities to create work environments for their staff that will deliver quality of life and quality of care outcomes. I believe that you will not achieve anything (for example with the ten step HAIRC initiative or with Essence of Care) without addressing it. It is key to an organisation’s success.

Better Jobs Better Care Study

We funded a four-year project (now in its fourth year) to look at changes in policy and practice with almost $16 million in grants from two national foundations – The Robert Wood Johnston Foundation and Atlantic Philanthropies. It is called Better Jobs Better Care. The main goals of the project were to study and test changes in long-term care policy and provider practice in order to:

- reduce high vacancy and turnover rates among direct care workers in all LTC settings
- raise workforce skills and quality
- improve quality of care to consumers.

We wanted to test some key assumptions:

- that coalitions of providers, consumers and workers are key to making sustained changes
- that public policies and workplace practices should support/reinforce each other
- that more and better research is needed to document the effectiveness of public policies and workplace initiatives.

We chose five demonstration projects, one in each of five states: Iowa, North Carolina, Pennsylvania, Oregon and Vermont. There is as much diversity in these five states as almost anywhere in the industrialised world and we believed that we could learn as much from them as we could from many industrialised countries. Each project was awarded up to $1.4 million over three years.

We asked each project to come to the table with a coalition of providers, consumers and workers. This was important. We know from experience that policy does not change with policy-makers from above; it changes from the ground up. In addition, we wanted to see public policies and workplace practices that would be working simultaneously to support each other. We also funded eight applied research projects to examine what interventions work in various settings. A separate, independent evaluation of the five demonstration projects was also conducted to document the effectiveness of their practices.
At the public policy strategy level we looked at the following:

- wage enhancements and health insurance benefits
- provider payment incentives for better retention
- new training requirements
- worker registries.

The North Carolina demo site has developed, for example, a new voluntary certification programme called NC NOVA in which organisations that meet certain criteria for quality – in terms of both person-centred and resident-centred care and workforce improvement – will be certified with a quality mark. The next phase of this project will be to tie this certification to enhanced reimbursement through the state’s Medicaid program. In effect, it is an incentive for providers – it is paying for performance.

In terms of workplace practice changes we looked at:

- organisational culture changes to empower and value direct care workers
- peer mentoring
- supervisor training programmes
- cultural diversity in the workforce.

Some Findings

Adapting to Suit Local Needs

What we have found, in these projects and from experience elsewhere, is that everything is local. We cannot dictate what organisations do but we can give them tools (rather than specific interventions) and allow them to experiment with their own communities, at the local level. They tailor the tools we give them to suit the needs of their particular community – the workforce, the people who are being cared for, the families and the location or geography.

The Value of Peer Mentoring

The most important finding to date has been the effectiveness of peer mentoring and supervisory training programmes. I would recommend that you invest in this sort of training. Forget about orientation training and book training. Train mentors to train and support their peers; what we have found shows that it helps to build a quality workforce. Retention is more important than recruitment and training. You need to work on programmes that develop and retain a quality staff.

The Importance of Reliable Data

Another lesson we have learnt from these projects is that getting reliable data on the long-term care workforce is important, yet most organisations do not have this data. Since turnover rates are a strong predictor of quality outcomes, it is essential that organisations gather and use this information to help them engage in quality improvement.
The Need for Buy-in and Support from All Stakeholders

We have also found that initiatives are more likely to succeed when they are fully supported by all of the affected parties. This means that you need to have all stakeholders working together on initiatives. Money to fund this sort of collaborative working must be built into budgets.

Sustainability

It is important to ensure that successful initiatives are sustainable. I recently completed some research on programmes in the US that were identified as best practice only to find that almost all of them no longer existed. Often the leadership changed or they went back to the status quo. The lesson here is that it is not enough to say that you are doing something – keeping on doing it is important. Sustainability is key. Scaling up and replicating effective programmes is more important and more cost effective than continuing to reinvent the wheel.

Issues from the 2005 IAHSA LTC Workforce Summit

This meeting, held in Trondheim, Norway, brought together providers from across the globe to discuss the future of the LTC workforce. The goals of the 2005 LTC Workforce Summit were:

- to understand the issues facing ageing services providers in recruitment, retention, training and dynamics of cultural diversity
- to foster ongoing shared learning and communication between and among interested parties
- to determine the common issues and questions that could provide a basis for collaboration on cross-national research.

We identified the following issues that are common across the industrialised world:

- recruitment concerns are a priority
- retention is a major concern across providers
- immigration is a double-edged sword
- cultural diversity of workforce and cultural competence
- the potential for technology in workplace adaptation and job redesign
- leadership and supportive management are critical
- what training/education, licensing and certification are most effective?

We identified several areas in which we could collaborate:

- developing job profiles
- developing standardised training programs
- creating cross-national peer mentoring opportunities
- developing an international best practices clearing house
- assisting technology transfer between developed and developing countries
- establishing ethical standards for cross-national recruitment
- developing cultural competency training programs
- doing collaborative cross-national research on recruitment and retention solutions.

In terms of future work at the IFAS and IAHSA, we plan to address the issue of sustainability in the Better Jobs Better Care projects; we are setting up the McHugh LTC Nursing Academy and Award to raise awareness about the profession of long-term nursing (as opposed to nursing in hospitals); we are developing collaborative projects with international partners; and we are pursuing funding in order to examine cross-national issues. The next IAHSA summit is planned for Malta in June 2007.

**Conclusion**

It is important that we act now. There is an increasing demand for home-based LTC but changing family structures and women’s labour participation means that there will be less informal care available in the future. In addition, we have a pool of traditional workers that is getting smaller and smaller.

I would like to say how delighted I am that you have formally acknowledged the importance of the quality of life issue. I attend many meetings on long-term care and ageing services all over the world and this issue has rarely arisen. It is important to remember that we are all in this together and have much to learn from each other. I hope that this is just the beginning.

**References**


Workforce Support and Development: Priorities in Long-Stay Dementia Care Settings in Ireland

Dr Suzanne Cahill
Director, Dementia Services Information and Development Centre

Introduction

The aim of this paper is to address the following questions:

- Why might staff in dementia care need support and development?
- How is quality of life for residents with dementia in long-stay care defined?
- How can staff best promote this?
- What type of staff support might ultimately improve residents’ quality of life?
- What are the priorities for the future in terms of supporting staff providing dementia care?

Population of People with Dementia in Long-Stay Care in Ireland

The table below, taken from O’Shea and O’Reilly (1999) shows the numbers of older people with dementia in Ireland in 1999 and the type of residential care setting in which they lived.

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I would like to thank Cecilia Craig, Maeve Clark, Orla Fagan and Mary Drury for their help in preparing this paper.
### Population of Older People and Those with Dementia in Residential Care

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>Aged Over 65</th>
<th>Aged Over 65 with Dementia</th>
<th>Percentage with Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>HB Geriatric Home/Hospital</td>
<td>5,082</td>
<td>950 +</td>
<td>19</td>
</tr>
<tr>
<td>HB Welfare Home</td>
<td>1,200</td>
<td>133 +</td>
<td>11</td>
</tr>
<tr>
<td>HB District/Community Hospital</td>
<td>1,560</td>
<td>224 +</td>
<td>14</td>
</tr>
<tr>
<td>Private Nursing Home</td>
<td>6,200</td>
<td>1,470-3,700</td>
<td>23-60</td>
</tr>
<tr>
<td>Voluntary Geriatric Home/Hospital</td>
<td>2,936</td>
<td>478-1,800</td>
<td>16-61</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>3,301</td>
<td>561</td>
<td>17</td>
</tr>
</tbody>
</table>

### Why Might Staff Need Support and Development?

There are many reasons why staff caring for people with dementia need support and development. Not least among these is the invisible nature of dementia care and the inappropriate residential environments in which people with dementia live. In addition, there are no written dementia-specific standards and current training is patchy and largely inadequate. Other reasons for dementia care staff needing support include their diverse ethnic backgrounds; the focus often being on the clinical aspects of care rather than on its psychosocial aspects; the change in the landscape of dementia care; and the absence of an explicit focus on quality of life issues in long-stay dementia care environments.

Traditionally, government interest in addressing workforce issues has largely been limited to analysing aspects of the workforce such as staff recruitment, staff ratios, markers of poor quality of care, health and safety issues, and clinical dimensions of care. There has been an absence of attention paid to quality of life issues in the area of dementia care. The emphasis in inspection and practice has tended to be on the physical rather than psychosocial components of care. This issue is well reflected in data recently collected for a HRB-funded study (HRB, 2002) looking at dementia care provided by staff in the private and voluntary nursing home sectors.

*The health board told me not to let patients make their own beds. Health boards are too rigid in their inspection – there should be a bit more humanity to them. They never really ask about how the patients are. They cause panic when they come in.*

*We have two women here who peeled the potatoes but that’s been phased out.*

*We don’t allow them into the kitchen. It’s against the law. The food law is very strict.*

*I was always a firm believer in keeping the kitchen open to residents but now we have loads of rules and regulations about not letting people in.*

*They can’t go out much, the proprietor keeps boxes out there and the traffic and the noise can be very difficult.*
Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland

What is Quality of Life in Dementia Care and How Can Staff Best Promote This?

The Alzheimer’s Disease International group developed a model based on factors impacting on quality of life for people with dementia. Factors identified by them include the environment, health and happiness, personhood and care issues as well as wider sociopolitical forces including public attitudes and understanding.

The model suggests that quality of life can be improved or disimproved by the appropriate manipulation of these specific variables. When, for example, the environment in which the person lives is restricted, when health or well-being is compromised or when there is lack of funding available, the quality of life of the resident is threatened. Quality of life can, conversely, be enhanced when these same factors are addressed in an appropriate way. Health and happiness, for example, can be promoted by good physical care, staff support and the quality of professional and family care provided.

What Type of Support Might Ultimately Improve Residents’ Quality of Life?

In my view and drawing on this model, three critical areas need to be addressed in order to improve quality of life:

- education and training
- the environment
- the philosophy of care.

Education and Training

Dementia-specific training can achieve three things: it can change attitudes; improve quality of care; and improve quality of life. A review of published research in this area shows that better educated professionals are more likely to see people with dementia as individuals and give less task-orientated care (Normann et al., 1999; Skog et al., 1999). They are more inclined to include relatives in partnerships in care (Shanley et al., 1998). They are more confident at providing support to people with dementia and their carers (Manthorpe et al., 2003) and are more likely to better understand and address challenging behaviours (Moniz-Cook et al., 1998). Research findings have also shown that training results in increased cooperation from residents and an overall increase in verbal contact initiated by residents and care givers.

A useful tool for assessing the effectiveness of dementia care training is the ‘Approaches to Dementia’ questionnaire developed by Lintern and Woods. The questionnaire is designed to measure staff attitudes to people with dementia and to document changes over time. It consists of 19 statements to which participants respond using a five-point scale: strongly agree; agree; neither agree nor disagree; disagree; and strongly disagree. Staff complete the questionnaire before and after training. If the training has been effective it is reflected in the scores on the person-centred sub-scale and the hope sub-scale.
Environment

The environment is a second area worth considering when attempting to improve quality of life of residents with dementia living in long-term care. As Marshall has pointed out (2001), ‘good design makes dementia care easier: it doesn’t make it happen.’ Listed below are the features of dementia-friendly environments identified by Marshall:

- familiar, domestic and homely
- unobtrusive concern for safety
- different rooms for different functions
- age-appropriate furniture
- safe outside space
- single rooms that are personalised
- good signage
- enhancement of visual access
- controlled stimuli
- scope for ordinary activities.

Philosophy of Care

Another area that needs to be addressed in order to promote quality of life in people with dementia living in residential care is the philosophy of the unit in which they reside. Person-centred care (a philosophy of care) has four main components:

- valuing people with dementia and those who care for them
- treating people with dementia as individuals
- looking at the world from the perspective of the person with dementia
- a positive social environment in which the person living with dementia can experience relative well-being.

To achieve person-centred care, all four of these components must be in place.
To assist dementia care staff and promote best practice in dementia care, we need a management system that is supportive of staff and not threatening to them. We also need to ensure that the philosophy of care in all facilities is person-centred, staff-centred and resident-centred. We need to provide opportunities for incremental staff training and to offer incentives to encourage participation in training. We also need to make sure that we reward staff for introducing change into the environment in which they work. In summary, we need to make sure that we provide a consistent, safe and stimulating environment for residents which feels like home.

References


Final Session

Lessons of the Day for Future Legislation, Regulation, Inspection, Accreditation, Standard Setting and Quality of Life Improvement Measures

Chair: Dr Siobhan O’Halloran
Dr Ciaran Donegan, Consultant Geriatrician, and member, NCAOP

I would like to look briefly at one issue – availability and access to rehabilitation services. I believe that addressing health issues is a very important step in achieving quality of care. Many older people have one or more chronic medical conditions, which tend to remit and relapse. Most people going into long-term care have access to multi-disciplinary assessment via multi-disciplinary teams. When they go into long-term care, however, they no longer have access to the services they need or find accessing them more difficult. I believe that people in long-term care need to have ongoing access to multi-disciplinary rehabilitation. This should include physiotherapy, occupational therapy, speech and language, nutrition, specialist medical input, geriatrician input and opinions. There is evidence to show that this approach to care works.

The medical needs of residents in long-term care settings, particularly in higher dependency units, create such demands on GPs’ time that systems become reactive to patients’ needs rather than proactive. This does not contribute to the development of the right ethos; it does not promote good standards of care.

A lot of changes happen without discussion with GPs or geriatricians. As a result, the question of who ‘owns’ care of patients has never really been fully resolved. We need to address this issue of clinical governance. One of the ways we can do this is to set up ongoing access to multi-disciplinary teams. This can take various forms. For example, it might be called ‘outreach’; it might be led by doctors or by specialist nurses. Whichever form it takes, however, I believe that this multi-disciplinary model of care should help us improve quality of care, standards of care and, by implication, quality of life. It helps build teams; it helps train staff; and it helps develop an ethos of care for older people.

To achieve this requires collaboration between all relevant bodies. I believe that the report, *Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland* (NCAOP), will be useful in informing decisions in relation to policy and funding. To achieve what we need to achieve we require funding and resources.

To conclude, as Dr Stone pointed out in her paper, if we are going to set up these models of care we need to set them up in a way that allows us to monitor and evaluate them so that we can gather evidence to help us determine whether or not they work.
Anne-Marie Ross, Services for Older People, Department of Health and Children

I would like to talk briefly about legislation and the setting of standards, which the Minister mentioned in his Opening Address. Inspections at present are conducted against standards in the 1993 Care and Welfare Regulations. Private nursing homes are inspected by the HSE.

The Health Bill 2006 will establish the HIQA on a statutory basis. It will also contain provision for a more robust inspectorial system involving the SSI. The Bill is in its consultation stage at present and I know that many of you make very valuable contributions.

In advance of HIQA being established and the legislation being passed, the DoHC is chairing a working group with members from the DoHC, the HSE, the SSI and the IHSAB. The remit of the group is to develop national standards that would apply to all long-term care settings. These standards should reflect the move towards person-centred care and quality of life. They are being developed in line with best international practice. It is intended that the standards be published in draft form in July 2006 and be available for a three-month consultation to allow all interested parties to make their views known.

Although not the focus of this conference I think standards of care in the home are worth mentioning. The DoHC is aware that, given the focus now and in the future on helping older people to remain at home for as long as possible, it will be necessary to look at standards of home care. We will be aiming to put in place standards to ensure that the care that older people get in their own homes is of a high quality and is appropriate to the person. This is likely to be a lengthy and complex process because of the issues involved, including, for example, access to private homes.

Quality of care is an important issue. It is important to have good standards, a good accreditation process and a good inspection process. But as we have seen here, and as the NCAOP report shows, quality of life must also be addressed. I believe it is the responsibility of all of us to help achieve this.

I have no doubt that the report, Improving Quality of Life for Older People in Long-Stay Care Settings in Ireland, will inform work within the DoHC, especially as we move away from the idea of residential care as a first option for the care of older people.
Michelle Clarke, Chief Inspector, Social Services Inspectorate

The SSI was set up as an independent body in 1999. It has been inspecting children’s residential centres under the auspices of the HSE and foster care for several years. It was the intention that the Inspectorate be expanded to do inspections in other areas. This is now being done under the Health Bill 2006.

Residential services provided by the HSE (voluntary and private organisations for older people and those with disabilities) have been identified as being in need of registration and inspection in recognition of the vulnerability of those citizens. Inspections take place against legislation, regulation and standards.

One of the aims of the DoHC in the draft Health Bill 2006 is to ensure that all residential services for older people will be registered. Registering centres can only take place against regulations and legislation. These are the standards that can be used to keep a centre open or to close it if the centre is not meeting those standards. There will also be standards in relation to other aspects of best practice. Our inspection reports will follow a model of commenting on all standards, whether they are regulatory ones or not. If the regulations and the standards reflect quality of life issues then inspections will reflect quality of life.

Inspections have three roles. The first, and most important, is that of coming to a judgement as to whether a service is safe and appropriate for the people who live there. This is dealt with by inspection and registration. The second role is to collect and collate information from all inspections nationwide to inform us about equity across the country, about which services are doing well, which need improvement, and to inform us about the need for funding. This information helps the DoHC, the HSE and other services at a strategic level; the information is used for planning older people’s residential services. Thirdly, the role of inspections is to serve the general public. The Inspectorate is accountable to the public for services that provide care for vulnerable citizens. For the purposes of transparency and openness; inspection reports are published. (Individuals are not identified in any report.)

In view of what has been discussed at the conference. It is important to recognise that inspections are only one way of helping to achieve good quality care and good quality of life for people in residential care. Inspections do not deliver the service but are there to support service delivery. Finally, as Anne-Marie Ross mentioned, the Health Bill 2006 is currently at consultation stage. The legislation has yet to be developed, standards have to be published and accepted, and the iHIQA has yet to be set up. This will take several years to roll out in full and it is important to keep this in mind.
Roisin Boland, Chief Executive, Irish Health Services Accreditation Board

The IHSAB was set up in 2002. It is an independent statutory body whose mission is to lead continued quality improvement initiatives in Ireland. To help achieve this we have developed a quality and safety framework that is supported by an accreditation process. It involves self-assessment against standards of excellence and is based on the principle of continuous quality improvement and safety. It involves a peer and a service user review. We welcome the development of standards for regulation. These will complement the accreditation standards.

Since 2002 we have been working with acute care services. Ninety per cent of all acute care hospitals have voluntarily applied to go through accreditation. Over the last year we embarked on two projects: to develop standards for palliative care centres (we are now starting to implement accreditation in those centres); and to determine the standards for residential non-acute care (which have now been finalised but are not yet operational).

When the iHIQA is established, the IHSAB will be integrated into it. The mission then will be to accredit the whole of the health services. To this end we are starting projects to develop standards for primary care and for hospital hygiene. These should be operational by the end of 2006.

We know that there are many initiatives throughout the country that aim to improve quality of care and quality of life. The next step is to ensure that these initiatives are structured and coordinated and that we all learn from them. We need to find examples of good practice and to understand the benefits that derive from this. We also need to find examples of bad practice in order to also learn from this. In continuous quality improvement (CQI), if information is not fed back into the system you are wasting your time.

Our experience working with acute care services has shown us that accreditation has an impact on the quality of service provision and, therefore, on patients. We know this because we have been measuring its impact in a study conducted by the NUI in Galway. I believe that when we implement the new standards the quality of life for patients and residents will improve.

I would like to congratulate Dr Murphy and her team and the NCAOP on an excellent report. Certainly, it will inform any standards and quality improvement initiatives that take place.
Prof. Eamon O’Shea, NUI Galway

The more I look and the more I read, the more I realise how little I know about quality of life, despite working on this study for over a year. It is a very ambiguous and difficult area. I would not like any of us to take from this conference a feeling of certainty about what it means or how it might be interpreted by policy-makers.

Quality of life is certainly not something that suddenly appears when we are 70 or 75 years of age or when we enter long-stay residential care. It is something that we should be thinking about now. A sense of personal identity and social connectedness evolve over a lifetime; we have to nurture these things. We have to appreciate them now. It is important that we think about ourselves, the story or narrative of our lives and the relationships that we have, rather than just thinking about them in a future tense.

Many of the issues that relate to quality of life are inherently personal and inherently objective – what matters for me may not be what matters for you. This leads to some of the interesting policy issues and conclusions from our work. If we are talking about quality of life – whatever about regulations and legislation etc. – the voice that must be heard is the voice of older people and their families. It is their voice that must now come back into the process. It must be heard when we make decisions and choices about how we go forward. It means that we need a lot more information from older people in long-stay care. We need to know who is doing what, where, and with whom; we need to know what is working and what is not working in long-stay facilities. We can only make good choices when we have good information from older people themselves.

If I asked you to write down five things that mean quality of life and quality of care for you now and to keep them in your pocket until needed in maybe twenty or thirty years time, what would you write? What constitutes quality of life for you in the context of residential care? There would, of course, be differences from person to person. What has happened is that those differences have been ironed out, homogenised or neglected. One of the key findings of the research is the need to personalise care and the experience of long-stay care. To personalise care you need to have the time and the information to allow people to make the right choices as to where to go to get what they want. This has implications for policy-makers and for the allocation of resources.

You could say this is a Utopian vision; it would cost too much money to achieve. But this brings us back to how we prioritise, which brings us back to how we view older people and how we view ourselves in the context of allocating public resources. Where do older people stand in terms of these resources? This is the critical question that underpins all of our discussions. What is it about older people that puts them to the back of the queue in terms of resource allocation? We have to take the lead now and say that we do not want an ageist public policy perspective to take hold. We do not want older people to be last in the queue. We want the funding necessary to achieve what is needed. We will not achieve equity for older people without resources.

We need to think of what it is we want in the wider philosophical context; we need to think about what constitutes quality, relationships and connectedness. We need to think about future generational solidarity and what that means in terms of resources and about ensuring that resources reach where they are needed. We also want our legislation to take into account the views of older people – this is essential.
By facing these issues now we can also be self-serving. It should mean that we have a much better chance that when it comes to our turn there will be a different type of environment, a different type of support for older people and different types of social values: a society where older people are at the centre of social care decision-making, both at home and in long-stay facilities, directing resources to maximise quality of life across all its domains.

Paschal Moynihan, Director, Older Persons Services, HSE Mid-Western Area

It is worth pointing out that a significant amount of work is currently being done in many public residential units and in private/voluntary nursing homes around the country to try to improve quality of care and the quality of life of residents. The HSE recently carried out a nationwide audit which uncovered a huge number of initiatives, many concerned with implementing standards. Much work is also being done in relation to quality of life issues. We saw examples of some of these in the parallel group exchanges.

If I were to focus on one particular aspect of public facilities it would be the buildings themselves. By and large, public residential units are very old; there are very few new units. Most of the units have the old style Nightingale wards with, in some places, 25 or 30 or more clients accommodated in the same ward. This is not conducive to promoting dignity, privacy, self-esteem or choice. In addition, in many units there is a limited number of toilets. In many there are no day room facilities. I believe that this is the first thing that we need to address. It is a fact that in terms of structure and environment many of our public residential units would not meet the Nursing Home Regulations. Those who work in such units deserve great credit – they are often difficult places in which to work and difficult places in which to deliver quality care and promote quality of life. Obviously, this is an issue that cannot be addressed immediately. We do, however, need to look at it and plan for the future.

The second issue I would draw your attention to is nursing home subvention. Many people in private nursing homes pay significant amounts of money to stay there. Meeting these costs, now and in the future, is a worry for many older people. Rates of nursing home subvention in Ireland differ widely. It would be helpful to all, and a major step forward, if subvention rates were made consistent throughout the country.

Anne-Marie Ross mentioned earlier, as did the Minister, that the focus of policy now is on maintaining people at home. This is very welcome. The downside, however, is that when people eventually need residential care they are likely to be much more dependent than they have been up to that point. This is something that needs to be borne in mind in planning and staffing residential facilities.

Finally, I congratulate the authors of the report, the NCAOP and everyone who presented papers at the conference. I am sure that the report and the conference deliberations will contribute to improvement in the quality of life of people living in residential care settings.
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Terms of Reference
NCAOP

The National Council on Ageing and Older People was established on 19 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

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