

**A six-month study of the impact of the Active Linkage Initiative on Quality
of Life in Licensed Boarding Houses in New South Wales.**

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I hereby certify that the work embodied in this thesis is the result of original research and has not been submitted for a higher degree at any other University or institution.

The conduct of this research was approved by the Hunter Area Research Ethics Committee (approval number: H – 180 – 1001).

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Abstract

This longitudinal study seeks to evaluate the quality of life of residents of licenced boarding houses in New South Wales, Australia following the implementation of a social, recreational and vocational program named the Active Linkage Initiative (ALI) over a six-month period. Sixty-six residents from five catchment areas across the state serviced by different ALI providers participated. The participants had a range of disabilities. The two main disability types represented were mental illness (57.6%) and intellectual disability (28.8%). The Comprehensive Quality of Life Scale – Intellectual Disability – Fifth Edition (Com-Qol – I5) (Cummins, 1997) was used to assess quality of life. The results suggest that ALI has contributed positively to the life experiences of these residents. Improvements were evident in the overall objective quality of life, and the overall domains of productivity, intimacy and emotional well-being. Objective improvements were particularly in the domain of productivity. Gains were also evident in the subjective domains of intimacy and emotional well-being. The other domains of material well-being, health, safety and place in the community showed no significant change over time. Discussion focused on the need for increased focus on habitative programming in the disability sector and the development of appropriate tools to evaluate progress. The need for further review of contentious legislation in the disability sector was also discussed.

Quality of life is an important issue for persons with disabilities in Australia. Over white Australian history there have been a number of models of service delivery to people with disabilities. In the past, the most common form of service was in institutional care. These institutions were large and hospital-like. However, during the past thirty years there has been a movement away from this form of care to community-based accommodation. This phase of service delivery has been coined the period of 'deinstitutionalisation' (Wolfensberger, 1975). As deinstitutionalisation has continued in Australia the issues of normalisation, community living and quality of life have been introduced (Woodill, Renwick, Brown & Raphael, 1994). These terms have become part of the vernacular of the disability field. They refer broadly to services provided to people with disabilities that enable, as closely as possible, for the disabled to achieve the lifestyle they might expect if they were not disabled (Flynn & Nitsch, 1980). As Australia continues to adjust policy, programs and practice to the ongoing changes in disability service, new programs have been developed to improve the quality of life of people with disabilities. A recent program is the Active Linkage Initiative (ALI). This program aims to provide social, leisure and vocational opportunities for residents with disabilities of licenced boarding houses in New South Wales. This thesis seeks to review the impact of ALI on the resident's quality of life.

The progress of philosophy and legislation in Australia with regard to service provision to people with disabilities has been very similar to that of many other western countries. While efforts have been made to improve the outcomes and degree of personal autonomy of persons with disabilities it is apparent that

some of the changes made to service delivery have not had the impact desired (Parmenter, Cummins, Shaddock & Stancliffe, 1994). In 1910 Australia established the invalid pension. Between that time and 1967 there were only minimal changes in the approach to service and to the life conditions for people with disabilities. During this time institutionalisation was the accepted mode of service delivery across a range of disability types. In 1967 the government began funding educational, residential, vocational and day activity programs, however, it was not until the 1980's that community-based residential options began to emerge for people with intellectual and/or psychiatric disabilities living in mental hospitals (Parmenter, Cummins, Shaddock & Stancliffe, 1994).

Parmenter, Cummins, Shaddock & Stancliffe's (1994) review of the history of Australian disability service provision describes the most influential changes to disability service delivery that developed from government initiatives begun in 1983. In particular they note the Handicapped Programs Review and the resulting publication of the Grimes Report (1985) *New Directions: Report of the Handicapped Programs Review and the Disability Services Act (1986)*. The focus of these documents was to improve the opportunities for disabled individuals, by increasing access to services and decreasing the restrictions placed on individual autonomy. The areas suggested for needing development were living environment, paid employment, competence and self-reliance, community participation, security, choice and positive image. The ideal of consumer focused and consumer driven practice was introduced, aiming to allow consumers with disabilities a primary role in the planning and execution of disability services

(Parmenter, Cummins, Shaddock & Stancliffe, 1994). Of key importance to the application of the Disability Services Act (1986) were the eleven disability service standards under which all government funded services were to operate with their adherence audited regularly.

These standards were as follows (cited in Australian Human Rights & Equal Opportunity Commission web page, 2004):

The Disability Service Standards

STANDARD 1: Service access - Each consumer seeking a service has access to a service on the basis of relative need and available resources.

STANDARD 2: Individual needs - Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.

STANDARD 3: Decision making and choice - Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.

STANDARD 4: Privacy, dignity and confidentiality - Each consumer has the right to privacy, dignity and confidentiality in all aspects of his or her life.

STANDARD 5: Participation and integration - Each person with a disability is to be supported and encouraged to participate and be involved in the life of the community.

STANDARD 6: Valued status - Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.

STANDARD 7: Complaints and disputes - Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service.

STANDARD 8: Service management - Each agency adopts sound management practices which maximise outcomes for consumers.

STANDARD 9: Employment conditions - Each person with a disability is to enjoy comparable working conditions to those expected and enjoyed by the general workforce.

STANDARD 10: Employment Support - The employment prospects of each person with a disability are to be maximised by effective and relevant support.

STANDARD 11: Employment Skills Development - The employment prospects of each person with a disability are to be maximised by effective and relevant training.

The changes to commonwealth legislation were intertwined with changes in the philosophy and structure of services in New South Wales. The application of the Disability Services Act (1986) and the above mentioned standards meant that all government funded services for people with disabilities were required to submit updated regular accounts of the level of adherence to the disability standards. All tenders for new services were also required to show cognisance of these standards.

Within the movement towards greater autonomy and choice and the establishment of community-based living, a number of residential options were established. The most well documented and researched form of residential care, other than institutions, is that of group homes (Cummins, 1993; Reiter, Shunit & Bendov, 1996; Donegan & Potts, 1988). In addition, in New South Wales, a number of clients who were assessed as more highly functioning than those in group homes were placed in licenced boarding house facilities formally known as Licenced Residential Centres (LRCs). These facilities were funded through a board and care arrangement with individual clients. They received some initial subsidization, however the ongoing costs were met by the board of individual

clients similar to a mainstream boarding house. While these facilities were established in accordance with the move to community-based residences, the size of the facilities range from 3 residents to over 100. The majority of these agencies represent quite a different scenario to the 'family' environment sought in group homes. Licenced boarding houses were not governed by the same Disability Standards of the 1986 Disability Services Act (see above) as they were not government funded and did not fit the criteria for services under this provision. They were licenced by the Department of Aging and Disability which addressed objective issues such as nutrition and safety requirements but licensees were not required to show their adherence to the Disability Service Standards. This produced diversity in the standard of care, highly dependent on the attitudes of the management and staff of respective houses. While there has been little research into the range of residential options now available to individuals with disabilities there has been no published Australian quantitative research investigating the quality of life of persons in boarding houses.

Deinstitutionalisation

Deinstitutionalisation refers to the movement of people with disabilities from institutional care with the objective of reversing the negative effects of being institutionalised. Some of the negative effects that have been found are: learned hopelessness, helplessness and unusual challenging behaviours (Halpern, Sackett, Binner, & Mohr, 1980); being seen as members of a deviant social group (Emerson, 1985); and a lack of basic human rights (Kebbon, 1997; Nirje, 1969).

Emerson (1985) details how various forms of resistance to the institutionalisation of people with disabilities have been present wherever institutions have operated. Similarly, Schreenberger (1981) cites the writings of Howe (1874) and Senguin (1846) as evidence of the long history of the movement. The domination of deinstitutionalisation in disability policy in the western world began in the 1970's following the political upheaval of the preceding decade, where civil rights were pushed most strongly into the public arena and consumer groups were activated to lobby government to change policy (Wolfensberger, 1975).

The resistance to institutional care, based on concerns about the effects of institutionalisation on physical and psychological health, a lack of basic human rights and reduction in adaptive functioning (Butterfield, 1987; Halpern, Sackett, Binner & Mohr, 1980; MacEachron, 1983; Meyers & Blacher, 1987), led to the closure of many institutions both in Australia and across the western world (Butterfield, 1987; Halpern, Sackett, Binner & Mohr, 1980). These closures led to new models of community-based care, including group homes and board and care facilities (Landesman, 1987).

Following the closure or reduction in size of many institutions and the subsequent introduction of community-based accommodation options, questions began to be raised with regard to the efficacy of these settings and whether they were in fact replacing larger institutions with a 'neo-institutionalisation' and isolation from the community (Gunzberg & Gunzberg, 1992). The initial studies conducted in the mid 1980's at the height of movement away from institutions were encouraging, with indications of improvements in living conditions and

increased access to staff (Halpern, Sackett, Binner & Mohr, 1980). The overall findings from this period suggest that these changes in client's living environment were not sufficient by themselves to produce positive changes in individual behaviour and ability to access the community (Baker, 2000; Cullen, Whoriskey, Mackenzie, Mitchell, Ralston, Shreeve & Stanley, 1995; Lehman, Slaughter & Myers, 1991). As Bruininks (1990) describes 'there is more than a zip code to changes in services'. He goes on to criticise the preoccupation of policy makers with the physical habitat of persons with disabilities whilst showing inadequate concern for social and psychological environments.

The main criticism of the movement into community residences is that while planning was exercised to find adequate housing in the community there was a lack of infrastructure and services to complement this movement in location in order to foster behavioural adaptation, social skill development, and leisure and recreational opportunities (Bruininks, 1990; Gunzberg & Gunzberg, 1992; Landesman – Dwyer, 1981; Neumayer & Bleasdale, 1996). Therefore, individuals who were displaying behaviour congruent with institutionalisation began to display similar behavioural patterns within smaller residences. These had in effect become mini-institutions (Bruininks, 1990; Gunzberg & Gunzberg, 1992).

Board and care facilities were introduced in Australia when larger institutions closed, as part of the deinstitutionalisation movement. In New South Wales the issues that had caused doubt about the efficacy of deinstitutionalisation became obvious in the 'boarding houses' or Licenced Residential Facilities

(LRCs) as they were formally known. In the early 1970s boarding houses were opened to meet the increasing need for accommodation arising from deinstitutionalisation. While some of the proprietors had formal training or experience working with people with disabilities this was not a requirement (Cleary, Woolford & Meehan, 1998). The boarding houses serviced people with a range of disabilities, the two major groups being those with intellectual disabilities and those with mental illness. The licences obtained for these residences focused primarily on physical living conditions with some limited support requirements (Aging and Disability Department, 1999). However, the licence requirements did not entail provisions for skill development or interaction with the community. The NSW Department of Aging and Disability (2000) conceded that while there was provision of clinical services such as doctors and psychiatrists, the majority of boarding house residents received minimal support in everyday life activities and had little contact with their wider community. Past research has indicated that the majority of residents' spare time is spent in individual pursuits with minimal contact in a group setting or with the larger community (Cleary, Woolford & Meehan, 1998). In addition to the minimal licensing requirements, the boarding house sector was not required to work within the Disability Standards. These are the standards under which government funded agencies are bound to operate.

Normalisation

The political roots of deinstitutionalisation are based in the theories of normalisation. Wolfensberger (1980), one of the key figures in developing the theory of normalisation, defines it as:

“ Use of culturally normative means (familiar, valued techniques, tools, methods), in order to enable persons life conditions (income, housing, health services, etc.) which are at least as good as that of average citizens, and to as much as possible enhance or support their behaviour (skills, competencies, etc.), appearances (clothes, grooming, etc.), experiences (adjustment, feelings, etc.), and status and reputation (labels, attitudes of others, etc.).” (p.80)

This definition clearly delineates normalisation involving much more than geographical change. Rather it emphasises the inclusion within the definition of the individual's life experience across a range of areas. However, it became evident over the past thirty years that although the physical settings of accommodation for people with disabilities may have 'normalised', the psychological environments do not appear to have undergone the same renovation.

Grunewald (1971, cited in Kebbon, 1997) proposes that normalisation has four phases of development. First a diagnostic stage, with a focus on diagnosing and formulating responses to individual needs; followed by specialisation, looking to the development of supports and services that are usually centralised.

Differentiation is the third stage where service delivery becomes more individualised and therefore more difficult; ending with decentralisation and integration, where self-determination is pronounced, characterising full normalisation.

Both of the above definitions show clearly how many of the core components of normalisation have not yet been reached in the process of deinstitutionalisation. The initial processes towards normalizing the experience of a person with a disability living in community-based accommodation may have begun but the individualised, decentralised processes have only just begun to take shape. While individual service planning is common among group homes, this is not experienced to the same extent by the boarding house population. This sector is not governed by the Disability Services Act (1986). The Act which produced such planning in government funded accommodation (Parmenter, Cummins, Shaddock & Stancliff, 1994).

There are some problems with applying normalisation theory across the field of disability research. Cummins (1997) states that applying normalisation theory across all groups fails to take into account the fact that some in the 'normal' population choose to live in circumstances that can be regarded as outside what would be referred to as a 'normalised' life experience. Further, applying this theory to all people with disabilities fails to consider the individual preferences of the disabled population. Applying normalisation principles may also have the effect of assuming that there is a positive linear relationship between objective life circumstances and subjective well-being without taking

into account the need to consider other variables. Corbett (1989) argues for caution in applying the principles of normalisation. She infers that the reality of a disabled persons experience in the mainstream community is often one of powerlessness and vulnerability in a harsh society that has little tolerance for the limitations of the cognitively impaired.

Active Linkage Initiative

The Active Linkage Initiative (ALI) program was developed by the Department of Aging and Disability (now Aging, Disability and Homecare) to improve the interaction of the boarding house population with the general service system and the community at large. Its aim was to “focus on the lifestyle needs of each boarding house resident....and design a support program specific to each resident” (Department of Aging and Disability, 2000, p. 10-11). The ALI program was established through a tendering process which recruited and funded agencies across New South Wales to activate a program based on the guidelines set by the Department of Aging, Disability and Homecare (formally Department of Aging and Disability). As funded agencies, these programs were governed by the Disability Service Standards.

These aims tie in closely with the principles of higher order normalisation proposed by Wolfensberger (1980). These principles address not only a living environment more similar to what may be expected in the community at large, but also a more culturally normative experience of behaviour, appearance, life experience, status and reputation. In order to meet these goals the proposed ALI

program aimed to facilitate access to community-based recreation and leisure services and mainstream educational and vocational agencies (Department of Aging and Disability, 2000). Facilitation of recreational activity is recommended by Luckey & Shapiro (1974) who recognise that recreational programming and skill development is essential if an individual is to find opportunities to relate to the wider community. However, the authors also review the difficulties inherent in this form of recreational program. There are few qualified staff who are aware of the needs of cognitively impaired individuals in recreation. In addition, few practical guidelines exist in the area, and public awareness of requirements and resources for these groups is minimal. Transportation problems and minimal financial support also present difficulties for these programs.

It was proposed that ALI would be delivered in three major components. The first of these was pre-skilling. It was envisaged that the skill levels of residents would be assessed and assistance given to develop the necessary skills for integration with the larger community. The second component was to link the residents with community-based leisure activities. It was envisaged that this process would begin with 'mentoring' residents into local community groups with a view to establishing mainstream community involvement. The third component was to assist residents to access educational and training opportunities within the community (Department of Aging and Disability, 2000).

In order to achieve the above aims the ALI program used a model based on programs centred around the Individual Service Plans of the residents and focusing on activities based in the wider community. Activities encompassing a

wide range of social, recreational and vocational interests were accessed or provided by ALI. Residents usually attended these programs in small groups and were often provided transport or assisted in getting to the venues via public transport. However, while this was the general mode of service delivery there was variation between the services with some focusing more on drop-in centres or skill based activities, while others preferred to focus on the social skills and integration of residents by participating more in community based leisure or sport activities.

Overall, the ALI program was developed to improve each boarding house resident's quality of life by training him or her in the specific skills that were deemed necessary to be an active participant in the wider community. It was acknowledged that boarding house residents were accustomed to institutionalised environments and that many would require opportunities to develop the social pattern of behaviour that would assist in integrating into the life of the general community, thereby increasing quality of life (Department of Aging and Disability, 2000). The current research aims to review the impact of the ALI service on the quality of life of residents.

Quality of Life

Quality of Life is difficult to define or quantify, particularly when used with the disabled population (Taylor & Bogdan, 1990). As the movement into community-based settings continues it becomes clear that despite improvements in living arrangements and the possibility of better access to the community,

people with disabilities in community care still have unmet needs that are difficult to express or have fulfilled (Stanley & Roy, 1988). Quality of life has become the social construct that has been used to explore the changing philosophy in service provision for people with disabilities. A new emphasis has been placed on equity (as determined by the consumer), empowerment and increased satisfaction with one's life. Quality of life has become the goal that services strive towards when seeking to apply the concepts of deinstitutionalisation and normalisation. (Schalock & Keith, 2000)

There is no uniform definition of quality of life for the wider population and the majority of research in the area has been conducted on marginalised or disadvantaged groups that seem to attract research interest due to the suspicion that they may be suffering a lack of it (Taylor, 1994; Taylor & Bogdan, 1990). Taylor & Bogdan (1990) assert that the dangers with this form of research may be the further dehumanising of people with disabilities or the application of standards for their lives which would be unpalatable in the wider community. They further state that quality of life needs to be researched in a way that emphasizes our common humanity rather than further marginalizing disadvantaged populations. Similarly, Taylor (1994) argues that while quality of life is a valuable area of inquiry it cannot be taken as the definitive approximation of a 'meaningful existence' and that due notice needs to be given to the limitations of scientific method and the inherent differences in how individuals define themselves. Hatton & Ager (2002) also emphasise the need for caution due to the history of western society in dealing with cognitive impairment. Constructs

such as IQ have been used by well-meaning practitioners to the detriment of consumers, sometimes leading to 'segregation and educative neglect' (p.258). Cummins (2001) also warns of the dangers of studying quality of life purely in the disabled population because measures often discount the possibility of excellence. However, he also argues that quality of life is a useful construct that, at this point in history, allows professionals to serve the people in their care in the manner that appears most useful according to their conscience and their training (Cummins, 2001; Cummins, 2002; Perry & Felce, 1995)

There have been many attempts to define quality of life. One author has collected over one hundred separate definitions (Cummins, 1996), and Hughes, Hwang, Kim, Eisenman & Kilian (1995) report over one thousand measures dealing with quality of life or one of the aspects contributing to it. Cummins' (1996) appraisal of the existing definitions for quality of life outlines the elements of an acceptable definition that seem to emerge from the literature. The key elements identified were:

1. A multi-dimensional model of quality of life that encompasses objective and tangible qualities as well as the lived experience of subjective qualities. He also found that most authors recommended a range of domains be examined.
2. An awareness and reflection of cultural norms and aspirations in the objective dimensions with recognition that these will change between cultures.
3. Recognition within the subjective domains that individuals will place varying importance on different areas in their life. Tools should give due weighting to these areas in an individual's experience.

4. Reflection of the current understanding of quality of life as a construct that encompasses all areas of an individual's experience.
5. An ability for the construct of quality of life to be operationalised.
6. Equal application to all people under all circumstances to avoid sub-groups having their quality of life being defined in a manner that would be unacceptable to the wider community.

Based on his appraisal of the literature Cummins (1996) offers the following definition:

'Quality of life is both objective and subjective, each being the aggregate of seven domains of: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Objective domains comprise culturally-relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by importance' (p.19).

One of the key elements to defining quality of life, as previously noted, is a focus on its multi-dimensionality. While there are some differences in the domains forwarded by key authors in the area many of the reported elements are very similar. Schalock & Keith (2000) identify eight core determinants of quality of life: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. Cummins (1996) research has identified material well-being, health, productivity, intimacy, safety, place in the community, and emotional well-being

as the core elements of quality of life. Key to the definitions given by each of these authors is the influence of how the individual is able to interact with the world and the social opportunities they are afforded by their lifestyle. This rejects the idea that quality of life is an individualised state focusing on health and functional status (Cummins, 2000), and brings the focus to interaction in the community with others (Rapley, 2000).

Assessing Quality of Life

When testing quality of life there are a number of methodological issues that warrant consideration. Some of the more important issues discussed by Heal & Sigelman (2000) when interviewing individuals with reduced cognitive capacity are responsiveness, reliability, consistency and agreement with factual records.

Heal & Sigelman (2000) discuss the difficulty of using mainstream quality of life tools with individuals with reduced cognitive function and the resulting low responsiveness. The difficulty arises because these tools are usually designed to be read by people with a reading ability of no lower than high school age, where many cognitively impaired individuals have neither the reading capacity nor the understanding to comprehend the questions. However, Sigelman, Winer and Schoenrock's (1992) research indicated that when questions were given using a binary choice or using faces to describe feelings, over 80% were able to provide accurate responses. Heal & Sigelman (2000) suggest that while it was evident in their research that those individuals with an IQ deemed

severely impaired were unable to answer verbal questions, those with mild or moderate functioning were able to respond to simple questions in a variety of forms. Hatton & Ager (2002) state that 'if the validity and reliability of quality of life interviews cannot be established for the majority of people with intellectual disabilities, then the utility of self-rated quality of life measures used directly with people with intellectual disabilities ... is questionable' (p.255). To which Cummins (2002) replies that most people with an upper-moderate or mild level of intellectual disability are able to reliably and validly respond to subjective quality of life questions. While there are difficulties in assessing this in severely impaired individuals due to the problems of validity when using proxy measures, he affirms that this should not lead practitioners to ignore the data indicating that the population of people with an intellectual disability is skewed towards the mild/moderate range (Cummins, 2002) who are capable of reliably responding.

Heal & Sigelman (2000) also discuss the issue of reliability. While their research suggests that two-week test-retest reliability was high (87%) when testing children with cognitive impairments, their results also suggest that this is inflated by that population's tendency to answer 'yes' to questions. When multiple-choice answers were given using faces the test-retest reliability was only 46%. However, when the few who were able to answer multiple choice questions without pictorial assistance were questioned the reliability rose to 72%. Cummins (2002) again states that while it is clear that most people with severe intellectual disabilities will not be able to use a binary scale, the majority of those with higher

level functioning can reliably respond to these questions when assessed using a pre-testing protocol.

The next criterion examined by Heal & Sigelman (2000) was that of consistency in responding. They looked at the issue of whether individuals with cognitive impairment would answer appropriately if positively and negatively worded questions were asked about the same issue. The trend to answer positively to both positively and negatively worded questions was strong, ranging from 39 – 51 %. They also propose that the cognitively impaired population is one that is particularly vulnerable to socially desirable responding. However, their research also suggests that the amount of experience an individual had in answering questions increased the consistency of their responses markedly.

The final area that was explored by Heal & Sigelman (2000) was that of the agreement of responses with informants or factual records. Their discussion analysed the low level of accurate responses when compared to these other two sources of data. The majority of the discrepancy came from underreporting by the cognitively impaired individual.

To counter these issues Heal & Sigelman (2000) suggested a number of strategies. The first is to use the optimal questioning techniques for the group. Given the result that verbal multiple choice responding was of little use for the majority of the group, binary choice questions are encouraged. They also noted that pictures enhanced the level of responsiveness and reduced the tendency towards recency when answering questions. The second approach they encouraged is to include an acquiescence sub-scale to assess the individual's

ability to reliably answer questions. The third strategy they proposed is to either rely entirely on carer's data, a suggestion that other research has shown does not always accurately predict the views or satisfactions of the consumer (Harner & Heal, 1993), or to compare carer's data with that of the individual client for accuracy. The last suggested strategy is intended to screen the individual to determine responsiveness to questions, to determine the validity of responses to simple questions and to gauge the presence of response biases such as recency and social desirability. This strategy would mean combining testing from the participant and the carer if the respondent proved to have difficulty maintaining accuracy of responses. Cummins (1997) Com-Qol – I advanced on the existing tools by providing a test with a pre-testing protocol as described above with questions progressively moving from concrete to abstract. However, as Cummins & Baxter (1994) concede this does not deal with the issues of response bias or provide information for individuals with severe cognitive impairment.

Some questions arise on using these recommendations when testing people with disabilities. Cummins (1997) reviewed the psychometric findings on likert scales and concluded that in order to reflect the highest level of variability it was preferable to use a higher number of points on likert scales. He found that when using a pre-test protocol to gauge the level of complexity an individual could handle, most people with a mild intellectual disability were able to reliably use a five point pictorial likert scale (Cummins, 1997; Cummins, 2002).

A further issue that has arisen from the literature with regard to assessing quality of life, is the conceptualisation of quality of life as a measure of a lived

subjective experience rather than a purely objective measure (Cummins, 2000; Rapley, 2000). This has implications for the kinds of questions that are required if one is to examine the construct of quality of life to the fullest possible extent. It also requires that questions deal with subjective as well as objective facets of the individual's life. This is a particularly difficult task in dealing with people with cognitive impairment as many do not have the words to communicate their feelings which makes their experience difficult to access (Perry & Felce, 1995; Taylor & Bogdan, 1990). As Cummins (1998) states, the process of determining a subjective measure of quality of life has been notoriously difficult to operationalise. He suggests that multiple facets of subjective well-being be analysed separately. Similarly, Felce & Perry (1995) suggest that life conditions and life satisfaction need to be interpreted in line with what an individual values in their experience. There is recognition from these authors of the inherent difficulty in accessing this information from individuals with cognitive deficits, however both Felce & Perry (1995) and Cummins (1996) suggest that pre-testing assessment of an individual's ability to discriminate between levels of satisfaction is a line of methodological rigour worth pursuing. Cummins (2002) concedes that this invariably rules out individuals within the severe range of impairment.

There has been recent debate about the efficacy of using subjective measures to assess the level of quality of life as a result of changes in living conditions (Cummins, 2001; Cummins, 2002; Hatton & Ager, 2002). While subjective quality of life remains a recommended area of assessment in the disability field (Schalock, 1997), the key issue in this debate is that while

objective quality of life can be altered by circumstantial changes, subjective quality of life seems to be more influenced by endogenous characteristics and usually has a non-linear relationship with environmental conditions (Cummins, 2001; Hatton & Ager, 2002). However, Cummins (2001; 2002) concludes that while this factor seems to remain 'homeostatic' or stable under normal, acceptable living conditions; he hypothesizes that when a shift occurs in subjective quality of life it is due to the previous standards of living being unacceptable, thus creating an instability in the subjective quality of life. That is, the standard of living has been outside the normal range and insufficient to maintain a stable quality of life (i.e. homeostasis). He further postulates that this increases the importance of subjective measures of quality of life since, similar to the physical homeostasis seen in blood pressure and temperature, when homeostasis is disrupted it is a clear indication of problematic circumstances (Cummins, 2002). This view is not shared by Hatton & Ager (2002) who argue that because this subjective quality of life needs aversive life circumstances to show significant change it is not a useful indicator of the success of service provision. In addition, they state that the lack of specificity about the required level of aversive circumstances for homeostatic defeat makes the variable unclear and unmanageable. However, Cummins' (2002) research has indicated that if a group has a mean subjective quality of life of less than 70% of the scale maximum on the Com-Qol (I), their subjective quality of life will be 'highly sensitive to improved living conditions' (p.265). Those above this threshold are likely to show less change on this measure than those below. This line of

questioning then begs us consider whether boarding house life conditions are aversive to the degree that they fall below the level of 'homeostasis' for subjective quality of life.

Comparison of Measures of Quality of Life

As previously discussed quality of life is a concept that has been assessed using many different definitions and many different tools (Cummins, 1996; Hughes, Hwang, Kim, Eisenman & Kilian, 1995). The question that remains when looking to assess quality of life in a population with cognitive deficits is which tool gives the most thorough, reliable and valid assessment of individual experience. Cummins (1997) conducted a review of thirteen tools that had been developed after 1985 and used the following criteria to assess their efficacy. While these criteria are not universally accepted they have received promising reviews from two expert groups of researchers (Cummins, 2001).

1. Both objective and subjective quality of life should be measured.
2. Each objective and subjective dimension should be measured through a number of life domains. These domains, in aggregate, should represent the total quality of life construct.
3. Measures of domain satisfaction should be weighted by the importance of each domain to the individual.
4. The instrument should have adequate reliability, validity and sensitivity.

5. The scale should be equally applicable to non-disabled people thus ensuring normative comparisons of life quality.
6. The response mode and choice of answers should reflect psychometric theory and strike a balance between reliability and sensitivity.
7. The instrument should be brief, simple to administer and easy to score.
8. A pre-test should be used to establish that respondents can comprehend the questions.

Of the thirteen instruments reviewed by Cummins (1997) only three addressed both objective and subjective quality of life in persons with cognitive deficits. He found that each of these instruments performed well on the following criteria: giving a clear definition of quality of life that was to be assessed; measuring quality of life across a range of domains in objective and subjective experiences; using simple administration and scoring; and providing an adequate level of psychometric data. However, there were some key differences addressed in the author's assessment of these tools with regard to the aforementioned criteria. The three remaining tools were the Quality of Life Interview Schedule (Developmental Consulting Program, 1990) (QUOLIS), the Quality of Life Questionnaire (Schalock & Keith, 1993) (QOLQ) and the Comprehensive Quality of Life Scale (Cummins, 1993) (ComQol – I). In reviewing these tests Cummins (1997) concluded that while the QUOLIS covers admirable breadth, its impractical nature, requiring two hours time for administration and a two-day training course, makes it an improbable instrument of choice. Cummins (1997)

declared the QOLQ and the ComQol-I both met the minimum standard according to the criteria already established. Both tools report acceptable psychometric properties, include objective and subjective measures and have the same number of questions per domain. Both tools were subjected to continual review and development. The two major differences between these tools are that firstly, the Com-Qol – I keeps the objective and subjective domains separate, while the QOLQ combines them; and secondly the QOLQ only attributes one of its four scales to satisfaction and the constructs measured seem quite different to those data from the objective scales. The Com-Qol – I uses the same domains for the objective and subjective scores (Cummins, 2001). However, as Cummins (1997) concedes there are limited data for the ComQol-I outside the author's laboratory. While the review criteria appear soundly based in the literature on quality of life it is important to remember that the reviewer was also the developer of Com-Qol – I, one of the tools that was found to be most useful. An independent review of the tools would be desirable.

Quality of Life in People with Disabilities

Within the current body of literature, many of the studies into quality of life of people with disabilities assess the impact of deinstitutionalisation on the person's experience following the closure of the institution they had inhabited. The majority of literature indicates that following movement into community-based accommodation, a significant increase in material well-being and home skills (i.e. cleaning, self-care etc) was evident. Lehman, Possidente & Hawker

(1986) conducted a study in the United States comparing ninety-nine residents of an in-patient psychiatric institution to ninety-two residents of community residence programs licenced by the state with a previous history of in-patient psychiatric care. They found an increase in objective life circumstances in those in community residences, although this group also had lower levels of clinical pathology. Cummins' (1993) longitudinal study of the St. Nicholas Project in Australia, where residents with severe/ profound intellectual disability aged between 5-26 years (mean age = 9) were moved into community residential units from a hospital, also indicated positive gains in objective quality of life indicators. Similarly, Conneally, Boyle & Smyth (1992) conducted a two year study of eleven individuals with severe/ profound intellectual disabilities. They traced their move from hostel accommodation to group homes in Ireland. The results indicated an improvement in objective life circumstances.

However, a common finding in the research into quality of life changes when a group is moved from an institution into community-based settings is that the level of integration with the wider community remains low. Lord & Pedlar (1991) undertook a qualitative study of the life experiences of eighteen people with severe 'mental retardation' four years after moving into a community setting from an institution in Canada. Results indicated that while most of the participants lived busy lives that might be viewed as productive, they were often viewed as visitors to the community rather than part of it. Cummins' (1993) research similarly noted that social integration remained very low following deinstitutionalisation. Donegan & Potts (1988) study of nine individual's with

mental handicaps living alone in the community also indicated a lack of social integration into the community. Studies seem to indicate that some of the major factors influencing the degree of social integration following a move to community-based accommodation are: the attitude of staff to interactions; activities experienced by the residents (Landesman-Dwyer, 1981; Lord & Pedlar, 1991), and the number of residents in the facility (Conneally, Boyle & Smyth, 1992).

The boarding house population is a unique group in a number of ways. Firstly, it does not group individuals in care based on type of disability. Most residences consist of a mixture of disability types, primarily intellectual disability and mental illness. The Department of Aging & Disability (1999) reported the following spread across disability types at that time: 40% psychiatric, 31% intellectual disability, 15% alcohol related brain damage, 5% aged specific problem, 5% physical illness, 3% organic brain syndrome; 43% with a dual diagnosis. The existing body of literature however does not provide data for such multi-disability residences, most look either specifically at those with intellectual disabilities or at mental illness.

While there are important differences between intellectual disability and mental illness there are cognitive deficits associated with both conditions. Some of the residents with mental illness who live in boarding houses are functioning within the normal cognitive range, however many have some form of cognitive deficit, either due to medication side-effects or to negative symptoms associated with mental illness. As Lehman (1988) states, while some mentally ill persons have

the capacity to complete extensive written questionnaires many are either unable or unwilling to do so.

The combination of disability types within boarding houses brings with it unique challenges in finding suitable quantitative instruments. The instruments used with this group need to be accessible for those with mental illnesses who are able to give reliable results about themselves but incapable of using traditional extensive questionnaires (Lehman, 1983; Lehman, 1998). They also must be accessible to those individuals whose main diagnosis is an intellectual disability or another diagnosis such as brain injury that involves impairment of higher levels of cognitive functioning.

Secondly, there are large differences in the number of residents per boarding house. The research on group homes suggests the usual number of residents is five or six (Cummins, 1993). However, the occupancy of boarding houses varies from three to over one hundred. The research by Conneally, Boyle & Smyth (1992) indicated that one of the significant factors in the progress of group home residents was the occupancy level of the group home. In contrast, Landesman – Dwyer (1981) states that there is little difference in quality of care between houses for 6-20 people. Given the large amount of variation between boarding house numbers this variable alone may be influential in the quality of life experienced by boarding house residents.

Quality of Life in Licenced Boarding Houses

Lehman, Slaughter & Myers' (1991) research in Los Angeles with psychiatric patients investigated the hypothesis that a 'quality of life gradient' exists. This gradient would show steady improvement in quality of life from state hospitals, to large community-based board and care residences, to small group homes, to scattered supported apartments. Their data, gathered on a quality of life interview devised by one of the authors of the study, suggested that this 'gradient' did exist for these groups in the areas of satisfaction with living situation, safety and health. However, no significant difference was found between the groups in the areas of family relations, number of leisure activities, social relations and non-violent victimization. These results support other studies that indicate material improvements do not always lead to social improvements (Bruininks, 1990; Cummins, 1993; Donegan & Potts, 1988; Gunzberg & Gunzberg, 1992).

Conneally, Boyle & Smyth (1992) conducted research into quality of life changes for residents with a severe and profound intellectual disability as they moved from a boarding house to smaller group homes in Ireland. Their findings indicate an improved level of adaptive behaviour, lower levels of inappropriate behaviour, an increased number of personal possessions, an increased number and variety of leisure activities, an increase in variety and frequency of outings outside the home (although this remained well below the average for similar aged non-disabled individuals), and improved perceptions of care by family members. These results support Lehman, Slaughter & Myers (1991) research into the improvement of life quality depending on accommodation facility. They further

suggest that there are significant areas of quality of life that are not attended to in a boarding house environment

There has only been one published study into quality of life in boarding houses in Australia (Cleary, Woolford & Meehan, 1998). This study focused on residents of boarding houses with mental illness in the Central Sydney Area Mental Health Service, one of the groups who were studied in this current research. The aim of the study was to investigate the residents' perception and understanding of life in a boarding house from a nursing perspective. The study was conducted using semi-structured interviews of fourteen residents of boarding houses in the Central Sydney Area. The participants were chosen in consultation with a multi-disciplinary team on the basis of their ability to give informed consent and their ability to articulate their experiences. While they were not randomly selected they were chosen to give a broad cross-section of the boarding house population. The data were analysed qualitatively.

The results of the study indicated that participants were generally satisfied with the quality of their accommodation and services. However, as a group, they did not have the protection of secure tenure afforded to private tenants. This may have caused them to be reluctant to complain about services and reinforced their disempowerment. The results indicated that daily living was highly structured with regard to meals and medication times and spontaneity did not appear to be encouraged. The major source of complaint in this area was lack of money. Social activities appeared to be quite varied but it was apparent that these activities were individual pursuits and were rarely performed in a group setting or in the

community. Some participants undertook activities that improved their social relationships but this depended on the individual's motivation. With regard to relationships with family, friends and the community the results indicated a variety of responses, some showing little contact, others having a number of close friends and associates. The final area of investigation by the researchers was the perceptions of the future. The results indicated that the participants saw little possibility for change in the future and a feeling of hopelessness was often described.

The researchers concede that there are a number of limitations to this study. The most obvious issues are the sample size and lack of randomisation that may mean these results are skewed by selection processes. In addition, the study was based on the premise that boarding house residents would have the cognitive capacity to be insightful about the qualities and restrictions of boarding house life and provide descriptive information. This information was less forthcoming than anticipated. The study also did not use data from those clients with reduced cognitive capacity who make up a large portion of the boarding house population, nor were people with disabilities other than mental illness included in the study. They also focused only on the Central Sydney Area where the boarding houses are closer to transport and hence community activity is more accessible than for residents of boarding houses in other areas of New South Wales. This is a factor that Conneally, Boyle & Smyth (1992) found to be influential in the number of opportunities afforded an individual. However, despite these limitations the study made clear the need for continued research into the quality of life of boarding

house residents. The research report recommended the need for a range of government agencies to liaise and work with community groups to acknowledge and recognise the presence of boarding house residents in their community and encourage their participation in mainstream and disability specific activities.

Clery, Woolford & Meehan's (1998) research was conducted two years before the ALI program was introduced into boarding houses. The ALI service was begun following the realisation of the lack of support received in the boarding houses to improve access to community-based recreation services and educational and vocational agencies (NSW Ageing and Disability Department, 2000). The ALI program's objectives were to deliver support services to residents of boarding houses by pre-skilling the residents to improve abilities to participate in the community; establishing and assisting residents in mainstream community integration; and by assisting residents to access educational and vocational training opportunities (NSW Ageing & Disability Department, 2000). Since this program was initiated there has been no published research into the impact of the program or the well-being of boarding house residents. Nor has there been any published research conducted using a quantitative research design and using responses from people with the breadth of level of disability that reside in boarding houses across the State.

The small existing body of literature dealing with the quality of life of boarding house residents gives us some indication of their lived experience and how a program concentrating on social, recreational and vocational needs might enhance this. The results can be broken into the domains of quality of life devised

by Cummins (1997), of material well-being, health, productivity, intimacy, safety, place in the community and emotional well-being.

Material Well-being

As Cleary, Woolford & Meehan (1998) discuss, money was a major concern for most boarding house residents interviewed and is a key issue for this population. This was felt particularly with regard to the limits this placed on choices of leisure and recreational pursuits. Data from the Department of Aging & Disability (1999) suggest that most residents pay between 87.5% and 100% of their pension for their boarding house accommodation leaving very little disposable income. In addition, research suggests that restrictive practices to 'protect' residents remain widespread and while there are some efforts to teach shopping skills in classroom environments, this rarely extends to the encouragement of residents to take full control of their money (Gunzberg & Gunzberg, 1992). Research into the movement from a boarding house or hostel to a group home has also indicated a marked increase in the number of personal possessions (Conneally, Boyle & Smyth, 1992; Lehman, Slaughter & Myers, 1991). It is unclear what the impact of the ALI program might be in this area. It is possible that as leisure pursuits were one of the areas where financial constraints frustrated clients the impact of a program that offered new experiences of leisure pursuits might lessen this dissatisfaction. However, the ALI program also provides a heightened interaction with the wider community that may in fact

emphasise the differences in economic status and their inability to afford more expensive leisure pursuits.

Health

In Lehman, Slaughter & Myers' (1991) research personal health is an area where residents saw a marked improvement when they moved into group home accommodation from a boarding house. However, the Australian research suggests that while residents of boarding houses were aware of health care providers entering the residence, it was not one of the key areas of importance (Cleary, Woolford & Meehan, 1998). Part of the boarding house reform strategy was to provide an increase in personal care services to residents, however this was a separate program to ALI. While there may be health gains over time for residents these may be due to the health care initiatives by the Department of Aging, Disability and Homecare over this time period, rather than ALI.

Productivity

The Cleary, Woolford & Meehan (1998) research does not speak directly of the residents experience of productivity, although they do note some of the residents were able to create opportunities to be productive for themselves by participating in individually determined activities. They also noted that in some cases residents were involved in household chores. Lehman, Slaughter & Myers (1991) found that residents of the Los Angeles board-and-care facilities participated in fewer leisure activities compared to residents of groups homes,

state hospitals and supported apartments. Conneally, Boyle & Smyth (1992) indicated this was a major area of improvement in variety and frequency of outings when moving from a hostel to a group home. Hoover, Wheeler & Reetz (1992) found that inadequate provision of leisure and recreation services for persons with intellectual disabilities contributed to poor quality of life. Similarly, Neumayer & Bleasdale's (1996) research indicate the need for a leisure education program where individuals with cognitive impairments could learn to use their free time in a way that didn't lead to boredom. ALI's focus on providing social, recreational and vocational activities for residents is designed to improve their level of productivity.

Neumayer & Bleasdale (1996) state that one of the most influential factors on quality of life in residents living in supported accommodation services in Australia was the opportunity to participate in gainful employment which allowed them an income, relief from boredom and an opportunity to contribute to society. Likewise, Reiter & Bendov (1996) found employment to be the highest determinant of quality of life in residents with developmental disabilities. While ALI is designed to focus on this area, in reality many boarding house residents have been so cut off from the wider community that their social skills have not been developed to a level that will allow vocational options to be explored in the near future without extensive skill development (Department of Aging and Disability, 2000). Therefore, it is probable that the increase in ALI activities will increase individual levels of productivity in leisure and recreational pursuits, while it is unlikely that this will extend to the vocational arena.

Intimacy

The domain of intimacy is made up of a combination of family contact and friendships (Cummins, 1997). Lehman, Slaughter & Myers (1991) found that Los Angeles board-and care residents tended to have fewer social relations than either patients in the state hospital or group home residents. This was also a core element of Cleary, Woolford & Meehan's (1998) investigation with Sydney boarding house residents. Many of the participants cited invasive or aggressive relationships as part of the boarding house life experience. In Neumayer & Bleasdale's (1996) research they found that most participants formed their friendship networks from segregated programs and were unconcerned about the stigma associated with such programs. The ALI program was designed to increase access to friendship and community networks with a view to meeting the intimacy needs of residents and giving opportunities for connection in new environments.

While some residents in Cleary, Woolford & Meehan's (1998) study of boarding house residents had maintained intimate relationships with family, many had not. Similarly, Lord & Pedlar (1991) found that for 80% of residents in group homes in Canada, family contact occurred less than once a month. It is unlikely that the ALI program would have much impact on family relationships as the majority of boarding house residents had only occasional relationships with families. The level of contact in family relationships had generally been in place for many years

Safety

Lehman, Slaughter & Myers (1991) found a marked increase in the perceptions of safety as residents moved from a boarding house to a group home. Similarly, in Cleary, Woolford & Meehan's (1998) research they reported that while most residents felt generally satisfied with their accommodation some indicated that there was often exposure to aggression or offensive behaviour. It is unlikely that the ALI program will make any improvements in the perceived safety experienced by residents. Although it may improve their social skills in the community, the program does not change the living environment where there is limited privacy and a small ratio of staff to residents.

Place in Community

Cleary, Woolford & Meehan (1998) noted that activities participated in by boarding house residents were usually individual pursuits or occasionally bus trips. There was little evidence of a 'normalised' experience of integrating with the community. Similarly, the somewhat controlled environment of boarding house life was thought to impinge on the personal freedom that might encourage more extensive community participation. Likewise, Lord & Pedlar's (1991) research indicated that the majority of participants in their study seemed more like visitors to the community rather than part of the community because focus was placed on keeping the residents busy rather than integrating with community life. Donegan & Potts (1988) found that there was reduced opportunity for

integration into community life due to the limited use of leisure facilities and described the need for more support and encouragement in this area. This is one of the key aims of the ALI program, with the model of service enhancement focused on integrating the residents into the life of their local community (Department of Aging and Disability, 2000). However, as previously mentioned the ALI program also works within the constraints of boarding house life and of funding. Gains in the residents' place in the community may be limited due to these constrictions.

Emotional Well-Being

One of the most powerful results in the research by Cleary, Woolford & Meehan (1998) is the pervading sense of hopelessness and fear about the future that was present in many of the residents interviewed. While their research did not focus directly on emotional well-being of residents there are numerous issues that would indicate that this might be an area of concern. Some of the issues that might lead to this conclusion are: the unpredictable nature of their tenure as residents; the many recent boarding house closures (Department of Aging and Disability, 2000); the absence of consumer rights as private tenants; and living with numerous people with challenging behaviours in an isolating environment. The ALI program is designed to increase exposure to the community and provide richer networks where residents can participate. As such, it is reasonable to suggest that as clients become supported by a wider range of people and increase their repertoire of activity, their level of emotional well-being may improve.

However, since the living environment does not change with the ALI program, some of the variables that may decrease emotional well-being may not be alleviated.

The aim of this study is to investigate the impact of the ALI program on the quality of life of residents in boarding houses in New South Wales using the ComQol-I.

It is hypothesised that residents who participate in a greater number of ALI hours will have increased quality of life.

It is hypothesised that there will be a positive relationship between the change in hours of participation in ALI and quality of life.

It is hypothesised that there will be an overall improvement in the objective quality of life of residents over time as the ALI program is implemented.

It is hypothesised that, in accordance with Cummins (2002) theory of 'homeostasis', that if the mean subjective quality of life for the group falls below 70% SM there will be an overall improvement over time in the subjective quality of life of residents as the ALI program is implemented. If the mean subjective quality of life for the group is measured to be above 70% SM it is hypothesised that there will be no significant improvement over time in the subjective quality of life of residents as the ALI program is implemented.

It is hypothesised that there will be no significant change in the domains of quality of life of material well-being, health and safety.

It is hypothesised that there will be significant gains in the domains of productivity, intimacy, place in the community and emotional well-being.

Method

Participants

Sixty-six participants contributed to the study. They comprised 17 female and 49 male residents of licenced boarding houses in New South Wales (see Figure 1). There were no participants between 18-22, five between 22-30, five between 31-40, seventeen between 41-50, twenty-five between 51 – 60, seven between 61-70, and seven 70+ (see Figure 2). Participants were drawn from five geographical areas that were serviced by different ALI providers. These areas were: the Hunter area, serviced by Castle Personnel Services Inc., the Western and South-Eastern Sydney areas, serviced by Aftercare, the Central Sydney area, serviced by the Newtown Neighbourhood Centre, the Central Coast area, serviced by Samaritans, and the Wentworth area, serviced by Blackheath Neighbourhood Centre. These areas were chosen as they represented a broad cross section of the clientele of the ALI project, incorporating both rural and metropolitan areas.

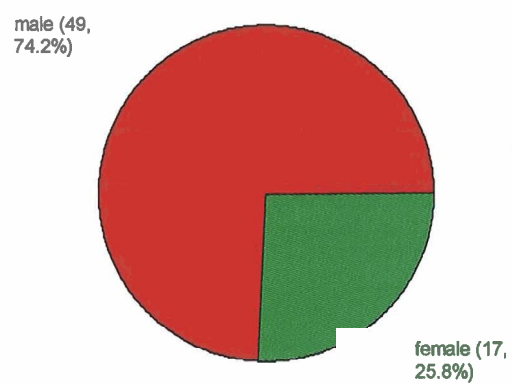


Figure 1. Gender of participants.

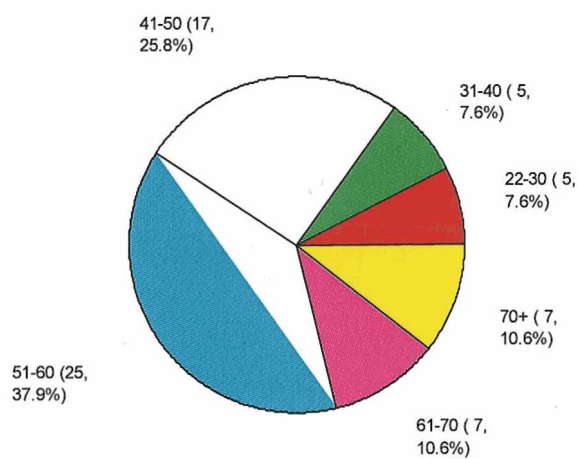


Figure 2. Age of participants.

Client lists were received from each of the ALI services and thirty residents were randomly selected. These thirty residents were approached by Dept. of Aging, Disability and Homecare staff and asked if they would like to participate. Some clients were unable to participate due to lack of access provided by the Licensed Residential Centre, while others chose not to participate. The participants comprised 13 clients of Castle Personnel Services Inc., 15 of Aftercare, 11 of Newtown Neighbourhood Centre, 17 of Samaritans and 10 of Blackheath Neighbourhood Centre (see Figure 3). Overall, of the 150 participants randomly selected, 56 did not consent to participate for the initial round of interviews or were not given permission to participate from the boarding house management. Out of those 94 participants who agreed to participate, the quality of life and demographic data in this report is based on data from 66 individuals. Twenty - eight individuals who had agreed to participate were unable to complete both rounds of testing for the following range of reasons: fifteen were either unable to complete the pre-test protocol and either responded acquiescently or were unable to discern between points on a two point pictorial likert scale; three were physically or psychologically unwell by the time of the second interview; two were unavailable to interview; six had relocated and two were deceased.

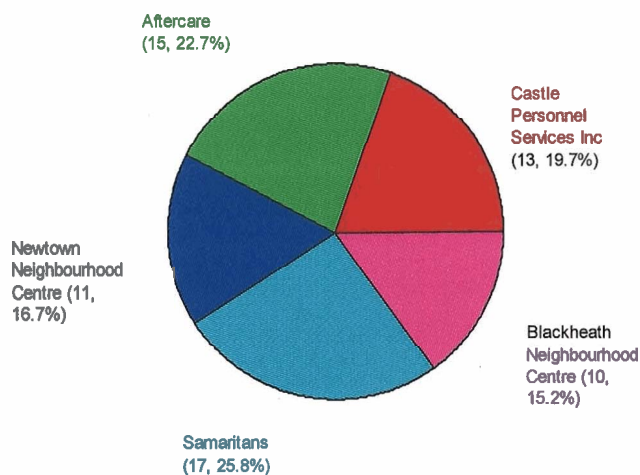


Figure 3. ALI provider of participants.

The participants comprised 36 (54.5 %) from metropolitan areas, and 30 (45.5%) from rural areas (see Figure 4). Transport was readily accessible for 38 (57.6%), somewhat accessible for 27 (40.9%) , and not accessible for 1 (1.5%) (see Figure 5). The primary disability type for each of the clients was: 4 (6.1%) alcohol related brain damage, 1 (1.5%) a hearing impairment, 38 (57.6%) a mental illness, 0% a physical disability, 1 (1.5%) a disability due to age, 19 (28.8%) an intellectual disability, and 4 (4.5%) other organic brain damage (see Figure 6). 11 (16.7%) also reported having a secondary disability.

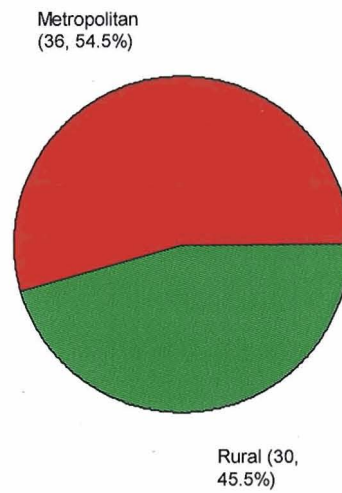


Figure 4. Location of participants.

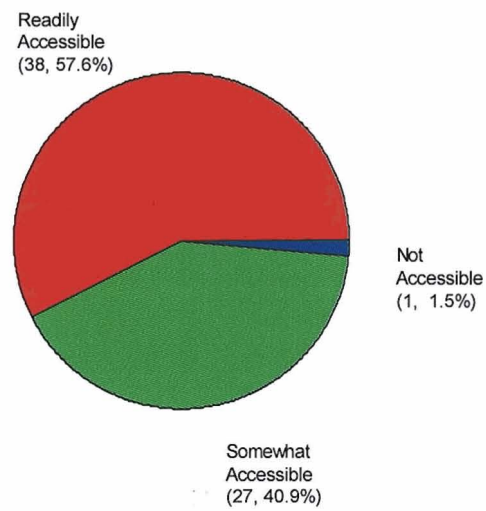


Figure 5. Transport available to participants.

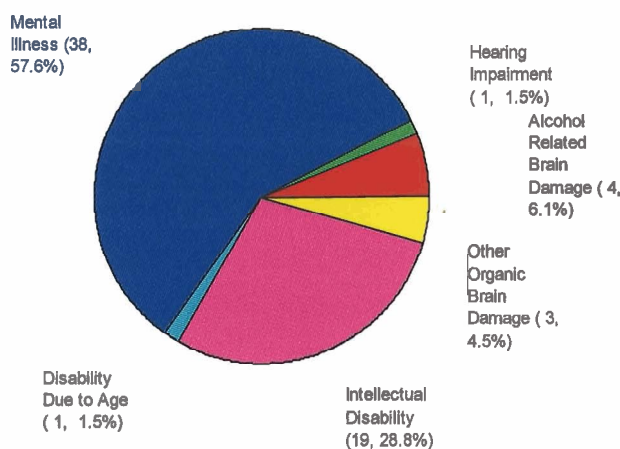


Figure 6. Primary disability of participants.

There was a wide range in the level of cognitive impairment within the sample dependent on the level of disability present. The sample ranged from those who had been diagnosed with mental illness and displayed only minor cognitive difficulties to those with high level cognitive impairment from an intellectual disability or brain damage. In order to assess the level of cognitive impairment present in the individual and to judge how and if testing would proceed a pre-test protocol was used that examined the individual's ability to discern between a 2, 3 or 5 point pictorial likert scale. From the results of this scale forty-eight participants were able to use a full five point scale, fifteen participants were able to use a three point scale and three participants used a two point scale (see Figure 7).

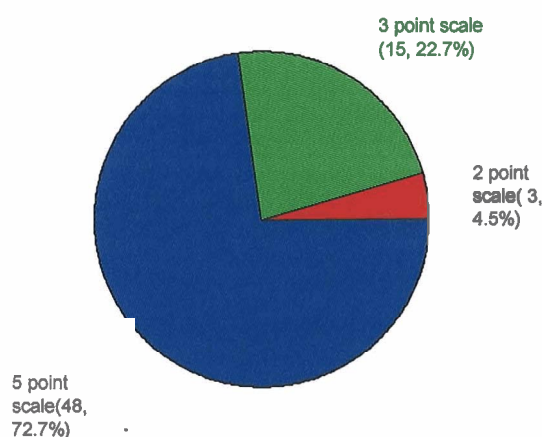


Figure 7. Ability to discern between choices on pictorial likert scale.

The participants spent an mean total of 49.6 hours (s.d. 44.75, median 40.58) with ALI services in the first six months, and an mean total of 68.9 hours (s.d. 87.8, median 32) with ALI services in the second six months. The participants spent a mean total of 11.34 hours (s.d. 25.9, median 0) in activities provided by services external to ALI (or linked services) in the first six months and a mean total of 22.2 hours (s.d. 61.11, median 0) in externally sourced activities in the second six months.

Materials

Quality of Life was measured using the Cummins (1997) Comprehensive Quality of Life Scale – Intellectual / Cognitive Disability (5th edition) (ComQol – I5) (see App. A). The ComQol – I5 relies on a pre-test protocol that assesses an individual's tendency

to respond acquiescently. The test comprises both an objective and a subjective section. The objective section of the test consists of 21-items dealing with objective information in the areas of material well-being, health, productivity, intimacy, safety, place in the community, and emotional well-being. The majority of the objective questions were completed on a five point likert scale by the administrator based on the responses of the participant. The subjective portion of the test comprised two lists of questions assessing the importance and the individual's satisfaction in the areas of material well-being, health, productivity, intimacy, safety, place in the community and emotional well-being. A pictorial likert scale was used to facilitate communication for participants and prior to testing, participants were assessed for their ability to use either a 2, 3 or 5 point pictorial likert scale.

The Com-Qol I-5 was devised by Robert Cummins (1997) to provide a test that could be administered to an individual with cognitive impairment that would assess both objective and subjective variables of Quality of Life and operationalise quality of life definitions (Cummins, 1997). It was also designed to allow for direct comparisons between those with and without cognitive impairment within the community. It has two parallel scales, one to be used with adults without cognitive impairment (Com-Qol – A) and the other for use with non-disabled adolescents attending school (Com-Qol-S).

Most of the literature regarding the Com-Qol-I has focused on formative issues in the development of the scale (Cummins, 1997; 1999; 2001;2002; Hatton & Ager, 2001; 2002). The Com-Qol-I has been used in an Italian-Australian comparison of quality of life of intellectually disabled people living in the community (Verri, Cummins, Petito, Vallero, Monteath, Gerosa, & Nappi., 1999).

In Cummins (1995) previous research he established the norms for subjective quality of life in western countries as 75 ± 2.5 % SM (percentage of scale maximum data). This norm was replicated in Cummins (1996) more extensive research setting a point of comparison for quality of life data. Cummins (2002) also postulates that although subjective quality of life is usually stable or 'homeostatic', if the group mean falls below 70% SM it is likely that the living environment is sufficiently aversive that subjective quality of life changes would derive from environmental improvements.

With regard to the internal reliability for the fifth edition of the Com-Qol-I, Cummins (1997) presents data indicating that the Cronbach's alpha for the objective domains are 0.14 for material well-being domain, 0.64 for the health domain, 0.35 for the productivity domain, 0.45 for the intimacy domain, 0.56 for the safety domain, 0.15 for the place in the community domain and 0.42 for the emotional wellness domain. The data for the subjective components for the test are as follows: Importance 0.48, Satisfaction 0.65 and Importance x Satisfaction 0.68. The 1-2 week test-retest reliability has been reported as 0.87 for importance and 0.82 for satisfaction.

A questionnaire was created to gather demographic data and assess the degree and type of ALI involvement with participants (see App. B). The questionnaire gathered data on age, sex, location, access to public transport, disability, hours of ALI activity, hours of activity in services linked to by ALI providers, types of activities, and a breakdown of support hours. These categories were used as they were already gathered by the funding body in progress reports.

Procedure

Application was made to the Hunter Research Ethics Committee to research the impact of the Active Linkage Initiative on the Quality of Life of residents of Licenced Residential Centres in New South Wales. Ethics clearance was obtained for the research protocol (Approval Number H-180-1001). The original study was also to include an investigation into adaptive behaviour changes but due to the reluctance of boarding house staff to participate in this part of the study it was not completed.

Following random selection of potential participants using a computer generated package, participants were approached by staff from the Dept. Aging, Disability & Homecare and asked whether they would like to participate in the study. They were provided with a information sheet (see App. C) and asked to sign or give verbal consent on a consent form (see App. D).

Upon the completion of this process ALI staff were asked to complete the demographic questionnaire using data they had gathered for the 6 months prior to testing. The experimenter arranged times to meet with each of the participants to conduct the ComQol – I5. Data was only used if the participant was able to accurately respond to the following questions screening for acquiescence and cognitive capability:

- Is that (watch/ item of clothing) yours?
- Did you make it yourself?
- Have you seen the people who live next door?
- Did you decide who got to live next door?

The objective questions were then administered and the participant informed that they could ask LRC staff for assistance if they felt this was necessary. The participants were then assessed for their ability to discriminate between 2, 3 or 5 data points using simple questions about themselves (see App. A). The subjective questions were then administered using the appropriate pictorial likert scale without LRC staff being present. A written copy of the Com-Qol – I5 was placed in front of the participant and completed as the questions were asked using the pictorial scale. Participants with literacy skills could read the questions if they desired.

This process was repeated six months following the initial data collection. ALI staff again provided the demographic information and support hours for the past six months, and the Com-Qol – I5 interviews were repeated with the participants.

Results

The data from this research were analysed using Minitab 13 and SPSS 10 statistical software. See Appendix E for the raw data.

Demographic Variables

Demographic data pertaining to participants, in particular information concerning their ALI provider, age, gender, location, availability of transport and type of disability were gathered are presented in Tables 1 to 6.

Table 1
ALI Provider of Participants

ALI Provider	N
Castle Personnel Services Inc	13
Aftercare	15
Newtown Neighbourhood Centre	11
Samaritans	17
Blackheath Neighbourhood Centr	10

Table 2
Age of Participants

Age of Participants (yrs)	N
18-22	0
22-30	5
31-40	5
41-50	17
51-60	25
61-70	7
70+	7

Table 3
Gender of Participants

Gender of Participants	N
Male	49
Female	17

Table 4
Location of Participants

Location of Participants	N
Metropolitan	36
Rural	30

Table 5
Transport Accessibility

Accessibility of Transport	N
Readily Accessible	38
Somewhat Accessible	27
Not Accessible	1

Table 6
Primary Disability Type of Participants

Disability	N
Alcohol Related Brain Damage	4
Hearing Impairment	1
Mental Illness	38
Physical Disability	0
Disability due to Age	1
Intellectual Disability	19
Organic Brain Damage	4

Relationship Between Demographic Variables

Cross tabulations and the χ^2 statistic were used to analyse the relationships between the demographic variables. The age of participants was categorised into seven categories for this analysis. Significant relationships were found between ALI provider and Age χ^2 (20)= 31.575, $p < 0.05$. Figure 8 shows the age distribution by provider and indicates a lower age range for the Castle Personnel Services Inc clients compared with other providers. Also significant were ALI provider and location χ^2 (4)= 56.692, $p < 0.05$, and ALI Provider and transport χ^2 (8)= 39.726, $p < 0.05$. Figure 9 shows the rural / metropolitan comparison of providers. Figure 10 shows the particular difficulty with transport experienced by Samaritans clients. There was also a significant relationship between location and transport χ^2 (2)= 29.224, $p < 0.05$. Figure 11 shows a comparison of transport accessibility and the rural/ metropolitan distributions. There were no significant relationships found between the other demographic variables.

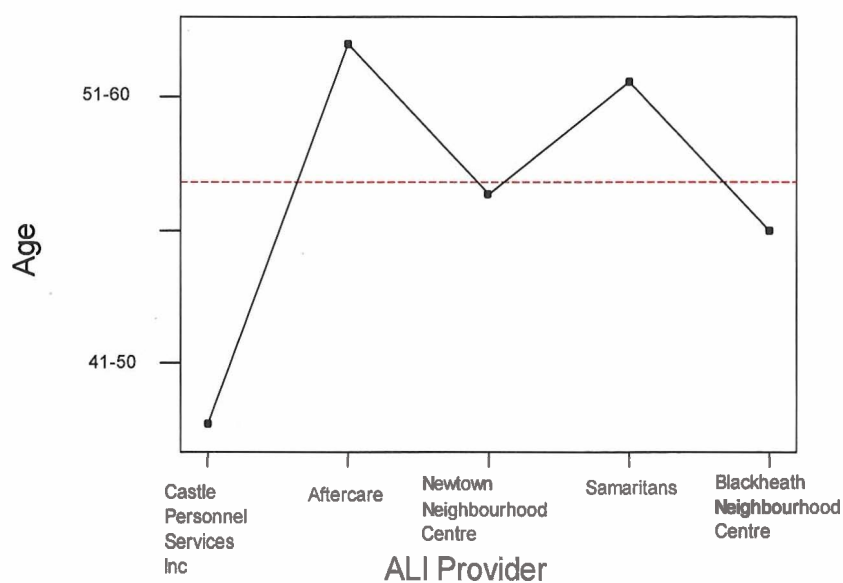


Figure 8. The relationship between ALI provider and age.

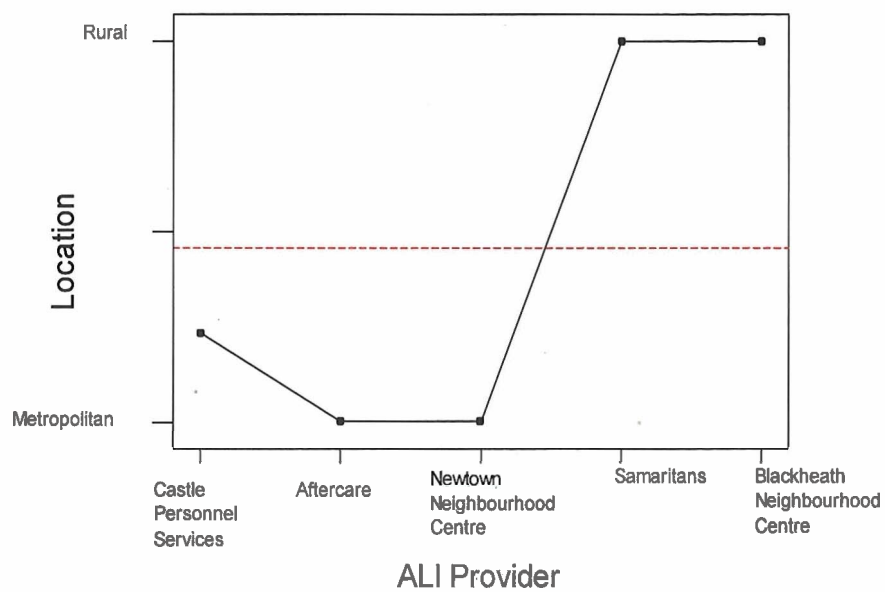


Figure 9. The relationship between ALI provider and location.

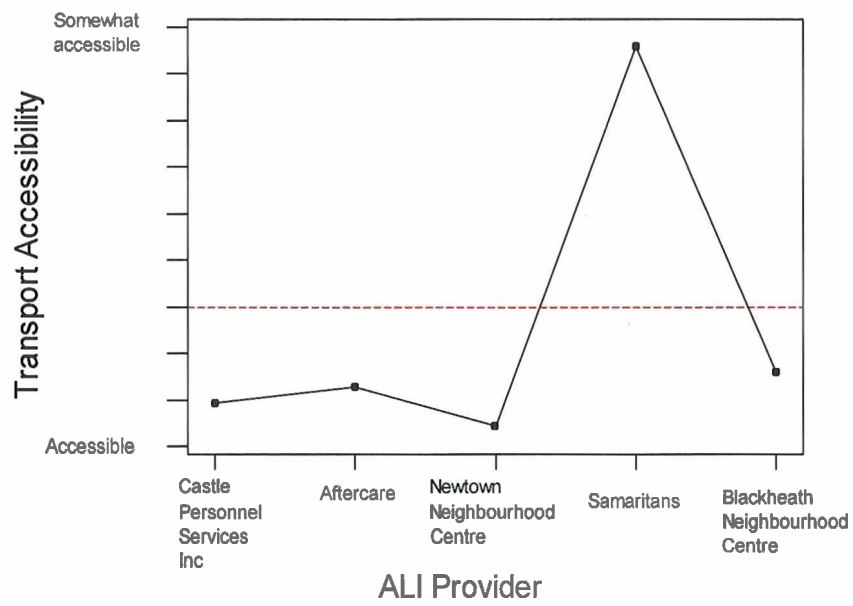


Figure 10. The relationship between ALI provider and transport accessibility.

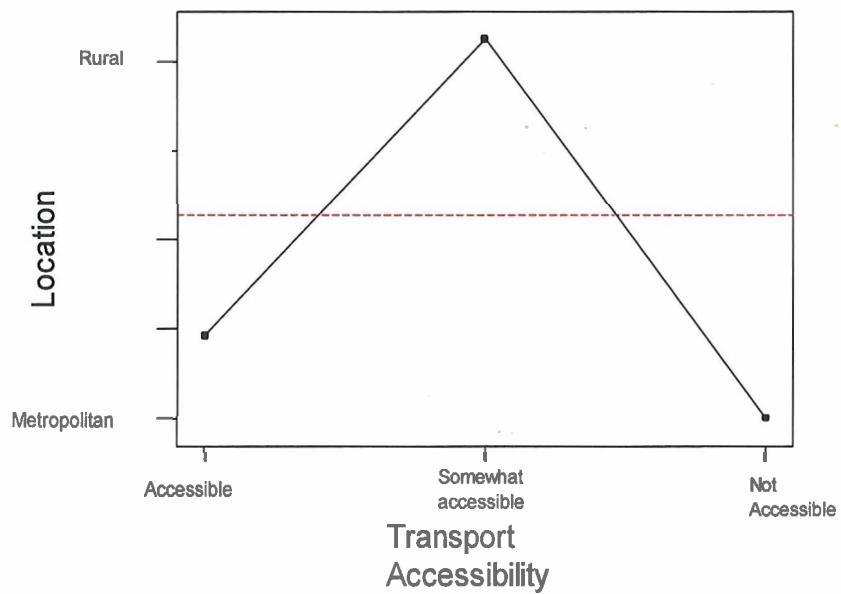


Figure 11. The relationship between location and transport accessibility.

The demographic variables show the ALI provider had a significant relationship with age, location and transport. Castle Personnel had a significantly younger sample than the other services who showed some variation between them. Samaritans and Blackheath Neighbourhood Centre were rurally located, while Newtown Neighbourhood Centre and Aftercare were located in metropolitan areas. Castle Personnel Services Inc. had a combination of rural and metropolitan locations. Most of the residents had ready access to transport apart from those residents serviced by Samaritans where it was only somewhat accessible. A significant relationship also existed between transport and location where metropolitan locations had ready access to transport while for rural locations transport was only somewhat accessible. These results give some indication of the variations between service providers and also the situations of the clients they serve.

Hours of Participation

The hours of participation in ALI were collected for the first six months and for the second six months of this study period. These were added together to give a total figure for ALI participation, and were also used to gauge the difference in ALI participation over time (see Table 7). A paired t-test was used to analyse the difference in ALI hours between times 1 and 2. The increase in ALI hours over time approached significance, $t(66) = 1.96, p = 0.054$

Table 7

Mean and Standard Deviation for Hours of Participation in ALI Program

Time 1		Time 2		Total (Time 1 + Time 2)		Difference in Hours of Participation	
Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
49.36	44.75	68.9	87.78	167.60	148.37	68.87	87.78

Figure 12 shows the mean hours of participation from time 1 to time 2, with an increase in participation hours at time 2.

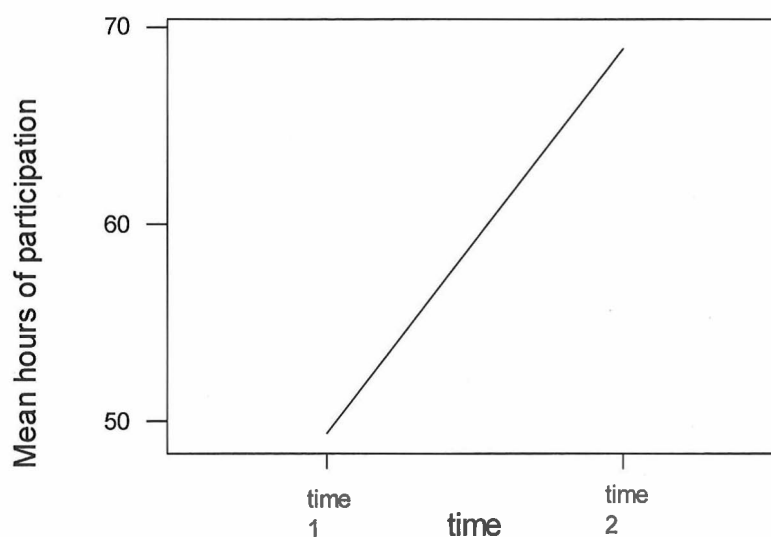


Figure 12. Difference in hours of ALI participation over time.

The Impact of Demographic Variables on the Hours of ALI Participation

Due to categorical and ratio data in the demographic variables ordinal logistic regressions were completed to analyse the impact of the variables ALI provider, age, gender, location and available transport and type of disability on the total number of ALI hours participated in. The difference between the hours of participation in the two time periods were also analysed using ordinal logistic regressions.

Total Hours of Participation

The ordinal logistic regression investigating the impact of the demographic variables on the total hours of participation yielded a G statistic that tested the null hypothesis that all slopes were zero. The results indicated $G(6) = 25.178, p < 0.05$.

The demographic variables that had a significant impact on the total number of hours participated in were ALI provider, $z = 3.34, p < 0.05$; Age, $z = 2.52, p < 0.05$; Gender, $z = -2.17, p < 0.05$; and location $z = -2.69, p < 0.05$. See Tables 8 to 11 for means and standard deviations for these variables and Figure 13 to 16 for means.

Table 8

Means and Standard Deviations for ALI providers in Total Hours of Participation over Time

ALI Provider	Mean	Standard Deviation
Castle Personnel Services Inc	266.5	222.5
Aftercare	193.7	162.2
Newtown Neighbourhood Centre	67.3	31.0
Samaritans	172.0	94.9
Blackheath Neighbourhood Centre	102.7	52.0

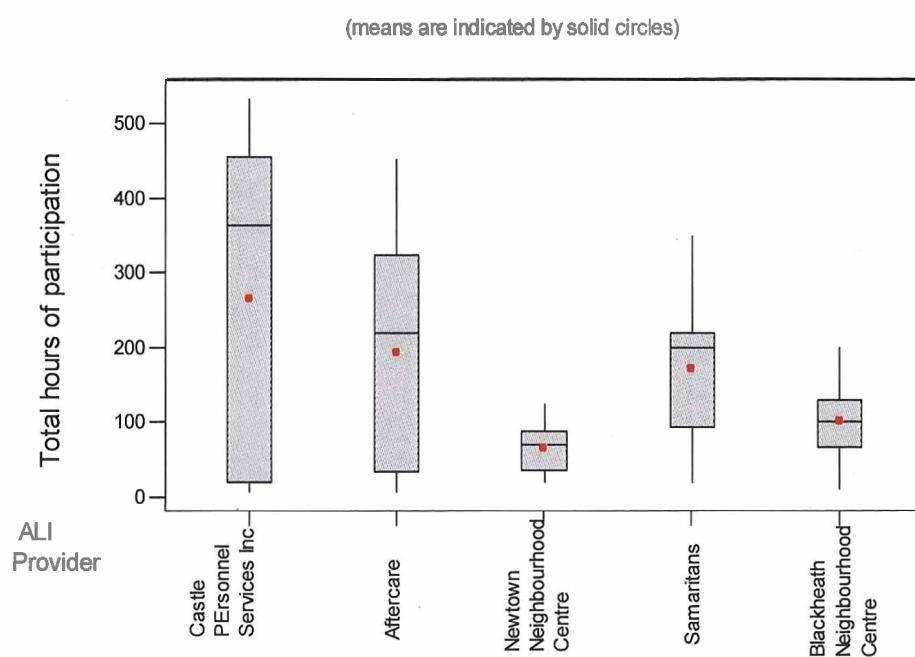


Figure 13. Box plots of total ALI hours by ALI provider.

Figure 13 shows the services in order from the highest number of total hours to the lowest were, Castle Personnel Services Inc, Aftercare, Samaritans, Blackheath Neighbourhood Centre, followed by Newtown Neighbourhood Centre.

Table 9

Means and Standard Deviations for Impact of Age in Total Hours of Participation over Time

Age	Mean	Standard Deviation
22-30	290.0	205.0
31-40	247.0	224.0
41-50	165.4	156.0
51-60	169.3	126.0
61-70	71.9	90.1
70+	118.4	95.5

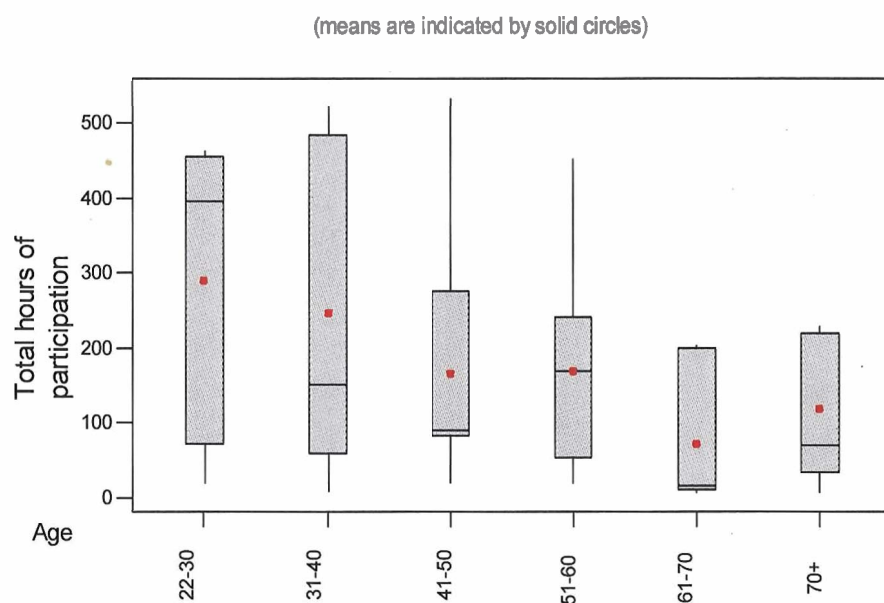


Figure 14. Box plots of total hours of ALI participation by age.

Figure 14 demonstrates how the age of participants shows a relationship with the total number of hours of participation. The trend was for the younger age groups to have the greater level of total participation. The 70 + age group defied this trend and showed higher total participation the 61-70 age group.

Table 10

Means and Standard Deviations for Impact of Gender in Total Hours of Participation over Time

Gender	Mean	Standard Deviation
Male	152.0	146.4
Female	212.5	149.0

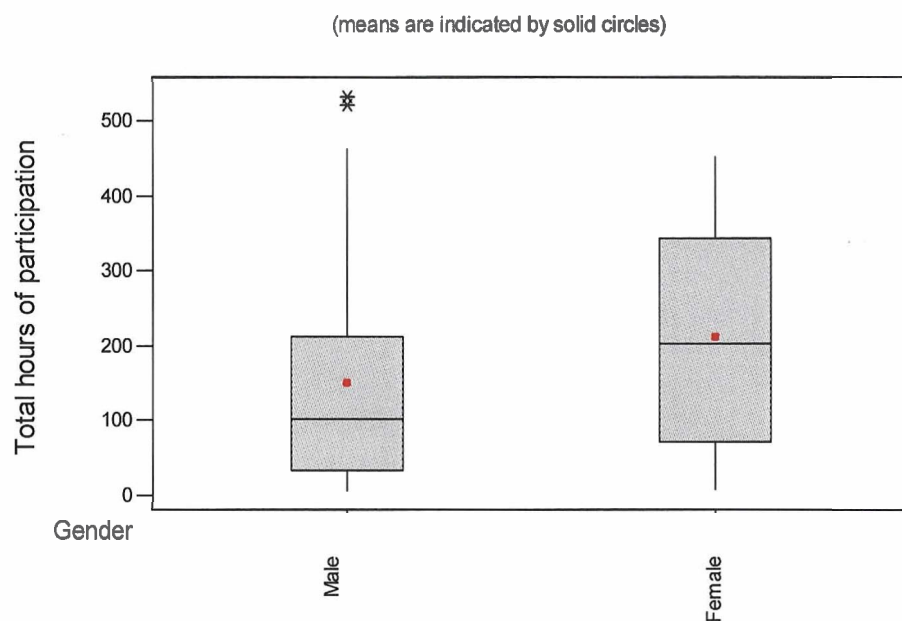


Figure 15. Box plots of total hours of participation by gender.

Figure 15 demonstrates that females had significantly higher total levels of participation in the ALI program compared with males.

Table 11

Means and Standard Deviations for Impact of Location on Total Hours of Participation over Time

Location	Mean	Standard Deviation
Metropolitan	157.7	162.3
Rural	179.5	131.4

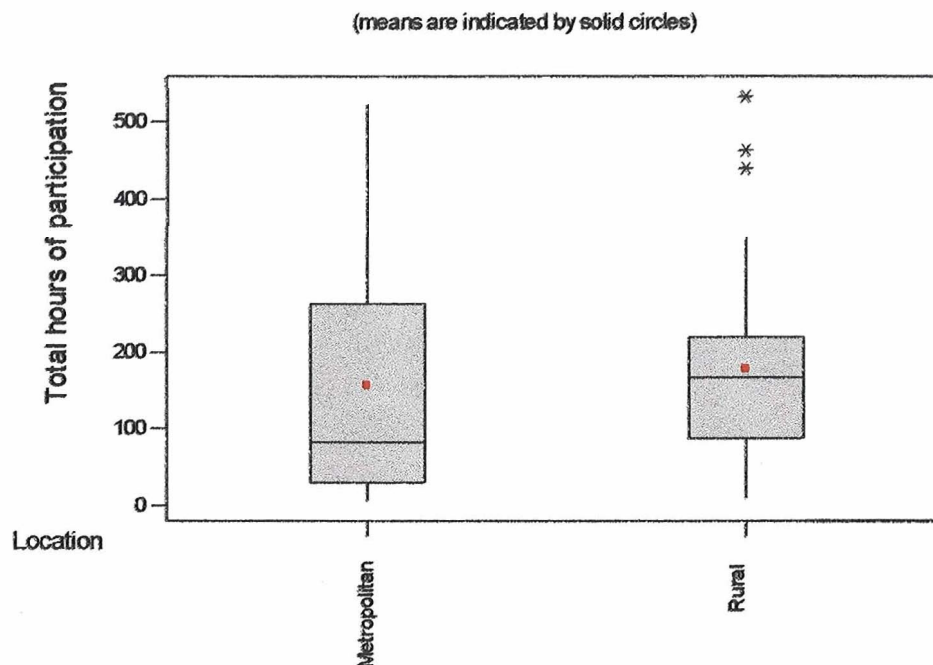


Figure 16. Box plots of total hours of participation by location.

Figure 16 demonstrates the comparison between rural and metropolitan location of boarding houses. The results indicated that rural participants had the greater total participation.

Difference in Hours of Participation

The demographic variables were categorical or ordinal in nature. Hence, ordinal logistic regression was used to analyse the impact of the demographic variables on the difference in hours of participation. The difference between hours of participation in the two time periods and demographic variables was analysed using ordinal logistic regression. The difference in hours of participation is simply taken as the subtraction of the hours of participation at time 1 from the hours at time 2. The ordinal logistic regression yielded a

G statistic that tested the null hypothesis that all slopes were zero. The results indicated $G(6) = 17.63, p < 0.05$.

The demographic variables that had a significant impact on the difference in the number of hours participated in were ALI provider, $z = 3.46, p < 0.05$, and location $z = -2.21, p < 0.05$. Age bordered on having a significant impact $z = 1.78, p = 0.76$. See Tables 12 to 14 for means and standard deviations for these variables and Figure 17 to 19 for means.

Table 12

Means and Standard Deviations for ALI Providers in Amount of Difference in Hours of Participation over Time

ALI Provider	Mean	Standard Deviation
Castle Personnel Services Inc	156.4	133.7
Aftercare	80.2	84.2
Newtown Neighbourhood Centre	27.3	24.3
Samaritans	44.6	39.2
Blackheath Neighbourhood Centre	24.7	26.7

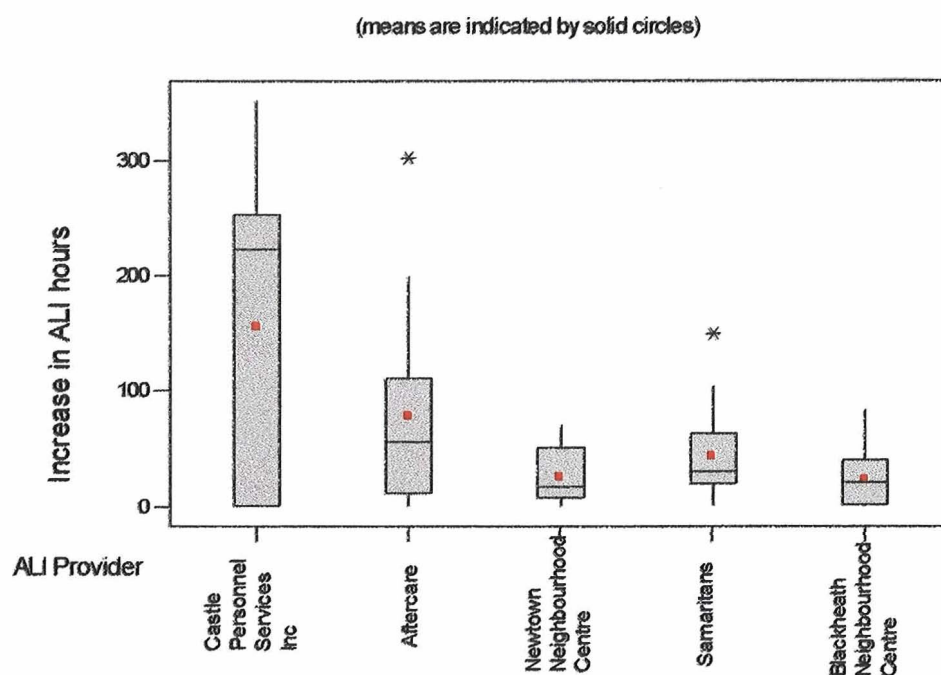


Figure 17. Box plots of increase in hours of ALI service by ALI provider.

Figure 17 shows the differences in participation over time with the greatest increase shown by Castle Personnel Services Inc., then Aftercare, Samaritans, Newtown Neighbourhood Centre, followed by Blackheath Neighbourhood Centre.

Table 13

Means and Standard Deviations for Age in Amount of Difference in Hours of Participation over Time

Age	Mean	Standard Deviation
22-30	176.9	119.1
31-40	65.7	95.2
41-50	74.3	100.9
51-60	70.3	79.3
61-70	13.1	20.1
70+	35.9	40.4

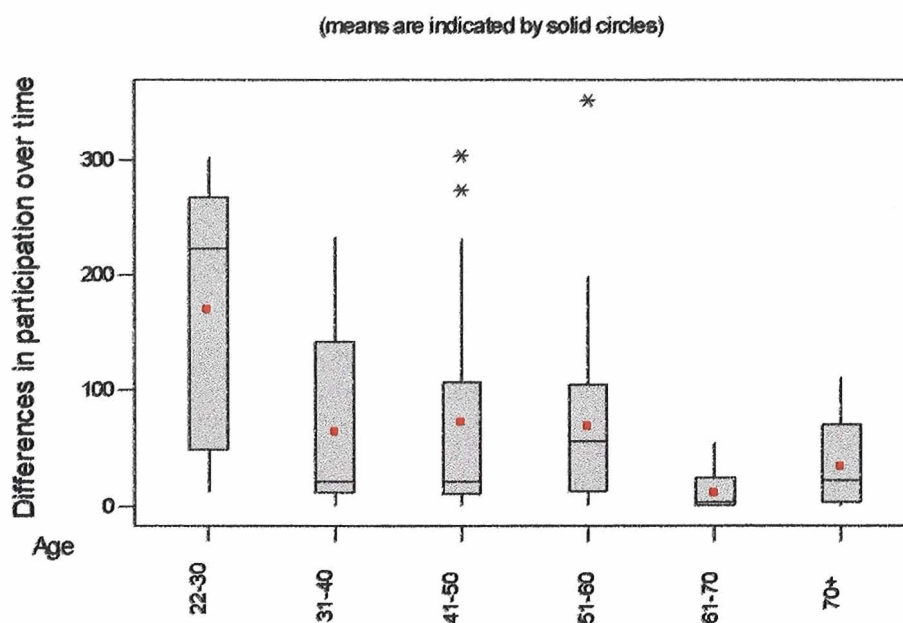


Figure 18. Box plots of differences in participation over time by age.

Figure 18 demonstrates the relationship between the age of participants and the level of increase in the hours of participation. The trend was for the younger age groups to have the greater level of total participation. Again, the 70 + age group defied this trend and showed higher total participation hours and a higher increase in hours than the 61-70 age group.

Table 14

Means and Standard Deviations for Impact of Location in Difference in Hours of Participation over Time

Location	Mean	Standard Deviation
Metropolitan	76.9	97.0
Rural	59.2	75.8

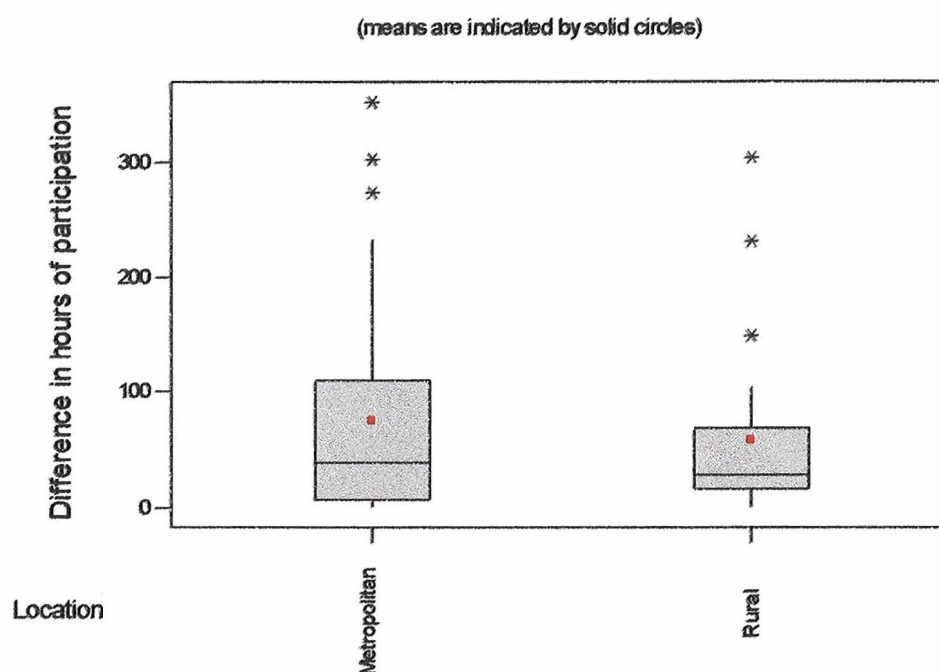


Figure 19. Box plots of difference in hours of participation over time by location.

Figure 19 demonstrates that metropolitan participants showed a greater increase in hours of participation over time than the rurally located participants. This contrasts with the total hours of participation where rurally located participants had higher levels of participation.

Com-Qol Results from the First Measure

The Com-Qol yielded overall scores for objective quality of life and subjective quality of life. A score for subjective quality of life weighted according to importance was also established. This was done by multiplying the subjective quality of life result by the amount of importance the resident placed on the domain. Results were also obtained for each of the domain scores. See Tables 15 and 16 for descriptive statistics.

Table 15

Com-Qol Results from the First Measure

	Mean	S.D.
Objective Quality of Life	61.18	7.61
Subjective Quality of Life	27.56	6.05
Subjective Quality of Life Weighted According to Importance	811.77	254.84

In addition, the ComQol yield domain measures in each of the domain of material well-being, health, productivity, intimacy, safety, place in the community and emotional well-being.

Table 16

Com-Qol Domain Results from the First Measure

	Mean	S.D.
Material Well-Being	25.74	7.49
Health	26.47	8.16
Productivity	23.85	8.56
Intimacy	26.08	9.66
Safety	30.26	8.99
Place in the Community	20.88	8.20
Emotional Well-Being	27.08	8.45

% Scale Maximum for First Measure

The mean scale maximum (%SM) score for unweighted subjective quality of life was obtained for the measure at time 1 to compare with the 70 %SM Cummins (2002) set as the minimal point to achieve homeostasis of subjective quality of life. Cummins (2002) asserts that in order for a subjective quality of life score to show variation in needs to fall below the point of 70% of the scale maximum. The results indicated the mean for subjective quality of life was above 70%SM at time 1 (see Table 17). According to Cummins (2002) 'homeostasis' theory, no significant changes in overall subjective quality of life would be expected from this group.

Table 17

Mean %SM for Subjective quality of life scores

	Time 1	Time 2
Satisfaction	78.74	80.82
Satisfaction weighted by importance	66.27	68.28

Com-Qol Results from the Second Measure

The Com-Qol yielded an overall score for objective quality of life and subjective quality of life. Subjective quality of life could also be weighted according to importance. Results were also obtained for each of the domain scores. See Tables 18 and 19 for descriptive statistics.

Table 18

Com-Qol Results from the Second Measure

	Mean	S.D.
Objective Quality of Life	63.62	6.97
Subjective Quality of Life	28.29	5.06
Subjective Quality of Weighted According Importance	836.44	248.75

Table 19

Com-Qol Domain Results from the Second Measure

	Mean	S.D.
Material Well-Being	25.17	8.44
Health	24.92	8.89
Productivity	25.71	7.70
Intimacy	28.55	9.29
Safety	30.06	8.58
Place in the Community	19.91	8.11
Emotional Well-Being	29.24	7.46

Com-Qol Results from Time 1 and Time 2

The Com-Qol results were available for comparison in objective quality of life, subjective quality of life and subjective quality of life weighted according to importance. The relationship between these variables and the level of participation was investigated. Changes over time were also analysed across these overall scores and across the domains of material well-being, health, productivity, intimacy, safety, place in the community and emotional well-being. The relationships between the domains were also explored.

The Impact of Hours of Participation on Quality of Life

Linear regression models were developed to analyse the relationship between the hours of participation and the variables of overall objective and subjective quality of life. These variables do not form ratio scales but nevertheless form robust ordinal scales that can sustain linear regressions without distorting the relationship. The results indicated that there was no significant relationship between the level of participation or the level of

change in hours of participation for objective quality of life, $F(2,63) = 0.79, p = 0.457$; subjective quality of life (unweighted), $F(2,63) = 0.98, p = 0.380$; or subjective quality of life when weighted according to importance, $F(2,63) = 1.20, p = 0.308$. Therefore, the level of participation was not a significant factor in the changes and interactions in quality of life in this study.

Changes and Interactions in Objective Quality of Life

Overall Objective Quality of Life

A paired t-test was conducted to explore the changes in quality of life over time in objective quality of life. A t – test was chosen due to the quasi-ratio nature of the overall quality of life scores, the sample size and the robustness shown by t-tests (Howell, 1992). The results indicated a significant improvement in the overall objective quality of life, $t(66) = 3.41, p < 0.05$ (see Figure 20).

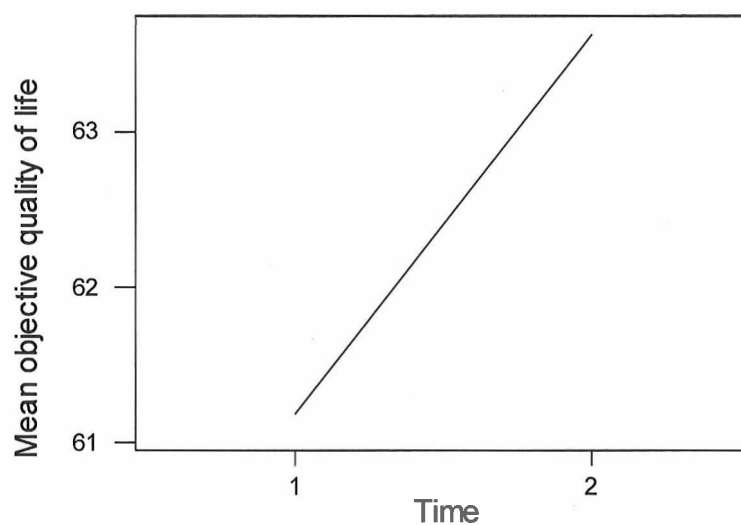


Figure 20. Changes to objective quality of life over time.

Objective Quality of Life Domains

The objective domain scores were analysed using a non-parametric test of related samples to assess changes over time. Results from the Wilcoxon Signed Ranks Test are available in Table 20. The results suggested no significant changes in the objective domain scores over time for all of the domains apart from productivity that showed a significant gain over time, $z = -5.423, p < 0.05$ (see Figure 21).

Table 20

Wilcoxon Signed Ranks Test Results for Objective Domain Changes Over Time.

Domains	<i>z</i>	<i>p</i>
Material	-1.328	0.184
Health	-0.357	0.721
Productivity	-5.423	0.000*
Intimacy	-0.215	0.830
Safety	-0.097	0.923
Place in community	-0.782	0.434
Emotional well-being	-0.172	0.863

* $p < 0.05$

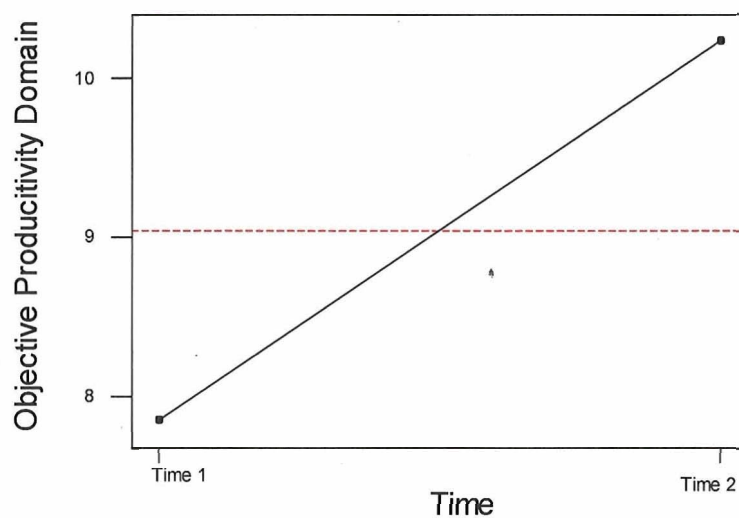


Figure 21. Comparison of objective domain of productivity over time

Relationships Between the Objective Quality of Life Domains

To examine the relationship between the objective domains non-parametric K-related samples were used with the Kolmogrov-Smirnov test. The results indicated that there was a significant relationship between the objective domain scores both at the first point of measurement, $\chi^2 (6) = 198.469, p < 0.05$; and at the second point of measurement, $\chi^2 (6) = 181.622, p < 0.05$. See Figure 22 for a graph of the mean domain scores over the two time periods.

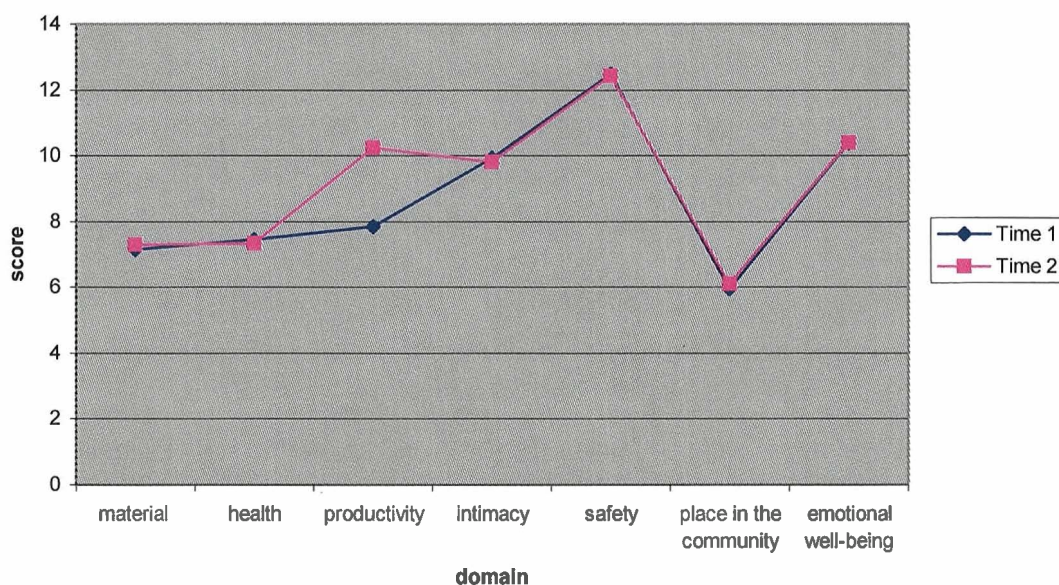


Figure 22. Mean objective domain scores.

The Impact of Demographic Variables on Objective Quality of Life

The demographic variables were categorical or ordinal in nature. Hence, ordinal logistic regression was used to analyse the difference between hours participated in. The difference between hours of participation in hours of participation is simply taken as the subtraction of the hours of participation at time 1 from the hours of participation at time 2.

Ordinal logistic regression was used to analyse the impact of the demographic variables of ALI provider, age, gender, location and transport available on the total objective quality of life. Demographic variables had no significant impact on the objective quality of life score, $G(6) = 6.794, p = 0.340$. There was also no evidence of a significant impact of demographic variables on the difference in objective quality of life over time, $G(6) = 2.854, p = 0.827$. These results indicate that the demographic variables were not a factor in the level of objective quality of life for the participants in this study.

Changes and Interactions in Subjective Quality of Life

Overall Subjective Quality of Life

A paired t-test was conducted to consider the changes in subjective quality of life over time. A t – tests was chosen due to the quasi-ratio nature of the scores, the sample size and the robustness shown by t-tests (Howell, 1992). The results indicated no change in the unweighted subjective quality of life $t(66) = 1.35, p = 0.183$. As the %SM was above the 70% set by Cummins (2002) this was anticipated to be the result.

Domains of Subjective Quality of Life

The subjective domain scores were analysed using a non-parametric test of related samples to assess changes over time. Results from the Wilcoxon Signed Ranks Test are available in Table 21. The results suggested significant changes in the domains of intimacy, $z = -3.120$, $p < 0.05$ (see Figure 23); and emotional well-being, $z = -2.515$, $p < 0.05$ (see Figure 24). There were no significant differences over time in the other domains.

Table 21

Wilcoxon Signed Ranks Test Results for Subjective Domain Changes Over Time.

Domains	z	p
Material	-7.44	0.457
Health	-1.105	0.269
Productivity	-1.30	0.896
Intimacy	-3.120	0.002*
Safety	-0.12	0.991
Place in community	-0.296	0.767
Emotional well-being	-2.515	0.012*

* $p < 0.05$

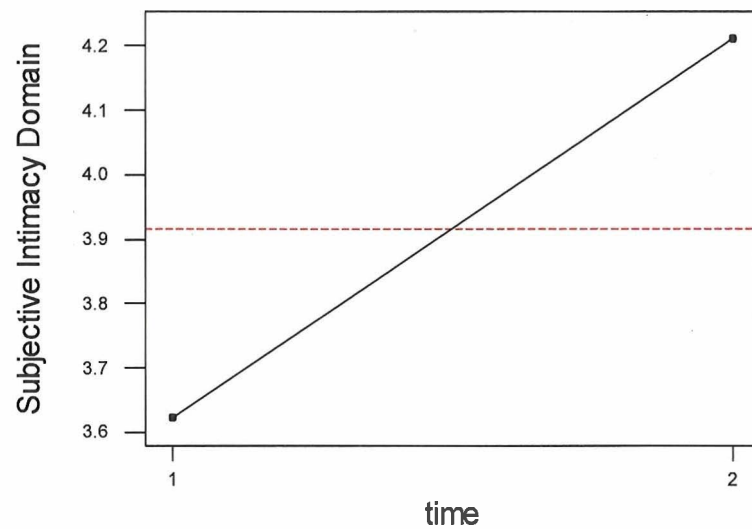


Figure 23. Comparison of subjective domain of intimacy over time.

Figure 23 demonstrates that participants showed greater satisfaction with the level of intimacy they experienced at the time of the second measure than they had shown at the point of the first measure.

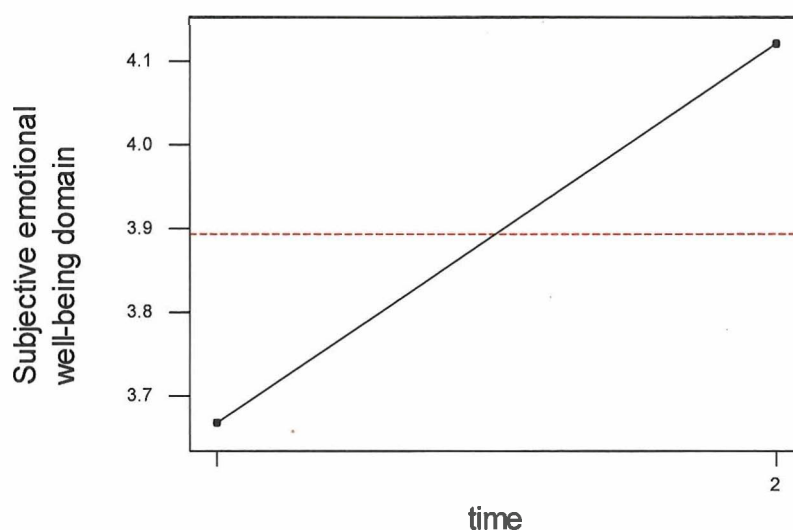


Figure 24. Comparison of subjective domain of emotional well-being over time

Figure 24 reveals that participants were more satisfied with their overall level of happiness (emotional well-being) at the time of the second measure than they were at the time of the first measure.

Relationships Between the Unweighted Subjective Quality of Life Domains

To investigate the relationship between the unweighted subjective domains non-parametric K-related samples were used with the Kolmogrov-Smirnov test. The results indicated that there was a significant relationship between the overall domains both at the first point of measurement, $\chi^2 (6) = 21.007, p < 0.05$; however they showed no significant relationship at the second time of testing, $\chi^2 (6) = 8.441, p=0.2.08$. See Figure 25 for a graph of the mean domain scores over the two times.

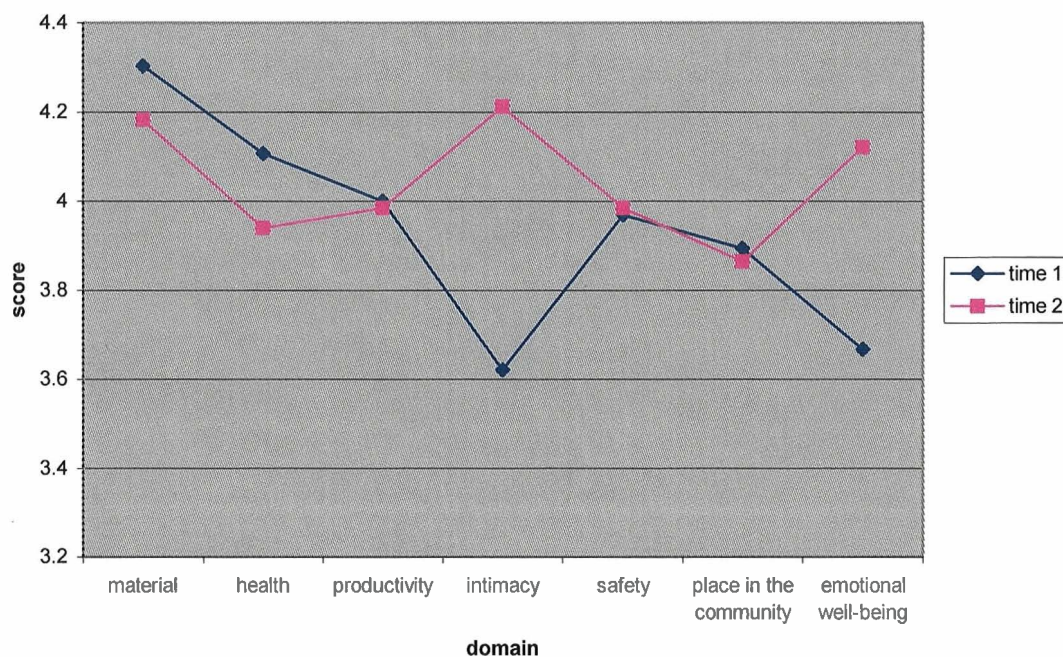


Figure 25. Mean unweighted subjective domain scores.

The Impact of Demographic Variables on Subjective Quality of Life

Ordinal logistic regression was used to analyse the impact of the demographic variables of ALI provider, age, gender, location and transport available on the total subjective quality of life. The relationship between subjective quality of life and the demographic variables was analysed using ordinal logistic regression. The results indicated that while there was no overall impact on unweighted subjective quality of life, $G(6) = 8.073, p = 0.233$; the residents location did show a significant relationship, $z = -2.13, p < 0.05$ (see Figure 26). There was no significant relationship between the demographic variables and the difference in subjective quality of life over time, $G(6) = 5.859, p = 0.439$.



Figure 26. Impact of location on unweighted subjective quality of life.

Figure 26 demonstrates that rurally located participants were more satisfied with their subjective quality of life than their metropolitan counterparts.

Changes and Interactions in Subjective Quality of Life Weighted According to Importance

Overall Subjective Quality of Life Weighted by Importance

A paired t-test was conducted to analyse the changes in subjective quality of life weighted according to importance. A t – tests was chosen due to the quasi-ratio nature of the data, the sample size and the robustness shown by t-tests (Howell, 1992). The results

indicated no significant change in the subjective quality when weighted by importance, $t(66) = 1.19, p = 0.238$.

Domains of Subjective Quality of Life Weighted by Importance

The subjective domain scores weighted according to importance were analysed using a non-parametric test of related samples to assess changes over time. The reason for choosing a non-parametric statistic in these cases is that, unlike the overall case, the reduction in numbers and categories in some of the individual domain variables would result in a serious contravention of parametric assumptions. Results from the Wilcoxon Signed Ranks Test are available in Table 22. The results suggested significant changes in the domains of intimacy, $z = -2.569, p < 0.05$ (see Figure 27); and emotional well-being, $z = -2.033, p < 0.05$ (see Figure 28). There were no significant differences over time in the other domains.

Table 22

Wilcoxon Signed Ranks Test Results for Subjective Domain Changes Weighted By Importance Over Time.

Domains	z	p
Material	-4.90	0.624
Health	-1.270	0.204
Productivity	-0.397	0.691
Intimacy	-2.569	0.010*
Safety	0.000	1.000
Place in community	-1.065	0.287
Emotional well-being	-2.033	0.042*

* $p < 0.05$

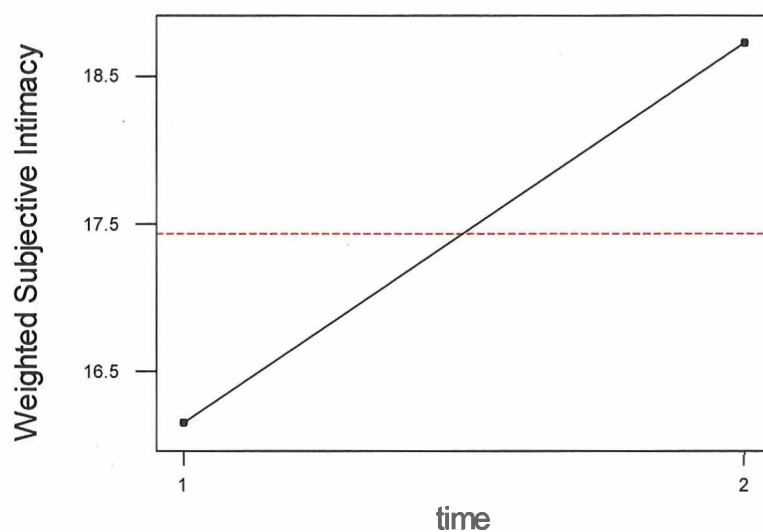


Figure 27. Comparison of weighted subjective domain of intimacy over time

Figure 27 demonstrates that when the satisfaction participants experienced with regard to their level of intimacy was weighted according to the importance they placed on intimacy, they were more satisfied at the time of the second measure than they had been the first time. This result was also found when there was no weighting for importance.

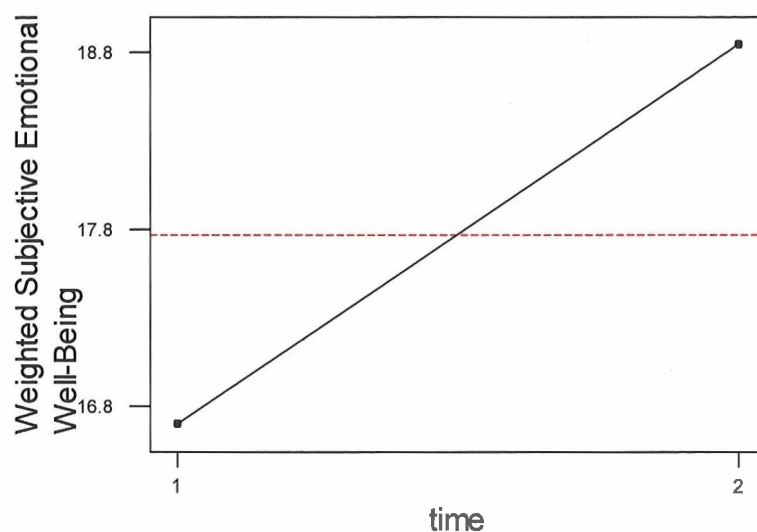


Figure 28. Comparison of subjective domain of emotional well-being over time

Similarly, Figure 28 demonstrates that when the satisfaction participants experienced with regard to their level of emotional well-being was weighted according to the importance they placed on it, they were more satisfied at the time of the second measure than they had been the first time. This result was also found when there was no weighting for importance.

Relationships Between the Subjective Quality of Life Domains Weighted According to Importance

To investigate the relationship between the weighted subjective domains non-parametric K-related samples were used with the Kolmogorov-Smirnov test. The results

To investigate the relationship between the weighted subjective domains non-parametric K-related samples were used with the Kolmogorov-Smirnov test. The results indicated that there was a significant relationship between the overall domains both at the first point of measurement, $\chi^2 (6) = 20.020, p < 0.05$; and at the second time of testing, $\chi^2 (6) = 21.066, p=0.2.08$. See Figure 29 for a graph of the mean domain scores over the two time periods.

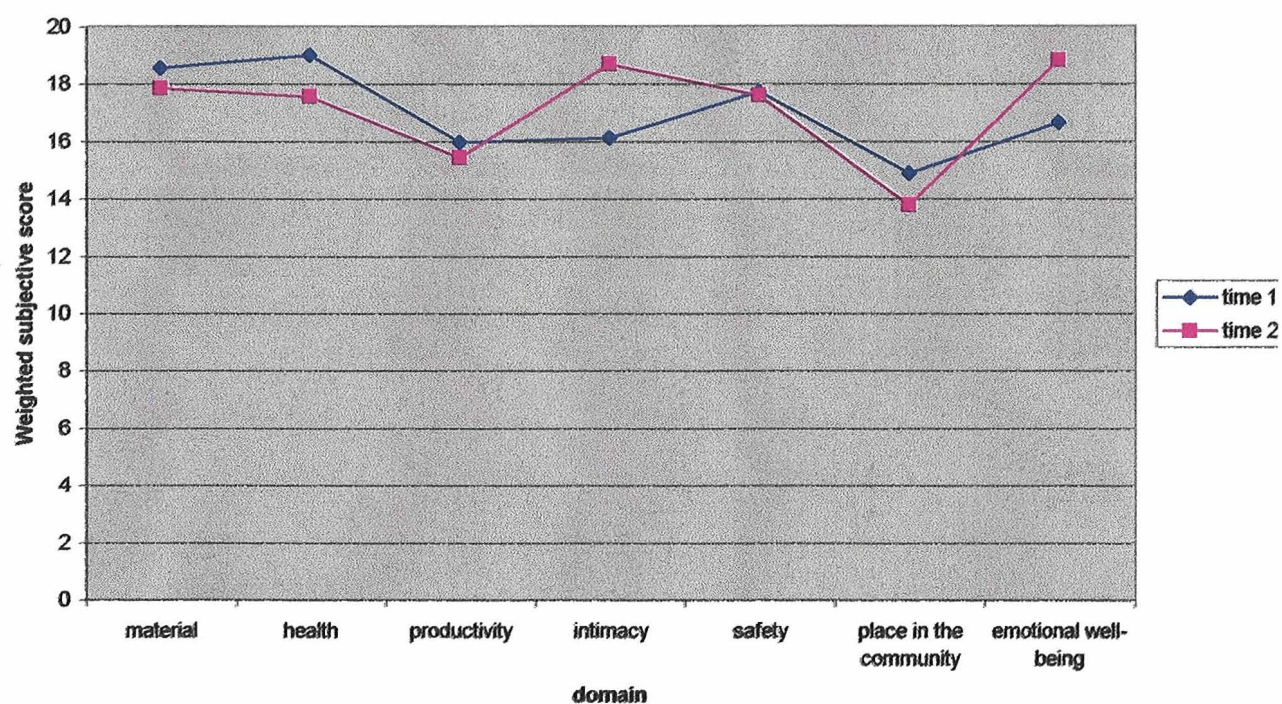


Figure 29. Mean weighted subjective domain scores.

The Impact of Demographic Variables on Subjective Quality of Life Weighted According to Importance

Ordinal logistic regression was used to analyse the impact of the demographic variables on subjective quality of life when weighted according to importance. The

relationship ($z = -2.51, p < 0.05$; $z = -2.33, p < 0.05$) (see Figures 30 and 31). However, there was no significant relationship between the demographic variables and the difference in weighted subjective quality of life over time, $G(6) = 6.458, p = 0.374$.

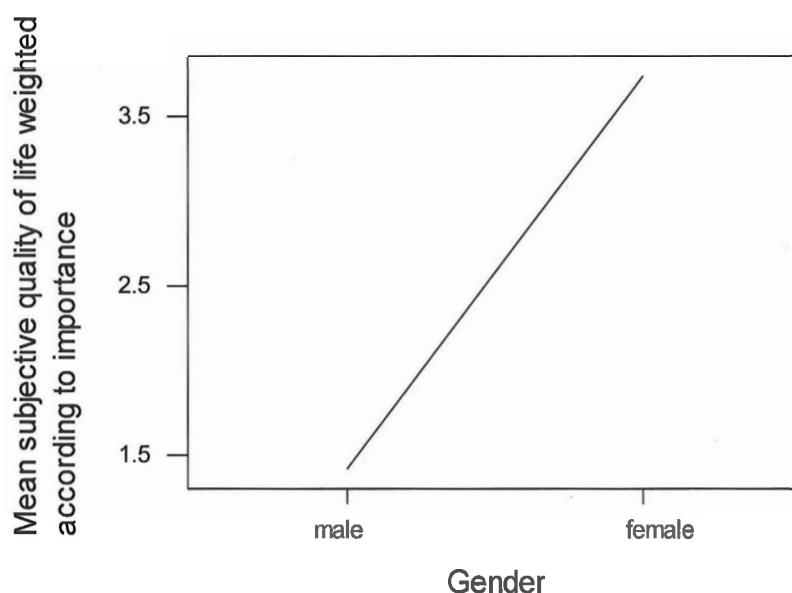


Figure 30. Impact of gender on weighted subjective quality of life.

Figure 30 demonstrates that when the participants satisfaction with their quality of life was weighted according to the importance they placed on it, females were more satisfied than males. This contrasts to the unweighted scores that showed no relationship with gender.

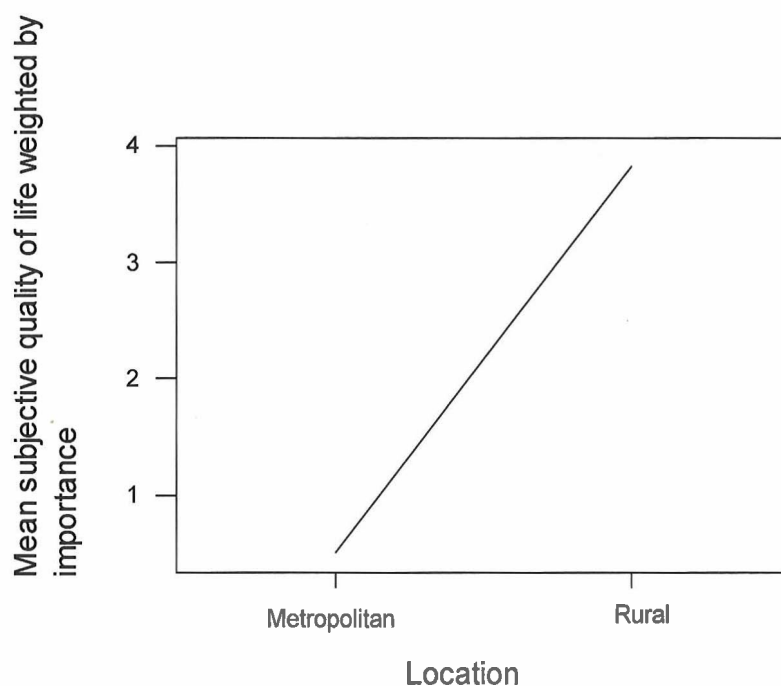


Figure 31. Impact of location on weighted subjective quality of life.

Figure 31 demonstrates that rurally located participants were more satisfied with their quality of life than their metropolitan counterparts when the importance placed on quality of life was accounted for. This result was also shown above when the importance placed on quality of life was not considered.

Changes and Interactions in Overall Quality of Life Domains

The data were analysed using a non-parametric repeated measures design to gauge changes in the overall domain scores over time. The overall domain scores were calculated using both objective and subjective data from the entire measure. The

Wilcoxon Signed Ranks Test suggested that the overall domains changed significantly over time in the areas of productivity, intimacy and emotional well-being (see Table 23).

Table 23

Wilcoxon Signed Ranks Test Results for Overall Domain Changes Over Time.

Domains	z	p
Material	-0.290	0.772
Health	-1.443	0.149
Productivity	-2.028	0.043*
Intimacy	-2.558	0.011*
Safety	-0.249	0.803
Place in community	-1.018	0.309
Emotional well-being	-1.976	0.048*

* $p < 0.05$

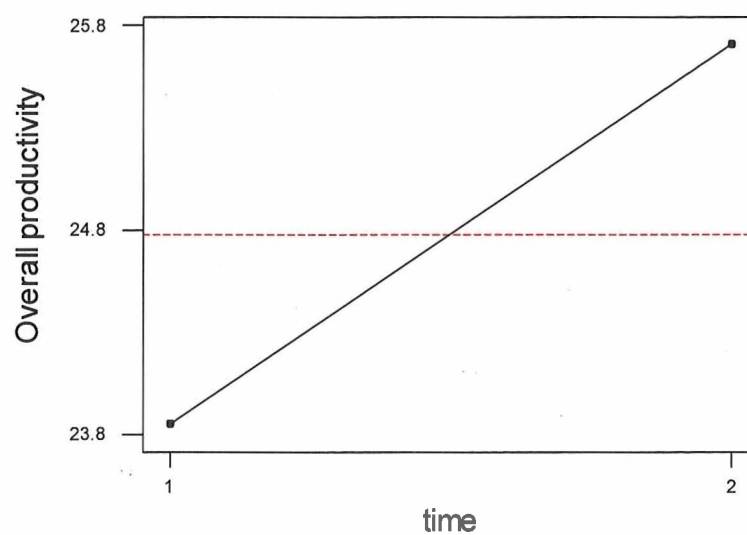


Figure 32. Comparison of overall productivity domain over time.

Figure 32 demonstrates that the overall productivity domain increased for participants at Time 2 when compared to Time 1. This was also found in the objective scores but not in the subjective domain comparisons.

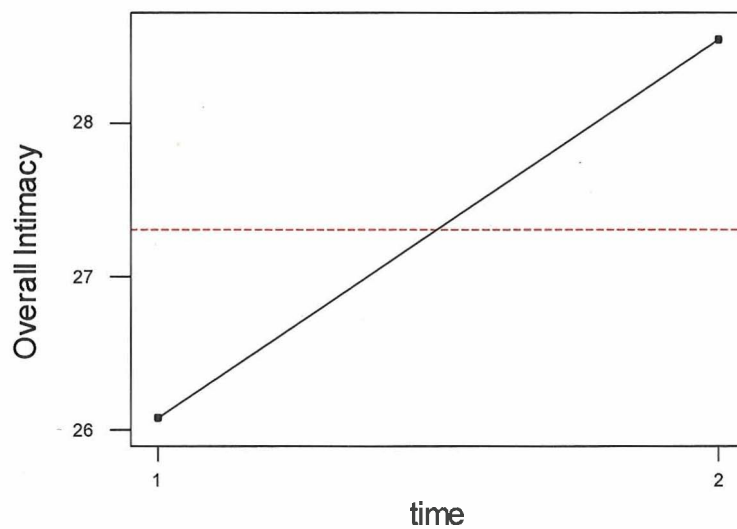


Figure 33. Comparison of overall intimacy domain over time.

Figure 33 demonstrates that the overall intimacy domain increased for participants at Time 2 when compared to Time 1. This result was also found in the subjective domain comparisons but not in the objective domain comparisons.

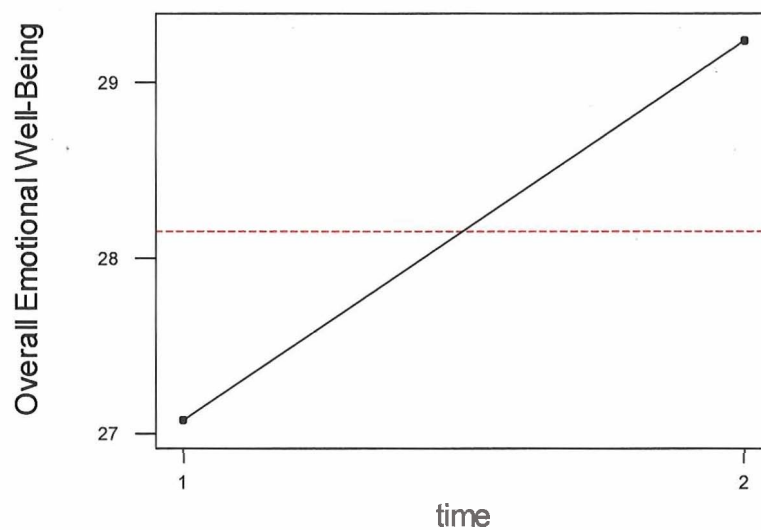


Figure 34. Comparison of overall emotional well-being domain over time.

Figure 34 demonstrates that the overall emotional well-being domain increased for participants at Time 2 when compared to Time 1. This result was also found in the subjective comparisons but not in the objective domain comparisons.

Relationships Between the Overall Domain Scores

To investigate the relationship between the overall domains non-parametric K-related samples were used with the Kolmogorov-Smirnov test. The results indicated that there was a significant relationship between the overall domains both at the first point of measurement, $\chi^2 (6) = 67.822, p < 0.05$; and at the second point of measurement, $\chi^2 (6) = 81.730, p < 0.05$. See Figure 35 for a graph of the mean domain scores over the two periods.



Figure 35. Mean overall domain scores.

Discussion

The aim of this research was to investigate the impact of the ALI program on the quality of life of boarding house residents over a six-month period. In order to gain this data participants were administered the Com-Qol-I5 and a demographic questionnaire.

It was hypothesised that the objective and subjective quality of life would increase with the hours of participation. This hypothesis was not supported. Neither the total hours of participation nor the change in the hours of participation had a significant relationship with the objective or subjective quality of life.

It was hypothesised that due to the impact of ALI on the boarding houses there would be a gain in the overall level of objective quality of life. The results support this hypothesis indicating a significant increase in the overall level of objective quality of life as measured by the Com-Qol-I5.

It was hypothesised that if the mean subjective quality of life for the group fell below 70% scale maximum (%SM) there would be a significant improvement over time in subjective quality of life as the ALI program was implemented; if the mean subjective quality of life for the group was above 70% SM it was hypothesised that there would be no significant improvement over time. The results indicate that the mean subjective quality of life at the first point of measurement for the group was above the 70%SM put forward by Cummins (2002) and remained above this point at the second data collection with no significant gain. This data supports the theory of homeostasis in subjective quality of life once it has risen above 70%SM with moderate rises in subjective quality of life not reaching significance.

It was further hypothesised that there would be no significant changes in the domains of quality of life of material well-being, health and safety. The results from these data support this hypothesis. There were no significant gains in the objective domains of material well-being, health or safety. There were also no significant gains in these areas for subjective quality of life with and without weighting by importance.

It was hypothesised that there would be significant gains in the domains of productivity, intimacy, place in the community and emotional well-being. This hypothesis was partially supported. The overall domain scores taking objective and subjective scores together indicated a significant improvement in the domains of productivity, intimacy and emotional well-being. There was no significant change in the domain of place in the community. The results from the objective domains indicated a significant improvement in productivity, but no significant increase in place in the community, intimacy or emotional well-being. In contrast, the subjective domains indicated an improvement in intimacy and emotional well-being. However, emotional well-being was no longer showed a significant increase when it was weighted according to importance. No significant improvement in the subjective domains of productivity or place in the community was observed.

In addition to the support given to the supported hypotheses, the data also indicated that there are a number of significant relationships arising from the demographic data. The demographic data have a significant relationship with both the total number of hours and the increase in hours over time.

The ALI provider had an impact on both the total number of hours and the difference in hours. The services in order from the highest number of total hours to the

lowest were, Castle Personnel Services Inc, Aftercare, Samaritans, Blackheath Neighbourhood Centre, followed by Newtown Neighbourhood Centre. A similar pattern was evident when looking at the differences in participation over time with the greatest increase being shown by Castle Personnel Services Inc., then Aftercare, Samaritans, Newtown Neighbourhood Centre, followed by Blackheath Neighbourhood Centre.

The geographical location of participants was important with this variable showing a relationship with both the total number of hours and the level of increase in hours. Comparison was made between rural and metropolitan location of boarding houses. The results indicated that rural participants had the greater total participation. However, the metropolitan participants showed the greater increase in hours of participation over time.

The age of participants proved significant with respect to the total number of hours of participation. The trend was for the younger age groups to have the greater level of total participation. A similar trend was obvious in the level of increase in hours over time although this did not quite reach 0.05 significance level. Interestingly the 70 + age group defied this trend and showed higher total participation hours and a higher increase in hours than the 61-70 age group.

Gender also seemed to be a factor of significance in participation level. Females had significantly higher total levels of participation than males although there was no difference between the sexes in the level of increase over time.

Interestingly, the type of disability was not a significant variable in the total hours of participation nor with the change in hours of participation over time. Similarly, access to transport did not appear to be a factor of significance.

The relationships between the demographic variables were also analysed. The results indicated that the ALI provider had a significant relationship with age, location and transport. Castle Personnel had a significantly younger sample than the other services who showed some variation between them. Samaritans and Blackheath Neighbourhood Centre were rurally located, while Newtown Neighbourhood Centre and Aftercare were located in metropolitan areas. Castle Personnel Services Inc. had a combination of rural and metropolitan locations. Most of the residents had ready access to transport apart from those residents serviced by Samaritans where it was only somewhat accessible. A significant relationship also existed between transport and location where metropolitan locations had ready access to transport while for rural locations transport was only somewhat accessible.

The demographic variables were also analysed for their relationship with quality of life. There was no relationship evident between demographic variables and objective quality of life. However, location was a significant factor for subjective quality of life both when taken on its own and when weighted according to importance. The results suggest that rurally located individuals show higher levels of subjective quality of life. The other significant factor in subjective quality of life was gender. Females showed higher levels of subjective quality of life when it was weighted according to importance however this relationship did not prove significant when the subjective scores were taken alone. Overall, subjective quality of life taken alone showed no significant relationship with the demographic variables. However, when weighted according to importance the relationship between demographic variables and subjective quality of life almost reached significance.

Methodological Issues

Before discussing the impact of the research on quality of life research for people with disabilities, the implications of this research for practice or the directions for the future, it is important to outline some of the methodological limitations of this study. As with most applied research there were a number of methodological concerns that may have influenced the results of this study. While there were precautions taken to limit the impact of these concerns it is conceivable that the results may have been influenced by methodological problems and should be interpreted with caution.

Participants

As previously mentioned the boarding house community is a diverse group in terms of disability type and level of impairment. Within this study we were aiming to investigate the impact of the ALI program on the entire population. However, one of the key issues is the lack of previous research that combines disability types when investigating outcomes. While some previous research has looked at a range of disability levels within intellectual disability (Boyle & Smyth, 1992; Cummins, 1993; Lord & Pedlar, 1991), and research has looked at mental illness or brain damaged consumers (Lehman, 1988; Lehman, Possidente & Hawker, 1986; Lehman, Slaughter & Myers, 1991); there has been no quantitative research on the boarding house population that is inherently varied in this area. To attempt to overcome this problem, a pre-testing protocol was used in the Com-Qol –I to assess the level of complexity the individual could cognitively manage to ensure that all participants were able to give valid responses to

questions. While this could not completely counteract the possible impact of the positive and negative symptoms of mental illness that may have limited the individual's ability to respond, it allowed an assessment of the level of responding to which they were capable. Theoretically, this would be effected if in a severe episode of their mental illness. Individuals were monitored closely throughout the interview for these symptoms and the interviews were discontinued if the consumer appeared to be mentally unwell at the time. However, it is possible that undetected symptoms influenced the data. There was also no available breakdown of the type of mental illness experienced by an individual which also may have influenced the results. However, the presentation of most residents who were in the mental illness category was consistent with psychosis and/ or schizophrenia.

In assessing the boarding house community across a number of geographical areas there were also some possible confounding variables. This data examined the impact of disability type, ALI provider, access to transport, geographical location, age, sex and the number and categories of activity participation, on quality of life. However, no data was available that looked at some of the qualitative differences across the groups. The areas where there may have been considerable differences were between the boarding houses, and between the ALI providers.

Within the boarding houses, some of the possible variables that may have influenced the results were: the level of individual choice available in different boarding houses, the number of individuals in the house with challenging behaviours, the model of care used by the house, the relationship of the boarding house staff with the residents, and the number of hours of staffing required under the houses licensing agreement. In previous research, one of the variables that has proven significant in the experience of people with

disabilities in the community is the attitude of staff (Lord & Pedlar, 1991). Therefore, further investigation of boarding house staff attitudes to issues such as autonomy and normalisation and the variables listed above, may yield a better understanding of the resident's experiences.

A further qualitative difference that is worthy of consideration is the differences between ALI providers. The results from this study indicated that the ALI provider had a significant relationship with age eg. Castle Personnel Services Inc catered for a significantly younger population. There was also a significant relationship between the ALI provider, location and access to transport. Aftercare and Newtown Neighbourhood Centre were placed in metropolitan locations with transport readily available, whilst Samaritans and Blackheath Neighbourhood Centre were placed in rural locations with transport only somewhat available. Castle Personnel Services had both rural and metropolitan houses who had varied access to transport. Qualitatively, other issues need to be considered. While there was a theoretical model for ALI espoused by the Dept. of Aging & Disability (2000), within the ALI services there are also a number of possible differences that may have been influential. These may include: the model of service delivery adopted at each service, the number of individuals serviced at a time, the types of activities used to integrate into the community, the level of staffing in each activity. Other differences to consider are: whether there was a skills focus or an activity focus, the quality of relationship with boarding house staff, the level of usage of individual service planning, staff turnover, the balance between permanent and casual staff, the level of training and experience of staff and management, the level of community integration existing prior to the research being conducted and differences in definitions of categories

of activity participation. The results from this study have indicated that the ALI provider was a significant factor in the level of participation of residents. These results may be due to the differences between providers in age, location and access to transport but other explanations should also be considered. The two neighbourhood centres, one in a metropolitan location and the other located rurally, showed the lowest level of participation overall and the lowest increase in hours of participation. The ethos of these centres, focusing more on 'drop-in' activities, may be a key contributing factor. It is important to note that neither the level of participation nor the level of increase in hours were significant factors of themselves. These variables all warrant future consideration but were impossible to control within this study.

A further issue pertaining to participant variables that needs to be considered was the perception of the researcher by the boarding houses and ALI services. The research was funded in part by the Department of Aging, Disability and Homecare to provide some further information to complement a review they were conducting of services. The researcher was also the Coordinator of the Castle Personnel Services Inc. ALI program. As the researcher had these multiple roles, reactions from boarding house proprietors and ALI staff seemed to be quite cautious. An example of the level of caution experienced by some boarding house proprietors can be encapsulated in the response of one of the proprietors,

"You can't trust the department with these questionnaires, invariably they're trying to do you out of some money".

Similarly, the ALI programs were quite suspicious of the researcher and a number expressed concerns that their funding might be jeopardised by the results of the research. While efforts were made by the researcher and by representatives of the Department of Aging, Disability and Homecare to explain that the research was entirely an independent, exploratory study and had no link to funding for boarding houses or ALI services it is possible that the level of caution may have influenced the accuracy of results.

A further complication with the multiple roles of the researcher was that as coordinator of the Castle Personnel Services Inc. ALI program the residents in the boarding houses serviced by Castle Personnel Services Inc were familiar with the researcher and had stronger rapport with her than the other residents of boarding houses across the state. In order to build stronger rapport with all the residents the researcher spent 5-10 minutes at the beginning of each interview talking in a more social manner. However, it is possible that the results may have been effected by the difference in rapport with the researcher. It is also possible that the results from Castle Personnel Services Inc. may have been skewed positively by the researcher's bias. To counteract this a clear testing protocol was established to keep uniformity in the collection of the data.

Materials

As discussed in the introduction there is currently a great deal of debate surrounding the conceptualisation and measurement of quality of life (Cummins, 2001; Cummins, 2002; Hatton & Ager, 2002), in particularly the subjective experience of it. As

such, conducting research in the area is fraught with both conceptual and measurement considerations that require thought. These considerations have been discussed in the introduction. The more pressing issues when interpreting these results are with regard to using the Com-Qol- I and the demographic information that was gleaned from the sample of boarding house residents in this study.

The Com-Qol-I was devised for use with people with ‘an intellectual disability or other form of cognitive impairment’ (Cummins, 1997). Although the majority of boarding house residents would fit into the category of ‘other cognitive impairment’ all past research using the Com-Qol – I seems to have been conducted with people with an intellectual disability (Cummins, 1997; Verri, Cummins, Petito, Vallero, Monteath, Gerosa, & Nappi., 1999). It is unclear however whether the recruitment from group homes and sheltered workshops in the studies cited in the manual had a range of disabilities (Cummins, 1997). While the range of disabilities in this study may have been a factor influencing the results, the strength of the Com-Qol-I is that it has parallel versions for adults without cognitive disabilities and adolescents that differ little apart from the use of pictorial tools to assist responding. The standardisation results for all three versions are similar, suggesting that while the scale may not have been designed specifically for the population with mental illness it may encompass them as they were given the subjective options both pictorially and with the written questionnaire in front of them. There is no difference in the scale for the objective portion as it does not use a pictorial aide and staff were asked to assist with these answers for all participants. The reasons for choosing this tool is that it allows for differences in function which is of great benefit when working with such a cognitively diverse group. While there still remains

questions about the level of standardisation for such a group in comparison to other tools where there is no ability to adjust for cognitive level the Com-Qol-I was the most appropriate choice for the boarding house population to assess their lived experience.

An issue discussed by Cummins (1997) that limits the application of the Com-Qol-I is the lack of research conducted outside the author's laboratory. This has implications both for the psychometric data provided and the applicability of the data in different settings. While Cummins (1997) research is conducted in Australia it is not within the NSW Health system and as such there may be differences in the transferability of his data. There is also the question of the bias that may be present when reviewing the usefulness of a tool developed by oneself. Again, despite these constrictions, this tool remained the most suitable for the boarding house population. The standardisation groups, while different in some areas, were closer in demographics to the NSW boarding house population than any other tool that has been devised to monitor quality of life for people with cognitive deficits.

The other tool used in this study is the demographic questionnaire devised by the author (see App. B). There were a number of practical limitations that restricted the level of control the researcher had over the data. The first consideration is that the data needed to be gleaned directly from the ALI computer database that each service was using. The information in this database had already been put into categories and there was little room for movement away from what had already been entered. Therefore factors such as disability type, types of activities and age groupings could not be defined by the researcher leaving some problems given the level of interpretation that might impact on some of these factors.

Secondly, the demographic data on the number of hours in which residents participated in the program suggested that there were ALI hours and linked hours. These categories for ALI hours were included as the original model espoused by the Department of Aging, Disability and Homecare to develop the community integration of the residents recommended linkage to and brokerage of services (Department of Aging and Disability, 2000). However, it became apparent that some agencies had stopped calculating this information once an individual was linked with a community group without support. This meant that some participants may have been participating independently in the community without any recognition of this in the results. It was also evident that some agencies had adopted the brokerage model suggested in the departmental recommendations (Department of Aging & Disability, 2000), while others had used their own staff to support the residents in activities. This discrepancy made the linked hours variable of little use as there was no uniform way to monitor how these hours had been calculated. It may also have affected the total number of ALI hours for individuals linked to a variety of services who would hypothetically have benefited the most from the ALI program. The data suggests that services operationalised the ALI vision in different ways and may have decreased the impact of the number of ALI hours on quality of life.

The third issue with the demographic data was that there was no defined criterion for grouping activities into categories. This meant that these grouping were again open to the interpretation of each agency. As the agency entered their own data it is conceivable that agencies with different philosophies about service delivery may enter the same activity into two different categories based on the element they wished to emphasise. This

data was also used for reports to the funding body and therefore is likely to be skewed by what the agency believes is most important in receiving ongoing funds. For this reason the categories of activity involvement were not analysed in these results.

Procedure

There were also some issues that need consideration in the procedural implementation of this study. One of the issues with the design of the study is that it was a repeated measure over six months. Cohen & Swerdlik (1999) suggests that with all repeated measures there is an impact on the results simply by the fact that it is repeated. Heal & Sigelman (2000) also suggests this is an issue with accuracy for people with an intellectual disability who tend to perform more accurately on tests when they are familiar with them. However, due to the six-month gap between testing and the low level of memory of previous testing shown by most of the group, it is proposed that the impact of a practice effect would be negligible.

Another procedural issue is that due to the pre-testing protocol being used to control for inaccurate responses in the sample, the sample group consisted only of those individuals who had sufficient cognitive ability to participate. This meant that the data was possibly skewed due to the most disadvantaged group in the population not being able to participate. It also meant that groups may have been made up of more residents with a mental illness than would be representative of the population. The Department of Aging & Disability (1999) census stated that 40% of residents had a mental illness and 31% had an intellectual disability, while in this study 57.6% had a mental illness and 28.8% had an intellectual disability. While it is possible that these differences are due to a

changing focus in the boarding house population, the possibility of a skewed sample cannot be ignored. The data from this study indicates that 15 of the 94 participants who consented to participate were unable to continue due to inability to complete the pre-test protocol accurately. However, 74% of those who participated were able to use the full five point likert scale. Results need to be interpreted with this skewed sample in mind.

Another procedural issue that needs to be considered is the possible power imbalance that may have existed in interviewing. As previously discussed the objective questions were asked with the assistance of the boarding house manager and the subjective questions were asked in isolation. As it was necessary to use information from the boarding house manager, it may have been perceived that the researcher was in alliance with them. This would create a power differential that may have increased socially desirable responses. This power differential may have been further exacerbated by the choice of venue, as in order to gain privacy interviews were usually conducted within the doctor's room. The researcher sought to overcome this power differential by explaining that the answers were confidential, beginning interviews with social conversation and ensuring she was dressed in a casual manner to align herself with the residents. However, it is possible that there was an impact on the level of social desirability in the answers received. Similarly, the relationship of individual clients with their boarding house managers may also have been influential.

The final and perhaps most powerful procedural issue was that the research was not conducted as soon as the ALI program was begun. Funding was distributed for ALI in April 2000, however this research did not begin until April 2002 with the second round of interviews six months later. It is then quite feasible that some of the larger gains in

objective and subjective quality of life may have occurred before the first round of interviews. While there were moderate gains seen in this data, these gains may have been more noticeable had the research been conducted when ALI was first introduced into the boarding houses. While this study seeks a longitudinal appraisal of changes, it is possible that the conditions required for 'homeostasis' may have been reached in the initial stages of ALI thus decreasing the probability of marked changes in relation to subjective quality of life (Cummins, 2002) during the course of this study.

Design

There are a number of issues with the design of this study that may have been improved. The two main issues are the impact of the pre-test protocol and the use of a repeated measure design. As previously discussed the use of the pre-test protocol meant that a number of the possible participants were not able to participate due to cognitive constraints. While this protocol was essential in gaining reliable data, it may have been useful if the data had been included as Cummins (1997) suggests by asking the carer to respond 'as they think the person would respond' for those residents who were unable to complete the pre-test protocol. However, this technique has been thrown into question by Cummins (2001) who has recently concluded, based on his review of research, that this procedure is invalid particularly with regard to subjective quality of life.

The second area where design may have been improved is by using a between group design where comparisons were made between those individuals participating in the ALI program and those who had chosen not to participate. While this would have allowed a direct comparison, these two groups have little face validity as comparison

groups. The non-participants tended to be particularly high or low functioning and were mainly people with a mental illness. In addition, this group was also less likely to consent to interviews as they were often reluctant to engage on a social level that would be required either in an interview or in participation in the ALI program. Thus, while this may have been a useful avenue of exploration the participant limitations restricted research from this approach.

Implications for Quality of Life Research with People with Disabilities

The results from this study contribute to the body of knowledge on quality of life for people with cognitive deficits. The three main bodies of literature to which they contribute pertain to the impact of deinstitutionalisation and normalisation on people with disabilities, the assessment of quality of life for people with cognitive impairment, and the small amount of research on boarding house residents.

Deinstitutionalisation and Normalisation

The existing literature on deinstitutionalisation and normalisation shows two main movements. The first gave multiple evidences of the benefits of deinstitutionalisation and normalisation. It stated how detrimental institutions are for the well-being of residents and how improvements are needed to enable the movement to community-based living. Multiple studies indicated improvements in areas such as living skills, adaptive behaviour and maladaptive behaviour (Butterfield, 1987; Halpern, Sackett, Binner & Mohr, 1980; MacEachron, 1983; Meyers & Blacher, 1987) as residents moved from institutions to other forms of accommodation.

However, soon after the glowing reports about deinstitutionalisation, studies began to emerge indicating that these community-based agencies may in fact have become 'neo-institutions' (Gunzberg & Gunzberg, 1992). Examples were cited of residents returning to the kinds of behaviour seen as characteristic of institutional life. Studies also indicated that in many of the community-based residences there had not been sufficient planning to accommodate the needs of the residents for integration with their community (Baker, 2000; Cullen, Whoriskey, Mackenzie, Mitchell, Ralston, Shreeve & Stanley, 1995; Lehman, Slaughter & Myers, 1991). These findings suggested that residents experienced more isolation in community situations where their disabilities were more obvious. In an institution disabilities were the norm and they received greater acceptance. The main area of concern for the residents in community-based accommodation was the lack of social integration with the community and its impact on friendship and support networks for the disabled person. This occurred due to a lack of satisfactory support in recreational development (Bruininks, 1990; Gunzberg & Gunzberg, 1992; Landesman – Dwyer, 1981; Luckey & Shapiro, 1974; Neumayer & Bleasdale, 1996).

It seems as though this research is part of a third movement that investigates the impact of recreational development on community-based residents. This research adds support to the existing body of knowledge that indicates movement to community-based accommodation is not sufficient by itself to gain improvements in an individual's quality of life (Bruininks, 1990). However, time and support given to programs concentrating on the social, recreational and vocational development can foster a better normalisation (Luckey & Shapiro, 1974). This study also indicates that there are both objective and

subjective improvements in an individual's experience even when the living arrangements themselves remain unchanged, provided that strategies are implemented to improve community integration.

Quality of Life Testing with People with Cognitive Impairment

The body of literature pertaining to quality of life assessment in people with cognitive impairments has been under strenuous debate particularly over the last couple of years (Cummins, 2001; Cummins, 2002; Hatton & Ager, 2002; Wolfensberger, 1994). The areas of quality of life most discussed at present are: what constitutes a reasonable definition of quality of life applicable to the cognitively disabled and non-disabled population; and how can persons with cognitive disability be reliably and validly tested.

Key to the debate about assessing the construct of quality of life for persons with cognitive disability is the question about whether objective or subjective quantification is the most relevant means of understanding quality of life. Some have argued that due to the endogenous nature of subjective quality of life, only objective measures are sufficiently sensitive to a person's lived experience (Hatton & Ager, 2002). In contrast, Cummins (2001; 2002) argues a theory of homeostasis where subjective quality of life remains relatively stable in living conditions that would be generally satisfactory to the community at large, but when living conditions fall below an acceptable level, the homeostasis is defeated making subjective quality of life of great importance. The data from this study supports the theory of homeostasis described by Cummins (2001; 2002) demonstrating that while there were significant gains in overall objective quality of life, these gains were not significant when it came to the overall subjective quality of life.

A question that arises from this research is whether there are particular domains that show a greater sensitivity to objective life quality (Cummins, 2002). The result that is most thought provoking from this study is that across the domains where we expected results, objective gains were evident in productivity, while subjective gains were only evident in intimacy and emotional well-being. This calls to mind the question about whether there is a difference in how these areas are interpreted subjectively. The possibility arises that objective measures may not be able to adequately address concepts such as intimacy and emotional well-being due to their highly subjective nature. In contrast, an individual's productivity may be more obvious when examined through objective means. Cummins (2002) article discussing the caveats of which to be wary when using the Com-Qol-I refers to the possibility that emotional well-being or 'happiness' seems to present more of an affective response as opposed to the other domains in the scale.

The second area of recent debate in the measurement of quality of life in persons with cognitive deficits, is whether this group can be reliably and validly tested using self-report measures (Hatton & Ager, 2002; Heal & Sigelman, 2000; Sigelman, Winer and Schoenrock, 1992; Taylor & Bogdan, 1990). There have been questions raised about whether this group can offer reliable answers due to their difficulties with abstract thinking and retaining information accurately. Cummins (1997) approach to this was to introduce a pre-test protocol to allow testing to be conducted only with those individuals who evidenced adequate levels of cognitive function to answer questions reliably. His original approach to testing those who fell short of the standards of this protocol was to use proxy data from their caregivers. However, his later research has stated he believes

this technique does not return reliable results, leaving no alternative to gathering information from the severely disabled group. The technique of using a pre-test protocol has been thrown into question by Perry, Felce & Lowe (2000) who found that the majority of individuals tested were unable to complete this protocol (cited in Hatton & Ager, 2002). Cummins (2002) in contrast found that while most severely cognitively impaired individuals were unable to complete this protocol, it yields reliable data from most individuals with moderate to mild cognitive impairment and as the intellectually disabled population in Victoria was highly skewed towards mild/ moderate disability he states that most will be able to use the tool.

The boarding house population is unique in many ways due to the large variety in both house numbers and amount of supervision and freedom afforded residents. For the purposes of measuring quality of life the main dilemma in assessing this group was the range and level of disability types in the boarding houses. While there has been some research into quality of life with consumers with a dual disability of mental illness and intellectual disability (Baum, 2000; Gardner, Carran & Nudler; Lunsby & Benson, 2001; Moss, 2001), there has been no research completed on quality of life in a population that encompassing both groups. The Com-Qol-I was chosen as it was a scale with a pre-test protocol to assess cognitive capacity. It also had parallel forms for adults with and without cognitive disability, with similar norms, the only difference being the using of pictorial aides. To the author's knowledge, this was the first time the Com-Qol-I had been used with a group whose cognitive deficits came, not only from an intellectual disability but also from other conditions such as brain damage, negative symptoms of mental illness or medication side-effects. The results with this group were promising. Participants were

able to use a scale suiting their level of function, 74% of the sample being able to use the full five point likert scale. The results have indicated that while there may have been some minor differences in how the scale was used there was no significant differences between the disability types on their scores. While there were fifteen who were unable to participate due to being unable to complete the protocol, most seemed to find completing the scale using pictorial aides with written forms an acceptable manner of measurement. This should be explored with further psychometric analyses in future research.

Boarding House Research

There is minimal previous research investigating boarding house quality of life with only one qualitative study being conducted in New South Wales (Cleary, Woolford & Meehan, 1998), two years before the ALI program began. This research builds on the results of Cleary, Woolford & Meehan (1998) and begins to build a picture of the experience of boarding house residents since the operationalisation of ALI. The results from this study, as predicted, had no significant impact on the areas of material well-being, health and safety. However, this does not mean that this is not an area where there might be both subjective and objective improvements. Over the six months of the study there had been some initiatives implemented to improve the health of residents. It is interesting to note that there was no significant impact on quality of life in the health domain despite these initiatives. Cleary, Woolford & Meehan (1998) noted that health was an area in which residents were reasonably uninterested, while they were acutely aware of a lack of material possessions and the presence of other aggressive clients. Our results may indicate a similar nonchalance with regard to health since while these health

initiatives were happening residents had little interest in the area. Alternatively, the nature of health changes is more likely to be of longer term benefit and therefore changes may have been less noticeable over a shorter time period. With regard to material well-being and safety there was no indication of change across either of these areas adding little to the existing research.

The domains which showed significant change over time were productivity, intimacy, and emotional well-being. The area that showed objective improvements was productivity. The other area where it was hypothesised that change would occur was place in the community but the results gave no indication of a significant change. Lehman, Slaughter & Myers' (1991) study indicated that productivity was the area where the Los Angeles boarding houses fell short of all other forms of accommodation, including institutions. These results indicate that, as would be expected with a program focused on community participation, productivity was the area with the highest objective changes. With regard to place in the community it was clear from Cleary, Woolford & Meehan's (1998) study that this was an area where boarding house residents were isolated from the community in which they lived, with little evidence of a 'normalised' experience. Contrary to our hypotheses no significant gains were evident in this area. There are many possible explanations for this. It is possible that while ALI has provided much activity it has not yet given participants the skills to be part of the community rather than simply a 'visitor' (Lord & Pedlar, 1991). This may reflect a skill deficit but may also reflect a lack of individual attention in the ALI model. Funding may not be sufficient to provide the individual support needed to facilitate participants gaining a fuller sense of community status. In addition, this may reflect similar findings to Cleary,

Woolford & Meehan's (1998) research that indicated that the level of restriction for residents of boarding houses was not conducive to establishing an identity in the community. The refusal of some boarding house staff to allow the residents for whom they cared to participate in this research is a glaring example of the level of restriction experienced by some. This study suggests that with sufficient support and planning, productive lifestyles for people in boarding houses is a possibility and has been significantly improved in ALI participants. However, this study also indicates that more work needs to be undertaken to increase not only the activity of participants but also their community standing.

The domains that had significant subjective differences for quality of life were intimacy and emotional well-being. The existing research in boarding houses suggests that the environment is not as conducive to the development of satisfying social relationships as either group homes or institutions (Lehman, Slaughter & Myers, 1991). One reason may be that there is rarely the development of smaller more intimate groups within the boarding house and as Cleary Woolford & Meehan (1998) noted, activity was usually done individually or occasionally in a large group. The introduction of the ALI program meant that there were opportunities to participate in activities with three or four other people, providing a greater possibility of more significant relationships. Due to most ALI programs servicing a number of boarding houses it is also likely that residents were able to socialize with a broader spectrum of people, giving more possibility of connecting on a deeper level with likeminded individuals. This research advocates the need for residents to be exposed to a range of people and for them to be given choices about with whom and how they wish to socialize. The reasons for no objective increase in

this area may be that these residents may not have increased the number of people with whom they socialized but simply the quality of their interactions. This variable of quality of interactions may also be part of the explanation for the subjective increase in emotional well-being. However, as discussed previously changes to emotional well-being may also be due to an affective change rather than any objective improvement (Cummins, 2002). Cleary, Woolford & Meehan (1998) discuss the pervading sense of hopelessness about the future throughout their sample. The introduction of the ALI program that introduces interactions of higher quality and new choices may have begun to lift this sense of hopelessness in the boarding house population. The provision of a service to cater specifically to individual needs, while not altering the living environment, may have given residents the opportunity to consider the future less bleak.

Of interest to research into boarding house life are the differences that arose from the demographic data. The demographic domains specific to ALI, such as the ALI provider and the hours of participation will be discussed later. Of more general interest are those demographic variables that influence quality of life. While there was no relationship between demographic variables and objective quality of life, location and gender both showed significant relationships with subjective quality of life.

Participants who were rurally located showed higher subjective satisfaction than those in metropolitan areas. 54% of boarding houses in this study were metropolitan with the remainder rural, so the samples were roughly equivalent. Subjective quality of life reflects the satisfaction of individuals. The difference noted in this study may be due to the isolation of rurally located residents as there was a significant relationship between location and accessibility of transport in the results. It is possible that the isolation

inherent to rural living means that residents have had little with which to compare their living situation, as most of their interactions take place with one another. They also may have less exposure to the powerlessness and vulnerability described by Corbett (1989) that can be felt in the wider community. In comparison, the metropolitan group is more likely to be exposed to a wider range of people and living situations. A further explanation may be the significant relationship seen between location and the ALI provider. Given that location and ALI provider have a strong relationship, and that the number of participation hours was significantly related to ALI provider, this may have contributed to this result. Also of significance may be the relationship that existed between location and transport. In the rural areas transport, by necessity, was usually provided by services. This may have given the residents more security and confidence when interacting with the community. In contrast, those in metropolitan areas were often required to establish their own transport and may have been less satisfied with their contact with the community.

The gender of participants was also a variable with significance in subjective quality of life. Females showed higher subjective quality of life when it was weighted according to importance. This relationship was not significant when the importance placed on the level of satisfaction was not considered. This result indicates the higher level of importance women place on their subjective quality of life that elevates their scores. While these results should be taken with caution due to the smaller sample of females, it appears that when discerning between the genders, importance placed on variables is worthy of consideration.

Implications for Practice

While it is evident that there is a need for further research in this field, and that there are a number of methodological considerations that recommend caution in interpreting this research, there are number of positive indications and practical applications that can be drawn from this study.

Active Linkage Initiative

The results of this study add a quantitative element to the existing qualitative discussion about the efficacy of the ALI program that has taken place at a Departmental level. These results add support to the concept that a well-organised, individually oriented program seeking to increase community integration through social, recreational and vocational means may be a successful way to overcome the issues of community isolation that have been faced by boarding house residents. From these results, it appears that the ALI program has been effective in reaching some of the goals that were established at its inception and that the number of hours of participation in this program by residents continues to increase.

These results indicate that there have been overall improvements in the domains of productivity, intimacy, and emotional well-being for residents. Significant objective improvements were seen in the productivity domain. While subjective improvements were evident in the domains of intimacy and emotional well-being. These areas have been traditionally neglected when planning for community-based living so these results are encouraging. They suggest that while these areas may have been neglected when

these individuals were placed in community-based accommodation, this oversight may be beginning to be rectified through the application of the ALI program. However, the results also indicate that there was no obvious improvement in this time period in the areas of material well-being, health and safety or place in the community. While this may be due to there being little room for improvement it is also possible that while providing for the social needs of boarding house residents through ALI, some of the lower order needs such as material and safety considerations may have been neglected. Given that boarding house legislation continues to allow up to 100% of the residents pension to be taken the latter explanation seems feasible. Further work in improving both living standards and the social environment for boarding house residents should be encouraged. Similarly, a renewed focus on providing opportunities not only to participate in activities but also enter more fully into positions of community status may be worthy of exploration. As stated earlier, of note in this study are the restrictions obvious in the refusal to participate in this research that came from some boarding houses where the residents were given no autonomy to make this decision for themselves. Work needs to continue to allow residents the choices and freedom that were recommended in the Disability Services Act (1986) but continue to be neither monitored nor legislated in the licenced boarding house sector.

The relationship between ALI provider and the level of participation suggests, that there is great variability in the models of service delivery. This has implications for the ongoing programs within ALI. It may be useful for increased liaison and planning between services to occur and decisions to be made about whether there is a need for more cohesion between the services in their modes of service delivery. However,

differences between ALI providers in the age, location and transport available to residents would also need to be considered. While the ALI provider was not a factor in the quality of life of residents as measured by this instrument, these differences may have a positive or negative impact and are worthy of further attention.

Boarding Houses

While there has been considerable criticism of boarding house accommodation in the disability field, one of the key results in this research is that the subjective experience of quality of life for boarding house residents at the time of the first round of interviews was at a level above the 70%SM standard presented by Cummins (2002) as the baseline for acceptable living standards. This does not mean that there is not room for vast improvements in this sector but does indicate that the level of care in general seems to be of a sufficient standard to produce 'homeostasis' in subjective quality of life (Cummins, 2002). It is important to interpret this result cognisant of the criticisms of Hatton and Ager (2002) who believed Cummins (2001) theory of homeostasis to be unworkable as it relied on aversive circumstances to show change. However, while it is possible that the living conditions were always at an acceptable standard it is also important to note that the ALI program had been in place for two years prior to the study and given the marked improvements in overall objective quality of life that are supported by this data, it is also possible that the living standards may only have reached this level during these two years. As previously stated this study indicates the need for ongoing support for boarding houses both through the existing ALI program, but equally through the development of

initiatives that address the material well-being, health, safety and place in the community of residents.

Further implications for boarding houses arise from the result that rurally located residences had higher subjective quality of life than metropolitan residences. These results must be interpreted with caution since, as previously noted, the improvement may be due to isolation and lack of experience of the wider community. The balance between the principles of duty of care and dignity of risk are crucial in applying this result to practice. However, these results do indicate that location is a variable that warrants consideration when establishing boarding houses.

Disability Field

This research also presents a number of applications for the disability field. The criticisms about lack of community integration for residents has arisen mainly through research into group homes, with much of the research indicating a lack of social development for residents in this setting (Bruininks, 1990; Gunzberg & Gunzberg, 1992; Landesman – Dwyer, 1981; Neumayer & Bleasdale, 1996). The results from this study support the efficacy of a model where staff separate from the living environment are introduced purely to develop the individual social, recreational and vocational pursuits of residents. While many group homes have individual service plans it is possible that within the house structure where all resident needs are met by the same people, social, recreational and vocational needs may not receive the attention they warrant as time is taken up with the essential requirements of feeding, housing and cleaning for residents.

Thus, this ALI model may be an initiative that warrants investigation in further reaching areas of the disabled accommodation sector.

As previously stated, there also needs to be consideration of the ambiguities that exist in the regulation of the disability sector. The legislative requirements that produce intense monitoring of the funded sector do not afford the residents of unfunded services the consistency in the standard of care and rights that should be expected. Given that it is approaching 20 years since the Disability Services Act (1986) was formed these ambiguities need to be addressed.

Future Research

Quality of life has been heralded the outcome measure most suited to contemporary philosophy in disability services provision (Schalock & Keith, 2000). A plethora of studies have been conducted in group homes and institutions assessing quality of life using a number of different tools (Cummins, 1996; Hughes, Hwang, Kim, Eisenman & Kilian, 1995). However, as has been already discussed there has been very little research in the area of boarding house accommodation which seems a reflection of the neglect until recent times of this sector (Dept of Aging & Disability, 2000). With a view to the future of this industry there are a number of areas that warrant further investigation.

This study has supported the hypothesis that the ALI program with its focus on the social, recreational and vocational facets of an individual's life has made a positive impact on the quality of life of residents of boarding houses, particularly in the areas of productivity, intimacy, and emotional well-being. While this research presents some

evidence to suggest these areas have been impacted upon, there are a number of methodological considerations that limit the scope of these findings and more in depth research in this area would be warranted. Conceptually, research may be able to shed further light on the reasons for the objective changes in productivity while seeing subjective changes in intimacy and emotional well-being. Such research may assist with the development of quality of life domains that invite a re-appraisal of the effectiveness of questions in these areas, an investigation already begun by Cummins (2002).

Further boarding house research should also be developed to compare this group to other forms of accommodation. While this study indicates changes in quality of life there is no Australian data that compares the quality of life of the boarding house community to that of residents of group homes, institutions or semi-independent flats. As has been discussed the boarding house community seem to be within the normal range for their satisfaction with their living conditions. However, investigations would be warranted into whether the standard of care in this form of accommodation is of the same level as those services that are governed by the Disability Standards. Longitudinal studies may also look at whether the predicted changes in legislation bringing boarding houses in line with funded services in their governance by the disability standards will make an impact on the objective and subjective quality of life of this group.

This research was conducted beginning in April 2002 and the ethics and funding were received in early 2001. Unfortunately, this was just prior to the more recent debate being published into some of the issues pertaining to the Com-Qol-I and quality of life conceptualisation and measurement in general. While research indicates that this tool remains reasonably sensitive to change, valid and reliable (Cummins, 2002), the

Australian Centre on Quality of Life (ACQOL) has since been established and is developing a tool similar to the Com - Qol -I called the Personal Well-Being Index. This tool has arisen from the recent debate and aims to overcome the methodological issues that persist with the Com-Qol-I. Future research into boarding house accommodation and quality of life would do well to work in tandem with the studies of ACQOL.

Other areas warrant further research in quality of life. There is ongoing need, as the body of literature grows in this area, for psychometric data to be developed and reviewed in line with the increasingly clear conceptual framework. It is crucial that as quality of life becomes more frequently used as an outcome measure for disability services (Schalock & Keith, 2000), that the complexity, reliability and validity of tools to measure this area also receive similar attention and development. It appears that Australian researchers have taken up this challenge with the development of ACQOL, dedicated to further development of research in this area.

A further implication that arose from this study was the lack of research encapsulating the range of disabilities found in boarding houses and in many group homes. While this raises many methodological issues due the differences between these disability groups, it remains an area where it is necessary for practitioners to apply assessments of quality of life. Appropriate tools that have been standardised on this varied population are required to do this. While this study indicates the possibility of using existing tools, research is required to assess whether these groups are significantly different in their responses to self-report measures on quality of life. Comparative research is also an area that may be useful in investigating whether combining disability groups has any beneficial or detrimental impact on the disabled person's experience.

This research aimed to review the impact of the ALI service of the quality of life of boarding house residents. The results suggest that ALI has contributed positively to the life experiences of these residents. Improvements were evident in the overall objective quality of life, and in the overall domains of productivity, intimacy and emotional well-being. Objective gains were seen particularly in the domain of productivity. Gains were also evident in the subjective domains of intimacy and emotional well-being. There are numerous areas that warrant further intervention and research. However, these preliminary findings suggest that as the disability field and associated research moves to focus on recreational and habitative programming, boarding house residents are well placed to have continued improvements in their quality of life.

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**Appendix A – the Comprehensive Quality of
Life Scale – Intellectual/ Cognitive Disability
(Fifth Edition)**

3 ComQol - I5

[Questions are asked by the interviewer]

"I am going to ask some questions about your life. [Carer] can help you at the start. Later I will ask you to answer some questions by yourself. Is that OK?"

"If you do not understand a question, just let me know."

When were you born?

____/____/____
day month year

Client sex? (circle one)

Male

Female

Objective Scale

1(a) Where do you live?

A house ☐A flat or apartment ☐A room (e.g. in a hostel) ☐

Do you own the place where you live or do you rent?

Own ☐Rent ☐

(Prompt: Think about the things you own, like your clothes, furniture, etc.)

(b) How many personal possessions do you have compared with other people?

More than
almost anyoneMore than
most peopleAbout
averageLess than
most peopleLess than
almost anyone☐☐☐☐☐

(c) What is your personal or household (whichever is most relevant to you) gross annual income before tax?

Less than \$10,999 ☐\$41,000 – \$55,999 ☐\$11,000 - \$25,999 ☐More than \$56,000 ☐\$26,000 - \$40,999 ☐

2(a) How many times have you seen a doctor over the past 3 months?

None

1 - 2

3-4
(about once
a month)5-7
(about every
two weeks)8 or more
(about once a week
or more)☐☐☐☐☐

- (b) Do you have other disabilities or medical conditions? (other than an intellectual or cognitive disability) (e.g. visual, hearing, physical, health, etc.).

Yes

☐

No

☐

If yes please specify:

*Name of disability
or medical condition*

*Extent of disability
or medical condition*

e.g. Visual
Diabetes
Epilepsy

Require glasses for reading
Require daily injections
Requires daily medication

- (c) What regular medication do you take *each day*?

If none tick box

☐

or

Name(s) of medication

- 3(a) How many hours do you spend on the following *each week*?
(Average over past 3 months)

Hours paid work

0

☐

1-10

☐

11-20

☐

21-30

☐

31-40+

☐

Hours formal education

0

☐

1-10

☐

11-20

☐

21-30

☐

31-40+

☐

Hours unpaid child care

0

☐

1-10

☐

11-20

☐

21-30

☐

31-40+

☐

(b) In your spare time, how often do you have nothing much to do?

Almost always Usually Sometimes Not Usually Almost never

☐☐☐☐☐

(c) Do you watch TV? How much TV do you watch? (average over a typical week).

Hours per day

None

1 – 2

3 – 5

6 – 9

10 or more

☐☐☐☐☐

4(a) Do you have a close friend?
How often do you talk with your friend?

Daily

Several times
a week

Once a week

Once a month

Less than
once a month

☐☐☐☐☐

(b) If you are feeling sad or depressed does someone show they care for you?
How often?

Almost always

Usually

Sometimes

Not Usually

Almost never

☐☐☐☐☐

(c) If you want to do something special, how often does someone else want to do it with you?
How often?

Almost always

Usually

Sometimes

Not Usually

Almost never

☐☐☐☐☐

5(a) Do you sleep well?
How often?

Almost always

☐

Usually

☐

Sometimes

☐

Not Usually

☐

Almost never

☐

(b) Are you safe at home?
How often?

Almost always

☐

Usually

☐

Sometimes

☐

Not Usually

☐

Almost never

☐

(c) Are you ever worried or anxious during the day?
How often?

Almost always

☐

Usually

☐

Sometimes

☐

Not Usually

☐

Almost never

☐

- 6(a) Below is a list of leisure activities. Indicate how often in an *average month* you take part in or attend each one for your leisure (not for employment).

Activity	Number of times per month
(1) Go to a club/group/society	_____
(2) Go to a hotel/bar/pub	_____
(3) Watch live sporting events (Not on TV)	_____
(4) Go to a place of worship (e.g. church)	_____
(5) Chat with neighbours or shopkeepers	_____
(6) Eat out	_____
(7) Go to a movie	_____
(8) Visit family or friend	_____
(9) Play sport or go to a gym	_____
(10) Other (please describe)	_____

- (b) Do you belong to any club, group, or society?

Yes ☐ No ☐ If no, go to question (c)

Do you hold an *unpaid* position of responsibility?

If 'yes', please indicate the highest level of responsibility held:

- ☐ Committee Member
- ☐ Committee Chairperson/Convenor
- ☐ Secretary/Treasurer
- ☐ Group President, Chairperson or Convenor

- (c) Do people *outside your home* ask for your help or advice?
How often?

Almost every day	Quite often	Sometimes	Not often	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 7(a) Can you do things you *really* want to do?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (b) When you wake up in the morning, do you ever wish you could
stay in bed *all day*?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (c) Do you have wishes that *cannot* come true?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.1 Subjective Testing

3.1.1 Client testing for acquiescent responding

While acquiescent responding contaminates all survey and interview data to some degree, people with an intellectual or cognitive disability are particularly prone to this form of responding. There are two main reasons. The first is deference to an authority figure (the interviewer) learned as a consequence of institutional living or dependence on caregivers. The second is a defence against appearing incompetent when asked questions they do not understand. Agreement with the question, or answering in the affirmative, is the form of response that is least likely to generate a negative consequence for the person being questioned.

In using the ComQol scale with people who have a mild/moderate level of intellectual disability, and in the absence of pre-testing, we often find up to 25 percent of people consistently answer at the top of the importance or satisfaction scale. This may be due to the use of low - discrimination scales (2- or 3- point scales) such that the normal negative response-skew forces response consistency. Alternatively, it may represent acquiescent responding.

It is therefore recommended that pre-testing for subjective QOL commences with the brief acquiescence scale presented in Appendix A. If people respond affirmatively to the two acquiescent items, further testing on the subjective scales should not proceed.

3.1.2 Client testing for discriminative competence

The purpose of the following procedures is to establish whether the client is able to independently respond to the subjective components of the scale. Ideally the primary caregiver should leave during this testing. If their presence is unavoidable, the client must respond without assistance.

The testing moves through three phases which are designed to determine whether the client can:

- (A) identify items in order of magnitude,
- (B) use a scale by matching to concrete reference,
- (C) use a scale with an abstract reference.

The testing protocol moves responding from concrete to abstract. Within each of the three testing phases the tasks progress in complexity from binary choice to a choice involving five elements.

When the client makes an error, return to the previous (simpler) task, and repeat the question. If the client fails again proceed no further with that phase and move onto the next. The client must respond correctly, at least using the binary choice, in order to proceed to the next phase. If the client is unable to respond correctly to all three testing phases at least at the level of a binary choice, they should not be requested to complete the subjective scale.

Provided that the client is able to successfully complete each phase of this pre-testing, they may progress to the subjective ComQol-I5 subscale. The following should be noted:

- (a) The level of choice provided in the importance subscale should be determined by the maximum level of discriminative competence displayed during the third phase which used the concept of 'importance'. That is, if a client was able to complete phase (C) at the level of a three-point choice, then subsequent testing on importance will also use a three-point choice.
- (b) The subjective questions should not be asked in the presence of the primary carer if that can be avoided.

Equipment

The diagrams that are provided will need to be detached from this manual, or copied, so that they can be presented to the client as single pages.

Procedure

The client responds to the questions by pointing.

During testing, the client should be seated at a table with the drawings in front of them.

The following matters should be noted:

1. Whether to start testing at the beginning (size discrimination between two blocks) or the end of the sequence (abstract use of 5-step importance scale) is a matter for judgement on the part of the test administrator. In this, it is a balance between engaging in unnecessarily simplistic tasks which a client may find insulting, and incurring repeated failure due to starting at a level that is overly demanding. The best source of advice on a starting point is the primary caregiver. If in doubt, start low.
2. It is important that the client has a minimal experience of failure. If they cannot do a task, minimise negative feedback and return to a level of task at which they can succeed. Motivation can be enhanced through appropriate praise and encouragement.
3. As with the administration of all psychological tests, it is vital that the tester is completely familiar with the instrument before it is given. Practice sessions on family, friends and volunteers is an absolute necessity.

Testing procedure

Ask the carer and client to name some possession which the client regards as highly important. This will be used in the third phase of testing.

Item of importance _____

Subjective Testing: Phase 1

Order of Magnitude Test

Whether testing starts at (a), (b) or (c) is at the discretion of the test administrator. The advice of a primary carer is likely to be useful.

- (a) Present client with 2 blocks of extreme sizes.

Record of client
Success (✓) or
Failure (x)

Q: Please point to the **BIGGEST** block

Q: Please point to the **SMALLEST** block

☐

Note: If the client makes an error, repeat the instruction once. Unless it is certain that the client can complete this task, subjective testing should not proceed.

- (b) Present the 3 blocks of differing sizes.

Q: Please point to the **BIGGEST** block

Q: Please point to the **MIDDLE SIZED** block

Q: Please point to the **SMALLEST** block

☐

Note: If the client makes an error with (b), repeat task (a).

- (c) Present the five blocks of differing sizes

Q: Please point to the **BIGGEST** block

Q: Please point to the **SMALLEST** block

Q: Please point to the **MIDDLE SIZED** block

Q: Please point to the **SECOND BIGGEST** block

Q: Please point to the **SECOND SMALLEST** block

☐

Subjective Testing: Phase II

Scale with a Concrete Reference

Procedure: Present the two-blocked diagram and the two-step scale.

Instruction: "I am going to show you the blocks again." [present the two-block diagram].
"And some steps" [present the two-step diagram].

"I want you to show me how the blocks match the steps. There are rules. The big block fits on the top step. The small block fits on the bottom step.

So, when I point to the big block [point] I want you to point to the top step [point]. Is that OK?" Repeat if client seems uncertain.

"When I point to the small block [point] I want you to point to the bottom step [point]. Is that OK?"

Record of client
Success (✓) or
Failure (x)

[Point to the big block]

Q: "Where does the big block go on the steps?"
(client to point to place on the steps)

☐

[Point to the small block]

Q: "Where does the small block go on the steps?"

☐

If the client succeeds: proceed to the 3-block problem.

If the client fails: ask whether they would like you to go over the rules again. If affirmative, repeat the instructions. If negative, repeat the task.

If the client fails again, cease testing and do not proceed with the satisfaction or importance questions.

Present the 3-Block Diagram and 3-Steps

Instruction: Here is another set of blocks and steps. This time you can see there is a middle-size block [point] and a middle step [point].

Just like before, I want you to point to the step that matches each block Is that OK?

[Point to the big block]

Q: "Where does the big block go on the steps?"

☐

[Point to the small block]

Q: "Where does the middle-size block go on the steps?"

☐

If the client succeeds, proceed to the 5-block problem. If they fail, use the same strategy as described for failure in the 2-block problem.

If the client fails again, proceed to the next testing phase using only the binary choice.

Present the 5-Block Diagram and 5-Stairs

Instruction: "Here is the last set of blocks and stairs.

Just like before, I want you to point to the step that matches each block. Is that OK?

[Point to the smallest block]

Q: "Where does this block go on the steps?"

☐

Repeat for other blocks in the following sequence:

The middle-size block

☐

The second biggest block

☐

The second smallest block

☐

If the client succeeds, proceed to the next testing phase. If the client fails, repeat as before.

Subjective Testing: Phase III

Scale with an Abstract Reference

Recall: The possession named at the start of the objective testing which the client regarded as highly important to them.

Present: The 2-steps of importance

Instruction: "This time I am going to show you some steps that have a meaning. They are steps of importance. The top step [point] matches 'very important' and the bottom step [point] matches 'not important'.

So, let me tell you the new rules. If you think something is very important you must point to the top step [point]. And if you think something is not important you must point to the bottom step [point]. Is that OK?" Repeat if client seems uncertain.

- Recall the personal possession that is important to the client.

Ask "Is very important to you?"

☐

- Ask "Where would you put it on these steps

☐

- Ask "If something was not important to you where would you place it on the steps

☐

If the client succeeds: proceed to the 3-step problem.

If the client fails: ask whether he/she would like you to go over the rules again. If affirmative, repeat the instructions. If negative, repeat the task.

If the client fails again, cease testing and do not proceed with the importance or satisfaction questions.

Present: The 3-steps

Instruction: "Here is another set of steps. This time you can see there is a middle step [point]. this step matches 'somewhat important'.

Just like before, I want you to point to the step that matches how important something is for you. Is that OK?

Q: If something was very important, where would you put it on the scale? ☐

Q: Not important? ☐

Q: Quite important? ☐

If the client succeeds, proceed to the 5-step problem. If they fail, use the same strategy as described for failure in the 2-step problem.

If the client fails, proceed to test ComQol 'importance' and 'satisfaction' using binary-choice scales.

Present: **5-steps of importance**

"Here is the last set of importance steps.

This time there are five steps. There are three you have seen already and two new ones.

The ones you know are [point to each in turn] 'very, very important', 'not at all important', and somewhat important.

The new ones are [point to each in turn], 'a little bit important' and 'a lot important'.

So, going up the steps we have [point to each in turn] 'not at all important', 'a little bit important', 'somewhat important', 'a lot important', and 'very, very important'. Is that OK?

Q: If something was very, very important to you, where would you point? ☐

Q: Not important? ☐

Q: Quite important? ☐

Q: A little bit important? ☐

Q: A lot important? ☐

If the client succeeds, proceed with the ComQol importance testing using the 5-point scale.

If the client fails, repeat the sequence of the five-steps. If the client fails again, proceed with ComQol importance testing using the 3-point scale.

Importance Scale

Procedure: Test the client alone if possible, or with one close friend.
Use the 2, 3 or 5-point importance scale as previously determined.

Note: Record the level of scale complexity that is to be used:

☐

Instruction: “Now I want to find out how important some real things are to you. Just like before, I want you to point to the step that matches the importance you feel. Are you ready to start?”

Each question begins with “How important *to you* is/are...”

	<u>Response</u>
1. the things you have? Like the money you have and the things you own	_____
2. how healthy you are?	_____
3. the things you make or the things you learn?	_____
4. having a close friend or family?	_____
5. how safe you feel?	_____
6. doing things with people outside your home?	_____
7. your own happiness?	_____

3.2 Pre-testing for Domain Satisfaction

Procedure: Faces scales are provided in Appendix X

Now I want you to do a different job. It's another pointing job, but this time there are 2 faces.

One is a happy face [point], one is a sad face [point].

What makes you happy?

Record of client success
(√) or failure (x)

Reply - X

So if I said "How happy are you about X?", which face would you point to?

☐

What makes you sad?

Reply Y

So if I said, "How sad are you about Y?", which face would you point to?

☐

If the client succeeds: proceed to the 3-faces problem.

If the client fails: ask whether he/she would like you to explain the faces again. If affirmative, repeat the instructions. If negative, repeat the task.

If the client fails again, cease testing and do not proceed with the satisfaction questions.

Present: The 3-faces

Instruction: "Here is another set of faces. This time you can see there is a middle face [point]. This face is not happy or sad.

Q: If you felt very happy about something which face would you point to?

☐

Q: If you felt very sad about something which face would you point to?

☐

Q: If you felt neither happy nor sad which face would you point to?

☐

Present: The 5-faces

Instruction: "Here is the last set of faces.

This time there are five faces. There are three you have seen before and two new ones.

The ones you know are [point to each in turn] 'very sad', 'neither happy nor sad', and 'very happy'.

The new ones are [point to each in turn], 'a little bit sad', and 'a little bit happy'.

So, going over the faces again we have [point to each in turn], 'very sad', 'a bit sad', 'neither happy nor sad', 'a bit happy', and 'very happy'. Is that OK?

Q: If you felt very happy about X which face would you point to?

☐

Q: If you felt a bit happy about X, which face would you point to?

☐

Q: If you felt very sad about X, which face would you point to?

☐

Q: If you felt a bit sad about X, which face would you point to?

☐

Q: If you felt neither happy nor sad about X, which face would you point to?

☐

If the client succeeds, proceed with the ComQol satisfaction testing using the 5-faces scale.

If the client fails, repeat the sequence of the 5-steps. If the client fails again, proceed with ComQol satisfaction testing using the 3-faces scale.

Satisfaction Scale

Note: Record the level of scale complexity that is to be used:

☐

Each question begins with: "How happy or sad do you feel about ..."

	<u>Response</u>
1. the things you have? Like the money you have, and the things you own?	_____
2. how healthy you are?	_____
3. the things you make or the things you learn?	_____
4. your friends or family?	_____
5. how safe you feel?	_____
6. doing things with people outside your home?	_____
7. your own happiness?	_____

Appendix B – Demographic Questionnaire

Demographic Information

Name :

Boarding House:

Age: 18-22 22-30 31-40 41-50 51-60 61-70 70+

Sex: Male / Female

Location: Metropolitan / Rural

Access to Public Transport:

☐ Readily Accessible ☐ Somewhat Accessible ☐ No Access

Disability:

☐ Alcohol Related Brain Damage

☐ Disability Due to Age

☐ Hearing Impairment

☐ Intellectual Disability

☐ Mental Illness

☐ Other Organic Brain Damage

☐ Physical Disability

☐ Other

Hours of ALI activity from 1/4/02 until 31/10/02 – _____

Hours of time in linked services from 1/4/02 until 30/10/02 - _____

Types of activities involved in (tick more than one if appropriate):

☐ Disability specific services

☐ Non-Disability Services

☐ Federal Government Services

☐ State Government Services

☐ Local Government Services

Hours of support given from 1/4/02 until 30/10/02:

Client Liason	
Family Relationship Access	
General Administration	
General Liason	
Leisure (Individual)	
Skills Training (Group)	
Skills Training (Individual)	
Social (Group)	
Sporting Activity (Group)	
Sporting Activity (Individual)	
Travel	
Vocational	

Appendix C – Information Sheet

A STUDY OF QUALITY OF LIFE AND ADAPTIVE BEHAVIOUR IN RESIDENTS OF LICENCED BOARDING HOUSES

This study is being carried out by Laura Francke, a masters student in clinical psychology under the supervision of Dr. Michael Hunter. The aim of this study is to examine the effects of the Active Linkage Initiative (ALI) program on the quality of life experiences and the level of adaptive functioning in residents of licenced boarding houses.

Participation in this study will involve the completing of two questionnaires that assess your quality of life experience and adaptive behaviour. You will be asked to assist me to complete these questionnaires using information from yourself and the staff who work with you. These questionnaires will be administered at three six monthly intervals. In addition, you will be asked to consent to my talking to the staff of Active Linkage Initiative, staff at the licenced boarding house and using your file to gain further information about your involvement with the ALI program.

Your participation in this study is completely voluntary and non-participation will not affect your treatment. The programs provided by Active Linkage Initiative will not be affected by your participation in this study. All information that is used in the report will be coded and no-one will be able to identify you by the information in the report. When we have finished writing the report all information will be kept in a locked filing cabinet and will only be seen by the researchers. Staff at Active Linkage Initiative will receive a summary of the results.

If at any time during the study you decide that you don't want to be involved any information that has been gathered about you will be destroyed. Should you wish to know the results of the study you are welcome to ask me for them by putting your name at the bottom of the consent form and I will organize a time to explain them to you and give you a written summary of the results.

Thank you for your participation. If you have any questions regarding the study please call me at Castle Personnel on 49297711 or Dr. Michael Hunter at the University on 49215000.

DR. MICHAEL HUNTER

Signed.....

LAURA FRANCKE

Signed.....

The University requires that all participants are informed that is they have any complaints concerning the manner in which a research project is conducted it may be given to the researcher, or if an independent person is preferred, to the University's Human Research Ethics Officer, Research Branch, Chancellery, University of Newcastle, 2308, Ph: 49216333.

Appendix D – Consent Form

A STUDY OF QUALITY OF LIFE AND ADAPTIVE BEHAVIOUR IN RESIDENTS OF LICENCED BOARDING HOUSES

Consent Form

I have been asked to participate in the research project being conducted by Laura Francke under the supervision of Dr. Michael Hunter (Department of Psychology).

I give free consent by signing this form. I understand that:

1. Questionnaires will be completed, as described in the information sheet, using information given by me, the staff at the licenced residential centre where I live, and the staff at Active Linkage Initiative.
2. Information will be used from the file that Active Linkage Initiative has about me at their office.
3. My consent to participate is voluntary and non-participation will not affect my treatment.
4. I may withdraw from the project at any time and the information gathered on me will be destroyed if I do.
5. That all information about me will be treated respectfully and used only for research purposes.
6. That if I have any questions I have had them answered to my satisfaction.
7. That if I cannot understand some of the information I can have someone help me to understand it.

Signature

Date: __/__/2001

Verbal Consent Received

☐

Witness :

Enquiries about this study may be directed to Laura Francke c/o Castle Personnel Services Inc., 7/235 Darby St, Cooks Hill 2300, Ph: 49297711; or Dr. Michael Hunter, Department of Psychology, University of Newcastle, Callaghan, 2308, Ph: 49215000 If you wish to receive a summary of the results of this research, please supply your name and address below. A meeting will be organized to explain the results to you and a written copy will be given to you.

Name: _____

Address: _____

Laura Francke

Signed

Dr. Michael Hunter

Signed

Appendix E – CD Containing Raw Data