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A STUDY OF A MOVE FROM HOSPITAL TO COMMUNITY BASED CARE FOR PEOPLE WITH A MENTAL HANDICAP

DAVID JOHN DAGNAN

ABSTRACT

This thesis presents findings from a study examining some effects of a move to community based care on a group of 39 residents of Aycliffe Hospital; each person leaving was matched with two people who remained in the hospital. Both groups were studied before and at least 12 months after leaving the hospital.

A number of measures were taken that describe the characteristics of the subjects and homes. These include a novel method to describe the location of facilities around the homes.

A time budget methodology was used to measure activity outside of the home before subjects left the hospital, this was repeated at follow-up. The time budget consisted of a week long record of each occasion that the person left the home, also recorded were the destination, duration, mode of transport and people accompanying on each trip.

At follow-up a novel method was used to gain qualitative and quantitative data concerning subjects' familiarity with their neighbourhood. This involved accompanying the subjects' on walks around their neighbourhoods and required them to identify a standard list of facilities. Further measures at follow-up involved direct time sample observation of activity within the home. Semi-structured interviews were used to establish subjects' views of the move and of their current pattern of activities.

The outcomes for the movers are generally encouraging. Although they lose some independence they do not engage in less activity. They use more unsegregated facilities, and a range of maintenance facilities that not used in the hospital; some use unsegregated work and leisure facilities. Within the home movers have more opportunity for and engage in more domestic and personal behaviour. Of those that gave interviews, more movers than controls indicated that they were satisfied with their new homes, and in comparison with controls few movers would like to live elsewhere.

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WITH A MENTAL HANDICAP

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PhD

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The work presented in this thesis was initiated early in 1985 by Mr V. Gorman and the Unit Management Team of Aycliffe Hospital. It was supported by a grant from the Northern Region Health Authority. A research contract stated that the purpose of the study was twofold:

1. to explore methods available for measuring aspects of the lives of people with mental handicaps, and
2. to use these to study the relocation of residents of Aycliffe Hospital to alternative homes in the community.

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Chapter One

Introduction

Hospitals for people with mental handicaps have discharged residents into the community for many years (Jones, 1960). But in 1971 change from a hospital based service to one based in the local community became a central part of government policy. People with mental handicaps currently living in hospital were to be systematically moved out (DHSS, 1971).

The effect of a change in policy of this kind should be evaluated. It is important to know the effects of moving to community based care on those moved; it is important that the experiences of one district implementing the policy are made available to others. The central task of the present study was to examine the effects on people with mental handicaps of a move from Aycliffe Hospital into homes in the community.

The study is put into a research context by reviewing previous British studies of people with mental handicaps who have moved from hospital to community based care, or which compare hospital and community based care. The studies reviewed are particularly concerned with outcomes for clients rather than outcomes for other groups (staff or families) or with the economics of such services. The review is not exhaustive but deals with some of the major British studies. Many of these are discussed in more detail in other chapters when they are relevant to the type of work under consideration. Methodologically the work to be reviewed is of 4 main types; studies using interviews with carers; studies using interviews with the clients themselves; studies using records kept administratively or for the purpose of a research project; and studies using direct observation.

There are several examples of well resourced independent evaluation



of the movement of people with mental handicaps from long-stay hospitals to community based care in Britain. The Personal Social Services Research Unit at the University of Kent co-ordinates the evaluation of 12 Care in the Community projects for people with mental handicaps (e.g. Personal Social Services Research Unit, Summer 1984; Cambridge & Knapp, 1988). These evaluations are concerned with three questions; the outcome for the clients, the cost of providing the care, and how the projects work (Knapp, 1988). The initial publications from this group have documented details of the management of the projects involved; outcome data for people with mental handicaps has yet to be published. The measures that will be used in these studies emphasise the clients' well-being. Domains include: morale and life satisfaction, skills and behaviour problems, social contacts, engagement in activity, personal presentation, and the occurrence of 'significant events'. Methods will include: interviews with the clients, adaptive behaviour scales completed by the carer, time budgets and carer maintained records (Renshaw, 1985).

The Mental Handicap in Wales - Applied Research Unit has been evaluating the development of the NIMROD service which is 'a pilot, comprehensive, community based service for people with a mental handicap and their families (Blunden, 1975)'. The evaluation uses a multiple baseline approach as the introduction of NIMROD services to different districts was staggered (Blunden, 1975; Humphreys et al, 1983b). Most of these services are for people already living in the community and their families. Some are provided for people with mental handicaps who leave hospital (e.g. Evans et al, 1985) but this is not the main aim of the project. Consumer satisfaction, using both carers and people with mental handicaps themselves as informants is an important part of this research (e.g

Lowe & De Paiva, 1988; Humphreys et al, 1983a), other data are collected using an interview with parents, an adaptive behaviour scale and direct observation of clients' eating skills (Humphreys, 1983b).

Felce and his colleagues have evaluated community based homes for people with mental handicaps leaving hospitals (e.g. Felce et al 1980a; Felce, 1988). Early studies involved the evaluation of 'Locally Based Hospital Units' (LBHUs) which are 21-26 bedded units purpose built in community settings. Data were collected in 5 LBHUs, of which 4 were for children and 1 for adults, and 5 hospital villas, of which 2 were for children and 3 for adults. The data presented below concentrates upon the adult group as this is most relevant to the present study. The adult LBHU had 24 residents, and the 3 hospital villas for adults had a total of 119 residents; all are described as having severe handicaps. The hospital and LBHU residents were compared on the Wessex Scale which records physical disability, self-help skills and challenging behaviour (Kushlick et al, 1973; the scale is reviewed in detail in Chapter 2). Adults in the villas had more challenging behaviours, and were generally more able than those in the LBHU group. A variety of methods were used to compare the homes; these included:

1. The use of direct time sampled observation of resident engagement in activity within the home and of staff contact with residents. Engagement refers to appropriate purposeful contact with the environment. The level of engagement in the adult LBHU was greater than that in 2 of the 3 hospital villas and about equal to that in the third (Felce et al, 1980b). On average adults were engaged for 48% of time in the LBHU and for 39% of the time in the villas. The number of staff in

contact with residents at any one time was greater in the LBHU than in the 3 villas (Felce et al, 1980c).

2. The use of institution records to abstract residents' contact with their families. Records were kept of nights spent with families, trips with families and visits from families. An average of 63% of residents received any family contact in a year; there was little difference in this between the residents of the LBHU and those of the villas. However the average number of contacts with family per resident was greater in the LBHU than the hospital villas (Felce et al, 1980d).

4. The use of personnel records to study continuity of staffing. There was greater continuity of staff in the LBHU than in the hospital villas (Felce et al, 1980e).

5. The use of medical and nursing records to abstract details of resident's illness, and their contact with professional staff. In comparison with adults in the villas those in the LBHU received more primary medical care; a similar amount of contact with dentists and consultant psychiatrists; and considerably more regular contact with physiotherapists and occupational therapists. The adults in the LBHU had less recorded injuries and illnesses, but a considerably greater number of convulsions (Glossop et al, 1980).

Felce has continued to use direct observation in a series of studies of the activities of people with mental handicaps in different forms of residential care. The schedule used in these studies is described in more detail later, it continues to use

categories of engagement in appropriate activity and contact between staff and residents. Felce et al (1986a) studied a group of 6 people (mean age 46 years) with severe mental handicaps who were residents of a small community home, and 6 people (mean ages 42 years) who were in hospital care and who during the course of the study themselves moved into a small home. The groups were similar in terms of mental and chronological age, language skills, and adaptive behaviour. Two 3 hour video recordings of the subjects were made starting 1.5 hours before the evening meal; a continuous record of engagement in activity was then taken from the videos using a computer programmed for real-time data entry. The small home residents were engaged for a mean of 51% of the time. The hospital group was engaged for a mean of 23% of the time which increased to 56% of the time when they moved to a small home. The small home residents interacted with staff 17% of the time. The hospital group interacted with staff 1% of the time increasing to 14% when they moved to a small home. It was suggested that the increase in the level of engagement was related to a variety of factors such as improved staff performance due to systematic in-service training, environmental enrichment and management practices.

The same video recordings were analysed by Felce et al (1985) to study the effect of the material enrichment occurring between hospital and community homes. Inventories of the physical resources of the homes and hospital were taken and client access to each area was noted. Engagement was recorded in 40 categories each of which was specific to particular items on the inventory; for example behaviour associated with waste bins included putting rubbish in them and emptying them. Observations were continuous using the programmed lap-top computer. People living in the small

group home were engaged in specific activities for a mean of 37% of the time; those living in hospitals for 22% of the time, increasing to 40% of the time after moving to a small home. Residents of the small home used 34 of the 40 behaviour categories while those in hospital used 19 increasing to 38 after moving to the small house.

Saxby et al (1988) carried out follow-up observations on 10 of the 12 subjects who had been studied by Felce et al (1985, 1986)^A 2 years after the original studies. In the intervening years there had been a slight decrease in staff-resident ratios, due to an increase in the number of residents in each home. The method used was the same as in the previous studies. The results indicate no significant reduction in the proportion of time observed engaged in appropriate behaviour, although for 5 subjects the observed proportion of time spent engaged in appropriate behaviour had decreased in comparison to the earlier study. There was a significant decrease in staff-resident interaction, although this may not simply have been due to the decrease in staff-resident ratio; an alternative hypothesis may be that as residents were more skilled they required less prompting.

Thomas et al (1986) compared the levels of engagement in activity of 6 groups of people with severe mental handicaps matched upon age, mobility, continence, speech, self-help skills and behaviour disturbance. Two groups of 10 people came from 2 institutions, 2 groups of 10 from 2 LBHUs and 2 groups of 5 from 2 small group homes (8 beds). Observations were continuous using a lap-top computer. Engagement was noted for a mean of 2% and 5% of the time in institutions, 6% and 16% in larger hostels and 53% and 27% in small community homes. Staff-client contact was recorded for a mean of 3% of the time in both institutions, 3% and 2% of the time

in large community based hostels and 17% and 10% in small houses.

Further work has been carried out to systematically evaluate the degree of integration and community activity of people with mental handicaps leaving hospital. Felce (1988) discusses an approach to the study of community integration and activity that identifies 4 important elements: the maintenance of family relationships, the use of community facilities, gaining community acceptance, and development of activities and relationships. These have, so far, been operationalized in 2 studies.

Direct observation of the use of community facilities using time sampling has been used by Saxby et al (1986). Observations were made of 10 severely handicapped people during 6 visits to shops and 3 visits to pubs and cafes. Observations were made every 30 seconds and behaviour was classified into 5 categories: activities involving appropriate use of the environment in which observations were taking place, interaction with others, stereotypic behaviour, inappropriate behaviour and neutral behaviour. Appropriate activity was recorded for 29% of the time in shops and for 36% of the time in cafes and pubs. There was relatively little interaction with members of the public. A further element of the study involved interviewing publicans and shopkeepers; respondents were quite positive in their perception of the behaviour of people with mental handicaps using their facilities.

De Kock et al (1988) established details of trips into the community of people with severe handicaps, some of whom moved from hospital to community based units. Data were collected using daily reports routinely filled in by care staff. Records were kept for at least 3 years in hospital and at least 1 year after moving to

the smaller community houses (8 bed). Records were kept for 6 months in the case of comparison groups living in larger hostels (25 bed). The results for 10 people moving from hospital into the small community units indicated a change in the average annual frequency of trips into the community from 7 to 254 per person. Two comparison groups of 12 people living in 2 larger community units had an average annual frequency of 74 and 68 trips per person. To illustrate the reliability of this type of data collection the families of subjects in the study kept records of their visits to the homes over a period of three months; 94% of visits recorded by staff were also recorded by families, indicating good reliability for the records.

Hemming et al (1981) studied the move of 51 adults with mental handicaps from institutions to 2 purpose built units. The new units were themselves built in hospital grounds, and so are not strictly community based, but the design and methods used warrant the inclusion of the study in this review. The study used a matched pairs design, with each mover being matched, where possible, on sex, medical diagnosis, medication, temperament, employment and dependency; the percentage of subjects that were matched on any single variable varied from 34% to 80%. The Resident Management Practices scale (King et al, 1971) was used to demonstrate that the new units were less institutional than the previous hospital placements. The outcome variables included; changes in ability recorded using the Adaptive Behaviour Scale (Nihira et al, 1974) and changes in occupation and activities recorded using interviews with the carers and direct observation. Data were collected longitudinally with a pre-move measure and post-move measures at 9 months, 1 year and 2 years. The results indicated significant increases in staff-resident interaction, but

a slight reduction in day-time activity. There was an overall increase in the general Adaptive Behaviour Scale score and in the domestic activity score in particular 9 months after moving, although there was a decrease from the 9 month post-move levels for both variables after 1 and 2 years. A key feature of the results was that outcome effects were shown to be dependent upon the characteristics of the subjects and the environment from which they moved; for example those with IQs of above 50 who came from relatively 'free' institutions showed the least improvement in adaptive behaviour.

Shah and Holmes (1987) studied 2 groups of people with mental handicaps leaving a large institution, using matched control groups with measures before and one year after the move. Group 1 consisted of 27 'sociable, low dependency subjects' moving to a large National Health Service hostel in a residential street and Group 2 consisted of 14 'socially impaired behaviourally disturbed young adults with few skills' moving to a special ward in a smaller hospital. Control groups were matched on two or three level scales of sex, mobility, communication, self-help skills, continence, 'behaviour problems' and 'quality of social interaction'. Structured interviews with care staff were used to explore the pattern of activities of subjects both within and outside the home in the preceding month; interviews were also carried out with parents to establish their satisfaction with the wards and homes. Results indicated some difference in the number of activities within or outside the home; Group 1 showed a significant increase in independence within the hostel and Group 2 showed a significant increase in community based leisure activities. The control groups did not demonstrate such changes. Parental satisfaction with the hostel was significantly greater than it had been at baseline in

the hospital, there was no significant change in the satisfaction with the wards for the parents of those moving to the special ward or for the parents of controls.

Raynes and Sumpton (1987) interviewed carers of 175 people who had been part of the 448 person study group of King et al (1971); subjects lived in local authority hostels, voluntary homes, parental homes and hospitals. Two survey measures developed by Raynes et al (1979) were used; the Revised Resident Management Practices scale which measures the extent that the environment is institutionally oriented and the Index of Community Involvement which determines whether subjects had had contact with any of 14 community facilities in the previous month. Two further survey scales were developed for the study; the Index of Participation in Domestic Life which measured the extent to which subjects were permitted to carry out domestic tasks and the Index of Involvement in Decision Making which measures the subjects permitted involvement in decisions about every day activities. The data were collected by interview with the main carer, although effort was made to obtain some data through direct observation during visits to the staffed residential units. The results indicated that hostels had less institutional practices than the voluntary homes or hospitals (the family homes were not included in this measure) and that residents in the hostels had more opportunity for community activity, domestic activity and decision making. However the hostel residents were slightly more able, generally had less 'challenging' behaviour and were younger than those in the other homes.

A number of British studies have used adaptive behaviour scales to measure changes in skills following changes in environments.

Adaptive behaviour scales are widely used in clinical work with people with mental handicaps as assessments upon which need for services and programs to teach skills are based; they also provide baselines to establish the effectiveness of such interventions. There are a number of reviews of such scales (e.g. Meyers et al, 1980; Raynes, 1987). The British studies below have primarily used the Progress Assessment Charts (e.g. Gunzberg, 1977), of which there are a number of versions, each designed for use with people of different ages and with different degrees of mental handicap. The other scale that is widely used is the Adaptive Behaviour Scale (Nihira et al, 1974). This is an American scale the psychometric properties of which are known (e.g. Spreat, 1980; Stack, 1984). Both scales can be used to obtain an overall score that represents general skill level, and to obtain scores for individual skill domains.

May (1976) assessed the progress made by 25 people with mental handicaps who were residents of a local authority hostel which was shown to be 'highly 'normalized' according to the criteria of the '39 Steps Check-List' (Gunzberg, 1973). The residents were assessed using the Progress Assessment Chart 2 (Gunzberg, 1977), which is designed for the most able adults with mental handicaps. An initial assessment was made 'a few weeks before or after their arrival' and was repeated one year later. It is not stated whether the scales were completed by the researcher or by hostel staff. The group showed a significant general increase in skills, although relatively few individual skill areas showed a significant improvement. It was suggested that those specific areas in which skills did improve (e.g. mobility, leisure, clothes maintenance) were related to changes in opportunity and management practices.

Race and Race (1978) studied changes in adaptive behaviour in 6 residents of a 12 bedded, purpose-built unit in Slough. The Progress Assessment Chart 2 was completed twice, at 10 month intervals, the first occasion being after residents had been living in the home for between 3 and 14 months. The assessments were completed by social workers who were 'concerned with the group home'. The results were presented on an individual basis; there were few consistent changes, but all but one of the subjects showed an increase in communicative ability.

Locker et al (1984) evaluated two hostels in Inner London. One was an 18 bed local authority hostel, the other was a voluntary hostel that provided shared accommodation for 10 people with mental handicaps and 5 people without such handicaps. Each hostel resident was to be matched on age, sex, IQ and duration of institutionalization with one person from a hospital and on age, sex and IQ with one person living with their natural family. However problems were experienced in obtaining matches, and in placing clients in the voluntary hostel. The final study consisted of 12 people from the local authority hostel, with 8 hospital matches and 12 matches from their natural home, and 5 people with mental handicaps from the voluntary home, none of whom had controls. Each hostel resident, and their matches was assessed using the Progress Assessment Chart Two 1 month after entering the hostel and then at 4, 7 and 13 months. Assessments were made by a research assistant using hospital and hostel staff and parents as informants. Results indicated increased skills in those in the two hostels, with little change for those in hospital and no change for those in natural families. For those in hostels the largest changes occurred between assessments 1 and 2 with a much reduced rate of change over other periods.

Felce et al (1986b) studied 28 people with severe and profound handicaps (mean age 32 years). Ten were living in small group homes, 8 in parental homes and 10 in other residential environments (mainly hospital, with one local authority hostel). The subjects were assessed using 10 of the domains of the Adaptive Behaviour Scale (Nihira et al, 1974). Assessments were made at three points, each 18 months apart; the first assessment coincided with the opening of the small residential homes. Both graphical presentation and statistical analysis illustrate that there is a significant change in overall adaptive behaviour levels for those in small group homes compared to those in family homes or other settings. Changes in two individual domains were also statistically significant; these were domestic activity and self-direction.

Finally some British studies have used people with mental handicaps themselves as primary informants. Flynn (1986, 1987a, 1987b) studied 88 people living independently in the north west of England, 47 of whom had lived independently for 4 or more years. Case records, direct observation of the home environment and information gained from keyworkers were used in conjunction with interviews with the clients. The interview with the client discussed management of household tasks and satisfaction with aspects of respondents' lives, such as their daily occupations and neighbourhoods. These studies indicate a number of problems with victimization and debt; however 85 of the 88 subjects said they liked living in their current homes better than any previous home although it was noted that a number of people lived in relatively adverse circumstances (Flynn, 1987a). The importance of maintaining friendship links made in previous placements was

highlighted (Flynn, 1987b). Atkinson (1985b) studied the leisure activities of 50 people with mental handicaps who had left hospitals and were then living independently. Data were collected using interviews with both social workers and the clients themselves. Atkinson concludes that although their lives were not impoverished many of the clients' activities did not involve contact with other members of the community. She discusses reasons for limited participation in integrated activities and notes that there is a threshold between being an observer of community activities and being a participant that subjects were often unable to cross.

No British study has reported grossly negative effects of community based care when compared to hospital care, although some American studies have found such effects (e.g. Cohen et al, 1977) and some British studies have highlighted the possibility that initial positive changes may not continue at the same rate (e.g. Hemming et al, 1981). However the size of effects and areas of life that are studied vary considerably. Studies using direct observation generally indicate quite substantial effects between environments (e.g. Thomas et al, 1986). Felce et al (1986^a) found an increase of 33% of time engaged for the group that moved to a small unit during the course of the study; this would be equivalent of an extra 20 minutes in the hour if the result generalized across all periods of the day. However other studies, for instance those that have used survey methods to examine activity (e.g. Shah & Holmes, 1987), find relatively small effects. Much of this difference is probably due to the variation that exists between type of residential environment and groups of people being studied; some methods may also be more sensitive to some types of change.

The design and methodology used in the above studies varies considerably. The ideal design in an evaluation study of the movement of people with mental handicaps from hospital to community based care would use:

- (1) equivalent comparison groups, one which leaves the hospital and the other of which does not. Ideally the groups would be selected randomly from the hospital population,
- (2) data collection from both groups both before and after the move.

The strength of a randomized allocation to groups is that any variable that may effect a groups' scores on the outcome variable is randomly distributed across the groups, and any post-move group differences between the groups can generally be attributed to the move. In addition if both groups are randomly selected from a defined population, in this instance the hospital, then within the bands of sampling variation the groups are representative of that population (Cook & Campbell, 1979; Cochran, 1983).

This is the theory. In practice a number of problems arise in the use of randomized design for the evaluation of the movement of people with mental handicaps from hospital to community.

- (1) In randomly allocated groups the contribution of variation in an independent variable to variation in the dependent variable is a function of the ratio of the standard deviation of the independent variable to the size of the group. This will be small in large groups but in small groups the equivalence of

randomly selected groups cannot be assumed (Cook & Campbell, 1979; Cochran, 1983). For example Close (1977) randomly allocated 15 people with severe handicaps to two groups the equivalence of which he assumed. In such small groups there could be systematic group differences in important variables despite random allocation. The equivalence of such groups should be tested empirically, not just assumed.

- (2) It would only be possible to use a randomized design in this type of evaluation if all authorities to which subjects were being discharged were able to offer adequate services to all people in the hospital population, for example to people with more severe mental and physical handicaps, or those with challenging behaviour.
- (3) Problems can be encountered in convincing decision makers that randomization is an effective way of allocating scarce resources, although it is in fact the most equitable method (Cook & Campbell, 1979).

When randomization is not feasible other designs may be appropriate; most include the use of comparison groups selected through matching rather than randomization (e.g. Cook & Campbell, 1979; Emerson, 1985). This is the most commonly used method of selecting comparison groups in evaluation of moves from hospital to community based care (e.g. Hemming et al, 1982; Shah & Holmes, 1987).

Matching is not a precise process and may not produce entirely equal groups; there will often be variables that have an effect upon the dependent variable that are not used in the matching

process. For example Douglas (1960) reports a study of the school performance of children from premature births in which matching was carried out using sex, mother's age, social class, birth rank in the family, and degree of crowding in the home. In spite of this the groups were found to differ systematically upon 3 other variables (social level, maternal care and family interest in school progress) which were shown to contribute systematically to the dependent variable. Conroy et al (1982) matched a group of 70 people with mental handicaps who were leaving hospital with an equivalent number who were not. Matches were made on age, length of time in hospital, sex, level of retardation, a measure of self care ability and IQ; however the groups still systematically differed in mobility, vision, hearing and seizure problems. Cochran (1983) describes other problems in matching including the difficulty of finding appropriate matches when the matched variables are comparatively infrequent and the population of potential matches is small. In addition, the aim of matching is to reduce possible group differences in the dependent variable that are due to differences in the distribution of confounding independent variables. This implies some knowledge of which variables are confounding and which are likely to affect the outcome. This may be available from previous similar work, but it is often difficult to know these in each new situation.

Matching is not therefore an ideal method of creating comparable groups. But it is much better than not using any comparison group at all, or than using an entirely unmatched group which is even more likely to result in the confounding of important predictor variables and study group status (for example see the interview data presented by Conroy & Bradley, 1985). When possible the success of the matching should be examined empirically in each

study.

A further element in a good design in this type of study is data collection before as well as after the move. This will allow baseline differences in groups to be identified and is especially important in studies involving matching rather than random allocation to groups, as pre-move equivalence cannot be assumed on baseline measures. The longitudinal design allows change in a matched group moving from a hospital to be cautiously attributed to the move if the control group which does not move, measured over the same period, does not show the same change (Cook & Campbell, 1979).

Few British studies have designs that both use matching to obtain equivalent groups and take pre- and post-move measures (e.g. Shah & Holmes, 1987; Hemming et al, 1981). Most studies either make post-move only comparisons of similar groups (e.g. Felce et al 1980a; Raynes & Sumpton, 1987; Thomas et al, 1986), or have a longitudinal design with no comparison group (e.g. May, 1976; Race & Race, 1978).

Many studies have concentrated on outcomes such as skills or levels of engagement in activity. Increasingly, however, a wider range of variables is being studied, for instance those discussed by Felce (1988) and those being used by the Personal Social Services Research Unit (Renshaw, 1986). Methods are being used that document aspects of client behaviour that are unavailable from surveys using carers as informants. Some studies provide a detailed view of activity patterns and emphasise the use of the perceptions of the subjects themselves (e.g. De Kock et al, 1988; Flynn, 1987a, 1987b).

It is preferable to use a variety of methods, so that the weaknesses of any one may be less influential of the overall result. For example many studies rely upon carers as informants, here there is a potential for systematic bias, for example due to due to a desire to present the service in a positive manner. This is problematic when different homes are being evaluated as home and informant may be completely confounded. Studies that use a variety of methods do not depend upon a single data source, or a single view of the lives of people with mental handicap (e.g. Saxby et al, 1986; Felce, 1988; De Kock et al, 1988). The methods that are potentially most valid and most informative are those that involve direct assessment as there is no intermediary between the data and the researcher (e.g Felce et al, 1985, 1986^a; Saxby et al, 1986).

OVERVIEW OF THE PRESENT STUDY

General considerations

In this study a major limiting factor in the selection of methods and design was person-power. Whilst the collection of baseline data was considered important, in the early stages of the project opportunity to do this was limited by the number of researchers available: initially only a single, half-time research nurse (BH) was involved in data collection.

In addition it was unclear how many subjects would leave the hospital and so be available for the study. A larger number of subjects were identified as potential movers than eventually left the hospital. Baseline data were collected for them and for their controls. Thus if labour intensive methods had been used to collect baseline data much effort would have been spent on subjects who did not become part of the study group. Alternatively if all the subjects on which baseline data were collected did leave the hospital, it might have been impossible to follow-up all of them using the same measures as were used for the baseline.

For baseline data to be properly collected it is necessary to identify potential movers. In the present study a number of information sources were used:

1. Permission was given to attend Aycliffe Hospital Rehabilitation Panel meetings as observers. All discharges were channelled through this committee - in theory. All meetings were attended during the period in which subjects were taken into the study and copies of minutes were provided.

2. Close contact was maintained with the hospital Information Officer (Mr. E. Cox) whose extensive knowledge of the hospital and its residents was invaluable.
3. A final source of information was the hospital social worker. There were four (in series) during the period of the study. In principle any discharge to a Social Service home should be known to the hospital social worker.

When all these sources of information were used potential movers were generally identified in sufficient time to allow baseline data to be collected. However in the early stages of the project we did not always hear of people scheduled for moves, and 12 movers left the hospital before a complete set of baseline data could be collected. In addition there were 2 further movers who left the hospital later in the project without our learning of this from any of the 3 sources.

A further limitation imposed by person-power restrictions relates to the measurement of the reliability of the methods adopted. Ideally all measures should have their reliability assessed as part of the study. Resources were not available for this. When reasonably well established methods were used assessment of their reliability was not carried out within the study. When novel methods were used, however, it was.

The hospital, the subjects and the homes

Aycliffe hospital is situated 1.1 kilometers from the centre of Newton Aycliffe, 9.5 kilometers from the centre of Darlington and

18 kilometers from Durham City. It is the home of over 300 people with mental handicaps. There are 3 types of ward: 2 storey villas with separate wards on each floor, single storey wards for people with more severe handicaps or the more elderly, and satellite houses, on the edge of the hospital grounds, which have not always been wards but which are now part of the rehabilitation section of the hospital. As in most large hospitals for people with mental handicaps there are a number of basic facilities in the hospital grounds. These include: a general practitioner's surgery, residents' shop, dentist's surgery, a number of day occupation centres and a central 'community centre' in which various activities are held during the day, on most evenings and at weekends.

The nominal starting data of the project, coinciding with the appointment of BH, was 31 July 1985. Subjects were recruited if they left between 31 July 1985 and 1 January 1988. Thirty-nine people who had lived in the hospital for at least 12 months prior to leaving were resettled during this period (the 'movers'); this 12 month criterion excluded from the study short-stay residents for whom a move back to the community may have represented a return to their usual homes, following a period of assessment or respite care. Subjects were followed up, at least 12 months after leaving the hospital for the movers and at the same time for their controls. During this period one of the movers returned to the hospital, and as the aim of the study was to establish the effect of community based care this subject was not included in subsequent data collection. At follow-up the complete mover group numbered 38 people.

There are 19 community based homes to which residents were

discharged during the course of the study. Of these 7 are Social Services hostels; 2 are privately owned homes for old people; 3 are privately owned homes for people with mental handicaps, of which one is unregistered; 2 are National Health Service homes; 3 are run by voluntary agencies (MENCAP Homes Foundation); and 2 are the homes of people living independently of full-time staff support, one owned by a housing association and one by the local council. The homes are situated mainly in County Durham and Cleveland, although there is one in Wearside. The homes range in size from one for 2 people living independently to a 26 bedded Social Services hostel. The homes and wards are described in more detail in Chapter 2.

The design and the methods

The design adopted involves matching each person being considered for resettlement (the 'movers') with two people not at that time being considered (the 'controls'). Details of the matching procedure are given in Chapter 2. Two people were matched to each mover as it could not be guaranteed that any one control would not also be chosen to leave the hospital at a later date. When 2 controls were chosen one of them was randomly allocated to be a 'first control' to be followed up in situations when resources were not available to study both controls.

Prior to moving a number of measures of individual characteristics were taken (Chapter 2). They include a complete census of the hospital population using the Wessex Scale (Kushlick et al, 1973); which records age, sex, physical disabilities, self-help skills and challenging behaviour. These data were used in the matching process, to compare the mover group with the complete hospital

population (the 'stayers') and to assess empirically the equivalence of the movers and controls. The date of admission to Aycliffe hospital was obtained for all hospital residents. A measure of intelligence was taken for movers and controls.

A baseline measure of the number and type of activities engaged in outside the ward during one week was taken for each person considered for placement in the community and their two controls (Chapter 3). The measure uses a time budget method and records details of the trips made; the records are kept by care staff. A number of strategies were adopted to ensure the validity of records. The method gives high quality data and has the advantage of being suitable for collecting data on a large number of people; it is ideally suited as a baseline measure.

Thirty-nine movers fulfilled the requirements for inclusion in the study. One returned to the hospital before follow-up data collection and so 38 movers were followed-up after living in the community for at least 12 months. Their controls were followed-up at the same time. The following methods were used at follow-up.

Structural data were collected concerning the resources available, both in the home and in the local community, for all homes in which movers were resident at follow-up and in the wards in which controls were resident at that point. In the home this included basic data concerning staffing and clients and environmental characteristics of the homes and wards. This was collected through interview with the person in charge and through direct observation. The data concerning availability of resources in the local community were collected using information from staff. The quantification of features of community resources is relatively

novel and is presented in Chapter 2.

The same measure of activity outside the home described at baseline was used at follow-up for the movers and both controls. The reliability of the method was explored. The use of a design including baselines and a control group allows well controlled statistical exploration of the effect of leaving the hospital on a major indicator of community adjustment. In addition the details of trips recorded using the method gives considerable descriptive detail of activity patterns that is often not available from other methods. This is presented in Chapter 3.

As the time budget method relies upon the carers as informants a structured participant assessment was made of the individuals ability to independently locate community facilities (the 'neighbourhood walk': Chapter 4). This was carried out for movers and their first controls. The method is novel and provides quantitative data as well considerable qualitative data concerning the subjects' use of resources in their neighbourhoods. The reliability of the method was assessed and the relationship between the data obtained here and data concerning the availability of resources is explored.

Between 3 and 6 hours of direct observation was made for each mover and first control using a combination of structured time sample and participant methods; the behaviour taxonomy used is similar to that used in other British studies. There is no baseline measure available but pre-move scores from the Wessex Scale were used to analyse the effects of study group status and Wessex Scale scores on the observed levels of activity. This is presented in Chapter 5.

Finally a semi-structured interview was carried out with movers and first controls to discover their perceptions of their lives and their preferences regarding the places in which they had lived. The results are largely presented qualitatively, although some statistical analysis is included. This is presented in Chapter 6.

Chapter Two
Subjects and Homes

This chapter describes the characteristics of the people with mental handicaps who were involved in the study and of the places in which they live.

First the individual characteristics of the people are described.

This serves two purposes:

1. It allows comparison of the group that has left the hospital with the total hospital population. This demonstrates the criteria that have been operating, formally or otherwise, in the selection of people for transfer.
2. In this study the movers have been matched with a comparison group in the hospital. The limitations of matching have been discussed in chapter 1. As it is never exact characteristics in which the two groups may differ in spite of the matching may be identified.

Then the home environments in which subjects lived are described as are their local neighbourhoods. This serves three purposes:

1. It shows whether the intervention (moving to the community) makes a difference in terms of important structural features of the environment.
2. It indicates the nature of the homes provided for the subjects and so aids in the generalization of the results to other districts.
3. It illustrates variables whose effect upon behavioural outcomes will be explored in later chapters.

Individual Characteristics

There are a number of reviews of individual characteristics as predictors of successful community placement (e.g. McCarver & Craig, 1974; Sigelman et al, 1980³), but as to which characteristics are the more important there is little consensus. There are a number of reasons for this:

1. Reviews such as that by McCarver and Craig (1974) cover a wide period of time (1945 to 1970s). Changes in hospital populations and the services available mean that the predictors of success for people being discharged from hospital in 1945 may be different from those for people being discharged in the 1970s.
2. Different criteria of success have been used, for example: remaining in the community versus returning to an institution (e.g. Sutter et al, 1980); changes in adaptive behaviour (e.g. Silverman et al, 1986); congruence of skills learnt and skills performed in the new environment (Seltzer, 1981).
3. The individual characteristics that predict success depend upon the demands of the new environment; for example a different set of characteristics may suit a large staffed group home and an adult placement scheme. Bell and Schoenrock (1981) looked at predictors of performance in 13 activities relating to community functioning and found different individual characteristics to be important for different activities.
4. Many of the characteristics considered are correlated with

other predictors which themselves may have different effects. For example, duration of stay in hospital may be related to increased compliance with requests (Zigler & Balla, 1977), to 'challenging behaviour', to physical handicap (DHSS, 1980) etc. Multivariate analysis is necessary to disentangle the effects of such variables.

Five individual characteristics are considered here: sex, age, length of time in hospital, intelligence, and degree of disability.

Sex

McCarver and Craig (1974) found a slight difference in successful adaptation in favour of men, although others claim that women are more successful (e.g. Schalock et al, 1981); Edgerton (1967) found that women were more successful at attracting stable benefactors. However many studies do not separately analyse outcomes for men and women and so assume little effect for this variable

Age

A positive relationship has been found between age and community adjustment (Windle, 1962; Conroy et al, 1982). However Bell and Schoenrock (1981) found age to be related to only one aspect of community functioning, the use of cinemas.

Length of time in hospital

Studies reviewed by McCarver and Craig (1974) found an inconsistent relationship between time spent in institution and placement success. The period spent in institutions may have an effect upon

social behaviour (Zigler & Balla, 1977). For example people with mental handicaps who have been institutionalized may be more compliant (Rosen et al, 1974; Zigler & Balla, 1977). This may be both an advantage and a disadvantage in adjustment to community living. Compliance may, for example, lead to consistent use of road safety procedures but increase the chance of exploitation (Rosen et al, 1974). That people who have lived for long periods in hospitals can successfully adapt to community living is demonstrated by Singh and Balasubramian (1989) who report the successful rehabilitation of 4 women who had lived in hospitals for a mean of 40 years, and who had a mean age of 67 years.

Intelligence

Studies often demonstrate no relationship between intelligence and placement success. This may be due to a number of reasons. Intelligence may be related to other characteristics some of which have positive and some negative effects upon outcome; for example Bell (1976) found more intelligent people with mental handicaps in community settings had a higher probability of breaking the law. Studies of community adaptation often involve groups with a relatively narrow range of intelligence scores which will tend to reduce correlations of intelligence with any other variable (Berger & Yule, 1985). Bell (1976) in a study of 169 former residents of a state hospital who had a wide range of intelligence scores concluded that substantial differences in outcome are related to intelligence. These included differences in degree of independence, in jobs and in social activities.

Degree of disability

Degree of disability refers to both lack of adaptive behaviour and physical disability. Adaptive behaviour has been shown to relate to placement success, although there is little consistency in which skills best predict success (Bruininks et al, 1987). Inappropriate behaviour often predicts a poor outcome (Crawford et al, 1979; Schalock et al, 1981); measures of this are often included on adaptive behaviour scales (e.g. Nihira et al, 1974).

Reviews by Meyers et al (1980) and Harrison (1987) conclude that intelligence accounts for around 50% (studies range from 9% - 83%) of variance in adaptive behaviour. Higher correlations between intelligence and adaptive behaviour are reported in studies of populations with wider ranges of ability (Meyers et al, 1980). This does not mean, however, that people with severe handicaps do not have the capacity to learn important adaptive skills (e.g. Haring et al, 1976; Berkson & Landesman-Dwyer, 1977; Leland, 1978). Definitions of mental handicap now generally include reference to both intelligence and adaptive behaviour (e.g. Grossman, 1973; HMSO, 1983). Adaptive behaviour is important in identifying the training and resource needs of people with mental handicaps and their services.

METHODS

Sex and age

These were available from the Wessex Scale (Kushlick et al, 1973) details of the administration of these in the study are given later

in this chapter under degree of disability.

Length of time in hospital

The dates of admission to Aycliffe hospital for the hospital population were obtained from hospital records.

Intelligence

Intelligence is not included as a variable for comparison of the mover and the total hospital population as a complete data set was not available. It is used in comparison of mover and control groups only.

The Weschler Adult Intelligence Scale (Weschler, 1955) is widely used with groups with normal ranges of intelligence. It can not be used to assess those with severe or profound handicaps. The full test may require some time to complete and several abbreviated forms have been suggested (e.g. Doppelt, 1956; Watkins et al, 1988). These either use selected subtests, or selected items from all subtests. Short form scores can either be pro-rated (e.g. Britton & Savage, 1966) or a regression equation used (e.g. Doppelt, 1956) to obtain verbal, performance and full scale scores. Watkins et al (1988) compared 10 selected subscale forms of the WAIS and 3 selected item forms designed for people with mental handicaps and found that none provided results that were 'interchangeable' with scores from the complete test using a criterion of +/-3 IQ points. They suggest that abbreviated forms may be useful for screening purposes.

The Britton and Savage (1966) short form of the WAIS was in use at

Aycliffe Hospital at the time of the study and so was used in this study. The Vocabulary and Comprehension sub-tests are used from the verbal scale and the Block Design and the Object Assembly from the performance scale. Scores from the sub-tests are prorated to give the sub- and full-scale scores. This version was designed for use with an elderly population with whom the authors report scores from the short form that differ by a maximum of 2.8 points from the full test score. There is no data concerning its generalization to people with a mental handicap.

Subjects were tested using the Britton and Savage (1966) short form of the Weschler Adult Intelligence Scales by DD, CM, BH and MC. Testers underwent training given by the principal clinical psychologist at Aycliffe Hospital (MC) prior to administering the tests. A number of scores were available from the records of the clinical psychology department of Aycliffe Hospital, these were used when they had been completed after 1979, any test completed before 1979 was repeated. Movers and controls were visited in their ward environments where testing was carried out. All testing occurred whilst subjects were in the hospital.

Degree of Disability

The Wessex Scale (Kushlick et al, 1973) assesses both adaptive behaviour and physical disabilities and has been used as the basis of a number of national and local surveys (e.g. National Development Group, 1978; Aycliffe Hospital, undated). It was specifically designed for use in large scale surveys of people with mental handicaps (Kushlick et al, 1973). The categories of disability described by the scale have been used by many health and social services departments to plan their service needs (eg.

Martindale, 1975; National Development Group, 1978). The scale has been used by the National Development Team as the basis for their 'mental handicap assessment form' which is also widely used in service allocation and planning (National Development Team, 1984). A copy of the Wessex Scale and instructions for use are included as appendix 1.

The Wessex Scale consists of 15 items in which presence and degree of incapacity are scored on a three point scale; 1 indicating a high degree of incapacity, 2 a moderate degree and 3 no incapacity. There are a further 5 items which score the presence and degree of 'challenging behaviours'. There are a number of published methods of combining these items into scales representing functionally similar items (e.g. Kushlick et al, 1973; National Development Team, 1984). The reliability of the scales has been examined (Kushlick et al, 1973; May et al, 1982; Palmer & Jenkins, 1982). Palmer and Jenkins (1982) present Kappa values for the individual items and composite scales based on the ratings of 345 people with mental handicaps of all ages. Kappa is a statistic for scoring agreement of nominal and ordinal scales that takes into account chance agreement (Cohen, 1960; 1968); it varies between 0 and 0.99. Kappa values below 0.6 were recorded only for items relating to behaviour disorders, continence and sensory handicap. Palmer and Jenkins (1982) note that speed and ease of completion continue to make the Wessex Scale useful for large scale surveys.

There were 394 people in Aycliffe Hospital for whom the Wessex Scale was completed in the summer of 1980 as part of a local census of hospital populations. As the conditions under which the 1980 data were collected were not known and as degree of disability may have changed a new census was completed specifically for the

purpose of this study in September 1986. A copy of the scale and a set of instructions for its completion for each of the 398 people resident in the hospital at the time was distributed by the senior nurse of the area in which they lived. As this census was completed after subjects had begun to be taken into the study group 1986 Wessex Scale ratings are not available for 18 movers, for these the 1980 ratings are used. This is discussed further in the results.

RESULTS AND DISCUSSION

Comparison of Movers and the remaining Aycliffe Hospital Population

The characteristics of the group leaving hospital between July 1 1985 and January 1 1989 who had been resident in Aycliffe for at least 12 months ('movers') can be compared with the remaining hospital population from which the movers were chosen ('stayers'). For the 18 people in the study group for whom data from September 1986 is not available data from the 1980 census are used in the comparisons otherwise the 1986 data are used. As the 1980 data were collected up to 6 years earlier these scores may not have the same relationship to the current population as those for whom data were collected in 1986. To explore this a second comparison was made. This compared the most recent available data for all movers with the 1980 data for stayers. It would have been preferable to compare the 1980 data for movers with the 1980 data for stayers however for movers there were not complete data from 1980 as not all of the group were resident in the hospital at that point. Although the comparison made is not ideal any group differences that appear in both comparisons can be regarded as reasonably

robust.

Sex

There were 359 people in the hospital for whom the Wessex Scales were completed in 1986 who did not leave during the course of the study. Of these 213 (59%) were men and 146 (41%) were women. The 39 movers were 24 (62%) men and 15 (38%) women. The difference is not significant (chi-square = 0.016, df = 1, ns).

Age

In September 1986 the mean age of the stayers was 44.9 years (sd = 17.2) and the mean age of the movers was 44.2 years (sd = 16.4). Using a t-test for unrelated samples the difference is not significant (t = -0.25, df = 396, ns).

Length of time in Aycliffe

For movers the length of time in Aycliffe was calculated from admission to discharge date. For stayers the length of time in Aycliffe was calculated to 1 September, 1986 which is the middle point of the period over which cases were being taken into the study. The mean length of time in Aycliffe Hospital for the movers was 20.1 years (sd = 10.8) and for the stayers was 22.3 years (sd = 10.2). Using a t-test for unrelated samples the difference is not significant (t = 1.25, df = 396, ns).

These three results show that there is no difference between the mover and stayer groups in age, sex or the length of time that they had been in Aycliffe at the time that the movers left.

Degree of Disability

Comparisons between movers and stayers can be made using individual and composite items from the Wessex Scale.

As the Wessex scales were completed early in the study when research person-power was low the scales were distributed by senior nurses and there was little quality control over completion. One effect of this is that two Wessex Scale items that are selectively scored, depending upon an individual's score on a previous item, appear to have been misunderstood by the raters. People scored as unable to walk upstairs or anywhere else by themselves should then be scored on an item that scores their ability to walk with help; however most people had been scored on both of these items. Additionally those scored as able to talk in full sentences should then be scored on the clarity of their speech. In both cases the number of people scored on the second item did not match the number expected from answers to the first item. From direct observation of the movers and controls involved in the study and from examining the form of the question it appears that in both cases the second question has been misunderstood. These 2 items are not included in the following analysis (items 2e and 3; appendix 1).

Comparisons for the remaining items are presented in table 1. In 14 out of 19 ratings the two groups are significantly different. The skills that most differ between the movers and stayers are those whose absence entails more work by the care staff. The most highly significant items are those such as incontinence that may require extra laundry facilities and time to wash clothes and bed linen. Incontinence is one criterion by which a person may be

	GROUP				
	Movers		Stayers		
	n	%	n	%	
Wetting Nights					
Frequently	2	5.1	79	22.0	**
Occasionally	3	7.7	89	24.8	
Never	34	87.2	191	53.2	
Soiling Nights					
Frequently	2	5.1	20	5.6	**
Occasionally			103	28.7	
Never	37	94.9	236	65.7	
Wetting Days					
Frequently	2	5.1	77	21.4	***
Occasionally	2	5.1	89	24.8	
Never	35	89.7	193	53.8	
Soiling Days					
Frequently	2	5.1	37	10.3	**
Occasionally			88	24.5	
Never	37	94.9	234	65.2	
Walk by himself					
Not at all	2	5.1	70	19.6	**
Not upstairs			85	23.8	
Elsewhere	37	94.9	202	56.6	
Feed himself					
Not at all	1	2.6	33	9.2	*
With help	1	2.6	61	17.0	
Without help	37	94.9	265	73.8	
Wash himself					
Not at all	1	2.6	78	21.7	***
With help	2	5.1	113	31.5	
Without help	36	92.3	168	46.8	
Dress himself					
Not at all	1	2.6	80	22.3	***
With help	4	10.3	122	34.0	
Without help	34	87.2	157	43.7	

* p > 0.05
 ** p > 0.01
 *** p > 0.001

Table 1(i): Wessex Scale Items by Group

	GROUP				
	Movers		Stayers		
	n	%	n	%	
Attacks others					
Marked			34	9.5	ns
Lesser	9	23.1	92	25.6	
No	30	76.9	233	64.9	
Destructive behaviour damages property					
Marked			26	7.2	*
Lesser	1	2.6	54	15.0	
No	38	97.4	279	77.7	
Hyperactivity					
Marked	1	2.6	24	6.7	*
Lesser	1	2.6	56	15.6	
No	37	94.9	279	77.7	
Attention seeking behaviour					
Marked			22	6.1	ns
Lesser	6	15.4	73	20.3	
No	33	84.6	264	73.5	
Continually injuring self physically					
Marked	2	5.1	22	6.1	ns
Lesser	3	7.7	41	11.4	
No	34	87.2	296	82.5	

* p > 0.05
 ** p > 0.01
 *** p > 0.001

Table 1(ii): Wessex Scale Items by Group - Continued

	GROUP				
	Movers		Stayers		
	n	%	n	%	
Vision					
Blind or almost			22	6.2	ns
Poor	3	7.7	55	15.4	
Normal	36	92.3	279	78.4	
Hearing					
Deaf or almost	1	2.6	23	6.4	ns
Poor	3	7.7	33	9.2	
Normal	35	89.7	303	84.4	
Reads					
Nothing	28	71.8	301	84.1	*
A little	8	20.5	30	8.4	
Newspapers and books	3	7.7	27	7.5	
Writes					
Nothing	22	56.4	286	79.7	***
A little	15	38.5	56	15.6	
Own correspondence	2	5.1	17	4.7	
Counts					
Nothing	18	46.2	256	71.5	*
A little	12	30.8	69	19.3	
Understands money	9	23.1	33	9.2	
Speech					
Never a word	3	7.7	104	29.1	*
Odd words only	10	25.6	88	24.6	
Normal sentences	26	66.7	156	43.6	
Can talk does not			10	2.8	

* p > 0.05
 ** p > 0.01
 *** p > 0.001

Table 1(iii): Wessex Scale Items by Group - Continued

considered unsuitable for social services, voluntary or private care (e.g. Palmer & Jenkins, 1982; MENCAP, undated). People with no self-help skills may also be excluded from existing services as they require considerable direct care time. Problems with mobility may require special adaptation to homes or purpose built environments, involving considerable planning and costs. Sensory impairment and inappropriate behaviour do not in general distinguish the groups: there were small numbers with these problems in either group.

When the same comparisons were carried out using the 1980 data for stayers all comparisons that were significant using the 1986 data were significant in the same direction. It is therefore considered that the population has remained sufficiently constant to allow conclusions to be drawn from comparisons combining the 1980 data for the 18 movers for whom these are the only data available with the rest of the 1986 data.

Further Analysis

In the following analysis items are combined to create scales representing constellations of skills derived from those described by the National Development Team (DHSS, 1984). Combining items is more informative than consideration of individual areas of disability as people with more severe mental handicaps tend to have associated physical and behavioural disabilities (e.g. Richardson, & Koller 1985). The National Development Team (1984) describe a 4 category scale of disability which is constructed using a revised version of the Wessex Scale. Category 1 incorporates those with no problems in continence, mobility or self-help and no behaviour disturbance into one group. A single dichotomous variable

representing those in the National Development Team's Category 1 as one category and those in Categories 2, 3 and 4 as the second category can be calculated from the data collected for this study. Table 2 indicates that while 87.2% of the movers are in Category 1 only 26.7% of the stayers can be so described. This difference is highly significant (chi-square = 55.7, df = 1, p > 0.001).

The comparison of movers with the hospital population of 1986 indicates that the 39 movers are most simply described as generally having no incontinence problems, no mobility problems, no behaviour problems and no deficit in self help skills (87% can be so described). The mover group have been highly selected for lack of disability and the presence of most skills.

Other reports also indicate that the most able of the residents of mental handicap hospitals are generally those who have been leaving for community care both in Britain (Spencer, 1977; Social Service Committee, 1985; Knapp, 1988) and the United States (Bock & Joiner, 1982; Telles & Spreat, 1985). It is accepted in national and regional guidelines that resettlement will concentrate upon those people who are most able (DHSS, 1971; Social Services Committee, 1985; Northern Region Health Authority, 1987); however the continuing need for hospital provision has been questioned both locally (National Development Team, 1988) and nationally (Social Services Committee, 1985). It is possible that in future residential care will be needed for people with more severe handicaps. At present the opportunity is not being taken to explore methods of service provision for people with more severe handicaps.

There is economic pressure on authorities to resettle the most able

	GROUP				
	Movers		Stayers		
	n	%	n	%	
NDT1					
NDT Category Other	5	12.8	263	73.3	***
NDT Category 1	34	87.2	96	26.7	

*** p > 0.001

Table 2: National Development Team Category by Group

residents who require lower staffing levels and less physical adaptation to the buildings that they use. These may also be the people most acceptable to the receiving neighbourhoods. The importance of the resources of the receiving authorities to patterns of discharge has been indicated by Rao (1988). However those people left in hospitals will be relatively more costly to resettle and the able group are those for whom marginal costs in the hospital will be the lowest.

It is interesting to note that the physical characteristics of the residents are just as important in selection for discharge as are self-help skills. Stress is often put upon teaching skills contributing to increased independence as a prerequisite to being considered 'ready' to leave the hospital. However a 'readiness model' may be inappropriate as the hospital may not be able to prepare residents for community life. The demands of segregated settings are just different from those of integrated settings (Taylor, 1987).

Comparison of control group and moving group

Having discussed the differences between the movers and the stayers a similar set of comparisons can be carried out between the movers and the sub group of stayers who comprise the matched control group.

Controls were chosen using the Wessex Scale. An exact match was made upon sex, ability to walk with help, visual disability, auditory disability and speech ability; age was matched within +/- 5 years. The 4 Wessex ratings, sex and age were chosen for matching as predictors of performance on the outcomes used. If

more than two people who matched were available using these criteria then the two closest in age to the case were chosen. Before the second Wessex census of the hospital was carried out the data from the 1980 census were used to match. When available (from 30 October 1986) the 1986 Wessex census was used to match. Of the 39 movers there were 29 people for whom 2 controls were available, 6 people for whom 1 control was available and 4 people for whom there were no controls available; a total of 64 controls. In the cases where 2 controls were available one was randomly designated a first control and used for comparison in methods where data collection for both controls was not possible due to limitations of time. It will be clearly stated in the text when only a first control has been used.

Considering the problems with matching outlined in chapter 1 it is an empirical task to establish the actual degree of similarity in groups obtained. Variables other than those used in the matching process are now used to compare the mover group with the selected control group to establish if there are any consistent differences between the groups that may affect the outcome variables. Variables compared are length of time spent in Aycliffe Hospital intelligence scores and the non-matched items from the Wessex Scale.

Length of time in Aycliffe Hospital

As in the comparison with the total hospital population the length of time that the movers had been in Aycliffe was calculated from admission to discharge; for controls the period of time in Aycliffe was calculated to 1 September 1986, the middle point of the period over which cases were being taken into the study.

The mean length of time in Aycliffe Hospital for the movers was 20.1 years (sd = 10.8) and for the control group was 21.5 years (sd = 10.5). This is not a significant difference ($t = 0.63$ $df = 101$, ns). This is as expected as a major correlate of length of institutionalization is age, upon which the movers and controls are matched.

Intelligence

A considerable number of both movers and controls could not be tested using the WAIS. It should be noted that in cases of physical disability, verbal handicap or asocial behaviour people may be deemed not testable for reasons other than mental handicap.

Thirty-four movers were seen for testing, 5 had no available record and had left before testing was possible. Fifty-five controls were seen for testing, 4 died prior to testing and 5 left the hospital. Two analyses are carried out, first the proportions of both groups that were considered untestable are compared, then the groups are compared on the intelligence scores of those who were tested. Thirty-two controls (58%) and 17 movers (50%) were considered untestable, this difference is not significant ($\chi^2 = 0.57$, $df = 1$, ns). The median intelligence for the 17 movers who were tested was 53 (Semi-Interquartile Range 48.5 - 70) and for the 23 controls was 62 (SIR 57 - 66), using a Mann-Whitney test this difference was found to be not significant ($U = 154.5$, ns)

Continence, Mobility and Selfhelp Skills

The movers and controls were compared on Wessex items that were not

used in the matching process. The tabulation of these variables by group is presented in table 3. Only one of these 15 variables distinguishes the groups. Proportionally more of the moving group is able to write their own name. However care should be taken in interpreting this as about 1 in 20 comparisons are significant at the 0.05 level purely by chance. Although only one item is significantly different alone when the items are combined into the National Development Team classification discussed earlier the difference between the groups is significant (table 4, chi-square = 13.0, df = 1, $p > 0.001$).

It is important to note that the independent mobility item did not distinguish the groups (table 3). The variable used in the matching process was mobility with help, which has been shown to be inconsistently scored. This does not appear to have affected the adequacy of the match upon the other mobility item.

As matching may not produce equivalent groups it is necessary to empirically test the adequacy of the matches obtained. Matching on the 5 variables described has resulted in groups equivalent in duration of stay in hospital, on most of the non-matched Wessex items and in intelligence. However when Wessex items are combined the control group is generally more disabled than the mover group. This will need to be considered in interpretation of any between group differences in the dependent variables.

	GROUP				
	Movers		Controls		
	n	%	n	%	
Wetting Nights					
Frequently	2	5.1	6	9.4	ns
Occasionally	3	7.7	11	17.2	
Never	34	87.2	47	73.4	
Soiling Nights					
Frequently	2	5.1	2	3.1	ns
Occasionally			6	9.4	
Never	37	94.9	56	87.5	
Wetting Days					
Frequently	2	5.1	6	9.4	ns
Occasionally	2	5.1	10	15.6	
Never	35	89.7	48	75.0	
Soiling Days					
Frequently	2	5.1	3	4.7	ns
Occasionally			3	4.7	
Never	37	94.9	58	90.6	
Feed himself					
Not at all	1	2.6	2	3.1	ns
With help	1	2.6	5	7.8	
Without help	37	94.9	57	89.1	
Wash himself					
Not at all	1	2.6	3	4.7	ns
With help	2	5.1	12	18.8	
Without help	36	92.3	49	76.6	
Dress himself					
Not at all	1	2.6	3	4.7	ns
With help	4	10.3	15	23.4	
Without help	34	87.2	46	71.9	

ns = not significant

Table 3(i): Wessex Scale items not used in match by group

GROUP

	Movers		Controls		
	n	%	n	%	
Attacks others					
Marked			6	9.4	ns
Lesser	9	23.1	18	28.1	
No	30	76.9	40	62.5	
Destructive behaviour damages property					
Marked			2	3.1	ns
Lesser	1	2.6	10	15.6	
No	38	97.4	52	81.3	
Hyperactivity					
Marked	1	2.6	2	3.1	ns
Lesser	1	2.6	6	9.4	
No	37	94.9	56	87.5	
Attention seeking behaviour					
Marked			3	4.7	ns
Lesser	6	15.4	15	23.4	
No	33	84.6	46	71.9	
Continually injuring self physically					
Marked	2	5.1	1	1.6	ns
Lesser	3	7.7	8	12.5	
No	34	87.2	55	85.9	
Reads					
Nothing	28	71.8	49	77.8	ns
A little	8	20.5	6	9.5	
Newspapers and books	3	7.7	8	12.7	
Writes					
Nothing	22	56.4	46	71.9	*
A little	15	38.5	11	17.2	
Own correspondence	2	5.1	7	10.9	
Counts					
Nothing	18	46.2	42	65.6	ns
A little	12	30.8	13	20.3	
Understands money	9	23.1	9	14.1	

ns = not significant

* p > 0.05

Table 3(ii): Wessex Scale items not used in match by group

	GROUP				
	Movers		Control		
	n	%	n	%	
NDT1					
NDT Category Other	5	12.8	31	50.8	***
NDT Category 1	34	87.2	30	49.2	

*** p > 0.001

Table 4: National Development Team category by group

The home environments

Residential environments for people with mental handicaps have been poorly described in evaluation studies (Landesman-Dwyer, 1981; Emerson, 1985). It is not adequate simply to use terms such as 'institution' and 'community' as there is large variation in the care provided under insitutional and community labels. They have also become value loaded terms (Crissey, 1975; Social Services Committee, 1985).

Landesman (1986) notes 3 more discriminating classificatory systems that have been used: (1) typological, that is based upon shared characteristics such as size (e.g. Baker et al, 1974); (2) evaluative or outcome based (e.g. Butler & Bjaanes, 1978) and (3) administratively based (e.g. Raynes & Sumpton, 1987). However there may still be a great deal of variation within these categories and the use of any one alone would be of limited value.

Residential environments may usefully be categorized on dimensions (e.g. Willer & Intagliata, 1981). Two widely used dimensional approaches are considered below, that of Moos and his colleagues (e.g. Moos, 1973), used in psychiatric residential facilities (e.g. Milne, 1986) and that of Raynes and her colleagues (e.g. Raynes et al, 1979), used in residential facilities for people with mental handicaps.

Moos (1973) considers that six dimensions of the environment have been shown to have effects upon behaviour and can be used to describe residential and treatment environments. These are: (1) the architectural and physical design of the environment; (2) its behaviour settings; (3) its organizational structure; (4) the

characteristics of its inhabitants and staff; (5) its psychosocial characteristics and organizational climate; (6) the behavioural characteristics of residents. These dimensions are not intended to be independent (Moos, 1973). Moos and Houts (1968) present a Ward Atmosphere Scale which consists of 10 subscales which relate to three dimensions; a relationship dimension, a treatment program dimension, and an administrative structure dimension. The scale has been used to assess environments for people with mental illness in Britain (Moos, 1972; Milne, 1986).

Raynes and her colleagues (King et al, 1971; Raynes et al, 1979; Pratt et al, 1980; Raynes & Sumpton, 1987) have studied environments for people with mental handicaps. Raynes et al (1979) measure the following 4 'dimensions of care':

1. The management of daily events, using the Revised Resident Management Practices scale (RRMP) based upon features of a 'total institution' as described by Goffman (1961).
2. The speech used by staff to residents using the Informative Speech Index (ISI), a direct observation instrument that records the proportion of staff contact that has an informative element.
3. The physical environment, using the Index of the Physical Environment (IPE), based upon the environmental indices of Morris (1969), which records presence of basic resources.
4. Contacts with the community using the Index of Community Involvement (ICI), which records the number of individuals who had contact with certain community facilities over the

previous month.

These dimensions are relatively independent of each other (Raynes et al, 1979).

The dimensions of the two examples above include structure, process and outcome variables using Donabedian's (1966) model of quality assurance. For example; the architectural and physical design of the environment (Moos, 1973) are structural variables; the psychosocial characteristics of the inhabitants (Moos, 1973) and management practices (Raynes et al, 1979) are process variables; and contacts with the community (Raynes et al, 1979) and the behavioural characteristics of inhabitants (Moos, 1973) may be seen as outcome variables.

The environmental features that have been recorded in the present study are primarily structural. Operational policies and management practices were not measured directly although they are to some extent reflected in structural features of the environment. For example the presence of domestic and catering staff relates to the opportunity that residents will have to participate in certain activities (e.g. Felce et al, 1985). Structural variables will affect and be affected by process variables. Other aspects of process were observed informally during the study and are reported in appropriate chapters.

Structural Characteristics

Environmental psychology (Russell & Ward, 1982; Holahan, 1986) has established the important effects of aspects of the physical environment upon behaviour; for example features such as privacy

and crowding (e.g. Aiello & Thompson, 1980). The physical environment may be thought of as providing 'behaviour settings'. These are, 'complex social and environmental conditions that set the occasion for the occurrence of behaviour without functioning as discretely or immediately as discriminative stimuli (Twardosz, 1984; 126)'. In some situations the environment will act as a discriminative stimulus to specific behaviour.

One well researched variable is size. Increased space reduces aggressive behaviour in wards for people with severe and profound mental handicaps (Boe, 1977; Rago et al, 1978). Smaller units may even limit opportunities for contact between residents and friendship formation (Landesman et al, 1980; Romer & Berkson, 1980a, 1980b); though this is not found in all studies (e.g. Thomas et al, 1986; Felce et al, 1986^a). Felce (undated) has shown that in smaller homes staff congregate together less and work with small groups of residents more than is the case in hospitals or larger homes. However staff-resident interaction may only increase if staff-resident ratios increase as a result of reduced numbers of residents. If staff-resident ratios are increased by simply increasing the number of staff then the level of interaction may stay the same or even decrease. Work on the deployment of staff in teaching situations also indicates the value of small groups (e.g. Quilitch, 1975; Porterfield et al, 1980; Crisp & Sturmev, 1988). Harris et al (1974) recommend small groups of clients with individual staff members as the best structure for larger hospital wards.

There are a number of scales for assessing the structure of residential environments. These record the basic resources for a good quality environment. For example, King et al (1971; Raynes et

al, 1979) present the Index of the Physical Environment which records the availability of 'basic personalizing items', such as mirror to resident ratio, percentage of toilets with doors, percentage of dormitories with posters on the wall. Morris (1969) recorded aspects of British hospitals including basic decorative standards, presence of carpet and chairs, and aspects of the environment that created a homely atmosphere. A number of checklists have elements that record qualitative impressions of the 'homeliness' of the setting and the quality of the surroundings along with other more quantitative data (e.g Wolfensberger & Glenn, 1975; DHSS, 1980).

The present study has concentrated upon the basic structural characteristics of facilities such as size, resident and staff characteristics and basic resources, such as baths, toilets and bedrooms. Staff to resident ratios, home size, and access to basic resources have often been used as crude measures of quality of care (e.g. Davies, 1987). The 'homeliness' of the environment was not systematically assessed, although informal observations were made.

METHOD

Data on the staff and residents were collected using a short checklist completed with the person in charge. The checklist recorded number of care staff, presence of domestic and catering staff, number of beds, and sex and age range of residents. This data was collected for all homes in which movers were found at follow-up and in the wards in which controls were resident at that point. The staff and client checklists are included as appendix 2 and 3 respectively.

Data on the physical environment was collected by direct observation during a tour of the home. A checklist was used to record the number of rooms and the basic resources within each of the main rooms of the home, similar checklists have been used in other studies (e.g. Raynes et al, 1979; Felce et al, 1985). These data collection periods provided an opportunity to get to know the staff and the layout of the homes involved. The environmental checklist is included as appendix 4.

The privacy of the subjects was respected, and bedrooms were only entered in the presence of the subject or with their permission. Information regarding the access residents had to each room was collected from staff. To a limited extent this was validated in the direct observation periods.

RESULTS

Administrative Categories and descriptions of homes

The study involved 19 community based homes and 17 wards of Aycliffe Hospital. Data will be presented for each home. This emphasises the individuality of the homes involved and indicates the variation in characteristics. With the small number of homes in the present study this is preferable to subsuming all homes under the unsatisfactory heading of community or institutional homes and the presentation of summary statistics only. Significance testing is not carried out as this is a description of all homes and wards involved not of a sample of them.

Aycliffe hospital is situated 1.1 Km from the centre of the small

town of Newton Aycliffe and 9.5 Km from the centre of Darlington. The 17 wards involved in this study consist of 3 types of housing; single storey wards, mainly housing elderly people and those with severe physical and mental handicaps; 2 storey villas with separate wards on each floor; and satellite houses which are part of the rehabilitation program of the hospital and offer smaller and more normalized environments. Table 5 presents the 17 wards, ordered by size (number of beds) with the number of the control group that was resident at the time of the post-move data collection and the nature of the building (whether the building was originally a ward or not). Facilities on the Aycliffe site include a general practitioner's surgery, a dentist's surgery, residents' shop, public telephone, hairdresser's, a number of day occupation centres and a central 'community centre' in which are held various leisure activities during the day, most evenings and at weekends.

There were 19 community homes. Table 6 indicates the five administrative types of home encountered, the nature of the building (purpose built or not), the number of beds and number of study subjects in each. The nature of the building represents one aspect of the appearance of the facility, and the degree to which it is likely to blend in with the local neighbourhood. This is identified as an aspect of normalization in the PASS rating scale ('Building-Neighbourhood Harmony', p 12; Wolfensberger and Glenn, 1975).

Size and Staffing

Data regarding the staff to resident ratios and whether or not there are domestic and catering staff are presented for the hospital wards and the community homes in tables 7 and 8

	Size	Purpose Built	Number of Study Group Resident
Sunnside Lane	6	no	1
River House	12	no	6
East Lane	12	no	4
2 Head Road	12	yes	1
4 Left Road	14	yes	2
10 Left Road	15	yes	2
11 Left Road	15	yes	4
12 Head Road	16	yes	2
4 Head Road	18	yes	6
3 Left Road	18	yes	3
6 Left Road	18	yes	3
3 Head Road	18	yes	2
1 Left Road	20	yes	4
2 Left Road	20	yes	6
8 Left Road	20	yes	7
9 Head Road	24	yes	1
9 Left Road	28	yes	6
Upper Quartile	20		
Median	18		
Lower Quartile	13		

Table 5: Wards in which controls were living at second data collection, size, nature of building and number of study group

	Size	Purpose Built	Number of Study Group Resident
Social Services			
Stockton Road	6	no	3
Seaside	7	no	3
Mary Avenue	8	yes	1
Pool Street	10	no	1
Darlington Av	11	no	3
Willow House	14	yes	1
Bishop Lane	26	yes	4
Voluntary Sector (MENCAP)			
Centre Court	3	no	3
Mull Drive	3	no	3
Cleveland Way	6	no	3
Private Sector			
Teeshead	3	no	1
Haughton House	13	no	1
Townview	18	no	2
Ling House	20	no	2
Riverhill House	23	no	1
National Health Service			
3 Newside	8	yes	2
2 Newside	8	yes	1
Independent Living			
Aycliffe Way	2	no	2
Cathedral Way	4	no	1
Upper Quartile	18		
Median	8		
Lower Quartile	4		

Table 6: Community homes in which movers were living; size, nature of building and number of study group.

	Staff/ Resident Ratio	Domestic- Catering
Sunnside Lane	.75	yes
River House	.29	yes
East Lane	.38	yes
2 Head Road	.42	yes
4 Left Road	.89	yes
10 Left Road	.80	yes
11 Left Road	.80	yes
12 Head Road	.63	yes
4 Head Road	.44	yes
3 Left Road	.28	yes
6 Left Road	.50	yes
3 Head Road	.56	yes
1 Left Road	.22	yes
2 Left Road	.35	yes
8 Left Road	.50	yes
9 Head Road	.35	yes
9 Left Road	.43	yes
Upper Quartile	.35	
Median	.44	
Lower Quartile	.69	

Table 7: Staffing of wards in which controls were living at second data collection

	Staff/ Resident Ratio	Domestic- Catering Staff Yes/No	
Social Services			
Stockton Road	1.00	no	
Seaside	.86	no	
Mary Avenue	1.69	yes	
Pool Street	.45	yes	
Darlington Av	.32	yes	
Willow House	.25	yes	
Bishop Lane	.21	yes	
Voluntary Sector (MENCAP)			
Centre Court	1.00	no	
Mull Drive	.83	no	
Cleveland Way	.92	no	
Private Sector			
Teeshead	1.00	yes	
Haughton House	.46	yes	
Townview	.28	yes	
Ling House	.40	yes	
Riverhill House	.57	yes	
National Health Service			
3 Newside	1.38	no	
2 Newside	1.38	no	
Independent Living			
Aycliffe Way	0	no	not included
Cathedral Way	0	no	in summary statistics
Upper Quartile	1.00		
Median	.83		
Lower Quartile	.35		

Table 8: Staffing of community homes in which movers were living

respectively. Five figure summary data are presented graphically for number of beds in figure 1 and for staff to resident ratios in figure 2; these allows comparison of wards and community homes. The summary statistics for staffing ratios do not include the two homes of people who live independently.

The community homes are generally smaller than the hospital wards, and have a greater staff/resident ratio. The work of Felce (undated) and Harris et al (1974), suggests that having smaller group size with the same staffing ratios may increase the likelihood of staff-resident interaction, however this may depend upon staff having received specific instruction in methods of increasing resident involvement in activities (Felce et al, 1986). Staffing ratios reported here also need to be interpreted in the light of the different aims of community and hospital care. The aim of a community residential service may be to increase the resident's independence. When appropriate this may actually involve reducing the staff/resident ratio.

The employment^{of} domestic and catering staff is an aspect of structure that reflect basic policy and management decisions and affects the residents' opportunity to engage in domestic activity (e.g. Felce et al, 1985). In the hospital most meals came from a central kitchen and there was at least one whole-time equivalent domestic staff attached to each ward. In the community domestic or catering staff were employed in 8 (42%) of the homes, all of these were Social Service or private homes. In one private home the proprietor discussed the conflict in the need for residents to learn self-help skills but not wishing to be thought of as exploiting residents by having them do jobs that other people would be paid to do.

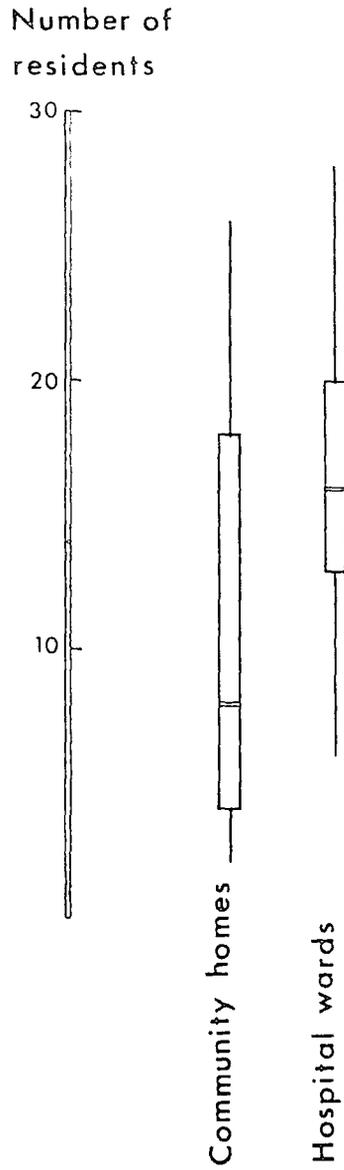


Figure 1: Graphical presentation of home size (number of residents) for 17 hospital wards and 19 community homes

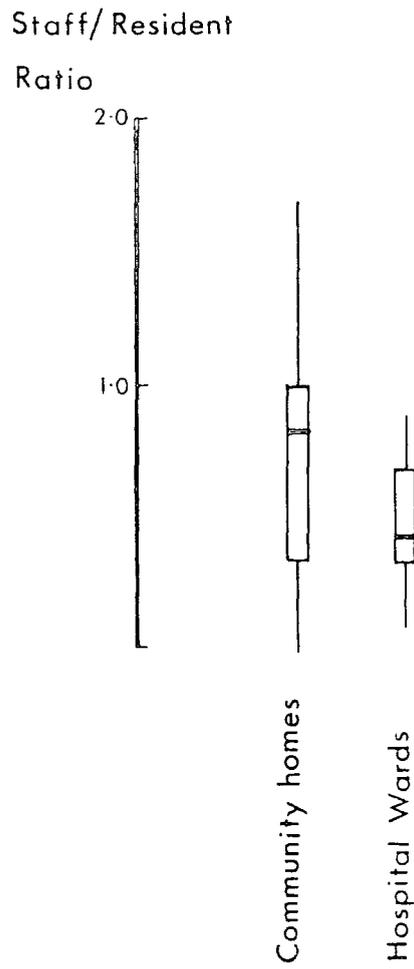


Figure 2: Graphical presentation of staff to resident ratio for 17 hospital wards and 17 community homes

Resident Characteristics

Data regarding the age range of residents (oldest resident to youngest resident), and whether the homes are mixed or single sex are presented for the hospital wards and the community homes in tables 9 and 10 respectively. The data for age range are presented graphically in figure 3.

The community homes have a generally smaller age range which may make it easier for residents to become friends as they may be more likely to share similar interests. Six (35%) of the hospital wards and 16 (84%) of the community homes were mixed sex. In fact 2 of the hospital wards here classed as mixed sex are actually two pairs of closely situated houses, one house being for men the other for women. Two of the 3 single sex community homes are homes for 3 people, this may be less inappropriate than in larger homes. A mixed sex environment is more normal (Wolfensberger & Glenn, 1975) and allows development of appropriate behaviour towards the opposite sex.

Personal Space and Basic Facilities

Data regarding the number of residents per bath, toilet, and bedroom are presented for the hospital wards and the community homes in tables 11 and 12 respectively. This data is presented graphically in figure 4. The access residents were allowed to the kitchen was also reported. The category of limited access may vary from no access at all to access limited only at certain times or to certain people. Hospital staff on 7 (41%) wards reported some form of limited resident access to the kitchen in the community this was

	Age Range of Residents (years)	Mixed Sex Yes/No
Sunnside Lane	22	yes
River House	31	yes
East Lane	31	yes
2 Head Road	39	yes
4 Left Road	32	yes
10 Left Road	21	no
11 Left Road	40	no
12 Head Road	47	yes
4 Head Road	42	no
3 Left Road	25	no
6 Left Road	25	no
3 Head Road	38	no
1 Left Road	41	no
2 Left Road	43	no
8 Left Road	51	no
9 Head Road	34	no
9 Left Road	37	no
Upper Quartile	41.5	
Median	37	
Lower Quartile	28	

Table 9: Characteristics of residents upon wards in which controls were living at second data collection

	Age Range of Residents (years)	Mixed Sex Yes/No
Social Services		
Stockton Road	27	yes
Seaside	38	yes
Mary Avenue	8	yes
Pool Street	27	no
Darlington Av	44	yes
Willow House	44	yes
Bishop Lane	40	yes
Voluntary Sector (MENCAP)		
Centre Court	10	no
Mull Drive	16	no
Cleveland Way	27	yes
Private Sector		
Teeshead	2	yes
Haughton House	39	yes
Townview	40	yes
Ling House	22	yes
Riverhill House	32	yes
National Health Service		
3 Newside	34	yes
2 Newside	10	yes
Independent Living		
Aycliffe Way	15	yes
Cathedral Way	25	yes
Upper Quartile	39	
Median	27	
Lower Quartile	15	

Table 10: Characteristics of residents in community homes in which movers were living

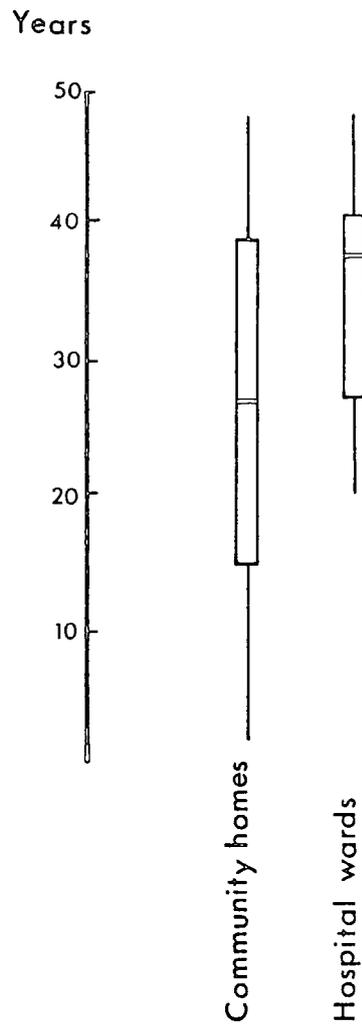


Figure 3: Graphical presentation of age range (years) of residents in the 17 hospital wards and 19 community homes

	Resident/ Bath Ratio	Resident/ Toilet Ratio	Resident/ Bedroom Ratio
Sunnside Lane	3.0	3.0	2.0
River House	6.0	3.0	1.5
East Lane	6.0	3.0	1.5
2 Head Road	6.0	6.0	2.0
4 Left Road	7.0	2.8	3.5
10 Left Road	15.0	3.7	15.0
11 Left Road	15.0	3.7	3.7
12 Head Road	16.0	4.0	16.0
4 Head Road	9.0	4.5	9.0
3 Left Road	9.0	9.0	9.0
6 Left Road	9.0	4.5	9.0
3 Head Road	9.0	9.0	4.5
1 Left Road	10.0	6.7	10.0
2 Left Road	10.0	6.7	10.0
8 Left Road	10.0	5.0	10.0
9 Head Road	8.0	4.0	4.8
9 Left Road	9.3	4.7	5.6
Upper Quartile	10.0	6.3	10.0
Median	9.0	4.5	5.6
Lower Quartile	6.5	3.4	2.7

Table 11: Ratio of residents to basic facilities in wards on which controls were living at second data collection

	Resident/ Bath Ratio	Resident/ Toilet Ratio	Resident/ Bedroom Ratio
Social Services			
Stockton Road	3.0	3.0	2.0
Seaside	3.5	2.3	1.7
Mary Avenue	4.0	1.6	1.0
Pool Street	5.0	5.0	2.5
Darlington Av	5.5	5.5	1.8
Willow House	4.8	3.4	1.1
Bishop Lane	1.6	2.2	1.0
Voluntary Sector (MENCAP)			
Centre Court	3.0	3.0	1.5
Mull Drive	3.0	3.0	1.0
Cleveland Way	3.0	2.0	1.0
Private Sector			
Teeshead	1.5	1.5	1.0
Haughton House	4.3	2.2	1.6
Townview	6.0	4.5	2.2
Ling House	5.0	5.0	1.4
Riverhill House	5.7	3.8	1.3
National Health Service			
3 Newside	8.0	2.7	1.6
2 Newside	8.0	2.7	1.6
Independent Living			
Aycliffe Way	2.0	2.0	1.0
Cathedral Way	4.0	4.0	1.0
Upper Quartile	5.5	4.0	1.7
Median	4.0	3.0	1.5
Lower Quartile	3.3	2.2	1.0

Table 12: Ratio of residents to basic facilities in community homes in which movers were living

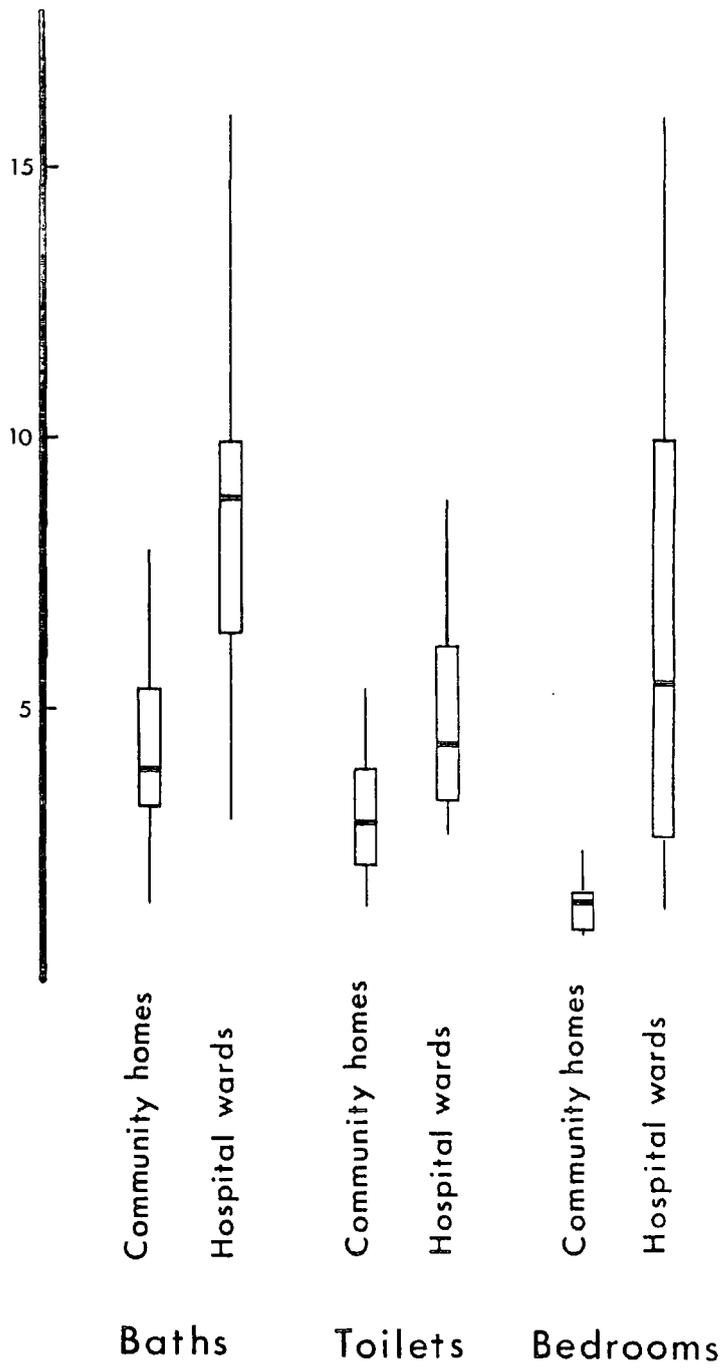


Figure 4: Graphical presentation of number of residents to each of three basic facilities in 17 hospital wards and 19 community homes

reported by 5 (26%) homes.

The effect of the smaller size of community homes is such as to make the general ratio of residents to facilities smaller. Staff on some wards were painfully aware of the limited nature of the ward facilities; some had one bath for between 12 to 15 residents. Since then wards have undergone redecoration and some have gained further basic resources.

DISCUSSION

These findings describe the differences between the hospital and community homes in this study. Homes in the community are generally smaller, tend not to be purpose built, are more likely to be mixed sex, and are less likely to employ domestic and catering staff. The smaller size of community homes means that movers have better access to basic facilities (e.g. bath, toilet); they are also more likely to have private bedroom areas. However not all homes fit the description of 'ordinary housing' as set out in model service descriptions (e.g. Jay, 1979; King's Fund, 1980); although few are purpose built many are considerably larger than 'ordinary' family homes. It is hazardous to discuss the 'typical' community home or hospital ward as there is considerable variation in most environmental characteristics and some community homes differ relatively little from some hospital wards. This overlap of environmental characteristics was also noted by King et al (1971).

Other differences between the hospital and community homes are difficult to quantify. Staff on most wards try to create a homely atmosphere. Most have pictures on the walls in the living areas,

many have potted plants, hanging baskets and ornaments; there are two wards with aquaria of tropical fish. In the final 8 months of this project most of the wards have undergone redecoration and many have received new furniture which although somewhat institutional has changed the appearance of the wards considerably. Although positive changes in the aesthetic appearance of a home are desirable in that they indicate that residents are valued they do not contribute greatly to the pattern of activities of the residents (Felce et al, 1985). This also indicates one difficulty of this type of assessment, environments are not static, they change quite a lot. Major characteristics of homes and wards (e.g. staffing ratios, size, number of baths) have changed over the course of the study, so data presented here should only be taken as indicative of differences at the time of the assessments.

The local neighbourhoods

One of the aims of community care is to foster social integration, thus the opportunities provided in the locality of the home are of importance.

Census data has been used in describing the siting of group homes in the United States (Finsterbusch & Greisman, 1983; Goldstein et al, 1987). Studies have examined neighbourhood features such as the length of time people had lived in their homes and the length of time that houses were vacant; both are interpreted as measures of satisfaction and attachment to the community. These correlate with other aspects of the quality of a neighbourhood such as the appearance and number of family homes as opposed to business properties (Finsterbusch & Greisman, 1983). A few studies have looked at the quality of a neighbourhood in terms of the facilities it offers, however this has generally been carried out using relatively imprecise measures. For example Donnegan and Potts (1988) recorded the number of facilities that were within a 'short walk' (5 minutes) of the homes of 9 people with mental handicaps living independently. Crapps and Stoneman (1989) studied the community activity of people with mental handicaps living in Family Care Homes in Georgia, USA and found a significant negative correlation between the distance from the home to the nearest city and the variety of community settings that the subject visited. There was no such effect for the absolute number of trips from the home. Bercovici (1981) noted that 'zoning' legislation in America leads to restrictions on where larger residential homes could be sited. In a qualitative study she found that the poor quality of neighbourhoods (lack of resources and physical threat in walking too far from the home) severely restricted contact with the

community.

The aspect of neighbourhood quality considered here is access to basic facilities. These data were collected at the same time as the neighbourhood walks were completed (chapter 4).

GENERAL METHOD

A list of facilities was drawn up using the list of public amenities in the Social Training Achievement Record (Williams, 1982) with some additions. The list comprised 23 items (table 13).

To locate the nearest instance of each these facilities the person in charge (or equivalent) of the subject's home was consulted. The information obtained was checked using any means that were readily available (for example by direct observation, by consulting other people in the locality, and by checking yellow pages or other reference sources).

As this is associated with a part of the study which presents a relatively novel method it was given priority for the collection of reliability data. To this end a member of the order of St. John of God (JT) who was at that time an undergraduate in the Psychology Department of Durham Univeristy was recruited to collect this data on those movers who at that time had been living in the community for over 12 months and their controls. The overlap of this set of subjects with the full data collection provides the reliability data. These results of this are reported before the full data set is considered.

Shop
Hairdresser
Doctor
Dentist
Optician

Public Telephone
Post Box
Post Office
Public Toilet
Police Station
DHSS Office
Polling Station

Pub
Cafe
Cinema
Bingo Hall
Swimming Pool
Sports Centre
Leisure centre/Dance Hall

Bus Stop
Railway Station
Church
Workplace/Day Centre

Table 13: Community facilities identified

RELIABILITY STUDY METHOD

There were 11 community homes and 11 hospital wards involved in the reliability study, these were the homes of movers who had been discharged for at least 12 months at the time of the first reliability data collection and the wards of their controls. Nine of the community homes were within urban areas of Darlington and Middlesbrough; 2 were in more rural areas. The management of the homes is as follows; 4 by Social Services Departments, 3 by private concerns, 1 by a voluntary agency, 1 by a Health Authority. Two are the homes of people who live independently in houses owned by the local council and a housing association.

The hospital has already been described. It has a number of facilities on site, but is geographically relatively isolated from larger population centres.

The distance to the nearest facilities was collected by JT, CM and DD. All 11 homes and 11 wards were seen by JT in the summer of 1987. CM revisited 10 homes and all 11 wards between Easter 1988 and Easter 1989. One home of two people living independently was visited by DD during the same period as its residents expressed the desire not to be seen by anyone associated with the hospital, where CM was a member of the nursing staff. The data collected by JT and CM were entirely independent as they were based in different places and the period of their involvement in the study did not overlap. However DD was aware of the data collected by JT hence the data for the one home rated by DD were less independent, the effect of this is discussed later.

RELIABILITY STUDY RESULTS AND DISCUSSION

The median of the distances to the 23 local facilities was calculated for each home separately from the data collected by rater 1 and the data collected by rater 2. There is little variance between hospital wards so a single median value from the hospital to the 23 facilities was calculated; for each rater all distances from each of the 11 hospital wards to the 23 facilities were pooled and a single median was calculated. In fact the data for the hospital and the community are multimodal, medians are used although there is no wholly satisfactory method for summarising such data. How this type of data may be best presented is considered in more detail later.

Prior to calculating inter-rater agreement some univariate statistics for each rater are presented. As recorded by rater 1 the median distance from the 11 homes to the facilities is 0.7 km (SIR 0.5 - 1.0 km), and the median distance from the hospital to the facilities is 0.4 km. As recorded by rater 2 the median distance from homes to the facilities is 0.6 km (SIR 0.5 - 0.8 km), and the median distance from the hospital to the facilities is 0.4 km.

The median distance to facilities for each home as recorded by rater 1 was plotted against the distance as recorded by rater 2 (figure 5). Pearson's r for this relationship = 0.9, indicating good agreement in the rating of the distance to the nearest facilities. To establish whether the lack of independence of the one rating made by DD and JT has inflated this value the correlation was performed a second time without this data point.

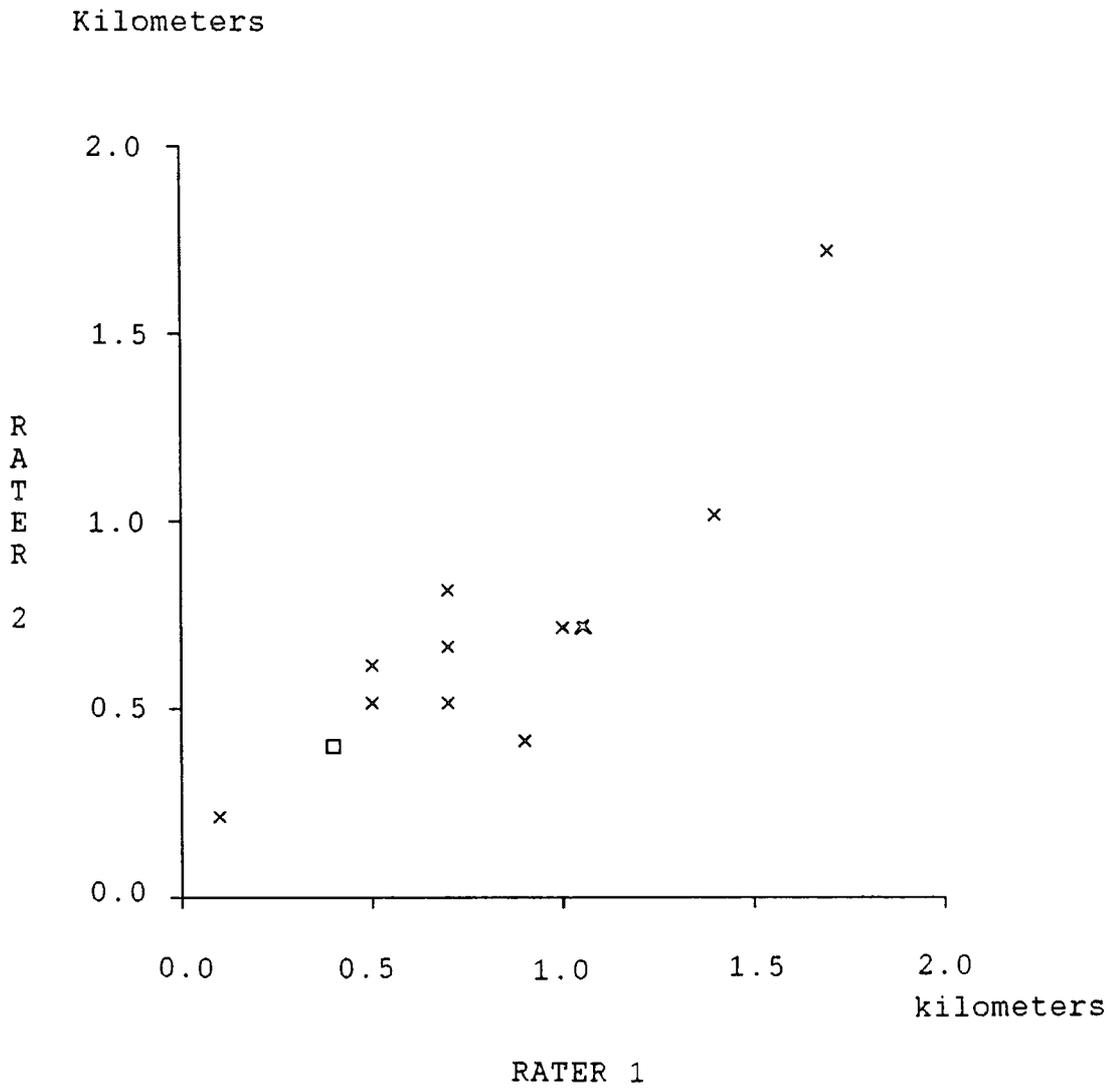


Figure 5: Median distance from home to facilities as estimated from the data of rater 1 and the data of rater 2

□ = Hospital
 X = Community homes

When not included Pearson's r is still 0.9 indicating that it does not disproportionately contribute to the agreement between first and second rating.

It might seem trivial to establish the reliability of distances to the nearest of each facility since these can, in principle, be measured without error. But it is necessary to distinguish between the theoretical reliability of the measure and its reliability in practice, i.e. as it would be used in monitoring the quality of care. In practice the facility identified as the closest was not always the same on both occasions. This was for two main reasons; the person-in-charge did not consistently identify the same instance of each facility as the closest and the raters had a different degree of familiarity with the localities. Rater 2 had a more extensive local knowledge of the areas. There appears to have been some error in measurements taken from maps but this was relatively minor in comparison. It is important to note that in practice that this type of 'physical' data will not always have a high degree of reliability.

FULL DATA SET RESULTS

In the full data set both distance and direction of facilities are considered, the reliability data reported above has ignored directional data as these were not collected by rater 1.

The distance to and direction of the 23 facilities from the hospital and 13 of the community homes were collected by CM, the distance and direction data for the remaining 6 community homes were collected by DD. All data to be discussed in this section are

presented in table 14.

The median of the distances from the community homes to the nearest facilities is .525 km (SIR .475 - .712), the median distance from the hospital wards to the nearest facilities is 0.4 km. The data concerning distances is presented for each home and the hospital in table 14. The median distance for the hospital falls below the first quartile of the distances for the community homes. However it should be noted that all but one of the community homes have a median of 1.0 km or less from the facilities, and so have reasonably good access to these resources. The one home that is a median distance of 1.7 km from the 23 facilities is situated on the edge of a moorland town and for this home the majority of facilities are either in this town (about 1.7 km distant) or in more distant towns (up to 32.0 km distant).

This data is presented in a raw form for each community homes and for the hospital in figures 6 to 25, the figures show the direction and distance of each facility as a line from the central point which is the home. The figures are ordered as they are in table 14 and have a scale of approximately 6 centimeters to 1 kilometer; a line which ends in a dotted line indicates that the actual position of the facility is too far from the home to be illustrated on the figure page. The figure representing the hospital uses the central administration building as the focal point. Graphical displays of this kind are suitable summaries of the data if a small number of homes is involved. If numerical summaries are required (for example to compare large numbers of homes) simple medians and ranges can be used for distance measures. However summarising this data by median distance alone ignores the direction of facilities. The 'average' direction of facilities and the spread of facility

Home	Median Distance	Mean Angle	Circular Variance
Social Services			
Stockton Road	.40	107.27	.64
Seaside	.50	323.39	.27
Mary Avenue	.60	132.93	.28
Pool Street	.75	7.24	.58
Darlington Av	.50	141.85	.61
Willow House	.80	27.13	.31
Bishop Lane	.50	88.04	.39
Voluntary Sector			
Centre Court	.20	75.07	.39
Mull Drive	1.00	203.78	.21
Cleveland Way	.50	338.37	.27
Private Sector			
Teeshead	.30	163.23	.12
Haughton House	.20	245.61	.66
Townview	.50	21.09	.29
Ling House	1.70	164.51	.27
Riverhill House	.55	39.55	.55
National Health Service			
3 Newside	.70	348.15	.46
2 Newside	.70	348.15	.46
Independent Living			
Aycliffe Way	.65	107.29	.25
Cathedral Way	.40	208.36	.23
Upper Quartile	.475		.27
Median	.525		.31
Lower Quartile	.712		.56
Hospital	.40	73.78	.62

Table 14: Summary statistics of distance and directional data for facilities around community homes and hospital

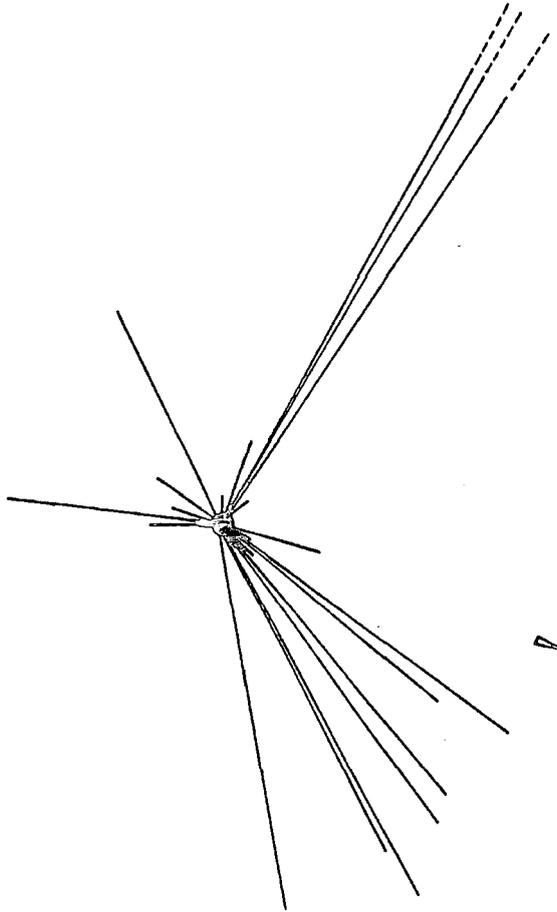


Figure 6: Stockton Road; raw data - distance and direction to facilities

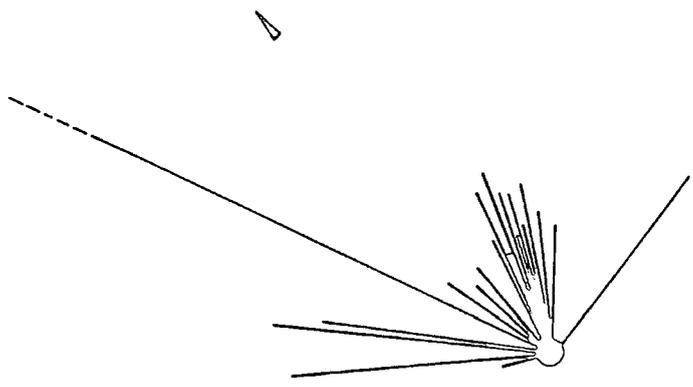


Figure 7: Seaside; raw data - distance and direction to facilities

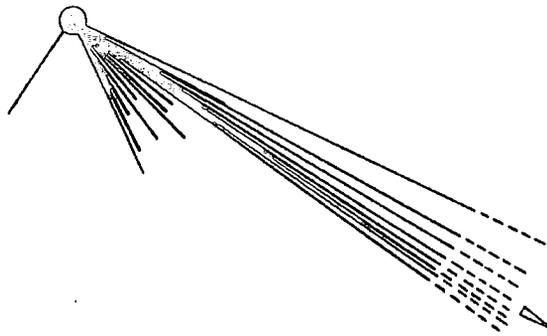


Figure 8: Mary Avenue; raw data - distance and direction to facilities

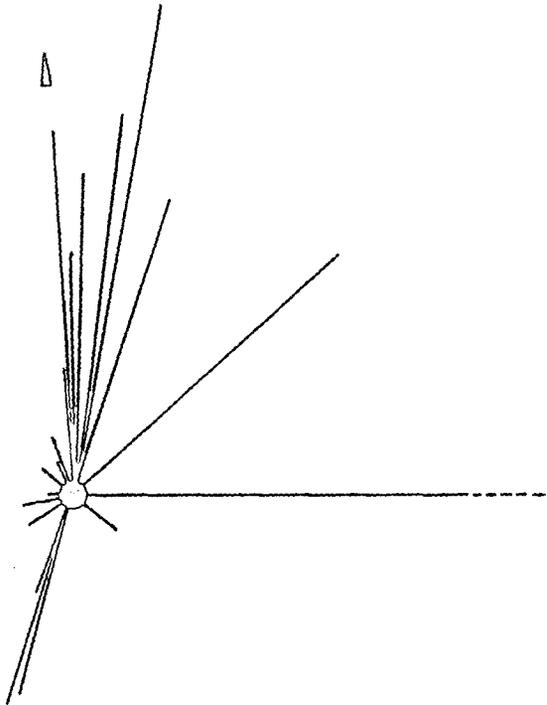


Figure 9: Pool Street; raw data - distance and direction to facilities

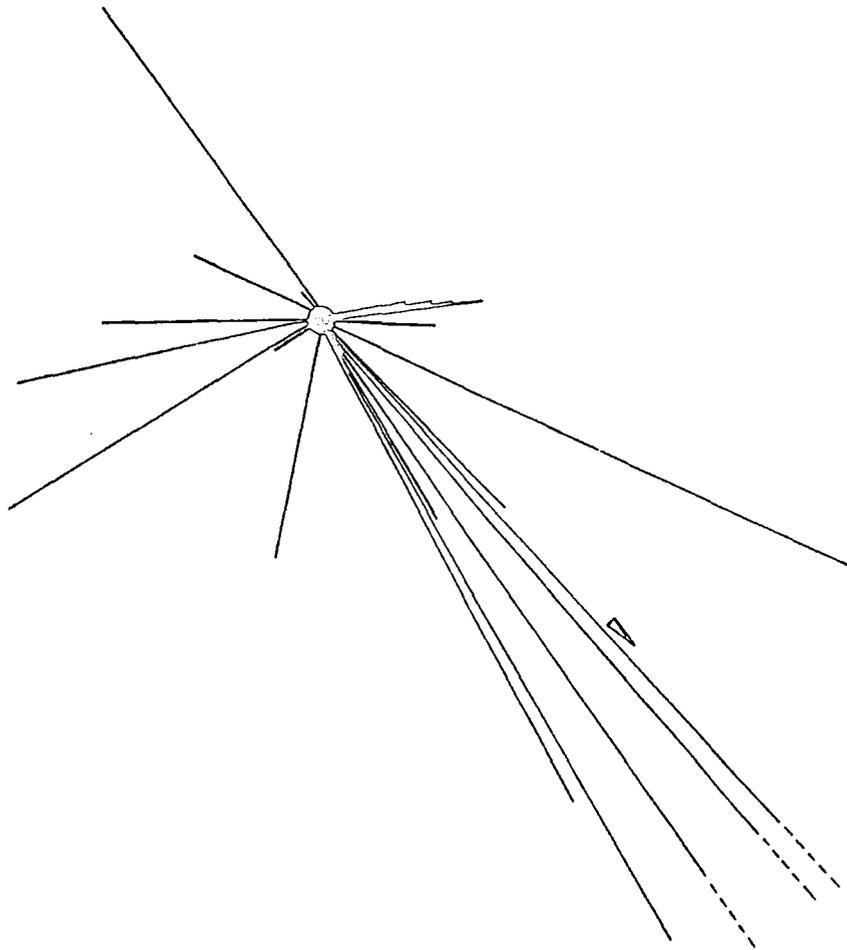


Figure 10: Darlington Avenue; raw data - distance and direction to facilities

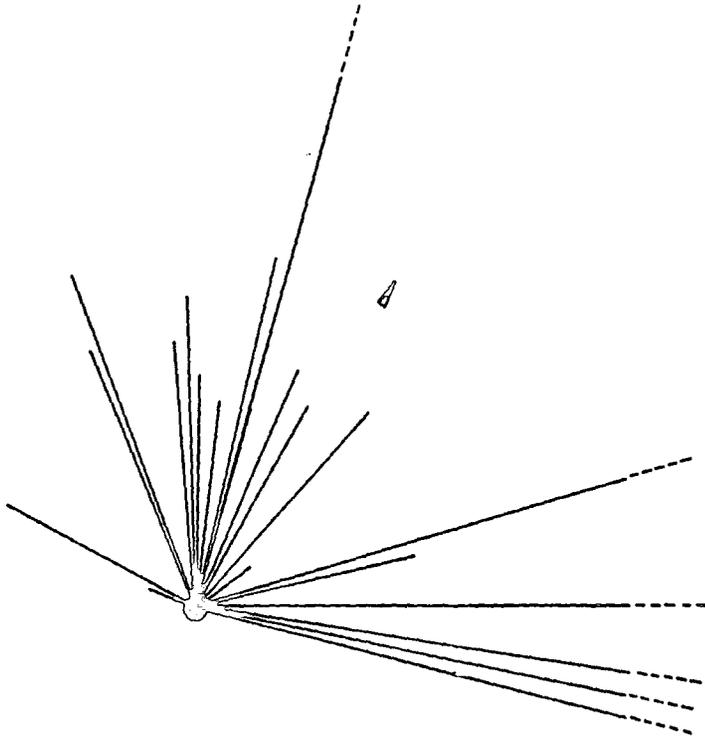


Figure 11: Willow House; raw data - distance and direction to facilities

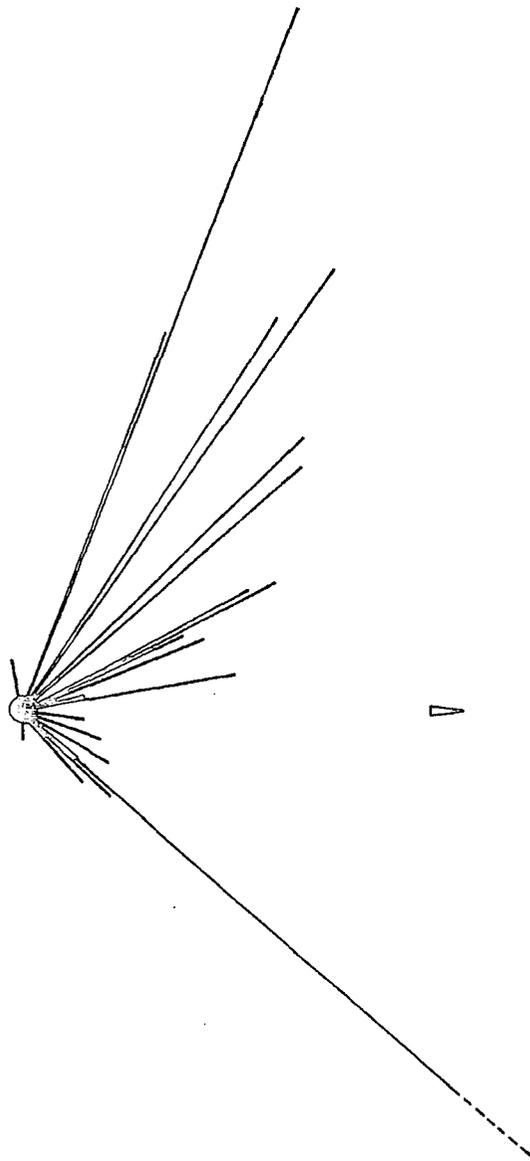


Figure 12: Bishop Lane; raw data - distance and direction to facilities

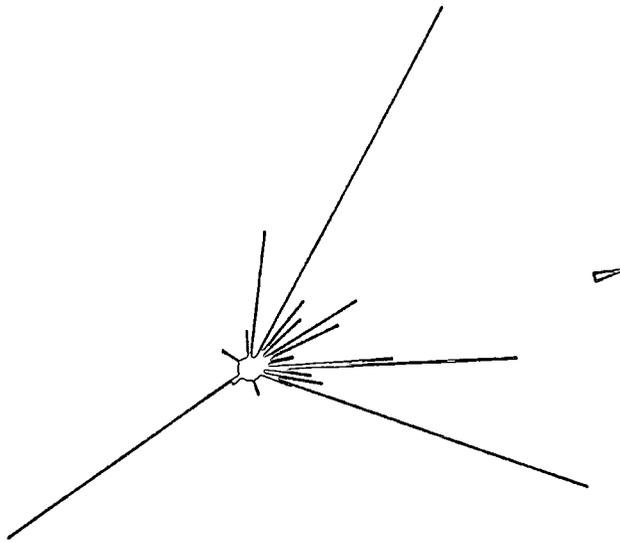


Figure 13: Centre Court; raw data - distance and direction to facilities

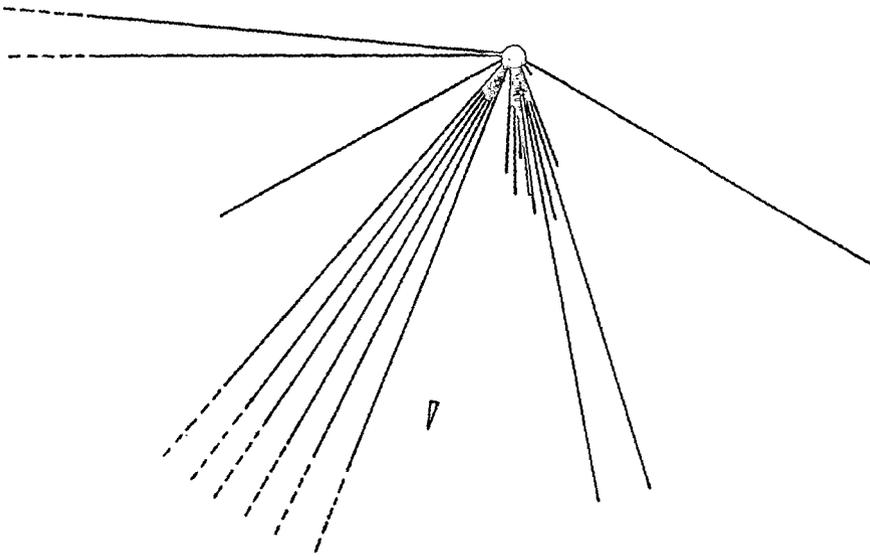


Figure 14: Mull Drive; raw data - distance and direction to facilities

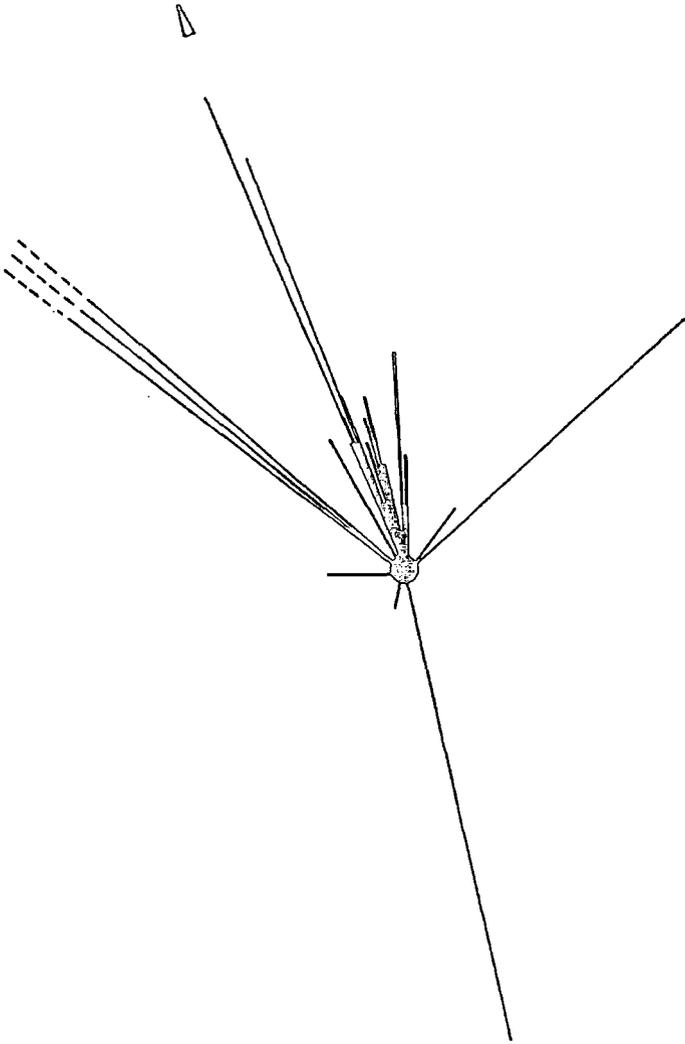


Figure 15: Cleveland Way; raw data - distance and direction to facilities

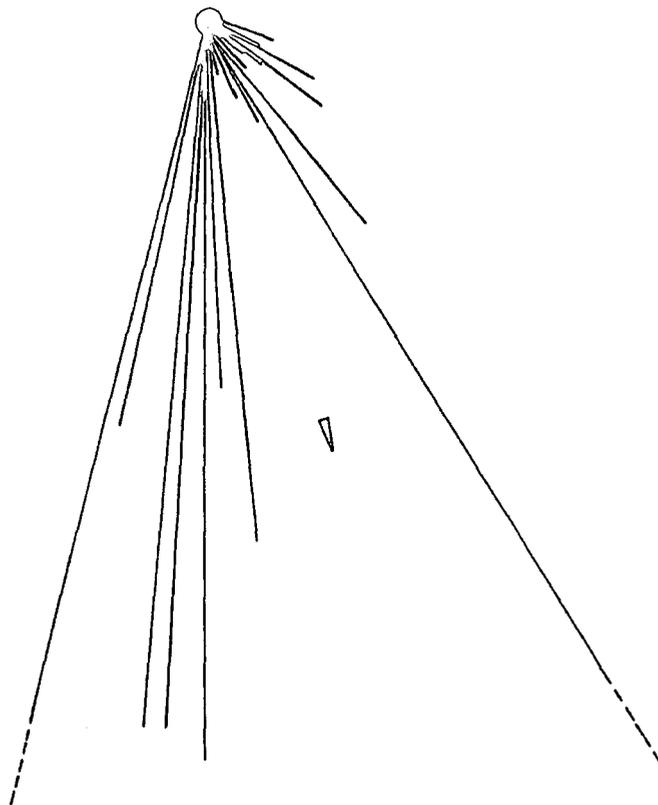


Figure 16: Teeshead; raw data - distance and direction to facilities

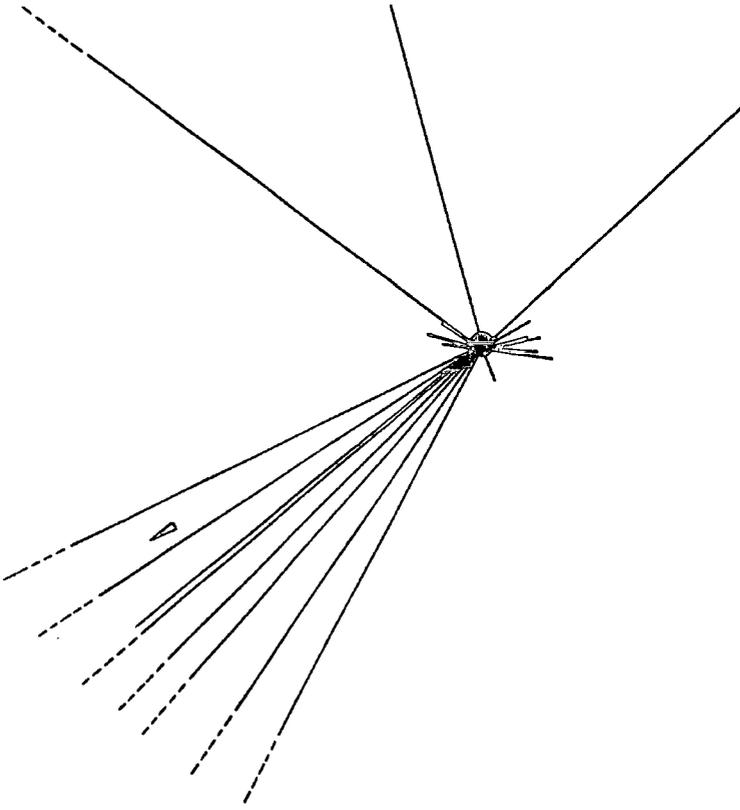


Figure 17: Haughton House; raw data - distance and direction to facilities

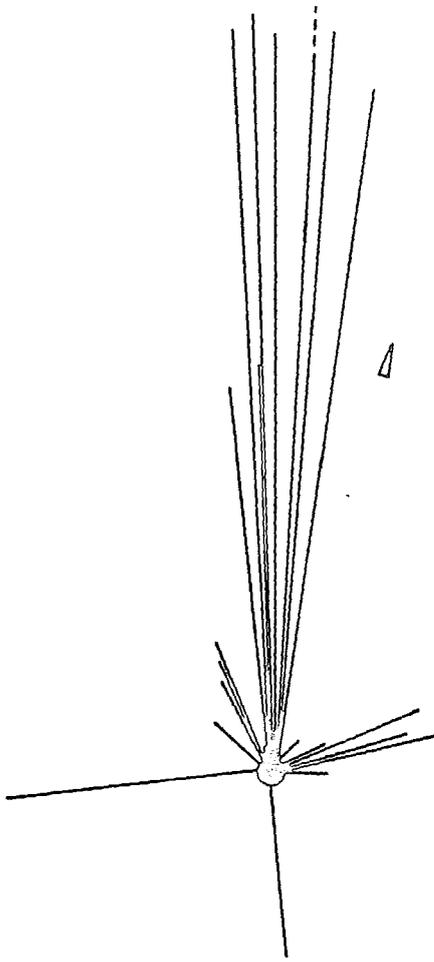


Figure 18: Townview; raw data - distance and direction to facilities

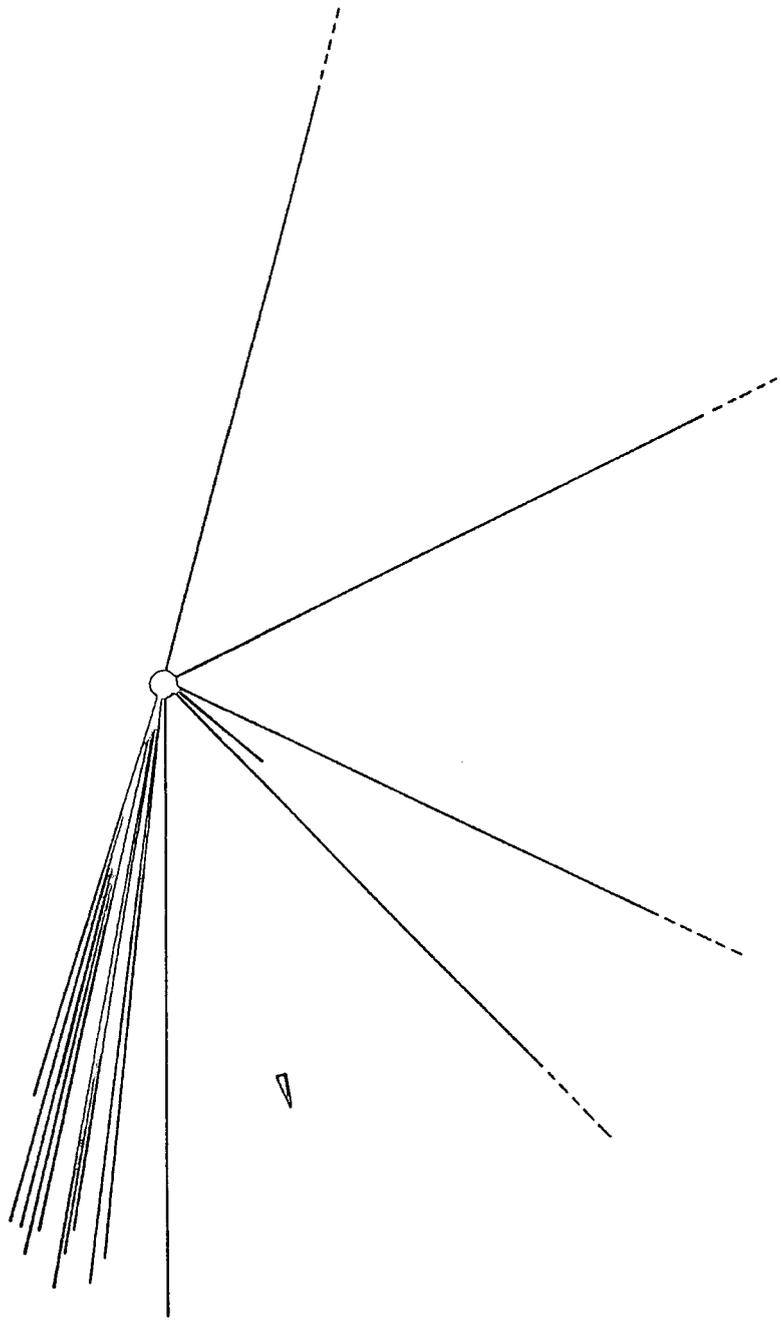


Figure 19: Ling House; raw data - distance and direction to facilities

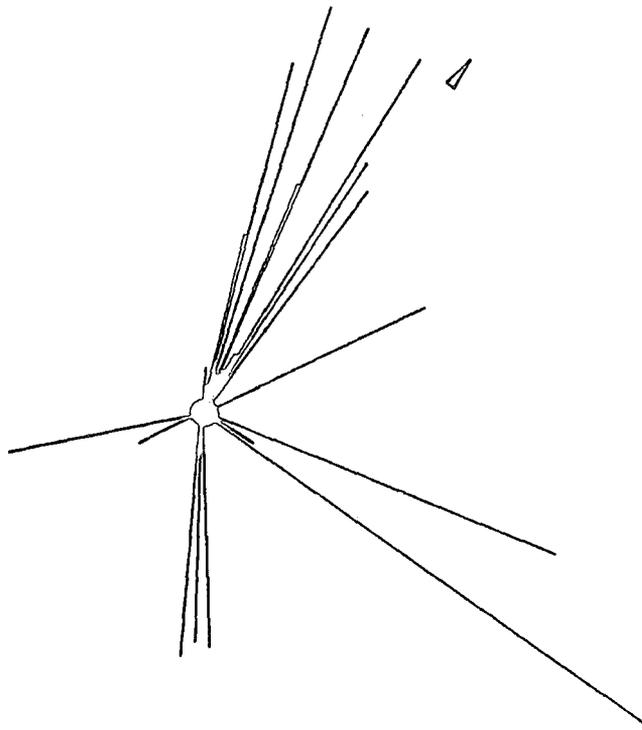


Figure 20: Riverhill House; raw data - distance and direction to facilities

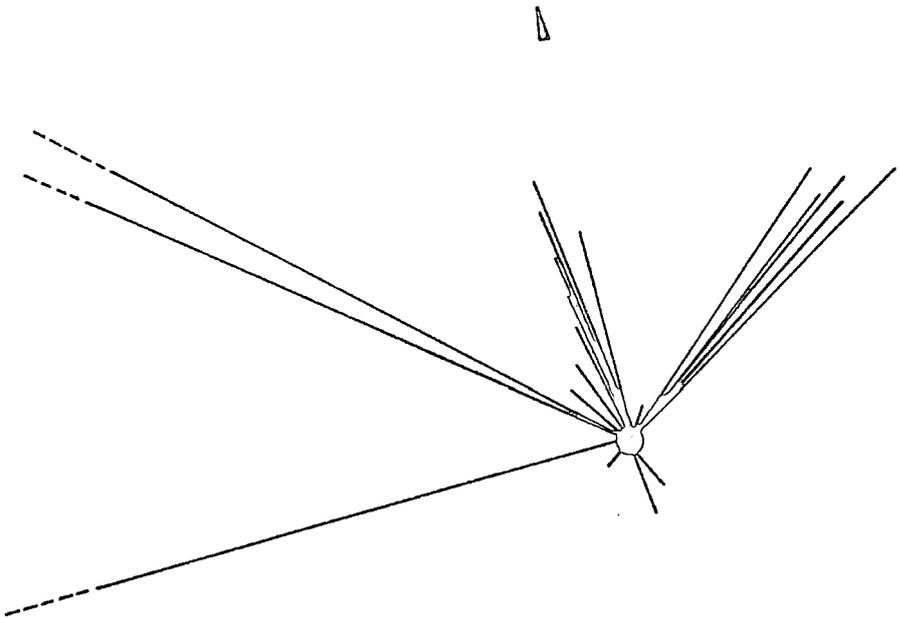


Figure 21: 3 Newside; raw data - distance and direction to facilities

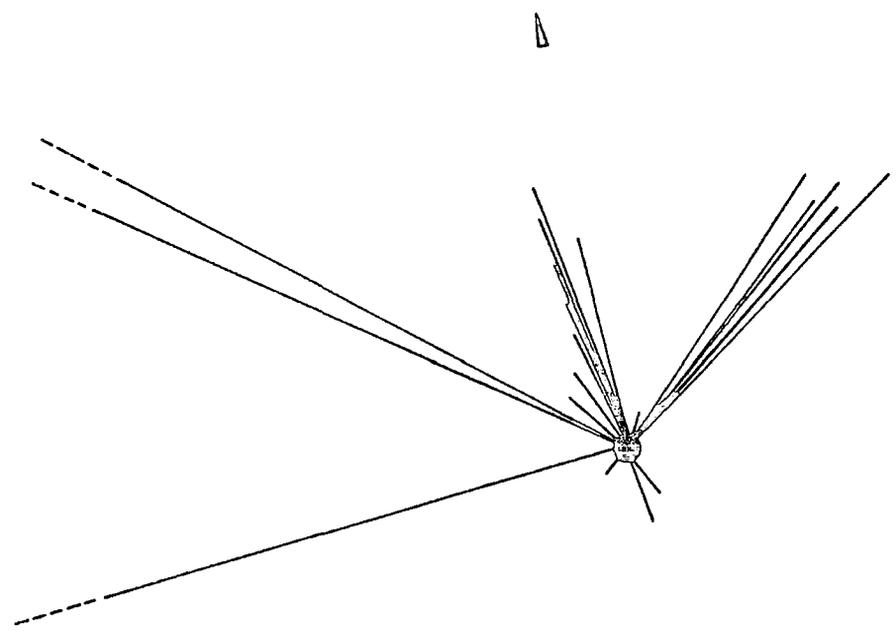


Figure 22: 2 Newside; raw data - distance and direction to facilities

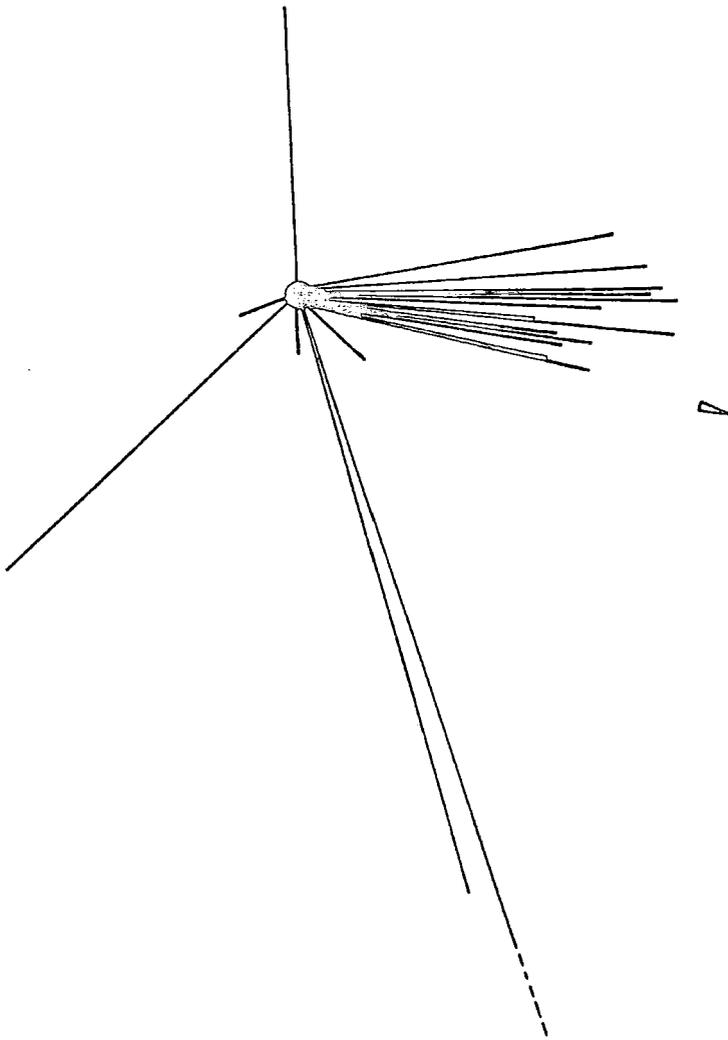


Figure 23: Aycliffe Way; raw data - distance and direction to facilities

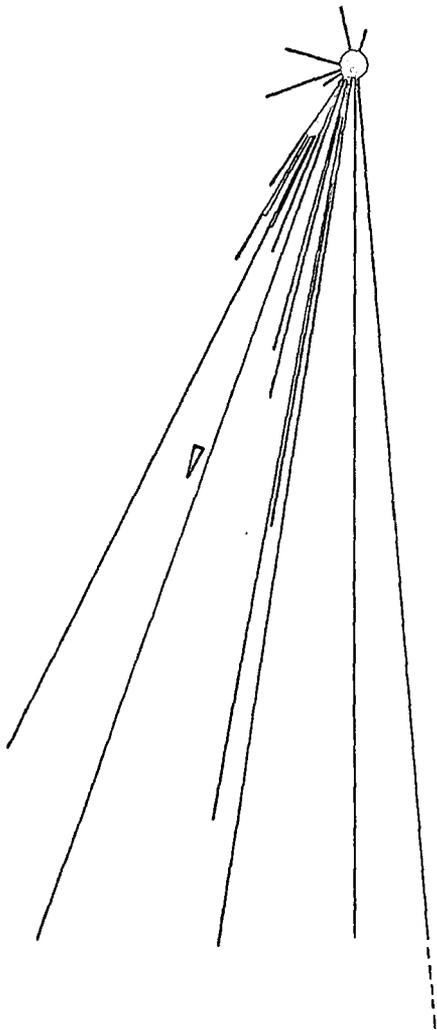


Figure 24: Cathedral Way; raw data - distance and direction to facilities

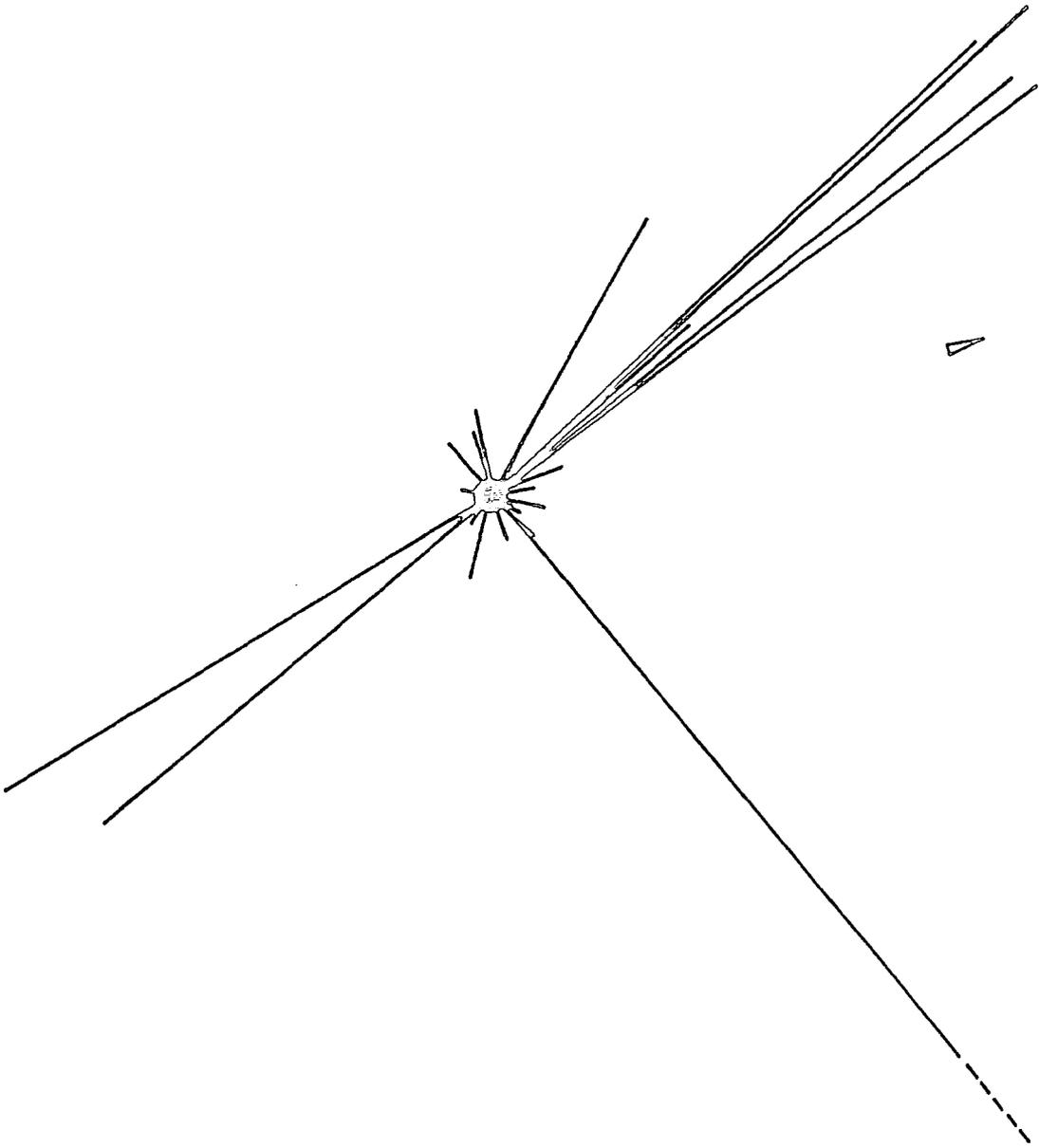


Figure 25: Aycliffe Hospital; raw data - distance and direction to facilities

directions may be indicators of neighbourhood quality. For example if most facilities are in the same general direction this may be advantageous to groups whose mobility is limited both physically and economically. In addition it may be easier to teach mobility skills when fewer routes are needed.

The summary of directional data is complicated by its cyclical nature (angles of 1 degree and 365 degrees are close together, not far apart). Appropriate methods for summarising mean direction and the concentration of directions are reviewed by Upton and Fingleton (1989). The mean angle is calculated using vector addition, assuming a unit length for each vector. First a total horizontal displacement, X, is calculated,

$$X = \sum_j \sin\theta_j$$

and a total vertical displacement, Y,

$$Y = \sum_j \cos\theta_j$$

the mean angle ($\bar{\theta}$) is then calculated thus:

$$\bar{\theta} = \tan^{-1} (X/Y)$$

This calculation does not allow for the cyclical nature of the sine, cosine and tangent functions and a further adjustment is required thus:

$$\bar{\theta} = \begin{cases} \text{Tan}^{-1} (X/Y) & \text{if } Y > 0, X > 0; \\ 180^{\circ} + \text{Tan}^{-1} (X/Y) & \text{if } Y < 0; \\ 360^{\circ} + \text{Tan}^{-1} (X/Y) & \text{if } Y > 0, X < 0. \end{cases}$$

Using the data collected by Rater 2 mean angles have been calculated for all homes, these are indicated upon the figures 6 to 25 with a small arrow, and are presented in table 14. Angles are expressed clockwise from the azimuth (north) as although mathematicians tend to measure angles anti-clockwise from the positive x-axis most applied data uses azimuthal angles, these are more easily interpreted and so are used here.

In addition a measure of the degree of concentration of directions (R) can be calculated:

$$R^2 = X^2 + Y^2$$

This is standardized by division by the number of cases:

$$\bar{R} = R/n$$

The value of \bar{R} varies between 0 and 1 with higher values having the greater 'concentration' (Upton & Fingleton, 1989). This can be converted to a figure that is analogous to linear variance (Mardia, 1972), named circular variance:

$$\text{Var} = 1 - \bar{R}$$

Circular variance is more easily interpreted due to its similarity to linear variance and so will be used here.

The circular variance and distance for each home and the hospital is presented in table 14. It can be seen that the values for mean angles and concentration of directions contribute to the description of the directional data available. They can be used in comparisons of homes of different types and may be related to some of the behavioural outcomes of the homes' residents.

Circular variance for the hospital has been calculated from a central point (the administration block); one effect of this is possibly to make the circular variance of the hospital greater than it may be for any individual ward, as the administration block is a point around which the hospital facilities are well distributed. However this is the most appropriate means of representing the hospital as it would be inappropriate to pool the data from the individual wards; there is no 'average' direction to a facility from the 19 wards involved.

DISCUSSION

Median distance and circular variance of the facilities around a home are simple summary measures relevant to assessment of the quality of an area around a home. Studies of leisure facilities (sports centres, parks, playgrounds) have shown, unsurprisingly,

that the people who use the facilities most often are those who live closest to them (Dee & Liebman, 1970; Burton, 1977). The relationship varies according to the location of the facilities (urban or rural), their quality (Burton, 1977) and the number of streets that must be crossed to reach them (Dee & Liebman, 1970). These considerations may be especially important for people with mental handicaps, whose mobility is limited for physical and economic reasons.

That most facilities are in the same direction may be important to people with limited mobility and would aid learning routes to facilities. Summaries of circular variance and median distance would be valuable in comparisons of homes of different types. It would also be of interest to establish whether people with mental handicaps living in homes with facilities that are closer and that have smaller circular variance are able to locate more of the facilities than are those in homes with greater distances and circular variance. An initial analysis of this type is carried out in chapter 4.

Although mean direction is not of use in comparing facilities it may be of use in other ways, for example if highly valued facilities are not in the same general direction as the mean direction this may have implications for the use of these and other facilities. The mean direction may also be of use in calculating the reliability of directional information.

Although the median distance to facilities from the hospital ward is less than the lower quartile of median distances for community homes most facilities are within 1.0 km of the homes. This indicates that, at least on this variable, the homes are

appropriately placed to encourage integrative use of most general facilities.

The equivalence of the facilities within the hospital and those outside of the hospital can be questioned. Although the function of facilities may be similar, the skills required to reach and use them and the opportunity they offer for normalizing experience are considerably different. This is further considered in chapter 4 where it is suggested that a facilities value to residents should be an important criteria for deciding its quality.

This section has considered physical aspects of the local neighbourhood, it would be equally valuable to consider social characteristics. An implied aim of care in the community is increased care by the community (Bulmer, 1987), however the description and identification of high quality neighbourhoods is not simple. The traditional caring neighbourhood was a product of adverse conditions and in most areas this does not exist in the way envisaged in assumptions underlying community care (Bulmer, 1987). However attempts to foster community activity and cohesiveness have shown some success (e.g. Abrams et al, 1986; Baldwin, 1987).

It may be possible to describe the social characteristics of a neighbourhood in relation to people with mental handicaps by consideration of the behaviour and attitudes of people in the neighbourhood towards the new residents (e.g. Felce, 1988). It may also be possible to use census data to identify the nature of the neighbourhood, for example the proportion of family to multi-occupied homes, or of young families to retired people. Gatrell (1988) reviews the use of British Census data in health related studies.

CONCLUSION

This chapter has presented a description of the movers and controls who are the subjects of this study. The study group represents the least disabled of the current hospital population and as such their outcomes may not generalize to any other group. However selection of the most able residents for discharge has been recorded in other areas (e.g. Spencer, 1977) and a national survey of regional plans for services to people with mental handicaps (Wertheimer et al, 1985) found relatively little long-term planning for people with more severe handicaps; hence this study may not be too atypical of the situation in other areas. The nature of the group means that different methods can be applied to the study of their lives than would be the case in a less able group. The most important point to arise from the first section of this chapter is that although the mover and control group do not differ in particular areas of disability, in terms of a combination of skills and disabilities the mover group is generally less disabled. This will need to be considered in interpretation of any post-move differences in outcomes for the groups.

There are examples of people with severe and profound handicaps benefitting from movement to community based homes (e.g. Rawlings, 1985a, 1985b) and many of the Care in the Community pilot programs offer services to representative samples of hospital populations (Knapp, 1988). There are also examples of ways in which people with 'challenging behaviours' can be supported in the community (Blunden & Allen, 1987). That it is possible to support more severely handicapped people in community settings is recognized by the House of Commons Social Services Committee (1985) who state that the issue is not whether it is possible to care for people with severe

handicaps in the community but:

...the extent to which society is willing to pay more than at present in return for giving severely mentally handicapped people the closest approximation to normal life (Social Services Committee, 1985, paragraph 54).

Thus the unrepresentative nature of the mover group in terms of disability is not purely because the methods are not available to support people with more severe handicaps in the community.

The basic physical and social resources of the community homes and wards involved in this project have been described. The measures used indicate important differences between the environments; movers have greater access to basic personalising resources, than do controls; community based homes have staffing patterns that may enable more use of these resources. This may be expected to positively effect the quality of the lives of the residents.

Effort has been made to describe the homes and wards involved in this study, although it is in fact difficult to describe complex interventions (Graham & Birchmore-Timney, 1989). Exact replication of a districts community residential care provision is not required as local variations in need make different demands upon services. However description of services in evaluation studies need to be in sufficient detail to allow service providers to establish the relevance of the present study to services in which they are involved. This may require a different approach to the one adopted here, and is discussed further in the final chapter.

Finally this chapter has presented novel means of describing features of the quality of the neighbourhood around the home. Although access to community resources is considered an important

variable in enabling integrative activity (e.g. King's Fund, 1980) quantitative description of these features has not previously been attempted. In the present study all but one community home has the majority of facilities included in the test list within 1 kilometer, which may be considered good access. This compares well with the hospital, as it should be remembered that hospitals were built to offer most facilities on one site. The quantitative data obtained here will be included in analysis of behavioural outcomes in chapter 4.

Chapter Three
Diary Record of Activities

A central aim in community care has been to provide for a way of life that facilitates contact with friends, neighbours and family and use of local community facilities (DHSS, 1971; Social Services Committee, 1985). Parental and other advocacy groups have often questioned whether this can be achieved (e.g. Spreat et al, 1987; Halliday, 1987; Donegan & Potts, 1988). This has been echoed in academic literature (e.g. Malin, 1982; Atkinson, 1983).

Work and leisure activities have been considered in some detail in people with mental handicaps.

Work

Work fulfills a number of needs including: material needs, respect of others and self esteem, social activity, and creativity (Neff, 1977; King's Fund, 1984). Its importance is indicated in the way that people identify themselves and are identified by others according to their occupation. Life may be increasingly leisure centred (Roberts, 1970) and people with mental handicaps have been described as 'a new leisure class' (Jeffree & Cheseldine, 1982). However the implication that people with mental handicaps are not likely to find work has been challenged (Wertheimer, 1983).

In Britain one of the main sources of employment for people with mental handicaps living in the community is Adult Training Centres managed by Social Service Departments (DHSS, 1971; National Development Group, 1977). The National Development Group Pamphlet Number 5 (National Development Group, 1977) recommended a change in emphasis in Adult Training Centres from training and occupation based on an industrial model to education in the widest sense of vocational, social and personal competencies. Recently centres

have increasingly been seen as having a networking role, from which use may be made of other facilities (Social Services Committee, 1985). It has been suggested that training centres in hospitals for people with mental handicaps should be organized in a similar fashion (National Development Group, 1978, p 53). For people living independently or in family homes the day centre may be the most important service received (Bayley, 1973; Whelan & Speake, 1977). However ATCs have been slow to take up suggested roles (National Development Group, 1984) and many continue to rely upon industrial contracts or offer 'entertainment' rather than education (Wertheimer, 1983).

Successful alternatives to segregated work in ATCs have been demonstrated; for example supported employment (e.g. Whelan & Speake, 1979; Gaylord-Ross, 1987; Hill et al, 1987). In this people with mental handicaps are placed in competitive employment with one-to-one support for an initial period. Support is also given to the employer and the rest of the work-force. Other means for providing normalized work experience include enclaves and workcrews (Mank et al, 1985). Indeed it has been suggested that the success of a vocational service could be judged in terms of the degree to which an adult with a mental handicap achieves economic self-sufficiency (Kiernan & Stark, 1985). Although supported employment programs have been demonstrated in Britain (Porterfield & Gathercole, 1985; Gaylord-Ross, 1987) we are still some way behind the United States in accepting that people with mental handicaps can obtain and maintain jobs in the open market (Wertheimer, 1985).

Leisure

Although leisure has a recuperative function and may be limited by the resources made available by work (money, time etc.) it is increasingly viewed as a time in which to develop identities and group membership. For many people these centre upon the family and leisure activities and roles change as family roles develop (Rappaport & Rappaport, 1975; Kelly, 1983). The roles fulfilled in age-appropriate family activity are difficult to replicate for people with mental handicaps. Yet these activities may be especially attractive as a means of 'passing' (Edgerton, 1967) and especially powerful in terms of their valued status.

The activities of people with mental handicaps are seen as serving a number of functions. These include:

1. An opportunity for self expression. This corresponds to definitions of leisure as an expressive and recuperative activity. Wehman (1977) considers that leisure may be especially important for people with mental handicaps as their vocational tasks are often highly repetitive.
2. An opportunity for cognitive and behavioural development (Luckey & Shapiro, 1974; Burton, 1977; Wehman, 1977).
3. An opportunity to develop a normalized, socially integrated lifestyle (Wolfensberger, 1972; Salzburg & Langford, 1981). This function is the most particular to people with mental handicaps.

Normalization was first systematically described in Scandinavia

(Nirje, 1976; Bank-Michelson, 1976). Scandinavian definitions emphasise normalization of routine and environments. For example:

The normalization principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society (Nirje, 1976; 231)

Wolfensberger's more detailed conceptualization of normalization is currently one of the most influential ideologies in the field of mental handicap. Its premise is that the way in which services are provided reflects and affects the way in which the service recipients are perceived. Normalization requires:

The use of culturally normative, and optimally even culturally valued, means to enable (societally devalued) persons to achieve and maintain valued social roles (Wolfensberger & Thomas, 1983; p 18).

Both approaches regard as important the opportunity that people with mental handicaps have for interaction with members of the wider community. Wolfensberger stresses the importance of activities taking place in normative or valued settings and highlights that the means by which these ends are achieved are as important as are the ends themselves (Wolfensberger, 1972; Wolfensberger & Thomas, 1983).

A key concept in normalization is integration (Wolfensberger, 1972, 1981). Its importance is widely recognised and is reflected in its presentation as a major aim of services to people with mental handicaps (Tyne & Wertheimer, 1980; DHSS, 1971; King's Fund, 1980; Felce 1988). However the definition of integration has at times been vague. It has been used synonymously with deinstitutionalization, as if all non-institutional care is

integrated (eg. Heal, 1980). It has been treated as a dichotomous variable; a service or lifestyle being viewed as either integrated or segregated. When viewed as a continuum (e.g. hospital, staffed hostel, supported group home to independent living) it may be confused with the degree of support offered by a service (Taylor, 1988). It is increasingly recognised that the view that people need to be 'ready' to move to less segregated environments is unproductive as segregated environments may be the least effective places to learn adaptive skills (Taylor, 1987). With sufficient support even people with severe and profound handicaps can be maintained in integrated environments; as they gain in independence support can be withdrawn.

Wolfensberger distinguishes between physical and social integration. Physical integration is:

...the physical presence of a (devalued) person or persons in ordinary settings, activities, and contexts, where non-devalued people are also present (Wolfensberger & Thomas, 1983; 18).

This can be relatively easily achieved and is necessary but not sufficient for social integration. Social integration is:

...participation by a (devalued) person or persons in social interactions and relationships with non-devalued citizens that are culturally normative both in quantity and quality, and that takes place in normative activities and in valued, or at least normative, settings and contexts (Wolfensberger & Thomas, 1983; 18).

An implication of distinguishing physical and social integration is that not only is it important to indicate that activity is taking place in community environments but that the degree to which the environment provides opportunity to meet 'non-devalued' people and

the extent to which they are actually becoming acquainted is also important (e.g. Firth & Rapley, 1987). Felce (1988) presents a framework for studying integration; elements include the maintenance and development of social networks, the use of community facilities and community attitudes to people with mental handicaps. This framework has been used to a limited extent in a series of studies that have examined aspects of integration using records of trips, direct time sampled observation of engagement in community environments and the attitudes of people providing integrated services, such as shopkeepers and publicans (e.g. Saxby et al, 1986; De Kock et al, 1988). These studies are discussed in more detail later.

A number of possible theoretical frameworks exist for exploration of the quality of social interaction within a particular setting or relationship. These include Barker's 'zones of penetration' (Barker & Schoggen, 1973) which will be further considered in the next chapter.

Community activities of people with mental handicaps

The use of community facilities has been measured as a dependent variable in multivariate studies of community adjustment (e.g. Birenbaum & Re, 1979; Willer & Intagliata, 1981; Seltzer, 1981; Bell & Schoenrock, 1981; Hemming et al, 1981). Its measurement in these studies is often brief, using retrospective survey methods with carers as informants. This generally does not provide a clear picture of patterns of activity.

Studies specifically concerned with activity and social contacts

also often use survey methods. Little work has attempted to describe in detail the activities of people with mental handicaps using other methods, although qualitative studies have given insight not generally available from survey methods (e.g. Atkinson, 1985b; Edgerton, 1967). For instance Atkinson (1985b) studied 50 people with mental handicaps living independently and concluded that although their lives were not impoverished they could have been involved in considerably more activities. She discusses reasons for limited participation in activities and notes that there is a threshold between being an observer and being a participant that subjects were often unable to cross.

Studies of people with mental handicaps living in the parental home show that in this situation most activity is carried out with the natural family. Only 42% of Adult Training Centre attenders in Dublin ever went out with a friend (McConkey et al, 1983). Of adolescents with mental handicaps living with their families in Manchester 75% never visited friends out side of school time (Cheseldine & Jeffree, 1981). A lack of knowledge on the part of parents was often cited as a reason for the low use of facilities (Cheseldine & Jeffree, 1981; McConkey et al, 1981). Similar dependence upon the family for activities and contacts was demonstrated by Katz and Yekutieli (1974) in Israel.

Hill and Bruininks (1981) interviewed staff concerning the leisure time activities of 2271 residents of community homes and hospitals. They found that in the previous week 43% of the residents of the community homes had been shopping, 33% had been out to eat and 27% had been to the cinema or theatre. Of the hospital residents fewer had been shopping (12%) or out to eat (15%) but slightly more had been to the cinema or theatre (35%). Only 16% of community

residents and 5% of hospital residents had visited a friend from outside and 16% of community and 4% of institution residents had one or more monthly contact with a non-handicapped peer. For both groups 75% of all special friendships were with staff. Results indicate the importance of staffing for social and leisure activity; the major reason for lack of activity was reported as being 'there was no one to take him/her'.

Raynes and Sumpton (1987) interviewed carers of 175 people who had been part of the 448 person study group in King et al (1971) to determine whether subjects had had contact with any of 14 community facilities in the previous month. They found some differences between Social Services homes, voluntary homes, parental homes and hospitals. Hospital residents were less likely than the other 3 groups to have been to a bank or pub, hostel residents were more likely to have been to a social club or sporting event. The authors note that there were few activities that differed with the residential environments and only small proportions of people in any of them had had contact with most community facilities. In regard to employment 80% of people in hospital had daytime occupation (30% part time) compared to 83% of people living in parental homes, 96% of voluntary home residents and 100% of the hostel residents. Only 5% of the whole group were in unsegregated employment.

The studies reviewed so far have involved comparison of homes types without any consideration of baseline scores for their residents. To adequately allow for possible selection of residents into types of homes longitudinal studies are necessary. Relatively few studies have used a longitudinal approach.

Firth (1986) presents results from a longitudinal study of 5 young people with mental handicaps moving from hospital to a house in the community. The number and duration of contacts in one month was noted using 4 weekly interviews with care staff conducted prior to moving and 6 months after. Interviews recorded number and duration of contacts with family and other non-handicapped people and the number and duration of activities outside of the home. Contact with family increased for 4 out of 5 of the young people, doubling on average from hospital to community. Contacts with non-handicapped people (excluding immediate neighbours) doubled both in duration and number. The majority of contacts appear to have been service related, the study again indicates the importance of the networks of staff and their knowledge of the local community and its facilities.

Shah and Holmes (1987) conducted a study of 2 groups of people with mental handicaps leaving a large institution using matched control groups with measures before and one year after the move. Group 1 consisted of 27 'sociable, low dependency subjects' moving to a large National Health Service hostel in a residential street and Group 2 of 14 'socially impaired behaviourally disturbed young adults with few skills' moving to a special ward in a smaller hospital. Structured interviews with care staff established the number of leisure activities both within and outside the home in the preceding month, and the numbers of people taking part in daily educational or vocational activities. Results showed few differences in the number of activities within or outside the home; the low dependency group became more independent within the unit and the high dependency group showed an increase in leisure activities in the community. The new homes both appear to have been relatively institutionalized so environmental differences may

not have been sufficient to have had major effects on the behaviour of the subjects.

O'Neil et al (1981) presents a longitudinal study of 26 people (mean age 39 years; mean IQ 42) moving from hospital to community homes. Activities within and outside the home in the previous week were established through an interview with the carer prior to moving and at 8 and 30 months after the move. The results are presented for 2 groups, those who had high rates and those who had low rates of activity prior to moving. Although both groups showed a significant increase in activity 8 months after the move the previously low activity group exhibited the greater increase in activities. However most of this increase was associated with activities within the home. The increase in 'away from home' activity that was noted was also mainly in the initially low activity group. There was little change for either group in the rate of work or educational activities.

In summary the main features of activities of people with mental handicaps are:

1. For people with mental handicaps living at home most activity is within the confines of the family. Although this is probably true for many non-handicapped people (Kelly, 1983; Rappaport & Rappaport, 1975), the roles of people with mental handicaps within the family are often inappropriate to their age (e.g. Flynn & Saleem, 1984).
2. People with mental handicaps living in staffed homes also have limited social contacts and are dependent upon formal carers for mobility and new acquaintances (Hill & Bruininks, 1981;

Firth, 1986). Qualitative and quantitative evidence suggests that they have few friends amongst handicapped and non-handicapped peers and when they do engage in activities they may participate in a peripheral manner (eg. Atkinson, 1985b).

3. Few people with mental handicaps hold jobs on the open market (Raynes & Sumpton, 1987). Day placements often offer entertainment rather than education or employment (Wertheimer, 1983).
4. The few longitudinal studies of moves from hospital to community care show little increase in activities outside the home. A number of studies suggest that changes in the level of activity after resettlement may be different for people with different baseline characteristics. O'Neil et al (1981) found people with low baseline activity rates show the largest increases. Shah and Holmes (1987) found that more dependent people showed increases in the use of community leisure facilities. These studies emphasise the importance of baseline characteristics in predicting patterns of activity.
5. In describing the activities of people with mental handicaps survey methodology offers limited and potentially unreliable information. The aspects of facility use that indicate the difference between high quality and lower quality patterns of use may not be accessible using this methodology (e.g. Felce, 1988). The retrospective nature of the task and the limited knowledge of any one informant of the range of activity engaged in by the subject limits the reliability and validity of the data (e.g. Harrison, 1987). Other aspects of facility

use need to be recorded, for example the nature of the settings used and the nature of the trips made to reach facilities.

An alternative to retrospective interviews is the use of time budgets or diaries. These are a 'systematic record of a person's use of time over a given period (Young & Willmott, 1975; p 336).' The sequence and duration of behaviour is generally recorded along with other details of activities (Converse, 1968; Young & Willmott, 1973). Time budgets have been used in a variety of sociological investigations (e.g. Andorka, 1987) and have been widely used in the study of health and age related behaviour (Kleemeier, 1961, Freer, 1980; Verbrugge, 1980; Little, 1984). Continuous observation could be used to collect the same type of data, although in practice this is rare due to the person-power requirements (but see Barker & Wright, 1951; Crapps et al, 1985).

Time budgets can be completed by the respondent at or near the time that the activities take place or in a detailed retrospective interview soon after the period being discussed (eg. Juster 1985; Gershuny & Thomas, 1980). Recent time budget studies tend to use intensive interviews soon after the target period, often with practice diaries or other exercises to sensitize the subject to the task (e.g. Robinson, 1985; BBC, 1984). There are less problems with literacy, motivation and task comprehension in interviews than in subject completed records (Chapin, 1974).

A number of assumptions are made of features of time budget data that imply validity. It has been assumed that more valid data is indicated by more reported activities (Verbrugge, 1980, Juster, 1985) and that less valid data are indicated by; more time not

accounted for, more activities that begin on the hour or the half hour and more stylized day to day reporting (Juster, 1985). However these assertions are untested as no studies compare time budgets with unambiguously valid data such as direct observation. Many features regarded as indicators of low quality data are also features of institutional settings where fewer activities and a highly routine pattern of activities are often found (Goffman, 1961; Morris, 1969).

The potential quality of the data is the reason for preferring time budget over other methods. Compared to interview they appear to be more valid for rare events and are an equally valid record of more common events (Verbrugge, 1980; Juster, 1985). They have the advantage of being able to record details of activities that may be unavailable to interview. Time budget methods have rarely been used in studies of the activities of people with mental handicaps.

The evaluations of 'Care in the Community' projects being carried out by the Personal Social Services Research Unit will use 'time budget' techniques to record activities and contacts of people with mental handicaps (Renshaw, 1985). Details of the techniques are not presented although they are said to be similar to the methods employed by the NIMROD evaluation team (eg. Evans et al, 1985).

Evans et al (1985) studied 4 people with moderate and severe handicaps who moved from hospital to a small home in the community. A member of staff kept a one week diary before and after the move. The diary recorded activities in the home, and the duration and location of activities outside of the home. The diary records were analysed individually and do not indicate changes in behaviour following resettlement. The study presents reliability data,

comparing diary records with data gathered during direct observation on two evenings during the week that the diary was completed. For 3 out of 4 diaries mean agreement on location and activity was 73.4%. The fourth diary had considerably lower agreement. The authors suggest more guidance to staff regarding completion of the diaries would have improved this.

De Kock et al (1988) established details of trips into the community made by people with severe handicaps using daily reports routinely filled in by care staff. People moving from hospital into small (8 bed) community units showed a change in the annual frequency of trips per person from 7 to 254 (the trips in the hospital, however, did not include those made within the hospital site). Comparison groups in 2 larger (25 bed) community units had a mean annual frequency of 74 and 68 trips per person. To illustrate the reliability of this method the families of subjects in the study kept records of their visits to the homes over a period of three months, agreement between these and the homes' records was high (88%). In the small homes 55% of the trips consisted of shopping, 19% eating or drinking out, 12% leisure or cultural and 14% other purposes. The results should be interpreted with some caution as the initial study does not take into account activities within the hospital and because trips with multiple purposes were classed as a separate trip within each category of activity.

Studies have asked people with mental handicaps themselves to keep diaries. Atkinson (1985a) reports using open-ended diaries to supplement information from case notes and interviews concerning 50 people with mental handicaps living independently. Seventeen diaries representing 34 people were obtained. The diaries served

as a cross-check for the other data collection methods. However the members of this relatively high ability group were reported as feeling threatened by the academic nature of the task, and many needed to elicit the help of benefactors in their completion.

Edmonson (1974) used a daily diary completed by the subject to record participation in activities of 25 men with mental handicaps. All were clients of a vocational rehabilitation centre and 13 held jobs on the open market at the time of the study. The diaries consisted of one 48 page booklet for each day. The booklets illustrated 170 different categories of activity using pictorial symbols. Those activities in which the subject had been engaged during that day were noted by the subjects. Subjects were given 2 training sessions in the use of the diaries and completion for the day was prompted by a phone call from the author. Each subject completed the diaries for 2 weeks. The results suggest that they were effective as they reported more routine and more occasional activities than an intensive questionnaire carried out in conjunction with the diaries. The study group appears to have been relatively able and most lived with families or others who could help in the completion of the diaries.

METHOD

The present study recorded details of all trips made from the ward or home using diaries completed by care staff over the course of one week from Sunday morning to Saturday night. Diaries were discussed with the person in charge of each home or ward and left for completion starting the following Sunday. Each consisted of a front page upon which was the name of the subject, the date that

the diary was to start and instructions for its completion. The instructions asked for a record to be made of every occasion that the subject left the ward or home. It was stressed that entries should be as accurate as possible, and that if no trip occurred on a shift this should be indicated by writing 'none' and the record signed. An example of the front page with instructions is included as appendix 5. The rest of the diary consisted of one page per day with headings for the following information concerning each trip; an example sheet is presented in appendix 6:

- a. The date of the trip,
- b. The destination - with enough detail to allow recording of the following: an Ordnance Survey National Grid reference; whether the destination was unsegregated (not specifically for people with mental handicaps); and the purpose of the trip,
- c. The time the subject left the home, and the length of time they were away,
- d. The mode of transport used,
- e. The people accompanying the subject.

Staff of the wards and homes were told that they would be visited during the week that the diary was being completed to see if there were any problems. Additionally a number of people (DD, MC, CM, BH) were named on the diary to be contacted in the event of any problems. The unannounced midweek visit allowed a check that the diary was up to date to that point. A similar check was made when the completed diaries were collected.

If a diary was not up to date, contained periods of missing data or insufficient information the staff were asked to repeat data collection for a second week. The effect of this was that diaries rarely had missing data. Staff completing the diaries realised that the quality of the data was of importance to the researchers and that work would be minimized by careful completion.

Diaries were completed when movers and controls were identified in the hospital (the 'pre-move' measure) and again, for both groups, at least 12 months after the mover had left the hospital (this is called the 'post-move' measure for both groups). At follow-up the diary was completed in the same way. The midweek visit for cases and first controls coincided with the evening of direct observation described in chapter 5. The data collected during direct observation are used for validation of the diary data.

Subjects

Of the 39 movers one returned to the hospital within 12 months and so is not included in the study. Diaries were not completed at follow-up for the three cases that live independently so data for them and their controls are not included in the following analysis. This gives a potential group of 35 movers.

In the case of 11 movers, information that they were being considered for discharge was not received before they left the hospital; baseline data was hence collected for only 24 of the 35 movers. It was usually possible to collect data for controls at or near the time that the mover left; however data for 12 controls were not collected due to poor matching early in the project

(controls were selected at the point that movers left so there was no pre-move data) and so baselines are available for 44 controls. At follow-up diaries were completed for each mover and their controls during the same week if possible. Follow-up data was collected for all 35 movers and for 52 controls, 3 controls having died and 1 having been discharged since baseline data were collected.

RESULTS

Number of trips

There are 40 controls and 24 movers for whom both pre- and post-move data are available. There was 1.6 years (sd = 0.6) between completion of the first diary and the second for the controls and 1.9 years (sd = 0.4) for the movers. The difference is probably due to data collection for movers being at the point that they were identified and for some controls being at the point that movers left, sometimes many months after the mover they were matched with had been identified. When possible follow-up data was collected during the same week for movers and their controls. This is confirmed by calculating the number of years after the start of the project (1st June, 1985) that the follow-up diaries were completed. The mean time from this date to the collection of follow-up data is 2.9 years (sd = 0.6) for controls and 2.9 years (sd = 0.5) for movers. This confirms that the difference in time between first and second diary collection is due to variation in time of pre-move data collection. For movers diaries were collected a mean of 1.6 years (sd = 0.3) after leaving the hospital.

There were 66 people for whom follow-up diaries were available and for whom one evening of direct observation (reported in chapter 5) was made; this includes all cases other than those living independently and their first controls. The level of agreement on trips made according to the diary and trips noted during the evening of observation was calculated. In 12 cases the date of observation did not coincide with the period covered by the diaries, mainly due to diaries having to be repeated. Of the remaining 54 diaries 50 agreed with observational records on whether or not a trip was made during that evening, 32 agreeing there was no trip and 18 agreeing there was 1 trip; the 4 disagreements were all trips observed but not recorded in the diary. Reliability was calculated using Kappa (Cohen, 1960), which is a statistic for calculating the agreement of nominal data that takes into account chance agreement. The Kappa value for this data set is 0.84, which indicates a reasonably high level of agreement (the range of Kappa is 0 to 0.99)

As matching was not on number of trips it is important to examine baseline differences in the matched pairs to determine the effectiveness of the match. Of the 35 movers there are 4 for whom no controls were available, there are 12 who left in an early phase of the study for whom baseline data is not available and there are 2 who have controls for whom there is no baseline data hence the correlation is derived from 17 movers and their controls. For 13 movers the matched point represents the mean of 2 controls and for 4 movers it represents 1 control.

Figure 26 is a graphical presentation of this data. Pearson's r for the relationship between number of trips for these 17 cases and

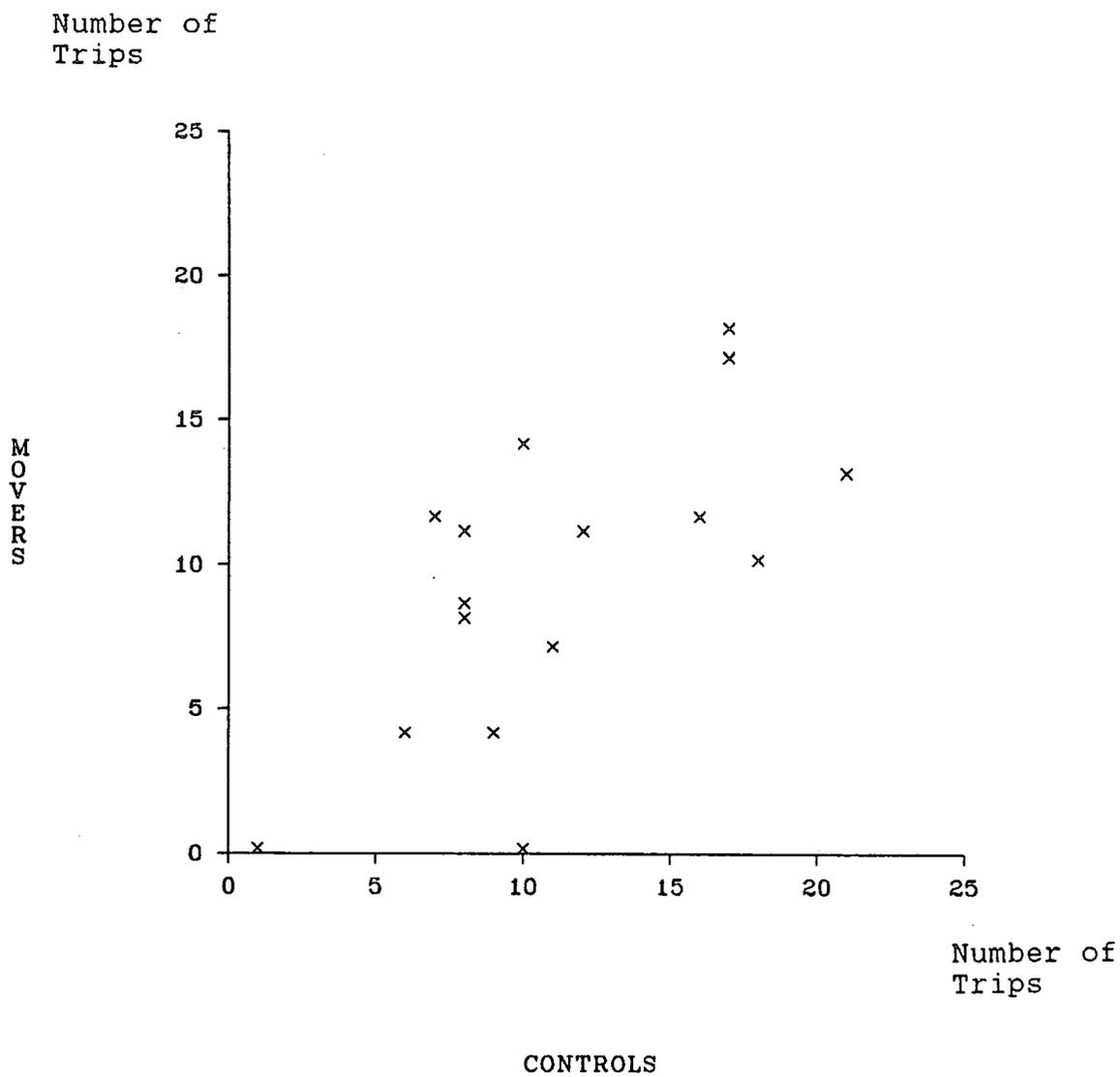


Figure 26: Plot of number of trips made at baseline by movers and their controls

controls = 0.63. The strength of this relationship deserves comment. The match upon 5 items from the Wessex Case Register and age and sex is a reasonable predictor for the number of trips that movers and controls made from the ward at baseline. Although the problems of matching have been discussed, it seems that it has in fact been reasonably effective.

Because of the effectiveness of the match a related-sample t-test is appropriate for this data. The mean number of trips at baseline for these 17 movers was 10.9 (sd = 5.2), for the 17 control data points was 9.4 (sd = 5.2), the difference is not significant ($t = 1.41$, $df = 16$, ns). It can be stated that as a result of matching controls were selected who did not differ as a group from the 'movers' on baseline number of trips.

The major point of interest in this data is whether moving out of the hospital has an effect upon the number of trips recorded at follow-up. All subjects for whom there are pre and post-move diaries available are included in this analysis. This gives a group of 24 movers with a mean of 10.9 (sd = 5.5) pre-move trips and 40 controls with a mean of 10.0 (sd = 6.1) pre-move trips. As these groups include 2 controls for some movers and some movers whom there are no controls available the baseline difference is tested using a t-test for unrelated samples; consistent with the results of the previous paragraph, it is not significant ($t = -0.5$, $df = 62$, ns). The number of trips made at baseline is plotted against the number of trips made at the second data collection for each subject in figure 27. Analysis is carried out with the number of trips at follow-up as the dependent variable and the number of baseline trips and whether or not the subject moved out, as independent variables.

Number of
Trips

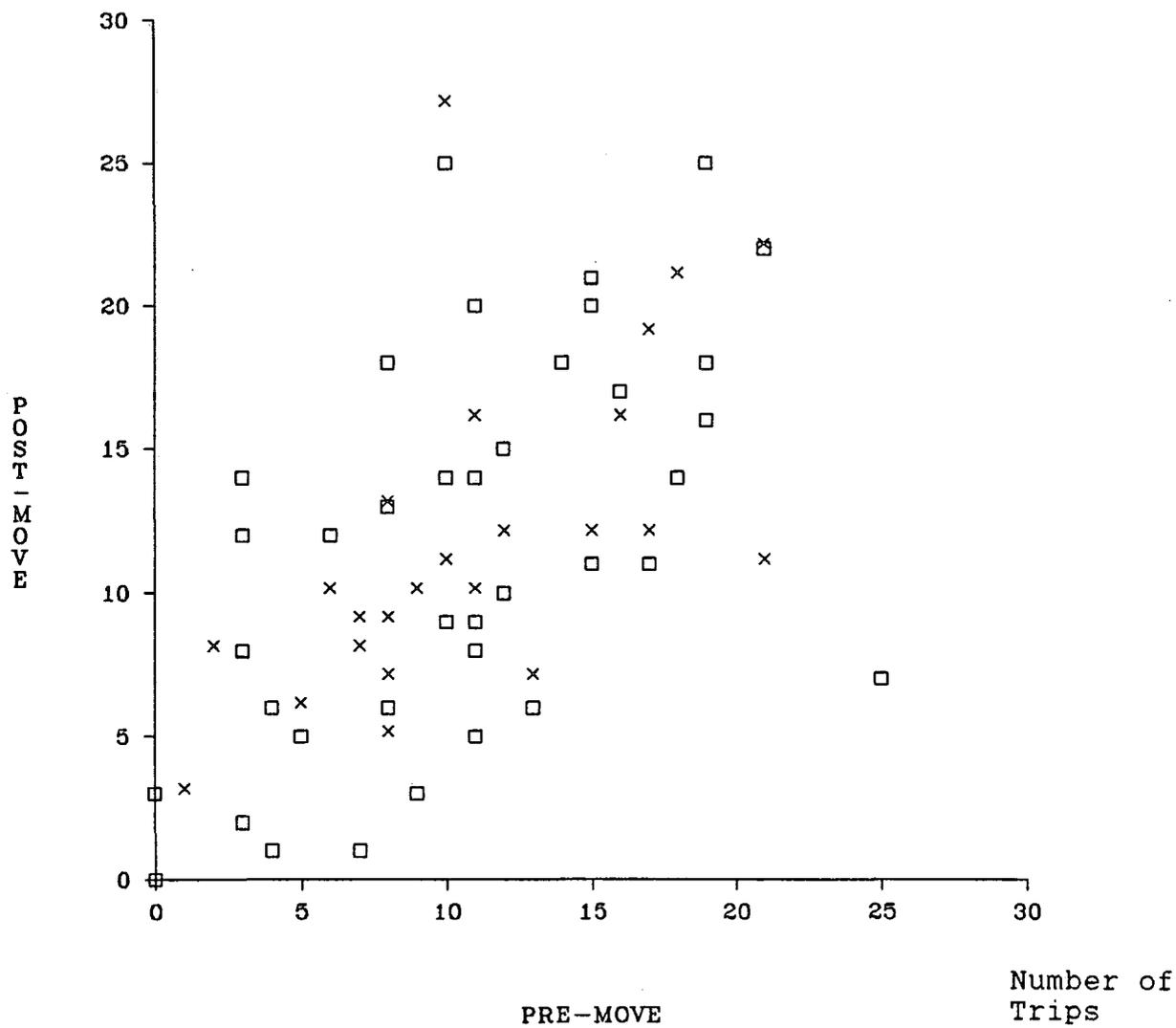


Figure 27: Plot of number of trips made at pre-move and number of trips made at post-move for movers and all controls

□ = Hospital
X = Community homes

First two regression analyses were carried out using the 2 independent variables separately. The 2 unstandardized regression coefficients (B) and their standard errors are presented in table 15. As can be seen the regression coefficient for the regression of number of post-move trips onto number of pre-move trips does not include 0 within 1.96 times the standard error; this indicates that the slope of the regression line is significantly different from 0 (i.e. that trips made at follow-up can be predicted from baseline trips). The regression coefficient for the regression of number of post-move trips on mover or control status on follow-up number of trips includes 0 within 1 standard error; the difference between the group is therefore not significant.

To explore this data further it can be modelled in a multiple regression analysis; the statistics from this are presented in table 16. It can be seen that when baseline data is entered at the first step the ratio of the variance explained by the regression line to the residual variance is highly significant ($F = 36.3$, $df = 1,62$ $p > 0.0001$). When status is entered into the model the further variance that is explained is trivial ($F = 0.07$).

This analysis confirms what was suggested from the simple regression i.e. that mover or control status does not add to the accuracy of the estimate of the dependent variable that is possible knowing baseline scores.

The results so far have a number of implications:

1. The reliability of the diary method has been demonstrated. The consistency of the 2 data collections is high. The second

Variable	B	SE B
Baseline Trips	0.67	0.11
Status	0.54	1.46

Table 15: Statistics for separate regression of baseline trips and study group status; B is the unstandardized regression coefficient

Step	Variable	Sum of Squares	DF	F Ratio	Signif of F
1	Pre-Move Trips	1027.7	1	36.33	>0.0001
2	Status	2.1	1	0.07	ns
	Residual	1700.5	61		
	Total	2779.2	64		

Table 16: Statistics for regression of post-move trips on pre-move trips and study group status

data collection in the community was completely independent of the first; community staff had no knowledge of the content, or even the existence, of the baseline diary. The level of agreement between the number of pre and post-move trips (Pearson's $r = 0.6$) represents consistent characteristics of the individual subjects over a period of at least 1 year.

The agreement of diary records with observation (Kappa = 0.84) also suggests a good level of validity. It is interesting to note that diary errors were all errors of omission; there is no evidence of a systematic overestimation of number of trips by staff in community homes and wards.

2. Matching on mobility, sensory handicap, speech ability, age and sex predicts to baseline scores. If baseline estimates of number of trips are not available then matching after the move on similar, preferably pre-move, individual characteristics would be worthwhile.
3. The importance of a baseline measure is clear. Moving to the community did not affect the number of trips made. The better predictor of number of trips made at post-move was number made at baseline; this will be discussed in greater detail later.

The importance of the baseline measure can be illustrated by examining the number of trips made from each home by movers. The raw number of trips made at follow up is plotted for each mover by home in figure 28. In this figure the homes are ordered as they were presented in Chapter 2, by administrative category and by increasing size within each category. It can be seen that there is considerable difference between homes. From this data presentation

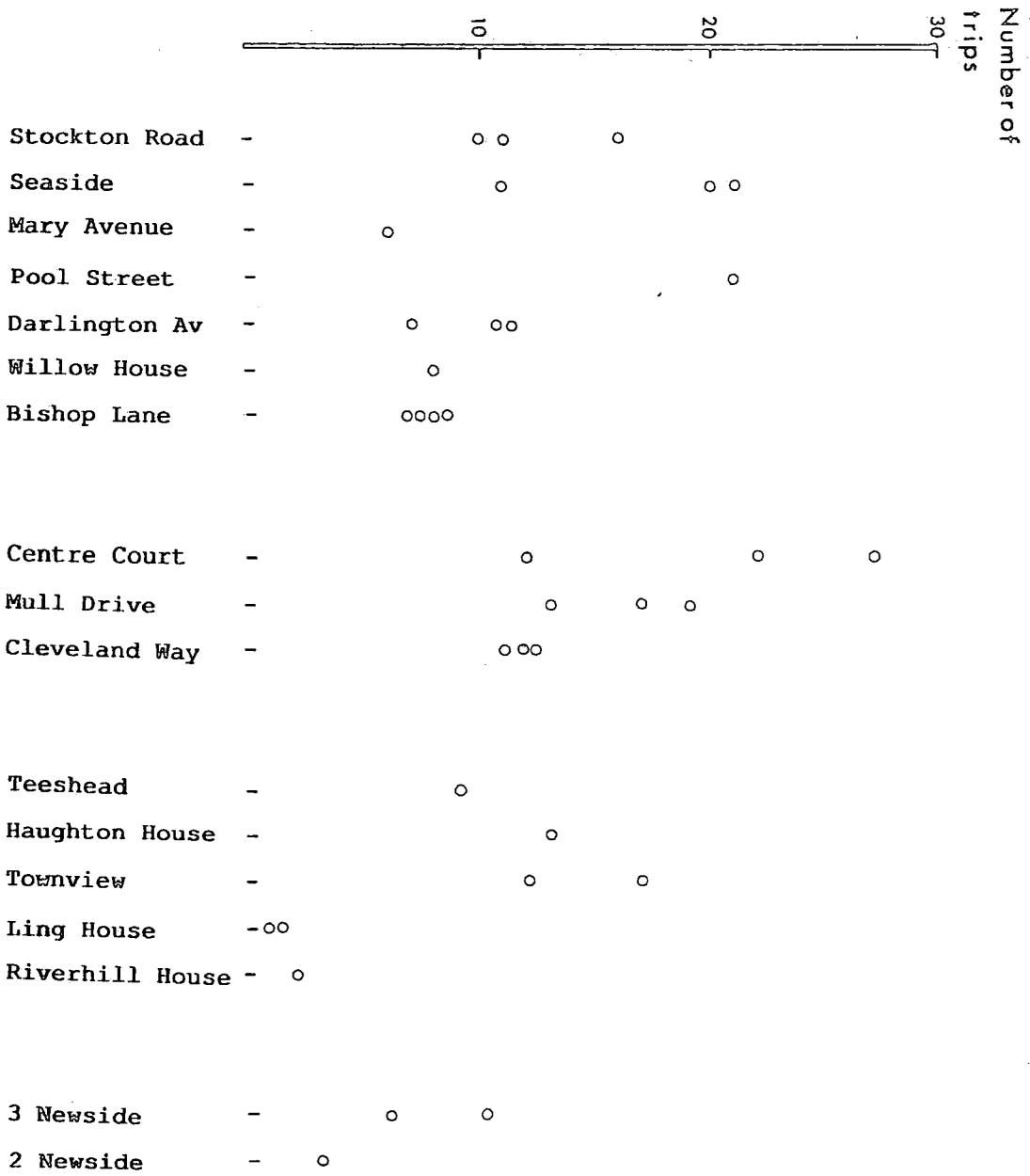


Figure 28: Plot of number of trips made by movers at post-move by home. Homes are ordered as in table 6, by administrative category and by increasing size within category

it would appear that some homes 'perform' better than others. In fact fewer trips are made from larger homes: the correlation, r is -0.5 . However the importance of the baseline characteristics of subjects should also be taken into account in this situation. Figure 28 can be redrawn using residual scores (the amount that trips made differs from that which is predicted by bivariate regression on baseline scores). This is shown in figure 29. This plot identifies homes in which residents are going out more or less than predicted from the baseline scores of their residents.

For the 24 movers with baseline data available a regression analysis can be carried out with the number of trips at follow-up as the dependent variable, and the number of baseline trips and home size as independent variables. The statistics from this are presented in table 17. When baseline data is entered first its effect is highly significant ($F = 12.57$, $df = 1,22$ $p > 0.01$). When home size is entered second its effect is not significant ($F = 3.07$, $df = 2,21$, ns).

This analysis demonstrates an important point. There may be considerable inter-home differences in behavioural measures for people with mental handicaps, and this may be shown to be related to features of the home, such as size. However in this analysis this difference has been shown to be due to the baseline characteristics of the residents, who are selected differentially into different homes. When baseline differences are taken into account the effect of home size is then not statistically significant. This finding is important in relation to the interpretation of studies that compare types of home but do not include baseline measures.

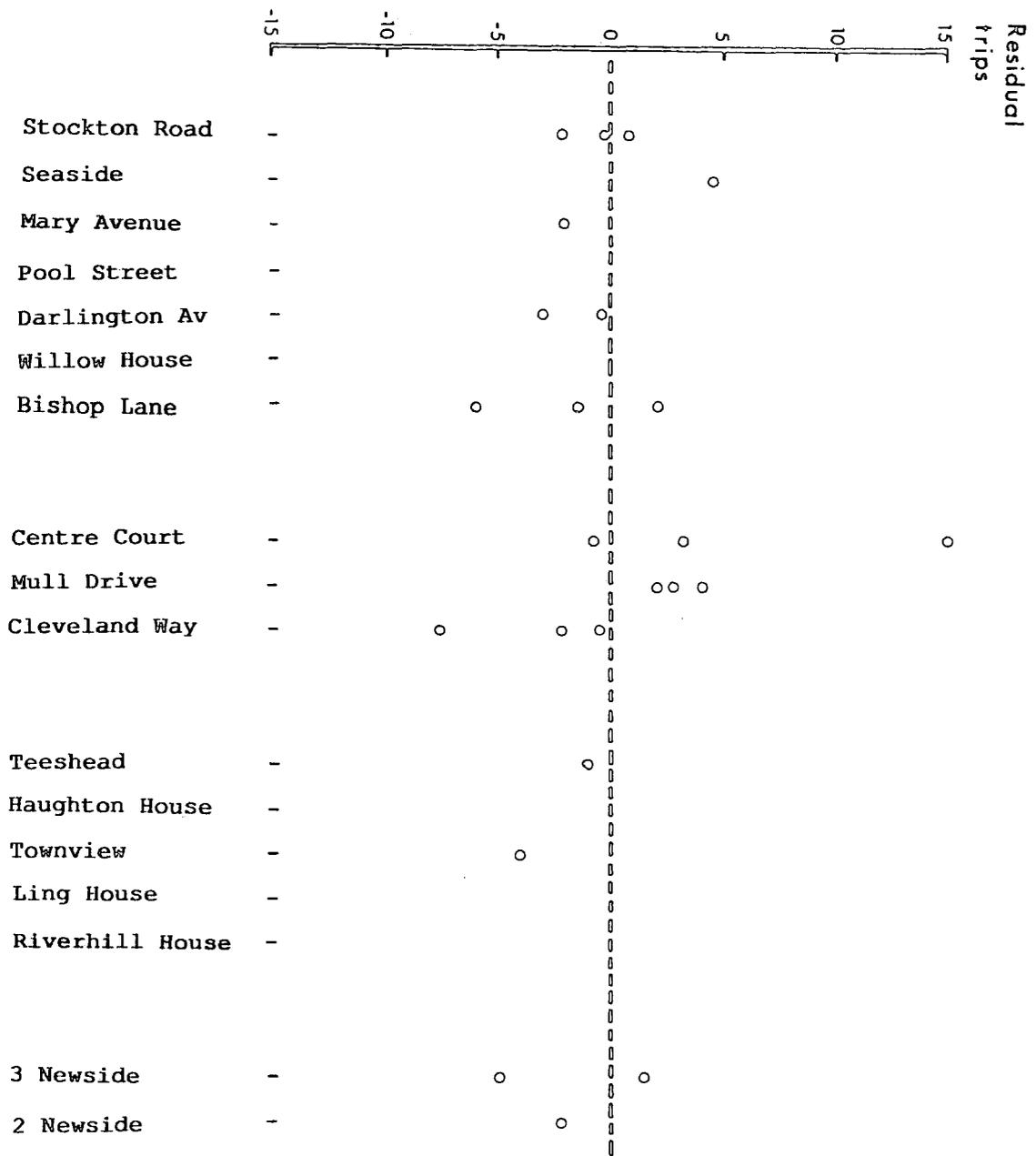


Figure 29: Plot of residual number of trips made after accounting for number of trips predicted from baseline scores

Step	Variable	Sum of Squares	DF	F Ratio	Signif of F
1	Pre-Move Trips	279.1	1	12.57	>0.01
2	Home Size	62.3	1	3.07	ns
	Residual	425.8	21		
	Total	767.2	24		

Table 17: Statistics for regression of post-move trips on pre-move trips and home size for movers

Although there is no difference in the number of trips made due to moving out of the hospital, movers and controls may differ in the types of trip made. Here the characteristics of the trips are post-coded and there was no specific hypothesis at the beginning of the study. In addition a large number of comparisons are possible from this data, there are 22 characteristics of trips considered in this section, comparisons could be made of pre- to post-move scores and between groups; a minimum of 88 statistical comparisons. By chance alone at least 4 of these comparisons would be expected to be significant at the 0.05 level. The use of statistical comparisons in this situation is of little value and would make it difficult to recognise those situations where statistical analysis has been used in an appropriate manner. However the details of patterns of activity and their change over time are of interest at a descriptive level.

In the remainder of this section the results come from all movers and controls for whom at least one data point is available. The pre-move data refers to 44 controls who made a mean of 9.9 trips per week (sd = 6.3) and 24 movers, who made a mean of 11.0 trips per week (sd = 5.5). The post-move data refers to a group of 52 controls who made a mean of 10.8 trips per week (sd = 7.0), and 35 movers who made a mean of 11.4 trips per week (sd = 6.2).

Throughout this section trip characteristics are presented as medians with semi-interquartile ranges as their distributions do not conform to the requirements of parametric summary statistics.

Trip distance

In chapter 2 it was shown that the median distance to basic

facilities was 0.5 km in the community and 0.4 km in the hospital. Although this difference is small the same direction of difference is found in comparison of the actual distances travelled. In the pre-move measure controls had a median trip distance of 0.28 km (SIR 0.13 - 1.7) and movers a median of 0.69 km (SIR 0.28 - 3.70); the reasons for pre-move differences between groups are discussed later. In the post-move measure controls had a median trip distance of 0.22 km (SIR 0.12 - 0.35) and movers a median of 1.84 km (SIR 0.96 - 2.57). Movers are travelling further on each occasion in the post-move measure.

Purpose of trip

The purpose of the trips was coded using 28 subcategories, which combine to give 3 major categories; work (including education), maintenance (purchasing goods, receiving services etc.), and leisure (social activities, entertainment etc.). The categories used are similar to those used in geographical studies of urban activity (e.g. Daniels & Warnes, 1980), studies of time use (e.g. Szalai, 1972; Chapin, 1974), and studies of the activity of people with mental handicaps (e.g. O'Neil et al, 1981; De Kock et al, 1988). Items making up the 3 categories of work, leisure and maintenance are presented in tables 18, 19 and 20 respectively.

Work

In the pre-move measure the controls made a median of 6.0 (SIR 3.0 - 9.0) trips to work per week and movers 4.5 (SIR 0.0 - 8.75). At the post-move measure controls made a median of 5.5 (SIR 1.25 - 10.0) trips to work and movers 4.0 (1.0 - 5.0). Many movers and controls make a median number of work trips of greater than 5 (i.e.

-
- 01 - Work/Day Placements - in hospital, for example
Queens/Falcon Centre
Pre-retirement Group
 - 02 - Other hospital activities - Gardens/Sewing room/Mail Delivery
 - 03 - Work/Day Placements - ATCs
Competitive Employment
Other day services/Art Centres etc.
 - 04 - Aycliffe Community Centre. Day time (Sun-Sat, 9-6)
 - 05 - Multi-purpose trips including work.

 - 41 - School
 - 42 - Day time education, further education
-

Table 18: Items making up the category of work activities

-
- 20 - Aycliffe Community Centre (6pm onwards)
 - 21 - Wards
 - 22 - Admin block/other buildings
 - 23 - Homes (family)
 - 24 - Homes (staff/friends/volunteers)
 - 25 - Cinema/theatre
 - 26 - Pubs/Social clubs/dancehall/Parties not in homes
 - 27 - Holiday
 - 29 - Community Centre/Leisure Centre/not in Hospital

 - 31 - sports activities/centres/play or watch/swimming
 - 32 - walk/walking dog/meeting people/
walking someone home/countryside
 - 33 - other active leisure (eg. fete/fair/dog show etc)

 - 34 - church
 - 35 - museums
 - 36 - hobby classes

 - 50 - General visits/town centres/multiple visits e.g. including
maintenance and leisure, but not work
-

Table 19: Items making up the leisure categorisation

-
- 11 - Doctors/Dentist/Hospital (medical)
 - 12 - Hairdressers
 - 13 - Cafe/Restaurant/Fast Food
 - 14 - Bank/Post Office/DHSS Offices etc
 - 15 - Post Box/Telephone Box (communications)
 - 16 - Shopping
 - 17 - Library
-

Table 20: Items making up the categorisation of maintenance activities

more than one trip per day). They return to their home for lunch, and hence a full days work may be recorded as 2 trips. This is often the case in the hospital. The data are hence best presented as the number of days per week on which the individual goes to work at least once. This is presented for movers and controls in pre- and post-move diaries in table 21. In addition the median total time that is spent on trips related to work in a week is presented in table 22.

These tables indicate that there has been relatively little change in the number of days people attend work placements. A greater proportion of controls than movers attend work placements for 5 days per week (especially in the post-move measure) and controls spend more time at work. This may reflect the relative lack of day placements available in the community (Social Services Committee, 1985) and the ease of access to work placements in the hospital. However the difference was present in the pre-move measures, which may reflect the slightly higher ability of the movers for whom many of the hospital work placements do not offer sufficient challenge. That so many movers have day activities is due to the efforts of home staff to explore a range of alternative day placements for their clients. Both groups spend longer in work during the week in the post-move measure, perhaps reflecting generally greater emphasis upon work activity in recent years.

Leisure

In the pre-move measures the control group made a median of 2.0 (SIR 1.0 - 5.75) leisure trips per week, and the movers 4.5 (SIR 2.0 - 7.75). In the post-move measures the controls made a median of 4.0 (SIR 1.0 - 8.0) leisure trips per week, the movers a median

	Pre-Move		Post-Move	
Controls				
Days	n	%	n	%
0	10	22.7	11	21.2
1	1	2.3	3	5.8
2	1	2.3		
3	5	11.4		
4	6	13.6	8	15.4
5	21	47.7	30	57.7

Movers

Days

0	7	29.2	8	22.9
1	2	8.3	4	11.4
2	2	8.3	3	8.6
3	1	4.2	5	14.3
4	2	8.3	2	5.7
5	10	41.7	13	37.1

Table 21: Number of days on which at least one work trip was recorded

	Pre-Move	SIR	Post-Move	SIR
Controls	14.9	2.7 - 24.0	20.8	2.6 - 27.9
Movers	12.5	0.0 - 25.6	16.6	3.3 - 32.5

Table 22: Median hours spent in trips to work per week

of 4.0 (SIR 2.0 - 9.0). Table 23 presents this data as the number of days per week on which at least one leisure trip is made. The total time spent on leisure trips per week is presented in table 24.

These tables indicate that proportionally more controls than movers have no leisure activity on any day, though the differences are slight and there has been little change over time. Movers spent more time in leisure trips in the pre-move measure than did controls; this difference has diminished in the post-move measure when controls spend more time in leisure trips than at pre-move, whilst movers spend less.

Maintenance

Maintenance trips are mainly shopping, but also include visits to dentist, doctor, hairdresser etc. as defined in table 20. In the pre-move measure controls made a median of 0.0 (SIR 0.0 - 1.0) maintenance trips per week and movers a median of 0.0 (SIR 0.0 - 3.0). In the post-move measure controls made a median of 0.0 (SIR 0.0 - 0.0) maintenance trips per week and movers a median of 2.5 (SIR 0.0 - 4.25). Table 25 presents data on the number of days per week upon which at least one maintenance trip was made for movers and controls. The median total time that is spent on maintenance trips in a week is presented in table 26.

Movers had more maintenance trips in the pre-move measures than did the controls. There is then an increase in the number of trips made, in time spent in trips and in the proportion of the group who made at least one maintenance trip in a week. There has been little change for the controls, and it is in the opposite

	Pre-Move		Post-Move	
Controls				
Days	n	%	n	%
0	10	22.7	10	19.2
1	8	18.2	7	13.5
2	5	11.4	6	11.5
3	5	11.4	4	7.7
4	9	20.5	6	11.5
5	4	9.1	6	11.5
6	1	2.3	7	13.5
7	2	4.5	6	11.5
 Movers				
Days				
0	2	8.3	4	11.4
1	4	16.7	2	5.7
2	3	12.5	5	14.3
3	2	8.3	8	22.9
4	6	25.0	6	17.1
5	5	20.8	3	8.6
6	1	4.2	5	14.3
7	1	4.2	2	5.7

Table 23: Number of days on which at least one leisure trip was recorded

	Pre-Move	SIR	Post-Move	SIR
Controls	4.2	0.7 - 10.2	6.5	1.4 - 13.5
Movers	9.1	3.9 - 15.2	7.8	3.8 - 16.5

Table 24: Median hours spent in leisure trips per week

		Pre-Move		Post-Move	
Controls					
Days		n	%	n	%
0		31	70.5	44	84.6
1		7	15.9	7	13.5
2		3	6.8	1	1.9
3		3	6.8		
4					
5					
6					
7					
Movers					
Days					
0		12	50.0	10	28.6
1		5	20.8	8	22.9
2		1	4.2	2	5.7
3		5	20.8	9	25.7
4				3	8.6
5		1	4.2	2	5.7
6				1	2.9
7					

Table 25: Number of days in which a maintenance trip was recorded

	Pre-Move	SIR	Post-Move	SIR
Controls	0.0	0.0 - 0.6	0.0	0.0 - 0.0
Movers	0.1	0.0 - 1.4	1.9	0.0 - 2.6

Table 26: Median total hours maintenance trips per week

direction.

Although it was shown that there was no change in the total number of trips made according to movers or control status there are a number of changes in the pattern of activities out of the home. Changes have occurred for both groups in work, maintenance and leisure categories. The major changes include an increase in time spent in work by both groups, an increase in time spent in leisure for controls, but a decrease for movers and increased time and number of maintenance activities for movers. There are a number of baseline differences in the pattern of activities of the two groups.

These results show that the movers are taking up maintenance opportunities available in the community that are not available in the hospital, this has not greatly affected the number of leisure and work trips. The generalizability of this finding could usefully be tested in further samples using statistical testing of focused hypotheses set up in advance.

Other features of trips may also be important as they indicate the quality of the contact that people with mental handicaps have with their community. These include:

1. Use of unsegregated facilities. Hospitals are inherently segregated environments and it is important to discover whether people moving to the community do come to use unsegregated facilities; this is one of the aims of community care (DHSS, 1971; Social Services Committee, 1985). Trips were coded as to either segregated or unsegregated environments.

2. Mode of transport. Trips were coded as either by foot, by public transport, by private car, by segregated transport arranged by the home, hospital or other segregated service or by some other form of transport. This indicates whether people are using ordinary means of transport, or whether travelling is itself a segregated activity.

3. Accompanying people. Trips were coded as either made alone, with staff, with residents, with staff and residents, with relatives or with other people (e.g. non-handicapped friends or volunteers). This is important both in relation to the degree of independence that the subject has, and to the potentially stigmatizing effects of travelling in groups of people who are also handicapped (Wolfensberger, 1972).

As can be seen there are many categories, some of which were used relatively rarely. Rather than present long lists of values throughout this section data are presented graphically using 'box and whisker' plots of 5 number summaries. Key points and values will then be considered in the text.

Use of unsegregated facilities

The use of integrated facilities is presented in figure 30. This indicates that for controls there has been little change in the small number of integrated facilities used (medians of 0 in both measures). For movers the number of integrated facilities used has increased considerably from a median of 1.0 (SIR 0.0 - 7.5) to a median of 7.0 (SIR 2.0 - 11.0). This would indicate that a considerable proportion of movers trips in the post-move measure

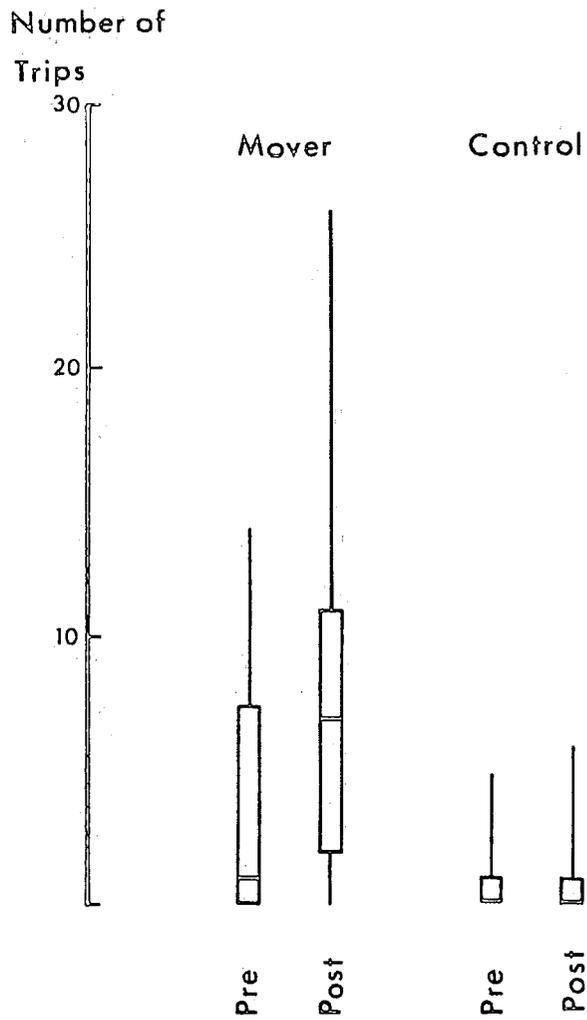


Figure 30: Box and whisker plot of number of trips made to integrated facilities by movers and controls in pre- and post-move measures

involve use of integrated facilities.

Mode of Transport

Data presenting the use of different forms of transport in before and after move measures are presented graphically for movers in figure 31 and controls in figure 32. There is little difference between movers and controls at pre-move. For controls most trips are made by foot (within the hospital), few are made by any other means and there is little difference in pre- and post-move measures. For movers there is a decrease in the number of trips made by foot, from 9.5 (SIR 7.0 - 14.0) in the pre-move measure to 6.0 (SIR 1.0 - 9.0) in the post-move measure and there is a slight increase in the use of other forms of transport, indicating that as less facilities are accessible by foot a greater variation in the modes of transport used in post-move activities.

Accompanying people

Data for the number of trips made with different classes of people accompanying are presented for movers in figure 33 and controls in figure 34. For controls there has been little change in the person accompanying them, most trips are made alone. For movers (figure 33) there has been a considerable decrease in the number of trips made alone, from a median of 7.5 (SIR 1.0 - 11.0) to 0.0 (SIR 0.0 - 4.0). This is accompanied by a large increase in the number of trips made in a group of at least one member of staff and one other resident, from 0.5 (SIR 0.0 - 2.0) to 6.0 (SIR 2.0 - 8.0). There is relatively little change in other categories.

This section summarises changes in the types of trips people have

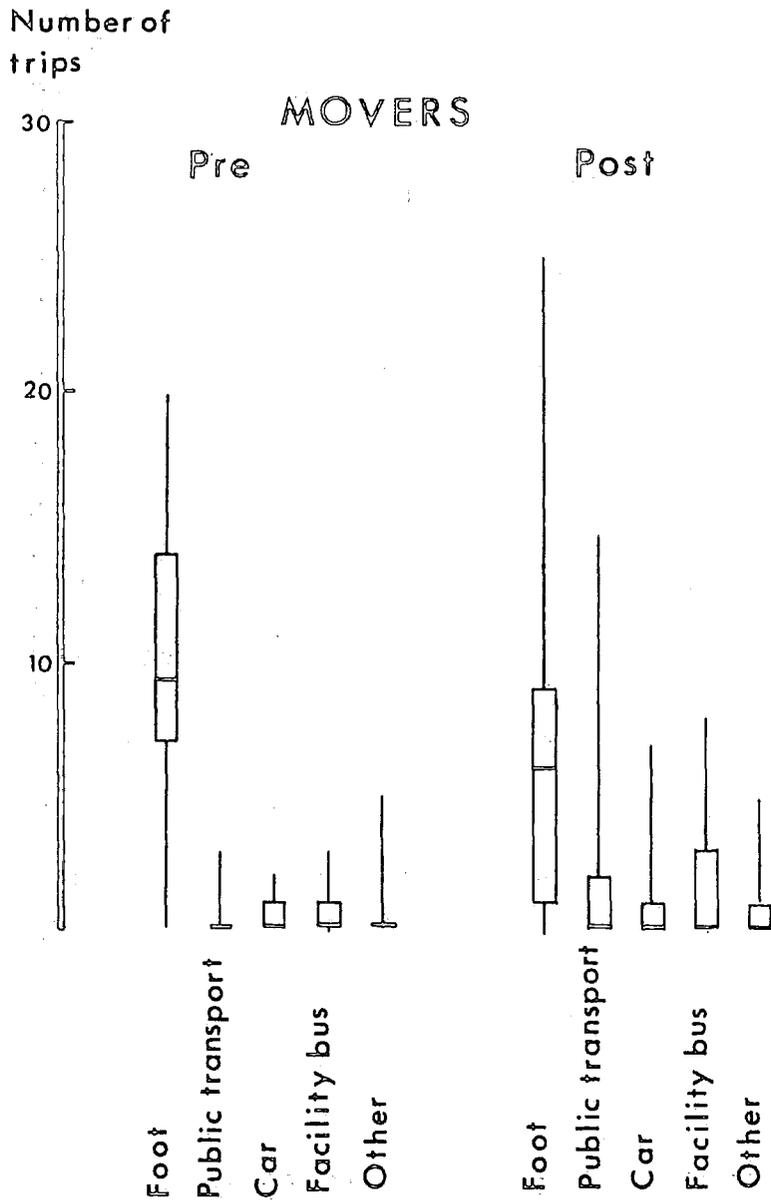


Figure 31: Box and whisker plot of number of trips made by mode of transport for movers in pre- and post-move measures

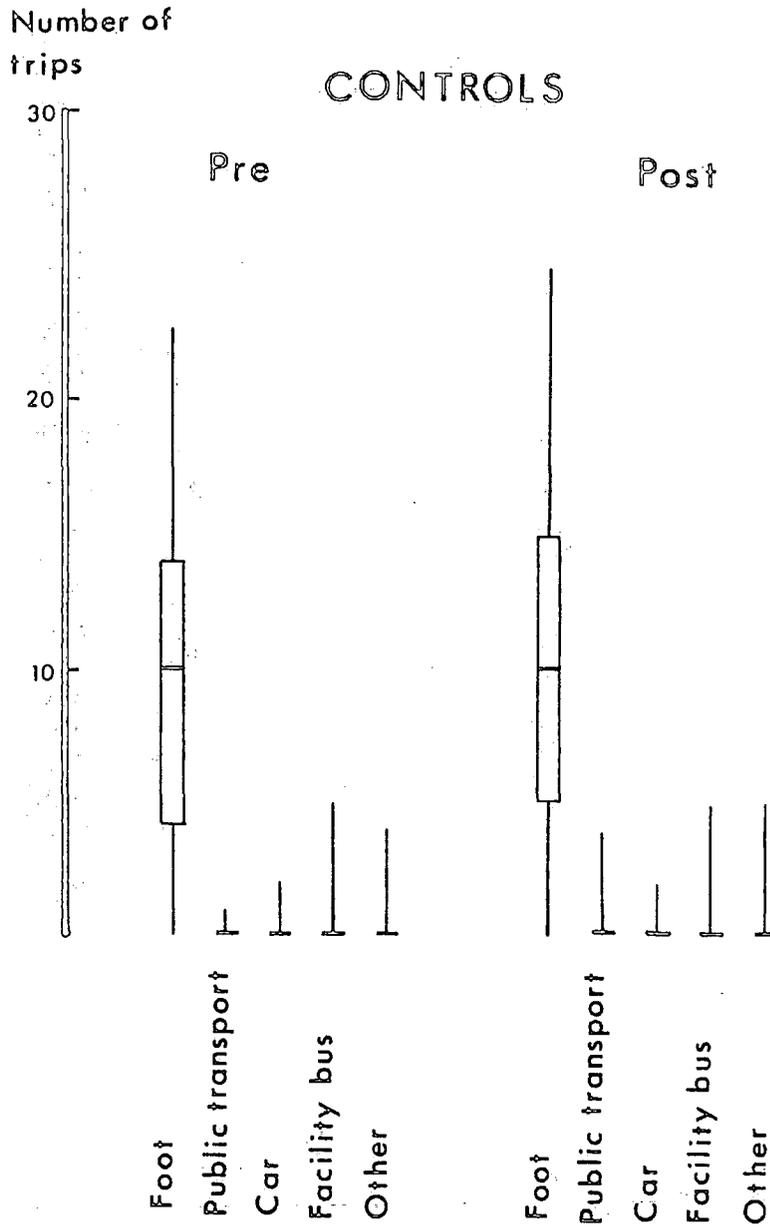


Figure 32: Box and whisker plot of number of trips made by mode of transport for controls in pre- and post-move measures

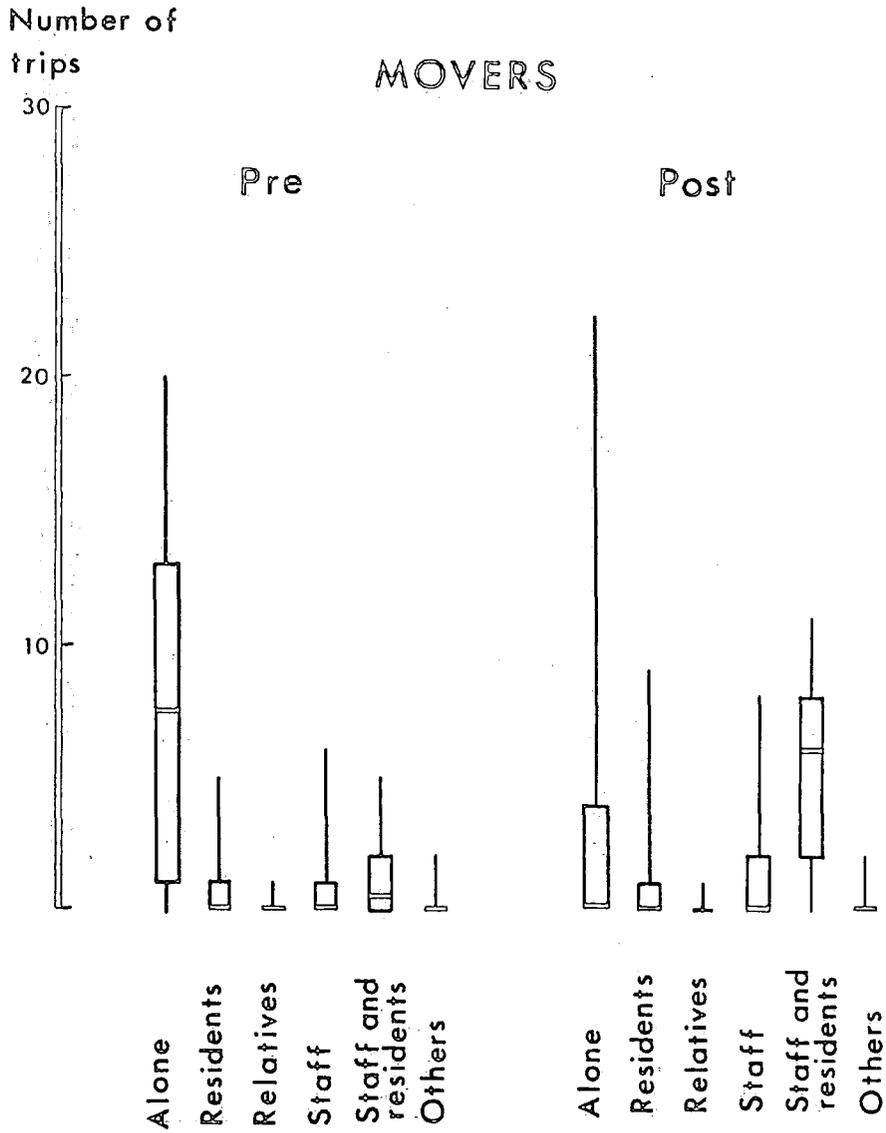


Figure 33: Box and whisker plot of number of trips made by people accompanying on trips for movers in pre- and post-move measures

made. For movers there is a increase in the number of unsegregated facilities used and some increase in the variety of means of transport used. However there is a loss of independence in terms of the number of trips made alone which is accompanied by an increase in the number of trips made with staff and at least one other resident. For controls there has been little change in any of these characteristics.

DISCUSSION

This chapter has demonstrated that the number of trips made as recorded in a seven day diary does not significantly change when movers leave the hospital; neither is there a significant difference between the number of trips made by movers and controls on the post-move measure. A regression analysis demonstrated that the number of trips made on the post-move measure is best predicted by the number of trips recorded on the pre-move measure. The importance of baseline measures is further demonstrated as the number of trips made from community homes is also correlated with home size (Pearson's $r = -0.5$); a regression analysis showed that this is explained by pre-move number of trips. This illustrates an important point; that observed outcome differences between groups or between environments may be due to selection of residents. This can be best demonstrated using multivariate analysis with baseline measures or variables that are analogous to the selection criteria as independent variables.

Although there are no changes in the number of trips due to mover or control group status descriptive analyses shows that there have been changes in other features of activities. For controls there

are small increases in the amount of leisure and work activity but little change in the other characteristics of trips. For movers there are increases in work and maintenance activity and a decrease in leisure activities. Movers make more trips to unsegregated facilities, make less trips by foot and less trips alone than they did on the pre-move measure. Movers make use of community facilities that are less available to controls (e.g. maintenance facilities, such as shops) and use more varied means of transport. However there has been some loss of independence in terms of number of trips made alone, with an associated increase in trips made in groups.

There are few segregated shops and basic service facilities outside the hospital and so most maintenance facilities used by movers will be unsegregated. Leisure facilities may not be integrated as many movers attend social clubs specifically for people with mental handicaps (e.g. Gateway clubs, run by MENCAP), although use is also made of unsegregated leisure facilities, such as pubs. Most movers attend segregated work placements; there are a few examples of unsegregated work or educational activities.

These findings can be expressed in a more positive manner. Movers are making the same number of trips as they did in the hospital despite the fact that they travel further on trips, that the use of unsegregated facilities may require more staff time than the equivalent use of segregated facilities and that less trips are made alone. It was possible that people leaving the hospital would continue to use segregated facilities and achieve only a limited physical integration. In fact movers are using a number of unsegregated facilities, and whilst this does not guarantee social integration it is a necessary condition to achieve it.

The finding of no change in overall number of trips coincides with findings of relatively minor changes in activities outside the home in a number of other studies (e.g. O'Neil et al, 1981; Shah & Holmes, 1987). An exception is De Kock et al (1988) who found a major increase in the annual number of trips made by severely handicapped people who moved from hospital to eight bedded homes in the community. However the baseline measure in this study did not include trips made within the hospital. Whilst these trips undoubtedly represent segregated activity it is more informative to record all trips and to code them so these can be distinguished. De Kock et al (1988) do not give the reader the opportunity to judge the quality of trips made within the hospital. It can be argued that the pattern of activities in hospital should be a minimum criterion to be at least matched when people move to the community; whether this is in fact an appropriate criterion will be further considered in the final chapter.

Comparison of the levels of activity found in the current study with those found in other studies is generally difficult as few use the same measurement scales and summary statistics. For example Hill and Bruininks (1981) recorded percentage of people who had engaged in certain activities at least once in the previous week. Aveno (1987) used a scale of engagement in different types of activity of 'never, seldom, occasionally, frequently'. De Kock et al (1988) used percentages of mean number of trips made annually to represent numbers of trips made in particular categories of activity. The use of medians in the present study precludes a comparison as medians are not additive and cannot be used to calculate percentages of total number of trips for different categories. In the present study the total number of trips made



was normally distributed allowing use of descriptive statistics and significance testing based on this distribution; trip type was not so distributed.

De Kock et al (1988) attribute increases in the use of community facilities to the location of resources, staff to resident ratios, staff orientation and management autonomy (p 136). In the present study the hospital and community environments have been shown to differ on many of these variables (chapter 2) but there is no difference in the number of trips made. There are a number of possible reasons for this; it may be that these differences in the homes do not, in fact, have an effect upon this behavioural outcome; that there is some type of ceiling effect; or that this highly able group is less affected by environmental changes. It is not, at present, possible to distinguish between these alternatives, although the discussion of all results of this thesis in the final chapter suggests that the final alternative is the most likely. Although environmental differences have not affected total number of trips they may have been instrumental in changes in other aspects of facility use. For example the importance of non-institutional management practices and flexibility of routine would be expected to affect the ease in which trips outside the home can be made; the increased autonomy of community homes should facilitate access to facilities in comparison to hospital wards (Rawlings, 1985a, 1985b). For example, leisure trips to the hospital community centre, which occur at the same time every week, may require less autonomy from the ward staff than leisure trips to unsegregated community facilities, which are likely to be less rigid in their routine (Goffman, 1961) and which may necessitate the absence of staff (as trips are generally accompanied) and the rescheduling of other activities (e.g. meals, shift changes). It

may be that increase in staff autonomy in the community is balanced by an increase in demands associated with community facility use.

In the present study an apparent effect on number of trips made for home size was minimized once baseline trips were accounted for. A number of studies find differences between homes in their use of community facilities (e.g. Aveno, 1987; Butler & Bjaanes, 1978). For example Aveno (1987) compared the rates that severely handicapped residents of American group and foster homes engaged in 12 leisure activities. Group home residents engaged in significantly more of many activities (for example: going to the library, to bars or clubs; for walks, to swimming baths or out 'on dates') although there was no difference in relative frequency. A plausible hypothesis would be that these differences reflect selection of residents into particular home types, rather than differences resulting from the type of care.

The loss of independence must be interpreted in the light of the relatively safe hospital environment. It is possible to send someone with limited skills from a ward to the hospital community centre unaccompanied. Although this trip in the hospital may have a similar function to one in the community the skills required are very different. Few cars travel on the hospital roads and those that do travel slowly and give way to residents. Lack of road skills is a major limiting factor in independence for community residents. The comparison between trips made in the hospital and in the community is complicated by the different value that tends to be put upon segregated and unsegregated trips; the question of how best to approach this problem is discussed in later chapters.

Although there was no significant difference at baseline between

movers and their matched controls in number of trips, baselines of other features of trips were often quite different (for example see table 24). It is possible that the movers and controls already differed at baseline due to selection. The baseline measure was taken after a mover had been identified as a candidate for relocation and in some cases they already lived in one of the satellite houses as part of the rehabilitation process. The pattern of activities of movers in the pre-move measures may have already been affected by their selection. This may explain baseline differences in variables such as maintenance and use of unsegregated facilities which may be encouraged from the rehabilitation facilities. A wide variation in the pattern of activities of different hospital wards has often been reported (e.g. King et al, 1971). This may also affect observed pre- and post-move comparisons. For example Hemming et al (1981) and Conroy et al (1982) found people with mental handicaps who moved to the community from more deprived wards showed greater increases in activities and skills than those moving from less deprived wards.

In addition to the substantive conclusions, a number of methodological points can be made.

The diary method has reasonable validity. That consistency was found between pre- and post-move measures when, for movers, the care staff who filled in the post-move diaries had no knowledge of the earlier records indicates that diaries are reliable. The agreement between the one evening of observation and the diary record for that evening does not indicate systematic over-estimation of number of trips; there is, in fact, some suggestion from agreement with observation that trips recorded in diaries may be a conservative estimate. That consistency in diary

records was found in records of only one week is important. It suggests that this short period may be reasonably representative of an individual's general pattern of activities. This may be because activities generally have a stylized pattern, or it may represent a physical limit on the number of trips that can reasonably be made in a week.

The representativeness of the activities of one week could be further explored using diary completion over a number of weeks and in different seasonal periods. From this could be established the shortest period necessary to obtain consistent data (although the data presented here is quite strong evidence that a week is sufficient), and any seasonal variation. Other features of diary data that could be further explored include the tendency to round times (Young & Wilmott, 1975) and stylized day-to-day activities, both of which may represent either unreliable recording (Juster, 1985) or an underlying regularity in the way people organize their time.

In the present study diaries were completed from Sunday to Saturday, so the possible effect of fatigue may reduce the validity of records made in the last days of the week (Verbrugge, 1980). If analysis by day of week were of interest the starting day of diaries should be randomized so that any fatigue effects are evenly spread. The validity of diaries is often assessed from features of the data such as those mentioned above; for example rounding of times and stylized day to day reports (Juster, 1985). The opportunity to properly study such features exists in health related areas where there is regular contact with clients. Service records (both routine and those kept for research purposes) could be used to validate diaries kept by clients. In addition diary

records could be used to structure interviews; the subjects own evaluation of their activities could then be placed upon diary entries (e.g. Little, 1984).

One disadvantage of the diary method is that data are gathered using staff as informants. A method for gaining data concerning the use of community facilities that is independent of carers is described in the next chapter. However the diaries appear reliable and staff were happy to complete them in spite of the commitment of time they required. This concurs with a review of health diaries (Verbrugge, 1980) that suggests that the length of time a diary is kept does not affect participation or completion rates, which were high in the studies reviewed, which required health diaries to be kept for up to 5 months.

In conclusion it has been shown that the number of trips made during post-move measures, and post-move differences between homes in the numbers of trips made, are well predicted from the number of trips made in the pre-move measures. Although moving out of the hospital has little effect upon the number of trips made from the home the pattern of activities is different; more use is made of unsegregated facilities and a wider range of activities and transport are used. These differences reflect effort on the part of community staff, as less trips are made alone and trips are generally of a greater distance. The findings are generally positive and although there has been some loss of independence in terms of trips made alone this must be balanced against the increase in the use of unsegregated facilities and the associated increased opportunity for social integration.

Chapter Four
Neighbourhood Walk

This chapter describes a further method for studying the use of community facilities by people with mental handicaps. Much of the background to the method has been considered in the previous chapter. However problems of methodology are reiterated here as they are relevant to the method.

It was noted that previous work has largely used survey methodology with carers as informants (e.g. Hill & Bruininks, 1981; Aveno, 1987). However interviews may not be the best method to gain information regarding place use. Their reliability is affected by the period of time over which recall is required, question wording and the perceived context of the interview (Cannell & Kahn, 1968; Schuman & Presser, 1981; Dijkstra et al, 1985). Carers may only be involved with the subjects for part of the day so it may be difficult to decide which carer is the most appropriate as an informant (e.g. Harrison, 1987; Mealor & Richmond, 1980). Information from any one carer may be limited.

There is also a potential problem of systematic bias if carers are used as data sources in evaluation of the services they provide. Bible and Sneed (1976) demonstrated a high level of staff reactivity to accreditation (evaluation) in an American institution. All scheduled programs in the hospital were 'indexed with the Program Co-ordinator' and so it was possible to make discrete observations at the scheduled time and location to establish whether programs were being completed. The number of patient training programs completed on two wards increased from 28.9% and 32.5% of possible program completion at other times to 85.5% and 84.5% on the day of an accreditation visit. Reactivity has been demonstrated in experimental studies (e.g. Rosenthal, 1976; Rosenthal & Rosnow, 1969); however there have been relatively

few demonstrations of reactivity to the evaluation of service delivery as it requires unobtrusive measurement. If methods were generally available that were so unobtrusive as to be able to properly identify reactivity to evaluation then they may be good methods for the evaluation itself; although in practice they may be too cumbersome for routine evaluation and there is widespread and justifiable dislike of covert inspection of this kind. However the possibility of biased report for carers does exist.

Time budgets were used as an alternative to surveys in the work reported in the previous chapter. Their advantage is that details of trips that may not be recalled accurately over longer periods in interviews can be recorded near the time they occur. The comprehensive nature of the data reported in the previous chapter indicates something of the advantage of this method. However when diaries are completed by care staff, they do not offer a solution to the possibility of biased reporting. The problem is especially acute in comparing homes since the reporters are completely confounded with the home.

An alternative to the use of carers as informants is to use the residents themselves. They are able to give information unavailable from others, and their use as respondents establishes that their views are valued (Morrison, 1978; Nathan et al, 1980; Williams & Shoultz, 1982). Methodology in interviewing people with mental handicaps is considered in more detail in chapter 5, in this chapter a different approach is used.

This approach involves direct assessment of the residents' current knowledge of their neighbourhood. For a subject to be able to locate a resource in their neighbourhood implies a minimum level of

contact with it in the past, this has face validity. Methods for assessing knowledge of the environment are found in areas of environmental psychology (e.g. Walmsley, 1988) especially those which involve the collaboration of psychology and geography in study of the use, knowledge, perception and value that people place upon their geographic environment (e.g. Downs & Stea, 1973).

One of the most widely used techniques has been to require the subject to indicate spatial knowledge using representations of the environment (Canter, 1977; Walmsley, 1988); for example using scale models, aerial photographs (e.g. Hart, 1979), large scale maps and maps drawn by the subject (e.g. Mathews, 1984). The advantage of using an analogue representation is that assessment can be carried out quickly. One of the problems with these techniques is that the effective use of each type of representation may require different skills and it may be unclear whether lack of these skills or lack of knowledge of the environment is limiting performance. For example Mathews (1984) found that children could more easily identify features of their local area using aerial photographs than self-drawn maps, however self-drawn maps were more effective when they were asked to identify places on their regular route to school.

One of the best examples of work in this area is by Hart (1979), who identified 4 aspects of environmental behaviour that had generally been approached separately; spatial activity, spatial knowledge, the values and feelings associated with places, and place use. He combined quantitative and qualitative techniques in a detailed study of the experience and use of the geographic environment by young children in a small American town. This study is notable for the degree of information that was gained through

extensive contact with the subjects and for the use of a variety of complementary data collection methods.

Hart approached the four aspects of environmental behaviour as follows:

1. Spatial activity was studied using interviews, geographical 'diaries' which were drawn on acetate over an aerial photograph and informal observation.
2. Spatial knowledge was explored using maps and models drawn and built on large sheets of paper and models built in sand.
3. Values and feelings associated with places were studied using interviews and a technique in which the children took the researcher to their 10 'most special' places. Polaroid photographs of these were taken and sorted into preferred order by the children.
4. Place use was studied using observations from a car of all known places used, and by diaries.

In addition a series of intensive case studies of a number of families was used to illustrate constraints upon the children's behaviour.

Techniques such as these have not been used in relation to people with mental handicaps. In a pilot study Patton (1986) found that the task of drawing a map of a route taken around the local area was too difficult for four men with moderate handicaps. Interestingly the maps produced were not pictorial, but appear to

have been an attempt to produce a plan; however the details of the instructions given are unclear. Further work using alternative methods of accessing environmental knowledge such as aerial photographs or scale models may be interesting.

The technique adopted in this chapter is similar to that used by Hart (1979) in assessing how his subjects valued the places they used. The present method involves asking the subject to take the researcher to certain local facilities. There is little similar work with people with mental handicaps. Atkinson (1985a) reports the piloting of a 'participant-observation' exercise in which 17 people with mental handicaps were to be accompanied 'on selected journeys' and 'observed engaging in community activities'. No results are given in this study although it was reported that subjects were rather unwilling to be accompanied, some contriving to be out when the observer came to start the observations and others trying to 'lose' the observer. It appears that subjects felt stigmatized by being accompanied. In Atkinson's study the data collectors were undergraduates and the mismatch between researcher and subject may have made the subjects more self-conscious. However the possibility of gaining insight into the subjects' use of ordinary facilities was noted although the author's view implied that she thought the method relatively ineffective, and it does not appear to have been pursued further.

The direct assessment of knowledge recognises a distinction between performance and ability. Performance is the way in which skills and opportunities are actually used, and can be measured using diaries and surveys. Ability relates to skills possessed, regardless of whether they are used and may be assessed directly, with a degree of validity not found in indirect methods.

This distinction between ability and performance is seen in adaptive behaviour scales which are widely used in assessment with people with mental handicaps; for example compare Gunzberg's Progress Assessment Charts (Gunzberg, 1977) and the Berewecke Checklists (Jenkins et al, 1983). Many scales sacrifice the sensitivity necessary to identify small changes in an attempt to cover as wide a range of activities in daily living as possible (King et al, 1980). Also as scales generally concern skills in all areas of living they often require considerable contact with the subject for their completion. Because of this many use carers as informants (e.g. Williams, 1982), again introducing the possibility of systematic bias. The approach described here involves intensive study of a small group of skills associated with a basic aspect of the use of community resources. As it is focused on a single set of skills it is possible for researchers to carry out the complete assessment.

GENERAL METHODS

In the method described in this chapter information regarding the use of community facilities is obtained directly from clients, without the use of survey techniques. The method involves assessing the ability of the client to locate each of a number of facilities, independently of care staff, using a 'neighbourhood walk'. The method gives some quantitative data, of a kind that can reasonably be used in comparisons of different homes or programmes, and an opportunity for recording qualitative data concerning aspects of the subjects lives.

The facilities which subjects were required to identify are those for which the nearest instance was located in chapter 2. For convenience these are reproduced in table 27.

Each subject was visited in their home where an initial appraisal was made of their ability. If they were not mobile for physical reasons, or had a severe or profound mental handicap making it obvious that they would not reach any outside facility, then the neighbourhood walk was not attempted. Staff were consulted regarding the proposed task. For any resident for whom there was doubt (either on the part of the staff or on the part of the researcher after meeting the resident) the neighbourhood walk was attempted.

The researcher asked the resident to accompany them on a trip around the neighbourhood. The route taken was influenced by the direction of the main facilities and the direction in which the subjects wished to go. It was often a familiar route. In some cases a particular facility was mentioned by staff or subject and this was made the initial destination. The criterion for a facility to be scored as located required the subject to take the rater to the facility. The task included demonstration of crossing roads, boarding public transport and any other skills necessary for reaching a facility independently. Items on the test list were continually prompted for both when facilities were not visible to the researcher and when they were. Many residents were capable of understanding the task completely and mentioned facilities that were on the list and also some that were not. Records were made by the researcher during the walks using a Philips Pocket Memo tape recorder; the facilities identified were recorded on a standard sheet.

Shop
Hairdresser
Doctor
Dentist
Optician

Public Telephone
Post Box
Post Office
Public Toilet
Police Station
DHSS Office
Polling Station

Pub
Cafe
Cinema
Bingo Hall
Swimming Pool
Sports Centre
Leisure centre/Dance Hall

Bus Stop
Railway Station
Church
Workplace/Day Centre

Table 27: Facilities on the Neighbourhood Walk test list

Following the walk the straight line from the home to each facility was plotted and the distance noted. The route taken and the order in which the facilities were reached was marked on a large scale map. A written account of the trip was made soon after the assessment was completed. This recorded comments made by the subject, their ability in skills such as crossing roads and using public transport, and accounts of contacts made with other people.

This is an entirely new method and nothing is known about its reliability. The neighbourhood walk was therefore completed with a proportion of the movers and controls by two independent raters, so that reliability could be assessed, this part of the study is presented first.

Reliability Study

METHODS

Study environment

There were 11 community homes and 11 hospital wards involved in the reliability study. Nine of the community homes are within the urban areas of Darlington and Middlesbrough; 2 are in more rural areas. The management of the homes is as follows; 4 by Social Services Departments, 3 by private concerns, 1 by a voluntary agency, 1 by a Health Authority. Two are the homes of the people who live independently in houses owned by the local council and a housing association.

Subjects

The subjects consisted of 18 movers (8 men and 10 women) who had been discharged for at least 12 months at the time of the reliability study and their 15 first controls (8 men and 7 women). Their mean age at Easter 1989 was 47.3 years (sd 1 7.6). Their mean duration of stay in the hospital (to discharge for those who moved, otherwise to the mid-point of the period over which discharges took place) was 18.7 years (sd 11.8).

Physical mobility is an important variable in this method. Sensory and motor disabilities were available from the Wessex Scale (Kushlick et al, 1973) as described in chapter 2. Twenty-nine of the reliability group were rated as being able to walk upstairs and elsewhere without help, 1 could walk but not upstairs, 3 could not

walk at all without help. Thirty-one of the subjects had normal sight and 2 had poor sight; 30 had normal hearing, 2 had poor hearing and 1 subject was rated as being deaf or almost deaf. None of the subjects that were taken out on walks in the reliability study were rated as having any of these disabilities.

The reliability data were collected by 3 people: JT, a member of the Hospitaller Order of Saint John of God and an undergraduate at Durham University at the time of the study; CM and DD. The eighteen movers and 15 first controls were seen by JT in the summer of 1987. CM revisited 16 movers and 15 controls between Easter of 1988 and Easter of 1989. The 2 other movers were seen by DD, as they expressed the desire not to be seen by anyone associated with Aycliffe Hospital, where CM was a member of the nursing staff. The data collected by JT and CM were entirely independent. The 2 raters were based in different places and the periods of their work with the project did not overlap. The data for the 2 subjects seen by DD did not have the same degree of independence as DD was closely involved in the work of JT. This is discussed further in the results.

For the movers the median time from leaving the hospital to the first data collection visit of rater 1 (JT) was 1.6 years (SIR 1.4 - 1.7), and to the first data collection visit of rater 2 (CM/DD) was 2.4 years (SIR 2.3 - 2.7). For the full reliability group the visits of rater 1 and rater 2 were 0.8 years apart (median, with SIR 0.7 - 1.0).

RESULTS

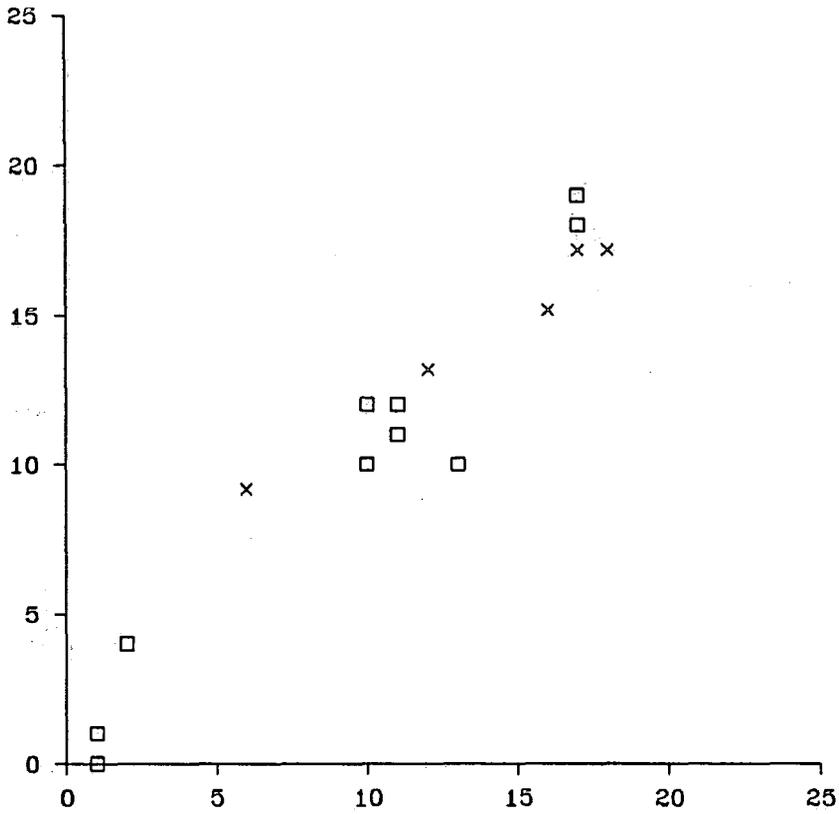
Thirteen out of the 33 people were not taken out by either rater. Of these 11 were movers and 2 were controls. They either did not wish to take part, or had severe physical or mental handicaps. These 13 people included all 8 of the group who had been rated as having some physical or sensory handicap although this handicap was not always the primary reason for not going on the walk. The remaining 5 either did not wish to go on a walk or had severe mental handicaps so that the requests were not understood or such that they were judged not to be capable of completing the task.

Of the 20 people that were taken out by at least one rater there were 5 that were taken out by one but not by the other. Of these 3 were controls and 2 were movers. The 3 controls consisted of one man who dramatically changed in physical ability following a road accident between rating 1 and rating 2; one man who declined to take part in the study with rater 2 (as was his right); and one woman who rater 1 found could identify 2 facilities but who rater 2 did not take out. The 2 movers represent one man who did not wish to take part with rater 2 and one man who rater 1 took out but who could not identify any facilities, and who rater 2 did not take out.

For those people who went out with both raters ($n = 15$) the number of facilities identified with rater 1 is plotted against the number identified with rater 2 in figure 35. Pearson's r for this relationship is 0.97, indicating a high level of agreement in the number of facilities each subject reached with the two different raters. To establish whether the lack of independence of the 2 ratings made by DD and JT had inflated this value the correlation

Facilities
Located

R
A
T
E
R
2



Facilities
Located

RATER 1

Figure 35: Number of facilities located by movers and controls when taken out by rater 1 and when taken out by rater 2

□ = Controls
X = Movers

was calculated a second time without these subjects. These subjects are the 2 highest scoring movers (points 17,17 and 18,17), when they are excluded Pearson's r is 0.96, indicating that they do not disproportionately influence the level of agreement.

It is possible for there to be a high correlation between the number of facilities reached by subjects with rater 1 and rater 2 and also for there to be a systematic difference between them. The median number of facilities reached by the subjects with rater 1 was 11.0 (SIR 6 - 17) and with rater 2 was 12 (SIR 9.0 - 17). This difference was tested using a Wilcoxon matched-pairs test. It was not significant ($Z = -1.1$, ns).

Although not assessed systematically there is also considerable consistency in the qualitative details of the neighbourhood walks. The following are extracts from the raters' records of the walks. The first example is of a 65 year old man with slight physical handicap who lives in a privately run home for 18 people. The walks take place during the summer and are in an urban area.

John then suggested that we have a coffee in the nearby cafe, which we did. His knowledge of the amenity extended to knowing the price of a cup of coffee (15 pence) before we had entered... He took me a few yards back to the cafe which he says he visits regularly 'every Saturday' and indeed staff in the Cafe seemed to know him well, making him welcome and tidying up his clothes before he left.

These observations prove quite consistent. The following is an extract from the account of the second rater of a walk with the same man carried out 10 months later:

John took me over the road to a cafe which was an amusement arcade and coffee shop combined. A couple of the assistants greeted John and asked him how his holiday had been. John introduced me as his friend and we sat down for coffee. He

informed me that this was one of the cheaper cafes and that he and his friend Lawrence (a fellow resident) visited it every Saturday.

Observations were also made in the hospital. The example here is of Tommy who is matched with John. Tommy is in his early sixties and in spite of the matching is physically less disabled than John. Both raters were taken into the hospital administration offices:

Tommy was very definite that he wished to take me to the administration block first. He told me, 'this is where all the gaffers are'. He took me into (consultant psychiatrist)'s office, politely asking his secretary if he was in, which he wasn't. He then knocked on every office door, said hello, and told the occupants that he was showing me round.

He also showed the second rater around the administration block:

On arriving at the rear of the administration building Tommy showed me the telephone kiosk. He then introduced me to a number of the administrative staff, often without bothering to knock on doors. He particularly showed me the cashier's room.

It is very important to this man that he is more able than most of the hospital residents. Many of the facilities that he showed raters were maintenance and staff facilities, illustrating the people and places that he values. The degree of consistency in the reports of the raters appears to be high although in this initial use of the neighbourhood walk there has been no attempt to standardize the qualitative observations made, precluding formal study of reliability. The quantitative aspects of the method described here are reliable. The full data set for movers and controls is now considered, and comparisons are made between the two groups.

Main Study

METHODS

Subjects

All movers and first controls were eligible for this part of the study. Twenty-four movers and 29 controls were seen by CM between Easter of 1988 and July, 1989. Fourteen movers and 4 controls were seen by DD in the same period; one first control had left the hospital and in this case the second control had also previously left. Data are therefore available for 38 movers and 33 first controls.

The reliability study found that those with physical or sensory disability were not taken out on walks, although not only for this reason. Table 28 presents Wessex ratings for movers and first controls involved in the neighbourhood walk. The 3 items shown relate to physical disability and are those that are likely to affect independent mobility: ability to walk without help, vision and hearing. As these items were used in matching, the groups are not significantly different on any of them. Some people have multiple disabilities, and table 28 represents 8 movers and 9 controls who have at least one rated disability. Few subjects with any rated disability were taken out on walks; those that were are commented upon individually.

For movers the median period between discharge and first trip or assessment in connection with the neighbourhood walk was 2.3 years (SIR 1.7 - 2.5). For controls the median period between the middle

	GROUP			
	Movers		First Controls	
	n	%	n	%
Walk by himself				
Not at all	2	5.3	3	9.1
Not upstairs			3	9.1
Elsewhere	36	94.7	27	81.8
Vision				
Blind or almost				
Poor	3	7.9	3	9.9
Normal	35	92.1	30	90.1
Hearing				
Deaf or almost	1	2.6	1	3.0
Poor	3	7.9	1	3.0
Normal	34	89.5	31	93.9

Table 28: Physical Disability Items from Wessex Scale

point of the period over which cases were taken into the study (1 September, 1986) to the first trip or assessment was 2.5 years (SIR 1.8 - 2.7). Using a Mann-Whitney test the difference is not significant ($U = 524.0$, ns).

Exact durations of trips were not recorded and some were quite long (up to 5 hours). Three movers and 1 control required two separate visits, as the subjects had 2 geographically separate areas that they wished to visit, for instance the hospital and the local town, and this could not be done in one day.

RESULTS

Numbers taken out

Eighteen movers (47%) and 25 controls (76%) were taken out on the neighbourhood walk (table 29), this is a significantly smaller proportion of movers ($\chi^2 = 5.96$, $df = 1$, $p > 0.05$).

Of the 19 movers who were not taken out 3 had a severe physical handicap that meant they were not independently mobile, 1 was not taken out because of a heart condition that caused concern to home staff. Of the 8 controls not taken out 4 had a severe physical handicap. The remainder of both groups were not taken out either because they did not wish to be or because they had a severe mental handicap so that they did not understand the instructions or could not use roads independently.

	GROUP				
	Movers		First Controls		
	n	%	n	%	
NEIGHBOURHOOD WALK					
No	20	52.6	8	24.2	*
Yes	18	47.4	25	75.8	

* p > 0.05

Table 29: Number of movers and first controls taken out on a neighbourhood walk

Number of facilities identified

A comparison can be made between those movers and controls who were taken out on the neighbourhood walk. The median number of facilities identified by the 18 movers was 12.5 (SIR 4 - 16) and by the 25 controls was 7 (SIR 1.5 - 12). These data are presented graphically in a box and whisker plot in figure 36. There is a tendency for movers to identify more facilities; however a Mann-Whitney test indicates that the difference is not significant ($U = 168.5$, ns).

Two movers and 4 controls who were recorded as having some physical disability were taken out on a neighbourhood walk. The 2 movers had poor hearing and reached 15 and 16 facilities; both well above the mover group median. Of the four controls one with poor hearing reached 10 facilities, one with poor eyesight reached 2, one who was unable to walk upstairs unaided reached 9 and one with poor eyesight who was also unable to walk upstairs reached 6. Although two of these scores were below the control group median for those who went out on a walk there does not appear to be a marked effect of physical disability on the number of facilities located. Neither the one mover nor the one control who did not reach any facilities when they were taken out were rated as having any physical handicap.

Effect of Environmental Features

Several variables may affect the number of facilities located. Of particular interest are those features of the physical availability of facilities in neighbourhood of the home as described in chapter 2; the median distance to facilities and the circular variance.

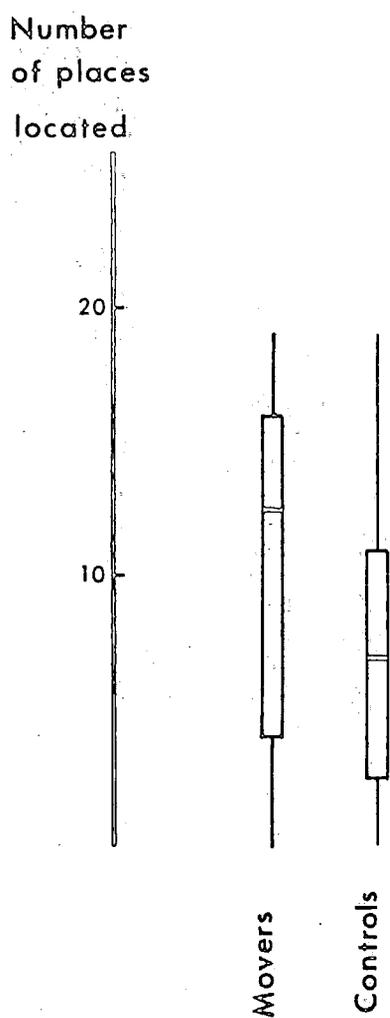


Figure 36: Box and whisker plots of number of facilities located by movers and controls when taken out by rater 2

Two analyses are carried out using these variables:

- (1) Comparisons of the median distance and circular variance for the homes from which movers went out on walks and homes from which movers did not,
- (2) Analysis of the effect of these environmental variables on which facilities are reached by those movers who did go out.

Of 11 homes in which there is more than one mover there are 5 homes from which no movers were taken out (consisting of 14 movers), 5 from which all were taken out (consisting of 13 movers) and only one home from which 2 residents were taken out and 1 was not (this one man was able but did not wish to go out). So homes are virtually totally confounded with the data for subjects. To explore the effect of environmental variables upon whether or not subjects are taken out it is therefore appropriate to take the home as the unit of investigation rather than the subject. The one home from which two men went out on walks but one man did not is not included in this analysis; leaving 18 homes for analysis.

The median distance to facilities for the 8 homes from which people were taken out is 0.50 km (SIR 0.425 - 0.72) and for the 10 homes from which people were not taken out is 0.57 km (SIR .47 - 0.72). Using a Mann-Whitney test this difference is not significant ($U = 34.5$, ns). The median circular variance for the homes from which people were taken out is .26 (SIR 0.21 - 0.28), and for those from which people were not taken out it is .46 (0.30 - 0.62). Using a Mann-Whitney test this difference is significant ($U = 10$, $p > 0.01$). This shows that facilities around homes from which subjects were not taken out vary in direction more than those around homes

from which subjects were taken out. The circular variance and median distance are negatively related (Pearson's r is -0.24). The negative relationship between circular variance and distance is because a group of facilities will tend to have a smaller circular variance around a point the greater is their distance from the point. Although the correlation is relatively small it is possible that an effect for distance may be masked by the larger and opposite effect of circular variance.

This possibility can be investigated with a multiple regression model using whether people went out from the home as the dependent variable and circular variance and median distance to facilities as independent variables. In this case there is a dichotomous dependent variable for which logistic regression is appropriate.

A number of programs will carry out logistic analysis. All give parameter estimates which can be interpreted as regression coefficients and some give estimates of the degree of fit obtained with different models. In the present study the analysis was carried out using GLIM. The program gives parameter estimates with their standard errors and a measure of the change in the fit of the model as each variable is entered into or taken from the model. The measure of fit in GLIM is the 'scaled deviance'. In the logistic model it is hazardous to interpret the scaled deviance associated with a model as an absolute measure of the goodness of fit, however it is possible to treat change in scaled deviance as variables are added to or taken from the model as the likelihood ratio chi-square (Royal Statistical Society, 1987; Aitkin et al, 1989), although this should be interpreted with caution and be used only as a general guide in assessing goodness of fit. Hence the changes in deviance are used to determine the effect of the

addition of variables into the model.

Table 30 shows the changes in deviance and their associated significance for the entry of circular variance and median distance. Values are given for the entry of circular variance at the first step and median distance at the second to establish if circular variance is acting as a suppressor variable on the effect of median distance. It can be seen that after circular variance is taken into account median distance is still not a significant predictor. The parameter estimates for the model with both circular variance and distance are presented in table 31. The parameter estimate for circular variance in the model is around twice its standard error. That both changes in deviance and the relationship of the parameter estimate to its standard error indicate the significance of circular variance in this model suggests that this may be a reliable result, although caution is necessary in view of the very small data set.

Using the data for movers who were taken out on the walk the features of the facilities located on the walk were compared with those that were not located. For each individual a median distance and circular variance was calculated for those facilities located and for those facilities not located. The median of the median distances to those facilities reached by movers was 0.4 km (SIR 0.3 - 0.7) and the median of the median distances to those not reached was 1.4 km (SIR 0.8 - 1.6). This difference was significant; using a Wilcoxon Matched-Pairs test $Z = -3.0$, $p > 0.01$. The median of the circular variance to those facilities reached was 0.25 (SIR 0.15 - 0.31) and the median of the circular variance to the nearest instance of those not reached was 0.30 (SIR 0.23 - 0.37). This difference is also significant ($Z = -2.0$, $p > 0.05$). This shows

Step	Variable	Change In Deviance	DF	Significance
1	Circular Var.	6.73	1	P > 0.01
2	Med. Distance	1.72	1	ns

Table 30: GLIM scaled deviance changes in sequential fitting of circular variance and median distance as independent variables in a logistic regression analysis

Variable	Parameter Estimate	Standard Error
Circular Variance	-11.18	5.1
Median Distance	-2.50	2.2

Table 31: Parameter estimates and standard errors for the model with both circular variance and median distance fitted in a logistic regression analysis

that the facilities reached were closer to the home and less spread out than those not reached, this indicates the importance of accessible facilities.

Finally a multiple regression analysis was carried out using the number of places found as the dependent variable and circular variance and median distance as independent variables. Table 32 presents the results of this analysis. When circular variance is entered first the ratio of the variance explained to that not explained is not significant ($F = 3.07$, $df = 1,16$, ns). When the median distance is entered second the further variance explained is trivial ($F = 0.03$). There no effect for either variable on the number of facilities reached by those movers who went out on a neighbourhood walk.

Qualitative data

The qualitative data available from the rater's reports of 'neighbourhood walks' provide information regarding aspects of the subjects' use and perception of facilities available to them in the community.

Initial reactions to the task varied. Most subjects accepted the request to show the rater around the locality, some thought it a little odd:

I explained to Tommy that I would like him to show me round the hospital and tell me what each department was. He immediately pointed buildings out saying what they were. He questioned why I was asking, 'I am a high grade you know, I know where everything is'.

I asked Sally to show me round the hospital and tell me what the buildings were and what they were used for. She laughed

Step	Variable	Sum of Squares	DF	F Ratio	Signif of F
1	Circular Variance	108.4	1	3.07	ns
2	Median Distance	1.2	1	.03	ns
	Residual	564.3	15		
	Total	673.9	18		

Table 32: Statistics for regression of places located on median distance to facilities and circular variance

and giggled for several minutes. I asked her what was so funny and she said, 'You know what they are Carol'.

Jill was not willing to take me all the way up the drive to the bus stop, she considered that describing where it was should be sufficient.

In most cases, with encouragement, the subject was able to adequately adopt the required role, even at times introducing the researcher as a stranger who was being shown round:

We met a woman with a number of other people with mental handicaps who obviously was known to Jim and who greeted him. Jim explained what he was doing, 'I'm just showing him round Seatown, showing him where the places are, he's not been here before'.

A further methodological difficulty is the tendency of even the most able people with mental handicaps to give control of situations to the rater. Even when the subject does not do this other members of the community may try to do so. A number of observations documented this:

We went across the road to the bus stop and boarded the bus for Oldtown. Donald did this well but whilst I tried to appear not to be with him on boarding and paying the fare the driver turned to me rather than Donald to tell me how much the fare was... The driver assumed that we were going to the terminus and that I was with him and supervising him.

It is difficult for raters not to intervene when it is obvious that the subject is in some difficulty:

A bus arrived and Simon boarded, I followed and asked for Walker Street which the driver informed me was not on his route. I signalled to Simon who by this time was seated on the back of the bus. He immediately got off, and on the bus behind which by chance went to Walker Street. It was obvious he took 'pot luck' with these buses although he knew that he could only use his pass on the cream and blue corporation buses

He took the money from his wallet to pay for the shoes and left it on the seat while he tried the other shoe which the assistant had given him. I pointed this out, he then picked up the money and passed it to me. I prompted him to keep the money and pay for the shoes himself, which he did.

Sometimes the subject did not wish to act independently:

Upon reaching Downhill Road we turned right and walked to where it joins Carlisle Road, here Paul stopped. He did not look at me but was obviously waiting for prompts. We stood while I explained to him that I wanted him to cross by himself, but he would not. Eventually I said it was alright to cross and he followed me. We reached the point opposite the church and again we stopped and waited for each other to lead the way across the road. Paul was quite relaxed, but waited to be told to cross, despite prompting he only crossed when I did.

I asked her to take me to the bus stop, which she did but would not cross the road as she said it was not allowed.

The rater was under instructions to allow the subject to lead the activity but it was difficult to always achieve this, especially when others intervened or when the subject was getting into difficulty. On other occasions it was obvious that subjects had been taught (or had learnt) not to attempt certain activities independently.

The raters' records of the walks offer a rich source of information regarding the subjects use of the local community:

I asked John if he knew the whereabouts of the various facilities on the test list and he seemed quite confident that he did. On Westway Road there were a number of shops and together we walked along the row. He identified the public telephone, the chemists, the pet shop ('where you buy your dog food'), the newsagents ('paper shop'), a supermarket ('food shop'), a small community centre ('a coffee shop'), a public house ('the one my brother takes me to'), a travel agent ('where you go to fly on holiday') and the shop 'where

you book the horses'.

We then walked up to the clinic and Andrew pointed out 11 and 12 Head Lane which he said were "the kids' wards". As we walked back down the drive he pointed out the King's Centre and said "that's where the girls work". Andrew then took me back to the community centre and pointed out the shop which he said he went to with his brother when he visited.

Through noting how facilities are identified information has been gained concerning how they are perceived, their previous use and why some facilities are preferred to others:

We walked down Jamesgate and into Southgate and went for a coffee and doughnut in McDonald's. Jack had previously pointed out a cafe but said he liked to come into McDonald's because it was so clean and the staff were so friendly. Each attendant that served a customer obliged them with 'Have a nice day'.

We decided to go for a coffee, and started towards the cafe that he had just pointed out. Mark seemed a little reluctant and said, 'It's a bit expensive in there'. I explained that I would be paying but he seemed happier when I suggested we try another one. He lead the way to a cafe by the station. Although both were presentable shops the second cafe was self-service (as opposed to service at the table), which may have made him feel more comfortable. It was also the one that he usually went to.

There were occasions when interactions indicated frequent use of facilities:

He lead the way to the newsagents where he bought a birthday card. He was once again known to the staff in the shop, who asked if he was going to buy his 'usual cigar'. The assistant left her cash till and helped John to choose his card.

We returned via the same route but turned into Stampgate where George stood for ten minutes watching men at work on a building site. George stated that he came here every morning along this way and that the men had told him that it was going to be a new shopping centre.

The value that subjects put upon community contacts was obvious.

Paul is a non-verbal man, but is quite able in other ways:

He pointed out the church and the community centre which most residents of Ormsby Square attend on at least some days in the week. Just beyond the church is the vicarage. Paul lead me towards this, into the garden and up to the door, which he knocked. We stood for a while, but there was no reply. Paul wandered around to the side of the house and saw that there was a car there, he came back to the front of the building and knocked on the door again. Again we stood and there was no reply. I suggested to Paul that as there was no one in we move on, he was quite put out that there was no answer but headed on towards the shopping centre.

Observations were made of the subjects' ability to cross roads and use public transport.

The bus arrived and I was impressed with John's independence in boarding as the steps are steep. John showed his pass and said he was going to town... Because of his physical disability John was unable to cross the road as quickly as me. He made good observations before attempting to cross but once on the road carried on regardless hoping the traffic would stop for him. He appeared confident in this.

Bill was very careful when crossing major roads but did not show as much attention when crossing smaller ones. We boarded the bus and Bill showed his pass and I asked him where I should ask for. He replied 'town centre'.

These reports indicate something of the previous use of facilities, and give information regarding subjects' perception of their community. They also indicate (as did the accounts included in the reliability section) that subjects have used facilities enough to know details such as prices, and for staff to know them on friendly terms. The neighbourhood walks also give valid observation of skills for general use of the community.

A final point of interest is that on a number of occasions subjects

performed in ways that staff had not predicted. One elderly man within the hospital was reported by staff as never going out. Although he is obviously quite able and is known to have lived in a hostel in the local town for some time it is difficult to motivate him to do anything. The diary record confirmed this; the baseline and follow-up assessments in 1986 and 1988 both indicate that he made no trips out of the ward at all. However:

I had only gone to the ward to be introduced to Bill and make an appointment for a later date but he went for his coat and wanted to show me straight away.

...he pointed out the community centre, toilets, King's centre and the clinic. He was quite surprised that 5 Head Lane was closed and that H7 had been demolished, an indication that he had not been round the hospital grounds for quite a while.

After being shown around the hospital grounds a second visit was arranged when Bill showed a familiarity with public transport and the facilities of the local town:

When we boarded the bus he did not hesitate in asking for the town centre. When we arrived Bill asked if we should get off, I left the decision to him, he said we had better get off the bus here or we would have to walk further... Bill was very confident and careful when crossing the roads... We arrived back at the ward at 12.30 and he seemed eager to go into town with me every week.

In all this man identified 10 facilities in the hospital grounds and 9 outside of the hospital.

A second example concerns a younger man with Down's Syndrome living in a 6 bed Social Services hostel. The researcher was told that he would probably find the local shop and post office. He initially found the shop but when asked to find the post office was confused by being asked to reach it starting from a place (the shop) where

he would not normally start:

He proceeded along Redcar St and stopped at Palace Road. He again looked puzzled, muttered something I could not understand and pointed to the road. Again he stood and looked in different directions and decided to walk along Palace Road towards the town centre. His pace quickened as if he knew where he was. Steven stopped at the zebra crossing, which was situated just round the corner from his home. I realised that this was what he was looking for at the end of Redcar Street.

After crossing the road Steven located the Post Office. The staff of his home were very pleased that he had succeeded in reorientating himself on approaching it from a different direction. Again ability had been discovered that would not have been reported by care staff.

DISCUSSION

This chapter has reported on a method of discovering the extent of the knowledge of their neighbourhoods of people with mental handicaps. The quantitative aspects of the method are reliable, and contact with the subjects during data collection provides considerable qualitative information concerning their level of integration. The method has value in using the client as a direct informant and requires a similar amount of time to many other data collection methods such as intensive interviewing or structured direct observation.

The results reported here indicate that fewer movers than controls were taken on neighbourhood walks. However for those people who were taken there is no significant difference between the groups in the number of facilities located. Considering the long period of

time that controls have been living at Aycliffe (mean 21.8 years), the relatively short period that movers had been in their homes at the time of assessment (median 2.3 years) and the extra demands associated with use of community facilities compared to those in the hospital (chapter 3) it is encouraging that so many movers went out and appeared well orientated. Half of the movers have had sufficient contact with their local neighbourhood to be able to reach a number of basic facilities independently. Being able to reach the facilities is a first requirement for their use.

Those facilities located by movers were closer to the home and in a more similar direction than those not located. However the median distance and the circular variance from the subject's home of the entire set of facilities were not good predictors of the total number of facilities reached. It is surprising that these features of the environment do not have any effect upon accessibility of facilities; the failure to indicate an effect here may be because most of those taken out were so able as to be unaffected by the slight variation in these variables (e.g. for all but one home the median distance is less than or equal to 1 kilometer). Further differentiation between movers taken out on walks is not possible using the disability measures available in this study.

The finding that the circular variance of facilities was a significant predictor of whether or not movers in a particular home were taken out on walks deserves comment. This has two possible interpretations:

- (1) Homes with a larger circular variance offer less opportunity and so subjects are deemed unable to take a researcher out through lack of practice.

(2) People who are less able to go out independently have been selected into those homes with larger circular variance.

It is not possible to unambiguously decide between these two as there is no baseline data. However a number of points can be made. The selection hypothesis is consistent with the findings in chapter 3 of the importance of baseline scores in predicting post-move mobility for movers. In addition there is little overlap between community homes from which people were taken out and those from which they were not. Of 11 homes in which there is more than one mover there are 5 homes from which no movers were taken out, 5 from which all were taken out and only one home from which some residents were taken out and others were not. On balance it seems likely that the significance of circular variance in predicting whether or not a mover is taken out is due to subject selection into these homes. However this is a somewhat surprising result as the more subtle features of home siting, such as circular variance, are unlikely to have been at the forefront of considerations regarding planning for home development and the placement of residents. Although it is not possible, with the present data, to establish with any certainty the effect of access to resources around the home it appears to be a valuable area to consider in more detail in future work.

The fact that there is a significant difference between mover and control groups in the number of people taken out deserves discussion. The reliability study indicates that inconsistencies in the judgement of whether or not to take a person out were often due to the subject not wishing to take part with one rater or to physical changes in the subject. In general, however, there is

quite good agreement between staff and raters over whether a subject will be able to locate any facilities. It is likely that raters have been making the judgements of whether to attempt the walk on the basis of handicap rather than disability or impairment. Harris (1971) provides a distinction between impairment, disability and handicap. Impairment relates to a physical incapacity that may or may not interfere with activity. If the impairment interferes with an activity then it is a disability. The Wessex ratings of vision and hearing are ratings of impairments; the rating of ability to walk without help is of disability. Handicap reflects the importance of a disability in the life of the subject. Implicit in this definition of handicap is the fact that a disability may be handicapping in one situation but not in another. It appears that in the neighbourhood walk assessment raters and staff implicitly recognise that a person may be handicapped in independent mobility in the demanding environment of the community when people of equal impairment and disability may not be handicapped in independent mobility in the hospital. This indicates a loss of independence for movers, an important finding when considered alongside the results of the diary analysis which also indicated that movers go out less alone.

Less movers than controls are able to go out independently, which means that they are more reliant upon staff, friends and relatives for use of resources within the community. It is important that the situation of these people is monitored closely, to ensure that their lack of independence does not limit their potential social integration.

Although the importance of pre-move abilities has been stressed there is evidence that some movers have acquired basic road safety

skills since leaving the hospital. One mover, a man with Down's Syndrome who has no verbal ability was assessed on the neighbourhood walk as being able to reach two facilities, the local Gateway supermarket and a bus stop en route to this shop. The neighbourhood walk came at the end of 3 years of intensive and structured training, that had taken place nearly every day since this man left the hospital. The task of walking to the supermarket to buy a pint of milk had been broken down into small steps including the most difficult and important skills concerned with crossing the busy road in front of the shop. The achievement of being able to complete this task reflects considerable effort on the part of both the subject and residential staff. Although no baselines are available prior to leaving the hospital an advantage of structured teaching is that a detailed record is kept of assessments and progress, which indicates something of the progress this man has made.

Qualitative data suggests that some of these movers have had sufficient community contact to have established themselves as regular and known users of resources. A problem with surveys and staff completed diaries is that although they give considerable information regarding the pattern of activities, this rarely goes beyond details of physical integration. The neighbourhood walk involves observation of the subject during their contact with the neighbourhood and the qualitative data thus provided has begun to offer information regarding the social integration of people with mental handicaps. Social integration may be further clarified through the use of a framework such as that of Barker and Schoggen (1973) who categorize opportunities for valued participation offered by behavioural settings. They describes 'zones of penetration' indicating the degree to which a 'human component' in

a setting has control of the situation. Zones range from 0 to 6; zones 1 and 2 are onlookers and spectators while people in the higher zones exercise an increasing degree of participation and control. Studies imply that people with mental handicaps generally can be regarded as occupying zone 1; that of an onlooker or peripheral member (Edgerton, 1967; Atkinson, 1985b). Although the lower order zones are necessary components of a setting and being on the periphery of a group is not incompatible with being valued, an aim of community care may be conceptualized as to increase the level at which people with mental handicaps engage in settings that they use.

There are a number of points for consideration in the future use of this method. One is how the judgement of whether the walk should be attempted could be made more objective. It may be more informative to suggest that anybody who is considered unable to go out independently should be observed being taken out by care staff (possibly accompanying on an already planned trip). This would offer opportunities to observe the skills of the subject and make a more accurate judgement as to their ability to be independently mobile in the community. This would also enable some comment as to the characteristics of trips made with staff, and possibly some judgement as to the value of trips to the subject. It is also important to systematically record the raters reason for not taking a subject out.

A problem alluded to in chapter 2 is that it is difficult to make comparisons between facilities identified in the hospital and the 'equivalent' ones in the community. For example the use of the local newsagents in the community and the use of the resident's shop in the hospital may be functionally similar but may not be

comparable in terms of the skills required to reach and use the facilities. Normalization theory suggests that the use of generally valued facilities is important for people who may be viewed as deviant. A number of approaches may be used to make sense of these differences. One is to use 'social validation' techniques in which the normality of situations and performance is judged by reference to the opinions of valued associates or by reference to the behaviour of an appropriate (generally non-handicapped) comparison group. This is of relevance to many judgements made in this thesis and is considered in the final chapter.

However an alternate of ascribing value to facilities is to use the preferences of the subjects themselves. The list of facilities used here was drawn up without reference to the views of the clients, and in the results each facility is given equal weight. The method could be made more pertinent if we knew how people with mental handicaps themselves value each facility. The value given to particular places by children was explored by Hart (1979) who asked them to take him to their 10 'most favourite' places. A polaroid camera was used to take photographs of the places which the children later sorted into preferred order. A similar method could be used here. Otherwise valued places could be identified in an interview or using photographs. They could then be given more weight than those identified which are less valued. This could be done on an individual or group basis, although whether there would be a consensus on valued places is an empirical question, to which we do not as yet have an answer. Whether subjects give greater value to unsegregated facilities would be an important result in making comparisons between functionally similar hospital and community facilities.

The neighbourhood walk could also be used as a means of validation of other forms of data collection. For example the interviews used by Crapps et al (1985) could have been more effectively validated using this technique in place of the unstructured observation method described in their study. Organizational records, time budgets and surveys could all be validated in this way by assuming that subjects should, in general, be able to take the researcher to places that they are reported as using independently. There seems to be a lot of potential in combining a man-power intensive but highly valid technique such as the neighbourhood walk with others that are potentially less valid but which may access the performance of a more comprehensive range of activities.

Tests of achievement can be categorised according to whether they use an absolute (criterion referenced) or relative (norm referenced) standard against which to compare subjects (Glaser, 1963; Kiernan, 1987). The potential reliability of the method could be further improved by reference to techniques used to produce reliable criterion referenced tests (e.g. Kiernan, 1987), to which this method can be likened. The reliability of these are affected by a number of features (Kiernan, 1987; Gunzberg, 1977). Two will be considered here. One is the rigidity of interpretation and application of the criterion. The other is real differences in performance in response to different raters. In the current task different elements of the criteria have been more or less uniformly interpreted. Whether or not to take the subject out resulted in five disagreements out of 18 due both to different interpretations of criteria by raters. Suggestions have been made for improving the consistency of this judgement. The number of facilities independently located by a subject achieved a very high degree of

reliability. Neither criterion interpretations nor reaction to raters causes a great deal of unreliability. Although the criterion regarding various requisite skills (road skills, public transport etc.) could be made more explicit it does appear that the method is robust using the present minimum criterion instructions. This is necessary in a practical method that may be widely used in evaluation research.

The reliability of the qualitative aspects of this method could be assessed further if researchers were asked to comment upon a standard set of features of the task, for example; pedestrian behaviour, road crossing skills, use of public transport and interactions with others. Reliability and validity in qualitative data are discussed by Kirk and Miller (1986). They indicate that inter-rater reliability may not be entirely appropriate in this area as the interaction of the researcher's characteristics with the subjects may produce different but equally valid information. Campbell (1979) suggests that it may be possible to partition the results of two researchers both studying a number of subjects to establish the differences between results due to researchers and those due to subjects. This appears to be analagous to a qualitative analysis of variance. Kirk and Miller (1986) also stress the use of field notes to establish the validity of the researcher's final report. This would also improve reliability by ensuring that the structure of the method has been adhered to.

The methodology of the neighbourhood walk reflects the importance of using people with mental handicaps as informants. The walks take the subjects into their communities, and make the data collected more illuminating as regards the feelings associated with the use of different facilities than do formal interviews.

Ethnographic observations and interviews give a great deal of information concerning the lives of people with mental handicaps (e.g. Edgerton, 1967; Langness & Levine, 1986). However their use on the scale needed for service evaluations require a heavy investment of time from skilled observers. The initial data gathered using the approach described here suggest that a less extensive approach that structures the contact between researcher, subject and environment can provide a considerable amount of good quality data, which has posed some interesting questions regarding the relationship between the use of facilities and their location in respect to the home. Data are collected independently of service providers, are relevant to analysis of quality of life provided, are reasonably reliable and can be summarized in a semi-quantitative way so as to allow comparisons across different types of home.

Chapter Five
Direct Observation

One criticism of institutional care is that it offers an unstimulating environment that encourages passive behaviour (e.g. Goffman, 1961; Clarke & Clarke, 1954; Morris, 1969). In the 1960s enquiries into allegations of ill-treatment in hospitals for people with mental handicaps also highlighted low levels of patient activity (e.g. DHSS, 1969). This chapter is concerned with the level of activity of subjects within their homes and wards.

The reports and studies mentioned above along with other changes in the social and political climate (Scheerenberger, 1987) gave extra impetus to the debate regarding services that people with mental handicaps should receive. 'Better Services for the Mentally Handicapped' (DHSS, 1971) described characteristics of community based residential services. With regard to home based activities people with a mental handicap should be:

...encouraged to do the sort of household jobs people normally do in their own homes. In every way their activities should be as nearly the same as those of people in a normal home environment as their handicap allows. (DHSS, 1971, p 36)

It is made explicit that this should also apply to hospital care (DHSS, 1971, p 39). Similar statements are found in subsequent government publications (e.g. Jay, 1979; Social Services Committee, 1985) and other models of care for people with mental handicaps (e.g. King's Fund, 1980). Both Wolfensberger's influential approach to normalization (Wolfensberger, 1972) and research concerning skill teaching to people with mental handicaps stress the importance of daily engagement in normal household activity.

Normalization has been described as consisting of two 'dimensions of action': the interaction dimension and the interpretation

dimension (Wolfensberger, 1972). The interaction dimension refers to the activities of people with mental handicaps; the interpretation dimension refers to the way in which people with mental handicaps are perceived and depends upon presentation and labelling; the two dimensions are interactive. Activities are important in gaining and maintaining skills, which both affect the way in which people with mental handicaps perceive themselves and the way that they are perceived by others, which in turn affects opportunities to engage in further activity (Wolfensberger & Thomas, 1983).

The value of engaging in activities in normal environments is also noted in consideration of optimum conditions for learning self-help skills relevant to life in the community (Cuvo and Davies, 1983). The introduction of natural reinforcers into a training program for the purpose of maintenance is difficult when environments do not normally provide such reinforcers (Twardosz, 1984). Maintenance will also be difficult when environments do not provide the opportunity to practice a skill (Snell & Browder, 1986). Generalization to natural environments often has to be programmed into training that takes place in artificial situations (e.g. Matson & Earnhart, 1981).

The curriculum of skills that are taught to people with mental handicaps may be established using the 'criterion of ultimate functioning' (Brown et al, 1976). This assumes that skills taught should be relevant to the environment in which the student will eventually live rather than following, for example, a curriculum derived from a developmental model (e.g. Switzky, 1979; Baldwin, 1985). If curricula are developed using 'criteria of ultimate functioning' it may follow that skills will be most effectively

taught in environments similar to those in which they will eventually be used.

Emphasis upon activities and skills is reflected in current definitions of mental handicap which include references to social and self-help skills. The Mental Health Act of 1983 defines mental impairment as:

...significant impairment of intelligence and social functioning (DHSS, 1983; page 3).

The American Association on Mental Deficiency states that:

Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior...(Grossman, 1983, p 11)

There are many rating scales for assessing adaptive behaviour (a generic term for social and self-help skills). A review by Meyers et al (1980) notes that studies have listed up to 132 published scales. These are widely used in teaching skills to people with mental handicaps (e.g. Bruininks et al, 1987). They have also been used in research to identify skills associated with successful community adjustment (e.g. Schalock et al, 1981) and as an outcome measure in evaluation studies (e.g. Hemming et al, 1981; Conroy et al, 1982; Felce et al, 1986b). Their use in research reflects their familiarity to professionals working in mental handicap; the speed and ease with which they can be completed; and the well known psychometric properties of some of the scales (eg. Spreat, 1980; Stack, 1984; Sturmey et al, 1988).

However a number of features of adaptive behaviour scales limit

their effectiveness in research. These include: the limits of information contained in recording just the presence or absence of skills; the common use of carers as informants with the possibility of systematic bias (e.g. Meador & Richmond, 1980); the problems of comparing skills and changes in skills in groups of people with mental handicaps having wide ranges of level of ability; that they record skills in a great number of areas and so may be relatively uninformative about any one area (e.g. King et al, 1980); some scales measure performance of skills and some measure ability which may lead to ambiguity in determining whether skills or opportunity to use them is being assessed; finally most scales assess skills without taking into account the environment in which the person is functioning.

Although direct observation does not record ability it has been used in research to provide dependent variables conceptually similar to those provided by adaptive behaviour scales. This has a number of advantages: data are usually collected directly by the researcher; recording skills performed in the natural environment emphasises the importance of the resources available in the environment; changes that may be too small to be indicated upon some adaptive behaviour scales may be accessed. The methodology is well established, and direct observation is widely used in applied behavioural analysis, and in research relating to people with mental handicaps.

Observational method

Most evaluation studies using direct observation use functional taxonomies of behaviour, these categorize behaviour according its consequence (Hutt & Hutt, 1970; Martin & Bateson, 1986). A few

studies have used qualitative taxonomies (e.g. Whatmore et al, 1975; Bjaanes & Butler, 1974) based upon the evaluation of behaviour (e.g. appropriate/inappropriate). These can be used in conjunction with each other. The alternative to functional and qualitative taxonomies is a morphological taxonomy (Hutt & Hutt, 1970) which categorises behaviour according to its form or structure.

The optimal observation data is continuously recorded and provides instances, times and durations of the activities of interest. The most recent studies (e.g. Felce et al, 1986a) have taken advantage of the availability of portable computers and specially written programs (e.g. Owen, 1986; Marsh, 1988) to make continuous records of complex behaviour. However when this is not possible it may be necessary to sample the observation period. This may be done using interval or momentary sampling techniques.

1. In interval sampling (Repp et al, 1987; Powell et al, 1975; Cone & Foster, 1982) the observation period is sampled by dividing it into equal duration periods which are either continuous or discontinuous. The nominal occurrence of a behaviour is then recorded during each period. This is also referred to as one-zero sampling (Martin & Bateson, 1986; Altmann, 1974). An item of behaviour may be recorded if it starts or finishes in the interval (partial interval sampling), or only if it occurs throughout the whole of the interval (whole interval sampling). Partial interval sampling will systematically over-estimate and whole interval sampling systematically under-estimate the occurrence of behaviours (Powell et al, 1975; Cone & Foster, 1982).

2. Observations may be made at the end of each interval and the behaviour occurring at this point recorded. This is point sampling (Martin & Bateson, 1986) or momentary sampling (Cone & Foster, 1982).

Unless the intervals are very short (e.g. 5 seconds) interval sampling of either type is less accurate than momentary time sampling (Repp et al, 1987). The accuracy of momentary time sampling itself varies with the inter-observation interval (e.g. Powell et al, 1977; Brulle & Repp, 1984) and the duration of the observed behaviour (Harrop & Daniels, 1985). Repp et al (1987) suggest that when using momentary time sampling an inter-observation interval of 30 seconds is adequate for most purposes, although others consider a shorter interval may be necessary (e.g. Harrop & Daniels, 1985). The accuracy of momentary time sampling is increased when results are averaged across groups of subjects; error is especially problematic when data are presented from single observations for single subjects (Mansell, 1985). A number of evaluation studies present individual subject data derived from momentary time samples using large inter-observation intervals (e.g. Mansell et al, 1984).

A number of studies use 'scan sampling' strategies (Martin & Bateson, 1986). This involves sampling the behaviour of each one of a group of subjects in turn. Sampling all the behaviour of one individual over a period is referred to as 'focal sampling'. Scan sampling may be used in evaluation research when the home is the primary unit of evaluation, however it may introduce long inter-observation intervals if results are then presented for individual residents.

Review of Studies

Evaluation of the quality of residential, day care and educational settings has frequently involved observation of levels of purposeful engagement with the environment. Risley and Cataldo (1973) note that this is a criterion upon which educational and residential environments are often intuitively evaluated. They have developed systematic observational procedures; for example the 'MANIFEST Description of Resident Activity' (Cataldo & Risley, 1974) and the Planned Activity Checklist (Risley & Cataldo, 1973), which has been used in evaluation of educational environments for people with mental handicaps (e.g. Porterfield et al, 1980; Quilitch, 1975).

The studies reviewed here are those that compare environments using structured time sampling observation of activities. Others that use less systematic observation procedures (e.g. Evans et al, 1985) or that are primarily descriptive of single environments (e.g. Mansell et al, 1984) are not reviewed. Emphasis is upon British studies as they examine environments likely to be more similar to those in the present study, although a series of American studies by Landesman and her colleagues (Landesman, 1987; Landesman-Dwyer et al, 1978, 1980) are also reviewed as they illustrate an important point better than most British studies.

Observation of engagement in purposeful activity has been widely used as an dependent variable in residential evaluation in Britain by Felce and his colleagues (e.g. Felce et al, 1980b; 1980c; 1985; 1986^a); the influence of Cataldo and Risley's work in this has been acknowledged (Mansell et al, 1982).

The first evaluation studies of residential services to people with mental handicaps carried out by Felce were of the 25 bedded Wessex Region Locally Based Hospital units (LBHUs), described by Felce et al (1977). These studies compared levels of engagement of groups of adults and children living in LBHUs and similar groups in villas of 'traditional mental handicap hospitals' (Felce, et al, 1980a; 1980b). Observations were made at 5 minute intervals between 7.30 and 19.30 using a scan sampling technique. Residents' behaviour was scored as engaged, or not-engaged; if engaged whether contact was with objects or people was recorded. Children in LBHUs were found to be engaged for 40% of the day, compared with 31% in hospital villas; adults were engaged for 48% of the day in the LBHU, and 39% in hospital villas.

Felce et al (1986) studied a group of 6 people with severe mental handicaps who were residents of a small community home and 6 people who were in hospital care and who, during the course of the study, themselves moved into a small home. This second group were observed before and three months after moving. Observations were made from two three hour videos for each subject that started 1.5 hours before the evening meal. Observations were made continuously using a lap-top computer programmed for real-time data entry. The small home residents were engaged for a mean of 51% of the time. The hospital group was engaged for a mean of 23% of the time which increased to 56% of the time when they moved to a small home. The small home residents interacted with staff 17% of the time. The hospital group interacted with staff 1% of the time increasing to 14% when they moved to a small home.

The same video recordings were analysed by Felce et al (1985) to specifically study the effect of increased opportunity due to

environmental enrichment occurring between hospital and community homes. Inventories of the physical resources of the homes were taken and client access to each area was noted. Many items present in the small homes were not available in the institutions. Engagement was recorded in 40 categories each of which was specific to particular items in the home; for example the waste bin had an associated behaviour involving 'depositing' or 'emptying'. Observations were continuous, using the programmed lap-top computer. People living in the small group home were engaged in specific activities for a mean of 37% of the time. Those living in hospitals for 22% of the time, changing to 40% of the time after moving to a small home. Residents of the small home used 34 of the 40 behaviour categories while those in hospital used 19 increasing to 38 after moving to the small house. The authors note:

A third of the time spent by people in the small homes using their material environment was spent engaged with items that were either not present or were inaccessible to people in the institutions (p 345).

This pair of studies are notable as they are the only recent British observational studies to offer baseline data.

Thomas et al (1986) compared levels of engagement of 6 groups of people with severe mental handicaps approximately matched upon age, mobility, continence, speech, self help skills and behaviour disturbance. Two groups of 10 people came from 2 institutions, 2 groups of 10 from 2 LBHUs (25 bedded hostels) and 2 groups of 5 from 2 small group homes (8 beds). Each subject was observed for 12 five minute periods between 8.30 and 18.00 excluding meal times; observations were continuous using a lap-top computer. Engagement was noted for a mean of 2% and 5% of the time in institutions, 6% and 16% in larger hostels and 53% and 27% in small community homes.

Staff-client contact was recorded for a mean of 3% of the time in both institutions, 3% and 2% of the time in large community based hostels and 17% and 10% in small houses. Although the data are interpreted as indicating environmental effects the lack of baseline data makes selection of subjects into the different homes according to factors that affect observed engagement an alternative explanation. Groups were matched on a number of variables; but this may not create entirely equal groups (e.g. Cochran, 1983)

Rawlings (1985a; 1985b) studied 2 groups of people (aged between 18 to 35 years) with severe and profound handicaps who were matched upon severity of handicap. Both groups had 'severe behaviour disorders' (mainly severe stereotypies, self-injury or aggression) and were non-communicative. One group of eleven people lived in 2 social services and 1 voluntary home (having 8, 4 and 12 residents) and the other group of 12 lived in 3 wards (14, 15 and 15 residents) in hospitals for people with mental handicaps. Engagement was recorded using the Client Behaviour Measure (Porterfield et al, 1981) which records engaged, inappropriate, stereotyped and neutral behaviours. Observations used a scan sampling technique with a 30 second inter-observation period. An interval sampling method (10 seconds observation, 20 seconds recording) was used as it was found to be difficult to distinguish stereotyped from engaged behaviours using a momentary strategy. Observations were made over the period of the evening meal. In the wards engagement was observed for a median of 20% of the time and in the community homes for 46% of the time. In the wards contact with staff was observed for a median of 7% of the time and in the community homes this was observed for 13% of the time. Both of these differences were statistically significant. However no baseline data were collected.

American studies have also used direct time-sampled observations of activities in the home. Landesman and her colleagues (Landesman-Dwyer et al, 1978, 1980; Landesman, 1987) developed the 'Home Observation Code', an extensive categorisation of 69 major items of behaviour each being further coded on 6 possible aspects of the behaviour (concerning communication and received assistance). These studies use relatively large populations and try to identify relationships between features of home environments, individual characteristics and observed activity patterns in each home. However some categories in this schedule include both engaged and not-engaged behaviour so it is difficult to make a direct comparison with those British studies that use engagement as a unifying category.

Landesman-Dwyer et al (1980) made observations of 406 (79% moderately handicapped or more able) people with mental handicaps who were resident in 26 of Washington State's group homes. Observations were made between 5.00 am and 2.00 am during one weekend and one week day. Each subject was observed using momentary scan sampling 'at least once every 15 minutes'. An inventory of facilities in and around the home was made and staff were interviewed about individual residents' characteristics. A detailed account of the percentage of time observed in each activity category is presented. Although a baseline activity measure was not available several characteristics of the residents were shown to be associated with activity. People with milder handicaps had less inactivity and more general social behaviour than those with severe handicaps; men engaged in more unstructured activity and women in more academic and self care activities; children engaged in more organized activity and eating and adults

in more household maintenance. This study indicates the effects of the characteristics of residents in different homes upon observed behaviour.

Landesman (1987) presents a longitudinal study involving a move from 40-60 bed dormitory units to 14 bed 'duplexes' on a single site, each duplex having double or single bedrooms. Subjects were 147 people with mental handicaps (67 female, 80 male) with a mean age of 35 years. None had severe medical or behavioural problems, although few were verbal. Observations were made in 3 minute blocks using a 30 second inter-observation interval; 8 observations were made every 2 weeks for 18 months (6 months baseline and 12 months post-move). Although the environments were significantly different (in staffing variables, environmental opportunity and management practices) relatively slight changes in behaviour were noted the major change being an increase in time spent watching television. There was a significant increase in the number of movers who were observed for the first time to engage in household activities and to eat other than at mealtimes.

Five clusters of baseline behavioural profiles were established using factor analysis of pre-move observations, and these were used to determine whether environmental changes would differentially affect people with different characteristics. Landesman found that those who were more handicapped and dependent upon staff for interactions and activity and those who had a high level of 'object related' behaviour (as opposed to those with more general environmental and social activity) showed the biggest increases in activity after the move. Those who were less dependent upon their environments, either because of severe stereotypic behaviour or because they were highly verbal and socially able and hence

initiators of their own activities were less affected by the move.

Landesman (1987) suggests a general rule:

...individuals who initially are more dependent on the immediate, concrete environment are more likely to be affected by external changes than are those whose baseline behavior is less noticeably linked to their surroundings (p 115).

It should be noted that although these moves involved large changes in the environment there were relatively minor changes in behaviour. Landesman's studies indicate the importance of baseline characteristics in analysing behaviour change in relation to environmental change: her findings are of general importance to this thesis and are considered further in the final chapter.

In summary:

1. Different levels of activity between hospital and community homes have been consistently found in British studies (although see Evans et al, 198 , for a study that found no change). Many variables are potentially relevant to this difference. These include; size (Landesman-Dwyer et al, 1980); increased environmental opportunity (Felce et al, 1986^a; Horner, 1980); changes in staff practices (Rawlings, 1986a, 1986b; Porterfield et al, 1980); and changes in budgeting and staffing policy (Felce et al, 1986^a).

Few of the British studies, however, use a longitudinal design with baseline measures before leaving the hospital as well as measures in the new environment. In the British studies reviewed above only two related studies do this (Felce et al, 1985; 1986^a). Most studies make matched comparisons across

settings; these allow an alternative interpretation of differences in terms of differential selection of clients into different homes.

The American studies of Landesman (1987; Landesman-Dwyer et al, 1980) indicate the importance of taking baseline characteristics into account in analysing effects of environmental changes.

2. Observation methodology is time consuming and British studies tend to use small groups of subjects and often present results for individuals (e.g. Felce et al, 1985; 1986^A). Although large differences are noted the use of small groups generally precludes the use of statistical analysis. Some studies are effectively single case designs (e.g. Felce et al, 1986^A). More effective use of multiple baseline techniques could be made although other aspects of single subject design, such as reversal of intervention are not applicable.

Studies such as Landesman (1987) observed 147 people for around 15 hours per person over the course of 18 months and so the data presented can be analysed more extensively. Studies of one or a few homes will not separate effects of variables such as subject and home characteristics.

3. Studies often use scan sampling methods (e.g. Rawlings, 1985a, 1985b; Felce et al, 1980^b). This is often summarized in a way that masks individual variation; for example a home with a reported level of engagement of 40% may represent 4 out of 10 individuals engaged all of the time or each individual engaged for 40% of the time. Scan sampling also has the

effect of increasing the inter-observation interval for each subject which affects the accuracy of observations when data are then presented for individual residents (e.g. Mansell et al, 1984). Scan sampled studies (e.g. Felce et al, 1980a, 1980b) report that the inter-observation period for each individual varies according to how many residents are in the home; results may disproportionately represent those people who do not go out or who are more often found in public situations within the home.

4. British studies often evaluate high profile service provision. Although these services act as models results from them may not generalise to the 'typical' district or region. British studies reviewed here concern people with severe handicaps; this may not represent the typical person with a mental handicap leaving hospitals at present (e.g. Spencer, 1977; Chapter 2).

5. Engagement is a useful classification to retain. Studies have focused on different aspects of engagement; e.g. Mansell et al, (1982) focus on domestic and maintenance activities and Porterfield et al (1981) on recreational activities, additionally the behaviour considered in these categories is slightly different in the two schedules; but the use of a unifying concept such as engagement allows some comparison across studies. The functional nature of engagement and associated activities allows comparison across groups with wide ranging levels of ability. For example engagement in leisure activity by a person with a severe handicap may be morphologically very different to that of someone with a mild handicap although the behaviour is functionally equivalent.

METHOD

The present study uses direct observation to compare the activity of movers and controls in the subjects' wards and homes. A momentary time sample of focal individuals was used.

Observation schedule

The behaviour categories used in this study are based upon two previously published and related measures; the Client Behaviour Measure (Porterfield et al, 1981) and the Activity Measure (Mansell et al, 1982). Both have engagement as a central discriminator.

1. The Client Behaviour Measure (Porterfield et al, 1981) has engaged, inappropriate and neutral categories of behaviour. Engaged behaviours are further coded according to complexity, age appropriateness and whether they involve contact. The engaged categories are similar to those used in the present study and include both leisure and maintenance activities.
2. The Activity Measure (Mansell et al, 1982) has engaged, inappropriate and neutral categories. It also has a code for location and the nature of any interaction. Engaged categories are predominantly of maintenance behaviour. There is only one category of leisure behaviour.

The behaviour categories used in the present study are included as Appendix 7. Categories of engaged and not-engaged behaviour are retained. The schedule has 4 categories of engaged behaviour:

personal activity, domestic activity, active leisure activity, and passive leisure activity; and 3 categories of not-engaged behaviour: stereotypic behaviour (which would include self-injurious behaviour), being a passive recipient of the behaviour of another person (e.g. Rawlings, 1985a, 1985b) and neutral behaviour. As these categories are not logically mutually exclusive (e.g. a person could be engaged in domestic activity and stereotypic behaviour at the same time) their definition makes explicit a hierarchy of scoring precedence (the order in which they are presented above). Making categories mutually exclusive by definition is described by a number of authors (Bindra & Blond, 1958; Mansell et al, 1984) and is often necessary when using a functional taxonomy.

Verbal or non-verbal contact with a person is recorded by noting the category of the person with whom contact is made. Contacts are categorized as with; formal carers, non-handicapped others, service recipients or relatives (from Atkinson, 1986), overlap in these categories is also possible (e.g. simultaneous contact with a service recipient and a carer) so they are also defined to be mutually exclusive.

The location (room, outside area) that each observation occurs is recorded.

Observation Procedure

Observations were carried out on one evening during the week in which the mobility diary was being completed so that the observations would also act as a validity check for the diaries. Evenings were chosen as a time of day when all subjects could be

found in their homes. They are also a time when a range of personal, domestic and leisure activities can be expected.

One hour of momentary time sampling with a 30 second inter-observation interval was completed immediately following the end of the evening meal. A second hour of time sampling was carried out starting as soon after 19.30 as possible. The cue for observation was supplied via an earpiece from a Sony Walkman (WM-R2) tape recorder with a 60 minute tape upon which was recorded a short note at 30 second intervals. The portable cassette recorder is both cheap and flexible (King & Wesson, 1985) and preferable to using a stop watch or other visual cueing which is suggested by Porterfield et al (1981). The cassette recorder is relatively unobtrusive, although on two occasions staff and residents admitted to assuming that the observer was deaf.

Observations were recorded on a standard sheet, a sufficient supply of which were carried in an A4 binder. Each sheet had space for 10 observations, a reminder of the main activity codes and space to enter the 5 figure code that represented each behaviour and its location. There was also space to write the nature of the activity observed. The record sheet is presented in appendix 8.

Reactivity is a potential source of bias in results (e.g. Johnston & Bolstad, 1973), so the observer arrived at the home well before the evening meal to allow some habituation to his presence. The observer tried to take part to a small extent in the activities of the home; it was felt that a complete lack of participation would be both inappropriate and intimidating, and lead to more reaction. This approach concurs with that adopted in studies using the 'Activity Measure' (Mansell et al, 1982). Unstructured

observations were made before and during the meal, between the two time sampled periods and for a short time following the second time sampled period. Unstructured observations particularly over mealtimes were concerned with the management practices of the residence (e.g. King et al, 1971; Raynes et al, 1979). These are considered in conjunction with results from the structured observations in the discussion. The unstructured observations were written-up as part of a report on each evening of observations.

Subjects

All 38 movers and their first controls were considered in this part of the study. After visiting the 2 homes where 3 of the movers lived independently it was clear that direct time-sampled observation would not be possible in these homes. The observer was treated as a guest and the residents could not be persuaded to 'carry on as normal'. In the 1 non-registered private residential home it was also not possible to make observations as the subject was continually interacting with the observer. Implications of this will be discussed later.

There was an initial group of 38 movers eligible for this part of the study. The 3 people who live independently and their controls are excluded, their situation requires different methods. The other case mentioned above, who was living in a private home is also excluded along with his control. Hence data for 34 cases and 30 controls are analysed.

Activity outside of the home

Time sampling was not carried out if the subject left the home as

continued time-sampled observation was considered to be stigmatizing. This was considered less the case by staff in the hospital where facilities are used only by other people with mental handicaps. So this did not produce bias concerning these activities no observations outside of the home in either environment are included in this analysis. These considerations result in a minimal loss of data. If the subject left the home the observer usually accompanied on a participant observation basis.

Activity in bathrooms, toilets and bedrooms

There are differences between how hospital and community facility staff and residents perceive private behaviour (e.g. Mansell et al, 1984; Pratt et al, 1980). For example hospital staff and residents did not always consider it unacceptable for the observer to be present in dormitories whilst residents were undressing. In order that different perceptions of privacy did not lead to a bias in recording of potentially private categories of behaviour all activities in bedrooms and bath/toilet areas were regarded as private.

RESULTS

Observations were made at the same time as the follow-up diaries were being completed for movers and first controls. For movers observations were made a mean of 1.6 years (sd 0.3) after leaving the hospital.

The figures given below of time observed in a particular category are all the medians of the percentage time each individual subject

was observed in that category of behaviour.

Observable behaviour

The median total time subjects spent in the home during the two observation periods was 2.0 hours for both groups. Movers were observable in public activities for a median of 95% (SIR 75% - 100%) and controls for 95% (SIR 72% - 100%) of this time. The median observable period for both groups was therefore 1.9 hours.

Engaged behaviour

For controls a median of 39% (SIR 21% - 67%) and for movers 69% (SIR 48% - 85%) of observed time was spent in engaged behaviour. Using a Mann-whitney test the difference is significant ($U = 336$, $p = 0.019$). This is presented as a box and whisker plot in figure 37. Engaged behaviour is made up of four more specific categories of behaviour which are considered below.

Controls spent a median of 6% (SIR 3% - 13%) and movers 12% (SIR 7% - 17%) of observed time in personal activity. This difference is significant ($U = 353$, $p > 0.05$). In this context personal behaviour is mainly eating and drinking other than during the main evening meal; the higher levels for movers probably represents differences in the organization of meals, which are discussed later.

Controls spent a median of 2% (SIR 0% - 10%) and movers 8% (SIR 3% - 26%) of observed time in domestic activity. This difference is significant ($U = 278$, $p > 0.01$). This difference results from time spent in domestic activities such as washing-up, cleaning, laundry,

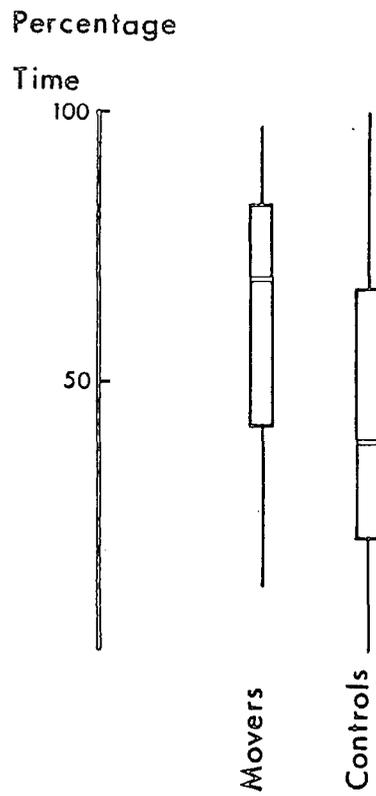


Figure 37: Box and whisker plot of percentage of observed time in general engagement category for movers and controls

and ironing, which are generally not available to residents in the hospital.

Controls spent a median of 0% (SIR 0% - 11%) and movers 1% (SIR 0% - 13%) of observed time in active leisure activities, this difference is not significant ($U = 508$, ns). Controls spent a median of 0% (SIR 0 - 19%) and movers 7% (SIR 2% - 25%) in passive leisure activities. This difference is not significant ($U = 390$, ns). Active leisure activities were rarely observed in either setting. Passive leisure activities consist mainly of watching television, and were observed in both settings.

Although all differences are in favour of the movers only domestic and personal activity are significantly different. These differences may be related to management practices, particularly around mealtimes. The component categories of non-engaged behaviour are not considered separately as 2 of the 3 classes (stereotypic behaviours and recipient of others' behaviour) were rarely observed; time spent not engaged represents mainly neutral behaviour.

Contact

Contact was scored as a variable that occurred both in conjunction with and not in conjunction with other behaviour. For controls a median of 10% (SIR 4% - 16%) and for movers 13% (SIR 7% - 21%) of observed time was spent in contact. This difference is not significant ($U = 389$, ns). Figure 38 presents this data using box and whisker plots.

Controls spent a median of 6% (SIR 1% - 11%) and movers 8% (SIR 5%

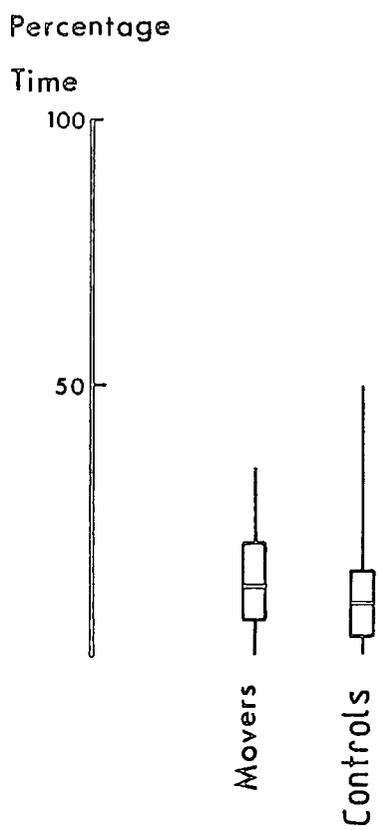


Figure 38: Box and whisker plot of percentage of observed time in general contact category for movers and controls

- 14%) of observed time in contact with a formal carer. The difference is not-significant ($U = 392, ns$). Controls spent a median of 0% (SIR 0 - 4%) and movers 2% (SIR 0% - 5%) of observed time in contact with a fellow service recipient. The difference is not significant ($U = 430, ns$). Results indicate that movers have more contact with both categories of person. No contact with relatives and little with non-handicapped friends was observed for either movers or controls during time sampled observations.

The importance of baseline measures has been stressed both in chapter 3 and in the introduction to the present chapter. Although baseline observations of activity were not available it is known that the mover and control groups differ in their level of disability using the dichotomous measure derived from the National Development Team's categories in chapter 2. In this chapter only 30 first controls have been used to form the control group; of these 15 (50%) are in the National Development Team's Category 1 compared to 29 (85.3%) of the mover group (table 33). This difference is significant ($\chi^2 = 7.67, df = 1, p > 0.01$). Pre-move disability may be expected to contribute to variance in observed levels of post-move activity (e.g. Landesman-Dwyer et al, 1980; Landesman, 1987). Bearing this in mind the comparisons found to be significant above (engagement, personal and domestic activity) are reconsidered in more detail below.

Further analyses can be carried out using percentage of time observed engaged as the dependent variable, and the subject's study group status and level of disability as two dichotomous independent variables. The statistics from a regression analysis of this data are presented in table 34. When level of disability is entered at

	GROUP			
	Movers		Controls	
	n	%	n	%
NDT1				
NDT Category 1	29	85.3	15	50.0 **
NDT Category Other	5	14.7	15	50.0

** p > 0.01

Table 33: National development team category by mover and first control group

Step	Variable	Sum of Squares	DF	F Ratio	Signif of F
1	NDT Category	4627.3	1	6.62	>0.05
2	Status	1574.9	1	2.32	ns
	Residual	29887.5	61		
	Total	36089.7	64		

Table 34: Statistics from regression of general engagement on NDT category and study group status

the first step the ratio of the variance explained to the residual variance is significant ($F = 7.30$, $df = 1,62$, $p < 0.01$). When status is entered second the extra variance explained is not significant ($F = 2.77$, $df = 2,61$, ns).

This analysis demonstrates that although there are differences between movers and controls in percentage of time observed engaged this can be predicted from differences in level of disability established at least 1.6 years previously and before leaving the hospital in the case of the movers.

The distribution of standardized residuals (the difference between the observed scores and the scores predicted from the model) for the engagement variable are sufficiently normal (i.e. mean of 0, sd 1) to allow the use of multiple regression analysis. However the distributions of the other two variables considered here (domestic activity and personal activity) are highly skewed. There are a number of subjects in both groups for whom there was no observed domestic or personal activity and so it is not possible to transform the data to obtain a more normal distribution. To allow analysis the data for domestic and personal activity were each split into two categories about the median of the combined scores of the two groups. Subjects with scores less than or equal to the median were put into one category and those with scores greater than the median were put into the second category. Logit analysis was then carried out on this data using the numbers in these categories as the dependent variable and study group status and level of disability as independent variables. Logit analysis is a variant of loglinear analysis that is used in model fitting with categorical data for which there is a defined dependent variable. It allows the analyst to establish the simplest model that

adequately fits the data by comparing data predicted from a hierarchy of models and the observed data.

The analyses are presented as the contingency table for the data, the models that were fitted and the goodness of fit statistics which summarise how the observed values differ from the values predicted from the model. As there are two independent variables four models are presented in each analysis; a saturated model, which as four variables, a grand mean, an interaction term and the two independent variables, which must fit the observed data exactly; an additive model, which includes both independent variables but without the interaction term; and the two main effect models each of which includes only one of the two independent variables.

Table 35 presents the analysis for personal activities. The simplest model to fit the data requires only study group status as an independent variable. The model using level of disability alone does not predict the observed data satisfactorily (the chi-square value for this model is significant, indicating that the predicted data differs from the observed data). This indicates that pre-move level of disability is not necessary to predict the observed group difference in the personal behaviour category, nor is it sufficient when used alone.

Table 36 presents the analysis for domestic activity. Here either status or level of disability alone adequately predict the observed data. There does not appear to be any means of separating the independent effect of these two, either is a sufficient predictor of the observed data.

Personal Activity

	Less Than Median		Greater Than Median	
	n	%	n	%
Status				
Movers				
NDT Category				
NDT Category 1	11	34.4	18	56.3
NDT Category Other	1	3.1	4	12.5
Controls				
NDT Category				
NDT Category 1	12	37.5	3	9.4
NDT Category Other	8	25.0	7	21.9

MODEL	df	chi-square	significance
Saturated Model			
Personal Activity [PA], PA by Status, PA by NDT Category, PA by Status by NDT Category	0	0.00	1.0
Additive Model			
Personal Activity [PA], PA by Status, PA by NDT Category	1	0.06	0.81
Main Effects Models			
Personal Activity [PA], PA by Status	2	3.09	0.21
Personal Activity [PA], PA by NDT Category	2	9.19	0.01

Table 35: Contingency table of personal activity by NDT category and study group status, with possible models

Domestic Activity

	Less Or Equal To Median		Greater Than Median	
	n	%	n	%
Status				
Movers				
NDT Category				
NDT Category 1	10	31.3	19	59.4
NDT Category Other	2	6.3	3	9.4
Controls				
NDT Category				
NDT Category 1	8	25.0	7	21.9
NDT Category Other	12	37.5	3	9.4

MODEL	df	chi-square	significance
Saturated Model			
Domestic Activity [DA], DA by Status, DA by NDT Category, DA by Status by NDT Category	0	0.00	1.0
Additive Model			
Domestic Activity [DA], DA by Status, DA by NDT Category	1	0.63	0.43
Main Effects Models			
Domestic Activity [DA], DA by Status	2	2.51	0.28
Domestic Activity [DA], DA by NDT Category	2	4.13	0.13

Table 36: Contingency table of domestic activity by NDT category and study group status with possible models

The difference between the groups in general engaged activity is explained by the group differences in level of disability. Study group status is not required. Using a logit analysis personal activity is shown to be solely predicted from study group status, the simplest fitting model does not include the level of disability. Domestic activity is equally well predicted by status or level of disability alone, there does not appear to be any way of separating their effect for this variable.

DISCUSSION

There is more engaged behaviour in the mover group than in the control group. The difference is considerable. The median percentage of observed time spent engaged for movers is twice that of controls. At the levels observed this represents an extra 40 minutes spent in engaged behaviour in two hours.

However further analysis indicates that differences in the level of disability between the groups predicts the observed differences and when these are taken into account they reduce the effect of mover or control group status to a non-significant level. For the two sub-categories of engaged behaviour that also differed significantly between the groups further analysis indicates that status is the best predictor of the data (or at least an equally good predictor as in the case of domestic activity). This is probably because personal and domestic behaviour are particular instances of engagement and are more open to influence by specific management practices and specific environmental opportunities. The more general variable of engagement is not as dependent upon specific environmental opportunities being a combination of 4

categories.

The demonstrated importance of National Development Team category emphasises again the importance of pre-intervention measures. In most British studies groups are taken from existing residences (e.g. Felce et al, 1980; Rawlings, 1985a, 1985b; Thomas, 1986). Although in many studies effort is made to match subject groups this does not always create groups equal on other variables (Cochran, 1983). They are not equal in the present study. In studies where a baseline is not included selection of people with different abilities into different homes cannot generally be ruled out as an alternative explanation of any observed differences between the homes.

In only one British study reviewed here is baseline data offered, and this is for only 6 subjects (Felce et al, 1986a). This study noted considerable increase in observed engagement (23% to 56%). It is hazardous to generalize from one group of 6 people. However it is possible that more severely handicapped people may be more influenced by changes in environments. Landesman (1987) found that people with more severe handicaps who are either dependent upon staff initiated activity or are highly object dependent will show larger changes in behaviour following changes in their environment. Most of the subjects in the present study are in fact amongst the most able and independent of the hospital population and so according to Landesman's findings may be less influenced by changes in environment. It is surprising that so few studies have used designs that include a baseline as the need for this in evaluation studies has been indicated by a number of authors (e.g. Landesman, 1981; Seltzer et al, 1983; Emerson, 1985).

The figures obtained here can be compared with those found in previous British studies of hospital and community settings. Comparison is possible because many studies have used the same types of schedule although care must be taken as definitions of engagement and other categories have been slightly different. The present study finds a median of 35% engagement for hospital controls. Previous British studies have found levels of engagement ranging from 1.8% (Thomas et al, 1986) to 39% (Felce et al, 1980) for people with severe handicaps in hospitals. The present study finds a median of 69% engagement for movers in community facilities. Previous British Studies have found levels of engagement of 6% (Thomas et al, 1986) to 39.2% (Felce et al, 1980) in 25 bedded community homes and 36.7% (Felce et al, 1985) to 56% (Felce et al, 1986) for smaller 8 bedded homes. The levels reported by Thomas et al are low because the observations that she reports do not include meal times. Much of the observed engagement reported in other studies is associated with these periods. The higher figures found in the present study are probably due to the greater ability of the current group compared to that of the subjects in previous British studies, it may also reflect slight differences in the definition of categories. In the present study observations were not made during the main period of the evening meal. It is therefore likely that the figures from the current study represent considerably higher levels of engagement than previously reported in British studies.

There is consistently more of all types of activity in the community homes of the present study, although only the levels of personal and domestic activity were significantly different from those in the wards. Felce et al (1986) reports average levels of time occupied in personal behaviour of 13% in hospital compared 16%

and 20% in two small community homes. Again these figures include mealtimes in the observation period and are higher than the levels observed in the present study (median: 6% control; 12% movers). The use of means in previous British studies as summary statistics may also inflate reported observations. In the present study many people were observed in quite low levels of activity, but the distributions have long tails towards the higher scores.

Although there are differences between the environments experienced by movers and controls (see chapter 2) care must be taken in attributing observed group differences to these. The observed effect of being in the mover group has been shown to be in part due to the lower disability level of this group. However in the categories of personal and domestic behaviour which can be regarded as more environmentally dependent there does appear to be an effect for study group status in addition to that of disability.

Meal times have been seen as important indicators of management practices (King et al, 1971; Raynes et al, 1979; Alaszewski, 1986). In the present study the greater levels of personal activity for movers may represent time spent socializing with tea or coffee after a meal which was observed more often in the community settings. It is possible that this is a result both of staff eating with residents and of the increased flexibility when meals are prepared in the home. In no hospital wards were staff observed eating with residents. In 13 community homes staff were observed eating with residents, 2 homes have no staff and in 4 homes staff were not observed eating with residents (1 Social Service and 3 private homes). In one of the private homes and the one Social Services home staff on an evening shift were observed to eat the same food as the residents but at a different time and in a

different place. There are a number of possible effects of staff eating with residents; there is opportunity to learn appropriate mealtime social skills through modelling, and through the possibility that staff will notice inappropriate behaviour more when they are eating with residents. There is also a reduction in the staff/resident inter-personal distance which is a feature of total institutions (Goffman, 1961).

In the hospital meals come from a central kitchen and are already served on plates. Crockery and left-over food must be taken back to the heated trolleys for collection by porters. This limits flexibility. Some of the satellite houses made imaginative use of what was supplied at breakfast to allow residents to cook in the evening but this was exceptional and in general there was little opportunity for residents to cook meals, serve meals, make choices as to what to have and in what amount, wash up or put cutlery and plates away. It also limits flexibility in planning the day and results in a 'rigidity of routine' which has been identified as a feature of a total institution (Goffman, 1961). Residents of wards for more dependent people tend to be seated at tables waiting for the meals to arrive for long periods (observed for up to 20 minutes). This is one of the features of an institutionally oriented environment according to the Revised Resident Management Practices Scale (Raynes et al, 1979). In the community all homes cooked their own meals. Residents were observed helping in preparation in 11 out of 19. In the other 8 homes evening meals were often taken relatively early (4.00 pm in one home) to fit with the hours worked by catering staff.

The greater engagement in domestic activity by movers than controls represents more time spent washing up and clearing up after meals,

as well as engagement in other activities (laundry and cleaning) not available in the hospital. Felce et al (1986⁴) report a mean of 7% domestic behaviour in hospital compared to 28% and 30% in two small (8 bed) community homes. Much of this behaviour may have been related to meal times as these are considerably higher figures than found in the present study (median: 2% controls; 8% movers). In the present study movers were often observed helping staff in the kitchen preparing meals. It is often part of the operational policy of community homes that residents will be encouraged to be involved in day to day domestic activities (e.g. North Tees District Health Authority, undated; Darlington District Health Authority, 1985). Although a number of Social Services hostels have regulations that limit the access of residents to kitchen areas, and few are involved in cooking more are involved in clearing up and washing-up after meals. In the hospital washing-up returns to the central kitchen and the major domestic tasks involve clearing tables and making drinks. Often these tasks are done by regularly the same resident, usually one of the most able on the ward.

Leisure activity is the mainly passive watching television and listening to the radio. In many hospital wards the television was on continually. But it was rarely watched: attention was more often directed to the activities of staff and residents. Watching television in the community homes was generally a more social activity. The smaller size of the homes and the associated lower noise and general movement makes it easier to watch a television program.

Movers were in contact with staff and residents consistently more than were controls, although the differences were not significant.

Landesman-Dwyer et al (1980) found residents of larger facilities (18 - 20 residents) engaged in 4 to 5% more social behaviour with peers than did those in smaller facilities (6 - 8 residents). Previous British observational studies have demonstrated relatively little contact between people with severe mental handicaps in any setting (Felce et al, 1986; Rawlings, 1985a; 1985b), although the Landesman-Dwyer studies were of more able subjects. The present study finds relatively little contact between subjects.

A number of methodological points can be considered.

The observation schedule proved easy to manage. It would have been possible to collect data using a shorter inter-observation interval (possibly 10 or 15 seconds). This would allow more accurate presentation of individual results (Mansell, 1985). It is possible that, with training, a schedule of the complexity of the present one could be used to record continual data with paper and pen. The increased availability of portable computers and programs for continual recording of observational data may make this unnecessary (Owen, 1986; Marsh, 1988).

There was no opportunity in the present study to determine the reliability of the observations. However the schedule was not complex, complexity having been shown to be related to unreliability (Kazdin, 1977a); and it is similar to others of established reliability that have been used in this type of research. For example Rawlings (1985a, 1985b) used the Client Behaviour Measure (Porterfield et al, 1981) with an interval sampling strategy and reported a Kappa value of 0.86 for observer agreement over client behaviour; Mansell et al (1984) used the Activity Measure (Mansell et al, 1982) and reported a mean level of

observer agreement for engagement of 89%.

The validity of the observations are most seriously threatened by the limited range of situations in which they were made. Observations here were made on one weekday evening; hence variation due to the time of year, time of day or day of the week was not sampled. The possible effect of the time period over which observations take place is illustrated by the variation found in previous studies depending upon the inclusion of mealtimes.

The time consuming nature of observations is a major factor limiting making more and representative observations. Sampling over a wider range of situations but for shorter periods on each occasion could be considered. Walbran and Hille (1988) observed staff-resident interaction and recorded little variation across weekdays and weekends when using 30 minute or 5 minute periods of momentary time sampling with a 15 second inter-observation interval. However this study was conducted in a hospital for people with mental handicaps where features of total institutions (Goffman, 1961) may be expected to cause little variation in patterns of activities across days. Data may not be so uniform in smaller homes in the community. Landesman (1987) made observations every 15 minutes from 6.30 to 9.30 am for two weeks for 14 subjects. She found that 8 three minute observation periods with an inter-observation period of 30 seconds which sampled times of day over two weeks adequately represented all behaviour that was recorded for more than 2% of the time in the larger data set. There are disadvantages in shorter sampling periods, for example they may be less sensitive to infrequent events and reactivity may be a greater problem as habituation is more difficult to achieve.

In most homes the observer's presence was well accepted. The observation visit was generally at least the third in the space of a few weeks and often there had been considerably more contact, so the observer was not a total stranger. The staff were asked on each occasion to comment on the 'typicality' of the subjects behaviour during observation and in only one case did staff express the opinion that the subject behaved somewhat differently to normal (in this case the man in question spent more time in his bedroom). However reactivity was too great in 3 homes to allow structured observation. These were the 2 homes of people living independently and the 1 unregistered private home. One hypothesis is that the size of the home affects how easily the observer will be 'ignored', however in other small homes there were no such problems. An alternative hypothesis is that in these 3 homes the subjects had considerably more choice over how to spend their time. In other homes staff actively directed behaviour, giving cues that the observer was to be largely ignored. This extra independence may tend to be associated with smaller size, and hence may be confounded with study group, causing some interaction of reactivity and group.

It is possible that reactivity does not affect major activities in staffed settings. In many wards and homes staff were aware of the institutional nature of some of their practices; at times they were quite apologetic about them. However this did not stop them being carried out and it is not clear that the observer's presence was having any effect.

In general it appears that observations of this type are an effective method in evaluation of interventions designed to change patterns of activity. However structured observation may be most

suited to aspects of interaction, and detailed aspects of activities such as the use of particular resources (e.g. Walbran & Hille, 1988; Felce et al, 1985). To adequately sample periods of the year, days of week, times of day may require a heavy investment of time. A wider sample of days and times could be gained using detailed time budgets such as have been used in a number of large scale surveys of time use (Chapin, 1974; Szalai, 1972; BBC, 1984). Each data collection would require a relatively short period of time, but gives only an indirect measure. Direct observation could be used over shorter periods to collect reliability data for the time budgets and to observe behaviours, such as interpersonal contact, not recorded in time budgets. This would also provide the direct contact with the homes and residents that is necessary to aid interpretation of quantitative findings.

This chapter reports direct observation used to record differences in activities between control and mover groups. Differences in level of disability between the groups has been shown to explain differences in engagement although the effect of mover or control group status was significant for both personal and domestic activity categories. It was suggested that these are more environmentally dependent behaviours and the opportunities offered to engage in them differ considerably between the environments.

Chapter Six
Interviews with Subjects

The criteria used so far to orient this study of the lives of people living in hospital and community based homes have been derived from local and national policy statements and academic literature. However mention has already been made of the importance of the clients' view in the evaluation of services, and this chapter describes data gathered directly from the subjects regarding their concerns and the lives they lead.

There is increasing interest in involving the 'consumer' in the evaluation and planning of human services (e.g. Kelman, 1976; Morrison, 1978; Shaw, 1984; Martin, 1986). Aspects of services that are important to the consumer may be different from those considered important by the service provider. This is partly underlies the increasing use of quality of life measures as one outcome in medical interventions (e.g. Hollandsworth, 1988). However whether a consumer model is truly appropriate to human service 'industries' is questionable (Gartner, 1977; Creighton, 1977). Consumer behaviour requires opportunities for choice, the availability of information (Creighton, 1977), active information seeking, willingness to make judgements independent of the advice of service providers and cost-sensitive behaviour (Hibbard & Weeks, 1987). These are in 'stark contrast' with the traditional passive patient role (Baldwin, 1985). In fact real choice is rarely available in human services (Creighton, 1977). Hibbard and Weeks (1987) find that even in health care systems that set out to offer the opportunity for people to exhibit consumer behaviour only a small minority will do so.

The professional role implies inequality of power between professional and client (Haug & Lavin, 1981), and is antithetical to the roles involved in a consumer model. Medical quality

assurance techniques, such as audits, generally evaluate services against professionally defined indices of quality (Donabedian, 1966; Baker, 1983; Demlo, 1983). Although there is an increased emphasis upon recipient satisfaction with services (Griffiths, 1988; DHSS, 1989) the competence of lay persons to establish preferred outcomes is not widely accepted.

Even those examples of increasing consumer choice in social services that have influenced recent policy (e.g. Griffiths, 1988) do not make choice directly available to the client. For example Challis and Davies (1980) describe the Kent Community Care Project for elderly people, an innovative feature of which was the 'provision of a decentralised budget to experienced social workers who would take responsibility for the co-ordination and development of care (Challis & Davies, 1980, p 5)'. Although choice of services 'bought' is flexible and closely matched with the needs of the client they are still controlled by the professional. This is not analogous to the choice of a consumer of production industry goods.

Although the direct application of the consumer model may not be appropriate in health care. Methods of involving recipients in the planning and evaluation of services are necessary; models based upon co-operation may be more appropriate than consumer models based upon competition.

Interest in consumer involvement in human services has been paralleled by a movement away from congregate models of care and a concomitant increases in self-determination for people with mental handicaps. This has been due to a number of factors, including:

1. The work of advocate and pressure groups for people with mental handicaps (Jones, 1960; Scheerenberger, 1987). Advocacy groups have supported many of the litigative actions against American institutions for people with mental handicaps (Conroy & Bradley, 1985; Taylor, 1987).
2. The civil rights movements of the 1960s and 1970s which legitimized and structured radical pressure groups (Gartner, 1977).

The political activities of deviant groups have clearly been modelled and shaped by successes and failures of the civil rights movement (Kitsuse, 1980, p 3).

The 1960s and 1970s saw several statements of the rights of people with mental handicaps (Scheerenberger, 1987) and the development of theories of advocacy and normalization (Wolfensberger, 1972, 1980) highlighted the means by which the aims of advocacy and rights movements could be realised.

Passivity and dependency has often been attributed to institutionalization (Goffman, 1961), although there is reason to believe that it may be part of the general socialization of people with mental handicaps (e.g. Zigler & Balla, 1977; Rosen et al, 1974, 1975). Involving people with mental handicaps in service evaluation is especially important as it is part of the process of increasing self-determination. Normalization suggests that the style of service delivery affects the way people in receipt of these services are perceived (Wolfensberger, 1972). Making people with mental handicaps central figures in evaluation of the services they receive presents them as competent people; and presents their views as valued.

The ability of people with mental handicaps to speak for themselves has been established in advocacy groups in the United States and Britain (Williams & Shoultz, 1982; Nirje, 1972). Gaining the views of the service recipient generally involves an interview. There are, however, difficulties in interviewing vulnerable people.

The most widely quoted and influential studies on the interviewing of people with mental handicaps mainly concern the effect of question form on response (e.g. Sigelman et al, 1980^b; 1981a; 1982; Budd et al, 198^l; Shaw and Budd, 1982). These studies use 3 groups of subjects with mental handicaps: institutionalized children (N = 50, mean age = 14 years, mean IQ = 48); children living in the community (N = 57, mean age = 14, mean IQ = 48); and institutionalized adults (N = 42, mean age = 23, mean IQ = 40). Figures below refer to the adult group, which is most relevant to the present study. Some studies were only done with one of the other groups; this will be made clear when they are quoted. The data were collected in two twenty to thirty minute interviews carried out one week apart. Carers were interviewed to establish agreement between respondents. Additional work was carried out with those who were the least responsive in the initial interviews to explore responses of less verbally able people.

The studies establish responsiveness, test-retest reliability and factual agreement with carers for a number of different question forms. The results are summarised below.

1. Responsiveness to yes/no questions was high (80% for all groups). Reliability was also high (85%) but varied according to content; those questions in which positive answers would

endorse socially undesirable statements were least reliable (Sigelman et al, 1981a). Agreement with carers averaged 73%.

Acquiescence was demonstrated by presenting pairs of polar opposite questions in the same interview; 40-50% said yes to both questions (Sigelman et al, 1981b). Polar opposite questions use antonyms to express opposite meanings rather than negation. Question content affected responses; more respondents endorsed the desirable question, 'Are you usually happy?' (95% answering yes) than the less desirable version, 'Are you usually sad?' (46% answering yes). Acquiescence was inversely related to intelligence (Sigelman et al, 1981b).

Acquiescence was tested further in less verbally able respondents (both institutionalized children and adults with a mean IQ of 31). The rate was again high and varied considerably according to content. Forty-eight percent (range 28% - 73%) of questions to which the answer should have been 'no' (e.g. 'Are you Chinese?') were answered with 'yes' (Sigelman et al, 1981a). However the more easily verifiable the question the less acquiescence was found. The levels of acquiescence here are considerably higher than those found in other studies; for example Conroy and Bradley (1985) which is discussed later.

2. Consistency of response to either-or questions was studied using question pairs with reversed response options in counterbalanced order (Sigelman et al, 1981a, 1981c). Responsiveness was high (69%), as was response consistency, with little effect of response position: 13% chose the last option both times, 2% chose the first option both times. The

difference was not statistically significant (Sigelman et al, 1981a). Sigelman et al (1981c) further studied the either-or format offering both pictorial and verbal response options. Questions with pictorial options were responded to at a higher rate than the verbal versions and the response position effect was less marked: 11% chose the last option both times and 14% the first option. Although agreement with an informant was slightly higher for the verbal questions (67%) than the pictorial ones (60%) agreement in the verbal presentation was confounded with position bias, which did not occur in pictorial presentations.

3. Sigelman et al (1981a) found that 3 or 4 option multiple choice questions had low response rates (58%). Higher responses were achieved with the use of pictures as prompts (Sigelman et al, 1982). For children living in the community high agreement with answers from significant others was found (96% agreement for verbal form, 81% for the pictorial forms).
4. Sigelman et al (1982) and Budd et al (1981) studied the use of open-ended questions. Appropriate response averaged 57% (Sigelman et al, 1981a). Questions involved listing activities engaged in and neither the provision of a list of possible activities nor the use of probes improved rates of response. When compared to information from carers this question format is reported as generating higher agreement than the same question in a yes-no format and the same level of agreement as either-or questions.

Most of this work concerns bias arising from question form. Variation due to question content is noted but is given little

attention. That the interview is a social event and influenced by both content and context is widely recognised (e.g. Mischler, 1986; Cannell & Kahn, 1968). A 'stimulus-response' model of the structured interview that assumes the same question will always elicit the same response is generally inappropriate (Cannell & Kahn, 1968; Brenner, 1978). However the extent of the influence of context has been rarely explored in interviews with people with mental handicaps, although there is reason to believe that they may be particularly sensitive to such effects.

Shaw and Budd (1982) studied whether acquiescence stemmed from cognitive limitations or from a 'social desirability' effect. Twenty-four adults with mental handicaps (mean IQ = 49) rated the desirability of 24 behaviours in a workshop situation. They were then asked about the same behaviours in 2 ways; 'Is it against the rules to ___?' and 'Are you allowed to ___?' Subjects were more likely to acquiesce to questions mentioning desirable behaviours and 'naysay' to those mentioning undesirable behaviours regardless of the question form. Shaw and Budd suggest that both cognitive limitations and social desirability have effects; misunderstanding of questions causes a response style to be adopted and social desirability determines the direction of bias. But how they separate these effects is unclear. Social desirability effects are related to low status which is likely to be confounded with lower intelligence.

Shaw and Budd (1982) found that people with a mental handicap are sensitive to question content. That they are also sensitive to the context of an interview or testing situation is powerfully demonstrated by Rosen et al (1974, 1975). Greatly different levels of acquiescence to potentially dangerous requests were reported

depending on whether questions were put by a smartly dressed professional or an (apparent) peer (see also Bedrosian & Prutting, 1978; Owings & Mcmanus, 1980). Zigler and his colleagues demonstrate that people with mental handicaps are very responsive to social reinforcement and hence are especially likely to try to respond in desirable ways (Zigler & Balla, 1977). This problem in interviewing people with mental handicaps has been under emphasised in previous studies of the interview method.

The Problem of Response Bias

Attempts to establish bias involved in interviewing people with a mental handicap have been greatly influenced by the work of Sigelman and her colleagues. Two of her techniques are widely used; referral to carers and inclusion of questions that will identify inconsistent response. However there are problems with both techniques. The use of probes is also considered.

1. Referral to Carers

When referring to carers items with positive connotations (e.g. level of happiness) may lead to a desirability effect on the part of both the carer and the client which is likely to inflate agreement between them (Sigelman, 1981b). Establishing which carer is the most appropriate informant is also a considerable problem. Mealor and Richmond (1980) found that teachers and parents differ in their ratings of adaptive behaviour of children with mental handicaps. This may be due to systematic bias or to true variation in behaviour in the different environments observed.

In an important study Nathan et al (1980) found that people with

mild mental handicaps were more accurate informants about their own and their best friends behaviour on items from the AAMD Adaptive Behavior Scale than were members of care staff when both were validated against direct observations.

2. Response Consistency

Establishing response consistency involves using question form to indicate bias. Two techniques have been used; one involves presenting pairs of mutually contradictory questions, the other involves balancing questions so that an equal number of 'yes' and 'no' responses are required to present a desirable profile.

Questions that adequately demonstrate contradiction are difficult to phrase (Rorer, 1965; Schuman & Presser, 1981). Negation reversals are more completely contradictory than polar reversals (Bentler et al, 1970). In fact many of the stimuli used in studies of people with mental handicaps would be considered inadequate in studies of non-handicapped populations. For example Shaw and Budd (1982) used questions of the form, "Is it against the rules to?" and "Are you allowed to?" to demonstrate 'naysaying'. These may not be contradictory responses, you can be allowed to do something even though it is against the rules, and not allowed to do something that the rules permit. One of the most common 'contradictory question pairs' involves asking if the subject is happy in their current home and whether they would like to be elsewhere (e.g. Heal & Chadsey-Rusch, 1985; Conroy & Bradley, 1985). Again these are not contradictory, you can be happy where you are, but think that you would be even happier elsewhere.

The phrasing of questions so that 'yes' and 'no' responses are

balanced is also a common technique (e.g. Howie et al, 1984). However the construction of question forms to which the positive or desirable answer is 'no' can be difficult. Some questions are very rarely put in forms that require a negative answer and attempts to do so may result in syntactically complex constructions. When questions of this type are presented they may cause some confusion; experimental demonstration of this would be useful.

Contradictory items constructed in either-or forms may be more useful however they are rarely used. Sigelman (1981a) reports response levels to this form equal to those of yes-no questions. An advantage of this question form is that it is easier to construct items that are mutually contradictory if a positional response strategy is being applied.

The use of probes

The use of probes enables bias to be further explored (e.g. Heal & Chadsey-Rusch, 1985; Howie et al, 1984). They may also be more appropriate in interviews that explore satisfaction when global judgements may lose information and may not accurately represent feelings and values (Diener, 1984). For example, satisfaction with residence may not be an easy single judgement, probes for satisfactory and unsatisfactory aspects will be more informative. Probes, however, call for a reasonable level of verbal ability on the part of the respondent.

Previous studies using interviews

Many studies that have used people with mental handicaps as informants confirm Mischler's (1986) view that as interviewing is

regarded as a standard research technique studies do not present accounts of the interview nor describe strategies adopted to reduce bias (see also Atkinson, 1988). This is despite demonstrations that nominally standardized interviews are rarely, in fact, conducted in a standardized manner (Mischler, 1986; Dijkstra et al, 1985). Studies of people with mental handicaps that do discuss response bias often adopt methods of establishing reliability and validity as described by Sigelman. However as they have used interviews in applied settings the effect of content and contextual factors in the responses has sometimes also been recognised.

Applied studies that have used interviews with people with mental handicaps are reviewed here. Emphasis is given to those studies that have contributed to methodological discussion and that have studied client satisfaction rather than using the client as a data source for factual information. Satisfaction is of particular interest here as it is difficult to validate from other data sources.

People with a mental handicap who live independently have often been used as data sources for factual information and satisfaction with areas of life. Even with this more able group precedence is often given to data from other sources such as keyworkers and case notes (Flynn, 1987a, 1987b; Donnegan & Potts, 1988; Atkinson, 1988). For example Flynn (1986, 1987a, 1987b) studied 88 people living independently in the North West of England, 47 of whom had lived independently for 4 or more years. Case records, direct observation of the home environment and information gained from keyworkers were used in conjunction with interviews with the clients. The interview discussed the management of household tasks and the respondents' satisfaction with aspects of their lives, such

as their daily occupations and neighbourhoods. These studies indicated a number of problems with victimization and debt, however 85 of the 88 said they liked living in their current homes better than any previous home although it was noted that the group did not complain as much as the author thought was justified (Flynn, 1987b). Recommendations for interviewing arising from this work include: establishing the communicative skills of the sample beforehand, validating responses with significant others, and introducing questions flexibly according to the context of each interview.

A number of evaluation studies of staffed residential services have used interviews with people with mental handicaps as one of a number of sources of data. These studies often use structured interviews because they are easy to analyse in a multivariate study. They generally report little of the structure and context of the interview and most are concerned with respondent's satisfaction (e.g. McDevitt et al, 1978; Aninger & Bolinsky, 1977). These must be interpreted with caution considering the potential bias in structured interviews. However a number of studies have interviewed people with mental handicaps as a central part of the work, and presented details of the method.

Heal and Chadsey-Rusch (1985) report the 'Lifestyle Satisfaction Scale'. This was standardized on 38 people with mild and moderate mental handicaps and has 29 items in 4 subscales concerning services, community, and friends and free time and general satisfaction. There is a single question on satisfaction with work and a series of 3 paired questions to measure acquiescent response bias. The items measuring acquiescence assume that satisfaction with present state and desire for change will be mutually exclusive; for example the question 'Do you like living here?' is

paired with, 'Would you like to move back to (previous placement)?' Some questions probe for examples to supplement single word responses, in these cases an example is required before the item can be positively scored. The interview uses a regression equation of sub and total scale scores on acquiescence to adjust raw scale scores for acquiescence.

Howie et al (1984) report a 24 item interview for people with a mental handicap based on the Revised Resident Management Practices Scale (Raynes et al, 1979). Verbal and non-verbal response forms were tested, the non-verbal form involved physically indicating the preferred written response! The interview was piloted on 36 people having IQs between 30 and 70, and is balanced so that 12 items require a positive response and 12 require a negative response to represent a 'desirable' answer; probes were used for some questions. The authors report only 50% consistent responding between verbal and non-verbal methods. This was attributed to misunderstanding of complex question forms as the attempt to obtain a balance of positive and negative items results in syntactic structures rarely encountered in normal speech, e.g. 'Do you want to have the staff say when you are allowed to use the radio and T.V.?' The non-verbal task involved indicating a written response which seems to have been, paradoxically, more difficult than the spoken response, as it required reading ability.

The Pennhurst Longitudinal Study (Conroy and Bradley, 1985) included study of the 'consumer satisfaction' of some of the people with mental handicaps who were moved from Pennhurst Hospital in the United States following a court ruling that institutional care was unconstitutional. Subjects were 30 people who moved (level of handicap; 7(23%) mild, 8(28%) moderate, 13(43%) severe, 2(7%)

profound) and a un-matched comparison group of 26 people who remained in the hospital (level of handicap; 5(19%) mild, 7(27%) moderate, 9(35%) severe, 5(19%) profound). Subjects in both groups were selected as having good verbal ability. The interview was conducted once in the hospital and a second time 6 months after leaving, the comparison group was interviewed at the same times. The interview consisted of 12 yes-no, 3 either-or and 4 open-ended questions and 7 multiple choice items with '5 facial drawings (big smile, small smile, neutral, small frown, big frown) (p 125)' as alternative responses; there were 6 pairs of questions as acquiescence checks. Considerably less acquiescence is reported here than by Sigelman. Conroy and Bradley (1985) record 14% acquiescence whilst Sigelman et al (1981a) record 43% acquiescence for an institutionalised adult sample. The lower rates found by Conroy and Bradley are probably due the subjects having been selected for verbal ability. The pictorial responses were reported as having been fairly easy to respond to.

Wyngaarden (1981) discusses experiences gained in interviewing 440 people with a mental handicap (41% mild handicap, 31% moderate handicap, 21% severe handicap, 4% profound handicap), living in a variety of community settings (Gollay et al, 1978). Only 13% were not interviewable, although another 15% had a great deal of trouble with some of the questions (criteria for these classifications are not given). Wyngaarden notes that the process (contacting, confidentiality etc.) of interviewing people with a mental handicap is rarely reported. She recommends using 'simply phrased open-ended questions' and rephrasing the question to obtain the fullest response possible. Easy and non-threatening questions should be asked first. Questions involving wishing and preferring are reported as being difficult as judgements of this nature have

'rarely been asked of many respondents'. It was found to be necessary to reassure respondents that the field staff were not employees from the state institutions, where they had previously been resident.

Flynn and Saleem (1985) interviewed 12 people from an Adult Training Centre (mean age 29 years) who had a 'reasonable level of receptive and expressive language' and lived at home with their parents. The interview covered 11 topics (money, cooking, laundry, shopping, cleaning, home, neighbours, friends, support, interests and the ATC), and used 'simply phrased, open-ended questions', following the advice of Wyngaarden (1981). The 2 areas in relation to which most respondents expressed a desire for change were work and living independently; many respondents wanted to have paid work and most wanted the opportunity to live away from the parental home. In general subjects valued the opportunity to practice independent skills.

Project '74 (1976), interviewed 116 clients of three training centres and their parents and the residents of one hostel for people with a mental handicap (90% mild or moderate handicap) in Wandsworth. The questionnaire consisted of 17 questions concerning feelings about Training Centres and home life and used probes to gain more detail of particular areas. The interview used both open and closed questions. A number of the closed questions appear to have been prone to acquiescence, although differences between parental answers and client answers were accepted as representing different points of view rather than assuming greater validity for either party. Findings from the study include; the value placed upon paid employment; dissatisfaction with current industrial based activities; the limited choice and independence that most

respondents had in basic activities (e.g. bedtime, having their own key to their home, sharing bedrooms, choosing furniture and clothes); and the high proportion who valued more choice and independence.

In summary:

1. Interviews with people with mental handicaps are an important component of evaluation studies. They enable the clients' view of evaluation criteria to be investigated, if this has not been done prior to the study. Including interviews with this client group as part of an evaluation is also part of the process of establishing the valued status of people with mental handicaps.
2. Research has concentrated upon bias due to and controlled by question form. Problems with acquiescence and construction of methods to detect this indicate that structured interviews may not always be the most appropriate interview form. When closed questions are used they should be either-or questions with control for the possibility of a positional response bias. However when possible open questions are preferable.
3. The use of carers as corroborative informants is of doubtful utility. The potential for systematic bias in the use of carers as data sources in evaluation of the services that they provide has already been highlighted. There is evidence that people with mild mental handicaps can be more valid respondents concerning their own activities than are service providers (Nathan, 1980).

4. There is evidence that people with mental handicaps are highly sensitive to the social demands of the interview. Content and context are likely to be just as important as question form and interview structure. However these have received relatively little attention.
5. The use of global questions regarding satisfaction with areas of life may loose information. The use of probes and open ended questions allows answers to be further explored, and may also be used to establish the consistency of the response.
6. The concerns found most commonly in people with mental handicaps include the opportunity for paid work, gaining independence, and the opportunity to engage in activities and practice skills.

METHOD

The interview

The interview was semi-structured and covered 4 main areas; home life, work activities, leisure and friends. Open question forms were used where possible. However closed questions were sometimes unavoidable. When closed questions were used they were often in an either-or format, and when possible were followed up with probes.

Efforts were made to encourage the respondents to consider certain areas, but if the respondent did not show interest in these areas they were not pressed. The areas were selected as relevant to the

aspects of life that had been observed in the other data collection methods used in this study and included the following:

1. The Home Environment. People were asked to give accounts of their daily routine. Probes were simple, e.g. 'And then what do you do?', 'What do you do there?' etc. If not discussed by the respondent then participation in activities such as cooking, shopping, laundry and washing up were mentioned by the interviewer. People were asked to choose the good and the not-so-good points about their current lives.
2. Previous Homes. To create a situation in which judgement of the present situation was in context (Cannell & Kahn, 1968) and to put the demands of the present environment into perspective for both parties previous homes were discussed. A narrative account of daily activities was encouraged for each residence mentioned. Factual detail (ward, names, dates) was encouraged where possible.
3. Vocational and day activity . These were generally discussed in relation to daily routine.
4. Leisure activities. Public houses, social clubs, the community centre at Aycliffe Hospital, hobbies and home based leisure were brought into the conversation by the interviewer if not mentioned by the respondents.
5. Social Networks. Best friends, friends in the environments already mentioned and any others were discussed. Relationships and contact with family were discussed.

The interview encouraged narrative accounts which gives the respondent more control over content (Mishler, 1986). It was considered that people would tell us of things they considered important. However one direct question concerning preference was consistently used. This related to the preferred place of residence, and both reversed either-or forms and follow-up probes were used. When possible the questions were put at least twice at different points in the interview.

The respondent's perception of the interviewer and the context of the interview was not well controlled, and will be considered further in the discussion.

The interview context.

The interview gave the final data collected in this study. In most cases there had been up to 4 previous contacts with the home. In homes where more than one subject was resident there may have been considerably more contact. The interviewer was always known to the respondent.

The interview was generally conducted in private. In many hospital wards this was not easy but it was found that a private interview could be conducted in the corner of a ward.

The purpose of the interview was explained in terms of wanting to know what peoples' lives are like in the places they live. It was stressed that the interviewer was not a member of staff of the hospital or the community homes. When it was considered relevant it was also stressed that the interviewer was not involved in moving people from homes or the hospital.

All interviews were recorded using a high quality portable cassette tape recorder (Sony WM-D6C) and a good quality stereo microphone. All respondents were asked if recording of interviews was acceptable. To assist understanding that the interview had been recorded the tape was played back to those respondents who expressed a desire to hear it.

Interviews were transcribed from the tapes by the author. Simple transcription conventions were followed for marking pauses and statements that were unclear (e.g. Button et al, 1986) but the main interest was in content so non-verbal or para-vocal features of the interviews were not documented. As the interviews are taped more detailed addition to the present transcriptions would be possible in the future.

Analysis

Content analysis is the systematic, objective and theoretically relevant analysis of communication data (Holsti, 1968). It has been widely used, for example, in analysis of propaganda and the media (Krippendorff, 1980; Holsti, 1968).

Units of analysis may vary from the single word to the complete text (Holsti, 1968). Analysis at the level of words and phrases can be carried out by computer using concordance or other analytic programs, but units should be appropriate to the purpose of the study, and the form of the interview used here is such that no one easily identifiable unit would be appropriate. Considerable effort has been made to probe and rephrase questions and so answers are generally not single statements. In interviewing people with

mental handicaps it is particularly important that all references to a subject are considered together as overall consistency of the wrong kind may indicate response bias.

All exchanges relating to the areas of interest were collected in a computer file. The items used as examples in the results are taken from this file, which is available, in full, in appendix 9.

SUBJECTS

All movers and their first controls were eligible for this part of the study. The potential pool of respondents was thus 38 movers and 34 controls. Two movers and 1 control did not wish to be interviewed, and a number of interviews were of limited duration, mainly due to the interviewers inability to keep the subjects interested.

RESULTS

All recordings were considered. For an answer to be considered appropriate it had (1) to be appropriate to the area under discussion, (2) involve a response that consisted of more than one word and (3) generally involve further response to probes. It was considered that making criteria for response inclusion quite stringent would improve the identification of consistent comments, which may be preferable when only using a single analyst. Each interview was searched for comments relating to each area. Interviews from 19 cases and 17 controls contained at least 1 usable comment using the above criteria.

Accounts of daily activities will be considered under four headings; (1) domestic activities, (2) work, (3) leisure, and (4) contact with friends and relatives. Figures quoted in the following analysis represent those interviews that included adequate answers. These figures do not indicate differences between the groups but indicate the number of informants who chose to express themselves about that topic and from how many responses the example quotations are chosen. In these sections responses simply illustrate respondents accounts of their activities. The final section involves analysis of statements of preference concerning place of residence; in this section judgements are made concerning expressed satisfaction and a brief statistical consideration of the group differences is given.

1. Domestic activities

a. Cooking.

Hospital residents receive most meals from a central kitchen and have limited access to those few facilities that are available in wards. Responses from controls indicate that they are aware of these limitations. Five controls reported that they did not do any cooking, 3 reported that they did; 2 of these reported that this was during off ward training activities:

dd: Do you do any cooking yourself normally?

cc: Well . I can't at the moment 'cos the cooker doesn't work, it's got a wire loose.

dd: Oh I see, but when the cooker does work do you do some cooking?

cc: Aye I do meals, we used to do meals, we're going to start doing them again.

dd: ...did you enjoy doing cooking?
pb: Instant whip or sago.
dd: That's nice.
pb: But I'm no good at cooking I don't know how to do it, I don't know the know how.

Aycliffe residents know the hospital routine. They also know the limitations of the system; one concern was the lack of choice in meals:

dd: What time does your tea come along here?
ch: Half past five, won't be here yet it has right up the lodge to go to.
dd: Aye, yes.
ch: With the lads, then it has the girls to go to then when it comes back it has right down the male end to go then it has sixes to go at the top - it's always the same meals over and over.

There is, in fact, some choice. A diet sheet is completed. However it is difficult to make reasonable choices as only a short time is given to complete the sheet and in larger wards consulting each resident would take too long. The sheet is completed some days before the date for which the meals are requested.

Thirteen movers discussed cooking. Seven reported having the opportunity to cook in the home:

dd: ...do you do the cooking here much?
df: Yes.
dd: What sort of things do you cook?
df: Just Saturday.
dd: Just Saturday - You've got a rota haven't you?
df: (nods).

fm: ...make me breakfast.
dd: You make your breakfast?
fm: Aye.
dd: What do you make?
fm: Cornflakes and a cup of tea.
dd: Do you make it for yourself do you?
fm: Aye.

Eight community homes employ catering staff. These are all private and Social Service homes. Six movers reported this:

dd: So then you have your breakfast, do you cook it or does someone else?

ma: No.

dd: Who cooks your breakfast for you?

ma: One of the ladies does, you know, what do you call it, with the glasses.

dd: Is that cooked for you or do you have to do it yourself?

wd: They do it, the toast, in the kitchen.

dd: In the kitchen?

wd: Yes.

dd: Ah.

wd: You've come to see me?

dd: They do?

wd: You've come to see me?

dd: I have yes, do you do any cooking yourself?

wd: No I can't do that I burn, burn, burn me fingers off.

b. Washing up

In the hospital meals come from the kitchen on plates and not much crockery is kept on wards. Washing up of anything that belongs on the ward is part of the job of domestic staff; this was pointed out by 3 controls:

dd: How about washing up, do the washing up much?

eg: No.

dd: No, you don't?

eg: The domestic washes up.

dd: How about the washing up and that, do you have to do that?

ss: I don't do the washing up, there's a woman comes to do that.

In the rehabilitation section of the hospital some washing up may be done by the residents - or possibly not:

pb: Dennis does the washing up, he does it.
dd: Dennis does it, does he?
pb: He usually does it, 'cos he, he's doing all our washing up while we're doing nought, he does it breakfast dinner and tea.
dd: He does it all?
pb: Should do it, but I don't do it, he washes up.
dd: Would you like to wash up?
pb: We've been getting into trouble, all of us like, for not helping to do the washing up, some they won't do nothing.

dd: What do you do when you're not working?
jm: Wash the dishes, again, get the cups out for the breaks on a morning, wash the dishes then put the mop on, I should say on a morning, then the staff trays there, I take into the kitchen and wash their dishes for them - then sometimes Paul Derwent doesn't come in to dry the dishes so I dry them for him and put...

Ten movers talked of washing up. Three that claimed not to do it reported that it was done by other residents. Catering and domestic staff in Social Services and private homes generally finish work around 5 pm and often washing up from the evening meal is then done by residents and care staff.

dd: ...do you do the washing up?
jp: Not always.
dd: Not always - do you like washing up?
jp: No, not really, it has to be done though.

dd: ...do you do the washing up or does someone else do the washing up?
fm: Oh someone else goes and does it.
dd: Someone else does it, who does it usually?
fm: James Prize (resident)

dd: Do you have to do the washing up sometimes?
ik: Washed up this morning.
dd: Eh?
ik: Did it all.

c. Laundry

In the hospital laundry goes to a central facility. Five controls

reported not doing laundry: 4 mentioned that it was done centrally;

2 pointed out some of the possible inconveniences of this:

dd: How about washing your clothes do you do that?

wo: No, there's no washer here.

dd: There's no washer here?

wo: Aye - they get mixed up your clothes.

dd: Yes?

wo: Why aye.

dd: How come?

wo: Cos the lad there talks on the telephone, he's not careful.

cc: I got some trousers from there as well (a shop in Darlington), blue ones and grey ones, the blue ones at the laundry, they been there four months, four months they been there, they ain't come back yet.

dd: Shouldn't take them that long to wash them should it?

cc: That laundry does, it does for Bishop Auckland, here, Earls House, Winterton.

dd: Really it does all of the laundry does it?

cc: It does all of the laundry...

Staff concurred with this view of the laundry service. In some cases the residents 'best clothes' are not sent to the central facility but are washed by hand or in one of the washing machines available on a few wards. Residents appear to be involved in this only rarely.

Most movers had little experience with laundry at Aycliffe and their memories prior to institutionalization often did not include use of automatic washing machines and electric irons. Many movers must have learnt new skills. Seven people reported doing laundry.

The first quotation is from a man living independently:

dd: Have you got a washing machine here?

pb: Yes I've got one second hand, I've got to get another one.

dd: What's wrong with the one that you've got?

pb: Conks out sometimes.

dd: How about clothes, washing your clothes do you do that?
jp: Yes, I wash the clothes.
dd: You wash your clothes?
jp: Iron them and that.

In some Private and Social Services homes laundry is not done by residents:

dd: ...do you have to wash the clothes?
tc: No that's all done for us.

d. Shopping

The opportunity to go shopping was discussed. Shopping for basic provisions is not necessary in the hospital setting, but 5 controls reported shopping. The nearest shop to the hospital is the newsagents in School Aycliffe, although by July 1989 this had closed, early in the study residents went to this shop, often on errands for staff:

dd: ...do you do any shopping?
pb: No I go out to the shops for (nurse) when she wants anything, you know, she lets me keep the change, bits and pieces, that's about it I think.

However, as the result of a serious road accident involving one of the residents, this was stopped:

dd: ...do you ever go to the shop at the top there?
wo: No, lad got killed
dd: Eh?
wo: A lad got killed there.
dd: He did didn't he, I heard about that.
wo: Aye (name).

Although it is some distance to the nearest town some controls report shopping there, often for clothing:

dd: Where do you buy all your clothes?
mw: Newton Aycliffe, Darlington or Durham, Newcastle.

In the community 11 movers reported shopping, for a wide range of goods:

dd: ...do you go shopping from here much?
tc: Just for meself.
dd: Just for yourself?
tc: My paper, Evening Gazette and that and fruit, apples and oranges and that.
dd: You don't go out shopping for other things, is that all bought for you?
tc: No, all done for us.

dd: Where do you go shopping?
sg: Fine Fare.
dd: Fine Fare?
sg: Yes.
dd: You go down there by yourself?
sg: And Eileen.
dd: With Eileen?
sg: With Eileen and Paula sometimes.

dd: How about shopping do you go shopping
jp: Yes.
dd: What sort of thing do you go shopping for?
jp: Clothes and that.
dd: Where do you go clothes shopping?
jp: To the clothes shop.

dd: Where do you go shopping?
df: Saltburn.
dd: What sort of things do you buy when you go shopping?
df: Records.
dd: You buy records?
df: Tapes.

In summary more movers report some domestic activity. There is also more variation in the activities reported by movers compared to controls. Factual information is reported. This may be used to validate the interviews by comparing it with data from direct observation or from techniques similar to those described in the

neighbourhood walk.

2. Work

Work is of central importance to a normal lifestyle (King's Fund, 1984). However, as reported in chapter 3 it is the area in which movers make the least use of integrated facilities.

Six controls reported work. Some of the hospital activity centres undertake contract work:

dd: What sort of things do you do during the day?

og: I just do contract now.

dd: Contract work?

og: Yes.

dd: What sort of thing is that?

og: Christmas tags, you put, you put five in a little plastic bag, about that big, I've got to check them to make sure they're all there.

...

dd: What do you think about that sort of work?

og: Alright.

dd: Do you like it?

og: Mmm.

dd: Which do you prefer, is it better doing this or was it better doing, was it better in the canteen?

og: Well its better doing the contract.

dd: It is?

og: Well I mean I never got a rest in the cafe.

Some controls report little interest in the activities of work placements:

mw: I go every day.

dd: Where to?

mw: Kl's lower.

dd: Kl's lower, I know it, what is it that you do there?

mw: Eh?

dd: What sort of things do you do there?

mw: Just ordinary things, I don't do anything.

dd: You don't do anything?

mw: No.

Others express satisfaction with work placements:

pb: I go to the Kings's Centre and I do woodwork.
dd: You go to the King's Centre?
pb: Monday to Friday.
dd: On a Monday to Friday?
pb: Cos we don't do anything on a Friday afternoon just watch television.
dd: Yes?
pb: Yes.
dd: Do you like going to the King's Centre?
pb: Yes.
...
dd: ...can you think of something else that you'd rather do for work then?
pb: I asked Alice she says, what would you like to do, I said woodwork, cos that's a good hobby that I had.

In British and American hospitals for people with mental handicaps the most able residents used to perform tasks that helped in their day-to-day running. (Edgerton, 1967; Ryan & Thomas, 1987). Many movers and controls could remember working in the gardens, in the laundry or in the sewing room. There are still some hospital residents who do tasks of this type. Two controls reported making beds:

ss: Make beds in the morning like, that one there and that one there.
dd: Yes?
ss: Make beds in the morning, I go up there and make beds in the morning and this one here and go straight to work in the afternoon.
dd: What work do you do in the afternoon.
...
ss: Depends on what Dougie gets to do, I sometimes run messages you know.
dd: Oh, you run messages?
ss: Aye, I run messages.
...
ss: Aye boy, well I go in like and I asks her and I helps the jobs she says like, go a message for me, Johny, go up the shop, so I go up, I say right, I don't need money for going, I give her money back you see.

Some of the most able residents on a ward may help with the care of their less able peers:

dd: ...what's the things that you do around the house?
og: Well I have a bath and I tidy the washing and that.
dd: Do you help out with the other people?
og: I've just bathed Nelly Palmer.
dd: You bathed her?
og: Yes, before tea, before I went to the shop for Liz.
dd: You give the staff a hand eh?
og: I don't mind.

In the community 13 people discussed work, 2 reported not working. Movers often attend Adult Training Centres, some of which, although segregated, adopt the educative and networking roles suggested in recent government publications (M.D.T, 1977; Social Services Committee, 1985). However some activities described at the Adult Training Centres appear to be little different from those at the hospital training centres. In general people were satisfied with these activities:

dd: What sort of work do you do at Black House?
ec: (incomprehensible)
dd: What?
ec: Cards.
dd: Cards?
ec: Yes.
dd: What do you do with cards?
ec: Put string through them David.
dd: Put string through them?
ec: Yes.
dd: Oh I know, do you do anything else there?
ec: No.
dd: Do you enjoy doing that?
ec: Yes.

Not everyone liked these centres:

dd: ...is there anything that you don't like?
ik: Hmm, the centres horrible.
dd: What is?
ik: The centre gets on your nerves.
dd: The sound is?
ik: The centre.
dd: The centre, which centre is that?
ik: Haldon Road.
dd: Is that where you work?
ik: Mmm

dd: What's it called, the centre?
ik: Haldon Road.
dd: Haldon Road.
ik: Mmm.
dd: What's bad about it, what don't you like about it?
ik: Don't like the centre now.
...
dd: What do you do at the handicraft centre (Haldon Road)?
ik: Catalogues.
dd: Catalogues?
ik: Yes.
dd: What do you do with them?
ik: Look at them.
dd: Look at them?
ik: Mmm.
dd: Do you do anything else?
ik: No.
dd: No, nothing at all, is that good or bad, the handicraft centre?
ik: Its too noisy.
dd: Its too noisy?
ik: Mmm.
dd: Would you rather go somewhere else?
ik: Yes.
dd: Where else would you rather go?
ik: Don't know.

Looking at (and occasionally cutting up) old mail-order catalogues is an aimless activity that is often seen in institutions for people with mental handicaps.

Some movers have more varied work, this was often in more innovative, although still largely segregated, environments which differ quite considerably from traditional ATCs. They are often alternatives established through the efforts of residential staff:

df: Starting me new job in a months time.
dd: In a month, what are you going to do?
df: Gardening.
dd: You're going to do gardening?
df: And bricklaying.
dd: Really, you look pleased about that.
df: Yes.
dd: Yes, is it going to be better than your old job or worse do you think, better than your old job or worse?
df: Me new job.
dd: Your new job?
df: Better

tc: It's first a course, I finish at four o'clock Monday and then

the other three days I'll finish at five.
dd: So it's a long day isn't it?
tc: Yes.
dd: What sort of thing will you be doing?
tc: Cooking.
dd: Cooking?
tc: And waiting on.
dd: Waiting?
tc: Yes.
dd: Do you have to wear a bow tie?
tc: (laughs) no, just a badge.

The impression gained is that for a number of movers work is more varied than it is for controls. Although most express a moderate level of satisfaction with work, respondents express extra interest in more varied activities.

3. Leisure

The main site of leisure activity outside the wards in the hospital is the 'Community Centre', where leisure activities are held most evenings and at weekends. Six controls talked of leisure activity outside of the ward and all mentioned the Community Centre; the church services mentioned below are held in the centre as well:

dd: Do you go out much June?
jm: Just to church and to the bingo and Communion on a Tuesday.
dd: When do you go to the bingo.
jm: On a, on a Sunday night and a Thursday night.
dd: What do you win at the bingo?
jm: I won a bottle of conditioner, a small bottle and that once...

There is little weekly variation in the activities of the community centre.

dd: Tell me some of the things that you do here when you're not working, do you go out much?
pb: No.
dd: No?
pb: Aye, discos sometimes, disco for half an hour, there's one this afternoon, video tomorrow afternoon with television, watching videos down the community centre, disco on a Saturday night,

Monday night video, on a Tuesday night bingo, on Wednesday Gateway Wednesday, bingo Thursday, Bullseye on a Friday, that's tonight Bullseye.

Two controls report using public houses. Both lived in satellite houses:

dd: ...do you go to the pub much?
og: With Anne, I've got a new drink.
dd: What's that?
og: Its yellow stuff, I don't know what they call it, but you put lemonade in it an it goes like -
dd: Very fizzy?
og: No like, oh I can't - like liquid paraffin, not liquid paraffin, like methylated spirits, medicine, its like that, I can't really think what it is.

ic: ...I do go with June and that.
dd: Yes, and what do you do when you go out?
ic: A walk, a walk out.
...
dd: Do you go to the pubs?
ic: Yes I do.
dd: What do you do when you go to the pub?
ic: Have a drink at pub.
dd: What do you have to drink?
ic: Pop.

Eleven movers mentioned leisure activity outside the home; 7 of these described segregated social clubs for people with mental handicaps, an example of which is the Gateway Club run by MENCAP:

dd: Who do you go with to the Gateway club?
wd: Er, Joyce, Joyce, works in there, he takes you to the club.
dd: He takes you to the club does he?
wd: Aye.
dd: You go to the Gateway Club a couple of times a week don't you?
wd: Yes.
dd: Do you like it there?
wd: Like it there yes.
dd: What sort of things do you do?
wd: Play, play dominoes.
dd: Yes?
wd: Darts, there's everything there.

A number of other activities used unsegregated facilities. Movers

talked of adult education, one man discussed his camera club which is attended with other non-handicapped people, one man regularly attends a folk club at the local art centre. The most commonly mentioned alternative to segregated social clubs was the public house:

dd: ...do you go out much?
hl: I go out much.
dd: You do, where do you go?
hl: The park.
dd: You go to the park, what do you do at the park?
hl: Feed the ducks.
dd: You feed the ducks, you go to feed the ducks, anything else that you do at the park?
hl: I just look at the boats.
dd: Anywhere else that you go out to?
hl: I'm going out tonight.
dd: Where are you going?
hl: For a half.
dd: For a half, which pub are you going to?
hl: Down there...

dd: ...do you go to the Gateway?
sg: Yes and I go to the Gateway Club - not now (meaning not tonight).

...
dd: What else, you go to the folk club don't you?
sg: Yes I went last night.
dd: Did you, what was on, was there somebody singing there last night?
sg: Yes a lady singing last night.
dd: A lady singing, was she good?
sg: Yes, with a guitar.

...
dd: What other places do you go, do you go to the pub much?
sg: Yes I go to the pub much.
dd: Which pub do you go to?
sg: Spinning Jenny sometimes.

Considering that people with mental handicaps have been labelled a 'new leisure class' (Jeffree & Cheseldine, 1982) there is relatively little variation in the activities reported by either group. Leisure activities in the hospital are based in the segregated community centre. In the community many movers also use segregated facilities although some report unsegregated activities. Staff report that a number of movers have decided that they do not

wish to use segregated social clubs.

4. Friends and relatives

a. Friends

Scheerenberger & Felsenthal (1977) interviewed 75 residents of community homes in America and found that 80% reported having a 'special friend'. McConkey et al (1983) found that only 42% of 167 adults attending Adult Training Centres in Dublin who lived with their parents ever went into town with a friend. Hill and Bruininks (1981) reported that 70% of special friends of people in an institution were staff. Qualitative aspects of the relationships between people with mental handicaps and their friends and relatives have been documented (e.g. Edgerton, 1967; Flynn, 1987b).

In the hospital 9 controls talked about friends; 5 claimed to have no special friends:

dd: What about friends here do you have friends here?
pb: No, stick to meself.
dd: Stick to yourself - do you like to have friends here?
pb: I talk to the lads, these here, I ask them if they're alright and that.
dd: Yes.
pb: They push you about, tell you to buzz off and that you know
dd: So you don't have many friends here?
pb: Not really, I just say hello to them.
dd: Would you like to have more friends?
pb: No, I don't know, I ain't a person for them.

dd: ...who is your best friend here do you reckon?
ss: Well everybody's me friend here.
dd: Everybody?
ss: Yes.
dd: Have you got any special friends in the hospital?
ss: Oh, I got no special friends.

Two people reported best friends who were residents:

dd: Do you have friends here?

jm: Well Alice Cales, that girl that's just gone out, she's a friend sometimes, but sometimes she nags on but I take no notice of her.

Two reported best friends who were staff:

dd: ...do you have any friends here?

cc: Aye, I got three.

dd: You got three, who's your best friend?

cc: Mary (name) over the centre, Edith, Arthur.

dd: Is Mary a staff?

cc: Staff, she works at the centre she does, and Edith works at the centre she does, one of the wards she's got, at the female end, F6 she's got, when she was there for 5 weeks I used to make all her beds for I did.

Landesman-Dwyer et al (1980) suggest that residents of larger homes (18-20 beds) may have more opportunity for friendships with fellow residents. However in the observations made in the present study (chapter 5) there was no evidence of this; this concurs with other British observational studies which found more interaction in smaller than larger community homes (e.g. Thomas et al, 1986). Obviously in small homes it is important that residents are compatible and a number of authors have published accounts of small homes that indicate the possible effect of residents not getting on with each other (e.g. Race & Race, 1978; Malin, 1983; Atkinson, 1983).

In the community 2 movers reported having no particular friends:

dd: What are friends?

ik: Got none.

dd: Got none?

ik: No.

Twelve movers named best friends, 2 of these named people outside of the home:

tc: Behind the old people's home my friends live there.
dd: You have friends there, where did you know them from?
tc: I knew them from Aycliffe.
dd: From Aycliffe, did they used to work there or live there?
tc: No, they have a son at Aycliffe and that's how I came in touch with them...

For 5 movers the first named friends were staff:

dd: Who's your best friend here?
ma: Er, Miss, Genette and that.
dd: Does she live here or does she work here?
ma: She works here but we always say to her, er, how's your bairns getting on?
dd: She's got kids has she?
ma: Two little girls.

Four movers named residents of the home in which they currently lived:

dd: Who is your best friend here do you think?
jp: David.
dd: David, is it good or bad to have friends do you think?
jp: Sometimes its nasty.
dd: Sometimes its nasty, why, when is it nasty?
jp: When he has to do things.
dd: Oh I see.
jp: He can get awkward.

b. Family

An important major variable that influences family visits to people with mental handicaps is the distance that relatives live from the home or hospital (Campbell, 1968; Ballinger, 1970). As most movers are resettled back to their original home areas it would be expected that people living in the community would receive more

contact with family. De Kock et al (1988) used institutional records to demonstrate change in annual contacts with the family from a mean of 11 to a mean of 40 for 10 adults with severe or profound handicaps who moved from a traditional hospital to 2 small (8 bed) homes. Other characteristics of people with mental handicaps living in hospitals have been found to have a small effect upon level of family visiting, for example, age (Ballinger, 1970) and challenging behaviour (D'Onofrio et al, 1980).

The hospital does not have set visiting times, although there is a visiting day (third Saturday in the month) when transport is arranged from Cleveland and special activities (e.g. sales of work, refreshments) are held. When asked about their family 8 controls talked about living with their families prior to admission to the hospital; 5 talked about current contact with their families:

dd: Do you see any of your relatives very much?
cc: Aye they come and visit me they do.
dd: They do?
cc: Aye.
dd: Who comes?
cc: Me mam.
dd: Your mam?
cc: And me sisters.
dd: Your sisters?
cc: Aye.
dd: Do your sisters live in Middlesbrough now as well?
cc: They all live in Middlesbrough.
dd: In the same house or are they spread out?
cc: They're married.
dd: They're married, have they got any kids?
cc: I'm an uncle.

Some currently had no visits from their family. Age is often mentioned as limiting visits of close relatives:

dd: ...have you got any body that comes to see you?
wo: No.
dd: No, not at all?

wo: I have a sister in, oh, er, Dundee.
dd: In Dundee?
wo: I used to have a brother in Hartlepool but not now.
dd: Not now?
wo: He's retired now and all.
dd: Aye, he would be.
wo: And Herbert.
dd: Eh?
wo: My other brother and all, Herbert.
dd: Where does he live?
wo: Well he lives in Hartlepool as well, he's married.
dd: Does he ever come to see you?
wo: He doesn't go.
dd: Does anybody come and see you?
wo: No.

Thirteen movers talked of current contact with their family. However in the community there are other constraints upon family contact; the man quoted below lives five minutes walk from Middlesbrough city centre:

tc: ...I like The Crescent best and I like South Road best 'cos it was easy to get to see me sisters, easy to get to me brothers but now me sisters moved and me brothers moved. I have a sister that lives in Vicarston Road, that's the one that lives down town. I have two sisters that live down town, one is in (unclear) Road, the other lives in Vicarston Road, the other 4 live out of town, I have one lives in Belfast.
dd: In Ireland, what is she doing there, is her husband a soldier?
tc: Husband in the army, every time he goes over there she goes over with him.
dd: That's your brothers and sisters, do you see your mother and father much?
tc: I haven't seen me Mum and Dad for nearly four months, cos I can't get the bus fare, it's nearly one pound thirty a time.
dd: How much?
tc: One pound thirty, they live in Raby Oldton, it's hard to get there from here. It's hard to get there 'cos I get four pound pocket money a week and I can't possibly pay one pound thirty every week, they asked me to go every day and I can't go every day.

Two talked of limited or no contact with family. The man quoted below lives in Darlington:

dd: Have you got any brothers and sisters?
ec: Yes.
dd: Where does your sister live.
ec: She lives in Darlington.
dd: Do you see her much?

ec: Not much no.
dd: What's her name?
ec: Sylvia

There is an impression from the interviews that movers visit the family home more often than the family visits the movers. Movers report more contact with families, however there is no baseline for this, and existing family contact may have been a factor in selection for discharge. Again the fairly detailed factual information given here would be independently verifiable.

5. Place preference

The quality of data collected from those who could respond is good. The responses to questions relating to satisfaction with present home and feelings regarding preferred place to live were rated by DD on (1) satisfaction with current homes and (2) whether or not respondents expressed an opinion regarding a preferred place to live and if they did where it was. These ratings were made from items in response to specific questions because a global rating from a complete interview is difficult as respondents may express satisfaction with some aspects of their homes but not others.

Items from 12 controls and 18 movers were available. These are available in Appendix 10.

Statements were rated by DD as either expressing satisfaction with the current home, as expressing dissatisfaction or as being unclear or contradictory. A second rater, who had not been previously involved in the study and who did not know any of the subjects, independently rated the statements. There was complete agreement between raters on 27 statements; the disagreements represent the

statements of one mover which were rated as indicating satisfaction by the second rater but as being unclear by DD, the statements of one control which were also rated as indicating satisfaction by the second rater but as being unclear by DD and the statements of a second control which were rated as representing dissatisfaction by the second rater but as representing satisfaction by DD. The agreement between raters has a Kappa value of 0.84. The disagreements indicate that the ratings made by DD are slightly conservative as to the degree to which judgements can be made from the data. The disagreement in the rating of the one statement as dissatisfied by the second rater but as satisfied by DD seems to have stemmed from the strength of feeling expressed concerning the desire to live elsewhere which was taken by the second rater as indicating dissatisfaction with the current home.

For the following analysis the ratings made by DD are used. Seven controls and 16 movers made statements that clearly expressed satisfaction or dissatisfaction, the cross tabulation of these statements is presented in table 37. As can be seen proportionally more of the movers expressed satisfaction with their current homes. The exact probability of this observed distribution or of a more extreme occurrence was calculated using Fischer's Test and is 0.042. There is a less than 5% probability that the observed distribution in the degree of satisfaction of movers and controls would occur by chance.

Using data from the respondents who made statements that were judged by DD as expressing satisfaction or dissatisfaction, a comparison can be made of those people who would rather live elsewhere and those who would not. There was complete agreement between the two raters over this judgement.

	GROUP			
	movers		controls	
	n	%	n	%
Satisfied				
yes	13	81.3	4	57.1
no	3	18.8	3	42.9

p = 0.0419

Table 37: Satisfaction with current home for movers and controls who gave unambiguous responses

Of the 7 controls, 6 said that they would prefer to live in places other than the hospital. Although not included in this analysis one man who was contradictory in statements concerning satisfaction with the hospital was very definite in his desire to live at home. This compares with 4 out of 16 movers who stated that they would rather live elsewhere. These were 3 movers who were not satisfied with their current homes, two of whom would rather live at Aycliffe and one who would rather live in another home, and one mover who was satisfied with his current homes but who would prefer to live with his sister.

The crosstabulation of this data is presented in table 38. Using Fischer's Test the exact probability of this distribution is 0.0011, there is a less than 1% probability that the observed distribution would occur by chance.

Of the 7 controls who expressed unambiguous opinions 3 did not like the hospital. The main reasons offered related to the other residents:

dd: ...how long have you lived here?
wo: A long time.
dd: A long time is it, how do you like it?
wo: It's alright.
dd: Can you think of somewhere better to live or is this it?
wo: (unclear)
dd: You don't know where else?
wo: Nowhere to go is there.
...
dd: So what do you reckon is this a good place to live?
wo: Ah, this is a load of rubbish.
dd: Eh?
wo: They pick on you half of them
dd: Do they?
wo: Why aye.
dd: Hmm.
wo: They talk to themselves half of them, when they're in bed.
dd: Do they, do you have trouble sleeping?
wo: Aye

	GROUP			
	Movers		Controls	
	n	%	n	%
Prefer to live elsewhere				
yes	4	25.0	6	85.7
no	12	75.0	1	14.3

p = 0.011

Table 38: Preference for living elsewhere for movers and controls who gave unambiguous responses regarding satisfaction with current home

Four controls were at least reasonably satisfied with the hospital:

dd: What do you think about living here?

og: It's alright you know but you have to run after them alot.

dd: Yes?

og: I don't mind it, but I get really bad tempered.

dd: Well that's understandable, everyone does that, don't they?

og: I been in these places since I was sixteen...

Most of the controls would prefer to live elsewhere; living at home was mentioned by 3 controls:

dd: ...how do you like living at South Cottages, alright?

pb: It's alright.

dd: Its alright is it?

pb: I'd sooner be at home for good.

dd: Would you, but do you like living here?

pb: Yes.

dd: Its alright?

pb: For the time being.

dd: For the time being, can you think of a better place to live?

pb: No, only at home like.

dd: At home, yes...

...

dd: So where, you'd rather live where?

pb: I'd sooner go home for good.

...

dd: You like living here though?

pb: I'd sooner go home.

Three stated that they would like to live in a hostel:

dd: You'd rather live?

jm: At Aycliffe.

dd: At Aycliffe?

jm: If I get the chance, I'd rather be out to a hostel.

dd: You'd rather live in a hostel, why is that?

jm: 'Cos you can go and visit your people there.

One control preferred the hospital and there were two people who were too anxious about leaving to express an opinion and may also have preferred Aycliffe:

dd: So what's good about being here, to being at the other places?
mw: This is nicer.
dd: Is it?
mw: Much quieter really, than you will find in that other home.
dd: Was it?
mw: Oh yes.
...
dd: Do you think it would be nice in a hostel or do you think it
wouldn't be nice in a hostel?
mw: I like being here

Of the 16 movers who gave unambiguous opinions 13 had positive feelings about their current home although one of these would also like to live with his sister:

dd: Can you think of somewhere better to live, somewhere nicer to live?
df: Yes, Margaret's.
dd: Pardon?
df: With Margaret.
dd: Live with Margaret, who's Margaret?
df: Me sister.
dd: Your sister, so you think that would be better?
df: Yes.
...
dd: ...so what's the best thing about being here?
df: Don't like Aycliffe.
dd: Don't like Aycliffe, what about here, here, what's good about it, what's the best thing about it?
df: Seaside (current home) is better.
...
dd: ...what was bad about it, what didn't you like about it?
df: Too noisy.

dd: ...what was good about being at Aycliffe can you remember?
hl: Didn't like it.
dd: What was, what didn't you like, what was bad about it?
hl: Too noisy.
...
dd: So you like living here
hl: Hmm.
dd: Is it better or worse than living at Aycliffe?
hl: Yes.
dd: Which is that, is it better or worse?
hl: It's better, get plenty of fresh air.
...
dd: Did you used to have friends there?
hl: Yes.
dd: Can you remember what they were called, your friends?
hl: Forgot now, I like it here best.

Three movers expressed some dissatisfaction with their current

homes:

dd: Do you like living here?

ec: No, not really David.

dd: You don't?

ec: No.

dd: Why's that...can you think of somewhere better to live?

ec: Yes.

Four movers would rather live somewhere else; the two men quoted above, one of whom would rather live with his sister and one who would rather live in a different house (one in which he knows the residents and which is managed by the same organisation as manages his current home). The other 2 movers who would rather live elsewhere would prefer to live at Aycliffe. However both of these realise that this is not an option open to them:

dd: Did you like being at Aycliffe?

wd: Yes once I did, I can't go back now, eh.

dd: Hmm.

wd: No.

...

dd: So which is better, is it better being here or better being at Aycliffe, better being here or better being at Aycliffe, here or Aycliffe?

wd: Aycliffe is the best.

dd: Aycliffe was the best?

wd: Yes it is.

dd: Better than here?

wd: Yes, I can't go back there now.

...

dd: So which is best do you reckon, living here or living at Aycliffe, which is the best place to live Aycliffe or here, which is the best do you reckon?

wd: Aycliffe was the best, working there, Aycliffe.

dd: Aycliffe was the best?

wd: Yes, best at Aycliffe, yes.

dd: So which is best, here or Aycliffe?

ma: Aycliffe?

dd: Which is the best place to live?

ma: Here, I canna go back, its getting bombed down.

dd: Yes, its getting bombed, but if it wasn't getting bombed would you want to go back there?

ma: Back there, but I can't.

(The reference was to the demolition of parts of the hospital)

Questions concerning feelings and preferences relating to place of residence proved to be surprisingly successful considering previous work that finds choices to be difficult for people with mental handicaps (e.g. Wyngaarden, 1981). A larger proportion of movers were satisfied with their current placements. However the data has been obtained from a small proportion of the total study group, and although the differences are striking interpretation therefore needs to be tempered with caution.

DISCUSSION

The use of open-ended interviews resulted in at least one appropriate response from 50% of the study group. Criteria were used so that only answers that could be judged on their consistency were considered for analysis. That 50% could make at least one response that fulfilled these stringent criteria illustrates that high quality data can be obtained from some groups of people with mental handicaps, which confirms the results of previous work (e.g. Project '74, 1976; Flynn & Saleem, 1986).

The factual content of the responses was high, and demonstrated that subjects had insight into their current situation. The high factual content would allow independent validation of some aspects of the interviews. There is, however, no a priori reason to suspect that responses are not accurate. People with mild mental handicaps have been shown to report their own and their best friends abilities more accurately than care staff when responses are validated against direct observation (Nathan et al, 1980). In

retrospect the interviews used in the present study were too open, and in many cases the major part of an interview was idiosyncratic; more structured interviews could have been used with this more able group.

Movers report more varied activities both in the domestic sphere, and in work and leisure. However those attending segregated leisure and work facilities did not report activities very different from those described by controls. When different activities were reported, they were valued by the respondents. A larger proportion of movers than controls were satisfied with their current homes, and more controls thought of places where they would rather live. Only 4 movers thought of somewhere they would rather live, and one of those expressed no dissatisfaction with his current home. Of the controls only one who gave unambiguous data would rather stay put. Others would rather live with family or friends or in a hostel. Increased opportunity for contact with the family was often given as a reason for thinking life outside of the hospital would be preferable.

Evaluation studies often find that people are generally satisfied with social and health services (Shaw, 1976, 1984; Gutek, 1978 Justice & McBee, 1978; Denner & Halprin, 1974; Thomas et al, 1980). This may not accurately represent true feelings for a number of reasons:

- 1). People may find evaluating public services difficult (e.g. Bayley, 1973). There is a possible conflict in asking current or potential clients of a service to criticize it (Shaw, 1976, 1984; Gutek, 1978) as they may suspect this will affect their future treatment.

2). Satisfaction and dissatisfaction with services are not mutually exclusive. Shaw (1984) suggests that clients consider ideal services to be unobtainable, and so tend not to criticize services. Client opinion must be based on good information regarding possible services (Shaw, 1976).

It is therefore quite surprising that so many controls express a desire to move, although this is not synonymous with dissatisfaction with current home. In fact most controls do not know what it would be like to live in community based homes and so cannot make informed judgements. For movers comparison between the hospital and their current placement is more realistic. However Flynn (1987b) found that 85 out of 88 people living independently stated that they preferred their current homes to previous institutional placements. She considers that knowledge of the alternatives may actually make these people less likely to criticize their current home. People with mental handicaps may be both unwilling to criticize and worried about the prospect of change.

The rating of overall satisfaction with current home is a difficult task. In this case the author's judgement of satisfaction is made from responses to specific questions as a global rating from the complete interview is unsatisfactory as people may be satisfied with some but not other aspects of homes (e.g. Diener, 1984). It is perhaps surprising that there were not more contradictory responses. Obviously in future work the reliability of these judgements should be established.

The few overt statements of dissatisfaction are clearly important.

Movers generally did not wish to return to Aycliffe; however there were exceptions. A quality assurance technique labelled 'sentinal health event tracing' (Demlo, 1983) could be usefully adapted to explore these exceptions. In the medical field sentinal health event tracing involves a list of medical events that are considered indicative of problems in health service delivery. Their occurrence is examined in detail. In the present case intensive study of the situation of these individuals and what makes them unhappy with their current placements could result in useful information regarding aspects of services that other recipients may also consider to be unsatisfactory. The two people who felt they were happier at Aycliffe realised that the option of returning to the hospital was not available to them. This is further evidence of the accuracy of the respondents perceptions of their situations.

A number of people refer to noise as a source of dissatisfaction. Noise in wards for young people with mental handicaps has been shown to be a potential inhibitor of speech development (Glen et al, 1978). Other psychological effects of noise as an environmental stressor are reviewed by Holahan (1986) and Russell and Ward (1982). High levels of noise may be noted by visitors to wards, but negative feelings concerning continuous exposure to this may be underestimated. This is an example of a feature of quality of life that was important to respondents but which was not predicted. It illustrates the importance of direct, unstructured interviewing.

Statements of satisfaction may be affected by the respondent's perception of the purpose of the interview. In this study the subject's perception of the role of the researcher was not systematically explored. Further study of this in relation to

evaluation studies using people with mental handicaps as informants, would be valuable. Atkinson (1988) uses notes made at the time of the interview to illustrate the process of interviewing people with mental handicaps. Qualitative data from the interviewer may be a useful guideline in judging the extent that the respondent was influenced by their perception of the purpose of the interview.

In considering reaction to the interview it is important to try to consider its context to the respondent. Many subjects have been in institutions for a long time; for some Aycliffe is not the first or only institution in which they have lived, and within Aycliffe very few (if any) have spent all their time living in one ward. So for most respondents the experience of residential services is one of change, rather than stability. Although the move to 'community care' is a major policy initiative for the professionals working in the area, to the clients involved a move to the community may simply be yet another move. The context of the service being evaluated may be explored using life history interviews (e.g. Tagg, 1985). These have been used with some success with people with mental handicaps (Langness & Levine, 1986) and some of the current study group are able to give detailed accounts of their lives (Watson, 1989; Mattock, 1989).

It is possible that people with mental handicaps will perceive the research interview as an assessment for yet another move. For example following an interview, although not during it, one elderly man became concerned that he would be forced to move from a home in which he was settled and happy. It is not surprising that to this respondent a visit from a smartly dressed man complete with briefcase, notes and a tape recorder brought to mind assessment

prior to other moves that he had experienced. Considerable effort was made to ensure that subjects realised that the researcher's visit was not at all related to possible moves; but it is likely that they were not always convinced.

Care staff have a part to play in preparing and supporting subjects in evaluation studies; but care staff themselves may not always have fully understood or trusted the relationship between the researchers and the service providing agencies. Research visits were always discussed with officers-in-charge and with the staff on duty. However the formality of the situation may be one cue that the subject uses to associate the research situation with previous assessments. The success of the 'neighbourhood walk' (chapter 4) in collating qualitative information indicates the value of exploring other similarly informal ways of conducting research interviews.

Other interview techniques may be useful. Group interviewing (e.g. Mischler, 1986; Hedges, 1985) may be used in combination with individual interviews, especially if carried out over a period of time. Here subjects may gain from seeing other respondents safely report aspects of their lives, although group pressure may result in increased conformity of views. As the interviewer is likely to be viewed as high status techniques for empowering respondents may be useful (Mishler, 1986). These may involve enabling the respondent to control the content and order of discussion, which may give a more coherent narrative than is often gained from structured interviews. Mishler further suggests different relationships from within which the interview could be conducted; for example with the interviewer purely as a reporter, in the sense that ethnographic interviews are reporting rather than trying to

structure encounters (e.g. Spradley, 1980); with the respondent as a co-researcher, themselves trying to find out about their own experiences and being involved in the analysis of the data; or allowing the interviewer to become an advocate for the subject, changing the role of the interviewer to one of working for the subjects (Mishler, 1986). All of these changes of relationship between the interviewer and respondent may result in increased access to the perceptions of the subjects. The emphasis upon respondent empowerment involves changing the respondent's status. If this is to be fully achieved it is important for the respondent to collaborate in the stages of evaluation prior to data collection, such as in decisions regarding the criteria and standards of the study and decisions concerning preferred methods (e.g. Martin, 1986; Blunden, 1988).

It is particularly important that techniques of establishing the preferences and satisfaction of people with more severe handicaps be established. The use of pictures as non-verbal response options (Sigelman et al, 1981a, 1981c, 1982; Budd et al, 1981) deserves further study. Conroy & Bradley (1985) had some success in the use of a series of faces showing varying degrees of happiness (smile to frown) as a response option. The best type of pictorial stimuli in this situation needs exploration (e.g. should a picture be of a 'generic nurse', or the Sister of the respondent's ward). Photographs of key individuals in the respondents life were successfully used in a study of role perception using the repertory grid technique with 12 people with mild mental handicaps (Hulbert & Atkinson, 1987). However the use of very simple questions with pictures as response options may alienate more able respondents (Schuman & Presser, 1981) and not gain access to the considerable information available from them. A possible solution may be to use

standard picture based questions but allow further discussion of the issues raised by those people with sufficient verbal ability. This would both widen the range of people from whom standard minimum information is gained and when possible allow extended response. There will, however, still be a group of people with profound and severe handicaps that will not be able to respond. The problem of recording their preferences and satisfactions is unsolved.

Steps in this direction may involve increased use of advocates (those with no potential conflict of interest) or others who know the individual well. Bogdan and Taylor (1989) discuss the relationship of those who are very severely and profoundly handicapped with 'partners' (those who do not view them as excessively deviant) and note that these people often claim access to the subject's feelings. It may be possible to use these perceptions directly or to use them to establish idiosyncratic behavioural signs that indicate a positive or negative response. This is considered further in the final chapter.

There appeared to be little adverse reaction to tape recording of interviews, in fact there was considerable interest in listening to the tape once it was completed. There are advantages in recording interviews. The tape is available for independent or further analyses and it establishes a permanent record of the subject's verbal ability. It is often stated by staff and carers that verbal ability increases upon movement from hospital. The records made in this part of the study, although sometimes not directly used in the current analysis, may be valuable in further follow-up of this study group.

Open-ended interviews have allowed people with mental handicaps to express their own opinions regarding their lives. The results indicate that movers use more integrated facilities and generally report more varied activities. Respondents were able to make consistent value judgements concerning preferred residential services. Respondents had a high degree of insight into their current situations and many gave factual data that could be independently validated. The opportunity for activities and social interactions were of importance to respondents. Significantly more movers than controls were satisfied with their current homes. Significantly more controls than movers could think of places that they would rather live than their current hospital ward.

Chapter Seven

Discussion

This thesis has presented findings from a study examining effects on the lives of residents of Aycliffe Hospital of a move to community based care. The methods used, where possible, have collected data independently of service providers, and have used the subjects themselves as data sources.

THE PRINCIPLE RESULTS SUMMARIZED

The current study group comes from amongst the most able of the hospital population. Eighty-seven percent of the movers were in the National Development Team's category 1 compared to 27% of the remaining hospital group. The National Development Team's category 1 represents people who have no disability in the constellation of Wessex Scale items made up of mobility, continence, self-help skills and challenging behaviour items. The group who moved are therefore less disabled than the remaining hospital population.

Matching was used to obtain a control group similar to the movers on variables considered as important predictors of the outcome variables. However it was noted that the accuracy of matching in relation to other non-matched variables needs to be tested empirically. In the present study the mover group was generally more able than controls; 49% of controls are in the National Development Team's category 1, more than in the hospital population as a whole, but still less than in the movers. This difference in level of disability has important implications in interpreting outcome when a true baseline is not available.

The community homes generally gave residents more access to domestic facilities and private space than the hospital, and had

staffing patterns that encouraged residents' participation in domestic activities. In the neighbourhoods of the community homes most basic facilities are within 1 kilometer of the home and are unsegregated; the hospital provides many functionally similar facilities on site although these are all segregated. Directional data for facilities were presented graphically and as a summary statistic. The circular variance was presented for each home and was used in comparisons of homes and as a predictor of behavioural outcomes.

The study has reported on two methods for recording the use of facilities outside the home, trip diaries and neighbourhood walks. The methods have allowed the collection of comprehensive data, avoided the use of survey methods and developed the use of clients as informants.

Diaries were used to record trips made outside the home or ward; pre- and post-move diaries were kept for both movers and controls. The method had considerable consistency over a period of at least 12 months, which is impressive considering the relatively short period over which diaries were kept. In addition the trips recorded in the post-move diaries were validated against those noted during one evening of direct observation. A Kappa value of 0.84 was recorded for agreement between these methods. All disagreements consisted of trips noted during observation but not in the diaries. In terms of absolute number of trips there was no change due to moving out of the hospital and the major predictor of the number of trips made at post-move was the number made at pre-move. Variation in post-move trips that might otherwise have been attributed to features of the home, such as size, was also shown to be mainly accounted for by baseline scores. Although

there was little change in the number of trips made the nature of the trips did change in comparison to baseline and to those of the control group. More use of integrated facilities, more maintenance trips (shopping etc.) and a wider variation in types of travel were recorded for movers. These changes did not occur in the control group. However less trips were made alone by the movers, indicating some loss of independence.

A second method, the neighbourhood walk, assesses the ability of people with mental handicaps to locate facilities in their local neighbourhood. It provides quantitative data that can be used in comparisons across different types of homes and qualitative data on the degree of social integration of the subject. The reliability of the method was studied and the agreement between the number of facilities each subject located with two different raters was high: Pearson's r is 0.97. There also appears to be good agreement in qualitative features of the raters' reports of neighbourhood walks, although this was not studied systematically. Whilst 76% of controls were considered able to take a researcher to at least one community facility this was the case for only 47% of the movers. However for those subjects that did take the researcher out there is no statistically significant difference between the groups in the number of facilities located. The relationship between these outcomes and environmental data concerning siting of facilities was explored for movers. The circular variance of local facilities for community homes from which people were taken out was significantly smaller than for those from which they were not taken out and those facilities identified by subjects were significantly closer to the home and geographically closer to each other than those facilities that were not so located. However there was no significant effect found for the distance to facilities and their circular variance on

the number of facilities located by those movers who were taken out. The qualitative data indicated that many of the people who went out on walks were highly mobile and familiar with their surroundings; many were well known to other members of the community.

Time sampled direct observation was used to study activity within the home. The taxonomy used was similar to that used in previous British studies, and coded the level and type of active engagement with the environment. Movers were engaged for 69% of observed time and controls for 39% (medians). But this difference was shown to be only predictable from differences in disability between the groups as recorded on the Wessex scale before movers left the hospital; differences between the groups in levels of domestic and personal activities were not so predicted and may be attributed to changes in the environment.

Finally semi-structured interviews with the subjects indicated that some were able to report in detail on aspects of their lives. Many of respondents were able and willing to state preferences regarding places to live. A greater proportion of movers than controls were happy with their current placements. A greater proportion of controls than movers would like to move from their current homes.

In summary these findings are generally encouraging. Movers are engaging in at least as many activities at follow-up as they were at baseline, and at least as many activities as are observed in the control group. If the criterion of value is a normal pattern of activities (Wolfensberger, 1972; King's Fund, 1980) most movers are better off than they were or would be in the hospital.

Whilst collecting data in this study I was often impressed with the effort and thought that hospital staff put into their work, even though they were mostly well aware of the limitations inherent in hospital based care. Activity in the hospital is best illustrated by one man's list of leisure activities:

dd: Tell me some of the things that you do here when you're not working, do you go out much?

pb: No.

dd: No?

pb: Aye, discos sometimes, disco for half an hour, there's one this afternoon, video tomorrow afternoon with television, watching videos down the community centre, disco on a Saturday night, Monday night video, on a Tuesday night bingo, on Wednesday Gateway Wednesday, bingo Thursday, Bullseye on a Friday, that's tonight Bullseye.

The regularity of these activities may not be unlike that of the activities of people without handicaps outside of a hospital. However all of the activities mentioned above took place in the same building and with the same people.

Hospitals have often tended towards rigidity of routine, staff-resident interpersonal distance, block treatment and the general depersonalization of their residents (Goffman, 1961). These features are still observable to some extent even in the most progressive of the hospital wards. In some wards residents were observed queueing after the evening meal to have their faces and teeth cleaned and their hair brushed; on many wards mature adult residents were observed in nightclothes before the night-shift staff came on duty (usually by 8.30 pm); on others residents were observed sitting at tables waiting for the evening meal to arrive for up to 20 minutes.

A number of general issues are raised in this study that may be

relevance to future policy decisions.

The characteristics of those leaving the hospital

The movers are much the most able people from the hospital, and there are few examples in the present study of community care for people with more severe handicaps. There is still discussion concerning future need for hospital provision for people with a mental handicap (e.g. National Development Team, 1988; Northern Region Health Authority, 1985). However, whether or not hospitals continue to offer some services this study has found little evidence of community services being developed for people with more severe mental and physical handicaps and those with challenging behaviour. There are models of how this group of people may be cared for in the community (e.g. Blunden & Allen, 1988; Jay, 1979) and pilot services based on these models are being developed in some Northern Region Districts; but an opportunity is at present being missed for wider local experimentation and associated evaluation.

The siting of residential facilities.

At present most community homes have at least half of the 23 facilities studied here within 1 kilometer of the home. Effort should be made to site homes closer to facilities that are valued by their residents, as the evidence of the present study is that those facilities that are closest to the home are the ones that are most easily located by the subjects. In general location should be considered carefully in siting homes. One of the community homes studied was considerably more isolated than the rest, the residents of this home were dependent upon private transport to reach any

facility, as the nearest village was too far to walk and there was no public transport service. Although this is only one home and it is not possible to generalize from the experience of its residents it is inevitable that the siting of a home such as this is incompatible with an aim of encouraging the use of unsegregated facilities in the local neighbourhood.

Increasing the opportunity for appropriate activity.

Compared with the hospital controls movers were more likely to use unsegregated facilities for out of home activities. However there was a noticeable reliance upon segregated work and in some cases, particularly in larger hostels, congregate use of segregated leisure facilities. Methods to enable unsegregated work such as presented by Porterfield and Gathercole (1985) are not in evidence in relation to this group of movers. The few examples of unsegregated work include one man on a 'Restart' program, which is by its nature of limited duration, and one man who voluntarily helps a handyman in maintenance of local sheltered housing for elderly people. Movers use some unsegregated leisure facilities, but for many segregated 'Gateway' type clubs are a major part of their leisure activities. The use of facilitators, such as leisure volunteers (e.g. Gathercole, 1981; Corcoran & French, 1977), and other means of encouraging non-segregated work and leisure should be explored further.

The larger Social Service and private hostels that catered specifically for people with mental handicaps also offered limited household activity. Most residents of these homes were actually quite able as these homes can not take very disabled residents. But the employment of domestic and catering staff, and regulations

regarding the use of kitchen and other domestic areas, means that the opportunity for domestic activity in the home is limited. While some movers in these homes were observed in some activity of this type, the range of activity was small (for instance the preparation of food and the use of vacuum cleaners were rarely observed). Other Social Services homes, for example in Cleveland, have negotiated the employment of no domestic staff, often employing an equivalent number of care workers. Less demarcation may be part of necessary initiatives if residents are to be more involved in household activities.

For a few movers patterns of activity were extremely limited. Those that caused most concern were living in homes for elderly people where they were often amongst the most well orientated residents. It appears that the subjects had been placed in these homes because they were old, whereas the residents without mental handicaps had been placed in the homes because they had other disabilities associated with old age; this did not necessarily make them similar. The members of the study group that were in these homes had little or no opportunity for activity outside the home, and no opportunity for domestic activity inside the home. Interviews with the owner of one of these homes highlighted the difficulty of caring for client groups who have very distinct needs without one of the groups receiving less appropriate care.

Placement permanence.

Government publications concerning community care stress the importance of permanence in placements:

...residential homes for the mentally handicapped are a

permanent substitute family home (DHSS, 1971; p 35)

...we describe a range of local residential accommodation
...for providing a permanent home to (other) mentally
handicapped adults (Jay, 1979).

The need for services to be flexible whilst providing stability is challenging; the skills, confidence and hence independence of people with mental handicaps will change over time. Services will need to be able to respond to increased independence as well as increased dependence due to ageing and illness (e.g. Edgerton et al, 1984). Long-term evaluation is necessary to establish how the homes studied in this thesis respond to these changes in their clients.

Of the original 39 people who left Aycliffe Hospital 5 moved during the time of our contact, although only one of these returned to the hospital. Four out of the 5 moves were due to problems with the original placement, for example problems in relationships with other members of the home, problems with law-breaking (attributed to the influence of people in the original neighbourhood), and in one case due to placement breakdown in the Durham Social Services Family Placement Scheme. The fifth move was between two private homes with the same owner and was into the geographical area where most of the subjects' family lived; the second house had not been open at the time of the original move.

Placement breakdown cannot always be avoided, although considerable effort can be (and is) put into matching of co-residents. In one case recorded above the client who was moved was obviously far more able than the other residents of the home, and the original placement may have been inappropriate. Most moves did not involve

return to the hospital and for those interviewed after the move they did not appear to have been traumatic; however they do not reinforce the idea of permanence of placement. The subjects may not have been disturbed by the moves because they had not yet come to expect these placements to be permanent! One further woman, who has at present been living in a large hostel for nearly three years, is being considered for a move to a more independent and normalized home. This illustrates the problems of the 'readiness' approach to placement (Taylor, 1987). More stability would be achieved if people could be placed in small homes straight from hospital; the intensive support that would undoubtedly initially be needed could then be withdrawn over time as appropriate.

Further evaluation

There were examples, particularly in the voluntary sector such as the MENCAP homes in Darlington, but also in some Cleveland Social Services Homes, of small groups of people leading normal and active lives. To a casual observer these homes would have appeared the most effective of those in this study.

However it must be noted that they generally cater for the most able and least challenging clients. It will be extremely important to properly evaluate small homes, under similar management, that care for people with more severe mental and physical handicaps. Any meaningful evaluation of different homes must take into account characteristics of the residents involved as assessed before the move. If this is not done the risk is that homes that try to provide services to people with more severe handicaps will appear less favourably in any monitoring process. The findings in the present study are quite clear and indicate that the effects of

baseline can be quite subtle. For example most of the mover group were in the National Development Team's category 1, however their baseline scores on number of trips made varied considerably and, when used as a predictor, accounted for much variation in the outcome measure - variation that might otherwise easily have been attributed to the homes involved.

The importance of pre-move baseline or pre-move measures of disability have been demonstrated in other studies. The work of Landesman (1987) in particular demonstrates that different outcomes may be found for people with different baseline behavioural characteristics. Other studies have shown similar results; O'Neil et al (1981) found that people with low levels of pre-move activity showed bigger changes in activity on moving to the community; Shah & Holmes (1987) found that higher dependency people showed increases in use of community leisure facilities. Hemming et al (1981) found that "residents with IQs over 50 from relatively 'free' large institution environments (p 168)" showed the least improvements in quality of life. The implication from these results is that smaller changes in behavioural outcomes can be expected from those people who were independently active or less dependent upon the physical environment in their pre-intervention environments. This would concur with the present findings which shows relatively slight changes in absolute levels of activity for the high ability group involved. The changes that do occur appear to be related to structural differences in the environment that allow more variation in activity; for example more trips to unsegregated facilities, although not more trips in general; more domestic and personal activity although not more engagement in general.

The importance of baselines indicates the need for well managed continued monitoring of residential services to people with mental handicaps. In a more openly competitive system of service provision (e.g. Griffiths, 1988) the only way in which a home will be effectively evaluated will be to know what residents could do before they entered the new home. Of the methods described here some, such as the diaries, are relatively easily administered, although analysis of the data that is generated is rather complex and may require some expertise. However it is true, in general, that effective evaluation takes a lot of work. If monitoring officers are deployed full time, then the methods described here are manageable and provide quantitative information on the lives of people with mental handicaps that goes beyond the structural measures that are often used in quality assurance techniques (e.g. DHSS, 1982; 1984; Lang & Clinton, 1983).

SOME FUTURE ISSUES

There are a number of 'outstanding issues raised in this study. Three will be considered in more detail here.

1. Valuing outcomes

The primary task in future work of the kind reported in this thesis is to systematically incorporate the subjects' views of which outcomes are important. This is a key part of the larger task of evaluating different outcomes.

It has been stressed in relation to the objective measures used in this study that the subjects' view of their activities must be

taken into account. It is not known, with any certainty, whether subjects would value the use of unsegregated facilities and a wider range of activities, over the independent use of segregated facilities. However most movers in the present study are satisfied with their current homes and few wish they lived elsewhere. Hospital residents were less satisfied; and most of those who gave unambiguous responses would like to live in their family home or in hostels. This suggests that loss of independence is not a major factor in the judgement of satisfaction being made by movers, although those movers whose responses were included in the interview analysis are likely to have been the most able movers who may have experienced less loss of independence.

A potentially effective means to incorporate the views of the subjects in this type of work is to use data collected in other methods as a focus for subjects' opinions. Imaginative use may be made of informal settings to gain the confidence of the client for this task. The method described by Hart (1979) that incorporated both the identification of important places and of their relative value to the subject has great potential with the present client group. A similar method could also be used around the home to begin to establish those elements of home life that subjects find most rewarding. More formal interviews could be based upon previous diary records to provide a structure that would make discussions of greater relevance to the client.

One outstanding difficulty with the use of subjects to value outcomes is that the techniques suggested above are not suitable for people with more severe or profound handicaps. The views of people with less severe handicaps may to some extent also be representative of those with more severe handicaps, however it is

important to begin to study the views of people with severe and profound handicaps in their own rights. Although British studies have examined services to people with severe handicaps they have mostly used direct observation and staff completed records (e.g. Saxby et al, 1986; Rawlings, 1985a, 1985b; De Kock et al, 1988). The problem of finding out the preferences of this group has not been approached. In fact the applicability normalization which stresses the importance of taking the clients' views into account has been questioned in relation to people with severe handicaps (e.g. Hendrix, 1981; MacKay et al, 1988).

It has been noted that when others know people with severe mental handicaps well (e.g. family, friends, professional carers, advocates) they may claim to have insight into their feelings (e.g. Bogdan & Taylor, 1989). It may be possible to use such insight directly, or to use them to establish an idiosyncratic set of behavioural indicators for use in future observation of positive and negative feelings in single case studies. It is possible, in principle, to establish at least the reliability of these judgements using two carers to establish how well they agree in judgement of the feelings being expressed by a person with severe or profound handicap. This would entail observation of people with severe handicaps in direct contact with the community, and in other activities, so that their affective responses could be recorded.

The exploration of the use of pictures to allow non-verbal response options may also permit interviews to be formulated that would widen the range of possible respondents in an interview situation, although this still may not include those with the more profound handicaps. Interviews involving pictures could be combined with probes to allow more extensive discussion with people with greater

verbal ability. With careful presentation position biases could be controlled. This is an important area to explore further, as a more structured approach would allow presentation of results in a more quantitative manner.

A further problem has been alluded to by Flynn (1987a, 1987b). This is whether people leaving hospital, or those who have only experienced relatively impoverished settings can be expected to make accurate judgements of the desirability of their current situation. In the present study not all subjects were critical, even of environments that appeared quite impoverished. Milbrath suggests that judgements of people only just beginning more independent lives are heavily influenced by their previous experiences and the values of their immediate communities (Milbrath, 1982). This may mean that an informant's aspirations, values and beliefs will be as they were in the hospital. Birenbaum (Birenbaum & Seiffer, 1976; Birenbaum & Re, 1979) found that over time clients' satisfaction with a large community unit decreased. The authors related this to changing aspirations, due to contact with peers who had moved on to even more independent living. One conclusion is that social integration is necessary to allow people with mental handicaps to become aware of a wider range of resources and values and so become more effective evaluators of their own situation. Until this occurs the judgements of people with mental handicaps may not be sufficiently critical of their services.

Other methods of valuing patterns of activity may be necessary to supplement the judgements of people with mental handicaps. One method may be to judge the degree to which patterns of activity are normative (e.g. Wolfensberger, 1972). Wolfensberger (1972) defines the use of the word 'normative' in his definitions of

normalization:

The term 'normative' is intended to have statistical rather than moral connotations, and could be equated with 'typical' or 'conventional' (p 28).

Thus one aim of normalization is to create a pattern of activities that is as similar as possible to the typical or conventional pattern for an appropriate comparison group of valued people. Wolf (1978) states that behavioural interventions should be 'socially valid'. Kazdin (1977) describes two techniques for establishing social validity: (1) social comparison and (2) subjective evaluation. A social comparison involves using an appropriate (generally 'non-deviant') peer group to establish a normative standard. In subjective evaluation the individual's behaviour is evaluated by a group for whom the behaviours of the clients are particularly relevant. Social comparison most reflects the 'statistical' nature of normal behaviour as defined by Wolfensberger.

Examples of the use of social validation with people with mental handicap are found in studies of skill teaching. For example O'Brien and Azrin (1972) taught 12 institutionalized adults appropriate table behaviour using a combination of behavioural techniques. The final performance was compared to that of 12 covertly observed customers in a local restaurant. In the four weeks following completion of training the subjects made less errors than the comparison group. The use of social comparison groups in relation to specific behaviour is relatively common. There are fewer studies that have considered more general features of community life. Groarke (1987) investigated the 'community integration' of former students of a special school with people of

'normal' ability who had attended a school in the same local community. Fifty men and 10 women from each school were subjects, all had left school between 10 and 16 years prior to the study. Information on vocational, social and personal adjustment was collected in a structured interview. Although equal proportions of both groups were employed (77% of ex-special school and 80% community school) the special school attenders were in more manual jobs and were economically less well off. Sixty-five percent of special school attenders lived at home with their parents compared to 38% of community school attenders; 12% of the special school attenders were married compared to 55% of the comparison group; and 26% of the non-married special school group had a 'special girl-friend or boy-friend' compared to 81% of the comparison group.

Further exploration of the use of social comparison groups in studies of community living for people with mental handicaps would be of value. The use of a hospital comparison group alone, as in the present study, is limited as, although it gives a baseline for comparisons it offers no basis for deciding how good outcomes should be. There are many large collections of data that describe activity patterns of a wider population along with basic demographic data (e.g. BBC, 1984). The use of these in this context may be usefully explored.

The identification of an normative peer group may be difficult for groups such as people with mental handicaps leaving hospital; but with imagination it may be possible. Groups may be found that are similar to people with mental handicaps in group homes on variables such as size of living group (e.g. large families or people sharing houses); being in transitional stages in their lives (e.g. first year nursing or college students or recently married

persons); or having recently moved into a new area. As normative standards may vary according to the comparison group used, work of this type should involve specifying which variables have been used to select the comparison group.

There are problems in using normative standards. Normal behaviour may not, in some contexts, be desirable, either politically (e.g. Dalley, 1983) or in other ways (see further the 'conservative corollary', Wolfensberger, 1972). However this may be a useful way of testing the adequacy of outcomes along with the use of clients views. The method may highlight major areas of life in which people with mental handicaps do not live like other people, which the people with mental handicaps themselves may not be aware of.

2. The description of services

It has been noted that adequate description of the services involved in a study is important to the interpretation of the relevance of the results of the study to any other service (Emerson, 1985; Landesman-Dwyer, 1981). In the current study an attempt has been made to describe the services and populations involved. However description of complex services to the extent that would allow replication may not be possible. Ideally services are responsive to local need, and exact replication would rarely be desired.

An alternative may be to achieve replicability by evaluation at a lower level. Cook et al (1985) indicate three levels at which evaluation can take place; the program, the project or the element. Graham and Birchmore-Timney (1989) suggest four levels; systems, programs, components and techniques. Residential, leisure or

vocational initiatives may be viewed as programs; the components of the program would be, for example, assessment, liaison, and advocacy; the techniques involved may include a particular assessment form or method of record keeping. It has been suggested that it would be valuable to concentrate evaluation at the level of component or technique as this level can be properly described and may be generalizable (Rutman, 1977). A program can then choose components that are most suited to local need. However components (and programs) do not operate in isolation and it is not clear that a component can be taken out of the context of other components in a particular program as is suggested by Graham and Birchmore-Timney (1989).

It may be preferable to explore methods of describing complex systems so that the context of components and results can be made explicit, and so that the emergent properties of complete systems can be taken into account. Blunden (1988) indicates the potential value of 'soft-systems' analysis in describing human organisations (e.g. Checkland, 1981; Naughton, 1984). This involves the application of systems theory to situations where there are no clear single objectives or invariant means-ends relationships and recognises the unique nature of complex systems involving people. Soft-systems analysis acknowledges that there are many different ways of defining a system. The aim is to describe the system in such a way as to generate insights that are useful in a particular evaluation. The method described by Naughton (1984) and Checkland (1981) involves building a 'rich picture' of a system that accounts for its structure and also its more particular interpersonal aspects. From this are generated 'root definitions' which are basic accounts of what the system is for. Different root definitions may lead to different insights into the system. This

may be especially relevant in an area where it has been acknowledged that particularly charismatic individuals can make a difference to the general delivery of service (Wolfensberger, 1976; Crissey, 1975). This approach is also consistent with recent work concerning the management of successful organizations (e.g. Peters & Waterman, 1982). Some of the most successful businesses operate on a 'tight-loose' philosophy. In this a few major aims and guiding philosophies are defined but the processes used to achieve these are flexible, innovative and responsive to local consumer need. Thus it should not be assumed that one successful group home for people with a mental handicap will be the same as any other.

In relation to the description of services being evaluated it should be noted that the present study has been concerned with a 'standard' service. Much reported research concerns specially resourced or pilot schemes (e.g. Blunden, 1975; Cambridge & Knapp, 1988). Although these services may be useful as models of excellence, they simply may not be representative. For instance most of the Personal Social Services Research Unit pilot schemes serve a cross-section of hospital populations (Knapp, 1988), which may not be the case in other services. Further evaluation of how normally resourced services operate, which may involve soft-systems description, would be valuable.

3. Longitudinal study

One of the basic requirements for a good evaluation study is a longitudinal design, with collection of baseline data in the pre-intervention environment. Community care is intended as a long-term change in the way services are provided (DHSS, 1971) and it is especially important that longitudinal data are collected.

For people moving from hospital (or those moving from or remaining in their natural homes) community care represents the style of service that they will be likely to receive for as long as they require services. Evaluation of this naturally requires repeated measures.

A small number of studies have followed people intensively for short periods of around 12 months (e.g. Locker et al, 1984; Kleinberg & Galligan, 1983). Most of these have used adaptive behaviour scales. They tend to show increased adaptive behaviour skills immediately following moving to more normal settings; however some then demonstrate a slowing in learning or even a decrease in skills over time. For example Kleinberg and Galligan (1983) used an adaptive behaviour scale to study the experience of 20 people with mental handicaps who moved from a 'developmental centre' to two family homes and a converted staff apartment building. The study demonstrated positive changes in language ability, domestic activity, responsibility and social interaction in the first 4 months after moving, with a levelling out or even a loss of skills over the following 8 months. Birenbaum and Seiffer (1976) and Hemming et al (1981) also recorded a slight decrease in activity over time following initial gains upon moving to new homes. Others have shown small but more consistent increases over time (e.g. Locker et al, 1984; Conroy et al, 1982). One interpretation is that the initial increase in recorded skills is due to increased opportunity to perform skills already possessed, which leads to an initial high level of activity; and that learning of new skills occurs slowly or hardly at all.

Few studies have followed subjects over longer periods of time. An exception has been the work of Edgerton and his colleagues

(Edgerton, 1967, Edgerton & Bercovicci, 1976; Edgerton et al, 1984). who have followed the same group of people, using qualitative methods, for over 20 years. Initial concerns were predominantly with 'passing' (hiding the fact of disability), in which the aid of a benefactor was important (Edgerton, 1967). Over the years these people generally became less dependent, although some continued to live quite unstable lives. It was suggested that as people get older problems of age overtake problems associated with mental handicap (Edgerton et al, 1984).

Birenbaum and his colleagues (Birenbaum & Seiffer, 1976; Birenbaum & Re, 1979) followed up 48 residents of a large community home over a period of 4 years. The study reports a gradual decrease in use of facilities in the community, although proportionally more trips were made independently of staff over time due to the decrease in trips made with staff. Client satisfaction with the home also decreased, possibly due to changing aspirations, as many of those interviewed had contact with other residents who had moved on to more independent living. This was especially noticeable 3-4 years after moving (Birenbaum & Re, 1979).

Saxby et al (1988) carried out follow-up observations on 10 of the 12 subjects who had been studied by Felce et al (1985, 1986^a) 2 years after the original studies. In the intervening years there had been a slight decrease in staff-resident ratios, due to an increase in the number of residents. The data for the complete group indicates no significant reduction in the proportion of time observed engaged in appropriate behaviour, although for 5 subjects the observed proportion of time spent engaged in appropriate behaviour had decreased in comparison to the earlier study. There had been a significant decrease in staff-resident interaction

although the reason for this was unclear; it may not simply have been due to the decrease in staff-resident *ratio* .

Changes recorded in the first 12 months of placement may be unrepresentative of those that may occur in the longer-term. An initial high level of input would be expected to help people 'settle in' and establish a satisfactory pattern of activities. Studies often do not show a uniformly positive change in outcomes over time (e.g. Birenbaum & Seiffer, 1976; Kleinberg & Galligan, 1983). However data concerning longer term outcomes are rare. The exceptions (e.g. Birenbaum & Re, 1979; Edgerton et al, 1984; Saxby et al, 1988) are important as they indicate that outcomes and concerns of people with mental handicaps living in the community continue to change over longer periods of time. There are few recent British studies of this type.

Further studies with a longitudinal design would be informative. It would be possible to follow the present study group over a considerable period of time, possibly at five or ten year intervals. Ideally this would involve the same types of methodologies as used here and would offer a great deal of information regarding long-term adjustment to community living.

CONCLUSION

This thesis has presented findings from a study examining some effects of a move to community based care on a group of residents of Aycliffe Hospital. The outcomes for the current group of movers are generally encouraging. Although they loose some independence they do not engage in less activity. They use more unsegregated

facilities, and a range of maintenance facilities that not used in the hospital; some use unsegregated work and leisure facilities. Within the home movers have more opportunity for and engage in more domestic and personal behaviour. Of those that gave interviews, more movers than controls indicated that they were satisfied with their new homes, and in comparison with controls few movers would like to live elsewhere.

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Appendix One

Notes of Guidance

Section 1

The resident's name will already have been entered on the form. Please check spelling and amend if necessary.

Section 2

General: If this person is incapacitated due to temporary injury, etc. please code the normal ability.

- (a-d) Wetting and Soiling. Frequently - more than once a week. Wetting or soiling which occurs during an epileptic fit should be recorded in the same way as wetting or soiling of any other kind.
- (e-f) Walking. This question aims to assess only whether the person is ambulant and to what degree. Thus, if he or she needs help with walking because of blindness, or because of the danger of fits, this should not be recorded as an incapacity of walking.
- (g) Feeding. A person is able to feed himself without help if:
(a) He does not cause undue disturbance by messy eating, nor take an unreasonable time to finish eating if left to himself.
(b) He does not need to have food specially prepared after it has left the central kitchen.
- (h) Washing. If a male can wash himself but only has to be shaved, this should be scored Without help.
- (i) Dressing. If a person dresses himself but is unable to tie his shoe-laces, this should be scored With help.
- (j) Vision. If a person wears spectacles his vision should be assessed as with spectacles.
- (k) Hearing. If a person wears a hearing aid, this should be assessed as with hearing aid.
- (l) Speech. This first question on speech is a measure of the ability to use language, it is not a measure of speech defect. Thus, if a person uses sentences he should be scored as Sentences and normal even though his speech is difficult to understand.
- (m) Reading. Score Nothing if this person is unable to read or recognise his own name.
Score A little if this person can read or recognise his own name.
Score Newspapers and/or Books if he or she is able to read and understand a newspaper or simple book. (A person who only looks at pictures should be scored as reading Nothing.)
- (n) Writing. Score Nothing if this person is unable to write his own name or is only able to copy it.
Score A little if this person can at least write his own name without copying.
Score Own correspondence if he is able to write brief letters to his family without help in composition or the actual process of writing.
- (o) Counting. A person would score Nothing if he is quite unable to count or, even if he can count, e.g. up to 5 or 10, he cannot make use of this at all.
A person who scores A little would be able to recognise small values, e.g. would be able to sort out 4 sheets or 5 pillows or 3 spoons, etc.
A person who scores Understands money values would be able to make small purchases at a shop and give or receive correct change.

Section 3

This item has been added because we think it is important to know not only if a person can use language, but also whether or not his speech can be understood.

Section 4

Please code behaviour irrespective of whether or not the person is on drugs at the time of rating.

Definitions of rating

Marked. If this behaviour has occurred during the last month and continues to present problems of management.

Lesser. If the behaviour appears to be between Marked and No.

No. If this behaviour never occurs or if it occurs so seldom that it is difficult to remember when it last occurred.

Editor sign:

date:

WESSEX CASE REGISTER FORM

CONFIDENTIAL

FAMILY NAME

DATE OF BIRTH

DAY		MON		YEAR	
<input type="text"/>					
10		12		14	

CHRISTIAN NAME

AGE NO
2

Grade: 1. Mentally Handicapped
 2. Severely Mentally Handicapped 17
 3. Not Known
 (Please enter appropriate code in Box)

INITIALS
7

ADDRESS (if applicable)

ABILITIES, PLEASE ENTER APPROPRIATE CODE (e.g. 1, 2, 3 or 4) IN BOXES PROVIDED

WALKING (Nights)	1.Frequently	2.Occasionally	3.Never	<input type="checkbox"/>	19
WALKING (Nights)	1.Frequently	2.Occasionally	3.Never	<input type="checkbox"/>	21
WALKING (Days)	1.Frequently	2.Occasionally	3.Never	<input type="checkbox"/>	23
WALKING (Days)	1.Frequently	2.Occasionally	3.Never	<input type="checkbox"/>	25
WALK WITH HELP	1.Not at all	2.Not upstairs	3.Upstairs & elsewhere	<input type="checkbox"/>	27
NOTE: If this person walks by himself upstairs and elsewhere. Please also Code '3' (walk with help)					
WALK BY HIMSELF	1.Not at all	2.Not upstairs	3.Upstairs & elsewhere	<input type="checkbox"/>	29
FEED HIMSELF	1.Not at all	2.With help	3.Without help	<input type="checkbox"/>	31
DRESS HIMSELF	1.Not at all	2.With help	3.Without help	<input type="checkbox"/>	33
WASH HIMSELF	1.Not at all	2.With help	3.Without help	<input type="checkbox"/>	35
VISION	1.Blind or Almost	2.Poor	3.Normal	<input type="checkbox"/>	37
HEARING	1.Deaf or Almost	2.Poor	3.Normal	<input type="checkbox"/>	39
SPEECH	1.Never a word	2.Odd words only	3.Sentences & Normal	<input type="checkbox"/>	41
			4.Can talk but doesn't		
READING	1.Nothing	2.A little	3.Newspaper &/or Books	<input type="checkbox"/>	43
WRITES	1.Nothing	2.A little	3.Own correspondence	<input type="checkbox"/>	45
COUNTS	1.Nothing	2.A little	3.Understands money values	<input type="checkbox"/>	47

HOW CLEAR IS THE SPEECH IF THIS PERSON TALKS IN SENTENCES IS THE SPEECH (Enter appropriate code in Box)

1. Difficult to understand even by close acquaintances. Impossible for Strangers?
 2. Easily understood by close acquaintances. Difficult for strangers? 49
 3. Clear enough to be understood by anyone?

BEHAVIOUR PROBLEMS (Enter appropriate code in Box)

- GETS OUT OR ATTACKS OTHERS 1.Marked 2.Lesser 3.No 51
- TEARS UP PAPERS, MAGAZINES, CLOTHING OR DAMAGES FURNITURE 1.Marked 2.Lesser 3.No 53
- EXTREMELY OVER ACTIVE, PACES UP & DOWN DOES NOT SIT DOWN FOR A MINUTE 1.Marked 2.Lesser 3.No 55
- CONSTANTLY SEEKING ATTENTION - WILL NOT LEAVE ADULTS 1.Marked 2.Lesser 3.No 57
- CONTINUOUSLY INJURING HIMSELF PHYSICALLY, e.g. HEAD BANGING, PICKING AT SORES, EATING EYES 1.Marked 2.Lesser 3.No 59

Please enter today's date

DAY		MON		YEAR	
6	1			6	6

Please enter M (male) or F (female) 68

- this person suffer from epilepsy Yes No 70
- diabetes Yes No 72
- cerebral palsy Yes No 74
- Down's syndrome Yes No 76
- Any other chronic medical condition? Yes No 78

Please specify:

name Ward

End. Thank you.

284

Appendix Three

Client Information

1. residential places.

1.1 total places number _____
(residential and short-term care/residential)

1.2 total residential places number _____

1.3 residential places in use at time of visit number _____

comments _____

1.4 total short-term care/residential places number _____

1.5 short-term residential places number _____
in use at time of visit

comments _____

2. day-care places

2.1 total places number _____

2.2 total day care places in use at time of visit number _____

comments _____

3. client group information

3.1 maximum age age _____

3.2 minimum age age _____

3.3 number of males number _____

3.4 number of females number _____

4. key worker system score yes = 1, no = 0 _____

notes _____

Appendix Four

2000

address of home

date

names

1. _____ id _____

2. _____ id _____

3. _____ id _____

4. _____ id _____

5. _____ id _____

home _____

ID _____

Number

Access

number of bedrooms	_____	_____
number of toilets	_____	_____
number of bathrooms	_____	_____
number of staff rooms	_____	_____
kitchen	_____	_____
dining room	_____	_____
living room	_____	_____
pantry	_____	_____
stairs	_____	_____
hall/corridor	_____	_____

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

living room/day area

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

furniture

easy chairs

count

dining chairs

count

sofa/settee

count

stools

count

2-4 person tables

count

4+ person tables

count

other seating list _____

leisure

games

score yes = 1, no = 0

list _____

musical instruments

score yes = 1, no = 0

list _____

hobby material

score yes = 1, no = 0

list _____

for items below score: 1 = 0 items, 2 = 1-5 items,
3 = 6-10 items, 4 = 11-50 items, 5 = 50+ items

books

score as above

magazines/newspapers

score as above

records

score as above

tapes

score as above

electrical

record player

score yes = 1, no = 0

tape recorder

score yes = 1, no = 0

radio

score yes = 1, no = 0

television

score yes = 1, no = 0

video

score yes = 1, no = 0

computer

score yes = 1, no = 0

medical

drugs

score yes = 1, no = 0

drugs cupboard

score yes = 1, no = 0

storage

bookcase

count

side-board

count

equipment straoage

count

list further features not mentioned above

dining room

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

scored during meal yes = 1 no = 0

tables

2-4 person

count

5+ person

count

dining chairs

count

table cloth

score yes = 1, no = 0

table mats

score yes = 1, no = 0

list

items that could possibly be found in the kitchen area or dining area

pepper/salt	score yes = 1, no = 0	_____
vinegar/mustard	score yes = 1, no = 0	_____
sauces	score yes = 1, no = 0	_____
crockery shelves	score yes = 1, no = 0	_____
cutlery drawers	score yes = 1, no = 0	_____
found in _____		

items below score:

1 = not enough items for all residents and staff

2 = enough items for all residents and staff

3 = more than enough items for all residents and staff

cutlery

plates	score as above	_____
side plates	score as above	_____
bowls	score as above	_____
cups	score as above	_____
saucers	score as above	_____
knives/forks/spoons/tea spoons	score as above	_____
glasses	score as above	_____

serving dishes	score yes = 1, no = 0	_____
serving spoons	score yes = 1, no = 0	_____

cold drinks containers	score yes = 1, no = 0	_____
tea/coffee pot	score yes = 1, no = 0	_____
milk jug	score yes = 1, no = 0	_____

kitchen

area where the majority of the cooking takes place, if meals are prepared at a central kitchen then the area with snack preparing facilities hob/grill/toaster/kettle/beverage preparation facilities

access

2 = free

1 = specific, permission only, accompanied by staff, only for certain activity

0 = no access

sink				
sink	count	_____	_____	
tap	count	_____	_____	
washing-up liquid	count	_____	_____	
scourer/ or equivalent	score yes = 1, no = 0	_____	_____	
cloth	score yes = 1, no = 0	_____	_____	
bowl	count	_____	_____	
washing-up	score yes = 1, no = 0	_____	_____	
cooker				
electric	count	_____	_____	
gas	count	_____	_____	
belling/hob/grill	count	_____	_____	
microwave	count	_____	_____	
deep frier	count	_____	_____	
fridge/freezer				
fridge	count	_____	_____	
freezer	count	_____	_____	
food/drink	score yes = 1, no = 0	_____	_____	
dishwasher				
dishwasher	count	_____	_____	
powder	count	_____	_____	
snack makers				
grill	count	_____	_____	
toaster	count	_____	_____	
bread	score yes = 1, no = 0	_____	_____	
sandwich toaster	count	_____	_____	
kettle				
electric	count	_____	_____	
oven-top	count	_____	_____	
hot water boiler	count	_____	_____	
misc. electrical				
food processor	count	_____	_____	
deep fat frier	count	_____	_____	
score: 1 = 0, 2 = 1-10, 3 = 11-50, 4 = 50+				
pots/pans				
pots/pans	score as above	_____	_____	
cake tins/baking tins	score as above	_____	_____	
casserole/in oven cooking containers	score as above	_____	_____	

utensils

tin openers	score yes = 1, no = 0	_____
grater/peeler	score yes = 1, no = 0	_____
chopping board	score yes = 1, no = 0	_____
weighing/measuring equipment	score yes = 1, no = 0	_____
cutting knives	score yes = 1, no = 0	_____

list further items _____

food		
fresh	score yes = 1, no = 0	_____
tinned	score yes = 1, no = 0	_____
dried	score yes = 1, no = 0	_____
frozen	score yes = 1, no = 0	_____
storage jars	score yes = 1, no = 0	_____

towels		
paper towels	score yes = 1, no = 0	_____
tea towels	score yes = 1, no = 0	_____
hand towels	score yes = 1, no = 0	_____

beverages equipment		
tea bags	score yes = 1, no = 0	_____
tea leaves	score yes = 1, no = 0	_____
coffee	score yes = 1, no = 0	_____
sugar	score yes = 1, no = 0	_____
milk	score yes = 1, no = 0	_____
tea pots	score yes = 1, no = 0	_____
milk jugs	score yes = 1, no = 0	_____
sugar bowl	score yes = 1, no = 0	_____
coffee pot	score yes = 1, no = 0	_____

list further items _____

note if kitchen has large, 'commercial' type equipment:
 score yes (commercial equipment) = 1
 no (household type equipment) = 0

utility/laundry room

the room where 'clothes- washing/cleaning/ironing/drying'
takes place it may be a multi-purpose room.

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

laundry

washing machine count

tumble drier/spin-drier count

washing powder score yes = 1, no = 0

conditioner score yes = 1, no = 0

washline

washline(out side) score yes = 1, no = 0

pegs score yes = 1, no = 0

clothes horse count

iron

iron count

ironing board count

wash basket count

clothes score yes = 1, no = 0

sink score yes = 1, no = 0

storage

storage area score yes = 1, no = 0

work surface/tables count

chairs count

list other items _____

bedroom

sleeping area whether communal or individual

record clients initials _____

record total number of bedrooms in building count _____

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

bed

bed count _____

pillow count _____

linen score yes = 1, no = 0 _____

fitted sheets score yee = 1, no = 0 _____

duvet score yes = 1, no = 0 _____

dressing table count _____

alarm clock score yes = 1, no = 0 _____

wardrobe count _____

cupboards count _____

bedside cabinet count _____

furniture

easy chair count _____

dining chair count _____

basin

basin+taps score yes = 1, no = 0 _____

soap score yes = 1, no = 0 _____

flannel score yes = 1, no = 0 _____

towel score yes = 1, no = 0 _____

list other items _____

bathroom

in a large facility it may not be possible or necessary to record all bathing areas, record the bathroom generally used by the individual being visited.

access

2 = free

1 = specific, permission only, accompanied by staff, only for certain activity

0 = no access

bath

bath	count	_____	_____
are the baths partitioned	score yes = 1, no = 0	_____	_____
if only one bath n room score = 1			
taps	count	_____	_____
non-slip mat	count	_____	_____

and/or shower

shower head	count	_____	_____
shower controls	count	_____	_____
shower curtain	count	_____	_____
non-slip mat	count	_____	_____

bathing items

nail brush	score yes = 1, no = 0	_____	_____
scrubbing brush	score yes = 1, no = 0	_____	_____
towels	count	_____	_____
paper towels	score yes = 1, no = 0	_____	_____
bathroom scales	score yes = 1, no = 0	_____	_____

basin

basin	count	_____	_____
taps	count	_____	_____
soap	score yes = 1, no = 0	_____	_____
towels	count	_____	_____
paper towels	score yes = 1, no = 0	_____	_____

mirror

full length mirror	count	_____	_____
less than full length mirror	count	_____	_____
shaving mirror	count	_____	_____

list other items _____

toilet

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

bathroom/toilet same room?

score yes = 1, no = 0

toilet

toilet

count

toilets are partitioned

score yes = 1, no = 0

if only one toilet in room score = 1

cistern

count

chain pull

count

handle flush

count

urinal

count

toilet paper

score yes = 1, no = 0

toilet cleanser

score yes = 1, no = 0

toilet brush

score yes = 1, no = 0

air freshner

score yes = 1, no = 0

coat hook/clothes hanger

score yes = 1, no = 0

hand basin

basin

count

taps

count

soap

score yes = 1, no = 0

towels

score yes = 1, no = 0

mirror

score yes = 1, no = 0

list other items _____

entrance hall

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

tables

count

telephone

a.coin box

score yes = 1, no = 0

b.private 'phone

score yes = 1, no = 0

telephone directory gpo

score yes = 1, no = 0

local/individual directory

score yes = 1, no = 0

stair case

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

steps

hand rail

light switches

light fittings

windows

count
score yes = 1, no = 0

count

count

count

count

floor covering

carpet

wood

lino'

score yes = 1, no = 0

score yes = 1, no = 0

score yes = 1, no = 0

ornaments

pictures

china

flowers/plants

count

count

count

store rooms

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

store rooms

hoovers score yes = 1, no = 0

brooms score yes = 1, no = 0

dust pans brushes score yes = 1, no = 0

cloths score yes = 1, no = 0

polish/wndow cleaner score yes = 1, no = 0

disifectant/detergent score yes = 1, no = 0

mop/bucket score yes = 1, no = 0

list other items _____

pantry

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

pantry
food

score yes = 1, no = 0

garden/outdoor areas belonging to facility

access

2 = free

1 = specific, permission only, accompanied by staff, only
for certain activity

0 = no access

garden areas

paths	score yes = 1, no = 0	_____
flower beds	score yes = 1, no = 0	_____
vegetable garden	score yes = 1, no = 0	_____
bird table	score yes = 1, no = 0	_____
lawn	score yes = 1, no = 0	_____
greenhouse	score yes = 1, no = 0	_____
garden shed	score yes = 1, no = 0	_____

list any other prominent feature _____

staff rooms/office areas

access

2 = free

1 = specific, permission only, accompanied by staff, only for certain activity

0 = no access

office furniture

desk	count	_____	_____
office chairs	count	_____	_____
dining chairs	count	_____	_____
easy chairs	count	_____	_____
filing cabinets	count	_____	_____
shelves	count	_____	_____
bookcase	count	_____	_____

telephone

internal telephone	score yes = 1, no = 0	_____
external telephone	score yes = 1, no = 0	_____
telephone directory	score yes = 1, no = 0	_____
local/specific directory	score yes = 1, no = 0	_____

medical

medicine cupboard	score yes = 1, no = 0	_____
first aid box	score yes = 1, no = 0	_____
medicine trolley	score yes = 1, no = 0	_____
medicine containers	score yes = 1, no = 0	_____
medicines	score yes = 1, no = 0	_____
cardex	score yes = 1, no = 0	_____
medical/nursing notes	score yes = 1, no = 0	_____

administrative

financial records	score yes = 1, no = 0	_____
miscellaneous records	score yes = 1, no = 0	_____
notice board		
rota list		

list other items _____

structural/general

below are listed structural and other general features of a room that could be expected to occur in any room. this section needs to be completed for all of the above areas. please record below the room that this sheet refers to.

miscellaneous

waste bins	count	_____	_____
radiators	count	_____	_____
electric heaters-floor or wall	count	_____	_____
gas fires	count	_____	_____
solid fuel burner/open fire	score yes = 1, no = 0	_____	_____

structural

doors	score yes = 1, no = 0	_____	_____
door locks	score yes = 1, no = 0	_____	_____
engaged/occupied sign	score yes = 1, no = 0	_____	_____
are the locks and engaged signs functioning ?	score yes = 1, no = 0	_____	_____
	score 0 if locks not present	_____	_____
windows	score yes = 1, no = 0	_____	_____
light switches	score yes = 1, no = 0	_____	_____
light fittings	count	_____	_____
wall sockets	score yes = 1, no = 0	_____	_____

ornaments

curtain/blinds	score yes = 1, no = 0	_____	_____
picture a. wall	count	_____	_____
b. on sideboard/sill etc	count	_____	_____
mirror a.full length	score yes = 1, no = 0	_____	_____
b.less than full length	score yes = 1, no = 0	_____	_____
clock	score yes = 1, no = 0	_____	_____
china/ornaments	count	_____	_____
soft toys	count	_____	_____
flowers/plants	count	_____	_____
lamps a.table	count	_____	_____
b.standard	count	_____	_____
fruit bowl	count	_____	_____
ash trays	count	_____	_____

wall covering

wallpaper	score yes = 1, no = 0	_____	_____
wall paint	score yes = 1, no = 0	_____	_____
wall tiles	score yes = 1, no = 0	_____	_____
brick	score yes = 1, no = 0	_____	_____

floor covering

lino	score yes = 1, no = 0	_____	_____
tiles	score yes = 1, no = 0	_____	_____
carpet	score yes = 1, no = 0	_____	_____
mat	score yes = 1, no = 0	_____	_____

telephone

internal telephone	score yes = 1, no = 0	_____	_____
external teelphone	score yes = 1, no = 0	_____	_____
gpo telephone directory	score yes = 1, no = 0	_____	_____
local/individual directory	score yes = 1, no = 0	_____	_____

Appendix Five

1. Please make a record on these sheets of every occasion on which each of the above named leaves the home.
2. Columns are available for:
 - Resident's name: Christian names will do.
Please be as specific as you can so that we can find the places (e.g. give the name and road of pubs; give address rather than "gone home").
 - Where they go: You may not know these exactly. Please be as accurate as is possible in the circumstances.
 - What time they left and how long they were away: On foot, by bus, car, train, taxi.
 - How they travelled: Give names and e.g. "staff", "relative of x".
 - Who went with them:
3. You may not know all details of every journey made. Don't worry: just record the ones you know of as accurately as possible.
4. Please make a record for each shift or period of the day. Use as many sheets as necessary for each. We appreciate that trips are not often made during the night, but please use a sheet for the night so we can be sure. If there are no trips during a shift or period just write "none" over the sheet. It is important that we have a signed record covering the whole of each 24 hour period, even if the resident doesn't leave the home.
5. If there are any special factors that you think need taking into account (e.g. staff shortage, illness of resident) please add a comment at the bottom of the relevant sheet.
6. We will visit you during the week to see how things are going. If you have any problems in the meantime, contact Dave Dagnan at Durham University Psychology Department. Durham (091) 374 2000 ext. 2615.

With many thanks,

Dave Dagnan
Bernadette Howard
Mary Carey
Robert Drewett

Appendix Six

Day:

Date:

Residents Name:

Where Did They Go?	About What Time?	How Long Away?	How Did They Get There?	Who Went With Them?	Your Name

Appendix Seven

Observation: Category Definitions

This schedule codes 4 aspects of behaviour. Whether the person is actively engaged with the environment, the activity they are engaged in, if the activity involves contact and who with and the location of the activity.

1. Engaged

Scoring of behaviour in this category depends on the individual participating in a purposeful activity that entails interaction with the physical or social environment.

2. Not-Engaged

This category is scored if the individual is NOT participating in any activity. This includes being the passive recipient of the behaviour of another person, or non-goal orientated activities (e.g. stereotypic behaviour).

At each observation an individual MUST be scored either engaged, not-engaged, or a missing observation code made.

1. Engaged Activities

If an individual is scored as engaged then the activity they are engaged in MUST be scored as either Domestic, Personal, Active Leisure, Passive Leisure as well. If they are purely engaged in conversation then engagement is scored, activity is scored zero, and the category of person with whom they are interacting is scored.

As a number of these activities could be occurring at the same time there is an explicit hierarchy for scoring. Personal takes precedence over Domestic which takes precedence over Active Leisure which takes precedence over Passive Leisure. If contact is going on at the same time as any of these activities then they are both scored.

1.0 Contact Only

If a person is purely engaged in contact with another person then engaged activity should be scored 0 but the class of person with whom contact is made should be scored

1.1 Personal

This category includes self-maintenance activities.

Examples.

Bathing; Washing; Dressing; Undressing; Combing/Brushing Hair; Putting on Make-Up; Shaving; Toileting; Eating; Drinking.

The activity should be written in the space provided.

Preparation for and tidying up from a personal activity should be recorded under the Domestic heading.

Many of these activities will be private and not observable. When this is the case only the location of the subject should be recorded and the appropriate missing data code should be entered

1.2 Domestic Activities

Environment-maintaining behaviour.

Examples.

Laying or Clearing Tables; Washing Up; Putting Away; Cooking; Shopping; Laundry Activities; Bed Making; Cleaning; Painting, Decorating and General Environmental Maintenance; Tidying up after and Preparation for Activities listed as Personal; Activities that would generally be considered work of the Facility Staff.

The activity should be recorded in the space provided.

1.3 Active Leisure

Leisure activities that involve active participation.

Examples.

Playng Games; Sports; Dancing; Hobbies; Reading; Writing; Table Top Activities; Academic Work.

The activity should be written in the space provided.

1.4 Passive Leisure

This category includes leisure activities that only require watching or listening on the part of the subject, it also includes smoking.

Examples.

Listening to Radio, Tape or Record Player; Watching Television; Watching live entertainment; Smoking.

The activty should be recorded in the space provided.

2. Not-Engaged Behaviour

If a individual is scored as Not-Engaged then they MUST be scored as either Stereotypic, Passive Recipient or Neither. Again a hierachy of scoring presedence is defined, stereotypic behaviour takes precedence over passive recipient behaviour which take precedence over neutral behaviour.

Engaged behaviour take precedence over not-engaged behaviour.

2.1 Stereotypic Behaviour

Behaviour will be scored as Stereotypic if it is the only activity that is occuring. Stereotyped Behaviour may occur in conjunction with Engaged Activity (Koegel & Covert, 1972; Rawlings 1985a & 1985b). If so the Engaged aspect of the activity should be scored, and the presence of stereotypic behaviour should be noted in the space for extra information.

Examples.

Whole Body Rocking or Weaving; Finger Flapping/Flicking; Facial Stereotypies; Stereotypic Vocalisations; Higher level activities such as repetitive skill exhibition are scored as stereotypic activities, for example repetitive placing of single piece of jigsaw, repetetive door opening and closing.

The behaviour should be recorded in the space provided.

2.2 Passive Recipient

This will be scored when an individual is having a task performed for them by another person but a response is not elicited.

Example.

Being Washed; Being Dressed/Undressed.

The behaviour should be recorded in the space provided.

2.3 Neither

Neutral behaviour.

Example.

Sitting, standing, sleeping, movement between activities if not obviously part of an activity, watching activities of others whilst not part of that activity.

The behaviour should be recorded in the space provided.

3. Contact

This category includes verbal or physical contact that is directed from another person to the subject or to another person from the subject. Contacts can occur alongside both Engaged and Not-Engaged categories. A contact is scored by recording one of the 4 categories of person who makes contact or to whom contact is directed.

3.1 Formal Carers

Individuals whose contact with the individual is through 'referral, recruitment, role related obligations or professional competence' (Atkinson, 1986).

Example.

Care Staff; Doctors; Social Workers; Therapists; Psychologists; Observers; Volunteers.

3.2 Relatives

This group should include 'adopted' as well as 'blood' relatives.

Examples.

Mother; Father; Siblings; Aunts; Uncles; Cousins; Grandparents.

3.3 Service Recipients

This group includes others who are in receipt of of the same specialised services as the subject.

Example.

Household companions; attenders of specialised social clubs or specialised workplaces.

3.4 Non-Handicapped Others

A non-handicapped person who does not have any of the above relationships with the subject.

Example.

Non-Handicapped Friends; Neighbours; Acquaintances; those who offer a service to the general population (eg. shopkeepers).

Missing Values

There are two classes of missing data. One is the occurrence of behaviour on the part of the subject or any other person that makes it impossible to observe the behaviour. The other is due to a failure on the part of the observer or observation equipment.

Private Behaviour Code 888

Private behaviour on the part of the subject or others in the same room, generally in the bathroom, toilet or bedroom, any behaviour in these rooms should be recorded as private. Also chosen privacy; an active choice of the subject to be alone, no matter what the nature of the behaviour engaged in.

When possible location should still be coded in these situations.

Missing Observations Code 99999

Failure on the part of the observer to record ongoing behaviour; due to equipment failure or inability to locate the subject.

Location

Location should be coded for each observation. Example codes are given below. Locations specific to a home, such as 'Aycliffe Community Centre', can be coded specifically with the option to collapsed into a generic code during analysis.

-
- 01 Kitchen
 - 02 Kitchen/Diner
 - 03 Dining room
 - 04 Living/Dining Room
 - 05 Living Room
 - 06 Bedroom
 - 07 Corridor/Hall/Stairs/Landing
 - 08 Staff Room
 - 09 Bathroom/Toilet
 - 10 Laundry/Utility Rooms
 - 11 Pantry/Store Rooms
 - 12 Outside- Facility grounds
eg Aycliffe Grounds
 - 14 Aycliffe Community Centre

 - 88 Private behaviour location unknown
 - 99 Missing Observation
-

Appendix Eight

Sheet Number _____

Time of First Observation _____

Individual ID _____

1_ ENGAGED

1_ PERSONAL

1_ stereotyped activity

1_ Formal Carers

666_ others privacy

2_ non-engaged

2_ DOMESTIC

2_ passive recipient

2_ Relatives

777_ ob'ee's privacy

3_ LEISURE ACTIVE

3_ neither

3_ Service Recipients

888_ chosen privacy

4_ LEISURE PASSIVE

4_ Non-handicapped Friends

999_ missing data

ACTIVITY _____

Appendix Nine

Domestic Actcivities

Cooking

dd: Do you do any cooking yourself normally?
cc: Well I can't at the moment cos the cooker doesn't work, its got a wire loose.
dd: Oh I see, but when the cooker does work do you do some cooking?
cc: Aye I do meals, we used to do meals, we're going to start doing them again.

dd: ...do you do any cooking or anything?
eg: No.
dd: You don't do any of that?
eg: No.
dd: Would you like to do some?
eg: Yes.

dd: ...did you enjoy doing cooking?
pb: Instant whip or sago.
dd: That's nice.
pb: But I'm no good at cooking I don't know how to do it, I don't know the know how.

mw: Yes its a nice cookery part that we have.
dd: Is it and what sort of things do you make?
mw: Cakes and all that.

dd: Who cooked the breakfast this morning?
ic: Peter did.
dd: Peter did?
ic: Peter did, yes he did.

dd: What time does your tea come along here?
ch: Half past five, won't be here yet it has right up the lodge to go to.
dd: Aye, yes.
ch: With the lads, then it has the girls to go to then when it comes back it has right down the male end to go then it has sixes to go at the top. It's always he same meals over and over.

wo: You know what we had for tea the other day?
dd: What was that?
wo: It was liver, and potatoes, liver, you can't eat that with no teeth in.
dd: I see what you mean you got no teeth?
wo: Aye.
dd: Oh.
wo: It's no good.
dd: What sort of things do you like eating then?
wo: I wouldn't eat liver, its rubbish meat, a bit of bloody meat, meats half cooked and all.
dd: Is it now.

dd: ...do you go in the kitchen and make things?
ss: Oh it depends upon who's on, you know what I mean.
dd: Eh?
ss: It depends if I get caught making it by the charge nurse and get put to bed.
dd: Really?
ss: Oh aye.

Washing up

3 mention not washing up, usually pointing out domestics do it
3 mention doing washing up

dd: What do you do when you're not working?

jm: Wash the dishes, again, get the cups out for the breaks on a morning, wash the dishes then put the mop on, I should say on a morning, then the staff trays there I take into the kitchen and wash their dishes for them - then sometimes Philip Docherty doesn't come in to dry the dishes so I dry them for him and put...

pb: Dennis does the washing up he does it.

dd: Dennis does it, does he?

pb: He usually does it, 'cos he, he's doing all our washing up while we're doing nought, he does it breakfast dinner and tea.

dd: He does it all?

pb: Should do it, but I don't do it, he washes up.

dd: Would you like to wash up?

pb: We've been getting into trouble, all of us like, for not helping to do the washing up,, some they won't do nothing.

dd: How about washing up, do the washing up much?

eg: No.

dd: No, you don't?

eg: The domestic washes up.

dd: How about the washing up and that do you have to do that?

ss: I don't do the washing up there's a woman comes to do that?

dd: Do you like washing up?

pb: Aye...I don't know.

dd: Fair enough I don't much like washing up either.

pb: The domestic washes up when she's on.

dd: Does she?

dd: ...do you do the washing up?

cc: I'm setting the tables today, I have set the tables.

dd: So you take it in turns to do the washing up and set the tables and other things?

cc: I wash up tommorrow at tea time, I do.

dd: Do you like washing up and things?

cc: Aye.

Laundry

dd: What about washing, washing your clothes do yoy do that?

pb: Oh, the staff does that.

dd: The staff does it?

pb: I used to but they've stopped it now.

dd: When did you used to do it?

pb: Well it was before christmas.

dd: Why did they stop you doing it?

pb: Probably we played up with the machine; probably it - don't think they liked us - liked us washing you know, probably, I didn't know how to use them I used to be shown by Peggy.

dd: Aye.

pb: I don't know what to do to use them.

dd: That's all right its something you have to learn isn't it?

dd: How about washing your clothes do you do that?

wo: No, theres no washer here

dd: There's no washer here?
wo: Aye, they get mixed up your clothes.
dd: Yes?
wo: Why aye.
dd: How come?
wo: Cos the lad here talks on the telephone, he's not careful.

cc: I got some trousers from there as well (referring to shop in Darlington), blue ones and grey ones, the blue ones at the laundry, they been there four months, four months they been there, they ain't come back yet.
dd: Shouldn't take them that long to wash them should it?
cc: That laundry does, it does for Bishop Auckland, here, Earls House, Winterton.
dd: Really it does all of the laundry does it?
cc: It does all of the laundry...

Shopping

dd: ...do you ever go to the shop at the top there?
wo: No, lad got killed
dd: Eh?
wo: A lad got killed there.
dd: He did didn't he, I heard about that.
wo: Aye (name)

dd: ...do you do any shopping?
pb: No I go out to the shops for (nurse) when she wants anything, you know, she lets me keep the change, bits and pieces, thats about it I think.

dd: Where do you buy all your clothes?
mw: Newton Aycliffe, darlington or Durham, Newcastle.

cc: Stack of shops in Darlington, got these in Darlington, these in Darlington, cost five pounds, got two pair for five pounds.
dd: Really?
cc: Got two pair.
dd: Thats not bad is it...

ch: ...and I do all the beds in our dormitories.
dd: You do?
ch: I do all that side then I do this side.
dd: You still do that, its hard work isn't it?
ch: But I don't do them beds in there, that other dormitory.

dd: ...whats the things that you do around the house?
og: Well I have a bath and I tidy the washing and that.
dd: Do you help out with the other people?
og: I've just bathed Nelly Palmer.
dd: You bathed her?
og: Yes, before tea, before I went to the shop for Lynn.
dd: You give the staff a hand eh?
og: I don't mind.

In the community

Cooking

dd: Who cooks the dinner?
hl: Paul.

dd: Paul?
hl: He's off, he goes off at five tonight, somebody else comes on tomorrow morning.

dd: ...do you do the cooking here much?
df: Yes.
dd: What sort of things do you cook?
df: Just Saturday.
dd: Just Saturday - You've got a rota haven't you?
df: (nods).

dd: ...do you do the cooking much?
jp: On a Monday.
dd: Ahh.
jp: I can't do it on a Monday now.
dd: Yes?
jp: I used to do it on a Monday
due to rota change following new activity for Jo.

dd: ...tell me some of the things that you do in the house?
sg: The washing up.
dd: You do the washing up?
sg: Making the dinner.
dd: And making the dinner?
sg: And breakfast and tea.
dd: And what?
sg: Dinner, breakfast and tea.

dd: ...do you cook you own breakfast and that?
ec: No.
dd: Who does that?
ec: Alan (fellow resident).

fm: ...make me breakfast.
dd: You make your breakfast?
fm: Aye.
dd: What do you make?
fm: Cormflakes and a cup of tea.
dd: Do you make it for yourself do you?
fm: Aye

dd: So then you have your breakfast, do you cook it or does someone else?
ma: No.
dd: Who cooks your breakfast for you?
ma: One of the ladies does.
dd: You know, what do you call it with glasses.

dd: ...do you help with the cooking?
jw: Sometimes.

dd: Do you go to work?
et: Sometimes.
dd: Eh?
et: Do cookery and that you know.
dd: Oh aye.
et: Cleaning and make the tea.

dd: ...do you do any cooking or anything?
rc: No the cook doesn't come in today.

dd: How about cooking?

lg: I can't make it

dd: Is that cooked for you or do you have to do it yourself?

wd: They do it, the toast, in the kitchen.

dd: In the kitchen?

wd: Yes.

dd: Ah.

wd: You've come to see me?

dd: They do?

wd: you've come to see me?

dd: I have yes, do you do any cooking yourself?

wd: No I can't do that I burn, burn, burn me fingers off.

Laundry

dd: Have you got a washing machine here?

pb: Yes I've got one second hand, I've got to get another one.

dd: Whats wrong with the one that you've got?

pb: Conks out sometimes.

dd: ...do you have to wash the clothes?

tc: No that's all done for us.

dd: Who does the washing?

ik: The lady comes to take it away.

dd: How about washing your clothes, do you do that here?

sg: Ironing as well.

dd: ...what about washing your clothes do you do that?

df: Wash me clothes on Sunday.

dd: On Sunday do you?

df: 'Cos I won't be here.

dd: Oh, of course, it'll be your birthday on Sunday won't it, you won't be washin your clothes on this weekend will you?

dd: How about clothes, washing your clothes do you do that?

jp: Yes, I wash the clothes.

dd: You wash your clothes?

jp: Iron them and that.

Washing up

dd: ...do you do the washing up?

jp: Not always.

dd: Not always, do you like washing up?

jp: No, not really, it has to be done though.

dd: ...tell me some of the things that you do in the house?

sg: The washing up.

dd: ...do you do the washing up or does someone else do the washing up?

fm: Oh someone else goes and does it.

dd: Someone else does it, who does it usually?

fm: John Proud (resident)

dd: ...how about the washing up?

ec: Alan does it, Alan does it (resident).

dd: Alan does it?

ec: Aye.

dd: ...do you like doing the washing up?
ma: No I don't wash, Elizabeth does, but I dry.
dd: You do the drying, you like drying?
ma: Yes, thats what I dod at Aycliffe.

dd: How about the washing up?
jp: I do me bit, I do me bit.
dd: Yes.
jp: (to passing staff) don't I do me bit?

dd: Do you have to do the washing up sometimes?
ik: Washed up this morning.
dd: Eh?
ik: Did it all.

dd: ...do you have to do any washing up?
tc: Just wash the pots.

dd: ...who washes up?
wd: Someone in here washes up.
dd: Do they, do you do the washing up sometimes?
wd: Not me.
dd: You don't?
wd: No.

Laying tables and making beds were not mentioned in the community, more important activities in the hospital when done for larger number of people.

Shopping

dd: ...do you go shopping from here much?
tc: Just for meself.
dd: Just for yourself?
tc: Me paper, evening gazette and that and fruit, apples and oranges and that.
dd: You don't go out shopping for other things, is that all bought for you?
tc: No, all done for us.

ik: Been this morning to the village.
dd: You've been to the village?
ik: Yes.
dd: What did you buy?
ik: Hand lotion.
dd: Ahh, what else do you buy when you go shopping?
ik: Two pairs of shoes, two pairs of brazzieres and two petticoats.

dd: What other shops do you go to?
jp: Oh - We go to Tescos or Fine Fare, anywhere.

dd: What sort of shopping do you do?
hl: To get some drawing paper.

dd: Do you go shopping?
fm: Yes.
dd: Where do you go shopping?
fm: Down town.
dd: What sort of things do you buy?
fm: Oh - groceries.

dd: ...do you go somewhere else during the day?

mm: I just, er, sometimes on a weekend, to get some new clothes like I
go down the town like.

dd: You do?

mm: Yes, I go to the market like.

dd: It's a good market that, isn't it?

mm: Yes.

dd: What sort of things do you buy down there?

mm: Cakes.

dd: ...do you go shopping sometimes?

ec: Yes.

dd: Where do you go shopping?

ec: Fine Fare.

dd: Where do you go shopping?

sg: Fine Fare.

dd: Fine Fare?

sg: Yes.

dd: You go down there by yourself?

sg: And Eileen.

dd: With Eileen?

sg: With Eileen and Paula sometimes.

dd: How about shopping do you go shopping

jp: Yes.

dd: What sort of thing do you go shopping for?

jp: Clothes and that.

dd: Where do you go clothes shopping?

jp: To the clothes shop.

dd: Where do you go shopping?

df: Saltburn.

dd: What sort of things do you buy when you go shopping?

df: Records.

dd: You buy records?

df: Tapes.

dd: And tapes when you go shopping.

Work

In the hospital

dd: What sort of things do you do of an afternoon?
cc: Table work again.
dd: Do you enjoy doing that sort of thing, table work?
cc: No.
dd: No, what don't you like about it?
cc: Too boring.
dd: Boring is it, what would you rather be doing do you think, if you had a choice what would you do?
cc: Don't know really
dd: Would you rather work outside or would you rather work inside?
cc: Work out
dd: Outside, what would you do, gardening, farming?
cc: No.
dd: No, what sort of thing would you rather do?
cc: Cookery.

dd: What sort of things do you do during the day?
og: I just do contract now.
dd: You do contract work?
og: Yes.
dd: What sort of thing is that?
og: Christmas tags, you put, you put five in a little plastic bag, about that big, I've got to check them to make sure they're all there...
dd: What do you think about that sort of work?
og: Alright.
dd: Do you like it?
og: Mmm.
dd: Which do you prefer, is it better doing this or was it better doing, was it btter in the canteen?
og: Well its better doing the contract.
dd: It is?
og: Well I mean I never got a rest in the cafe.

dd: ...do you go to work?
eg: Yes.
dd: Do you like going to work, what do you do?
eg: Contract work.
dd: Yes, you said that, what sort of thing is contract work, what does contract work mean?
eg: Like, well, christmas parcels to sell.

ss: Make beds in the morning like, that one there and that one there.
dd: Yes?
ss: Make beds in the morning, I go up there and make beds in the morning and this one here and go staright to work in the afternoon.
dd: What work do you do in the afternoon.
...
ss: Depends on what Dougie gets to do, I sometimes run messages you know.
dd: Oh, you run messages?
ss: Aye, i run messages.
...
ss: Aye boy, well i go in like and I asks her and i helps the jobs she says like, go a message for me, Sammy go up the shop, so I go up,

I say right, I don't need money for going, I give her money back you see.

pb: I go to the Falcon Centre and I do woodwork.

dd: You go to the Falcon Centre?

pb: Monday to Friday.

dd: On a Monday to Friday?

pb: Cos we don't do anything on a Friday afternoon just watch television.

dd: Yes?

pb: Yes.

dd: Do you like going to the Falcon Centre?

pb: Yes.

...

dd: ...can you think of something else that you'd rather do for work then?

pb: I asked Alice she says, what would you like to do, I said woodwork, cos thats a good hobby that I had.

dd: What do you do at work June?

jm: Put those cards, what you saw us doing, put those cards into the plastic bags.

dd: Christmas tags?

jm: For christmas tags.

dd: Do you enjoy going to work June?

jm: Yes.

dd: Whats good about it?

jm: Because you get your break there, at ten o'clock and nine o'clock and, sorry, three o'clock.

dd: Would you rather do something else?

jm: No I don't think I'd rather do something else.

mw: I go every day.

dd: Where to?

mw: Fl's lower.

dd: Fl's lower, I know it, what is it that you do there?

mw: Eh?

dd: What sort of things do you do there?

mw: Just ordinary things, I don't do anything.

dd: You don't do anything?

mw: No.

In the community

df: Starting me new job in a months time.

dd: In a month, what are you going to do?

df: Gardening.

dd: You're going to do gardening?

df: And bricklaying.

dd: Really, you look pleased about that.

df: Yes.

dd: Yes, is it going to be better than your old job or worse do you think, better than your old job or worse?

df: Me new job.

dd: You're new job?

df: Better

...

dd: ...do you enjoy going to work there?

df: Yes.

dd: Or would you rather go somewhere else?

df: Work somewhere else.

dd: You'd like to work somewhere else?
df: At the motor bike (unclear).
dd: Where?
df: Making motorbikes.
dd: Make?
df: Making motorbikes.
dd: making motorbikes, you want to make motorbikes?
df: Yes.
dd: Do you know anybody who does that?
df: Works at Redcar.
dd: Yes, does he, he makes motorbikes?
df: Yes.

dd: What sort of thing do you do for work?
jp: Cutting grass and that.
dd: Cutting grass and that, where do you go for work?
jp: Old peoples houses.
...
dd: ...do you enjoy that job?
jp: Yes.
dd: Do you enjoy working with Norman?
jp: It passes the time away doesn't it?
dd: It does that.
jp: Its no good walking about all the time.
dd: No.
jp: No good doing that.
dd: No.
jp: Got to do something.
dd: Yes, if you enjoy it it extra good isn't it?
jp: Yes, I enjoy it.

dd: What do you do during the day, do you go out to work?
sg: Yes, Beck House on Monday.
dd: Beck House on Monday?
sg: In the gardens on Monday.
dd: Yes?
sg: Monday morning afternoon on the garden.
dd: What do you do there?
sg: Dig weeds up.

dd: What sort of work do you do at Beck House?
ec: (incomprehensible)
dd: What?
ec: Cards.
dd: Cards?
ec: Yes.
dd: What do you do with cards?
ec: Put string through them David.
dd: Put string through them?
ec: Yes.
dd: Oh I know, do you do anything else there?
ec: No.
dd: Do you enjoy doing that?
ec: Yes.

dd: Do you enjoy going to work every day?
mm: Yes.
dd: What do you enjoy about it?
mm: Everything, anything.

dd: Do you go to work?
fm: Where?

dd: Here.
fm: No, I work inside this house.

hl: I go out on the bus, pick up the lads.
dd: Pick the lads up, where do they go?
hl: Work.
dd: Oh they go to work do they, do you go to work?
hl: I'm on holiday.
dd: Oh of course.

dd: So what do you do when you're at work?
ma: Knitting all the time.
dd: You do knitting do you?
ma: Yes.
dd: Do you do anything else?
ma: No.

...

ma: Oh, we do painting, first keep fit, I do it on a chair
dd: you sit on a chair to do keep fit?
ma: On a chair, yes to do keep fit.
dd: Do you enjoy keep fit?
ma: Yes.
dd: What other things do you do, you do keepfit and you do knitting,
do you do anything else?
ma: I try to learn to dance.

dd: ...is there anything that you don't like?
ik: Hmm, the centres horrible.
dd: What is?
ik: The centre gets on your nerves.
dd: The sound is?
ik: The centre.
dd: The centre, which centre is that?
ik: Hundens Lane.
dd: Is that where you work?
ik: Mmm
dd: Whats it called, the centre?
ik: Hundens Lane.
dd: Hundens Lane.
ik: Mmm.
dd: Whats bad about it, what don't you like about it?
ik: Don't like the centre now.

...

dd: What do you do at the handicraft centre?
ik: Catelogues.
dd: Catelogues?
ik: Yes.
dd: What do you do with them?
ik: Look at them.
dd: Look at them?
ik: Mmm.
dd: Do you do anything else?
ik: No.
dd: No, nothing at all, is that good or bad, the handicraft centre?
ik: Its too noisy.
dd: Its too noisy?
ik: Mmm.
dd: Would you rather go somewhere else?
ik: Yes.
dd: Where else would you rather go?
ik: Don't know.

tc: Its first a course, I finish at four o'clock monday and then the other three days I'll finish at five.

dd: So its a long day isn't it?

tc: Yes.

dd: What sort of thing will you be doing?

tc: Cooking.

dd: Cooking?

tc: And waiting on.

dd: Waiting?

tc: Yes.

dd: Do you have to wear a bow tie?

tc: (laughs) no, just a badge.

...

dd: ...what do you like about it?

tc: I like the cooking.

dd: You like the cooking?

tc: The cooking and the waiting on.

...

dd: ...have you worked at other places?

tc: Yes.

dd: Where was that?

tc: At Upton Hall.

dd: At Upton Hall, in the gardens?

tc: No, metal work.

dd: Metal work was it, did you like that?

tc: No.

dd: No, what didn't you like about it?

tc: It was too hard.

dd: Too hard was it?

tc: Yes, never stopped all the time.

dd: From when you get up in the morning, what do you do then?

lg: Work.

dd: Go to work?

lg: Yes.

dd: Where do you go to work?

lg: Over there.

dd: Over there?

lg: Yes.

dd: WhAt do you do at work?

lg: Eat me dinner, no pudding.

dd: No pudding?

lg: Cake.

dd: Some cake?

lg: Yes.

dd: What do you do at work, what sort of work do you do?

lg: Nothing to do.

dd: Theres nothing to do there?

lg: No.

dd: ...what are you doing during the day now?

wd: I'm working, working at the centre, painting, with pictures

dd: You paint pictures eh?

wd: Yes.

dd: Aye, you enjoy that?

wd: Enjoy it, yes.

dd: Where is it, whats the place called, do you know?

wd: Er, that centre that we go down, er, over there.

dd: I know it, so what do you do there?

wd: Er, painting pictures of houses.

Out of home leisure

In the hospital

ic: ...I do go with June and that.

dd: Yes, and what do you do when you go out?

ic: A walk, a walk out.

...

dd: Do you go to the pubs?

ic: Yes I do.

dd: What do you do when you go to the pub?

ic: Have a drink at pub.

dd: What do you have to drink?

ic: Pop.

dd: ...do you go out in the evenings?

mw: Not very much.

dd: Do yo go out to the discos?

mw: Yes.

dd: Do you enjoy the discos?

mw: Yes.

dd: Do you like dancing?

mw: Yes.

dd: Who do you dance with?

mw: My boyfriend.

dd: Your boyfriend?

mw: Yes, John Scott.

dd: Do you go out much June?

jm: Just to church and to the bingo and Communion on a Tuesday.

dd: When do you go to the bingo.

jm: On a, on a Sunday night and a Thursday night.

dd: What do you win at the bingo - or what can you win at the bingo?

jm: I won a bottle of conditioner, a small bottle and that once...

dd: Tell me some of the things that you do here when you're not working, do you go out much?

pb: No.

dd: No?

pb: Aye, discos sometimes, disco for half an hour, theres one this afternoon, video tomorrow afternoon with television, watching videos down the community centre, disco on a Saturday night, Monday night, video on a Tuesday night, bingo on Wednesday, Gateway Wednesday, bingo Thursday, Bullseye on a Friday, thats tonight Bullseye.

dd: Do you go out much?

ss: Not very much like, go out to the club and back here for half past eight, as soon as I come in I get me boots off and I go straight to bed at nine o'clock.

...

dd: So you go down the community centre then?

ss: No, of a night I do, Saturday night I do.

dd: Saturday, whats on there of a Saturday?

ss: They do a disco.

dd: A disco?

ss: Aye.

dd: Oh aye, you like the disco?

ss: For a change.

dd: Who do you go down there with?

ss: By myself
dd: By yourself, what other things go on down at the community centre?
ss: Bingo, bingo and all sorts.
dd: That's good, when I went down to see the bingo you were helping
the ladies at the table weren't you?
ss: Yes.
dd: Giving them a hand with the cards?
ss: Yes.
dd: Eh?
ss: Well I'm not going to sit about doing nought.
dd: Well I know you like to do things.
ss: Well you see some of them can't mark their boards.
dd: Aye.
ss: Some of them, they say will you mark the boards and I say, aye.

dd: Do you go out at night here?
js: To the centre.
dd: To the centre and what do you do there - what do you do at the
centre?
js: I get the bingo ready.

dd: ...do you go to the pub much?
og: With Anne, I've got a new drink.
dd: What's that?
og: Its yellow stuff, I don't know what they call it, but you put
lemonade in it and it goes like -
dd: Very fizzy?
og: No like, oh I can't - like liquid parafin, not liquid parafin,
like methelated spirits, medicine, its like that, I can't really
think what it is.

...
dd: Do you go down to the community centre down here much?
og: Mmm.
dd: What do you go down there for?
og: See a dance, bingo.
dd: You like the bingo?
og: I do but I don't win.
dd: Well not everybody can win can they?
og: I don't mind, they only get shampoo and talcum powder, if i get
some bought back I only give it to the kids.

cc: Just the centre.
dd: You go to the community centre?
cc: On a Monday, Tuesday, Thursday, Saturday, Sunday.
dd: What sort of things do you do over there, you go to the bingo?
cc: Bingo, disco, pictures.
dd: Pictures?
cc: Thats a Sunday.
dd: Oh they do films do they?
cc: Good films, video films.

...
dd: ...do you ever go out to the pub or anything?
cc: No.

5 people mentioned televisionas a major leisure activity

dd: Whats your favorite program?
ic: Coronation Street.
dd: Ah, Coronation Street.
ic: Yes I do.

dd: Do you watch the tele much?

wo: Sometimes.
dd: Whats your favorite program on the tele do you reckon?
wo: Er, what do you call it.
dd: Whats your favorite program on the tele?
wo: James Bond.
dd: Is it?
wo: James Bond.

In the community

dd: Do you go out much?
pb: Well just down the town, Mondays and Fridays had it been summer I'd have been in the garden tidying up like trying to get it nice again the way I used to have it but I got to get a greenhouse first and then i got to get some plants growing...
dd: Who do yu go with to the Gateway club?
wd: Er, Joyce, Joyce, works in there, he takes you to the club.
dd: He takes you to the club does he?
wd: Aye.
dd: You go to the Gateway Club a couple of times a week don't you?
wd: Yes.
dd: Do you like it there?
wd: Like it there yes.
dd: What sort of things do you do?
wd: Play, play dominoes.
dd: Yes?
wd: Darts, theres everything there.
dd: ...do you go out?
lg: No, I been to the dance.
dd: The dance?
lg: With Philip.
dd: You been to the dance with Philip.
lg: Get a cup of coffee.
dd: ...so do you go out much other than that, you say you go to the Broadway pub?
tc: I only go there when I'm in the mood for it, I only have one half cos I'm on tablets see, only one half, only one half.
dd: Do you go to the pub much?
jp: Yes.
dd: Which pub do you go to?
jp: Anyone.
dd: Anyone?
jp: I don't drink beer, I drink lemonade, I don't drink beer, I don't drink beer, I don't drink it.
dd: ...where else do you go to, is there somewhere else?
jw: The club.
dd: The?
jw: The club.
dd: The club, what nights that?
jw: Wednesday night.
dd: Wednsday night?
jw: Yes.
dd: What sort of things do you do there?
jw: Play dominoes.
dd: Anything else?
jw: Pool.
dd: Pool?

jw: Table tennis.

ma: We went to the dance.

dd: You went to the dance on Monday night?

ma: Joan took us it was raining.

dd: ...do you go out much?

hl: I go out much.

dd: You do, where do you go?

hl: The park.

dd: You go to the park, what do you do at the park?

hl: Feed the ducks.

dd: You feed the ducks, you go to feed the ducks, anything else that you do at the park?

hl: I just look at the boats.

dd: Anywhere else that you go out to?

hl: I'm going out tonight.

dd: Where are you going?

hl: For a half.

dd: For a half, which pub are you going to?

hl: Down there...

dd: Do you go to any clubs?

ec: Just the Gateway.

dd: The Gateway, what do you do at the Gateway?

ec: Play snooker.

dd: You play snooker do you?

...

dd: Do you go to the Fireside Club?

ec: Yes.

dd: What do you do there?

ec: Sing hymns David.

...

dd: Which is better do you think the Fireside Club or the Gateway?

ec: The Gateway.

dd: ...Do you go to the gateway?

sg: Yes and i go to the Gateway Club - not now (meaning not tonight).

...

dd: What else, you go to the folk club don't you?

sg: Yes I went last night.

dd: Did you, what was on, was there somebody singing there last night?

sg: Yes a lady singing last night.

dd: A lady singing, was she good?

sg: Yes, with a guitar.

...

dd: What other places do you go, do you go to the pub much?

sg: Yes i go to the pub much.

dd: Which pub do you go to?

sg: Shuttle and Loom sometimes.

dd: ...do you go out in the evenings?

jp: Yes.

dd: Where do you go?

jp: All around Saltburn.

dd: Any special places?

jp: Down the beach.

...

dd: ...anywhere else?

jp: The machines, them bandit things.

dd: The one arm bandits?

jp: They're down there...

dd: Tell me some of the things that you do here when you're not at work, do you go out much?

df: Yes.

dd: Where do you go?

df: Go out to see me friends.

dd: See your friends, where do your friends live?

df: Down the beach.

...

dd: ...do you play football sometimes in the evenings?

df: Middlesbrough, er, Guisborough.

dd: Guisborough, oh, who do you play against?

df: Rob and -

dd: Who?

df: Rob and Brian.

dd: Oh I see, do you enjoy that?

df: And Keith.

...

dd: Do you go to the library, where is the library?

df: Just down round the corner.

dd: What do you get out of the library?

df: A book of cars.

dd: A book of cars - do you go to the swimming pool?

df: Just the sports centre

Television

dd: ...what do you do when you stop in, when you stop in?

jp: I just watch the television of a night man.

dd: What's your favorite program on the tele?

jp: All things.

dd: Do you watch tele much?

mm: Nighttimes

dd: Nighttimes, whats your favorite program?

mm: Theres not much on like.

dd: Theres not much on is there?

mm: No.

dd: What do you like watching?

mm: Like films like.

jp: I bought a book yesterday.

dd: Did you?

jp: How to clean tanks out it tells you.

dd: How to clean tanks out?

jp: It tells you in the book.

dd: Oh, I see, fish tanks.

jp: You know what I mean.

dd: What do you do during the day here

hc: I knit.

Friends

In the hospital

dd: Do you have friends here?
ic: Hmm Hmm.
dd: Who'se your best friend here?
ic: At Aycliffe as well you know.
dd: Your best frinds at Aycliffe are they?
ic: They are, some of them are, some of them they are, some of them are you know at Aycliffe as well.

dd: What about friends here, have you got friends here?
ch: I wouldn't have any friends here.
dd: You wouldn't?
ch: Not bristow I wouldn't
dd: No?
ch: I talk to the other girls but not her she's got too much of a tongue.
dd: Anybody else you don't like here?
ch: I like all the girls here.
dd: Yes.
ch: Just the one I don't like, her you see.

dd: Who's your best friend on the ward, what' their name?
mw: I haven't got a best one.
dd: No, can you describe what a friend is, what is a friend?
mw: A friend is a person you talk to.

dd: Do you have friends here?
jm: Well Anne Caotes, that girl thats just gone out, she's a friend sometimes, but sometimes she nags on but I take no notice of her.

dd: What about friends here do you have friends here?
pb: No, stick to meself.
dd: Stick to yourself - do you like to have friends here?
pb: I talk to the lads, these here, I ask them if they're alright and that.
dd: Yes.
pb: They push you about, tell you to buzz off and that you know
dd: So you don't have many friends here?
pb: Not really, I just say hello to them.
dd: Would you like to have more friends?
pb: No, I don't know, I aint a person for them.

dd: What about friends here, ahve you got many friends here do you reckon?
wo: One ot two
dd: One or two?
wo: Aye.
dd: What are they called?
wo: Some of them like, Stephen Eddleton

dd: ...who is your best friend here do you reckon?
ss: Well everybodys me friend here.
dd: Everybody?
ss: Yes.
dd: Have you got any special friends in the hospital?
ss: Oh I got no special friends.

og: I found friends.
dd: Good friends?
og: Very good friends.
dd: Who are they, anyone in particular?
og: Anne Patterson, the staff in here, the staff on the wards as well.

dd: ...do you have any friends here?
cc: Aye, I got three.
dd: You got three, who's your best friend?
cc: Mary (name) over the centre, Edith, Arthur.
dd: Is Mary a staff?
cc: Staff, she works at the centre she does, and Edith works at the centre she does, one of the wards she's got, at the female end, F6 she's got, when she was thee for 5 weeks I used to make all her beds for I did.

...
dd: ...are all your friends just staff?
cc: Kenny, Kenny, the one who was shouted for a cup of tea, went down there.
dd: Was he the man who sits at your table?
cc: Aye, I watch TV with him sometimes.

Family

dd: Do you see any of your relatives very much?
cc: Aye they come and visit me they do.
dd: They do?
cc: Aye.
dd: Who comes?
cc: Me mam.
dd: your mam?
cc: And me sisters.
dd: Your sisters?
cc: Aye.
dd: Do your sisters live in Midellsborug now as well?
cc: They all live in Midelsbrough.
dd: In the same house or are they spread out?
cc: They're married.
dd: They're married, have they got any kids?
cc: I'm an uncle.

dd: Was your dad still alive?
og: Was then, but he's not now, she is (step mother).
dd: She is?
og: Mmm, she doesn't bother with me though, haven't seen her for twenty odd year, I'm not bothered though, she thinks I'm still at Rampton, I've been here eighteen year nearly.

dd: ...have you got any body that comes to see you?
wo: No.
dd: No, not at all?
wo: I have a sister in, oh, er, Dundee.
dd: In Dundee?
wo: I used to have a brother in Hartlepool but not now.
dd: Not now?
wo: He's retired now and all.
dd: Aye, he would do.
wo: And Herbert.
dd: Eh?
wo: My other brother and all, Herbert.
dd: Where does he live?
wo: Well he lives in Hartlepool as well, he's married.

dd: Does he ever come to see you?
wo: He doesn't go.
dd: Does anybody come and see you?
wo: No.

pb: I stay with my brother and sister, my sister lives down the road, two or three minutes walk from where they are, and they both have a telephone, but I don't ring me sister, I don't know her phone number, my brother, Doris I rang last Sunday, the week before about going home the weekend, she says she'll write.

...
dd: So how often do you see them?
pb: Hard to tell, couldn't say.
dd: That's alright, do they come and see you?
pb: No, they don't come, they have two or three times, I go to them.

dd: ...who have you got who are relatives?
mw: I had me father.
dd: You had your father.
mw: And me two brothers.
dd: Your two brothers, is your father still around?
mw: No he's dead now.

...
dd: ...how often does Tommy come and see you?
mw: Sometimes during the week.
dd: Does he, what do you do when he comes to see you?
mw: I go out with him.
dd: Do you, where do you go out?
mw: Walk round the grounds.

In the community friends

dd: ...what about friends have you got any friends here?
df: Angela.
dd: Angela's your friend is she, she's your girlfriend.
df: And John.
dd: And John yes.

dd: Who is your best friend here do you think?
jp: David.
dd: David, is it good or bad to have friends do you think?
jp: Sometimes its nasty.
dd: Sometimes its nasty, why when is it nasty?
jp: When he has to do things.
dd: Oh I see.
jp: He can get awkward.

dd: Tell me who is your best friend do you think?
sg: Eileen (staff).

...
dd: Who else is your friend then Sandy, who else is your friend.
sg: Paula and Margaret (staff).

dd: Tell me something about your friends, have you got any friends?
ec: Just Paula.
dd: Who?
ec: Paula.
dd: Paula, is she your friend?
ec: Yes.

dd: ...tell me what is a friend?

hl: Brian and Winn (staff).

dd: Who's your best friend here?

ma: Er, Miss, Genette and that.

dd: Does she live here or does she work here?

ma: She works here but we always say to her, er, hows your bairns getting on?

dd: She's got bairns has she?

ma: Two little girls.

dd: You got some friends here, do you have any friends?

jw: Yes.

dd: Who is, who's your friend here?

jw: Harry (name).

dd: Harry.

jw: And Larry Conolly.

dd: Larry Conolly?

jw: Hmmm.

dd: What about friends, who's you're best friend do you think?

jp: I've got plenty of friends, I can't call them, any amount of them.

dd: Any amount of them?

jp: I couldn't fault them I couldn't.

dd: Who's your best friend do you think?

jp: Anybody.

dd: Anybody, would you like to have more friends or do you think you've got enough friends?

jp: I could fall out with them but I don't want to because they're all good to me.

dd: What are friends?

ik: Got none.

dd: Got none?

ik: No.

dd: Have you got any friends here?

wd: Friends here.

dd: Have you got any friends here, who's you're best friends here?

wd: Linda and Mandy.

dd: Are they people who live here or are they staff?

wd: They're staff here.

tc: Behind the old peoples home my friends live their.

dd: You have friends there, where did you know them from?

tc: I knew them from Aycliffe.

dd: From Aycliffe, did they used to work there or live there?

tc: No, they have a son at Aycliffe and thats how I came in touch with them...

...

dd: ...what about people here have you got friends here?

tc: Yes, plenty of friends here, they're alright but sometimes they get on me nerves, sometimes they're alright, when you ask them to move out of the way of the tele they get nasty with you sometimes, they stand in the way of the tele, justfor the benefit, so you can't see anything, I tell them to move, I say excuse me can you move the tele please and they move straight away.

dd: Have you got any friends here?

lg: Philip.

dd: Philip, any other friends?

lg: Molly.

dd: Molly.

lg: Betty.
dd: Betty.

Community Family

tc: ...I like the avenue best and I like darenth Crescent best cos it was easy to get to see me sisters, easy to get to me brothers but now me sisters moved and me brothers moved, I have a sister that lives in Bishopton Road, thats the one that lives down town, I have two sisters that live down town, one is in (unclear) road, the other lives in Bishopton Road, the other 4 live out of town, I ave one lives in Belfast.

dd: In Ireland, what is she doinf there is her husband a soldier?

tc: Husband in the army, every time he goes over there she goes over with him.

dd: Thats your brothers and sisters, do you see your mother and father much?

tc: I haven't seen me Mum and Dad for nearly four months, cos I can't get the bus fair is nearly one pound thirty a time.

dd: How much?

tc: One pound thirty, they live in Corby Newham, its hard to get there from here, Its hard to get there cos I get four pound pocket money a week and I can't possibly pay one pound thirty every week, they asked me to go every day and I can't go every day.

wd: Mam and Dad and sisters and Brothers at home in Darlington now.

dd: They live in Darlington?

wd: Yes.

dd: Do you see them much?

wd: Yes once I did been at home, last Sunday, in the car, my brother come for me in the car.

dd: Do you see your family much?

pb: Well as much as I can - aye when we can, 'cos its four pound for the two of us to go up there.

dd: Have you got any other relatives in Newcastle?

pb: Got me brother that lives up there.

hc: I've got one sister, Ivy.

dd: Ivy?

hc: Hmm.

dd: Where does she live?

hc: Only her and her husband.

dd: She's married has she?

hc: Bobby, Bobby Craggs.

dd: How about relatives, have you got any brothers and sisters?

jp: Yes I had many sisters, I've only got three left.

dd: Three?

jp: Yes.

...

dd: Do you get to see them very much?

jp: Well -

dd: You get up to Morpeth sometimes?

jp: I was up there last time, Margarets going to take me up again, to see our lass, she's going to fetch her through to see.

dd: To see you here?

jp: And when she comes up here she'll take her back again.

dd: That'll be nice, yes?

jp: She's going to write a letter to her, tell her she's going to fetch her through.

dd: Do you know how old she is?

jp: She's over eighty our lass.

dd: Is she older than you?

jp: Yes, I'm only 76.

dd: Only 76?

jp: Yes.

dd: Where does (your aunty) live?

jw: (name) farm

dd: How often do you go to see her?

jw: Nearly every night.

dd: Nearly every night?

jw: Yes.

dd: You going there tonight?

jw: Yes.

dd: How far is it?

jw: Not far, couple of minutes walk.

dd: ...do your Mom and Dad and sisters come and see you?

ma: Er I go home, I see me sister at home, Muriel.

dd: What's your sister called?

ma: Muriel.

dd: Muriel.

ma: When I come out of the Taxi, muriel is walking slowly.

dd: Does she walk slowly?

ma: No me.

dd: Do your relatives come to see you?

hl: Hmm.

dd: Which relatives?

hl: Me sister and me brother.

dd: Your sister and your brother, where does your sister live?

hl: South shields

dd: Does she come to see you often?

hl: When she phones.

dd: She phones, does your brother come and see you often?

hl: Hmm.

dd: How often does your brother come and see you?

hl: Once a month.

dd: Do you have any relatives round here Fred?

fm: No.

dd: Have you any brothers and sisters?

fm: No I'm the only one in the family.

dd: Where does your mother live?

mm: Middelsbrough somewhere.

dd: Do you go to see her much?

mm: Sometimes I, when me brother comes like.

dd: Have you got any brothers and sisters?

ec: Yes.

dd: Where does your sister live.

ec: She lives in Darlington.

dd: Do you see her much?

ec: Not much no.

dd: Whats her name?

ec: Sylvia

dd: Have you got any brothers or sisters?

sg: No sisters, just brothers.

dd: No sisters, just brothers eh, where do they live?

sg: Bishop Auckland.

dd: Bishop Auckland?
sg: Yes.
dd: Do you see them much?
sg: Saw them at Christmas (interview conducted end of march).

dd: ...have you got any relatives?
jp: No, no father.
dd: Is your mother still alive?
jp: She is, she's still living.
dd: Do you see her much?
jp: She never comes round much.
dd: Hmm.
jp: Me two brothers come.
dd: Yes?
jp: Me two brothers come up.
dd: Yes, where do they live?
jp: With me mother.

df: Margaret.
dd: Is she your sister?
df: Yes.
dd: Do you go to any other, where does she live, where does Margaret live?
df: Redcar.
dd: Not far is it, she's coming to see you is she?
df: Tomorrow.
dd: What's she coming to see you for, what for?
df: Presents gonna get me presents.
dd: Presents for your birthday...

Appendix Ten

Place preferences

In the hospital

dd: What ward is this?

tt: Male seven.

dd: Do you like living here?

tt: Yes thanks.

dd: Can you think of somewhere better to live?

tt: Where?

dd: Where...ok...

dd: Can you tell me what you enjoy doing here, whats the best thing about being here?

ic: I don't know, I don't know that.

dd: You don't know, is there anything that you don't enjoy doing?

ic: No nothing...

...

dd: What was it like living there?

ic: Alright, alright (laughs)

dd: Was it alright?

ic: Yes it was alright.

dd: What sort of thing did you do there?

ic: I don't know, I don't know

dd: Ok, what was the best thing about being at Aycliffe?

ic: Alright, alright now, over there.

dd: It was alright?

ic: It was over there.

dd: Can you tell me what the ward is?

js: One's Upper.

dd: Do you like living here?

js: Yes.

dd: Can you think of a better place to live, can you think of somewhere else you would rather live?

js: Yes.

dd: Where?

js: (no reply).

...

dd: Do you like it at Aycliffe?

js: Yes.

dd: What do you like best about it, whats the best thing do you think, whats the best thing about it?

js: No.

dd: Ok, is there anything you don't like about it...anything bad about it?

js: Aye.

dd: Is there, what don't you like about it?

js: It's the second of June tomorrow.

dd: Do you like living here?

ch: No.

dd: No, thats alright you don't have to like it.

ch: 'Cos Bristows got a big mouth she's moaning all the time at the table, she doesn't sit beside me like, 'cos elsie's getting sick of her moaning, she swears and calls you all sorts, she called me a bastard today.

...

dd: Would you like to live somewhere else do you think?

ch: I would go yes, when I get this off, me bag off, I don't want to go with a bag on, I've got a hostel at Bishop (referring to catheta).

dd: Yes.
ch: But I'm wearing a bag here, I don't want to go with a bag on.

dd: So whats good about being here, to being at the other places?
mw: This is nicer.
dd: Is it?
mw: Much quieter really, than you will find in that other home.
dd: Was it?
mw: Oh yes.
...

dd: Do you think it would be nice in a hostel or do you think i
wouldn't be nice in a hostel?
mw: I like being here
dd: You like being here?
mw: Yes.
dd: Would you like to go to a hostel?
mw: I wouldn't mind.
dd: You wouldn't mind, what do you think would be the best thing about
being at hostel?
mw: Eh?
dd: What do you think would be the best thing about being at hostel?
mw: Trying to behave yourself.
dd: So what do you think about living here?
mw: I'll have to get used to staying here won't I.
dd: What do you think about that, it's alright here is it?
mw: Yes.
dd: Do you think it would be better somewhere else?
mw: No.
dd: Ok.

dd: You'd rather live?
jm: At Aycliffe.
dd: At Aycliffe?
jm: If I get the chance, I'd rather be out to a hostel.
dd: You'd rather live in a hostel, why is that?
jm: 'Cos you can go and visit your people there.
...

dd: Is there anything bad about Aycliffe, anything that you dislike?
jm: ...just can't stand it amongst these patients.
dd: Why's that?
jm: Cos some of them are always arguing with you and fighting.
dd: And you dislike that do you?
jm: Ah huh.

dd: ...how do you like living at South Cottages, alright?
pb: It's alright.
dd: Its alright is it?
pb: I'd sooner be at home for good.
dd: Would you, but do you like living here?
pb: Yes.
dd: Its alright?
pb: For the time being.
dd: For the time being, can you think of a better place to live?
pb: No, only at home like.
dd: At home, yes...
...

dd: So where, you'd rather live where?
pb: I'd sooner go home for good.
...

dd: You like living here though?
pb: I'd sooner go home.

dd: ...how long have you lived here?
wo: A long time.
dd: A long time is it, how do you like it?
wo: It's alright.
dd: Can you think of somewhere better to live or is this it?
wo: (unclear)
dd: You don't know where else?
wo: Nowhere to go is there.
...
dd: So what do you reckon is this a good place to live?
wo: Ah, this is a load of rubbish.
dd: Eh?
wo: They pick on you half of them
dd: Do they?
wo: Why aye.
dd: Hmm.
wo: They talk to themselves half of them, when they're in bed.
dd: Do they, do you have trouble sleeping?
wo: Aye
...
dd: Where do you go shopping if you go?
wo: I go home.
dd: You go home?
wo: I wish I could
dd: You wish you could, where is home?
wo: Hartlepool

dd: ...do you like living here?
eg: Yes.
dd: Yes, can you think of a better place to live?
eg: A hostel.
dd: A hostel, why do you think that would be better.
eg: Be able to see me mam more.
...
dd: Which is better do you think living here or living at 6 Queens?
eg: Living here.
dd: Here's better, whats better about here than 6 Queens do you think?
eg: This is quiet.
...
dd: What do you enjoy about living here?
eg: I like having birthday cards.
dd: Anything else thats good about living here?
eg: You get your tea here.
...
dd: So where would you rather be living do you think?
eg: A hostel.
dd: A hostel.

dd: Whats the best bit about living in the hospital do you reckon,
whats the best bit, what do you like best about it?
ss: Why don't get me bloody wrong, what are you trying to do get me
wrong or something?
dd: Eh?
ss: What are you trying to do get me wrong or something?
dd: Oh no, I'm not getting you wrong, I just wanted to know...

dd: What do you think about living here?
og: Its alright you know but you have to run after them a lot.
dd: Yes.
og: I don't mind doing it but I get really bad tempered.
dd: Well that's understandable, everybody does that don't they?
og: I been in these places since I was sixteen.

...
dd: So what do you thinks good about here?
og: Well they help you up here.
dd: Do they, oh up here, do they help you as much as on the wards?
og: No, well when you sit down they expect you to look after, to follow them, and that, I don't mean the kids, I like, they look after you when you're poorly up here.
...
dd: So what do you think is good about here?
og: Well they help you up here.
dd: Do they, oh, do they help you as much as on the wards?
og: No they won't listen to you, well (name) used to listen to us, and (name) when they were on DSU and F4 East, well I was on DSU with (name), she wouldn't lisen to me so I duffed her.
dd: Oh dear, so what else, is there anything else good about being here?
og: Yes.
dd: What else?
og: I've more freedon here, the staff are good to me, do anything for you.
dd: Aye they're nice up here, is there nothing bad, nothing you don't like?
og: No, well when you sit down they expect you to look after, to follow them and that, I don't mean the kids, I like, they look after you when you're poorly up here.
dd: But the rest of the time?
og: They expect you to run after them all the time, when they won't do their jobs, they won't do their jobs.
dd: You don't think so?
og: Well (name) was poorly yesterday, she was sick.
dd: So she couldn't do her jobs?
og: Couldn't do the washing up, she hasn't done it today, she might do it after tea.
...
og: Did you see (name) yesterday?
dd: No.
og: No, she had two social workers yesterday.
dd: Did she?
og: About me.
dd: About you?
og: She's taking me home to live with her.
dd: Is she now, when's that?
og: Before Christmas.
dd: Before Christmas, that's definite is it?
og: Well we're not quite sure, we've got to wait you know.
dd: Well, that'll be good won't it.
og: Hmm.

dd: So do you like living here?
cc: No, I'd like at home.
dd: You'd rather live at home?
cc: Yes, if I was at home I'd work at the supermarket.

In the community

dd: Can you think of somewhere better to live, somewhere nicer to live?
df: Yes, Margarets.
dd: Pardon?
df: With Margaret.
dd: Live with Margaret, who's Margaret?
df: Me sister.
dd: Your sister, so you think that would be better?

df: Yes.
...
dd: ...so whats the best thing about being here?
df: Don't like Aycliffe.
dd: Don't like Aycliffe, what about here, here, what's good about it,
whats the best thing about it?
df: Hollingside is better.
...
dd: ...what was bad about it, what didn't you like about it?
df: Too noisy.
dd: Too noisy, you like it quiet?
df: (nods)
...
dd: So which do you think is the best place to live, here or Aycliffe?
df: Here
dd: Here

dd: ...what was it like living at West Cottages
jp: It wasn't nice at all.
dd: It wasn't?
jp: The staff weren't nice to you.
dd: No, what were they like?
jp: Bawling at you.
dd: Bawling?
jp: Shouting and that.
...
dd: What did you think about living at Aycliffe, when you lived there
did you like it?
jp: No.
dd: No?
jp: I was there too long really.
dd: I reckon you're probably right.
jp: I was there too long.
...
dd: ...was there anything that you liked about it at all?
jp: Getting out - I though I never were going to get out, I thought I
was never going to get out of there.
dd: You did, its a nice place this isn't it.
jp: Oh I like it here yes.
...
dd: ...you like it here yes, you like it living here, yes?
jp: Its better than the hospital.
dd: Its better than the hospital, that's smashing.
jp: I shouldn't have been there should I?
dd: I don't know why, there's no reason -
jp: They said I shouldn't have been put in there.
...
dd: Can you think of somewhere better to live?
jp: You mean go somewhere else, you mean move somewhere.
dd: If you could, cos I don't have anything to do with that.
jp: You can't move nobody?
dd: No...If you could would you like to or would you like to stop
here?
jp: I'd rather stop here.

dd: Did you like Aycliffe then?
sg: Yes.
dd: You did?
sg: Yes.
dd: Which is better do you think living at Aycliffe or living here?
sg: It's better living here.
dd: Better here?

sg: Yes.
dd: What's better living here, what's better about it do you think?
sg: I like it better.
dd: You like it better?
sg: Much better...
...
dd: ...tell me what you think about living here then?
sg: T's alright.
dd: Tell me-
sg: T's alright.

dd: Do you like living here?
ec: No not really David.
dd: You don't?
ec: No.
dd: Why's that, can you think of somewhere you'd rather live?
ec: Yes.
dd: Where's that?
ec: Don't know
...
dd: So which is best living here or living at Aycliffe?
ec: I'd like to live at Hogarth Court David
dd: You'd like to live at Hogarth Court.
ec: Hoagrth Court, yes.
dd: Why do you think you'd like to live at Hogarth Court?
ec: It's a nice place, David.
...
dd: Can you think of somewhere you'd rather, somewhere better to live?
ec: Yes.
dd: Where would that be?
ec: Hogarth Court, David.
dd: Why do you think you'd like Hogarth Court?
ec: It's a nice place.

dd: What was good about being at Aycliffe?
mm: It wasn't very much like.
dd: It wasn't very much...can you remember anything that was bad about being at Aycliffe, anything that you didn't like?
dd: I used to be there, it's changed now like, they've knocked the () down like.
...
dd: ...whats not the same about here, whats not the same about the hospital.
mm: There's more shops here like, there's not many shops at Aycliffe like.
dd: Aye thats right, any other differences.
mm: Its different, this place is different like, when there's kiddies out there.

dd: You lived at the DSU?
fm: Yes.
dd: I know, I know, what was it like there?
fm: Oh it wasn't bad.
dd: It wasn't bad?
fm: No
...
dd: ...what did you enjoy there, what did you like about Aycliffe?
fm: Oh there was nothing I liked at Aycliffe.
...
dd: Which is the best place to live, is it better to live here or better to live at Aycliffe
dd: Which is the best place to live, here or Aycliffe?

fm: Here

dd: ...what was good about being at Aycliffe can you remember?

hl: Didn't like it.

dd: What was, what didn't you like, what was bad about it.

hl: Too noisy.

...

dd: So you like living here

hl: Hmm.

dd: Is it better or worse than living at Aycliffe?

hl: Yes.

dd: Which is that, is it better or worse?

hl: Its better, get plenty of fresh air.

...

dd: Did you used to have friends there?

hl: Yes.

dd: Can you remember what they were called, your friends?

hl: Forgot now, I like it here best.

dd: So which is best here or Aycliffe?

ma: Aycliffe?

dd: Which is the best place to live?

ma: Here, I canna go back, its getting bombed down.

dd: Yes, its getting bombed, but if it wasn't getting bombed would you
wnat to go back there?

ma: Back there, but I can't.

dd: Do you enjoy living here?

jw: Yes.

dd: It's alright is it?

jw: Yes.

...

dd: Do you like living round here in Midelsbrough, do you like it?

jw: Yes.

dd: Can you think of anywhere else to live or do you like round here
best?

jw: I like it round here the best

dd: Yes, I work there sometimes.

et: There's nothing to do there is there?

dd: At Aycliffe?

et: Aye.

dd: Its better here then?

et: Aye.

...

et: Soon be christmas.

dd: It's not that late on is it...you said earlier that you liked
living here better than Aycliffe is that right?

et: Aye, get out more

dd: Eh?

et: It aint a bad house.

dd: It's alright eh?

dd: Which is better do you think, living here or living at Aycliffe,
which was best?

jp: They asked me if I want to go back again, I said no, I'm happy
here.

...

dd: So what do you think is good about being here, what is the best
thing about living here?

jp: I'm happy.

dd: You're happy here - anything else that's good about it, whats good

about it do you think, what do you enjoy doing here?
jp: I'm happy and I get plenty of good food anyway.
dd: Smashing, alright.
jp: I'm happy.
dd: Is there anything not good about it or is there anything not good?
jp: No its all good, I've plenty of good friends here, I couldn't fall out with them, I could but I wouldn't fall out with them, they're good friends I couldn't fall out with them, i'm well in with them.

dd: Do you like living here?
ik: Aye.
dd: You do, can you think of a better place to live?
ik: No.

...

dd: ...what was good about being at Aycliffe?
ik: Allright.
dd: What was good, what was allright about it?
ik: They was always fighting.
dd: Eh?
ik: They was always fighting, the bairns.

...

dd: ...which one did you like best, here or Ayliffe
ik: Aycliffe.
dd: You liked Aycliffe better?
ik: Aye.

...

dd: Which was better here or Aycliffe?
ik: Here.
dd: Here?
ik: Hmm.

dd: ...what did you enjoy doing best at Aycliffe?
hc: I knitted at Aycliffe.
dd: Did you, is that what you enjoyed best?
hc: Yes.
dd: Was there anything that you didn't enjoy about Aycliffe, anything that you din't like about it?
hc: They were rough.
dd: Eh?
hc: Rough.
dd: Its rough is it?
hc: Yes.
dd: What was rough?
hc: Edith used to run out on the drive, we'd shout edith, edith, come back here, didn't work.

...

hc: It was nice downstairs.
dd: It was was it?
hc: Used to talk to the nurses.
dd: Ah it sounds nice, how long did you live at Aycliffe then?
hc: A long time.
dd: So did you like living at Aycliffe?
hc: Didn't like it.

...

dd: You like living here then?
hc: Yes it's alright here.

dd: What do you reckons better about living out here than living at Aycliffe?
pb: Aycliffe?
dd: Yes, what do you reckons better about here?
pb: Well you can go anywhere you want really, come in when you like

and that, but there you got to be in at certain times that's the only trouble with Aycliffe.

...

dd: What did you like best about it?

pb: What Aycliffe?

dd: Yes.

pb: Well you could get out like doing your shopping down the town, and you're getting used to doing your own shopping when you're out like and all, and your own cooking and looking after yourself, she doesn't like doing it much.

dd: What didn't you like about it do you think, what was the worst thing about being there?

pb: Well the worst thing that I didn't like was when you was in the lodge it was your own business what you used to do, it was when you had to go to work and you come back and find all your cases been tampered with and your clothes slung all over the flipping room, I used to hate that.

dd: Did you like being at Aycliffe?

wd: Yes once I did, I can't go back now, eh.

dd: Hmm.

wd: No.

...

dd: So which is better, is it better being here or better being at Aycliffe, better being here or better being at Aycliffe, here or Aycliffe?

wd: Aycliffe is the best.

dd: Aycliffe was the best?

wd: Yes it is.

dd: Better than here?

wd: Yes, I can't go back there now.

...

dd: So which is best do you reckon, living here or living at Aycliffe, which is the best place to live Aycliffe or here, which is the best do you reckon?

wd: Aycliffe was the best, working there, Aycliffe.

dd: Aycliffe was the best?

wd: Yes, best at Aycliffe, yes.

dd: So what do like best about living here do you reckon?

tc: I find it alright, I like it.

dd: That's good. that's good, anything you don't like?

tc: No.

dd: Fine.

...

dd: ...what did you think about living at Aycliffe?

tc: Terrible.

dd: Terrible was it, so what didn't you like about it?

tc: Didn't like it at all.

dd: Didn't you like anything about it?

tc: No I didn't like anything about it, I stood fifteen years there.

...

dd: So which is better do you think, Darenth Crescent or here?

tc: Well, they're both nice I think, I like both areas, I like the avenue best and I like Darenth Crescent best...

...

dd: So which is the best place to live out of the places that you've lived?

tc: This one.

dd: This one?

tc: Yes.

dd: ...do you like living here?

lg: Yes.

dd: Can you think of somewhere better to live?

lg: Yes?

dd: Where's better to live?

lg: Here.

dd: Here's better...

dd: ...which is best do you think do you think it is best here or at
Aycliffe?

lg: Better here.

dd: Better here.

lg: Josephine.

dd: Josephine, where does Josephine live?

lg: Aycliffe.

dd: Whats good about being here, do you like it here, do you like
being here?

rc: Yes.

dd: That's good...

...

dd: Which do you think is best, living here or living at Aycliffe,
which was best?

rc: See I live near Darlington but I couldn't get to Darlington cos
there's no () see, when my Dad gave up the bungalow he went to
live with me Ma's sister, I used to go there for me holidays, used
to stay the night there.

