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**THE MEANING OF QUALITY IN LIVING SERVICE
ENVIRONMENTS :**

**AN ANALYSIS OF THE EXPERIENCES OF PEOPLE WITH DISABILITIES,
ELDERLY PEOPLE, AND SERVICE WORKERS**

Ruth Marquis

Student Number : 0917631

**A thesis submitted in fulfilment of the requirements for the
Award of Doctor of Philosophy (Human Services) at the
Faculty of Health and Human Sciences
Edith Cowan University**

Principal Supervisor

Dr Robert Jackson

Date of Submission

May, 1998

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

ABSTRACT

The purpose of the study was to examine the experiences of both people with disabilities and elderly people and to identify their perceptions of quality as it relates to living in a service or being supported by a service to live in the community. The study was naturalistic in design and used a phenomenological approach and inductive analysis. It involved immersion in living services for a two year period, in-depth interviews with people living and working in services and participant observation. Fifty service users between the ages of twenty-one and ninety-six, and twenty-six service workers between the ages of twenty-six and fifty-four were informants in the study.

The study comprised of three phases. The first phase involved repeated in-depth interviews with service users in two disability and two aged care living services to examine the experiences of people living in services and their perceptions of quality. As a result of the consistency with which relationships with key staff members emerged in the context of quality experiences, selected service workers who were named by service users were also interviewed. The findings in this phase indicated that relationships experienced by service users in their encounters with service workers were more significant in service users' evaluation of quality than tangible acts of physical and environmental care. Relational experiences of people living in services were variable. Some informants experienced consistent validation and socio-emotional support, whilst others experienced role distancing and negative communication experiences. Service workers who were interviewed as a result of being identified by service users in the context of quality, attached importance to the relational domain in the acts and behaviours of providing a service. They also attached personal meaning to their roles as

service workers and shared the view that their role as service worker was underpinned by an ethos of communality.

The second phase of the study involved accessing another five disability and five aged care services to collect further data to support or refute the findings from phase one. As a result a large data bank was established to confirm the consistency with which relational experiences in living services were linked to perceptions of quality by both service users and service providers. Acts and behaviours which were consistently present in the context of quality were also identified and the need for emotional support in the living context was further confirmed.

The third phase of the study involved an in-depth analysis and identification of commonly experienced categories of relationships between service users and workers. Relationships were categorised into ethical and technical living service experiences and exemplars used to illustrate findings. Data analysis indicated that service experiences lie on a continuum, with mutually supportive relationships between service users and workers at one end, and physical and psychological abuse at the other. Experiences were variable in singular service contexts. This highlighted the individual nature of service relationships between service users and workers and the need to articulate human service as relationship. It also highlighted the inadequacies of using standard measures to evaluate quality in living services.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief :

- I. incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;
- II. contain any material previously published or written by another person except for where due reference is made in the text; or
- III. contain defamatory material.

Signed :

Date : 15/9/98.

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Firstly, I extend my sincere gratitude to service user informants in this study who permitted me to enter and leave their worlds and trusted me to truthfully interpret their experiences. Your experiences will remain embedded in my consciousness and hopefully will touch the consciousness of readers. Thank you also to service worker informants. Your contribution to the lives of service users provides hope that lives can be improved by 'human' service.

Special thanks all my friends and confidential listeners and especially my key advisors, Carolyn Cusack, Alan Wilson, Heather Freegard, and all the other human service users and workers who responded to my requests for advice during the development of the study. Special thanks also to Romo Paul Janssen who has been an inspiration in 'walking the talk' of human serving.

My positive experiences of supervision from Bob Jackson and Margaret Sims were critical throughout the development and implementation of the study and writing of the thesis. The outcome owes much to Bob's critical comments, encouragement, and good natured debate which made supervision an enjoyable experience. Bob's extensive experience in the human service field has provided important guidance in the development of the study. Our relationship has been based on mutual respect and shared values. Margaret, who has been instrumental in my pursuance of doctoral studies, has always been a rock. She has provided a necessary feminist perspective, and has always been approachable and encouraging.

Finally, I would like to thank Don, Christopher, and Judith Marquis, for their constant love and support.

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This chapter will describe the legal and philosophical context in which the study took place, the purpose and significance of the study, a statement of the problem the study sought to address, and the theoretical perspective underpinning the research. Describing the legal and policy context of current living services for people with disabilities and elderly people will highlight the importance for a study of this nature which sets out to determine how policies are enacted through the day-to-day experiences of people living in services. It is particularly important to acknowledge the emergence of human service as large and highly regulated industries despite their philosophical underpinning in humanitarian values.

1.1 BACKGROUND TO THE STUDY

1.1.1 LIVING SERVICES FOR PEOPLE WITH DISABILITIES IN AUSTRALIA

Recognition of human rights has guided important philosophical and legislative changes in development of living services for people with disabilities throughout the world since the end of World War II. As a signatory to the Rights of Disabled Persons (1975) Australia has been obliged to ensure that people with disabilities are protected from discrimination and assisted to enable their independence and integration in all aspects of community life (Annison, 1996). Following the 1981 International Year of Disabled Persons which heralded changes in addressing the rights of people with disabilities world wide, the Australian Minister for Social Security, Senator Don Grimes, spearheaded a

national review of services for people with disabilities in Australia. A series of public consultations, involving extensive input from consumers of services and their families, resulted in the publishing of the New Directions Report of the Handicapped Programs Review (1985) followed by a key piece of legislation, the Commonwealth Disability Services Act (1986). The Disability Services Act articulates principles and objectives that set the framework for policy objectives for people with disabilities in Australia. The transition from institutional based to community based services became a major purpose of the Act and the policies surrounding it. The focus for organisations was now to give priority to consumer outcomes which embraced the principles of normalisation and community integration, rather than simply maintaining organisations to provide services.

In 1993, Western Australia enacted the State Disability Services Act which established an independent Disability Services Commission. The regulations created under the state Disability Services Act include principles and objectives based on legal and moral rights which form the bases for standards of service provision. Participation in decision making in service implementation is one of the main thrusts of the Disability Services legislation together with opportunities for personal development, income generation, the right to ensure that services are accountable to people with disabilities themselves, and other 'quality of life' outcomes which are common to other Australian citizens. People who require support to live in the community, according to the current legislation, have the right to control their day-to-day activities and lifestyles. As people's homes are

the core of social life, the home environment is primarily the place where life quality is most affected from both a material and relational perspective.

In the period 1996-97, there was estimated to be 305000 people with disabilities in Western Australia. Ninety-six per cent of people with disabilities lived in the community, either independently or with family or friends who also provided seventy-four per cent of all their assistance. Residential services were accessed through the Disability Services Commission for 2481 people. Of these 925 lived in community residential facilities (e.g. group homes), and 845 people lived in supported community living (community houses). The remainder lived in residential hostels (Disability Services Commission Annual Report 1996-97). The Commonwealth Government had developed standards, based on 'quality of life' indicators and measures, to judge organisations on the quality of their service delivery. A transition of responsibility for services from Commonwealth to State governments was effective by 1994, and it was now that the complexities and practical implications of assimilation of people with disabilities into the community were becoming known as people attempted to survive on limited social and financial support. Although policies and procedures had been carefully developed, and funding had been directed to meet the needs of people with disabilities, it had become clear that it was informal community networks which were also integral to the assimilation of people with disabilities into mainstream society.

The majority of funding for people who required support to live in the community was co-ordinated by large organisations which employed staff to

provide care and support. Smaller organisations had co-ordinators who supported individuals to employ their own workers, and a few people had direct funding and managed their own funds. The degree of autonomy in regards to who has the control of finances was varied. This had important consequences for people with disabilities who had high support needs.

Transitional accommodation services focused on deinstitutionalisation and relocated people from large congregated settings into smaller groups in suburban houses according to the principles of normalisation. Service development in this area embraced the group home model. group homes are characterised by shared facilities and staff. Staff work in rosters and might rotate between a number of different homes in the same organisation. The group home approach is mainly due to limited funding arrangements and high support needs of a number of people who previously lived in institutional services. This means that people with high support needs are required to share homes with other people with similar levels of support to enable sufficient care hours to be provided. People who live together are not always compatible, and there is no strategy in place for changing homes, when incompatibility causes problems for residents. Matching residents and staff in group home situations is complex. There is also a high turnover of staff and many casual workers, such as students, add to the complexity of the group home culture. Activity patterns in group homes are also largely dependent on the commitment, energy, and motivation of staff. There is considerable variance between group home settings with respect to the degree of 'normality' and sense of belonging of service users.

Some individuals from families who are no longer able to provide the necessary care, opt to live alone and have their services co-ordinated by small local agencies. Limitation in funding, and lack of social supports, result, for some, in many hours of solitude.

1.1.2 DISABILITY SERVICE STANDARDS

In 1992 a National Disability Services Standards Working Party was established to develop service standards and an associated monitoring process to meet the principles and objectives of the Western Australian Disability Services Act. Eleven standards were endorsed in 1992 by the Commonwealth Government which took effect from March 1993. Transfer of responsibility from Commonwealth to States in 1994 led to the development of State Standards for all services excluding employment services which remained the responsibility of the Commonwealth Government. These eight standards, which had been significantly developed from the previous Commonwealth Disability Service Standards form the basis of the monitoring process which is intended to achieve continuous improvement of services (Disability Services Commission, 1997). Monitoring teams comprising a representative of the Disability Services Commission in Western Australia and one or two independent service providers from other agencies are involved in visiting organisations and reporting on their compliance with standards. Consumer participation in the monitoring of quality assurance within services is stated as an integral element of the process. The emphasis on the standard monitoring process is towards the improvement of

services. Endorsement of the Disability Service Standards are the minimum requirements to be upheld by any service in terms of 'quality.'

In an attempt to discourage control of people's lives by service practices, a strong ethos of empowerment and choice permeates the standards. Encouraging empowerment and supporting people to make decisions and choices about daily events and long-term lifestyle issues is an important objective of the legislation, as is consumers' rights of involvement in decisions about how their needs are met. Services are expected to facilitate and encourage consumer control in day-to-day and life-style decision making, and the rights of each person to exercise control over his (sic) life is not to be restricted by the policies and procedures of the agency (Standards 2&3). A strong emphasis on service staff respecting consumers' choices and decisions, their privacy and dignity, is stated as well as the need for ensuring that confidentiality in records and personal information is not compromised (Standard 4). Consumers' rights to be supported in raising concerns about an organisation which does not provide them with appropriate services is also stated (Standard 7). Each agency has a responsibility to ensure that the best possible staff support is made available to consumers (Standard 8).

1.1.3 LIVING SERVICES FOR ELDERLY PEOPLE IN AUSTRALIA

People aged 75 and over are becoming the fastest-growing segment of the Australian population. The proportion of people aged 65 and over will comprise 12% by the end of the century and is predicted to escalate to over 20% by the year 2030 bringing an increase in the old-old age group of people (those between

eighty-five and one-hundred) increased morbidity, fewer informal supports as a result of the dropping birth rate, and a larger proportion of people who will access nursing homes and hostel environments (Rowland, 1991; Minichiello, Alexander, & Jones, 1992). As the biological changes of ageing become increasingly evident at ages greater than seventy-five to eighty-five years, the participation rate of people accessing living services will also demonstrate this trend (Blake, 1981; Andrews & Carr, 1990; Minichiello, 1990). The prevalence of dementia also increases to around 22% at ages eighty-five to eighty-nine (Preston, 1986; Jorm & Korten, 1988). In Western Australia 13.5% of the total population of 1.6 million, were aged sixty and over. This is projected to rise to 14.2% by the year 2001 and 23.2% by the year 2031. Although exact figures are not available, between 7% and 8% of people over the age of sixty live in residential services (Commonwealth Government of Australia, 1991).

Due to what was described by Rowland (1991, p. 22) as the "population momentum" the Australian Government has introduced individual packages of community options for elderly people to be cared for at home. This was influenced by the innovative community options program in the United States in Wisconsin (McDowell, 1990). Comparative research into residential and community options programs, however, has concluded that the capacity for carers and community services to support elderly people at home is limited when high levels of dependency and limited funding exist (Gray, Sims, Farish, & Sullivan, 1995). An increase in the ageing population, and increase in longevity as elderly people take responsibility for their health outcomes due to the influence of

health behaviour research findings, also paradoxically suggests that a larger population may access formal services, as genetically determined conditions which are not preventable lead to functional impairments in the later years of life.

The introduction of nursing home benefits in 1963 saw a doubling of the numbers of nursing home beds and a significant expansion of hostel accommodation between 1963 and 1985 (Department of Community Services and Health, 1986). In 1985, due to a number of major reports which criticised the aged care sector including the excessive concentration on institutional accommodation and the failure of facilities to match services to individual needs, a national review of nursing homes and hostels was established, also by Senator Grimes. Publication of the report: Overview and recommendations of the nursing homes and hostels review (1986) established a framework of reforms for aged care policies which shifted the emphasis to community care. A ratio of one hundred places per one thousand persons aged seventy or more was established for nursing homes and hostels (Sax, 1993). New systems of funding arrangements, separating direct care costs from capital costs, were also introduced which linked dependency levels of residents with staffing ratios.

By 1991, Commonwealth multi-disciplinary geriatric assessment teams funded by the Commonwealth Government and operating through State Health Services, covered the assessment of most of the population over seventy to match services to individual need (Bartlett, 1993). By utilising existing community services, the number of people accessing nursing homes reduced by fifty percent

from the previous process of medical referral. In general terms, people who are eligible for nursing home accommodation have multiple physical and/or cognitive disabilities which require ongoing medical and specialist intervention (Minichiello, 1990; Sax, 1993). Some people will live for many years in this accommodation, while others are admitted towards the final months and years of life. It is predicted that there will be a critical shortage of nursing home accommodation by the year 2006 if current policies in favour of increasing home and community care sectors continue (Gibson & Liu, 1996).

Nursing home environments are characterised by shared accommodation, although limited single accommodation is available in most places. Due to lack of space usually only a few personal items can be kept and many people have few personal possessions apart from perhaps a television, radio and personal photographs. Nursing homes operate on fixed daily routines and people congregate for meals and other activities. As funding for nursing homes is assessed on the physical dependency needs of individual residents, they are oriented towards the physical care of residents and employ large numbers of permanent and casual staff with a high turnover of workers. Recruitment and selection of service workers is the responsibility of the administrator and residents are not usually involved in the selection process. Nursing homes in Western Australia are either administered as not-for-profit, or to make profit from service users. Nursing home residents pay eighty-seven per cent of their aged pensions to subsidise costs. Both systems are also heavily subsidised by State and Commonwealth funding, however, current initiatives by the Howard

Government are considering entrance fees for nursing home accommodation which will be means tested. Entry to nursing homes is usually sudden, as a result of some medical trauma, and not through choice. It is also worth noting that euthanasia, both voluntary and assisted, is also on the political agenda at this time in history, presenting another ethical issue in the context of resourcing an expanding need for aged care services.

Some frail elderly people who have moderate levels of disability choose to live in hostel accommodation. Hostel services also attract government subsidies and charge entrance fees which are used to subsidise services, in addition to the weekly care costs of eighty-seven percent of the aged pension.

People living in hostels do not require nursing care but may require some assistance with activities of daily living. Hostel accommodation is characterised by single rooms and people are able to bring a few personal items of furniture and other personal possessions. Hostel residents use community facilities for medical and other needs and have opportunities to be more socially mobile. Many hostel residents maintain their affiliation to community networks and are able to live reasonably independently. Meals in hostel environments, however, are also provided centrally, and people congregate for meals and other activities. Recruitment and selection of service workers is similar to nursing home procedures and residents are not usually involved in the process. Hostel staff work in rosters and there is a tendency to rotate staff around different groups of service users on a regular basis.

1.1.4 NURSING HOME AND HOSTEL STANDARDS

Until 1987 the Commonwealth and State Governments each had systems of inspecting nursing homes to check compliance with design regulations, health and safety issues and staffing standards. In 1987 the Commonwealth Government implemented a system of monitoring 'outcome standards' and relied on the states for regulating the more tangible aspects of buildings, fire prevention and safety. The outcome goals which underpinned the Commonwealth monitoring process have a focus on 'quality of life' and quality of care, which were developed in consultation with service providers, consumers and professional sources (Lindemeyer, 1986). The thirty-one standards adopted to guide the monitoring process were grouped in seven categories of objectives related to health, social independence, freedom of choice, homelike environment, privacy and dignity, participation in a variety of experience, and safety. Standards associated with objectives specify the practices involved. Evaluation of compliance with standards is undertaken by a team of assessors who use participant observation, and interviews with staff and clients to assess compliance. Services which do not meet standards are given a period to demonstrate their willingness to comply, otherwise, they risk defunding.

Despite the positive contribution and the coherency of consumer participation in assessment of outcome standards, the vulnerability of consumers in the service context weakens the process. Frail elderly individuals are unlikely to complain about their treatment in services which sustain their physical and emotional viability. There is also a tendency for minimum standards to become accepted as

the overall measure of quality rather than providing the basic 'quality of life' outcomes. Also, generic 'quality of life' outcomes may not address the specific issues facing nursing home residents in their day-to-day service lives. There is a need to articulate the meaning, for example, of privacy and dignity for people living in nursing homes. People living outside service contexts, are not faced with the daily problems of maintaining a sense of personal identity while living in a service environment.

Following the Ronalds report (Ronalds, 1989) which highlighted numerous concerns about the processes and outcomes of nursing home life, a strategy for user rights in residential care was adopted by the Commonwealth Government (Commonwealth Government of Australia, 1989). The charter outlined rights including contractual agreements, between management and residents related to individual needs, grievance procedures, community visitors arrangements, and advocacy services.

From January 1991 similar outcome standards were introduced for subsidised aged persons' hostels. An amended standard was introduced in 1992 which especially addressed the need of people with dementia. Hostel standards place a strong emphasis on the improvement and maintenance of social skills, reduction of personal isolation, and the promotion of self-esteem and competencies (Sax, 1993). Training of staff who worked in nursing homes and hostels was also identified as a key quality issue by the Commonwealth Government (1991) and resources were directed towards the development and implementation of competency training packages at a national level.

1.1.5 SUMMARY

Disability and aged care services have become highly regulated and costly public industries. Policies have been developed to promote quality in the delivery of services and processes outlined to determine expenditure and continued financial support of organisations which provide services. National competencies have also been developed for workers in aged care and disability services to encourage the employment of trained workers. Although public consultations with consumers and families have been undertaken throughout the process of development of services in disability and aged care in relation to the development of service standards, research is lacking regarding service users' direct perspectives and experiences.

1.2 THE PURPOSE AND SIGNIFICANCE OF THE STUDY

In an ideal world families and community members would provide homes for vulnerable members of society. For numerous reasons, however, a significant number of people in Australian society live all, or part of their lives, in service worlds. There is an expanding need for services which provide homes for people. Due to an increase in the prevalence of disability caused by developmental factors, trauma, or ageing, services are required which sustain the viability of people who, without formal supports, are at risk of being uncared for.

Formal human services provide safeguards for vulnerable members of society. They have also become significant industries in the employment market. As an industry dependent on the welfare dollar, human services are required to be

accountable to the community at large. It is not surprising, in the current economic rationalist social ethos, that human service processes have followed the path of manufacturing industries in the development of measures or 'products' of services. Outcome based accountability which is linked to funding, has resulted in the development of standards and procedures which, if complied with, ensure the financial sustainability of services to continue to provide employment, and services, for a considerable number of people. Outcome oriented standards, however, although based on generic 'quality of life' constructs, may fail to address the fundamental issue that life in a service world may present different priorities in terms of 'what is important' in comparison to life outside of services. As a result, services may 'gloss over' or only superficially address some of the issues which are believed to be important by people living in the services themselves.

There is a need for a study to examine and raise consciousness to the range of experiences of people living in services and what is important to them in terms of quality. This will provide insight into whether quality, as it is articulated in policy documents and standards is coherent with the experiences of people living in services. Service lives are not 'ordinary lives' irrespective of how dreams of 'normality' of idealistic politicians and service providers may be. Service lifestyles are 'service specific' and as such, have other dimensions to day-to-day living which need to be understood by people designing and evaluating services. It is this meaning of living in a service which may form the most powerful quality life experiences for people who live in service worlds.

The issue of quality, therefore, also needs to be understood from the perceptions of people living in services. In Australia, people with disabilities and elderly people are the majority of people using services which provide support in daily living activities. By identifying the meaning of quality and describing quality interactions in services through a process of qualitative research, people living in services themselves have a voice. No other studies have been found which have investigated the experience and meaning of quality in residential services in Australia across disability and aged care contexts.

The purpose of this study is to give a voice to the people whose life experiences are controlled by what we, as service workers and community members, deem to be important. This is an effort to 'listen and learn' from the people, interpret the essence of their experiences, and identify what is important to them. The study also attempts to raise the consciousness of service administrators and workers to the potential to help or harm people whose social worlds are constructed around service contexts. Our 'jobs' are their 'lives'.

1.3 STATEMENT OF THE PROBLEM

Living services for people with disabilities and elderly people are complex social environments. Evaluation of quality outcomes for people living in services is routinely undertaken through monitoring processes. Yet, how much is understood about the shared experiences of people who live in services and what does quality mean to them? Therefore, the problem to be examined is:

What are the shared experiences of people with disabilities and elderly people who live in service environments and what are their perceptions of quality?

1.4 THEORETICAL PERSPECTIVE AND RESEARCH APPROACH

In order to address the problem a symbolic interactionist perspective based on naturalistic design and inductive analysis, and a phenomenological approach is adopted to gain informants' perspectives on quality. Theoretical issues will be taken up later in greater depth in the methodology chapter.

Symbolic interactionist theory presents a view that the construction of meaning is a product of the interactions between the self and others. A view of human nature as being reflective, creative and active, and the human capacity for reflection is heavily emphasised (Blumer, 1969). The meaning of living in a service and what is perceived to bring quality to the experience will depend on the value and definition the service is given by informants in the context of their day-to-day lives.

A phenomenological approach is one whose objective is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanations and as free as possible from unexamined preconceptions and suppositions (Speilberg, 1975). The purpose of phenomenology is to create a more thoughtful understanding of relating to, and, experiencing the world. As individuals need meaning, "phenomenology offers a way to arrive at that meaning" (Munhall, 1994, p. 215).

The study involved the analysis of interviews with fifty service users and twenty-six service workers in seven disability and seven aged care areas across twenty-four living contexts in the Perth Metropolitan area, and the immersion of the investigator in living environments over a two-year period. The study developed in three phases, the first phase being an in-depth examination of quality across four agencies which was then expanded to another ten agencies to validate findings. The third phase identified information rich cases for further analysis and description.

1.5 STRUCTURE OF THE THESIS

The first chapter is followed by a critique of literature on the history of the quality movement and different approaches to the measurement of quality in human service contexts. Literature on 'quality of life' studies for people with disabilities and elderly people is also presented. The literature presented in this chapter sets the context for the study. Significant literature is presented in the findings and discussion relevant to the emergent themes of the research.

Chapter 3 presents the rationale for the design of the study and describes the research sequence, sampling and procedures. Three further research questions are presented with rationale for their development.

Chapter 4 presents the findings and discussion. Major themes and sub-themes are described from the analysis of research interviews, observations and field notes. This chapter is in four parts, each addressing one research question. Relevant literature related to the findings is presented throughout this chapter. It

has been necessary to research a large amount of international literature due to the diversity of studies across the separate populations of people with disabilities and elderly people. Considerable literature is quoted from 1985-1990 as many studies were undertaken during this period of service change and development. Classical studies and philosophical views from earlier prominent writers are also used to strengthen the discussion. Throughout this chapter italics are used for direct quotes by informants which are either single words or phrases. Due to the lengthy description of major themes, sub-sections have been bracketed to assist the reader.

Chapter 5 concludes with further discussion of the findings in the context of different philosophical approaches in human services and their implications for service users and the evaluation of quality. Recently developed competency standards for workers in disability and aged care services are critiqued in the context of the findings of the study. Recommendations for service development are presented.

Chapter 6 presents as an epilogue, poetry and prose written during the research to enhance the reader's understanding of the experiential worlds of people living in services as their lives were experienced by the investigator. References and Appendices complete the thesis.

1.6 DEFINITION OF TERMS

AGENCY: A human service organisation accessed in the course of the study.

SITE: A living context auspiced by a human service organisation (e.g. group home).

SERVICE: A general term used as a noun to mean a human service organisation or as a verb to mean the acts performed in caring for people living in human service contexts.

GROUP HOME: A house in a suburb of Perth where a group of people with disabilities live and staffing and funding arrangement are controlled by a human service agency.

COMMUNITY HOUSE: A house in a suburb of Perth where one or more than one person with a disability lives. Services are co-ordinated by a service worker and individuals have control over employment of service workers, daily routines and activities.

NURSING HOME: A congregated setting for frail elderly people who require daily health care characterised by communal public areas and shared accommodation, although some single accommodation is available. Routine health practices have high priority.

HOSTEL: A congregated setting for elderly people who require some support with daily living activities characterised by single accommodation and communal

public areas. Meals are provided in communal dining areas and opportunities are available to be engaged in other activities through choice. Residents access local community services for health and social requirements.

SERVICE WORKER: A person employed to provide a service in a living environment for people with disabilities or elderly adults. No distinction is made in the study between professionally trained staff and support workers.

SERVICE USER: A person who requires assistance from a service worker in any aspect of daily life.

Chapter 2 will critique literature on the concept of quality in human services by exploring the evolution of the quality movement, the 'quality of life' concept and past studies in human service contexts for people with disabilities and elderly people.

2.1 INTRODUCTION: THE CONCEPT OF 'QUALITY' IN HUMAN SERVICES

According to Edgerton (1990, cited in Heinlein, 1994) quality is the human service buzz word of the decade. Goode (1990) suggested that the term quality of life as an outcome measure in the lives of people with disabilities, has achieved national and international notoriety whereas Osborne (1992, p. 438) suggested that "quality is not a thing but a concept and has no independent existence in the world". The multidimensional objective and subjective components of quality which influence individual and organisational expectations in human service settings, renders quality a complex concept to evaluate. Osborne also questioned the usefulness of the concept of quality in helping to understand service performance. To be useful, quality as a concept, according to Osborne, must be able to be operationally defined in the context of human services as "...both fit for its purpose and excellent in disposition" (Osborne, 1992, p. 439). The purpose of human services, as they relate to 'quality of life' experiences, can only be considered 'fit' by people who are directly receiving services. Service excellence is also an elusive concept, which may be the reason

that evaluations of services are commonly directed to tangible, material, quantifiable components, and overlook the more subjective aspects of service involvement or 'what it's like' to live in a service. According to Shea (1992, p. 143) recent emphasis on the evaluation of service quality has had a focus on '“good paper rather than good service or quality lives”'.

The quality movement has its roots in the manufacturing industry and has a priority in providing effectiveness measures in outcome statements. Focusing on performance indicators, however, is at odds with the fundamental values of human services which adopt a 'quality of life' approach based on humanitarian concern. Although the term 'quality of life' features prominently in human service literature, only a few research studies describing ways in which 'quality of life' can be enhanced have been reported and reports have been described mainly in abstract terms (Szalai & Andrews, 1980; Walker & Rosser, 1988; Mukherjee, 1989).

The operationalising of 'quality of life' into service outcome measures has been a feature of an economic rationalist approach to service delivery in the 1990s. The complexity of a 'quality of life' construct, as a human service outcome objective, was debated in the disability literature by Nirje (1969), Blatt (1979), Edgerton (1990), Schalock (1990b), Parmenter (1992), and Ralph and Clary (1993), whilst Luckasson (1990), Taylor (1990), and Wolfensberger (1994), cautioned that the 'quality of life' construct lends itself to the quantitative measurement of life value and may endorse a belief that some humans are more worthy of life than others. Used as a sensitising concept, however, 'quality of life' offers a useful direction

along which to evaluate the subjective experiences of people with disabilities in human services (Taylor, 1994).

'Quality of life' research in Aged Care services has also been the subject of considerable research over recent years (Nussbaum, 1983a; Pearlman & Jonsen, 1985; Osberg, Mc Ginnes, De Jong, & Seward, 1987; Grossman & Weiner, 1988; Lidz, Fischer, & Arnold, 1992). As the ageing population in Australia increases, there is also a danger that 'quality of life' measures may be used as decision making tools for access to medical interventions and human service programs. The 'quality of life' construct in the aged care arena, is even more likely to be misinterpreted in the current economic rationalist context, to conform to resource availability as an ageing population places large demands on public welfare funding.

Although the quality movement and the 'quality of life' movement have similar and competing values, in relation to what issues are important in human service delivery, both operate in heavily controlled bureaucratic systems which are largely concerned with the protection of the public interest and the use of funds. Evaluation procedures in human services also uphold this reality and have direct implications for the current and future lives of people living in services. It is important to understand how people in services experience quality in the current political climate which is characterised by expanding human service systems which are becoming increasingly complex and bureaucratic in their decision making, and further removed from the day-to-day realities of service users.

2.2 A CRITIQUE OF THE QUALITY MOVEMENT IN HUMAN SERVICE EVALUATION

The quality movement was founded on measurement which can be traced back to early civilisations and standards of weights and measures. One of the foundations of quality control owed its origins to early printers such as Caxton and Guttenberg who developed interchangeable parts for printing presses, allowing the distribution of books. The concept of quality and its relationship to technology is therefore deeply embedded in history. Quality assurance has also strong links with the armaments industry and the mass production manufacturing processes which were developed in the 18th and 19th centuries. The World Wars further developed quality inspection systems and the influence of armament manufacturing is still evident on quality assurance and accreditation systems (Dickens, 1994).

The link between technology and quality mirrored the emergence of a Cartesian world view, and the mechanistic paradigm which popularised medicine as science and human beings as machines constructed of separate parts. Current human service models, which have been influenced by medicine, also direct their funds towards the solution of human problems within the Cartesian framework and may view the person as separate to the problem. This is reflected in the growth and development of a variety of specialised human services and the use of objective measures to assess quality.

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An increasingly competitive situation in public services has led to the development of human service delivery as an industry. Viewed as an industry, human services are at the 'high process-low product' end of a continuum, with people becoming raw material who trigger a production process of 'care'. According to Vuori (1982), human services could be subjected to quality control procedures, whereas Dowson (1991, cited in Dickens, 1994, p. 36) suggested that human service users "have varied and flexible needs which cannot be provided within the framework of conventional management models of service". In agreement with Dowson, Sundram (1994) suggested that mechanistic standards and rigid processes have not only created a lot of work but averted attention from consumers. According to Sundram, large scale systems destroy innovative practices and may give an illusion of development by changing language and terminology while leaving the underlying reality unaffected.

Schwartz (1992, p. 153) also alluded to the limitations of objective measures and suggested that "people who believe in regulatory control working could be accused of 'magical' thinking". Heavily controlled bureaucratic systems are different from social movements and personal caring relationships. As idealistic and caring people are drawn to moral enterprises and people in need, they tend to be driven away by bureaucratic machinery. Social regulation is often founded on protectionist doctrines and regulatory procedures which largely serve the viability of providers and the public interest (Jacobson, 1992). Normann (1991, cited in Osborne, 1992) has drawn attention to the links between quality of service and organisational survival for service producers. He discussed the

moment of truth in service interactions as the direct interaction between the primary service worker and service user. It is the success of this relationship, according to Norman, which leads to service user satisfaction and service survival.

Current management literature placing emphasis on efficiency, effectiveness and quality has influenced human service practices. Services now need to demonstrate that they are of sufficient quality to justify their continued existence. In addition, financial constraints on public spending due to a recession in the world economy, has led to competitive tendering of services. This leads to greater management control through contracting processes and a priority in providing outcomes to prove effectiveness.

Along with the quality movement, other significant changes have influenced the values, organisation and culture of services. These include the ideology of community care, the 'deprofessionalisation' of services and the self-help movement. The growth in consumerism in industry also has its counterpart in human service environments with the growth of the consumer and advocacy movement which evolved around forty to fifty years ago when a shift in widely accepted values took place across Europe and the United States. This weakened people's faith in authority and the motives of professional groups generally, leading to concern for professional and institutional practices (Sedgwick, 1982; Williamson, 1992).

Consumer satisfaction with service delivery is now accepted as a key issue in service delivery outcomes. Consumer satisfaction measures as a means of involving service users in the quality process, when they are quantified, are characteristically outcome focused and based on an assumption that predetermined service objectives accurately define the needs of people receiving services. Human service measurement is a value based procedure and as such is prey to the different interests of service users, providers and society at large. The focus of measurement and the paradigmatic approach will by nature favour particular interests over others.

The growth of human service systems as complex bureaucratic structures responsible for large numbers of workers and service users has also paved the way for the adoption of a management culture in human services. Implementation of quantitative measures and statistical analysis of service outcomes was a logical development, as quality management theories influenced manufacturing industries in the 1980's (Crosby, 1979; Deming, 1982; Taguchi, 1986; Juran, 1988; Dickens, 1994). The major thrust on the early development of standards of quality also came from the manufacturing industry where demand for interchangeable parts for weapons with predictable performance, required the development of criteria for inspection and monitoring performance against pre-determined standards. It soon became clear that building in quality from the start of a process was economically advantageous rather than a post-hoc approach (Crosby, 1979). The pre-eminence of quality as the topic for management and industry in the 1990's has resulted in human services joining the bandwagon

'total quality management approach' which stresses quality as the responsibility at all levels within an organisation (Dickens, 1994). This merges with wider issues of leadership and organisation culture.

As total quality management has a focus on team building and organisational loyalty, it could be argued that, as an enculturation process for human service workers, it lacks the essential involvement of service users and creates cultural divisions between workers and users. This top down management approach to quality may intensify the inequalities between service users and providers. The failure of upper management to have personal involvement in the process is also suggested by Juran (1994, p. 23) as being "significant in the failure of total quality management initiatives". Peppers and Rogers (1993) emphasized dialogue and interaction with consumers to determine what consumers really want from services, acknowledging the relational context of quality. The essential element of a total quality management approach is its emphasis on the involvement of workers' values and attitudes in the development of a quality service. The evidence suggests that superficial organisational change occurs as the result of a total quality management approach whilst organisational culture at a deeper level remains unchanged (Collard, 1989; Cormack, 1992; Bright & Cooper, 1993).

Another approach to control quality in industry by bringing employees at all levels into decision making processes was referred to as quality circles (Robson, 1984; Lawler, 1985; Oakland, 1989). Attempts to utilise this technique in human services incorporating O'Brien's five service accomplishments (O'Brien, 1987b)

and involving service users and families in the process have been described by Howell and Abbot (1990). Although common vision and values may be built through group consensus and service user-worker relationships strengthened as a result of collaborative discussion, quality circles are difficult to facilitate and require skilful group leaders with sound knowledge of group dynamics to achieve the involvement of all members. Service users and families as vulnerable recipients of services may also find such groups intimidating.

Seminal works in the service industry field by Rosander (1990) and Zeithaml (1990) discussed the differences between service industries and manufacturing industries. Service industries have intangible elements which do not lend themselves to precise measurement. Performances differ from provider to provider and as such are difficult to standardise. As human interactions are the context of human service systems, delivery within organisations may have considerable variation. Human services also involve direct interactions between service users and workers. The nature of the service relationship is at the heart of quality and users' experiences of these interactions will influence their perception of quality (Brown, 1993a). In specific service contexts, such as living environment services which provide long-term support for people with chronically disabling conditions, the relational context of the service is likely to be even more significant in service users perceptions of quality. The use of management methods to evaluate service quality in these contexts have considerable limitations. Human services cannot be measured using the mechanistic methods of production line industries as the values which underpin

services are essentially humanistic and do not lend themselves to reductionist approaches. In order to evaluate quality in human service contexts qualitative methods must also be used and in-depth analysis of the experiences of people who use human services acknowledged as a significant contribution to human service research

In recognition of the difficulties in measuring quality in human services and the significance of service user satisfaction in evaluation processes, Zeithaml (1988) developed a measurement tool which attempted to objectively measure the satisfaction of service users (SERVQUAL Zeithaml, 1988). The original ten dimensions of SERVQUAL following factor analysis, produced five factors of importance to users of services, one of which 'empathy' denoted the importance of interpersonal relationships. Cronin and Taylor (1992, cited in Dickens, 1994, p. 24) questioned equating service quality with service user satisfaction, and suggested that satisfaction was a transient measure specific to particular situations whereas service quality was a form of attitude. They favoured an experienced based approach to service quality which they believed was an antecedent of service-user satisfaction. Other authors also emphasised the significance of the interactive aspects of service involvement beyond the core functions of a service and acknowledged the intangible nature of the relational context and the difficulties of measurement (Lehtinen, 1991; Schvanveldt, 1991). As service users' experiences are so closely linked with service quality, service users are an integral part of the process. Davidow and Utall (1989, p. 194) stated:

setting up service standards and monitoring variations in service production, just as companies monitor variations from a set of technical standards when manufacturing a product, is a myopic way to control service quality.

Human services are founded on values which stress altruism, spiritual development and the relief of human suffering (Dickens, 1994). Human service values, however, may not be articulated as a conscious level (Wolfensberger, 1987). The rise of professionalism and attractive career paths for service workers may even attract workers into human services who have not internalised the value systems so necessary for human services to operate with humanitarian philosophies at their vertex. In human service systems, unlike manufacturing industries, choice may not be made by the service user but by another acting on their behalf. The uniqueness of the interpersonal caring relationship in the service process also renders a management model approach incoherent with the value base of human services. Care is not a commodity which is coherent with outcome based production line systems. An emphasis on input rather than outcome and the importance of service user and provider interaction processes is the basis for quality in human services (Whittington, 1989). The influence of values, attitudes, professional enculturation and stereotypes about service users will influence the interactions of service workers and their behaviours towards service users in the process of serving.

Despite the subjectivity of the human service process, systems have been developed with the intention of statistically analysing quality in services. In

deference to the highly subjective 'soft' elements of serving which are concerned with values, attitudes and interpersonal behaviour, as opposed to the 'hard' elements which are procedurally oriented, measurement tools have included aspects of the interpersonal and ethical elements which characterise human services (Donabedian, 1980; Maxwell, 1984; Zeithaml, 1988; Dale, Lascelles, & Plunkett, 1990).

The collection of performance indicators was another approach which tabulated measurable indices of performance in relation to service standards. The main benefit of performance indicators was the management of staff ratio, and, although popular, they had little predictive power in the benefits of a particular service to service users, although in some instances where services may be critically understaffed they have been used to demonstrate service gaps. Performance indicators may also have the unintended consequence of over regulating worker interactions with users of services, as they are task oriented indices. Service interactions may become rigid and unspontaneous as a result of the introduction of indicators, with service workers performing to meet the needs of the performance indicators rather than the needs of service users. This diverts workers from the essential nature of a 'human' service, which requires a spontaneous approach which is flexible to the diverse needs of users of services.

Although performance indicators were originally developed to compare services to judge comparative performance, indicators can also be developed around service standards which are linked to legal requirements, professional practice, statements of values and philosophies. According to Vladeck (1980, p. 155),

“The need for government regulations arises from the weakness of consumers”. This is currently a popular way to evaluate human services in Australia . One of the main problems with this, is the abstract and ambiguous nature of some of the qualities required of services which do not lend themselves to definition as simple behavioural objectives. The articulation of standard statements also lack explanation of the order of importance of service issues. It is simpler to quantify simple and tangible behavioural outcomes such as 'performing daily care activities', rather than 'treating people with dignity and respect'. As a result, important qualities from the perspective of people receiving services may be overlooked or ignored. There is also a problem that standards become norms in themselves, rather than a basis for continual improvement. This is particularly relevant when standards are used for funding contracts and involve considerable documentary evidence.

The definition of service users' requirements as they are articulated in standard statements are also strongly influenced by professional values. The practice of peer review to monitor standards amongst agencies, further supports the investment that professional groups have in accrediting formal service arrangements. Connection between standard monitoring and day-to-day improvement in practice was questioned by Bible (1976), whose research demonstrated that although there were significant improvements in service user/worker interactions during visits by a monitoring team, this was immediately reversed once the monitoring exercise was over. The 'snapshot'

nature of team observation cannot accurately gauge the actual and lasting experiences of service users in their interactions with workers.

There are no universally accepted criteria of service quality in human services (Knoll, 1990). The literature supports the position that measures of quality in human services which have been adapted from manufacturing industries have characteristics which are inherently flawed in their application to human services. Furthermore, a systems approach to measuring quality in human services may divert service workers from personal interactions with service users both in allocation of time and in encouraging a focus on regulatory procedures and documentation. Although service standards attempt to address some of the values underpinning services, the monitoring process can only at best present a cursory assessment of the experiences of people living in service environments.

2.3 'QUALITY OF LIFE' RESEARCH IN HUMAN SERVICES

2.3.1 PEOPLE WITH DISABILITIES

'Quality of life' is the conceptualisation of the 'fit' between a person and meaningful life experience. 'Quality of life' is a subjective concept in relation to the person whose quality of life is in question. Despite this, the term 'quality of life' has been accepted as a universal description within human service systems as an indication of satisfaction with living experiences.

Various approaches have attempted to conceptualise and measure 'quality of life'. Flanagan (1978: 1982) demonstrated that six areas showed the largest

correlation coefficients with over-all 'quality of life' in relation to how well needs and wants were met, using a normal population in the United States. Flanagan's study, involving three thousand subjects, concluded that material comforts, health, work, active recreation, learning, and creative experience were generic 'quality of life' indicators. According to Flanagan, a person's 'quality of life' should be evaluated according to their personal needs and values rather in some centralised way.

Richardson (1981) when analysing literature on 'quality of life' for people with learning disabilities in Britain, America and Scandinavia, suggested that there was a need to research the way in which recipients of services were affected, in the context of their interpersonal relationships and activities, by the environments they experienced. Despite living in a homely environment, having access to community facilities and being looked after by caring staff, people with disabilities might still have unmet needs which were difficult to express and fulfil (Stanley, 1988). This view was supported by Parmenter (1992) as particularly relevant in the current Australian political climate where legislative and bureaucratic forces are shaping the future for people with disabilities

During the 80's 'quality of life' research for people with disabilities focused on gains in adaptive behaviour or increase in level of skills as being an indication of 'quality of life' status (Campo, Sharpton, Thompson, & Sexton, 1997). 'Quality of life' indicators such as autonomy, security, and interpersonal relationships have been defined by Lind (1980) as integral to 'quality of life' experiences, however, few observational studies exist to validate the complex patterns of

interaction by which these life qualities can be investigated (Clark, 1989). Subjective values of lifestyle satisfaction also require consideration in the study of 'quality of life' (Schalock, Keith, Hoffman & Karan, 1989; Perry and Felce, 1995). 'Quality of life' is best understood from the perspectives of the person and embodies feeling of well-being and fulfilment (Schalock, 1996).

Another common perspective of 'quality of life' studies was the acceptance of pre-determined aspects of service design as the basis for evaluating programs which were assumed to improve 'quality of life'. In an attempt to understand the outcomes of community integration programs for people with disabilities, multidimensional models involving subjective and objective components based on community adjustment constructs have been implemented by a number of researchers e.g. Halpern (1985), Halpern, Nave, Close and Nelson (1986), Brown, Bayer and McFarlane (1989), Borthwick-Duffy (1992), Schalock (1990), Felce and Perry (1995). A person's interaction with her/his environment was addressed in the domains of occupation, residential environment, social support and personal satisfaction. Quality of service has also been linked to 'quality of life' (Heming, Lavender, & Pill, 1981; Seltzer, Sherwood, Seltzer, & Sherwood, 1981; Schalock, 1990; Henry, Keys, Balcazar, & Jopp, 1996).

A number of studies from a social ecological perspective have been undertaken in Australia, the United Kingdom and North America as a conceptual framework for evaluating the effects of institutional reform and deinstitutionalisation on people with disabilities (e.g. Crawford, Thompson, & Aiello, 1981; Kiernan, 1981; Stucky & Newbrough, 1981; Murrell & Norris, 1983; Edgerton, 1984;

Parmenter, 1988; Goode, 1988: 1991; Parmenter, Briggs, & Sullivan, 1991; Schalock, 1991). Resident-oriented variables were measured and compared with environment oriented variables, to determine the best 'fit' between person and environment. This represented a shift away from the individual to the wider social system and reflected the interdependence between the person and their environment also reflected in the World Health Organisation classification of impairment, disability and handicap (1980). In keeping with current philosophies on fostering community relationships for people with disabilities, the 'person-environment fit' addressed interactions between people and the wider social system and the service system itself was not an emphasis of research. For people who live in services, the service system provides another layer to their social ecology. Experiences of people in their interactions with the system, also needs to be considered. Because services are monitored and funded according to ideological principles does not guarantee that quality interactions will be experienced by people living in services. The quality of their relationships with people in the service system will also influence over-all 'quality of life'. 'Quality of life' measures have mainly adopted objective criteria which evaluated quality in terms external to the experience of life, by equating welfare to socio-economic status, or interpersonal behaviours as a measure of well-being (Osborne, 1992). There is currently general agreement that 'quality of life' is the interrelationship among multiple environmental and personal factors (Hughes & Hwang, 1996).

Rescher (1972, cited in Osborne, 1992) argued that there are two domains related to 'quality of life' being the conditions of life and the experience of life. This was interpreted by Robertson and Osborne (1985) as 'welfare' and 'happiness'. Welfare represented the needs of the individual in society, whereas happiness was related to their subjective well-being. Well-being was defined as having three components, being, life satisfaction (a cognitive self-assessment of progress) self-esteem (a basic feeling of self-worth and an acknowledgement of strengths and weaknesses) and happiness (a transitory mood of life satisfaction) (Abrams, 1985; Davies and Challis, 1986, cited in Osborne, 1992). Parmenter (1992, p. 249) cited Goode (1988) as suggesting seven major 'quality of life' categories, being, social, life domains, life events, psychological/psychosocial, over-all quality of life, and outcome behaviours. Objective, subjective and combined measures related to these categories have been classified by other researchers (Brown, Bayer, & MacFarlane, 1989; Parmenter, 1992).

Schalock (1991) suggested that a person's perceived 'quality of life' resulted from three aspects of life experiences: personal characteristics, objective life conditions and perceptions of significant others. Schalock's model conceptualised two main 'quality of life' areas, being, the 'quality of life' for people in general and the 'quality of life' of individuals from their own perspective. Schalock's model, used a structured interview format and was based on a four factor scale addressing independence, productivity, community integration and satisfaction. Schalock (1991) supported a view that 'person-environment match' may be a more appropriate paradigm than 'person-

environment fit' in relation to 'quality of life' research. Structured interviews with people with cognitive impairments, however, are problematic and obtaining the individual's own evaluation of 'quality of life' is a greater challenge because it requires an ability to understand questions and express feelings (Borthwick-Duffy, 1990). Involving other people to reply on behalf of people with cognitive impairments has also been shown to be unreliable (Cummins, 1992; Perry & Felce, 1995b). Any interpretation of an individual's 'quality of life' requires an understanding on a personal level what people's experiences are (Taylor & Bogdan, 1996). This requires long-engagement and in-depth knowledge of the person concerned. Individuals reliant on service systems may also be under social pressure to suppress dissatisfaction with services in evaluating 'quality of life'.

Many researchers have grappled with the development of a universally accepted conceptual model to measure 'quality of life'. An individual's unique perspective confounds the development of models which can be applied across populations (Hughes & Hwang, 1996). In criticism of the values underpinning the development of 'quality of life' standards, and questioning the ethnocentrism of the development of measures Galambos (1996), and Taylor and Bogdan (1996), cautioned that conceptual models of 'quality of life' may project Anglo-American, middle class values.

Human services literature proliferates with studies on 'quality of life' outcomes in living services for people with disabilities which used objective criteria based on social and psychological indicators to evaluate quality (Raynes & Sumpton,

1987; Stanley & Roy, 1988; Cattermole, Jahoda, & Markova, 1990; Conneally, 1992; Osborne, 1992; Flynn, 1994). Studies have had a significant focus on the transition from institutional environments to community living in which 'quality of life' indicators have largely been depicted by behavioural changes, increased opportunities for involvement in valued roles and activities, and consumer satisfaction with service delivery. A number of instruments employed to attempt a subjective measurement of 'quality of life' in human services, although providing relevant quantitative data for use by service administrators and funders, were unable to provide in-depth information which increased understanding of the lived experiences of people using services in their day-to-day interactions (Campbell, 1981; Murrell & Norris, 1983; Borthwick-Duffy, 1992; Schalock, 1990; Felce & Perry, 1995). Outcomes that reflect the person's interactions with their environment might be a more valid way of determining service outcomes (Bronfenbrenner, 1979; Landesman-Dwyer, 1985; Brown, Bayer, & MacFarlane, 1989; Goode, 1991). 'Quality of life' is significantly impacted by the caring and bonding of caregivers, peers and friends in a person's daily context (Stark & Faulkner, 1996).

A number of instruments which assess 'quality of life' related to environmental characteristics exist (McLain, Silverstein, Brownlee, & Hubbell, 1979). PASS and PASSING (Wolfensberger & Glenn, 1975; Wolfensberger & Thomas, 1983) were paired by an underlying ideology by incorporating the principles of social role valorisation into evaluation practice. Although PASS and PASSING provided important objective quantitative measurements of program coherency

in relation to the underpinning ideology, they did not have a major focus on the interpersonal interactions between people in services which also influenced 'quality of life' experiences. The evaluations focused on content, setting and administration of the program, and had multiple foci on roles and activities within the service setting and the interconnectedness of the service with the external environment. Service users themselves were not involved in evaluation outcomes leaving an important area of information unaddressed.

There is general agreement that there is little relationship between objective social indicators and self-assessment of well-being, life satisfaction and life quality (Ingelhart & Robier, 1986; Lewis & Ryan, 1986 cited in Parmenter, 1992). Social and psychological indicators are problematic in that 'quality of life' is measured at one point in time and skewed towards socially desirable factors. The relationship between personal satisfaction with life and societal welfare is not clearly determined (Parmenter, 1992). The meaning of 'quality of life' to an individual is a difficult concept to determine.

In developing a conceptual model of 'quality of life' using a client and sponsor questionnaire Brown, Bayer and MacFarlane (1989) defined 'quality of life' as the discrepancy between a person's achieved and unmet needs and desires, and also the degree to which people have control of their environments. In Brown's study, formal and informal supports were seen as crucial in determining the quality of the environment, and the model contained items which objectively addressed service philosophies and attitudes and subjectively addressed perceived supports and personal satisfaction. Brown has used the information

deriving from the model as grounding for discussion on future development of services rather than as an end in itself. This is in response to the views of Emmerson (1985) who advocated that evaluation research should be specific to individuals in their environments rather than focus on outcomes based on adaptive behaviour. Recent longitudinal studies in Canada based on Brown's model (Brown et al., 1989) involving two-hundred and forty people across five agencies showed that not many gains were made over a three year period. Most people's subjective concerns related to starting and maintaining relationships. Although subjective concepts such as freedom of choice and happiness were important variables in Brown's model, they did not rate as highly as those from which 'hard data' could be obtained. There was little discussion about the interactions of people with others in their environment and their degree of autonomy (Parmenter, 1992).

Following on from Brown's model, Goode (1991) developed a similar model based on social research and policy. Goode's model upheld the position that 'quality of life' is specific to an individual's environment and basically the product of the relationships between people in each life's setting. This placed an emphasis on the interactional environment of settings such as living services, where people's interactions have more potential for significantly influencing happiness. Goode also suggested an ethnomethodological approach to assessing the 'quality of life' of people with disabilities in living services including the 'quality of life' of staff, recognising the influence of the relational context of services on people's lives. The use of observational methods which captured the

richness of relationships people form with others in their environment and greater involvement of researchers in the research context, was also suggested by Goode as important in understanding the experiences of people with disabilities and significant others in their lives.

Knoll (1990) discussed the rationale for the development of standard measures as having been integral to the development of programs which supported deinstitutionalisation and suggested that current evaluations of 'quality of life' have shifted to a focus on community integration and the development of individualised support systems. It has often been the superficial elements of community living that has been the focus of attention on 'quality of life' studies for people with disabilities, rather than the degree of autonomy and quality of interpersonal relations (Parmenter, 1992). Romney (1994) suggested that future research required researchers to dispel the myth of uniformity in favour of individual variability in studies of 'quality of' life. Taylor and Bogdan (1990, cited in Schalock, 1990) suggested that as 'quality of life' was not the focus of study for people without disabilities, care needed to be exercised in studying people with disabilities as they may run the risk of being singled out even more as 'different' and dehumanised.

Goode (1991) argued that 'quality of life' was the product of relationships between people in a variety of life settings and cautioned about the generalization of 'standards' of quality. The richness of the relationships experienced by people in their environments, and reflection on their 'real' social identity as it is experienced by them, according to Goode (1991) may provide a

more insightful investigation of 'quality of life'. This required researchers getting much closer to the people themselves.

Addressing what quality of life actually means for people with developmental disabilities from an epistemological perspective may be of more value than pushing ahead too quickly with the development of indices that may manifest theoretical definitional, operational and methodological problems (Goode 1991, cited in Parmenter, 1992, p. 256).

Other studies using Goode's procedures have been implemented in Finland and Sweden to develop instruments which can be used to test the capacity of services to meet the expressed needs of clients. The essential ingredient of 'quality of life' is defined by the Swedish researcher Dugge (1990, p. 7) as "the worthiness the person experiences in his/her specific situation". The use of people with disabilities, themselves, in the development of measurement tools was positive but the use of instrumentation once formalised also may have had the tendency to present a 'one size fits all' approach to 'quality of life' and subjective components-were likely to have lesser value in the search to apply a recipe for 'neat' research.

Turnbull and Brunk (1990, cited in Schalock, 1990, p. 191) suggested that 'quality of life' is measured by relationships:

... the extent to which people choose to be with each other,
the ways in which they give form to their choices to be with
each other, and the nature, extent, and duration of their

relationship. For people with disabilities who have less opportunities to develop non-service relationships, people working in services become key people in the way they experience a relational life.

In keeping with the view that people themselves were the most accurate source of information, a symbolic interactionist approach has been suggested by other authors as a way of gaining insight on the meaning of having a disability from the perspectives of people with disabilities themselves (Barton & Tomlinson, 1984; Taylor & Bogdan, 1984; Parmenter, 1988). From a symbolic interactionist perspective the existential nature and the social nature of living with a disability may be in conflict with each other. From this perspective, 'quality of life' represented the degree to which people meet their needs to create their identities.

Quality of life represents the degree to which individuals have met their needs to create their own meanings so they can establish and sustain a viable self in the social world (Parmenter, 1992, p. 267).

Parmenter also suggested that a symbolic interactionist approach to 'quality of life' would essentially include three components for people with disabilities. Firstly, the person's perception of self, secondly their behavioural responses to ecological situations which influence them, and thirdly the responses that the setting might make to the individual. As well as the emphasis on material and occupational well-being, Parmenter emphasised autonomy and self-determination and social interaction relationships. The strength of Parmenter's model, if models

can be applied at all, lay in the emphasis on how people with disabilities perceived themselves, and there was much stronger emphasis on involvement of the individual as defining the major determinants of their 'quality of life'.

In support of a symbolic interactionist perspective, other authors have taken a view that the concept of 'quality of life' has no meaning except from the experiences of individuals as 'quality of life' means different things to different people (Taylor & Bogdan, 1990). Ethnographic studies involving the analysis of in-depth interviews and participant observation, although methodologically challenging and often highly time consuming, provided rich accounts of how individuals with disabilities experience their lives (Taylor & Bogdan, 1990). Research of this nature permitted others to learn from people with disabilities themselves about their lives, and recognised the value of their experiences in evaluating what is 'good' or 'not good' about living in a service. Longitudinal ethnographic studies involving patterns of self-reported life satisfaction over time have demonstrated the importance of intrinsic factors rather than objective environmental variables in an individual's perception of 'quality of life' (Edgerton, 1996).

According to Goode (1991, p. 5), superficiality in thinking on 'quality of life' serves "... rhetorical, political and professional purposes, but does not help people with disabilities achieve a better quality of life". There is a danger that the research process can abet the aims of pressure groups while contributing little to the lives of people living in services. Goode also suggested that the term 'quality of life' is seductive in its simplicity and there was a need not to overlook the fact

that 'quality of life' for people with disabilities was embedded in the wider society. Blatt (1979) has exposed the abuse of people with disabilities as a result of their isolation from the general community, yet often for people with disabilities their experience of community becomes a service program rather than the spontaneous and informal associational life which characterises non-disabled life.

In evaluating group homes for people with intellectual handicaps, over a three year period Felce and Toogood (1988), Felce (1989), and Perry and Felce (1995), concluded that friendships outside family or staff remained limited and people's contact with the general public was almost entirely at a casual acquaintance level. Other research supported these findings (Todd, Evans & Beyer, 1990; Barlow & Kirby, 1991; Clegg & Standen, 1991; Emmerson, & Hatton, 1996; Rapley & Beyer, 1996). People who acknowledged the problems of the associational lives of people with disabilities proposed that intentional communities for people with disabilities might positively affect their 'quality of life' by expanding their opportunities for long-term relationships (Vanier, 1979; Turnbull, 1990). Attitudes of staff towards people with disabilities may also have inhibited their social integration and 'quality of life' experiences (Parmenter, Briggs, & Sullivan 1991; Grant, McGrath & Ramcharan, (1994).

More recently, international researchers have shifted their focus on the meaning of 'quality of life' for people with disabilities as it was reflected in their sense of self, personal efficacy, belongingness and relationships. (Holm, Holst, & Perl, 1994; Parmenter, 1994; Woodill, Renwick, Brown, & Raphael, 1994). A number

of authors have agreed that 'quality of life' could not be assured through prescriptive regulations due to the subjectivity, cultural differences and transient nature of 'quality of life' (Edgerton, 1990; Goode, 1990; Heinlein, 1994). Any research on 'quality of life' required the researcher to suspend class biases and personal assumptions and pursue the meaning of 'quality of life' from the values and beliefs of the people concerned (Taylor & Bogdan, 1996).

A person-centered planning approach shifted the focus from organisational outcomes to person-centered outcomes as a quality measure (Goode, 1990). This required maximum flexibility in the delivery of services. Researching 'quality of life' in populations where participants have severe cognitive impairments was also difficult (Borthwick-Duffy, 1990; Rosen, Simon, & McKinsey, 1995). A study by Parmenter et al., (1991) demonstrated that subjective measures of life satisfaction and happiness could be addressed in populations with severe levels of disability although the study used an interview schedule and did not involve lengthy engagement over time with people with disabilities to observe their lives and interpret their experiences. Providing information on quality in the lives of other people is always open to personal interpretation and bias. A key factor in research which used informants other than people with disabilities themselves was having a level of intimacy which develops from continuity in relationships and a positive attitude towards the person involved. Predicting preferred activities for people with severe cognitive impairments required long engagement and knowledge of the individual (Newton, Ard, Horner, & Toews, 1996; Taylor & Bogdan, 1996).

The major current trend in supporting people with disabilities and the shift from a programming approach towards supporting personally valued life outcomes has become a focus of study. A recent study by Campo, Sharpton, Thompson and Sexton (1997) involving sixty adults with severe cognitive impairments examined interrelations among personal lifestyle characteristics and community-home program characteristics with 'quality of life' factors concluding that 'quality of life' experiences by study informants related to personalised opportunities and autonomy. The significance of family and friend networks to 'quality of life' was also highlighted. In discussing the important role of staff attitudes in generating opportunities for people with disabilities, Campo et al., (1997) concluded that the holistic structure of the environment rather than staff training or competence per se was a key factor emerging from the study. An increasing number of advocates and people involved in service development have called for service workers to become more involved as facilitators in the relational development of people living in services (Knoll, & Ford, 1987; Newton, Ard, Horner, & Toews, 1996; Campo et al., 1997).

Research on 'quality of life' issues for people with disabilities until recently has focused on the development of models which attempt to provide psychometrically sound data collection instruments which were applicable across populations. There is general agreement that a discrepancy exists between objective and subjective elements in 'quality of life' research. The focus of research has shifted from objective indicators of program outcomes to more closely examine the subjective experiences and perceptions of people with

disabilities, however, studies address quality from a broader perspective than the service environment itself. 'Quality of life' is also closely linked to service quality for people with disabilities who rely on service workers to provide care and support in their living environments as services are a part of their ecology. There is a need for a close examination of quality from the perspectives of people living in services, to identify the way in which human service interactions influence the quality of their day-to-day experiences. This is particularly important in populations of people with high support needs who may have restricted opportunities to develop social identities outside of formal services. An in-depth examination of this kind will provide important insights into what emerges as important to people living in services.

The assumptions that organisational policies and procedures accurately represent the priorities of people living in services and translate into meaningful action on the part of people working in services may overlook the reality of the complex interpersonal nature of living services for people with disabilities.

2.3.2 ELDERLY PEOPLE

Various studies have nominated different conditions as being necessary for 'quality of life' in elderly populations and concluded that coping, social support, good health, and locus of control played an important role in perception of 'quality of life' in later years (Lieberman & Tobin, 1983; Pearlman & Uhlmann, 1988; Koenig, Smiley, & Gonzales, 1989; Burbanck, 1992; Witmer, & Sweeney, 1992). To this description, a fourth factor was added on concern about disability

and dependence (Kendig, 1989). 'Quality of life' determinants for elderly populations in Australia have been articulated by the Jones Committee (Jones, 1992, p. 2, cited in Sax, 1993) as: "Their perceptions about themselves and the attitudes of others, their roles, health and activity, financial security, and comfort".

Living service environments for elderly people have also been the focus of considerable research. Social and economic resources available to older adults are directly related to the value attributed by the public who permit services to be provided. As demands for funding of services to this group are likely to significantly increase over the next three decades, older adults with physical and cognitive impairments may be even more vulnerable to reduced service quality due to the increasing demands made on the welfare dollar by the provision of humanitarian care. Methods used for determining benefits such as, clinical outcomes, cost-benefit analysis and cost-effectiveness may discriminate against elderly people (Childress, 1984; Pearlman & Jonsen, 1985; McCallum, 1990; Sax, 1993). Discriminatory practices and attitudes are said to permeate almost every aspect of the lives of older people as the young and old are locked into fierce competition for public funds (Daniels, 1988; Picton, 1991).

Definitions of quality must include elements that are meaningful to service users and also take into account the environment, including less tangible outcomes. The standard of medical care may be high, yet 'quality of life' of people in living services may be poor (Kane & Kane, 1988). Evaluation of quality of care is safer and more practical than evaluation of 'quality of life' which may be why

procedures focus on technological issues and the use of structured rating scales (Booth, 1985; Lohr, 1988). The focus on the technical dimension of service delivery inevitably excludes consumers from participation in quality of care assessments.

Studies of 'quality of life' outcomes in hostel and nursing home environments for older dependent adults in Australia, England, and the United States, have mainly focused on behavioural outcomes and program content (Gallacher, 1986; Lemke & Moos, 1986; Grossman, 1988; Clark & Bowling, 1989; Cox, Kaeser, Montgomery, & Marion, 1991). The physical environment, recreational activities and the social environment have been identified as three major factors which affect residents' 'quality of life' (Kahana, 1982; Clark, 1989; Kayser-Jones, 1990; Ross, 1990; Cox et al., 1991). Measures of outcomes which encompassed physical and mental functioning and life satisfaction have also been the focus of studies (Kane & Kane, 1982; Bond, Atkinson, & Bond, 1986; Cox, 1991). Quantitative studies using a variety of 'quality of life' measures have concluded that positive interpersonal relationships were important to elderly people whether they lived in services or in the community (Pearlman & Jonsen, 1985; Booth & Phillips, 1987; Faulk, 1988; Umoren, 1992; Fisher, 1995). In a study by Umoren (1992) in Columbia, resident satisfaction was measured against Maslow's hierarchy of needs. The study concluded that the continued opportunity for personal growth of residents was dependent on positive relationships with staff. Booth and Phillips (1987) undertook a longitudinal study in England over a two year period to compare quality, satisfaction, and the

degree of independence between elderly people living in community group homes and traditional nursing homes. The study concluded that there was no evidence that group home environments were more enabling for elderly people but that group homes reported a higher incidence of mutually supportive relationships which positively influenced subjective well-being. Observational approaches to provide insights into the interactional environments of nursing homes have concluded that negative interactions between staff and residents were common and that the caring practices were characterised by routinisation and control (Godlove, Richard, & Rodwell, 1981; Clark & Bowling, 1989; Hofland & David, 1990; Lidz & Arnold, 1990).

The analysis of discourse has also experienced growth as a field of inquiry which has provided unique insights into understanding everyday social action. Studies of institutional discourse by Gumperz (1982), Paget (1986), Grainger, Atkinson and Coupland (1990), and West and Frankel (1991), have demonstrated that differentials in communication between professionals and care recipients were exaggerated in aged care environments, resulting in the detriment of effective communication, and that service system requirements were prioritised over residents' needs. When orientation to the physical care task was given priority, the care recipient's relational needs frequently conflicted with the task oriented goals of providers, and residents' priority needs for emotional support were not addressed (Atkinson & Heritage, 1984; Grainger, 1993). Although observational studies and discourse analysis provided valuable insights into communication between service users and workers from which inferences of positive and

negative interactions were drawn, they were limited in that they drew inferences from the researcher's perspective and were not participatory in nature.

A significant qualitative study by Cartwright (1991) interviewed relatives and friends of elderly people who had died in nursing homes, concluding that the last year of their lives lacked stimulation and communication. Staff informants in the same study had more positive views of residents' lives, demonstrating a difference in perceptions of quality between families and staff. Hopelessness, boredom and monotony, have been reported by service users in other qualitative studies (Powillis, 1990). In contrast, living services for elderly people can be rich in communicative activity, which has been demonstrated as positively related to psychological well-being (Parmalee, 1982; Nussbaum, 1983b; Nussbaum, Holladay, Robison, & Ragan, 1985; Agbayewa, Oluwafemi, Ong, & Wilden, 1990; Mor, Branco, Fleishman, & Hawes, 1995). Interactions between elderly service users and service workers normally contained some disclosure of competence issues (Coupland, Coupland, Giles, Henwood, & Wiemann, 1988). Alternatively, when access to meaningful interactions were restricted, elderly services users had little opportunity for control or self-definition. Stereotyping of elderly people by service workers reproduced ageism and was detrimental to their quality of life (McIntosh, 1996).

Studies to investigate relationships between staff ratio and quality of care concluded that higher staff ratio did not result in an increase 'positive' life-enhancing care but task assignment on administrative tasks increased (Hile & Walbran, 1991; Sixsmith, Hawley, Stilwell, & Copeland, 1993). Quality indices

have also focused on the relationship between facility size and quality with mixed results. Some studies indicated that small services were more home like and avoided the negative characteristics of institutions whereas others showed that larger facilities benefited from economies of scale and standards of clinical care (Kosberg & Tobin, 1972; Greene & Monahan, 1981). However, larger facilities have also been proven to negatively influence the quality of personal relationships (Lemke & Moos, 1986).

Comparisons between profit and non-profit living environments for elderly people have also been the subject of research (Greene & Monahan, 1981; Elwell, 1984; Lemke & Moos, 1986). The maintenance of maximum levels of autonomy for elderly people has been identified as crucial to 'quality of life' experiences in residential services (O'Connor & Vallerand, 1994; Hertz, 1996). Studies of autonomy across profit and non-profit making services indicated that non-profit making services demonstrated greater autonomy, participation, less structure, and a higher rate of staff enrichment than services which were privately owned. A considerable body of psycho-social literature in institutional environments for elderly people showed that lack of autonomy had negative effects on emotional and physical well-being (Baltes & Baltes, 1986; Rodin, 1986; Rowe & Kahn, 1987; Lidz & Arnold, 1990). Recommendations from studies of autonomy in long-term care environments suggested that professionals or family care-givers must also change, and extend the time spent in communication with elderly people to promote their autonomy and well-being (Hofland, 1988).

(22%) and pleasure (19%) emerged as the most frequently cited categories for both groups (DePaola & Ebersole, 1995). A weakness of McCarthy's study was the use of family members as respondents. Another study by DePaola and Ebersole (1995) to examine whether or not nursing home residents reported an absence of meaning as the result of social discontinuity, also resulted in relationships (56%) most often being reported as providing meaning. This was followed by pleasure (16%) and health (9%). DePaola and Ebersole's study used only self-reported data. The most popular meaning category, relationships, was consistent with other studies using younger populations. The only exception was a singular study on eminent people who placed relationships second to life work (DePaola & Ebersole, 1995). According to Williams (1990, p. 25), living in a service was as much a matter of the spirit as it was of the body:

Redirection of philosophy and practice from the prevailing task-centred care practices to person-centred individualised care is urgently needed if those who live and work in our long-term care institutions, as well as families and friends who visit are all to be sustained and nurtured in both body and spirit. -

The need to address and nurture 'spirit-sustaining' relationships between service users and workers was promoted by Williams (1990: 1994) as integral to 'quality of life' in long-term environments. This view was supported by Lubinski (1978: 1995) and Kaakinen (1992) who commented on the influence of formal communication systems in aged care environments and the negative influences this placed on people living there. Self-regulatory beliefs based on

residents' own perceptions of communication rules also inhibited their communication with other residents. Observational studies have demonstrated that nursing home environments "... either overtly or covertly restrict human interaction, particularly spoken communication" Lubinski (1978, p. 17). This has significant implications for the 'quality of life' of residents.

A shift in ethical orientation away from individual emphasis towards an emphasis on relationships between individuals who live and work in services has been proposed by Noddings (1984). A review of the literature on 'quality of life' studies for elderly people living in services lacks identification of service 'quality' from a phenomenological perspective. In deciding what is important in the day-to-day lives of people living in services, people funding services and those in a 'hands-on' capacity need to be able to understand how services are experienced by recipients and what is important to them, so that services can be sensitive to, and focused on, important issues to the people using them.

2.4 SUMMARY

Literature has highlighted the complex context of the evaluation of quality in living services for people with disabilities and elderly people. 'Quality of life' constructs have consisted of mainly objective criteria to evaluate 'quality of life'. Evaluation practices have been influenced by the manufacturing industry and have had a focus on tangible outcomes which are underpinned by assumptions that service outcomes are comparable to 'quality of life' experiences for people living in services. 'Quality of life' for people in living services, may have as

much to do with their experience of 'service' as an integral focus of their life's experience. The reality for some people with severe disabilities, however idealistic the projections of service developers are, is that 'service' is the endpoint of their living experience. This is particularly relevant in aged care services. Quality outcomes for people living in services also need to be directed towards the service environment itself and the important social interactions which impact on life in the process of service delivery. By providing interpretations of commonly shared living service experiences across multiple settings information can be obtained to gain insight, raise consciousness, and develop sensitivity to what are the crucial quality elements in living services from the people most affected.

This chapter will describe the theoretical perspective underpinning the study, the sequence of the research, rationale for the research questions, data collection and analysis, and ethical issues and limitations.

3.1 THEORETICAL PERSPECTIVE

The purpose of this research was to gain knowledge of informants' experiences and perspectives on quality in living services. The theoretical framework underpinning the study is symbolic interactionism. Symbolic interactionism has its roots in sociology and has an assumption that society, reality and selves are socially created through interaction processes (Blumer, 1969; Lindesmith, Strauss, & Denzin, 1975). Meanings (or 'truth') arise out of an individual's experience.

A symbolic interactionist approach to the study of living services promotes a view that the human environment does not consist of objects which intrinsically carry meaning, but that social life is constructed through interaction with others. Blumer (1969) suggested that using survey methods and statistical techniques in attempting to determine correlations among sociological variables to identify causal relationships, failed to recognise the dynamic nature of the social research context. Symbolic interactionism has a long history of use in the social sciences (Patton, 1990; Denzin & Lincoln, 1994; Taylor & Bogdan, 1998).

The symbolic interactionist position is based on the view that:

Human beings act in situations on the basis of the meanings situations have for them.

The meanings derived from situations arise out of social interaction between people over time.

Meanings are handled through an interpretative process used by the person in dealing with the situation at hand (Blumer, 1969, p. 3).

As the meaning of quality in living services is created through service users' interpretations of their day-to-day interactions, a symbolic interactionist approach provides a way to closely examine service interactions and their meanings. Immersion in the living context over an extended period also provides opportunities to discover some of the subtle meanings of living in a service and how these influence the lives of informants. Extended periods of observation will assist with understanding the meaning of service 'quality' (or what is 'good') from the perspectives of people using living services, and how people make sense of their day-to-day experiences (Guba & Lincoln, 1983; Leininger, 1985). A collaborative, participatory approach allows informants to control the content and interpretation of the data and acknowledges the experiences of informants as experts in investigating 'quality' (Reason, 1988; Whyte, 1991; Frideres, 1992).

Focusing on the subjective experiences of every-day life in a living service to communicate them in a meaningful way attempts to "... guarantee that the world

of social reality will not be replaced by a fictional non-existing world constructed by the scientific observer” (Schutz, 1967, cited in Holstein & Gubrium, 1994, p. 263). A phenomenological perspective is compatible with the collaborative research approach and interpretation and verification of the data by informants.

The phenomenological world is a world of conscious, perceptual, living people in constant contextual interaction. This interdependency implies that “... there is no world without a consciousness to perceive it and similarly no consciousness without a world to be conscious of” (Valle & King, 1978, p. 12). In order to understand human experience from the actors’ point of view the phenomenologist utilises three general strategies i.e. phenomenological reduction, imaginative variation and interpretation (Keen, 1975). The purpose of the method is to investigate and describe all phenomena, including human experience in the way phenomena appear in their fullest depth and breadth (Spielberg, 1965). Unconstrained descriptions of life in a service which reflects the personal realities of informants provides a way of viewing the human experience of living in a service and may present useful information to guide the development of the service. The assumption in using a phenomenological approach is that “... there is an essence or essences to shared experience and that these essences are mutually understood by people sharing a common experience” (Patton, 1990, p. 70). A process called bracketing reduces the risk of phenomena being reflected through preconceptions of researchers (Cohen, 1987, p. 31). Advocates of phenomenology argue that since consciousness is in the world, the study of experience raises consciousness. Another important concept is that the

researcher is an integral part of the research process and maintains a self-conscious position throughout the research.

3.2 SEQUENCE OF RESEARCH

Data collection and analysis took place over a two year period between July 1995 and November 1997. The research design comprised of three phases.

3.2.1 PHASE 1

The initial phase, from July 1995-May 1996 involved an intensive study with multiple visits to four service agencies, two in disability services (involving six separate living sites) and two in aged care services, and repeated interviews with sixteen service user informants, participant observation, recording of fieldnotes and literature research to gain an understanding of the meaning of quality from the perspectives of people living in services.

The first interviews of the sixteen informants in phase one asked informants to explain the meaning of quality related to living in a service and provide descriptions of experiences in the context of quality. These initial interviews generated 286 pages of double spaced transcriptions for inductive analysis. Patterns in the data revealed that behaviours in the domain of interpersonal relationships appeared more consistently in descriptions of quality in services than task related behaviours directed towards physical care or environmental care. Co-coding of interview data by research supervisors and colleagues confirmed that interpersonal relationships were shared across interviews as

integral to quality experiences with greater consistency than task related behaviours. Returning to conduct member checks with informants in phase 1 confirmed that relationships with service workers were the most valued elements in service users' perceptions of service quality.

Having established the link between service worker relational behaviours and quality experiences, discussion with supervisors and key advisors led to the development of a further three research questions which were designed to identify service workers who provided quality experiences, the common relational and task behaviours which were characteristic of quality experiences and the nature of relationships which were commonly shared across settings. A second round of interviews was conducted with the initial sixteen informants, to identify acts which were consistently experienced in the context of quality. This information would identify the characteristics of service workers and acts of serving which were commonly perceived by service users as quality service experiences. This generated a further 176 pages of double spaced transcriptions for analysis. The initial sixteen service user informants were invited to identify key service workers whom they considered relationally supportive. These nine identified service workers were subsequently interviewed in phase 1. Inductive analysis of 187 pages of transcripts from service workers provided thematic data which identified shared experiences and perceptions of quality from service workers' perspectives. Returning to service worker informants to confirm interpretations, and co-coding interview data with research supervisors and

colleagues to justify interpretation of categories and themes confirmed and triangulated findings.

3.2.2 PHASE 2

The second phase of the study from August 1996-January 1997 involved collecting further data from informants from a range of agencies in disability and aged care to explore whether emergent categories and themes from the analysis of phase one data were consistently shared across different environments. A further five disability services (involving eleven separate sites) and five aged care services were accessed and a further thirty-four service users and seventeen service workers, who had been identified by service user informants as key people in the context of quality, were also interviewed. This phase provided further immersion in multiple living environments allowing for the collection of extensive fieldnotes and confirming emergent themes from phase one findings. This added to the large data bank of examples of quality interactions and also identified negative cases for comparison in the dissertation. A further 636 pages of service user transcripts and 410 pages of service worker transcripts were transcribed.

3.2.3 PHASE 3

The third and final phase of the study from August-November 1997 involved further analysis and the identification of relational themes from the phase 1 and phase 2 data and selection of information rich cases to be presented as exemplars of the variable relational experiences of living service informants. Informants

were contacted to supplement data and provide further information such as personal history to enrich case descriptions. This phase generated a further 24 pages of transcriptions. The research design is displayed in the following figure:

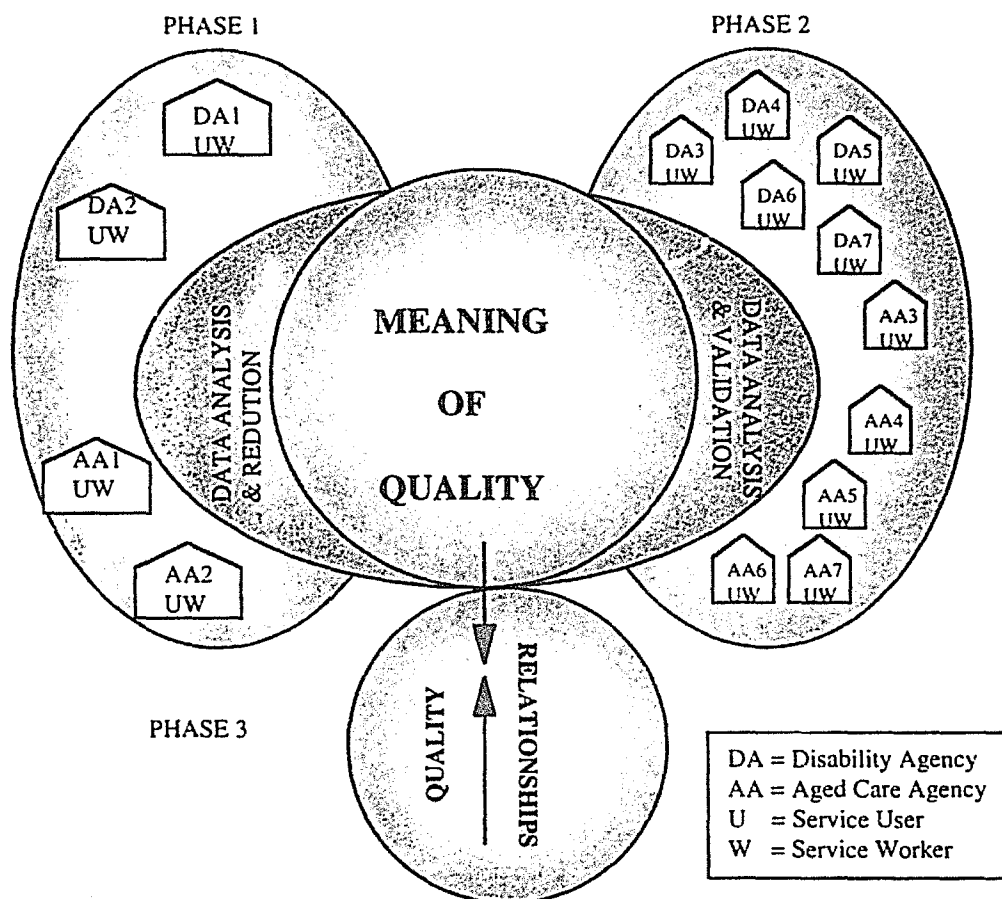


FIG.1 RESEARCH DESIGN

The figure represents the three phases of the study. Phase one involved data collection, data analysis and reduction from four agencies. Phase two involved further data collection, analysis and validation from a further ten agencies to interpret the meaning of quality for people living in services. Phase three examined categories of relationships which had emerged from phases one and two.

3.3 RESEARCH QUESTIONS

In collaborative research, the research question is usually developed in consultation with informants. In this case, as the research was instigated by the researcher's interest in the issues of 'quality' the overarching question was guided by consultation with key people who used and worked in services. It was assumed that other questions would naturally flow from the initial question according to the direction that informants chose.

Initially informants were asked to describe their experiences of living in a service and provide descriptions about what was important and valued. This was directed at answering the following question:

Question 1: What are the experiences of people with disabilities and elderly people living in services and what are their perceptions of 'quality'?

e.g. What is it like for you living here?

What's important to you in your day-to-day life?

What does 'quality' in a service mean to you?

This allowed informants to tell as much of their stories related to living in a service as they wished. Communication between the interviewer and informants then proceeded according to the directions informants' chose.

The first overarching question was used to identify what meaning quality had for people living in services, related to their experiences of interacting with other people, and their environment. It has been demonstrated that literature abounds with studies which use pre-determined quality of life indicators as the basis for developing interview schedules and questionnaires (Kahana, 1982; Murrell & Norris, 1983; Pearlman, 1985; Booth & Phillips, 1987; Goode, 1988; Edgerton, 1990; Kendig, 1989; Schalock, 1990b; Parmenter, Briggs, & Sullivan, 1991; Cummins, 1992; Osborne, 1992; Umoren, 1992; Flynn, 1994). The purpose of this question was to attempt a completely open-ended approach to identify key quality domains to guide the development of the study by bracketing assumptions about what quality experiences might be for people living in services. From analysis of interview data related to question one, which consistently linked quality service experiences of service users with relational behaviours of service workers, three further questions emerged and were incorporated in subsequent interviews. The next question related to service workers' experiences:

Question 2: What are the experiences of 'valued ' service workers and what are their perceptions of quality?

e.g. What's it like for you working here?

What does quality in a service mean to you?

The second question acknowledged the relational domain of the living service as it was emerging from the data and that services are basically interactional dyads.

Literature indicates that worker issues such as power relationships, worker stress, and high turnover influence service quality, and the continuity of worker / service user relationships (Gubrium, 1975; Taylor, 1978; Maslach, 1982; Bersani & Heifetz, 1985; Burchard & Thousand, 1987; Collopy, 1988; Hofland, 1988; Felce, Repp, Thomas, & Ager, 1991; Grau, Chandler, Burton, & Kolditz, 1991; Williamson, 1991; Jacobsen, 1992; Dickens, 1994; Carrell, 1997). The second question allowed the perspectives of service workers also to be considered and the meaning that working had for them as well as their perspectives on what was important to service users.

The third question was incorporated to elicit descriptions of specific interactions in the service environment which were interpreted by service users as positive and negative experiences.

Question 3: What are valued characteristics of living services from the perspectives of service users?

e.g. How would you describe a good living service?

Are there things about living in a service that you don't like?

The third question examined the key elements of quality in a service. Although literature is also available which stresses the relational aspects of service systems (Noddings, 1984; Sarason, 1985; Van De Veer, 1986; Downs, Javidi, & Nussbaum, 1988; Nussbaum, 1988; Weimann, Gravell & Weimann, 1988; Walton, 1989; Zeithaml, 1988; Wuthnow, 1991; Woodill, Renwick, Brown, &

Raphael, 1994; Moore, 1995; McIntosh, 1996; Trewek, 1996) none has been found which articulates the relational acts which demonstrate the key quality experiences shared by people with disabilities and older adults living in services. The purpose of this question was to identify the relational acts which were considered important by service workers by providing examples of positive and negative experiences which consistently emerged across settings.

The fourth question examined service relationships in greater depth and identified information rich descriptions of positive and negative service encounters:

Question 4: What is the nature of service relationships between users and workers in living services?

e.g. Can you tell me about people you share your life with here?

Is there anyone here you feel close to? Can you explain why?

Have you had any problems?

The fourth and final question emerged as the human service context was identified as an important area of relational support by people in the study. Although some recent literature exists to support this view (Lutfiyya, 1993), studies focus mainly on informal social supports for people with intellectual disabilities outside of formal services (Perske, 1988; Bogdan & Taylor, 1989; Firth & Rapley, 1990; Amado, 1993; Forest, 1991; O'Brien & O'Brien, 1993b). This area is not well articulated in research of people with disabilities and older

populations in living services. By focusing more deeply on relationships within services, it was hoped to obtain further knowledge about the consistency of relational experiences across agencies and also gather in-depth descriptions which demonstrated the variability and richness of relational experiences and the meanings they had to informants.

3.4 RESEARCH PROCEDURES

3.4.1 INFORMANT SELECTION

As the purpose of the research was to understand the meaning of quality from the perspectives of people living in services, informants were selected who could provide thick descriptions of their experiences of living in typical service environments such as group homes and community houses for people with disabilities, and nursing homes and hostels for elderly people. The size of the sample was not determined at the beginning of the research as it was important to adopt a flexible approach to allow for further theoretical sampling to verify relationships between categories as they emerged from the data and allow saturation to be reached (Patton, 1990; Strauss, 1990; DePoy & Gitlin, 1994; Taylor & Bogdan, 1998).

Informants were selected by a process of purposive sampling of people who had lived in services for extended periods (DePoy & Gitlin, 1994). When obtaining a purposeful sample the researcher selects informants according to the needs of the study (Patton, 1990). This particular group of service users was selected for their experiences of living in a service for a prolonged period and having the

ability to provide information-rich data for in-depth study (Morse, 1986; Patton, 1990; Taylor & Bogdan, 1998). Informants were selected across disability and aged care services in the Perth Metropolitan area which were typical of current models of service. All people who were approached to become involved consented to be interviewed. People with disabilities living in the community were identified through personal networks and either contacted directly by the investigator or introduced through key service workers known to the investigator.

Seven disability agencies and seven aged care agencies were involved. When service workers were involved in assisting the investigator to access informants, formal written applications to conduct the research were sent to service administrators to comply with agency policies and consent forms to be completed by informants included (Refer Appendix 1 and Appendix 2). Although service staff could be acting in a gatekeeping capacity by providing names of people who would positively report on their experiences, this was also seen to strengthen the positive approach, and as demonstrated in the findings, despite this likelihood, a number of negative cases emerged.

The study planned to take an 'optimistic' approach as described by Bogdan and Taylor (1990) as it was attempting to identify the meaning of quality by adopting a focus on positive aspects of living services. Due to the large number of agencies which provided services in the areas of disability and aged care, discussion was generated initially with key advisors who were involved as workers and service users in the area of disability services and aged care services

to identify living services which had reputations of providing quality services. Although all the agencies involved were subjected to regular standards monitoring procedures to comply with funding arrangements and could be assumed to provide quality in the delivery of services, it was still considered important in the initial investigation of quality to gauge reputation by discussion with key advisors, and the community at large. Four agencies, two providing services to people with disabilities and two providing aged care services were identified and approached to provide access for data collection in the first phase of the study.

3.4.1.1 PHASE 1-Service User Informants

The initial four agencies were selected following discussion with key advisors. It was proposed that four or five people from each agency would be interviewed. Sixteen service user informants agreed to be interviewed for phase one of the study. This would allow for the collection of sufficient data to identify shared experiences and variation in experiences. Previous involvement in qualitative studies had demonstrated that repeated interviews with information rich informants had the potential to generate large amounts of descriptive information for analysis. Informants were included who met the following criteria:

Living in a group home, community house, hostel or nursing home service for a minimum of one year (preference to be given to people who had long-term experience of the service i.e. experiential experts);

Able to communicate verbally or by independently using a communication device;

English as a first language.

3.4.1.2 PHASE 1- Service Worker Informants

From the analysis of the initial sixteen interviews with people living in services, relationships with service workers emerged as the most consistent issue in the meaning of quality experiences. Relational behaviours appeared in the data more consistently in the context of quality experiences than task oriented behaviours. Returning to informants to validate interpretations confirmed this finding. Nine service worker informants were identified by service users in the course of interviews as being key people related to quality experiences in living services. There were no other inclusion criteria other than being named by service users as integral to the meaning of quality. All service workers who were approached agreed to be interviewed. (Refer Appendix 3 for demographics of service workers and users in phase one and Appendix 4 for chart linking service users and workers in phase one)

3.4.1.3 PHASE 2 Service User Informants

As quality in services is usually measured according to competency statements and task related outcomes it was considered important to further investigate the meaning of relationships within services as this was the key issue emerging from phase one. It was decided to expand the study to interview people in multiple settings to find out if experiences and meanings of quality were commonly shared across different living environments. A convenience sample of a range of settings in disability and aged care agencies with a variation of size, locality and

funding arrangements were accessed. This included agencies who were funded by the government and non-government sectors, and charitable, religious, and private agencies. A purposive sample of between three and five informants were selected from each agency. Thirty-four service user informants were interviewed and information rich cases identified.

3.4.1.4 PHASE 2 Service Worker Informants

From the analysis of the interviews with thirty-four service users informants in phase two, seventeen service worker informants were identified by service users in the context of quality and subsequently interviewed. (Refer Appendix 5 for demographics of service workers and users in phase two and Appendix 6 for chart linking service users and workers in phase two)

3.4.1.5 PHASE 3 Service User and Worker Informants

From analysis of phase two interviews, a comprehensive picture of living service contexts and patterns of interactions which were consistently experienced across multiple agencies was created. The importance of relationships between service users and workers and their link with service users' perceptions of 'quality' was also strengthened. Further exploration of the nature of relationships between service users and workers related to the four main relational categories which had emerged from the analysis of the seventy-six service user and worker interviews was carried out in phase three.

It was decided that the study would not be complete without a more in-depth account of the variable relational experiences of people living in services and that

a case-study approach would be an appropriate way to capture the meaning of informants' experiences in their own words. From the data bank, information rich cases were identified as exemplars of categories of relationships which had emerged from phases one and two. Five relational dyads were selected as examples of relational quality and four individual cases were selected to demonstrate a lack of quality in their relational context. Informants were contacted when further information was required.

3.5 DATA COLLECTION AND ANALYSIS

In keeping with a phenomenological approach data collection involved a series of in-depth interviews. In-depth interviews involved face-to-face encounters between the researcher and informants directed towards understanding informants' perspectives on their experiences as expressed in their own words (Taylor & Bogdan, 1984, p. 77). By retrieving the informants' world and attempting to understand their perspectives in language which was natural to them, the possible distorting effect of using symbols and language which were not part of their everyday usage was reduced. In-depth interviewing is particularly useful when a researcher wants to gain access to, and an understanding of, activities and events which cannot be observed directly by the researcher (Minichiello, Aroni, Timewell & Alexander, 1990). Open-ended questions and active listening allowed informants to communicate their feelings in order to empathise with, and confirm what they were conveying (Minichiello, Aroni, Timewell, & Alexander, 1990; Kemper, 1992). It was important to relate to informants as people and not just as sources of data (Taylor & Bogdan,

1998). A visit was usually made to the service context before making appointments for interviews, to meet the people involved and to 'get a feel' for the situation. The interviews began with a short time for social talk to set people at ease.

In the context of living services, in-depth interviewing allowed informants who were currently living in services to give accounts of actions and patterns of actions relevant to their perspectives of 'quality'. By conducting interviews in the homes and places of work of informants according to their preferences, an informal and familiar environment was created where informants were more likely to relax. The problem of acquiescence of people with intellectual disabilities which has been discussed by other researchers (e.g. Heal & Sigelman, 1990; Matikka & Vesala, 1997) was overcome by prolonged engagement, and questioning which allowed topics to be confirmed throughout the interview. Rich descriptions of 'good' and 'bad' experiences were then able to be obtained.

The interview format consisted of asking informants to provide descriptions of events and experiences. This was considered a non-threatening strategy and allowed the informant to take control of the interview (Taylor & Bogdan, 1984). Probing questions were used to gain more detailed information and questions were asked only when the researcher found it necessary to clarify what the informant was relating. Informants' feelings regarding interactions which had been of particular significance were actively pursued. Initially the researcher had considered using a series of semi-structured open-ended questions in the interview situation, however, after piloting this format it was decided that this

method inhibited the information flow in a situation which proved to be an emotional experience for many people who were interviewed. Structuring the interview questions also restricted responses by pre-determining areas of importance. A structured interview format was, therefore, deemed inappropriate in this situation. The purpose of the initial visit was to introduce the interviewer, build rapport, and discuss the study and any concerns people may have about confidentiality. This helped to relax informants and focus their attention on the research purpose. Informed consent was either given in writing or recorded on tape. Service worker informants were contacted by telephone to arrange a time and place of meeting.

The recording of interviews was a means of obtaining a full and accurate record and validity was enhanced by the preservation of authentic data. Prior permission had been obtained from informants to record interviews. Interviews ranged in length from one to two hours. This was exclusive of the time spent with informants initially to establish rapport and answer questions related to their involvement with the study and assure that confidentiality would be maintained. Field notes were not recorded during interviews as this may have inhibited participation in communication by the researcher. Field notes, related to the researcher's observations and experiences of the research situation describing the physical context, actors, and observed interactions between actors in the environment were recorded immediately following each interview. Service records were accessed for clarification of demographic data of service users and job descriptions of workers.

One hundred and twenty four hours of transcriptions of interview tapes generated approximately eleven hundred pages of descriptive information related to informants' experiences of living in services. The same procedures were used in both phase one and two of the study with the addition of more regular probes being used in phase two to validate phase one findings. Saturation was reached prior to final agencies being approached, but it was considered important to continue interviewing across agencies to provide researcher immersion in as many different contexts as possible to enhance the research experience. During three interviews, two with elderly people and one with an informant with an intellectual disability, it became clear that concentration on the research focus was problematic and they were becoming confused about the purpose of the interview and the presence of the interviewer. These interview data were not included in analysis.

In situations where people used communication devices which could be very tiring for informants in an interview situation, people were encouraged to reflect on research questions and provide further information in their own time. Despite the restrictions and slowness of the data collection with the three informants who used communication devices, rich accounts of their experiences were collected. Two people with disabilities also had problems with articulation and required repeated interviews.

Data collection and analysis took place simultaneously. Validity checks were built in by returning to informants to confirm themes as they emerged and triangulation was also built in by randomly co-coding interviews with the

research supervisors and colleagues experienced in qualitative methods by providing transcriptions in hard copy and comparing emergent categories and themes.

The procedure was as follows:

A coding system was established and computer records kept of interviews in entirety and rationale for categories of analysis as they emerged.

Interview data were stored on a computer disc and each participant was given a code.

Statements were numbered according to the page number and paragraph of the interview.

Significant words or statements which consistently appeared in the data related to the research questions were extracted from the transcripts after they had been underlined and highlighted.

Significant statements were coded to allow for ease of identification and comparison both across and within transcripts.

Codes were compared and clustered to form categories of information about informants' experiences.

Categories were compared and contrasted until patterns of themes emerged.

Themes were expressed in single words, phrases, sentences, paragraphs or even entire documents.

Categories were assembled into clusters of themes, which were then further clustered into major and minor themes according to the significance with which they emerged in the data.

Comprehensive descriptions of themes were written which were then reduced for the dissertation.

Raw data were drawn on to illustrate themes and codes replaced by pseudonyms for the dissertation.

Finally, literature was reviewed to support or contradict findings.

(Colaizzi, 1978; Leininger, 1985; Gubrium, 1988; Patton, 1990; Denzin & Lincoln, 1994; Strauss & Corbin, 1990; DePoy & Gitlin, 1994; Taylor & Bogdan, 1998).

As the data were being analysed and emergent themes identified, it became clear that common experiences and meanings of quality were shared across the disability and aged care contexts. Due to the similarities in the data, a distillation of shared meanings across disability and aged care populations was to be reported in the dissertation. The literature was researched for relevant studies in both disability and aged care which either supported the findings or presented alternative views for discussion. A comparison of the findings between disability and aged care data was discussed when differences occurred.

The large amount of data collected seemed prohibitive at first and transcriptions and analysis seemed never ending. As multiple informants and contexts were

accessed in phase two it became easier to extract themes to verify relationships from phase one data and it was worth the effort to demonstrate the consistency that relational issues in agencies influenced quality experiences for people living in services. As the research progressed, observations across multiple contexts increased sensitivity to patterns of interactions which were consistently shared across agencies. The context of living services and the experiences of people in them had by now become so much a part of the daily life of the investigator that it was difficult to extract herself (sic) from the people and their environments even when the point of saturation had been reached.

Informants consistently reported that they valued the interview situation, even when in the course of reflection on their lives many people consistently expressed emotion. It became clear that for some people the interview provided personal validation and they were keen for visits to continue. A few informants continued to contact the investigator on an ongoing basis for social contact and also to find out how the study was progressing.

3.6 CONFIRMABILITY OF FINDINGS

Discussion has taken place by several authors over the last decade on the rigor of qualitative research (Miles & Huberman, 1984; Leininger, 1985; Lincoln & Guba, 1985; Morse, 1986; Minichiello, Aroni, Timewell, & Alexander, 1990; Van Manen, 1990; Sandelowski, 1993; Munhall, 1994). Rigor in a 'naturalistic' sense, is not defined in terms of reliability and validity but in terms of credibility, fittingness, auditability and confirmability.

Credibility is the criterion against which the truth value of qualitative research is evaluated and is achieved when, “ data interpretation will be at least ... credible to the audiences that are in the best position to judge them “ (Guba, 1983, p. 113). Credibility was established by repeated interviews with multiple informants, immersion in the research context in multiple settings over an extended period, co-coding data with colleagues, and returning findings to informants for validation of categories of analysis as they emerged.

The second term fittingness is met when the findings of a study: “Fit more or less well into a context other than the one in which they are derived (and) ... seem to be well borne out within the local context that spawns them” (Guba, 1983, p. 118). Immersion in multiple contexts over time, past experience of working in living services, on-going discussion with key advisors as themes developed, and review of relevant literature strengthened fittingness.

Auditability, the third criterion is achieved, when investigators can: “Review each decision and the consequent action, verifying that substantially and methodologically sound options were chosen ... (ensuring) ... that documentation of the decision trail be adequately maintained” (Guba, 1983, p. 122). Auditability was represented by ensuring clear, meticulous recording of the analysis. Triangulation was based on convergence of data from multiple sites and co-coding of interviews by colleagues experienced in qualitative methods to confirm emergent themes.

Confirmability simply asks that the inquirer report her (sic) data in such a way that it can be confirmed for other sources if necessary. Confirmability is achieved when auditability, creditability and fittingness are established. Confirmability for this study was established around three related issues. They were: the rigor of the research techniques; the collaborative approach; and the credibility of the researcher who had a history of supervision of research projects and had published in the qualitative field (Patton, 1990).

3.7 LIMITATIONS

The major limitation was the vulnerability of informants who were service users and workers and dependent on services for physical and emotional support and work. This may have resulted in representing a more positive view of the service experience (Kuleshnyk, 1984). Even with this constraint, however, negative situations were consistently reported. When people knew the interviewer they were more likely to develop trust in the interview situation and rich data were more likely to be provided. Establishing relationships with people who were sometimes lonely and vulnerable, and creating a relaxing environment in a service context was difficult. Some contexts also lacked privacy to carry out the research which was inhibiting for informants. The study context was restricted to group homes and community houses for people with physical and intellectual disabilities and nursing homes and hostels for elderly people as these are the most common service models for these populations in Western Australia. A number of younger people with disabilities continue to live in nursing homes and hostels. These models of service are considered obsolete by funding bodies and

are awaiting devolvement to more appropriate community based living arrangements. The population of people with psychiatric disabilities was not included. Living services for people with psychiatric disabilities follow the same models. Ethical problems in accessing this population were considered too problematic to include them in the study. All of the study informants in aged care services were Australian of Anglo-Celtic origin. This reflects typical characteristics of people currently living in aged care services and other cultural groups were not deliberately excluded. Ethno-specific aged care environments in Perth were not accessed as this would have added another complex dimension to the study. The majority of informants in disability services were also from Anglo-Celtic or European cultures. Two people from Asian backgrounds who had lived in Australia for most of their lives were interviewed. There were no apparent cultural differences in relation to the data. The study was limited to interviewing informants in seven disability and seven aged care agencies. The qualitative method does not allow for generalisability of findings.

3.8 DELIMITATIONS

The study selected 'expert' informants in order to examine information-rich cases. The open-ended approach and long-engagement with informants enabled relationships to evolve where informants felt comfortable in disclosure. The reputation and past experiences of the interviewer also supported the development of trust, and the willingness to be flexible with contact helped form positive relationships. The extended and intensive period of data collection over a two year period allowed immersion in the physical and emotional milieu of

services. The multi-site approach allowed investigation of whether some common experiences were shared by different populations in different settings.

3.9 ETHICS

When agencies were approached formally, written permission to carry out the research preceded entering the context. In informal situations, telephone contact was made directly with potential informants to explain the nature of the study. Informed consent was either given in writing or more often recorded at the beginning of each interview during the initial period of socialisation and 'warming up'. Informants could withdraw at any time or decide that all or parts of interview data were not to be used. Two informants requested that some content of interview data was not to be disclosed in the study and this was adhered to. Permission to use pseudonyms in the dissertation was given.

Codes were assigned to agencies and informants to ensure that neither agencies nor informants could be identified. Group data were reported apart from the case study exemplars where care has been taken to provide information which cannot be traced to individuals while ensuring rich descriptions were reported. Pseudonyms were assigned to informants prior to raw data being reported in the dissertation as this was seen to create a more personal account of the findings and preclude the identification of informants which is a key issue for people in the study who have made critical statements and who fear repercussions.

The major ethical dilemma which emerged during the study was the disclosure of physical and emotional abuse by some informants which they asked to remain

confidential. Without disclosing individuals, the investigator felt ethically bound to try to put some safeguards in place and, with informants' permission, through informal networks has organised for either people working in services or volunteer advocates to 'befriend' the individuals in question. This has been done without involving details of the incidents. The investigator's contact number had been made available to the service users concerned, should they themselves decide that they need assistance or want copies of the interview data to use in advocacy. In this way, the ethics of the research acknowledges that there may be an ongoing commitment to people who otherwise may be left unsupported.

4.1 INTRODUCTION

This chapter will consist of findings and discussion arising from the analysis of fifty service user and twenty-six service worker interviews. The findings consist of a distillation of data from all the stages of the study as discussed in the methodology chapter. People with disabilities are referred to by first name pseudonyms and elderly people by surname pseudonyms in keeping with the style of address preferred by informants in the interview context. The chapter is written in four parts, each part addressing one research question and will consist of:

1. One major and four sub-themes which relate to the experiences of people in living services and their perceptions of 'quality service'.
2. One major and five sub-themes which describe the experiences of service workers and their perceptions of 'quality serving'.
3. Valued service characteristics from the perspective of service users.
4. Four themes representative of service relationships which are experienced by service users and influence their perceptions of 'quality'.

4.2 QUESTION 1: WHAT ARE THE EXPERIENCES OF PEOPLE WITH DISABILITIES AND OLDER ADULT USERS OF LIVING SERVICES, AND WHAT ARE THEIR PERCEPTIONS OF QUALITY?

Service users' experiences of living environments are in large part constructed through interactional sequences. Interviews with service users are dominated by descriptions of interpersonal interactions with service workers and the influence of relationships with service workers in their assessment of service quality. Negative cases are also presented and discussed.

One major theme, HUMAN SERVING and four sub-themes, GROWTH, FRIENDS, THEM AND US and DIS-SERVICE emerged from the analysis of interview data with fifty informants in answer to question 1. Themes are displayed in the following figure

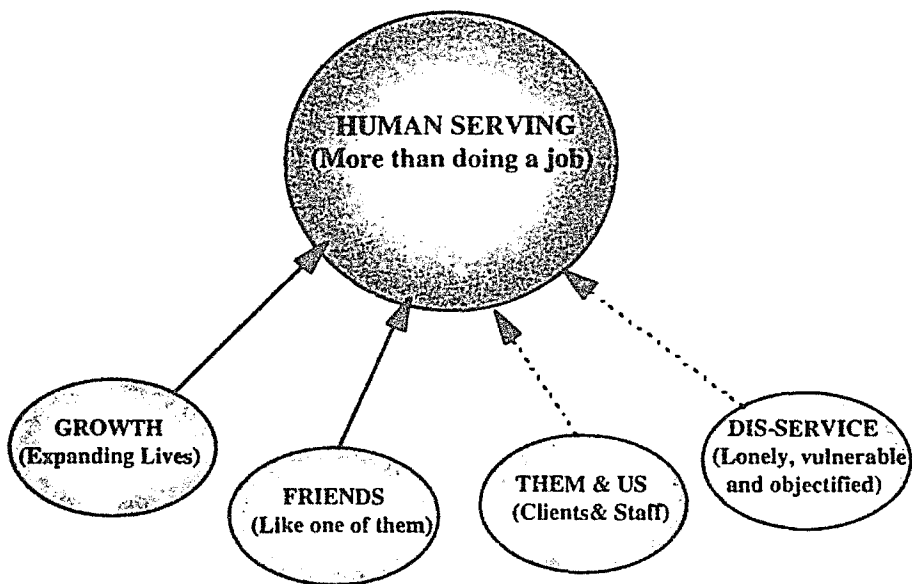


FIG. 2 QUESTION 1 EMERGING THEMES

In the data, multiple examples are present to support the emergence of each theme. It is also significant that contrasting experiences are evident in the same service, which has important implications for considering the way that services are evaluated. Interview data and case study examples are used from both the disability and aged care populations to emphasise service users' common experiences. Sub-themes are presented as they are consistently described by informants from the most valued to the least valued 'quality' experiences with the major theme 'Human Serving' overarching other service themes.

4.2.1 MAJOR THEME: HUMAN SERVING

(More than doing a job)

The major theme 'Human Serving' describes the value to service users of the interpersonal qualities associated with the service as opposed to the outcomes of the service itself. That is, the means whereby the service is experienced through the interpersonal transactions between service users and workers, rather than the technical procedures involved. 'Human Serving' is about sensitive understanding and a responsiveness to the person that goes beyond the presenting 'service condition' and beyond having a view of the person which is framed only in the context of a client role. 'Human Serving' requires a sensitivity to the phenomenology of the person. From service users' perspectives 'Human Serving' is about being 'cared about' as opposed to being 'served'.

Because service oriented living environments are policy driven, 'Human Serving' requires workers to reframe 'provision of service' into 'act of serving'.

According to (Walton, 1989, p. 33) 'The concept of relationship, whether conceived as ontologically given, or as a matter of choice, is a first step in understanding the nature of ethical service'. Noddings (1984) supported the notion of an ethical ideal in human service relationships and proposed that the relationship was essentially non-rational. In discussing Bronfenbrenner's (1979) view of development as being enhanced by enduring irrational involvement to nurture competency Noddings (1984, p. 62) suggested that in ethical service we meet the 'other' morally in service relationships. Relationships in services which arise out of love or natural inclination to help are devoid of perfunctory or grudging characteristics. The need for the development of emotional attachment in the care giving relationship in order to maximise developmental potential is widely accepted (Maier, 1994, Baumeister, 1995). This is also true of people in service relationships, when relationships are identified as being centrally important between service users and workers.

Most important in the emotional bonding between caregivers and care-receivers are feelings of attachment and mutual personal connectiveness, goodwill and a sense of continuous presence ...(Maier, 1994, p. 38).

Across disability and aged care services informants clearly articulate quality service from 'more than doing a job' in the communication and acts of concern which they perceive to be oriented towards their continued viability as developing people and also towards their personal well-being. This generates not only positive feelings towards the service (in the embodiment of the service worker concerned) but also fosters feelings of being worthwhile, liked, and alike.

In ideal terms living services are both organised for the provision of care and as intricate social structures supporting the social development of people living in services. People with disabilities who leave family homes or institutional environments to live in local communities have expectations that their lives will expand experientially in material, occupational and relational domains. When high levels of assistance are required, however, the living situation may become a total environment for people who have limited access to community resources. As a result, relationships with service workers become the major source of human contact (Felce, Repp, Thomas, & Ager, 1991; Felce & Repp, 1992; Sinson, 1993; Perry & Felce, 1995). Elderly people who enter nursing homes and hostels also find that their social world is partly or totally constructed through their service experiences (Nussbaum, Holliday, Robison, & Ragan, 1985; Larue, 1992; Sixsmith, Hawley, Stillwell, & Copeland, 1993; Mor, Branco, Fleishman, & Hawes, 1995). As a result, 'quality of life' experiences for people who are highly dependent on living services is strongly influenced by the nature of their interactions with service workers.

(People with disabilities)

Experiencing 'human' serving is described by Peter, a man with cerebral palsy who has lived alone in a community house for five years due to the incapacity of his parents to continue to provide physical care and also his wish to live his own life. Peter is totally dependent for survival on care-givers who come at pre-determined times during the day to attend to his daily care needs. Due to his physical disability, Peter's speech is difficult to understand. He spends much of

his time on the Internet which he accesses with the use of a head pointer. On the 'Net', he explains, people are unaware that he has a disability. He can communicate with other people and develop 'computer' relationships more easily than face-to-face relationships. He describes his current living situation as 'lonely' but more like 'normal' living than it was with his parents. Like the majority of people interviewed in this study, Peter has few connections with people other than service workers. Relationships with service workers, and their interactions with, and responses to him, are highly significant in the way Peter views himself as a social being. Peter describes a 'good' service:

Well ... what I call a good service is about attitude ... about being open ... having a laugh together and knowing that what you tell someone doesn't go any further. It's an attitude ... an attitude of caring.

(So...what does caring mean to you?)

It's about caring across the board. It's not just about how they look after the place and me and the things that need done ... it's about having a good attitude ... the way they talk to me ... just like anyone else. Some people are excellent at their job as far as the things I need done for me goes ... but they're not interested in me as a person except that they have a job caring for me.

(And when you're in a situation where you feel that the other person has a good attitude ...what's that like for you?)

It's healthy ... and I relax.

(Trust)

The word 'trust' is consistently used by informants with disabilities in describing their perceptions of 'quality'. The development of trust in receiving a service is directly related to the development of trusting relationships with key service workers. Trust relationships permeate life and according to Baier (1992, cited in Peterfreund & Denise, 1992, p. 421) " In entering into a trust relationship , we are relying on others' competence and willingness to look after, rather than harm". As people are dependent at a fundamental level on other people, it could be argued that trust is the fabric of society. Without trust, service encounters are unlikely to advance further than technical procedures. The development of trusting relations is seen as a fundamental safeguard and a sign that the worker's power advantage will not be abused (Hasenfield, 1994). As a basis for service interactions, trusting relationships between service users and workers provides a safe platform to address problems (Ippolitti, Peppey, & Depoy, 1994; Clegg, Standen, & Jones, 1996; Gardner & Smyly, 1997).

For people who have limited social contact and a need to rely on others for physical and emotional support, trusting relationships with key providers are not only related to physical safety but also to emotional security. In discussing trust as important in relationships with service workers, people relying on services describe trust in terms of confidentiality rather than the tangible acts of health and physical care. Trust in service relationships develops over time and is separate from reliance to carry out the activities associated with care. Trust

requires recognition of the other's goodwill which goes beyond the assessment of the work habits of people providing living services. Govier (1992, p. 20) suggested that "a balance between separateness and appropriate interdependence, is effected and maintained in a caring, trusting, mutual relationship".

Andrew, a man with a head injury who has had difficult experiences with services in the past, describes his current relationship with Mark, a key service worker, as trusting:

What I like about Mark is that he's a good guy. I can really trust him.

(Can you explain what you mean by that?)

Well ... he's always there for me ... when I need him ... and that. I know I can trust him with anything.

In contrast, Andrew describes a non-trusting prior experience with another service worker who had controlled his finances:

She was taking full control of my bank book and only allowing me thirty dollars a week for food. I had a key card and she took the key card off me and cut it in half in front of me to stop me using it altogether. I just never trusted her.

Andrew's trust in Mark, means that he will contact Mark when he needs help. Mark provides support for Andrew without 'controlling his life'.

In trusting others, people are also vulnerable to loss. For people whose central relationship is with a key worker, loss is experienced when the worker leaves or

when trust is not reciprocated, as Patrick a young man with physical disabilities who perceived that he had a close friendship with a carer explains:

I got really close to her ... but she really let me down. She complained about me. I thought we were very close but I was wrong. I'm careful now and don't get close to people. I don't trust them, because it can be very hurtful when things go bad. It's lonely not having anyone to share things with ... but it's safer that way.

When large service organisations control staffing, people living in group homes feel that they have little choice in their support workers nor do they feel that a support worker is 'theirs' because they are shared by other service users in other houses. They are also concerned about lack of loyalty and confidentiality. As a result, there is also less likelihood of personal relationships developing as people feel less able to trust workers who are perceived to owe their primary allegiance to the organisation. A young man, Steve, living in a group home explains:

Well...when you get a good one (service worker) one that you trust ... it doesn't take long for the 'rest' to get to them. They start off good and then they get just like the rest. They just do things their way.

(And how do you cope with that?)

I just pretend it doesn't matter. You get used to it.

Goffman (1961b, p. 107) has written about the way that individuals "pretend to embrace a role in order to conceal a lack of attachment to it". Other authors have also suggested that power relationships in the service context promote the internalisation of categorical roles (Davies & Jenkins, 1997). For Steve, who is

totally physically dependent on service workers, playing the expected role of service user, and accepting loss of control, is a necessary strategy within his service context. He explains further:

Well ... sometimes they like you to beg a little ... a little bit of power there ... you know what I mean? But inside I'm just laughing at them.

Although Steve lives in the community, institutional stereotyping of him by service workers as 'helpless' and 'other' continues to foster the unequal binary system of 'staff-client' division of power in his current environment. Steve feels powerless to bring about change.

It is also characteristic of group homes that staff change frequently and work strictly to rosters which allows little flexibility for service users to pursue their individual activities. Patterns in the data indicate that the larger the group of people living together, the more control staff have, and the more routinised the living environment becomes. People with disabilities in group homes who have previously lived in larger institutional environments believe that their physical environment and opportunities for community participation have significantly improved, but there is consistent reference to '*things being just the same*' reflecting their feelings of frustration that service workers continue to exert a major control over their lifestyle. This is despite the fact that autonomy for service users is strongly articulated in Western Australian Disability Service Standards (1997).

Discussion of confidentiality issues also emerge as important quality factors in living services. Over time, participants make their assessment of workers and decide whether or not the person is trustworthy of their confidences. When service workers communicate on a personal level and perform the tangible acts of serving according to the way service users like them done, they are more likely to be assessed as being 'genuine' people and 'not just in it for the money'. When trust develops with key workers, service users are more prepared to disclose intimacies and consequently receive emotional support.

Katy, a woman with a physical disability is totally dependent for self-care and has lived in a group home with a friend with a disability for five years. Katy discusses the importance of trust in receiving a service in describing Sally a key service worker who has become her closest friend:

I guess that the thing that makes me feel as though we are very close is the fact that she really is prepared to do anything for me ... um ... and it doesn't matter how personal it is. I guess I would trust her with something that I didn't want the rest of the world to know about .. she shares her life in a way that has nothing to do with working here.

Learning to trust is often a trial and error situation and as one person states “you can only find out who you can trust when you realise that you can't, and that can be hurtful”. For service user informants in the study, trust is an important quality of a service that transforms it from professional to personal. In personal serving there exists a high state of consciousness of the reality of the other person. Unlike supplying information and performing actions, it is not directly

observable, "It enters the reality of the observer in the shape of verbal and nonverbal expressions" (Kuiper, 1983, p. 474).

Trust is discussed by Shauna, a young woman with an intellectual disability who lives in a rented unit with a friend who also has a disability. Shauna and her friend receive services to help look after their rented home. Shauna has had what she describes as 'bad' experiences in her previous attempts to house share. Despite health problems and restricted mobility Shauna is determined to live with her friend and 'do things like other people'. Shauna also describes her views of a 'good' service as it relates to her relationship with a key service worker and the validation she experiences for 'being a likeable person':

Mark is really nice ... you can trust him. I like his personality.

He listens to me. He likes me too. He's really kind and gentle the way he talks. He's always there for us when we need him ... and when I'm gloomy and that.

(He's always there for you?)

Yeah ... what I like about Mark is that he's gentle ... never shouts at you and that ... just listens ... not yells ... and he's confident ... and that gives me confidence too.

O'Brien and O'Brien (1993a) suggested that people with disabilities who have limited opportunities to develop trusting relationships test the trust of other people to test and strengthen the relationship. When trust develops over time as a result of the personal quality and resilience of the server/servee interactions, this allows intimate, non-judgmental serving to develop and task oriented, routine service to recede. This does not mean that the quality of task

performance is diminished in the eyes of participants, in fact, the task performance of service workers who have positive personal relationships with participants is also assessed as being of a high quality. One informant summed up quality in a service worker coming into her home as '*... not just a guest or an outsider*'.

Relationships between service users and workers in environments which are not characterised by trust are described as being '*distant*' and causing people to '*feel uneasy*'. Some service users express high anxiety related to 'the influence particular staff have in their lives. This is exaggerated when service users have high needs for physical support. Two participants in separate services describe persistent stressful feelings in service relationships where workers do not relate well to them as, '*building up inside*' and '*waiting for a bomb to go off*'.

(Communication)

The importance of interpersonal communication in positively relating to service users and the confirmation of being personally connected to others is consistently evident in the '*good*' descriptions of experiences across informants.

Simon has cerebral palsy and uses a wheelchair for mobility. Simon lives in a group home with another younger man who has a brain injury and physical disabilities. They do not relate well to each other. Previously, Simon has lived in a nursing home and has moved to a suburban house in the hope of having a more normal lifestyle. In a typical day, the only people Simon comes into contact with are the other house resident and service workers. Simon's lack of social

networks is common to people with disabilities who have spent much of their lives in institutional environments (Todd, Evans, & Beyer, 1990; Barlow & Kirby, 1991; Clegg & Standen, 1991; Rapley & Beyer, 1996). Simon requires maximum assistance with self-care. Simon expresses what to him 'quality' in receiving a service means, although he feels that he has never experienced a 'quality' service.

(What do you think's important about getting a good service?)

Well ... for me it has been very difficult. A few people handle the job well and are social, but others don't talk and are just watching the clock. I'm just a part of their duty. They're just here for the money.

(If you had a choice how would you like it to be?)

I'd like to have generous people ... fun ... and willing to talk to me. People who are happy to come here and notice your health. People who talk while they're here.

(When they don't talk ... what is that like for you?)

It's quite dreadful ... I can't describe it. I just go into my room and stay there while they're here. It's a very hard thing to put up with. I really feel they don't like me and sometimes if I talk to them they don't answer me.

(That must be very hard. So what is it that keeps you going?)

Well ... just the hope that maybe one day ... my life will be improved.

A number of studies have examined the frequency and quality of interactions between service workers and service users in the field of developmental disabilities and concluded that people using residential services experienced little

attention from workers and in cases where people had high levels of cognitive impairment, personal-social involvement was further reduced (Cullen, Burton, Watts, Thomas & Walter, 1983; Seys, & Duker, 1986; Walbran, & Hile 1988; Hile, & Walbran, 1991). Hile and Walbran (1991) recorded less than 12% of workers' time was spent interacting with service users and that increase in worker ratio resulted in increased time in worker social interactions and less time directed to people living in services. Explanations for this have been suggested as relating to worker commitment to the underlying values of human services and also to the perceived lack of common ground for communication to take place with people who have severe cognitive disabilities. In this study, similar experiences are described by people with physical disabilities who do not have cognitive or communication problems, suggesting that worker value systems and stereotyping of service users into the role of 'other' occurs irrespective of the degree of disability. Simon's experiences are mirrored by Ross.

Ross, who lives in a group home in an adjacent suburb discusses his experiences. Ross has lived most of his life in a service and has occupied his current home for five years. Previously he lived in a nursing home with forty other people with similar disabilities. He now lives with another man who also has a physical disability. Both men use motorised wheelchairs for mobility and are totally dependent on others for daily living activities. The two men are compatible and maintain a sense of humour as they relate their day to day living experiences. Ross describes 'good' and 'bad' service experiences:

(Ross ...what's important to you about getting a service?)

Well ... having someone you get along with is more important than doing the job, I think. It's good when you know that they like working here. I get on really well with some of them now. It must be something in me ... they say they really like working here and that makes me feel really good.

(What do you mean by getting along with?)

Well ... having someone here who understands me and talks to me like any other person. Some people ... they kind of shut off from you. You can get that feeling from different ones that I'm just a job. There's one who comes here and just watches TV and doesn't talk. She's kind of here like a shag on a rock ... and this is our house. We just go out when we know she's coming ... we just don't want to be around her.

Communication styles are a way of assessing whether the person wants to be there. When service users are ignored by service workers this is very devaluing, especially if service users are unable to communicate verbally. People who lack verbal abilities use other senses, such as sight and touch to experience the presence and attitude of service workers. Jane, a woman with cerebral palsy who lacks purposeful movement or verbal abilities is an astute observer of people who enter her life. Her poetry and responses to interview questions provide rich insights about people who enter her life and their reactions to her disability. The way that people touch her body convey to her their attitudes about their work and their acceptance of her:

The way people touch me is my way of knowing that they care about me. Some people are gentle and take time, and others hurry with everything. It's the difference between being just a

body needing washed or a real person. I can feel their attitude right away in the way they touch me.

Communication through touch is important, whether people have verbal communication abilities or not, and 'gentle' and 'unrushed' touch in personal care activities communicates 'warmth.' Alternatively when people are viewed to be 'only in it for the money' they are perceived to provide impersonal service.

Ross who requires a high level of physical care describes the difference in personal and impersonal care through touch, from workers who are 'rostered on' to work in his group home:

Some people ... they wash you properly and dress you properly and make sure you've got all your creams on and that you're sitting comfortably in the chair. But some ... they just throw you in the chair and hope for the best and just give you a shower with just one flannel full of water ... things like that. If I were doing it myself I would be really particular. But I can't tell that person, because if I told him I would just get in an argument ... so I don't say nothing ... just wear it. Every time the staff changes we wonder what's coming on!

(Respect and Autonomy)

Respect is considered to be the precursor of personal relationship development. In respectful encounters the elements which define professionalism, such as fixed routines, and a degree of distance, are less overt, and serving becomes responsive and personal. It is also important for people to be openly accepting about the lifestyles of participants without attempting enforce their own values. Kuiper (1983, p. 480) suggested that in human services "Helping people means doing

things for them which properly belong to their own sphere of activity". This represents a respect for the other person and an acknowledgement that people have individual preferences.

On occasions, service users make requests of a service worker which cannot be followed through due to personal ethical values of workers. Requests are commonly of a sexual nature. The relationship is able to survive if it has a solid foundation of respect for the 'other' and open discussion of each other's point of view takes place. When the service worker recognises the boundaries of the service user's sphere of activity, they are able to do things in a way that respects service users' autonomy without controlling and devaluing lifestyle habits.

Respect is also enacted in the way that the service worker attends to the physical environment. The development of respect is an integral element of what is described by informants as a 'good' service. A 'good' service worker doesn't have to be continually reminded to perform tasks. They know the way that the service user wants things done and are familiar with the environment and anticipate service users' needs, fostering a collaborative relationship which is described as 'relaxed' and 'easy going' by people living in services. Clare a woman with a severe physical disability describes her satisfaction with a service worker Wendy:

The thing I like about Wendy is that she just comes in and gets on with the job. She knows what I like done and I don't have to keep telling her every time. It's more like a friend coming in than a worker.

For people who are able to have full control over selecting and training their caregivers there is a real sense of place and ownership in living situations. When people have left insitutional services to live in ordinary community homes and have been used to sharing both the physical environment and service workers with many others, it is important to have control of selection of their caregivers. A sense of place is not only about having a personal location but is deeply embedded in the meaning of personal relationships and the extent to which they offer personal continuity and a sense of belonging (Relph, 1976; Hill, 1996; Walker, 1996). When people have the choice of deciding who they will invite into their home, this for them means 'having an individual service'. Clare continues:

At first I was worried about finding the right carers. The sort of people who you can trust to do the job the way I like it and who would keep quiet about my business. I've had a few ups and downs, but now I think I've got a really good bunch. They know that when they come here it's my house, not their place of work, and I feel that I'm in charge of my life at last.

Service users who have control over recruitment and employment of workers, consistently state a preference to have workers who are not formally trained involved in their lives because they do not bring previously conceived ideas to the work. People who have had previous experience of institutional life, especially valued carers who have no medical training or institutional experience, as '*People who are trained think they know better than the client*'. Having control over training people in personal care activities is consistently stated as valued by

people who have moved out of large organisations. As one man states, *'at last, after all these years, I can decide what's done with my own body'*.

People also value workers who express a genuine concern for their health and well-being and look beyond the disability context to encompass emotional and other aspects of their lives. For service users, this represents seeing them as viable, healthy and developing individuals. Workers who freely give time to engage in social activities unrelated to the service, also induce feelings of being liked and foster friendship.

(Continuity)

Personal social isolation is a common experience of informants, especially if they live alone. Despite a strong desire to form natural relationships with neighbours and other people in the community, and having the support of key workers to do this, relationships with service workers and family are expressed as being the most stabilising in informants' lives. High staff turnover influences meaningful relationships being formed between people living in services and support staff (Braddock & Mitchell, 1992). Valuing helpfulness and close human relationships have also been demonstrated to influence the meaning human service workers find in their work and subsequently the reasons they remain engaged over long-term (Askvig & Vassiliou, 1991; Henry, Keys & Schaumann, 1993).

When service relationships are central in the lives of people with disabilities, severance of the relationship understandably has the potential to generate feelings of loss and associated grief reactions. Forming attachments to people is

an important element of personal continuity (Maier, 1994; Hill, 1996). Loss of central relationships with key workers have similar effects to loss of central relationships for people who do not live in service environments. One man, Patrick, who lives alone and requires total care to meet his daily living requirements formed a deep attachment to a female service worker, Emma, who had recently left the service to travel overseas. For Patrick, the relationship with Emma was central in his life, however, he now acknowledges that Emma's perception of the relationship was more of a casual friendship. Patrick says:

I really loved her. When she left I felt so alone and if I could have, I would have ended it all. It's bad enough being like this, but I feel so lonely now, because I used to look forward to seeing her and having her to share things with.

When service workers are the most consistent people in their lives, it is important for people living in services to have relationships which allow for sharing the highs and lows of day-to-day life and to be able to 'have a laugh like normal people'.

For people who require daily assistance with personal care, having a high turnover of service workers may affect privacy and feelings of personal dignity. It may also be tiring to continually educate workers in personal preferences and adapt to new personalities and feelings of anxiety about whether people will 'fit in' with the service user's lifestyle. When carers leave after short periods, people in services become disillusioned and guarded about new workers entering their lives. Melissa a resident of a group home explains:

When you know a new persons being rostered on, you just keep you're fingers crossed that you'll get on OK. A few times, we've had people here who haven't given a damn ... haven't known how to talk to us, and it just makes you feel terrible and really stressed out when you know it's their day on.

Continuity in relationships with key workers is important, and continuity is perceived by service users as an indication that people like them as people, and also like the work. The negative effects of high turnover of service workers is also consistently discussed in interviews, particularly when positive relationships have been experienced. Alternatively, when socially isolated people have mainly had contact with one service worker on a personal level, having different people coming into their home has the potential to provide stimulating conversation and a feeling of *'the outside world coming in'*.

(Friendship)

People consistently use the word *'friend'* to describe service workers who are considered to provide quality service and who are perceived to show respect. Uditsky (1993, p. 87) suggested the need for human services to avoid regarding friendships as yet another service technology to be programmed to order. In this study the use of *'friend'* to describe service workers who are liked and enjoyable to be with has different interpretations in relation to the degree of intimacy and perceived reciprocity of the relationship. Reciprocity is defined by service users as *'giving and getting'*. When mutual relationships are present they are more rewarding and intense but also more prone to loss and uncertainty. For five

service users, relationships have developed to the extent that they have become 'life sharing' and encompass roles of close friendship/family dimensions. For others, friendship may be simply a feeling of shared pleasurable experience. Perceptions of being in a friendship relationship in the service user and worker dyad has the potential to generate feelings of well-being and confidence and having a 'good' service. When friendship is used to describe relationships between service users and workers, service users report feeling more motivated to try out new and challenging activities, secure in the knowledge that emotional support is available if things go wrong. Andrew, a man with an intellectual disability describes this in the context of losing his job:

I was really down on myself when they told me I wasn't working out in the job . Thank God Judy was around ... she's a really good friend. We went out for a drink and talked about it. I suppose , like Judy said, I'll just have to keep trying. I'm not the only person who's lost a job .

(Summary)

Analysis of informant interviews clearly link positive relationships as fundamental to the experiences of quality in a service. Relationship between service users and workers emerge as the most consistent theme in people's perceptions of quality, or lack of quality, and critical to the quality of lives of people who rely on services for day-to-day living. Patterns in the data, however, across the twenty-six people with disabilities interviewed in this study demonstrate that more than half of the people interviewed are experiencing non-supportive relationships with one or more service workers which may almost

certainly influence their emotional well-being. Although all of the people interviewed, apart from one man who lives in a group home also had validating experiences through positive relationships with people who worked in services, it is difficult to comment on how 'good and bad' encounters between service users and workers balance out in an overall context of 'quality'. Bearing in mind that people in services lack opportunities for relationship mobility to the extent that other community members may have in seeking out relationships which make them *'feel good'* about themselves, incompatible relationships with service workers and the potential for misuse of power, renders them highly vulnerable in the complex relational contexts of living environments.

(Elderly People)

Elderly people in hostels and nursing homes witness the shrinking of the world in which they've been active and become progressively isolated from family and friends. They find that their basic needs are met by persons who are members of other families with ties outside the living service, and who are less able or unwilling to make close relationships (Larue, 1992; Powers, 1992). The appreciation of personal identity and values, emotional expressiveness, and affection in relationships, have been established as important aspects of attachment for people in nursing homes (Noelker & Townsend, 1985; Powers, 1991) and considerable research has demonstrated relationships between resident-staff affinity, survivability and life satisfaction (Noelker & Harel, 1978; House, Landis, & Umberson, 1988; Nussbaum, Thompson, & Robinson, 1989; Powers, 1992). Similarities and differences in socio-demographic characteristics

and length of contact between residents and service workers have also been demonstrated to influence interpersonal closeness in nursing home environments (Blau, 1960; Caudill & Patrick, 1989).

Mrs Jones, a nursing home resident describes what quality in a service means to her:

The important thing is the friendliness and the attitude of the staff. I appreciate everything they do for me and I need a lot of help now that I can't walk, but I know that when people take the time and interest to talk to me, that makes the difference between feeling that I'm just another body or a person in my own right.

(Trust)

Analysis of interview data from aged care contexts strongly supports the contention that quality in living services focuses on the relationships with service workers as being integral to positive adaptation to living in a hostel or nursing home. Among elderly participants 'trust' is a consistently stated concept and is primarily articulated in terms of confidentiality and concern on behalf of service workers which goes beyond the day-to-day routine tasks of care-giving. Trusting relationships for this group are a way of 'banking up' security in someone who might act in the person's best interests if their physical vulnerability was to increase. This strategy is not so critical for people living in hostel environments when they are able to maintain ongoing regular personal relationships in the community, however, people living in nursing homes and

who are socially isolated, go to great lengths to establish and maintain relationships with workers.

One nursing home resident, Mrs White who has chronic respiratory problems discusses the importance in her current life of a nurse Val, who has been involved with her physical needs for three years:

They're all nice but Val's special. I know that when she's here she'll make sure that things get done for me right. She's been a good friend ... that's for sure. The days that she's on ... I'm not so worried.

(You're not so worried?)

No ... I feel safe with Val around. We have a nice chat about her family ... three girls she's got ... and she's such a hard worker.

For Mrs Glenn, who is almost completely blind and unable to walk, trust relates to people taking time to understand that any changes to her physical environment renders her even more vulnerable. In her dark, dependent world, the presence of unannounced people in her nursing home room causes anxiety. She is totally dependent on the trustworthiness of others and their attitude towards her daily needs. Rotation of familiar staff is particularly difficult for her as she relies on others to understand her need for a structured environment over which she can exercise some control. On the morning of the interview she was distressed:

It is important to me to be able to trust people to put things back in the same place. It's very distressing when they don't do that and I get all lost. That's a new girl on today and she doesn't know me. I get tired of saying what to do and not to

do ... and I don't want to weep while they're here, but I only lost my sight two years ago and I need to know that I can put my hand out and reach things I need. I only see people when they bring my food or put me on the commode. If I can find the radio and turn it on, it's not so lonely.

In contrast, Mrs Glenn talks about her 'friend' Joan, an activities co-ordinator:

Joan is a great support to me. I feel better when she comes into the room.

(Can you help me to understand what you mean by feeling better when Joan comes?)

Well ... she's bright and happy ... we talk about normal things ... about the garden ... things that are going on ... and what she's doing. She understands what it's like for me. She always tells me she's coming into the room when she comes. If I just hear someone coming in and I don't know who it is or what they've come for ... that can be very frightening.

When trusting service relationships are not established, people express fear and vulnerability, such as Mrs Wilson, a hostel resident who relies on a walking frame for mobility and is afraid to express her fears to the hostel manager for fear of 'rocking the boat'.

Do you see this walker? I take it into the dining room and put it up against the wall ... but the manageress takes it and moves it outside in case someone falls over it. I have to sit there until it's brought to me. If there ever was a fire in that dining room then all of us on frames would be stuck.

(And have you ever spoken to her about it?)

I never have ... but she knows I don't like it. I can't walk without it. There are forty-four of us in the dining room and if

*this is taken away from me and I want to get out quick, I
can't. It sits against the wall and it's not in anyone's way
but rules are rules I suppose. If there was ever a fire in there
.... I would be stuck.
(It sounds like that's a real worry for you)
Yes every day when I have to go in there I think about it.*

Alternatively, when service workers who are in senior positions are perceived to operate within an empowering ethos, the accounts of hostel residents about their role in the service have less of a conforming nature. When elderly people in services experience an ethos of empowerment they more consistently report being satisfied with their interactions with staff. Patterns in the data suggest that quality is experienced when there is an acceptance of individual differences and a willingness on behalf of workers to circumvent rules to meet the preferences of residents. This is observable in a small wing of a large institutional service where sixteen hostel residents have been supported to maintain their autonomy and fully participate in decision making about day-to-day activities. Although situated in a lower-socio economic area of Perth, in urgent need of building maintenance, and externally projecting a greater institutional image, the relational quality is very different from Mrs Wilson's situation, where well maintained gardens and a middle-class image divert the causal observer from recognising the subtle control of residents. Recent studies have supported the relationship between staff ideological orientation and psychosocial well-being of residents in aged care facilities (Bagshaw & Adams, 1985-86; Collopy, 1988; Lidz & Arnold, 1990; Timko & Moos, 1990; Coffman, 1992).

(Communication)

In nursing home environments, relationships with service workers are the most consistent in residents' lives. As nursing home living environments are characterised by congregated activities and many situations of living in close shared proximity with other elderly people, communication with workers is highly important in reinforcing a sense of identity. Many studies have identified that few relationships are formed between people living in nursing homes (Townsend, 1962; Restinas & Garrity, 1985; Downs, Javidi, & Nussbaum, 1988; Kaakinen, 1995; Kovach & Robinson, 1996). It is also characteristic of informants in this study, that although people share bedrooms, few have relationship with each other apart from cursory greetings. The formations of communication partners among nursing home residents may also be limited by lack of privacy, stereotyping and loss of communicative abilities (Lubinski, 1978; Sigman, 1981; Nussbaum, 1993; Kaakinen, 1995; Lubinski, 1995).

Although other studies have commented on the reluctance of elderly people living in nursing homes to express loneliness (Carp & Carp, 1981b; Heller, Price, & Hogg, 1990), feelings of loneliness are consistently expressed throughout interviews in this study. Small acts of kindness or brief communication of a personal nature is experienced by people living in nursing homes as service 'quality'. It is not uncommon in the analysis of interview data to find accounts of small gestures of friendliness which had taken place months previously, presenting as examples of service excellence. Communication of a personal nature by staff who share their own experiences, stories about family activities,

opinions of current events, use of humour and any talk which does not directly involve the acts of care or reinforce the role of nursing home resident are perceived by service users to represent an interest in them and acknowledgement that they share a common existence with people working in services. Survey research has supported the view that interactions which are characterised by perceptions of continuity of respect from the past, positively influences life satisfaction for people living in nursing homes (Ghusn, Hyde, Stevens, & Hyde, 1996).

Mrs Martin has lived in a nursing home for eight years. She shares a room with another resident who has lost the ability to communicate. Mrs. Martin, although physically frail, can walk and is mentally alert. Her experiences of living in the nursing home have not been positive over-all. She spends her days reclining on her bed listening to 'talk back' programmes on a small transistor radio. This is her contact with the outside world and as she describes it, *'it's my best friend'* and *'what keeps me sane'*. The contact Mrs. Martin has with service workers revolve around the tasks of hygiene and other tangible body maintenance activities. She lives with ninety-seven other people but describes herself as lonely. The most significant person in Mrs Martin's life is a tea lady called Patsy who comes from a different ethnic background. Patsy, according to Mrs Martin is the only service worker who relates to her as a *'person'*.

(So ... if I asked you to describe a good experience related to living here ... could you describe it for me?)

Well I suppose there is one person here who understands me ... that's Patsy. She just seems to understand me ... she

says my name and asks how I am. It's just that feeling between one person and another.

(It's just that feeling?)

Yes I'm happy when I talk to her because I know she's interested in me. Just a few words make a lot of difference. She makes sure I get my tea just the way I like it. I can't describe what it would be like if nobody spoke to you ... I can't describe it. It would be very terrible because I'm a human being, and I can still talk, and I'm interested in people. Some of the people who come on in the afternoon don't speak at all. I don't bother anymore.

For some users of aged care services a lack of positive relationships, and in some cases negative experiences in the way that service workers relate to them, result in a view of the service as being 'poor' and their role in the service as being 'just somebody's job'.

In another nursing home Mrs. Burns describes her service life. She has lived in the nursing home for one year, following a stroke.

(What are the things that you think are good about living here?)

There's cleaners that come in to clean your room every day and your bed is made every day and you can make an appointment to talk to the sisters if you need to talk.

(If you want to talk at other times is that OK?)

Well ... they're very busy you know. It's better to make an appointment.

(If you had the chance to employ people to work here ... what sort of people would you choose?)

Well ... I'd look for people to look after older people that aren't rough with them, and if they wanted to, they'd talk to them. I shouldn't get any people that were rough with old people because I should think that you've got to look after them properly until they die. I know what rough handling's like ... I do. Looking after old people is more than just doing a job ... you've got to care about them.

(Friendship)

During observations in nursing home environments interaction seeking behaviours were frequently initiated by service users towards service workers. These are observed to be more successful and responded to, if directed towards clinical activities, rather than personal-social communication. Consistent interactions which go beyond the service role to the personal domain are likely to be interpreted by service users as *'friendship'*. This is supported by the findings of Nussbaum, Holladay, Robison and Ragan (1985) who also reported the term *'friend'* consistently used by elderly residents of nursing homes to describe their relationships with service workers. This has also been supported by studies of younger populations using services (Weismann & Appleton, 1995). Informants who believe that they have friendly relationships with workers, perceive that the interactional context is mutually enjoyable and that they are less a person to be cared for than one to be enjoyed. An optimistic approach to the acts of caring also reinforces a view that service workers enjoy interactions and consequently *'like'* the person in the service. As a protective mechanism, relational bonds may enhance the ability to cope with developmental changes and loss in situations

where self-esteem and identity are threatened, such as entering a permanent care situation (Powers, 1991; Brandstadter & Greve, 1992; Umoren, 1992).

There is little expectation on behalf of nursing home residents that relationships will be formed with workers, as they are always perceived to be overworked, but there is strong evidence that friendly relationships are desired by elderly informants in this study. In situations where, despite the constraints of the service environment, relationships of a personal and self-disclosing nature are formed, residents speak of their meaning in glowing terms as *'friendship'*.

Mr Williams describes his contrasting service experiences and his perceptions of service 'quality'. He has lived in this nursing home for two years since his elderly wife became frail herself and could no longer care for him. Mr Williams shares a room with three other men none of whom are able to speak. Mr Williams sits in a chair with his back to the window facing the door to the room and attempts to engage any passers-by in conversation. He has had an interesting life including prospecting for gold in his twenties. He managed his own company prior to retirement. Mr Williams describes the importance of empathetic touch in his interactions with nurses:

Quality? I think that's about the caring of the people here. The friendliness ... and just getting a comforting tap on the shoulder for reassurance. That gives me such a boost ... and then I know I'm not so alone in life you know ... and not just a dot in their book.

Mr Williams' experiences have not always been so positive, as when he was coerced into using a wheelchair by a therapist:

I was railroaded into trying it (a wheelchair) out by this therapist. A bullying sort of person she was. I said I didn't want it but she wouldn't take no for an answer ... wouldn't listen . I didn't want to make waves.

Perceived 'friendliness' and 'taking time to talk and listen' are also important to people living in hostels who fear deterioration in their health and the probability of another relocation to a nursing home and loss of status. Service workers who are described as 'gentle in nature' and share information about their families reinforce the connection that hostel residents have with the wider community and also reinforce their roles as 'normal' people and being in a friendly relationship. Overall, the analysis of interviews with hostel residents consistently demonstrates that friendship relationships with service workers are considered normal, just as for people who do not live in services, forming relationships is common when interactions are frequent. This may also be explained by the fact that residents of hostels have opportunities to reinforce social roles outside the hostel environment. Residents of nursing homes have limited social mobility, reduced communication, and therefore little opportunities to practice normal social interactions.

Mrs Grace has lived in a hostel for three years. Her major roles in life have been as wife, mother of six and now a grandmother. Her husband died ten years ago and she has also lost a daughter recently through illness. Mrs Grace expresses

acceptance of her current living situation and the relief of no longer being responsible for managing a home. In common with other elderly people interviewed, she is adamant that she would not live with any of her children, as she does not want to 'be a burden on anyone'. When questioned about what 'quality' meant to her in her living situation, Mrs. Grace responds:

What I think about 'quality' is that staff are the main thing.

(Can you help me to understand what you mean by that?)

Well ... they need to be friendly ... here they are very friendly.

It's like you and I talking to each other ... you sound friendly

... I think you are. It's just talking about ordinary things ...

like ordinary life. You have a lot to do with staff here, and if

they have that little bit of friendly feeling toward you that's

important. Take Mary ... she really understands me ... and

knows when things are worrying me. When people talk about

your children then you know they're interested in you and

bothered to get to know you. It makes it a more friendly

atmosphere like being at home.

(Like home?)

Yes ... you've got nowhere else to go now ... you've sort of

burned your bridges.

Despite the equalising nature of friendship relationships (Hays, 1988) within hostels there is consistent reference to the need to 'accept the rules', and if a staff member has a more powerful position and controlling manner, it is difficult to express discontent about issues. Literature supports a view that negative interactions arise when relationships involve unequal social exchange. Studies have demonstrated that psychological distress results when there is power

imbalance in aged care environments (Cohen, 1990; Collopy, 1990; Collopy, Boyle, & Jennings, 1991; Cohen et al, 1995). Conformity to the '*resident role*' is likely to be exaggerated in the controlled environments of service systems (Timko & Moos, 1990; Cohen, Werner, Braun, Kraft, Gerber, & Williams, 1995).

(Continuity)

Continuity of staff is also important to elderly people and influences their sense of security and trust in the service. When large groups of people live together it is difficult to experience individuality as routine practices are directed towards maintaining equal standards of care and idiosyncratic needs may be considered less important and more difficult to fulfil. It is difficult for people who do not live in this situation to understand the confusion and anxiety which is consistently expressed in the data relating to the large numbers of service workers who rotate through people's lives and through necessity become intimately engaged in their bodily needs for a time and then move on. Continuity and trust are closely related, and, as has been discussed earlier, some personal knowledge of service workers generates security in what may be an otherwise vulnerable role of 'resident'. Eventually many people die in aged care services and having someone familiar to talk to about fears related to death and dying is critically important for some people. People may not discuss their fears with friends and relatives for fear that they may find the discussion difficult and reduce their contact. As a result, visiting times tend to be characterised by superficial social conversations which maintain the comfort of friends and

relatives. A nursing home resident, Mrs. Owen, describes the link between continuity and trust:

People are always changing here and you never get to know anyone well. They're always chopping and changing. I think people should be left in one place for a time so that you can get to know them and then if there's anything you want to talk or ask about, you can do that. When they're new you don't know who they are. It's important to have someone to trust and to talk to. I know my cancer's getting worse and I'm worried about what will happen at the end. I got very close to Janice (nurse). I could talk to her, but she's left now to have a baby. She was here for five years and really knew me. They're all very nice, but there isn't anyone specially close to me in the way that Janice was.

(Summary)

Quality in 'Human Serving' from the perspectives of elderly informants is primarily about the experience of existential concern, empathetic communication, including touch, and the security which comes from trusting relationships with key service workers. The essence of quality in 'Human Serving' is about positive and affirming relationships between service users and workers. It is much less about the tangible, material service elements, or 'indicators' which are commonly measured as 'outcomes'.

Within disability and aged care settings there are many similarities in the way people experience living services through their interactions with service workers.

The service processes and structure of the environment may also support the

enablement or disablement of positive human relationships. The consistency with which the word '*friend*' was used to describe positive relationships with service workers demonstrates the way people living in services strive for social relations which are non-objectifying, meet their needs for attachment, and which are perceived by them as establishing and maintaining a positive social identity in the absence of opportunities to pursue or maintain natural affiliations with people in the wider community.

Data from the fifty service user informants indicate that enabling relationships are more likely to develop in smaller community homes for people with disabilities where caregivers are shared with only one or two other people. There are, however, also enabling relationships in the aged care area. Analysis of interview data suggests that relationships with service workers are more actively sought in nursing home environments rather than hostels. The reason for this may relate to the greater social mobility of hostel residents who commonly access community activities and are able to maintain natural friendships. The physical and cognitive frailty common to participants living in nursing homes, make them more dependent on relationships within the setting. Respect and autonomy do not consistently emerge in aged care data as separate from friendship relationships, whereas in interview data of younger people with disabilities, issues related to respect and autonomy consistently appear in their interpretations of quality. Elderly people, despite describing experiences which are disrespectful and disempowering, are less critical of their services overall. This may be due to feelings of heightened vulnerability and the likelihood of

increasing dependence on services due to health issues and the fact that few of them have any previous experience of living in a service and therefore are unable to make comparisons.

The four married couples (two of whom live in disability services and two in aged care services) who were interviewed, although identifying that communicative behaviours of service workers are an important aspect of service delivery, do not describe the need for disclosure of intimacies or the development of central relationships with service workers, perhaps because their relational needs are already met within their partnerships.

Sub-themes of the major theme HUMAN SERVING, i.e. GROWTH, FRIENDS, THEM AND US, and DIS-SERVICE, will now be presented and discussed.

4.2.1.1 GROWTH

(Expanding Lives)

“When the service relationship conveys a degree of personal feeling which nourishes the wholeness of the other it creates a relationship which encourages growth” (Walton, 1989, p. 43). In a climate of ‘Growth’ individual autonomy and emotional connectedness are recognised and consciously addressed in the service relationship. Service users experience warmth, affection and unconditional support, and the opportunities available to them are limited only by their own choices rather than stereotypical expectations and the role boundaries of service systems. There is maximum flexibility in the way that

service workers engage in meeting the requirements of people living in services. Informants consistently refer to '*growing*' as a result of opportunities for a greater variety of experiences. Growth is not described in terms of tangible outcomes of service involvement in the day to day activities surrounding the living environment e.g. 'skills training'. This is termed 'learning'. 'Growth' relates to the social and emotional development or 'coping' abilities of service users as they encounter, gain, and lose, roles and relationships.

The sub-theme 'Growth', relates to the way that the relational context of a service supports the personal growth and development of service users and their mastery of new situations. Six people with disabilities living in the community across four separate service agencies discuss an expansion of life roles and activities which foster their belief in themselves as 'able'. The expansion of roles is an important element in the development of self-concept and confidence to engage in social activities.

The sub-theme 'Growth' was experienced only by people with disabilities who were interviewed. 'Growth' did not emerge as a sub-theme of 'Human Serving' in data from elderly informants in this study, possibly due to the restrictions of aged care environments including reduced opportunities for relationship development, staff continuity factors, health procedures and staffing arrangements, and regulations which dominate the lives of elderly people who live in services. Internalization of the sick role and the generally held belief that people enter nursing homes to die rather than to live may also prohibit elderly people who enter permanent care situations to find meaning in their experiences

in a context of 'Growth'. People with disabilities who experienced a relational context of 'Growth' had either lived in a family or institutional context prior to their current living arrangement. The positive relational nature of their current service is attributed to one or two key service workers who do not view disability as a barrier to gaining experience in community life. The relationships with these key workers are central relationships in the lives of service users. For three of the participants, this represents their closest relationship. Only one of the service workers involved with this group has any formal training in human service work. Four female and two male carers are instrumental in the experience of 'Growth'.

People who have mainly known roles of child, or institutional resident, describe their opportunities to develop an adult identity through an expansion of adult roles. Reg a middle aged man with cerebral palsy describes his seventeen years as a resident of a nursing home. In the nursing home Reg had been ridiculed and labelled with a devaluing nickname because he liked to talk. As Reg is unable to perform any other physical movements independently, speech is his greatest 'gift'. He is articulate and well informed about a variety of current events. In the institutional environment Reg described how his 'gift' was considered only to be of nuisance value.

Reg now lives alone in a community house in an inner city suburb and is responsible for selecting and organising his support workers. It was due to a service worker, Roy, who admired and believed in Reg, and supported him in his long struggle to leave the institution, that Reg partially owes his current lifestyle.

I used to think a nursing home was all I could get ... but now I can employ my own people and do just as I like ... thanks to Roy. In the nursing home I shared a room with five other men and everything had to be done together and at a certain time. This might sound strange to you, but I used to call it a glorified prison.

In contrast, Reg describes his current life:

It's entirely different now. People actually like talking to me. I feel a different person ... that's it. Like star wars .. I've landed! ... on my home planet ... among my own people.

When people reach out to each other, they confirm each other's existence. Roy's belief in Reg and consequently Reg's belief in himself has led to many attempts by Reg to establish a place in society. Reg admits that many of his attempts to be accepted have not been successful, but his relationship with Roy and another key worker Linda, ensures that he has a secure base from where he can explore the world. Reg affirms his resilience to set-backs and determination to keep trying to forge legitimate recognition of himself as a contributing person. One of his favourite activities is to be dropped off at the local shopping complex where he will spend many hours watching people pass by and attempt to engage them in conversation. Sometimes he 'strikes lucky' and meets new people. He is optimistic about expanding his circle of friends outside of service workers:

You know ... I still believe that there are other people out there who might become friends like Roy and Linda. I just haven't met them yet.

Within a context of 'Growth', there is a minimum of routine and formalisation. People are encouraged to be spontaneous in their choice of activities. Shared interests, shared social networks and activities outside the boundaries of 'service' between service user and worker are common. There is consistent evidence of the responsiveness of the service worker to meet the requirements of situations which encourage growth in service users.

A young man with an intellectual disability, experiences 'Growth' through his relationship with Jeff, a service worker. Luke, proudly describes his weekend of adventure with his 'good mate' Jeff, who had invited him to share his weekend activities. Luke talks about his fear and excitement at meeting a physical challenge:

Did you know ... one weekend we went canoeing? We turned the canoe upside down and there were two straps to hang onto and I did that! I canoed like a champion I did!

'Growth' does not occur in a climate of paternalistic benevolence but in what is perceived as an authentic liking and enjoyment in each other's company. In fact, little of what emerges in the analysis of informant interviews relating to the theme of 'Growth' can be articulated as tangible service outcomes, yet the positive affect on participants in their description of 'quality' interactions clearly supports the value of the encounters.

'Growth' is not only related to positive life experiences, but also experienced in situations of loss. An example is the story of Julie a young woman with physical disabilities who describes her experience following the sudden death of her

father, who was her primary caregiver, and the critical and unselfish support of Ann, a service worker who moved in to live with her to support her voluntarily in the early stages of acute grief:

She stayed with me ... I don't know what I'd have done without her ... gone into a home I suppose ... but you don't want to be with strangers, especially then. She really got me through the bad times. I just wanted to die too. I'm much better now thanks to Ann.

Ann's personal obligation to Julie transcended the role of service worker. She had fulfilled a role that could not be 'bought' or 'categorised' in service language. O'Brien & O'Brien, (1993, p. 5) suggested that "Who comes into a person's life may be the single greatest factor of influence on what that life becomes". For Julie, Ann's support played a major influence on her healthy recovery. The intensity of Ann's involvement over an extended period provided a safe environment for Julie's grief to be expressed. Ann is no longer a carer for Julie, but keeps in touch on a friendship basis.

Julie's experience of Ann's unselfish concern for her well-being, is mirrored in the experience of another woman, Katy who has physical disabilities and deteriorating health. Katy is widely respected for her courage in overcoming her physical frailty to engage fully in community life. She has lived in a group home for five years following an extended period of living in an institutional environment. Katy expresses her personal growth not primarily in terms of her increased control of her living environment, but through the shared experience of child rearing as Godmother to the infant daughter of her friend and caregiver,

Sally. Sally's sensitivity to the losses in Katy's life as a woman with a disability unable to bear children of her own, prompted her to share her experience of pregnancy and childbirth and subsequently she has invited Katy to play a role in the upbringing of her daughter. The relationship between Katy and Sally is a loving friendship which has grown over time despite the boundaries of 'service worker' and 'service user'. Katy talks about the meaning of her relationship with Sally:

Well the thing that makes me feel that we are very close is the fact that she really is prepared to do anything for me and it doesn't matter how personal it is. I would trust her to share her feelings with me too. If anything happened to her I'm pretty sure she would leave the responsibility of bringing up her daughter to me. She's said it more than once. Although she knows that physically it's not practical, she'd still want me as involved as possible.

Through her relationship with Sally, Katy has grown and is continuing to grow and experience different responsibilities through the upbringing of Sally's daughter. This is not perceived by Katy to be a token gesture on Sally's part, but a deeply felt love and respect for her by electing her to a position of trust based on a knowledge of her capacities as a wise and nurturing adult to contribute to a child's development.

The former examples of the sub-theme 'Growth' illustrate the quality experiences in service environments which have been fostered by the human connection between service users and workers. This requires equality in the

service encounter and a recognition of human attributes people have in common as opposed to their differences. In informants' descriptions of service workers who are instrumental in 'Growth' inclusive terms are used in discussing joint activities. i.e. 'we' and 'us'.

Walton (1989, p. 137) discussed the true mission of a human service as being instruction towards fostering growth and development which is not only effective, but also includes the capacity to act. A service where people experience 'Growth' is characterised by relationships which are anchored in caring acts on behalf of people who use the service. In 'Growth' people are provided with opportunities which challenge their potential to freely explore unfamiliar social territory supported by a caring key worker. According to Noddings (1984, p. 73) in the subjectivity of the service context, "The responsive cared-for in the fullness of the caring relation, feels the recognition of freedom and grows under its expansive support". This is in keeping with the views of Mayeroff (1971), who stressed the purpose of caring being self-actualisation of another, and Heidegger (1962, p. 159), who suggested that freedom is bestowed on the other in an authentic relationship of care which "... frees the other in his (sic) freedom for himself". 'Growth' contexts in living services are not 'controlled', but 'fluid' service environments which generate opportunities for spontaneous and flexible support.

Acts of serving in a 'Growth' context are characterised by respect for the individual lifestyles of people living in services and a willingness to carry out tasks in a way that reinforces the autonomy of the service user. This is described

by Lisa, a young married woman with cerebral palsy who requires full assistance for physical care. As a newly married woman and home maker, Lisa expresses her individuality through the physical abilities of her caregivers, especially Doreen, whom she describes as *'like a sister'*.

Lisa describes how she goes about selecting people to care for her:

Well ... it's hard to interview people ... but I go by instinct. It's just the way they talk to you and whether they look at you when you're speaking. You can tell by the expression on their faces whether they want to care for you or not ... whether they can accept you. Take Doreen, we're more like sisters the way we communicate. We've got a friendship ... really. I feel really close to her and I'd trust her with anything. I know she likes to be here. She respects me and listens to my point of view ... puts herself in my position, like. She'll look at my side of things and won't take sides if there are any problems ... she gives me the benefit of the doubt.

Lisa views her relationships with service workers as being the 'most important part' of having a service. She says: *'It's more important to get along with them than them being good around the place ... you can always teach them that'*.

For Janet who also has a physical disability and requires a similar level of care as Lisa, trust and respect are also key elements of quality. She describes her trust in a particular service worker, Suzie, with whom she shares her intimate world of personal experiences, hopes and dreams. Suzie is the one person whom Janet will allow to organise her photograph album. She also describes her relationship with Suzie as *'just like sisters'*.

Care tasks according to Lisa and Janet are also performed differently by Doreen and Suzie. They describe a higher level of autonomy in decision making and 'having things done my way'. When asked to provide an example of this Janet says:

I can't do anything for myself... but I still have standards and ways I like things done. Suzie is like my arms and legs. She does things just the way I'd do them ... if I could ... without arguing.

Growth in a service context thrives on caring friendships which have developed to a deeper level of intimacy and trust. Perceptions of service users in this study articulate experiences of meaningful relationships with service workers which provide the springboard for their exploration of new situations. Acts of serving encourage service users' autonomy and support choice and individuality. 'Quality of life' studies for people with disabilities have supported the importance of feelings of personal autonomy and life satisfaction (Brown, Bayer, & Brown, 1992; Parmenter, 1992; Joyce, 1994; Perry & Felce, 1995; Matikka, 1996).

4.2.1.2 FRIENDS

(Like one of 'them')

In the absence of a simple definition of a friendship relationship, people generally define friends by subjective factors such as someone they can trust or confide in (Adams, 1986; Lowenthal & Robinson, 1986; Duck, 1991). The sub-theme 'Friends' is the most consistent description of service quality across the

fifty interviews with service users in both disability and aged care living environments. All informants in the study allude to friendship as an important element of quality in a service, even if they do not experience this themselves. Perceptions of friendship, however, vary. Descriptions of relationships and acts of service workers which symbolise friendship to people living in services are influenced by the formality of the service environment. In an institutional context, e.g. a nursing home, 'Friends' may be experienced in simple communication behaviours such as listening, communicating concern about a person's well-being, or taking an interest in family members, whereas, in a community house for people with disabilities, 'Friends' is more commonly symbolised by feelings of trust, self-disclosure, sharing of intimacies and presenting a happy disposition in the role of service worker.

'Friends', as a service element, provides positive relational experiences but does not have the life sharing qualities of 'Growth'. Although reciprocation is perceived by service users to be a characteristic of 'Friends', mutual self-disclosure of an intimate nature may be present, but it is not a highly consistent feature of the data.

Taken at the most basic level, 'Friends' according to informants in the study, relates to feelings of being liked and valued. Experiencing 'Friends', is a validation of individuality and a buffer to depersonalisation and loneliness. In the absence of 'Friends' services become neutral, task oriented experiences. Service practice has been critiqued by Schon (1983) as rooted in technicism and professional rationality. In the context of 'Friends' professional distance and

impartiality is replaced by personal involvement. A sense of connectedness, and being '*understood*' are experiences consistently described by informants.

Literature on the functions of friendship, reflect the presence of a mutual relationship, and perceptions of equality (Rubin & Coplan, 1992). It has been shown that friendship may also involve altruistic acts, such as generosity, co-operation and helpfulness (Berndt, 1981a; Berndt & Perry, 1986) although few correlations between friendships and patterns of interaction have been empirically demonstrated (Hartup, 1986). The recognition of certain attributes of service workers broadly encompassing empathetic relating, is interpreted as friendship by people living in services. For some informants, their perception of friendship only extends as far as a feeling of empathetic relating on behalf of the service worker. In others, friendship is expanded to activities beyond the expectations of paid work including advocacy, and informal social interaction. Common to all situations is the experience of being attached, being cared '*about*' (in contrast to being cared '*for*') and having a personal history beyond the identity of service user.

Clare, a young woman with a physical disability, lives in a group home with a friend who also has a physical disability. Clare discusses her life and her friendship with Wendy a service worker. Clare's family lives in a rural area and she moved from the country to live in nursing home accommodation in town so that she could attend high school. Clare has lived with her friend for the past five years. She receives services daily from a local organisation through which she met Wendy. Clare has a full-time job in a government department and enjoys all

the normal activities of her peer group. Although she finds the need to use a motorised wheelchair for mobility restricting, she manages to lead an active social life with Wendy's support.

Clare has come through some difficult times living with her disability and what she describes as '*hating life*'. She talks about '*getting out of depression*' and '*not feeling sorry for yourself*' because other people distance themselves from her and life becomes more lonely. Prior to Wendy coming into her life Clare had mixed experiences with service workers. Clare describes the difficulties of being dependent on other people to help with her personal care:

It's difficult with the personal care stuff. I mean ... you always have to have relief staff and you think ... ' Oh gawd ... here we go again. ' I wonder how long they'll stay... and how much do you want them to know about you ... because they might not be here for very long.

Clare defines 'quality' in receiving a service in the context of her relationships with service workers, especially Wendy, who is described as a '*good friend*' and someone with whom she shares a reciprocal relationship:

(Clare ... What's important to you about getting a service?)
Well ... I like to have people here whose attitude's in the right place ... easy going. It's hard to explain because they're friends. They don't treat you like you're different to anybody else. You know, they come to you with problems or you go to them with a problem. I mean ... I think that's the way it should be otherwise it just doesn't work. Take Wendy, ... we're totally at ease with each other. She's not one of those people who has a bad day and sulks ... and she's very motivating. I

just value her friendship because I know she'll be there if I need her.

A similar experience of friendship is described by Jean, a woman with cerebral palsy. She requires assistance for all her daily living needs. She lives in a unit in a small development with her dog for company and spends long hours alone at home between visits from her caregivers. Jean has few social or family contacts but has a close relationship with Carol, one of the service workers who assists her most days.

Jean describes herself as 'lonely' but 'hopeful' of finding a partner to share her life. Her relationship with Carol is currently the most important in her life.

(Jean ... tell me what's important to you about getting a service)

Well ... it's all about carers ... when they're good ... they're a lot more like a friend ... they care about me.

(Can you give an example of that?)

Well ... there's one I'm particularly fond of called Carol... she's got warmth and she likes me. I can really feel it.

(You can feel it?)

Yes ... it's the way she talks to me ... touches me. Some people don't give a shit ... but Carol... she does more than anyone else and more than she's paid for. She believes in me and that's really important. She's a top lady. A good friend.

Clare and Jean are representative of a group of people who have restricted opportunities for social interaction due to disability and therefore limited availability of naturally forming social support networks. Social support

networks have implications for physical and psychological health and reduce feelings of isolation and loneliness (Peplau & Perlman, 1982; Pennebaker, 1985; Pennebaker, Kiecolt-Glaser, & Glaser, 1988; Prager, 1996) For Clare and Jean, who are at risk of social isolation, service relationships fulfil an important role in maintaining well-being.

Studies of perceived life satisfaction have strongly indicated that relationships are the most important element and that they give meaning to life across the life-span (McCarthy, 1984; Devogler-Ebersole & Ebersole, 1985; Burbanck, 1992; Prager, 1996; Romney & Evans, 1996). Studies of non-institutionalised elderly people have demonstrated that a disintegration of informal networks accompanies age and chronic impairment (Adams, 1989; Bury & Holme, 1990; Girling, Huppert, Brayne, & Paykel, 1995). As a result, older adults revise the criteria they use to define friendship, and definitions of friends are commonly extended to include acquaintances (Adams, 1986; Johnson & Troll, 1994).

For the elderly study informants, particularly those living in nursing homes, opportunities to develop relationships are even more restricting than opportunities for people with disabilities who live in the community. Relationships with valued workers are also described as friendships, although patterns in the data are less reinforcing of friendship characteristics, such as reciprocity, for this group of informants.

Mrs Jones has lived in a nursing home for the past year following the sudden death of her husband who had also been her carer. She has severe osteoarthritis

and is unable to walk. Her previous roles in life included wife and mother of four. Three of her children live in Western Australia and one daughter and her children live in an adjacent suburb. Mrs Jones 'lives for' visits from the family which occur about once a week. She has a quick wit and is a keen follower of team sports on television. Mrs Jones discusses the importance to her of people listening to her and respecting her point of view. Quality in a service for Mrs Jones is described in the context of her interactions with her 'friend' Pat , a nurse.

There's one girl Pat who's such a friendly, loveable person and you can't help but like her. It's just her nature. She's a mother and she's got two babies. I feel she's like one of my own family ... you know. She's loveable and gentle and tells me about herself. I can see her coming and think she's always happy to see me. She talks to me about the family ... things that are on her mind ... just for half an hour or that. It makes you feel like one of them.

Studies of friendship between service workers and elderly people have supported the view that these relationships fulfil a need for love and belonging (Huss, Buckwalter, & Stolley, 1988; Kuipers & Moore, 1995; Moore & Gilbert, 1995; Clegg, Standen, & Jones, 1996) and people in institutional environments who have emotional support have been shown to have higher levels of life satisfaction (Huss et al., 1988; Williams, 1994). In this study emotional support from workers positively influences informants' perceptions of receiving a 'good' service.

Elderly participants consistently state their reliance on key workers who provide them with 'normal' interaction and affection. It is common for service users to refer to key staff members as not only 'friends' but 'family' and they make consistent reference to using 'close' staff members in a counselling capacity. An elderly resident of a hostel Mrs Mann explains: *'I can talk to Mary (a nurse) about anything ... I know I can trust her to keep things to herself. She's just like one of the family'*.

Feelings of also being able to offer advice on home and family matters is also valued by service users. They feel respected when their life experiences are acknowledged and this reinforces their identity as useful and wise people.

Analysis of the fourteen interviews with informants living in nursing homes shows consistent references to being at 'the end of life', such as, 'being here to die', 'life being over'. Frequent reference is also made to 'living for the family', although family contact does not occur more than once weekly for most people who were interviewed. Relationships with key workers take on greater importance for people who have no family, or when family relationships are less supportive. For one elderly nursing home resident Miss Evans, who has no family contact, a nursing assistant, Gwen, is an important social contact:

I was a school teacher and never married and have no children of my own. It's only now that I realise how lonely I am in my old age. That's why I like to talk to Gwen about her family. I like to give her money to buy them a little present at Christmas ... although I know it's not really allowed.

Themes emerging from the analysis of hostel residents' interviews also support the value of relationships with service workers. Hostel residents may be both active community members and institutional residents, a dual role which can prove awkward. They report problems in maintaining old friendships due to the inability to reciprocate 'family' hospitality in the hostel environment: This is discussed by Mrs Cook:

It's not so easy keeping up with old friendships when you come to live in a place like this. I get invited out to friends' homes, but I can't have them back and cook a meal for them like I used to.

As a result of these inadequacies in service environments and restrictions on maintaining normal patterns of social reciprocation, people in hostels also meet some of their relational needs through friendships with service workers. Friendships between hostel residents and service workers may be influenced by residents' opportunities to continue to practise social communication, or that they are perceived to be more 'alike' service workers, and less socially stigmatised and emotionally dependent overall than nursing home residents.

Empathetic touch also conveys friendship to elderly informants who describe episodes of affection and reassurance involving key workers and their actions. When people are unable to reach out themselves because of physical frailty, this behaviour is even more important. Miss Evans, who has motor neurone disease describes the actions of a valued service worker, Gwen: *'I was so upset when*

they told me that I needed more tests and Gwen just came up and gave me a hug. It was just what I needed. I felt that somebody cared'.

Literature has suggested that touch can communicate comfort, positive self-appraisal, and affection to nursing home residents (deWever, 1977; Mulaik, Megenity, Cannon, Chance, Cannella, Garland & Gilead, 1991; Buschmann & Hollinger, 1994). According to Burgoon (1991, cited in Moore & Gilbert, 1995, p. 11) non-verbal behaviour such as touch conveys 'affection and immediacy'. Interview data supports the interpretation of gentle touch as both reassuring and personally validating.

In discussing the quality of life of elderly people McIntosh (1996, p. 36) suggested that professional staff need to develop more skills in communicating with elders as "... the restricted access they have to meaningful interactions with little opportunity for control or self-definition of identity, adversely affects their quality of life". Informants who express friendship in service relationships also describe validating behaviours of workers such as *'taking the time to listen'*. Friendship communication also provides *'normal talk'* and a perception of *'being like other people'*. In friendly encounters, people feel less of a division between the role of service user and the role of worker, and are more likely to comment positively on their service experiences.

4.2.1.3 THEM AND US

(Clients and staff)

The sub-theme 'Them and Us' describes consistent reference by service users of service interactions which are impersonal and reinforce their dependency and the role of service user. Service encounters in the context of 'Them and Us' have been experienced by forty-two of the service users at some time in the process of living in a service. For seven of the participants with disabilities and eight of the participants in aged care environments 'Them and Us' was their most consistent service experience at the time the study was implemented. 'Them and Us' relates to both communication and task related activities and depicts non-valued encounters of service users when workers are insensitive to the culture, life experiences and values of people living in services.

According to Kuiper (1983, p. 474) a number of human relations are characterised by inequality. In the service relationship, collective responsibility may be the guiding service value, but to provide a personalistic service, the individual autonomy of service users must also be respected. In a personalistic service, the capacity and respect of the service user is uppermost. In the context of 'Them and Us', narrow interpretations of service users' needs, create a relational ethos of 'difference'. Authority is in the hands of the service worker and compliance is expected as a matter of course. Reciprocity in service relationships is missing and service users experience indifference. 'Them and Us' exemplifies interaction without relationship.

Studies by Bowlby (1969), Patton, Connor and Scott (1982,) Kohut (1984), Wolf (1988), and Stroebe, Stroebe, Abakoumkin and Schut (1996), demonstrated the need to avoid feelings of loneliness and alienation and the need for people to develop a sense of belongingness, comprising companionship, affiliation and connectedness. Theoretical literature on belongingness suggested that people experience "... a need for validation of belongingness and attachment throughout the lifespan" (Lee & Robbins, 1993, p. 233). Changes in a person's belongingness status can "positively or negatively affect their emotional responses" (Baumeister & Leary, 1995, p. 505). People feel lonely when they lack social attachment, and social exclusion commonly causes anxiety (Tambor & Leary, 1993; Baumeister & Leary, 1995). For people living in impersonal service environments, and who have less opportunity develop social attachments as a result of reduced mobility, relationships with service workers, if they lack warmth and affection, compound feelings of worthlessness and vulnerability. Research evidence has stressed the importance of friendships in the treatment and care of elderly people (Reed & MacMillan, 1995) and people with disabilities (Amado, 1993).

For participants in the study who live in the context of 'Them and Us' there are two main relational experiences. The first is the mechanistic approach of the service worker who competently fulfils the tasks of body and environmental care with minimal personal interaction. The second relational issue is the power inequality experienced when service workers interact in a way which stifles

autonomy. The latter is described by Steve, a young man with a physical disability who lives with another man with a disability in a group home.

Steve is able to use a motorised wheelchair to get around the local neighbourhood. He is trendily dressed, enjoys cigarettes, beer, computer games and music, particularly reggae. He has lived in this house for around two years. Due to his disability and deteriorating health, Steve requires maximum assistance with all his self-care activities. He relies on service workers from a local organisation to provide daily support. Over-all, his relationships with service workers have not been positive. He copes with this with good humour and has given up expecting to be treated other than a recipient of a service. He describes the 'Them and Us' phenomenon in a recent interaction with a regular 'care' giver:

I asked him if he would give me a shower and he told me to get lost ... in fact that's not really what he said ... he told me to get fucked.

(Was there anything unusual about asking for a shower at that time?)

No. I approached him again and asked him nicely ... you know ... and he said he'd do it after his TV programme was finished. Just a little power there ... you know ... I had to beg a little.

For Steve, the important thing about quality in a service is being treated as an equal. He doesn't like to ask for help all the time and would like people to come in and ask if he needs help. He says: *'I wish it could be like they want to help ... not just a job. Just like ordinary people helping out because they like me'.*

According to Steve, when workers *'abide by the rules'* it distances people. He believes that people are told by the organisation supplying his care givers not to become too attached. He philosophises about the reason for this perhaps being because *'... if they get too close ... they miss out in the end'*. (Referring to his own death)

For Steve, quality service experiences are when people talk normally, appear pleased to be with him, take an interest in his life and communicate about day to day things like *'normal people'*. This is not his regular experience. He talks about *'always having to be on guard'* against the *'mob culture'* of service workers who will discuss the way he lives, with other people in the system. It is for this reason that he fiercely guards his privacy.

The following story of Steve's experience of not being like 'one of them' and the personal loss resulting from the status of being 'other' is told in Steve's words:

Well ... I had a girlfriend once but 'they' certainly put an end to that.

(Can you tell me about it?)

Yes. After I moved in here, I got really close to the girl next door and we began to have a real relationship ... and that ... and I used to stay over there sometimes at night. Somehow or other what was happening got through to (the organisation) ... don't know how. I need people to get me out of bed ... but because of the work place agreement they said that they couldn't come to her house. They said they couldn't come over there. I didn't see what difference it made because they had to get me out of bed anyway ... so what's it matter if it's

my bed or her bed? They said they weren't allowed to work in that house ... part of the workplace agreement.

Anyway ... she asked if they would show her how to use the hoist and she would get me out of bed herself ... but they wouldn't do that either. She was really upset. It was as if we were doing something wrong. It caused a real split between us and that was the end of that. She still lives next door, but it's really awkward now between her and the carers because she told them what she thought. It was as if we were doing something they didn't approve of. We've split now anyway.

You can feel the air in here with some of them sometimes and know they don't want to be here ... it's an attitude. It's like it's their territory. They don't talk to you good. Like you're in a wheelchair and that sort of thing.

Steve's experience is supported by other people with disabilities in this study who live in group homes where staffing is controlled by service workers rather than users of services. Other elements emerging from interviews with participants across disability and aged care services in their contact with service workers in the the context of 'Them and Us' are '*no normal talk*', '*rushed handling*' and '*unhappy to be here*'.

When interacting with those people who have a severe disability and inability to communicate it is even more important to acknowledge the 'sameness' of the other person. People with multiple handicaps are unable to initiate communication and are at risk of relational deprivation. An expert insight into the world of silence, total physical incapacity, and dependence on others, is offered by Jane.

Jane has a severe form of cerebral palsy resulting in an inability to move independently. She has no verbal communication abilities and communicates using a headpointer and a computer keyboard. Jane lives alone in a community house and has her service co-ordinated by a small community based organisation. She interviews and employs people to assist her with all her daily activities.

Jane is a writer and a thoughtful observer of people. In the eight years that she has lived in the unit, forty-one people have been involved in her care. Jane has had contrasting experiences in 'quality' serving. Jane likes to know about the lives of her care givers as this is her link with the 'outside' world. She likes 'interesting' people who have had 'interesting lives' to be involved with her and is insightful about the way people communicate, especially through touch, and the influence this has on her feelings of either being a 'real' person, or in contrast a 'work routine'. As she explains:

Even though I can't talk ... I like people to look into my eyes when they speak to me. Then I know they're speaking to me and not just anybody. If they look into my eyes then they can see I'm listening. I can tell right away if they accept me as a person or just an empty body the way they touch me and speak to me. I like to know what they've been doing and talk about normal things. It feels as if I'm not a person if they don't look at me. It feels terrible.

For aged care informants the 'Them and Us' experience is also consistently present in the data, although the nature of the experience is not as confrontational as for the disability group. This may be due to institutional

monitoring of behaviour in general and the fact that service workers commonly work in pairs and monitor each other. Elderly people are less comfortable in discussing lack of perceived quality in their living environment, but they frequently contrast what they *'like'* about a service with what they *'don't like'*. As a group, they are also more complimentary about their living contexts and there is a general acceptance that things are the way they are meant to be perhaps due to their lower expectations and gratitude about receiving a service at all. However, twenty-two of the twenty-four people interviewed when questioned about improving a service, refer to their need for more human contact of an equal relational nature. Unequal involvement prevents the growth of trust and the development of beneficial relationships which are necessary for adjustment and adaptation (DeLongis, Folkman, & Lazurus, 1988; Homes & Rempel, 1989; Lidz & Arnold, 1990; Powers, 1992). In the context of impersonal service, people receiving care make great efforts to initiate communication of a personal nature.

A nursing home resident, Mrs Clarke, describes her strategy for interaction. She has severe osteoarthritis and chronic pain and has lived in a nursing home for four years. She shares a room with another resident who does not communicate. When Mrs Clarke entered the nursing home, she was able to eat independently. The severity of her arthritis is such that she can no longer move her limbs except for some weak finger movements which allow her to operate the remote control for her television and a motorised wheelchair. Moving is very painful for Mrs Clarke. Mrs Clarke spends all day in bed apart from an hour each morning when

she gets transferred into a motorised wheelchair and is able to move around the nursing home. Mrs Clarke came to Australia when her family was young. Her husband has been dead for eighteen years. She has two daughters who visit weekly. She speaks about her past life, her husband and the pride she had in maintaining their home. She now lives in a room devoid of personal possessions. A bunch of artificial flowers, a box of tissues and an Easter card taped to the wall are the only personal belongings visible. Mrs Clarke has bright eyes, and a keen sense of humour. For Mrs Clarke quality in services is about people using her name. Despite chronic pain, she moves around in her wheelchair solely to engage workers in daily greetings:

(Mrs Clarke ... what are the things that are most important to you about living here?)

Well ... I have a little chat with the staff. That's why I go up and down in my chair. There aren't many other people to talk to here.

(There aren't many people to talk to?)

No ... but I make up for it . I chat to the staff ... but I don't stop them working ... I have a chat ... but it's all quick , quick.

(It's all quick quick?)

Aye ... they can't sit down and talk to you. I just go up and down and say ... 'how are you'...or 'good morning'. A few words goes a long way. Then you feel you're not just a number. Yes. ... that's what I like best ... when they call me Jenny ... you see.

(That seems to be really important to you?)

Oh definitely. When they call me Jenny... then I know I'm not just a number.

For Mrs Clarke, superficial encounters with service workers are her only 'normal' activities and she is prepared to endure considerable pain to make the necessary contact.

Interactions without an ongoing bond of positive emotional concern are less than satisfying in the care giving context (Baumeister & Leary, 1995). Studies have confirmed that quality rather than quantity in relational interactions are predictive of health outcomes (Reiss, Wheeler, Kernis, Spiegel, & Nezlek, 1985) and that mental health is affected negatively by conflict, criticism and social undermining (Carnelly, Pietromonaco, & Jaffe, 1994). Informants who live in the context of 'Them and Us' are devoid of opportunities for intimacy, self-disclosure, enjoyment and personal validation in their day-to-day social interactions. Their daily lives are not only non-fulfilling but chronically unhealthy. For people living in the context of 'Them and Us' daily rituals and interactions are characterised by 'differences' creating barriers to supportive relationships. Despite the adverse conditions, people in services strive to maintain social bonds even if the interactions are neutral or conflicting. The resilience of people living in impersonal services is a testimony to the strength with which people face the day-to-day struggle of maintaining a sense of identity and respect for self in the 'Them and Us' context.

4.2.1.4 DIS-SERVICE

(Lonely, vulnerable and objectified)

The sub-theme 'Dis-service' describes the lowest quality relational experience of people living in services. Five informants, three in aged care and two in disability services live in the context of 'Dis-service'. Dis-service relates to being objectified, and serving a service function of being a 'throughput' or 'funded' item. Being dis-serviced means devaluation and psychological abuse. People interviewed in the context of 'Dis-service' are afraid, lonely and devoid of relational nurturance.

The experience of loneliness is independent of the amount of social contact a person has. The examination of quality of interactions and supportive relationships are useful indicators in the evaluation of loneliness (Luftig, 1988; Hojat & Crandall, 1989; Adams & Blieszner, 1995). The aching emptiness of loneliness has been acknowledged as a physiological phenomenon provoked by the absence of individual and community relationships and contributing significantly to physical ill health and premature death (Weiss, 1982; House Landis & Umberson, 1988; Brdar & Despot, 1989). In discussing the need for relational connectedness as fundamental to life Lynch (1977, p. 14) suggested "We must either learn to live together or we increase our chances of dying alone". People existing in the context of 'Dis-service' are alienated from normal social interactions, and express feelings of loneliness and powerlessness.

In researching friendships between people with disabilities and community members, Amado (1993, p. 69) stated that "Although people with disabilities may now be experiencing more opportunities to be physically present and to participate with community members, they may not have specific friendship interactions to be any less lonely". People with disabilities living in the community, and elderly people living in larger congregated services who live in the context of 'Dis-service' share not only loneliness experiences, but also persistent anxiety.

Service acts which reinforce 'Dis-service' are '*ignoring*', '*bullying*' and '*rough handling*'. 'Dis-service' has potentially serious consequences for survival. This is described by Ross, a man who lives in a group home. In addition to having a disability, he has a serious respiratory condition and requires a ventilator at night:

Something went wrong with my oxygen machine and I felt that I was suffocating. I rang ... but he didn't come for a long time. When he did he wasn't too happy with me. That was a near thing.

Dis-service also relates to informants' perceptions of physical help which is experienced as '*careless*', '*rough*', and '*rushed*'. One nursing home resident described an incident which caused a leg injury due to what she perceived as '*rough handling*' during showering. Although this was a singular incident and balanced by other positive experiences, she continues to discuss her anger and feelings of vulnerability that '*it might happen again.*' Another younger informant

with respiratory problems living in an organisational home describes his dread of being assisted by a service worker who 'throws' him into his wheelchair despite being asked to lift him gently due to his weakened physical condition.

Mr Clarence a nursing home resident describes his dread of not having his toileting needs met in time:

One thing I don't like is if I feel a bowel movement coming on, I want it attended to now ...and not in half an hours time ...which is sometimes what I get. We have a bell to push which supposedly summons help ... but sometimes someone will come in and switch it off and say ... 'you'll have to wait, we're busy.

(What's it like for you when you have to wait?)

It feels like my bowels are going to erupt any time. You couldn't understand what it feels like. I say ... 'if that's your attitude ... piss off'. Because it's their attitude that riles me.

Another informant, Miss Strong, describes her experiences of 'Dis-service'. She has lived in a single room in a nursing home for one year. Miss Strong held a senior nursing position prior to retirement. She has never married but had an interesting life working overseas and travelling extensively and had lived in a retirement village until a physical illness interfered with her mobility. The interviewer's visit is an important occasion for Miss Strong as she has few human interactions during the day. She had wanted to have her hair washed for the occasion and had arranged for this to happen, but no-one had come to attend to her. Her bed is unmade and the commode unemptied when the interviewer arrives. She is embarrassed, but says that this often happens.

Miss Strong is tearful throughout the interview. She frequently talks about her loneliness and feelings of being ignored and disliked. She feels that she has '*done something wrong*' because few people enter her room or communicate with her about '*normal*' things. She talks about the contrast between her current existence and her past life:

I've been all-round the world working and doing all those things and then suddenly I've got to lie like this for the rest of my life and I say 'I wish I could drop dead' ... but nobody will let me.

When asked about quality, Miss Strong talks about her experiences of working as a director of a nursing home many years ago, and how well she had got along with people who lived there. Quality to Miss Strong is about kindness which is enacted through communication. Miss Strong's role as a service provider renders her current experiences as a recipient of services even more poignant as she discusses her unmet needs and objectifying experiences as a nursing home resident:

I think that kindness is the top thing really. When people are lying there and have no-one ... that's what they need. I'd like to be able to have a talk with the staff sometimes. People just never come in ... except the kitchen staff who bring the meals ... they're very nice.

(So talking about ordinary things is important to you?)

Yes ... you'll often get two girls working with me in the bed and they don't speak to me at all. They just talk about their boy friends or where they went last night.

(Just talking to each other?)

Yes ... I think that's wrong. I think when you're bathing someone you should talk to them at least ...but they just talk to each other and ignore me. I suppose they're doing the work that's necessary ... but it would make such a difference to be spoken to ... otherwise I'm just a body.

Ken, a young man with an intellectual disability lives alone in a unit and receives services from two small organisations, one of which he describes as '*not good for me*'. Ken describes his version of 'Dis-service' in a service interaction with Will who had been employed to support Ken to improve his abilities in looking after his home:

(Ken ... can you tell me some things that you like about getting help at home ?)

Well ... I like Tim...he's all right.

(What makes Tim all right?)

He helps ... he talks to me right ... he's not lazy like Will. Will ... he came last week and lay on the couch reading a book and I was doing all the work. I started to talk but he didn't answer me. I can't stand it when he ignores you and doesn't pay attention. It makes me so mad!

For Ken, recognition as a valued, independent and contributing adult has been a long and persistent journey with many setbacks. Ken's frustration at being ignored by Will causes anger and maladaptation which has the potential for aggressive retaliation which risks placing Ken in the role of 'problem'.

In discussing the risk of objectification of people in service relationships Noddings (1984, p. 66) suggested that many people are reduced to cases by the

machinery that has been instituted to care for them. A difference in status and the authorisation of the helping role prevent an equal meeting between helper and helped. Controlling behaviour is a characteristic of 'Dis-service', limiting service users' autonomy and development for elderly people (Booth, Bilson, & Fowell, 1990; Hertz, 1996) and people with disabilities (Matikka, 1996; Davies & Jenkins, 1997). People experiencing 'Dis-service', use compliant passivity as a strategy to cope with their anxieties in relating to service workers who are not trusted.

Although descriptions of discrete incidents of 'Dis-service' have at some time been experienced by more than half of the study informants, at the time of the study, five informants live in an overall context of 'Dis-service'. The physical living environments of the service users in this context are materially comfortable and cared for. The five informants also belong to services which have recently been evaluated through the standard monitoring process. Also within these service environments, other informants were satisfied with their care and in some cases experienced 'Growth' and 'Friends' in their relationships with service workers. This highlights the individual nature of living in a service and the importance of compatibility between service workers and users. This questions whether evaluation methods which are quantitatively oriented and evaluation processes which lack support for people who are dis-served by service workers to safely expose their experiences, are effective in discovering and resolving situations of abuse. If people lack trust in the service environment, they are unlikely to trust officials who monitor government regulations and who

pay brief visits to their homes. Clearly, there needs to be some other means of providing a safe means of supporting people who are dis-served on an ongoing basis. Risking further 'Dis-service' by complaining, even although formal grievance procedures are in place, places people who live in services in highly vulnerable situations.

4.2.2 SUMMARY

To answer the question: What are the experiences of people in living services and what are their perceptions of quality, the following statements emerge from analysis of the data:

1. Relational experiences with service workers are central to the evaluation of 'quality' by service users in living services.
2. Loneliness and isolation may often result for people with a disability and elderly people living in services. This is influenced by their degree of social mobility, family and friendship networks, and the presence or absence of personally validating relationships experienced on a regular basis.
3. Relationships with service workers may often be central relationships in the lives of people with disabilities and elderly people living in services.
4. Service user and worker relationships develop over time, influence self-concept and may be threatening or validating for service users. Continuity of supportive relationships with key workers is integral to the provision of emotional support.

5. Friendship relationships with service workers have the potential to result in opportunities to expand activities and roles.
6. When service workers who are central to the lives of service users leave, service users may experience grief and loss.
7. Dis-service occurs when service workers reject service users through verbal and non-verbal interactions.
8. People living in services may experience devaluation in the way service workers' interpret and enact worker roles.

Due to the large amount of data which described the importance of the service user/service worker relationships in the evaluation of quality, the next question addresses the experiences of service workers who have been identified by service users in the context of quality serving. The meaning of serving and the meaning of quality from the perspectives of service worker informants is presented in answer to the next question.

4.3 QUESTION 2. WHAT ARE THE EXPERIENCES OF 'VALUED' SERVICE WORKERS AND WHAT ARE THEIR PERCEPTIONS OF QUALITY SERVING?

Analysis of interview data from twenty-six interviews with service workers, who had been named by provider participants as providing a valued service generated one overarching theme SERVING OTHERS and five sub-themes, BLURRING THE BOUNDARIES, COMMUNALITY, OPENING THE

DOOR, FINDING MEANING IN SERVING, and WEIGHED DOWN. The positive nature of the interview data, reflects the methodological intent, which was identification of the meaning of service quality. Patterns in data from service worker interviews are also consistently dominated by their relationships with service users. Themes are displayed in the following figure:

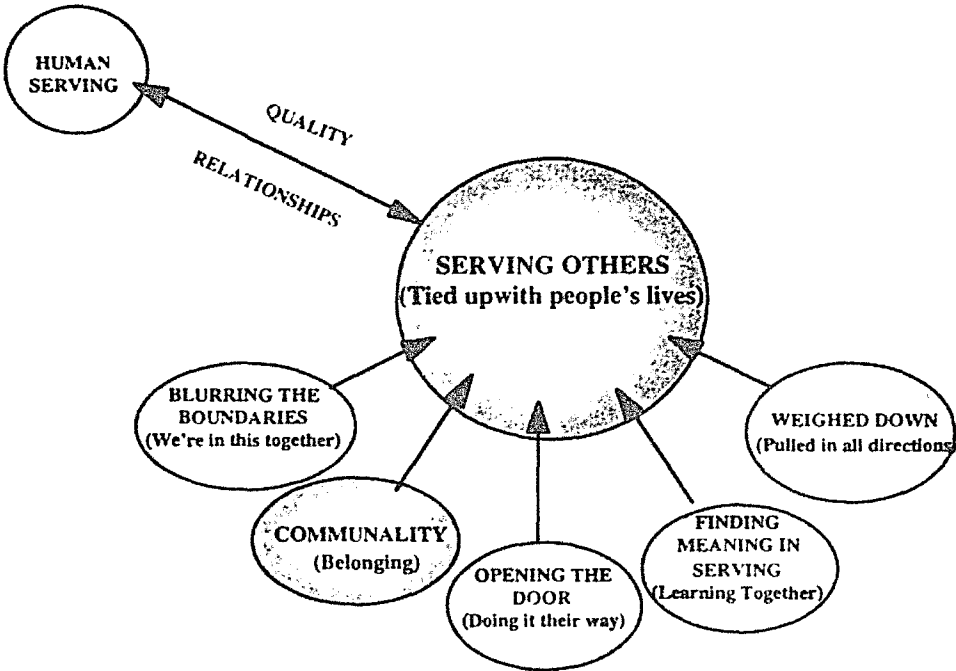


FIG. 3 QUESTION 2 EMERGING THEMES

4.3.1 MAJOR THEME: SERVING OTHERS

(Tied up with people's lives)

In describing 'Serving Others', service worker informants articulate their work in the context of relationships rather than roles and careers. They view the development of positive relationships with service users as the initial and important connection which commonly precedes involvement in the more

tangible acts and activities of serving. According to service worker informants in the study, relationships are the foundation of quality in their serving. In relationships which are 'accepting', service workers form meaningful ties with service users which challenges the 'affective neutrality' of professional services (Parsons, 1951 cited in Bogdan & Taylor, 1987; Clegg, 1996). Positive personal attributes of service users are consistently described by service workers. Despite the 'service labels' and program objectives which provide the context for the initial contact, interview data of service workers, who are named by service users as providing valued service, are dominated by descriptions of service users which demonstrate personal knowledge, liking and friendship.

Tim, a support worker for Ken, a man with an intellectual disability, describes the relational nature of his service role, and the time he invested in developing Ken's trust in order to create a context for growth. Tim also expresses his respect for Ken's abilities:

I've known Ken for just over two years and it took me a few months to get to know him and feel comfortable with him, as he's the sort of guy it takes time to know. I really feel he's just started to confide in me in the last year and we've come such a long way. He has so much potential and it never fails to amaze me what he can do.

Tim also experiences satisfaction in Ken's achievements and views his personal investment as worthwhile:

For me ...what I get out of it is seeing him develop ... seeing him happy and being able to talk about more things. I feel as

though he's having chances he never had before and he's so appreciative. He's different from anyone else I know. He's a friend to me and I get a lot of fulfilment ... feeling that I'm doing something important.

Joy, a registered nurse, who has the job description of 'clinical specialist' also describes the importance of her work in the relational domain. Joy expresses sensitivity to the social-emotional context of the nursing home milieu, but admits that in carrying out her role, according to her own values, she often bears the criticism of some of her colleagues who are more 'system oriented':

It's hard to deliver personal care in bulk. It can't be done in a task oriented approach because relationships are so important, although I do get criticised for the amount of time I spend with people in what they call 'non-nursing duties'. It's important to me to have good relationships as many people here are lonely and have lost friends and family. That's what I consider as quality in a nursing home and I invest a lot of time in getting to know people. I don't think you can be trained into this area. You have to like people and show them respect.

(Empathy)

In positing that the interpersonal qualities which characterise a service are no less important than the outcome itself, Sarason (1985, p. 2) suggested that physicians and other providers of services need to develop a responsiveness which goes beyond the presenting 'condition' to include sensitivity to the phenomenological plight of the individual. A willingness and giving of oneself to understand the context of another's life, is necessary to effectively address the

complex context of people in services. This approach was also supported by Morgan (1993) and Benoliel (1993) who proposed that the need to bring oneself as a person into professional interactions was characteristic of a personal service.

Service workers also express the 'giving' nature of their work and a sense of personal benefit or 'getting as much as I give'. The reciprocity of being in a service relationship which fulfils a need to be engaged in 'helping' activities is expressed by service workers even in situations where service users, due to the severity of their disability, are unable to verbally or non-verbally express their appreciation. Garry a service worker describes his sense of personal purpose in serving Joe, a man with multiple disabilities. Garry's commitment to serve Joe is motivated by his spiritual and religious sentiments:

(Garry, when you talk about being appreciated by Joe can you give me an example of what you mean?)

Well, Joe can't speak or move much ... but I guess ... I just know that I'm doing my best for him and that somehow he knows that. It's hard to describe ... but I just get so much out of it. I suppose I feel close to Joe and try to think what I'd want if I was in his situation. I see myself as a partner in his suffering.

Other informants' involvement, although originally motivated by monetary needs, have taken on other meanings related to humanitarianism or social justice. Jill, a therapist who works in a nursing home, describes the transformation of her relationship with residents:

When I first came to work here, it was convenient for me ... close to home and part-time. But ... as I 've got to know

people, I find myself becoming a champion of their rights with other staff. I genuinely care about the people here ... I suppose some people would say I'm not professional. But ... I see so many needs which aren't being met ... simple things ... and I really grieve for them. I see them as people with multiple losses ... and multiple needs.

An activities co-ordinator, Joan, describes her empathy for a woman with dementia who was anxious and confused one evening and the way she met her need for human contact by holding her hand and reading poetry. Joan's sensitivity to the need for human contact is described:

I was on the late shift one night and I heard Mrs. Walters crying out down the corridor. She does it a lot in the evening. I thought ... all right I'll go down and sit with her. I sat with her ... just sat with her and held her hand ... she just wanted someone to be near her and talk to her. I read her some poetry and she stopped crying. She began to talk about her husband and how things used to be. I spent about twenty minutes with her and the sister came down to give her some medication and said ... 'oh, now that you're with her she's all right ... she doesn't need this now.'

In referring to the debate between traditional (reasoning) ethics and feminine (feeling) ethics, Walton (1989, p. 112) discussed assumptions of human separateness or connectedness. A morality that stresses relationship, according to Walton, involved connection with others. Walton also suggested that an ethic of relationship provided a counterbalance to individualism based on a narrow self-interest. The meaning of serving, according to service worker informants,

supports Walton's view that valued action in human services requires relating which reflects a recognition that people are connected in essential ways. The deeper reality of serving is demonstrated in the relating behaviours of service workers who have been recognised by service users as concerned allies. By giving to others in the acts of serving, service workers may also be nourished by their own love of the other.

In conceding that empathetic relating to others, is based on a response characterised by feeling and sensitivity rather than knowledge, Noddings (1984, p. 30) suggested that feeling precedes action in caring for others. In the process of reflective feeling or empathy, analysis is suspended and:

... we receive what there is as nearly as possible without evaluation or assessment. We are in the world of relation, having stepped out of the instrumental world ...We are not attempting to transform the world but we are allowing ourselves to be transformed. This is clearly not a degradation of consciousness ...

Exchange between service users and valued workers in the relational context of 'Serving Others' is characterised by an emphasis on social, as opposed to economic exchange. Although financial reward is initially the reason for entering the service context for workers, relationships between both groups are of a nature that transforms serving into valued personal relationships. Investment of self and the establishment of bonds of gratitude and affection are some of the features which distinguish relationships between informants in the study from

description of serving as purely economic exchange. This is described by Val, a nursing assistant:

I like to think that I'm not just a carer or a person who showers and prepares meals. A lot of the time I'm their friend foremost. When you get tied up with people's lives ... you get extremely close. We talk about our families and they tell you their problems. It's a lot about listening ... really.

(Friendship)

Service workers consistently describe their roles as 'friend', 'mentor' or 'helper'. 'Friend' is the word most commonly used to describe their relationship with service users. The nature of service friendships are not only the building blocks for other friendships, but establish equality in the service context. The growth of non-paid relationships is considered essential to the integration of people with disabilities who have left institutional environments. The role of service workers as intermediaries in the development of friendships has been acknowledged as an important element of a residential service (Perske, 1980; Strully & Strully, 1985; Amado, 1993). A good relationship in the service situation has potential to generalise to other settings (Elks & Kirkhart, 1993, p. 562). Enjoyment in sharing activities with service users often outside the paid context of 'serving' is consistently discussed by service workers assisting people with disabilities living in the community .

Mark, a young support worker for John, for the past two years, is trying to foster friendships between John and other community members. Mark's value of

his friendship with John sets positive expectations for John to enlarge his friendship network. Mark describes his friendship relationship:

I do provide John with some direct services, but I would also say that there's a friendship which has developed. I still want him to know that I'm paid for what I'm doing, but I would regard it also as a friendship relationship ... outside of the things I do as a support worker. We have a lot in common outside of the work thing and have some good times together. You can't help but like John.

In some situations, the development of friendship networks is explicit in the serving context. Jill, a therapist who works in a nursing home explains that developing and nurturing friendships is something that she consciously does:

As a group of people ... I think they have the right to be valued. They've earned that right to respect and dignity in their old age ... and friends. That's something they don't retain when they come in to nursing homes. Many of them don't retain their friends and staff have to take on these roles ... even if they are paid roles they have to take them on as they often don't have anyone else.

The struggle professionals have with the label or name to call people whom they serve has been discussed by Gaventa (1993, p. 55) who suggested that:

Persons in the field are just beginning to find a professional language and image that allow caregivers to talk about their enjoyment of 'client', feelings of mutuality and reciprocity in the relationships, and the way that both parties have been called beyond themselves to a deeper understanding of what is good.

Friendships in service relationships positively influence the quality of the service encounter for both groups as people report more relaxed companionable interchange in the living environment. This is particularly important in living services from which other activities and relationships can be launched. When relationships are of a friendship nature, however, this can lead to feelings of guilt in relation to the financial benefits in the role of service worker.

Suzie, a support worker, who has no previous experience of human service work, discusses her initiation into the relational context of the small community based service which employs her:

When I first started working here ... I just couldn't believe that this was the way it worked. I had to come to grips with the fact that some people have to pay to have people help them and be their friend. It's just like visiting a friend, and I feel awkward about the money side of things, although I need the work. You have to be personally involved to give that quality of care.

Service workers in small community based agencies in the disability field frequently refer to the 'family like' ethos of the service context and their compatibility both with the people in the service and also with the service ethos. Recent research has supported the relationship of goodness of fit between staff and organizational attitudes and continuity of service (Witner & Sweeney, 1992). Work and friendship are considered health promoting characteristics for people generally. Service workers consistently describe the service agency as being like a 'community' of people made up of 'friends and family'. Phrases like 'loving' the involvement with the individual, and 'enjoying' their company is a characteristics

of the attitude of service workers in this study to their role. Mark describes his enjoyment of his work:

I smile a lot being with him. I genuinely enjoy it and I think if you're genuine about it ... it shows through. You can't get past it if it's just a fill in or something you're doing on the way to somewhere else.

Friendships with service users are characterised by reciprocation rather than benevolence or obligation. Service workers also feel supported in their relationships with service users. Mark continues:

The people themselves are outstanding. They are great people to be with and I learn a lot about myself from being with them. It's not just a matter of me giving them some sort of expert service. I think it's very much a two way thing and I've gained a lot out of being with them.

Forming relationships, however, is not without risks as Wendy a support worker for people with disabilities discusses:

I suppose relationships become more intensified because there are few people involved with the people here and the relationship side of things becomes so important ... they may not have other contacts. Here you give one hundred per cent of the time and that can be really exhausting ... but it also has its rewards. We all take risks in forming relationships.

(Collectivism)

Having a sense of 'community' in a service environment benefits service workers who feel personally attached, and supported by, a community of people who are

like minded. Humanitarian concern and 'doing good work' towards the ultimate goal of creating a better society is a strong motivator in service workers relentlessly pursuing the challenge of helping people with disabilities find a social place. According to Schwartz (1992, p. 65) when people become dependent on a service, relationships that were formed were likely to be broken as service workers 'danced in and out' of their lives. In contrast, it is characteristic of service worker informants in this study, that they see their involvement as being long-term and extending beyond their current roles. Graham, a co-ordinator of a small community based service for people with disabilities explains:

Well ... we're not just a service organisation. We're more about the people involved ... the clients, workers and families. It's about trying to meet all our needs ... like a little community really. Although the government provides the funding .. it really is kept going by the people here and we try to keep a strong focus on why we are here.

Friendship relationships with people living in aged care environments is also consistently expressed by service workers in this study. Searching for common ground to establish relationships is characteristic of people named as providing 'quality' service. It is also common to this group of workers that they recognise the need to give attention to individuals who are avoided by other workers. In relating to a resident who is excluded from many of the activities of the service, Mary, a nurse discusses her belief in the need for inclusion:

For all the people living here, I always try to find something in common. Other people will say '... Oh you can't do anything

with them'. But I know that there's always some little thing that will work. One man was one of the most extraordinary hobos that you've ever come across and people would avoid him ... but I don't avoid these situations I think it's unprofessional. We're here for people after all and I treat him just the same way as any other Western Australian . You've got to realise it's traumatic for people to leave their homes and come here.

(Loss)

In the aged care environment long-term engagement also has potential for loss. Martha, an activities co-ordinator in a nursing home discusses her feelings when she has periods of absence. Due to her close involvement with a people who are deteriorating physically and cognitively, loss of relationships with service users is a common, but no less, painful experience:

Well ... at my age the people here get to be like family. So ... it's one big family and when I go away on holidays ... there's a lump in my throat and I think'... Oh, I'm not going to see them for so many weeks'. I wonder then if they will remember me when I come back ... and I hope they will.

In a similar service role in another aged care environment, Joan, reinforces Martha's experiences. Having to quickly resolve the death of residents with the expectation of developing new relationships with their immediate replacement is difficult:

It's hard not to get close. Some people think you shouldn't but you wouldn't be able to work in this job if you couldn't get close. We do lose people and that's hard ... because even if

they're not our family it feels like it. It's a shock to come in and find somebody dies in their sleep ... the stress is there ... but you have to get on with it. The next day they'll be someone else in their room and that's hard to take ... but that's part of the job. There's a whole new person with a whole new set of needs in their place. This is what I find the hardest thing.

Service workers in the disability field also express loss as a result of leaving a service which involves parting from service users. Roy, who has previously worked in an institutional environment and now supports people with disabilities in a community setting, expresses sadness for the lives of people who continue to live in the institution and also loss of relationships with them:

It's hard to leave people that you really care about and I think of them a lot. But, realistically I can only be deeply involved with a few people. I often wonder if there's anyone else looking out for them now that I'm gone.

When service workers formed close ties with people with deteriorating health conditions, they were also constantly aware of the impending loss. Sally, a carer for Katy a woman with deteriorating health describes her fear of her friend Katy becoming ill:

I know time is running out and we've had so many warnings that she's getting weaker. I don't know how I'll cope when the time comes. We are so close. Closer than most sisters.

(Quality time)

The description 'quality time' is articulated by service workers as episodes of attention to service users which are not structured in the day to day routine

tasks of providing a service. Quality time is about 'being with' people as opposed to 'doing for' people. The need for people to have time to talk is recognised, without this being forced upon them.

Jill, a therapist, who considers the socio-emotional needs of nursing home residents as equally important as their clinical care, uses her time to listen and acknowledge people's individuality in establishing relationships:

Some residents don't like their personal space invaded and that has to be respected. Sometimes it's just about listening initially and being interested in their lives. It's important to listen ... it's a validation really.

When people are unable to communicate verbally, it is also considered important to spend time with them. Martha, an activities assistant in a nursing home, describes how she relates to people with high levels of physical and cognitive impairment and validates their need for human connection:

When people can't communicate ... it's important to spend time with them. I usually give them a soothing hand or head massage ... but not everyone likes that. Sometimes I brush their hair ... or just sit with them and be there for them. I usually put music on ... soothe them and hope that they're listening. I read poetry and things that they like. There's not an awful lot to do ... really ... if they're really withdrawn into themselves ... but I'd like to think, if that was me lying in bed, not moving ... that someone would hold my hand ... I hope that they would.

Quality time is also described consistently by service workers supporting people with disabilities. Service workers gauge the quality of experiences both by their enjoyment of the interaction with service users and their perception that it had provided mutual enjoyment. Quality time is experienced in the context of social relations through shared enjoyment in activities. Tim, a support worker for a man with intellectual disabilities, describes quality time:

Well ... me ... I just know when it's been a good experience for Ken, because I feel good about it too. Take the time we went to the Italian restaurant and had this really hot spaghetti. Both of us were red in the face and laughing our heads off. I think at times like that you feel good just being out with each other.

On a more serious note, Ann, a service worker who supported Julie a woman with disabilities in the weeks following the death of her father explains the quality of their time together:

It was a really difficult time for Julie and for me too, because I had known Julie's father really well and I liked him a lot. His death was so sudden. But I suppose it was the quality of the time I had with Julie in the weeks after he died, that really cemented our friendship. You can't go through that with someone without feeling that it's really special.

(Promoting autonomy)

A belief in the value of autonomy for people in living services is consistently discussed by informants and considered to be a critical element in 'quality' serving. The system-defined role of the service worker in the act of serving is subservient to the preferences of the person living in a service. This is described

by one service worker, Doreen, who cares for a young woman with a severe physical disability as: *'...leaving my world outside their door and becoming their working body during the time I'm with them'.*

Linda, another support worker for a man with cerebral palsy who had spent most of his life in an institution discusses her role in supporting his ability to make choices:

Probably the biggest thing of all is for you to remember that you're there for him. If he wants to go shopping one day ... then that's what you do. If he wants to sit down and talk ... then that's what you do. It's taken a long time for Reg to give himself permission to choose. He needs someone to help him live his life in his way.

Although complete autonomy rarely exists, as people are largely dependent on other people, independence and self-determination are considered to enrich life. People's autonomy is threatened by illness and disability (Nussbaum, 1993; Matikka, 1996). Their ability to make decisions about their lives may be impaired more as result of the disempowerment experienced in relating to the rules dictated by professionals or service systems rather than by their own ability to make choices (Timko, Nguyen, Williford, & Moos 1993; Cohen et al., 1995). For people who have long experiences of institutional living, it is particularly difficult to direct others to serve. In more formalised aged care environments, institutional policies and customs act to constrain service users and workers from finding levels of interactions which support autonomy .

Despite this constraint, valued servers in aged care environments, who recognise the importance of choice, are also able to provide opportunities for autonomy to be exercised. Laura, a nursing assistant, describes how she maintains a climate of choice in a hostel environment:

I think about how I would feel if I suddenly found myself living here. I try to encourage people to make as many choices about their day to day activities as the system will allow. Things like ... where they have tea, or when their room's cleaned, the time they get up in the morning, are important. This is meant to be their home after all. It is a lot more work for me ... but they really appreciate it.

According to Williamson (1992, p. 58) autonomy involved respect, support, information, control, choice and decision making. Autonomy has also featured prominently in 'quality of life' literature and service standards in disability services and aged care service standards in Australia. For people with cognitive impairments, the principle of autonomy is largely focused on informed consent. Writers in the areas of disability and aged care have agreed that environments which have the imperative of time and task efficiency, often presented situations where service user autonomy was overridden by worker decision making (Gubrium, 1975; Hofland & David, 1990; Timko & Moos, 1990; Moody, 1992). Although archetypal clinical relationships which disregard autonomy, are reported by service user informants in this study, these are not associated with service worker informants who are named as operating in an ethos of 'quality'.

(Respect)

Respect for the accomplishments of service users is strongly featured in interview data. For service workers in the area of disability services, service users are respected for their tenacious efforts to overcome the handicapping effects of living with a disability in society. This often requires the involvement of the service worker over a long-term to provide the support and motivation for service users to overcome setbacks. Sandra a service worker describes serving Mike, a man with an intellectual disability:

At first I thought he would never be able to use the bus by himself, and it has taken a long time to convince him that he had the ability. I really admire the way he stuck at it. Other people would have given up long ago.

In living services in aged care, having a knowledge of and respect for the past life roles and abilities of service users is a consistent theme of service workers. All the service worker informants in this area provide colourful, positive awareness of the personal identities of service users and they acknowledge that this influences their ability to address some of the more frustrating situations of 'serving'. Joan, an activities co-ordinator discusses the difficulties she experiences in continually meeting the needs of people with memory loss:

You know, sometimes, I just get so worn out repeating myself every two or three minutes. But then I think, well ... she was once like me ... with a family to look after. She's come through the depression and brought up a family with little money while her husband was out of work. When I think of what she's

done in life, I regret that sometimes I become irritated by her constant demands and try hard to be really kind.

Analysis of interview data of service worker informants provides strong evidence of their commitment to create relationships which foster development and autonomy in service users. They also acknowledge that they themselves benefit from positive service relationships. Many writers have agreed that the basis for quality in human services relates largely to the competence, social interaction skills and caring attitudes on the part of service workers (Whittington, 1989; Williamson, 1991; Dickens, 1994). This is visible to service users through interaction styles, which have their roots in the personal values of workers (and sometimes, the values of the service). Analysis of interview data from valued service workers in this study supports this view.

Sub-themes of the major theme SERVING OTHERS i.e. BLURRING THE BOUNDARIES, COMMUNALITY, OPENING THE DOOR, FINDING MEANING IN SERVING, and WEIGHED DOWN will now be presented and discussed.

4.3.1.1 BLURRING THE BOUNDARIES

(We' re in this together)

The sub-theme 'Blurring the Boundaries' describes experiences of service workers which relate to the absence of boundaries between the roles of service workers and users in the context of serving. Although 'Blurring the Boundaries' is more consistently evident in data from the disability service area, which may

relate to more fluid service arrangements, aged care environments also show evidence of 'Blurring the Boundaries' by service workers. In the context of 'Blurring the Boundaries' service workers describe role flexibility and willingness to act for service users in ways other than that demanded by job descriptions. In 'Blurring the Boundaries' service workers describe their involvement less in terms of work than of relationship. Wendy, a caregiver for a young woman with physical disabilities, explains her inability to 'draw a line' between her work and personal involvement:

I love it so much, I don't class it as a job. I like to think of it as a friend situation rather than coming in and doing a job and then going home and forgetting about it. They say, you know, these high powered people that you shouldn't really get involved ... but it's hard to draw a line.

When role blurring becomes habitual, it is difficult to determine what is paid work and what is friendship. Roy, a carer describes his working context:

It became a friendship ... and that blurred the boundaries. I didn't see people as people that I worked for in a formal capacity. It began to feel that I was doing things for people who were friends of mine ... whether it was something formal like running them to the workshop or whether it was running them down to the pub ... whether it was paid or unpaid ... it wasn't clear cut the difference. It was similar to be at work or not at work.

It is also common for people to describe a 'family like' relationship with people in their working environments. Gwen, a nurse, articulates her role:

It's difficult for me ... because I just don't see any difference between the people here and my own parents ... although they live overseas. That's why I find myself doing things for them over and above what's expected here. They are like my extended family.

In human service organisations, interpersonal relations between service users and workers are a major mode of intervention and the effectiveness of service interventions is dependent on the ability to generate co-operation between the two groups. According to Hasenfield (1994, p. 18) the best form of co-operation was based on trust. In the organisational context, trust tended to be impersonal when contact between service workers and users was sporadic and lacked personal dimensions (Hasenfield, 1994). Impersonal relations between service users and workers are asymmetrical and render service users vulnerable to resource control by service workers. In role blurring which has characteristics of personal friendly relationships between service users and workers, the quality of such relationships may deflect the 'impersonal trust' which Shapiro (1987, p. 635) described as "vulnerable and impotent". In themes emerging from service worker informants there is considerable evidence that trusting and equal relationships are valued by service workers who feel a personal moral obligation to meet the needs of service users despite the constraints of professional and organisational enculturation for impersonal relations.

'Blurring the Boundaries' also has the potential to be problematic when service hierarchies discourage personal involvement. Roy, a carer for a man with physical disabilities, describes a previous working environment which

discouraged 'Blurring the Boundaries'. Roy's friendly relationships with service users caused conflict between Roy and his supervisors.

I would follow things through and get them done and make sure that they were right and put a bit of extra effort in ... and from my point of view it certainly enhanced things. What it did though, was that it harmed my relationship with my superiors. That wasn't what they perceived to be a good attitude at work. They wanted me to do what they did ... and what 98% of the other staff did which was clock on when you got there ... do what you had to do and then clock off and out of there and have no further interest. When you were on, primarily you answered to your superiors ... that was really where your loyalties had to be ... to your superiors and the organisation.

Roy, who had no formal training as a service worker, describes his disappointment in the role distancing behaviours of other workers who did not operate in a relational context and who resented his inability to conform to the cultural norms of the organisation:

So ... it wasn't very long before things at work started to go a bit badly for me because what I didn't understand was that I thought that everyone who worked in a place like that were there because they were good people ... they were kind, they were caring and that they wanted to do things for people with a disability and they had the ability to help. When I found that that wasn't the case ... I was shocked, and when I found that not only was that not the case ... but actually they totally resented that type of expectation and anyone who acted in that way ... that made life with my co-workers very difficult which actually didn't stop me from going the way I was going

because I felt very strongly about what I was doing and why I was doing that ... but it put me at odds with quite a few and led to my dismissal.

In discussing the qualities of effective interdependence in service relationships from a service worker's point of view, O'Brien and O'Brien (1993, p. 17) suggested a need to guide service workers to make essential relationships with people with disabilities as a safeguarding mechanism. Interdependent relationships defy efforts to set clear boundaries around job descriptions or service specifications and recognise the need to adapt to changing circumstances as the lives of people in services change (O'Brien & O'Brien, 1993, p. 20). Predetermining the needs of people living in services by controlling service delivery processes through adherence to task oriented job description, such as those inherent in 'competency standards' hardly seems appropriate if services are seriously committed to meet the individual and varied needs of people living in services. Breaking everything down into sets of tasks may make relationships more difficult to achieve. A commitment to 'Blurring the Boundaries' between the role of worker and ally is the first step in the development of interdependent relationship for workers in this study. Criticism from other workers who do not support relational serving is more likely to be experienced when services are highly structured and rule oriented. Despite system constraints, service workers who practise interdependence in relationships with service users, report positively on their feelings of being needed and involved in worthwhile work and their inclinations to participate in meeting the needs of service users in the long-term.

4.3.1.2 COMMUNALITY

(Belonging)

The meaning of the sub-theme, 'Communality' relates to a sense of belonging among other human beings in the spirit of 'community'. For service workers this involves service users, other workers, the service organisation and the community at large. The role of workers' involvement with service users is viewed as having a wider social significance. 'Communality' also relates to the willingness of service workers to share the suffering and joy in the lives of people living in service environments. In the context of 'Communality', there is a sense of being part of a shared commitment to something larger than oneself. This is consistently expressed as a practice ideology. Mark, a support worker in a small community based organisation explains the motivation for his initial involvement:

I guess I always had it set in my mind that I wasn't happy with the way society was and I guess I was angry with social inequality and social injustice for a lot of different people. I guess I see people with disabilities as being one of these groups who were put down to maintain some sort of power structure within society. When this job came up ... it seemed to fit in with my ideals.

In commenting on the breakdown of community, Schwartz (1992, p. 3) suggested a need to rediscover " ... the importance for all people of being and feeling embedded in a web of personal relationships". The relational needs of people receiving services must also be addressed if services are to claim quality

outcomes. In surrendering active control in the process of relating, the communal individual focuses upon 'being' over 'doing' in a relationship (McAdams & Powers, 1981). Professional/bureaucratic systems are unlikely to create contexts of caring and may act as barriers to the development of a psychological sense of community, the absence of which can have debilitating consequences and lead to experiences of transience and loneliness (Sarason, 1974; McKnight, 1987; Schwartz, 1992).

Believing in the value of service users and their rights to have their needs met is fundamental to the way service worker informants serve in the context of 'Communality'. Joy, a nurse, discusses her views of residents of an aged care complex and their right to be recognised and respected as members of the wider community as well as experiencing community within the service:

I view them as members of the community. They're members of our community and I believe that they deserve as much respect as anyone else who lives outside of here. I don't view them as second class citizens ... and I've had a couple of run ins with GPs since coming to Perth. I've got no problems about facing up to anyone who doesn't give them the service they require. I view people here as an essential part of the wider community. We're not just a community in itself.

Authors have agreed that the creation of service environments that are communal in orientation, required efforts to counteract the legacy of patriarchy, competition and power, and recognise that working relationships which acknowledged the needs of service workers were also important for a collective

effort (Noddings, 1984; Benoliel, 1993; Morgan, 1993). In the context of 'Communality' service workers attached wider social meaning to their work. They viewed not only their central service relationships with clients as important, but also their attachments to users' families, other service workers, and community members. The wider purpose of community development and integration of people with disabilities is explicit in the intent of service workers in the disability field. Graham, a co-ordinator of a small service for people with disabilities discusses the deliberate evolution of a communal ethos for the service:

The processes we use here to support people are essentially dependent on people giving the support like any other community member. We recruit through our grapevine, our own connections, and people are appointed because of their resourcefulness and the extent of their own relationships with other people in the community. So ... our grapevine is very powerful ... it's never ending.

In aged care environments, study informants also consistently discuss the need to create supportive communities in the living environment to promote belongingness and well-being. In the highly regulated environment of an aged care nursing home and hostel complex, Jill, a therapist discusses her communal approach.

I've developed my philosophy through my experience in working in aged care and I often think of people in relation to the wounds they've experienced. I think of them as grieving for their past lost roles and lost lives. I try to create a sense of community within the centre here, because we all have to live

and work together. I try to provide opportunities for people to take on new roles other than the role of resident.

‘Communality’ is an elusive concept, but the experience of being in communion with other human beings is a basic human need. Social prejudices negatively influence the inclusion of people with disabilities and elderly people in Western societies, however, opportunities for communality can be found in many different situations, as groups of people come together united by a common purpose although past history of congregation and abuse in institutional environments has been well documented for people with disabilities (Goffman, 1961; Blatt, 1966, 1979; Wolfensberger, 1975c; Taylor, 1978). Communality in service environments, although not a substitute for communality in the general populace, can also provide additional opportunities for personal validation, if personally valued relationships exist between service workers and users. Vanier, (1979, p. 71) suggested that even communities with moral values were fallible due to external and internal forces of self-interest. In discussing the absence of a stabilising sense of community in modern society (Sarason, 1974, p. 154) suggested that “... we may be becoming one world but we seem increasingly to suffer from feeling that each one of us is one person alone”. The lack of dynamism and interpersonal commitment that heightens the sense of aloneness was cited by Sarason as the most poignant feature of life in our communities. Creating a sense of ‘Communality’ in daily life could be viewed as an antidote to the isolation of people living in services which is shared by many other people in society. Service workers operating in a relational context who attempt to build

community spirit in the service environment are also motivated by a need to experience 'Communality' themselves. As Tim, a service worker states:

I'm happy with this working situation and the social contact is great. Socially, I'm a very quiet person and this gives me an outlet too. I feel really supported by the organisation and the families. It's the first time that I've worked in a place where the philosophies were fully consistent with my ideals.

In criticising the paid helping relationships which characterised human service systems, Wolfensberger (1975) suggested that the sharing response of service workers was trained out of them in their professional socialisation. The necessity to share oneself was, according to Wolfensberger, critical to the mission of helping wounded people. For service worker informants in this study, 'Communality' is an explicit value which underpins their serving. The degree of 'Communality' is influenced both by the values of the individual worker and the extent to which they attempt to meet their own needs for 'community', and by the structure of the service. 'Communality' was most consistently found in interview data collected from service workers in small, locally co-ordinated community living services.

Despite dilapidated buildings, a highly institutionalised image, and hierarchical management structure, a dynamic and communal living context is experienced by a group of older adults in an aged care complex in an outer city suburb due mainly to the values and communal approach of Rosie, a hostel supervisor. Rosie explains her communal approach:

There are forty people living here ... and they're all individuals but they also have living here in common too. The first thing I did when I came here, was to get a number of committees going, so that people could have a voice on the way they wanted things done. Some people hardly knew each other even though they had been living here for years. It's had lots of spin offs and I think that by listening to each other, people have become more open and tolerant ... including me. I feel that they consider me a part of their community and it's much more satisfying working in this sort of environment.

The sociologist Talcott Parsons (1942, cited in Walton, 1989, p. 24) made a distinction between organic and functional services. People involved in organic services were connected by a common bond. Organic services were “embedded in community” whereas functional services, according to Parsons, lacked awareness of the ethical dimension which promoted a ‘person’ orientation as opposed to a systems approach.

Examples of communality between service workers and users are consistently described in this study by services workers who have been named as providing valued services. Vanier (1979) who founded L'Arche communities, although viewing intentional voluntary communities as close to an ideal way of supporting people with disabilities in their day-to-day lives, also suggested that external authority and formal systems were also necessary to act as a safeguard against the decline of communal settings which have historically proven to have limited life spans.

Generating a culture of communality, such as those encountered in two of the small locally based agencies providing services for people with disabilities in this study, may be a viable means of generating communal experiences for people living and working in services, and may positively influence workers remaining involved in support roles over long-term. Evidence from this study suggests that the interdependence between service users and providers in their essential need to be communal with each other, is the strongest means of effecting communality in services.

4.3.1.3 OPENING THE DOOR

(Doing it 'their' way)

Autonomy and decision making for service users and strengthening people's own interests are articulated as important aspects of 'serving'. Supporting autonomy for people with disabilities who have limited opportunities to choose, and experience the results of choice, and also for elderly people who are at risk of having their choices removed by systems, is described by the sub- theme 'Opening the Door'. Opening the door for Joe, a man with multiple disabilities, is described by a service worker Garry:

What he needs is someone to help him live his life his way. You have to have an open mind and be prepared to do what's needed ... even if you don't feel like it. I'm very aware of maintaining his individuality and freedom of choice. I see myself as being here to open his door on the world.

Bronfenbrenner (1979) in his seminal work on the ecology of human development, discussed the need to balance the power in favour of the developing person in order to effectively practice competency across settings. Mentoring relationships between people with and without disabilities is a powerful motivator of developing competency in making successful choices. Service workers recognise that choice offers control and that sudden changes in pre-arranged activities on behalf of service users demonstrate their freedom to make choices and exerts their authority in the relationship. Although this causes inconvenience, service workers are able to stand back and observe the positive outcomes in the long-term. Having a view of service users as having rights to make choices, underpins the context of 'Opening the Door'. If service users are seen as persons capable of making independent choices then there is a moral obligation to treat them as equal. According to Walton (1989), this strengthened the ethical dimensions of a service. For people who have experienced long-term institutionalisation, making choices can be difficult, and frustrations arise in relationships between service users and workers when choice situations are deflected by service users.

Karen, a co-ordinator of a community service for people with disabilities, voices her concerns about the possible abuse of power by service workers in the context of 'opening the door.' She describes the challenge of constantly having to 'step back' and 'avoid the trap' of influencing the choices of service users:

They've gone through the first part of their lives being children under the power of their parents and then gone

through another significant period being residents under the power of an institution. They've never known how to take control and so ... people who work for them will take the power because it's there for the taking. There's such a lack of experience in making decisions and such a fear of making the wrong decisions. You sometimes find yourself falling into making decisions for them without realising it.

In analysing psycho-social research studies on aspects of autonomy for elderly people in service environments, Rowe and Kahn (1987), Hofland (1988: 1990), and Groger (1994), concluded that lack of control had negative effects on emotional, physical and behavioural well-being and that dependency was the result of environmental factors and specific learned interactions. Meta analysis of observational studies in aged care living environment contexts demonstrated reinforcement by service workers for dependent behaviour (Hofland, 1988). In aged care contexts, maintaining autonomy is not necessarily demonstrated by participation in activities, but by maintaining control over choice of participation. Vigilance in recognising opportunities for choices to be made in institutional environments where the overriding ethos might encourage dependency, is described by Jill, a therapist:

The staff ask me to do a shower assessment ... but it's not showering that's important ... it's the way that residents want it done. They may have certain likes and dislikes that are very important to them ... and that's all the more relevant when they leave their homes to come and live here. You have to be open to their suggestions.

Development of autonomy is also linked with competence and effectiveness. Although people's autonomy to function as active agents is reduced by illness and disability, the ability to make decisions is based more on past experience rather than current circumstances. The willingness with which elderly people give up autonomy on entering service systems may be testimony to the patriarchal structure and control of institutional environments, rather than individual ability. For people with disabilities the transition from institutional to community settings is compounded by the impact of past experiences of institutional life. In this study, autonomy, as a basic human characteristic is recognised by informants as an important element of serving others.

Flexibility in service delivery processes is also a characteristic of 'Opening the Door'. Routine and habitualised service 'programs' are criticised by participants as meeting the needs of the system rather than the service user. Jeff, a support worker describes a previous experience of a routine service and the ineffectiveness of the process:

To me a service has to be used as a person needs. If the service becomes some sort of routine, then it's not being effectively used. Take, Luke, he had transport training twice a week for two years, and still couldn't use the bus. He can now, because we've incorporated it naturally into what he wants to do. I try to avoid interfering in his life. It's really up to him what he considers to be useful, not up to me. I have to try to respond to him.

Service workers use their personal measure of 'what is right' when advice is sought. It could be described as 'what would I do in that situation'. *'When I'm really put on the spot the best way I have of deciding is what I would do myself in that situation'*.

In discussing paternalism as a threat to autonomy Childress (1982b), Reamer (1983), and Van De Veer (1986), suggested that autonomy was an internally problematic concept. According to Collopy (1988,) Hofland (1990,) and Powers (1992), autonomy could be ethically perplexing even in situations where service workers were committed to service user self-determination. Helping interventions are also at risk of being judged by the motivations and goals of the helpers and not by the preferences of those helped. To make judgements about autonomy, caregivers must give attention to the moral careers and past preferences of service users as well as their current motivations, but this may also present problems for service workers by creating a passive uninvolved model of involvement (Collopy, 1988).

The ethical issues in promoting autonomy and 'dignity of risk' for people with disabilities is consistently described by service workers as *'not interfering in their lives'*. Service workers are sometimes concerned about the outcomes of decisions made by service users when these might be potentially harmful. Carol, a support worker for a woman with physical disabilities describes her ethical dilemma, in supporting the choices of Jean:

She wanted to be sexually active and to meet men and experience that, as she never had before ... and we tried just

about every way for her to have relationships without success and so eventually she asked me to help her find somewhere where she could get sexual relations without ridicule or laughter. We finally found an organisation which sent someone out and he was really sensitive to her situation. She was so appreciative. I feel so angry that she has to pay for it ... and a lot of money. I could never do that myself and don't condone it ... but I m not saying that it was wrong for her.

Collopy (1988) in discussing programmatic issues in service environments which enhance community, suggested that the encouragement of autonomy in long-term care situations is essentially linked to the communication behaviours of service workers. Autonomy as an intrinsic factor in 'quality of life' literature across disability and aged care studies was universally acknowledged. In this study service workers who are valued by users of living services demonstrate their commitment to maintain and develop opportunities for practising personal choice. By doing so, they respect the individuality and rights of users of services.

4.3.1.4 FINDING MEANING IN SERVING

(Learning together)

Service workers describe many situations which for them have resulted in personal growth and development. The sub-theme 'Finding Meaning in Serving' relates to the consistency in service worker data which describes situations with services users which have application to their own lives. 'Learning' relates both to qualities attributed to service users which are admired by workers and also to

the perceived personal development taking place in the lives of service workers as a result of their involvement in living services.

Karen, a co-ordinator of a small community based organisation reflects on the qualities of Coral, a volatile young woman with an intellectual disability. Despite Coral's reputation of being 'difficult to manage' Karen believes that Coral has qualities which she lacks:

I tend not to look at the disability but at the person and I learn a lot from the people here. Take Coral for example ... I've learned a lot from her. She's so giving and so forgiving. She's trying life out ... in a way ... and she's intellectually disabled. She gets upset and then it's gone. It's such a short duration and she never bears a grudge. I wish I could be more like her.

Karen's response to Coral is mirrored by a nurse, Pat, who admires the courage of a nursing home resident who is nearing death:

There's one lady ... Mrs Brown, who's quite remarkable really. We seem to have struck up an immediate friendship ... it must be chemistry or something. I like to sit with her. One of the things I remember her saying to me is '... you know Pat, dying is so humbling'. That's pretty special stuff. Although it's hard for me to watch her die ... it's a privilege too.

The search for meaning in life is the central core of existence. Frankl (1964, p. 3) suggested "... to live is to suffer, to survive is to find meaning in the suffering". Finding meaning, according to Frankl, can be achieved by work, experiencing a

value or by suffering. Frankl (1964, p. 114) in commenting on love as a value, stated:

by his love, the loving person, enables the beloved person to actualise his potential. By making him aware of what he can be and of what he should become, he makes these potentialities come true.

Statements such as '*loving the work*' or '*loving involvement with the people*' consistently appear in the interview data of service workers. One carer employed by a small organisation to support people with intellectual disabilities talks about the perceptiveness of service users and their ability to '*see into*' service workers and attributed service users as having intuition about '*knowing what was good*'. Another talked about the good intentions of fellow service workers who operated in the context of love as '*shining through*'.

Human service work at first glance may appear to stem from altruistic and selfless motives in which others and their well-being take precedence. However, other reasons that people serve, may be motivated by the gratification of personal needs for approval and self-worth, or even expiation of feelings of guilt through good deeds for others. For other people the need for close personal relationships and intimacy may be fulfilled through involvement in services (Maslach, 1982).

In this study, reflection on the lives of service users and self-reflection on the meaning of serving relationships by service workers gives meaning to their work, which transforms their working experiences into meaningful personal

involvement. Personal relationships with service users are stated as 'important' in the lives of informants. It is a characteristic of the service workers interviewed, that they enjoy relationship satisfaction in their personal lives outside of the service environment. They consistently express a view that their working life is enhanced by 'good' relationships with service users. Service worker data also supports the view that self-development and in some cases spiritual development is a benefit of serving.

Spirituality has to do with issues of depth and significance in life and requires self-reflection. Throughout life and for many reasons, "people remain stuck in the narrow ethics of self-centred individualism, whereas others, develop altruistic values" (Bianchi, 1991, p. 60). It is common for service workers interviewed for this study, to describe altruistic acts in the process of serving. Giving freely of oneself is a characteristic which consistently relates to finding meaning in the serving context. Throughout interviews with service workers shared relational situations which are not paid working situations are described.

Tim a young support worker for Ken, a man with an intellectual disability explains meaningful service. For Tim, involvement with Ken, is perceived as expanding his social network as well as benefiting him as an individual who has a need to help others:

To help in a way that benefits someone ... benefits you in the long-run. Helping Ken helps with understanding people. I've found peace in my life and if there's any way that I can share it with others I want to do that. I really want my life to be

around people ... yeah ... that's really what I want ... to help in any way I can.

Association with service users commonly requires personal adaptation which develops qualities which are transferable to other situations. Understanding the limits of personal capacity for patience and tolerance in situations which can be highly demanding and working on developing mechanisms for greater efficacy in the service environment not only apply to the work situation, but also have application to other relational contexts.

Pat, who works in a hostel environment, discusses her development through her involvement with residents:

I often think about my future and whether or not I'll require this sort of care and think of my work not only as helping them, but also as a learning curve. I'm becoming much more patient and sensitive to the need of my friends and family too as a result of working here.

Serving John a man with an intellectual disability who required support with community access has not been without feelings of embarrassment for Mark due to John's spontaneous and uninhibited enjoyment of life, but through his relationships with John, Mark has overcome some of his own social shyness:

I used to get embarrassed being out with John. He has such a sense of humour and will laugh really easily and attract attention to himself ... but he is so spontaneous that I can't help joining in too. I used to be shy, but I guess I'm getting over that due to my relationship with him.

Intrinsic reward through serving is also a characteristic of the sub-theme 'Finding Meaning in Serving'. The interdependence of the serving relationship *or 'having my own needs met'* is also acknowledged. Healthy dependency requires an "awareness and sensitivity to the needs of people who help us satisfy our own needs" (Margulis, Derlega, & Winstead, 1984, p.114). The interdependency of the service context is explicit in statements of service workers such as '*needing to help people*', '*getting out of it more than I give*' and '*feeling needed*'. Mark explains the importance of a sense of being needed by others:

It's very important to me ... because I like giving. I get rewarded from this. For me it's a very important part of my life. There's definitely a sense of being needed and that's very satisfying. But I don't see myself as the be-all and end-all either. I want John to need a lot more things too and I'm just a part of that and that is more satisfying than the money.

Interdependency and fulfilment of a need to be involved in helping relationships reinforces meaningful contact and sustainability in the role of service worker. This positively influences maintaining the role long-term.

The personal reward of long-term involvement is described by Joy, a nurse in an aged care environment:

I'm a person who likes long-term situations. The quick in and out ... the superficial kind of service doesn't appeal to me ... it's too superficial and you just seem to carry out protocols and procedures and then the person's gone. I like getting involved with people long-term. It gives me a sense of being and a sense of usefulness.

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Finding personal meaning in the context of serving, is perceived by service workers to be mutually beneficial. Personal growth and development results through personal reflection on involvement in the lives of service users. The positive interdependency between service workers and service users reinforces satisfaction and long-term involvement in service relationships.

4.3.1.5 WEIGHED DOWN

(Pulled in all directions)

The sub-theme 'Weighed Down' relates to experiences of service workers when system demands or needs of service users are so high that service workers have problems coping. Service users' '*needs*' is the terminology consistently used by this group when they feel overwhelmed in the service context, as opposed to 'demands.' At the time of interview, six service workers operate in the context of 'Weighed Down', four in aged care environments and two in disability services. When the serving context is 'Weighed Down', service workers discuss leaving or having a break. Leaving the service does not mean that the relationship with service users will end.

Working in the context of human need may be more emotionally demanding if the situation has personal relevance to the worker. This has the potential to result in overidentification with feelings of service users (Maslach, 1982). Ann, a single mother and carer for Julie, a woman with disabilities who is socially isolated, found that she was central in meeting the needs of Julie. Because Julie lacks family support and has no other social networks, the situation became

overwhelming for Ann, who found herself living life in Julie's life context at the expense of her own. Eventually Ann resigned, but was able to maintain her friendship.

(What was it like for you around the time that you were trying to leave?)

It took me ages to finally pluck up the courage to tell her I was leaving. It was really bad ... but I didn't feel guilty because she was a friend as well and I knew I'd still see her ... and once I'd finally said that I was going ... it was like a weight dropped off my shoulders. The work had been really getting me down. I was practically living with Julie at the expense of my own family. It just wasn't healthy for her or for me ... and I couldn't go on.

In aged care environments, when there are large numbers of people with support needs, and few service workers willing to spend time fostering relationships, the few workers who do, often find that they are in high demand. Joan, an activities assistant discusses her experiences:

It is exhausting because there are so many people living here and they are all so needy. Sometimes I feel as if I'm being pulled apart ... trying to make sure that nobody misses out.

Role conflict is considered a major factor in job related stress when separate demands are placed on workers and compliance with different roles proves difficult (Maslach, 1982; Milton, Entekin, & Stening, 1984; Mitchell, Dowling, Kabanoff, & Larson, 1992; Carrell, Jeannings, & Heavrin, 1997). The values of the individual worker, management expectations, and peer expectations may contribute to role ambiguity. Sometimes compliance with formally articulated

service roles conflicts with the values of service workers related to what should receive priority in meeting the needs of service users. In these situations, the loyalties of service workers who operate in a relational context, are caught between management, peers and people living in services. In this study, conflict of this nature is more likely to occur in highly structured environments. Numerous studies support the view that multiple levels of authority within organisations which place high priority on professional control and technical outputs, have higher levels of role stress, job dissatisfaction and health problems (Milton et al., 1984; Carrell et al., 1997).

Roy, a support worker for people with disabilities discusses his past experiences of 'Weighed Down' as the result of operating in a context for people with disabilities which he describes as exclusive rather than inclusive of service users. Peer pressure eventually resulted in Roy leaving the working environment to establish a small community based service:

Staff would come in and clock on and they'd have their whinges and moan because they had to shower this one or that one. They'd do a few things and then it would be time for a cup of tea and they were meant to have 10 or 15 minutes ... 45 minutes later I'd go in there and say ... 'can you help so and so because they're busting out there', and I'd have to drag one of them out because half the time the supervisor would be in there with them as well. If they could have stayed in the staffroom the whole day they would have ... and if one of the residents came near them they would say ... 'go away you're listening at the door ... go away'. They were exclusive

rather than inclusive ... it was just very exclusive ... it was totally unnecessary and I resented that greatly.

Sensitivity to the needs of service workers for emotional support due to the personal losses sustained by elderly people in moving from family homes into service environments often mean that service workers interviewed for this study fill a need that other workers do not view as important. This can be overwhelming for service workers who feel morally obligated to address the losses experienced by services users. Gwen, a nursing assistant, explains:

There's nothing on my job description that says I should spend time talking and listening to people. But ... I can see that that's exactly what's needed here. Other people just 'do the job' and are watching the clock for the next tea break. I often don't get a break and I know some of the other staff don't like the fact that I get so involved. Sometimes I'd like to say to them that if they were just a bit more giving then I wouldn't get so weighed down with it all, but I won't. Thank goodness I've got a holiday coming up.

The burden of what is considered excessive documentation which also takes time from direct serving is consistently discussed throughout interviews, both in disability services and aged care. Departmental procedures to monitor standards are considered inappropriate by the majority of informants. Workers question the value of entering a service and taking a 'snapshot' view as not being particularly relevant. A nurse, Pat, expresses anger at the demands of excessive recording of information on residents. She also comments on standard monitoring:

Our standards are a lot higher than the monitoring team measurements and that makes me quite angry as I think we can achieve a lot more. I certainly don't think that they (the standards) improve the quality of care. You can't make people compassionate by introducing standards.

Strain in the working environment for informants was ascribed mainly to attempting to meet the relational needs of service users in highly structured contexts which do not articulate the socio-emotional needs of service users as priority. This is described more frequently in aged care living environments, than in disability services. The flexibility of service worker involvement in small, community based services, allows a more fluid and responsive approach, although there is also potential for unhealthy relationship development in this context. It must be emphasised that the service workers interviewed were identified as providing a 'quality' service. The potential for the abuse of vulnerable people in living environments which are both structured and flexible, is well known. The individual values and motivations of service workers are ultimately the most powerful safeguards for ensuring the well-being of people living in services.

4.3.2 SUMMARY

From the analysis of interview data of twenty-six service workers who have been named as providing valued service by service user informants the following statements emerge:

1. Valued' service workers consciously serve in a relational context.
2. Valued' service workers circumvent job descriptions and system constraints and place strong emphasis on the socio-emotional needs of people living in services.
3. Positive interdependence between service workers and users encourages sustainability in the role of worker
4. Encouraging the development/maintenance of service users' autonomy as a key element of serving is explicit.
5. Serving fosters personal growth.
6. Serving in the relational context, has potential for loss, peer conflict, role burden and ambiguity.

Having identified the variable experiences of people with disabilities and elderly people living in services and their perceptions of quality, and having identified shared characteristics of service workers who were named in the context of quality and described the meaning of serving and their perceptions of quality, the next question addresses key quality characteristics in living services from the analysis of data from service users' interviews.

4.4 QUESTION 3: WHAT ARE VALUED CHARACTERISTICS OF LIVING SERVICES FROM THE PERSPECTIVES OF SERVICE USERS?

The characteristics of living service workers and the acts of serving which are considered important by users of living are presented in answering this question. They will be contrasted with negative cases. One major theme, RIGHT ATTITUDE, and five sub-themes, CONFIDENTIAL LISTENING, NORMAL TALK, LASTING, PARTING, and RESPONSIVE SERVING, will now be discussed. Themes are displayed in the following figure:

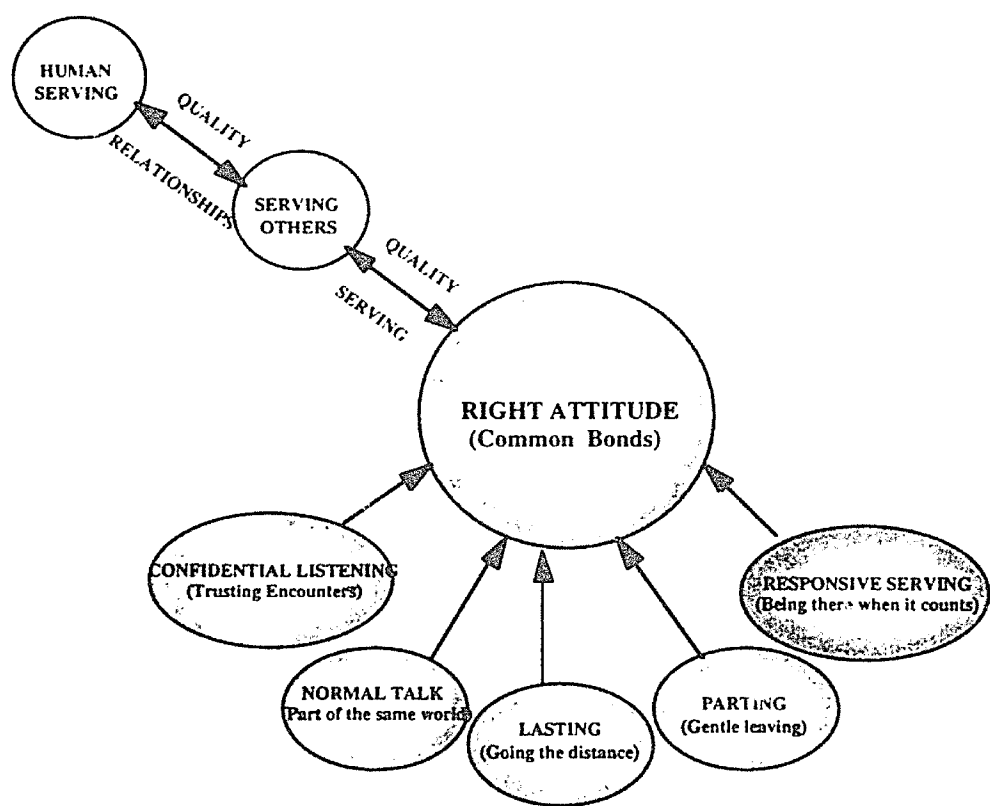


FIG. 4 QUESTION 3 EMERGING THEMES

4.4.1 MAJOR THEME: RIGHT ATTITUDE

(Common bonds)

According to service user participants, 'Right Attitude' on behalf of service workers is an essential characteristic of a valued service. 'Right attitude' is described as 'caring' about the service user. It is not just the acts of physical care, but also the supportive relationship or the 'caring about' the person. Caring in the context of 'Right Attitude' is not a rational, reasoned, carefully thought out phenomenon. Caring is about relating in a way that recognises the common bonds of humanity and having affection and compassion for another person. 'Right Attitude' is not about objective detachment in service acts, but it is about subjective serving and willingness to try to understand the other's reality. This is what Martin Buber (1965) referred to as inclusion, a relational process which sees things from both self and other's point of view.

Noddings (1984, p. 14) has discussed the problems of defining caring as an act or thought. In discussing the need for people to become "better than we are", Noddings suggested that caring required struggling to view the other's reality and acting out of concern based on our own ethics. When mutual inclusion occurs, Buber (1965, cited in Noddings 1984) suggested that the relationship changed and became more of a friendship. This is consistent with both service user and service worker data in this study. Service users consistently talk about the 'Right Attitude' of service workers they relate to easily. People consistently reported feeling relaxed, happy, supported and confident to enter new situations with

service workers who are perceived to have 'Right Attitude'. In service environments which are characterised by 'Right Attitude' people feel liked and respected. 'Right Attitude' can be described as the 'key to the door of quality' in living services.

'Right Attitude' is described by Joyce, a woman with an intellectual disability. The importance of a service worker '*taking time*' in helping her learn to sew fosters feelings of being liked and having the potential to learn:

*I like Judy helping me. She takes her time ... not rushing.
Sewing's a bit hard for me ... but Judy says I'm good. I think
I'm good too. I like Judy helping. She likes me too.*

Arguably, any caring relationship requires respect of the other person (Walton, 1989). Respect is about being considerate and not interfering in another person's life. It also implies that the other is capable of conscious choice, deserving of recognition, and belongs to a common humanity despite the different roles of service user and service worker. 'Right Attitude' on the part of service workers generates feelings of inclusiveness. A nursing home resident, Mrs. Owen, talks about the hostel environment that she had left to enter the nursing home and the way that staff interacted with her in an equal relationship. This was '*different*' and '*missed*' in her current situation:

Well ... they used to come in the room and they'd sit down and talk to me. And night staff when they came round, they used to come in every morning. I used to get up about four or five o'clock every morning . I had my own fridge and I kept my own tea pot, mugs and things and they'd come in and say

.... 'Oh yes'....and I'd say 'Oh yes ... it's six o'clock I'm ready now' ... and we'd put the tea on.

(Together?)

Yes....and she'd sit and talk, which ever one of them it was, and we'd talk about all sorts of things.

(So....what was that like?)

Well ... it was like we were equal ...we were very close.

'Right Attitude' also fosters autonomy. People living in the context of 'Right Attitude' are more likely to ask for what they want or to complain knowing that this is acceptable. Attitudes of service workers in their capacity to care are influential in creating an enabling environment where service users can practise autonomy. Lisa, a woman with a physical disability describes 'Right Attitude':

It's important to have the right attitude in this sort of situation. I need someone who'll see things my way and who won't take it the wrong way when I ask for things to be changed, and who doesn't get moody. They need to understand that I have ideas about the house as well, like Doreen, she's great around the place ... and good company too.

When service workers are involved who do not display a 'Right Attitude', service users may respond with anger, withdraw from contact, or experience anxiety. Dependence on the service worker who has '*bad attitude*' especially when physical frailty is present, causes anxiety and retreat into compliant dependency. In these situations service workers are consistently described as being focused on the environment around the person while '*ignoring the feelings*' of the person living in a service. The person becomes an object of care tasks and

the living environment an extension of a service system rather than a home. Simon, a man with a physical disability describes this as '*like being a stranger in your own home*'. Other informants with disabilities talk about '*dreading*' the arrival of particular service workers who create an atmosphere of tension and 'difference'.

(Verbal Communication)

Communication is the key to 'Right Attitude' and people living in services develop ways of interpreting verbal and non-verbal behaviour, to gauge the attitude of service workers towards them. Service users are highly sensitive to episodes of verbal abuse and rough or rushed handling, even if this is a singular occurrence in a history of 'Right Attitude'. If situations are not openly resolved between service users and workers, a single episode is likely to have long-lasting detrimental effects on the service relationship. Although, 'any one can have a bad day at work', in a service situation when people have few social contacts and rely on service workers for human contact, service users are less able to 'shrug things off' as they have fewer opportunities to engage in positive interactions with other people.

From service user interview data, a pattern of consistently unresolved minor conflicts demonstrates a need to raise consciousness around communication issues and the important meaning that this has in the lives of people living in services. Doug, who has a physical disability, describes the breakdown of his

relationship with Cheryl, a support worker he had known and liked for many years:

One day I was in the van. We were going to the cinema and it was dark and she said 'Which way is it Doug?' It was dark, and I wasn't too sure and she shouted 'Which bloody way Doug?' That just threw me ... took me by surprise that much when she spoke to me like that. I had a totally different outlook on her then ... it just really dropped the lid ... and I never felt the same about her again.

Service users' interpretations of 'Right Attitude' are influenced by their perceptions of whether the worker appears 'happy' to be in their company. People who do not communicate spontaneously or are continually absorbed in their own problems make service users feel 'shut off'. For people who have limited social contacts and reinforcement of their worth through personal interactions, service workers' affect in carrying out tasks sends messages that people are 'good to be with', or 'not good to be with'. People who are restricted in mobility and communication, have limited opportunities to seek out their own social interactions and have more time to reflect on interactions with service users. Creating a positive, friendly, and relaxed environment in the service encounter is important in what may be an otherwise sterile existence for people living in services. When people enter the environment and engage in cheerful communication, service users are likely to value their involvement and be relaxed in their presence.

Service users mirror the moods of service workers in their interactions with them. This results in service being a pleasant or unpleasant experience. A positive affect is also an important characteristic of a 'quality' service. Positive affect on behalf of service workers does not necessarily signify a close relationship. When service workers display positive affect, opportunities are available to engage in superficial conversation, share a joke, and generally divert people, who are socially isolated, from their loneliness. People living in services also feel 'accepted' and 'normal'.

Miss Evans a nursing home resident discusses the importance of having positive communication experiences:

I spend a lot of time by myself and it's easy to get stuck in feeling sorry for yourself. When you look around you at the people here it can be quite depressing. That's why I look forward to Gwen's days on. I feel more like a normal human being when she's around. We have a chat about all sorts of things and can share a laugh together. She helps me look on the bright side.

Peter, who has a physical disability and lives alone describes a similar need for social interaction:

I don't expect all of them to be friends. But I think the least they can do is to come in and be pleasant ... and talk while they're here. When I'm stuck here alone all day ... I look forward to people coming in and having a bit of a laugh ... not down in the dumps all the time. Anyone can have a bad day. But you've got to imagine what it's like for me too.

Being '*gentle*' in verbal communication style is consistently discussed by service users as an attribute they value in workers. When communication between people is '*gentle*', it conveys an empathetic understanding of the other person and service users feel less vulnerable and more confident in entering into activities or personal discussion. Gentleness in service worker acts and communication creates a relaxing, supportive environment. Service users will often delay asking for assistance, particularly in the area of personal hygiene, until '*gentle*' workers are available.

The way in which personal hygiene is assisted conveys powerful messages about the attitude of the worker. What is commonly an embarrassing activity for service users can be transformed, by supportive workers, into an act of caring. Informants who are dependent for assistance in this area comment that they '*never get used to it*'. This is stated by both elderly people who have become disabled and young people with disabilities who have always been assisted. Sensitivity to the feelings of people requiring assistance and gentle and confidential handling is integral to 'Right Attitude'.

Julie, a woman with a physical disability, has had mixed experiences of service life. Currently Julie lives in a community house and employs her own service workers. She describes another experience prior to entering her current home, when she had to use a respite service from another organisation. She is outraged that her bodily functions were the topic of staff jokes, but does not feel that she could have complained:

Sometimes you try to get on with them ... but it's impossible. They just want to finish with you as soon as possible . It pisses me off the way staff would talk about personal things ... toileting and stuff. I used to hear them laughing about us. I never wanted to 'go' when some of them were on.

(Empathetic Touch)

'Right Attitude' also relates to the way that people are touched in self-care activities, which is assessed by service users as '*kind*', '*quick*' or '*rough*'. If people experience '*rough*' touch, then their perceptions of the service are '*bad attitude*'. Interactions with people who demonstrate rough touch are avoided at all levels and communication is limited to essential information sharing.

A number of researchers have studied expressive, non-necessary touching as conveying empathy or attention to people in service contexts (Watson, 1975; Fanslow, 1990; Mulaik et al., 1991; Weiss, 1992). There is general agreement that touch communicates relational messages about how people feel in the relationship and also a sense 'being there' for the other person (Mulaik et al., 1991). Comforting touching behaviours by service users in this study are described as, '*reassuring*', '*friendly*' and '*meaning a lot*'. When people looking for affection are deprived of touch, they are at risk of thinking of themselves as untouchable and unloved with a resulting loss of self-esteem in their interactions with service workers. People who have left family relationships to live in a service, may have an increased need for touch as reassurance. Touch is also needed to a greater extent by people who are confused and have lost their ability to communicate by any other means, such as people with dementia. When

elderly people are confused, gentle, reassuring touch may be their primary means of validation. Consistent references to feelings of reassurance through touch are present in data across aged care agencies.

Mr Williams a nursing home resident describes his need for non-task related touch:

Well ... when you leave the family to come into a place like this, you don't think about the things that you'll miss. I was married for nearly fifty years and it's the being close to someone that I miss the most. Getting a comforting tap on the shoulder gives me such a boost.

For people with physical disabilities who have limited funding and high levels of care needs, care activities involving touch can be quick and impersonal. Alternatively when touch is used for communicating liking and empathy, this is highly valued. Jane, a woman with severe physical disabilities and without verbal communication abilities, is unable to reach out to touch other people. Using a communication device, she describes 'Right Attitude' as displayed by a service worker Angela and her appreciation of prolonged touch: *'She brushes and strokes my hair at least twenty times. I love it when she does my hair'.*

(Respect)

Objects of meaning provide a sense of personal continuity over time and service workers' respect for personal possessions is important to people living in services. For people who have few personal possessions, objects in their environments may have special meanings (Czikszentmihalyi & Rochberg-Halton,

1987; Jackson, 1996). Pauline, a young woman with an intellectual disability living in a group home proudly displays her collection of porcelain dolls, a link with her family life. Pauline's parents add to her collection on special occasions. Although the dolls may not provide the most image enhancing objects in Pauline's environment due to their associations with childhood, service workers have recognised the important symbolic meaning of the dolls for Pauline in the context of her family affiliations. Similarly for Mat, who has an intellectual disability and lives in a community house, having his own Christmas tree is a great joy. His preference to continue to display his tree long after Christmas is respected by his support workers.

In nursing homes and hostels for elderly people, service users experience the shrinking of their material world. The few personal possessions that remain in their lives are carefully chosen and displayed as a reminder of life roles and relationships. The presence of personal objects may be used by elderly people in institutional environments to transcend the present and re-experience the emotions of past events (Jackson, 1996). 'Right Attitude' is about displaying sensitivity to the individual's personal space and the objects that occupy it, including the way they are arranged, as opposed to treating their living space as a 'work' area. One nursing home resident is very attached to a soft toy which belonged to a child who had died and becomes distressed when service workers suggest that this might create an inappropriate and childlike image.

Material objects are a link to personal histories. Sensitivity to the meaning of objects and the memories they reinforce is another element of 'Right Attitude'.

Recent research has highlighted the important roles played by personal objects in the lives of elderly people (Rochberg-Halton, 1984; Rubenstein, 1992). Objects represent connection to others, and may serve as defences against negative changes and events (Rubenstein, 1992 cited in Gubrium & Charmaz, 1992, p. 65). For people who have been separated from families, personal objects provide a source of reassurance and connection with self. In later life “the potential for objects to signify and reinforce personal identity may be the greatest” (Rubenstein 1992, p. 57).

The way that mundane tasks around the home are carried out have significant meaning for the way service users view the worth of service workers and indicates ‘*being respected*’. When people are physically unable to perform tasks necessary for independent living, their sense of competence is validated or threatened by the actions of service workers in carrying out their instructions. When service workers respect and enact routines and tasks according to the choice of service users, service users experience a greater sense of autonomy, competence and effectiveness. They also feel attributed with organisational abilities. One woman with an intellectual disability describes the way her tea towel is folded as an indication of whether she is respected by a service worker. For a nursing home resident, Mrs Martin, being given a plate instead of a paper towel to hold a piece of cake, represents to her that she is worthy of a plate which requires washing, respected as a person and ‘cared about’:

The other afternoon they brought in a little piece of cake and put it here on a paper and I said ... ‘Why don’t you bring a

plate?’ ... and they said ... ‘We don’t bring plates in the afternoon, it’s too much washing up’. I find it hard to lift the paper because of my arthritis and I get crumbs all over my bed. I just get on with trying to eat it as best I can ... but I don’t like any mess on the bedcover. I don’t think it’s right. They should bring a plate.

People with disabilities who have either left institutions or family homes have a strong sense of personal ‘place’ and an excitement about creating an individual life style. Just as any group of people would express a range of views about what is acceptable, study informants also have personal views about the way they want their homes to appear. In the context of ‘Right Attitude’, people view as important having things done *‘just the way I like it’* and without the *‘stamp of approval’* of service workers, not only in respecting individuality, but also in confirming personal autonomy.

Acts which represent ‘Right Attitude’ and which might be considered routine and insignificant by people working in services, are described in detail by people in living environments as indications of how they evaluate ‘attitude’. Ways that people enter the personal space of people living in services, by knocking on doors and waiting to be invited to enter, convey messages of who has the right of ‘place’. For Peter, a man with a physical disability and limited verbal communication, despite the fact that he could not survive without daily help from service workers, his long struggle to have his ‘own place’ is negated when people enter his home as a ‘right’ rather than a ‘privilege’. Nevertheless, service users, in this study are reluctant to confront issues of loss of autonomy, for fear

of losing workers. Peter says: *'Better the devil you know than the devil you don't know'*.

(Summary)

Most people receiving services feel inadequate to judge the technical competencies of service workers, and as a result, develop an intense emphasis on service workers' personality or caring functions (Tagliacozzo & Mauksch, 1972; Roter, 1977). Personal contact, communication and concern have been identified by people as the most important aspects of caring functions (Roter, 1977). Although the personalistic aspect of human serving is highly valued, it is viewed as extra or 'the icing on the cake' of receiving a service, not as an essential characteristic of quality, despite the evidence that for informants in this study 'quality' is assessed more frequently on the willingness to relate on a personal level and personal attributes of workers than on technological competencies and efficiencies.

Human services do not commonly conceive the service user-worker relationship as an important part of their role and there is a tendency to regard the socio-emotional needs of service users as peripheral to what are considered 'real' concerns which usually relate to some tangible physical, functional deficiency, lack of funding, or other system constraint. Literature has supported the view that "reinforcement of distancing between providers and consumers of services is accomplished through a wide variety of practice strategies" (Roter, 1977, p. 286). 'Right Attitude' from the perspectives of informants in this study is

described in acts of serving involving relationships which convey messages of warmth, inclusion and acceptance, provide emotional support and freedom to create personal lifestyles and environments without judgement, and perform tasks in ways that demonstrate respect for personal 'place'. 'Right Attitude' is conveyed primarily through the domain of interpersonal communication based on respect for the other.

Sub-themes of the major theme, RIGHT ATTITUDE, i.e: CONFIDENTIAL LISTENING, NORMAL TALK, LASTING, PARTING AND RESPONSIVE SERVING will now be presented and discussed.

4.4.1.1 CONFIDENTIAL LISTENING

(Trusting encounters)

The sub-theme 'Confidential Listening' relates to caring relationships and behaviours in which service users can discuss intimate concerns with service workers in a climate of trust. According to Hind (1981, p. 14) "The increased vulnerability which arises with intimacy is tolerated only if accompanied by a belief that the partner will not exploit it". 'Confidential Listening' is dependent on the development of trust. Although 'trust' and beneficence are implicit in the service user-worker dyad, 'Confidential Listening' requires a deeper level of trust in service workers and a reliance that personal disclosures will not be shared with the 'service'. This is particularly important when people have left institutional environments and have had experience of full disclosure of their personal lives. Lisa, a woman with a disability who now lives in the community explains:

After a life time of having to be careful about everything I said, at last I can have some control over who comes into my life. I've worked out who I can trust to keep private about things. It makes a difference knowing that you can share things in your life without them being broadcast to everybody.

Sharing and disclosure of 'self' is a high-risk situation (Villard & Whipple, 1976; Duck, 1991). Confidential self-disclosure provides service users with a relational climate of affirmation and support and requires the communication of empathy on behalf of service workers. Empathy has been recognised as one of the powerful and confirming of communication experiences (Villard & Whipple, 1976; Rogers, 1990; Neville, 1996). Empathy communicates acceptance and understanding. Rogers suggested that "Listening of this very active kind, is one of the most potent forces for change I know" (Rogers, 1990, p. 136). Disclosure can also be a two-way thing. Lisa describes the trust she has in a service worker, Doreen, and the way they are able to share confidences:

Doreen was going through a hard time herself with the break-up of her marriage and I had just been ditched as well. It was like we were in together and she was the only one I felt I could talk to about how humiliated I felt because she could understand. I knew she would keep our talks to herself, because she trusted me with her feelings too. I could cry when she was around but had to put on a front with other people.

The expression of empathy through taking time to engage in confidential listening provides reassurance and a sense of supportive alliance for people dependent on services. This is expressed consistently by people who have high physical care

needs and ailing health. Mrs. Owen, a nursing home resident explains her fear of dying alone:

It's not that I'm so worried about death itself ... but I worry that there might not be anyone around, and whether or not it will be easy or more difficult at the end. I find it so hard to talk about these things, as I don't want to let people know I'm so frightened ... but I am.

Elderly informants who have regular contact with family members, report using relatives to confide in, but others 'put on a good front' because they don't want to upset children by disclosing their anxieties about the future. At a stage in their lives when many elderly people who have limited family contact are pre-occupied with death, opportunities are lacking to offload their worries, which are understandably considerable.

It is important for service users to be able to talk to another without fear of confidences being shared. The meaning of the word 'privacy' for service workers, relates to listening and confidential sharing of intimacies, including fears, rather than tangible physical acts related to privacy during personal care tasks. There is an assumption that privacy, dignity and respect for people in the way their physical needs are attended to is a minimum requirement of a human service. Quality serving also requires confidentiality between service users and workers when intimate personal information is shared. People who live in an environment where records are kept about every aspect of their existence and read by many service workers, are disinclined to share confidences, as one elderly man says, '*My thoughts are the only part of me I can keep for myself*'.

A 'quality' service recognises the need to provide opportunities to arise naturally for 'Confidential Listening'. This is not about being prescriptive or introducing another 'specialist' service worker, but about nurturing a climate where people feel able to trust and confide in others, just as people do in normal day-to-day life, without documentation or discussion with other service workers. For one nursing home resident Mrs Martin, a tea lady named Patsy is a trusted confidante:

The thing about Patsy is that she's just so caring. She takes the time to talk to me, although her English isn't so good. I can tell her when I'm miserable and know that she'll listen to me and care about how I am. You've no idea how lonely it is on the days she's not here.

It has been acknowledged that it is of central importance to people to be able to share aspects of themselves with others and to feel understood and accepted as the people they are (Chelune, 1984; Rogers, 1990; Duck, 1992). The importance of confidential self-disclosure is heightened in living environments where people have less opportunity for natural relationships. Confidential listening requires a service worker to invest themselves in the concerns of service users. Marcel, the existentialist philosopher (1971, p. 25) referred to disposability or "being present" with the other in order to attempt to empathise with their reality. Alternatively Noddings (1984) from a feminist perspective preferred, the term 'engrossment' or being a duality with the other. She (sic) referred to "feeling with" the other in order to be receptive to them. Villard & Whipple (1976, p. 15) described "other- centred" listening as an attempt to actively experience others

as well as ourselves, rather than just experiencing ourselves in the presence of others. Service users in this study expressed their experiences of empathetic and confidential listening as *'being there for me'*.

'Confidential Listening' is also an antidote to loneliness for service users who have no other intimate relationships available to them. For young people with disabilities this is most likely to be as a result of reduced social acceptance and opportunity, whereas elderly informants express loneliness as a result of the loss of significant relationships incurred by their physical distancing from important others in their lives. People who live in partnerships in services express less need for confidential listening. People who spend long hours alone at home, are particularly vulnerable to relational deprivation and depression. Julie, a woman with a physical disability who lives alone, and whose central relationship has been with a service worker who has recently left, describes her 'emptiness':

I often think ... there's got to be more than this. My life's empty apart from Lou (her cat) there's just no-one to turn to when I'm feeling down. People come and go but they're not interested.

The situational context of the living environment service influences the development of 'Confidential Listening'. Regulated environments such as nursing homes, operate in a way that encourage service workers to report on their interactions with service users to other workers as part of the service system. Trusting relationships with service workers may then be a greater risk for people living in services. Baier (1992, p. 426) suggested:

Since human beings are obviously not self-sufficient, trust relationships are basic to our existence. So it is inevitable that those we trust will have discretionary power in various circumstances and use it wisely.

When service users are able to relate to workers in a way that allows the safe disclosure of confidences, they have high praise for the service worker involved and perceive that the relationship is a friendship. Others who have had negative experiences of trusting others with confidence resign themselves to loneliness. The instability of the service user/worker relationship and lack of continuity in more structured service environments, also influences the development of trusting relationships and opportunities for 'Confidential Listening'.

According to Grainger, Atkinson, & Coupland (1988, p. 192) the telling of personal concerns was a critical component of intergenerational talk in the care of elderly people. Grainger (1993) suggested that talk embodies critical aspects of caring itself and played a part in the construction of caring norms and ideologies. Grainger's qualitative research highlighted the importance of 'troubles talk' which parallels the painful self-disclosure discussed by Coupland, Coupland, Giles, Henwood and Wiemann (1988) as a means of offering psycho-social support to elderly people in nursing homes. Grainger et al., (1988) also demonstrated that the need for service users to disclose 'troubles talk' to service workers was commonly deflected and that this may be psychologically damaging for service users.

Amado, Conklin, & Wells (1990, p. 69) suggested that “having friends is not a luxury but a necessity to life”. Although people with disabilities have increased opportunities to be physically present and participate in community activities, they may not be any less lonely due to the lack of specific friendships. Even when people are surrounded by other people, the lack of involvement with others may result in state loneliness if the relationships they have with other people are deficient in quality or quantity (Weiss, 1982; Hojat & Crandall, 1989; Erwin, 1993; Williams, 1994). This makes the acts of service workers as trusted ‘confidential listeners’ even more essential to the emotional health of people living in services.

Because of the risks involved, those relationships successfully negotiated in sincere self-disclosure hold the potential of being perhaps the most meaningful and intense in all of human experience (Villard & Whipple, 1976 p. 150).

4.4.1.2 NORMAL TALK

(Part of the same world)

For service users engaging in ‘Normal Talk’ is another measure of how they perceive the service worker accepts them as people. ‘Normal Talk’ signifies that they are participants in the ‘normal’ world and related to, not only as ‘service user’, but *‘just like anyone else’*. Normal social interaction through ‘Normal Talk’ establishes social relations which precede the establishment of relationships (Duck, 1992). The interactions between service user and provider during ‘Normal Talk’ also reinforces that the service user has the ability to offer

opinions and relate to the experience of the other person. The value of 'Normal Talk' is described by Doug, who has a physical disability:

There's not many people around here during the day apart from the carers ... it's a quiet street. I go down to the shops and have a yarn with the deli owner but that's about all. I think people might be put off because my speech isn't that good. That's why I try to pick people to work for me who'll talk away to me while they're here. I watch a lot of TV but it can get really lonely.

The content of 'Normal Talk' is any topic which does not reinforce service roles or service related activities. 'Normal Talk' interactions are non-specific spontaneous discourse of a superficial nature which may include self-disclosure of a non-intimate kind. Through 'Normal Talk', service users learn about the lives of workers and feel that there is some sharing of information which indicates an openness in the relationship. Mr. Williams, a nursing home resident describes 'Normal Talk':

One of the 'girls' has a son interested in cricket. She saw me reading the sports page one day and we got talking ... a real cricket fanatic she is too. The next thing ... she brought me in a cricket book of her son's. I really appreciated that ... it was an expensive book too. I've met her son since ... a fine lad he is ... we had a great yarn. It's the sort of thing that makes you feel good about yourself and not just an old 'has-been'.

Results of studies of activities in aged care environments (Nussbaum, 1983a; Ward, Sherman, & La Gory, 1984; House, Landis, & Umberson, 1988; Kaakinen, 1995; Lubinski, 1995) suggested that communicative activity not only influenced

psychological well-being but also general health. House, Landis and Umberson (1988, cited in Nussbaum, 1988, p.160) also emphasised that although this was a concern for the population in general, "...it becomes critically important for elderly individuals who are battling to maintain physical well-being each day within the nursing home".

Studies of conversation content between service users and workers in nursing home environments have concluded that conversations are mainly oriented towards the problems of service users (Nussbaum & Robinson, 1984; Robinson & Nussbaum, 1986; Kaakinen, 1995). Service worker self-disclosure of a personal nature was rare (Coupland, Coupland, Giles, Henwood, & Weimann, 1988; Kaakinen, 1992). Although interpersonal communication was identified as important for elderly people in living services, practice philosophies failed to demonstrate adherence to this principle and socio-emotional care was given secondary priority to material care (Weaver, Willcocks, & Kellaheer, 1985; Barlett, 1993). "Service workers who report feelings of affinity towards service users, however, report different patterns of interaction with those residents with whom they have a closer relationship" (Nussbaum, 1988, p. 162).

According to Ryan & Cole (1988, p. 173) "Service workers generally over accommodate their speech to stereotyped expectations of elderly people's communication needs, as opposed to the actual needs". This has also been observed in interactions with people with disabilities in institutional environments (Goffman, 1961a: 1961b). Several studies have documented speech characteristics used in communication with elderly service users including slower

rate of speech, exaggerated intonation, use of high pitch, increased loudness, repetition and simplification of vocabulary and grammar (Ashburn & Gordon, 1981; Caporael, 1981; Coupland, Coupland, Giles, Henwood, & Weimann 1988; Shadden, 1995; Whitbourne, Culgin, & Cassidy, 1995). Caporael (1981) implied that the use of 'baby' talk by service workers was more related to their personal stereotypes than to the functional level or the preferences of service users. In reviewing studies of institutionalised elderly Ryan, Giles, Bartolucci and Henwood (1986) also noted that speech modifications by younger service workers were not universally appreciated by older service users and that a significant number of study participants complained of being a recipient of demeaning speech. Compared with community elders, nursing home residents were more accepting of communication styles (Whitbourne, Culgin, & Cassidy, 1995).

For residents of aged care hostels and nursing homes, who have lived in family situations prior to entering the service, talking with service workers around family issues helps to create a social world in the service setting. It also allows them to continue to practise family roles by sharing personal experiences and offering advice. In this way positions are equalised during the encounter and valued former life roles are reinforced. Mrs. Owen, a resident of a nursing home explains her equal relationship with 'quality' service workers:

Sometimes staff talk to me about their children and with some of them I feel as close as daughters. I always accept people and listen to their problems . Although I've had a lot of tragedies in my life, it's my natural nature to cope ... always.

When the service user is unable to communicate verbally, 'Normal Talk' is still important, as fewer opportunities to engage in communication can be initiated by non-verbal service users. 'Normal Talk' is inclusive of non-verbal service users as social beings. 'Normal Talk' is an important environmental as well as emotional stimulus. Jane, a woman with a disability who uses an electronic communication device explains:

It's so quiet in here anyway. I look forward to people coming and chatting to me about what's happening in the world. Just because I can't speak, doesn't mean to say that I'm not able to listen and have opinions.

Valued 'Normal Talk' frequently relates to the families and social activities of service workers which are not related to their service role. Service users who have limited family and social contacts are interested in sharing the experiences of workers through 'Normal Talk'. This is described by Jane who is restricted in her social mobility due to the severity of her disability as, '*bringing in the outside world*'. Although not a substitute for engagement in a variety of personal experiences, 'Normal Talk' can expand the lives of service users who otherwise interact mainly with technology.

People with disabilities in institutional environments have also borne the brunt of stereotyping and devaluation in the use of language (Goffman, 1961a; Blatt, 1979; Wolfensberger & Thomas, 1983; Zola, 1992). Verbal interactions which are experienced as 'patronising' by people in living services, convey messages of 'child' and 'dependent' (Wolfensberger & Thomas, 1983). When service workers

are central in the relational context of service users communication content is even more important that they are sensitive to the implications of their communication. Villard & Whipple (1976, p. 176) have suggested “Ultimately we only truly know and experience ourselves through the eyes, the thoughts and the touch of others”. For people with disabilities who have had limited experience of social interaction through a lifetime of educational and social segregation, experiencing ‘Normal Talk’ is not only an important reinforcer of identity, but also a way of expanding their abilities for social communication which is transferable from the service context to the wider community (Racino & Williams, 1994). Reg, who has spent most of his life in an institution prior to moving into a community home, comments on the new people he has met through the joint efforts of his support worker and friend Linda:

One of the best things about living here is that I've met different people and get a chance to talk about more interesting things. God ... it was so boring before ... day in and day out the same thing ... but now I never know who I might meet by chance.

Through engagement in ‘Normal Talk’ service users build up a repertoire of conversation content which makes interactions more interesting and socially reciprocal. ‘Normal Talk’ as a valued interaction is described consistently in interview data from both people with disabilities and elderly informants.

4.4.1.3 LASTING

(Going the distance)

The sub-theme 'Lasting' describes the need for continuity with service workers in the lives of people living in services. Although, for people who have limited social mobility, a variety in service workers can also be stimulating, service users discuss the need for continuity of relationships with key service workers, particularly in situations which involved intimate care. As one woman, Lisa, who has been cared for all her life explains: *'I don't think you ever get used to it. Strangers seeing your whole body ... I mean ... how would you feel?'*

In this study, continuity in serving within the disability field is closely linked to the nature of relationships between people living in services and service workers. Even when loss is experienced as a result of getting close to a particular worker who leaves, as one informant quoted: *'Better to have loved and lost than never to have loved at all'*. When interactions between workers and service users are only merely polite and superficial, lasting involvement is perceived as a liking for the person. Frequent changes of service workers are described as *'exhausting'*, *'worrying'*, *'like being on a train'* and *'on a shelf in the supermarket'* by service users who feel their lives are 'open books'.

Clare, a woman with a physical disability discusses the importance of lasting relationships with care-givers:

*It takes time to get to know people and in this sort of situation
you find yourself having to share so many parts of your life*

with people who come in to help. I mean ... nothing's really private. That's why it's important to get people in who'll stay long-term. Then it becomes more like a normal family type relationship instead of it being like on a shelf in a supermarket.

Studies have confirmed that retention of 'quality' staff is among the most important and persistent problems in disability services (Slater & Bunyard, 1983; Burchard & Thousand, 1987; Jacobsen & Ackerman, 1992). Investigation of demographic variables, pay and conditions, and organisational loyalty and their relationship with job tenure, have provided varied information about why people sustain their involvement in human service contexts (Morris & Sherman, 1981; Maslach, 1982; Bersani & Heifetz, 1985; Burchard & Thousand, 1987; Jacobsen & Ackerman, 1992; Deckard, Meierko, & Field, 1994; Clegg, Standen, & Jones, 1996). Possessing values coherent with working with people with disabilities and viewing the work as meaningful has also been shown to relate to sustained involvement (Askvig, & Vassilou, 1991; Henry, Keys, Balcazar, & Jopp, 1996).

Research has also shown consistently that the quality and quantity of interactions between people with disabilities and service workers is diminished in service environments (Cullen, Burten, Watts, & Thomas, 1983; Felce, Mansell, de Kock, Toogood, & Jenkins, 1984; Markova, Jahoda, Cattermole, & Woodward, 1992, and that positive interactions between people living and working in services formed a fundamental feature of 'quality' (Calculator, 1988; Cattermole, Jahoda, & Markova, 1988; Powers, 1992; Racino & Williams, 1994;

Gardner & Smyly, 1997). Quality interactions are more likely to occur when relationships are long-standing and personal.

Other research findings have linked personal relationships, identity and belongingness to feelings of well-being (Jahoda, Cattermole, & Markova, 1990; Clegg & Standen, 1991; Racino & Williams, 1994; Baumeister & Leary, 1995). Although there were encouraging reports of natural and long-lasting relationships developing in the lives of people with intellectual disabilities (Edgerton, 1988; Perske, 1988; Forest, 1991; Amado, 1993), lack of enduring friends, few social activities and loneliness were among the problems facing people with disabilities in living services (Schalock & Lilley, 1986; Kennedy, Horner, & Newton, 1989; Rosen & Burchard, 1990; Todd et al., 1990; Barlow & Kirby, 1991; Clegg & Standen, 1991). This explained why service workers may be the main source of social support for some people with disabilities (Rosen & Burchard, 1990). In this study, all younger informants with disabilities who live in community houses and group homes have service workers as central to their social support networks, or have an expectation that social support will be provided within the service. Eight of the younger age group of people with disabilities interviewed have no regular and binding links with families or friends and most of the others socialised mainly within family networks or with paid service workers outside of work hours.

Personal continuity is experienced through ties with people, places and possessions. Continuity in relationships is highly important in helping sustain a sense of identity and is also closely related to life quality (O'Brien, 1987;

Wright, Haycox, & Leedham, 1994). Continuity of relationships with key providers has emerged as an integral characteristic of service 'quality' from the perspectives of service users in this study. Study of quality of life has also supported the relationship between staff continuity and well-being for service users in aged care environments (Agbayewa, Ong, & Wilden, 1990; Cox, Kaeser, Montgomery, & Marion, 1991).

In aged care environments, scheduling of staff which rotate people frequently are barriers to continuity of care. In some aged care services, the practice of rotating workers appears to consciously discourage relationship formation. This is acknowledged by elderly people living in services who accept that the system '*Doesn't encourage people to get too close*'. The importance of lasting relationships with key service workers is described by Mr Williams, a nursing home resident, who discusses the friendship he felt he had with a nursing assistant Barbara and the disappointment he felt when she was promoted and transferred to another position in the service without him knowing. Sometimes service workers are unaware of the important role they play in the social world of people living in services:

I wondered what had happened to Barbara as she just didn't appear for a time. She was such a warm cheerful girl and always had a kind word for me. I was worried that something had happened to her and eventually asked on of the sisters who told me that Barbara had been promoted and worked over in the other section in an office job of some sort. I'm really pleased for her, of course, but miss having her around,

and wish she was still here. That's what happens when you get fond of someone. It leaves such a gap, you know.

Commonwealth Government standards of care support the relationships between quality, continuity and personalised service (Williamson, 1992, p. 124). A high turnover of workers involved in intimate care activities, and the need for continual explanation of care needs causes embarrassment and stress. Continuity of relationships with service workers promotes security for elderly people in living services and frequent changes of care-giver can cause anxiety. Many elderly people in living services have declining communication abilities. If they are to be partners in service decisions and experience affiliation in the process “service workers must be willing and able to participate with them in the creation and maintenance of satisfying relationships” (Weimann, Gravell, & Weimann, 1988, p. 236). Considering the literature which stresses the need for social support and communication with elderly people in the creation of healthy lifestyles, it is important that services consider continuity as a key ‘quality’ issue in day-to-day practices.

Service workers named by service users as ‘valued’ are involved long-term and have established comfortable positive relationships. Quality in services is linked to both length of time and relational experiences. This is the quality and quantity mix of a ‘good’ service. Alternatively if continuity is experienced in ‘bad attitude’ an unhealthy lifestyle is created for service users.

4.4.1.4 PARTING

(Gentle leaving)

Although 'Parting' as a sub-theme of 'Right Attitude' is closely linked with 'Lasting' and could be viewed as a dimension of 'Lasting', the consistency with which statements relating to leaving a service appear in the data identifies 'Parting' as a key quality issue. 'Parting' is about disengaging from people as opposed to disengaging from a service. 'Parting' describes the human dimension of leaving a service role. Sensitivity to the need to part gently and positively from service users is an important characteristic of quality serving.

When key workers resign from a service, outcomes for service users relates to the system's ability to resolve loss and support a process of 'Parting' as opposed to leaving. In a supportive culture, service users have the potential to 'grow' through the experience, but if this is lacking, they may develop maladaptive behaviours and an inability to foster new relationships with workers, and may even sabotage replacements. In some cases, service workers are insensitive to the important role they play in service users' lives and the leaving process can be '*devastating*'. One young woman, Janet, who had what she thought was a close relationship with her service worker, Adam, tells her story:

I just happened to overhear him talking to Di one day and telling her he was leaving in a couple of weeks to travel overseas. There he was, so happy to be leaving ... and I was devastated. I felt as if my world had been crushed. I thought

*we were close and that he would have told me at least before
Di.*

The extent to which 'Parting' from service workers influences the lives of service users, is strongly related to the nature of the service relationship. Two key elements influence the resolution of loss: firstly, there is the issue of centrality or being a key person in another's life, and secondly, the unequal or equalising nature of the relationship and degree of dependency.

Throughout life, people mourn a variety of losses including physical, social or spiritual separation, which may result in loss of confidence and an inability to cope with normal daily events. Literature on grief resolution has demonstrated the centrality of the relationship with a higher risk of physical and affective disorders among people who have experienced a significant loss (Kubler-Ross, 1969; Raphael, 1980; Parkes & Weiss, 1983; Worden, 1983; Stroebe, Stroebe, Abakoumkin, & Schut 1996). It has also been established that positive social support networks, opportunities for reflection, and having someone to talk with, influence healthy recovery (Rees, 1984; Byrd & Taylor, 1989; Lattanzi-Licht, 1989; Longman, Lindstrom, & Clark, 1989). Recovery from loss is also influenced by anticipatory grief and opportunities to work through the impending loss with the key person prior to the loss actually occurring (Raphael, 1980; Parkes & Weiss, 1983; Hegge, 1991; Lindemann, 1994). Opportunities to discuss with key service workers, their impending resignations and validate the relationship which exists may assist with resolution of the loss of their involvement. Realisation that the attachment has been mutually valued may

reinforce confidence that new relationships can be formed with other people. An acknowledgement that the attachment has been mutually valued is appreciated by the service user is described by Clare, a woman with a disability:

Pam worked for me for nearly five years and we hit it off from the start. It was a shock when she told me she would be leaving because her husband was transferred over East. We talked about it a lot and the things we'd done and the laughs we had. She was as sorry to go as I was to lose her, but we'll always keep in touch.

Ken, a young man with an intellectual disability discusses his 'friend' Candy, a service worker. When she left the service, Ken had to be supported through his loss of attachment by another support worker. Ken talks about Candy leaving:

I did a lot of things with my 'girl friend' Candy. I really loved her. She's gone now, but when she left I gave her my favourite CD to remember me. She cried ... I think she was sad too.

A woman with an intellectual disability, Pauline, has her room adorned with photographs of her 'very best friend' Jackie, who had been a service worker in Pauline's group home for three years. Jackie had left to travel overseas and Pauline cries when she describes 'really missing her' and 'being sad' until Jackie comes 'home'.

According to Perls (1969, p. 100) "people can relate to others in a 'floating in and out' type of way making surface level contact or alternatively develop a commitment to long-standing loyalty". Longer contact with people supports the development of deeper attachments, which, when broken, are likely to cause

pain and sadness. Although deep love and affection can be experienced through deep attachments, these bonds also have potentiality for unhealthy dependence. This needs to be explicit in service relationships when central attachments are formed. Service workers may not be aware of the felt attachments of people living in services because their own lives are relationally enriched. It is more difficult for people living in services to expand their social world. When there is a sudden leaving and loss of friendship, service users may feel rejected and depressed if there is no explanation offered. A process of 'letting go' gently softens the process of leaving.

Uditsky (1993, p. 86) discussed the need to protect people with disabilities "against false promises and discontinuity". In discussing the problems of artificially generating relationships between people with disabilities, service workers, and community members, Uditsky warned against the presumptions of relationship development as yet another programmatic issue. Discontinuity in the lives of people with disabilities who live in service environments as service workers rotate through their lives, add to other harmful and unnatural characteristics of formalised support (Wolfensberger, 1975c; Schwartz, 1992; Lutfiyya, 1993). Yet, positive relationships enrich people in all aspects of social life. Although not considered a substitute for naturally acquired friendships, relational richness is to be pursued in service environments in the context of 'Right Attitude', and 'Parting' is an important part of the process.

This study demonstrates that informants experience some service relationships as friendship. The capacity to define relationships in services as friendship,

although this might be idealised in an institutional setting which has potential for non-relationship or relational deprivation, is evidence enough that people feel supported and accepted by others in the service context. In any relational context there is potential for gain and loss, acquiring knowledge about self and others, and finding meaning. It is for this reason that 'quality serving' is conscious of the need to 'part gently' from people in services and address the issue of personal responsibility as in any other relationship. Learning to let go of valued relationships is a necessary attribute for the development of healthy relational experiences. High risk categories in the healthy resolution of loss include people who are socially isolated, have had multiple losses and elderly people (Bugen, 1976; Parkes, 1985; Brandstadter & Greve, 1992; Stroebe, Stroebe, Abakoumkin, & Schut, 1996). For elderly people living in services, loss of key service workers adds to the multiple losses of home, family and community.

Unequal power between service users and workers and unhealthy dependency in relationships has more potential for harm when there is an abrupt departure. This was evident following an interview with one woman with disabilities Janet who had discussed her great friendship with a key worker and how 'like sisters' they were. Contact with Janet for a second interview resulted in an emotional breakdown as, between sobs, she talked about how her friend had unexpectedly given notice that day:

I don't know what I'll do without her (sobs). She is my closest friend. They'll never be anyone else to take her place. She's

never said she wasn't happy here. I feel so miserable and useless and wonder what's the point of it all.

In aged care contexts people also consistently describe 'missing' workers who have been supportive, although there is a general resignation to the fact that work in aged care is commonly transitory. This means that the emotional support for people living in aged care contexts may rest with a few key workers who invest in the people long-term and who are forced to divide their time between many people in need of support. When key workers leave, parting gently, validates service users and reinforces that they are 'alike' rather than 'just a job'. Mrs. White explains:

When I heard that Pat was leaving, I felt really upset, but I was glad that we were told and I could tell her how much I appreciated all she'd done for me over the years. I was able to give her something to remind me by and that was important to me. The last time one of the nurses left, she just suddenly disappeared without letting on and I felt so let down. After all we'd been through, I felt like I was just a piece of the furniture.

4.4.1.5 RESPONSIVE SERVING

(Being there when it counts)

The sub-theme 'Responsive Serving' is descriptive of serving which nurtures autonomy and acknowledges different identities and preferences. 'Responsive Serving' is characterised by flexible and non-judgmental help and lack of routine.

Barriers to responsive serving are formal service structures and 'not right attitude'.

Flexibility in services is characterised by "high labour-intensity and a move away from facility-based service" (Wright, Haycox, & Leedham, 1994, p. 120). People are recognised as the key element of enabling and supportive services and "support for both service users and workers is a high priority" (Taylor, Racino, & Lutfiyya, 1987, p. 70). In this study, small locally based agencies for people with disabilities are valued by service users for the flexibility of contact. This contrast is described by people who had experienced both routine, institutionally based 'programs' and 'Responsive Serving'. Ross, a man with a disability who has spent fourteen years in a nursing home before moving out says:

In the other place, every day had to have a program, whether I liked it or not, and I used to do some bloody useless things just to keep the peace. Now, one of the best things is being alone when I like. I still have trouble with some staff ... but when I get a good one he's worth his weight in gold. I don't have to fit in with their rosters now. I can make my own.

This is not the case in some situations. When large organisations remain in control of funding, people living in the 'community' have lives which still revolve around rostered shifts. They have the potential to live in mini-institutions in suburbia with fewer opportunities for quality interactions with service workers. 'Roundabouts and swings' is how one man, Simon, resigned to the fact that things will never be any different for him, describes his experiences.

In aged care environments which are characterised by large highly regulated accommodation facilities which are oriented towards the medical model, informants are less likely to experience flexibility in contact. Limited contact, standard routines and an emphasis on meeting pre-determined standards of physical care, diminish opportunities for responding to personal needs on an individual basis. 'Responsive Serving' is commonly limited to occasional and superficial encounters which display an awareness that individual needs might not be met in a 'one size fits all' or 'batch' fashion. When such encounters occur, they are idealised by people living in aged care environments.

Despite stereotyping and system constraints, innovative service workers strive to create episodes of 'quality' for elderly people living in services. Two elderly women informants were taken for a gourmet picnic in a local park by a chef volunteer. This '*special*' occasion developed out of one service worker knowing the women and their past family activities. The experience has had long-term benefits. For one day they relinquished the role of nursing home resident and became '*like ordinary people*'. Potent 'quality' experiences have the potential to reconnect people with the world and their identities.

'Responsive Serving' is closely linked to personal autonomy and a willingness by service workers to respect the preferences of service users in the way that tasks are carried out. Autonomy has become a key area of human service research both in disability services (Legault, 1992; Nosek & Fuhrer, 1992; Joyce, 1994) and aged care contexts (O'Connor & Vallerand, 1994; Cohen et al., 1995; Hertz, 1996). In aged care environments, for example, clothing and the way it is

worn has significant personal meaning for informants in this study. Self-presentation in the way that people dressed may remain the only control they have in an otherwise regulated and externally controlled life. It is also symbolic of respectability and social normality for a generation of people for whom modesty and cleanliness of dress is culturally important. For one informant, Mrs. Burns, wearing a petticoat means 'respectability'.

The regular girls know that I always wear a petticoat, but some of the new ones don't bother. One day I didn't even have pants on and my son came to take me for a walk. I didn't think that that was right ... but I didn't want to say anything.

A young woman, Lisa, considers that having the support of service workers to dress the way she does lets people know that she is aware of normal trends:

There isn't much 'll make the wheelchair groovy ... but I can do the best with the rest of me. Down at the club ... you don't want to look like a 'dag'. Doreen knows that I have my own style and doesn't interfere.

Presentation of service workers also conveys messages of responsive serving. Mature service workers serving elderly informants in shorts and T-shirts may also be interpreted as a lack of respect. A nursing home resident, Mrs. White, expresses her disapproval:

The girls here wear shorts. I've never seen anything like it. Imagine ... and some of them grandmothers themselves. I don't think it's right to come here dressed like that. It wouldn't happen in my day.

'Responsive Serving' displays sensitivity to the socio-cultural context of the person in a service. The need for cultural sensitivity is heightened in congregated environments such as nursing homes and hostels for elderly people. In disability services 'Responsive Serving' is 'personal serving' and adjusts time and place to meet the expressed needs of service users. 'Responsive Serving' is a form of entrepreneurship. By being creative, fluid and adaptable, resilient and optimistic, positive daily experiences and opportunities for development can be generated for people in living services. 'Responsive Serving' focuses on the strength of the personal encounter to create meaning and is not diverted by the bureaucratic barriers and system constraints of formal services. Responsiveness is a characteristic of 'human' serving.

4.4.2 SUMMARY

To answer the question: What are the valued characteristics of quality in living services from the perspectives of service users, the following statements emerge from analysis of the data:

1. Valued elements in living services are evaluated by service users through the attitudes of service workers as they are conveyed in communication, cultural sensitivity, respect and acts of serving.
2. Confidentiality in personal disclosure between service users and workers is based on trust and provides reassurance of beneficence.

3. Communication about normal social events reinforces the role of belonging to a wider society and being alike.
4. Continuity in relationships between service users and key workers is an important element of quality.
5. Opportunities to end relationships with workers gently is important for confirmation of self-worth and re-establishment of other positive relationships with new workers.
6. Service processes which are individual, non-routine and adapt to the needs of people living in services provide opportunities for quality experiences which can have long-lasting effects on well-being.

The next step in the study examined in greater depth, categories of relationships between service users and service workers which had emerged during the first two phases of the study. By identifying information rich cases and discussing their experiences greater insight could be gained related to the variable experiences of people living in services and the influence of the relational context of living in a service on 'quality of life'.

4.5 QUESTION 4: WHAT IS THE NATURE OF SERVICE RELATIONSHIPS BETWEEN SERVICE USERS AND WORKERS IN LIVING SERVICES?

This section will discuss ethical and technical approaches in human services and describe four themes representing the experiences of service users in the study from their descriptions of interactions with service workers. The themes are SHARING THE INNER CIRCLE, LIKE ONE OF THEM, CLIENTS AND STAFF, and TASKS AND WORKERS.

4.5.1 HUMAN SERVICE RELATIONSHIPS

Human services, like any interactional context, create problems for people working in services choosing between various courses of action. Choice, according to Kierkegaard (cited in Peterfreund & Denise, 1992) is about freedom, and contrasts with the conformity of following others. Choice in this context is about conscious choice founded on moral worth, rather than self-interest or conforming to rules. Kierkegaard (cited in Peterfreund & Denise, 1992 p. 225) stresses the importance of choice as determining moral character, whether it is about critical or insignificant issues in the lives of people:

The heart of human existence lies in the power of choice.
Indeed the manner in which one chooses is as meaningful as
the content of choice.

In choosing to relate ethically to people living in services, service workers who have been identified by service users as providing quality relational experiences adopt a general principle of potentiality in their interactions with people living in

services. Goodman (1988) suggested that to be human is not just to display the full range of human characteristics but also to be bound up with potentialities and capacities. Goodman (1988, p. 200) also suggested that a person is not someone who has already developed the abilities required for personhood but one who has the natural capacities whether they are developed or not. Acceptance of people with severe disabilities as valued human beings was discussed by Bogdan and Taylor (1987: 1989) who described the social construction of people with disabilities by people without disabilities who had intimate relationships with them and who attributed them with the potential for thought, feeling, reciprocation and individuality. The ability of service users and workers to engage in interactions based on human commonalities as opposed to stereotypes underpins quality experiences in living services.

Stereotyping of users of living services is fostered by role descriptions of service workers, which, by focusing on task oriented service rather than relational serving in recruitment, distance them from the human needs and characteristics of the people they serve. In dividing face-to-face-interaction into unfocused (just being in another's presence) and focused (sustained engagement with another) Goffman (1961b, p. 87) discussed the rules of recruitment and division of labour of formal service environments. In living environment services, differences in status and roles are influenced by the formality of the service structure. Human service technologies which underpin practice are consonant with dominant cultural beliefs about what is desirable and acceptable to do. Practice ideologies reflect belief systems of 'what is good' for people receiving services.

Compartmentalising the needs of people in living services means that workers can be selective in addressing a limited set of client attributes.

According to Hasenfield (1994, p. 16), “Social and psychological isolation occurs by limiting the ability of the clients to introduce social relations and attributes not deemed relevant into the service processes”. When a person acts solely in terms of the normative performance demands of the position, it is unlikely that the relational context will be characterised by growth and friendship. Activities are obligatory and roles are symbolised in status cues, for example, of dress and interaction .

Despite the constraints of systems and role descriptions, it has been demonstrated in this study that some participants have transcended their role obligations in their interactions with people living in services. They have a view of service users as equal, valued human beings with whom they share significant life events and from whom they receive validation of their own humanness. In discussing different motives for helping other people Wuthnow (1991, p. 93) suggested that “giving of oneself when it is not articulated in the language of duty may be legitimised in the language of fulfilment”. The idea of reciprocity is a common way for people to make sense of the “The most effective means we use to limit our compassion is to create a distinction between our roles and ourselves”. In living services, service workers who set boundaries to their caring function, associate their caring activities with specific roles rather than identifying them with their entire selves. It may be argued that by focusing on roles, service workers have a way of detaching from situations in good

identities as human beings. Coles (1993) also discussed serving others as both necessary to individuals and to society at large and suggested that in serving others we also serve ourselves. This view was supported by Noddings (1984, p. 14) who, in discussing Kierkegaard's view of the need to see another's reality as a possibility of one's own, suggested that "The caring for self, for the ethical self, can emerge only from caring for others". Ethical caring, according to Noddings, referred to an actuality, not just a verbal commitment. It is also about caring which does not occur naturally and even though the reality of the other may be repugnant we are still motivated to act on their behalf.

A number of studies of older populations have concluded that a positive relationship exists between friendship in older populations and their psychosocial well-being (Strain & Chappell, 1982; Restinas & Garrity 1985; Hays, 1988; Burbank, 1992; Powers, 1992). Authors also suggested that nursing homes may offer service users a new social world and potentially new friendships if they are able to communicate (Restinas & Garrity, 1985; Gutheil, 1991; Powers, 1991). Research in resident-staff relations in care giving environments have provided evidence that service users actually lived longer when positive relationships existed between the two groups (Noelker & Townsend, 1985; Nussbaum, 1988). Other research has demonstrated that elderly people living in services who had positive relationships with service workers, reported fewer physical symptoms than those who were limited in their interactions (Miller & Lelievre, 1982; Cox, Kaeser, Montgomery, & Marion, 1991; Timko, Nguyen, Williford, & Moos, 1993).

paid employee (Sumarah, 1987). Accounts of friendships between people with disabilities and staff members may be a natural extension of a supportive working relationship in which people can enjoy genuine friendships with each other (Walker & Salon, 1991; Lutfiyya, 1993). For people with disabilities who lack other friendship networks, their relationship with a key service worker may be the only trusting relationship in their lives. This raises issues of vulnerability and potential loss. Despite the inherent risks of friendships which have their beginnings in unequal service roles, participants in this study have described important and rewarding relational experiences derived from such friendships. Service is a relationship between people which necessarily involves ethical questions. This study has shown that relationships between service users and workers are not always positive and some have been described as harmful. Some participants experience relationships which are warm and comforting, while others are treated as if they do not exist. Without an attitude of acceptance and trust, people are at risk of becoming objectified.

In living services which lacked relational quality, relationships of a client and staff nature are characterised by an underlying ethos of rationality and technical efficiency. Although tangible care tasks are rendered to the individual and environment according to what is dictated in job descriptions, service users experience detachment and loss of control of their environment. According to Noddings (1984, p. 51) “although we believe that rules of behaviour are made for the benefit of others, they also make it easier to fulfil the minimum requirements of caring. Noddings went on further to comment that “if we behave consistently

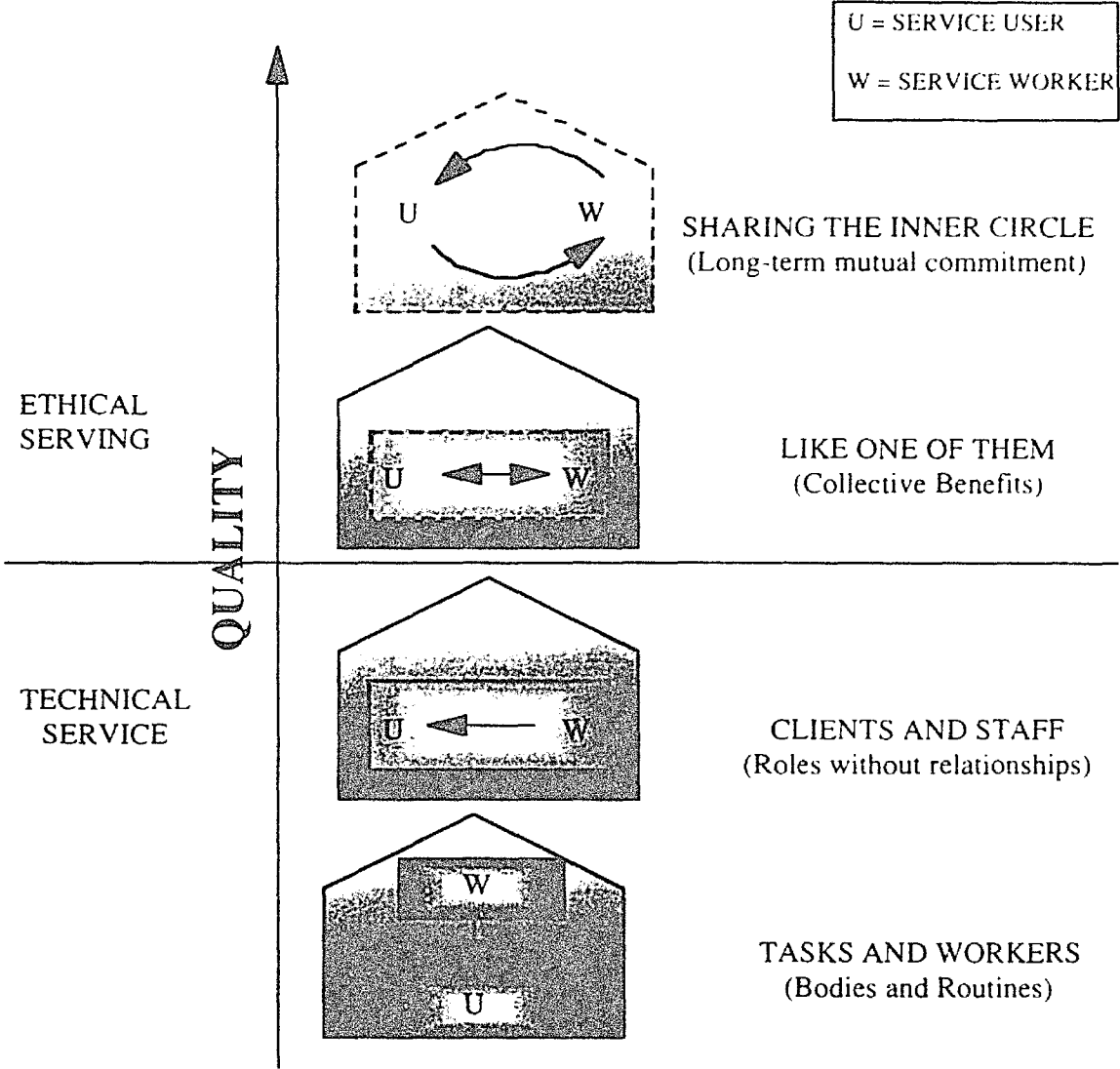
and automatically by rule, we cannot be said to care” (p. 51). Alternatively, rules may also may provide safeguards for people whose energies are finite and who are consistently in the forefront of caring demands. Some people, in order to perform the tasks involved in serving groups of people with high physical demands, may unintentionally suppress their consciousness that those individuals also have socio-emotional needs.

Service workers may also feel depersonalised in the institutional environment and differences in demographics between service users and workers may inhibit the development of friendships. Research into the attitudes of service workers has demonstrated that they express high expectations of their relationships with service users. This is tied to their self-concept as nurturing and compassionate people (Heiselman & Noelker, 1991).

Differences in quality of relationships in services, suggest that services can either be described as ethical (providing quality experiences) or technical (lacking quality experiences) in their relational context. Ethical services are further divided into the themes ‘sharing the inner circle’ and ‘like one of them’ and technical services are divided into the themes ‘clients and staff’ and ‘tasks and workers’.

Case studies will now be used to demonstrate themes i.e. SHARING THE INNER CIRCLE, LIKE ONE OF THEM, CLIENTS AND STAFF, and TASKS AND WORKERS.

Themes are presented and discussed from the most valued to least valued relational experiences as they consistently appeared in the data and are displayed in the following figure.



4.5.2 ETHICAL SERVING

4.5.2.1 SHARING THE INNER CIRCLE

(Long-term mutual commitment)

‘Sharing the Inner Circle’ describes the highest quality serving relationship. Service users and workers have life-sharing capacities. Their relationships are significant, mutually supportive and long-lasting. Examples of ‘Sharing the Inner Circle’ were only described in this study in living services for people with disabilities. This may be due to the smaller and more flexible service types in disability services which support a less ‘professional’ approach to meeting people’s needs.

Exemplar 1 REG and LINDA

Reg is fifty-six years old and has had a physical disability since birth. Reg communicates formally and uses words carefully. He presents as highly educated and well-informed, although his opportunities for education were severely restricted due to segregation from mainstream education as a result of having a disability. Much of his information has been absorbed through the media. He enjoys discussing ‘issues’. Reg could be described as ‘verbose’ as he loves to talk with people and is limited in his opportunities. He tends to ‘go overboard’ with talk when he has the chance to socialise.

Reg left home to live in an institution when he was in his twenties as it physically became more difficult for his parents to care for him. There was no

other option to provide him with the necessary physical care. For eighteen years he shared a room with five other men, who also had physical disabilities, in a nursing home managed by a large charitable organisation. There were no curtains or any other form of privacy for Reg in the room he shared with the other residents. All his daily experiences, including his eating and toileting habits were recorded, as were those of all the other residents. Organisational rules and routines dominated his life during these years.

Due to the belief of a service worker, who was newly employed by the institution where Reg lived, that people like Reg could live more humane lives, funding was secured to enable Reg to leave the institution. This did not occur without strong advocacy for someone acting on Reg's behalf, and there was also resistance from people within the organisation who did not believe that people with disabilities of the severity of Reg's could survive in community settings. The months leading up to the transistion to his current home, was a time of great stress for Reg. He feels that he *'has come through that time well'* and *'become stronger as a person because of my struggle'* although at the time he admits to being *'scared witless'*. Reg now, through choice, lives alone in a rented apartment in an inner city suburb and recruits his own care-givers. The funding for his hours of care is co-ordinated through a small agency. People with disabilities who use the agency form the Board of Management and employ the co-ordinator.

Reg is unable to participate in any of his daily care activities. His joints are fixed in positions which do not allow him to sit or lie straight. In his previous

institutional environment, Reg's activities were restricted to scheduled routines and organised 'outings'. Visits to his elderly parents' home were his only individual activity. Reg now has funding to provide thirty-five hours of care each week. He has the maximum number of care hours which can be funded under current policies to assist people with disabilities to live independently. This means that he spends much of his time alone at home as most of his care hours are used for personal care. Reg considers that this is still a vast improvement on his previous life. He listens to radio and watches television daily to keep abreast of news and current events. Reg loves the company of other people. He likes to be dropped off at the local shopping centre where he can sit, watch, and hopefully chat to people passing by.

Reg does not look back with any bitterness on the eighteen years of life he spent in institutional care. He is philosophical about those years and can even discuss them with some humour and gratitude for the services he received. He remains optimistic about his future, despite the fact that as he ages, he is experiencing increased pain and reduced mobility. *'As long as I can speak and listen to people I consider myself one of the lucky ones'* he says. He has lived alone in his current home for eight years and the control over the recruitment of his personal care workers is described by Reg as the most *'wonderful improvement'* on his previous life. The service worker who initially advocated for Reg and assisted Reg to move is still involved in co-ordinating his care hours, but it is a special relationship with Linda a care-giver that has significant meaning in Reg's life.

When Reg first met Linda she was eighteen and had just begun training to be a nurse. She had no prior experience of working with people with disabilities. Reg describes the early years of Linda's involvement and the concern he showed her due to long hours of study and also her work for him. *'She had no father'*, he explains, *'and so I felt that I should be looking after her too ... I was always reminding her that she had to eat properly and look after her health'*.

Linda has been Reg's carer for five years. During that time she has married and had two children. She has also graduated with a nursing degree but continues to provide care for Reg who describes his feelings about his relationship with Linda: *'When I'm around her I'm really relaxed and feel that I haven't got a care in the world. It's just wonderful'*.

Reg's relationship with Linda has developed a 'family' like ethos, and he frequently visits her home and has her children visit him. He has been accepted as a 'grandfather' figure by Linda's young children. For Reg, whose previous experiences of interacting with young people have been characterised by fear and ridicule, the acceptance and normality of his relationship with Linda's children is a source of great pleasure.

It's just wonderful to think that she's made me a grandfather to the kids. They come here and climb all over me. I've never had the chance to be close to children until now. It's good for them not to be frightened of disabled people.

(It sounds like that's really important to you)

Yes, it makes me feel more like a normal person.

Reg considers his relationship with Linda as central in his life and is able to discuss private thoughts and feelings with Linda in a climate of mutual trust. This is even more appreciated following his years of institutional living where he says, '*I had to be careful about everything I said, as everyone knew everyone else's business*'. Reg also views the relationship with Linda as reciprocal:

We can talk to each other about anything. Sometimes she needs to off load on me too now and again. She's like a member of my personal family and I'm a member of her family ... it's more that a friendship.

(Can you tell me how you feel in the relationship with Linda ... and why it's different from others?)

Yes ... I feel different in the fact that she loves me and I love her... I feel that love.

Reg also realises that he is vulnerable in the relationship and acknowledges that circumstances in Linda's life may change and result in her moving to live elsewhere. He is philosophical about this, and although he admits that it would be '*hard to take*', he feels that the benefits of knowing Linda and being involved with her family will continue as '*good memories*'.

Linda is a young woman with two small children who came to work for Reg after leaving school and to subsidise her studies in nursing at a local university. Linda was raised in a rural community and prior to meeting Reg, had no personal experience of disability and was unaware that people with disabilities lived in institutions. On learning about Reg's life up until that time, Linda says she felt '*horrified*' that Reg had spent so long apart from other people. Linda says that

she 'had never met anyone like Reg before' and what she found the saddest thing about his life was his lack of confidence in making decisions, even about simple everyday activities and his need to have approval for any decisions he did make:

When I first met Reg, he was the first person with a disability I had really spoken to. I had no idea that people like Reg lived in institutions. He was like a little boy who was coming out into the world. He asked approval for everything. It has taken a long time for Reg to say just what he wants for himself.

Linda also values her special relationship with Reg and the role he plays in her family life. She talks about her first meeting with Reg and what he had taught her about the world and human nature over the five years they have known each other. Linda admires Reg for his 'patience' and 'enjoyment and appreciation of simple things'. She views him as having a 'gentle, kind nature' and genuinely enjoys his company. Although she does find his continual talking wearing at times, she recognises that this is a result of his loneliness and limited contact with other people.

Linda continued to care for Reg through her two pregnancies. When lifting him became too difficult, her husband also became involved as a care-giver for Reg. In this way the continuity of their relationships was unbroken. Reg has been involved in Linda's family life and rituals. She admires him as a gentle and wise person and shares her hopes and aspirations with him. As result of this open relationship, Linda and Reg have trust in each other.

Linda's role as friend has also involved conflicting feelings related to her paid role as care-giver. She confirms an on-going commitment to maintaining their relationship as superceding her involvement in her paid role:

Reg is more to me than a client. I feel guilty at taking the money to look after him because it's like helping a good friend, but I need to earn a living. I know I should be looking for a more well paid job now that I'm qualified, but at the moment I want to keep being Reg's primary carer. I know I'll need to find more work soon ... but I'll still be involved with Reg. He is such a part of our lives now. The kids love him. He's like one of the family and I couldn't imagine that we wouldn't always be friends.

Exemplar 2 KATY and SALLY

Katy is a forty-two year old woman with a progressive physical disability. She lives with another woman who also has a disability. Katy's institutional life, in contrast to Reg's, was more environmentally comfortable and opportunities were provided to be involved in paid work, contribute to organisational policies and develop community roles and relationships. Katy is quiet and thoughtful in her interactions with people and had many friends in the institution where she lived, although she also felt the need for more privacy and individuality in her lifestyle. She views her current situation as a great improvement, but would like to live alone rather than share a home if that were possible. Current funding arrangements will not provide the hours of care that Katy requires to live alone.

Katy has a close relationships with Sally, a thirty-two year old service worker who had worked in the institution where Katy lived and had been chosen by

Katy to work for her for the past five years in a group home. Katy describes their relationship:

With Sally ... I know that she doesn't judge anything I do or belittle or demean things I care about. She shares what's happening in her life with me too.

(Can you give me an example of that?)

Well ... we share a great deal of our lives. She'll tell me things about her family that she wouldn't tell other people. When her daughter was born she wanted me to be at the birth too. Because I can never have children she wanted me to share it with her. It was important for her for me to be there ... giving her support.

Katy goes on to describe the importance of the 'family' relationship she has with Sally and her child:

I guess the fact that she's prepared to share so much of her family life with me is important ... because I know I'll never be able to have children. Being part of her daughter's growing up is very important to me and the fact that she trusts me to be an influence and share the upbringing of her daughter. I am her godmother.

Katy is also aware of her own vulnerability in the relationship: *'I do worry that if she ever leaves this area I won't have so much contact and that's something I don't want to think about.'*

Sally is a slightly built young woman who is careful and reflective about her descriptions of her involvement with Katy. Sally says she '*fell into*' working in the disability area. It was not a conscious choice on her part, but came about due

to an opportunity to train in a practical course as a care-giver at a time when she was single and unemployed. Sally has now worked in the area for over ten years both in institutional environments and now, with Katy in a group home. During the time she has worked for Katy, Sally has married and had a child. Sally's relationship with Katy is central in her life. Katy was bridesmaid at her wedding and has the role of confidante. The blurring of employee role and close friend also causes conflict:

She's one of my two closest friends. A friend is someone you can share your life with ... the good times ... and the bad times. She became a friend because she was interested in my life. The hard thing is to remember that I'm working ... even though it is for a friend. It's a very fine line between friend and carer.

Sally describes how she fulfils the role of service worker. She talks about her compassion for Katy and her willingness to act totally in Katy's interests so that Katy may experience life through her physical abilities:

It's not like I'm a robot, because I'm a friend as well ... but I am like ... her hands and feet ... the motions of her thoughts and wants, being there for her in whatever she wants me to do.

Sally considers her relationship with Katy as integral to sustaining her involvement as care-giver. Caring for Katy is physically demanding. She acknowledges that there are other people within the organisation she would choose not to work for because of their 'attitude'. It is important for her that

people she works for also treat her with respect and not just as someone '*paid to do the heavy work*'.

Sally's friendship with Katy also makes her vulnerable to loss as Katy's health is progressively deteriorating. Sally speaks of her experience of a recent critical period in Katy's health when she maintained a vigil at Katy's side as she slipped in and out of consciousness. Katy was not expected to survive. Long, close involvement with Katy and watching her health deteriorating has been difficult. She says:

I kept saying no ... no ... she's not dying ... and when she pulled through it was such a highlight. I suppose ... I thought ... it was like ... in a way ... to let us know that some day she is going to die. I don't want to think about that

4.5.2.2 LIKE ONE OF THEM

(Collective benefits)

The theme 'Like One of Them' is characteristic of service relationships which are personal, experienced by service users as reciprocal, and consistently described as friendship. In the context of 'Like One of Them' both service user and worker express enjoyment in their interactions.

Exemplar 2 MR. COLLINS and JOY

Mr Collins lives in a nursing home. He is formal in his communication and concerned that he looks 'smart' and clean shaven for the interview. Mr Collins had a stroke three years ago and is paralysed down one side and uses a wheelchair for mobility. He is a widower and lived by himself following his

wife's death. He has one son who lives in a country town whom he rarely sees. He describes himself as a 'loner' and 'having little in common' with the other residents. He believes that the standard of care he receives is 'unsurpassable' and in particular he names Joy, a nurse, as 'exceptional'. According to Mr Collins, Joy has been his friend and confidante and has provided emotional support through a difficult period when he had financial worries involving a close family member's misuse of his savings. He 'describes Joy as : *'a good friend ... a good person ... and a very good nursing sister'*. Mr Collins *'has a lot of time for'* most of the staff who care for him. When probed about the particular significance of his relationship with Joy he says:

I suppose she went that extra distance for me when I was really at my lowest. I knew that I could trust her to give me good advice. She always seems to give that little bit extra, if you know what I mean. Although I'm an independent sort of person, there are times when you need to off-load. Joy is someone I can trust with anything.

The relationship with Joy is very important to Mr Collins. In the relationship he views himself as less incapacitated and able to discuss 'normal' things like news events and personal interests. He also enjoys knowing about Joy's life outside of work and hearing about her family and activities. He describes this as *'bringing in the outside world'*.

For Mr Collins, who has no other social contacts outside of the living environment, his relationship with Joy is the most significant in his life: *'She's been an exceptional friend to me'*.

Joy is a nurse who presents as articulate and efficient. Joy is middle-aged, married with adult children and has worked in many different clinical areas in senior positions. She has also undertaken a number of extra courses, including a course in grief counselling at her own initiative, so that she could '*better help the people here*'. Although she could work in more senior and well-paid positions, Joy prefers to work in the nursing home situation because she '*likes elderly people*' and feels that she is offered an opportunity to use all her professional and personal abilities. She says she '*gets a lot out of working here*' and describes her work as '*holistic*' and '*personally fulfilling*'. In this environment she explains:

I get a lot of satisfaction out of small accomplishments, not great big achievements. Like when someone smiles ... that's really worthwhile. With long term aged care you become very much a friend or a family to the people you look after. It's very small things that make a difference.

Joy has her own way of thinking about '*what is important*' to the people who live in the nursing home, and as a result, what is important in her capacity as service worker. She describes details of small personal preferences of residents which are not routine, but she gives them high priority, and feels that this is appreciated. Joy finds it '*impossible*' to meet the needs of all the people who live here but sees herself in the role of advocate and watches out for anything that she feels might be lacking in the lives not only of the people whose care she is assigned to supervise, but also the nursing home community as a whole. There are sixty people living in the nursing home and because Joy recognises their need for emotional support and companionship she works extra hours unpaid to

compensate for the time she doesn't spend on documentation during her paid working day. She says:

I tend to get side tracked ... usually on some personal issue with a resident. The documentation gets behind. It's getting right out of hand anyway. It's a case of priority ... and getting off at 3.30 is not my highest priority. I very rarely go home on time and I always have extra work to do.

Joy describes her relationship with Mr Collins as 'special'. According to Joy, Mr Collins is not the most popular resident with service workers. He has a reputation for being cantankerous and difficult to please, but Joy describes him as a strong independent person, who has a lot of dignity and who finds it particularly difficult to enter a communal living situation. His wife is dead and his son rarely visits. Joy interprets his difficult behaviour as bravado and a way of pretending he is not sad and lonely. She persisted in her relationship with him and now believes that they can discuss anything with each other. She makes time to acknowledge him on a daily basis and tries to spend quality time with him at least once a week when they'll sit and have a cup of tea together.

Joy views the nursing home environment as primarily a relational setting and makes frequent reference to the 'task orientation' that current policies and funding emphasise as being important in terms of 'quality of life' for residents. Although aware of the necessity for health care, Joy considers that 'compassion for the situation that people find themselves in when they come here can't be overlooked', and, particularly in Mr Collins' situation, 'helping him achieve a

sense of dignity and worth in his last few years has become the main focus of my contact'.

When probed about why her relationship with Mr Collins was especially significant Joy says:

I suppose it was just something about him that reached out to me. He always tries to give the impression of being so self-contained and correct, but I could see the sadness there. The reward of getting him to open up and share some of those things with me was worth the persistence. I really like him and appreciate his friendship and that he's interested and takes the time to ask me about my life too.

Exemplar 2 MRS WHITE and VAL

Mrs White has lived in a nursing home for the past two years. She entered the nursing home following the death of her husband who was her primary carer. She has two daughters and five grandchildren who have regular contact. Mrs White has a number of health problems and is severely overweight. She is unable to walk independently or get up from sitting without help. She describes herself as 'pretty useless' but does so in a joking way and appears to be resigned to her current living situation. She has her own room and bathroom in a new aged complex and spends most of her day watching sport on television. She had struck up a friendship with another resident who had died and now feels that 'there's no point in getting to know anyone else as we're all here to die anyway'. Mrs White considers herself to be lucky at being allocated a room in this complex. She expresses satisfaction with her care and says that the people who

care for her are *'mostly nice girls but they're always changing'*, reflecting the high turnover of staff which is characteristic of aged care services. Mrs White is especially fond of a young nurse called Val. She describes Val as *'just like a daughter'* and *'looks forward to the days when Val is on duty'*. Val, according to Mrs White, has a hard life as a single mother of three young children. She expresses concern that Val is slightly built and has to work physically hard to assist her with personal care. Mrs White uses humour to cope with her situation, she says *that 'it would be no good crying all the time and drawing attention to myself'* but admits that the loss of her husband was sudden and unexpected and still a great source of sadness for her. She says:

When you need help with everything like I do you're life's an open book and so the only thing you can keep private is your feelings. Sometimes I can't help myself having a little weep about everything and that's when I talk to Val. Although she's just young, I feel that I can trust her to keep quiet. She knows what it's like to be lonely. She seems to understand that I don't want every Tom, Dick and Harry in here when I'm miserable. She's been really good to me.

Val is a friendly young woman who works mainly evening rosters in the nursing home. She lives close by and works to support her three young children. She admits that her current working situation is convenient for her and allows her to spend time during the day with her children, which are her first priority. She also says that she enjoys her work, as she is a *'people person'* although she finds it physically tiring.

Val expresses liking for a number of people she works for, although, she admits, she finds some people more difficult to communicate with and harder to get to know. When probed, Val names Mrs White as one of three people she feels she has become particularly close to. She describes Mrs White as a '*giving person*' who always likes to have a joke. Val's relationship with Mrs White has developed over time and on discovering a common interest in sport. Val also expresses insight that Mrs White uses humour to cover up her sadness, and it was on one evening that Mrs White '*had a good cry*' about her husband's death and the death of her friend in the next room, that Val feels their '*friendship*' became deeper. She says that they have an '*easy*' relationship and feels that Mrs White is interested in her '*as a person, not just a worker*' too.

Val regularly brings photographs of her children to show Mrs White whom, she says, is always interested in their activities. She acknowledges that she '*probably steps over the line*' as far as other workers are concerned in her involvement with some of the residents, but apoloisingly says:

Well, it's just the way I am and what keeps me working here, because the work is very hard and unpleasant at times. But somehow, if you get to know the people then it's like you're doing things for a friend or a relative and that makes the dirty work easier to take. I'd do the same thing for my own mother if she needed it and that's how I cope on a bad day ... try to see the people here as close relatives and that usually stops me from getting bad tempered or irritable.

Exemplar 3 JOHN and MARK

John is a fit young man who has an intellectual disability as the result of a road accident as a child. He has a bright personality and appears to have lots of interests and fun in his life. He talks excitedly about his previous week's activities which involved his support worker and 'good mate' Mark. John lives in an apartment in an inner city suburb. Previously John had lived with his parents who have frequent contact and who are supportive of his wishes to live more independently. John likes activities which involve physical exertion, like walking, jogging and climbing. He also likes going to the movies and trying out new food. John has a number of support people involved in his life to help him with day-to-day household activities, but he names a support worker, Mark, as his 'closest buddy'. John describes Mark:

*Mark's a helper and a friend. Sometimes he comes to help ...
but at other times we go out together.*

(You go out sometimes ?)

*Yeah ... we go to the movies. Last week we saw 'Showgirls' ...
but I really like John Travolta best. Mark likes him too.*

(So ...what makes Mark a friend?)

*Well ... I like him. He 's happy to be out with me. I get to do
what I want to do. He 'listens. He tells jokes and we laugh. He
sings a lot too. He's a really good mate. We have good fun.*

John has not always experienced the quality of relationship which he has with Mark. He describes this in the context of receiving services which have imposed routines and programs which have been developed by other people. John appreciates his freedom in the current service context and talks at length about

the new experiences he has enjoyed in Mark's company. John describes Mark as a *'good mate and a helper'*. John also realises that some community activities are difficult for him, but confidently expects that he can *'learn a lot'* with the help of Mark. John makes frequent comments on the *'good mate'* Mark is and the good times they have together. John has Mark's mobile telephone number and says he can call him when he needs help or just to talk. In this way John has control over Mark's involvement in his life.

Mark is a young man who has worked with people with disabilities for three years. He also has a view of his relationship with John which is more than just *'service oriented'*. He describes his enjoyment of his involvement with John and *'feeling guilty'* about being paid to provide support. Mark describes his involvement with John as a time of personal growth for himself. He sees the relationship with John as a *'two-way thing'*.

Although meeting John came about through my work ... I would describe our relationship as a friendship. You need to have a good flowing relationship. Tonight for example, I'm going to see a film with John as a friend. I genuinely enjoy being with him. John is a wonderful character, so spontaneous in his enjoyment of life. I'd still be friends with John even if I wasn't working for him.

Mark attributes John with many positive characteristics and enjoys social contact with John:

What I get out of the relationship is a level of social interaction which I value and sometimes you feel needed as a service provider. I think that's a plus to feel needed. I know

I'm not a parent ... but an informal friend. It's a similar feeling that I get from friends. I'm needed by them and valued in their lives.

4.5.3 TECHNICAL SERVICE

4.5.3.1 CLIENTS AND STAFF

(Role without relationship)

'Client and Staff' relationships are characterised by 'professional' distancing. Interactions are mainly 'service oriented' and impersonal, although socially appropriate greetings and task competency are experienced.

Exemplar 1 MR CARSON

Mr Carson is a widower and has lived in a nursing home for four years. He left hospital to return home to his unit in an inner city suburb following a stroke, but a fall at home resulted in his entrance to a nursing home. Service workers and other residents are Mr Carson's only source of human contact. He experienced active service in the second world war and has a military approach to his current living situation, which is reflected in his concern for punctuality and the neatness of his room.

Mr Carson has his own room, which is clean and well cared for. He is tidily dressed, clean shaven and seated in a chair with a cushion supporting his paralysed arm. His radio and a newspaper are within reaching distance. His favourite hot drink is brought to him and placed in the '*right spot*'. He considers the standard of care he receives as '*high quality*.'

He views his relationships with service workers as '*correct*' and '*professional*' yet when questioned about what was important in his life as the interview progresses, Mr Carson expresses his longing for personal communication and companionship, although he wanted to be clear that this was not in any way a criticism of the service:

They're very kind all of them ... they're always asking if I need anything, but they rush past at such a rate. They never have time to spend even two or three minutes for a chat. That would make such a difference .

Communication with other residents is not a preferred option for Mr Carson, who finds the daily exposure to people who are progressively deteriorating mentally and physically, difficult to observe:

There's a lounge room here, but I don't like going there as you don't want to see where you're heading. So ... I rely on the 'girls' for company ... but they hardly ever have time to drop by ... they're so busy.

Mr Carson has few activities available to him in his current context. He is embarrassed by his disability and need for assistance with items of personal care. He describes feeling lonely and having little enjoyment of life. He talks about the '*rules of the house*' and his belief that '*in these places everyone must obey the rules or else the system would collapse*'. He is unable to name any of the service workers who care for him, but can describe them by appearance. According to Mr Carson, he doesn't have any special relationship with any staff member. He

'keeps himself to himself' and gets through each day as best he can. Television is his diversion from the monotony of his current life.

Mr Carson has swelling of his paralysed hand due to fluid retention. When questioned about his discomfort he responds: *'It's nothing really. I don't want to bother them or become a nuisance. There are other people as well as me here to be looked after.'*

Mr Carson's enculturation as a service recipient has socialised him into a passive, compliant and lonely individual who is eager to please and who lacks a means of confirming his identity through meaningful interactions with others. Communication between Mr Carson and 'staff' is formal and polite, however, content appears to relate only to his role as service user.

Exemplar 2 MARY and DAN

Mary and Dan are married and have previously lived in an institutional environment. They now share a unit in an inner city suburb with their dog, Bindi. They have lived here for eight years. Displayed around their apartment are many photographs of their wedding. Mary and Dan have cerebral palsy and use wheelchairs for mobility. They require assistance with all aspects of self-care and home care.

Dan communicates slowly and thoughtfully and Mary has no means of verbal communication but uses gestures and facial expression to supplement the messages she records on her cannon communicator which is attached to her wheelchair. They make a lot of eye contact with each other and often break into

laughter during the interview as they recall experiences with service workers. They belong to a small agency which co-ordinates their services but they are responsible for recruiting their care providers. Mary and Dan are 'expert' care recipients, having had more than fifty service workers involved in their lives since they moved into their current home. They have become philosophical about their involvement with service workers and consider it a 'bonus' when they have 'friendly' communication. Mary and Dan describe their experiences with people who come into their home:

You can tell right away, by the expressions on their face if they want to be here or not. Sometimes, it feels uncomfortable ... like we shouldn't be married or sleeping together ... you can tell by the way they look at you. Most of the time, people just come in and do what needs to be done, without talking much. I suppose that's what they're paid for ... but it would make all the difference if they were more friendly. (Dan)

I can soon tell whether they're going to work out or not. Some people are here for the money. They're always watching the clock. They don't last long ... but it's hard to find the right people. (Mary)

Mary and Dan also comment on their continual need to establish their autonomy in their own home, in the way they like their care activities carried out and also in the care of their environment:

They come in and start to do things without asking the way we like things done. It's like it's their place ... just like it was in the hostel. I suppose because they see that we're disabled ... they think that we haven't got a clue about anything!

Due to the severity of their physical disabilities, Dan and Mary are unable to go further than their local neighbourhood without the assistance of other people. Despite having lived here for a number of years, they have not formed friendships with other non-disabled community members. They have little family involvement and service workers are their main 'social' contacts:

Despite having the ability to select their own service workers, Mary and Dan have had their '*ups and downs*'. Being a 'couple' they are able to support each other and use humour to cope with difficult experiences. As Dan says '*... there's no point in getting mad ... we just laugh it off and think ... Oh well ... tomorrow's another day*'.

Although they have the power to dismiss service workers if they are not happy with the way they provide care, they are reluctant to do so. As a result of their experiences, Dan and Mary have limited their expectations of relationships with service workers to politeness and being '*able to do the job*'. They are continually struggling to assert their autonomy in the 'service' context of their own home.

4.5.3.2 TASKS AND WORKERS

(Bodies and routines)

When people living in services become 'tasks' to be completed they are stripped of their identity and useful only in that they are a product of the service industry. In this study of fifty service users in living environments which had the purpose of identifying 'quality', five participants lived in the experience of 'Tasks and Workers'.

Reporting the other side of 'quality' which is the harmful and systematic reduction of people to service 'throughputs', is not intended to deflect attention from the good service situations, but rather, to attempt to contrast ethical service situations with the experiences of people who are less fortunate in their service involvement. It is also necessary to demonstrate that services have difficulties in monitoring individual quality as that rests largely on the personal interactions between service users and workers and the motivations of service workers to act with or without beneficence.

Exemplar 1 ROSS

Ross previously lived in an institution and now lives in a group home with another man with a disability. Ross has multiple care needs. He has limited interactions with people outside his service environment. He relies on service workers to provide all his daily care activities. Ross's service is controlled by a large organisation. Although Ross is meant to be involved in the selection of his care attendants, he is aware that the organisation undertakes a selection process without his input and he feels unable to refuse to have workers who are sent to him for his 'approval' for fear of developing a reputation of being 'difficult'. Ross has a history of 'Dis-service' by individuals and organisations. Ross discusses the power relationships between himself and his caregivers:

*Well ... we're stuck with this and can't do anything about it.
They make the decisions and we have to listen to them. It can
mean a lot of trouble for us if we complain .*

Due to his high level of physical needs, Ross requires total care for hygiene and eating. The way that Ross is lifted and touched by service workers convey strong messages of 'like' or 'dislike'. In some situations with uncaring service workers Ross is afraid that what he calls '*rough handling*' might have detrimental effects on his severe cardiac condition. He does not believe that this is intentional on their behalf but rather that workers do not like caring for him and are '*keen to get the job over as quickly as possible*'. When he has suggested that he is moved more carefully, his comments have been ignored by some service workers. As he says with a laugh, he feels angry, but '*after thirty years of relying on 'them', you just get used to it. I'm surprised I'm still here!*'

Ross tries to find ways of communicating with service workers which might foster better relationships. He is particularly sensitive to his toileting needs and almost apologetic that he requires help. He makes allowances for service workers who obviously find the tasks involved in assisting him in this area, distasteful. In some relationships he casts himself into the role of 'child' by adapting his behaviour and responses in a way that he believes will please service workers, and make the situation less embarrassing for himself.

I just play this game with her. I know she hates cleaning me up and so I joke with her that she's like a 'mum' to me. The funny thing is that she's so much younger.

Ross is a keen gardener. Although he is unable to physically work in his garden, he enjoys it when his neighbour comes over to plant for him. Service workers rarely comment on this creative part of Ross' life. According to Ross, he is just a

'meal ticket for most of them'. It would be nice, he remarks, if they just took an interest in him as a person. In some situations, workers have been *'off hand'* and *'annoyed'* when he has asked for help which is not routine or strictly according to what they are being paid to do. One service worker who has been prepared to be more helpful is highly complimented by Ross . He has little expectation, however, that his *'good luck'* will last.

Exemplar 2 MISS CAIRNS

Miss Cairns is a physically frail lady who lives in a single room in a nursing home. She is unmarried and has no close relatives. Miss Cairns is a university graduate and had a professional career. She has a sharp intelligence and often uses examples from current affairs to demonstrate a point that she is making about the society we live in and the way that elderly people are treated as she talks about her current situation.

She lived alone for most of her life, and had entered the nursing home to recuperate from orthopaedic surgery the year previously. A fall and subsequent injury while living in the nursing home, resulted in a fractured pelvis and now Miss Cairns is unable to walk. She has resigned herself to remaining in the nursing home for the rest of her life, but is obviously unhappy. Although she appreciates that she is *'washed and fed'* she feels that she has no identity and that people don't know who she is or as she says, *'what makes me tick'*. She feels that the staff work very hard, but that there *'aren't enough of them'*. It is very distressing for her when she is incontinent while waiting for assistance.

Miss Cairns has little contact with other residents with whom she says she shares no common interests. She is mentally alert and was an avid reader until she developed cataracts. The radio is her only source of companionship. Miss Cairns feels lonely and uncared for in her current situation. Her room is colourless and devoid of any personal cues about who she is as an individual or what her life has been prior to, what she describes as her '*incarceration*'.

Miss Cairns describes the routine care she receives on a daily basis as being '*washed, polished and placed*'. There is a high turnover of staff and she worries about who might be responsible for her care needs. Care is painful when people are not gentle with her. Sometimes, when staff are very busy, she comments, '*they don't even tell me their name, or ask mine*'. She expresses anger at being talked down to or given childish nicknames, although she tolerates this indignity for fear of upsetting workers and developing a reputation of being '*difficult*'. Her appearance is important to her, but she says sometimes she is not given choices about her clothes or hair style. Sometimes she doesn't have underwear put on because '*people can't be bothered*' and that is also a source of anger and humiliation.

She finds the combination of smells in the communal dining area interferes with her ability to eat. She also finds congregation with other elderly people with disabilities distressing and prefers to eat alone in her room. This she says '*saves my sanity*'.

Miss Cairns leads a lonely and monotonous life and finds her current situation 'intolerable' but feels powerless to change it. She hopes that she will die soon. On completion of the interview Miss Cairns begs the interviewer to return to visit her. *'I can't remember when I last had a real conversation and that's so important you know'*.

4.6 SUMMARY

Exemplars of people in living services, have been used to demonstrate the variety of experiences of informants in the study and the importance of the relational context in examining service 'quality'. Many issues need to be addressed related to the expectations of people living in services for their interactions with workers to be characterised by qualities of liking and respect. In many cases, service users have expanded their lives and strengthened their self-concept through positive relationships with service workers. In others, service users experience devaluation and psychological abuse, perhaps non-intentionally, due to their objectification as routines and tasks of service systems.

It is clear, from the study, that a higher level of consciousness of relational issues in services is required in the articulation of serving roles, the recruitment of service workers, and the training of people who, irrespective of defined roles, share life experiences with service users and who have the potential to powerfully influence their lives. The issue is, perhaps, not only the problems of articulating 'quality' in real terms instead of the tangible outcome measures currently in use, but also the lack of consciousness of administrators to the

experiences of people living in services and the meaning of 'quality' as it is enacted through day-to-day service interactions. Ultimately service 'quality' is experienced at the 'coal face'.

"To the general public, human services are viewed (Offe, 1984 cited in Hasenfield, 1994, p. 3). Human services are microcosms of society. They also have the potential to do good or harm to people who are vulnerable in the service relationship. In looking into the eyes of people in services we see ourselves, and in reversing inequalities we can also empower ourselves as well as users of services. In being honest we can admit that there are things that we like and dislike about ourselves and others, but we can still act ethically.

Personal care depends on people who value themselves and their relationships with others. Becoming a person who cares is an ongoing and lifelong process that is developmental in character and dependent on a social environment responsive to personal needs for care and assistance (Benoliel, 1993 p. 9).

In discussing the importance of relationships over individualism Benoliel (1993, p. 11) went on to suggest that:

Relational ethics acknowledges that pain and separation are experiences that can't be conquered and destroyed. They are part and parcel of the human condition and humans have the choice of living through these experiences with others or of withdrawing from involvement in such relationships.

Perhaps it is possible to find ways of socialising service workers towards integrated personalistic service rather than being trapped in stereotypical service

roles and relationships. The relational experiences of human service users described in this study demonstrates that some service relationships embody the values of caring, commitment to the welfare of others, trust and responsiveness to human needs. The possibility for acting in the best interests of others is as unrestricted as the potential for control and devaluation.

The findings are displayed in the following figure linking the major themes emerging from research questions. Human service quality is the combination of positive relational communication and acts of serving which are described by service user and worker informants in this study in the context interpersonal relationships. The quality triangle formed by the three quality components is inclusive of positive relational experiences and exclusive of impersonal service experiences.

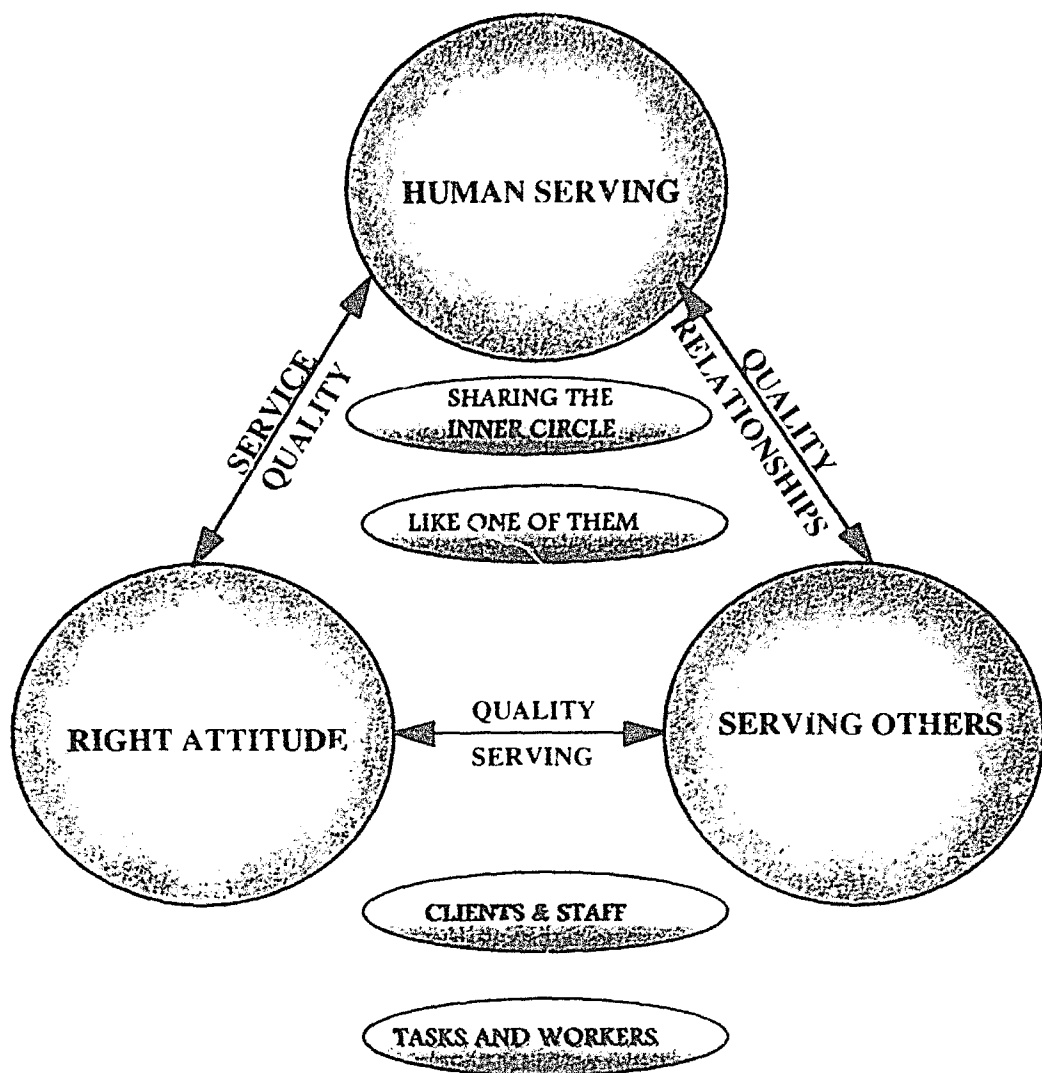


FIG. 6 FINDINGS

This chapter will discuss conflicting human service approaches, critique current competency standards in disability and aged care services, and conclude with recommendations.

5.1 QUALITY INFLUENCES IN LIVING SERVICES

5.1.1 PERSONALISM AND TECHNOLOGY

Findings from this study suggest that the essence of human service quality is relationship. Service users view relationships with service workers as central to their perceptions of quality in living service environments. Service workers who were identified by service users as providing a quality service consciously serve in a relational context. Relationships involve person-to-person interaction and dialogue. According to Walton (1989, p. 27), the question of whether a service relationships was ethical or not “depends on whether it involves the other in a non-objectifying way, and whether it is mutual and dialogic rather than unilateral and paternalistic”. If people are not seen to be the centre of value in human services then they are at risk of becoming subordinate to the needs of the system, or commodities to be traded for service funds rather than people to be supported.

The variable experiences of the people in this study describes the different approaches to serving others and clearly articulates what is judged to be

'quality'. In human services, like other interactional contexts, people struggle to make choices and respond to the demands of people and systems which are often in conflict with each other. Providing a personalistic service, or a service which places the individual at the core of service, is at odds with operating in a highly structured mechanistic and systems driven environment. Accountability procedures which are systems driven are removed from the experiences of people and become flat and meaningless documents which articulate the values of the system, and are at best, superficial in their presentation of what life means for people receiving service. The rise of the human sciences in the 20th century has been marked by the demise of the person (Battye & Slee, 1985). A business orientation in human service implementation causes quantification, mechanisation and standardisation. The mechanistic approach is not only a feature of modern human services, but is common to other social institutions in contemporary society.

In discussing the conflict between personalism and dehumanization Pascoe (1980) cited Blamires (1963, p. 163) as suggesting that the influence of the machine in industrialised society had become:

... accepted as a pattern of significance applicable quite outside the realm of the technological, applicable even to the domain of human relationships ... this can be seen in popular assumptions about the nature of human societies and communities, and about the way the human brain and the human will grapple with the affairs of life.

In designing human services as mechanistic systems and procedures, the purpose of human serving loses its meaning and the totality of human experiences is missed. Although tasks oriented towards physical care and safety are essential to most informants in the study, if they are not performed in a way that confirms the value of the service user in the relational domain, the service experience is viewed as being of a lesser quality. When service tasks take precedence over human needs both the service worker and user are depersonalised, the one attending to the functions of the machine, and the other becoming the dysfunctioning part to be 'fixed'. This allows for no development of relationship between the two. In this study, it was disconcerting to find how often service users reported their unmet need for personalistic serving, demonstrating that a mechanistic approach is commonly experienced by informants in the study. Although, when service workers 'bent the rules' or consciously created environments which enabled supportive relationships to be formed, people living in services felt connected with, and supported by workers who also reported personal satisfaction in their interactions.

A personal sense of control, although clearly articulated in standards in both disability services and aged care services, is impossible, when routines and schedules are imposed by systems. When services are responsive and flexible, it has been demonstrated that potential for growth exists. Even people who have left their family homes to enter institutional environments have the potential to find meaning in the experience if they have opportunities for choice and a sense of personal connectedness to other people. Creation of a social world through

relationships with others has potential to provide a mediating structure between the impersonality of the environment and the basic need to relate, act out personal drama, and find a capacity to develop resilience through enduring loss.

Although autonomy is strongly articulated in service standards, the meaning of participation becomes blurred as a result of the exercise of power in bureaucratic settings. The asymmetrical power relationships between service worker and user is maintained throughout the formal structures of human services. According to Hasenfield (1994, p. 279), "Power not only controls the information and socialisation processes, but also fatalism, self-depreciation, apathy and the internalisation of dominant values and beliefs". Hasenfield suggested that in bureaucratic systems "voices are inclined to become echoes rather than grievances and demands". Hasenfield went on to support Paulo Friere's view that dependent societies developed a culture of silence that in turn lends legitimation to the dominant order. The consistency with which people in this study discuss problems incurred in speaking out about negative incidents supports this position. As Banks (1984, cited in Skidmore 1994, p. 16) suggested:

All our lives are symbols. Everything we do is a part of a pattern we have at least some say in. The strong make their own patterns and influence other people's, the weak have their courses mapped out for them.

At a process level, the study indicated that the service workers' moral evaluation of the service user will determine the treatment the service user receives. This

will also be influenced by whether the service worker adopts a personal philosophy of 'free will' in face-to-face service encounters, or acts as a functional part of the service system in carrying out service demands. In proposing that people have the free will to make decisions and choices Pascoe (1980) suggested that without free-will people could not be considered as personal selves and would sink into deterministic existences. Yet, clearly, from the analysis of interview data in this study, determinism is alive and well in human services, as both service users and workers enter services and fit into existing events by responding to their environments in pre-determined ways.

Service user informants in this study demonstrate the need for relationships which are viewed as equal and frequently use the word 'friendship' to describe service workers who engage in communication which validates their sense of self. This provides a sense of belonging, emotional integration and stability and reassurance of their worth and value. Stereotypical views about service users by society and reinforced by system practices create barriers to friendly encounters. As Skidmore (1994, p. 44) stated:

Practitioners are similar to tourists, day-trippers and visitors in that they intrude on a person's geography of being from time to time. Each of these practitioners will carry something of a stereotyped image into the client's world.

Yet, despite the barriers created by social stigma and systems, it has been found in this study that service workers and users are capable of forming and sustaining mutual relationships which are carried outside the service environment into

normal social life. These situations are created out of a desire for relationship and demonstrate that people are capable of not just becoming cogs in the economic and political wheels of service systems, but can create their own realities through personal visions of what is right. Peck (1990) claimed that any relationship involved turmoil and required people to meet the demands of positive and negative elements. In human service environments turmoil may be created through a focus on valuing competencies more than the caring aspects of relationship. An over reliance on methods and protocols which are systems driven and characterised by efficiency and regulations diminishes the need to be able to choose to be among people rather than bouncing between the system demands and individual needs. In supporting this view Peloquin (1993, p. 938) stated:

Helpers wrap themselves in their procedural authority, binding themselves so tightly in their concern for the right method, the latest technology, that it is no wonder their actions seem constricted.

In this study service workers who describe engagement in mutual relations with service users discuss finding meaning in the serving experience through reciprocal relationships. Finding meaning in service interactions was found to be a positive characteristic for service workers and promotes their personal well-being. Acting out of compassion in the best interests of others lifts service workers above system demands and in itself liberates them also from the regulated environment of human services. In relation to the choice to act personally and with beneficence Pascoe (1980, p. 18) suggested:

Some theorists hold the view that humanity is thoroughly depraved, inalterably evil, fundamentally egocentric and vigorously intent in satisfying its own selfish need. Others attribute positive nobility and basic nature of goodness to humanity whose essence is composed of the attributes of creativity, productivity, compassion and generosity.

As well as the complexities of system demands on workers who enter services, which also place them as vulnerable dependants on the system, the situation is further complicated by their personal experiences of life and prior relationships. It would be unrealistic to expect that individuals will always relate positively to others, especially when high emotional and physical needs exist. Occasional maladaptation to individual situations, however, is vastly different from continuous objectification of people in the process of 'care'. Until appraisal systems and training of human service workers can grapple with the articulation of values which shift from system to personal, human services will continue to be confusing and unhealthy environments for people who live and work in them. Service workers, in this study, who have been identified as valued by service users on the basis of their personal relationships with them, have found personal satisfaction in their roles and service relationships and could be described as personalistic servers. Their descriptions of their involvement with service users show absence of conformity to, or paranoia about, system demands. They are also empowered in the serving environment.

For society at large, trust to care for vulnerable people has been placed in the hands of human service systems. People living in services, also place themselves

in vulnerable positions by trusting service workers to act in their interests. According to Baier (1992), trust altered power relationships. Even in situations where people are vulnerable, the vulnerability, Baier (1992) suggested, is still to some extent mutual, as love and nurturance were common goods and harm to these would mean self-harm (a question of 'doing unto others'). The consistency with which the word 'trust' was linked with 'quality' throughout interviews with service users in this study, reinforces the need for service workers to develop mutual relationships in serving.

Yet, the complexities of meeting human needs through formal systems alone may be insurmountable. Litwak (1985, cited in Hasenfield 1994, p. 8) suggested that in formal systems:

If the staff members did decide to provide such individualised services, it would mean neglecting their present standardised tasks, neglecting most residents in favour of a few, and/or working well beyond the limits of a normal work day.

This leads to the compartmentalising of needs into specialisations. It is little wonder that people who are treated in 'parts' commonly experience social and psychological isolation due to the lack of opportunity to introduce social relations into specialised service processes as other aspects of services are seen to be more important. The absence of reference to social and psychological support in service worker job descriptions is a powerful indication that people in service worlds are not viewed as social beings. Neither are interventions such as formal 'social skills' programs able to meet the need for social relations.

People do not learn to relate through programs but through the love, genuine interest, and informal supports of others to explore mutual ways to communicate feelings.

Cartesian thinking, objectivity and detachment, and power relationships present barriers to personal serving. Recognising and respecting the interdependent context of living services is necessary if services are to become organic, rather than functional systems. According to Benoliel (1993), personal care is about being informed, having the opportunity to talk with someone who's listening, to participate in decisions, and to be able to express feelings. The role of the service worker is then to support the integrity of the person by helping them seek meaning in the experience. Benoliel also suggests that a personal service engenders a spirit of community and sense of being part of a shared commitment to care for others. This is larger than the 'self' and enhances the well-being of the collective placing relationships with others over individualism.

In discussing the business orientation of services, McKnight (1977) suggested that the ideology of service is above politics and that the overarching universal of serving is love of others. Professionalisation of services, according to McKnight, has caused the translation of human needs into deficiencies which are defined as a series of technical problems. McKnight referred to 'wearing the mask of love' which hides the self-interests of professionals to build self-sustaining systems. This view was reinforced by Cocks (1995, p. 13) who suggested that service systems were in decline due to the "lack of capacity for renewal and revitalisation of our efforts in a way that is true to people rather than serving

formal systems". The problem of staying focused on the needs of service users as opposed to systems' needs, according to Cocks (1995) was also morale threatening for people working in services. The diversion of service workers from person-oriented serving to instrumental system oriented service reflects a shift from being grounded in the life experiences of people living in services. Without this empathetic understanding of the experiences of vulnerable people, it is difficult to act out of compassion and concern. Instrumental thinking which reduced human beings to machines, according to Pascoe (1980), violated the dignity of the person and was in conflict with the fact that people were created with a social nature which caused them to seek relationship.

The more highly structured the system of service the more service workers' behaviours are influenced and controlled by powerful service norms and mores. There are also the constraining influences of peer pressure and group sanction which fosters competition and rivalry more than co-operation and collaboration between peers (Benoliel, 1993). Human services need to attend to the growth and development of human connections and relationships more than the growth and development of people as separate beings. The separation between different groups of service workers mirrors the isolation of people in services. Collectivism as a value needs to be considered for everyone involved to enable services to become care-giving communities rather than hierarchical teams (Benoliel, 1993). Community building is healthy for all people in society (Peck, 1990; England, 1992; McKnight, 1994; Jason & Kobayashi, 1995; Turner & Louis, 1996). Human services have the potential to develop community

orientations where people can learn to relate in a way that fosters their merging with people outside of service environments. At the end of the day the home environment is most influential in creating relational well-being.

Many attempts have been made to improve the quality of life for people with disabilities over recent years. Policies have addressed the need for independent lifestyles and choice, but the emotional aspects of people's lives have been largely unaddressed (Waitman, & Conboy-Hill, 1992; Gardner, & Smyly, 1997). According to Gardner and Smyly (1997):

... we sometimes forget the most basic needs: to be listened to, to be valued, to be respected, and above all to have someone to talk to who will truly listen and make sense of the important events in our lives (p.26).

A training culture has dominated the field of developmental disabilities and life for some people has become a long and never ending program. Research in the area of developmental disabilities has also been dominated by a positivist approach to support program implementation. The researcher as 'expert' paradigm, although useful in providing information for academics, funders and policy makers, has little meaning for people with disabilities themselves or permits us to listen and value their stories. There is a need to consider different ways of understanding people with developmental disabilities. In this study it has been demonstrated that some people develop central relationships with key workers. Such relationships require further definition and support for their development. It has also been demonstrated that harmful encounters also occur

and lives may become a series of directives providing little opportunity to learn to relate to people in a way other than 'client'. Often the only close relationship people experience is with service workers. This is a key issue in service quality and 'quality of life' experiences.

Review of recent studies in care contexts for elderly people has demonstrated that researchers have moved beyond designing models as solutions, and have focused on the lived experiences of people in nursing homes. The contribution of nurse researchers in this area is considerable (e.g. Lind, 1980; Kemper, 1992; Munhall, 1994; Moore & Gilbert, 1995). Qualitative studies have provided insight into the problems of congregation and regulatory approaches in the provision of care and the effect these methods have on the well-being of elderly people. As a result, the competency standards for the aged care industry reflect the needs of people throughout life to have opportunities to sustain intimate relationships. In this study it has been demonstrated that validating relationships also develop between service users and workers in aged care contexts, but to a lesser extent than people with disabilities in this research. Translation of competencies into positive experiences for people living in nursing homes and hostels also requires a personal commitment to view 'care' as 'relationship'.

It is easy to feel overwhelmed when addressing the problems of people living and working in services. Yet, there is evidence in this study that some people are able to negotiate the less healthy influences of systems in serving others. Although the purpose of this study was not a comparison of models of living service in the context of 'quality of life' for service users, patterns in the data

suggest people living in small locally co-ordinated services for people with disabilities consistently experience positive relationships with service workers and are also most consistently described as being responsive to individual needs and preferences. A quality key factor which emerges in these contexts is the control that service users have in the selection and retention of workers. Descriptions of 'dis-service' and impersonal relationships in the disability data emerge from group home contexts where large organisations retain control of staffing arrangements. Patterns in the aged care data reveal no difference between hostel and nursing home models and suggest that the range of experiences described by service users occur in both contexts.

The other issue which demands comment is the consistency with which service users create social relations around the service environment due to a lack of natural associations with community members. The lack of success of formal services to engender natural relationships between people with disabilities and other community members has been discussed throughout the literature and findings chapters. This questions the nature of service systems and the way policies are interpreted at a grass roots level. Small locally based services in this study provide more opportunities for natural friendships with neighbours to develop and consciously create experiences which bring people into normal social situations with neighbours and others. Group home contexts retain an impression of social distance. The regulatory procedures surrounding the group home model e.g. staffing levels and documentation procedures, maintain an ethos of institutional living and hierarchical control.

In conclusion, serving others well is not just a job. The quality characteristics of serving as articulated by informants in this study have relational elements which, if absent from the serving context, create experiences which impact negatively on the lives of people in services. There is no prescriptive solution to this problem. It questions the meaning of being human, and recognising the human needs of others to relate as 'one of the same'.

Perhaps, as a beginning to developing more humane approaches, services and training institutions could emphasise the important communication element of serving others in a way that validates their existence, however, different that may appear to be. Quality serving however, can not be trained or imposed, it comes from within. It is an ideal that, when it is observed in practice, provides hope that good things can emerge from difficult situations.

5.1.2 COMPETENCY MEASURES: TASKS AND RELATIONSHIPS

5.1.2.1 DISABILITY SERVICES COMPETENCY STANDARDS

National competency standards for workers in the disability and field are currently in their final draft format. The standards describe the "knowledge, skills and attributes required for effective service provision" in the disability sector (Disability Services National Competency Standards, 1996 p. ii). The competency standards were developed by workers and employers in the disability field in consultation with consumer organisations and reflect a national commitment to workforce training and recognition and upgrading of workers' skills. They are also significantly motivated by industrial awards and enterprise

bargaining and underpin a system of accreditation for workers and organisations. Competency standards are designed to achieve national consistency and transferability.

The values underpinning the Australian Disability Services Act (1986) are also reflected in the articulation of the standards which have a strong emphasis on empowerment, choice and recognition of individual differences. Definition of competency standards focus on what is expected of the worker in the workplace and represent a shift in ideology from academic learning to practical on the job experiential learning. Competency standards are expressed as outcome objectives and components of competencies are describes as “task skills, task management skills, contingency management skills and job/role environment skills” (Disability Services National Competency Standards, 1996, p.6). Supervision of the acquisition of competencies in the workplace may be made by people with disabilities and their families or by other workers or administrators in the area. This reinforces the principles of self-determination and autonomy for people with disabilities if it is widely practised.

For some people with disabilities, however, such as those interviewed in this study, empowerment in the living service context is an ideal, rather than a reality. A lifetime of living in a service and limited opportunities to develop autonomy within the service context, physical and psychological vulnerability, and past experience of service life may lead people who are dependent on services to ‘aim to please’ in their responses to competency initiatives. Hopes of receiving a better service by pleasing workers, or at least preventing further deterioration in

relationships which are not supportive may be the motivating factor for people in services to be ineffectual in an appraising role. Transferring ideals into practical realities is inherently difficult in the complex relational structures of human service organisations where status inequalities may be entrenched.

Statements of rights and responsibilities of service workers in the context of empowering people with disabilities and engaging in appropriate communication, are at risk of remaining esoteric and flawed in their translation to meaningful action without also being explicit about articulating human service in the context of interpersonal relationships. Without emphasising the relational context of the human service encounter, the competency document will serve only to measure worker competency as task centred. For example "effective communication" (Disability Services National Competency Standards, 1996, p. 37) is "designed to enhance interpersonal relationship" but has a focus on method and technique rather than content; "Correct manual handling" (Disability Services National Competency Standards, 1996, p. 44) is described in the context of health and safety regulations and may, in practice, be impersonal and convey a lack of empathy.

Competency in carrying out tasks does not presume that the service is perceived as one providing 'quality' experiences for people living in services. This has been demonstrated in this study. Competency standards do not necessarily yield quality when they are limited to the definition of expected levels of performance. There is a need for human service leaders to develop new organic forms of

service systems which both protect people from maleficence and promote quality of life (Gardner, 1992).

5.1.2.2 AGED CARE COMPETENCY STANDARDS

National aged care competency standards (Commonwealth Government, 1997) for direct care workers provide a comprehensive description of the values underpinning aged care services. Relationships with elderly people and recognition of the need for emotional, psychological and spiritual support in the service context are stated. Issues such as loneliness, loss and intimacy are also recognised and addressed. Social rights are articulated as “freedom of association, friendship, and involvement or non-involvement” (p. 30). Other relational competencies such as “communicating appropriately” (6A p. 32) and “establishing a relationship of trust and respect for individual differences” (9A p. 39) provide workers with examples of positive relational behaviours as a guide to interaction. Sensory, physical and cognitive changes associated with ageing and their possible impact on communication and relationships are also recognised and addressed.

The ethos of the aged care competency standards is characterised by a personalistic approach to meeting the needs of service users and guides for workers combine task and relational domains. Findings from this study support the need to address many of the contextual variables described in the competency document. As aged care services move towards a process of accreditation, it will be important to monitor the experiences of people, such as

those in this study, to ascertain whether statements of correct action for workers translate to positive experiences of people living in services. Elderly people, who are physically and emotionally vulnerable may be even more likely to respond positively to objective evaluation methods if these are used in accrediting service agencies.

Staff continuity is not addressed in either disability or aged care standards. Continuity of service workers is a key factor to the development of trusting relationships in service environments. The complex dynamics and cultures of service agencies and their commitment to building community to support users and workers may positively influence staff continuity. Communalities in service environments, however, requires a relinquishing of status for managers who may strongly identify with hierarchical roles.

5.1.3 RECOMMENDATIONS

Recommendations support the findings of the study and the need to raise consciousness to relationships in human service living contexts. Competency standards, although useful in drawing attention to the skills required for functional performance may not be explicit in articulating important relational issues.

The problem of recommendations is the obvious danger of becoming prescriptive and adopting a task orientation which again diverts the focus from 'being' to 'doing' in human service environments. The establishment of accepting relationships between service users and workers is the foundation on which

other quality related behaviours must be established. Statements of rights for service users e.g. being treated as a valued individual, confidentiality, and fair treatment, are impotent as statements per se without consciousness of the meaning from the perspectives of the people concerned.

It is proposed from the findings of this study that relationships between service users and workers have a powerful influence on quality in services and also influence 'quality of life'. Ways of successfully addressing relational quality in a 'training' context are problematic. Positive and accepting relationships can not be artificially constructed. They evolve from personal philosophies, genuine feelings, and recognition that people are connected in fundamental ways. Building 'community' in service environments may be one way of fostering a sense of connection between people and meeting common needs. For this to happen service ideology would need to shift from an ethos of 'management' to one of 'collectivism'. Services in this study which have embraced this ethos have demonstrated the benefits for service users and workers.

For the purpose of making recommendations in keeping with the findings of the study a stance of 'doing no harm' is adopted. As a minimum requirement of a human service, at least people need to be acknowledged for their essential worth as human beings in communication and acts of serving. It is also necessary that people who are responsible for advocating for quality are available to vulnerable people so that they have a safe place to discuss their concerns. The recommendations are as follows:

1. Human service agencies, workers, and service users recognise and address issues of relational ethics as a guiding principle in creating 'quality' services.
2. Human service agencies recognise their responsibilities as relational contexts for service users and that this is reflected in organisational mission statements, policies, job description forms, and training of human service workers.
3. The importance of building community in the service context is explicated within service environments and, in collaboration with service users, workers, and other interested people, human service agencies develop ways of creating relational environments which recognise and support individual relational needs and attributes.
4. Human service agencies and workers recognise that continuity of relationships with supportive service workers is crucial to the experience of having a quality service. Relationships with service workers may be central in the lives of people living in services and service agencies must recognise the need, and be responsible for, ensuring that emotional support is available for service users, particularly when separation occurs.
5. Human service agencies recognise that evaluation and monitoring of service 'quality' are strongly focused towards the examination of tangible outcomes and are unlikely to disclose situations where negative relational experiences

and abuse occurs. Other safeguards need to be developed for people who are dis-serviced to safely voice their concerns.

6. Human service agencies identify service users and/or workers within human service environments who are conscious of the values and meaning of relational 'quality' for people living in services and who are recognised and supported by administrators as advocates for quality, including personal advocacy.
7. Competency standards in disability services are developed further to address relational issues in human service contexts.
8. Positive examples of service user and worker relational contexts and service environments which promote a community ethos, are identified and publicised as exemplars from which others can learn and role model.
9. Friendships between service users and workers in human services are recognised, valued, and supported by human service agencies and other people concerned with the welfare of people living and working in services.
10. Future research is required to investigate the extent to which findings from this study can be generalised to a wider population of people living in service systems. With further evidence of the need for relational quality to be addressed, it may then be possible to develop ways of raising consciousness and training service workers and users to enhance the quality of the day-to-day experiences of both living and working in service

environments. This could be the initial step in creating care-giving communities and combatting the impersonal effects of systems.

EPILOGUE: THE PHENOMENOLOGY OF LIVING SERVICES

This chapter contains a selection of verse written during the process of the research and presented as both the investigator's experiences and her (sic) interpretations of the experiences of people who were interviewed and observed in the course of the study. In the process of phenomenological research, relationships between informants, investigator and environments can pervade the consciousness of the investigator. The use of descriptive verse provides a personal catharsis of the research experience. There is no order to the verse, it is presented as it entered the consciousness of the investigator.

People in living services long to be accepted by service workers in the service relationship. They also gauge the attitude of workers by the care taken carrying out tasks. They can feel rejected when service workers leave.

ENTER WITH CAUTION

Come in to my world softly, with care and caution

Look into my eyes

Tell me I'm 'us'

Touch my body like you would your own

Listen to my stories, tell me yours, don't shut me off

Stay a while

Make sure the tea towel's folded before leaving

(Oh yeah ... and when you're pissed off with the job ... break it to me gently).

Some people living in services lead monotonous and predictable lives never getting close to others, despite surface contact with many service workers. Sometimes a person will enter their life and 'make a difference' and provide expanding opportunities. A relationship with a key worker can become central in the lives of people who are lonely. This is interpreted by one man, who formed a close attachment with a service worker as 'being in love'.

CHANGE

Mine was a shrinking life of half-circles-180 degrees

Forwards, backwards, left, right

Like branches on a Christmas tree ... sameness ... sameness

People hanging on me a while

Like musical bells ... repeating tones

Nice to look at, changing nothing

Growing statically

For more than half my life

Then you came along

The world is round

I grow bigger, fuller

Can this be love?

Visiting an inner city townhouse on a very hot night in February where a young man with an intellectual disability lived in a co-residency arrangement with a young support worker, I was struck by the similarities in their physical appearance and the seeming equality of their relationship as 'learners' in the activity of making a pizza. The fun and laughter was infectious. They obviously enjoyed each others company and joked continuously.

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FRIENDS

Hot night

Two mates in the kitchen

Tall, tanned, T-shirts

Strong, young, sweaty

Making pizza

Grease stained book... hard to read

Mountain of cheese, spilling over, adding everything

Laughing, arguing, colliding, scratching heads

Look closely

Two mates in the kitchen

Who's the helper, who's the helped?

Both

Jenny, a woman in a nursing home lives for recognition by other people. She measures the quality of each day in the frequency that service workers use her name. In a body that had long ceased to function, Jenny's bright eyes and sense of humour, won my admiration for her resilience. I felt enormously sad and still do when I think of Jenny's life. I continue to think of her frequently.

CALL ME JENNY

Talk to me

Talk to me

Show me you're there

Look at me

Look at me

Show me I'm here

And please ... call me Jenny

Some elderly people living in services try to find meaning in the experience. Others question their continued existence. Without continual reinforcement of their human identity and past achievements, people can feel objectified. Their only relationships are with objects in their environment. Rooms are often devoid of personal possessions which symbolise continuity of past life roles. Communication may also fail to reinforce identity as people become objects of care. One elderly woman lives in a small room with only service equipment for company. A bed, commode and wheelchair fill the space in her life which once familiar others occupied. She worries about the 'future'.

IS THIS ALL THERE IS?

Is this all there is?

Heavy time, aching worry

Who am I? What am I?

A chair ... or a bed ... or space?

No ... not space

Space is light and free, reaching out, enveloping, sensing

Maybe a bed

Solid, heavy, useful, owned

No ... not useful ... except as a prop ... to a system

Maybe a chair ... a chair with wheels

Shining, hard, moving forward

No ... not moving forward

No ... not shining

But, hard ... yes ... hard

Hard enough to bear the brunt of wear and tear

For a time anyway

Yes ... that's it ...

I'm a chair with wheels, waiting for 'tomorrow'

People with disabilities continue to hope that service workers or other people will enter their lives and bring new experiences and companionship. Some people never give up hoping.

MAYBE TODAY

Maybe today there'll be a new face, a different face

Someone who won't look away when they see me

Someone who'll talk about anything

Someone who'll forget what time it is

Maybe today there'll be a new face, a friendly face

Moving from an institutional environment into a community home is full of possibilities for good things to happen. It can also be abusive, when service workers use the power of their physical superiority and service roles to disempower physically weaker service users. This is the experience of one young man who describes his psychological abuse in a relationship with a service worker. He has to 'beg' for assistance. He uses humour to get through each day, and in his thoughts attaches nicknames to his adversaries.

THE BEGGING BOY

Beg a little, beg a little, one, two, three

Beg a little, beg a little, nothing's free

If you want to get a life, make sure the power's with me

Beg a little, beg a little, one, two, three.

Now....how will I play it today?

What'll work?

Depends I suppose whether it's the 'big hairy one' or the 'bitch'

The curtains part, the stage lights up

But ... hey ... nobody's written the script

Is this what they call theatre arts?

A bit of ad libbing as we go along?

Therapists call it 'role play'
I call it bloody stupid
Life's a joke
But not a joke
It's bloody serious!

Oh well ... some people gotta beg to survive in this life.

People in living services, like other people, experience love and the vulnerability of being in a relationship. This may be real or imaginary, requited to unrequited. People nourish themselves with feelings of love.

IN SYNC
The words don't need to be out there
I know ... you know
The air between us is even, shared
Not me or you taking more than our share
In sync with each other
Should I risk... that when you know me
You'll still be there?

LOVE
You know, don't you, that I love you?
I enlarge in your presence
When you're with me I put my happiness out there
It's like living up a level
Together
Will it last?

One woman with a severe physical disability, continues to hope for a loving relationship with a man. She visits clairvoyants who tell her that this will happen. She fantasises about her 'prince'. The reality is, that she has to pay for intimacy.

THE PRINCE

*One day my prince will come
I know it ... it was written in the tarots
I keep a crystal by my bed.*

*Sitting, and thinking, and hoping, and praying
That some day ... yeah ... yeah ... my prince will come
On a white charger
Will there be room for my wheelchair?*

*I'd give my right arm for a man, sharing my bed, the hotness of his
body
My right arm doesn't work... who'd want it?
OK ... I'll give my legs
My legs don't work either
Nothing much to bargain with have I?*

*What about myself ... mature, witty, intelligent, loving?
Is that enough?*

*One day my prince will come
He won't mind that I can't caress him
I know it ... it was written in the tarots
I keep a crystal by my bed.*

Sex is so relaxing ... but expensive on a pension.

Having driven through the busy city on a sunny Monday morning on the way to interview some people living in a nursing home the business of the traffic and bustling lives of people in the streets and the business of the service environment provided a sharp contrast.

CROWDED

Monday ... another sunny day

*Traffic busy, bridges congested, people going places, merging,
separating, merging*

Monday ... another sunny day

*People busy, laundry congested, people stuck, washed, polished,
placed*

Outside the world changes ... inside people are 'thankful' and wait.

Sometimes service workers who recognised the needs of elderly people in living services are overwhelmed by their inability to 'share themselves around everybody'. Often these people become overburdened and leave. This was written following an interview with a much loved service worker who confided that she could no longer cope with the loneliness and sadness of the environment. She had begun to grieve about the impending separation. She looked exhausted.

TIRE D OF SEEING

Seeing the pain, the sadness the need

Feeling the load

*Trying to raise a smile, provide friendship, take minds off somewhere
else*

Trying to switch off ... live another life

It's all too much

Leaving

Grieving for leaving

Guilt

An evening with a man with an intellectual disability who lived alone in a nearby suburb was a really enjoyable experience. It was refreshing to enjoy his immediate acceptance of my being there without the usual boring, stilted, social preambles.

OPEN FACE

Open face, handsome face

No agenda, takes people as they are

No manipulation

Puts it all out there

Says it as it is

Sees it as it is

Trusting friendliness

And they give you a label?

It should be 'nice to know human'

'Institutional green' used to be the colour on the walls of most human service environments. Colourless beige is now the 'in' colour for large congregated environments. Beige, to me, is a flat and unimaginative choice, when nature reflects so many beautiful colours. People in institutional environments sitting silently together in beige existences look like ghosts of who they have once been. I reflect on my contrasting colour experiences and fear of living in a beige environment. I wonder if people living in 'beige' feel the same way. They too have surely lived colourful lives and associate colour with significant experiences.

BEIGE WALLS - UGH!!!!

It used to be green and now it's beige

Beige is a nothing colour

Nebulous beige

Nothing people and beige belong together

Give me yellow, bright shining yellow

Yellow for sunshine and happiness

*Make it deep beautiful turquoise, like a Spanish sea in summer
Let me languish in sensual ochre like an African river bed in drought
With elephant spoor dotted along the banks
Or violet, the soft richness of violet, like sunset on a heather covered
mountain in August
But not beige
Beige is nothing
I am not nothing
I can't live with beige
Please ... don't make me live with beige
It doesn't match my complexion.*

Interviewing a woman in a nursing home one morning, I observed the way service workers approached her roommates and the difference between 'service' and 'serving'.

*HARD AND SOFT SERVICE
Marching footsteps in a hurry
Door opens
Clean, efficient, cropped woman schedules shower
Cipped speech, colourless conversation, quick execution
Leaves, closes door and that's that.
Feet tap and pause, door opens slowly
Head pokes round, smiling, eyes bright, warm tones
Gentle touching woman eases shower
Talks soothingly, laughs, perfumes body
Plumps cushions, touches hand and leaves
It takes all kinds to make this world*

One afternoon interviewing a woman in a nursing home, I thought how incongruous her presence in this environment was. She had a sharp and inquiring mind. I had a strong sense of connection and we discovered we had many common interests. This could be me in the future ... God ... I hope not.

THE THINKING WOMAN

What are you doing here, thinking woman?

Stuck in this characterless being box of nothingness

*Your bright mind meets mine half-way to fuse in search of meaning
of our shared existence in this moment*

I share your reality for a time ... only a moment

Our only difference is the mechanics of our bodies

*My parts are moving, yours are still ... apart from your mind which
would win a race with mine any day*

Wearing a petticoat was a sign of respectability for an elderly resident of a nursing home, and one that I can relate to from my own childhood. The petticoat is symbolic of so many things that she holds dear, including links with her past culture. It's a pity that the service has not recognised this. How could I ... a stranger, discover this so easily and it isn't known to people who have performed her intimate care? Hasn't anyone ever taken the time to get to know her? She explains the symbolic meaning of her petticoat and reminisces about her childhood.

THE PETTICOAT

Respectability and petticoats go together

Nice girls always wear petticoats

Don't forget my petticoat please

I feel naked without it

Even if there's no-one to know it's missing

It doesn't feel right

It's a part of me you don't know

How could you?

*Did you know that as a young girl my mother used to sew lace on my
petticoat by hand beneath a gas lamp?*

*We were poor, but somehow there was always lace for my
petticoat, precious lace, beneath the rough itching tweed*

*Rough tweed, heavy with the heavy rain of winter in that other life
... so far in time and distance now*

*Please don't forget my petticoat
My petticoat is who I am*

Spontaneity is a characteristic of one young man with an intellectual disability. His service worker also finds himself becoming caught up with his enthusiasm for life.

*HAPPY DAYS
Happy, happy days
Happier with you*

*I can do anything
I want to sing . . sing ... sing*

*Why is everyone looking at me?
Aren't they happy too?*

Service workers who relate on a personal level, attribute people living in services with having raised their consciousness to some of the fundamental things in life which can be lost in the seduction of modern society. A service worker talks about the forgiving nature of a young woman with an intellectual disability and what she has learned from the association.

*LESSONS
You teach me a lot
Simple things ... too simple to be written in text*

*Important things
Too important not to know*

*Funny ... all these years and I never knew
How simple life is*

Forgive ... forget ... fly

One 'supervisor' of an aged care environment wears jackets with padded shoulders and likes to know who comes and goes. She didn't like me being there. She towered over me and told me in a loud voice that her role was 'to protect the people here from people like you'. It was a very unpleasant encounter. I could feel myself getting angry ... and walked away. I wonder if she knows that people living here are afraid of her.

IT'S HARD TO BE 'IN CHARGE'

Look... you don't know how hard it is to be in charge

I'm in charge of this place

I know what these people need

They're vulnerable

I'll decide who comes in here and who doesn't

The power and the glory, forever, and ever ... Amen

Sometimes people living in services try to stay positive but admit there's not much to live for. Lives are routine and habitual.

MAKING THE MOST OF IT

More is more than less

Anytime in life

Life is more than death

Any kind of life

Don't think of the losses

Think of the now experiences

Now ... now ... now

This is just another blimp in the dynamics of becoming

But God ... I wish it wasn't so predictable

A man who has spent many years in an institution loves to talk and is excited that he has opportunities to meet people other than 'service people'. His favourite activity is to be dropped off at the local shopping centre where he will sit and try to engage people in conversation.

'NEW' PEOPLE

Can you believe this?

I had a great day today

Today I met a 'new' person

*That makes more than twenty people I know now ... and I'm only
fifty-four*

How many more people do you think I can get to meet?

Gee ... what a great day!

Some small locally based services have a strong sense of communality. Service workers have visions of an ideal world where they can also find acceptance and freedom to enter and leave having developed relationships which are long-lasting and always welcoming.

COMMUNALITY

Shared space

Shared dreams

Shared lives

Forgiveness

Not owning the air we breathe

Borrowing, lending

Generous reciprocation

Free to come and go

No expectations other than presence

No attachments, no loneliness

Together

One young woman with a disability has recently married. She has grown in confidence. but is also vulnerable in the relationship, like other people. She has control over

employing her service workers and asserts herself for the first time in her life as a married woman and employer.

JEE-Y... LOOK AT ME NOW!

I'm a married woman now

Big husband ... call me Mrs.

Don't give me any of your patronising shit

I'll do the hiring and firing

I'll decide when I want you

I'm in charge

*But if you really look closely ... you'll see that I'm just another
woman*

Gentle, fearful, insecure.

This is the interpretation of the experience of a young woman with an intellectual disability when she was having a rail installed in her bathroom just prior to the interview. It seemed like everybody else was making decisions in her personal environment. People were insensitive to the signs she was giving that she didn't want so many other people involved. Eventually she 'gave up' left abruptly ... the only way she could display her autonomy.

DON'T HASSLE ME

I haven't got the words, your words are just sounds

Tone and movements tell me what you're saying

*Too many people ... too much noise ... five people in one bathroom ...
my bathroom*

I can't make out what's happening

All these people talking at each other

Stuff it ... I'm outa here

Put the bloody shower rail anywhere you like!

Sometimes relationships develop out of admiration for the courage of people living in services to stand up for their point of view, even when this goes against the 'approved' lifestyle of living in a service. This is a man I have known for many years, have had many 'hassles' with, and greatly admire ... but he doesn't know it. He has a progressive disability and service life has involved many traumatic experiences, but despite his physical frailty and extreme social vulnerability he continues to speak out for what he believes are his rights. I interviewed him in the second phase of the study having had no contact with him for the past eight years. He hadn't lost any of his fighting spirit.

DIFFICULT BASTARD

'Yes ... I know you ... you difficult bastard

I have to admire you

'You're an alternative stereotype

A hippie in a wheelchair

Smoking pot

Wearing caftans on hot summer days

After all these years you're still wheeling along

Hanging out for each breath ... fighting for your share

I have to admire you ... you difficult bastard

Taking on the world 'chair on'

I see you coming and smile

'Getting one over's' what keeps you going

You win

Sometimes people living in services and service workers discover common passions. This discovery may change the nature of their relationship by equalising their

interactions. In large institutional settings the discovery of shared interests can result in a person standing out in the crowd. A man with a severe physical disability, who experienced years of negative stereotyping and a service worker developed a long lasting friendship through their common love of the composer Chopin. Through this interest their relationship has developed into valued social contact.

CHOPIN

Did you know that Chopin's my favourite composer?

I have a friend who does, because he's hers too

Chopin ... masterful nymph of the keyboard

*Glissandos ... diminished sevenths ... eight note spans of decadent
chords*

Powerful polonaises

Nourishing nocturnes

Magical mazurka's

Blissful ballades

Stormy studies

*Fingers with minds ... interpreting perfection ... transcendence ...
out of this body*

*Chopin ... transports me out of this body ... into a world of
perfection*

Did you know that Chopin's my favourite composer?

My friend does

Chopin brought us together.

The social sterility of some service environments leave long lasting impressions. For one woman in a nursing home, an Easter card is the only precious personal possession in her environment. She has shared a room with a stranger for four years. They have little social interaction. The situation she lives in is made even more poignant when she recalls how in her younger life her main interest was decorating her small home with her

husband. She described herself as 'house proud.' The Easter card taped to the wall beside her bed decorates her current life.

THE EASTER CARD

*Taped to the wall ... an Easter card
Yellow chickens, hatched egg, yellow wall
Not quite straight ... open ... 'Hope you have a happy Easter mum'*

*An Easter card hangs in August
Cherished long after the use by date
Precious symbol of another time
Proud reminder of another life created
From this now useless shell of shapeless, flaccid, flesh*

*An Easter card hangs in August
Memories of children clinging, warm
Happy tiredness, active, life of giving
Walls with flowers, labelled jars on shelves depicting seasons
Now forlorn*

'Hope you have a happy Easter mum'

Observing frail elderly people with severe cognitive impairments who spend most of their lives lying down, and trying to interpret their experiences of contact with other humans. Do they have a sense of 'humanness' in their interactions with service technologies? Are they conscious of their lives? Have they chosen to withdraw from reality? What are the experiences created for them by the service?

NOTHINGNESS

This seems like nothingness ... floating on a sea of meaningless sounds

Lying in whiteness in this still but not silent existence

Shadows cross the threshold ... faceless encounters ... robotic intentions

Seeing but not seeing, my silent, motionless existence ... lacking intentionality

Touched by hard metal, cold hands, rough cloth

Returning to the safe unconsciousness of the past

This seems like nothingness ... light and shadow ... persistent existence

Roused from the other warm world of sunshine

Cold hands, hard metal, intrusively entering

Rough cloth, meaningless sounds, amoebic shadows

Seeing, but not seeing my parallel existence

Living in another world of powerful time and purposeless motion

Returning to the safe unconsciousness of yesterday

This seems like nothingness ... cold and warm ... irrational existence

Unrelenting hardness ... surrounding, not cradling

Escape into meaning in the lightness of another world

World without intrusion, world of safety, softness, nothingness

Always holding

Always accepting

Peaceful persistence, silent existence

Life in limbo

The overwhelming sense of loneliness of people's service lives is a reminder of the existential loneliness we share. Some people in services find meaning in their suffering.

LONELINESS

So many people in my life

And yet ... I am so lonely

Are they not like me?

Are we not on the same journey of existence?

Are they not also lonely?

I will never know

Because they don't recognise the essential truth

That our inward existence is 'alike'

Our functional lives are only the shell

Spiritually we are equally advantaged in finding meaning

Perhaps I have the advantage of living with suffering

Existence is lonely for all of us

Unless we find our 'essence' in each other.

Humour is used by a man in a nursing home to perpetuate his sense of fun and sexuality despite his current immobile life. He creates a social life through his reputation as a 'bit of a lad'. He had an interesting life of adventure, hardship and, laterally, wealth.

THE GOLDFIELD FELLA

*When I was a young man, just aged seventeen
I prospected for gold in Kalgoorlie*

*Now that I'm ninety and just a 'has been'
I flirt with the new nurses nightly*

*I might seem an old bloke
But look closely now
You'll see that my thinking is sprightly*

*If you can't have a 'real' life
Then .. well, what the hell
Have a joke ... and try living brightly
Or you'll die with monotony rightly
Life's a tease ... so I flirt with 'em nightly.*

So many people sitting, watching and waiting. Always around the nurses' station or in the entrance halls of living services, people hope that someone new or familiar will enter their world and relate to them.

SITTING ON A CHAIR IN THE BAY

*Sitting on a chair in the bay
Watching the time fly away
Sitting on a chair in the bay
Watching time*

*I left my home in Midland
Boarded a one-way bus
Brought me to this haven
Where no-one wants to know my name*

*Sitting on a chair in the bay
Watching the seasons pass away
Sitting on a chair in the bay
Marking time*

A nursing home resident is very fond of the tea lady. She considers their relationship a friendship.

PATSY THE TEA LADY

You are the sunshine of my life ... Patsy

Shining metal trolley and wide smile

You make my tea just the way I like it

That tells me that you care about me, Patsy

The days are long and lonely between cups of tea

You ask me how I am and spend a few moments

Precious moments for me ... if you only knew

You are the most important person in my life

I live on for your visits ... my friend Patsy

Long involvement with families sometimes fulfils visions that a 'regular' life can be lived. This is about a young woman and her mother, I have known for twenty years and who was married during the study. She was also an informant in phase two.

THE BRIDE

The beautiful bride, swathed in white satin

Long veil winding down the aisle

*Proud parent pushing wheelchair bedecked with ribbons and
translucent tulle*

I waited at the church excitement mounting

Bridal car and trailer

Ribbons flying, tulle tangled

Nervous laughter

*I walked from the church and waited
Beautiful bride, tall strong husband, tenderly pushing chair
Not a dry eye in the crowd
Your day, your hopes, our hopes together
I visited your home
Bright, happy colours
Scones baking, mother visiting
Tea waiting*

*I remember the first time we met ... long ago
Anxious mother, small child, jerky movements
Dreams shattered
Life of care ... different now*

*Three women drink tea
Share experiences of normal lives.*

A man with an intellectual disability is proud of the favourite pie he cooked with his service worker. He 'shows it off' frequently during the evening.

*THE PIE
Mountainous peaked pie ... steam escaping ... thick brown gravy ...
junks of succulent meat
My pie ... did you know I made this pie?
I can have it for tea ... and breakfast and lunch tomorrow, if I
like
It's a really big pie ... my favourite pie
I made it
Would you like some with your coffee?*

Sometimes, we relate strongly to others because of they remind us of past memories of significant people in our own lives. A nursing home resident's stoicism reminds me of my mother.

YOU REMIND ME

*When I look at you
I think of my mother
Soft, white skin
Round body
Waistless*

*When I enter your room
I think of my mother
Shiny photographs
Embroidered covers
Crochet cushions
Respectability*

*When I talk to you
I think of my mother
Upright silence
Hidden secrets
Formal conversation
Outwardly resilient
When I leave you
I think of your daughter
Do you talk with her?
Share your secrets?
Risk exposure of your vulnerability?*

Or ... is this your way of coping?

Entering the driveway of an old religious institution, now converted to a nursing home and hostel complex for elderly people, I feared the worst. It was in this environment that I met the most autonomous group of elderly people in the study. Terrible image, but surprising what lay underneath. This is why we need to look deeper than the 'tangibles'.

THE OASIS

Brick tomb

Brown floors

Endless corridors

Benign virgins

Crowded spaces

Muted sounds

Endless doors

Brown floors

Suddenly ... an oasis

Small groups of people talk

Leave and join

Sip tea

Question me

Clear tables

Arrange cushions

Change expressions

Body language

Colour coded vitality

An oasis in a human desert

Creates hope

One person can create life in an institutional environment. Such a person is Rosie, a hostel supervisor who has helped to irrigate the desert and provided an oasis in an institution.

THERE'S NO-ONE LIKE ROSIE

Some people are lucky ... they have Rosie

Round, rosy, Rosie

The hostel supervisor

Stacks and counts the linen

Talking brightly to her 'helper'

Mrs Jones

Rustles in the pantry

Looking for that special drink

For Garry, the 'gardener'

Takes time to listen

Admires photos of Mary Ward's great grandchildren

Talks about her own

Softly enters Danny's 'place'

He likes his 'peace and quiet'

He used to be a school teacher

Some people work

Rosie relates

People like Rosie

A 'moving' experience of how small requests can become major clinical issues in the service world. I wonder if service workers will ever develop consciousness of how upsetting their insensitivity and use of power, in the guise of regulations can be for people living in services.

THE 'HUMAN' MOVING SERVICE

*He only asked if he could sit in his room
Quietness to talk, privacy
He was a small man
Gentle face, someone's grandfather*

*'Moving' problem!
Strong woman calls 'superior' worker
Quick, smart woman with mobile phone, enters
Both stand over small, gentle man*

*'He doesn't need to go anywhere
No-one in this room hears or understands'*

*Frail, hunched woman in the next chair looks over quickly
Returns to the safety of personal objectivity
Large woman in wheelchair loses slipper
I bend to help, our eyes meet, knowingly*

*'He doesn't need to go anywhere
No-one in this room hears or understands'*

*Small gentle man begins to cry, apologises
I apologise causing 'problem'
Prepare to leave*

*Large metal hoist is summoned without asking
Small man is mechanically moved into wheelchair
We walk to the 'safety' of his room
I wish we could have walked away.*

It seems to me, it is all so simple. Why can't we get it right? Do we really care

QUALITY

*Some day ... when we reflect on how simple it all is
We'll wonder how we lost the plot
Creating for ourselves an economic abyss
Where we chose to fight to keep our status and lose ourselves
When all that was needed was recognition
That we're all in this together.*

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APPENDIX 1

Dear

Following our telephone discussion, I am applying to undertake research in your agency. The purpose of this study is to determine factors which impact on people living in human service environments from a service user perspective. People with disabilities who live in the community and older adults who live in aged care contexts will be informants in the study. Information from the study will provide insight for people responsible for service development and evaluation about what is actually important to people living in services and what are the commonly shared issues related to service quality across multiple agencies.

The research method requires my spending time observing and interviewing people living in (agency). I would like to make a preliminary visit to discuss informant selection with you and introduce myself to the people concerned to explain first-hand the purpose of my involvement and obtain informed consent.

All the data received will be treated with confidentiality and anonymity of informants and agencies will be preserved by using a numerical coding system. Only group data will be reported and pseudonyms will be used for the purpose of writing the dissertation. People may withdraw from the study at any time or choose not to have particular data reported.

I have spent many years working in disability and aged care contexts and have experience of communicating with populations which have diverse abilities. It is my intention that the interview situation, as well as providing relevant information, is a validating experience for informants. It has been my experience of past research that studies of this nature have this potential.

I will be pleased to discuss the findings with you and any interested people on completion of the study. Please do not hesitate to contact me if you require further information.

Yours sincerely

Ruth Marquis

Thank you for agreeing to take part in a study which involves talking to Ruth Marquis, a graduate student at Edith Cowan University, about your experiences of living in (agency). Please sign the consent form below to meet with the University's ethical requirements.

I agree to be interviewed by Ruth Marquis, a graduate student at Edith Cowan University, about my experiences of living in a human service. I understand that any information I provide will be treated with utmost confidentiality and my name will not be disclosed. I am also aware that I can withdraw from the study at any time or demand that information I have given is not reported.

Informant signature.....

Researcher signature.....

Date.....

Code.....

INFORMANTS PHASE ONE (DISABILITY)

SERVICE USER GROUP

Agency	Age	Sex	Disability	Years	Type
1					
	21 (D1)	M	Intellectual Disability	2	Community House
(3 sites)	35 (D2)	M	Intellectual Disability	3	Community House
	25 (D3)	F	Physical Disability	2	Community House
	42 (D4)	M	Physical Disability	2	Community House
2					
(3 sites)	40 (D5)	F	Physical Disability	5	Group Home
	23 (D6)	F	Physical Disability	5	Group Home
	50 (D7)	M	Physical Disability	5	Group Home
	22 (D8)	M	Physical Disability	2	Group Home
	49 (D9)	M	Physical Disability	5	Group Home
TOTAL	9	6M 3F			

SERVICE WORKER GROUP

Agency	Age	Sex	Years	Title	Type
1					
	26 (DW1)	M	1	Carer	Community House
	28 (DW2)	M	5	Carer	Community House
	49 (DW3)	M	8	Co-ordinator	Community House
2					
	32 (DW4)	F	5	Carer	Group Home
	36 (DW5)	F	5	Carer	Group Home
TOTAL	5	3M 2F			

APPENDIX 3 (continued)

INFORMANTS PHASE 1 (AGED CARE)

SERVICE USER GROUP

Agency	Age	Sex	Years	Type
1				
	82 (A1)	F	1	Nursing Home
	81 (A2)	M	5	Nursing Home
	94 (A3)	F	8	Nursing Home
	96 (A4)	M	2	Nursing Home
2				
	78 (A5)	M	3	Hostel
	80 (A6)	M(m)	5	Hostel
	78 (A7)	F (m)	2	Hostel
TOTAL	7	4M 3F		

SERVICE WORKER GROUP

Agency	Age	Sex	Years	Type	Title
1					
	44 (AW1)	F	5	Nursing Home	Activities Co-ordinator
	46(AW2)	F	6	Nursing Home	Occupational Therapist
	48 (AW3)	F	4	Nursing Home	Nurse
2					
	52 (AW4)	F	8	Hostel	Nurse Supervisor
TOTAL	4	4F			

PHASE 1. LINKS BETWEEN SERVICE WORK AND USER GROUPS

DISABILITY	AGED CARE
<div>AGENCY 1</div> <div><div>D1</div><div>D2</div><div>D3</div><div>D4</div></div> <div><div>DW1</div><div>DW2</div><div>DW3</div></div> <div><div></div><div></div><div></div><div></div></div>	<div>AGENCY 1</div> <div><div>A1</div><div>A2</div><div>A3</div><div>A4</div></div> <div><div>AW1</div><div>AW2</div><div>AW3</div></div> <div><div></div><div></div><div></div><div></div></div>
<div>AGENCY 2</div> <div><div>D6</div><div>D6</div><div>D7</div><div>D8</div><div>D9</div></div> <div><div>DW4</div><div>DW5</div></div> <div><div></div><div></div><div></div><div></div><div></div></div>	<div>AGENCY 2</div> <div><div>A5</div><div>A6</div><div>A7</div></div> <div><div>AW4</div></div> <div><div></div><div></div><div></div></div>

INFORMANTS PHASE 2 (DISABILITY)

SERVICE USER GROUP

Agency	Age	Sex	Disability	Years	Type
3					
(3 sites)	55 (D10)	M	Physical Disability	5	Community House
	40 (D11)	F	Physical Disability *	6	Community House
	39 (D12)	F(m)	Physical Disability *	6	Community House
	40 (D13)	M(m)	Physical Disability	2	Community House
4					
(3 sites)	42 (D14)	F	Physical Disability	2	Community House
	32 (D15)	F	Physical Disability	2	Community House
	25 (D16)	M	Physical Disability	2	Community House
	30 (D17)	F	Physical Disability	2	Community House
5					
(1 site)	47 (D18)	M	Physical Disability	5	Community House
	50 (D19)	M(m)	Physical Disability	5	Community House
	37 (D20)	F(m)	Physical Disability*	5	Community House
	39 (D21)	M	Physical Disability	5	Community House
6					
(1 site)	20 (D22)	F	Intellectual Disability	5	Group Home
	32 (D23)	F	Intellectual Disability	5	Group Home
7					
(3 sites)	42 (D24)	F	Intellectual Disability	2	Community House
	40 (D25)	F	Intellectual Disability	2	Group Home
	41(D26)	M	Intellectual Disability	2	Group Home
TOTAL	17	7M 10F			

APPENDIX 5 (continued)

SERVICE WORKER GROUP

Agency	Age	Sex	Years	Type	Title
3					
	39 (DW6)	M	6	Community House	Co-ordinator
	36 (DW7)	F	5	Community House	Carer
4					
	46 (DW8)	F	3	Community House	Co-ordinator
	40 (DW9)	M	3	Community House	Carer
	47 (DW10)	F	4	Community House	Carer
5					
	32 (DW11)	F	3	Community House	Co-ordinator
	30 (DW12)	F	2	Community House	Carer
6					
	35 (DW13)	F	6	Group Home	Carer
	37 (DW14)	M	4	Group Home	Carer
7					
	44 (DW15)	F	2	Group Home	Carer
TOTAL	10	3M 7F			

INFORMANTS PHASE 2 (AGED CARE)

SERVICE USER GROUP

Agency	Age	Sex	Years	Type
3				
	96 (A8)	M (m)	4	Hostel
	90 (A9)	F (m)	4	Hostel
	91(A10)	F	1	Hostel
	77(A11)	F	3	Hostel
4				
	85 (A12)	F	1	Hostel
	93 (A13)	F	2	Hostel
	87 (A14)	F	3	Hostel
5				
	95 (A15)	F	2	Nursing Home
	82 (A16)	F	1	Nursing Home
	83 (A17)	F	2	Nursing Home
6				
	95 (A18)	F	1	Nursing Home
	88 (A19)	F-	1	Nursing Home
	66 (A20)	M	1	Nursing Home
7				
	76 (A21)	M	2	Nursing Home
	71 (A22)	F	1	Nursing Home
	78 (A23)	F	2	Nursing Home
	82 (A24)	F	2	Nursing Home
TOTAL	17	3M 14F		

SERVICE WORKER GROUP

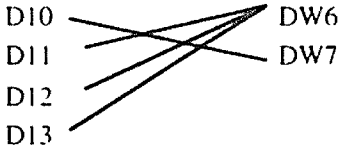

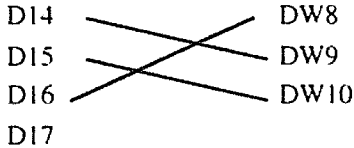

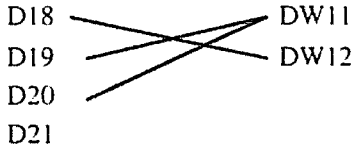

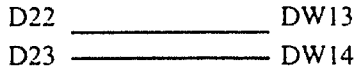
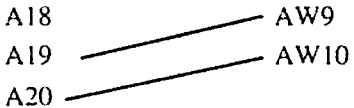
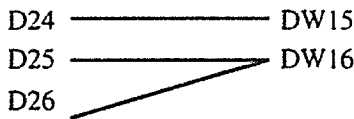
Agency	Age	Sex	Years	Type	Title
3					
	50(AW5)	F	4	Hostel	Nursing Assistant
	48(AW6)	F	6	Hostel	Nurse Supervisor
4					
	44 (AW7)	F	7	Hostel	Nursing Assistant
5					
	52(AW8)	F	2	Nursing Home	Nurse
6	30 (AW9)	F	3	Nursing Home	Nursing Assistant
	44(AW10)	F	7	Nursing Home	Activities Co-ordinator
7					
	28 (AW11)	F	2	Nursing Home	Nurse
TOTAL	7	7F			

TOTAL INTERVIEWS for data analysis 76 (actual 79: three interviews were not included due to articulation / orientation problems)

(m) married

• involves augmentative communication

PHASE 2. LINKS BETWEEN SERVICE WORK AND USER GROUPS

DISABILITY	AGED CARE
<p>AGENCY 3</p> <p>D10 DW6 D11 DW7 D12 D13</p> 	<p>AGENCY 3</p> <p>A8 AW5 A9 AW6 A10 A11</p> 
<p>AGENCY 4</p> <p>D14 DW8 D15 DW9 D16 DW10 D17</p> 	<p>AGENCY 4</p> <p>A12 AW7 A13 A14</p> 
<p>AGENCY 5</p> <p>D18 DW11 D19 DW12 D20 D21</p> 	<p>AGENCY 5</p> <p>A15 AW8 A16 A17</p> 
<p>AGENCY 6</p> <p>D22 DW13 D23 DW14</p> 	<p>AGENCY 6</p> <p>A18 AW9 A19 AW10 A20</p> 
<p>AGENCY 7</p> <p>D24 DW15 D25 DW16 D26</p> 	<p>AGENCY 7</p> <p>A21 AW11 A22 A23 A24</p> 