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Quality of life issues in residential services for elderly people: perceptions of service providers

Val Roche

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QUALITY OF LIFE ISSUES IN RESIDENTIAL SERVICES FOR ELDERLY PEOPLE

PERCEPTIONS OF SERVICE PROVIDERS
QUALITY OF LIFE ISSUES IN RESIDENTIAL SERVICES FOR ELDERLY PEOPLE:

PERCEPTIONS OF SERVICES PROVIDERS

by

Val Roche

Department of Community and Behavioural Studies
Western Australian College of Advanced Education
Claremont Campus
PO Box 224
CLAREMONT WA 6010

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Quality of Life Issues in Residential Services for Elderly People: Perceptions of Service Providers

List of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreword</td>
<td>1</td>
</tr>
<tr>
<td>Introduction</td>
<td>2</td>
</tr>
<tr>
<td>Description of facilities</td>
<td>6</td>
</tr>
<tr>
<td>Method</td>
<td>8</td>
</tr>
<tr>
<td>Results</td>
<td>10</td>
</tr>
<tr>
<td>Discussion of Issues which arose from results</td>
<td>17</td>
</tr>
<tr>
<td>Conclusions</td>
<td>22</td>
</tr>
<tr>
<td>List of References</td>
<td>24</td>
</tr>
<tr>
<td>Appendix</td>
<td>25</td>
</tr>
</tbody>
</table>
FOREWORD

The report contains feedback from a study undertaken by students enrolled in the Residential Care Unit, a part of the A.D.A. Working with the Aged course. The subject for study was "Quality of life in residential services for elderly people. This was seen as an important area for investigation because the number of elderly people will increase to 15 per cent of Australia's population by the year 2021, and it is likely that even with more community support services, some people will need residential care."

How to ensure "quality" in people's lives is a complex question. Few objective indicators are able to capture the essence of what it means for individuals to maintain quality in their lives. It is essential therefore, that human services workers engaged in residential care, attempt to unravel the different dimensions attached to the concept. The documents Living in a Nursing home (87), Rights of Residents in Nursing Homes and Hostels (89), Draft Standard of Aged People's Hostels (89) may provide some guidance to a positive and personally committed workforce.

The students who were engaged in planning and carrying out this project were Margaret Emmett, Kathleen Campbell, Patricia Wray, Bethany Byatt, Kathy Box and Diana Whyte. It is their thoughts, together with those of the author which are the foundation of this report. Our sincere thanks to all staff who supported us in the planning and implementation of the study.

Val Roche
Lecturer
Community and Behavioural Studies
Western Australian College of Advanced Education
Claremont Campus
QUALITY OF LIFE ISSUES IN RESIDENTIAL SERVICES FOR ELDERLY PEOPLE:
PERCEPTIONS OF SERVICE PROVIDERS.

Introduction

In recent years there has been a deliberate effort by the Commonwealth and State Departments of Community Services and Health together with employees of the residential care services to introduce standards of care in nursing homes and hostels for elderly people which could lead to increased quality of life experiences for the recipients of such services. The principles upon which these standards are based have been influenced by the principles of Social Role Valorization/Normalization (Wolfensberger 72, 83). There has also been a growing awareness amongst human service workers in such services, and the general public, that there is a need to advocate for, and protect the interest of consumers. There have been several instances of abuse reported by the media, and also as a result of "phone-in" services.

Quality of life, the focus of this study is a concept which has many interpretations. It is a complex concept since its interpretation, and subsequent measurement is influenced by many factors. Some of these are cultural values, ethnicity, politics and the economic health of a community. Also, age is a factor; people have different perceptions of what constitutes a "good" quality life at each stage of the life cycle. Temporal factors and prevailing care "fashions" will determine the type of standards which are applied in human service settings, residential care of the elderly being just one example of a fashion of institutionalization for recipients of human services. This fashion has its origins in the Eugenics movement of the early part of the twentieth century, although in Western Australia it has been a comparatively recent responsibility of the Commonwealth government in terms of financial support. Increasingly, in human services, standards of residential care which were perceived as adequate a decade ago have come under close scrutiny by advocates of people who are elderly and recipients of such care.
Recent Commonwealth government literature has focused on eight dimensions of life which can act as indicators or yardsticks of quality. The dimensions are as follows:

- Health care
- Social independence
- Freedom of choice
- Individual rights
- Provision of a home-like environment
- Variety of experiences
- Privacy and dignity
- Safety

These indicators are outlined in Living in a Nursing Home (87), Draft Standards of Aged Person's Hostels (89) and The Ronalds Report (89). The standards documents are used by evaluators of hostel and nursing home services in determining the quality of care. The indicators are intended to act as yardsticks for use by all persons responsible for care at all levels. Theoretically, they can guide service providers in planning options with the consumer. These are intended to meet his/her needs and thereby improve the quality of the person's life. The eight indicators outlined above represent fundamental needs which are common to all human beings. In relation to people who are recipients of nursing home or hostel care, however, there is an urgent need for service providers to be aware that they have the same needs as all people. In addition, there is a risk that they will not be met within a residential care environment.
The potency of measurement devices and standards documents as catalysts for change in residential care practices will to a certain degree depend on the perception of service providers towards the implementation of the guidelines contained therein. The positive visions couched in the above mentioned documents could become perverted by implementation practices which bear a superficial resemblance only to the standards which should have quality outcomes in people's lives. "Quality" cannot be measured by objective measures alone, (a pitfall of bureaucratic measuring devices and popular standards documents). What constitutes "quality" will involve a subjective judgement on the part of the perceiver, which in turn will be influenced by that person's own value stance.

This study was carried out the students enrolled in a residential care unit, part of the A.D.A. (Working with the Aged course) at the Claremont Campus of the Western Australian College of Advanced Education. It was the intention of the study to gain an understanding of service providers' perceptions of what constitutes a "quality" life in residential care. Also, it was felt important to gather data on providers' perceptions of factors which could constrain them in the provision of quality of life experiences for recipients of the services. The project had several aims:

1. To gain an understanding of staff perceptions of quality of life indicators outlined in the document Living in a Nursing Home, Standards for hostels and Nursing Homes, and The Ronald's Report.

2. To obtain staff views on factors which may constrain against implementation of the guidelines and standards.

3. To gain an overview of the quality of life indicators which staff feel exists in their facilities.

4. To gain an understanding of the consumer's viewpoint.
This report is a synthesis of the results of the students' investigations in relation to points 1-3 above. The author of the report and the students involved in the collation of the data would like to offer their sincere thanks to clients and service providers who opened up their homes and work places to them. They were impressed by the welcome which they received and the cooperation from all people involved in the study. We trust that the feedback contained in the report will be made available to all the people who participated in the information gathering stage.

The report is divided into several sections:

- Description of the facilities visited. In the interests of confidentiality, the facilities are designated as facilities "A", "B", "C" and "D".
- Method of data collection
- Results
- Discussion of the issues which emerged from the data which was collected
6.

Facilities Visited

Facility A

Type of Facility: Hostel
Location: Central Metropolitan Area
Size: 46 Permanent Beds, 1 Respite
Staffing: 22 Staff (2 trained nurses)
13 Domestic Staff
7 Personal Carers
2 Dementia program co-ordinators
Average Age of Residents: 78 years

Facilities B and C

Type of Facility: Nursing Home
Location: Northern Metropolitan Area (B); South Metropolitan Area (C)
Size of Each: 57 Permanent Beds, 4 Respite Beds
Staffing: Registered Nurses and untrained care staff
Domestic Staff
Physiotherapist, Occupational Therapist and assistants
Staff mainly part-time; no numbers given
Age of Residents: 46-101 years
Facility D

Type of Facility: Specialist Residential facility for elderly people who have psychiatric disorders.
Location: Northern Metropolitan area
Size: 21 "inpatient beds" (average stay - 12 weeks)
       3 Respite beds
Staffing: 18 Registered Mental Health Nurses
          8 Enrolled Mental Health Nurses
          3 Nurse managers
          1 Assistant Director of Nursing
Multi-disciplinary Team comprising:
          1 Psychiatric Registrar - Part time
          1 General Practitioner - Part time
          1 Psychologist - Full time
          1 Social Worker - Full time
          1 Community Care Nurse - Full time
          1 Physiotherapist - Part time
          1 Podiatrist - Part time
          1 Occupational Therapist - Full time
          1 Charge Nurse - Full time

Age of Residents: over 65 years
Method

Six students enrolled in the Associate Diploma of Arts (Working with the Aged) course at the Western Australian College of Advanced Education, Claremont Campus, with the help from the author, planned and carried out the data collection exercise.

Data for the study was obtained in the following ways:

- through standard interviews carried out with the facility manager/supervisor, and at least 1 direct care worker;
- discussion with consumers of the services;
- observation.

Four of the students visited the facilities in pairs, and two students visited independently. Students spent between 6 - 9 hours in each facility over a minimum of 1, to a maximum of 3 sessions. Each of the facilities was contacted before hand, and the aims of the project explained by way of a letter and/or telephone conversation. Supervisors were also asked to gain permission of residents of the homes, that they may be approached by students.

STANDARD INTERVIEWS:

The questions for the interview (see Appendix A) were based on the quality of life indicators as outlined in Living in a Nursing Home (87), Rights of Residents in Nursing Homes and Hostels (89) and Draft Standards for Aged Person's Hostels (89). Each interview question was divided into two parts;

- discussion of the meaning of each indicator
- discussion of the ease or difficulty of implementation of action outlined by each indicator.

In addition, students obtained background information about the facility. At the start of the interview, interviewees were asked to rank the quality of life indicators in order of priority. All responses were recorded in writing with permission of interviewees.
DISCUSSION WITH CONSUMERS:

Students were encouraged to spend time with consumers of the service in order to gain some understanding of the social reality of their lives. This aspect of the data collection exercise whilst focusing on quality of life indicators, was not intended as a formal interview.

OBSERVATIONS:

Students obtained information regarding accommodation, decor, formal and informal activities and interactions.

This report is a synthesis of the information gained from the interviews with supervisors and caregivers in the 4 facilities. Perceptions of consumers and observation data could be the basis of a future report.
# RESULTS

Table 1: Ranking of the Top 2 priority quality of life areas

<table>
<thead>
<tr>
<th>Area</th>
<th>Facility A</th>
<th>Facility B</th>
<th>Facility C</th>
<th>Facility D</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>S/visor Carer</td>
<td>S/visor Carer</td>
<td>S/visor Carer</td>
<td>S/visor Carer</td>
</tr>
<tr>
<td>Variety of Experience</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Independence</td>
<td></td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Privacy &amp; Dignity</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Freedom of Choice</td>
<td>1</td>
<td>1</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td>Homelike Environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rights of Residents</td>
<td>1.5</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Health Care</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Safety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1. The above table indicates that there was consensus between supervisors and caregivers in each facility with regard to the most important indicators of quality of life.

2. Across facilities there was some consensus in that; 5 out of the eight people interviewed indicated that Rights of Residents was either 1st or 2nd priority; 3 out of the eight people interviewed placed social independence, freedom of choice, or privacy and dignity in either the first or second ranking positions.

3. Health Care and Variety of experience were placed in the first two ranking positions by 1 person only from different facilities.

4. Homelike environment and safety were not ranked in the top two positions by any staff member interviewed.

Table 2: Reasons given for ranking position of indicators chosen

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Reasons Given</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rights of Residents</td>
<td>Because of their psychiatric condition, they cannot stand up for their rights; people tend to forget that residents have rights, and that they deserve to be treated as real valuable people; they are often overlooked; everybody has rights.</td>
</tr>
<tr>
<td>Variety of Experience</td>
<td>Life in a nursing home is so boring - a variety of experience gives people interest in life, something to live for.</td>
</tr>
<tr>
<td>Social Independence</td>
<td>If you have that, everything else will flow from it.</td>
</tr>
<tr>
<td>Freedom of Choice</td>
<td>It is every individual's right to have freedom to choose; without freedom of choice, life doesn't have much meaning; everyone needs to have control over his/her life.</td>
</tr>
<tr>
<td>Privacy and Dignity</td>
<td>I like mine, and respect all other humans. I would like the think that others would do the same.</td>
</tr>
<tr>
<td>Health Care</td>
<td>There is no quality of life if health care is overlooked. It is one reason why they are in a nursing home and so it needs to be addressed.</td>
</tr>
</tbody>
</table>
Summary of interviewees' responses to questions regarding:

a) definition of quality of life indicators and issues which arise in provision of care related to the indicator;
b) constraints to implementation.

1 and 2 Health Care and Safety

Definition as per government documents: choice of doctor, specialist information and definite health care plans, right to take risks, reduction of risk of infection and injury.

Interviewees' Responses: The most important issue was seen as provision of good quality health care, choice of doctor and health care professionals in whom the service user has confidence. In one Facility, this was not possible because of health department restrictions. People may not have a choice in other facilities because their residence was no longer in their home community and doctors were reluctant to visit. To overcome this constraint, one facility encouraged residents to visit surgeries when transport and finance was available.

All facilities have some form of health care plan which was reviewed on daily and at 3 - 6 month intervals, as required. Input for planning and implementation was mainly through staff and family, to a lesser degree. Although encouraged to do so, the resident rarely became involved in planning. Reasons given for this were the resident's condition, lack of motivation and also families tended to see health care as the responsibility of the staff. One facility felt that the biggest issue in relation to provision of good quality health care was the need for staff to see the residents as people first who may have illness from time to time, rather than patients first, and people second.
3. Social Independence:
Definition as per government documents; freedom to maintain social networks and to control movement and resources.

Interviewees' Responses Two of the facilities felt that the most important issue in relation to social independence was the maintenance of the person's social networks and daily life style. The other two facilities, also noted that contact with the community, family and friends was important. The major constraints in relation to the above were the person's mental state and socially unacceptable behaviour, lack of money, transport, lack of personal networks and motivation to maintain contact with the community and friends.

All facilities encouraged visiting of different degrees. One facility had made renovations to buildings in order to make special visitors' lounges. This facility, as one other, encouraged families to take the person out when they visited, and also invited them to take meals with their family members or friend. Volunteer transport was used by one facility, the volunteers being members of community groups to which the person belonged. One facility had instigated a "Quality of life enrichment programme", which involved development of individualized friendship relationships between a staff member and resident. Each pair spends at least one hour of quality time together each week.

It would appear that the overall difference between facilities was in the interpretation of "social independence". On the one hand, 2 facilities which tended towards a more medical orientation, took major responsibility for encouraging the person's social independence within the facility. This results in segregated, and limited participation in the community. On the other hand, the other facilities saw the need for the maintenance of the person's community support networks and hence encouraged their involvement in many areas of social activity.
4. **Freedom of Choice**  
Definition as per government documents; control over daily routines and personal activities, with the right of involvement in decision making, and ability to address grievances.

**Interviewees' Responses:**
All facilities acknowledged that freedom of choice diminished considerably when a person entered residential care. In all cases, the daily routines, effects of institutional living and staffing levels, were seen as major constraints in the area of choice. Other factors which influenced the amount of freedom of choice were, the person's mental and physical condition which often resulted in dependence on others. There was some flexibility in some aspects of the daily routines. Rising and retiring times were flexible in three out of the four facilities as was choice of food and activities. There was limited or no choice in selection of room, provision of single accommodation (in 2 out of the four facilities), or selection of a room-mate.

All facilities had informal grievance procedures. The major channel was through staff and in addition, 2 facilities used resident's committees or suggestion schemes.

5. **Home Like Environment**  
Definition as per government documents; appropriate design, decor, retention and arrangement of personal possessions and furniture, normal domestic activities.

**Interviewees' Responses**
Three out of the four facilities felt that the presence of personal possessions was important in the creation of a home like environment. Other factors perceived as important in the creation of such an environment were the layout of the building; and presence/absence of private facilities. Two of the facilities felt that a communal living setting could never be a "home" to the person, and as such creation of a home like environment was almost impossible. One facility felt that the personal attributes of staff facilitated the creation of a home like environment.
The major constraints to creation of such an environment were seen as: - staff attitudes and numbers, union regulations which affected staffing numbers at different time of the day, (i.e. penalty rates have to be paid after 12 midday), the motivation of residents; safety factors which prevented involvement in kitchen areas, catering arrangements where food is transported from a central kitchen. Two facilities had tried to overcome these problems through provision of small kitchen appliances which allowed residents to make their own toast, tea etc, also organised cooking activities in kitchens especially created for this purpose.

6. Privacy and Dignity
Definition as per government documents; rights to be addressed with respect, person's access to his/her own 'space' and facilities, maintenance of privacy for personal ablutions.

Interviewees' Responses
All facilities felt that the provision of single room accommodation was the most important consideration in an environment which seeks to respect the privacy and dignity of the person. However, in two of the facilities this was not possible because of the physical layout, which meant that few people had their own rooms. All facilities acknowledged the importance of space for storage of personal possessions, private ablutions, although here again, there seemed constraints to support of such an option. In 1 facility there was communal showering with minimal privacy afforded by curtains. In another facility, in the interests of safety, peepholes had been installed in bathroom doors, through which residents could be observed.

Interviewees offered a variety of solutions to overcome the difficulties of affording people privacy and respect. Some were; demolishing of building and residential services in favour of "Community Options" type programmes; provision of keys to some single rooms; ongoing staff education aimed at raising consciousness to the needs of elderly people; building programmes to provide single room accommodation with ensuites.
7. Variety of Experience

Definition as per government documents; access to appropriate activities and resources.

Interviewees' Responses

There was some variation between facilities in the type of activities which are provided for residents. All facilities provided traditional activities such as community outings in groups, concerts, cooking, bingo, carpet bowls. These were usually organised by the Occupation Therapist or staff similarly employed as activities co-ordinators. One facility had instituted the "Quality of life enrichment programme" in order that residents could receive a minimum of 1 hour quality time with a valued person (staff member) once a week. Pairing of resident and staff member was based on mutual liking for each other.

In all facilities staff planned and ran activities with varying involvement of voluntary groups. Resident "apathy" was seen as a major constraint to involvement in planning and running activities. Also, lack of volunteer resources and money were seen as additional barriers to implementation of community oriented activities.

8. Rights of Residents

Definition as per government documents; provision of an advocate who can protect and promote the rights of the individual.

Interviewees' Responses

All facilities acknowledged the importance of each person having an advocate. In one facility it was felt that a resident could not self advocate because of fear of reprisals from staff. In all facilities, most people were reported as having advocacy support either of a legal or personal nature. Advocates were noted as doctors, family, nurses, personal carers, friends and lawyers. In two facilities there were some people who had nobody to advocate for them. For these people, one facility felt that "the government" might be able to tell them how to overcome the problem.
DISCUSSIONS OF THE ISSUES WHICH ARISE FROM RESULTS

The following is a summary of the issues which arise from the interviewee's responses to question regarding understanding and implementation of standards aimed at increasing quality of life in residential care. The last paragraph of each section contains some suggestions which address the issues raised.

1. Health Care and Safety

Most people enter residential care for reasons related to physical or mental frailty. However, as noted frequently in the literature, (see Community Options report 1986), it is not the medical condition per se, which is the deciding factor, but the inability of the community to support the person in performing roles and responsibilities necessary for maintaining a home. "Good health" involves not only absence of disease/illness, but also psychological well being. This results from performance of numerous values social roles and knowledge that one has "real" support. This factor was not acknowledged by any of the facilities visited. All used individual care plans but within the limited scope of medical care. It was obvious from the responses that all facilities saw good quality medical care as essential, and this was individually planned and monitored.

It would seem essential for support of this objective that each facility re-examine the concept of "health care" within its wider context. Such an examination could begin with an analysis of the person's needs in all areas of his/her life. The analysis will require of the planners, that they have sound knowledge of the person for whom they are planning. This will result from the planners spending time getting to know the person's life, interests and wishes. It is likely that when needs conceptualized in this way are met, they will encompass social/psychological as well as medical well being.
2. Social Independence

In relation to the dimension of social independence, the major barrier which prevents the elderly person from maintaining contact with social networks and using ordinary community resources, will to a large extent be influenced by the attitudes of community members. Elderly people are often considered unproductive, non-contributing members of society and at the end of their lives. As community members, these attitudes will also be held by employees of services. The situation will remain unchanged however, as long as agencies which provide residential care for elderly people/people with psychiatric disabilities, perceive social independence as being something which is achieved through the formal group programmes offered to them. Although the programmes may play an important part in facilitating social independence, ultimately it will be unique to each individual and have different meaning dependent on his/her background, interest and needs.

Social Independence, as the other quality of life indicators, is dependent on the presence of a personal advocate who will be committed to maintaining the individual's personal relationships, resurrecting, where possible, those which have deteriorated, or creating new ones for people who have been alienated by their families and friends.

Alternatively another solution may be in the reallocation of a staff resource who could seek out pockets of community support. These may provide the starting point for re-establishment of relationships. The family and friends of the person may not always want or be able to take on the role in any more than a superficial way.
3. Freedom of Choice

Choice in everyday and life defining decision making is one need common to all people. However, it is one of the most difficult areas to address in residential care settings. There are many areas of decision making in which residents could be involved, but these are not always acknowledged as important by staff.

For some residents who have lost the ability to make choices as a result of institutionalization experiences, there is a need to gradually develop the confidence to consider choices in many areas such as – activities, friends, acquaintances, choice of soap, toothpaste, beverages, clothing. For staff involved in the facilities they will need to question their own commitment to support of this indicator. Such questioning may begin with an exploration of why people stop making choices, and the workers' contribution to their gradual decline in ability to make simple choices. It is also acknowledged that in some areas of life, there cannot, at present, be a situation of choice.

4. Homelike Environment

It is acknowledged that one will never be able to create a "home" within an institutional setting. "Home" will mean different things to different people. it is the place where a person's needs for companionship, identity, acceptance, love and security are met. As noted by all staff, the presence of personal possessions may help the resident maintain his/her identity and enhance a feeling of security when surrounded by familiar furnishings and "nicknacks" which contribute to a homely atmosphere. In one facility, although acknowledged as important, it was seen as less of a priority for the people whose stay was generally of a short term (up to 12 weeks). However, for these people, who have altered mental states, loss of personal possessions may increase the confusion on moving from one "home" to another.
Staff attitudes and catering arrangements may be other major factors which influence the "homeliness" of the environment since they will largely determine the resident's ability to have flexibility in daily routines. These may be factors of greater importance than personal possessions as they will influence the social environment and the degree of acceptance of the resident's needs to be treated as individuals. Both these factors contribute to the making of home.

5. **Privacy and Dignity**

All facilities were aware of the difficulties of implementing this guidelines which was ranked as either 1st or 2nd in importance from an array of 8 dimensions of quality of life. In communal living settings, it appears that they vary in the amount of privacy which people are afforded during showering, because of environmental (physical) constraints, and the attitudes of staff and the residents themselves. However, in respect to this indicator, it would appear that in other areas of the daily routine, e.g. visiting, telephone conversations, more attention could be given to the need for privacy as basic to human dignity.

Where peepholes are used in showering areas, in the interest of safety, it would seem important for the residents to be made aware that they are likely to be observed in the most private aspect of their daily ablutions.

6. **Variety of Experiences**

As noted in the summary of results with regard to this indicator, all facilities saw the need for a variety of activities. However, facilities differed in the interpretation of the concept of activity. Likewise, in relation to this concept, there was a feeling that residents were often unmotivated to become involved in activities.
For each person "activity" will differ depending on his own needs, backgrounds and interests. Therefore the conception of what constitutes activity requires consideration. A wider definition of the term could encapsulate informal daily routine activities which were performed by elderly people whilst in their own homes. Workers would possibly find that the residents of the facilities would become more motivated if engaged in activities which they initiated, and which were of a similar nature to those which they had engaged in for much of their lives.

This indicator is also closely tied in with the dimensions of social independence, dignity and respect. All of these have an implicit assumption that the person whilst engaging in activity related to the indicators, is performing social roles which are of value. It is acknowledged that many people in residential care cannot take on social roles at the same level as previously and in an independent way. However, a positive and creative staff member or advocate with indepth knowledge about the person, could support the person by creation of individual activities which reflect involvement in some aspects of positive social roles.

7. Advocacy

All facilities acknowledged that all people should have an advocate. However, advocacy was seen as resulting from a traditional arrangement (either staff, family, lawyer or advocacy groups), rather than from a relationship which results from personal interest or commitment to another human being.

As advocacy was seen as being in the top 2 ranking positions, it would appear that further consideration should be given to the meaning of the term. Advocacy may be better developed through the environment of previously uninvolved, unbiased citizens who take on an advocate role through personal commitment, rather than as a responsibility of their work or family role. Citizen advocacy groups may provide support in this area. Alternatively, an extension of the concept and developed in the Quality of life enrichment programme, may open other avenues of advocacy for people who cannot advocate for themselves. However, its success will ultimately be dependent on the quality of the relationship between the two parties involved.
CONCLUSIONS

On entering residential care of any type, the individual is put in a position of risk where the outcome is negative consequences for the quality of the person's life. The consequences have been documented at length by many critics of human services. They have also been brought to public attention by media reports and publications (for examples see Wolfensberger, 72., McCord and Marshall, 88., Newton, 82., Roche, 87., Murphy, 88., Montague, 82). The critics have investigated the social reality of people's lives at both objective and subjective levels, when they have become recipients of human services.

For many people the risks are minimal. There are much greater risks, however for those who are the most devalued, who have the highest levels of disability or advanced aged. Undoubtedly, for some people, their lives in residential situations have become more secure, and enriched in different ways. However, there may be a large proportion of people in residential care who have lost out in many ways because they have become recipients of such services which operate from a predominately medical model of care.

The loss may occur in all areas of their lives. That is in freedom of choice, autonomy, independence, relationships, richness of experiences, psychological health, and security.

The government documents which formed the basis of this study attempt to decrease the level of risks for individuals who enter residential care. However, policy documents, directives and legislation will be meaningless in terms of application, unless they are accompanied by personal commitment by ALL people who have an involvement or responsibility to maintaining quality lives for individuals in their care.
The students who undertook this project were extremely impressed by the interviewees understanding of the guidelines contained in the documents referred to in the introduction to this report. However, analysis of the responses made to the questionnaire has raised issues which may need deeper consideration if those personnel involved at all levels of care are to give their full support to implementation of policy.

It is acknowledged that the numbers of people interviewed in the study was small (10), and that the time spent in the facilities was relatively short. However, we trust that even with these limitations, the feedback on information gained, will be of some benefit to the recipients of the services.

Further reporting in this area would attempt to address the service recipients viewpoints in relation to quality of life indicators.
List of References


APPENDIX : INTERVIEW GUIDELINES

SCHEDULE OF INFORMATION GATHERING
CBS 2194  RESIDENTIAL CARE OF THE AGED

INTERVIEW GUIDELINES

SCHEDULE OF INFORMATION GATHERING
Quality of Life: Interview Guidelines

CONTENTS

<table>
<thead>
<tr>
<th>CONTENTS</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Background to Service</td>
<td>2</td>
</tr>
<tr>
<td>Quality of Life Questions:</td>
<td>4</td>
</tr>
<tr>
<td>Health Care</td>
<td>5</td>
</tr>
<tr>
<td>Social Independence</td>
<td>7</td>
</tr>
<tr>
<td>Choice</td>
<td>9</td>
</tr>
<tr>
<td>Home Like Environment</td>
<td>10</td>
</tr>
<tr>
<td>Privacy and Dignity</td>
<td>11</td>
</tr>
<tr>
<td>Variety of Experiences</td>
<td>13</td>
</tr>
<tr>
<td>Rights</td>
<td>15</td>
</tr>
<tr>
<td>Conclusion</td>
<td>16</td>
</tr>
<tr>
<td>Information Gathering Exercises</td>
<td>17</td>
</tr>
</tbody>
</table>
1. INTRODUCTION WITH SUPERVISOR

Thank supervisor for letting you come into facility ("Welcoming you") and his/her time.

1. Introduce selves BRIEFLY - 1 line introduction.

2. Explain the nature of your assignment and reason for the visit.
   a) to talk with manager (and direct care staff) about the issues which arise in the facility when people try to implement the latest policy guidelines.
   b) to spend a little time with people who live there in order to gain their perceptions of how they find their lives and spend their time.
   c) to learn a little about the facility size, number of people, live, work there, activities.

3. Discuss schedule for visits. (if not discussed previously)

4. First you want to "talk" with supervisor about the facility and his/her perceptions of the issues which arise in implementation of the guidelines related to the "Living in a Nursing Home" and "Rights of Residents in N.H." documents.

5. Explain that you have a lot of areas to cover and therefore will need to ask a lot of questions. You expect the interview to take 3/4 - 1 hr and does the person mind if your partner takes notes?

Note

1. * At any stage in the interview if the person doesn't want to discuss any information don't push - information is not that important. *

2. As you move from different areas of information about the facility/Quality of Life let the interviewee know by pre-phrasing with "I'd like to next move onto....".
Q1  BACKGROUND TO SERVICE

"Please tell us briefly about your service, its history, size who lives and works here and any future plans."

(In this question try and obtain information about number and ages of people, prevailing conditions (if any - or reasons why they come in; staffing numbers, trained/untrained and functions of each staff role).

Q2  Groups of people within facility - how are people placed in groups? for activities, for sleeping, eating, daily living activities, outings.

What criteria are used for grouping people together?

What size are your groups?

Do you feel that size affects the quality of experiences for the people within them? If so how?
3.

Q3  Could you tell me how people come to live in your facility? (What choice do they have?)
4.

**Quality of Life Questions**

Introductory statement and question:

"I will be moving now onto specific questions about quality of life and the issues which arise in implementation of the guidelines documents. I will be focussing on eight major areas.

The areas are
- Health Care
- Social Independence
- Privacy and Dignity
- Provision of a Home Like Environment
- Variety of Experience
- Freedom of Choice
- Safety
- Rights of Individuals

Q1 Which do you feel out of the above areas is the most important to address. That is, the area which will have the greatest impact on the person's quality of life.

Why?

Q2, to Q8 "Which do you feel is the next area of importance?"

Why?
5.

Quality of Life Questions

HEALTH CARE

Q1 What do you feel is the most important issue in relation to provision of quality health care?

Why?

Q2 "The document states that residents should have a choice of doctor, have definite health plans etc. What would be the problems for you in implementing the above guidelines."

Q3 In relation to health care plans:—
   a) do you have individualized plans for each resident?

   b) who is responsible for the planning and implementation?
6.

c) does the person (elderly) have input. (If not, why?)

d) are the plans reviewed — if so, how often and by whom?
Quality of Life Questions

SOCIAL INDEPENDENCE

Q1 What do you feel is the most important issue which arises in relation to helping the person maintain his/her social independence?

Why?

Q2 The documents state that residents should be able to maintain relationships with family and friends, have facilities to encourage them to visit, have freedom to come and go in the community and control over their own financial resources and also be involved in purchasing their own clothing and personal items. What would be the constraints which prevented you from implementing any of the above?

Why?
Q3 Could you tell me how or if you are able to facilitate visits back to the person's previous community or family?
Quality of Life Questions

CHOICE

I'm next moving onto the area of Freedom of Choice.

Q1 What constrains you in allowing freedom of choice for people who live in the facility?

Q2 The documents state that people should have freedom of choice in many areas of their lives and specifically in relation to address of grievances. Do you have a mechanism through which they can make complaints?

Q3 In what areas of the daily routines, room choice, activities are the people involved in decision making?
Quality of Life Questions

HOMELIKE ENVIRONMENT

I'm moving next on the area of creating a home-like environment.

Q1 What do you feel makes for a home-like environment?

Q2 How far are you able to provide a home-like environment. For example
   a) what kinds of personal belongings can be brought into the facility?

Q3 What flexibility is possible within the daily routine with regard to
   rising and bed times, meal times and choice of meals, showering and
   involvement in home-like activities.

Q4 What constrains you in implementing the above?
11. Quality of Life Questions

PRIVACY AND DIGNITY

I want to move on next to the area of Privacy and Dignity.

Q1 Could you tell me how you are able or contrained in ensuring the people's dignity and privacy is maintained.

Q2 Go onto this if person needs prompting

- Is there provision for the storage of personal possessions?

- Showering in private?

- Entertaining in private?

*For each one if "not" ask why - what are the difficulties?
12.

Q3 Could you describe how the situation could be improved.
Quality of Life Questions

VARIETY OF EXPERIENCES

I want to move on next to the area of activities.

Q1 Could you tell about the kind of activities that the people here are involved in?

Q2 How do you plan the activities?

Q3 Who is involved in the planning?

Q4 Are there any difficulties which you come up against in provision of a wide variety of experiences? Please explain.
Q5 How could you overcome this?
15.

Quality of Life Questions

ADVOCACY

I briefly want to discuss with you one of the major recommendations which appears in the "Rights of Residents in Nursing Homes and Hostels" document. This issue is that of Advocacy.

Q! Do you operate a system of Advocacy? Please explain (prompt if necessary - "Does each person have somebody who advocates, supports them in decision making which involves their daily and long term living experiences? )

If "No" Why?

If "Yes" is there an advocate - who is the person?
CONCLUSION

Thanks again for all his/her help.
Next step will put this information together with other information obtained and analyse the issues which seem to arise.
Possibility of a report detailing the information from the whole group.
Confidentiality will be maintained. Would they like a copy.

Check then OK for you to go onto the next stage of data collection.
17. INFORMATION GATHERING EXERCISES

INTERVIEW WITH DIRECT CARE WORKER

- leave out "General overview of facility", but ask about the people who live there - descriptions, numbers.

- activities that people get involved with (if not covered under variation of experiences)

- Quality of Life questions

SCHEDULE OF INFORMATION GATHERING EXERCISE

As you approach facility - "What impression do you get?"

1. Interview - manager )

2. - care giver ) Session 1

3. Spend a little time with person.
   Introduce self and why you are there.

Session 2

1a. Look around - with permission - kinds of facilities

   privacy/safety/access to community
   entertaining rooms/bedrooms only if invited

2. Kinds of activities - look at notice boards
   - talk with divisional therapist/similar if appropriate

3. Interactions between - staff and residents
   - staff and staff
   (any name, nicknames, calling, patronizing, verbal brutalization)
4. Appearance of residents.

5. **Spend time with a person** - Don't interrogate, let information flow freely.

Find out about:

a) how person spends time - kinds of things he/she does each day, weekly
   **VARIETY OF EXPERIENCES**

b) contact with relatives/friends  **SOCIAL INDEPENDENCE**

c) how do they find living there

d) what's the hardest thing

e) what's the nicest thing

f) about to have "own things" in room  **POSSESSIONS** Homelike environment.

g) **CHOICE** - if and with whom they share room.

h) Getting up and sleep times
   food  ) choice
   going out to community  )

Thank person for time. **DON'T PUSH** if person doesn't want to give you any
information - just observe.

On leaving facility both times - let Supervisor know you are leaving and make
arrangement for further visit and what you will want to do. Thank him/her
for help.

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<tr>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>28 Sept 83</td>
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**CHECK OUT**

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**RETURN DATE**

- 28 Sept 95
- 28 Sept 95
- 28 Sept 95
- 28 Sept 95
ROCHE, V.

Quality of life issues in residential services for elderly

Form 134/4/83