

**Deinstitutionalisation of People with a Learning
Disability:
Use of Community and Leisure Facilities.**

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Declaration

I declare that this thesis has been composed by myself and had not been submitted in candidature for any other degree, postgraduate diploma or professional qualification.

3552 words

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Preface

The work involved in this thesis has been driven by a combination of service demand and opportunism that has extended over a 14 year period. Hence the work depicted here has proceeded in a fairly idiosyncratic manner. Initially, a clinically useful instrument was needed to enable service planners to have a numerical representation of the extent to service users in Guernsey were out in their communities. This was considered to be an important outcome in determining the quality of service offered to them. At the time no such instruments were available. Therefore expedience dictated that one be developed. The measure, the Guernsey Community Participation and Leisure Assessment (GCPLA), was developed solely for the purpose of evaluating one particular service. Thus at the time, little thought was given to the need for examination of the psychometric properties of the measure. It appeared to have a high level of face validity and was able to distinguish between the community use of service users and the staff who provided care for them. The GCPLA became a routine and useful part of the Life Planning process for service users in Guernsey.

In the early 1990's South Thames Area Health Authority decided that Mount Pleasant Hospital in Hastings was to be closed and approached the Learning Disability Clinical Psychology Service to commission an evaluation of this closure. One of the parameters they considered to be important was the extent to which community use of the residents of Mount Pleasant Hospital increased following them moving to community based provision. It was considered that the GCPLA should be used in this evaluation and it was at this point that serious consideration was given to the investigation of the psychometric properties of the instrument.

The work also benefited from the opportunity to supervise a clinical psychology trainee in a service related research project. This project, because of its small scale and the requirement for simple statistics, looked at two groups of participants and hence focussed on those individuals with the highest and lowest GCPLA scores. This project enabled the development of the Robustness of Goals Scale and the investigation of inter-rater reliability with carers as respondents.

The work represented here comprises of three separate initiatives which were thematically linked. However, to claim that they each subsequent step was envisaged at the preliminary stages would indeed be disingenuous. As stated earlier, the work represented here was very much driven by service need at a particular time and perhaps fortuitously, these needs complimented each other.

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Baker, P. Measurement of Community Participation and Use of Leisure by Service Users with Intellectual Disabilities: The Guernsey Community Participation and Leisure Assessment. *Journal of Applied Research in Intellectual Disabilities* 13 (2000): 1-18.

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Abstract

The closure of institutions for people with learning disabilities and the subsequent relocation to community settings is now a well established part of social care policy. However, it has been argued that physically locating residential services in community settings does not guarantee active use and membership of those communities. It has also been argued that use of one's community, both for utilitarian and leisure purpose, is a fundamental component of quality of life. Initial research on community living tended to focus on people who had been resettled from hospital and tended to conceptualise adaptation to community living in terms of whether the individual was readmitted to hospital. Kennedy et al. (1990) suggested that although there was extensive discussion about the importance of assisting people with disabilities to develop and maintain satisfactory social lives, there was little empirical evidence to guide families, service providers and researchers. They went on to suggest that this paucity of information was due to a lack of appropriate measures.

Various measures of community & leisure use have been reported. However a range of problems exist with these that may compromise the reliability and validity of the data generated. In addition, rarely has normative data been produced that would enable comparison of individuals and groups of people with disabilities with non-disabled people.

The thesis describes the development of the Guernsey Community Participation and Leisure Assessment (GCPLA). This is a comprehensive assessment of community participation and the use of leisure, which produces both quantitative and qualitative data. Data are presented that suggest that the instrument is potentially both valid and reliable. A study comparing community and leisure use of service users and a staff control group showed that service users had a smaller range of activities, were less busy (had fewer frequent activities), and were more likely to access their communities in the presence of staff or carers, rather than alone or with friends. Suggestions for the use of the GCPLA are discussed including individual planning, service evaluation and training.

The impact of resettlement for the residents of a small learning disability hospital on their use of their communities and leisure was investigated using a mixed design in which changes in the dependent variable (GCPLA scores) were measured within-subjects (before and after leaving hospital) and between-subjects (using a comparison group of people who lived in the community throughout the study). This revealed that resettlement from hospital corresponded with significant increase in the range and frequency of leisure and community contacts. In addition, a standard multiple regression design was employed in order to explore the relative contribution of client and service variables to GCPLA scores. Community and leisure use was found to be related to place of residence, adaptive behaviour and the robustness of community goals within the service users individual plan.

Introduction

This section will introduce the concept of learning disability and attempt to give a historical perspective that explains the social policy that resulted in housing people with learning disabilities in large hospitals. The subsequent attempts to move people from these hospitals into a range of community settings will be described, along with a review of the literature that has attempted to evaluate these moves. A review of methodologies of measuring quality of life is conducted with a particular focus on community use. This is accompanied by an analysis of literature that attempts to explain the factors that would influence the use of community facilities by people with learning disabilities.

Learning disability

The term learning disability in the UK is used where an individual has a significant impairment of intellectual functioning, deficits in social functioning or adaptive behaviour which have been present from childhood (Emerson, Hatton, Felce and Murphy, 2001). Learning disabilities replaced previous terms that were judged to be stigmatising and outdated such as 'mental handicap', 'mental subnormality', and 'mental deficiency'. The use of the term learning disability is not entirely supported, with some advocacy groups preferring 'learning difficulty'. This term, however, is also used within the education system with a much less specific meaning. With great potential for confusion, in the USA, the terms 'mental retardation, or 'developmental disabilities' are more common, whilst internationally, 'intellectual disability' enjoys common use.

The criteria used to define the 'cut-off' in relation to intellectual and social functioning are also the subject of some disagreement. Usually, significant impairment of intellectual functioning is defined by reference to an IQ score of more than two standard deviations below the mean for the general population. This would mean a cut-off of 70 on a standard IQ assessment. Some professionals have argued for a 75 cut-off, partly because of the up-ward drift in IQ for populations over time. This is clearly more than an academic debate as the inclusion of people in the 70-75 IQ range would effectively double the population of people considered to have a learning disability. The Department of Health, in the White Paper Valuing People (2001), gave passing reference to a 70 IQ cut-off, but perhaps missed the opportunity to make a more categorical statement. Whilst most of the heat in the

debate has focussed on measurement of intellectual functioning, defining significant social impairment also presents major problems in relation to precise measurement.

In a review of prevalence and incidence, Emerson et al. (2001) concluded that there are no reliable statistics concerning the prevalence of learning disability in the UK. Local case registers have been found to be inconsistent in their classification and are often limited to strictly administrative purposes. Accordingly, in order to establish prevalence, it is necessary to extrapolate from the available research evidence. The studies cited by Emerson et al. (2001) used IQ assessments with mild learning disability classified as IQ 50 or 55 -70 and severe below 50 or 55. They found that in spite of differences in classification and methodology, European, North American and Australasian studies have produced broadly consistent overall prevalence of between 3 and 4 people with severe learning disabilities per 1,000 of the general population. These studies used IQ alone without consideration of social functioning. Studies that have screened entire populations have tended to indicate higher rates, 6 people per 1,000, than those that include only known users of services (McClaren & Bryson, 1987; Roeleveld, Zielhuis & Gabreels, 1997). Emerson et al. (2001) suggested that between 230,000 and 350,000 people in the UK would have a severe learning disability.

Studies of people with mild learning disability have reported less consistent findings. Studies that have screened entire populations show prevalence rates of 25-30 people with mild learning disabilities per 1,000 general population, whereas studies including only known service users report less than 10 per 1,000 general population. This would suggest that the vast majority of people with mild learning disabilities do not come into contact with specialist learning disability services. Emerson et al (2001) suggested a rate between 580,000 and 1,750,000 people in the UK with a mild learning disability.

Institutionalisation of people with learning disabilities: The historical and policy context

Until the 1960's people with learning disabilities in the UK either lived at home with their families or in long-stay custodial care institutions. These institutions date back to the 1840's when English philanthropists, influenced by the French humanitarian movement, established the first asylums, under the patronage of Queen Victoria. The Victorians embraced the idea of asylums for the vulnerable, housing such people in

purpose built sites away from the mainstream of society. The British Royal Commission in 1904 was appointed to consider the existing methods for dealing with imbeciles, feeble minded or defective people not certified under the Lunacy Laws. In 1913 the Mental Deficiency Act, acting on information from the Royal Commission, established a network of colonies for mental defectives that were said to need institutional care. The Act also attempted to support those who wished to keep their relatives within the community, by requiring local authorities to provide daily occupation and supervision. The National Health Service Act (1948) changed the name of the colonies to hospitals, reinforcing medicalisation of the phenomena of learning disability.

Between 1980 and 1998 the capacity of National Health Service hospitals for people with learning disabilities reduced by over 30,000 places. This has resulted in a large number of people with learning disabilities leaving hospitals in order to live in the community. Valuing People (2001) indicated that in 2000 there were 1,570 people in NHS long-stay places, 1,550 in NHS specialist places and a further 1,520 in NHS Campuses. As of October 2003, the Department of Health indicated that 700 individuals continued to be resident in some 20 learning disability hospitals in England (Emerson, 2003). Mansell & Ericsson (1996) argued that this shift in service provision, along with parallel initiatives in Northern America and other parts of Western Europe, was perhaps the most important development in the way services for people with learning disabilities have been organised over the past 25 years.

In Britain, the process of movement away from institutional based care began tentatively in the 1950's. A number of diverse driving forces were behind the deinstitutionalisation movement. Concern began to grow regarding the apparently increasing demand for residential care. The report of the Royal Commission on the Law related to Mental Illness and Mental Deficiency (1957) recommended that more provision should be made for people with mild learning disabilities in hostels in the community. The major impetus for the movement out of hospital was a series of public scandals in the 1960's. These revealed extensive ill treatment and neglect in squalid, over crowded surroundings. The influence was not immediate as, in spite of these concerns, the number of people living in hospital actually increased during this period and, by 1969, some 56,000 learning disabled people were living in hospitals (Sinson, 1993). The policy of institutionalisation was eventually officially challenged in a Government White Paper (Department of Health and Social

Security, 1971). This clearly stated that people with learning disabilities should not be unnecessarily segregated from the general life of the community and added the goal of providing community services for people with mild and moderate learning disabilities, setting clear targets for local authorities. This applied only to England and Wales, with the development of community services in Scotland occurring much later.

In the early part of the 1970's most new developments were of large (20-25 people) units for individuals who, in the main, had mild or moderate learning disabilities (Hemming, 1986). It was not until the late part of the decade that some innovative projects gave an indication of a service model change favouring smaller supported houses and a widening of emphasis to specifically include people with severe and profound learning disabilities (Mansell, 1976a; Mansell, 1980). Emerson (2003) in a recent survey identified a total of 53 NHS organisations providing 3,002 long-stay beds or residential placements for adults with learning disability. This survey also indicated that 62% of the people supported are living with 6 or more other people and 25% of people supported are living with nine or more others. These services are likely to be vestiges of the 1970's developments, although three of the organisations responding indicated that they had plans for the development of new campus-style facilities.

As a response to the scandal regarding the conditions at Ely Hospital and a consequent demonstration project (Cardiff and Vale of Glamorgan Community Health Councils, 1977; Welsh Office, 1978; Lowe & de Paiva, 1991b), national policy in Wales focussed on the development of community based services and the closure of institutions. This policy corresponded with the development of substantial community services by local authorities, however there was little impact on hospital numbers (Welsh Office, 1991; Welsh Office, 1992). Following this, hospital closures were identified as a priority, although at the time, some feared that defining community care as a local government responsibility was evidence of a lessening in central government commitment to hospital closure (Mansell, 1996).

In England, the main policy initiative in the 1970's focussed on transferring funds from the NHS to local government. The model of service provision was not explicitly addressed, although there was an implicit assumption of movement away from institutional provision as the NHS was responsible for the hospitals. The result was a general halt on new admissions, but with no parallel development of

alternatives. It is difficult to argue that the attempts to move people from hospital were as a result of a cohesive or unified policy of community care. Indeed, it was not until the late 1980's that deinstitutionalisation became even tacitly accepted as general policy, with the first large hospital closures, Darenth Park in Kent (Korman & Glennerster, 1985; Korman & Glennerster, 1990) and Starcross in Devon (Radford & Tipper, 1988). The National Health Service & Community Care Act (1990) imposed upon local authorities the responsibility for funding residential care, particularly emphasising that hospital care was to be for the purposes of short term treatment. Commitment to the closure of Learning Disability hospitals was eventually clearly made by the Department of Health in 1992 and later re-affirmed in Signposts for Success (National Health Service Executive, 1998). The closure of long stay hospitals was again an explicit objective in Valuing People (DOH, 2001). Objective 6.3 states a target of

'enabling the people currently living in NHS long-stay hospitals to move to more appropriate accommodation by April 2004' (p. 126).

Even in these more recent documents there is a lack of specific guidance in relation to acceptable models of community provision, with a range of service models deemed to be acceptable, including larger, segregated settings.

Perhaps as a result of the lack of clear and definitive policy statements regarding the closure of large learning disability institutions, it has been suggested that the type of community provision for those individuals resettled from hospital has, in the main, been determined by local decision makers rather than any national or policy commitment (Mansell, 1996). Similarly, Emerson & Hatton (1994) argued that rather than being a homogenous entity, the hospital closure programme has been implemented with significant variations over time and locality. This apparent lack of direction is surprising given the weight of studies that accompanied deinstitutionalisation and it would be wise to look to the studies in order to elucidate good practice.

Evaluation of the impact of deinstitutionalisation.

Emerson & Hatton (1994) emphasised the importance of evaluating the effect of relocation from hospital to the community on the quality of life of people with learning disabilities. They argued that whilst few people would wish to see a return

to large hospitals, strong opinions continue to be voiced regarding the need for some sort of institutional provision for those individuals with complex needs (e.g., Segal, 1990). They point out the hospital closure process is highly politicised and that many professionals, managers and researchers have a great deal of personal investment in the promotion of particular models of service provision. There is an obvious danger that dogma will dominate the debate, thus making it imperative that planning is driven by good quality research and that this research is applicable not only to those individuals who have already left hospital, but also to the minority waiting to leave. In their review of published studies pertaining to hospital closures they found 71 studies. Wide ranges of approaches were used to ascertain the effect of community-based care on the life experience or quality of life of service users.

Traditional general social science parameters.

Social Indicators of the material aspects of the person's quality of life, for example disposable income (e.g. Walker, Ryan & Walker, 1993); aspects of the physical environment (Felce, Thomas, de Kock, Saxby & Repp, 1985), and the number and type of personal possessions.

User satisfaction with overall quality of life (e.g. Stanley, 1988) and with services received (e.g., Knapp & Mansell, 1994).

Outcomes based on The Five Accomplishments (O'Brien, 1987).

Competence, the development of skills and abilities (e.g., Lowe & de Pavia, 1991).

Choice, the number of options available for that individual to receive or access (e.g., Cattermole, 1988)

Community participation, the ability of the individual to construct and maintain meaningful social networks (e.g., Malin, 1982; Markova Cattermole & Woodward, 1992).

Community Presence, the contact the individual has with their communities (e.g., de Kock, Saxby, Thomas & Felce, 1988).

Status & Respect, the acceptance of that individual within their community (e.g., McConkey, Walsh & Conneally, 1993).

Other Outcomes

Challenging behaviour, the impact on the presentation of challenging behaviour by the service user (e.g. Cambridge, Carpenter, Beecham, Hallam, Knapp, Forrester-Jones & Tate, 2001)

Participation in everyday household activity, the involvement of the individual in household tasks (e.g., Booth, Booth & Simons, 1990).

Staff contact, interactions between staff and service users (e.g., Orłowska, McGill & Mansell, 1991).

Outcomes for carers and staff, such as satisfaction or stress experienced by care staff (e.g., Emerson, Cooper, Hatton, Beecham, Hallam, Knapp & Cambridge 1993) and the opinions of informal carers (Walker et al., 1993).

Service Organisation (e.g. Cambridge et al., 2001)

Service costs (e.g. Shiell, Pettipher, Raynes, & Wright, 1992)

Almost a third of the studies in this review looked at some indication of a change in the amount or type of contact the individual has with their communities. At the most obvious and perhaps most fundamental level, lack of a presence in the community was the defining characteristic of those individuals residing in long-term institutions. Not surprisingly, community use is considered to be a key outcome associated with the relocation process. It is argued that this is an important prerequisite condition for social inclusion, that is building social networks and eventually the establishment of reciprocal relationships with a wider group of people who are not obligated to interact with the person with a learning disability through family relationship or employment (i.e. paid carers).

This initial review has been updated and refined to focus on UK studies that have attempted to evaluate community use as an outcome of deinstitutionalisation. It was considered necessary to restrict the review to studies from the UK in order to ensure

that valid comparisons could be made between studies. Twenty such studies were identified through a combination of computer-based searches of on-line data-bases (PsycLit, Medline, British Nursing Index), following up references cited in published reports and discussion with active researchers in the UK. Details of the publications reviewed are contained in Table 1.

The majority of the studies cited (55%) reported significant increases in the use of community-based facilities in smaller community based settings. A minority of studies (45%) reported no such change. Emerson & Hatton (1994) warned, however, that caution is required in interpretation of the results from these studies due to various methodological problems. In addition, they noted that any improvements generally occur from a very low baseline in hospital settings. This argument is supported by the two studies that attempted to make comparisons with the experience of non-disabled people (Ager, Myers, Kerr, Myles & Green, 2001; Stanley & Roy, 1998). They also argued that community contact in community based services may still be relatively superficial and infrequent (Donegan, 1988; Fleming, 1990; Stanley, 1988), and involve use of community facilities that allow little contact with ordinary members of the community (Lowe & de Pavia, 1991; Saxby, Thomas, Felce & de Kock, 1986). In addition, there was also some evidence that the frequency, variety and quality of community use may partly reflect the level of disability of the service users (Emerson, Robertson & Gregory 2000b; Fleming, 1990).

As previously argued, rather than being a heterogeneous entity, the hospital closure programme has been implemented with significant variations over time and locality. In particular, there is evidence of ‘creaming’ in the initial deinstitutionalisation projects, with those individuals with the least dependency needs being targeted to move. Indeed Emerson & Hatton (1996) argued that

‘Leading up to 1980, deinstitutionalisation in the UK primarily involved movement of those individuals with the least severe disabilities to a range of often pre-existing services’ (p.17).

It is also plausible that a parallel ‘creaming’ process took place with the staff of these projects. Initially care staff had some choice with regard to whether they worked in hospital or community settings. Presumably those who had a belief in the underlying principles and values associated with ‘Ordinary Living’ chose to work in

community settings. As the momentum for hospital closures gathered, there was less choice and therefore, staff who perhaps were in less accord with the above principles and values found themselves somewhat reluctantly working in community based provision. It could, therefore, be argued, that some of the assumptions based on the earlier studies of the deinstitutionalisation process may not be wholly applicable to the last wave of hospital closures. These early studies were based upon service users with very different dependency levels and needs, who were serviced by a self-selected staff group. It is argued here that there is a need for a newer, complementary literature that is applicable to this remaining group of people with learning disabilities who represent the remnants of those left in institutional settings.

Study	Settings	Design	Participants	Measures: Reliability, Normative data	Results
Ager et al. (2001)	1) Learning Disability Hospital 2) 18 Community-based homes	a) descriptive post move b) longitudinal (post move data collected between 6-9 months)	1) 76 Moderate, Severe, Profound LD. 2) 58 Moderate, Severe, Profound LD.	Life Experiences Checklist (Ager 1998) reliability (0.93-0.97) Normative data available Index of Community Involvement (ICI) (Raynes, Sumpton & Pettipher, 1994) reliability 0.98 7 day diary reliability (0.92-0.99)	Movers showed increase in ICI scores, activities that require a greater degree of personal autonomy remained infrequent. No gains or losses for 18 individuals.
Beswick (1992)	1) Learning Disability Hospital 2) Variety of community settings mostly staffed houses	Mixed design a) longitudinal (post-move data collected at 6 time points b) comparison group – movers v stayers	1) 20 'Stayers' 28 'Movers' 2) 28 'Movers'	7 day diary Inter-rater reliability 72-84% Checklist Inter-rater reliability 52-58% No normative data reported.	No difference in frequency of community activities, more activities in integrated settings. More contact with friends relatives.

Booth et al. (1990)	1) Learning Disability Hospital 2) Community Hostels	Longitudinal	1) 16 2) 16 Moderate, Severe, Profound LD.	Unstructured interviews with staff, relatives and service users. No reliability reported. No normative data reported	Staff report more service user time in community activities. Service users report more positive community relations. Staff reported that service users lack social interaction.
Bratt & Johnson (1998)	1) Learning Disability Hospital 2) Community staffed house	Longitudinal (post-move data collected at 2 time points)	1) 5 2) 5 Severe LD	Activity log. Inter-rater reliability 90% No normative data reported	More trips out of home to more varied places, more trips to integrated community settings.
Conneally, Boyle & Smyth (1992)	1) Community Hostel 2) Community Staffed Houses	Longitudinal (post-move data collected at 2 time points)	1) 11 2) 11 3) Severe, Profound LD	Diary No reliability No normative data reported.	Community houses: Increase in the number & variety of outings. Increase in the variety of in-home leisure activities
De Kock et al (1988)	2 studies Study 1 1) Learning Disability Hospital 2) Large Community Unit 3) Community Staffed	Study 1 Longitudinal study Study 2 Comparison Groups	Study 1 1) 9 2) 1 3) 10 Study 2 1) 24 2) 12 Severe, Profound LD	a) Daily criterion referenced diaries. b) Retrospective analysis ward\daily reports and individual case notes. a) no reliability b) Inter-rater	Study 1 More community and family contacts in the community homes Study 2 More community contacts, trend for more family contacts in Community Staffed Houses.

	Houses Study 2 1) Community Units (25 beds) 2) Community Staffed Houses			reliability 83-94% No normative data reported	
Dockrel, Gaskell, Rehman, & Normand (1993)	1) Post – MIETS service a) Hospital Homes Campus Homes b) Community Homes c) Community Homes	N/a descriptive	a) 3 b) 7 c) 7 Mild LD & Challenging Behaviour	Staff interview. No reliability. No normative data reported.	Use of community facilities higher in Campus & Community Homes than in Hospital Homes
Emerson et al (2000b)	1) Residential Campus 2) Community Staffed Housing Village 3) Village communities	Comparison Groups	1) 133 2) 281 3) 86 Moderate, Severe, Profound LD.	Modified version of Index of Community Involvement (ICI) (Raynes et al., 1994) No reliability reported No normative data reported	Service users in residential campuses had reduced number and variety of recreational or community based activities.
Evans, Todd, Blunden,	1) Learning Disability Hospital	Longitudinal	1) 4 2) 4 Severe LD	Diaries. Inter-rater reliability 42-87%	Community Homes 2 service users spent more time in the community

Porterfield & Ager (1987)	2) Community Staffed House				Unspecified measure of frequency of use of community amenities. No normative data reported.	More use of community facilities in community homes. Most frequent contacts were shopping & visits to pubs, cafes and restaurants.
Felce (1989)	1) Learning Disability Hospital 2) Large Community Unit 3) Community Staffed Home	Longitudinal and Comparison Groups	1) Not stated 2) Not stated 3) Not stated 4) 14 Moderate, Severe, Profound LD.	Measures of participation community activity imbedded with Individual Programme Planning system. No reliability reported. No normative data reported.	Increased community contact in community staffed house compared with hospital.	
Felce et al (1994)	1) Learning Disability Hospital 2) Parental Home 3) Community Staffed House	Longitudinal (pre-move learning disability hospital & parental home; post-move community staffed house.	1) 32 2) 4 3) 36 Moderate, Severe, Profound LD.	Day books. No reliability reported. No normative data reported.	Community Staffed Houses: User outings frequent during the day, infrequent during the evening. Users in house with goal planning showed more improvement than in non goal-planning houses.	
Fleming & Stenfert Kroese (1990)	2) Learning Disability Hospital 3) Community Hostel 4) Community	Longitudinal (services 1 & 2 pre-move, service 3 post-move	4) 9 5) 8 6) 17 Level of LD not stated			

	Staffed House					
Flynn (1989)	1) Independent living	N/a	1) 88 Range of LD	Structured interview	Leisure activities experienced 83 Passive home based 53 Active home based 77 Out of house non-segregated 28 Out of house segregated 58 Visiting people 67 Outings 33 Owning a pet	
Hemming et al (1981)	1) Learning Disability Hospital 2) Hospital-Based Residential Unit	Mixed Design: a) Longitudinal 1 (hospital unit), data collected at 4 points post move (up to 2 years) b) Comparison Groups ('movers' v 'stayers')	1) 38 'movers' 2) 33 'stayers' Range of LD	Therapeutic Community Assessment. No reliability or validity data reported. No normative data reported.	Residential Unit Decreased day-time off-site occupation. No change in on-site day time activities. Few non-routine activities pre- or post move.	
Jahoda, Cattermole & Markova (1990)	1) Hospital Leavers (learning disability hospital to community	Retrospective interviews with users & carers	1) 8 2) 7 3) 10 Mild LD	2 semi-structure interviews. Interrater reliability between 86-95%. No normative data reported.	Hospital Leavers 4 reported increases in semi-integrated and integrated activities. Most social contact with other people with learning disabilities. Less contact with family than all other groups. Home Leavers	

	<p>2) Home Leavers (parental home to community hostel)</p> <p>3) Home Stayers (parental home)</p>				<p>5 reported increases in semi-integrated and integrated activities. Increased contact with other people with learning disabilities. Home stayers No change</p>
<p>Love & DePavia (1990)</p>	<p>Study 1</p> <p>a) Learning Disability Hospital Parental Home</p> <p>b) Community Staffed Housing Parental Home with additional support</p> <p>c) Learning Disability Hospital (with additional</p>	<p>Longitudinal (users from 1 & 2 transferred to service 3) and Comparison Groups (data collected at 8 points over 5 years)</p>	<p>Study 1</p> <p>a) 22</p> <p>b) 5</p> <p>c) 27</p> <p>d) 35</p> <p>e) 30</p> <p>Study 2</p> <p>a) 10</p> <p>b) 14</p> <p>Moderate, Severe, Profound LD.</p>	<p>Interview Schedule Checklist.</p> <p>Inter-rater reliability 89-100%.</p> <p>No normative data reported.</p>	<p>Use of community facilities increased over 5 years for user in community staffed houses (service 3). Use of community facilities showed no change for those staying in hospital (most used facility parks).</p>

	support) Study 2 a) Parental home b) Learning Disability Hospital				
McHatton, Collins & Brooks (1988)	1) Learning Disability Hospital 2) Hospital Based Residential Unit	Longitudinal	1) 6 2) 6 Severe LD	Diaries completed by staff. Inter-rater reliability 85-87%	No change in the number of out-of-home activities.
Stanley & Roy (1988)	1) Learning Disability Hospital 2) Community Staffed House	Mixed Design a) Longitudinal 1 (7 'Movers' from hospital to community) b) Comparison group (7 'Movers' v 7 'Stayers'), 100 local people for social	1) 14 2) 7 Moderate LD	Modified version of NIMROD tool. No reliability reported. Normative data reported.	In community house no difference in the use of community facilities compared to pre-move and stayers, lower use of community facilities than local community.

		validation of measures.			
Walker et al (1993)	1) Learning Disability Hospital 2) Community Staffed House	Longitudinal	1) Unspecified 2) 62	Structured interview with staff. Unstructured interview with service users. No reliability reported. No normative data reported.	Staff report that service users have limited use of community services.

Table 1.

Review of UK studies that have evaluated community use of people with learning disability as an outcome of deinstitutionalisation.

Measurement of quality of life and people with a learning disability

This study has focussed on community use as an important quality of life outcome for people with learning disabilities. Since this study was conducted, investigators within the field of learning disability have been applying a greater level of sophistication to defining the concept of quality of life and to its measurement. This brief discussion will attempt to examine the extent to which the measurement of community use continues to be a valid indicator of quality of life.

In spite of a few remaining areas of controversy, there appears to be a growing consensus that quality of life is a multidimensional phenomenon. Although researchers have differed slightly in emphasis, there appears to be consensus highlighting eight dimensions (Schalock, 1996): emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. Although conceptualised as independent, together these dimensions are considered to represent a comprehensive analogue of the individual's quality of life. Hence, the frequency with which the person accesses his/her community and engages in leisure will be interrelated to other domain areas. In particular, the dimension of interpersonal relationships and building friendships and supports is highly likely to be related to community presence and integration. In addition, Schalock (1996) considers that the development of personal competence and engagement in meaningful activity are characteristics of the personal development domain with both potentially related to community presence and use of leisure. Leisure is also explicitly included under his physical well-being domain.

Most authors have emphasised the importance of the consideration of as many components as possible in order to provide a comprehensive quality of life assessment (e.g., Felce & Perry, 1995; Cummins, 1997; Hatton, 1998). Furthermore, many advise the representation of these domains as a single quality of life score (e.g., Cummins, 1997). Attempts to represent quality of life as a single score have attracted recent criticism. Hatton (1998) highlights the difficulties involved in summarising and standardising the individual's experience across many domains. A single score would inevitably need some deconstruction if a specific action were required to improve the services offered. For example, later in this study the impact of written goals for service

users in relation to community use is evaluated. It is extremely difficult to evaluate the effect of this sort of independent variable in relation to global quality of life indices. This is more readily achieved by focussing on the specific outcome that a variable is hypothesised to effect, in this case community use. Even consideration of objective quality of life conditions present major challenges, it would be equally as misleading to assume that all aspects of quality of life have equal weight as to attempt to establish relative importance of these aspects. Such a venture would invariably be led by ideological considerations or, at best be arbitrary, both of which would represent major challenges to validity. Even Cummins (2001) agreed to some extent, stating that subjective and objective indices of quality of life should be regarded as separate measures.

In an earlier paper, Cummins (1997) was very critical of what he termed the traditional approach to quality of life and people with learning disabilities. He described this as the objective measurement of life conditions (usually determined by normalisation) in the form of counts or frequencies and applied in a comparative sense to general population standards. He states that there are various problems with the interpretation of such data which limit their usefulness. He highlights the limitations of objective measurement and questions the underlying assumption that the people concerned should all live under objective life circumstances equivalent to the average of the general population. He argues that subjective well-being or quality of life i.e. the person's perception and satisfaction with their own life circumstances is more important. These subjective indicators of quality of life have been increasingly emphasised by researchers in the field of quality of life for people with learning disabilities (Felce & Perry, 1995, Schalock, 1996; Hatton 1998). Hatton (1998) argues that the addition of subjective assessment complicates an already complex quality of life model. The construction of a comprehensive quality of life instrument would involve assessment of both subjective and objective quality of life indicators within each of the dimensions and individual components of those dimensions. This would also ideally take into account the individual weighting and preference put on these domains and their components by each participant avoiding a priori assumptions regarding the relative importance of different dimensions of quality of life. Indeed, Cummins (1997) considered these, amongst other characteristics, are essential in a good quality of life scale and later reported widespread agreement within the International Association for the Scientific Study of Intellectual

Disability (IASSID) and the International Society for Quality of Life Studies (ISQoLS). He evaluated 13 Quality of Life scales for people with learning disabilities according to the fore-mentioned criteria. These included;

1. Assessment of Residents satisfaction and Family Perceptions Index (Bowd, 1988).
2. Quality of Life Questionnaire (Cragg & Harrison, 1984) COMPASS (Cragg & Look, 1992)
3. Residential Satisfaction Inventory (Burnett, 1989)
4. Life Experience Checklist (Ager, 1998)
5. Quality of Life Assessment Tool (Johnson & Cocks, 1989)
6. Consumer Satisfaction Survey (Temple University, 1988)
7. PALS (Rosen et al., 1995)
8. Lifestyle Satisfaction Scale (Heal & Chadsey-Rusch, 1985); Multi-faceted Lifestyle Satisfaction Scale (Harner & Heal, 1993)
9. Quality of Life Questionnaire (Brown & Beyer, 1992)
10. Leisure Satisfaction Scale (Hoover et al., 1992)
11. Quality of Life Interview Schedule (Developmental Consulting Program, 1990)
12. Quality of Life Questionnaire (QOLO) (Schalock & Keith, 1993)
13. Quality of Life Scale (ComQol-1) (Cummins, 1993a).

He concluded that only the latter two met the basic requirements for useful measures of quality of life. He also concluded that both scales required further development.

Particular criticism was levelled at the QOLO in regard to the intellectual and verbal skills required by the respondent to answer the questions. For example, for the question 'How successful do you think you are compared to others', the options all involve comparison to the average person. Other questions were equally verbose and complex, e.g. 'Do you feel your job or other daily activity is worthwhile and relevant to others'. The intellectual, memory and verbal skill demands are likely to make the instrument inaccessible to all but the most able of people with learning disabilities.

The accessibility of the subjective opinions of respondents with communication problems is remarked upon frequently (Ager, 2002; Ager & Hatton, 1999; Cummins 1997; Hatton, 1998). Felce & Perry (1995) describe a creative and informative account of best practice in elicitation of views of people with learning disabilities.

But, in spite of the best efforts of researchers to make the instruments as accessible as possible, the reality is that a significant minority of people with severe communication problems will not be able to either understand the questions being asked of them, or to offer their views in relation to these questions. This reality appears to have been glossed over or ignored by many researchers in this field. For example, Cummins (1997) recognised this as an issue and stated that this could be

‘resolved by pre-testing to establish that the respondent does have the cognitive capacity.....’(p.210).

He failed, however, to explain what should be done if the pre-test indicates that the person does not have the capacity. Clearly, relying on proxy opinion of carers, family or advocates is problematic in relation to subjective data, with Felce and Perry (1995) concluding that the existing literature on the ability of third parties to represent the views of individuals was not encouraging. Indeed, Cummins (2001) stated categorically that it was his view that the use of proxy responses in relation to subjective experience/opinion was invalid. He did state, however, that the situation in relation to objective data was less clear and dependent on the scope for interpretation.

A further and perhaps more fundamental problem with regard to subjective quality of life data, are the more recent findings that objective lifestyle and subjective satisfaction are not simply correlated, with subjective well-being more influenced by personality than change in life circumstance. Cummins (2001) used the Homeostatic Theory of Subjective Well-Being to explain the mechanism underlying subjective well-being. He argued that there is a dispositional brain-system that will maintain subjective well-being within a narrow, positive range. Further evidence comes from Edgerton (1996) who found that, over time, the subjective well-being of people with learning disabilities was remarkably stable. This is borne out by Emerson & Hatton’s (1996) review of deinstitutionalisation that indicated only short-term improvements in life satisfaction after moving from hospital but with little long-term change. Clearly, if subjective quality of life in the main reflects constitutional factors rather than objective life circumstance, people with learning disabilities are extremely vulnerable, given the well documented material impoverishment endured by this group of people. To base service provision on subjective quality of life indices would risk maintenance of the status quo. Ager & Hatton (1999) concluded that

‘objective measurement of life experiences may prove more powerfully emancipatory of persons with an intellectual disability than narrowly construed 'subjective' appraisals, as they may challenge services to account for the constrained experience of users’ (p.337)

This is an especially persuasive argument in the evaluation of the extent to which people with learning disabilities who have spent their lives in long-term institutions access their communities.

Cummins (1997) included the criteria that domain satisfaction should be weighted by the relative importance of each domain to that individual. This is a seductive idea, in that it would appear to meet the demands of both an individual and aggregate psychology in one measure. It is perhaps not surprising, that this goal remains to be satisfactorily met by any of the measures currently available. Clearly, whilst a laudable goal, the use of subjective quality of life data for people with learning disabilities presents major challenges for researchers and those responsible for evaluation of services. Interestingly, Cummins (2002) has now recognised the difficulties in weighting domains in relation to individual importance and has concluded that there were fundamental issues concerning scale construction which ComQol violates. Until such time as these issues are satisfactorily resolved, the use of objective quality of life data, ideally gleaned from the person themselves, should be considered to be key and fundamental.

Amongst Cummins’s (1997) characteristics of a good quality of life scale is the applicability to non-disabled people, thus ensuring normative comparisons of life quality. Various scales have sought to establish data derived from a non-disabled population in order to establish normative benchmarks for more meaningful comparisons (e.g., Ager 1998, Baker, 2000). It is still, perhaps, surprising that the development of quality of life indices for people with learning disabilities has developed separately from those applicable to the general population. This may well be attributable to researchers in ‘academic silos’, i.e. choosing not to look outside of their specialist areas. It may equally reflect some of the unique aspects of quality of life measurement that are specific to people with learning disabilities previously discussed.

The serious difficulties raised above in relation to the use of comprehensive quality of life measures in the evaluation of services for people with learning disabilities give grounds for serious concern. Ager & Hatton (1999) argued that there might be occasions

where a generalised and comprehensive rating of quality of life is not appropriate. It is argued here that there are distinct circumstances where the use of more 'traditional' measures is warranted. In particular, these would include situations where individuals lack the intellectual or communication skills to reliably report subjective satisfaction with aspects of their life quality. In these circumstances, attempting to glean 'proxy subjective' data would leave such individuals at the mercy of well-intentioned proxies, or would be in receipt of services that remain unevaluated, neither of which are acceptable options. In addition, one of the defining characteristics of people with learning disabilities in institutional settings is their lack of access to community facilities, making this a key and pivotal outcome, presenting some justification for having this as a predominant and even sole focus of evaluation. As argued by Ager (2002), it is important that

'we should not use the comprehensiveness of QoL assessments to avoid asking the very specific questions that may be most salient for particular service users in particular contexts' (p.374).

Measurement of community use

Initial research on community living for people with learning disabilities conceptualised community participation in very broad terms, success or failure being measured by whether the individual needed to be readmitted into hospital, e.g., Hemming (1982). Kennedy et al. (1990) suggested that, although there was extensive discussion about the importance of assisting people with disabilities to develop and maintain satisfactory social lives, there was little empirical evidence to guide families, service providers and researchers. They went on to suggest that this paucity of information was due, in part, to the lack of appropriate measures.

Various methodologies have been employed in the measurement of community participation and the use of leisure, however, a range of problems exists with many of them.

Many studies employed the use of simple activity diaries. This would appear to have a good deal of face validity and they have been used in several studies (e.g. Halliday & Woolnough, 1989; Hewson & Walker, 1992; Walsh, Coyle and Lynch, 1988). Joyce,

Mansell & Gray (1989), in their comparison of diaries with direct observation, did however find poor levels of agreement and suggested great caution in the use of diaries as a source of evaluative data. Of note, is that no reliability data were collected in these studies. Hewson & Walker (1992) and Walsh et al. (1988) collected data over relatively short periods of time (one week and two days respectively). This reduced problems associated with observer drift, but unfortunately produced problems with the representativeness of the data, minimising the possibility of recording anything other than very frequent community contacts or activities. The Halliday & Woolnough (1989) study did, however, collect data over a more prolonged period, allowing a more accurate representation of the individual's experiences to be obtained. The authors operationally defined 25 community and 4 segregated facilities, thus potentially increasing reliability.

Direct observation of the individual by the researcher would be more likely to give a more accurate indication of that individual's experience of their community. The practicalities involved, especially the amount of observation time required to obtain a reasonable sample of the individual's typical experience, often causes problems. In order to overcome this difficulty, methodologies are often selected that involve the use of time sampling (e.g. Johnson & Bailey, 1977; Mansell, 1994). Unfortunately, some problems arise with regard to validity, i.e., there is an increased probability of missing any contact or activity other than those that are very frequent. The required use of a limited number of predetermined categories of behaviour and classification of activity under very broad categories, will inevitably limit the extent to which such data comprehensively represents a true reflection of the individual's use of the community and leisure. In addition, the extent to which comparisons across studies involving different methodologies can be made, may also be impaired. The concept of engagement, used in such studies, has also attracted some criticism. Sturmey & Crisp (1994) considered that definitions of engagement failed to recognise qualitative differences between types and varieties of engaged behaviour. Joyce, Mansell & Gray (1989) have also argued that as services become more individual, direct observation becomes more intrusive. This increases the likelihood of those individuals being observed reacting to the observer in an untypical manner, as well as raising more general concerns about the acceptability of such procedures.

McConkey, Naughton and Nugent (1983) used a structured interview format to ask people with intellectual disabilities about contacts with people in their communities. The interview sought to establish which of the contacts were recent and who accompanied the respondent. The contacts appear to have been limited to certain service sector job categories. The study did not present criteria for the contacts neither did it present reliability, validity or normative data. The study gave some indication that only a minority of respondents had diverse or recent contacts and even fewer had the companionship of a friend.

Seager (1987) adapted the format used by, McConkey et al. (1983) increasing the contacts to 34 and expanding the notion of contacts to include activities. Seager (1987) classified the type of contact according to whether the individual was alone, supervised or with a peer group. Operational definitions for non self-explanatory contacts were provided. This study also found low levels of peer companionship, with supervised contacts far out numbering those made with peers. The number of contacts was significantly higher and less supervised, for people living away from the parental home. In order to ensure the reliability of the data in relation to estimation of frequency and timeframes, Seager (1987) only selected participants on the basis of tested ability with number and time. Unfortunately, methodological difficulties did not allow investigation of reliability, validity or the generation of normative data.

Lowe and de Paiva (1991) in their evaluation of NIMROD, a community based service for people with intellectual disabilities, devised an interview schedule whereby carers were asked the frequency of contact of the person with an intellectual disability with 18 types of community facility. In addition, frequency of contact the individual had with their relatives was asked of those living in residential services, and frequency of contact with friends asked for all participants living in either their parental home or residential services. Acceptable intra-coder and inter-coder (using taped interviews) reliabilities were found, as was inter-respondent reliability (with 2 carers independently interviewed). A comparison of the number of contacts with community facilities was made between those in receipt of the specialist NIMROD service, and hospitalised and home based comparison groups. No investigation of validity or normative data was presented.

Hayden, et al. (1992) sought to examine the social roles and activities of people with intellectual disabilities living in foster homes and small group homes. Direct care staff were asked to rate frequency of contact of the person with an intellectual disability with regard to 28 leisure activities. Each item was analysed separately with significant differences reported between foster and small group homes. Again the majority of participants (80%) were reported to require supervision. The proportion of activities accessed with different types of support was not reported, although the study did reveal that, typically, participants used their communities supervised and with other people with intellectual disabilities. Again, validity, reliability and normative data were not reported.

Raynes, Wright, Sheill & Pettipher (1994), in an evaluation of the costs and quality of community care for adults with intellectual disabilities, developed the Index of Community Involvement (ICI) (Raynes, Sumpton & Pettipher, 1989). This consists of 15 items; 14 of these ascertain whether clients have used specified facilities in the community within the past four weeks, and one item related to going on holiday in the previous 12 months. Direct care staff completed the ICI, with mean scores established for each service. No significant differences were found between Local Authority, Health Authority, Private or Voluntary Sector services. Although acceptable internal reliability was reported, no indication of test-retest or inter-rater reliability or normative data was given. In addition, the Yes –No format, whilst being sensitive to range of events, would not give any indication of frequency. Perry & Felce (1995), in an attempt to investigate the extent to which objective measures of quality of life agree, found no significant correlations between the ICI, diary records and the Programme Analysis of Service Systems 3 (PASS 3) social contact and community activity components (Wolfensberger & Glenn, 1975). This remained the case even when the ICI total score was separated into social contact and community activity components and each sub-score compared with the separate frequencies of social and community activities in the event data. This was in spite of there being significant correlations between the event data and the various indicators drawn from PASS 3. Thus there remain concerns regarding the validity of the ICI, with Perry & Felce (1995) concluding that it has limited sensitivity to frequency and might best be used in conjunction with other measures. Accordingly, Felce, Lowe, Perry, Baxter, Jones, Hallam, and Beecham (1998), in a later study, modified the ICI to broaden the definition of social activities and to make it sensitive to frequency.

Although acceptable inter-rater reliabilities were reported, no investigation of validity was carried out, neither were normative data presented.

In a series of studies investigating the longitudinal effects of deinstitutionalisation of a group of people with severe or profound intellectual disabilities (Stancliffe and Hayden, 1998; Stancliffe and Lakin, 1998), a variety of instruments were used to assess community contacts, integration and activities. Care staff were asked to indicate the number of community settings used by the service user from a list of 23, and the number of social activities participated in during the previous 30 days from a list of 20. Similarly, community integration was measured by the use of a 7-item scale of individual social activities during the preceding 6 months. They found that individuals who remained in state institution settings experienced substantially poorer outcomes on all measures. The size of the setting was important with those individuals in larger settings having poorer outcomes. The differences were no longer significant following adjustment for differences in adaptive behaviour as a covariate, with individuals who had milder intellectual disabilities enjoying greater community presence and integration. Individuals who remained in institutions following downsizing, experienced decreased community integration. Unfortunately, no psychometric or normative data were presented.

The Life Experience Checklist (LEC) (Ager 1990, 1998) has been developed as a measure of quality of life, attempting to represent the activities and experiences of the respondent. It was designed to be applicable to the broadest range of individuals, with normative data provided for a general population sample, in addition to populations of people with intellectual disabilities. Validity and inter-rater reliability data are reported, along with test-retest data using a group of undergraduate participants.

This use of questionnaires or structured interviews to measure community use or access to leisure has obvious appeal. They are able to sample meaningful time periods, have fewer problems with intrusiveness, or with the individual reacting in an untypical fashion to the presence of an observer and are easier to administer. The use of retrospective and/or third party accounts presents a potential challenge to face validity, thus making it essential that reliability and validity data are reported. The use of questionnaires and structured interviews also enables the production of readily

quantifiable data. In addition, normative data can be produced enabling direct comparison of the experience of individuals, or groups of individuals. Many of the above studies have achieved one of these, but only the Life Experience Checklist is quantifiable and has published reliability, validity and normative data. The LEC is, however, a broad-based quality of life measure and it contains only a few items relating to community presence and participation. These are imbedded within the checklist, which also includes many items concerning the individual's subjective experience. As discussed earlier the representation of quality of life as a single score makes analysis of data, specifically that pertaining to community use, difficult. It should be noted that no measures specific to community use could be found that have been developed for the general population, other than more general and comprehensive quality of life measures. The unique focus on assessment of community use for people with a learning disability is perhaps symptomatic of the extent to which they have been denied access to the community. More general quality of life measures are discussed more fully in the discussion section of this thesis.

A further issue in relation to the use of questionnaires and structured interviews is the opportunity they present for greater involvement of participants. In actuality, this was given scant attention in the studies mentioned above. It is probable that this reflects, at least in part, the difficulties associated with obtaining the type of information required from individuals with intellectual impairments. It is also likely to be a product of a paternalistic approach that has resisted, or at best failed to facilitate, involvement of people with learning disabilities in research and service evaluation. The recent changes in the nomenclature in this area have significantly shifted with the 'object' of the research in the human sciences changing from 'subject' to 'participant' (Chappel, 2000). A fuller discussion on the use of proxies in gathering information on behalf of people with learning disabilities is included in the discussion section of this thesis.

A means of obtaining reliable, valid, quantifiable data appertaining to an individual's use of their community and leisure was considered potentially useful and important. Such a measure should also endeavour to be accessible to people with learning disabilities themselves. Data generated should enable comparison of individuals and groups. In particular, normative data from a non-disabled sample was considered to be of critical importance as this would enable comparisons between a relatively culturally valued

group and people with disabilities. The unavailability of such a measure had led to difficulties in interpretation of data from different sources. For example, Emerson & Hatton (1994), in their review of studies related to the effects of relocation from hospital to community based services for people with learning disabilities, suggested that although improvements in community presence were noted, these generally occur from a very low base line in hospital settings. The existence of 'normative' data would have enabled wider and more valid comparisons.

Influence of personal characteristics on use of the community

There is limited and mixed evidence on the effect that individual characteristics of people with learning disabilities have on their community use. Research has mainly focussed on levels of adaptive behaviour and challenging behaviour, both which would effect the dependency of the individual on care staff. A number of UK studies have found significant associations between levels of dependency and either the variety or frequency of community use (Emerson et al., 2000b; Felce, Lowe, Beecham & Hallam, 2000; Perry, Felce and Lowe, 2000). In addition, Stancliffe & Lakin (1998) found a similar association in the USA. Similarly, Felce et al. (2000) reported a negative correlation between frequency of community activity and level of challenging behaviour, after taking account of the individual's level of adaptive behaviour. Others, however, have not found this association (Stancliffe & Lakin, 1998; Emerson et al., 2000b; Felce, Lowe and Jones, 2002a; Perry et al., 2000).

Comparison of broad service models and community use

As argued earlier, the weight of evidence from UK studies of the effect of deinstitutionalisation on community use demonstrates that community residence promotes involvement in community activities (Emerson & Hatton, 1996). This finding also appears to be the case in studies conducted in the USA (Conroy, 1996; Stancliffe and Lakin, 1998) and Australia (Cummins, 1993b). There is also evidence that this increase continues over time (Cummins et al. 1990; Rapley & Beyer, 1998).

Felce, Lowe & Jones (2002a) have argued that the aim of research needs to shift from comparative evaluation of broad over-generalised service types towards exploration of

the more specific elements of service provision that will determine quality outcomes for service users. Towards this end, Felce & Emerson (2001) suggested a finer typology of residential service provision.

- a) Institutions – campus facilities set apart from the community accommodating large numbers of people in settings which differ architecturally from culturally typical dwellings and accommodate groups larger than those typically found in those dwellings.
- b) Intermediate community settings – settings located singly in the community but which differ architecturally from culturally typical dwellings and accommodate groups larger than those typically found in such dwellings.
- c) Community houses – settings located singly in the community of culturally typical architectural design and accommodate groups of similar size to those typically found in such dwellings.

Emerson (2000b) found that people living in settings that providers identified as ‘supported living’ (mean size 2 people) participated in more community activities than people living in traditional group homes. A similar finding was reported by Felce et al. (2000), who found smaller size of service to be associated with greater access to community and leisure activities. However, Felce et al. (2002a) in a later study found that smaller residence size did not predict social or community integration. Various studies in the US have also found that the broad type and size of accommodation can have an impact on the frequency and variety of community use. Burchard, Hasazi, Gordon & Yoe (1991) found that the average number of weekly activities that took place in the community was significantly greater for people with mainly mild or borderline learning disabilities in one to two person, unstaffed but supervised apartments than for people with moderate to borderline learning disabilities in three to six person staffed group homes. They also found that residence type accounted for significant additional variance in hierarchical regression, after taking into account the different levels of learning disability. Stancliffe & Keane (2000) reported greater frequency of community use amongst people with similar dependency needs living in one to four person, partially staffed accommodation, compared to people living in three to seven person, fully staffed accommodation. Conroy (1996) showed that the frequency of community activity in a matched comparison group was significantly lower for people living in eight person group homes compared with three person alternatives. Howe et al. (1998) compared one

to three person 'supported' living arrangements with two to twenty person, traditional living arrangements for people with mild to moderate learning disability in a matched group comparison and found that people in the former group accessed a greater amount and variety of community activities.

The consensus from the studies cited thus far would tentatively suggest that, even after taking level of disability into account, general service characteristics influence the extent to which people with learning disabilities use their communities, with smaller services being associated with better outcomes.

Exploration of the determinants of high quality services

Emerson, Robertson, Gregory, Kessissogolou, Hatton, Hallam, Knapp, Netten, Lineham, Hillery & Durkan, (1999b) reported only relatively modest inter-correlation between outcome indicators after controlling for resident abilities, prompting them to conclude that quality in relation to various outcomes will be related to different factors in the design and operation of services. Felce & Emerson (2001) also argued that there are distinct problems when comparing broad service settings. First, setting description is often inadequate and, certainly in some early studies, absent. Second, classifications may lose meaning internationally. Thirdly, salient variables are rarely described. They cite in particular, staff & carer orientation, working methods, and staff performance.

Thus, there is a need to explore and differentiate these finer variables and their relation to quality outcomes for service users. There is evidence that inadequate support and low activity, at least among people with severe learning disabilities, are enduring problems, even in the most home-like community based facilities with high staffing levels and adherence to contemporary service philosophies (Emerson & Hatton, 1996; Emerson et al., 1999b; Felce & Perry, 1995). Most of the research in this area has focussed on measuring engagement in daily living activities through direct observation. Although not explicitly excluding community involvement, these studies have focussed mainly upon in-house activity rather than community activity. The extent to which the findings are directly applicable to service users' use of their community is doubtful. The research does however suggest variables that could be investigated with regard to their impact on community use. In common with studies focussing on community use, the extent of

resident engagement is related to abilities as measured by a standardised adaptive behaviour measure, where people with lower assessed adaptive behaviour have been found to be unoccupied for the majority of the time (Emerson et al., 1999b; Felce & Perry, 1995). One of the consequences of lower assessed adaptive behaviour is the need for greater support to engage in the activities of daily living. As discussed earlier, a similar relationship appears to exist between adaptive behaviour and community use (e.g., Emerson et al. 2000b; Felce et al. 2000; Perry et al. 2000).

There is evidence that the salient variable is not the amount of staff support, but rather the quality. Hewson & Walker (1992), Felce & Perry (1995) and Felce, Lowe & Perry (1999) demonstrated that the great majority of attention given to residents in community homes was in the form of general conversation, which contributed little to facilitating engagement in meaningful activity. Also, although people with greater dependency needs require greater support from staff, they did not receive it (Felce et al., 1998, 1999). There is clear evidence that staff care practices are important determinants of service users general engagement in meaningful activity (Mansell et al., 1984; Felce et al., 1986; Mansell 1994).

This research has been used to delineate what would be helpful process factors in facilitating meaningful engagement in activity and now describes an approach termed Active Support (Emerson & Hatton, 1996; Felce 1996; Mansell, 1998). It combines five elements that have been shown to be related to the attention residents with high dependency needs receive from staff and to their participation in the activities of daily living.

- I. Proactive planning of opportunity
- II. Planning staff responsibility
- III. Supporting participation through prompting demonstration and guidance
- IV. Provision of attention contingent upon engagement
- V. Staff monitoring

Each element has been shown separately to achieve higher levels of engagement in meaningful activity, although less attention has been given to the process of planning. The wider literature, however, would suggest serious limitations in planning procedures for people with learning disabilities. Shaddock (1991) investigated 50 plans drawn from

group homes for people with learning disabilities and found that goals and objectives were typically not written in specific measurable terms, criteria were not stated, and the conditions under which the behaviour should occur omitted. Cummins, Baxter, Hudson, & Jauernig (1996) analysed 163 plans from 11 community settings and found only 14% offered any criteria for evaluating performance. Stancliffe, Hayden & Lakin (1999) investigated the relationship between plans for 126 adults and found no significant change in outcomes associated with having an objective goal. This study did attempt to evaluate the effect of the technical quality of the goals, but no analysis of community goals was possible due to the small number of community goals present in the individual's plans.

In spite of these concerns, there is some general empirical support for the notion that more positive outcomes are associated with more sophisticated planning procedures, in particular in relation to community use. Several studies (Hatton, Emerson, Robertson, Henderson & Cooper, 1996; Emerson et al 2000b; Felce et al., 2000, Perry et al 2000; Felce et al., 2002a) have used the Group Home Management Scale (GHMS) (Raynes et al. 1994). This assesses the degree of 'resident-oriented' management practices within the setting. The studies above found that the use of community settings was related to either the total or domain scores of the GHMS. Emerson et al.(2000b) and Hatton et al. (1996) found that greater community use was predicted by greater emphasis on planning activities. Felce et al. (2002a) found that once individual characteristics (adaptive and challenging behaviour) had been controlled for, GHMS scores and higher staff to resident ratios predicted frequency of community activities. Perry et al. (2000) found a significant correlation between community use and the level of attention the individual received from staff within the house. Given no direct linkage between the behaviour of staff whilst in the home and community activity of the service user, it was hypothesised that the association may be due to general staff orientation, i.e. those staff who were inclined to give more attention to clients in the home would also be more likely to facilitate the client's community access.

Jones et al. (2001) evaluated the dissemination of Active Support training in 38 residences in Wales. Amongst other outcomes, they tentatively suggested that Active Support may produce a modest increase in social and community integration. The lack of confidence in this finding stemmed from various methodological weaknesses in the

research, including the reliability of the measure of community use. This study focussed upon a wide range of outcomes and did not attempt to differentiate those elements of Active Support that might facilitate greater community use.

Felce et al. (2002b) have suggested key differences in service factors that might influence participation in in-house versus community activities. They found that higher staff to resident ratios predicted greater frequency of community use, but had a negative impact on activity within the home. They suggested that the nature of staff support within the house might easily result in suppressing activity, whereas the role of staff in supporting community use is clearer cut. Use of community activities is demanding on staff resources and greater staff numbers may simply increase resident opportunities to go out. Thus, it is plausible that the five elements of the Active Support model would differentially affect community access. In particular, supporting participation through prompting, demonstration and guidance and provision of attention contingent upon engagement may be less important than proactive planning of opportunity and clear designation of staff responsibility. It is argued that these last two factors are likely to be influential in facilitating greater community use for people with learning disabilities in residential services

Purposes of the Current Study

1. An argument has been made for the need for a valid and reliable measure of community use, which would be sensitive to both range and frequency of community contacts. Furthermore, this measure should be universally applicable to all groups of people in society, making the generation of norms for non-disabled individuals a possibility. Thus, the first purpose of this study is the development of a psychometrically robust measure of the community use of people with learning disabilities. This will enable the generation of data representative of the experience of people with learning disabilities, as well as data pertaining to a non-disabled sample.
2. Previous studies have indicated that the depth and breadth of the lifestyle of people with learning disabilities has been found to be less than might be expected or desired (e.g. Hayden et al.1992; Jeffree & Cheseldine, 1981; Lowe & de Paiva, 1991;

McConkey et al. 1983). It was considered important to compare the patterns of community activity and leisure of service users with learning disabilities to that of a non-disabled control group in order that the quality of experience can be evaluated fully and objectively.

3. It has been argued here that the hospital closure programme in the UK has developed in a rather piecemeal and uncoordinated fashion, with variation over time and locality. By the mid 1990's, the majority of people had left institutional care, leaving a core of people who had arguably greater dependency needs. In addition, they were cared for by staff that, for whatever reason, had chosen to work in institutional settings, when employment in community based provision may have been available elsewhere. The closure of Mount Pleasant Hospital in Hastings on the south coast of England represented an opportunity to evaluate the impact of deinstitutionalisation on the community use of those people who once lived there. This particular hospital closure could be seen as an example, and possibly representative, of the last wave of deinstitutionalisation with its specific associated difficulties and challenges.
4. Research has identified specific individual factors that might potentially contribute to the community use of people with learning disabilities. However, there is little research investigating service factors that would specifically be associated with community use. With the assistance of a comparison group, this study will attempt to identify both client and service factors that contribute to community use.

Hypothesis 1

The frequency and range of community and leisure use of people with a learning disability will be significantly less than people who do not have a disability.

Hypothesis 2

Those individuals relocated from hospital will enjoy greater use of their communities once living in community staffed homes.

Hypothesis 3

The use of community in people in the resettlement and comparison groups will be related to individual factors.

- People with greater dependency needs will have less use of their communities.
- People who exhibit challenging behaviour will have less use of their communities.

Hypothesis 4

The use of community in both groups will be related to the presence of clear and coherent community goal planning.

Method

Development of the Guernsey Community Participation and Leisure Assessment GCPLA:

In the early 1990's the States of Guernsey Board of Health Learning Disability Service developed an individual planning system. It was acknowledged that there was a need for an instrument to aid the assessment and generation of community participation and leisure needs and monitor the outcome of interventions designed to increase and enhance the individual service user's experience of the community and leisure. At that time no such instrument was available that had robust psychometric properties and that would enable useful and meaningful comparisons of individuals. Consequently, the Guernsey Community Participation and Leisure Assessment (GCPLA) was developed and later published in the Journal of Applied research in Intellectual Disability (Baker, 2000). It is an instrument designed to gather quantifiable information regarding the quantity and quality of community based activities, contacts and leisure activities both individual and social (appendix 1).

Seager (1987) developed a structured interview designed to elicit quantifiable data pertaining to community contacts. This consisted of a checklist of 34 potential contacts arranged under five categories of activity, services, public transport, leisure sport and recreation, social and facilities/amenities. The GCPLA is an extension and development of Seager's structured interview. It consists of 53 operationally defined contacts/activities divided into the above categories plus an additional category of Indoor Leisure (see table 2.). This definitive list of items was derived by giving the original 34 items to 20 care staff working in learning disability services in Guernsey and asking them to indicate if they, or the service users in their care, would have any contact with each item. In addition, the inclusion of an 'other' item in each category was used to elicit suggestions for additional items. These categories and items were selected to, as far as was possible, to comprehensively represent every day community use. Following suggestions from care staff, an additional category relating to Indoor Leisure was included. This broadened the scope of the measure to include leisure based opportunities located both in and outside of the individual's home. Two items from the original list

constructed by Seager were removed. Launderette, as all 20 care staff indicated no use of this item by themselves or service users and outings due to difficulty with the relative lack of specificity of the term. As a result of this process a further 20 items were added with the previously combined item of boat/plane were made into two separate items.

The individual or carer is asked to indicate the frequency of contact or participation and rate this on a 5-point scale with

- 1- very occasionally;
- 2- 3 monthly or more frequently;
- 3- monthly or more frequently;
- 4- weekly or more frequently and
- 5- daily or more frequently.

This is converted into the Range score which represents the total number of activities/contacts accessed 3 monthly or more frequently. The three monthly frequency criteria was chosen to represent frequency of contact that was in some way meaningful and was, to a certain extent, a compromise given the number of items and the different frequency of normative use. Many items would have a relatively frequent normative use (e.g. local shop); whereas other would be less frequent (e.g. G.P.). The Range score is a combination of frequency and number of contacts. It is not meant to represent an absolute account of every individual community/leisure contact, rather it indicates an analogue of how the variety and frequency of an individuals experience of leisure and their communities maps on to general/normative experience.

Qualitative data are collected by asking the respondent to provide details of how these contacts are made. This is coded as

supervised i.e. the onus of choice and control lies with the carer and/or a major part of the carer's attention is concerned with vigilance of the individual;
accompanied, with carers but not supervised;
alone; or with a
peer group.

The inclusion of the category accompanied, i.e. being with a carer but not supervised was added following observation and discussion with staff as it was found to reflect the reality for a significant number of individuals living both in residential provision and at home. For example, a service user liked to watch the local football team play every Sunday morning. Occasionally, he would happily do this alone and unaided by staff. More often, he would attend with a member of staff who was merely present and played no supervisory role, usually this member of staff also liked football. On most occasions his support mode would, therefore, be classified as accompanied.

A. Services	D. Leisure, Sport & Recreation
Doctor GP	Fair/Fete/Festival
Dentist	Museum/Art Gallery
Hospital	Sport (participation)
Police	Sport (spectator)
B. Public Transport	Exercise/Aerobic Class
Bus	Cycling
Train	Cinema
Taxi	Theatre
Boat/Ship	Concert
Aeroplane	Park
C. Indoor Leisure	Beach
Craft	Walking
Games	Holiday
TV	Swimming
Videos	Sailing
Music (Listen)	DIY
Music (Play)	Gardening
Pets	E. Social
F. Facilities/Amenities	Disco
Local Shop	Pub
High St Store	Party
Post Office	Restaurant/Café
Hairdresser	Friends House
Supermarket	Neighbours Home
Chemist	Social Club (integrated)
Bank/Building Society	Social Club (segregated)
Place of Worship	
Large Retail Outlet	
Jumble/ Car Boot Sale	
Library	
Adult Education	

Table 2. GCPLA Activity Categories

Administration and Scoring:

Although the GCPLA is a checklist, it was originally intended that it should form the basis of a structured interview of the client's perception of their experiences. Only in those situations where the individual has insufficient cognitive or language skills are carers expected to answer on behalf of the individual.

Data describing the amount of contact is obtained by calculating the Range score (see above), i.e. the number of activities/contacts rated as being accessed three monthly or more frequently. Of related interest might be the Busy scores, an indication of the number of very frequent activity/contacts, which is derived by summing the amount of contact/activities rated as occurring more frequently than weekly. A representation of the mode of contact is obtained by adding the number of GCPLA items accessed more frequently than three monthly in each category of type of access, i.e. how many items does the individual access with a peer group, alone etc. In addition, a more detailed profile can be achieved by a separate analysis of community activities/contacts and in-home leisure activities.

The following are examples of the use of the GCPLA:

J.O. is a 40-year-old woman who lives in her own in a flat in a high rise block. She attends the local social education centre and has recently started a supported employment placement in a supermarket. She receives five hours of time from a support worker from the local Community Learning Disability Service. Important people in her life are her boyfriend and her parents. Although living away from home she has much contact with her parents, especially at weekends when they will expect to see her on both Saturday and Sunday. Her range score of 26 would indicate a large range of community leisure activities and community contacts. This score is higher than the mean score of the non-disabled control group. The main difference between her profile and that of the controls is the type of access. Her peer score of 5 is considerably lower than the 25 achieved by the non-disabled control group indicating a limited range of activities participated in with friends. This is also reflected in her accompanied score of 6,

which represents mainly community activities, participated in with her parents. Completion of the GCPLA highlighted the extent to which much of her community activity may have been designed to please her parents and accounted for the consequent diminished amount of time spent with her friends

C.K. is a 37-year-old woman with a severe learning disability living in a NHS house with 5 other people. She exhibits severe challenging behaviour including self-injury, faecal smearing and episodes of uncontrollable distress. Her range score of 4 includes only three activities/contacts in the community, swimming, the beach and walking. Only one indoor activity is represented, listening to music. All activities are rated as supervised with the exception of listening to music, which she does alone. The GCPLA highlights the impoverished experience of her community and the reliance on staff to enable the little access she has. The implications for service planning would indicate an enormous potential for increasing her access to her community and leisure activities.

A.B. is a 34-year-old man with a severe learning disability living in a NHS house with five other people. He is prone to occasional severe bouts of aggression toward others, which in the past has led to hospitalisation of a staff member. His range score of 21 is high, falling between the mean scores for service users and staff controls. This is achieved by a good deal of vigilance, as is represented by his supervision score of 20. He has only 1 activity recorded as alone, an indoor activity, 5 activities/contacts are accessed with friends, both scores being similar to the service user means. Whilst in many respects the high range score is achieved as a result of a well organised service, it was suggested to those involved in planning this man's service that they seek to reduce the amount of supervision, whilst maintaining the level of community access and use of leisure.

Evaluation of the Psychometric Properties of the GCPLA

Reliability

The reliability of a measure is defined as the extent to which it is free from random error components (Judd, Smith & Kidder, 1991).

Inter-Rater Reliability:

This investigates the correlation between scores on the same measure obtained from independent sources and is based on the assumption that the random error component is expected to vary rather than remain constant from respondent to respondent.

Participants & Settings

Inter-rater reliability of the GCPLA was examined with the assistance of 12 individuals with learning disabilities living in two 6-bedded NHS residential establishments in the Hastings area. The ages ranged from 20 years 2 months to 38 years 7 months with a mean age of 27 years 9 months and standard deviation of 3 years 3 months. All of the individuals involved were judged to have a severe or profound learning disability with limited language skills necessitating the use of care staff to complete the GCPLA on their behalf. All respondents had known the individual in their capacity as either head of home or keyworker for at least 18 months.

Measure & Design

The heads of homes were asked to complete the GCPLA on each individual in the home, and in addition the individual's keyworker was asked to complete the GCPLA independently. This was based on the assumption that both respondents would have access to similar knowledge regarding the activities of the individual to be assessed.

Test-Retest Reliability (people with learning disabilities as respondents):

This investigates the correlation between scores on the same measure administered on separate occasions and is based on the assumption that the random error component is expected to vary rather than remain constant from occasion to occasion

Participants & Settings

Test-retest reliability was examined with the assistance of 9 volunteers. These individuals all had a learning disability and attended either of 2 Adult Training Centres in the Hastings area. These included 7 men and 2 women with an

average age 43 years 8 months (standard deviation 3 years 6 months). All participants were judged by the staff to have sufficient language skills to be able to act as reliable informants.

Measure & Design

Participants were interviewed using the GCPLA on two occasions within a two-week interval.

Test-Retest Reliability (carers as respondents):

Participants & Settings

Test-retest reliability was examined with the assistance of the 12 participants involved in the inter-rater reliability study.

Measure & Design

The keyworkers of the above individuals were asked to repeat the GCPLA two weeks after initial completion.

Internal Reliability:

Internal reliability investigates the extent to which random measurement errors vary from one test item to another within the same measure.

Participants & Settings

In order to investigate the internal reliability Cronbach's alpha coefficients (Cronbach, 1951) were calculated on the frequency and support ratings gathered in relation to 107 people with a learning disability by combining data from three sources. This comments on the degree to which each item correlates with each other item.

1. Data derived from the 9 participants in the inter-rater reliability study with people with learning disabilities as respondents,
2. Data obtained from 60 participants in the evaluation of Mount Pleasant Hospital described later in this thesis

3. Data from the 38 participants in the study comparing community use of service users and care staff described later in this thesis.

Validity

Validity can be defined as the extent to which a measuring instrument measures what it purports to measure. There are many different definitions of validity and distinctions among different types or kinds of validity. For the purposes of this study the following definition was employed.

Content Validity:

Content Validity examines the extent to which the content of a test is relevant to the characteristic being measured, thus exploring whether a test or assessment reflects appropriately the domain under investigation (Pedhazur & Schmelkin, 1991).

Participants & Settings

The content validity was investigated with the assistance of ten 'experts', Clinical Psychologists working in the fields of Rehabilitation, Complex Care and Intellectual Disability.

Measure & Design

A questionnaire was designed to evaluate how relevant the items listed in the GCPLA were to their individual subcategory within the instrument, and how relevant these categories were to the overall notion of community participation and leisure. Respondents were asked to rate the relevance of the identified categories on a 5-point Likert scale (1=not at all, 2= slightly, 3= moderately, 4=quite a bit, 5 = extremely).

Concurrent Validity:

Concurrent Validity is a sub-type of criterion-related validity that explores the relationship between a test and other criteria that are measured or assessed at the same time. This often involves the correlation between the test in question and one or more other measures for which a hypothesised relationship is posited (Breakwell, Hammond and Fife-Schaw, 1995).

Participants & Settings

Concurrent validity was investigated with the assistance of 11 people with learning disabilities living in two 6-bedded NHS residential establishments in the Hastings area. Five participants were female and six were male. The mean age was 38.5 years (range 25-71, mean 12.5 years). All of the individuals involved were judged to have a severe or profound learning disability with limited language skills necessitating the use of care staff to complete the GCPLA on their behalf.

Measures & Design

Staff who had known the individual in their capacity as either head of home or keyworker for at least 18 months recorded all community and leisure activities for each client for four weeks in an individual diary. This measure was constructed for the purposes of this study. A separate sheet was given to staff listing community and leisure activities. In addition, they were asked to list any other activities or contacts not listed. At the end of this period a GCPLA was completed for each client along with a Life Experience Checklist (LEC) (Ager, 1990). The LEC is a broad-based 'quality of life' instrument with proven reliability and validity, designed to assess the range and extent of an individuals life experiences. It was designed for use with a range of clients, in particular people with learning disabilities. The diary data was transferred to GCPLA forms to enable direct comparisons to be made.

Comparison of community use of service users & care staff

Participants & Settings

Participants included all individuals participating in the Life Planning System operated by the States of Guernsey Board of Health's Learning Disability Service during a six month period in 1991 (n = 38). This included 18 men and 20 women with ages ranging from 19-77 years (mean age 42, sd 17.25 years). These service users had a range of learning disabilities ranging from profound physical and learning disabilities to mild learning disabilities. In addition, the GCPLA was

mailed through the internal post to all staff members of the States of Guernsey Board of Health Learning Disability Service. Forty-one staff member volunteers, including 19 men and 22 women with ages ranging from 19-52 years (mean age 38, sd 12 years), returned a completed assessment, representing a response rate of 57.6%. Although this group was not randomly selected from the general population, it can be argued that they represent a meaningful comparison group. An added dimension was that the two groups spent a considerable amount of their lives in each others company. The two groups were broadly similar in age and had a similar gender mix, a χ^2 analysis revealing no significant difference in gender mix within each group.

Measure & Design

The GCPLA was administered with or on behalf of each service user as part of the preparation for the individual service user's Life Plan review meeting routinely held every 9 months. Depending on the communication ability of the service user, the GCPLA was either used by the keyworker as the basis for a structured interview or completed on behalf of the service user. All GCPLA data regarding staff member participants was completed by self-administration. A simple two group comparison design was employed.

Evaluation of the closure and resettlement of Mount Pleasant Hospital

Participants and Settings

The study sample involved 62 individuals with a severe/profound learning disability who were residing in NHS provided residential services in the Hastings and Rother Health district in 1996. The resettlement group of 28 people resided in Mount Pleasant, a small Learning Disability Hospital that was due for closure and reprovisioning, located in an urban setting on the outskirts of Hastings. Twelve women lived together in one ward, with 2 additional wards for 7 and 9 men. The comparison group included 34 individuals who lived in community residential services. These individuals had all been moved from a range of long stay learning disability hospitals over the preceding 10 years. These houses were in a mixture of settings and architectural styles. Two houses were adjacent to

each other and purpose built in the grounds of an old learning disability hospital; the hospital had since been partly demolished or converted to flats. Both residential services housed 6 people, one being for women only. Two further 6-bedded houses were in ordinary semi-rural settings and, although originally architecturally similar to the neighbouring houses, had undergone adaptations that made them noticeably dissimilar. A further house was purpose built in a rural setting, with an architectural style that rendered it dissimilar to neighbouring properties. The final house, was an ordinary dwelling (i.e., not purpose built) in a remote rural location. Unfortunately during the period of resettlement two individuals residing in the hospital died and baseline data from these people were excluded from the analysis, resulting in a cohort of 60 participants.

The hospital closure and reprovisioning programme was phased over an eighteen-month period between 1996 and 1997. People in the resettlement group were moved to five 6-bedded purpose built houses. Each of these houses was architecturally identical and placed in a variety of rural locations. This type of provision would represent intermediate community settings (Felce & Emerson, 2001) as they differed architecturally from culturally typical dwellings and accommodated a larger group than those typically found in those dwellings.

Measures & Design

During the six months prior to the first group of people moving from hospital, GCPLA data were gathered regarding all participants in the resettlement groups and the comparison group (t1). Each participant in the resettlement group was reassessed six months after moving. All participants in the comparison group were reassessed during the 18 month period between the first and last group moving out of hospital (t2). All of the individuals involved were considered by the author, a Speech & Language Therapist and the service managers to have a severe or profound learning disability with limited language skills necessitating the use of care staff to complete the GCPLA on their behalf. The assessment was completed by either the individual's keyworker or the head of home/charge

nurse, in situations where the keyworker had not known the person for longer than 18 months.

During the six months prior to the resettlement of the first group of hospital residents, all participants were assessed on a range of measures. Due to resource constraints participants were assessed on the GCPLA alone at t2.

Adaptive Behavior Scale (1st Edition) Part 1 (Nihira, Foster, Shellhaus, & Leland, 1974).

Levels of dependency were assessed using this scale. It contains 66 items organised into 10 behaviour domains considered to be important to the development of personal independence in daily living. These include independent functioning, physical development, economic activity, language development, understanding number and time, vocational activity, self-direction, responsibility and socialisation. The scale gives an overall score ranging from 0-280. It has reported reliability of 0.74, and good validity is claimed by the authors, who state that the ABS part 1 is able to discriminate between people classified at different levels of disability, by clinical judgement.

Goal Rating Scale

This was specifically developed for this evaluation and was designed to rate the robustness of individual written community participation planning goals contained within each person's file. The concept of robustness was derived from the goal planning literature and encompasses both the specificity of the goal and the specific conditions and time frame for attainment. These reflect the elements of proactive planning of opportunity and staff responsibility outlined in Active Support (Emerson & Hatton, 1996; Felce 1996; Mansell, 1998). The measure consists of a Likert type scale ranging from 0 which would be indicative of no goals through to 4 which would indicate the presence of a goal about a specific area of activity with specific conditions or time frame for attainment. Inter-rater reliability of the Goal Rating Scale was assessed as part of a previous study (Reed, 1996) using the goals related

to 40 participants. These participants were not randomly selected as Reed's (1996) study involved only participants from both the resettlement and comparison groups with the 20 highest and 20 lowest scores on the GCPLA. It was considered that this reliability sample of nearly 80% of the participants would be acceptable, in spite of this not being a random selection of the cohort. Three independent raters rated these goals, with an inter-item agreement of 97%, i.e. all raters agreed on a specific item. (appendix 2)

Behavior Problems Inventory (BPI) (Rojahn, 1992, updated 1994)

Degree of challenging behaviour was assessed using the Behavior Problems Inventory (BPI) (Rojahn, 1992, updated 1994). This is a 32-item inventory requiring the respondent to rate the observed frequency of each specific topography described on a seven point scale from never to hourly. The scale has three categories of topographies: self-injurious behaviour (SIB), aggressive/destructive behaviour and stereotyped behaviour. The staff ratings were converted into a daily frequency of occurrence for each item/topography (i.e. less than monthly = 0.01, monthly = 0.03, weekly = 0.14, daily = 1, hourly = 16, more than hourly = 24). The BPI has proven psychometric properties and has been used in a number of studies of challenging behaviour. The inter-observer reliability of the BPI is reported as .84 for self-injury, .83 for aggression, and .89 for stereotopies and has global test-retest reliability of between 88 and 96%. The Inventory has good concurrent validity, correlating with the Aberrant Behaviour Checklist (self-injury .65, stereotypy .77, aggression .46) (Dura, Maliick & Rasnake, 1987; McGill, Hughes, Teer & Rye, 2001; Rojahn 1984; Rojahn, 1986; Rojahn, Polster, Mulick, & Wisneiwski, 1989; Sturmey, Fink & Sevin, 1993).

Both the ABS part 1 and the BPI were completed by either the individual's keyworker, or the head of home/charge nurse in situations where the keyworker had not known the person for longer than 18 months.

Table 3 illustrates a comparison of the resettlement group and the comparison group. A series of t-tests were carried out to test for significant differences in the two groups. The community group were significantly younger, reflecting the policy of moving younger people out of hospital first. Somewhat surprisingly the community group had significantly higher levels of self-injury than the group awaiting discharge from hospital.

	Men	Women	Age (mean)	ABS (mean)	BPI (mean)	SIB (mean)	Aggression (mean)	Stereotypy (mean)
Hospital (Resettlement Group)	13	13	50.6 (14.9) **	62 (44.7)	11.8 (20.9)	1.2 (3.1) *	0.3 (0.7)	9.5 (20.5)
Community (Comparison Group)	13	21	39.8 (10.2)	69.1 (37.7)	15.6 (23.7)	6.5 (13.5)	1.6 (5.8)	9.4 (15.4)

* <0.05 level (2-tailed)

** <0.01 level (2-tailed)

standard deviation in parenthesis

Table 3.
Comparison of Resettlement & Comparison Groups

A mixed design was employed in which changes in the dependent variable (GCPLA scores) were measured within-subjects (before and after leaving hospital) and between-subjects (using a comparison group of people who lived in the community throughout the study).

Predicting community use of people with a learning disability

Participants and Settings

This study involved the participants in the previously discussed evaluation of the closure of Mount Pleasant Hospital. It included both those individuals living in hospital awaiting resettlement and those already living in community residential services. Data obtained at t1 and t2 in the previous study were used in this study.

Measures & Design

In order to determine the variables that might best predict community access of people with a learning disability, multivariate analysis using linear multiple regression was carried out. This allows the assessment of the relationship between one dependent variable (DV) and several independent variables (IV). The DV studied were the GCPLA Range score at t1 and t2 respectively. The IVs included client characteristics (age, gender, ABS part 1, BPI and BPI category scores- aggression, self injury and stereotypy) and service characteristics (place of residence and robustness of community goals). The analyses of the scores derived at the same moment in time, i.e. t1, were considered to be the primary focus of study. With the GCPLA Range scores at t2 to act as a comparison, in particular commenting on the effects of the independent variables over time.

Generation of GCPLA normative data

Participants & Settings

A sample of 109 people with a learning disability was constructed by combining data from three sources all previously discussed. Data from the 38 service users in Guernsey who participated in the study of community use people with a learning disability and care staff, data derived from the 9 participants in the inter-rater reliability study with people with learning disabilities as respondents and data obtained from the 60 participants in the evaluation of Mount Pleasant Hospital. Although data from the latter two sources were not randomly selected, they had very similar means and standard deviations to the Guernsey cohort ($t=0.167$, $df\ 105$, $p=.494$ 2-tailed). Participants represented the full range of learning disability, with 56 women 51 men with a mean age of 40.6 years (sd 12.4) the youngest 20 and the oldest 79. It is therefore considered that the combined data are reasonably representative.

In addition, scores were derived for a non-disabled population from Guernsey staff participants in the study of community use of people with a learning disability and care staff. These were 19 men and 22 women, with a mean age of 34 years, the youngest being 20 and the eldest 51 with a mean age of 34.2 (sd 8.8) years.

Measure & Design

The Range score of the GCPLA represents the most valid, reliable and potentially useful summary of information. Thus, percentiles were calculated from the normative sample to facilitate comparisons of GCPLA Range scores with a learning disabled population. In addition, percentile scores were derived for a non-disabled population from the Range scores obtained from the Guernsey staff.

Results

Investigation of the psychometric properties of the GCPLA

Inter-Rater Reliability:

A Spearman's rank-order correlation coefficient (*rho*) was calculated for each pair of scores generated from the total items of the GCPLA (Table 4.). Acceptable reliability levels were found for all but the alone and Peer scores, i.e. above 0.7 (Martin & Bateson, 1986). The Accompanied scores, whilst being positively correlated were only approaching acceptability. The correlation between Peer scores could not be meaningfully calculated as none of the participants were rated as accessing activities with a peer group.

GCPLA Category	Correlation coefficient (Spearman rho)
Range	.83**
Very Frequent Activity	.84**
Alone	.77**
Peer	1.00
Accompanied	.62*
Supervised	.81**

* correlation significant <0.05 level (1-tailed)

** correlation significant at <0.01 level (1-tailed)

All participants were reported to have no activities experienced with peers at t1 or t2.

Table 4.
GCPLA Inter - Rater Reliability

Test-retest reliability (people with learning disabilities as respondents)

A Spearman's rank-order correlation coefficient (*rho*) was calculated for each pair of scores generated from the total items of the GCPLA. All scores had acceptable levels of test-retest reliability, with the exception of the number of very frequent activities (Table 5). No participant rated himself or herself as being supervised in either interview. The interviewers noted several potential sources of bias which should be noted if the GCPLA is to be used with self-respondents.

- At times it appeared that participants were referring to activities that they would like to be doing rather than those they actually participated in
- Some form of social desirability (e.g. oh yes I go to a lot of parties) was evident.
- Some participants did not differentiate between friends and paid carers.
- It was difficult for participants to decide on the time frame when judging frequency of activities.

GCPLA Category	Correlation Coefficient (Spearman rho)
Range	.87**
Very Frequent Activity	.56 ns
Alone	.97**
Peer	.93**
Accompanied	.96**
Supervision	1.00

* correlation significant <0.05 level (1-tailed)

** correlation significant at <0.01 level (1-tailed)

All participants reported no activities supervised at t1 or t2.

Table 5.
GCPLA Test - Retest Reliability
(Self-Respondents)

Test-retest reliability (carers as respondents)

A Spearman's rank-order correlation coefficient (*rho*) was calculated for each pair of scores generated from the total items of the GCPLA. Acceptable levels of test-retest reliability were found for the Range, Very Frequent Activity and Peer scores. No participant was rated as accessing activities accompanied but not supervised at either interview (Table 6). A less significant correlation was found between Supervision scores and a moderate correlation, approaching significance, was found with Alone scores.

GCPLA Category	Correlation Coefficient (Spearman r)
Range	.83**
Very Frequent Activity	.84**
Alone	.46 ns
Peer	.80**
Accompanied	1.00
Supervision	.47*

* correlation significant <0.05 level (1-tailed)

** correlation significant at <0.01 level (1-tailed)

All participants reported no activities accompanied at t1 or t2.

Table 6.

GCPLA Test - Retest Reliability
(Staff-Respondents)

Internal Reliability

Acceptable alpha coefficients were found for both the GCPLA Range scores (.88) and the mode of access scores (.83).

Content Validity

A statistical analysis was not conducted due to the small number of questionnaires completed. However, mean and range scores were calculated. The content of the GCPLA was rated as relevant to the six categories of the instrument (Table 7). The

range for each category (3-5) indicated that all respondents rated all the items from 'quite a bit' to 'extremely' relevant to the categories identified. The relevance of all the categories to 'Community participation and leisure' mean rating was 4 'quite a bit' relevant (range 3-5).

<i>GCPLA category</i>	<i>Mean</i> n = 10	<i>Range</i> n = 10
A. Services	4.5	3-5
B. Public Transport	4.4	3-5
C. Indoor Leisure	4.2	3-5
D. Leisure, Sport & Recreation	4.5	3-5
E. Social	4.2	3-5
F. Facilities/Amenities	4.2	3-5
Relevance of A-F to 'Community Participation & Leisure	4.0	3-5

Table 7.
'Experts' ratings of GCPLA item and category relevance

Concurrent Validity

A Spearman's rank-order correlation coefficient (*rho*) was calculated for each pair of scores generated from the diary data and the GCPLA (Table 8). A statistical analysis was not conducted for the category Services as ratings on both measures indicated no contact. All completed analyses indicated at least modest correlations between the measures with four significant.

<i>GCPLA Category</i>	Correlation coefficient (Spearman rho)
A. Services *	1.00
B. Public Transport	.534
C. Indoor Leisure	.652*
D. Leisure, Sport & Recreation	.517
E. Social	.576*
F. Facilities/Amenities	.737**
Total (categories B-F)	.682*

* correlation significant <0.05 level (1-tailed)

** correlation significant at <0.01 level (1-tailed)

Table 8.

Correlation between GCPLA Scores and diary recordings of community participation & leisure

The Pearson correlation (r) was used to determine the extent of relationships between the LEC and the GCPLA. A statistically significant correlation was found between the GCPLA category 'Leisure Sport & Recreation' and the LEC category 'Leisure' $r=.742$ $p<0.01$ (1-tailed), the GCPLA category Facilities/Amenities and the LEC category 'Opportunities' $r=.552$ $p<0.05$ (1-tailed).

Comparison of Service Users & Care Staff and the Establishment of Normative Data

The data clearly differentiated between the service users and staff control group's experience of community contacts and the use of leisure. The data indicated that the service users had a smaller range of activities and were most likely to access their communities in the presence of staff or carers rather than alone or with friends, all of these differences being statistically significant. Service Users were also less busy (had fewer frequent activities), although this was not a statistically significant difference (Table 9.). This supports previous research findings.

	Service Users		Staff Controls		Statistical Analysis
	Mean	S.D.	Mean	S.D.	
Range	18	(5.1)	24	(6.6)	t = 5.19, P<.001 2-tailed
Very Frequent					
Activity	11.3	(4.0)	13.5	(4.3)	ns
Alone	5.8	(6.4)	16.5	(5.9)	U =166, P<.001 2-tailed
Peer	1.4	(3.2)	21.6	(7.0)	U = 40.5, P<.001 2-tailed
Accompanied	13.1	(8.9)	0		
Supervised	7.2	(9.5)	0		

Table 9.
GCPLA Scores
Service Users & Staff Controls

In addition, the data relating to the type of access for each individual item revealed distinct contrasts between the staff controls and the service users (Table 10.). In general, the staff controls engaged in what might be considered to be routine maintenance activities alone, whilst leisure was accessed with peers. The exceptions were some items of indoor leisure that were accessed alone and some modes of public transport that were accessed with peers. In contrast, the service users accessed very few types of activity alone or with peers, the majority taking place accompanied by carers. Surprisingly few activities were considered to be supervised; these were mainly health related, i.e. visits to the GP, hospital and the dentist.

	Frequency (mean)		Support (mode)	
	Service Users	Controls	Service Users	Controls
A. Services				
G.P.	1.6 (1-3) SD 0.7	1.4 (1-3) SD 0.6	sup	alone
Dentist	0.9 (0-2) SD 0.5	1.1 (0-3) SD 0.5	sup	alone
Hospital	0.7 (0-2) SD 0.7	0.9 (0-5) SD 0.8	sup	alone
Police	0.0 (0-0) SD 0.0	0.5 (0-1) SD 0.5	n/a	alone

B. Public Transport				
Bus	1.6 (0-5) SD 1.5	0.9 (0-4) SD 1.5	acc/alone	alone
Train	0.1 (0-1) SD 0.9	0.8 (0-2) SD 1.00	Sup/acc alone	
Taxi	1.0 (0-5) SD 1.5	1.9 (0-5) SD 1.5	acc	peer
Boat	1.0 (0-4) SD 0.8	1.4 (0-4) SD 0.9	acc	peer
Air	0.9 (0-2) SD 0.8	1.5 (0-3) SD 0.8	acc	peer
C. Indoor Leisure				
Craft	3.2 (0-5) SD 1.8	1.7 (0-5) SD 1.6	acc	alone
Games	2.2 (0-5) SD 1.8	2.9 (0-5) SD 1.6	acc	peer
TV	4.2 (0-5) SD 1.7	4.8 (4-5) SD 0.4	acc	peer
Video	2.8 (0-5) SD 1.7	3.2 (0-5) SD 1.1	acc	alone
Music-Listen	4.3 (0-5) SD 1.7	4.3 (1-5) SD 1.0	acc	alone
Music-Play	1.0 (0-5) SD 1.3	1.2 (0-5) SD 1.8	acc	alone
Pets	0.7 (0-5) SD 1.8	2.7 (0-5) SD 2.4	sup	alone
D. Leisure, Sport & Recreation				
Fair	1.5 (0-4) SD 2.1	1.4 (0-3) SD 0.8	acc	peer
Museum	0.7 (0-3) SD 0.8	1.3 (0-3) SD 0.8	acc	peer
Sport/Participation	0.9 (0-4) SD 0.8	2.3 (0-5) SD 1.7	acc	peer
Sport/Spectator	0.6 (0-3) SD 1.7	1.5 (0.5) SD 1.5	acc	peer
Exercise	0.7 (0-4) SD 1.3	2.0 (0.5) SD 1.8	acc	peer
Cycle	0.2 (0-4) SD 1.7	1.4 (0-5) SD 1.5	acc	peer
Cinema	0.6 (0-3) SD 1.2	1.6 (0-4) SD 1.1	acc	peer
Theatre	0.4 (0-3) SD 0.8	1.0 (0-2) SD 0.9	acc	peer
Concert	0.7 (0-3) SD 0.9	1.1 (0-3) SD 0.8	acc	peer
Park	1.6 (0-3) SD 1.3	2.0 (0-3) SD 1.5	acc	peer
Beach	2.3 (0-4) SD 1.4	3.6 (0.4) SD 1.4	acc	peer
Walk	2.8 (0-5) SD 1.6	3.4 (0.5) SD 1.4	acc	peer
Holidays	1.1 (0-2) SD 0.8	1.6 (0.3) SD 0.8	acc	peer
Swimming	1.9 (0-4) SD 1.6	2.0 (0-5) SD 1.5	acc	peer

Sailing	0.1 (0-2) SD 0.5	2.5 (0-4) SD 0.7	acc	peer
DIY	0.1 (0-5) SD 1.1	2.0 (0-4) SD 0.8	acc	alone
Gardening	0.9 (0-4) SD 1.2	2.2 (0-4) SD 1.0	acc	alone
E. Social				
Disco	1.1 (0-4) SD 1.2	1.2 (0-5) SD 1.4	acc	peer
Pub	1.9 (0-4) SD 1.2	3.0 (1-5) SD 1.2	acc	peer
Party	1.3 (0-3) SD 1.4	2.0 (0-4) SD 1.0	acc	peer
Restaurant	2.9 (1-4) SD 0.9	3.1 (1.5) SD 0.9	acc	peer
Friend's Home	0.6 (0-4) SD 0.9	3.1 (0-5) SD 1.2	acc	peer
Neighbour's Home	0.4 (0-4) SD 1.8	1.2 (0-5) SD 1.5	acc	peer
Social Club (Integrated)	0.2 (0-4) SD 1.2	0.9 (0-4) SD 1.4	acc/alone	peer
Social Club (Segregated)	1.7 (0.4) SD 1.1	0.2 (0-3) SD 0.8	alone/peer	peer/alone
F. Facilities/Amenities				
Local Shop	3.2 (0-5) SD 1.3	4.1 (0-5) SD 0.7	alone	alone
High St. Store	2.3 (0-4) SD 1.3	3.4 (1-5) SD 1.0	acc	alone
Hairdresser	1.9 (0-3) SD 1.6	2.2 (0.3) SD 0.8	acc	alone
Supermarket	2.6 (0-4) SD 1.2	3.3 (0-4) SD 0.8	acc	alone
Post Office	1.5 (0-4) SD 1.3	3.0 (0-4) SD 1.1	acc	alone
Chemist	1.2 (0-4) SD 1.4	2.4 (0-4) SD 1.1	acc	alone
Bank	0.7 (0-4) SD 0.9	3.6 (1-4) SD 0.8	acc	alone
Place of worship	0.6 (0-4) SD 0.6	1.5 (0.4) SD 1.5	alone	alone
Large retail outlet	1.4 (0-4) SD 0.9	3.8 (1-4) SD 1.4	acc	alone
Jumble/Car boot sale	0.8 (0-3) SD 0.6	0.9 (0-4) SD 1.4	acc	Peer
Library	0.1 (0-4) SD 0.6	1.1 (0-4) SD 0.9	acc	alone
Adult Education	0.4 (0-4) SD 0.9	0.5 (0-4) SD 0.5	sup	alone

Figures in parenthesis = range

Table 10.
GCPLA Item Scores: Service Users & Staff Controls

Data relating to the percentage of activities/contacts accessed according to the type of support reflect the findings concerned with type of access, in that for service users the majority of activities (53%) were conducted in the presence of carers. 29% of the

activities were supervised and only 18% conducted either alone or with a peer group. This makes a stark comparison with the staff control group where 100% of the contacts were either alone or with peers.

Further analysis of the data pertaining to service users indicated that neither gender nor the place of residence (own/parental home or staffed residential service) was a significant factor affecting their GCPLA scores.

In order to obtain normative data percentile scores were calculated for the sample of people with learning disabilities and the non-disabled cohort described in the method section. These are presented in Table 11 and Fig 1.

Percentile	5	10	25	50	75	90	95
Intellectual Disability	9	12	14	17	22	26	28
Non-disabled Population	15	16	19	25	29	33	34

Table 11.
GCPLA Range Scores Percentiles

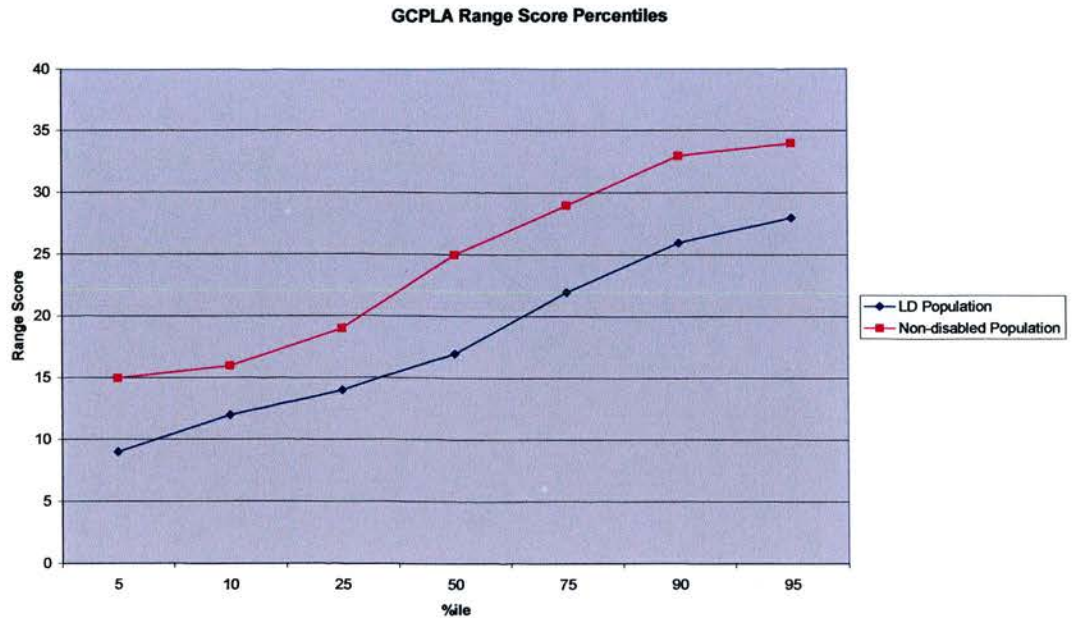


Fig 1
GCPLA Range Percentile Scores

Evaluation of the impact of deinstitutionalisation

In order to examine the effect of the move from Mount Pleasant Hospital to the community on the range and frequency of community contacts, the GCPLA Range score was calculated for all participants in the resettlement group and the comparison group at t1 and t2. In order to test for normality of distribution Kolmogorov-Smirnov tests were applied to both sets of GCPLA Range scores. The distribution of both was assumed to be normal (t1- Kolmogorov-Smirnov $Z = .77$; $p = 0.59$; t2 - Kolmogorov-Smirnov $Z = .86$; $p = 0.44$). A Repeated Measures ANOVA indicated a significant main effect of time $F(1,58) = 58.19$; $p < 0.01$ and a significant interaction between and group (i.e. resettlement group v comparison group) and time $F(1,58) = 24.57$; $p < 0.01$. This is illustrated graphically in fig 2 and GCPLA Range scores for each service user at t1 and t2 are shown in fig 3.

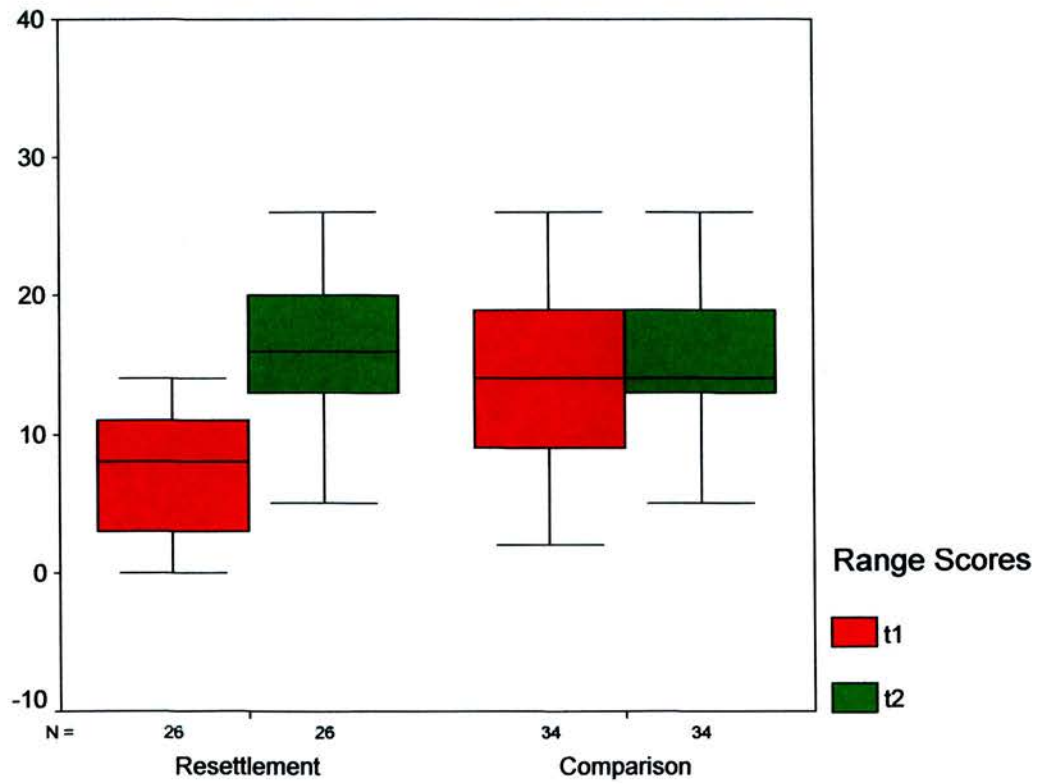


Fig 2. Box Plot Illustrating GCPLA Range scores at T1 & T2 for Resettlement and Comparison Groups

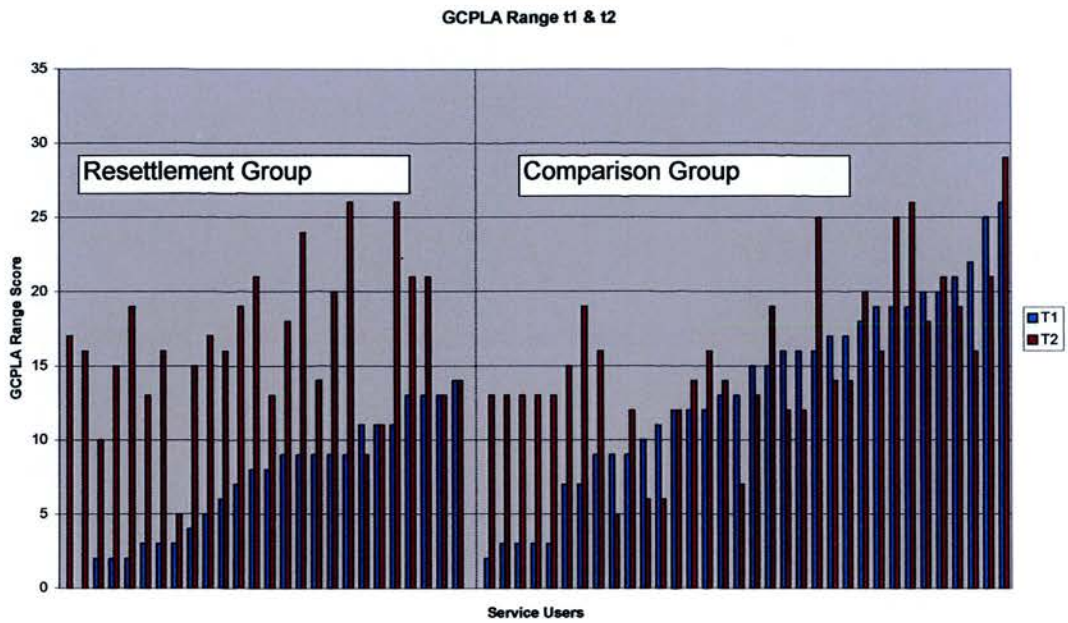


Fig 3.
Individual Service User GCPLA Range Scores

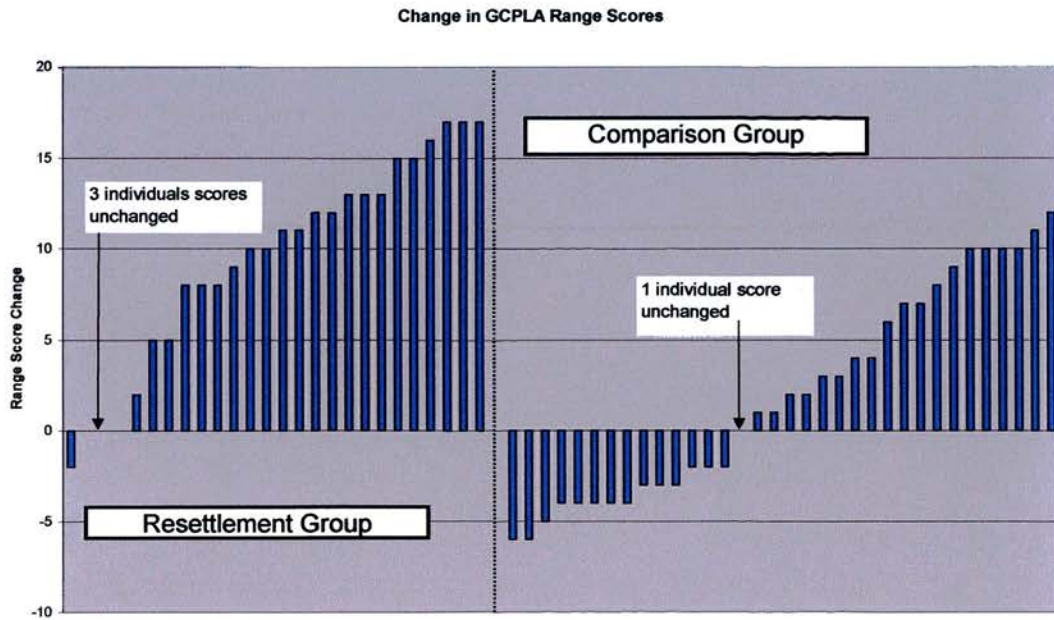


Fig 4.
Change in GCPLA Range Scores from t1 to t2

In order to investigate the hypothesis that those individuals relocated from hospital will enjoy greater use of their communities once living in community staffed homes, a priori comparisons were made involving a series of 3 t-tests carried out on GCPLA Range scores. Significant differences were found between the populations of all participants between t1 and t2, $t(59) = 5.9$; $p < 0.01$. Also significant increases were noted in the Range scores of the resettlement group six months after leaving hospital $t(25) = 8.3$ $p < 0.01$. Finally, a non-significant increase in Range scores also occurred in the comparison group between t1 and t2 $t(32) = 2.0$ $p = 0.05$.

To further illustrate the difference of scores at t1 and t2 the change in the Range score was calculated for all participants. This is illustrated in fig 4, this shows that in the resettlement group only one person had an decrease in their Range score, whilst in the comparison group 14 people showed a decrease.

Further analysis of the GCPLA Range scores was carried out in order to explore relative changes in community and leisure scores. Items on the GCPLA were analysed to produce two separate scores, those which involve access to the community (Services - Public Transport -Leisure, Sport & Recreation and Facilities/Amenities) and those that are primarily home based (Indoor Leisure and individual items Gardening and DIY in the Leisure, Sport & Recreation category). In order to test for normality of distribution Kolmogorov-Smirnov tests were applied to these scores at t1 and t2. The distribution of all four sets of scores was assumed to be normal (t1 Community score- Kolmogorov-Smirnov $Z = .81$; $p = 0.51$; t2 Community score- Kolmogorov-Smirnov $Z = .89$; $p = 0.55$; t1 Home-based score Kolmogorov-Smirnov $Z = .14$; $p = 0.14$; t2 Home-based score- Kolmogorov-Smirnov $Z = .99$; $p = 0.27$).

The GCPLA Community Range scores for the resettlement group and the comparison group at t1 and t2 were analysed using a Repeated Measures Mixed factorial ANOVA. This indicated a significant main effect of time $F(1,58) = 32.86$; $p < 0.01$ and a significant interaction between group (i.e. resettlement group v comparison group) and time $F(1,58) = 12.03$; $p < 0.01$. This is illustrated in fig 5. Similarly, the GCPLA home based activity scores were analysed with a non-significant main effect of time $F(1,58) = 2.71$; $p = .14$ and a non-significant interaction between time and group $F(1,58) = 0.36$; $p = .55$. This is illustrated graphically in fig 6. Individual service user community scores are shown in fig 7. and home-based scores in fig 8. The related change data is illustrated in figs 9 & 10.

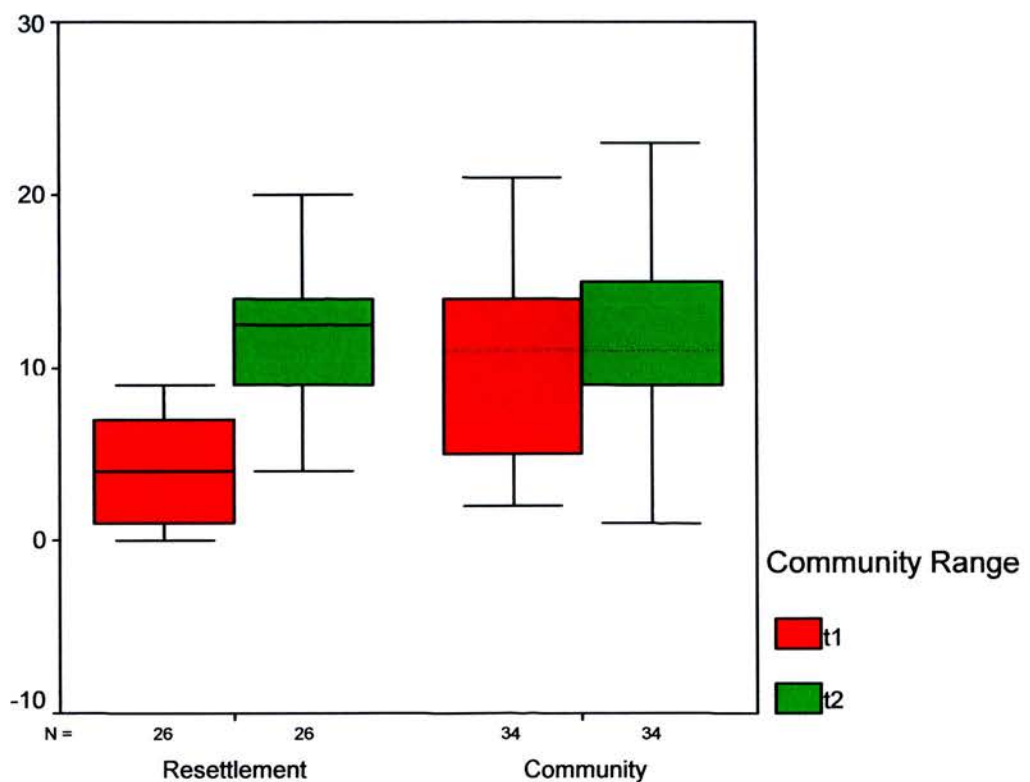


Fig 5.

Box Plot Illustrating GCPLA Community Range scores at T1 & T2 for Resettlement and Comparison Groups

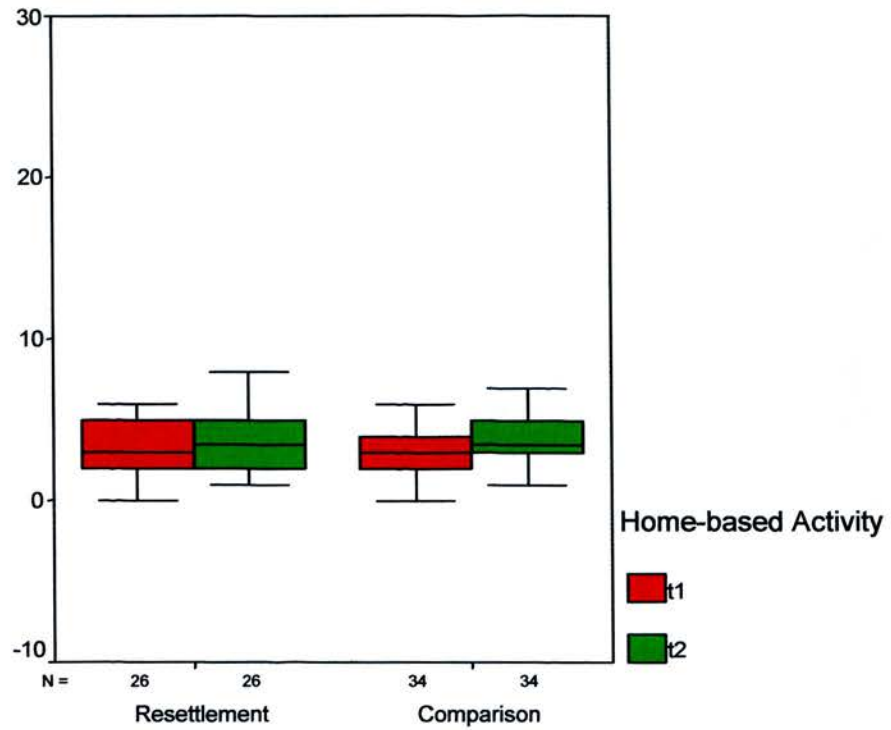


Fig 6.
Box Plot Illustrating GCPLA Home-based Range scores at T1 & T2 for Resettlement and Comparison Groups

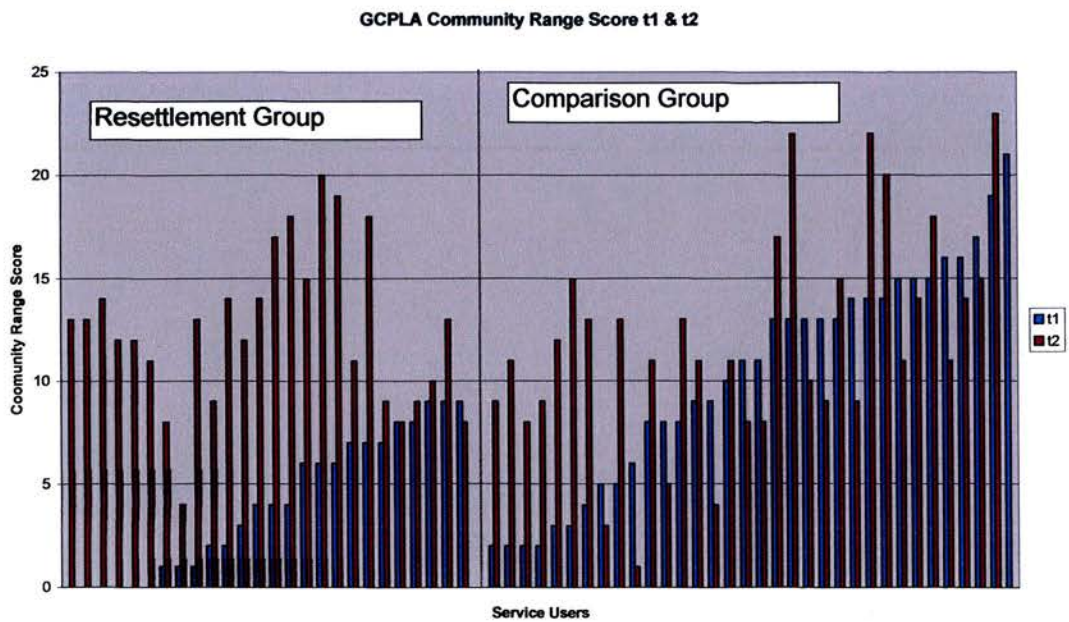


Fig 7. Individual Service User Community Range Scores

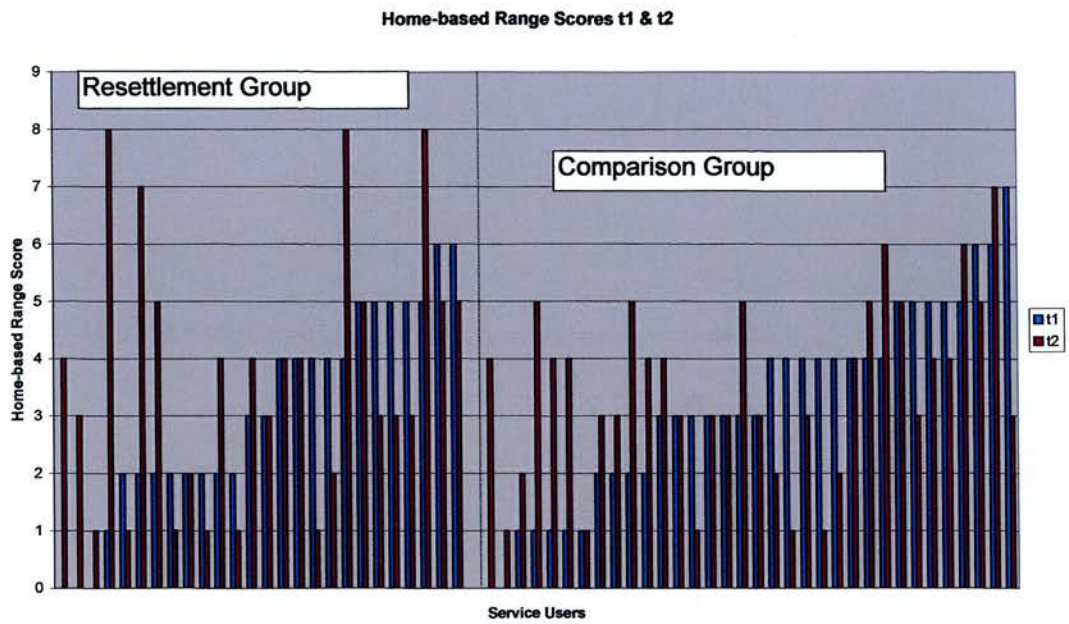


Fig 8
Individual Service User Home-based Range Scores

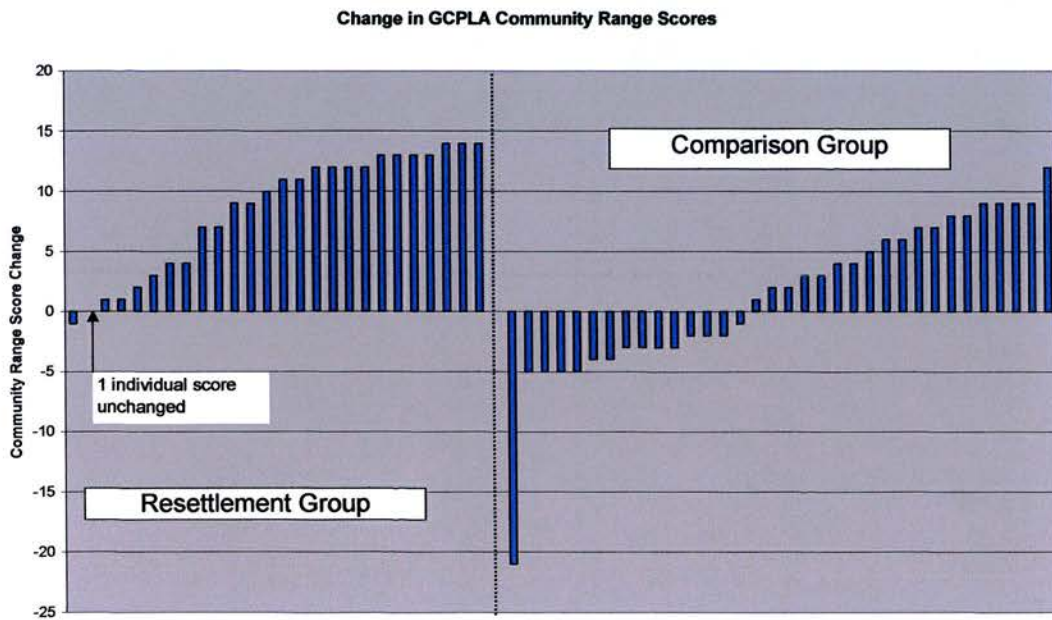


Fig 9.
Change in Community Range Scores from t1 to t2

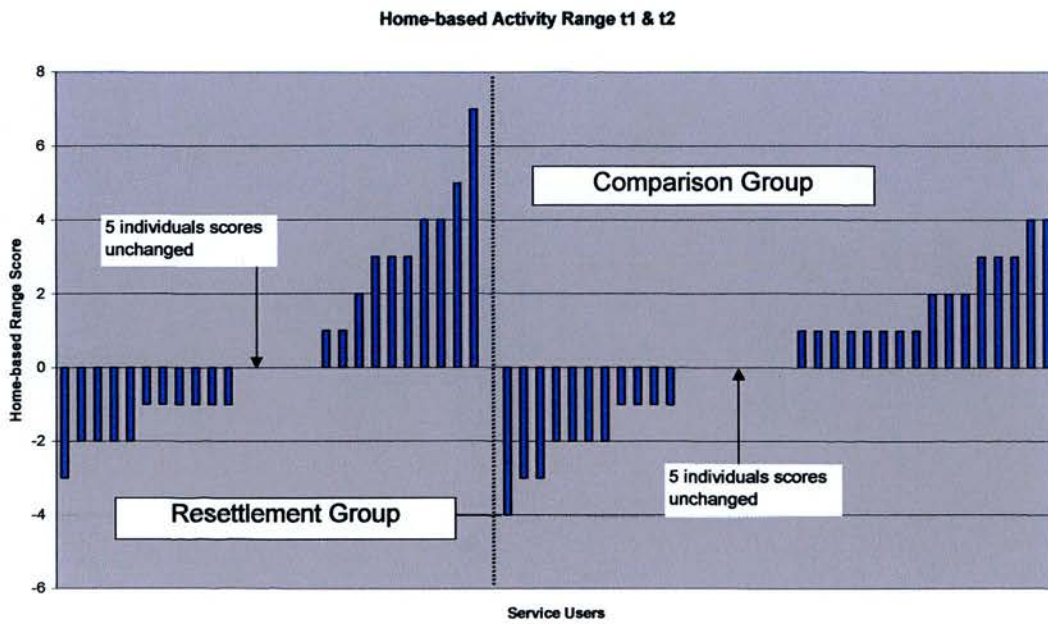


Fig 10
Change in Home-based Activity Range Score from t1 to t2.

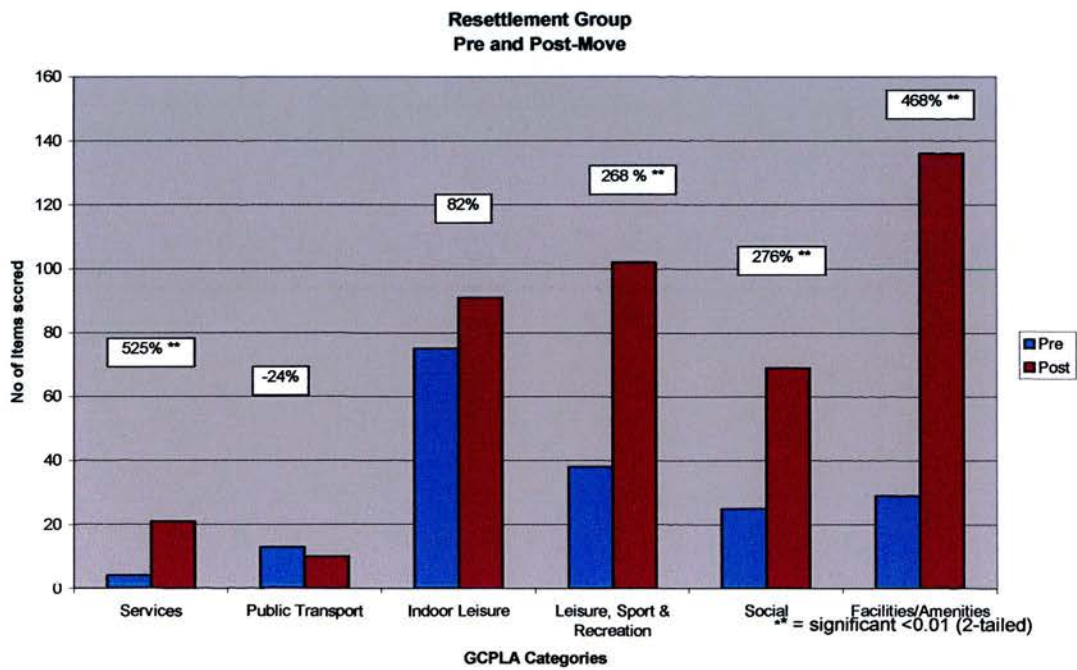


Fig 11. Resettlement Group Change in GCPLA Category Score following Moving from Hospital

In order to further investigate the hypothesis that those individuals relocated from hospital will enjoy greater use of their communities once living in community staffed homes, a priori comparisons were made involving a series of 3 t-tests carried out on the GCPLA Community Activities and Home-based activity Range Scores. In order to reduce the possibility of a type 1 error created by the number of tests carried out, a significance level of 0.01 was adopted. Significant increases were found on the Community Activity Range scores for all participants comparing scores at t1 and t2 $t(59) = 4.8$; $p < 0.01$. Community Activity scores for the resettlement group also increased significantly following movement from hospital $t(25) = 6.77$; $p < 0.01$, whilst scores for the comparison showed no significant difference during the same period $t(33) = 1.6$; $p = 0.12$. In comparison, home based activity scores for both the resettlement and comparison groups combined and individually showed no significant changes over time ($t(59) = 1.4$; $p = 0.15$, $t(25) = 1.2$; $p = 0.28$, $t(33) = 0.78$ $p = 0.44$) Thus the main effect on GCPLA Range scores in the resettlement group appears to be confined to increases in community activities and contacts following movement from hospital with no discernible change in home based leisure activity during the same period.

In order to examine the pattern of change in the lifestyles of people with learning disabilities once they had left hospital and were living in intermediate community settings, the number of items scored as being accessed with greater frequency than three monthly by the whole of the resettlement group were calculated for each GCPLA category before and after the move from hospital. In order to test for significance, a series of Wilcoxon tests were applied. Given the ordinal nature of the data a non-parametric test was chosen. This revealed that, following the move from hospital, the only category that showed a decrease, albeit non-significant ($z = 1.13$; $p = 0.26$) was public transport (24%). The following category scores showed significant increases, Services (525%) ($z = 3.02$; $p < 0.01$), Facilities/Amenities (468%) ($z = 4.48$; $p < 0.01$), Social (276%) ($z = 3.60$; $p < 0.01$), Leisure Sport & Recreation (268%) ($z = 4.00$; $p < 0.01$). Finally, Indoor Leisure (82%), showed a positive but non-significant increase ($z = 1.23$; $p = 0.22$). See fig 11.

A finer analysis of the rating of frequency of contact/access for each item on the GCPLA was carried out for the resettlement group. To enable further comparison, these

are presented alongside a similar analysis of the data gleaned from the non-disabled cohort who participated in the tests of validity reported earlier (fig 12a-64c). Given a relative small cohort number in the resettlement cohort and the untested psychometric properties of the GCPLA at an individual item level, descriptive statistics only are used and should be interpreted with caution.

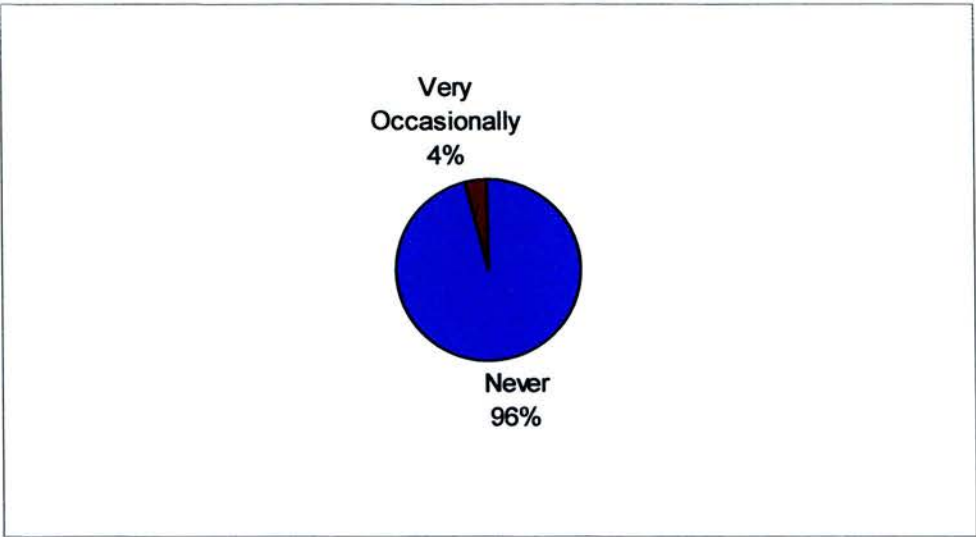


Fig 12a
Frequency of contact with GP in hospital

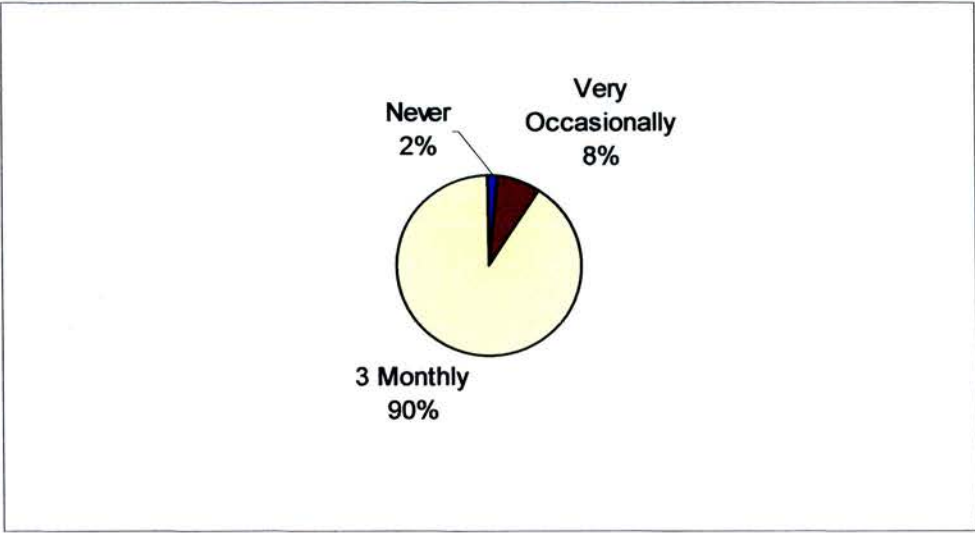


Fig 12b
Frequency of contact with GP in community

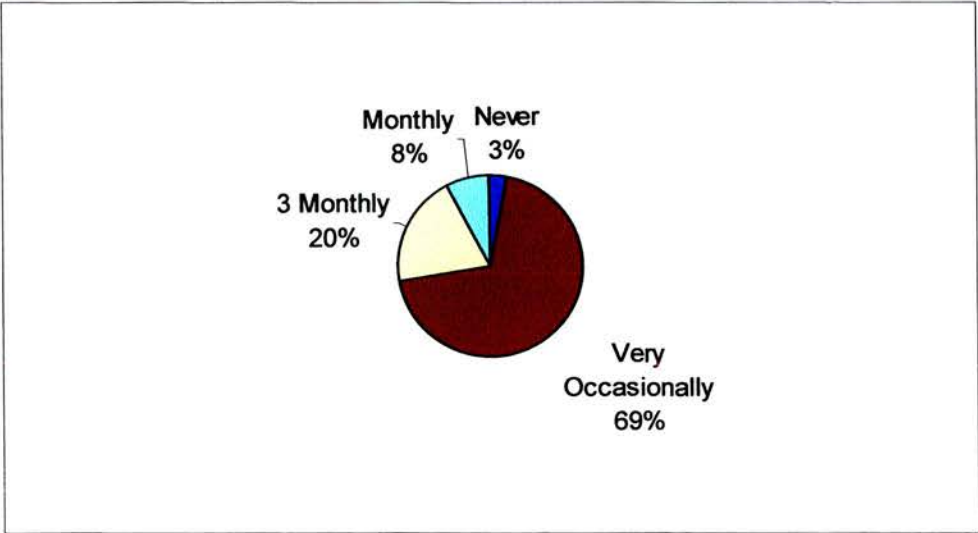


Fig 12c Frequency of contact with GP non-disabled cohort

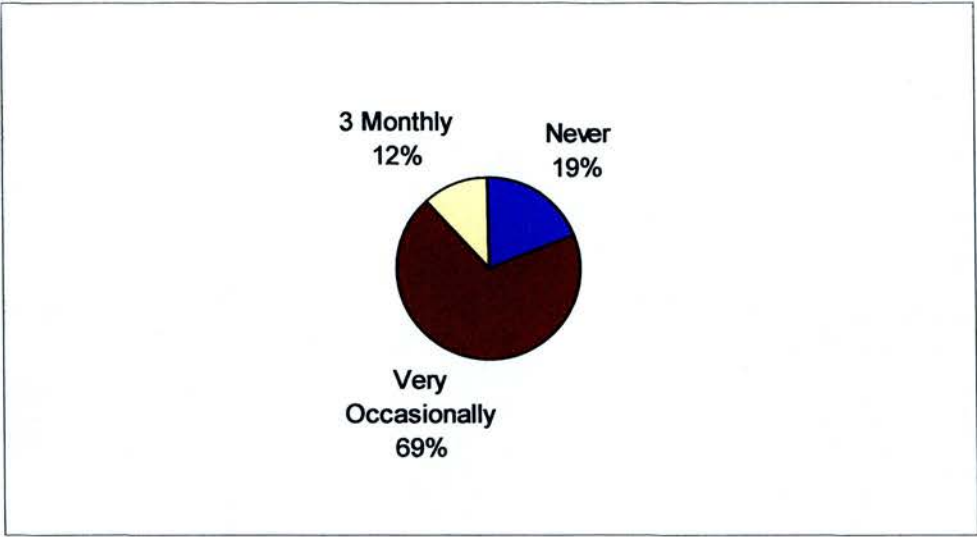


Fig 13a
Frequency of contact with dentist in hospital

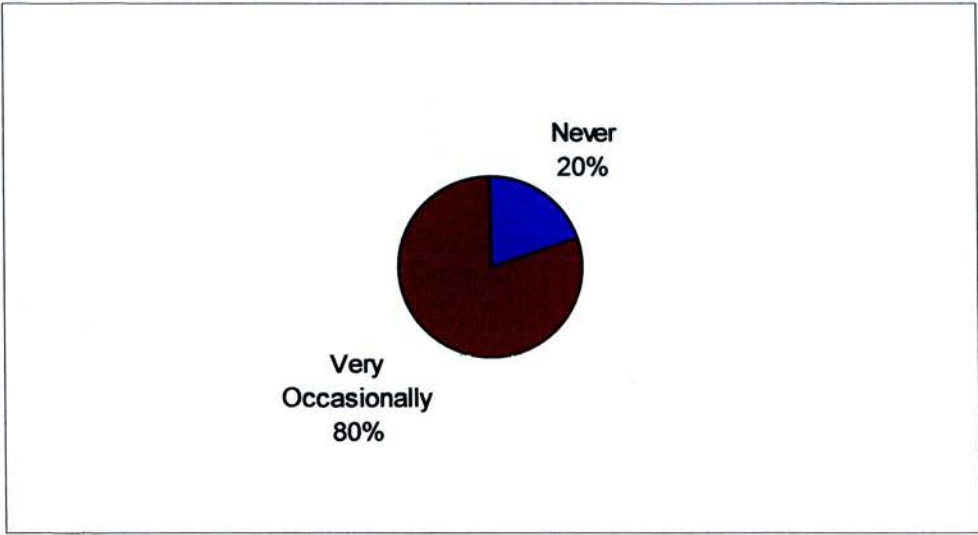


Fig 13b
Frequency of contact with dentist in community

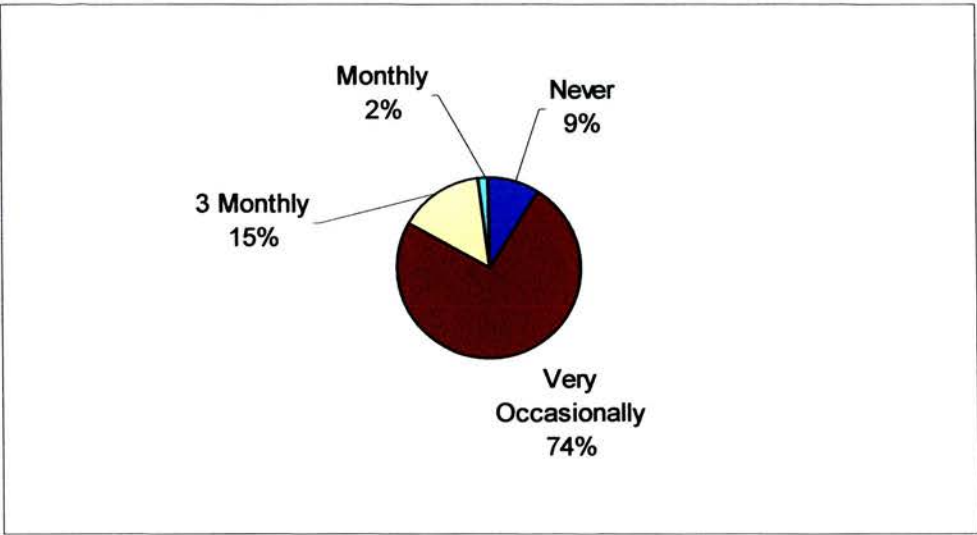


Fig 13c
Frequency of contact with dentist non-disabled cohort

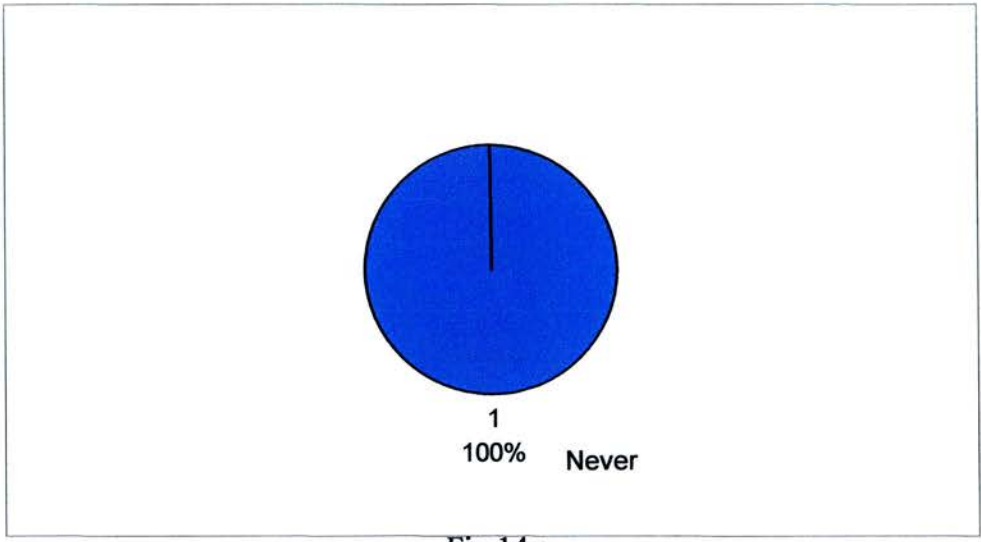


Fig 14a

Frequency of attending general hospital in hospital

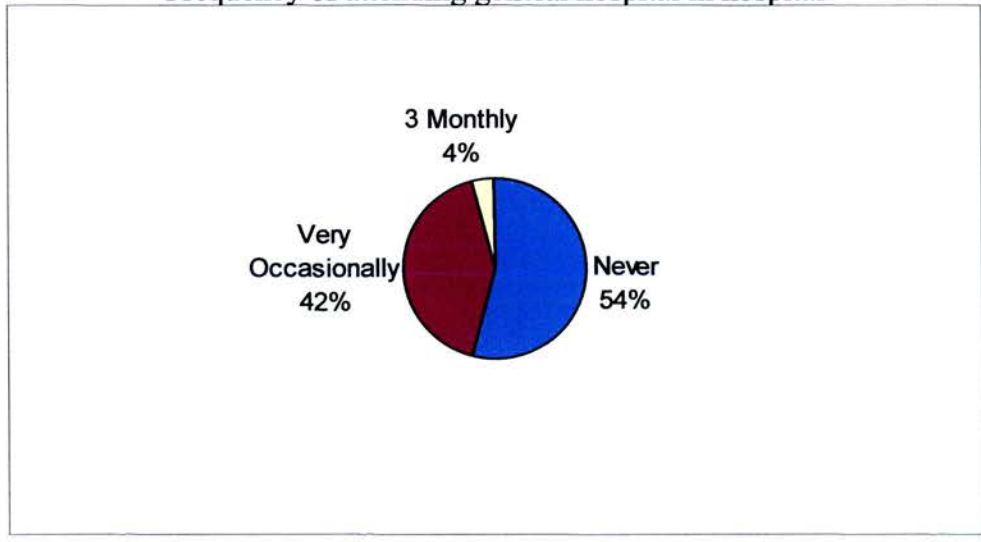


Fig 14b

Frequency of attending general hospital in community

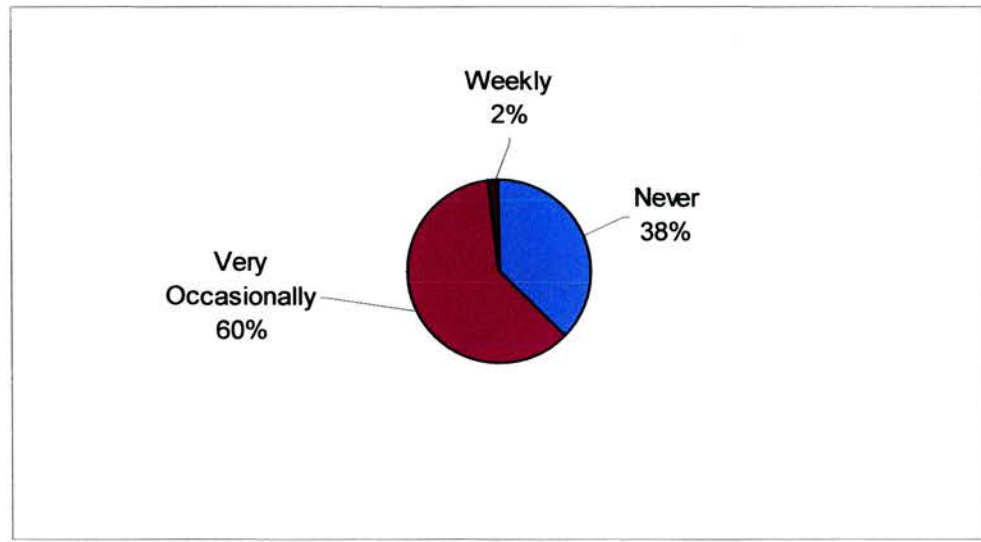


Fig 14c

Frequency of attending general hospital non-disabled cohort

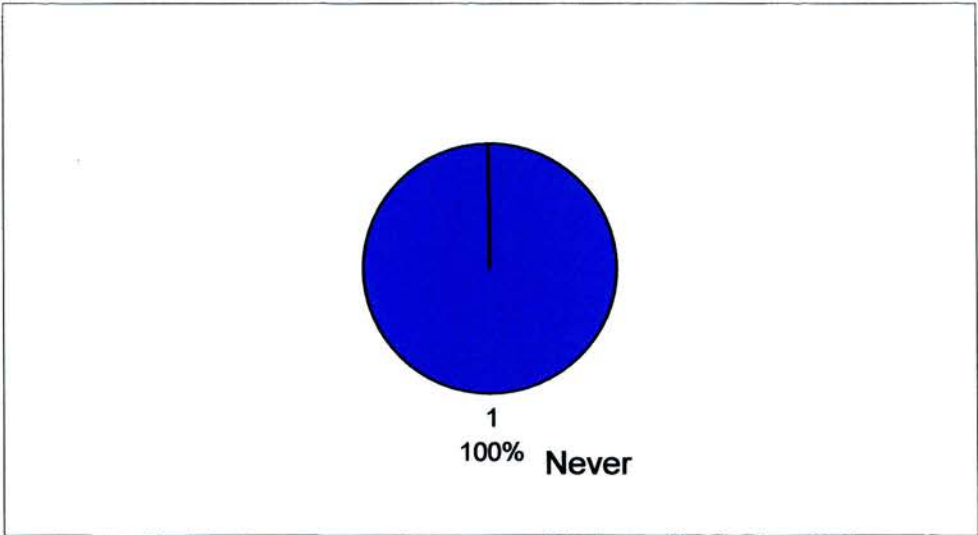


Fig 15a Frequency of contact with the police in hospital

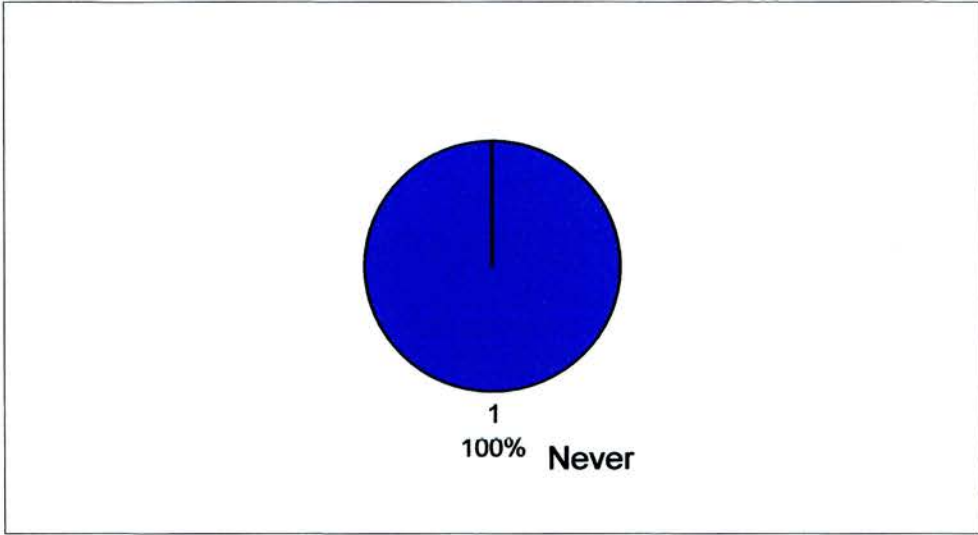


Fig 15b Frequency of contact with police in community

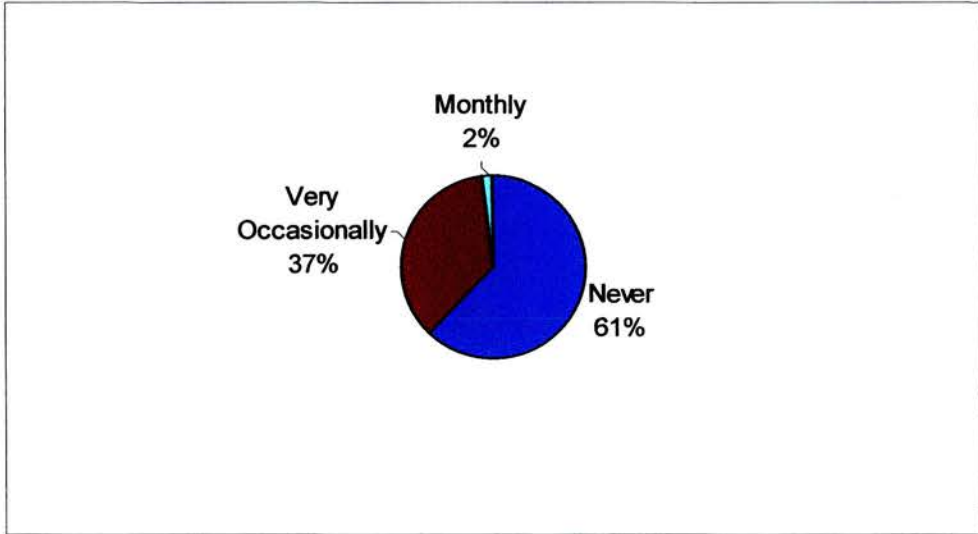


Fig 15c Frequency of contact with the police non-disabled cohort

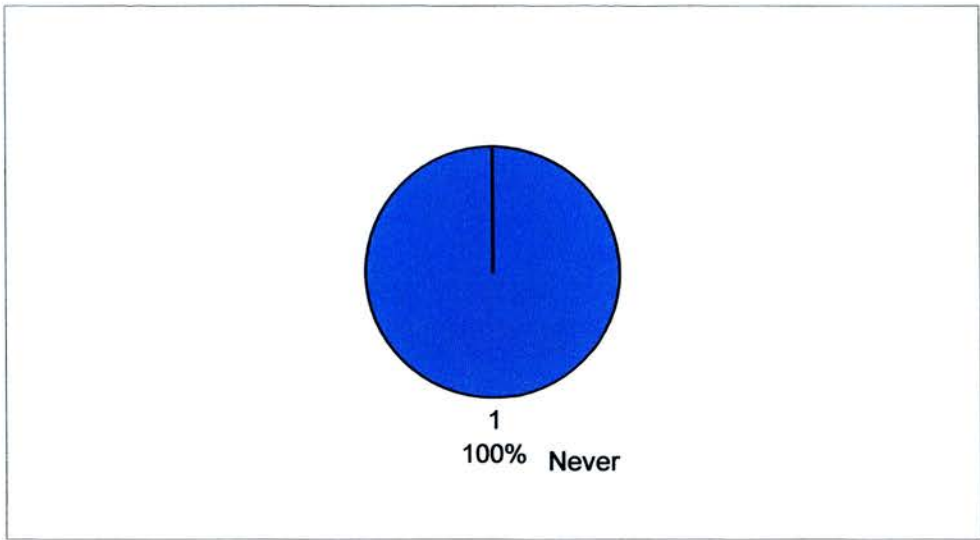


Fig 16a Frequency of use of buses in hospital

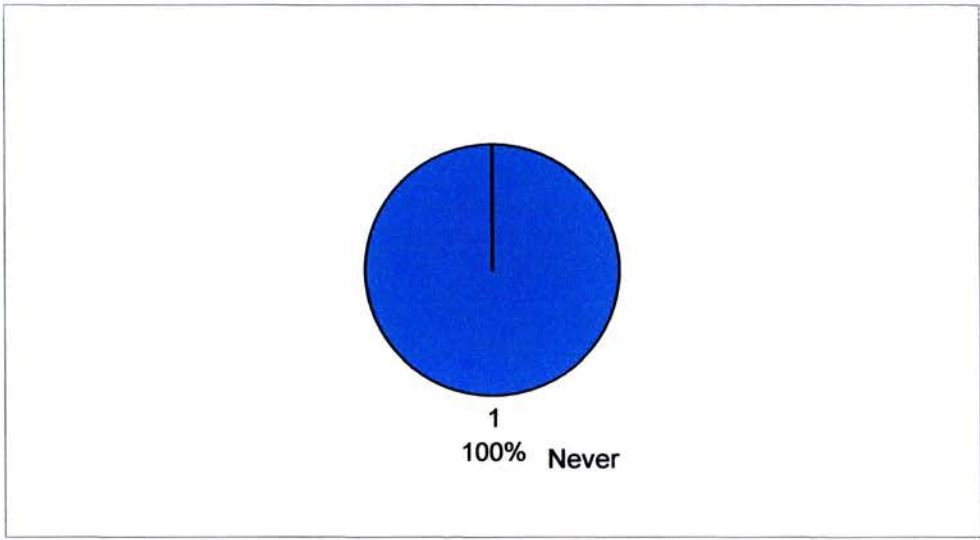


Fig 16b Frequency of use of buses in community

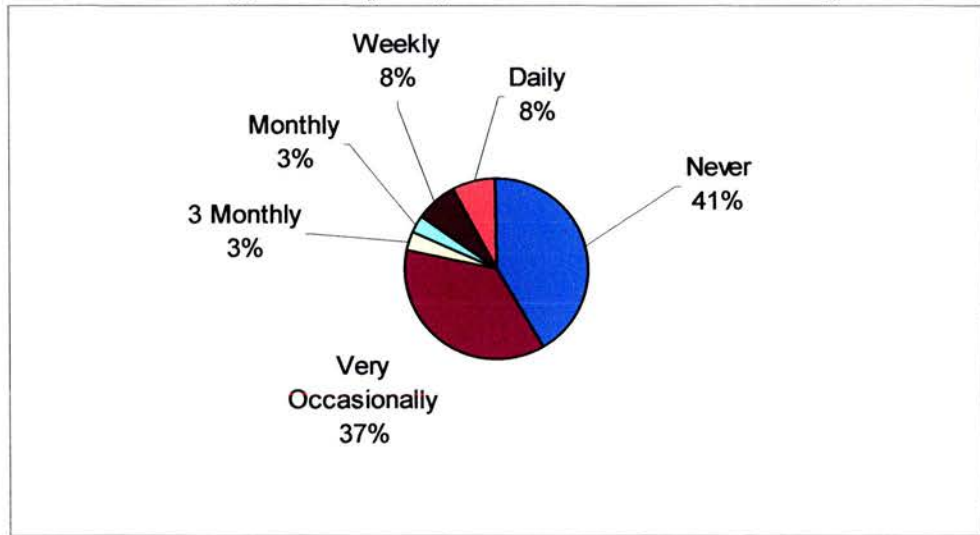


Fig 16c Frequency of use of buses non-disabled cohort

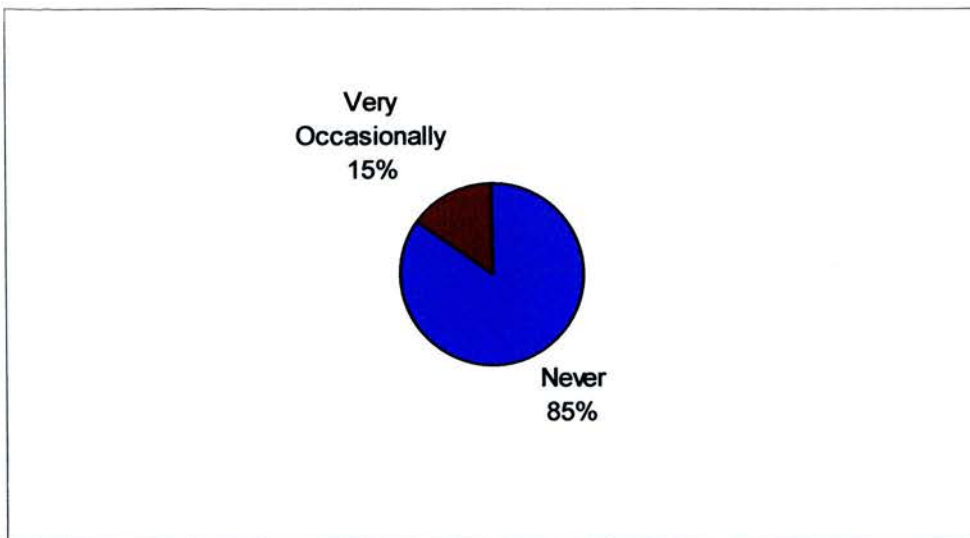


Fig 17a
Frequency of use of trains in hospital

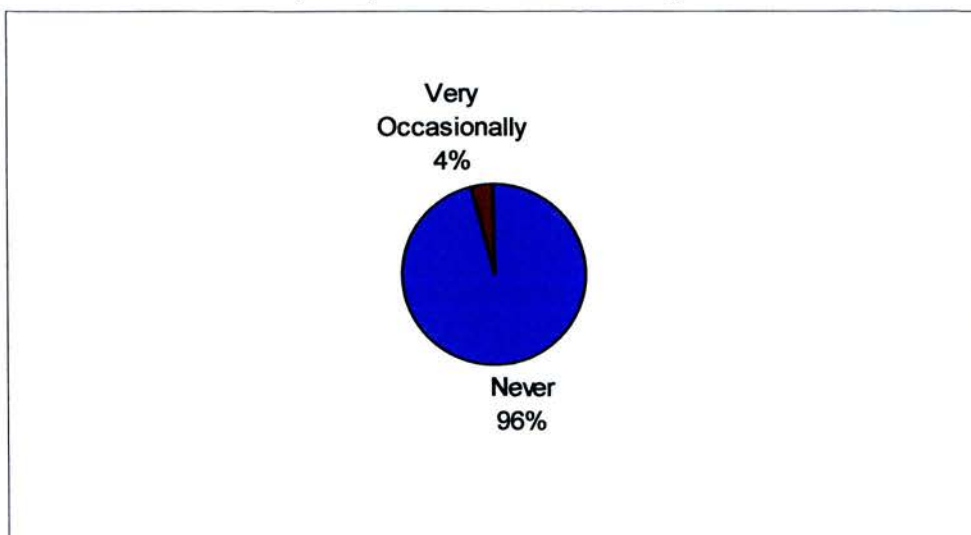


Fig 17b
Frequency of use of trains in community

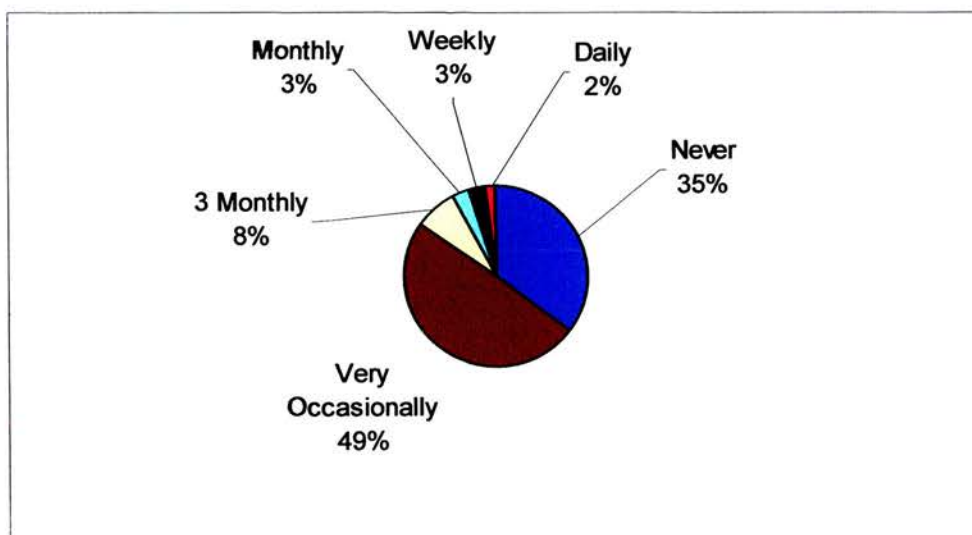


Fig 17c Frequency of use of trains non-disabled cohort

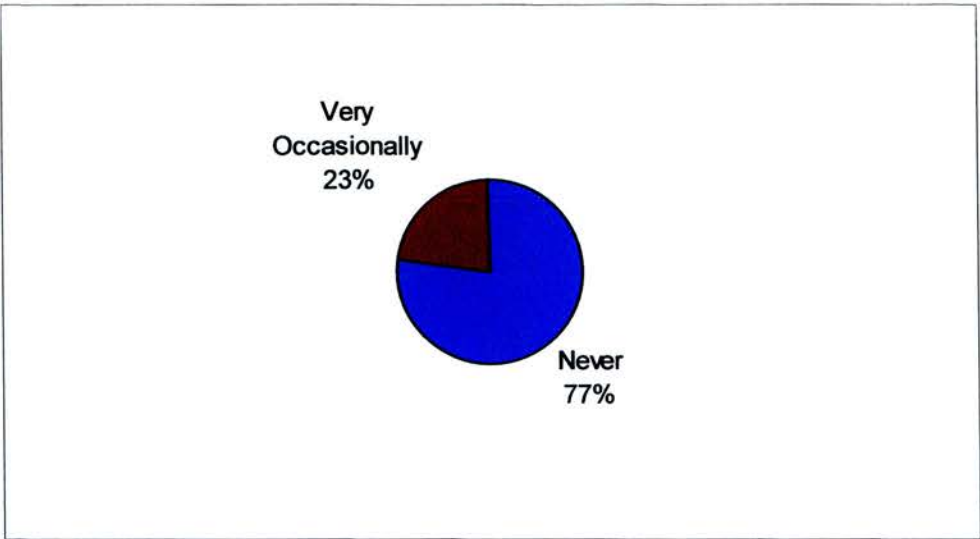


Fig 18a
Frequency of use of ferries in hospital

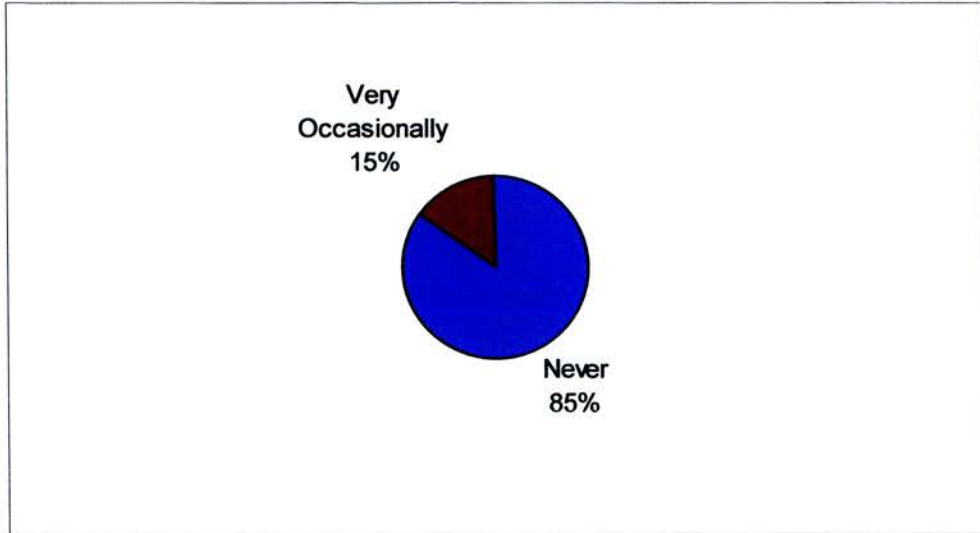


Fig 18b
Frequency of use of ferries in the community

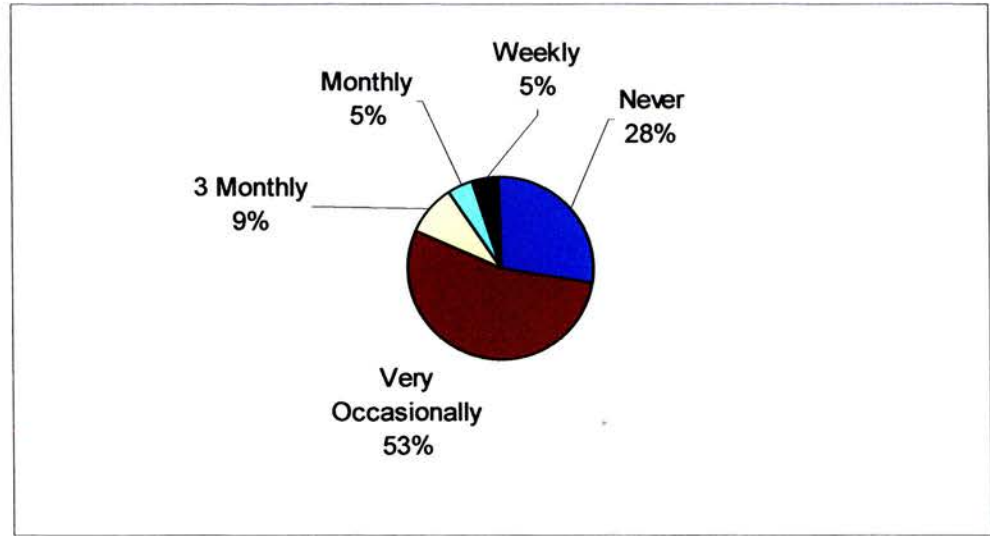


Fig 18c
Frequency of use of ferries non-disabled cohort

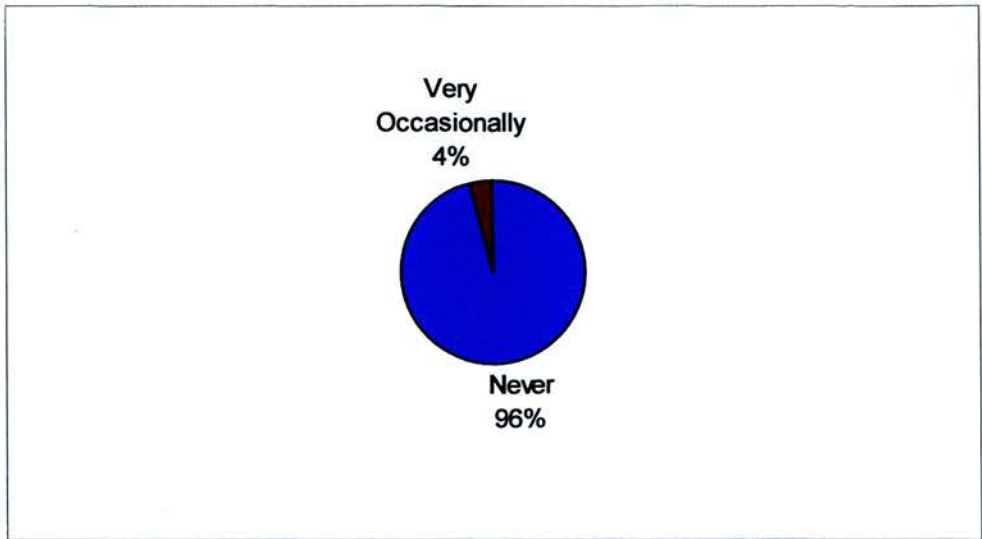


Fig 19a
Frequency of use of air travel in hospital

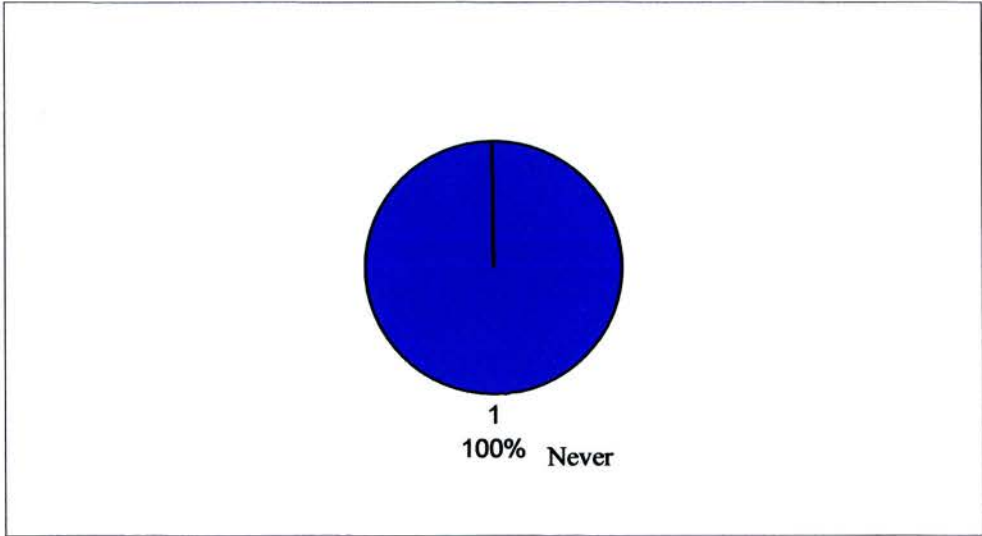


Fig 19b
Frequency of use of air travel in community

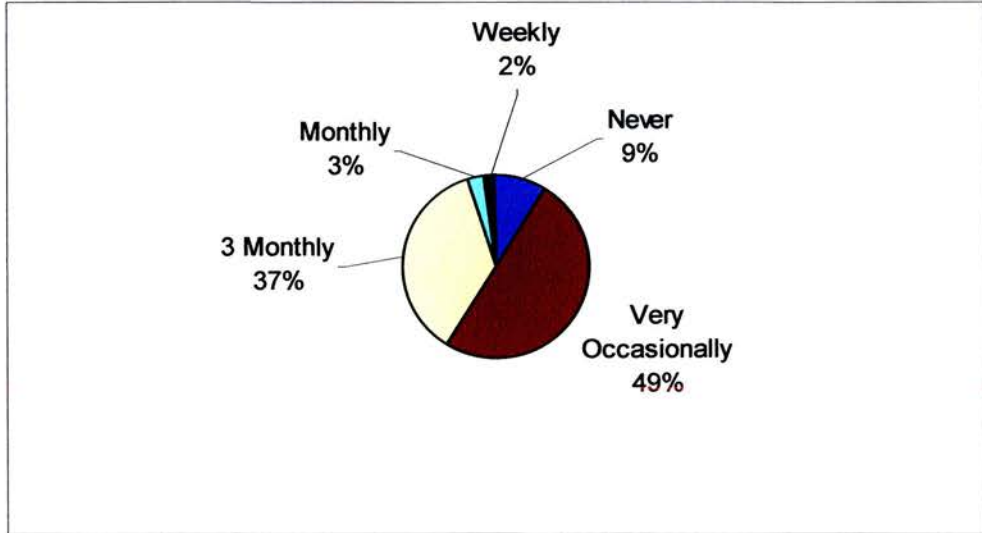


Fig 19c
Frequency of use of air travel non-disabled cohort

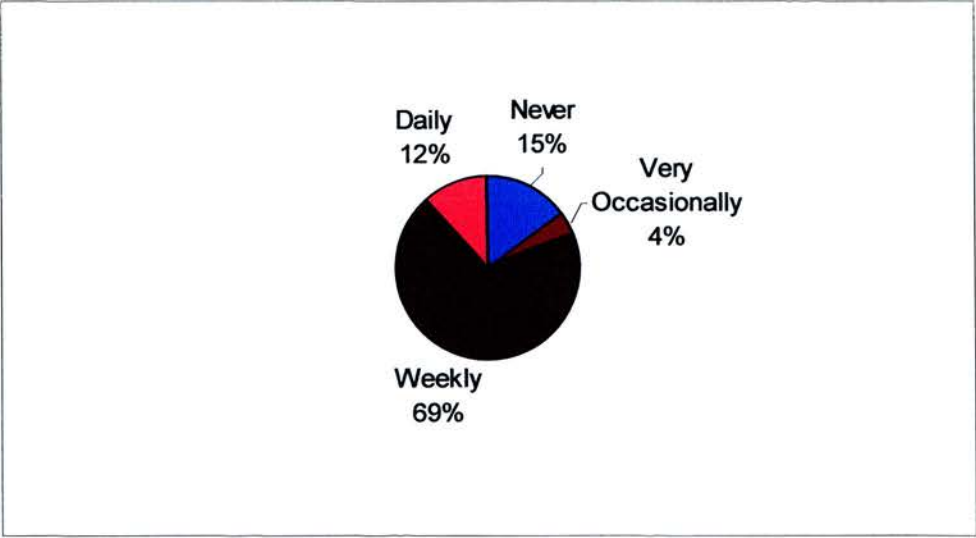


Fig 20a
Frequency of engagement in craft in hospital

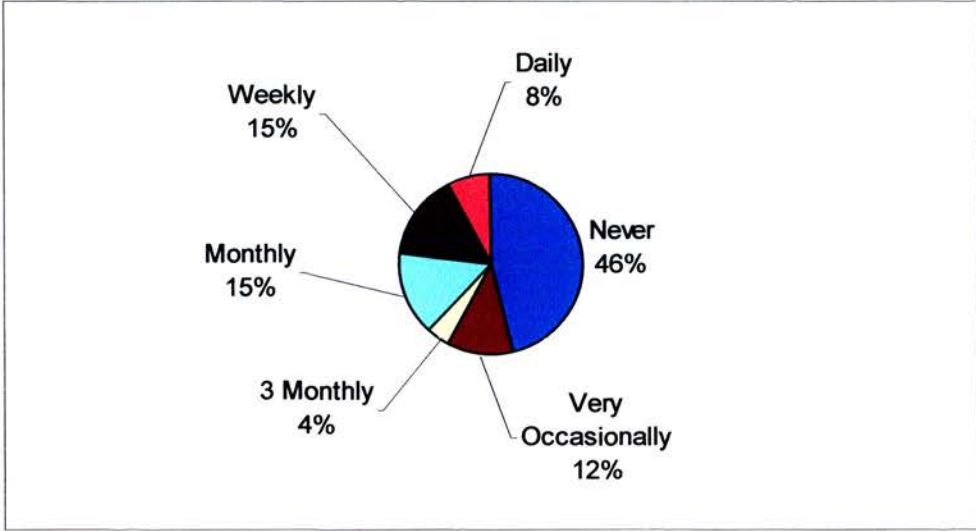


Fig 20b
Frequency of engagement in craft in community

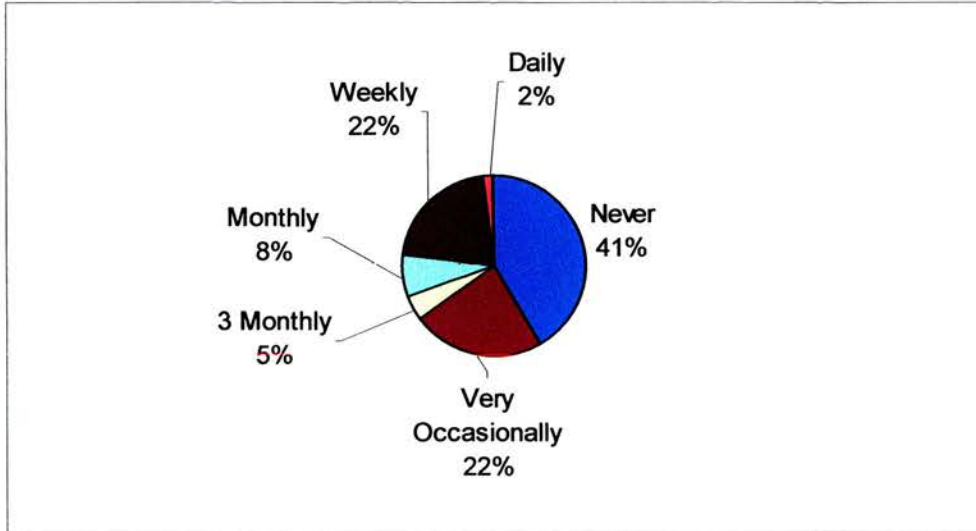


Fig 20c Frequency of engagement in craft non-disabled cohort

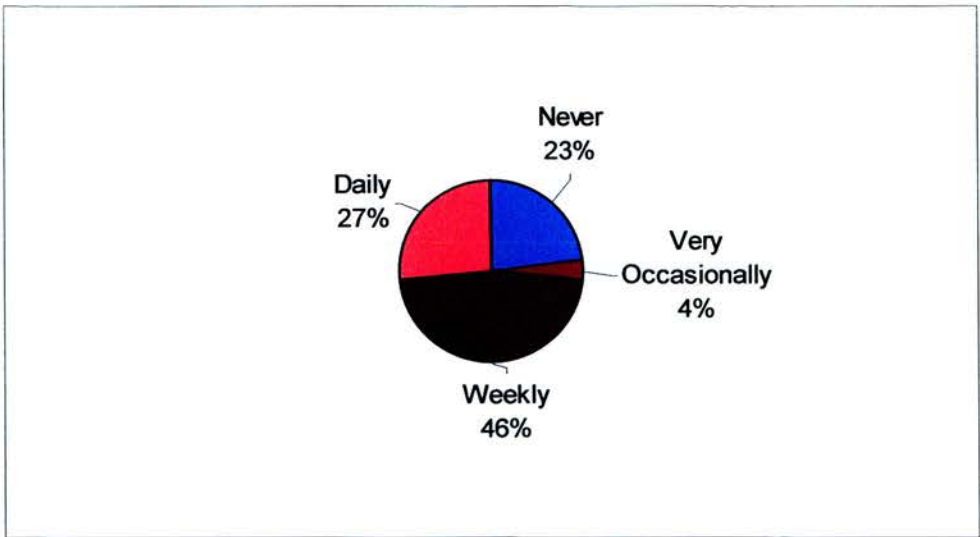


Fig 21a
Frequency of participation in indoor games in hospital

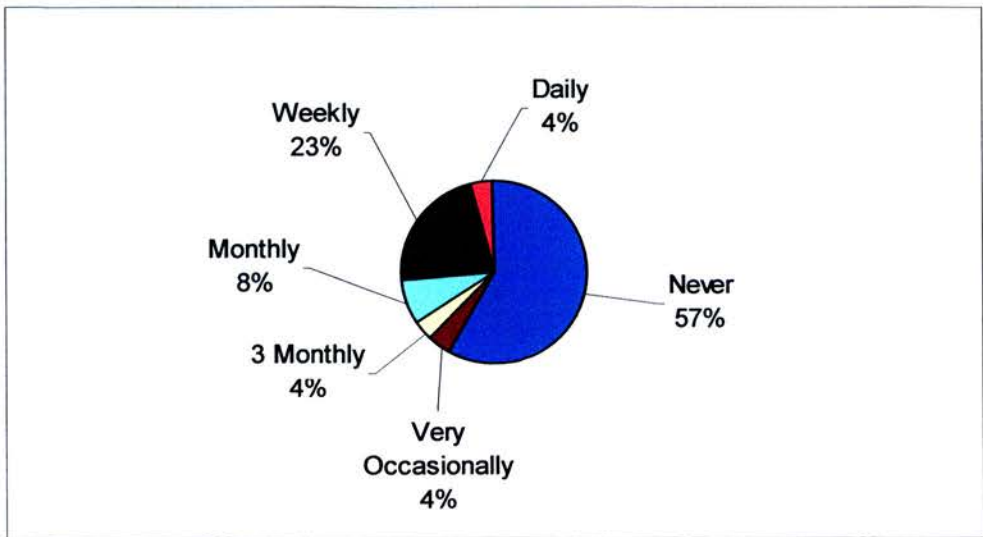


Fig 21b
Frequency of participation in indoor games in the community

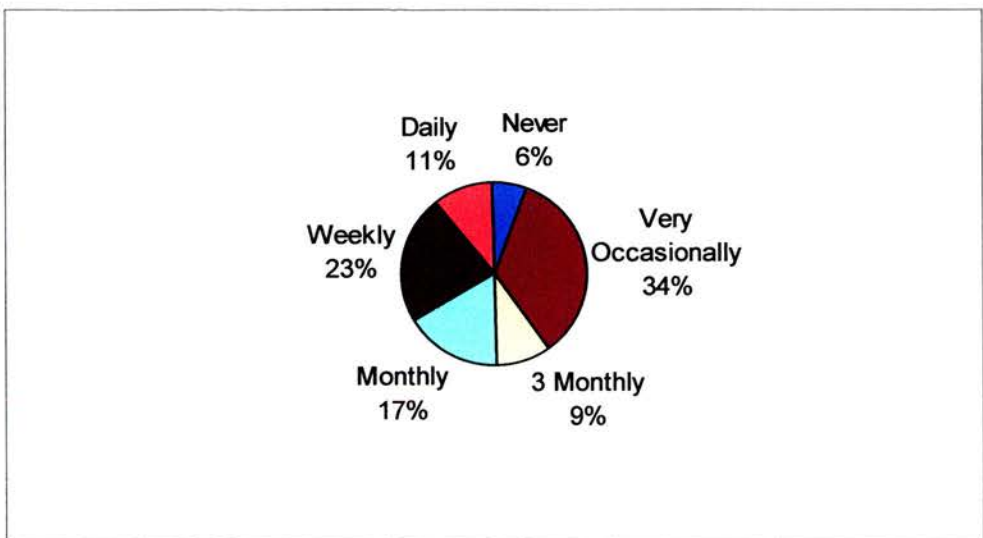


Fig 21c
Frequency of participation in indoor games non-disabled cohort

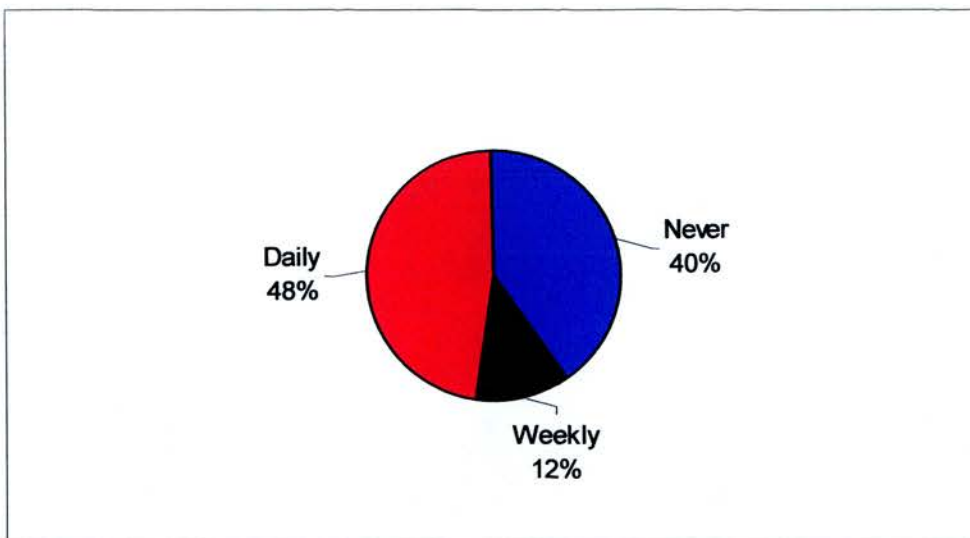


Fig 22a
Frequency of watching TV in hospital

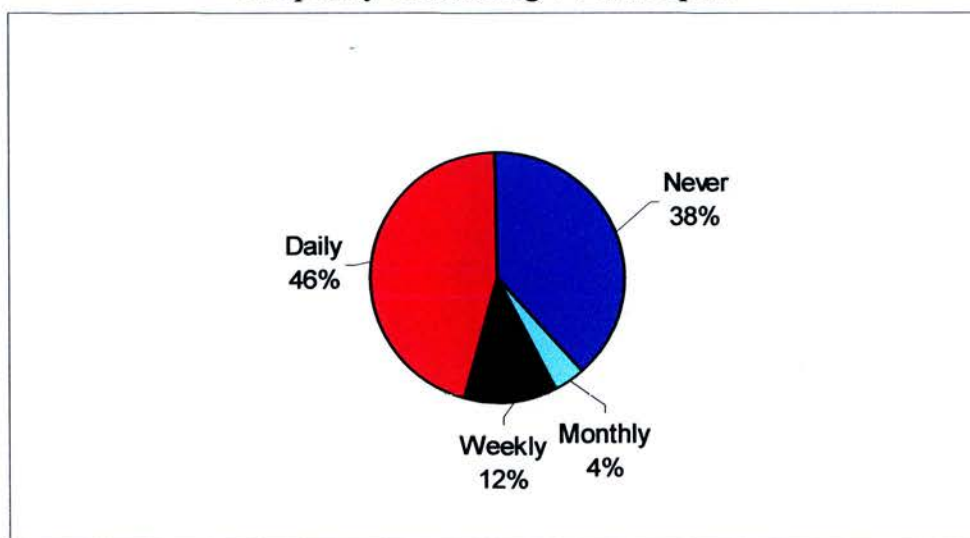


Fig 22b
Frequency of watching TV in the community

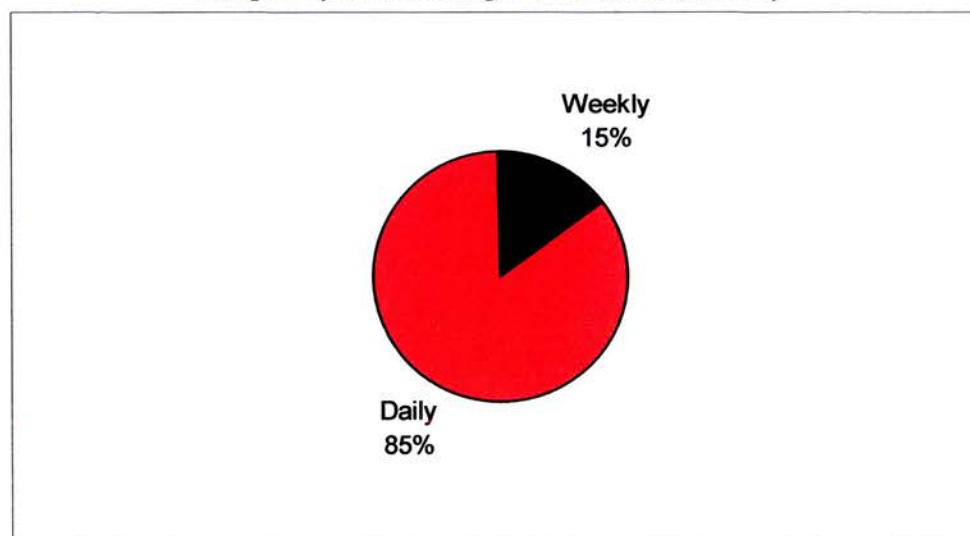


Fig 22c
Frequency of watching TV non-disabled cohort

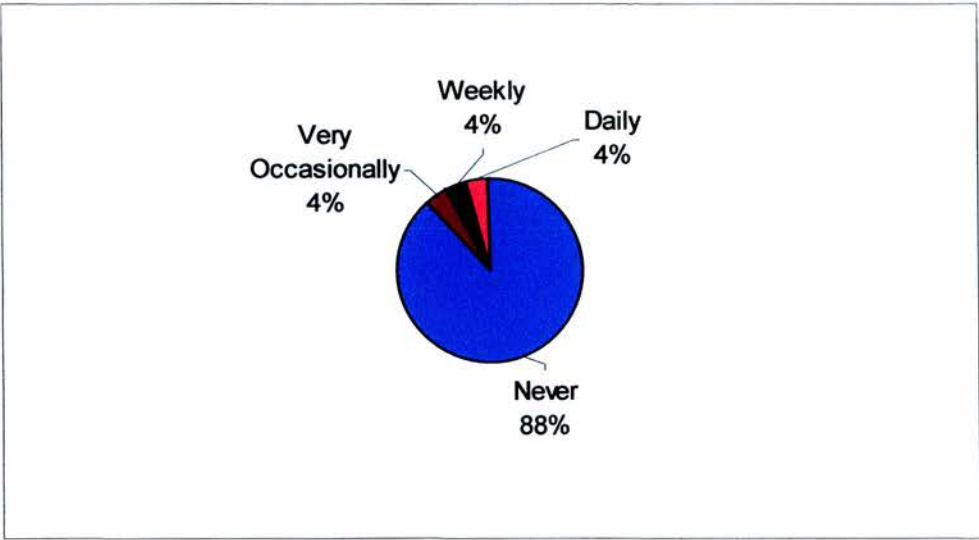


Fig 23a
Frequency of watching videos in hospital

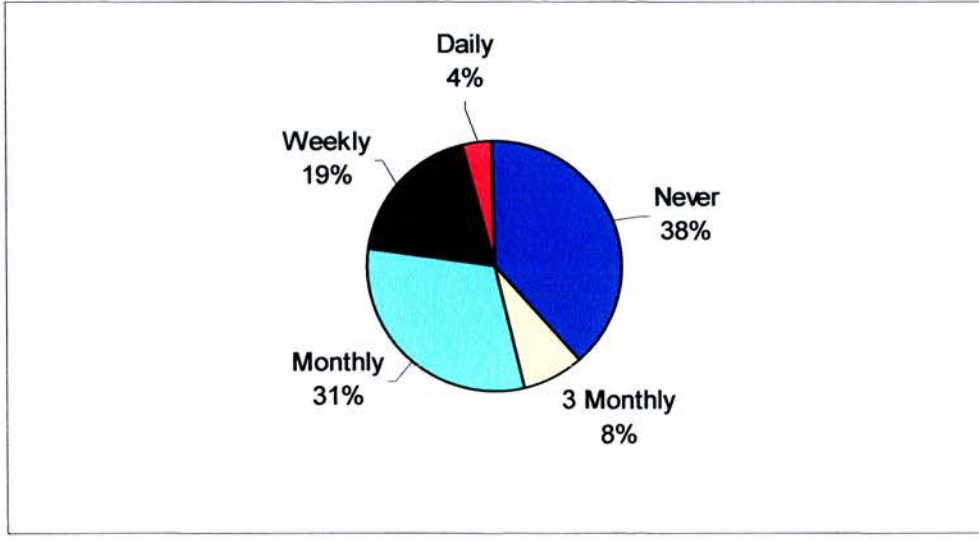


Fig 23b
Frequency of watching videos in the community

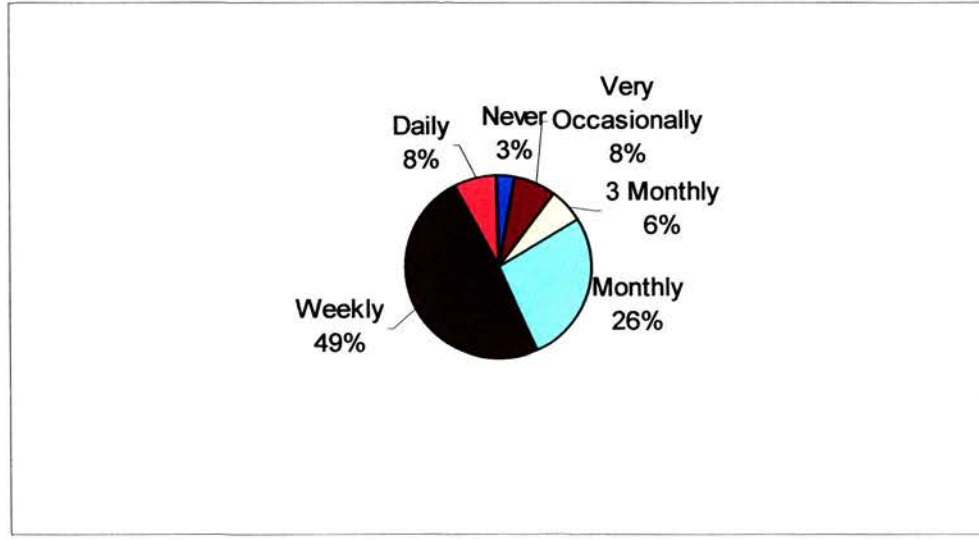


Fig 23c
Frequency of watching videos non-disabled cohort

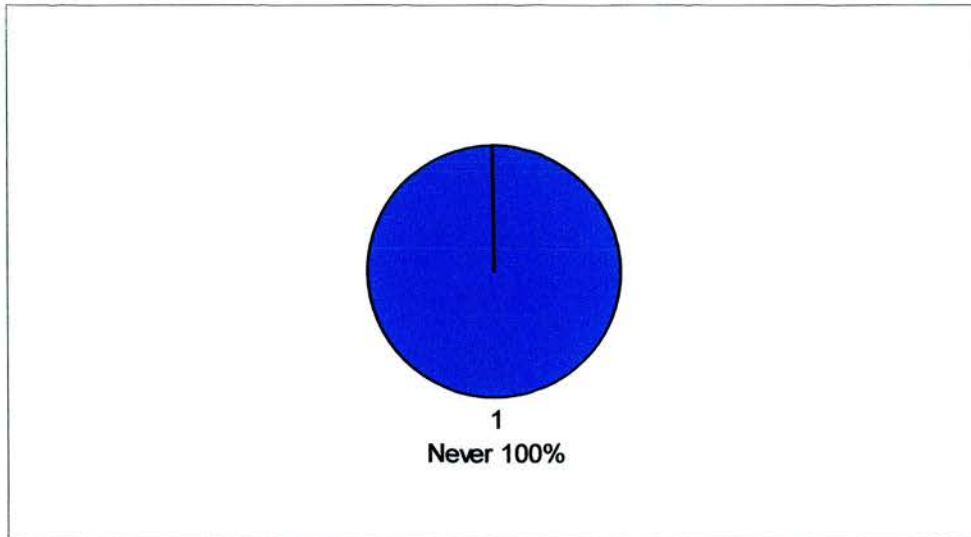


Fig 24a Frequency of caring for pets in hospital

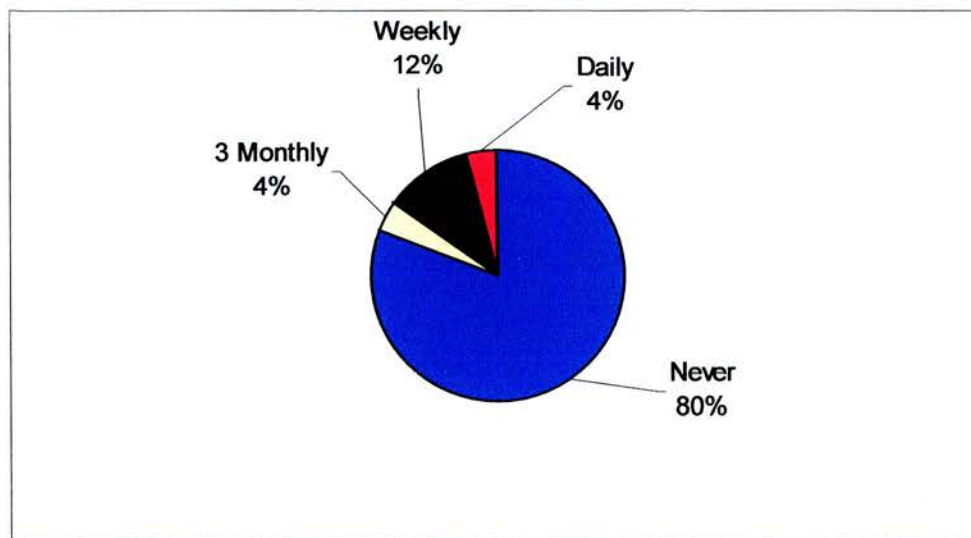


Fig 24b
Frequency of caring for pets in Community

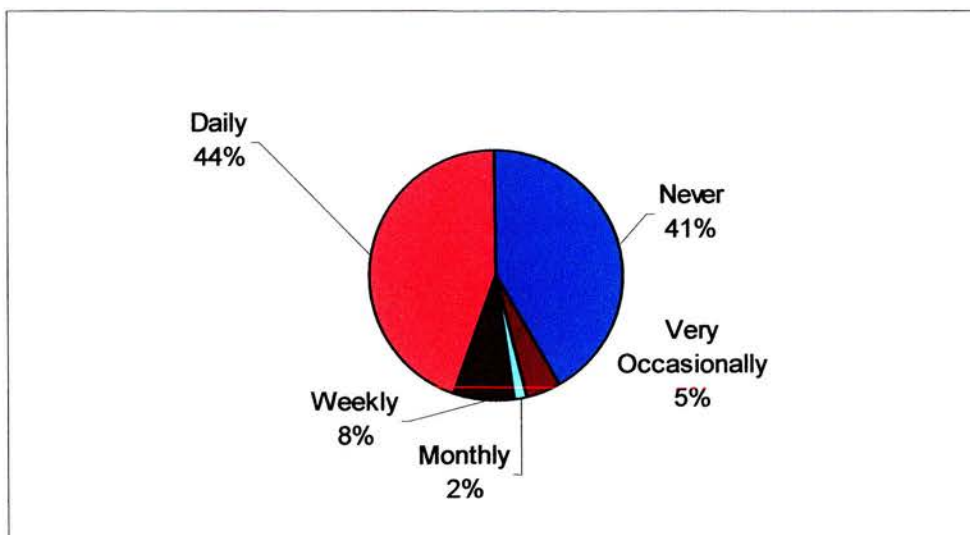


Fig 24c Frequency of caring for pets non-disabled cohort

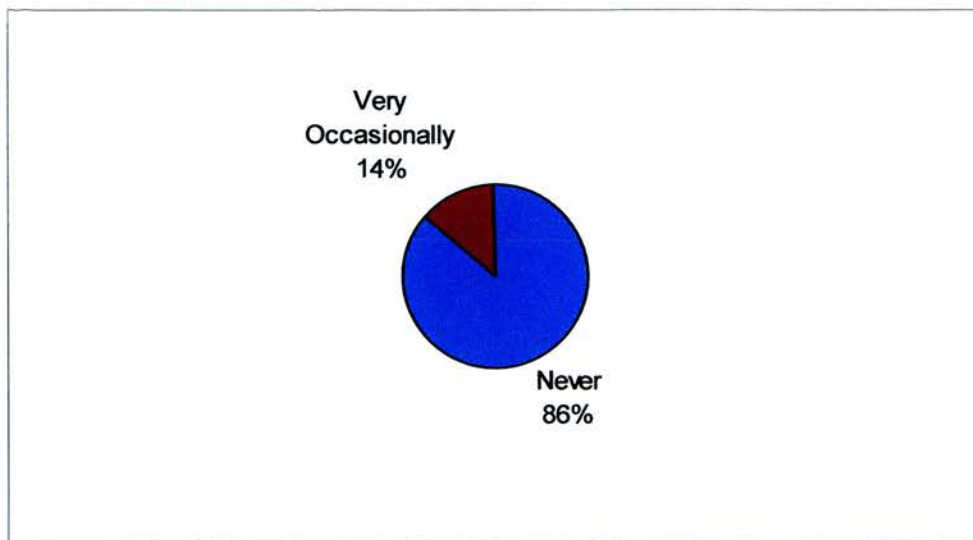


Fig 25a Frequency of participating in sport whilst in hospital

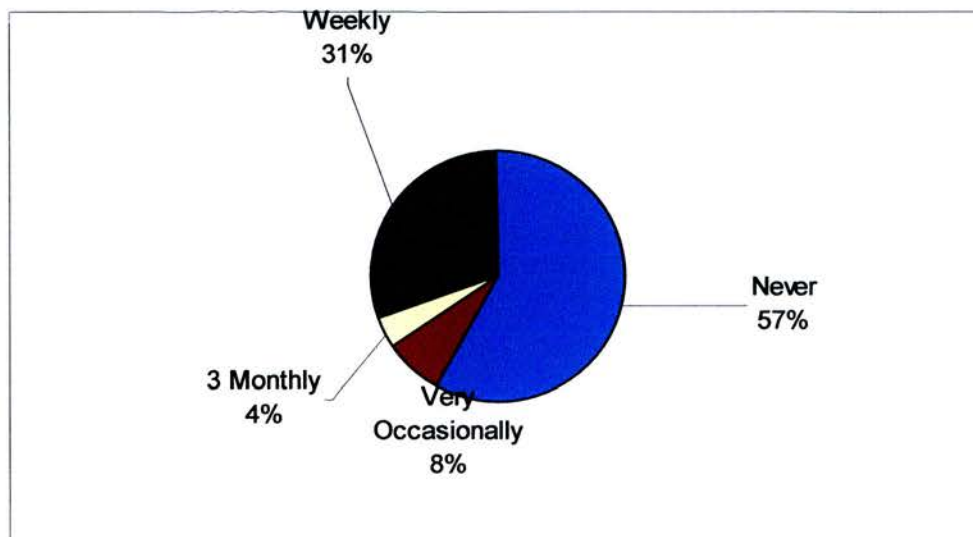


Fig 25b Frequency of participation in sport in the community

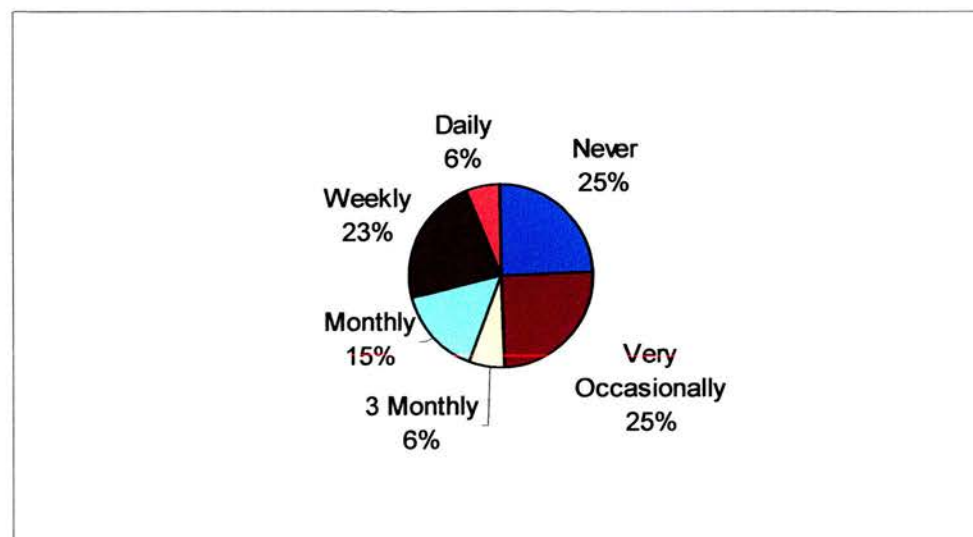


Fig 25c Frequency of participation in sport non-disabled cohort

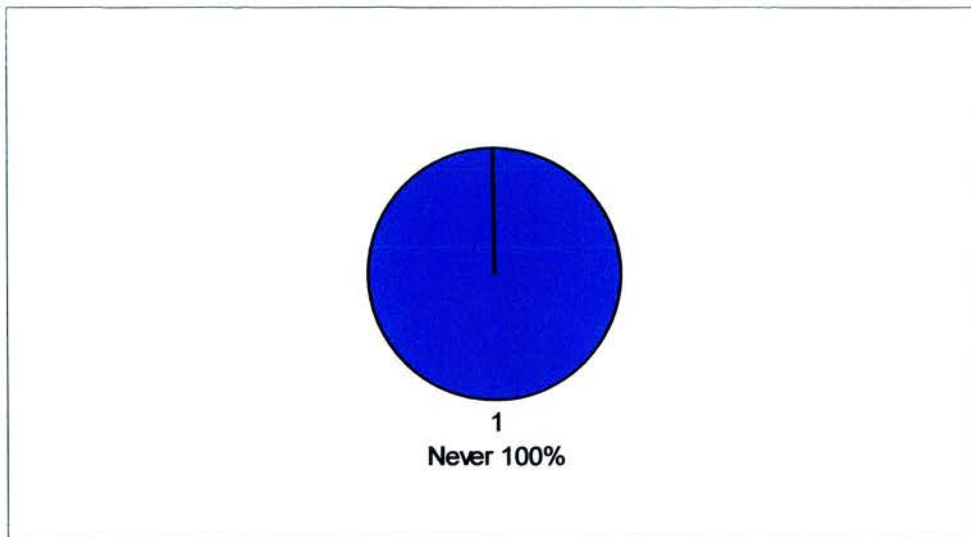


Fig 26a
Frequency of spectating sport in hospital

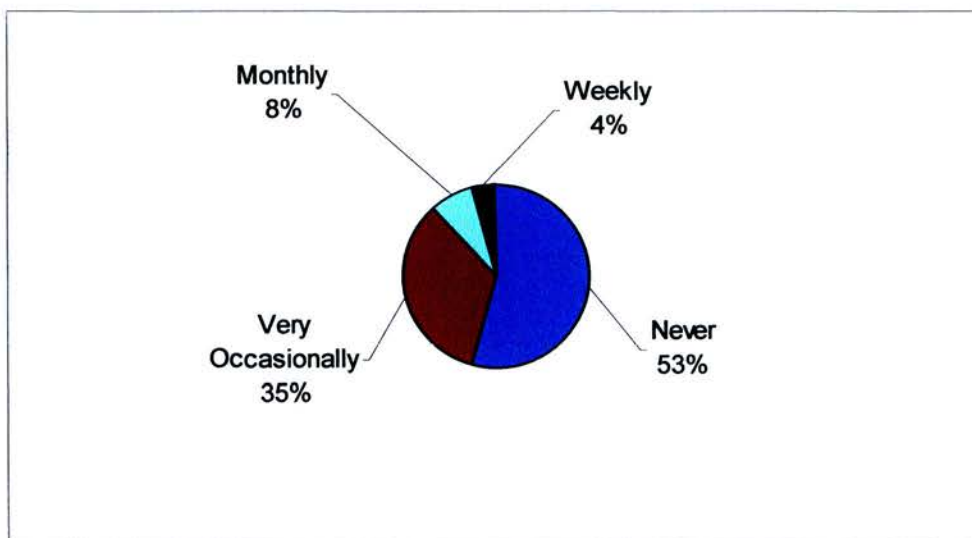


Fig 26b
Frequency of spectating sport in the community

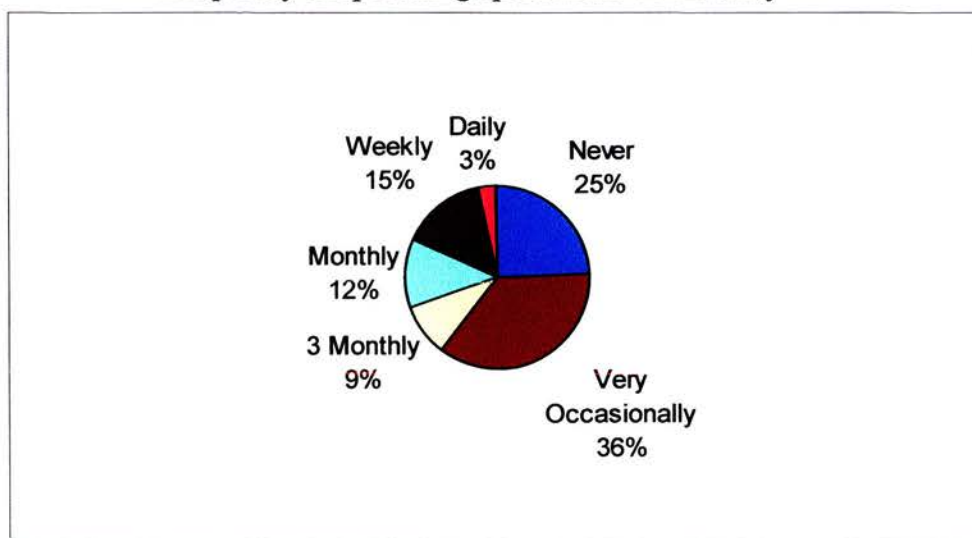


Fig 26c Frequency of spectating sport non-disabled cohort

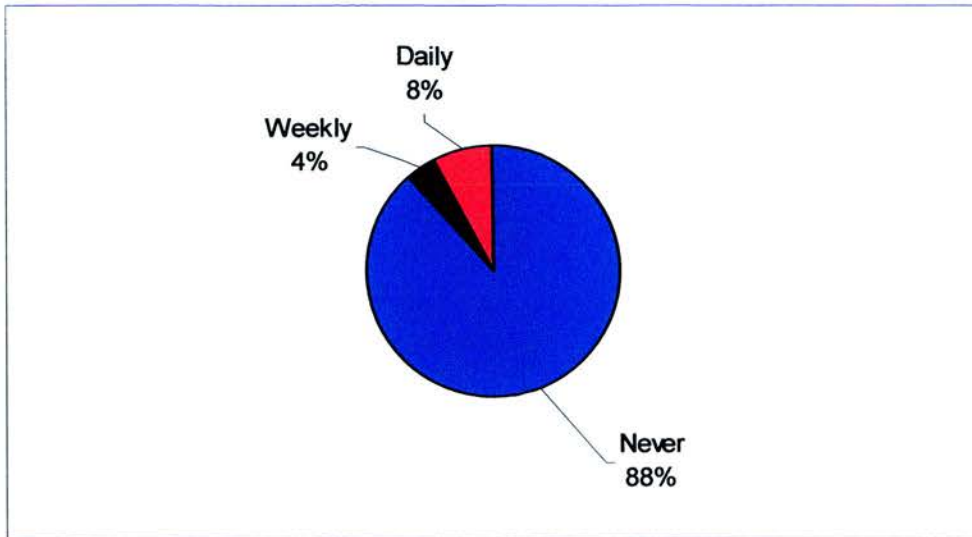


Fig 27a

Frequency of participation in exercise classes in hospital

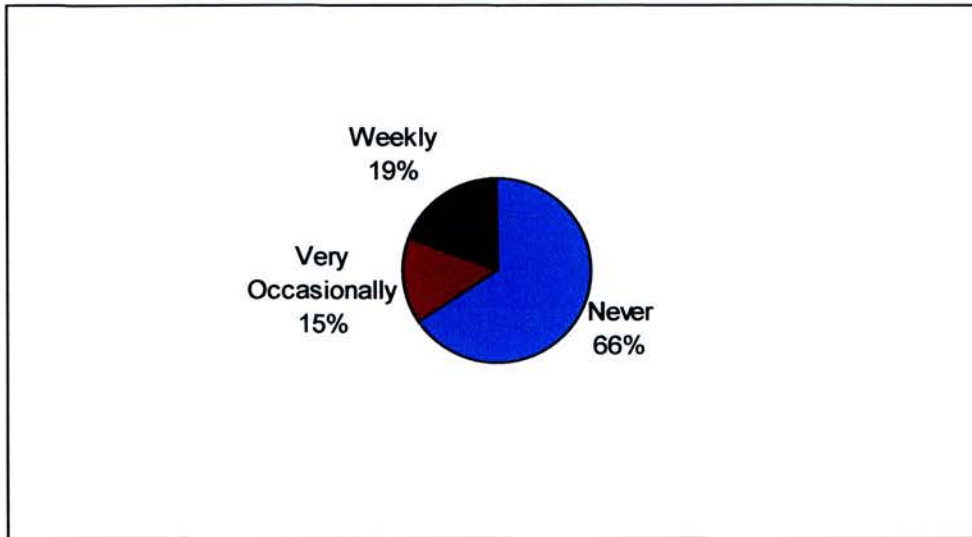


Fig 27b Frequency of participation in exercise classes in the community

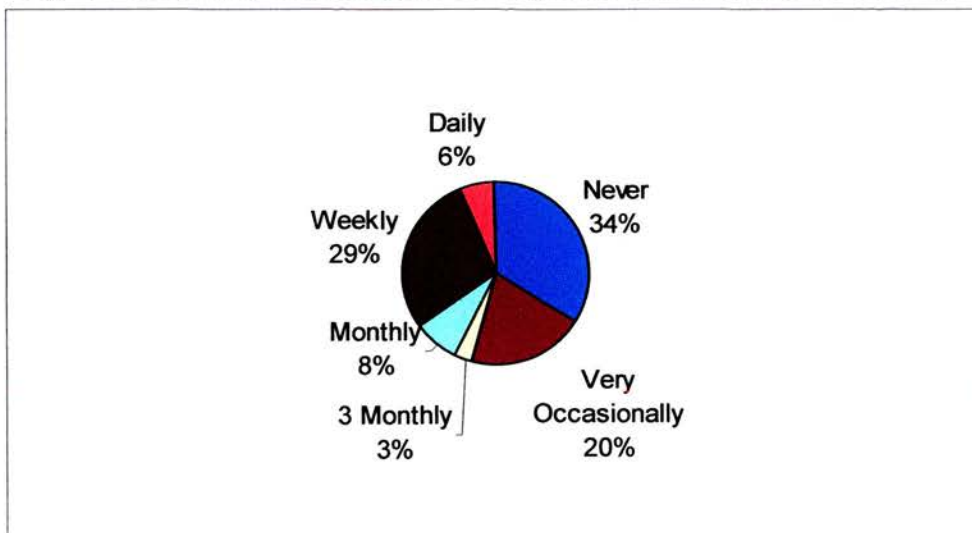


Fig 27c Frequency of participation in exercise classes non-disabled cohort

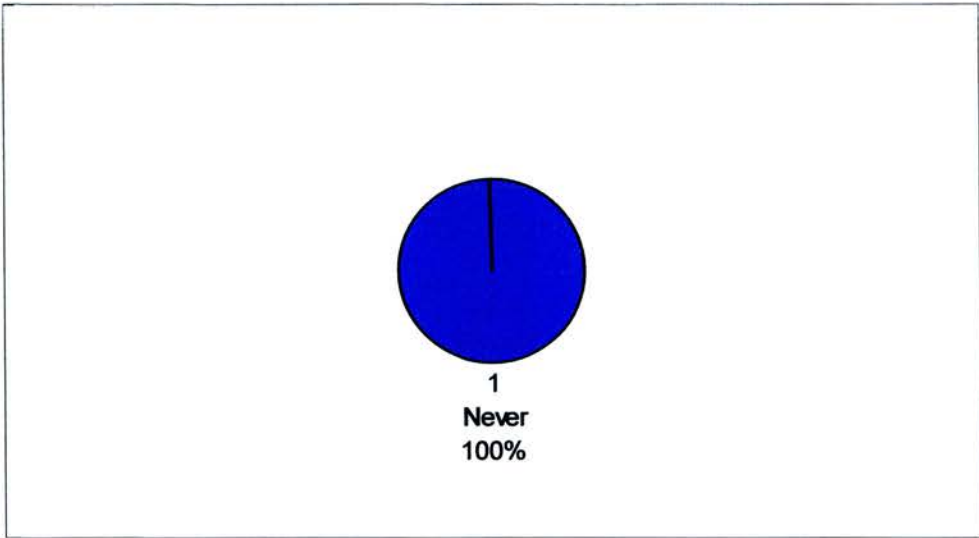


Fig 28a
Frequency of cycling in hospital

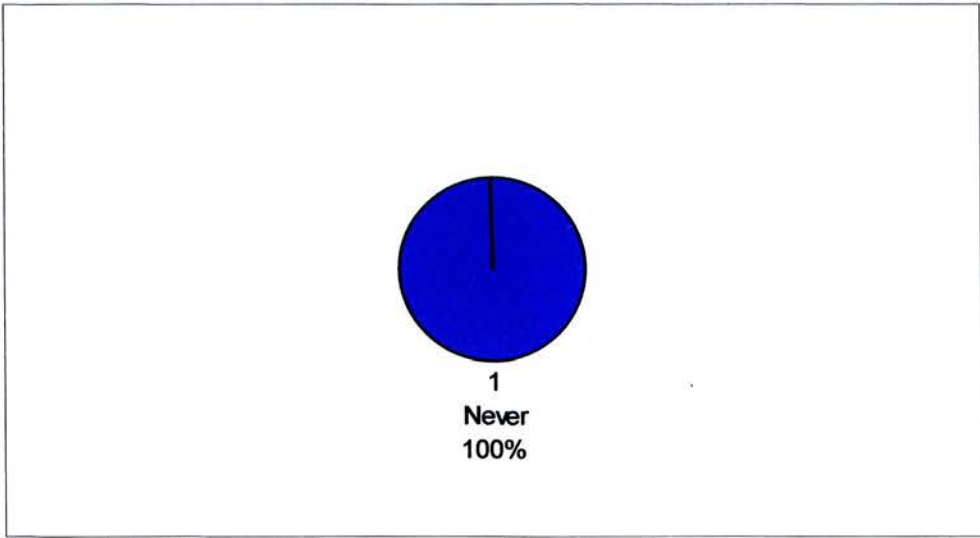


Fig 28b
Frequency of cycling in the community

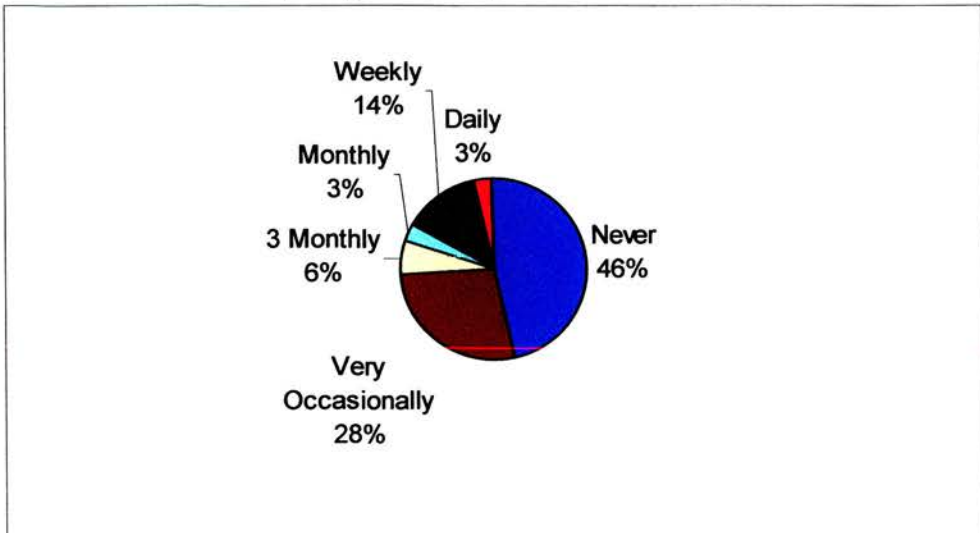


Fig28c Frequency of cycling non-disabled cohort

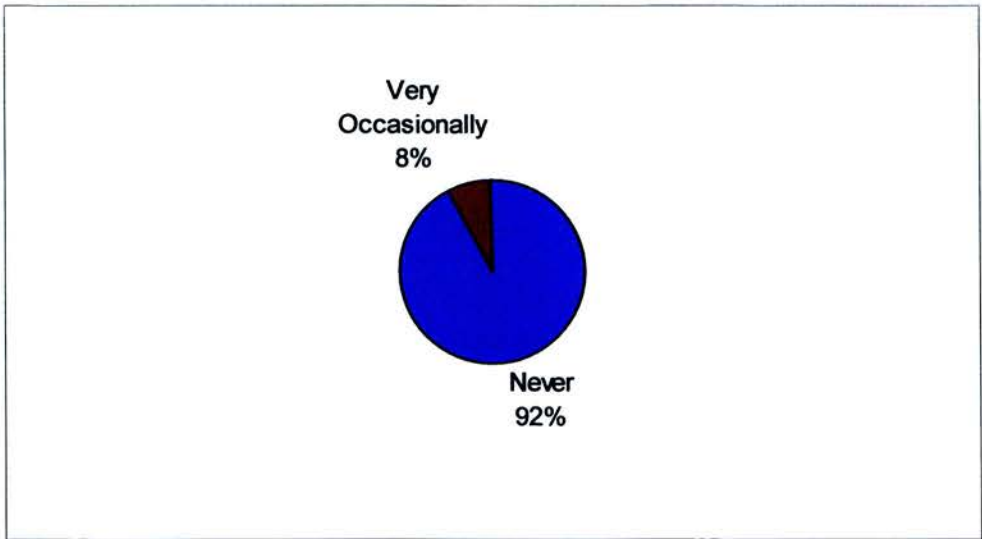


Fig 29a
Frequency of attending the cinema in hospital

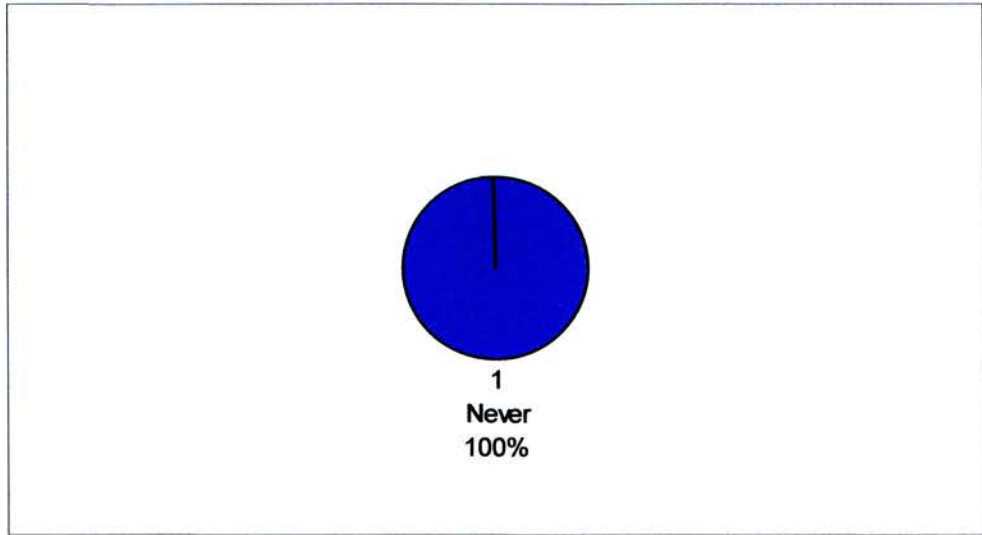


Fig 29b
Frequency of attending the cinema in the community

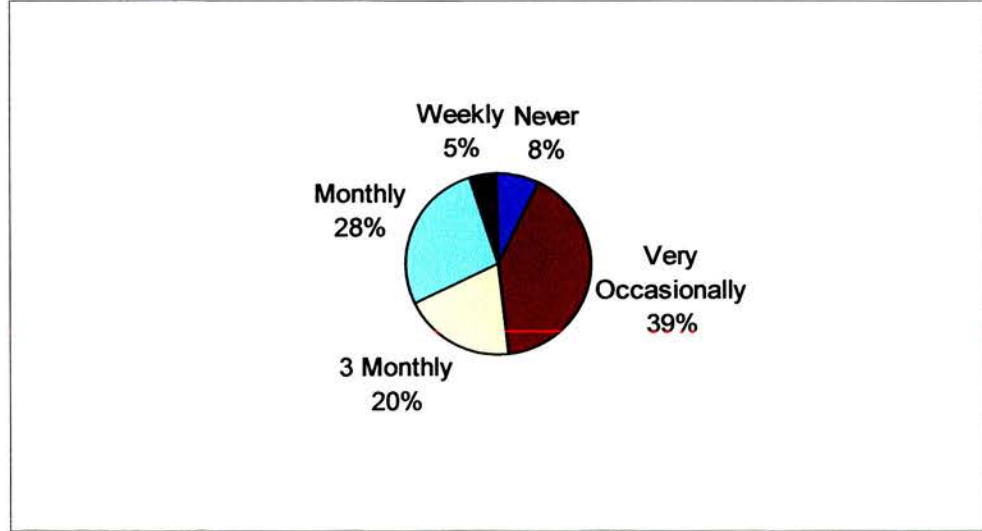


Fig 29c Frequency of attending the cinema non-disabled cohort

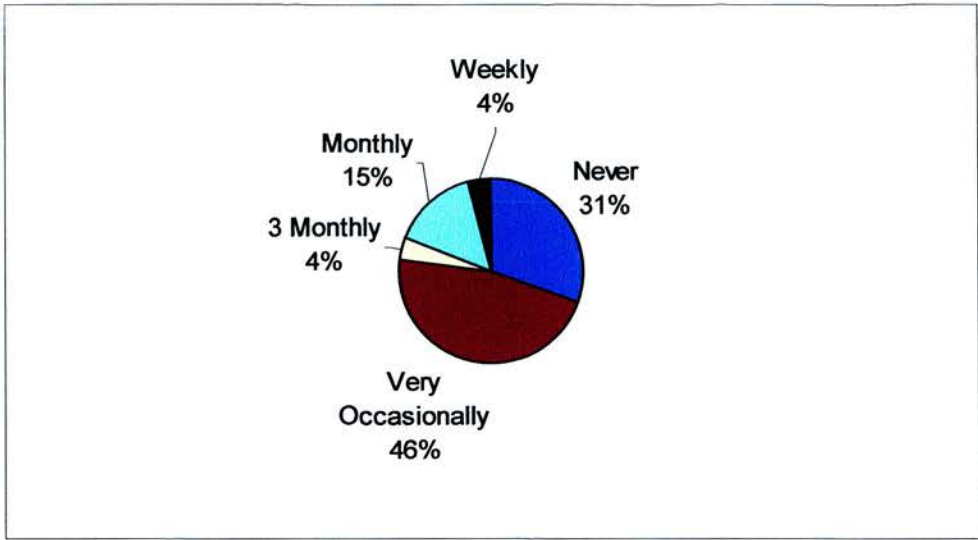


Fig 30a
Frequency of visiting the park in hospital

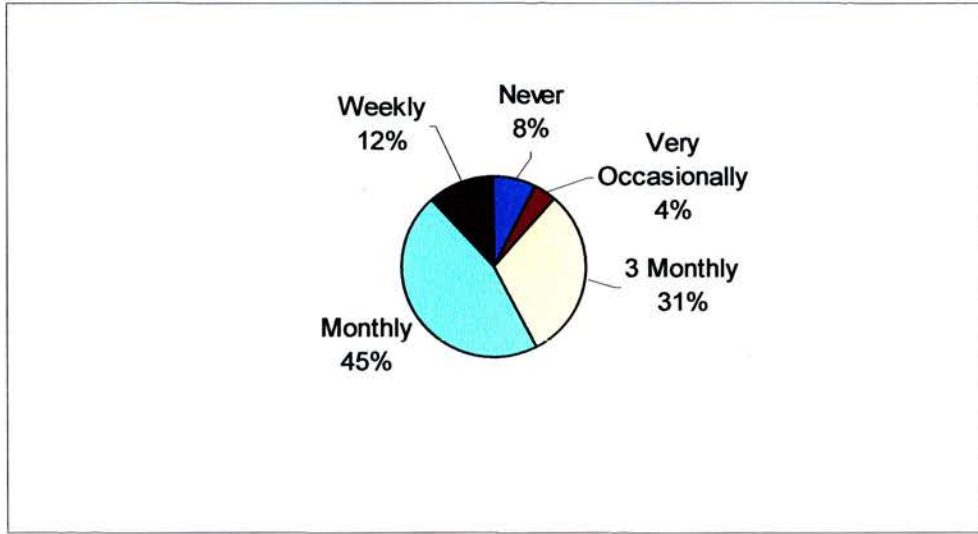


Fig 30b
Frequency of visiting the park in community

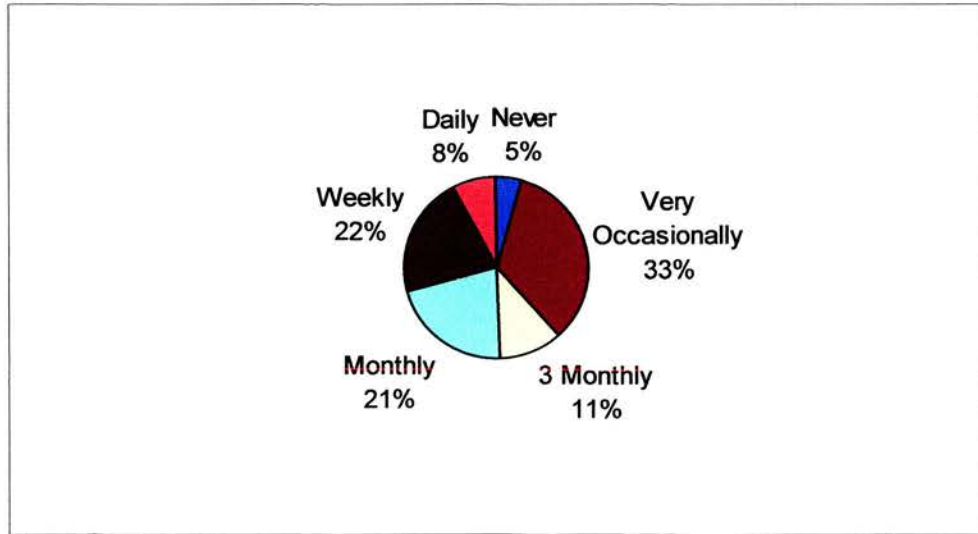


Fig 30c Frequency of visiting the park non-disabled cohort

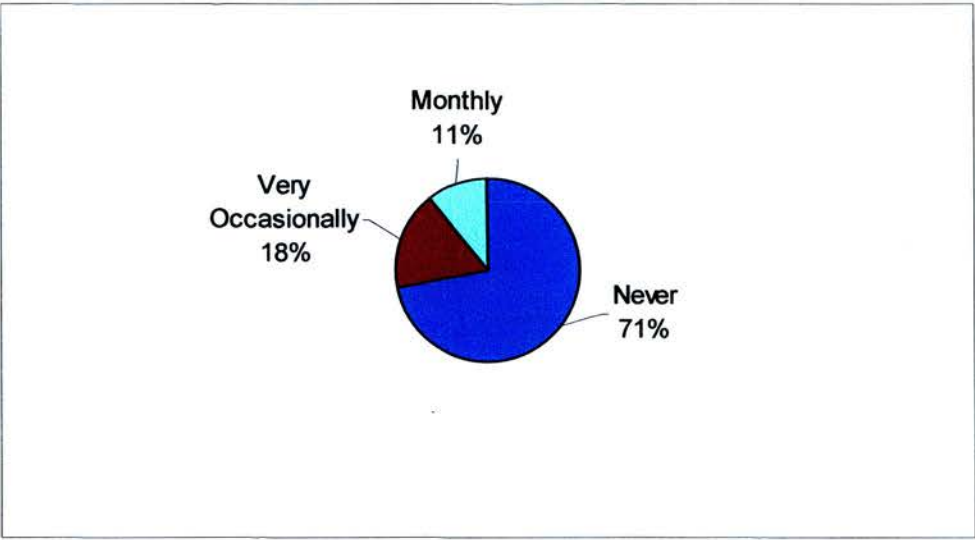


Fig 31a
Frequency of visiting the beach in hospital

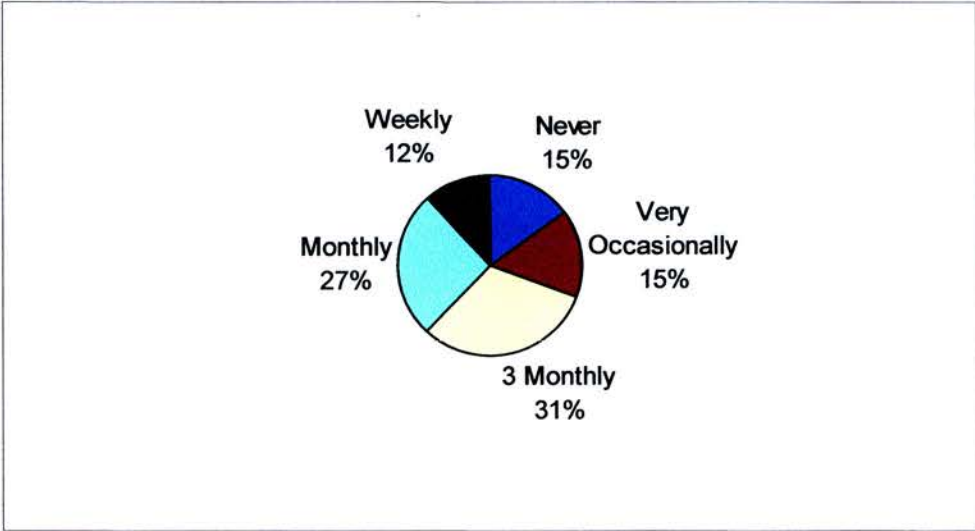


Fig 31b Frequency of visiting the beach in community

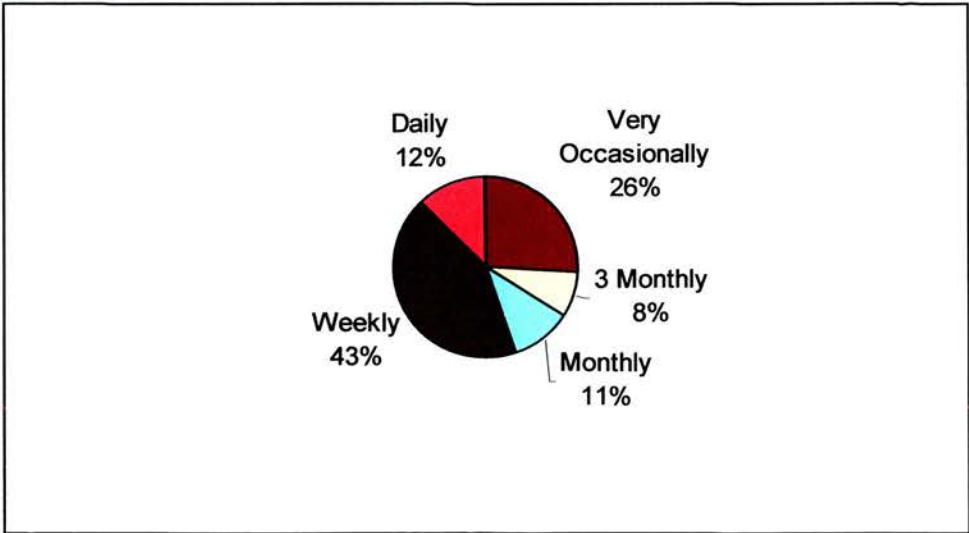


Fig 31c Frequency of visiting the beach non-disabled cohort

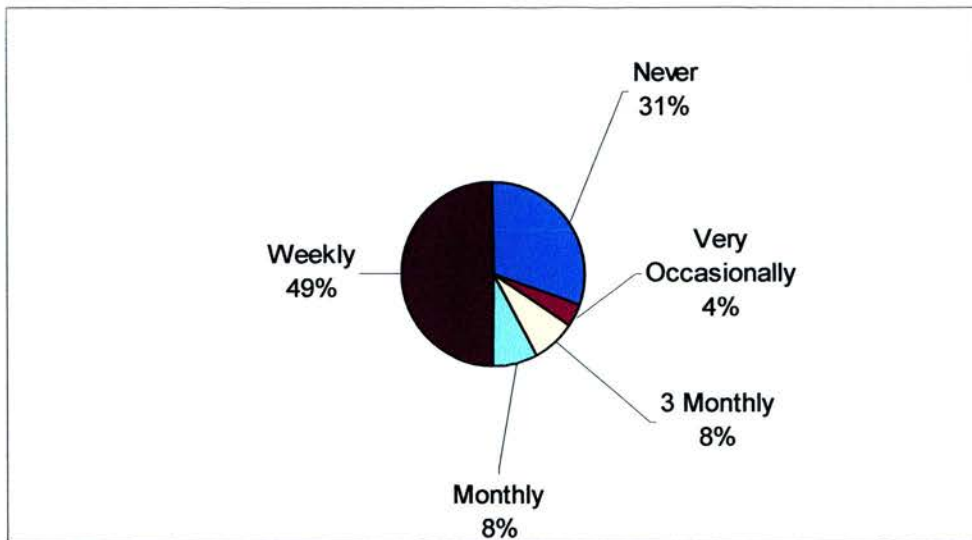


Fig 32a
Frequency of going for a walk in hospital

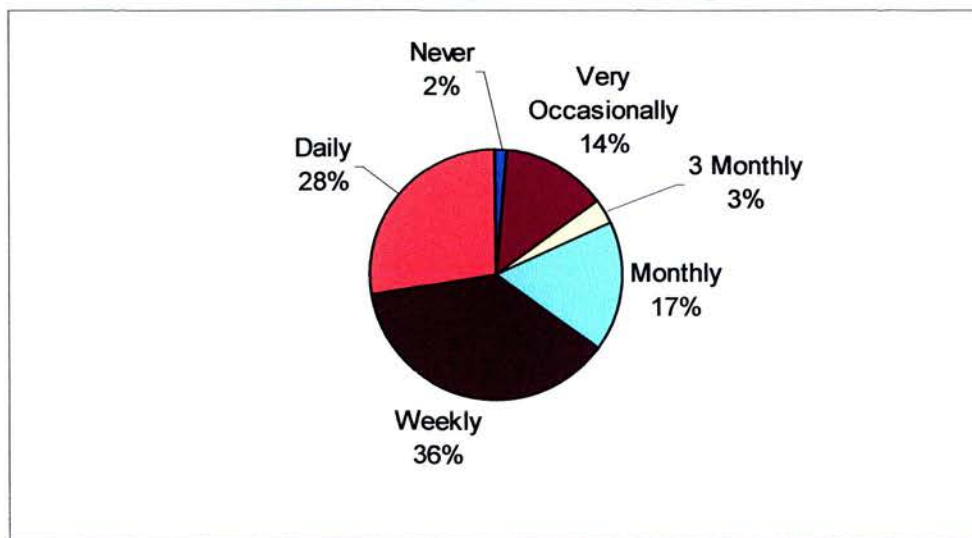


Fig 32b
Frequency of going for a walk in community

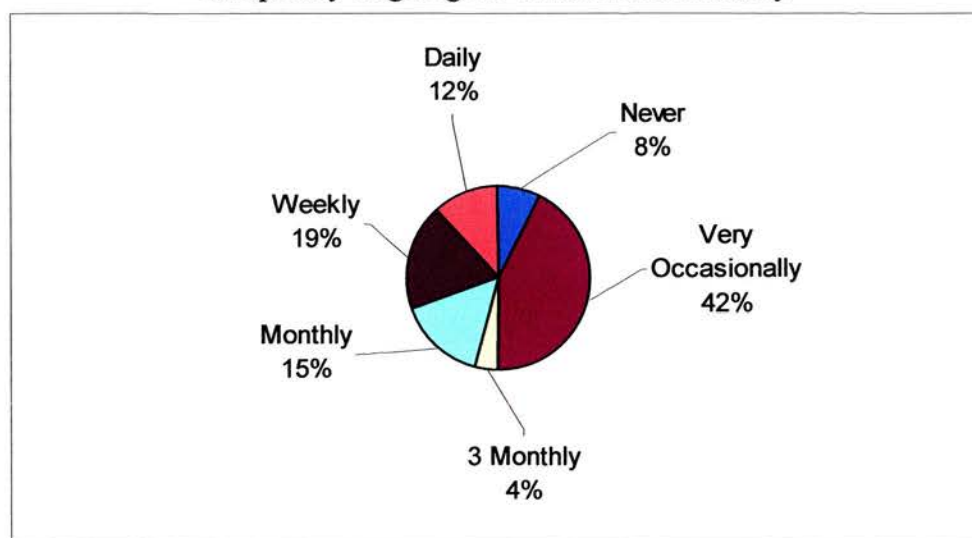


Fig 32c
Frequency of going for a walk non-disabled cohort

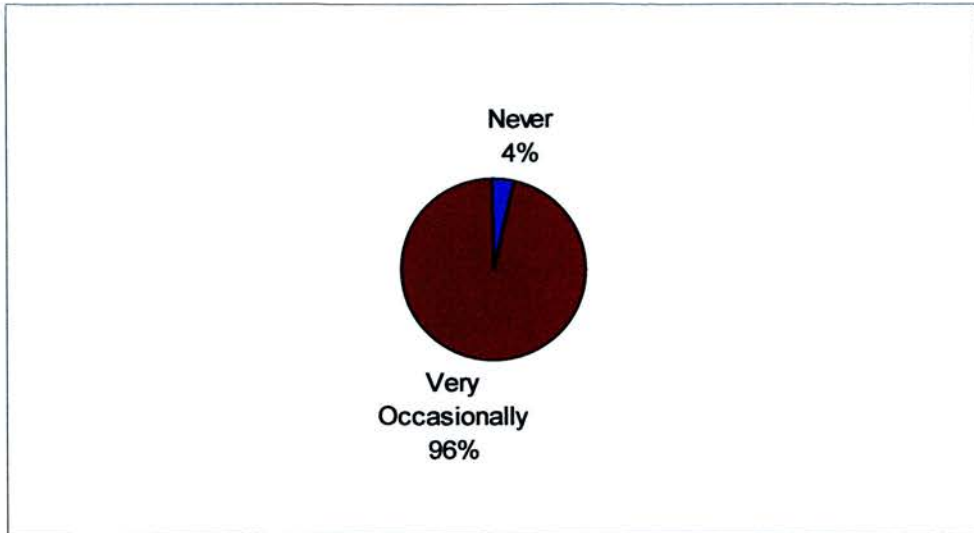


Fig 33a Frequency of holidays in hospital

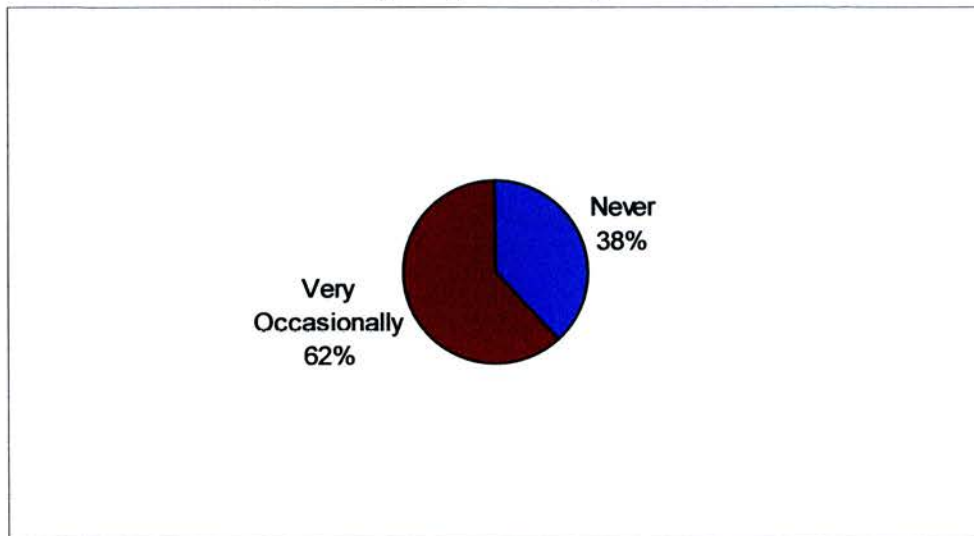


Fig 33b
Frequency of holidays in community

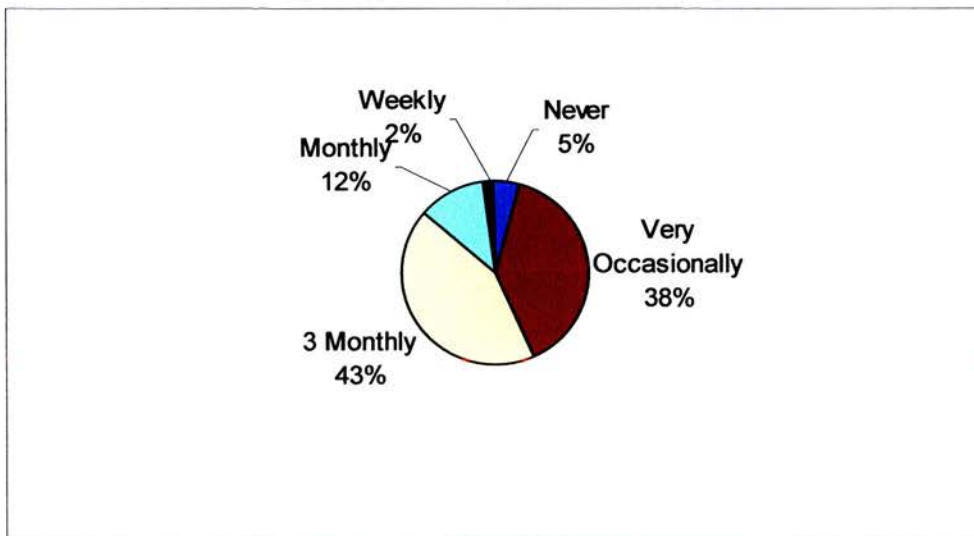


Fig 33c Frequency of holidays non-disabled cohort

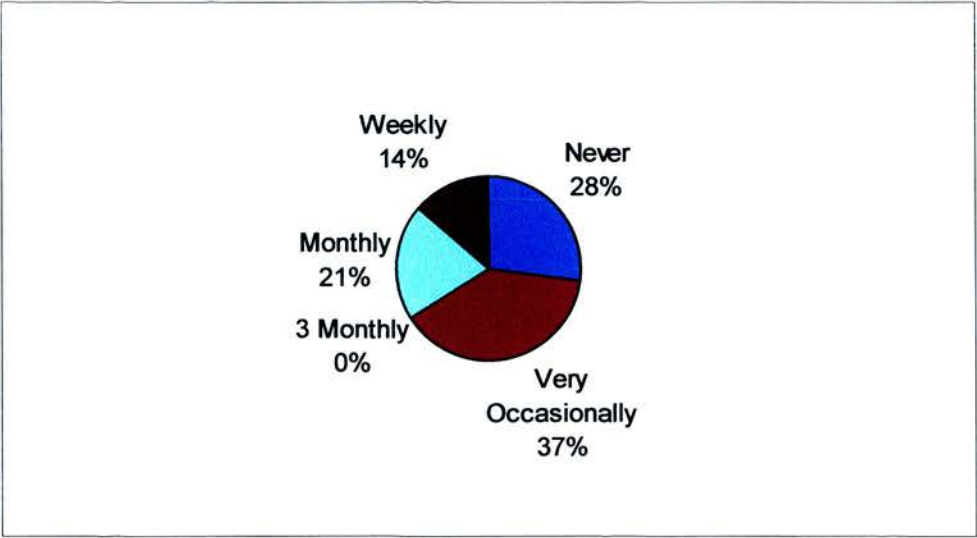


Fig 34a
Frequency of visiting the pub in hospital

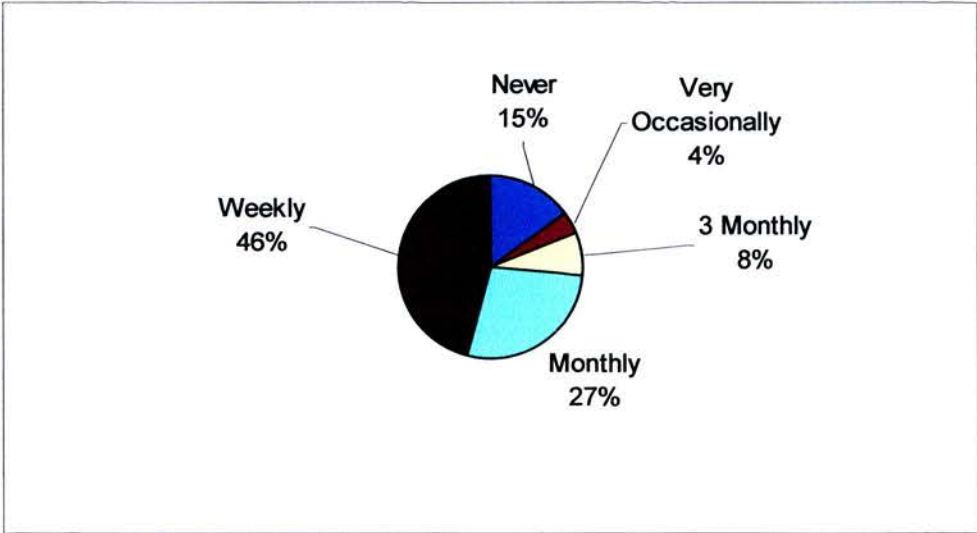


Fig 34b
Frequency of visiting the pub in the community

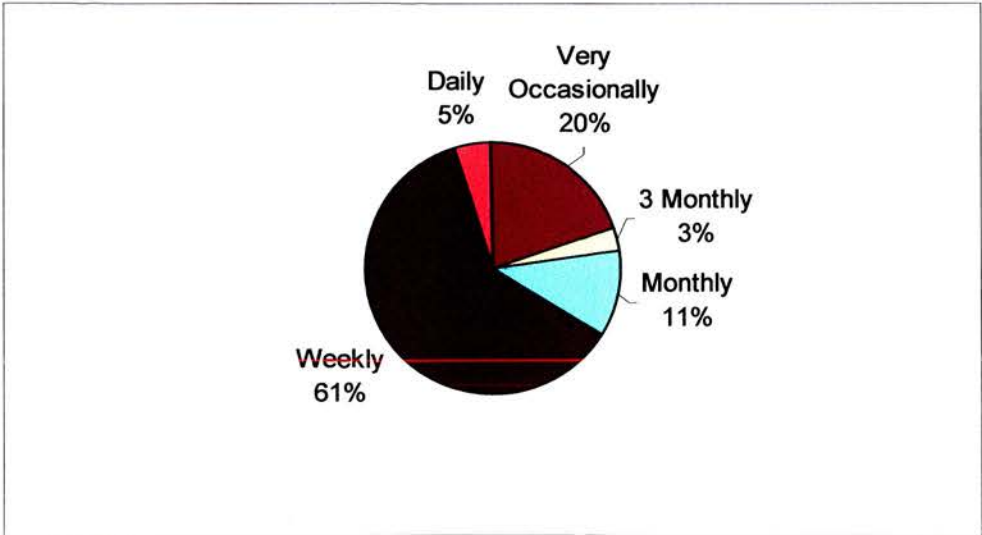


Fig 34c Frequency of visiting the pub non-disabled cohort

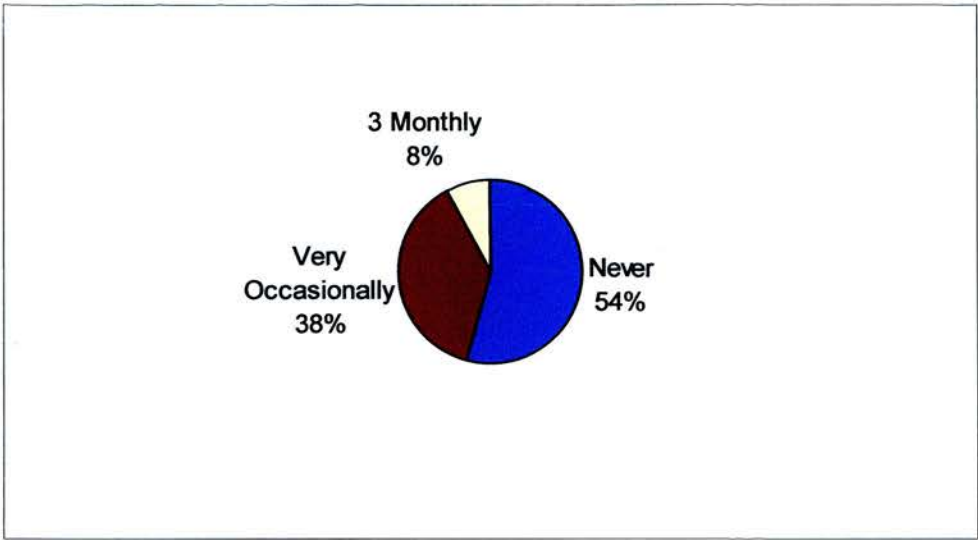


Fig 35a
Frequency of attending parties in hospital

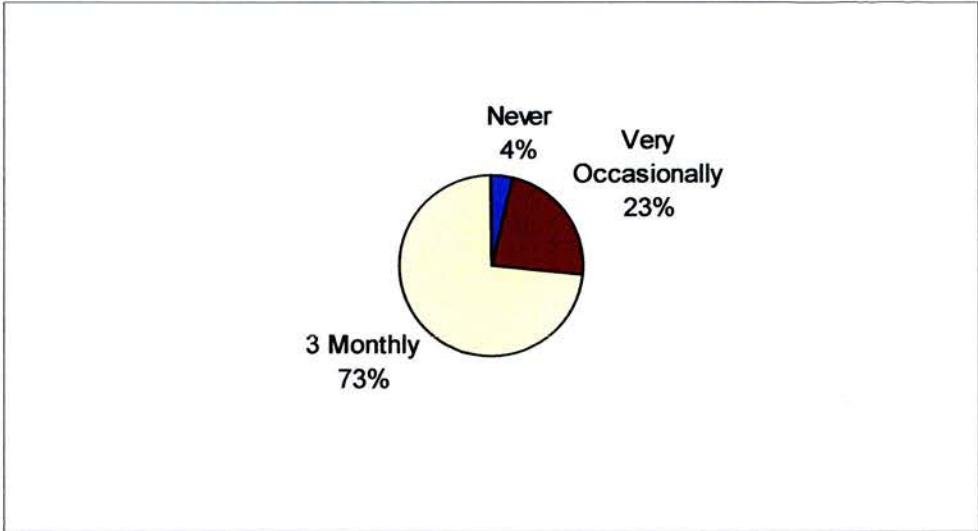


Fig 35b
Frequency of attending parties in the community

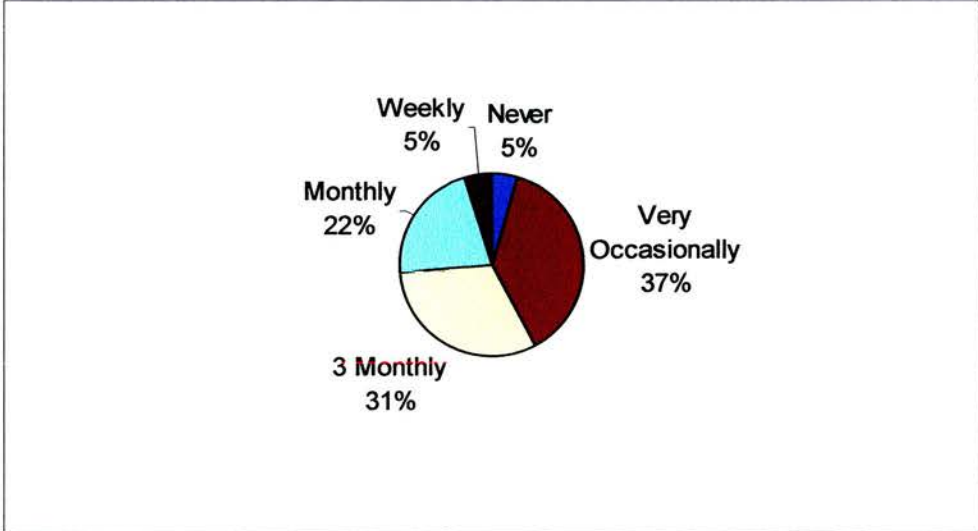


Fig 35c Frequency of attending parties non-disabled cohort

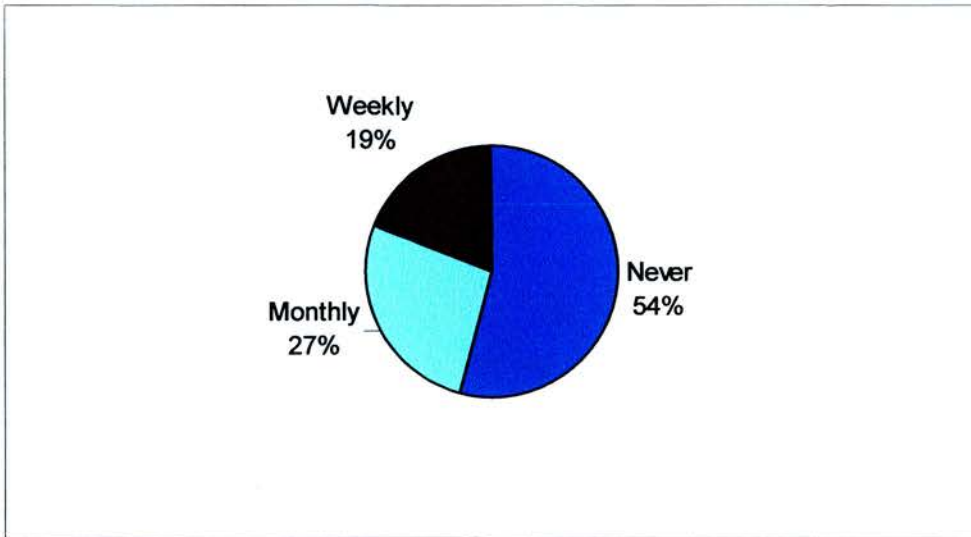


Fig 36a
Frequency of visiting cafes in hospital

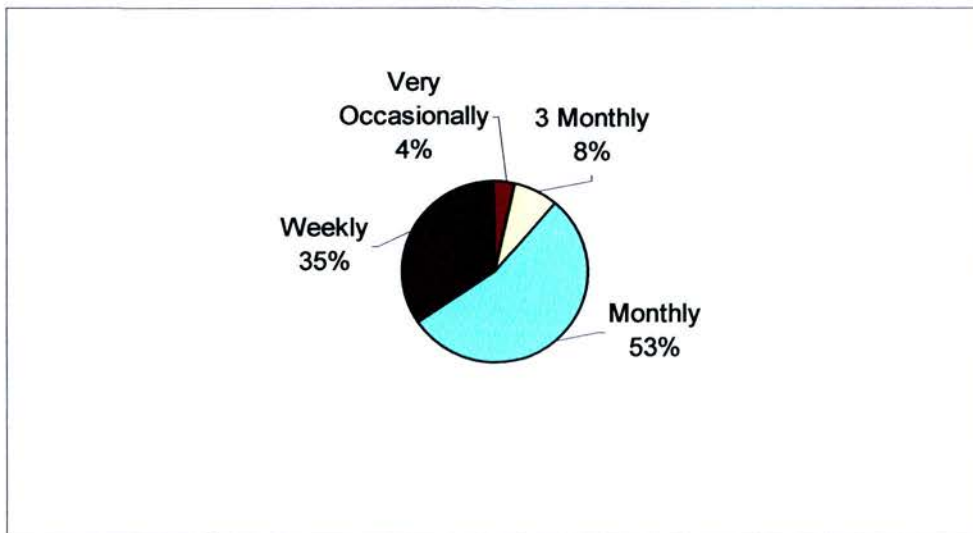


Fig 36b
Frequency of visiting cafes in the community

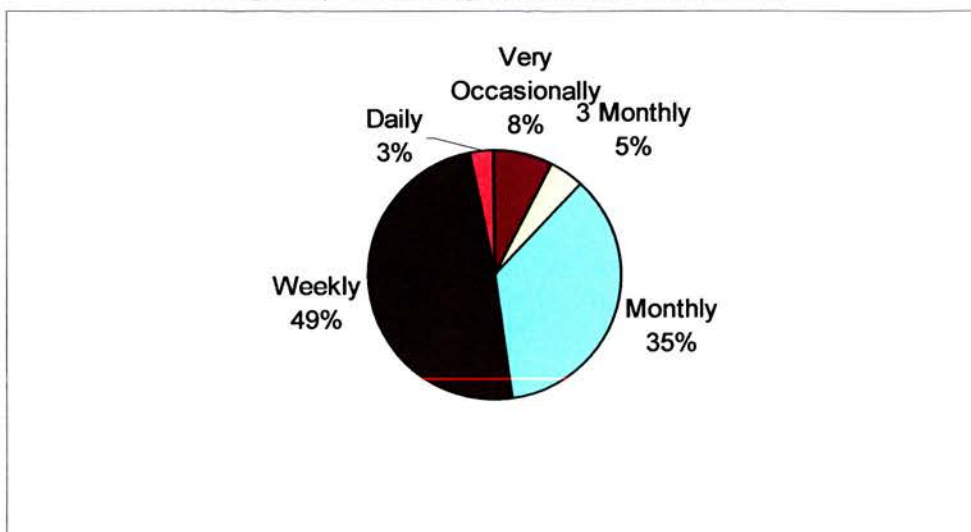


Fig 36c Frequency of visiting cafes non-disabled cohort

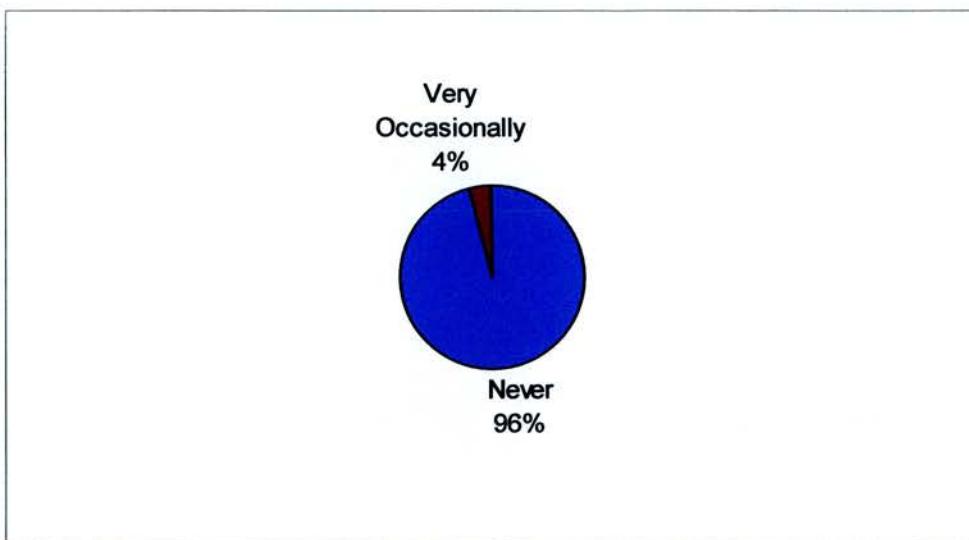


Fig 37a
Frequency of visiting a friend's house in hospital

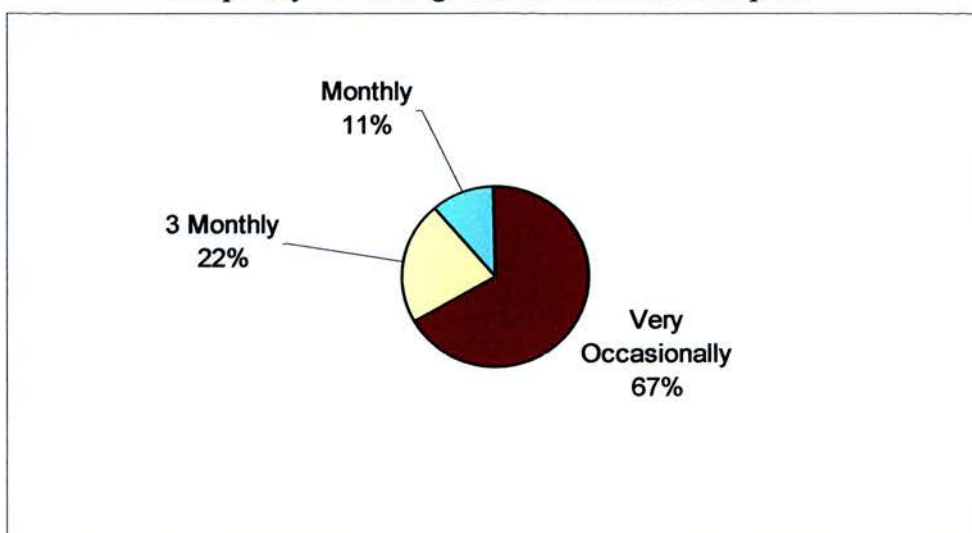


Fig 37b
Frequency of visiting a friend's house in the community

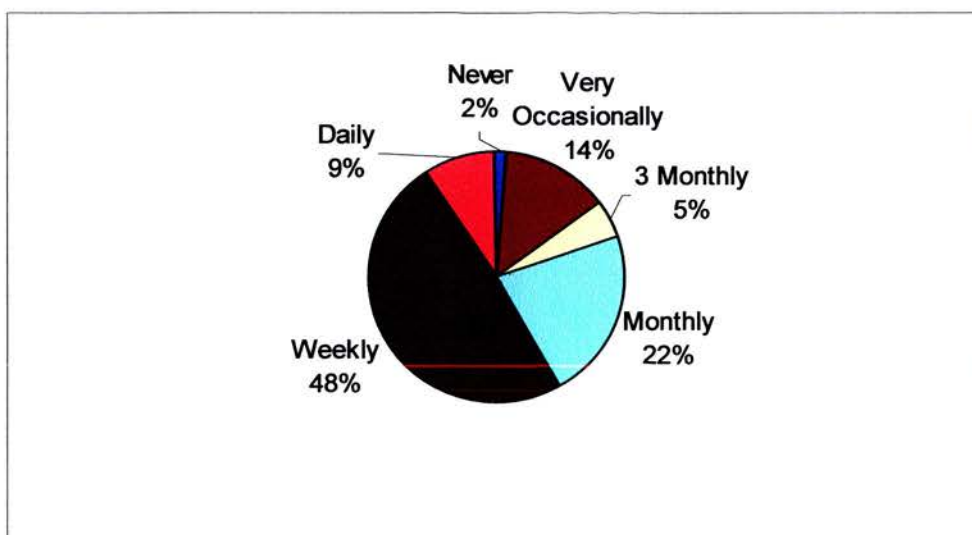


Fig 37c Frequency of visiting a friend's house non-disabled cohort

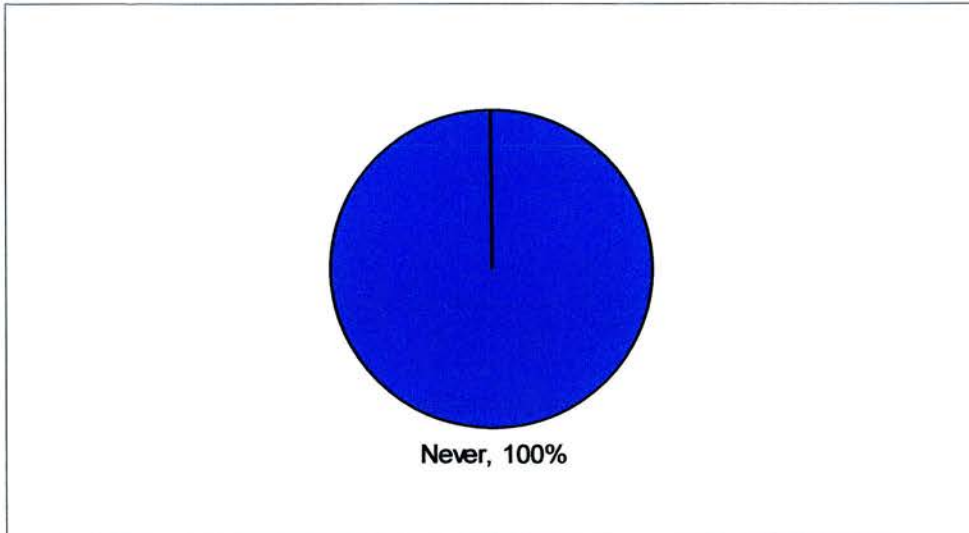


Fig 38a Frequency of visiting neighbour's house in hospital

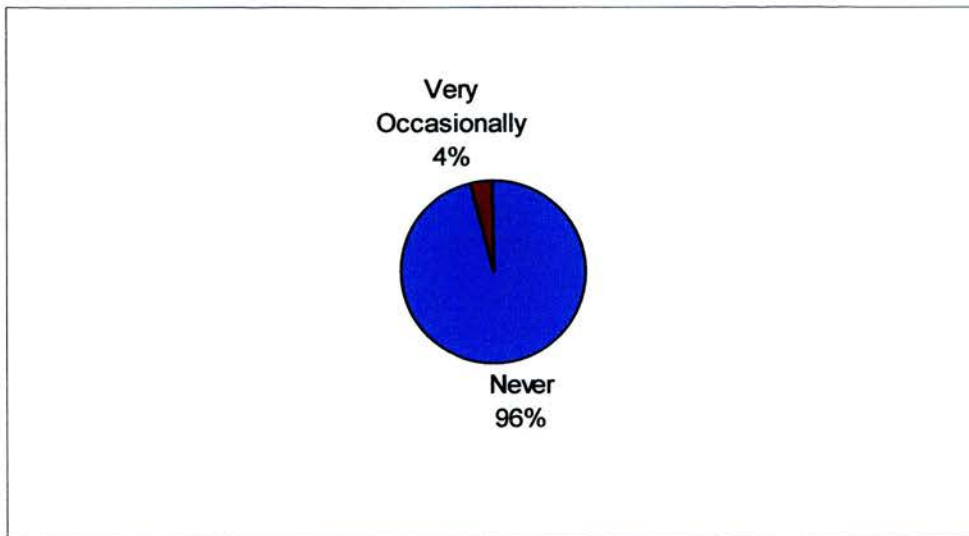


Fig 38b Frequency of visiting neighbour's house in the community

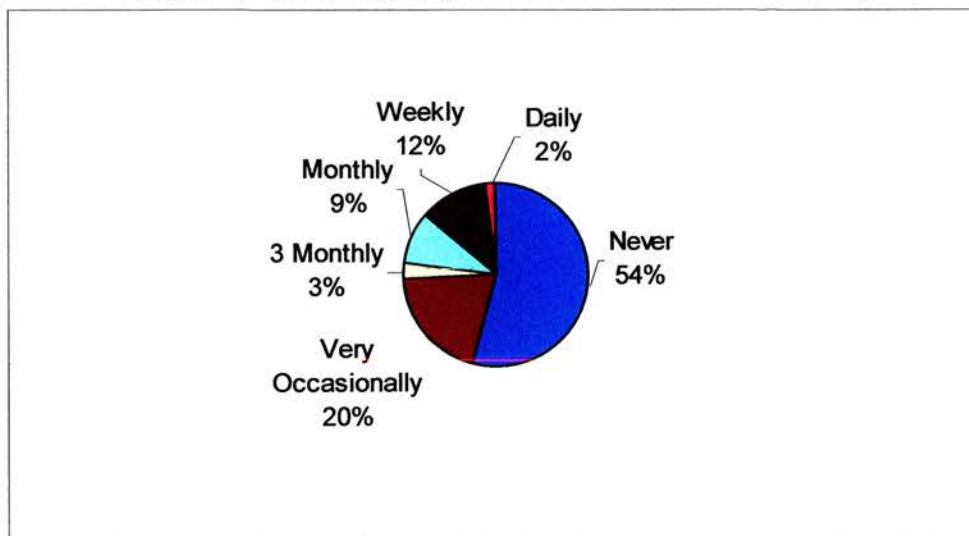


Fig 38c Frequency of visiting neighbour's house non-disabled cohort

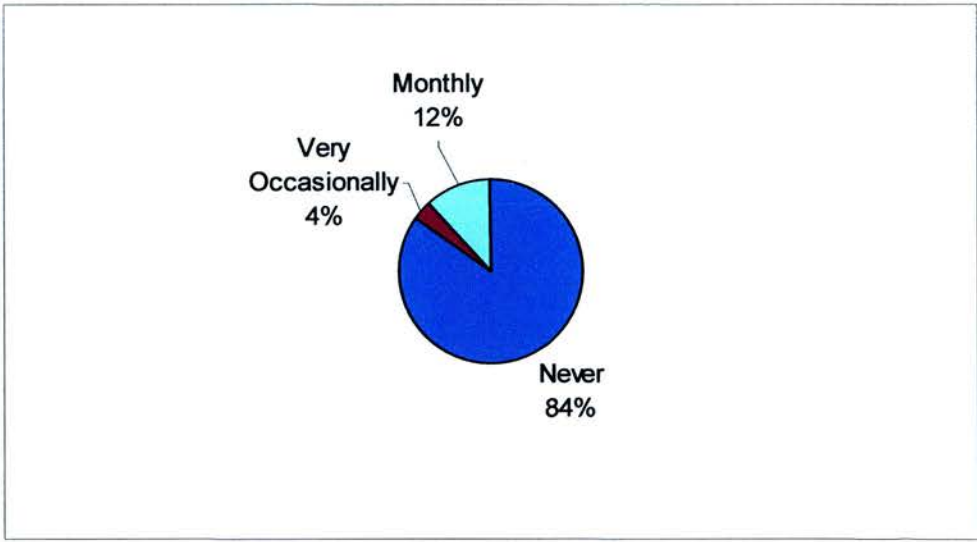


Fig 39a
Frequency of visiting a segregated social club in hospital

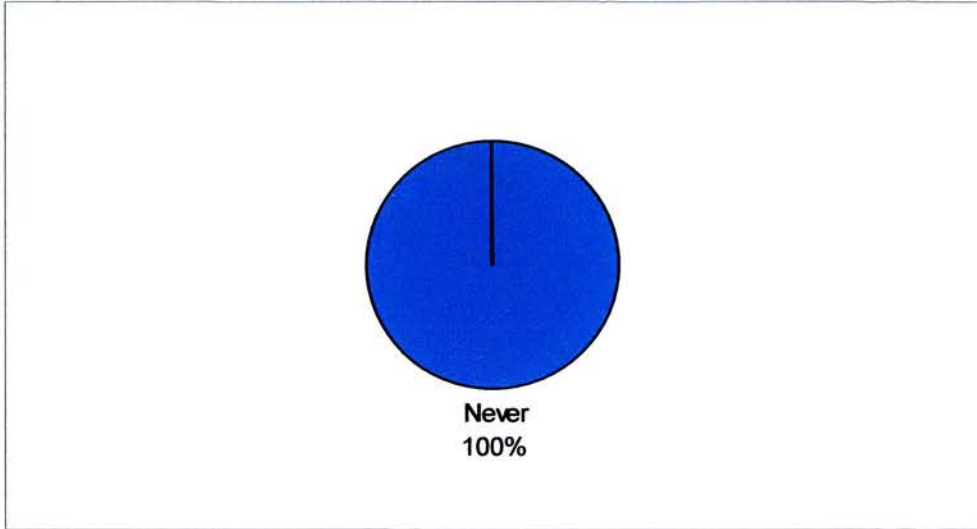


Fig 39b
Frequency of visiting a segregated social club in community

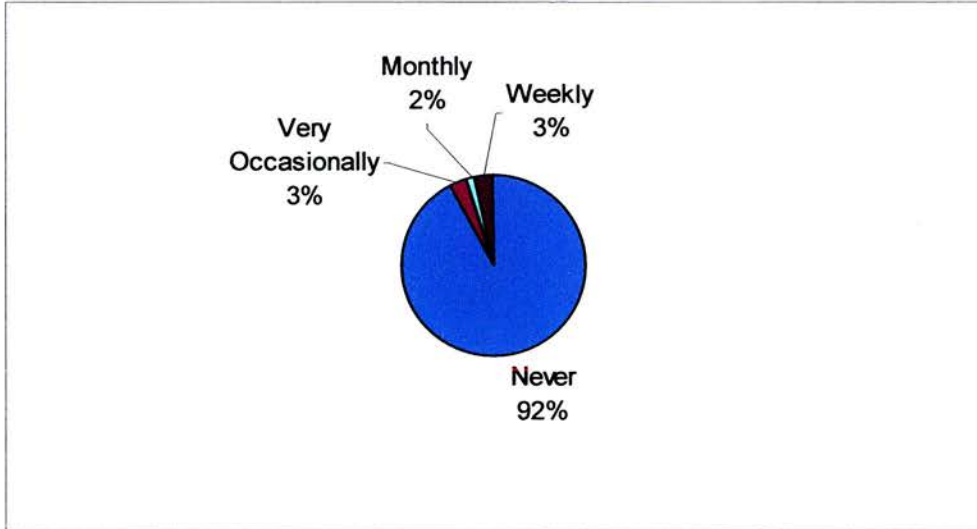


Fig 39c Frequency of visiting a segregated social club non-disabled cohort

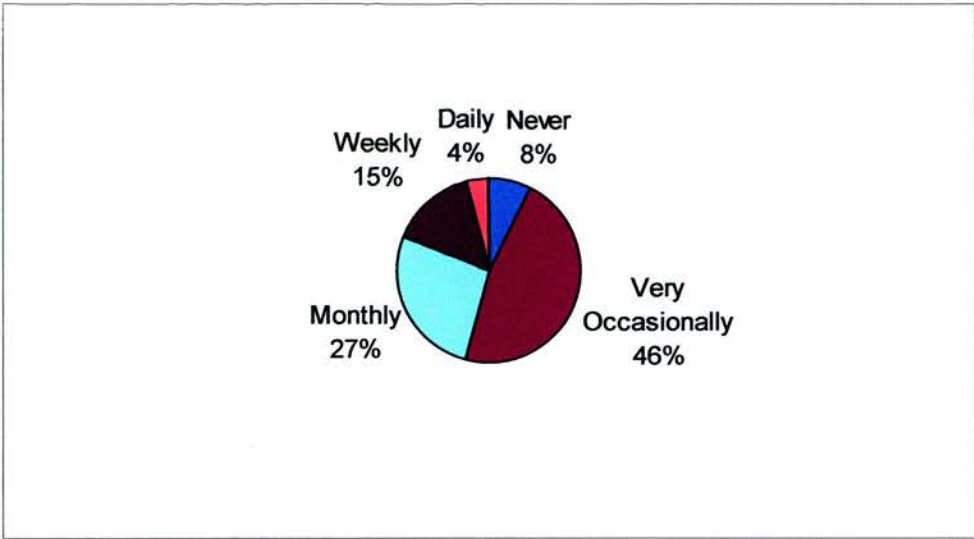


Fig 40a
Frequency of visiting local shops in hospital

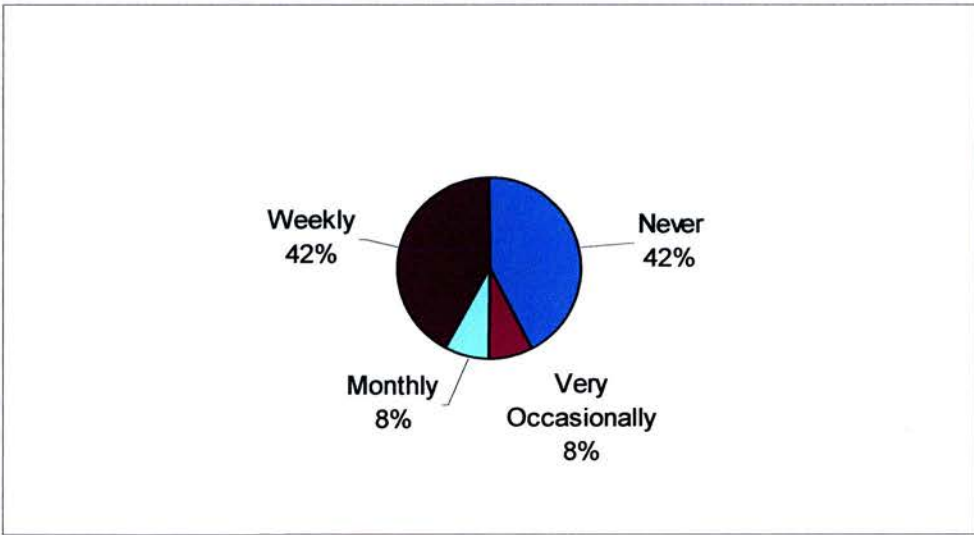


Fig 40b
Frequency of visiting local shops in the community

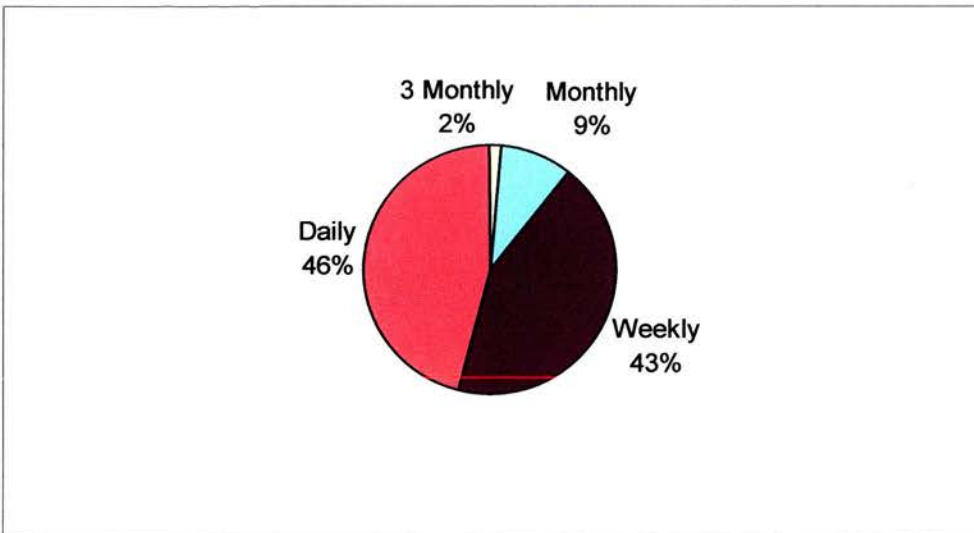


Fig 40c Frequency of visiting local shops non-disabled cohort

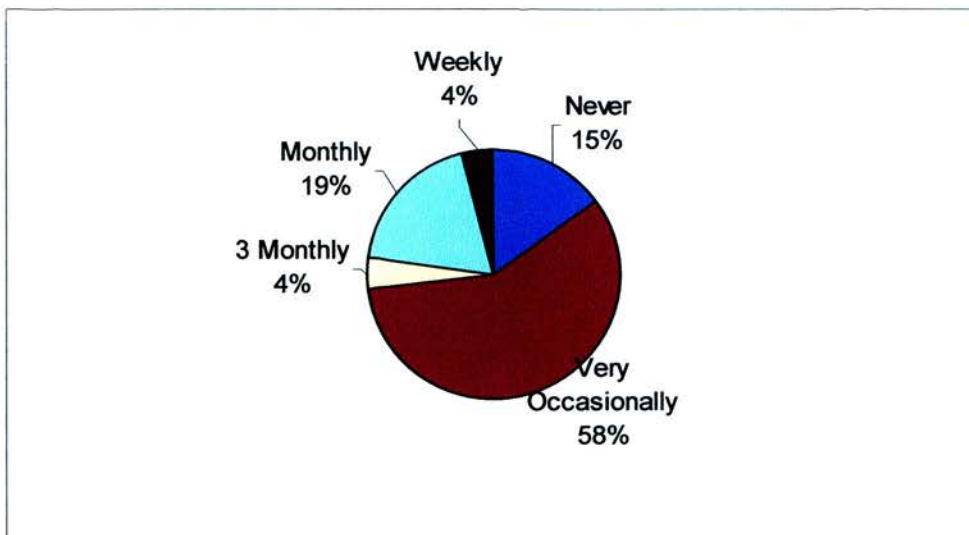


Fig 41a
Frequency of visiting High St stores in hospital

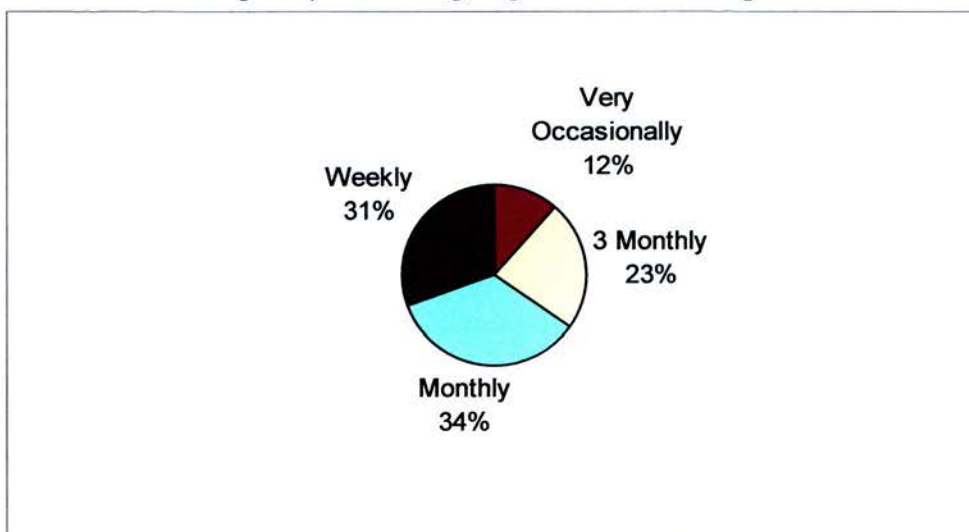


Fig 41b Frequency of visiting High St stores in community

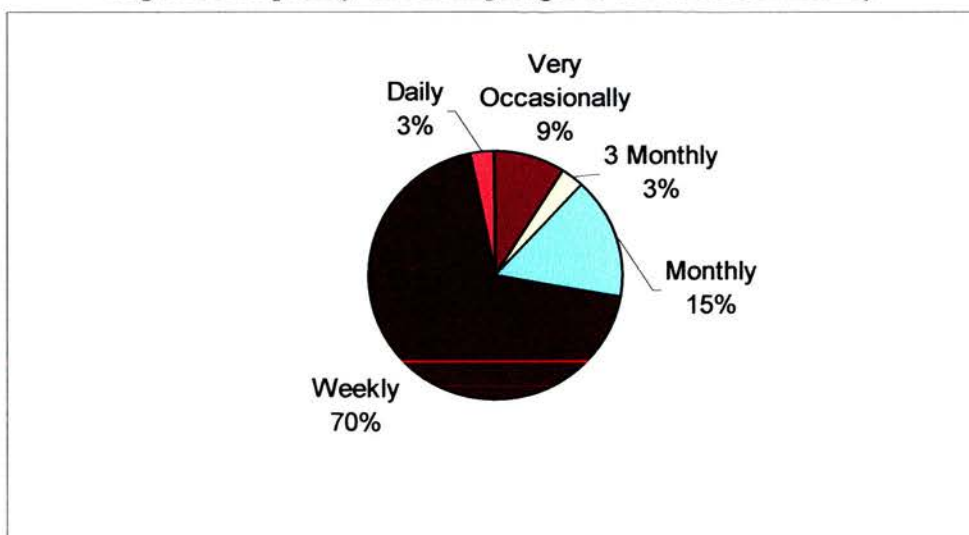


Fig 41c Frequency of visiting High St stores non-disabled cohort

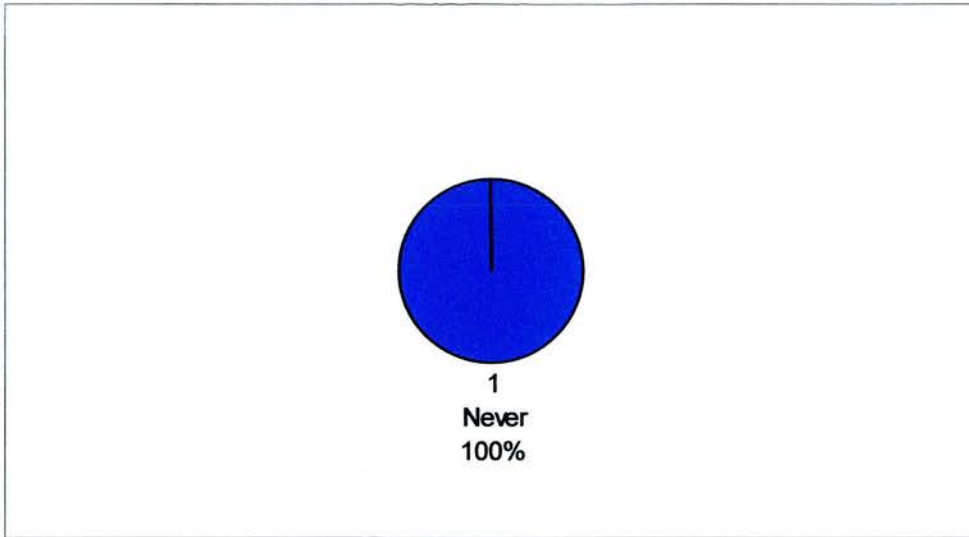


Fig 42a
Frequency of visiting a post office in hospital

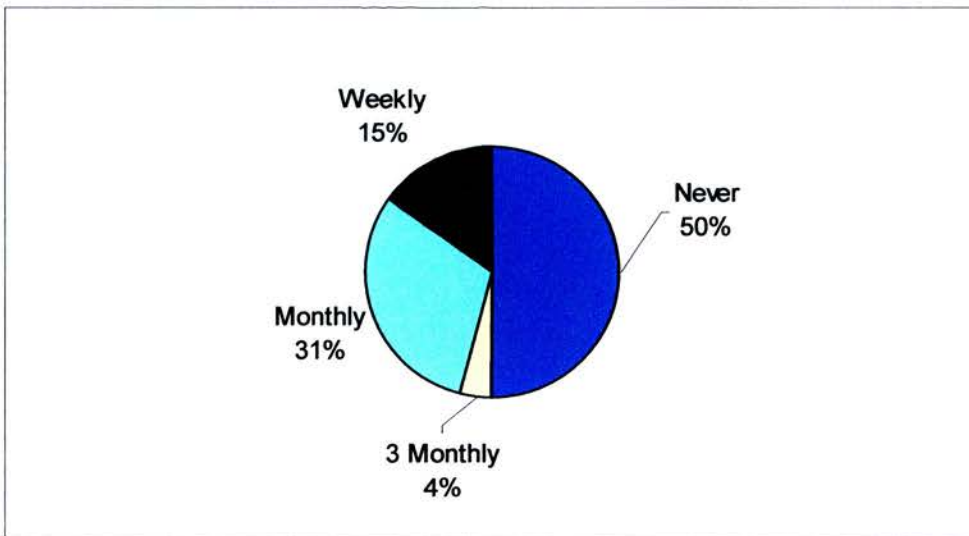


Fig 42b
Frequency of visiting a post office in the community

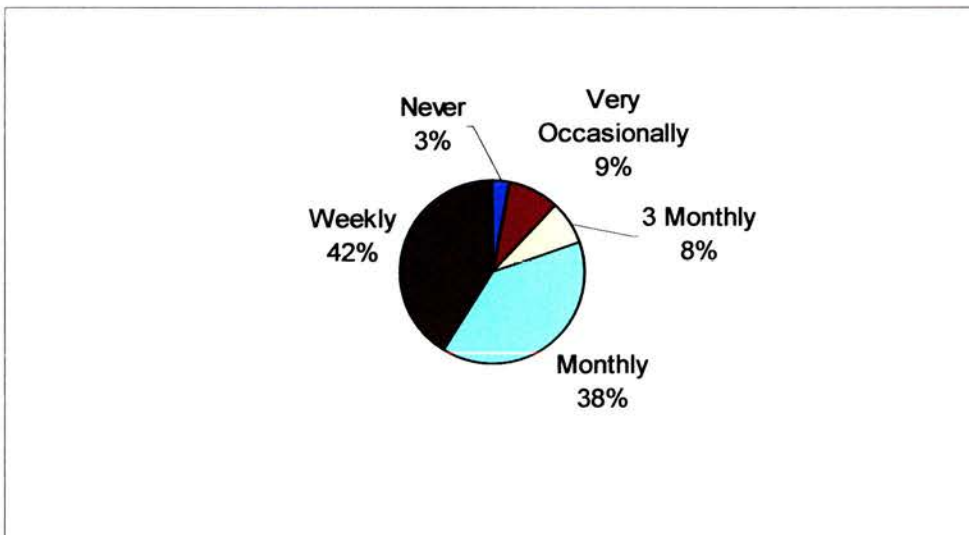


Fig 42c Frequency of visiting a post office non-disabled cohort

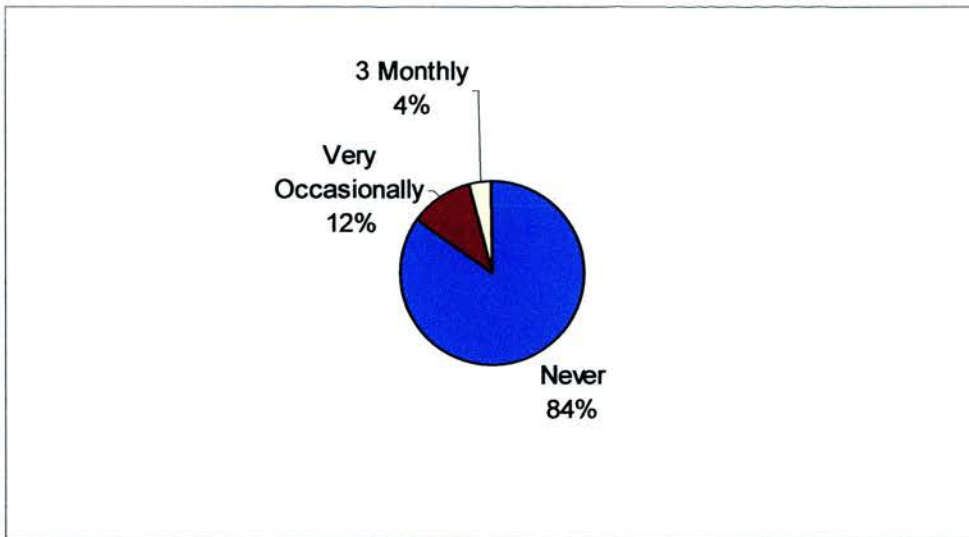


Fig 43a
Frequency of visiting a hairdresser in hospital

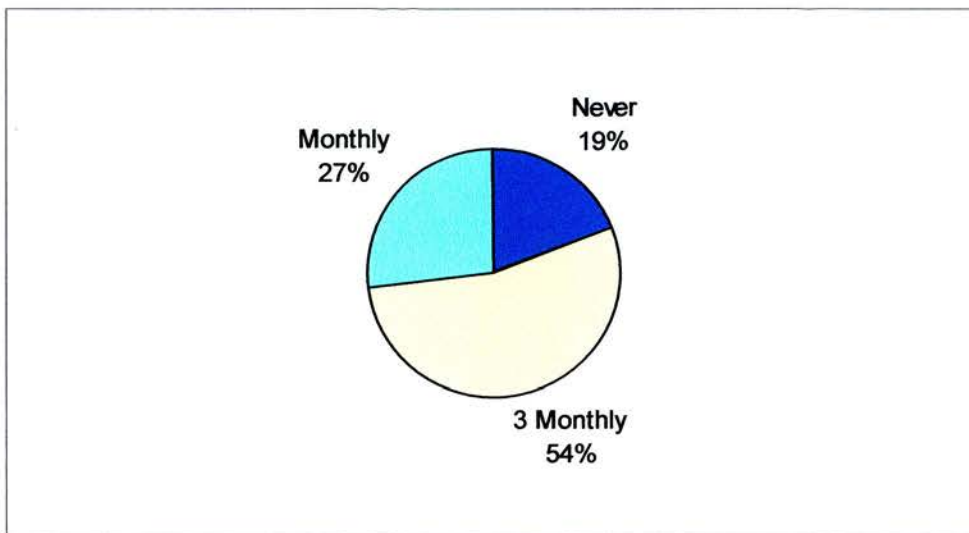


Fig 43b
Frequency of visiting a hairdresser in the community

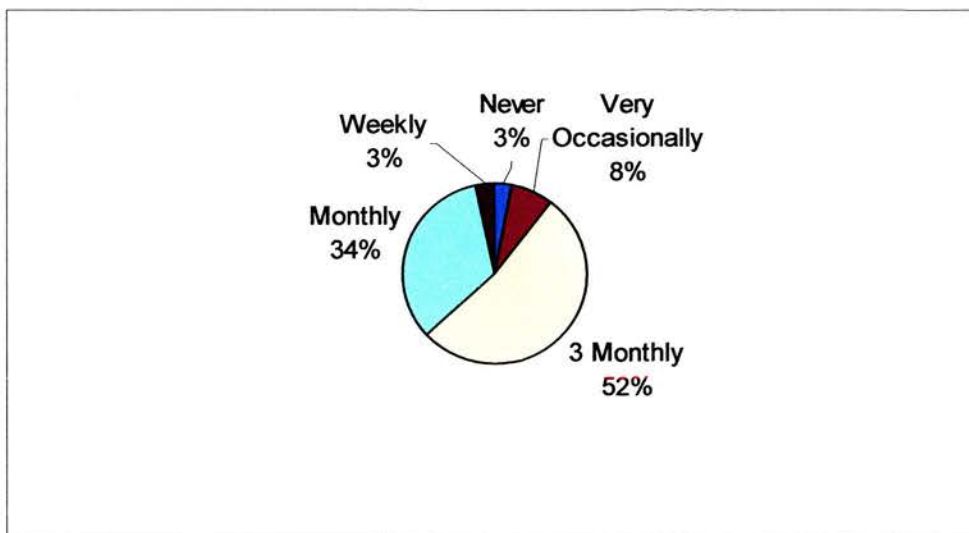


Fig 43c Frequency of visiting a hairdresser non-disabled cohort

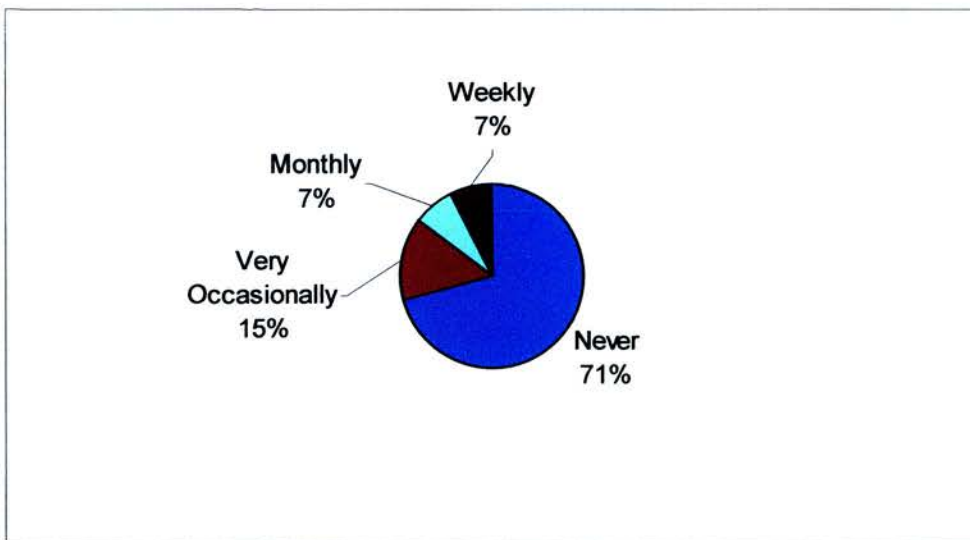


Fig 44a
Frequency of visiting a supermarket in hospital

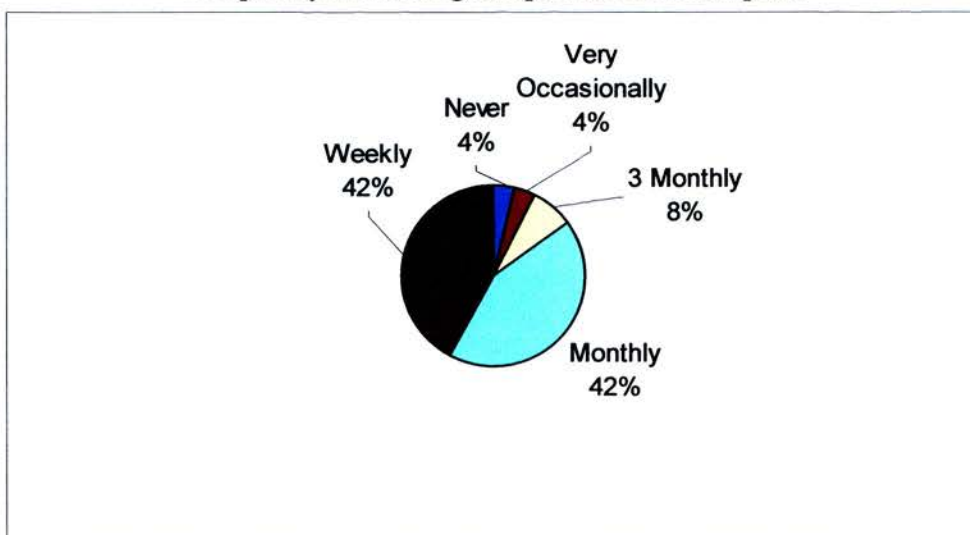


Fig 44b
Frequency of visiting a supermarket in the community

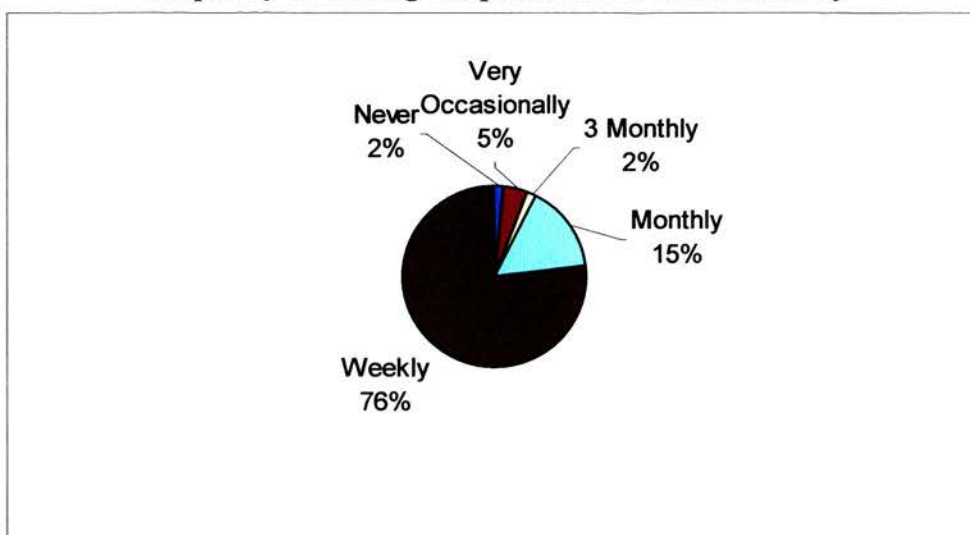


Fig 44c Frequency of visiting a supermarket non-disabled cohort

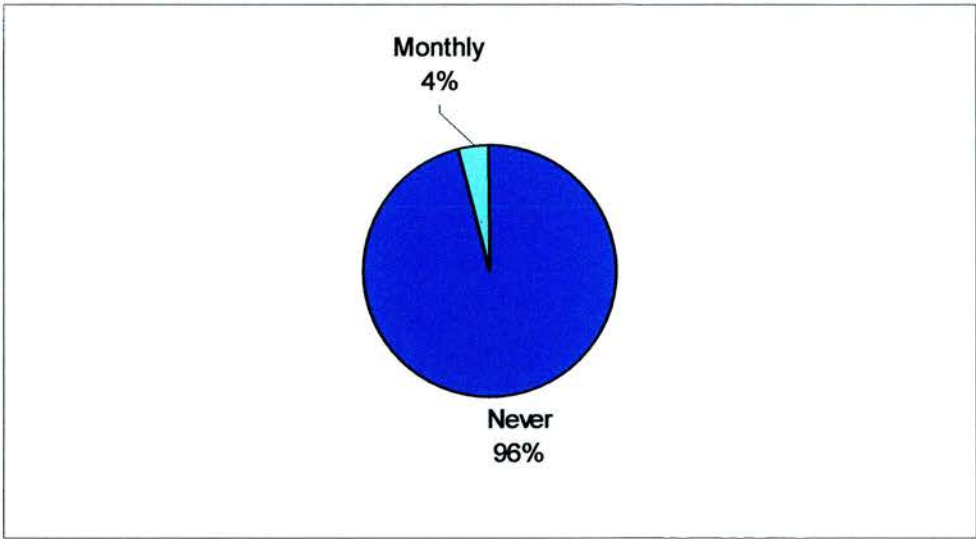


Fig 45a
Frequency of visiting a bank in hospital

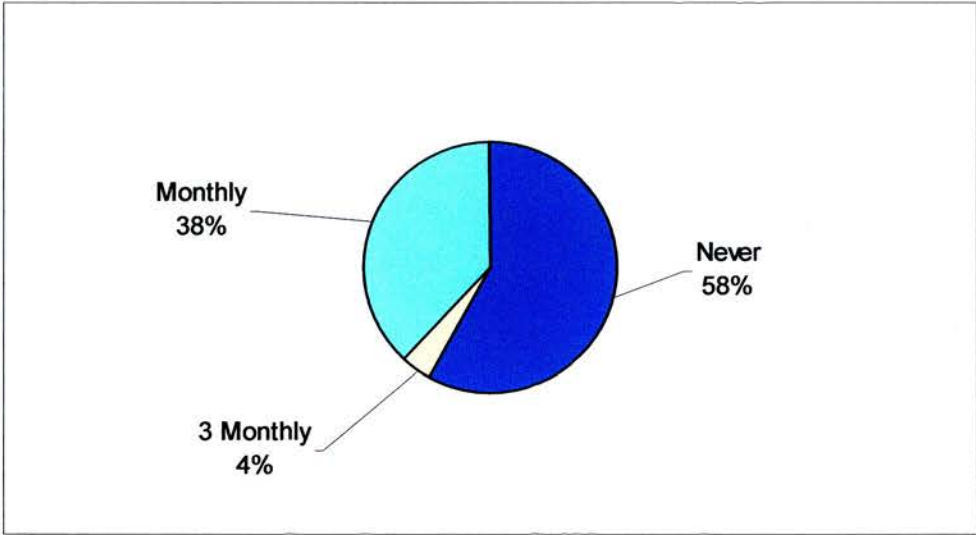


Fig 45b
Frequency of visiting a bank in the community

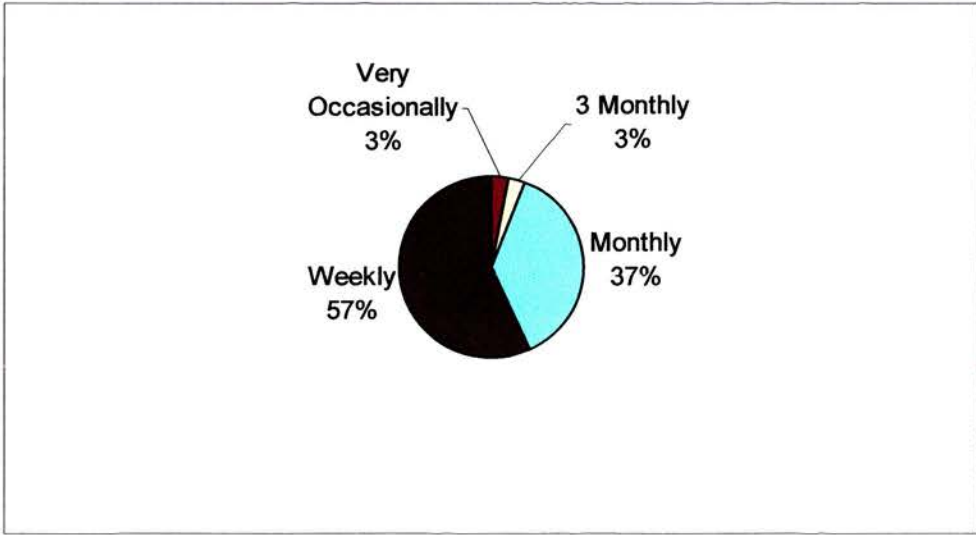


Fig 45c Frequency of visiting a bank non-disabled cohort

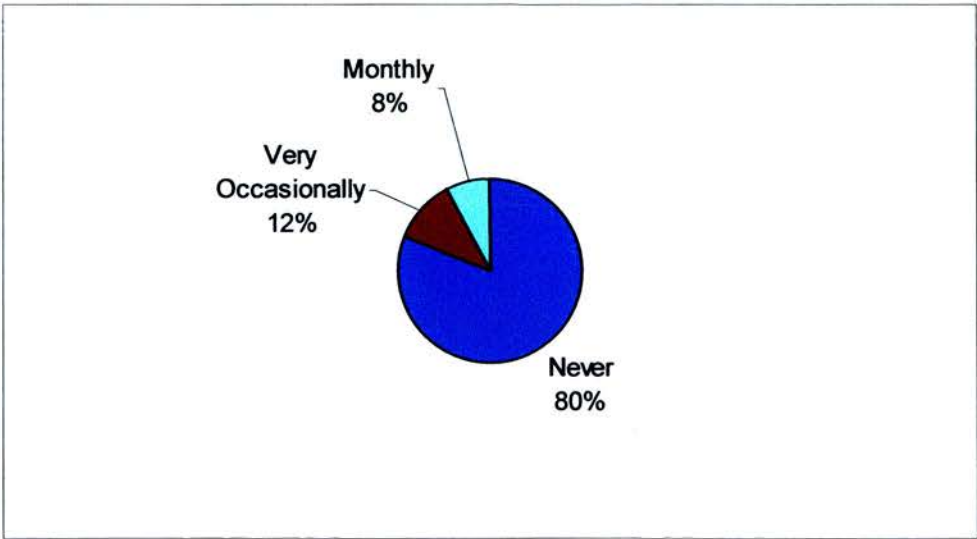


Fig 46a
Frequency of attending church in hospital

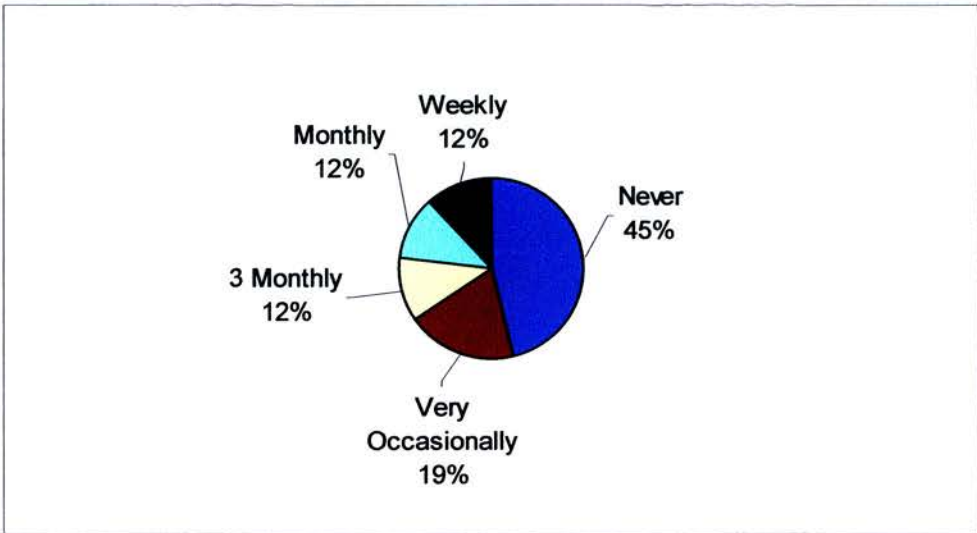


Fig 46b
Frequency of attending church in the community

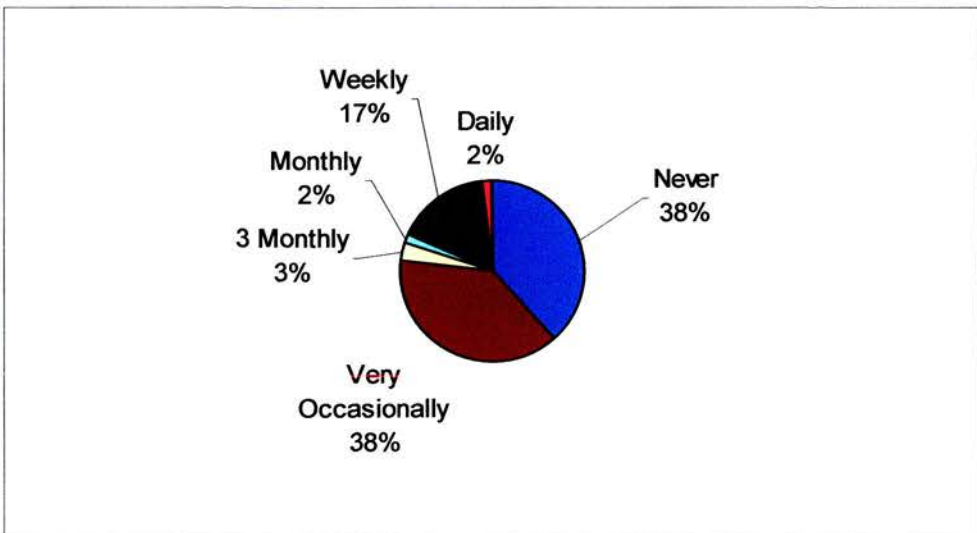


Fig 46c Frequency of attending church non-disabled cohort

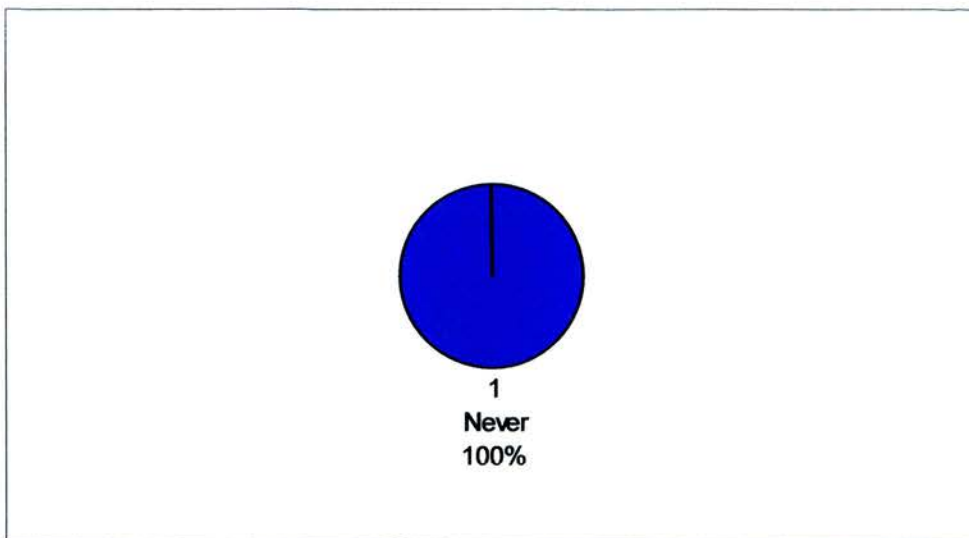


Fig 47a
Frequency of visiting a large retail outlet in hospital

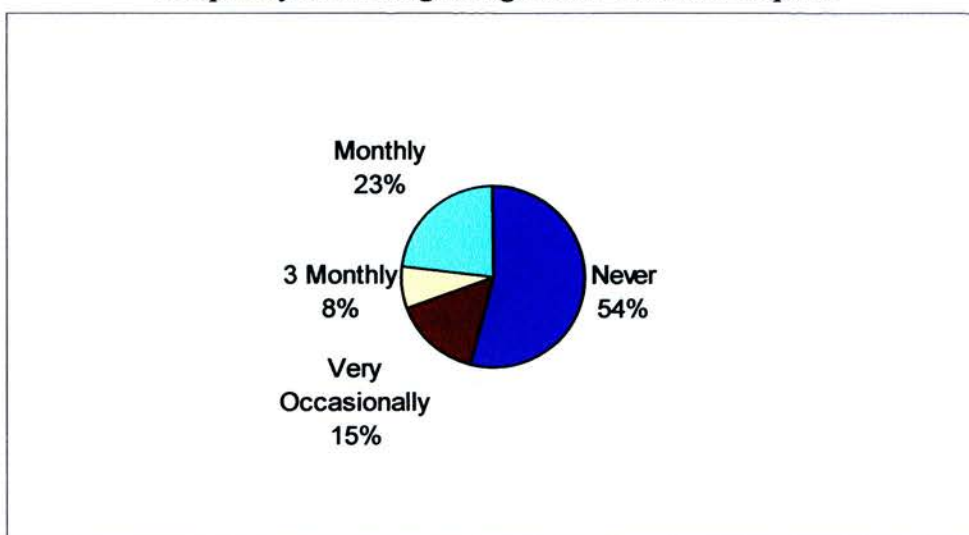


Fig 47b
Frequency of visiting a large retail outlet in community

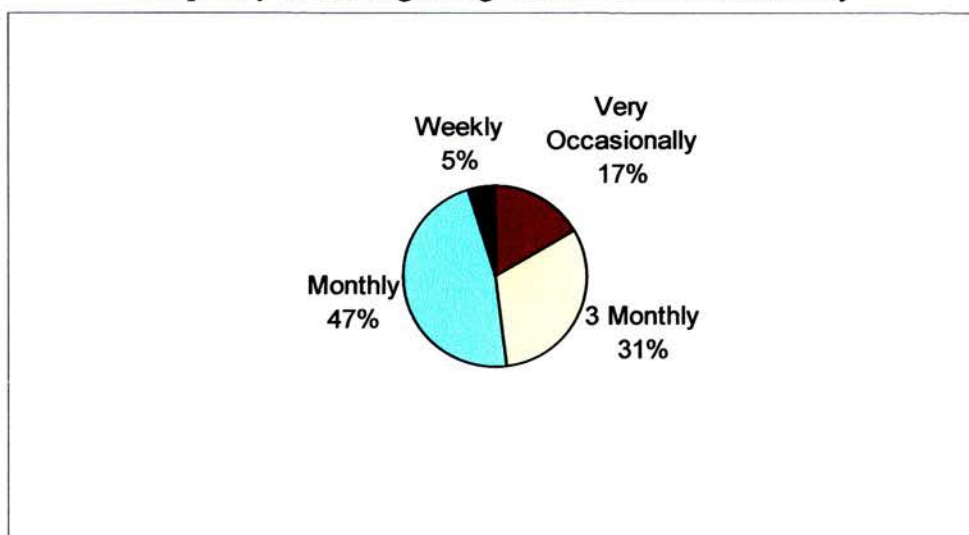


Fig 47c Frequency of visiting a large retail outlet non-disabled cohort

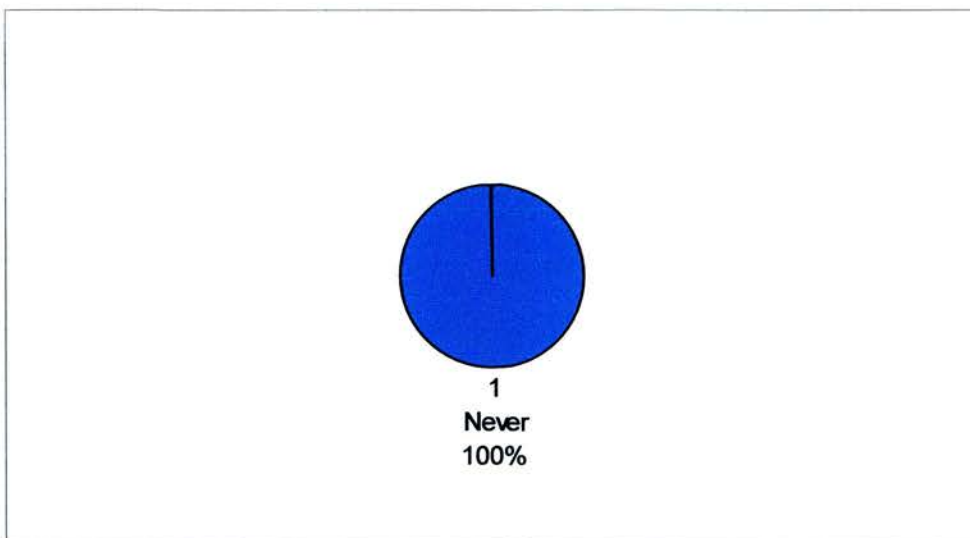


Fig 48a
Frequency of attending adult education in hospital

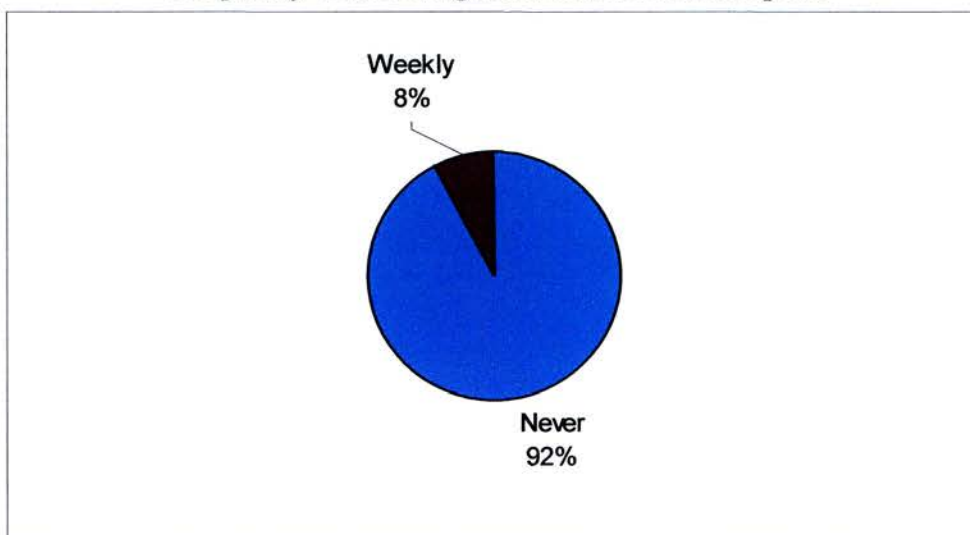


Fig 48b
Frequency of attending adult education in the community

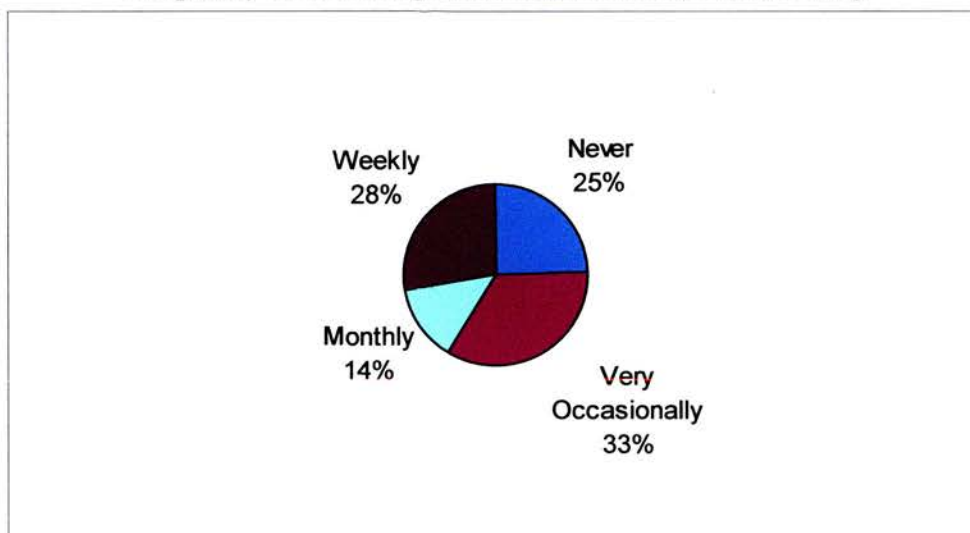


Fig 48c Frequency of attending adult education non-disabled cohort

There appeared to be a large increase in the use of General Practitioners (GP's) once individuals had moved to community settings. There would appear to be higher usage of the GP service amongst the resettlement group than the non-disabled cohort, perhaps reflecting the greater general health needs of this group (figs 12a-c). Similarly, nearly half of the resettlement group had now used the district general hospital, whereas prior to moving there was no use at all. Given the higher usage of GP's amongst the resettlement group, it is perhaps surprising that use of the district general hospital is lower than that of the non-disabled cohort (figs 14a-c). Use of the dentist had decreased following resettlement, prior to resettlement 12% of participants were rated as attending 3 monthly or more frequently, following resettlement none of the cohort used the dentist 3 monthly or more frequently, with everybody appearing to access very occasionally or not at all (fig 13a-c). There appeared to be no contact with the police before or after resettlement, this pattern appears to differ greatly from the non-disabled cohort (figs 15a-c).

Following the move from hospital there appeared to be no use of public buses with use of trains decreased (figs 16a-b, 17a-b). Use of means of transport associated with holidays (ferries and flights) was generally low at both times in comparison to the non-disabled cohort (figs 18a-c, 19a-c).

It would appear that whilst in hospital, frequent engagement in indoor craft activities was a common and frequent occurrence. However, movement from hospital appears to have corresponded with participation decreasing and more closely resembling participation by the non-disabled cohort (figs 21a-c). General patterns of watching the TV changed very little and remained much less frequent than the non-disabled cohort (figs 22a-c). Figs 23a-c would indicate that watching videos had increased, a viewing activity that would perhaps be more volitional (i.e. involve more choice). Also increased was contact with pets, where 20% of the cohort were involved in their care, compared with no involvement prior to resettlement. However, involvement in pet care is not as great as the 59% reported by the non-disabled cohort (figs 24a-c).

Figs 20a-b and 21a-b suggest that engagement in craft and indoor games had decreased following movement from hospital. In order to comment on the likelihood of this being as a result of a deliberate policy across the service a similar analysis was carried out for

the comparison group (Figs 49a-b, and 50a-b). No differences in pattern of access to these activities were apparent, suggesting that this effect was specific to the resettlement group.

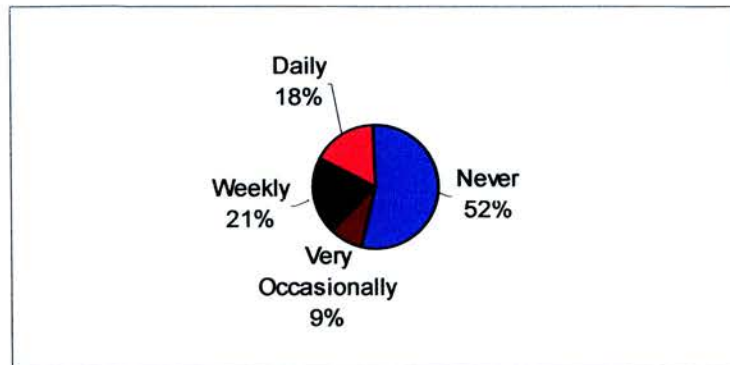


Fig 49a
Comparison group
Frequency of participation in craft at t1



Fig 49b Comparison group
Frequency of participation in craft at t2

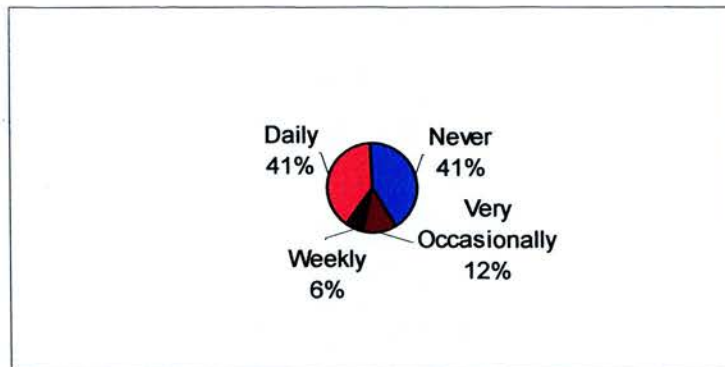


Fig 50a

Comparison group

Frequency of participation in indoor games at t1

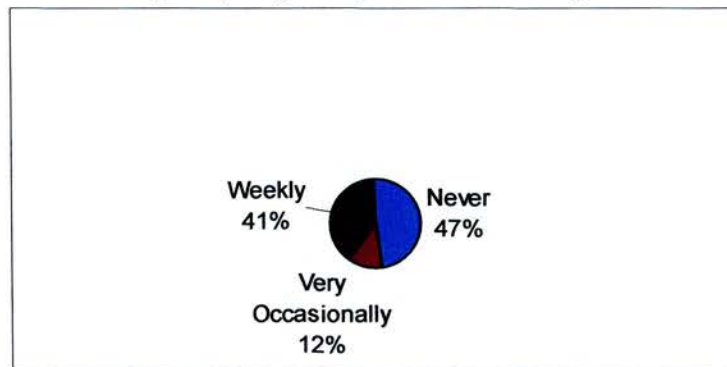


Fig 50b

Comparison group

Frequency of participation in indoor games at t2

Figs 25a-b would indicate a much greater participation in sport and figs 27a-b specifically reflect greater use of exercise classes since resettlement. This is mirrored in the degree to which individuals have increased their participation in spectator sport (figs 26a-b). Although the pattern of access in all three areas remains less frequent than that of the non-disabled cohort, nobody appears at any time to have participated in cycling (figs 28a-b), and nobody has visited the cinema once they have moved from hospital (fig 29a-b). The frequency of going to the park and the beach, and to some extent walking, generally appears to have increased, and more closely resemble the pattern of access of the non-disabled cohort (figs 30a-c, 31a-c, 32a-c). Somewhat surprisingly, figs 33a-b would indicate that whilst 96% of people in hospital appeared to have at least an occasional holiday, 38% of the cohort had no holiday once they moved out.

The frequency and amount of use of pubs, cafes and going to parties has increased since leaving hospital and more closely resembles the non-disabled cohort (figs 34a-c, 35a-c, 36a-c). All the people in the cohort now have at least very occasional visits to friends houses compared to only 4% whilst they lived in hospital (figs 37a-c). However fig 38b-c indicates that only 4% of the cohort had visited their neighbours, this contrasts starkly with the non-disabled cohort of which 46% had some experience of visiting neighbours. On moving out of hospital nobody in the cohort attending segregated social clubs (fig 39a-b).

Use of local shops had decreased whilst visits to High Street stores, large retail outlets and supermarkets had increased, although the amount and frequency of contact was less than the non-disabled cohort for all types of shops (figs 41a-c, 47a-c, 44a-c). Figs 42a-c show that nobody went to the Post Office whilst they lived in hospital, yet 50% had some contact once they moved to the community and that this rate of use is higher than the non-disabled cohort. Similarly, use of a bank was minimal in hospital, but after resettlement 40% of the cohort visited at least 3 monthly (figs 45a-b). Attendance at church increased substantially after the move from hospital and more closely resembles attendance by the non-disabled cohort (46a-c). Whilst in hospital few people visited the hairdressers, however after resettlement frequency of usage increased markedly and more closely resembled the non-disabled cohort (fig 43a-c). None of the cohort received adult education whilst in hospital; however after relocation 8% were attending weekly courses.

In order to investigate changes in the manner in which the participants accessed activities and contacts, supervision, accompanied, alone and peer scores were calculated for each individual. These were derived by summing the number of items accessed more frequently than three-monthly for each support type, i.e. the number of supervised items. The mean scores for the resettlement group at t1 & t2 are represented graphically in fig 69 and for the comparison group in fig 70.

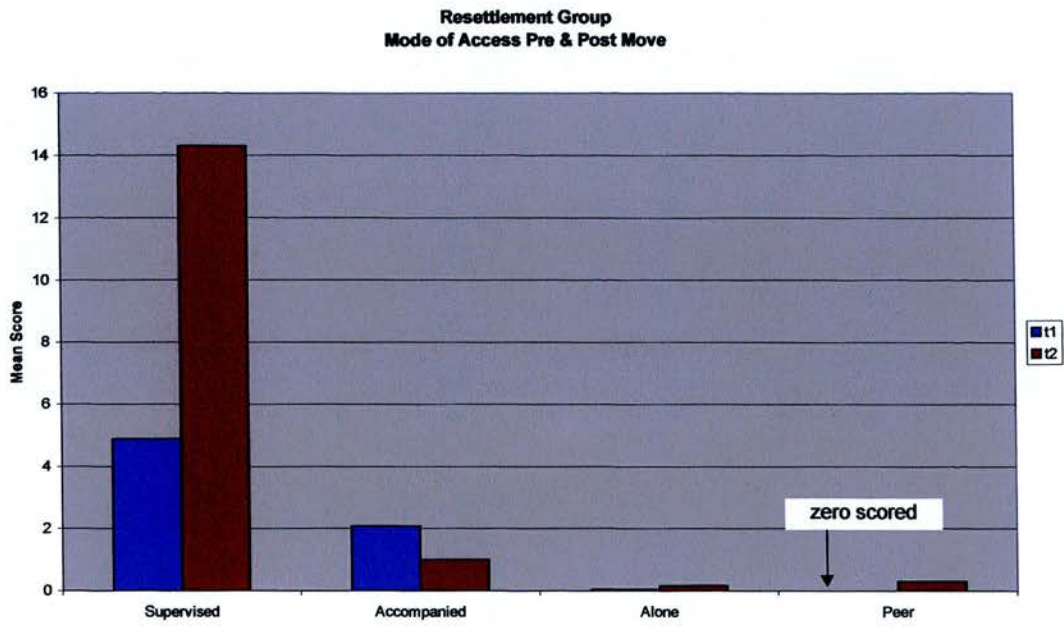


Fig 51.
Resettlement group mode of access pre & post move.

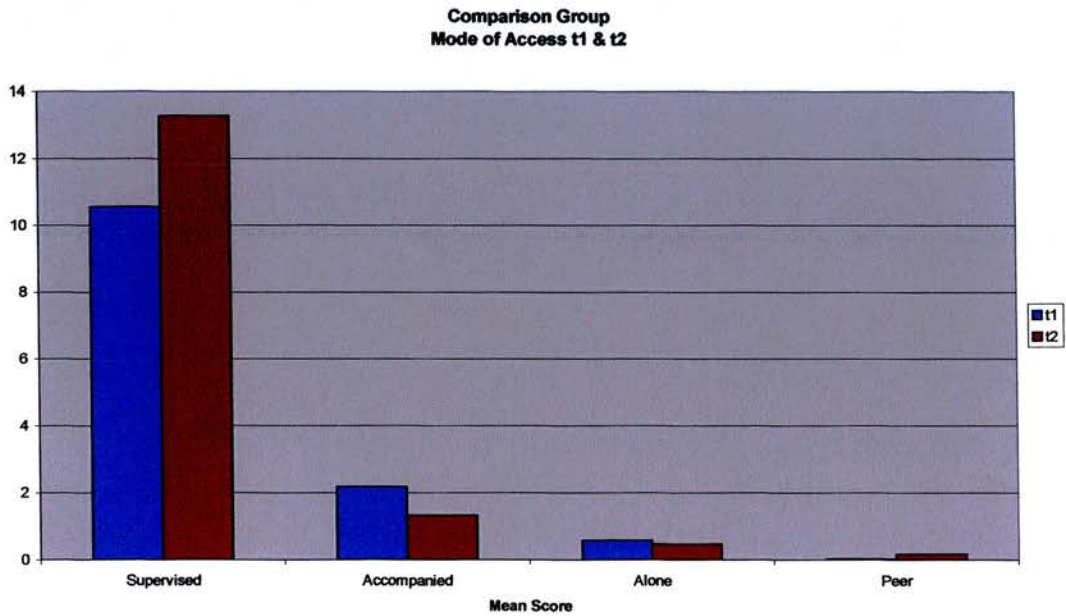


Fig 52.
Comparison group mode of access at t1 & t2

In order to test for normality of distribution, Kolmogorov-Smirnov tests were applied to Supervision, Accompanied, Alone and Peer scores for both groups. Only Supervision scores were normally distributed (t1- Kolmogorov-Smirnov $Z = .85$; $p = 0.47$; t2 - Kolmogorov-Smirnov $Z = .84$; $p = 0.47$). Accordingly, non-parametric tests were used and, in order to reduce the possibility of a type 1 error created by the number of tests carried out, a significance level of 0.01 was adopted. A series of Wilcoxon Signed Ranks tests were carried out on the mode of access scores for the resettlement group at t1 and t2. Only the Supervision score had changed significantly showing an increase $z = 4.36$; $p < 0.01$. A further analysis was carried out for the comparison group with a similar result ($z = 2.57$; $p < 0.01$).

Change scores were calculated for each individual in the four mode of contact categories. To compare the changes in scores of the resettlement group and the comparison group, a series of Mann-Whitney tests were carried out. The only statistically significant difference found was, that the magnitude of change in the Supervision scores of the resettlement group was greater than the comparison group ($z = 4.40$; $p < 0.01$). This would suggest that the increase in the number of community and in-house leisure activities for the Resettlement group were accounted for by activities and contacts that were predominately supervised.

This is further supported by an analysis of the mode of access of each individual GCPLA item accessed by either group at either time. All items were for some people at either time rated as being supervised. At t1 only one item (listening to music) for one individual was rated as being accessed with a peer group. However at t2, watching TV and videos, listening to music, participating and watching sport, walking, gardening, going to the pub and cafes/restaurants were all rated for some individuals as being accessed with peers. No obvious differences were discernible between the resettlement group and the comparison group. In the resettlement group prior to moving, one activity (indoor games) for one person was rated as participated in alone. In comparison, for individuals living in the community (i.e. the resettlement group at t2 and the comparison group) several in-house items were rated as being participated in alone including, craft, games, watching TV and video, listening to and playing music. Two individuals were reported to travel in a taxi alone. A variety of indoor leisure activities

were rated as being accompanied (i.e. staff present but not actively supervising), including craft, games, watching TV and video, listening to and playing music. This was at both t1 and t2 in both groups. Attending exercise classes, visiting the park, walking, gardening, attending social clubs and going to the supermarket were all rated as accompanied for some individuals in some circumstances with no obvious differences between the resettlement and the comparison groups.

Predicting community use of people with a learning disability

The independent variables identified were checked for intercorrelations (Table 11). The independent variable ABS part 1, place of residence and the Community Goal Rating Scale were all significantly correlated with GCPLA Range scores at t1 ($r > 0.05$). At t2 only ABS part 1 scores and GCPLA Range scores at t1 were correlated with GCPLA Range scores. Somewhat surprisingly, no significant relationship existed between BPI scores and GCPLA Range scores at either t1 or t2. It was, of course, accepted that this could have been indicative of there being no relationship between the manifestation of challenging behaviour and community use. However, this was considered to be worthy of further investigation before the null hypothesis should be accepted. This was judged to be necessary given that, in the UK, challenging behaviour is defined by reference to seriously limiting or denying access to and use of ordinary community facilities. Recent recognition of the socially constructed nature of challenging behaviour and criticism of the way in which it is assessed, concluded that

‘assessments that identify only a limited number of dimensions of impact of challenging behaviour may be insufficient to properly identify the significance of such behaviour to services and people with intellectual disabilities themselves’ (Oliver, McClintock, Hall, Smith, Dagnan, & Stenfert-Kroese, 2003). (p.53)

Clearly the BPI was limited in its consideration only of the number of behavioural topographies and the relative frequency of their presentation. Therefore a second method of identifying individuals with issues around challenging behaviour was used. Two experienced clinicians, a Speech & Language Therapist and a Clinical Psychologist who worked with the participants in this study at the t1 period were asked to rate the extent to which their clinical work with that person involved challenging behaviour issues. These were rated on 3-point Likert scale (0= no challenging behaviour

issues, 1= moderate, 2 = severe). This procedure was considered to capture the many socially constructed nuances involved in labelling of individuals as presenting challenging behaviour. It was reliant on a referral being made and accepted, hence involving the judgements of both direct care staff and clinicians.

In order to assist in this procedure, the case-notes of these people were provided to the clinicians. Inter-rater agreement was calculated for each individual in both the resettlement group and the comparison group. Inter-rater reliability of 80% was achieved. For the purposes of allocation of scores, where there were disagreements, a moderation process took place chaired by the author. The new challenging behaviour scores were positively, but not significantly, correlated with BPI scores ($\rho = 0.24$; $n=60$; $p=0.6$). Correlations between the BPI category scores were calculated, with significant positive correlations between self-injury ($\rho = 0.27$; $n = 60$; $p<0.05$) and aggression ($\rho = 0.40$; $n = 60$; $p<0.01$) and positive and approaching significant relationship with stereotypy ($\rho = 0.25$; $n = 60$; $p = 0.05$). Consequently, Challenging Behaviour Scores were calculated for each individual. However, no significant relationship was found between these scores and GCPLA Range at t1 or t2.

The Challenging Behaviour Scale was positively correlated with ABS part 1 scores, the Community Goal Rating Scale and place of residence, all of which in turn were found to be related to GCPLA scores. It is likely that these relationships are accountable for the lack of a significant relationship between GCPLA scores and measures of challenging behaviour effectively washing out an effect that would have been present. This is illustrated by fig 54, where although distribution of people rated as having no or moderate challenging behaviour issues are more or less evenly distributed across the resettlement and comparison groups, only one individual from the resettlement group is rated as having major challenging behaviour issues compared to nine individuals in the comparison group.

Spearman's rho	Range t1	Age	ABS	BPI	Aggression	Stereo	SIB	Residence	Comm Goals	CB Scale	Range t2
Range t1	1.00	-.17	.29*	-.18	-.08	.07	-.16	.50**	.31*	.04	.28*
Age	1.00	1.00	.36**	-.03	.01	-.10	-.09	-.38**	-.35**	-.26*	.08
ABS	1.00	1.00	1.00	-.05	.23	-.02	-.12	.14	.03	.29*	.30*
BPI	1.00	1.00	1.00	1.00	.48**	.81**	.55**	.10	.02	.24	.09
Aggression	1.00	1.00	1.00	1.00	1.00	.27*	.52**	.28*	.12	.40*	-.17
Stereo	1.00	1.00	1.00	1.00	1.00	1.00	.27*	.17	.07	.25	.20
SIB	1.00	1.00	1.00	1.00	1.00	1.00	1.00	.23	-.16	.27*	-.10
Residence	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	.20	.27*	-.13
Comm Goals	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	.33**	.03
CB Scale	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	.09
Range t2	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00

Table 11.

Correlations between independent variables

*. Correlation is significant at the .05 level (2-tailed)

** . Correlation is significant at the .01 level (2-tailed)

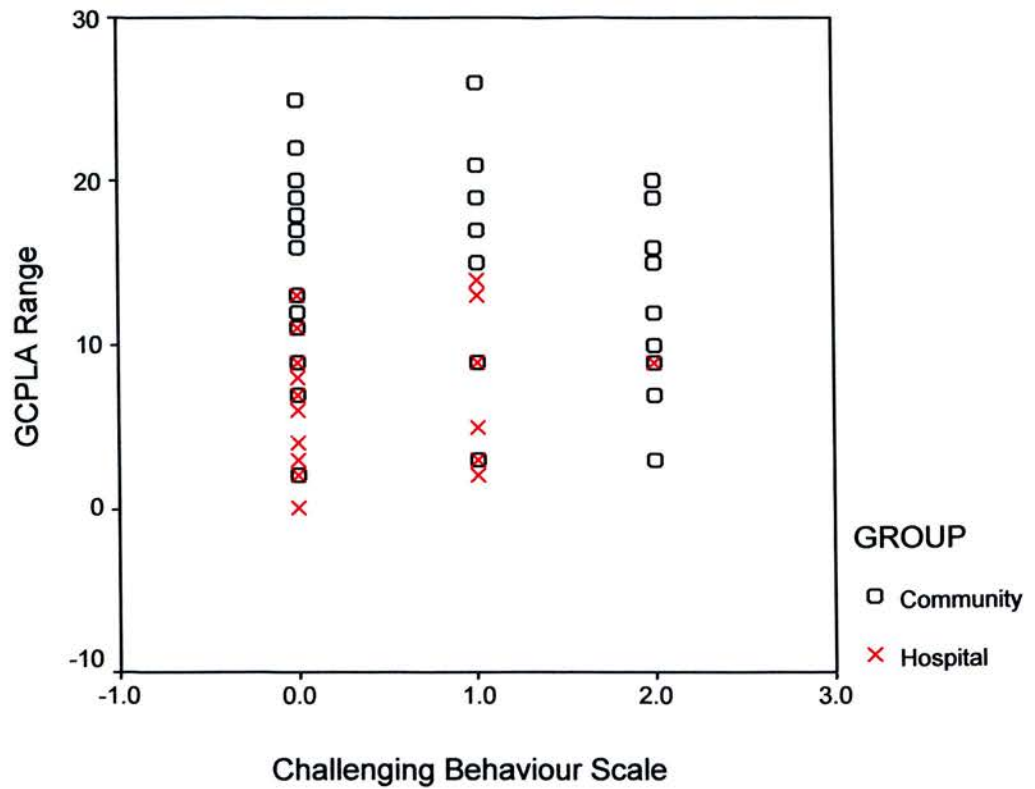


Fig 54
Scatter Plot of GCPLA Range Scores X Group X Challenging Behaviour Scale

Fig 55 reflects a similar finding in relation to the Community Goal Rating Scale which appear to be disproportionately more robust for individuals with challenging behaviour issues. For example, five out of twelve individuals in the major challenging behaviour group have robust goals compared to only one of twenty-five in the no challenging behaviour group.

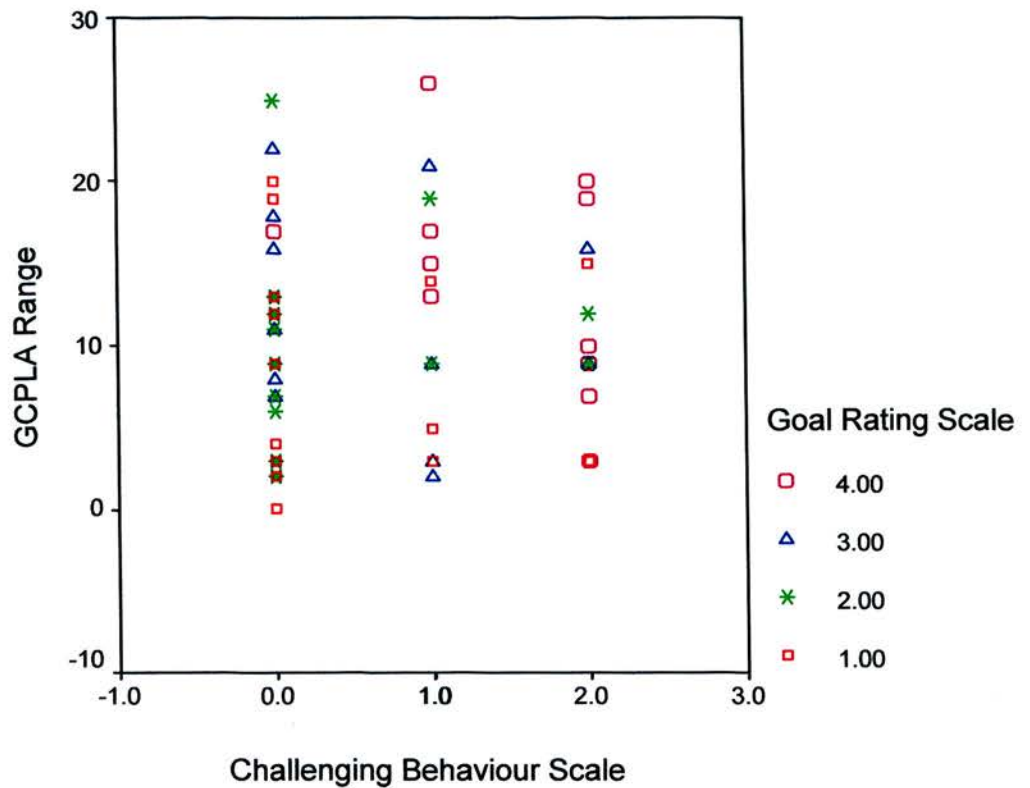


Fig 55

Scatter Plot of GCPLA Range Scores X Challenging Behaviour Scale X Community Goals Rating Scale.

Place of residence, Community Goal Rating Scale and ABS part 1 were entered in the regression analysis with the dependent variable of GCPLA Range score at t1.

Tabachnick & Fidell (1989) advise that the ratio of cases to independent variables is important, recommending 20 times more cases than IVs. In which case, the n of 60 for this analysis would be at the lower limits of acceptability. SPSS casewise diagnostics indicated that no outliers were present with a criterion of 3 standard deviations.

Previous analysis indicated that the dependant variable was normally distributed. The scatter plot of the standardised residuals against the standardised predicted values shows no obvious pattern thereby confirming that the assumptions of linearity and homogeneity of variance have been met (Fig 56).

Scatterplot

Dependent Variable: Range

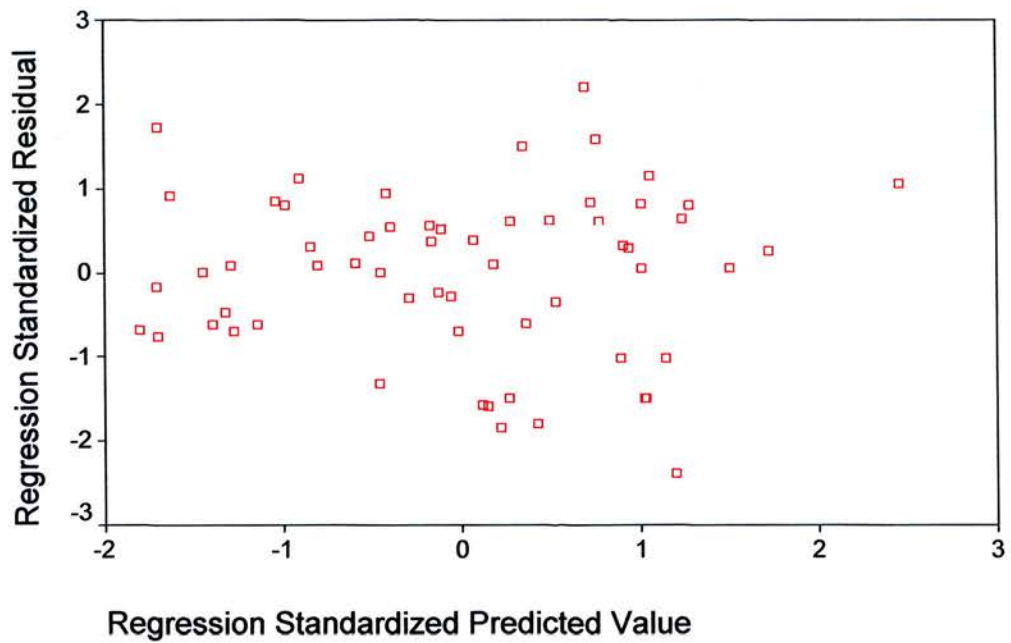


Fig 56.

Scatter plot of the standardised residuals against the standardised predicted values of the variable GCPLA Range score at t1

The results of the analysis are shown in table 12. The variables in the analysis accounted for approximately 38% of the variance in the GCPLA Range scores at t1. The multiple R was significantly different from zero: $F(3, 56) = 11.37, p < 0.01$.

Independent variables	Estimated regression coefficient (B)	Standard error of B	Beta coefficient	<i>T</i>	Sig of <i>T</i>
ABS part 1	4.470E-02	0.17	.28	2.66	.01
Community Goal Rating Scale	1.45	.63	.25	2.28	.03
Place of Residence	5.45	1.40	.42	3.89	.00

Table 12

Standard multiple regression with GCPLA Range Score at T1 as the dependent variable

A similar analysis was carried out for the GCPLA Community items as the dependant variable with place of residence, Community Goal Rating Scale and ABS parts 1 entered as independent variables in the regression analysis. The variables in the analysis accounted for approximately 43% of the variance in the GCPLA Community scores at t1. The multiple *R* was significantly different from zero: $F(3, 56) = 13.89, p < 0.01$.

Independent variables	Estimated regression coefficient (B)	Standard error of B	Beta coefficient	<i>T</i>	Sig of <i>T</i>
ABS part 1	2.828E-02	.14	.21	2.04	.05
Community Goal Rating Scale	1.35	.52	.27	2.58	.01
Place of Residence	5.45	1.15	.49	4.73	.00

Table 13

Standard multiple regression with GCPLA Community Score at T1 as the dependant variable

Discussion and Summary:

The GCPLA as a measure.

The GCPLA was designed to provide a direct comment on use of an individual's community, this is considered to be a prerequisite condition for social inclusion. It was not intended to be a comprehensive quality of life measure; neither was it designed to be a comprehensive measure of the objective conditions of a person's life. The eight dimensions of quality of life highlighted by Schalock (1996) include emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. The importance of the extent to which a person uses the community will be directly related to many of these domain areas. In particular, the dimension of interpersonal relationships and building friendships and supports is highly likely to be related to the amount and frequency of community contacts they experience. Schalock (1996) considers that the development of personal competence and engagement in meaningful activity are characteristics of the personal development domain, with both potentially related to community presence and use of leisure. Furthermore, leisure is explicitly included under his physical well-being domain. It is argued that whilst the GCPLA is not a comprehensive quality of life measure, it reflects an important key component of quality of life.

The relatively small numbers in each individual study limits the investigations of the psychometric properties of the GCPLA reported. In spite of this, the results would indicate that the GCPLA has at least the potential to be a useful instrument in the evaluation of an individual's access to their community and their use of leisure. This is especially so given the lack of available alternatives with acceptable psychometric properties and associated normative data. The instrument produces quantifiable, data enabling meaningful comparisons of individuals and groups of individuals. With the exceptions noted in the results section, it has a general proven capability to produce reliable and valid data, if used in similar circumstances to that in which the above studies were carried out (i.e., the assessment is rated by the individual, or by somebody with an adequate degree of knowledge regarding the individual). Of note is that the studies reported in this thesis have demonstrated that the GCPLA differentiated amongst certain groups. Specifically, it differentiated between people with a learning

disability and their staff and people with a learning disability living in hospital and those living in the community. This provides a useful commentary on the validity of the GCPLA.

Whilst it is important to emphasise that the GCPLA should be accessible to people with intellectual disabilities, this study indicates that a degree of caution needs to be applied in situations where people with learning disabilities are self-respondents. Several potential sources of systematic bias were in evidence. If these are apparent it would be necessary to directly address these by strategies such as cross-validation with other sources of information. The accuracy of the data is considered to be critical, any evidence of systematic bias should alert those engaged in the process of measurement. When this is the case, data gleaned from informed proxies has an important and perhaps predominant role. It is certainly not the intention here to exclude people with learning disabilities from participation in such research; rather it is argued that the nature of their participation should be given consideration. Clearly, if individuals struggle with concepts such as timeframes, and this information were available elsewhere, little would be gained by asking the individual to provide this information. In contrast, the role of the individual in determining what they consider to be important parameters of quality in their lives is considered critical and would not suitable data for proxies to make judgements. This is discussed in greater depth later in this thesis.

In summary the main uses of the GCPLA are considered to be as follows:

- i) The GCPLA enables a profile of an individual's use of leisure, and access to the community, to be developed. Such a profile used, in conjunction with a planning mechanism, will enable identification of needs, and, accordingly, will assist in the formation of a planned intervention designed to meet those specific needs. The quantifiable nature of the data will allow for objective evaluation of outcome of such interventions.
- ii) The GCPLA enables the generation of group data, thus facilitating evaluation of services on this important prerequisite condition for social inclusion.

- iii) Completion of the GCPLA within a staff training context, by staff, regarding their own use of leisure and access to the community, has the potential to enable powerful comparisons to be made between their own experiences and the experiences of service users. This could lead to insights that have may motivate staff groups in facilitating and enabling new community and leisure experiences for service users.

Normative community and leisure use and people with a learning disability

The comparison of a cohort of service users with intellectual disabilities, with a staff control group, indicated that the service users have a significantly more restricted range of activities/contacts. Previous studies have alluded to the general impoverishment of community experience of people with learning disabilities (e.g. Hayden et al.1992; Jeffree & Cheseldine, 1981; Lowe & de Paiva, 1991; McConkey et al. 1983), but rarely has this been demonstrated. This study also supports previous research which suggested qualitative differences in the mode of access of people with intellectual disabilities to their communities compared to the general population (Hayden et al., 1992, McConkey et al., 1983, Seager, 1987). These studies have found that the most common type of access of people with intellectual disabilities to their communities was supervised by staff or carers. These authors did not however attempt to define supervision. The current study has attempted to operationalise the concept of supervision. In particular, making a distinction between carers actively supervising (i.e., the onus of choice and control lies with the carer and/or a major part of the carer's attention is concerned with vigilance of the individual), and merely being present. Surprisingly few activities were consistently rated as being actively supervised; this effect was particularly pronounced for the Guernsey cohort who participated in the study comprising community use of service users with a learning disability and their care staff. This raises questions regarding the role of carers when supporting people with learning disabilities when using their communities; why are carers present for so many contacts if supervision is not required? It is a possibility that the unnecessary presence of carers could be counter-productive and may well serve as a distraction, hindering the chances of interactions taking place with other people. Further research into the role of care staff when escorting people with learning disabilities when out of the home is required, however this study suggest that carers may well benefit from, at

the very least, clarification of the roles in these situations. This is discussed later in the section of indications for future research.

The impact on community and leisure use of moving from a long-stay hospital.

Interpretation of some of the remaining results needs to proceed with a certain degree of caution. The limiting influence of factors such as the collection of data from individuals in one service in one geographical area, the unknown psychometric properties of some of the measures, and the use of multivariate analysis with simple rating scales, and small sample sizes, need to be kept in mind. Nevertheless, the results of this exploratory analysis may be considered of value in generating hypothesis for future, and more rigorous, investigation.

The data presented here would suggest that the move from hospital to the intermediate community settings corresponded with greater access to a wider range of community activities for the people involved. Similar increases did not occur in the comparison group, making it unlikely that this effect was attributable to any specific changes in general care practices that might have occurred across the whole service. A parallel increase in home-based activities did not occur in either the resettlement or the comparison groups, resulting in greater confidence in the hypothesis that these changes were directly attributable to the move from hospital and were specific to community use. This would suggest that the change in GCPLA scores represented a real increase in community use. The analysis of change at an individual GCPLA item level supports this conclusion. In particular, use of pubs, cafes, banks, post offices, hairdressers, places of worship, adult education, going to parties, visiting friends, parks, the beach, participating & watching sport, attending exercise classes all increased since leaving hospital. Following resettlement, contact/use of many of the items more closely resembled the non-disabled cohort; however, there were some significant exceptions. In particular, only 4% of the cohort had visited their neighbours; this contrasts starkly with the non-disabled cohort, of which 46% had some experience of visiting neighbours. It should be noted that none of the participants visited neighbours whilst they were living in hospital.

Some contacts appear to have decreased since the move to the intermediate community settings. Access to local shops decreased, as did the use of public transport. Several factors may contribute to this phenomena, each home was in a rural setting with relatively poor public transport links and had their own large vehicle with individual service users bussed to a purpose built day service, commissioned on block for people in the new and existing houses. Hence, there was an almost total reliance on the house vehicle for community access. The data also suggest that attendance at segregated social clubs for people with learning disabilities had decreased since the move from hospital, more individuals were not having holidays and attendance at the cinema and theatre had also decreased.

Valuing People (Department of Health 2001) highlighted the importance of access to the wider National Health Service for people with learning disabilities. The White Paper stated that mainstream services have been slow in developing the capacity and skills to meet the needs of people with learning disabilities. A specific objective in the White Paper was to have all people with a learning disability registered with a General Practitioner by June 2004. Whilst in hospital, general health needs were dealt with by the Consultant Psychiatrist and a Clinical Assistant (a part-time local GP), following resettlement the Clinical Assistant post disappeared and all individuals were registered with the GP most local to their home. This study has indicated a considerable increase in access to General Practitioners once the individuals had left hospital and, furthermore, the level of use was higher than the non-disabled cohort. Also, attendance at the local general hospital increased following resettlement. Whilst in hospital it was likely that the general nursing care of the people living there was handled by the learning disability nurses. This change may represent a shift from an arguably inappropriate form of general health delivery provided by specialist learning disability staff, to the generic services used by the general population. The apparent high rate of use of general practitioners perhaps reflects the greater general health needs of this particular group of people with learning disabilities. Of concern, given this conclusion, is that use of the district general hospital was lower than the non-disabled cohort. Clearly this requires further investigation; it is possible that staff in residential services are being asked to provide nursing care that would ordinarily be provided in hospital. The appropriateness of this would, of course, need to be judged on the standard of care provided to each person on an individual basis. It may well, however, represent a

worrying trend that may need to be challenged, with staff untrained in general nursing care being expected to carry out this function.

Whilst the overall GCPLA Range scores for home-based activities did not change following resettlement, some apparent changes on individual items were noted. The pattern of watching TV remained the same pre & post move from hospital. Of note, was that the frequency was less than the non-disabled cohort. In order to score on this item, individuals need to demonstrate that they are actively watching. Thus the difference in viewing between these people with learning disabilities and the non-disabled cohort would perhaps be due to some people in the learning disability cohort having a significant intellectual/cognitive disability thus not enabling them to do this. Whilst the pattern of actively watching TV remained the same, participation in craft and indoor games decreased. This could well reflect a move away from more institutionalised day activities. Without information regarding activities that were offered by way of replacement, it is difficult to make judgements as to whether this represented a positive innovation. The analysis of the participation in indoor games and craft of the comparison group indicated that little change had occurred. This would suggest that if this was a deliberate and planned service innovation, it was restricted to the resettlement group only, thus casting some doubt on this as an explanation and adding support to the hypothesis that this was directly related to the move from hospital.

Emerson & Hatton (1994) argued that many early studies on the effect of deinstitutionalisation were weakened, as they contained no comparison between those individuals who had left hospital and the general population. The implication being that once people were resettled from hospital, although community use increased, it remained low compared to the general population. As a result, they suggested that any improvements generally occur from a very low baseline in hospital settings. Whilst the GCPLA range scores increased significantly after resettlement, the mean score of 16 would be between the 25th and 50th percentiles in relation to the total learning disability cohort in this thesis. This score also compares poorly to the non-disabled cohort, (being on the 10th percentile) reflecting a perpetuation of a relatively impoverished range of community and leisure opportunities even after moving from hospital. Whilst for most individuals the frequency of contact in relation to many items increased, the only items that were rated as having similar contact to the non-disabled cohort were attendance at

dentists and hairdressers, listening to music, walking, going to cafes/restaurants and attending parties. Use of General Practitioners was at a higher frequency, perhaps reflecting the high levels of health need in this population, as discussed earlier.

The analysis of change in the manner in which individuals accessed community and leisure activities once they had left hospital, indicated that the majority of activities and contacts were supervised and that most of the new contacts and activities were also supervised. This perhaps gives some indication that the increases may have been as a result of a deliberate and co-ordinated effort by the service to improve community use of the service users. In addition, there was an indication that some home-based activities in the new community houses were now considered to be taking place unsupervised, i.e., being rated as alone, with a peer group or occurring in the presence of staff without active supervision. It is possible that this represents a genuine increase in independence of the service users.

The majority of studies reviewed by Emerson & Hatton (1994) reported an increase in personal competence following a move to smaller community-based residential provision. Felce & Emerson (2001) concluded, however, that these changes were also subject to a plateau effect, with people unlikely to make significant gains in the long term. They intimated that this might be due solely to increased opportunity for people to display their existing skills in the new environment. Thus the changes in mode of access to in-home activities reported in this study might not actually reflect new competencies, but rather new opportunities. For example, in the hospital environment the TV was often placed in a position that would minimise the chances of it being damaged or used as a 'weapon' in episodes of challenging behaviour. The effect would also be to place it out of reach for ordinary and appropriate usage by the residents of the hospital. Thus, the simple expedient of making it accessible, would increase independence without the necessity for a related increase in competence. Emerson & Hatton (1994) also concluded that increases on measures of adaptive behaviour found in previous studies might reflect differences in staff expectations rather than real differences in the abilities of the service users. An alternative hypothesis might then be that this change in the mode of access of in-house activity is a function of a change in either staff behaviour or perception of the nature of their role in relation to participation. It could well be that following the move from hospital staff see their role change to that of active facilitation

of participation, rather than merely being on hand to police or sort things out should they go wrong. Unfortunately, no ABS part 2 data was collected at t2 to enable further comment on changes in adaptive behaviour following the move from hospital.

Clearly, some specific service factors shaped the experience of the people who had been relocated from the hospital. In particular, the relatively remote rural or semi-rural location of the new houses and the consequent reliance on the house vehicle for community access effected the use of community facilities in the immediate neighbourhood. The perception of care staff with regard to their role in active facilitation of community participation is an area that requires further research. The results do suggest that, to some extent, staff controlled variables might well be related to leisure and community usage of those individuals in their care.

Influencing community use of people with learning disabilities.

The multiple regression analysis of factors that would best predict community access indicated that the following were the most reliable predictors of participation in community and leisure activities.

- not living in an institution,
- having relatively higher levels of adaptive behaviour and
- having individually written community access goals encompassing specificity of activity/contact as well as specific conditions and time frame for attainment.

Together these variables accounted for 38% of the variance in GCPLA Range scores. The same variables also accounted for 43% of the variance in scores specifically related to community activities/contacts.

The reported relationship between living in an institution and community and leisure use is consistent with the findings of previous research in this country (Emerson & Hatton, 1996) and elsewhere (Conroy, 1996, Stancliffe and Lakin, 1998, Cummins, 1993b). This is also in keeping with the effect of moving people out of institutions on their community and leisure use reported earlier in this thesis. In addition, the finding that those individuals with higher assessed adaptive behaviour enjoyed greater

community use supports the findings of previous UK research (Emerson et al., 2000b; Felce et al., 2000; Perry et al., 2000), with Stancliffe & Lakin (1998) in the USA and Cummins (1993b) in Australia finding similar associations.

It has been assumed in the case of people who do not organise and undertake their activity independently, that the way in which staff support activity would be key. A large amount of evidence has been gathered that would indicate a strong relationship between general engagement in activity and the receipt of some form of staff attention. Felce et al. (2000) and Perry et al. (2000) demonstrated that apart from adaptive behaviour, the extent of staff attention was the biggest predictor of resident engagement in activity. Moreover, various studies have suggested that the nature of this contact is key, with staff behaviours that resemble active facilitation being associated with greater levels of engagement (Felce et al., 1999 & Emerson et al., 2000a). Essentially, a service-related variable has been shown to go some way to mitigate the effects of the service user's level of disability. These findings would suggest that potentially controllable service variables may assist in the achievement of such outcomes for people with greater support needs and have encouraged the teaching and dissemination of Active Support.

This study has demonstrated a similar relationship between the robustness of the written goals in a service user's individual plan and the person's use of leisure and community activities. It remains unclear if this effect is directly attributable to the written goal *per se*, as there may be other related factors that might contribute to this phenomenon. For example, it is likely that those individuals with well-written goals may also benefit from other service related factors that would bring about greater leisure and community use. Also, the finding reported in this study that the people who presented challenging behaviour were more likely to have robust community and leisure goals is of interest and would be worthy of further investigation. These findings add support to Emerson et al. (2000b) and Hatton et al. (1996) who found that greater community use was predicted by greater emphasis on planning activities. Essentially this is a demonstration that good paperwork might indeed be able to contribute to genuine increases in quality of life of people with learning disabilities. Guidance and training on goal planning is readily available (e.g. Greasley, 1995) and, within the context of training in Active

Support, have been shown to have a positive effect on staff behaviour in terms of increasing levels of engagement in activity of service users (Jones et al., 2001).

One of the central components in the implementation of Valuing People (DOH, 2001) is that people with learning disabilities should have their needs and preferences highlighted through Person Centred Planning (PCP). The Guidance for Partnership Boards issued by the Department of Health (2001) emphasises the importance of the construction of plans from the service user's own perspective. This reflects the perceived failure of services to attend to those things that matter to the individual service user. PCP is presented as a radical departure from previous ways of planning for individuals with learning disabilities. This guidance has facilitated a large-scale programme of training and implementation, with PCPs for people who continue to reside in long-stay hospitals deemed to be a priority. Of note, is that performance management of this process appears to focus on the number of plans produced rather than the quality of the plans and the extent to which they are implemented. Whilst the emphasis on individualisation and focus on that which is of importance to the individual is laudable and timely, little direction is given by the Department of Health to the process of writing the goals. Mansell & Beadle-Brown (2004) in their critique of PCP highlight the importance of training staff to produce goals in a way that emphasises action that could make a tangible difference in the lives of people with learning disabilities. It is difficult to imagine how this can be realistically achieved without specificity of the goal and the delineation of the specific conditions and time frame for attainment.

Limitations of this study and implications for future research.

Reliability and validity of the GCPLA

This study has attempted to highlight the importance of community and leisure use for people with learning disabilities. This is considered to be a key outcome in any evaluation of services offered to this group of people. The need for a psychometrically robust measure with normative data is stated, and the efforts to develop such a measure are described. This measure has then been used as part of an evaluation of a closure of a small learning disability hospital, and the subsequent resettlement of a group of people

with learning disabilities. Data from this evaluation has been further used to attempt to identify both individual and service factors that might predict, and thus influence, use of community and leisure facilities.

The small sample sizes involved in all aspects of the study only point to the potential of the GCPLA as a useful, psychometrically robust instrument with normative data. In addition, the participants who have provided data have lived, in the main, in Guernsey and Sussex, and the extent to which these norms are a valid source of comparison to other locations or circumstances is uncertain. The inclusion of items relating to indoor leisure in an instrument predominately focussed on community based activity is open to question. However, the original purpose of the GCPLA was to reflect both community and leisure experience. The examination of content validity did not indicate that this category was problematic for the expert raters. Indeed, the flexibility to score the GCPLA with in-house activities taken out provides a potentially useful source of comparison data. Perhaps, in order to make this easier, the instrument should perhaps be revised. Future research would involve the collection of additional data from more diverse geographical areas and cultures to ensure wider representativeness.

The concept & measurement of community use

This thesis has focussed on community use as an important aspect of quality of life and it has been argued that this is an essential prerequisite condition for social inclusion. This is a logical rather than an empirically based argument. O'Brien's (1987) five service accomplishments included two that related to community; presence and participation. Implicit in this is the notion that a person may be physically present, yet not participating in the life of their community. The concept of community use is perhaps one stage further on from community presence and indicates more active involvement. This thesis along with much other work has accepted the importance of community participation as a gold standard, with little questioning as to whether this is an end in of itself or a means to an end. The more recent concept of social inclusion perhaps could be considered the ultimate standard, whereby the person with a disability is included as a valued participant in reciprocal relationships with people who are not obligated to spend time with them through either family connection or paid employment. A measure of social inclusion would of course be the ideal. This would

reflect the complex interactions between the person with a learning disability and those with whom they share their world, and the subjective experience of all those involved. Clearly a measure of community use only represents a small, yet vital, part of the process of social inclusion.

Cummins (1997) was very critical of the assessment of objective conditions of quality of life and he described instruments such as the GCPLA as a 'traditional' approach to quality of life for people with learning disabilities. He stated that there are various problems with the interpretation of such data limiting their usefulness, in particular stressing that the person's perception and satisfaction with their life circumstances is of greater importance. Accepting this criticism along with the finding reported earlier that the level of adaptive behaviour influences levels of use of community and leisure facilities, would indicate that more research is required that would examine the relationship between community use and the more subjective aspects of quality of life. In particular, this should focus on individuals for whom use of their communities might well have high associated costs. For example, some people with physical disabilities may well experience unacceptable physical discomfort or pain when out of the home, similarly some individuals with problems associated with autism might experience high levels of anxiety whilst accessing their communities. In such situations, this could well lead to questioning whether 'normative' use of their communities represented a quality lifestyle for these individuals. This highlights the importance of considering the individuals subjective evaluation of the value of certain experiences. As argued earlier in relation to the measurement of social inclusion, a simple measure of community use fails to take into consideration subjective evaluation of importance of the person's experiences. The difficulty in accessing such subjective information however, should not be underestimated, and continues to present a major challenge to researchers in this field.

The failure to consider the complexity of social inclusion and to consider subjective quality of life could be considered to be a significant shortcoming in this thesis. However, there is some justification. As argued in the discussion, the goal of developing a measure that effectively deals with subjective as well as objective aspects of quality of life has not been met and indeed, several leading exponents have given up this quest (Cummins, 2002; Schalock, Verdugo, Wehmeyer, & Jenaro 2004). One of the

principle difficulties has been the lack of correlation between objective lifestyle and subjective satisfaction, with the almost universal phenomena that people, virtually irrespective of their circumstance, will rate themselves as more or less satisfied with their quality of life. This is particularly the case in people with learning disabilities, who, have been socialised into being very grateful for any service offered, perhaps for fear of the service being withdrawn and being left with nothing. The importance of subjective information is indisputable, especially on an individual basis. The difficulty arises in terms of how useful it is, especially when dealing with groups of people. Furthermore, the subjective data for a significant number of people with learning disabilities is inaccessible due to either cognitive or communication difficulties. Whilst good practice guidelines are available regarding effective ways in which to elicit the views of service users, there will always be some people for whom it will be impossible. It was argued in the introduction that attempting to seek views from proxies regarding the importance of specific community contacts or satisfaction experienced with any aspect of quality of life of a person with a learning disability is unacceptable. These are significant obstacles that perhaps provide a somewhat pragmatic justification, at least in the short to medium term, for the place of measures such as the GCPLA.

On a related note the difficulties experienced in eliciting reliable GCPLA data from people with learning disabilities raises serious questions regarding using its use by them as self-respondents. Hatton (1998) raised similar concerns regarding the inclusion of subjective data from people with learning disabilities. He cited evidence that, in spite of the well intentioned belief of interviewers that they are asking questions in a disinterested fashion, people with learning disabilities regarded quality of life interviews as tests of their fitness to remain in community based houses, rather than as research interviews about their lives and preferences. This would create clear non-random error, indicating inflated levels of expressed satisfaction with community life. These response biases were, to some extent, evident in the responses of the people with learning disabilities who took part in the inter-rater reliability study. They tended to confuse their actual participation with desired participation, exhibited a bias (presumably based on social desirability) in favour of overstating participation in activity and did not differentiate between friends and paid carers. In addition, presumably due to cognitive limitations, many had difficulties in evaluating time periods and frequency of contact. As argued earlier, if the reliability of the data is to be

compromised, through cognitive or communication difficulties or social desirability bias, perhaps the measure would be best completed by carers. This is certainly not to exclude participants from the research process and subjective views should be sought when they are available.

Generic measures of quality of life

The development of measures to assess quality of life in people with learning disabilities has, thus far, had little influence from more generic attempts. As a response to dissatisfaction with traditional medical outcomes such as mortality and morbidity, The World Health Organisation has sought to devise a measure of quality of life that is psychometrically robust with a broad range of potentially independent domains. This major international multi-centre effort resulted in the development of the WHOQOL (1995), WHOQOL-100 (1998) and the shortened version the WHOQOL-BREF (Power, 2003). The initial focus of these instruments was the evaluation of quality of life in relation to health interventions. The WHOQOL has been applied generally in the field of mental health (Orley, Saxena & Herrman, 1998), in particular schizophrenia (Orsel, Akdemir & Dag, 2004), depression (Angermeyer, Holzinger, Matschinger & Stenger-Wenzke, 2002; Skevington & Wright, 2001) and psychosis (Herrman, Hawthorne & Thomas, 2002). In addition, adaptations have been made to render the WHOQOL applicable to young children (Jirojanakul & Skevington, 2000) and people with HIV/AIDS (WHOQOL Group, 2003). Further research could identify the applicability of these measures in relation to social care oriented interventions, and, in particular, focussed upon issues pertinent to people with learning disabilities. The proviso of such developments would be that the issues and difficulties surrounding assessment of quality of life in this population discussed earlier would need to be dealt with. People with learning disabilities could potentially benefit from aspects of the enormous amount of work thus far carried out that might generalise to their situations. In particular, this would allow crossover of lessons learned from interventions designed to improve quality of life in a number of related health and social care fields.

Generalisability of the findings regarding deinstitutionalisation

Mount Pleasant was one of the last of the hospitals to close. It had specific idiosyncratic features that may cast some doubt as to the generalisability of the findings of this study. The hospital was small, with only 34 people living there, in relatively small wards, with no more than 12 people living on a ward. The hospital was in the middle of an urban area with easy access to community facilities. It could be argued that these factors contributed to it being a relatively 'good' environment in relation to the standards set by the large institutions. Also, the staff group were, in the main, people who had chosen to work in the hospital rather than the many community based services where employment was potentially available. Any such changes in patterns of service or outcomes need to be judged in this context. Little specific information is available regarding the remaining hospitals to be closed in the UK, although as argued earlier, they are likely to have significant differences in relation to the first wave of institutions closed on which the vast majority of the literature in this area is based.

Implications for social policy in relation to people with learning disabilities

The policy to shift the care of people with learning disabilities away from large hospitals is unlikely to be reversed, with recent figures from the Department of Health indicating that in England only 700 people remained in hospitals (Emerson 2003). The balance of evidence would appear to indicate that this policy has been broadly successful in bringing about improvements in a number of key aspects of quality of life of those individuals resettled. Life in the community tends to be associated with more home-like and better material environments, increases in adaptive behaviour, more extensive participation in activities of daily living and greater involvement in leisure and community activity. Cause for complacency has however been questioned, with some arguing that institutional standards have not provided an exacting benchmark by which to judge community living (Lindsay, 2002). It is also apparent that there is a greater variety in the reprovided services than originally assumed. Emerson (2003), in an analysis of NHS long-stay and residential provision in England, found that of the fourteen NHS organisations that gave information on the location/clustering of residential places, four had some provision clustered on an institutional site and eight had some provision clustered (rather than dispersed) in a community setting with 25%

of people living with nine or more others. Also of note, was that three organisations appeared to have plans for the development of campus-style facilities. This is of particular concern given the evidence that appears to indicate that such provision is more costly and is associated with poorer outcomes for service users (Emerson et al., 2000b). Thus it may well be the case that, in the medium-term future, a major secondary deinstitutionalisation programme will be required in order to move people into services more genuinely based in the community.

It was argued in the introduction that one of the principle driving forces behind the hospital closure programme were the series of scandals concerning neglect and abuse in the large hospitals. The institutions were closed to correct this social injustice and the outcomes in relation to quality of life have only been added latterly by social scientists who were given responsibility to evaluate deinstitutionalisation. This would go some way to explain the piecemeal nature of the programme and the historical lack of guidance from central government. As community care budgets come under increased pressure, authorities are likely to discard the quality agenda and be motivated by keeping within the budget and avoidance of complaints. In this context, the community presence of people with learning disabilities may serve a major protective function. It can be argued the one of the principal setting conditions for abuse and neglect in the large institutions was being away from public scrutiny. Being present in the community means that the general public are potentially on hand, at least to some extent, to police the standards of care being offered. In addition, coming into regular contact with people with learning disabilities will keep issues regarding standards of care of people with learning disabilities in the public's consciousness.

Service types and characteristics are crucial determinants of quality and this is particularly illustrated by the suggestion made earlier, that one of the key factors in shaping the community and leisure experience of the people in this study appeared to be the geographical location of their new residential services. All were in relatively remote, semi-rural locations, with restricted access to local facilities, necessitating reliance on the service's car. These vehicles were generally people carriers, chosen specifically to allow transportation of large numbers of people. In the case of Mount Pleasant Hospital, in comparison, the hospital was in an urban environment with easier access to local facilities. The reality for these individuals was a loss of opportunistic community access

to local facilities, where the people were often known and considered to be valued customers. This is in contrast to group (i.e. 3-6 people) organised community access which is less likely to be individualised and more likely to be stigmatising. Those responsible for planning and designing the remaining hospital closures and the reprovisioning of existing community services need to take heed of these factors when deciding the geographically location of residential services for people with learning disabilities.

The association between the robustness of community and leisure goals and GCPLA scores reported in this study is encouraging. This suggests that the way staff support activity is crucial. This finding is particularly pertinent given the current attention to Person Centred Planning. The exponents of PCP intend its introduction to be a paradigm shift in the way in which services are organised for people with learning disabilities. Unfortunately, it is often the case that those who are charged with responsibility to shift paradigms, feel the necessity to denigrate all that has gone before. It is crucial, in the case of the implementation of PCP, that throwing babies out with bath water is prevented. The introduction of PCP is an enormous task that is likely to be beset by political difficulties. In particular, Mansell & Beadle-Brown (2004) suggest that if PCP did become at all widespread, cost-control mechanisms would be developed to constrain it within financial limits. This makes it imperative that a robust and balanced approach is taken whereby all elements of planning that make for good outcomes and process are given sufficient weight and consideration including;

- the service users aspirations,
- mobilisation of a wider social network,
- emphasis on support and
- clear delineation and operationalisation of individual goals.

Future research

The data in relation to this cohort is invaluable and a follow up would yield information regarding the durability of the effects discussed. In particular, data in relation to community use could be obtained along with challenging behaviour, adaptive behaviour, and a range of service factors.

The GCPLA requires reformatting and restructuring to enable data relating to in-house and community activities to be more easily discernible. Larger samples are required of both people with learning disabilities and non-disabled people. Every effort should be made to ensure these samples are as representative as possible. These larger more representative samples would enable more robust normative data to be produced. This would also make possible the isolation of individual and service factors that would best predict community use and analysis of data at an individual item level.

It was suggested earlier that care staff's perception of their role in relation to supporting individuals with a learning disability may well be a key factor in determining the nature of the care provided, in particular little is known regarding the expectations and definitions of roles care staff have when escorting people with learning disabilities outside of the home. This is an area that requires further investigation.

Active Support has delineated service factors that will facilitate engagement in meaningful activity. In the main this literature has been confined to activity within the home. Little practical help is available for carers in relation to community use. There is some evidence that community presence is relatively easily achieved. For example, many services would claim that the people they serve go shopping, a reality may well be that the person is sat in a mini-bus in the supermarket car park, or drinking coffee in the supermarket restaurant. Research is required to provide carers with practical guidance in relation to what to do to achieve more genuine social inclusion and this may well require being more strategic in use of the community, in order to maximise the opportunities for reciprocal relationships to build.

The incidental finding that individuals who present challenging behaviour were more likely to have more robust community goals in the individual plans is interesting. It is commonly assumed that individuals who present challenging behaviour get a less good deal from services. However, this finding appears to challenge this assumption and would appear to indicate that the presence of challenging behaviour issues perhaps is a predictive factor in services taking more care in planning for such people. This is an interesting hypothesis that is worthy of further investigation.

This study found that the use of general hospitals by the resettlement group was less than the non-disabled cohort. This was in spite of evidence that they had greater health needs. This finding was based on analysis at an individual item level of the GCPLA and should be treated with great caution. If this finding were to be replicated this would be a cause for great concern and is indeed worthy of further investigation.

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Appendix 1

Baker, P. Measurement of Community Participation and Use of Leisure by Service Users with Intellectual Disabilities: The Guernsey Community Participation and Leisure Assessment. *Journal of Applied Research in Intellectual Disabilities* 13 (2000): 1-18.

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Measurement of Community Participation and Use of Leisure by Service Users with Intellectual Disabilities: the Guernsey Community Participation and Leisure Assessment (GCPLA)

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Community integration is now an important principle guiding service provision for people with intellectual disabilities. However, it has been argued that research has contributed little in the way of guidance and that this is mainly because of the lack of appropriate measures. The Guernsey Community Participation and Leisure Assessment (GCPLA) is described in the present paper. The GCPLA is a comprehensive assessment of community participation and the use of leisure that produces both quantitative and qualitative data. Data are presented which suggest that the instrument is potentially both valid and reliable. A study comparing use of their community by service users and a staff control group showed that the service users had a smaller range of activities, were less busy (i.e. took part in fewer frequent activities), and were more likely to access their communities in the presence of staff or carers, rather than alone or with friends. Suggestions for the use of the GCPLA are discussed including individual planning, service evaluation and training.

Introduction

The closure of institutions and the emphasis on community care has meant that the community presence of individuals with intellectual disabilities is now an evermore likely circumstance. However, it has been argued that community presence is not the same as community participation and that an individual with an intellectual disability needs to do more than merely physically reside in a community to be part of that community:

'One of the most misleading and damaging misinterpretations of the normalization principle is that moving people into the community will solve the issue of social integration automatically.' (Brown & Brown 1987; p. 10)

Initial research on community living tended to focus only on those individuals who had been resettled from hospitals, and conceptualized adaptation to community living in very broad terms, success or failure being measured by whether the individual needed to be readmitted into hospital (e.g. Hemming 1982). Kennedy *et al.* (1990) suggested that, although there was extensive discussion about the importance of assisting

people with disabilities to develop and maintain satisfactory social lives, there was little empirical evidence to guide families, service providers and researchers. The above authors went on to suggest that this paucity of information was partly a result of the lack of appropriate measures.

Although various methodologies have been employed in the measurement of community participation and the use of leisure, a range of problems exists with them.

The use of simple activity diaries would appear to have a good deal of face validity and they have been used in several studies (e.g. Walsh *et al.* 1988; Halliday & Woolnough 1989; Hewson & Walker 1992). Moreover, Joyce *et al.* (1989) found poor levels of agreement in their comparison of diaries with direct observation, with accuracy dependent on the behavioural characteristics of the people being studied, and suggested great caution in the use of diaries as a source of evaluative data. It is important to note that no reliability data were collected in these studies. Hewson & Walker (1992) and Walsh *et al.* (1988) collected data over relatively short periods of time (one week and 2 days, respectively). Although reducing problems associated with observer drift, this unfortunately produced problems with the representativeness of the data, minimizing the possibility of recording anything other than very frequent community contacts or activities. However, the Halliday & Woolnough (1989) study did collect data over a more prolonged period, allowing a more accurate representation of the individual's experiences to be obtained. The data were derived from diary records and categorized using a list of 25 community and four segregated contacts/activities, thus potentially increasing reliability.

Direct observation would be more likely to give a more accurate indication of the individual's experience. However, the practicalities involved, especially the length of observation time required to obtain a reasonable sample of the individual's typical experience, often causes problems. In order to overcome this difficulty, methodologies are often selected which involve observing for brief periods or the use of time sampling (e.g. Johnson & Bailey 1977; Mansell 1994). Unfortunately, problems then arise with regard to validity, i.e. with brief observation periods there is an increased probability of errors where the contact or activity is infrequent or of short duration (Harrop *et al.* 1994). The required use of a limited number of predetermined categories of behaviour and classification of activity under very broad categories will inevitably limit the extent to which such data comprehensively represents a true reflection of the individual's use of the community and their leisure activities. In addition, the extent to which comparisons across studies involving different methodologies can be made may also be impaired. The concept of engagement used in such studies has also attracted some criticism, Sturmev & Crisp (1994) considered that definitions of engagement failed to recognize qualitative differences between types and varieties of engaged behaviour. Joyce *et al.* (1989) have also argued that, as services become more individual, direct observation becomes more intrusive. This increases the likelihood of reactivity as well as raising concerns about the acceptability of such procedures.

Given the difficulties associated with diaries and direct observation, the use of questionnaires or structured interviews to measure community participation or access to leisure has become popular.

McConkey *et al.* (1983) used a structured interview format to ask people with intellectual disabilities about contacts with people in their communities. The interview sought to establish which of the contacts were recent and who accompanied the respondent. The contacts appear to have been limited to certain service sector job cate-

gories. The above study did not present criteria for the contacts, and neither did it present reliability, validity or normative data. However, the study gave some indication that only a minority of respondents had diverse or recent contacts and even fewer have the companionship of a friend.

Seager (1987) adapted the format used by McConkey *et al.* (1983), increasing the number of contacts to 35 and expanding the notion of contacts to include activities. Seager (1987) differentiated types of contact as alone, supervised or with a peer group. Operational definitions for non-self-explanatory contacts were provided. The above study also found low levels of peer companionship, with supervised contacts far outnumbering those made with peers. The number of contacts was significantly higher and less supervised for people living away from the parental home. In order to minimize threats to reliability associated with the individual's intellectual disability, participants were selected on the basis of tested ability with number and time. Unfortunately, methodological difficulties did not allow investigation of reliability, validity or the generation of normative data.

Lowe & de Paiva (1991) in their evaluation of NIMROD, a community-based service for people with intellectual disabilities, devised an interview schedule whereby carers were asked about the frequency of contact of the person with an intellectual disability with 18 types of community facility. In addition, carers were asked about the frequency of contact of those living in residential services with their relatives, as well as frequency of contact with friends for all participants. Acceptable intracoder and intercoder (using taped interviews) reliabilities were found, as was inter-respondent reliability (with two carers independently interviewed). A comparison of the number of contacts with community facilities was made between those in receipt of the specialist service, and hospitalized and community-based comparison groups.

Hayden *et al.* (1992) sought to examine the social roles and activities of people with intellectual disabilities living in foster homes and small group homes. Direct care staff were asked to rate frequency of contact of the person with an intellectual disability with regard to 28 leisure activities. Each item was analysed separately with significant differences reported, where found, between foster and small group homes. Again, the majority of participants (80%) were reported to require supervision. The proportion of activities accessed with different type of support was not reported, although the study did reveal that, typically, participants used their communities supervised and with other people with intellectual disabilities. Again, validity, reliability and normative data were not reported.

In an evaluation of the costs and quality of community care for adults with intellectual disabilities, Raynes *et al.* (1994) used the Index of Community Involvement (ICI; Raynes & Sumpton 1986). This consists of 15 items; 14 of these ascertain whether clients have used specified facilities in the community within the past 4 weeks and one relates to going on holiday in the previous 12 months. Direct care staff completed the ICI, with mean scores established for each service. No significant differences were found between local authority, health authority, and private or voluntary sector services. Although acceptable internal reliability was reported, no indication of test-retest or inter-rater reliability, or normative data were given. In addition, the Yes/No format, although sensitive to range of events, would not give any indication of frequency. Felce *et al.* (1998) modified the ICI to broaden the detail of social activities and to make it sensitive to frequency with acceptable inter-rater reliabilities reported.

In a series of studies investigating the longitudinal effects of the deinstitutionalization of a group of people with severe or profound intellectual disabilities (Stancliffe & Hayden 1998; Stancliffe & Lakin 1998), a variety of instruments were used to assess community contacts, integration and activities. Care staff were asked to indicate the number of community settings used by the service user from a list of 23, and the number of social activities participated in the previous 30 days from a list of 20. Similarly, community integration was measured by the use of a seven-item scale of individual social activities during the preceding 6 months. The above authors found that individuals who remained in state institutional settings experienced substantially poorer outcomes on all measures. The greater the size of the residence and their status as private compared with state settings were both associated with poorer outcomes. However, the comparisons were no longer significant following adjustment for differences in adaptive behaviour as a covariate, with individuals who had milder intellectual disabilities enjoying greater community presence and integration. Individuals who remained in institutions following downsizing experienced decreased community integration.

The Life Experience Checklist (LEC; Ager 1990, 1998) has been developed as a broad measure of quality of life. It does not attempt to measure subjective well being, but rather, the activities and experiences of the respondent. It was designed to be applicable to the broadest range of individuals with normative data provided for a general population sample in addition to populations of people with intellectual disabilities. Validity and inter-rater reliability data are reported, along with test-retest data using a group of undergraduate participants.

The use of questionnaires or structured interviews to measure community participation or access to leisure has obvious appeal. These instruments are able to sample meaningful time periods, have fewer problems with intrusiveness and reactivity, and are easier to administer. However, face validity is decreased, thus making it essential that reliability and validity data are reported. The use of questionnaires and structured interviews also enables the production of readily quantifiable data. In addition, normative data can be produced enabling direct comparison of the experiences of individuals or groups of individuals. Many of the above studies have realized one of these opportunities, but only the LEC (Ager 1990, 1998) is quantifiable, and has published reliability, validity and normative data. However, the LEC is a broad-based quality of life measure, and it contains only a few items relating to community presence and participation. These are imbedded within the checklist, which also includes many items concerning the individual's subjective experience. This makes analysis of data specifically pertaining to community activity difficult.

A means of obtaining reliable, valid and quantifiable data reflecting an individual's experience of community participation and use of leisure is considered to be potentially useful and important. Data generated should enable comparison of individuals and groups. In particular, normative data from a non-disabled sample is considered of critical importance. Data pertaining to such a relatively culturally valued comparison group will aid direct comparison of data generated from assessments of people with disabilities. The unavailability of such a measure has led to difficulties in interpretation of data from different sources. For example, in their review of studies related to the effects of relocation from hospital to community-based services for people with intellectual disabilities, Emerson & Hatton (1994) suggested that, although improvements in community presence were noted, these generally occur from a very low baseline in

hospital settings. The existence of 'normative' data would have enabled wider and more valid comparisons.

Stancliffe (1999) highlighted the importance of gaining accounts from people with intellectual disabilities themselves regarding the quality of their lives. Therefore, it is considered important that any means of gaining information should be accessible to the self-report of people with intellectual disabilities. Only if the individual is unable to be interviewed should it be considered acceptable practice to ask a proxy to respond on the person's behalf. However, Stancliffe (1999) cautioned that proxy data are not a substitute for self-reports, and the two data sources should not be treated as being interchangeable.

The present paper describes the Guernsey Community Participation and Leisure Assessment (GCPLA; copies available from the author), an instrument designed to gather reliable, valid and quantifiable data pertaining to use of community and leisure facilities quickly and effectively. Its development, administration and scoring procedures are described, along with an investigation of reliability and validity. Data are presented which enable a comparison between individual scores and group scores including individuals with and without intellectual disabilities.

Materials and methods

Development of the GCPLA

The original purpose of the GCPLA was to support an individual planning system in the assessment and generation of community participation and leisure needs, and to monitor the outcome of interventions designed to increase and enhance the individual service user's experience of community and leisure activities.

Seager (1987) developed a structured interview designed to elicit quantifiable data pertaining to community contacts. This consisted of a checklist of 35 potential contacts arranged under six categories of activity. The GCPLA is a modified version of Seager's (1987) structured interview, containing the six categories and expanded to 49 operationally defined contacts (see Table 5). These categories and items were selected via an initial consultation process with care staff who were asked to inspect Seager's (1987) items and suggest additional items which might represent everyday activity. The individual or carer is asked to indicate the frequency of contact or participation over the previous 6-month period and rate this on a five-point scale:

- 1 less than every 3 months;
- 2 every 3 months or more frequently;
- 3 monthly or more frequently;
- 4 weekly or more frequently; and
- 5 daily or more frequently.

Qualitative data are collected by asking the respondent to provide details of the most usual type of contact. This is coded as:

- 1 *supervised*, i.e. the onus of choice and control lies with the carer, and/or a major part of the carers attention is concerned with vigilance of the individual;
- 2 *accompanied*, i.e. with carers, but not supervised;
- 3 *alone*; or
- 4 with a *peer* group.

The inclusion of the category 'accompanied' (i.e. 'being with a carer but not supervised') was found to be necessary since this reflected a reality for large numbers of individuals living both in residential provision and at home.

Administration and scoring

Although the GCPLA is a checklist, it is intended that it should form the basis of a semi-structured interview of the client's perception of their experiences. Only in those situations where the individual has insufficient language skills are carers expected to answer on behalf of the individual.

A representation of the amount of contact is obtained by calculating the range score, i.e. the number of activities/contacts rated as being accessed every 3 months or more frequently. An indication of the number of very frequent activity/contacts is of related interest. This is derived by calculating the number of contact/activities rated as occurring more frequently than weekly. A representation of the typical mode of contact is obtained by adding the number of items accessed more frequently than every 3 months scored in each category of type of access (e.g. How many items does the individual access with a peer group or alone?). In addition, a more detailed profile can be achieved by a separate analysis of community activities/contacts and in-home leisure activities.

The following examples illustrate the use of the GCPLA.

Example 1

J.O. is a 40-year-old woman who lives on her own in a flat in a high-rise block of flats. She attends the local social education centre and has recently started a supported employment placement in a supermarket. J.O. receives five hours of time from a support worker from the local community learning disability service. The important people in her life are her boyfriend and her parents. Although living away from home, J.O. has a great deal of contact with her parents, especially at weekends, when they will expect to see her on both Saturday and Sunday. Her range score of 26 would indicate a wide variety of community leisure activities and community contacts. This score is higher than the mean score of the non-disabled control group. The main difference between her profile and that of the controls is the type of access. J.O.'s peer score of 5 is considerably lower than the 21.6 achieved by the non-disabled control group, indicating a limited range of activities participated in with friends. This is also reflected in her accompanied score of 6, which mainly represents community activities participated in with her parents. Completion of the GCPLA highlighted the extent to which much of J.O.'s community activity may have been designed to please her parents and accounted for the consequent diminished amount of time spent with her friends.

Example 2

C.K. is a 37-year-old woman with severe intellectual disability living in a National Health Service (NHS) house with five other people. She exhibits severe challenging behaviour, including self-injury, faecal smearing and episodes of uncontrollable distress. Her range score of 4 includes only three activities/contacts in the community: swimming, going to the beach and walking. Only one indoor activity is represented, i.e. listening to music. All activities are rated as supervised with the exception of listening to music, which C.K. does alone. The GCPLA highlights her impoverished experi-

ence of her community and her reliance on staff to enable the little access she has. The implications for service planning would indicate an enormous potential for increasing her access to community and leisure activities.

Example 3

A.B. is a 34-year-old man with severe intellectual disability living in a NHS house with five other people. He is occasionally prone to severe bouts of aggression toward others, which in the past has led to hospitalization of a staff member. His range score of 21 is high, falling between the mean scores for service users and staff controls. This is achieved by a good deal of vigilance, as is represented by his supervision score of 20. A.B. has only one activity recorded as alone, an indoor activity; five activities/contacts are accessed with friends, both scores being similar to the service user means. Whilst, in many respects, the high range score is achieved as a result of a well-organized service, it was suggested to those involved in planning this man's service that they seek to reduce the amount of supervision, whilst maintaining the level of community access and use of leisure.

Results

Inter-rater reliability

Inter-rater reliability was examined with the assistance of 12 individuals with intellectual disabilities living in two, six-bedded NHS residential establishments in the Hastings area of the UK. The subjects' ages ranged from 20.2 years to 38.7 years, with a mean age of 27.9 years. All of the individuals involved were judged to have severe or profound intellectual disability with limited language skills, necessitating the use of care staff to complete the GCPLA on their behalf. All respondents had known the individual in their capacity as either head of home, or keyworker, for at least 18 months.

The heads of homes were asked to complete the GCPLA on each individual in the home, and in addition, the individual's keyworker was asked to complete the GCPLA independently. This was based on the assumption that both respondents would have access to similar knowledge regarding the activities of the individual to be assessed.

Q1 A Spearman rank-order correlation coefficient (ρ) was calculated for each pair of scores generated from the total items of the GCPLA (Table 1). Acceptable reliability levels were found for the majority of scores where the data permitted analysis, i.e. > 0.7 (Martin & Bateson 1986). The exception being 'accompanied' scores which, although having statistically correlated pairs of scores had a ρ of 0.62, below the standard of acceptability. None of the participants were rated as accessing activities with a peer group.

Test-retest reliability: people with intellectual disabilities as respondents

Test-retest reliability was examined with the assistance of nine individuals with intellectual disability who attended either of two adult training centres in the Hastings area. The subjects included seven men and two women (average age = 43.8 years). All participants were judged by the staff to have sufficient language skills to be able to act as reliable informants. Participants were interviewed using the GCPLA on two occasions separated by a 2-week interval.

Table 1 Reliability of the Guernsey Community Participation and Leisure Assessment (GCPLA); Spearman rank order correlation coefficients, ρ

GCPLA category	Inter-rater: carers (n = 12)	Test-retest	
		People with learning disabilities (n = 9)	Carers (n = 12)
Range	0.83**	0.87**	0.83**
Very frequent activity	0.84**	0.56	0.84**
Alone	0.77**	0.97**	0.46
Peer	1.00†	0.93**	0.80**
Accompanied	0.62*	0.96**	1.00†
Supervised	0.81**	1.00†	0.47**

*Correlation significant at the $P < 0.05$ level (two-tailed).

**Correlation significant at the $P < 0.01$ level (two-tailed).

†All participants reported no activity at times 1 and 2.

A Spearman rank-order correlation coefficient (ρ) was calculated for each pair of scores generated from the total items of the GCPLA (Table 1). All scores had acceptable levels of test-retest reliability, with the exception of the number of very frequent activities. No participant rated her or himself as being supervised in either interview. The interviewers noted several potential sources of bias which would need to be actively addressed if the GCPLA is to be used with self-respondents:

- At times, it appeared that participants were referring to activities which they would like to be doing.
- Some form of social desirability (e.g. 'Oh, yes, I go to parties all the time!') was evident.
- Some participants did not differentiate between friends and paid carers.
- It was sometimes difficult for participants to decide on the frequency of activities.

Test-retest reliability: carers as respondents

Test-retest reliability was examined with the assistance of the 12 participants of the inter-rater reliability study. The keyworkers of the above individuals were asked to repeat the GCPLA 2 weeks after initial completion.

A Spearman rank-order correlation coefficient (ρ) was calculated for each pair of scores generated from the total items of the GCPLA (Table 1). Acceptable levels of test-retest reliability were found for the range, very frequent activity and peer scores. No participant was rated as accessing activities accompanied, but not supervised, at either interview. Moderate, but non-significant correlations were found with supervision and alone scores.

Internal reliability

Scores derived from the intellectual disability normative sample (see the 'Comparison of Service Users and Staff Controls and the Establishment of Normative Data' section below) were used to calculate the internal reliability of the GCPLA. Scores related to

frequency of contact produced a Cronbach's Alpha coefficient of 0.93, whereas scores related to the mode of contact produced a Cronbach's Alpha coefficient of 0.82.

Content validity

Validity can be defined as the extent to which a measuring instrument measures what it purports to measure. However, there are many different definitions of validity, and distinctions among different types or kinds of validity. The following definition was employed for the purposes of the present study.

Content validity examines the extent to which the content of a test is relevant to the characteristic being measured, thus exploring whether a test or assessment reflects appropriately the domain under investigation (Pedhazur & Schmelkin 1991). The content validity was investigated with the assistance of 10 'experts', i.e. clinical psychologists working in the fields of rehabilitation, complex care and intellectual disability.

A questionnaire was designed to evaluate how relevant the items listed in the GCPLA were to their individual sub-category within the instrument, and how relevant these categories were to the overall concept of community participation and leisure. Respondents were asked to rate the relevance of the identified categories on a five-point scale from (1) 'not at all' to (5) 'extremely'. All 10 questionnaires were returned. Mean and range scores were calculated. The items of the GCPLA were generally rated as relevant to their respective category, as was the relevance of these categories to the concept of 'Community participation and leisure' (Table 2).

Concurrent validity

Concurrent validity is a subtype of criterion-related validity that explores the relationship between a test and other criteria which are measured or assessed at the same time. This often involves the correlation between the test in question, and one or more other measures for which a hypothesized relationship is posited (Breakwell *et al.* 1995).

Concurrent validity was investigated with the assistance of 11 people with intellectual disabilities living in two NHS residential establishments in the Hastings area. Five participants were female and six were male. The mean age was 38.6 years (range = 25–71 years). All of the individuals involved were judged to have a severe or profound intellectual disability with limited language skills necessitating the use of care staff to

Table 2 'Experts' ratings of Guernsey Community Participation and Leisure Assessment (GCPLA) item and category relevance

GCPLA category	Mean (<i>n</i> = 10)	Range (<i>n</i> = 10)
(A) Services	4.5	3–5
(B) Public transport	4.4	3–5
(C) Indoor leisure	4.2	3–5
(D) Leisure, sport and recreation	4.5	3–5
(E) Social	4.2	3–5
(F) Facilities/amenities	4.2	3–5
Relevance of categories A–F to community participation and leisure	4.0	3–5

complete the GCPLA on their behalf. All respondents had known the individual in their capacity as either head of home or keyworker for at least 18 months.

The relationship between the GCPLA and two alternative methods of data collection was investigated. Staff recorded all community and leisure activities for each client in an individual diary for 4 weeks. This measure was constructed for the purposes of the present study. A sheet was given to staff listing community and leisure activities. In addition, they were asked to list any other activities or contacts not listed. There is no doubt that diary data have a high degree of face validity; however, the reliability of diary recording has been questioned. The establishment of predetermined criteria maximized the potential reliability of the dairies whilst maintaining face validity. At the end of this period, a GCPLA was completed for each client along with a LEC (Ager 1990). The diary data was transferred to GCPLA forms to enable direct comparisons to be made.

A Spearman rank-order correlation coefficient (ρ) was calculated for each pair of scores generated from the diary data and the GCPLA (Table 3). A statistical analysis was not conducted for the 'Services' category because ratings on both measures indicated no contact. All completed analyses indicated at least modest correlations between the measures with three significant.

Spearman rank order correlation coefficients (ρ) were calculated to determine the extent of relationships between the LEC and the GCPLA. A statistically significant correlation was found between the GCPLA category 'Leisure, sport and recreation' and the LEC category 'Leisure' [$\rho = 0.742 < 0.01$ (one-tailed)], the GCPLA category 'Facilities/amenities' and the LEC category 'Opportunities' [$\rho = 0.552 > 0.05$ (one-tailed)].

In addition, supportive evidence of validity was obtained by investigating the relationship of GCPLA scores to a measure of adaptive behaviour and challenging behaviour. The assumption was that, the more independent the individual was, the higher their GCPLA score, and the more challenging, the lower the GCPLA score.

This was examined with the assistance of 60 individuals receiving residential services from a NHS trust in the Hastings area. These included 26 men and 34 women (mean age = 43.4 years). Twenty-five individuals lived in a small hospital and 35 lived in community houses. All of the individuals involved were judged to have a severe or profound intellectual disability with limited language skills, necessitating the use of

Table 3 Spearman rank order correlation coefficients comparing Guernsey Community Participation and Leisure Assessment (GCPLA) scores, and diary recordings of community participation and leisure ($n = 11$)

GCPLA category	Correlation coefficient (Spearman r)
(A) Services *	1.00
(B) Public transport	0.534
(C) Indoor leisure	0.652*
(D) Leisure, sport and recreation	0.517
(E) Social	0.576
(F) Facilities/amenities	0.737*
Total (categories B-F)	0.682*

*Correlation significant at the $P < 0.05$ level (two-tailed).

care staff to complete the GCPLA on their behalf. All respondents had known the individual in their capacity as either head of home, ward manager or keyworker for at least 18 months.

The respondents were asked to complete the GCPLA, the Behaviour Problems Inventory (BPI; Rojahn *et al.* 1989) and the Adaptive Behavior Scale (Part 1) (ABS; Nihira *et al.* 1974).

A Pearson's Product Moment Coefficient (r) was calculated between the GCPLA range scores, and the ABS and BPI scores. A significant correlation was found between GCPLA and ABS (Part 1) scores [$r=0.33$; $P > 0.01$ (two-tailed)]. A non-significant, but as hypothesized, negative correlation between the GCPLA and BPI scores was found ($r=-0.11$).

Comparison of service users and staff controls and the establishment of normative data

Previous studies have suggested that the depth and breadth of the lifestyle of people with intellectual disabilities has been found to be less than might be expected or desired (e.g. Jeffree & Cheseldine 1981; McConkey *et al.* 1983; Lowe & de Paiva 1991; Hayden *et al.* 1992; Stancliffe & Lakin 1998). It was considered important to compare the patterns of community activity and leisure of service users with intellectual disabilities to that of a non-disabled control group in order that the quality of experience can be evaluated fully and objectively (Emerson & Hatton 1994).

The participants included all individuals participating in the Life Planning System operated by the States of Guernsey Board of Health's Learning Disability Service during a 6-month period in 1991 ($n=38$). These service users had a range of disabilities from profound physical and intellectual disabilities to mild intellectual disabilities. In addition, the GCPLA was mailed through the internal post to all staff members of the States of Guernsey Board of Health Learning Disability Service. Forty-one staff member volunteers returned a completed assessment, representing a response rate of 57.6%. Although this group were not randomly selected from the general population, it can be argued that they represent a meaningful comparison group. An added dimension was that the two groups spent a considerable amount of their lives in each other's company. The two groups were broadly similar in age and gender, and a χ^2 analysis revealed no significant difference in gender mix within each group.

The GCPLA was administered as part of the preparation for the Life Plan review meeting routinely held every 9 months. Depending on the communication ability of the service user, the GCPLA was either used by the keyworker as the basis for a structured interview or completed on behalf of the service user. All GCPLA data regarding staff member participants was collected by self-administration.

A series of t -tests clearly differentiated between the service user's and staff control group's experience of community contacts and their use of leisure. The data indicated that the service users had a smaller range of activities, and were most likely to access their communities in the presence of staff or carers, rather than alone or with friends. All of these differences were statistically significant. Service users were also less busy (had fewer frequent activities), although this was not a statistically significant difference (Table 4).

Data relating to the type of access for each individual item revealed distinct contrasts between the staff controls and the service users (Table 5). In general, the staff controls engaged in what might be considered to be routine maintenance activities alone, whilst

Table 4 Results of *t*-tests comparing the Guernsey Community Participation and Leisure Assessment (GCPLA) scores of service users and staff controls

GCPLA category	Service users (n = 38)		Staff controls (n = 41)		Statistical analysis
	Mean	SD	Mean	SD	
Range	18	5.1	24	6.0	$t = 5.19^{**}$ (d.f. = 78)
Very frequent activity	11.3	4.0	13.5	4.3	$t = 0.82^{\dagger}$ (d.f. = 78)
Alone	5.8	6.4	16.5	5.8	$t = 7.5^{**}$ (d.f. = 78)
Peer	1.4	3.2	20.3	8.3	$t = 12.9^{**}$ (d.f. = 78)
Accompanied	13.1	8.9	0		
Supervised	7.2	9.5	0		

**Significant at the $P < 0.01$ level (two-tailed).

\dagger Not significant.

leisure was accessed with peers. The exceptions were some items of indoor leisure which were accessed alone and some forms of public transport which were accessed with peers. In contrast, the service users accessed very few types of activity alone or with peers, the majority taking place accompanied by carers. Surprisingly few activities were considered to be supervised; these were mainly health related, i.e. visits to the general practitioner, hospital and dentist.

The data relating to the percentage of activities/contacts accessed according to the type of support reflect the findings concerned with type of access, in that the majority of service users' activities (53%) were conducted in the presence of carers. Twenty-nine per cent of the activities were supervised, and only 18% were conducted either alone or with a peer group. This makes a stark contrast with the staff control group where 100% of the contacts were either alone or with peers.

Further analysis of the data pertaining to service users indicated that neither gender nor the place of residence (own/parental home or staffed residential service) was a significant factor affecting their GCPLA scores.

A normative sample of 109 people with an intellectual disability was obtained by combining data from three sources: (1) data from the Guernsey cohort of service users; (2) data derived from the participants in the inter-rater reliability study with people with intellectual disabilities as respondents; (3) and data obtained from another study pertaining to all service users of a NHS residential services in the Hastings area. Although data from the latter two sources were not randomly selected, these had an almost identical mean and standard deviation to the Guernsey cohort [$t = -0.167$, d.f. = 105, $P = 0.494$ (two-tailed)]. The participants represented the full range of intellectual disability, with 56 women, 53 men, and a mean age of 40 years, the youngest 20 years and the oldest 79 years. Therefore, it is considered that the combined data is reasonably representative.

The range score of the GCPLA represents the most valid, reliable and potentially useful summary of information. Thus, percentiles were calculated from the normative sample to facilitate comparisons of GCPLA range scores with a population with intellectual disability. Percentile scores were also derived for a non-disabled population from the range scores obtained from the Guernsey staff. These were 19 men and 22

Table 5 Guernsey Community Participation and Leisure Assessment (GCPLA) item scores of service users and staff controls

GCPLA category	Mean frequency (range)		Support (mode)	
	Controls	Service users	Controls	
<i>Service users</i>				
<i>(A) Services</i>				
General practitioner	1.6 (1-3)	1.4 (1-3)	Supervised	Alone
Dentist	0.9 (0-2)	1.1 (0-3)	Supervised	Alone
Hospital	0.7 (0-2)	0.9 (0-5)	Supervised	Alone
Police	0.0 (0-0)	0.5 (0-1)	N/A*	Alone
<i>(B) Public transport</i>				
Bus	1.6 (0-5)	0.9 (0-4)	Accompanied/alone	Alone
Train	0.1 (0-1)	0.8 (0-2)	Supervised/accompanied	Alone
Taxi	1.0 (0-5)	1.9 (0-5)	Accompanied	Peer
Boat	1.0 (0-4)	1.4 (0-4)	Accompanied	Peer
Air	0.9 (0-2)	1.5 (0-3)	Accompanied	Peer
<i>(C) Indoor leisure</i>				
Craft	3.2 (0-5)	1.7 (0-5)	Accompanied	Alone
Games	2.2 (0-5)	2.9 (0-5)	Accompanied	Peer
Television	4.2 (0-5)	4.8 (4-5)	Accompanied	Peer
Video	2.8 (0-5)	3.2 (0-5)	Accompanied	Alone
Music:				
listen	4.3 (0-5)	4.3 (1-5)	Accompanied	Alone
play	1.0 (0-5)	1.2 (0-5)	Accompanied	Alone
Pets	0.7 (0-5)	2.7 (0-5)	Supervised	Alone
<i>(D) Leisure, sport and recreation</i>				
Fair	1.5 (0-4)	1.4 (0-3)	Accompanied	Peer
Museum	0.7 (0-3)	1.3 (0-3)	Accompanied	Peer
Sport:				
participation	0.9 (0-4)	2.3 (0-5)	Accompanied	Peer
spectator	0.6 (0-3)	1.5 (0.5)	Accompanied	Peer
Exercise	0.7 (0-4)	2.0 (0.5)	Accompanied	Peer
Cycle	0.2 (0-4)	1.4 (0-5)	Accompanied	Peer
Cinema	0.6 (0-3)	1.6 (0-4)	Accompanied	Peer
Theatre	0.4 (0-3)	1.0 (0-2)	Accompanied	Peer
Concert	0.7 (0-3)	1.1 (0-3)	Accompanied	Peer
Park	1.6 (0-3)	2.0 (0-3)	Accompanied	Peer
Beach	2.3 (0-4)	3.6 (0.4)	Accompanied	Peer
Walk	2.8 (0-5)	3.4 (0.5)	Accompanied	Peer
Outings	3.1 (0-4)	3.1 (0-5)	Accompanied	Peer
Holidays	1.1 (0-2)	1.6 (0.3)	Accompanied	Peer
Swimming	1.9 (0-4)	2.0 (0-5)	Accompanied	Peer
Sailing	0.1 (0-2)	2.5 (0-4)	Accompanied	Peer
<i>(E) Social</i>				
Disco	1.1 (0-4)	1.2 (0-5)	Accompanied	Peer
Public house	1.9 (0-4)	3.0 (1-5)	Accompanied	Peer
Party	1.3 (0-3)	2.0 (0-4)	Accompanied	Peer
Restaurant	2.9 (1-4)	3.1 (1.5)	Accompanied	Peer
Friend's home	0.6 (0-4)	3.1 (0-5)	Accompanied	Peer
Neighbour's home	0.4 (0-4)	1.2 (0-5)	Accompanied	Peer

Table 5 continued

GCPLA category	Mean frequency (range)		Support (mode)	
	Controls	Service users	Controls	Service users
<i>Service users</i>				
Social club:				
integrated	0.2 (0-4)	0.9 (0-4)	Accompanied/alone	Peer
segregated	1.7 (0.4)	0.2 (0-3)	Alone/peer	Peer/alone
<i>(F) Facilities/amenities</i>				
Local shop	3.2 (0-5)	4.1 (0-5)	Alone	Alone
High street store	2.3 (0-4)	3.4 (1-5)	Accompanied	Alone
Hairdresser	1.9 (0-3)	2.2 (0.3)	Accompanied	Alone
Supermarket	2.6 (0-4)	3.3 (0-4)	Accompanied	Alone
Post office	1.5 (0-4)	3.0 (0-4)	Accompanied	Alone
Launderette	0.0 (0-0)	0.3 (0-4)	N/A	Alone
Chemist	1.2 (0-4)	2.4 (0-4)	Accompanied	Alone
Bank	0.7 (0-4)	3.6 (1-4)	Accompanied	Alone
Church	0.6 (0-4)	1.5 (0.4)	Alone	Alone

*N/A: not applicable.

women with a mean age of 38 years, the youngest being 19 years and the eldest 62 years (Table 6.).

Discussion

The relatively small numbers in each individual study limits the investigations of the psychometric properties of the GCPLA reported in the present paper. However, the results would indicate that the GCPLA has the potential to be a useful instrument in the evaluation of an individual's access to their community and their use of leisure. The instrument produces quantifiable data, enabling meaningful comparisons of individuals and groups of individuals. With the exceptions noted in the 'Results' section above, the GCPLA has a general proven capability to produce reliable and valid data if

Table 6 Range score percentiles of the Guernsey Community Participation and Leisure Assessment

Population	Percentile						
	Fifth	Tenth	Twenty-fifth	Fiftieth	Seventy-fifth	Ninetieth	Ninety-fifth
Service users with intellectual disability	9	12	14	17	22	26	28
Non-disabled subjects	15	16	19	25	29	33	34

used in similar circumstances to that in which the above studies were carried out (i.e. the assessment is rated by the individual or by somebody with an adequate degree of knowledge regarding the individual). Whilst it is important to emphasize that the GCPLA should be accessible to people with intellectual disabilities, the present study indicates that caution needs to be applied. Several potential sources of systematic bias were in evidence. If these are apparent, it would be important to directly address these by strategies such as cross-validation.

The main uses of the GCPLA are considered to be as follows:

- 1 The GCPLA enables a profile of an individual's use of leisure and access to the community to be developed. Such a profile used in conjunction with a planning mechanism will enable the identification of needs, and accordingly, will assist in the formation of plan designed to meet those needs. The quantifiable nature of the data will allow for an objective evaluation of the outcome of the planning process.
- 2 The GCPLA enables the generation of group data, thus facilitating evaluation of services on one of the more fundamental service accomplishments (O'Brien 1987).
- 3 Completion of the GCPLA by staff within a staff training context on their own use of leisure and access to the community enables very powerful comparisons to be made between their own experiences and the experiences of service users. This has been found to lead to insights which have been proven to motivate staff groups in facilitating and enabling new experiences for service users in these areas.

The purpose of the present paper is to present the GCPLA as an addition to the range of client outcome measures available. However, the investigation of the validity and reliability of the GCPLA has generated some interesting incidental findings. The comparison of a cohort of service users with intellectual disabilities with a staff control group showed the individuals with intellectual disabilities to have a significantly more restricted range of activities/contacts. Previous studies have indicated the general impoverishment of community experience, but rarely has this been demonstrated. The present study supports previous research which has suggested qualitative differences in the mode of access of people with intellectual disabilities to their communities compared to the general population (McConkey *et al.* 1983; Seager 1987; Hayden *et al.* 1992). The most common mode of access of people with intellectual disabilities to their communities was in the presence of staff or carers. The present study makes a distinction between carers actively supervising, and merely being present. Surprisingly few activities were consistently rated as being actively supervised, raising questions regarding why carers are present for so many contacts if supervision is not required.

Various studies have identified a relationship between the individual's adaptive behaviour and the extent of the use of their communities, with more able people enjoying greater use (e.g. Stancliffe & Lakin 1998; Emerson *et al.* 2000). A similar relationship was found in the present study. In spite of surveying a less able population, the individuals' level of independent functioning, as measured by the ABS (Part 1), appears to have an overriding influence over their use of their communities and leisure. The most commonly cited definition of challenging behaviour (Emerson *et al.* 1987) states that restriction in access to ordinary community facilities is integral to the phenomenon of challenging behaviour. However, the present study found a weak and non-significant negative correlation between individual's level of challenging behaviour, and their use of their communities and leisure. This suggests that challenging behaviour is a less powerful predictor of community access than adaptive behaviour. Clearly, the relationship between individual characteristics such as adaptive and challenging behaviour

and quality of life is complex. To a large extent, the relationship is dependent not only on individual characteristics, but is also influenced by mediating factors and features of service design in particular. Isolating such factors in order to bring about greater community access to all individuals with intellectual disabilities would be a welcome extension of the present study.

Acknowledgments

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Appendix 2

The Guernsey Community Participation and Leisure Assessment (GCPLA)

THE GUERNSEY COMMUNITY PARTICIPATION AND LEISURE ASSESSMENT

CLIENT: DATE:

AGE: SEX:

Overleaf is a list of potential activities or contacts clients may have access to.

For each activity, please look at the separate list of definitions.

Please indicate by a number in the column labelled **FREQUENCY** how often they do this:

NUMBER	DEFINITION
0	Never
1	Very occasionally
2	3 monthly or more frequently
3	Monthly "
4	Weekly "
5	Daily "

Please indicate by a number in the column labelled **SUPPORT** whether they usually are:

NUMBER	DEFINITION	NOTES
1	Supervised	Supervised = Either The onus of choice and control lies with carer, Or A major part of the carer's attention is concerned with vigilance for the individual, Or A combination of the two
2	With carers, but not supervised	Carer = relative or paid member of staff
3	Unaccompanied	-
4	With a peer group	Peer Group = includes all those who do not fulfil criteria of carer. If carer present rate as 1 or 2.

For those activities that are seasonal, e.g. beach, try to reflect how often the person would do this at the appropriate time of year.

ACTIVITY	FREQUENCY	SUPPORT
----------	-----------	---------

A. SERVICES

Doctor (GP)		
Dentist		
Hospital		
Police		

B. PUBLIC TRANSPORT

Bus		
Train		
Taxi		
Boat		
Aeroplane		

C. INDOOR LEISURE

Craft		
Games		
T.V.		
Videos		
Music (Listen)		
Music (Play)		
Pets		

D. LEISURE, SPORT & RECREATION

Fair/Fete/Festival		
Museum/Art Gallery		
Sport (Participation)		
Sport (Spectator)		
Exercise/Aerobic Class		
Cycling		
Cinema		
Theatre		
Concert		

0 = Never, 1 = Very occasionally, 2 = Quarterly or more frequently, 3 = Monthly, 4 = Weekly, 5 = Daily

1 = Supervised, 2 = Accompanied, 3 = Alone, 4 = Peer group

ACTIVITY	FREQUENCY	SUPPORT
----------	-----------	---------

Park		
Beach		
Walking		
Holiday		
Swimming		
Sailing		
DIY		
Gardening		

E. SOCIAL

Disco		
Pub		
Party		
Restaurant/Cafe		
Friend's House		
Neighbour's Home		
Social Club (Integrated)		
Social Club (Segregated)		

F. FACILITIES/AMENITIES

Local Shop		
High Street Store		
Post Office		
Hairdresser		
Supermarket		
Chemist		
Bank/Building Society		
Place of Worship		
Large Retail Outlet		
Jumble/Car Boot Sale		
Library		
Adult Education		

0 = Never, 1 = Very occasionally, 2 = Quarterly or more frequently, 3 = Monthly, 4 = Weekly, 5 = Daily

1 = Supervised, 2 = Accompanied, 3 = Alone, 4 = Peer group

SCORING

1	<u>Range</u>	<input type="text"/>	Add up the number of regular activities (a score of 2 or more in the Frequency
2	<u>'Busy'</u>	<input type="text"/>	Add up the number of very frequent activities (a score of 4 or 5 in the Frequency
3	<u>Independence</u>		
	Supervised	<input type="text"/>	Add the number of activities scoring 1 in the Support column
	Accompanied	<input type="text"/>	Add the number of 2s in the Support column
	Solitary activity	<input type="text"/>	Add the number of 3s in the Support column
	Peer	<input type="text"/>	Add the number of 4s in the Support column

SCORE ANALYSIS

	Category	Range	Busy	Supervised	Accompanied	Solitary	Peer
A	Services						
B	Public transport						
C	Indoor leisure						
D	Leisure, sport & recreation						
E	Social						
F	Facilities / amenities						

TOTAL							
--------------	--	--	--	--	--	--	--

'Community' (= Total minus C)							
'Leisure' (=C+D+E)							

GCPLA
Item Definitions/Criteria

A. Services

Doctor (General Practitioner)

A medical doctor working in the community as distinct from a consultant or specialist based in a hospital

Dentist

A dentist or hygienist in the community.

Hospital

Visiting a hospital either as a patient or visitor.

Police

Voluntary interaction with members of the police force in the general community or at a police station or its equivalent.

B. Public Transport

Bus

To travel as a passenger in a bus serving the public on a fixed route. Does not include coach or buses for private use.

Train

To travel as a passenger on a railway.

Taxi

To travel as a passenger in a taxi.

Boat

To travel as a passenger in a boat. Does not include recreation/enjoyment.

Aeroplane

To travel as a passenger by plane.

C. Indoor Leisure

Craft

To participate in the practical arts for purposes of education or recreation (e.g. pottery).

Games

To participate in a form or spell of play with formalised rules within the home (e.g. board games). Does not include indoor sports at a leisure centre.

TV

To actively watch by choice live transmitted television programmes. To watch actively requires evidence of attending for at least ten minutes (e.g. continued gaze, emotional response to the programme, protest if switched off or programme changed). Exclude situations where the TV is on in the individual environment with no evidence of attending.

Videos

To actively watch by choice (as in TV) visual images transmitted via a video cassette and video recorder to the television. Exclude situations where the video is on in the individuals environment with no evidence of attending.

Music (Listen)

To actively listen by choice to music (e.g. via radio, cd, cassettes, etc). To actively listen requires evidence of attention (e.g. singing/humming along, tapping feet, dancing, protest when music finishes). Exclude situations where the music is played in the individuals environment with no evidence of attending.

Music (Play)

To actively play by choice any musical instrument to whatever standard for educational or recreational purpose.

Pets

To take the major responsibility for the day to day care of a domestic or tamed animal kept for pleasure or companionship.

D. Leisure, Sport & Recreation

Fair/Fete/Festival

To visit a gathering of stalls/amusements for public entertainment as a member of the public.

Museum/Art Gallery

To visit for recreational or educational purposes a building used for exhibiting objects of historical, scientific, cultural or artistic interest.

Sport (Participation)

To actively participate by choice with others in a game or competitive activity with formalised rules in the community (e.g. leisure centre, park etc.) Include indoor (e.g. table tennis, squash) and outdoor (e.g. football, cricket) sports. Note, do not include swimming.

Sport (Spectator)

To actively watch by choice for recreational purposes a game or competitive activity with formalised rules in the community. Do not include watching sport on the TV.

Exercise/Aerobic Class

To actively participate by choice in an organised exercise session involving physical effort to sustain or improve health (do not include swimming or cycling).

Cycling

To actively ride by choice a bicycle for recreation purposes.

Cinema

To visit a theatre where motion pictures are shown and to actively watch a motion picture for recreational purposes.

Theatre

To visit by choice a building or outdoor arena to actively watch dramatic performances.

Concert

To visit a building or outdoor site to actively watch an organised public musical performance.

Park

To visit a large area of land in town or in the countryside that is kept mostly undeveloped for public recreational use.

Beach

To visit a shore/coastline for recreational purposes.

Walking

To move on foot (or wheelchair) for its own sake (recreation) i.e. include going for a walk not functional walking i.e. getting from A to B.

Holiday

To experience an extended period of recreation away from home.

Swimming

To swim in a pool or the sea for recreational purposes.

Sailing

To spend time on water for recreational purposes (i.e. not to get from A to B); (e.g. dingy, sailing, windsurfing).

DIY

To manually create, build, repair, maintain, utilities/furnishings/fittings within the home environment.

Gardening

To prepare and use a piece of land for growing/maintaining grass, trees, flowers, fruit or vegetables.

E. Social

Disco

A site used by the general public for dancing to recorded popular music (not covered under other categories e.g. party, concert).

Pub

An establishment open to the general public providing alcoholic drinks for consumption on the premises. Include hotel bars, exclude establishments specifically for people with disabilities.

Party

An organised social gathering of invited guests.

Restaurant/Cafe

Public premises where meals or refreshments may be had. Excluding public houses, hotel bars.

Friends House

A home of a person liked by the individual who is not a relative or present paid staff.

Neighbours Home

Visit to the house(s)/flat(s) immediately next door (also above-below) to their own for purposes other than vocational.

Social Club (Integrated)

A club which is not especially for disabled people.

Social Club (Segregated)

A club which is especially for disabled people or for disabled people to meet non disabled people (eg PHAB).

F. Facilities/Amenities

Local Shop

Small shops outside of town centres, serving a specific community.

High Street Store

Departmental stores and all other shops in a town centre or shopping complex.

Post Office

An establishment where postal business is carried out. Include franchises.

Hairdresser

An establishment where hair is cut or styled. Does not include a visiting hairdresser to the home.

Supermarket

Large self service store selling household goods and groceries.

Chemist

An establishment selling medical goods and toiletries.

Bank/Building Society

A financial establishment used for the purposes of investment and loans.

Place of Worship

Attendance at a building for the purpose of worship. Does not include social activities.

Large Retail Outlet

A retail outlet not included in High Street Store or Local Shop (e.g. large out of town furniture stores, DIY stores and garden centres).

Jumble Sale/Boot Fair

An organised event for selling to the general public, consisting of a number of stalls, etc.

Library

An establishment containing a collection of books for reading or reference rather than for sale.

Adult Education

A local education authority establishment (e.g. evening classes)

Appendix 3

Goal Rating Scale

Please score each goal by circling the number using the following categories:

No goal	Broad area of activity with <u>no</u> specific conditions or time frame for attainment (e.g. Increase community activities)	Specific area of activity with <u>no</u> specific conditions or time frame for attainment (e.g. To go swimming)	Specific area of activity with specific conditions or time frame for attainment (e.g. To go swimming once a week)
---------	--	--	--

1	2	3	4
---	---	---	---

EH1 To be able to do her own personal Shopping weekly on Saturday

1	2	3	4
---	---	---	---

EH2 Ideas for a short break to be discussed

1	2	3	4
---	---	---	---

FH5 To be encouraged to actively participate in shopping for her own personal toiletries

1	2	3	4
---	---	---	---

FH4 X to be able to participate in all aspects of shopping for toiletries

1	2	3	4
---	---	---	---

GH4 None

1	2	3	4
---	---	---	---

GH3 X to go to local garage daily straight after lunch

1	2	3	4
---	---	---	---

EH3 Identified needs: Pub weekly

1	2	3	4
---	---	---	---

HH4 X to join in group activities

HH4	X to join in group activities	1	2	3	4
HH3	No goals	1	2	3	4
HH2	More experience walking and swimming	1	2	3	4
FH3	Shopping for personal toiletries and visit to a cafe once per fortnight	1	2	3	4
FH2	To go shopping for personal toiletries and visit a cafe once per fortnight	1	2	3	4
GH2	Opportunity for leisurely walks to occur on a regular basis.	1	2	3	4
DH1	Possibility of getting X out onto a golf course for putting discussed.	1	2	3	4
HH1	More exercise (short walks)	1	2	3	4
GH1	None	1	2	3	4
FH1 weeks	X will be taken shopping for personal toiletries and visit a cafe every two	1	2	3	4
BH3	None	1	2	3	4
BH2	None	1	2	3	4

CH6	More educational input, libraries, computers etc.	1	2	3	4
CL1	None	1	2	3	4
AL1	None	1	2	3	4
IL1	None	1	2	3	4
CL2	To maintain mobility short walks around the grounds	1	2	3	4
BL7	Continue with outings with keyworker	1	2	3	4
BL6	Increase all forms of activity	1	2	3	4
BL5	Would benefit from regular outings.	1	2	3	4
AL2	None	1	2	3	4
BL4	Continue Aromatherapy.	1	2	3	4
IL2	None	1	2	3	4
IL3	To increase X's outside activities.	1	2	3	4

IL4	None				
	1	2	3	4	
IL5	None				
	1	2	3	4	
CL3	None				
	1	2	3	4	
AL3	None				
	1	2	3	4	
CL4	Continue with appropriate indoor/outdoor activities, including all house activities.				
	1	2	3	4	
BL1	Book holiday Increase local outings to farm, shop and cafe.				
	1	2	3	4	
CL5	To take regular exercise e.g. Swimming in public pool every week.				
	1	2	3	4	
DL2	Holiday on the Thames in July				
	1	2	3	4	
EL4	Short break to be arranged				
	1	2	3	4	

Appendix 4

Figs 64a – 72c

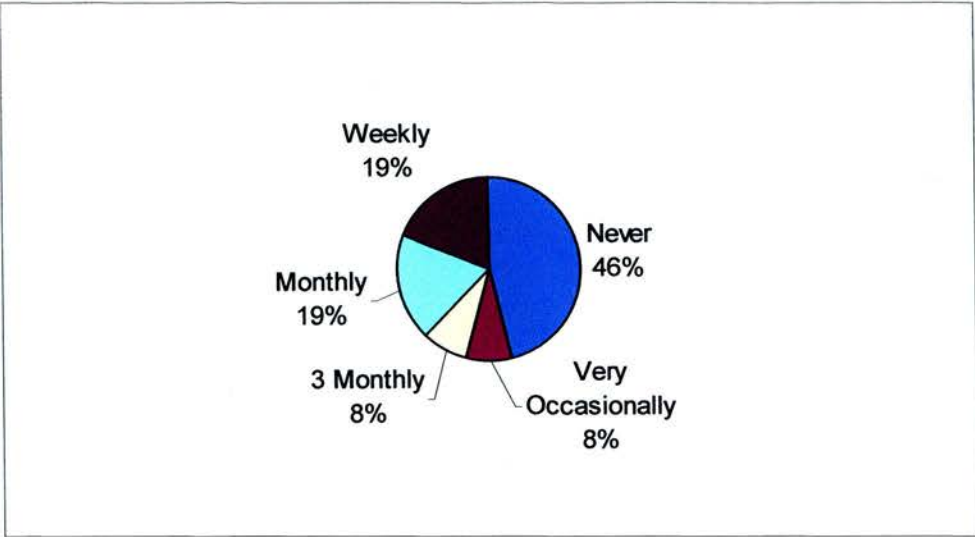


Fig 64a
Frequency of participation in swimming in hospital

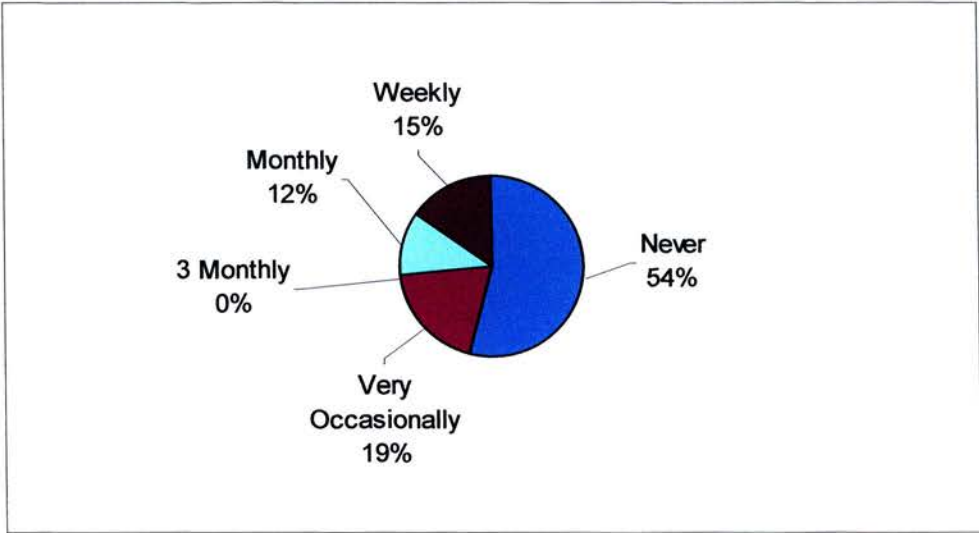


Fig 64b
Frequency of participation in swimming in community

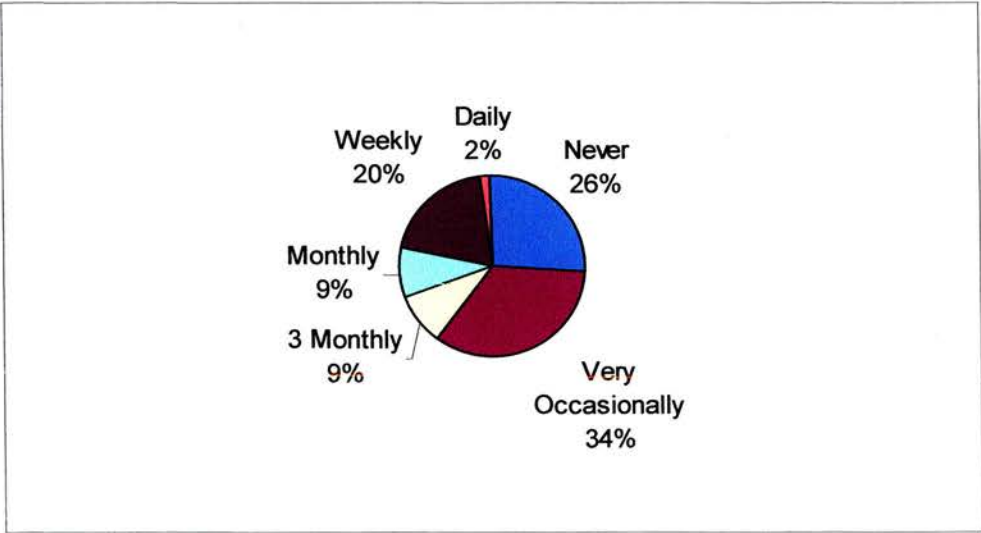


Fig 64c Frequency in participation in swimming non-disabled cohort

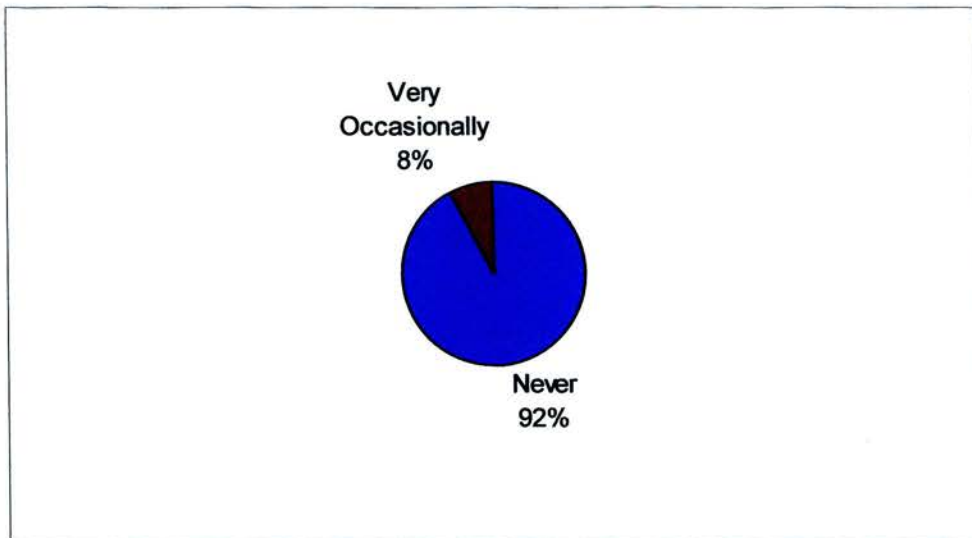


Fig 65a
Frequency of participation in sailing in hospital

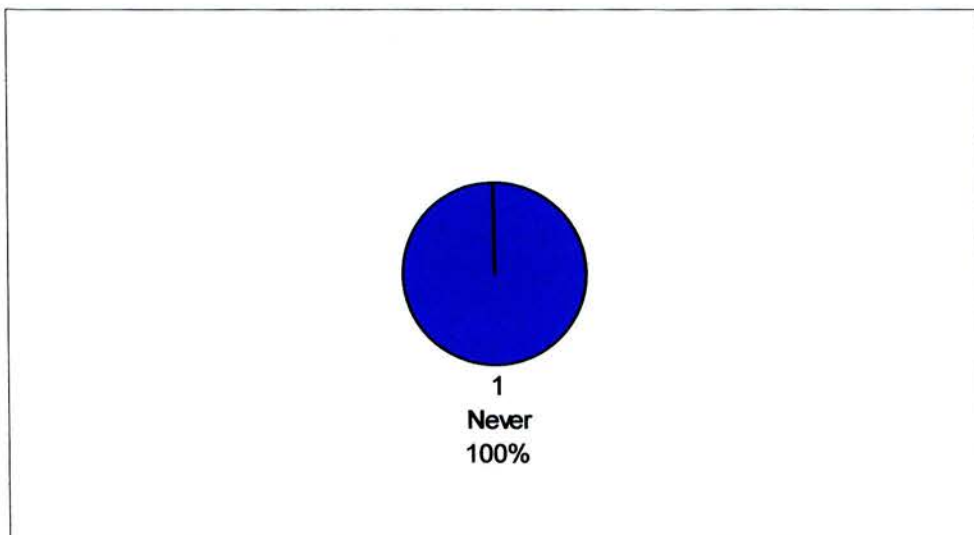


Fig 65b
Frequency of participation in sailing in community

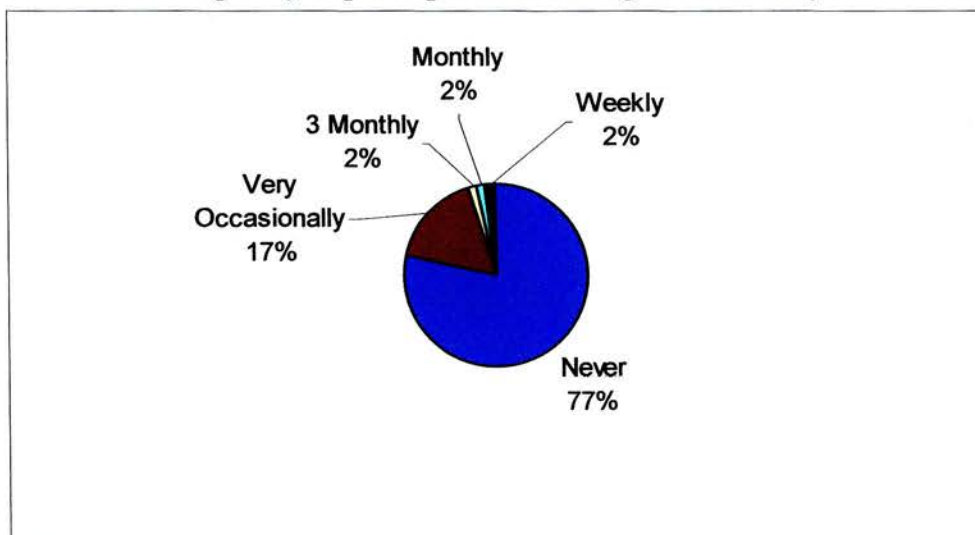


Fig 65c Frequency of participation in sailing non-disabled cohort

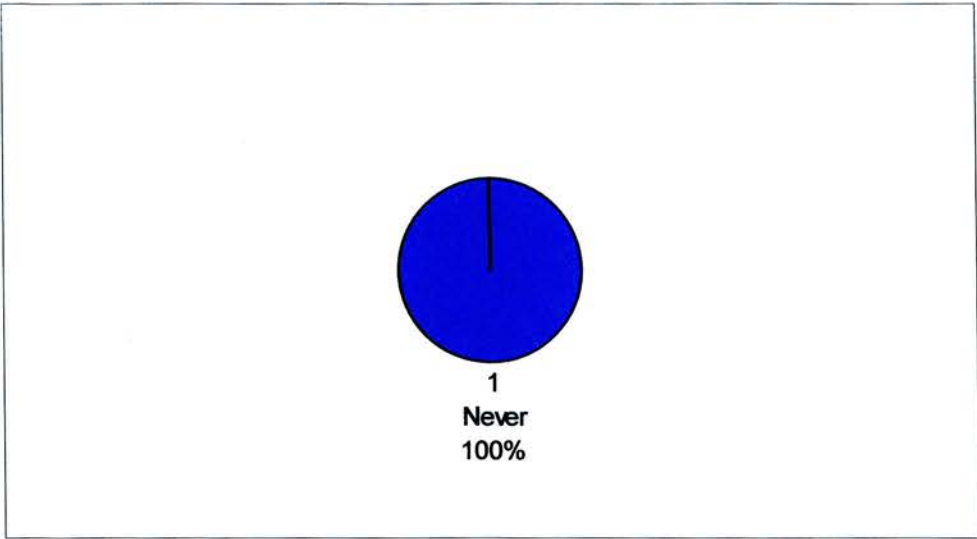


Fig 66a
Frequency in participation in DIY in hospital

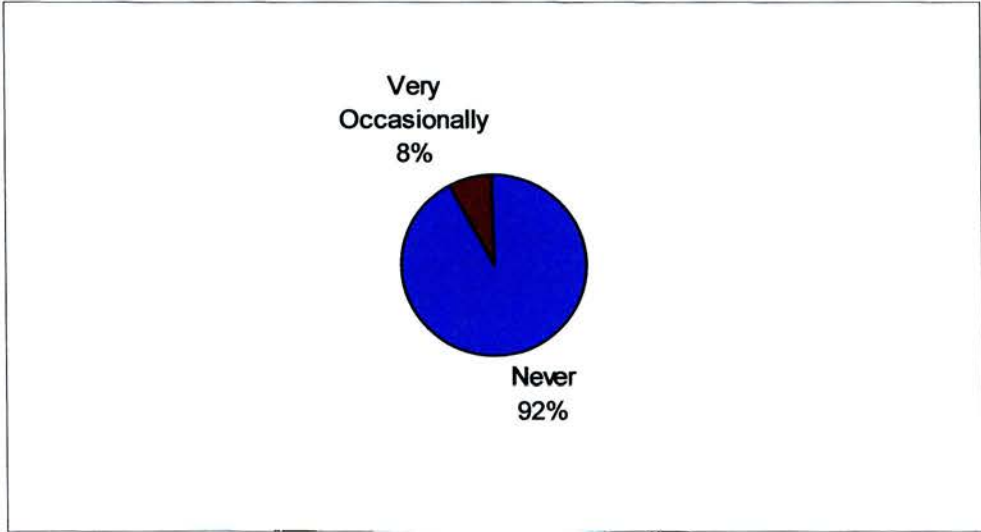


Fig 66b
Frequency of participation on DIY

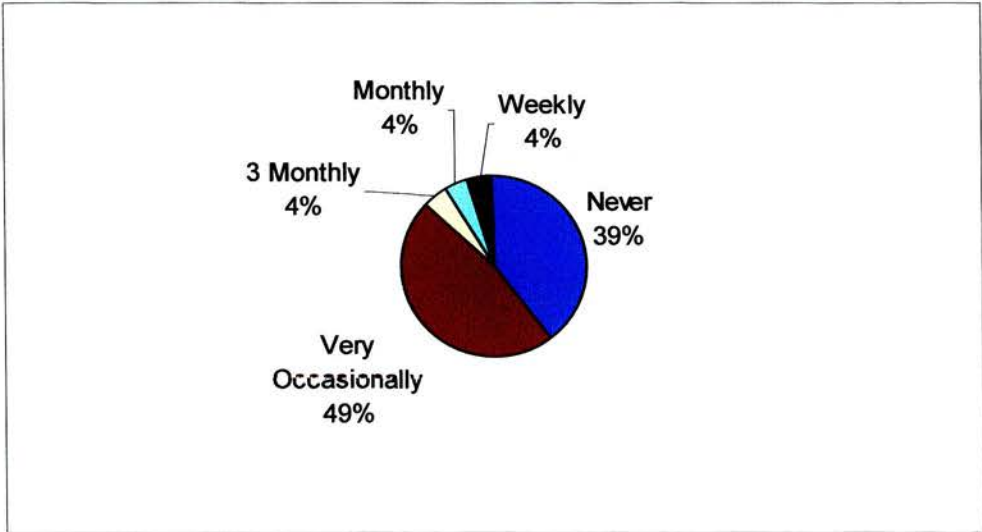


Fig 66c Frequency of participation in DIY non-disabled cohort

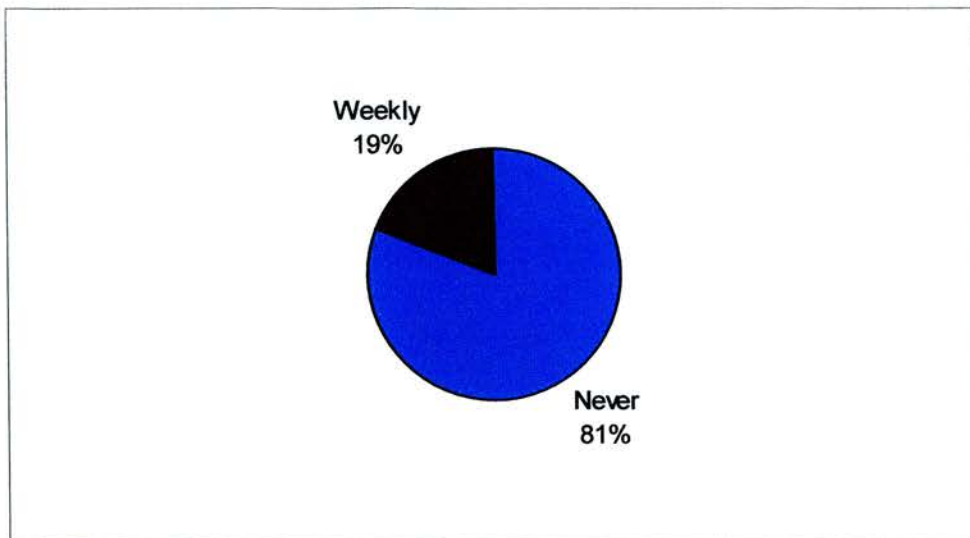


Fig 67a
Frequency of participation in gardening in hospital

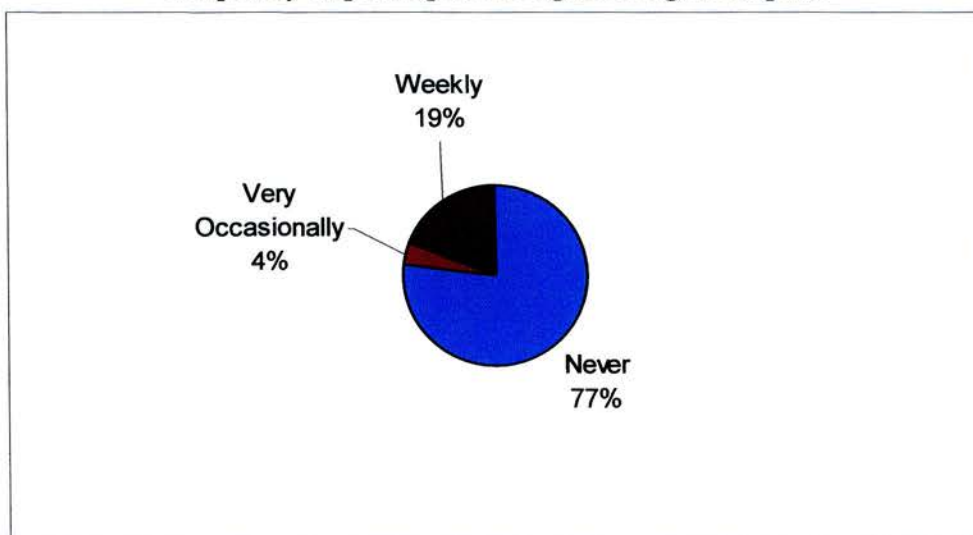


Fig 67b
Frequency of participation in gardening in community

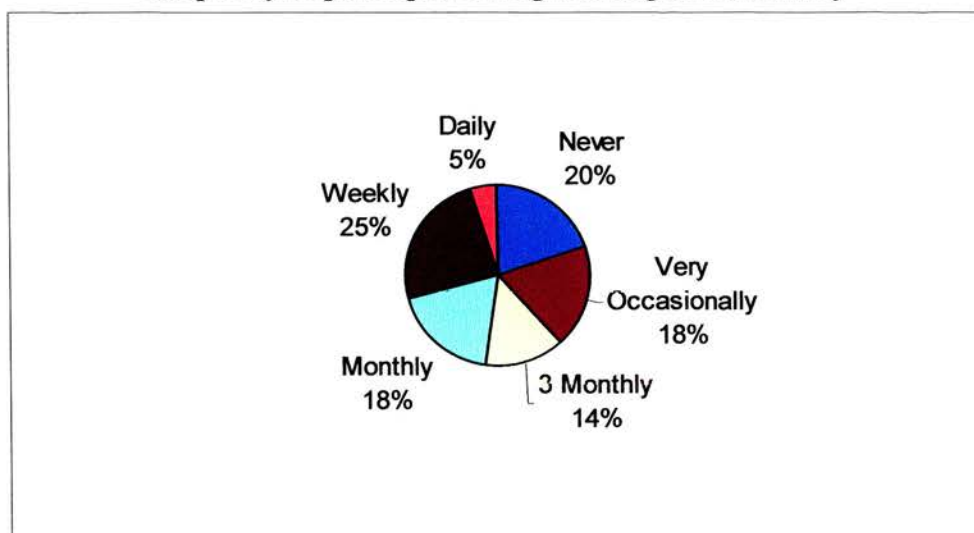


Fig 67c Frequency of participation in gardening non-disabled cohort

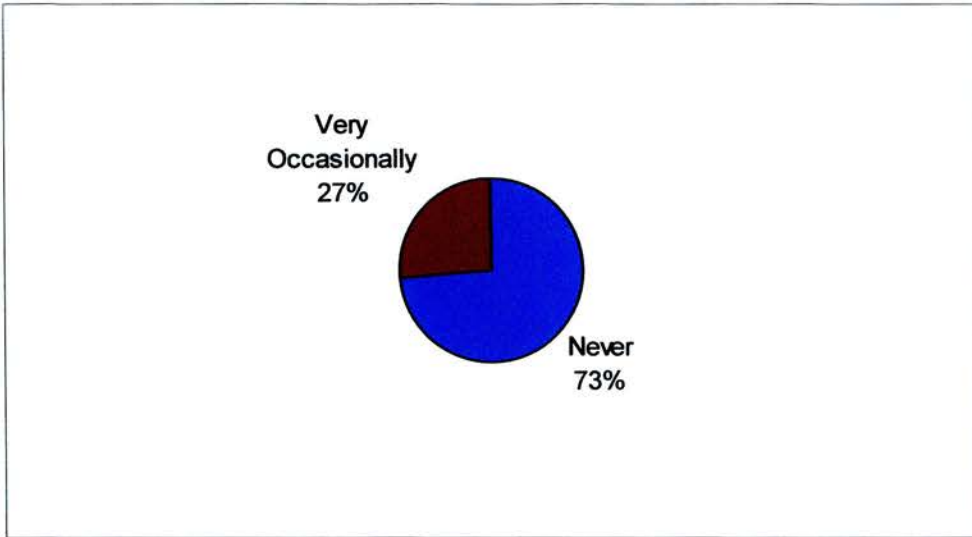


Fig 68a
Frequency of attendance at discos in hospital

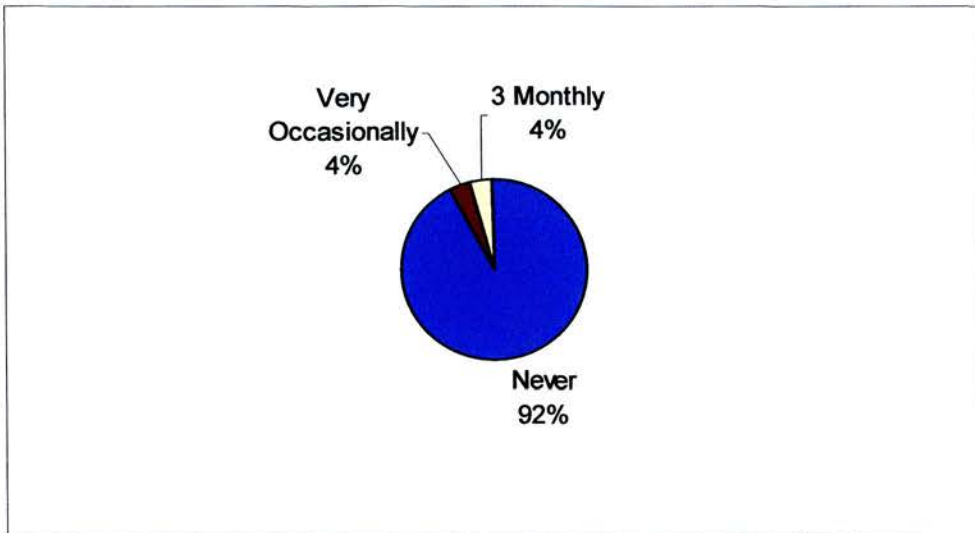


Fig 68b
Frequency of attendance at discos in community

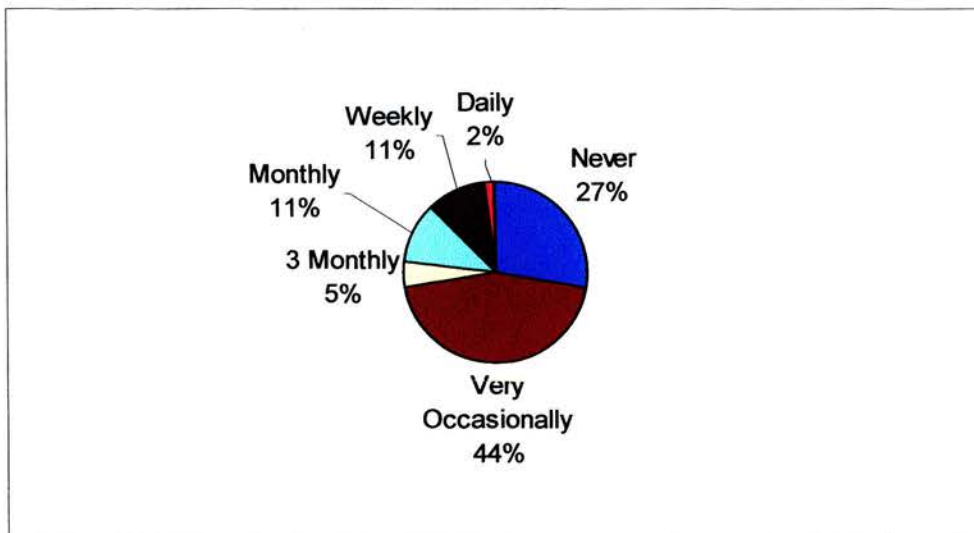


Fig 68c Frequency of attendance at discos non-disabled cohort

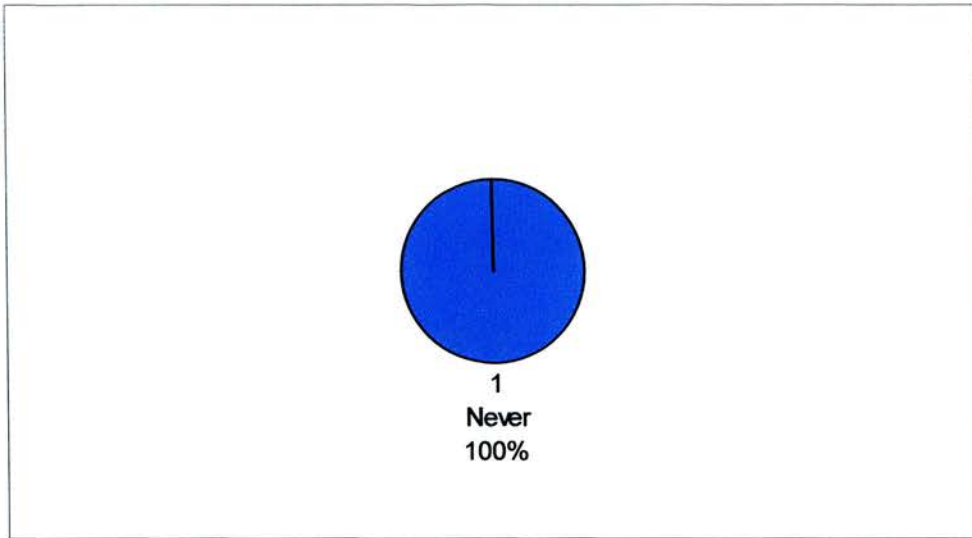


Fig 69a
Frequency of visiting an integrated social club

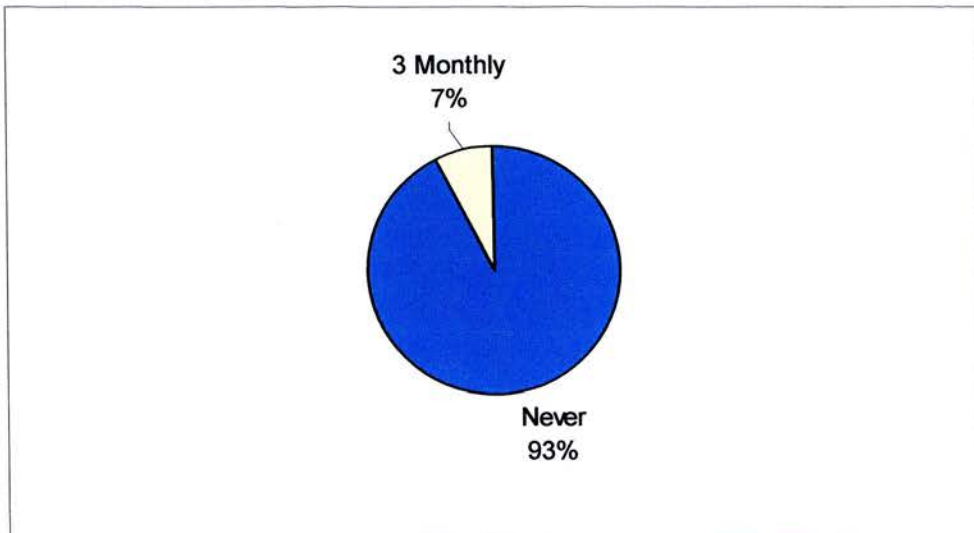


Fig 69b
Frequency of visiting an integrated social club

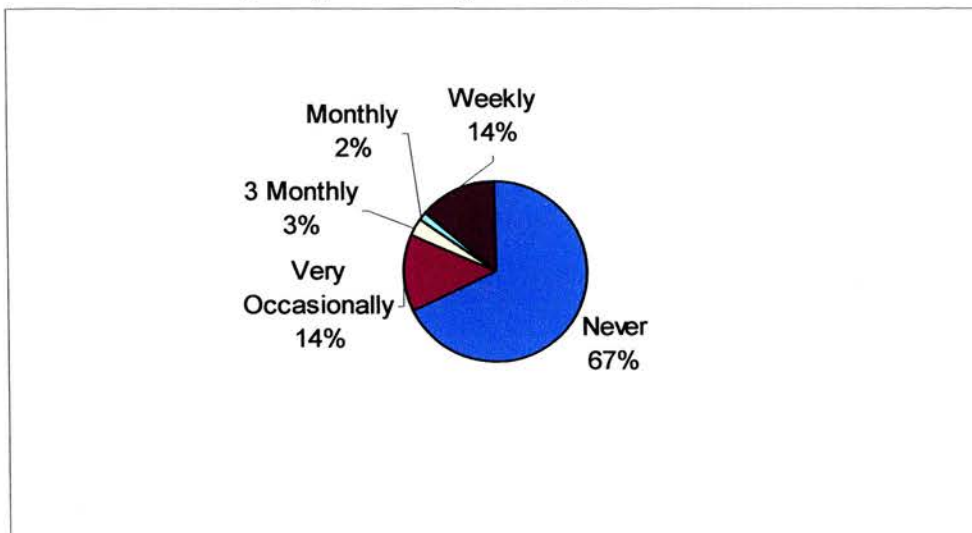


Fig 69c Frequency of visiting an integrated social club

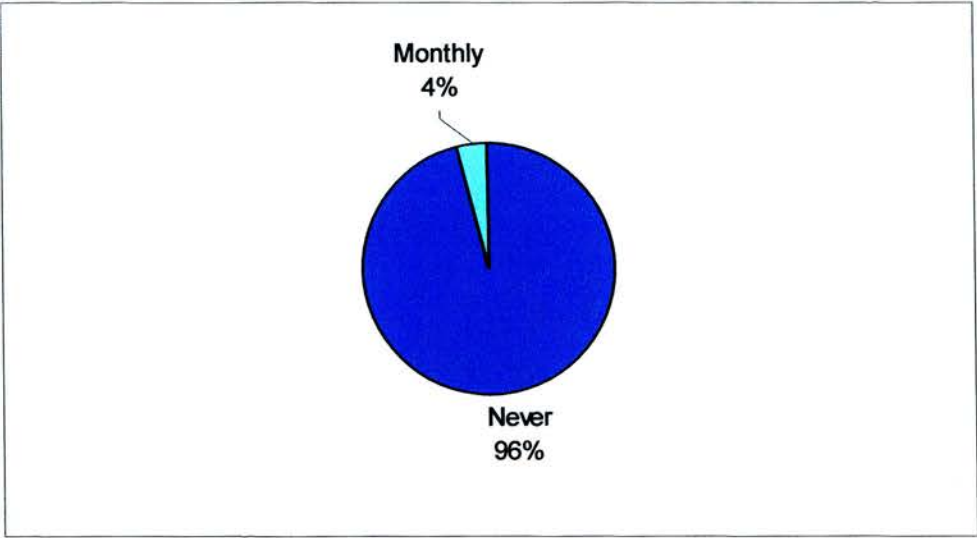


Fig 70a
Frequency of visiting a chemist in hospital

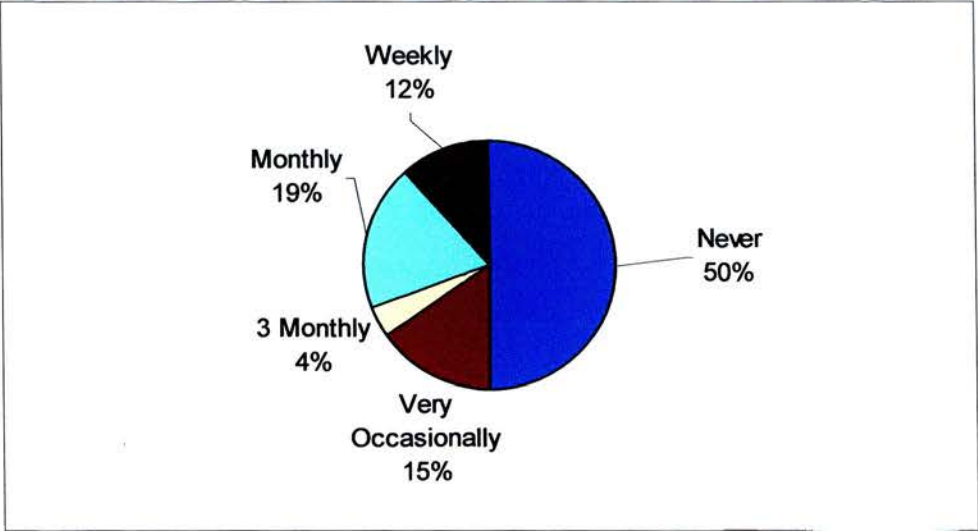


Fig 70b
Frequency of visiting a chemist in the community

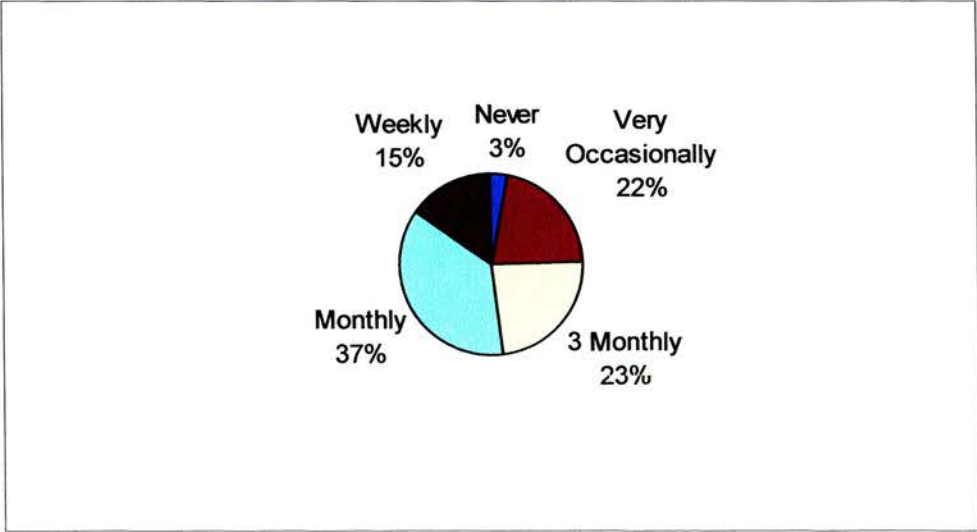


Fig 70c Frequency of visiting a chemist non-disabled cohort

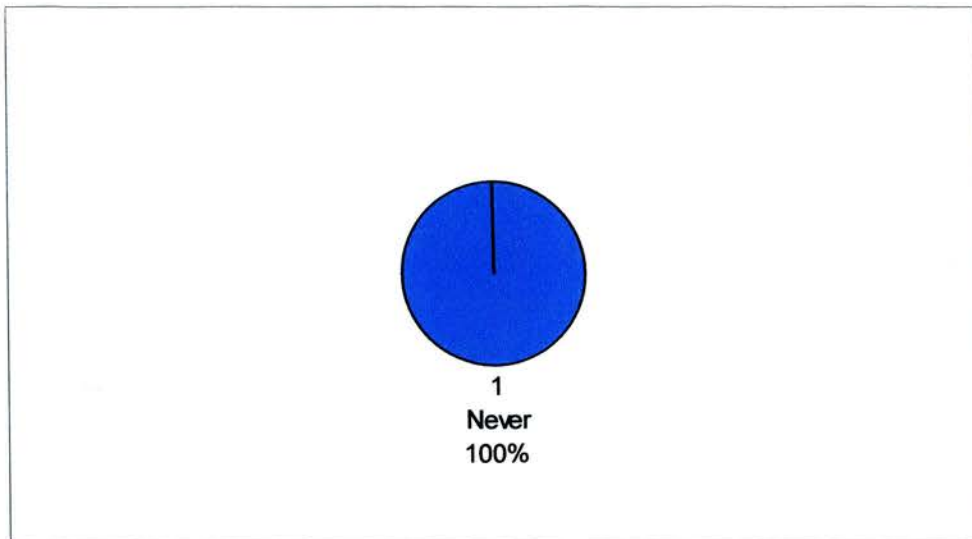


Fig 71a
Frequency of visiting jumble/car boot sales in hospital

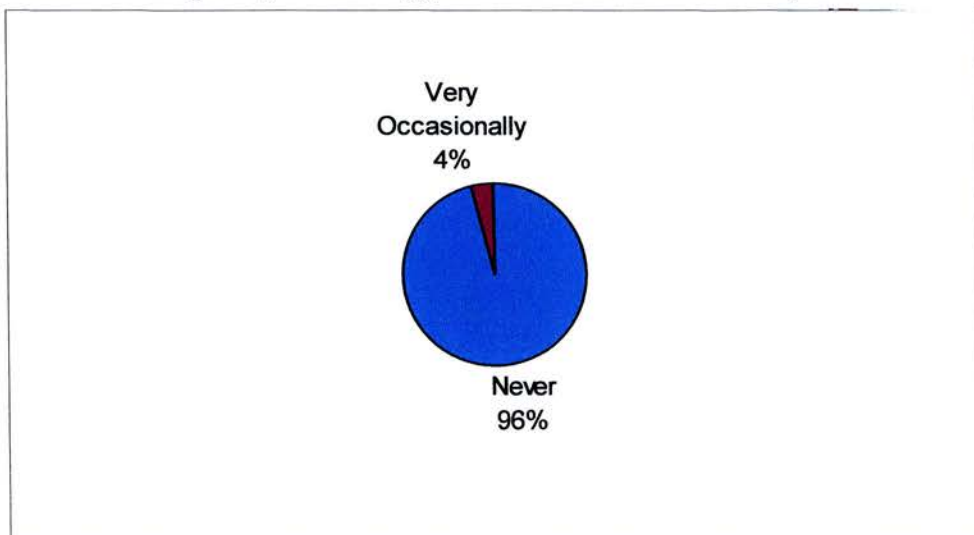


Fig 71b
Frequency of visiting jumble/car boot sales in the community

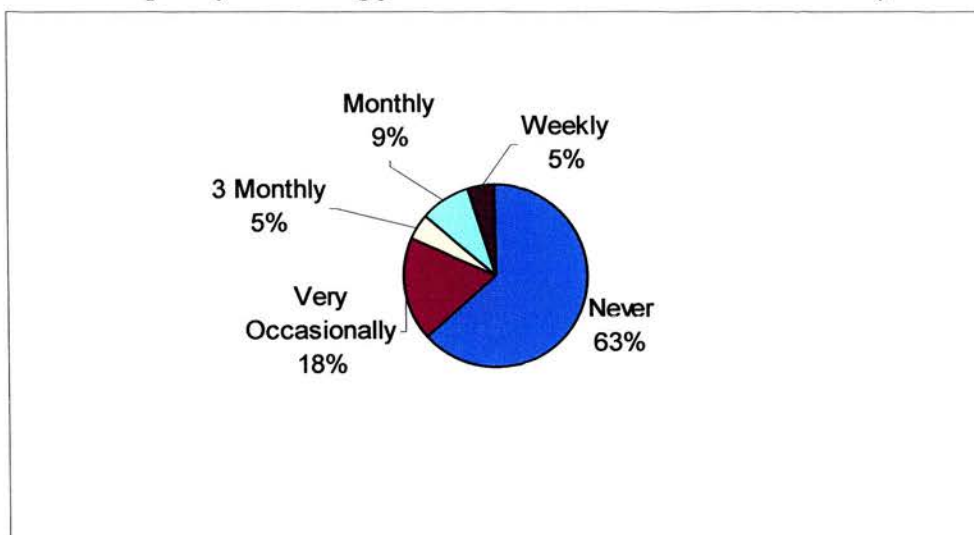


Fig 71c
Frequency of visiting jumble/car boot sales non-disabled cohort

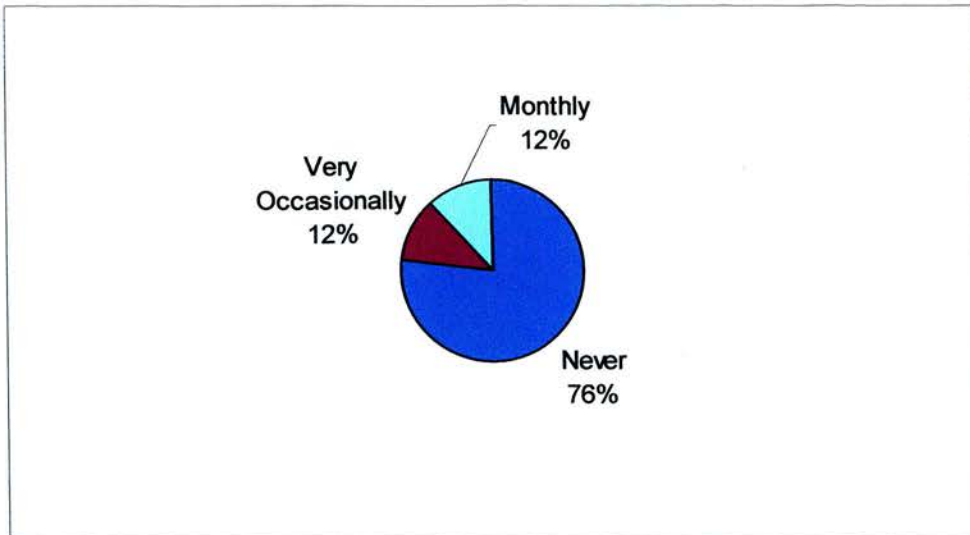


Fig 72a
Frequency of visiting a library in hospital

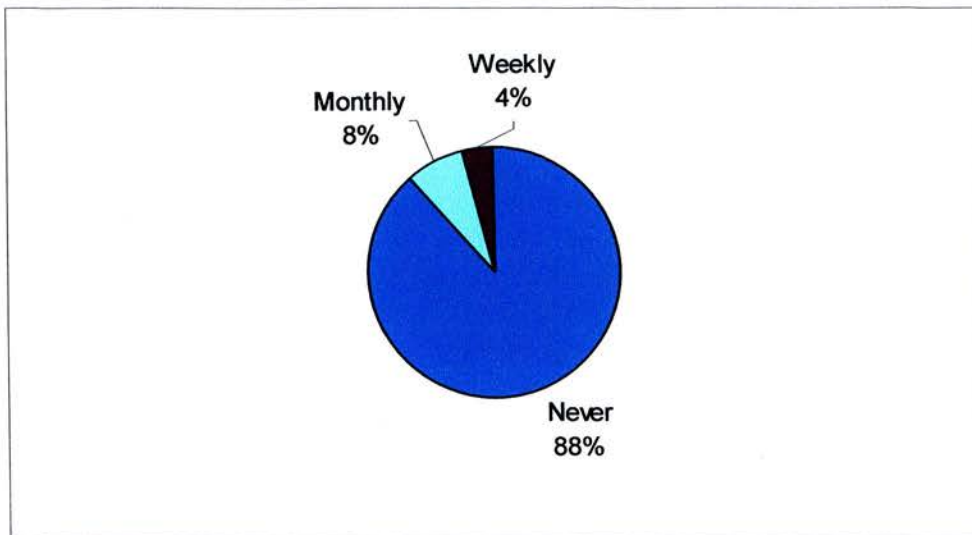


Fig 72b
Frequency of visiting a library in the community

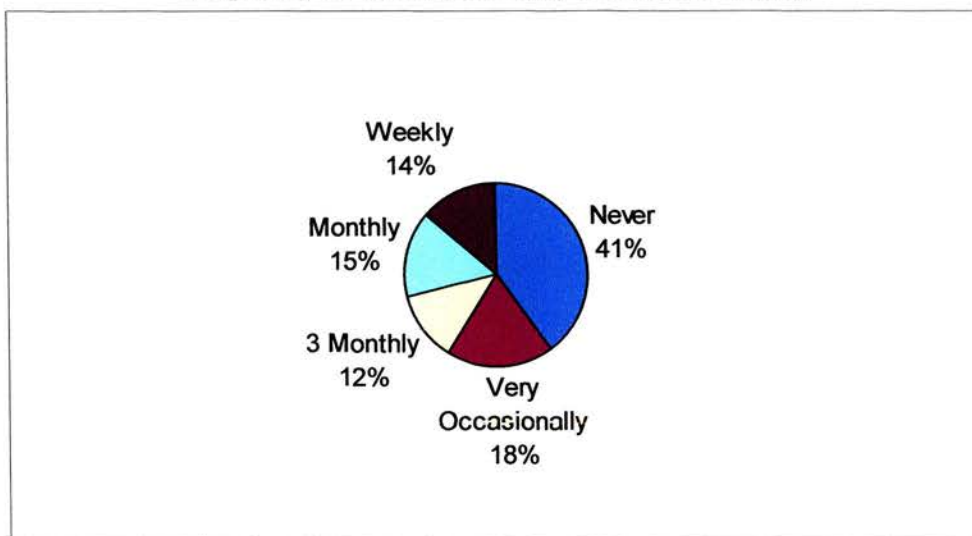


Fig 72c Frequency of visiting a library non-disabled cohort