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the community in County Durham*

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Activities of People with a Mental Handicap Living  
in the Community in County Durham.

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Marian Anne Dodds

Thesis submitted for the degree of Master of  
Arts at the University of Durham, Department of  
Psychology.

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## ABSTRACT

The aim of the study reported in this thesis was to obtain information on a group of people with a mental handicap living in the community. The study included 86 cases living in a variety of homes. The main distinction was between staffed and unstaffed homes, with 24 people living in staffed homes and 62 people living in unstaffed homes. Data were obtained on their general characteristics, on their occupational activities and on their leisure activities outside the home. The first chapter is a review of the relevant literature. The second chapter reports the methodology. Data were obtained in an interview with a main carer, or when the case lived alone, with him/herself. A questionnaire was designed for use during the interview and was partly based on the Wessex Schedule (Kushlick, Blunden and Cox, 1973). The third chapter provides the results of the study. The overall picture of the characteristics of the sample showed that only a minority had additional physical handicaps and only a minority required full assistance in all their personal needs. The results on the occupational activities was less positive. Only 6 cases were in paid employment; 50 cases attended an ATC. The cases from staffed homes were more likely to attend an occupational activity than those living in unstaffed homes. The results on the leisure activities revealed that although some led fairly active lives others did not. Few cases had friends for companions. The fourth chapter discusses the results in relation to previous research and suggests areas for further research. The implications of the study are also considered.

## CHAPTER ONE

### People with a mental handicap living in the community.

#### 1.1 Introduction.

The policy of Community Care can be traced back to the 1959 Mental Health Act which emphasised the importance of providing services within the community as alternatives to hospital. The impetus towards community care was almost certainly increased by recognition of the deplorable conditions in some long stay hospitals (DHSS, 1969) and the greater understanding of the adverse effects that large institutions had upon the development of people living in them (Goffman, 1961; Tizard, 1964; King, Raynes and Tizard, 1971). The realisation that people with even severe learning difficulties were capable of growth and development (Clarke and Clarke, 1974) was also of major significance.

The White Paper "Better Services for the Mentally Handicapped", set the framework for much of the ensuing debate about hospitals. It emphasised that people with a mental handicap should not be unnecessarily segregated from other people and that they should be supported as far as possible in the community. It envisaged a reduction by half in hospital places by 1991 (Ryan and Thomas, 1987). There are many schemes throughout the U.K. where children and adults are placed in ordinary housing and the literature is replete with evaluations of such schemes (e.g. Locker, Rao and Weddell, 1984; Shah

and Holmes, 1987; Raynes and Sumpton, 1987).

However, many people with a mental handicap already live in the community, either at home with their families, independently or in other residential settings. For example, a report issued by the Northern Regional Health Authority quoted that 2,500 people with a mental handicap were living in longstay hospitals; 10,000 were living in the community, either at home or in Social Services accommodation (Northern Regional Health Authority, 1987). It is important to consider the needs of this latter group in addition to the needs of those people moving from hospitals to community based homes. Little is known about those already living in the community. However their experiences, their general characteristics, their level of abilities and the activities they engage in constitute important types of data about the extent to which people with a mental handicap are integrated into the community in which they live.

The aim of this chapter is to consider the philosophy underlying community care, and the general characteristics of people with a mental handicap living within the community; and to review studies of their work and leisure activities.

## 1.2 Community Care

The White Paper "Better Services for the Mentally Handicapped" (1971) was an important milestone for developments in mental handicap. It provided the framework for new services based on multiple provisions within the community. Particular emphasis was placed on reducing the hospital population with a concomitant attempt to avoid segregation

from the ordinary community. The Jay committee (1979) issued a report which looked into mental handicap nursing and care. They listed a set of basic principles around which they built a model of the way in which care should be delivered. The argument was based upon the principle that people with a mental handicap, like other members of the public, should have access to all the general facilities and services that the community had to offer and that specialist services should be provided only when a need for them was identified. The report emphasised the right of each person to be treated as an individual, who would have needs that were unique and which would change over time, and who had the right to be involved in decisions affecting his/her life.

This principle places the individual at the centre, with services designed to meet the needs of the individual, without imposing isolation or segregation from the ordinary community. It presented a major challenge to service providers, requiring clarification of what the term 'care in the community' actually meant. A detailed discussion of the ambiguities surrounding the term is given by Bayley in "Mental Handicap and Community Care" (1973). According to Hattersley et al (1987) it has become a "threadbare cliché and, like all generalisations, has been interpreted in many ways, usually very loosely". They argue that many moves to the community "are muddled and ill understood", with uncertainty about who is eligible, and that many hospitals facing closure, delay in "defining and designing the alternative comprehensive community service". They go on to argue that three quarters of those with severe intellectual disabilities have always lived in the community, dependent on their parents, with little financial help given to funding their part of community services. An

investigation of these people, their needs and service requirements, may help to address some of the issues related to what community care and community living mean in practice to people with a mental handicap.

The movement into the community is based on the guiding goal of an 'ordinary life'. Central to this trend is the concept of 'normalisation', defined by Nirje (1970) as moving towards "patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society". This definition was extended to mean "as much as possible the use of culturally valued means to enable/establish and or maintain valued social roles" (Wolfensberger and Tullman, 1982). Normalisation does not mean that people with a mental handicap become normal. It does mean that they must be given proper respect and dignity despite their limitations. According to Wolfensberger the process of "recognising people with a mental handicap as competent individuals with equal rights and value is at the heart of normalisation" (Wolfensberger, 1980).

The Campaign for People with Mental Handicaps (CMH) argued that the aim of services should be to help people with mental handicaps lead as normal a life as possible. This includes a normal rhythm of days, weeks and years; normal sized living units; adequate privacy; normal access to social, emotional and sexual relationships with others; normal growing up experiences; the possibility of decent paid work; and choice and participation in decisions affecting their life and future (CMH, 1975). Their needs are seen as basically similar to those of other people, with the difference being that they may not be able to meet these needs unaided or as independently as others can, and

that they may have additional special needs.

Several implications arise from the principle of normalisation: 1) that every person should have the option of having a home; 2) that adults should be treated as adults; 3) that every person should be challenged and enabled to learn, and allowed to take risks in decision making; 4) that every person should be allowed to participate in the mainstream of community life and, as far as possible, either individually or in small groups, in all the resources of our society.

The principle of normalisation relies on a number of established concepts. One central concept is that of deviancy. Handicapped people are frequently seen as deviant. This occurs when they are seen as different from others, where the differences are viewed as significant by others and are negatively valued. It is not the differences that make for deviancy, but the fact that the differences are negatively valued. Although devaluation begins in the eyes of others, social expectations can lead to people devaluing themselves (e.g. Goffman, 1959). When a person is perceived as devalued he/she is cast into a particular role that carries with it powerful expectations. These expectations can then influence not only the attitude of the perceiver but also that of the perceived person. A person's behaviour can be influenced by the role expectations placed upon him/her. (This is referred to in the normalisation literature as 'role circularity'). People with a mental handicap have been cast in a number of roles: as a subhuman organism, as a menace, as a holy innocent, as sick, as an object of pity, and as childlike (Wolfensberger, 1980). The one that will be discussed here is the childlike role.

**notion of**  
The 'eternal child' is prevalent in work with people with a mental handicap (Wolfensberger, 1980; Hattersley, Hosking, Morrow and Myers, 1987). The idea that they are just children and must therefore be protected leads to restricted opportunities. This kind of age degradation can be subtle and can include, for example, engaging adults in recreation or leisure activities which are culturally viewed as appropriate for children or the use of language referring to adults as children.

Risks are a part of everyday life and are important for learning and development. However people with a mental handicap are often sheltered from risks. Overprotection can endanger the dignity of people with a mental handicap and keep them from experiencing the normal taking of risks which is important for human growth and development. Concern for their well being can again lead to restricted opportunities, imposing on them a life which gets 'wrapped in cotton wool': one which few people would voluntarily accept.

As referred to earlier, a number of implications arise from the principle of normalisation, one of which is that every person should have the option of having a home. However, simply locating a person with a mental handicap in an ordinary house, in an ordinary street does not ensure that he/she becomes part of that community. Wolfensberger (1980) differentiates between physical and social integration. Physical integration usually involves buildings and physical settings and is determined by four factors: the location of the home, its physical context, its ease of access, and its size. Social integration, on the other hand, takes place on a personal level and involves social interaction with handicapped and non-handicapped

people. Social integration is also determined by four factors: program features affecting social interaction: the labels that are given to the services and facilities, the labels and terms that are applied to the clients, and the ways in which service buildings are perceived.

Unless community opportunities are utilised people with a mental handicap will remain isolated. Atkinson (1982) referred to people with mental handicaps who were "pioneers" who "shunned training and rehabilitation schemes, severed connections with hospital and work for independence and a new normal lifestyle" but goes on to say that "although the pioneers enjoy home based leisure pursuits they lack the confidence to infiltrate far into normal leisure activities". Butler and Bjaanes (1978) in a discussion of community care homes and their normalising effect looked at the use made of community programmes by people from 160 community care homes. They found that the smaller facilities were "creating socially isolated total institutions within the community". These studies illustrate that social integration and becoming a part of a community does not automatically follow from actually living in that community. It is important for a person with a mental handicap to utilise community opportunities. If they do not then the home alone will not be enough to support the person in the normalising process.

As previously mentioned, although people with a mental handicap have the same needs as ordinary people they may not be able to meet them independently without additional help. For example many need training in community living skills, e.g. pedestrian skills; travel skills for using various means of public transportation; self care skills; money management; leisure and social activities; and vocational skills. A

number of studies have also concluded that people with a mental handicap may need help in making friends (Firth, 1986).

Not everyone with a mental handicap is new to the community in which they live. Many have lived all their lives at home with families and will continue doing so for many years to come. They represent a wide range of people with various levels of IQ, adaptive skills and abilities and live in a variety of social situations. A few have thriving social networks based on family relationships or other contacts. Many more lead more restricted lives with few opportunities to develop their social lives or form new relationships. For some, life in the community means only that their home is located in the community; for others it means a degree of participation in community life. The following sections review the relevant literature. The review is selective and concentrates mainly on British studies.

### 1.3 Studies of the characteristics of people with a mental handicap living in community settings.

Little information is available on the characteristics of people with a mental handicap living in the community. McConkey, Walsh and Mulcahy (1982) conducted a survey of adults with a mental handicap living in Dublin City. Using state disability records 712 people aged 15 to 64 years were identified as having a mental handicap. On interviewing, 150 were found not in fact to have a mental handicap. The remaining 562 people were successfully interviewed further. They did not say why the discrepancy existed. Ninety one per cent of those identified lived

with their families, 6% lived in a community hostel and 4% lived alone. Data were obtained on age, sex, living circumstances, communication, self care and community skills, freedom of movement and leisure activities. Of the interviews, 72.6% were with parents, 20% with another family member and 7.4% were with the person with a mental handicap.

**& Mulcahy**

An index was used, developed by McConkey and Walsh (1981), which rated the ability levels of adults in the areas of self care and social skills on a 4 or 5 point scale. The results from the study were presented in the form of pie charts. Therefore only the results quoted by the authors in the text will be referred to. They found that over 70% had intelligible speech, with only 10% unable to respond when spoken to (other than to their own name). Fifty per cent were able to take care of their own personal needs independently and 18% were dependent on others. The authors did not quote the percentages of people who needed help or who needed checking, the other two ability levels on the index. Seventy four per cent could manage all table activities, with 14% needing help with feeding and drinking. Nearly 50% were capable of coping with everyday money transactions; nearly 60% could tell the time and nearly 50% could write their own name. Sixty-four percent of the men and 47% of the women were able to travel independently. Related to this was the finding that significantly more men, 73%, compared with women, 57%, were capable of running and climbing without difficulty; 37% of the men, compared with 21% of the women tired easily.

McConkey et al summarised their results by dividing the population into four ability groups: 1) a high ability group; 2) a group

competent in self care group; 3) a group needing assistance in self care; and 4) a low ability group. The picture which emerged was, according to the authors, one that "belied the popular image of adults seen in the community". They found that the majority were capable of looking after their own personal needs and only a minority were dependent. Nearly 30% of the sample population came within the high ability group, 20% in the second group, 30% in the 3rd group and just under 20% in the low ability group.

The second study of interest is that of Cheseldine and Jeffree (1981). They looked at factors contributing to the use of leisure time by adolescents with a mental handicap. Two hundred and fourteen teenagers aged between 13 and 19 years were identified by 10 education authorities as "educationally subnormal (severe)" and living at home with their parents. Data were obtained through structured interviews with the parents on leisure activities, friendship patterns, level of independent skills and family structure and attitudes. Part of the study involved identifying factors which could contribute to leisure-time isolation. Using the Pathways to Independence Checklist they rated social skills, language, independence in mobility and money skills: each of which if lacking could present barriers to friendship formation and leisure activity participation. Their findings show that the majority had attained a level of independence at the table "which would enable them to mix with others in a familiar environment without causing undue embarrassment". Eighty percent had acceptable table manners and could spread butter or jam, 72% could help themselves to vegetables at the table and 87% could drink from a normal cup or glass. Only 4% did not have acceptable table manners and either ate with their fingers or had to be fed. Eighty six per cent could dress

independently, deal with buttons and take their coats off. Forty one per cent were able to use language appropriately and their speech was reasonable and intelligible. A further 42% had to augment their words with gestures. Sixteen percent could only be understood by other family members. The majority lacked independent mobility and were dependent on family or special transport to take them outside the home. For example, 93% were not capable of catching a familiar bus and 42% did not go further than their own cul-de-sac without an adult. Mobility and travel skills are needed to be able to get out into the community to make use of its resources. These often prove to be problems for people with a mental handicap.

Both studies present a fairly positive picture of the characteristics of people with a mental handicap living in the community. This, however, contrasts with the data obtained on the work and leisure activities of the same groups of people, which will be presented more fully in the following sections.

#### 1.4 The Occupational Activities of People with a Mental Handicap Living in the Community.

Work, leisure and social relationships are closely interlinked. Reiter and Levi (1980) identified having companions without a mental handicap and getting employment as two pressing needs for people with a mental handicap. Employment is important for a number of reasons. It puts a structure to daily life which helps a sense of purpose, provides access to many of life's pleasures, gives a feeling of being valued by

others and provides the opportunity for personal growth and social interaction. It is often through work that acquaintances are made which later develop into friendship.

Though work has long been considered critical by those concerned with the community adjustment of people with a mental handicap (Cobb, 1972; Brodin, 1976; Whelan and Speake, 1982), most reach adult life without the expectation of taking personal responsibility for their daily survival. People with a mental handicap are rarely seen as potential members of the labour force (Wertheimer, 1983). The satisfactions and rewards of work therefore remain unknown to them.

People with physical disabilities need help in getting and performing jobs. A number of schemes have been set up to help such people, e.g. employment rehabilitation centres and the Manpower Service Commission (Hattersley, Hosking, Morrow and Myers, 1987), through which many people with physical disabilities are given practical support. This makes it possible for them to function in ordinary working situations. However the needs and rights of people with learning difficulties do not appear to have been considered to the same degree. Hattersley et al (1987) argued that they too have the need to be supported in ordinary employment.

The traditional provision within the U.K. has been centres aimed at providing occupation. These evolved from occupation centres to adult training centres (ATCs) and were managed by Social Service departments. These centres have been criticised in that they put many people with lots of problems together in one place. This goes against the principle of normalisation which states that the more the number

and severity or variety of stigmata (defined as "overt and negatively valued characteristics") or the more people with such stigmata <sup>are</sup> placed together, the more impact they have. In addition to this, these centres tend to provide several different kinds of learning; domestic, money, leisure, literary, and speech. All are desirable but are not usually provided in a place of work. It is a characteristic of total institutions to blend all of life's activities into one place. Again this is contrary to the principle of normalisation and is not how ordinary life is lived.

For people with a mental handicap their future expectations seldom go beyond attending their local ATC. Less than 2% of those in ATCs move on to sheltered or open industry. Whereas 15 to 20% of the general population are unemployed, 98% of people with learning difficulties are unemployed for many years (Hattersley et al, 1987). While attending these centres people are dependent on welfare benefits and are not well paid for their efforts. There is clearly a need for greater efforts to be directed towards providing meaningful and paid employment for those with a mental handicap.

Two examples will be given to illustrate how effective solutions can be found. Work pioneered in the United States has demonstrated that mentally handicapped people with severe disruptive behaviour can be employed on a fully commercial basis. Bellamy and others (1979) have established a network of commercial business in electronics across America, which employs severely mentally handicapped adults (Hattersley, Hosking, Morrow and Myers, 1987) .

A project was initiated in Wales, referred to as Antur Waunfawr (the

"Waunfawr Venture"), which presented the opportunity for a small group of people with a mental handicap to work in a meaningful work situation. The aim was to establish an open employment opportunity for adults with mental handicaps. The project included renovating a row of five old derelict cottages to provide independent living accommodation, developing a small cottage industry and developing land near the building for horticultural, agricultural and animal husbandry activities. All the work was to be undertaken by adults with a mental handicap under supervision. The aims also included: developing the greatest possible degree of integration of the workers within the community: developing social, self help, recreational and communication skills to enable the workers to lead as normal and independent life as possible; developing independent living skills; and encouraging and assisting workers to attain employment with other employers in the community.

A number of studies have looked at the kinds of activities that people with a mental handicap engage in during the day. In a long term evaluation of services for people with a mental handicap living in Cardiff, it was found that 62% of those clients who lived at home and who used day services, attended ATCs compared with only 8% of those living in long term care (Humphreys, Lowe, McLaughlin and Blunden, 1984). Whelan and Speake (1977) in a study of ATCs found that 80% of those attending were young adults living at home.

McConkey, Walsh and Mulcahy (1982), in addition to obtaining information on general characteristics (section 1.3) investigated the types of day activities that the people in the sample attended. Only 5% of the adults were in open employment. Twenty one per cent of the

adults attended a long term sheltered workshop. A further 7% went to a short term training centre and 6% to a special day care unit for severely handicapped adults. Fifty four per cent were at home most of the day. They stressed the need to consider forms of protected employment or special supports in open employment.

Raynes and Sumpton (1987) examined the quality of life in four types of residence for people with a mental handicap. The study included 175 people living in either hospitals, voluntary or private homes, hostels or parental homes. The data were collected through interviews with a primary carer of each of the participants. Of relevance here are the data collected on the type of occupation in which people were involved, the location, and whether or not it was full or part time. The type of occupation differed significantly depending on where they lived. All those living in hostels were involved in activities which were described as training, compared with 86.2% in voluntary homes, 62.0% in hospital and 76.7% in parental homes. Twenty per cent of those living in hospital and 16.7% of those living at home did nothing. Only 4.8% (8 people), were in open employment. Of these 8 people: 3 were living in voluntary homes, 3 were living in hospitals, and 2 were living at home.

The findings relating to the timing of the employment also showed differences. All hostel residents were in full time occupation compared with 83.3% from parental homes, 79.3% from voluntary homes and only 48.8% from hospital.

The remaining studies reviewed in this section were important in that they elicited the views of the people with a mental handicap

themselves.

One study illustrates the importance of employment in the lives of people with a mental handicap. Scheerenberger and Felsenthal (1977) looked at the effectiveness of the community placement programs of 75 former residents of a public residential facility who were, at the time of the research, living in 1 of 3 types of residence: a foster home, a group home or an adult home. Their ages ranged from 7 to 77 years. The study elicited information on their attitudes and impressions of living in the community. The data was gathered through structured interviews using a 36 item questionnaire. One section was relevant for adult residents only and specifically looked at employment. Although 52 were enrolled in an adult activity, only 18 of these were involved in selecting their jobs. When asked "What would you like to do in the future?", 25 (51%) of the adult residents said they would like some form of employment. According to the authors this deserved additional attention by those agencies responsible for the adults.

Flynn and Saleem (1986) interviewed 12 adults chosen from an ATC register. They were aged between 19 and 44 years and all were living with their parents. Data were obtained using simply phrased, open ended questions. Eight of the twelve people said that they would like some form of paid employment. The authors noted that of all the topics discussed the two that led eight people to express a desire for change were living independently and work.

Donegan and Potts (1988) conducted a pilot study of the quality of life of 9 adults, ranging in age from 37 to 67 years, who had been

living alone in the community for at least one year. They found that only 3 were engaged in a daily occupation; two attended an ATC and one was in open employment. Two were unemployed. Four were retired; two from an ATC. The authors commented on the fact that eight of the nine participants in the study received Social Security benefit which meant that they had little money to spend which in turn may have contributed to their relatively infrequent use of community facilities.

The above studies demonstrate that people with a mental handicap are not really seen as potential members of the labour force. Few are in paid employment and even though they may have significant amounts of free time they may not have sufficient resources, either financial or personal, to be able to use this time fully. Many of the benefits derived from paid employment, material, personal and social are, as a result of this, denied to them. In addition to this, society does not value highly those with unlimited, enforced leisure (Wertheimer, 1983). This is contrary to one of the basic objectives of the normalisation principle which is to enable mentally handicapped people to become valued members of society.

#### 1.5 Leisure activities of people with a mental handicap living in the community.

Recreation and leisure activities provide important contributions to the quality of life of people with a mental handicap (Whelan and Speake, 1979). The constructive use of leisure is increasingly recognised as essential in training programs aimed at preparing people

for life and work in the community. Gollay (1976) in a study investigating the community adjustment of adults with a mental handicap, found a positive relationship between community adjustment and three factors: amount of preplacement training; engagement in recreation activities; and the range and availability of support services after placement. However according to Cheseldine and Jeffree (1981) the "normalising potential of leisure is yet to be realised". Research suggests that adults with a mental handicap may fail to adjust to community life because they are not aware of recreational resources available to them or have not learned to use them. The normalisation principle states that people with a mental handicap should have access to all the facilities and opportunities that the community has to offer. However it may be that they also need to be shown how to use them. Atkinson (1982) concluded that even the most independent adults, referred to as "pioneers", lacked confidence in entering far into normal leisure settings and that they therefore needed help to be able to use their leisure time fully.

The relationship between community adjustment and leisure illustrates the importance of thinking about and planning for the leisure needs of people with a mental handicap. Obtaining information about the leisure activities of those already in the community is an important step. A number of studies have done this.

Humphreys, Lowe and Blunden (1984), as part of the long term evaluation of services for people with a mental handicap in Cardiff, referred to as NIMROD, obtained data on clients' use of community facilities. Data were collected on the percentage of people using facilities available to everyone in the community, including cinemas,

pubs,shops, churches and public transport. Over a 6 month period, of the 22 people living in NIMROD houses: 100% used shops, 96% visited a pub, 86% used public transport, 82% visited other places of interest, including parks, and 73% attended clubs for people with a mental handicap. Of the 55 living at home: 91% used shops, 87% visited parks, 73% visited a cafe or restaurant, 62% attended special clubs such as Gateway and only 58% used public transport.

Although the findings of Humphreys et al seem to suggest that many people with a mental handicap living in the community use community facilities, several studies have shown that the leisure activities of people with a mental handicap tend to be solitary, passive or family based. Many of the people studied led impoverished leisure and social lives. It is important to bear in mind that the leisure activities of people with a mental handicap need to be looked at in the context of the leisure activities of non-handicapped people. Unfortunately few studies do this. Where normative data have been used it will be given.

The social isolation of people with a mental handicap has been documented by several studies. Tyne (1978) using a qualitative approach gave an account of the quality of life for residents living in various settings. He found that even the most independent people living in group homes or lodgings led unstimulating lives. For some, satisfaction was derived from the daily activities of work, shopping and watching TV in the evenings. For others, especially those lacking any real integration in the local community, either through family, voluntary associations or informal contacts, their life to the eyes of an outsider seemed "bleak". For those who voiced dissatisfaction with their new and more independent lives the source of the dissatisfaction

was the use of leisure. Tyne remarked that these adults "led curiously unstimulating lives".

Cheseldine and Jeffree (1981) also produced evidence that young people with a mental handicap living at home with their parents led restricted lives, spending most of their time "in passive and solitary activities". In a study investigating the use of leisure by mentally handicapped adolescents, 42 national organisations which made some provision for leisure activities for people with a mental handicap were identified. Of these, 26, including Gateway clubs and Riding for the disabled clubs, made some provision for adolescents with a severe mental handicap. They then went on to look at the leisure activities of a sample of teenagers with a severe mental handicap whose names were given by the 10 education authorities of Greater Manchester. The survey involved 214 families with adolescents with severe mental handicap. Data were obtained on their leisure activities, friendship patterns, level of independence skills (see section 1.3), and family structure and attitude, using semi-structured interviews with parents or guardians in the homes of the teenager. In response to the question "What does he/she do in his/her spare time?", the five activities most frequently reported were listening to music (89%), watching TV (87%), shopping (70%), trips in the car with family (60%), helping in the home (54%), and playing out (51%). (The figures in brackets refer to the percentage who mentioned that particular activity). As can be seen, the most popular activities were passive, solitary and/or family oriented. Only 40% mentioned going to a youth club or similar club, even though clubs such as Gateway are specifically for people with a mental handicap.

The authors went on to look at possible factors contributing to these teenagers leisure isolation. They found that the only skills which were lacking were those necessary for games and hobbies, e.g. picture recognition and numeracy, and independent mobility skills. In addition to this they found that the teenagers had difficulties in developing friendships. Fifty seven per cent said they had a special friendship but only 26% ever visited a friend and only 27% were ever visited by a friend. Therefore friends rarely contributed to the choice of leisure activities.

Information on the attitudes of the parents revealed that some parents or carers had become the main or only providers of both care and recreation and as a result had unwittingly restricted the opportunities of their son/daughter.

They concluded that though leisure was becoming increasingly important there was a danger that people with a mental handicap would remain isolated. This would present a problem if they were to remain in the community. Cheseldine and Jeffree suggest that one solution would be to apply methods used in work skill training to leisure time activities.

McConkey, Walsh and Mulcahy (1981) interviewed the parents and carers of 207 adults with a mental handicap living in Dublin city. Their findings were similar to those of Cheseldine and Jeffree in that many adults were lacking in opportunities rather than in capabilities. Though many were fairly able in terms of social skills and self care (section 1.3) the most popular activities were again passive and solitary. Seventy three per cent watched TV, 41% listened to music.

However, 38.6% engaged in club activities, 37.7% in various hobbies, 32.9% in outdoor sports and 13.5% in indoor games. Although these activities cannot be described as passive and solitary, the authors state that only about one third of the sample took part in community activities. McConkey et al also found that the more severely handicapped people tended to have more passive activities such as watching TV and listening to music. Sixty six per cent did not participate in community activities.

McConkey et al also obtained data on the people with whom the sample spent their leisure time, i.e. parents, siblings handicapped peers, non-handicapped friends and within the community in general. They found that the family were the most frequently mentioned companions, for 9.2% of the sample no one else was involved in the leisure activity. For 35.3% only the family were involved and for a further 29% family and one other person outside the family was involved. Only 10.6% of the sample engaged in leisure pursuits wholly outside the family. The percentage of adults who spent their leisure with parents was 69.6% and with siblings 54.6%: these percentages were similar for all four ability groups referred to in section 1.3. Only 21.7% shared any leisure activities with a non handicapped friend. The less able people were more likely to engage in activities with other handicapped people or alone.

McConkey et al compared the findings to those available on the leisure activities of non-handicapped people aged between 16 to 24 years. The most frequently cited activities for these non-handicapped people were watching TV (87%), listening to music (87%), attending dances (53%), going to the pub (46%), cinema (32%), night classes (25%). Dancing and

going to the pub were activities rarely mentioned by people in the McConkey et al study. Dowling, O'Donohue and Whelan (cited by McConkey et al) reported that 78% of young people in Dublin city regularly shared their leisure time with a friend compared with only 58% of the more able people and 28% of the less able people reported on by McConkey et al.

One problem with the McConkey, Walsh and Mulcahy study is that their results were at times difficult to follow. They did not always clearly define how the percentages relevant to the contexts in which activities occurred were calculated. Nevertheless the findings show that the most popular activities were passive, solitary and family oriented.

McConkey, Walsh and Mulcahy (1982) included data from 562 people with a mental handicap. This figure may include the 207 already referred to, though this is not made explicit by the authors. Although this study concentrated more on the characteristics of the sample they did briefly refer to leisure activities. The results confirmed those previously reported, that most of the leisure pursuits were with family members. For 64% leisure time was with parents and for 57% it was with siblings. For 46% of the sample all their leisure activities were with their family. Only 20% had a non-handicapped friend, although they quoted nearly 40% as sharing their leisure activities with a friend. They concluded that although the majority of adults were capable of looking after all their personal needs, they were socially isolated: they were to a large extent "home and family bound". McConkey et al emphasised the need to look at the preparation and the opportunities given to people with a mental handicap for

becoming involved in social activities outside work and away from home.

The barrenness of some people's lives was also illustrated in the McConkey, Naughton and Nugent study (1983). One hundred and sixty adults aged between 14 and 48 years were interviewed about the people with whom they came into contact when in the city or in their neighbourhood. All the adults attended day workshops for people with a mental handicap. These workshops are similar to British ATCs with the exception that all those attending have to make their own way there, usually by public transport. The findings showed that the people with whom they were most likely to interact with were local shopkeepers, bus conductors and chemists, followed by priests and shopkeepers in town. The place where they were most likely to meet people was at home. Data was also given on who accompanied the handicapped person. As previous studies have shown friends rarely featured as companions. Only 42% ever went with friends into the city and only 39% ever had a friend accompanying them around the neighbourhood. They quoted that "for around one sixth" of the sample all contacts in the city were with family and a further "one sixth" were always alone (percentages not given). They suggest that the value of their data lies in pinpointing aspects of community living which these adults are not experiencing. They concluded that "community living is not a reality for most adults who are mentally handicapped. Only a minority appear to have recent and diverse contacts.... and even fewer have the regular companionship of a friend".

Atkinson (1985) drew on research findings to answer the question "What do people with a mental handicap, living in the community, do in their

spare time?". The survey involved 26 men and 24 women aged between 29 and 74 years, all of whom had moved from a hospital to live independently. As all of the 50 participants distinguished between work time and leisure time it was possible to study each person's spare time activities. As the original data (Atkinson, 1984) are not available, quantitative data on leisure time activities cannot be given. However Atkinson (1985) reported that research revealed a "rich diversity of interests". Home activities included watching TV, listening to music and looking at magazines or newspapers as well as activities such as painting, rug making, and sewing to name just a few. Activities outside the home included travel for pleasure, walks, social visits to the pub and local cafe.

The findings seemed to suggest that at one level these people led full lives, listing many home based and community based activities from which they derived enjoyment. However looking more closely at 'social activities' or those activities which brought them into contact with ordinary people and which may or may not promote social integration, four main problems were identified. Briefly these were:

- a) The giving up of pursuits or activities that had once been enjoyed, either through financial problems, age, or ill health. In some cases this narrowed people's lives.
- b) The 'getting stuck' syndrome. People had a particular interest but did not have the confidence to expand that interest into a social hobby. This also included getting stuck in a particular role. One example is that of getting stuck in a mental handicap role.
- c) The problem of the threshold. Some people were unable to cross the threshold of making real contacts and developing reciprocal relationships with others in their community.

d) The adoption of observer status. Some people rarely joined in participatory activities but instead remained on "life's sidelines" observing.

These tendencies resulted in some of the participants in the survey remaining on the edges of community life. Atkinson concluded that in order to change them, people with a mental handicap needed training to help them develop social relationships and that this is as important as training other skill areas such as self care and domestic skills.

The review so far has concentrated on studies which have obtained information on the leisure activities of people with a mental handicap from parents or carers, and not from the people themselves. Self-advocacy is becoming increasingly popular in the field of mental handicap and it is therefore important to find out what people with a mental handicap themselves have to say about their lives and about the ways in which they spend their leisure.

Donegan and Potts (1988) in a pilot study of the quality of life of 9 people with a mental handicap living alone in the community gathered data on leisure activities both in and out of the home. All except one person had a narrow range of activities within the home, five activities or less. These activities included watching TV, listening to the radio or music, reading, hobbies, and entertaining. Similarly they found a low level of participation in generic leisure services. Only one person mentioned using a cafe. None of the participants reported using restaurants, cinemas, bingo halls, theatres, sports facilities or other activities which required money. Only four reported attending group social activities: the Church and a social

club.

Donegan and Potts concluded that these people had reduced opportunities for integration into the community because of their infrequent use of leisure activities. This in turn reduced the opportunity for contact with other people. The participants lived "on the fringes of society" rarely appearing in society except "as single individuals shopping, walking or catching buses". The authors cite lack of: money, companions, structured daily activities, and experience and confidence in coping with social situations, as the main factors responsible for their social isolation.

Firth and Rapley (1987) addressed the issue of how people make acquaintances and develop friendships in order to help people with a mental handicap living in the community widen their range of relationships and to improve their quality of life. Following a survey of the impact of leisure activities on the relationships of people with a mental handicap they conclude that the leisure and social lives of adults with a mental handicap living in the community could not be described as rich. Other than passive and solitary or family oriented activities, such as watching TV, leisure activities as such did not featured greatly in their lives. They went on to say that leisure activities alone do not provide these people with rich social lives but that it was also necessary to look at the impact of leisure activities on social relationships. The development of social relationships is an important area to look at but one which has only briefly been referred to in this thesis. However it does represent an important topic for future research. De Kock, Felce, Saxby, and Thomas (1985) stressed "it is the sustained and varied exposure to community

life in the company of confident people who model appropriate behaviour, which is likely to lead to the greatest number of opportunities for new experience, learning new skills and developing new relationships".

It remains that for people with a mental handicap leisure is frequently either family centred or a solitary affair. Atkinson (1985) gave two possible reasons for this:

1) Many people with a mental handicap remain segregated, leading their lives "almost exclusively within the confines of mental handicap subgroups, drawing support from designated carers and handicapped peers". This was echoed by Malin (1982) who concluded that "group home residents depend mainly on the support provided through official networks".

2) The way people with a mental handicap see themselves. Atkinson (1982) referred to "pioneers" who were living independent lives but who "lacked the confidence to infiltrate into normal leisure settings".

Wertheimer (1983) in a review of the research on leisure reported that the research was consistent in its findings that the following represent barriers to a fuller and more integrated life:

- 1) Lack of awareness of opportunities.
- 2) Lack of practical and social skills.
- 3) Lack of money.
- 4) Lack of friends.
- 5) Continued use of large group activities.
- 6) The size and location of residences.

If people with a mental handicap are to become valued members of society they must be given greater opportunities to meet and mix with people without handicaps. This means placing less emphasis on providing special leisure facilities and giving more help and encouragement in using ordinary facilities. Providing special activities leads to people with a mental handicap spending their leisure time wholly in the company of other handicapped people. If their day time activities include attending an ATC or a similar centre then it all adds up to a segregated existence even though they may be living in the community.

The above review mainly shows that people with a mental handicap lead fairly isolated lives. Many of their activities are passive, solitary or family based. Friends do not appear to feature to any great degree in their lives. Few have open employment. For many their daytime activities centre around ATCs or similar centres for people with mental handicaps.

An important step in meeting the vocational and leisure needs of people with a mental handicap is to first identify what they actually do. The objective of the present study is to try to gain a better understanding of the lives of a group of people with a mental handicap living in the community in County Durham, most of whom have never lived in a hospital or other large institution. The aims of the study are to:

- 1) Obtain information on their general characteristics.
- 2) Describe their occupational activities or occupations.
- 3) Identify the kinds of leisure activities that they participate in.

## CHAPTER TWO

### Method

#### 2.1 Sample Selection

In any research of this nature one main problem is obtaining an adequate representative sample. The sample in this study was obtained by approaching Durham County Social Services, which maintains an index of people with a mental handicap.

Establishing an index of people with a mental handicap is an important step in the planning of mental handicap services: "a well maintained register can help solve the problem of inadequate data and perhaps prevent the fragmentation of services" (Farmer and Rohde, 1983). The register is not an end in itself, but a tool to help those professionals involved in the care of people with a mental handicap improve the services they provide. In addition to providing an overall picture of the population with a mental handicap, it provides information on individuals (Farmer and Rohde, 1983); minimises the danger of individuals being 'lost' in the administrative system, which is especially important with decentralisation and increased care at home (Farmer and Rohde, 1983); provides data upon which to base research (Fryers, 1987; Cubbon, 1987); and reduces professional bias (Cubbon and Malin, 1985) as no one professional knows the entire mentally handicapped population. Aggregation of the data makes the

facts available to everyone.

Although there are advantages in maintaining a register, a number of problems do exist:

- 1) Establishing a register is time consuming and labour intensive (Farmer and Rohde, 1983).
- 2) Information could be misused unless the necessary safeguards are taken.
- 3) A potentially valuable system could be underused through a lack of awareness. Cubbon and Malin (1985) in a national survey of registers of people with a mental handicap found "an overwhelming enthusiasm for the contribution that registers could make to the planning and management of services. However this potential was not...always realised".
- 4) Unless adequate updating procedures are built into the system there is a danger that the information will be out of date before it is completed (Farmer and Rohde, 1983).

Durham County Council Social Services Department has maintained records of people with a mental handicap since the 1930s. In the early 1980s they developed a computerised index which takes into account the problems discussed above. It is basically a client information system, providing individual and aggregated information on the population with a mental handicap living in County Durham. The index will be used primarily as a tool for planning and coordinating future services and secondarily as a database with which formal research can be conducted. For the purpose of the index a person with a mental handicap is defined by Durham County Council Social Services as:

"...someone who, at some stage in his or her life, is deemed by a specialist to receive the services for mentally handicapped people provided by the Health Authority or the Local Authority Social Service and/or Education Department ".

This definition is based on current or anticipated future need for specialist services for people with a mental handicap and offers a pragmatic solution to the complex problem of definition. This definition does not, however, specify how or why a person is "deemed" to receive special services.

Referred to as the Client Information Index (mental handicap) the index is not yet fully operational. Following its initial development it is currently undergoing refinement which involves contacting the parents or main carer of each person named, verifying the information available and obtaining informed consent to the holding of information over and above basic details. Once refined the system's management will include a built in review procedure which will regularly update information: without this there would be a danger of the index becoming out of date. The review also ensures that all people with a mental handicap within the district have the opportunity of a regular visit from a professional, even if only yearly.

Although my use of this index proved fruitful, it had limitations. The need to use another agency as 'gatekeeper' to the target population inevitably limited the degree of control I had over the sampling procedure. The register was in the early stages of development when the initial request to use it in this research was made, and therefore there were more inaccuracies than there would have been had the

request been made a year later. Much of the original data for the index was extracted from records of people with whom the specialist services had had no contact for many years and as a result the information was sometimes out of date. (The nature of the inaccuracies will be discussed later). Since then much of the information on the index has been updated and amended.

The sampling frame for the study reported in this thesis was the above client index on which were listed the names of people defined as mentally handicapped currently living within Durham County. It was from this index that the sample was drawn. Five stages were involved:

- 1) Permission to obtain a list of names and addresses of people with a mental handicap was first obtained from the Director of Social Services.

- 2) A random sample of 205 names was drawn from the client index by the computer officer of the Social Services department using a computer package named 'Randxact' which produces "a statistically valid unrestricted sample".

- 3) From this original sample, 46 were excluded for one of the following reasons: were known to be deceased; were known to have moved out of the area; were under 13 or over 65 years of age; were living in hospital; had asked for no contact with social services.

- 4) A letter was sent from the Principal Co-Ordinator of Mental Handicap Services to each of the remaining 159 people, giving details of the research and asking whether they had any objection to being approached by a researcher. From this initial sample, 26 stated that they did not wish to be approached. No information is available as to why they declined.

- 5) The names, addresses, dates of birth and telephone numbers of the

remaining 133 were passed on to me for use in this research. No other details were given.

## 2.2 Arranging the Interview

On receipt of the names and addresses of those willing to participate each person was contacted by letter to arrange the interview. As Durham County Council Social Services covers 9 districts including Derwentside, Chester Le Street, Wear Valley, City of Durham, Easington, Teesdale, Sedgefield, Darlington, and County Durham, the sample was subdivided according to locality of residence. A maximum of 5 visits/day, 3 days/week was planned. One week before an intended visit each potential participant was sent a letter outlining the study and giving the date of my visit. Each case\* was visited on the day arranged. If no answer was obtained repeated calls were made until either a successful interview had been completed, or information had been obtained concerning the reason why the case was inaccessible. In all but 1 instance this was achieved. A maximum of 5 return visits

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\* The term 'case' is employed to identify the person with a mental handicap. It is not wholly satisfactory because of its negative connotations, and its association with professional jargon: a 'case' can be one person's lawsuit and another's psychiatric patient. It is nevertheless used to distinguish the sampled person from the respondents, and to reduce repetition of "person with a mental handicap". I would be glad to learn of a happier solution to this terminological problem. 'Client' is not an improvement, as the cases are not my clients, or necessarily anybody's.

were planned. Full records were kept which included the number of visits made, reasons why interview was not possible and brief details of those interviews which were successful.

As previously mentioned, information on the index at the time the initial request was made was sometimes inaccurate and out of date. This reduced the number of successful interviews. Of the original 133 potential participants 6 were deceased and therefore should not have been included in the initial sampling frame. A further 41 were lost from the sample for various reasons, detailed in Appendix 1. As shown in this table, for 2 cases I had serious doubts as to whether the person contacted was in fact mentally handicapped: to continue with the interview could have caused embarrassment, owing to the presence of other people. Durham County Social Services in checking their records also found a number of instances where the person registered was not in fact mentally handicapped. McConkey, Walsh and Mulcahy (1982) in a survey of mentally handicapped adults living in the community found that 150 out of 712 were incorrectly identified as mentally handicapped.

To briefly summarise, 86 interviews were successfully completed. This represents 54% of the original sample of 159. The remaining 73 (46%) either declined to take part; should not have been included; or were lost from the target group for the reasons stated above.

### 2.3 Characteristics of the Final Sample

The final sample consisted of 86 people with a mental handicap living in a variety of homes. Their ages ranged from 14 to 64 years with a

mean age of 33.4 years (SD 13.4). Fifty five were male, with a mean age of 33.5 years (SD 14.1) and 31 were female with a mean age of 33.3 years (SD 14.1).

#### 2.4 Home Setting

It is possible to classify these into staffed and unstaffed homes by reference to address, relationship of the respondent to case, family composition and the number of people in the household.

##### 2.4.i Staffed homes

Of the people with a mental handicap, 24 (28%) lived in 15 staffed homes which ranged in size from 3 to 53 residents. Not more than 3 people from the sample lived in any one home

##### 2.4.ii Unstaffed homes

Fifty four cases lived in their family home. Of these 31 (36%) were living at home with both parents; a further 16 (19%) lived with mother; and 3 (3%) with father. Four cases (5%) were being cared for by another family member. The remaining 8 (9%) lived independently in their own home. This information is summarised in Table 2.1, and a full breakdown of household composition is shown in Appendix 2.

#### 2.5 The Interview

The information was obtained through individual structured interviews in the homes of the cases. Most interviews were conducted with someone

	NUMBER OF CASES
Family home (with both parents)	31
Family home (with one parent)	19
Family home (with relatives other than parents)	4
Independent own home (with people other than relatives)	2
Independent own home (alone)	6
Staffed home*	24
Staffed Homes*	
	Number of residents
Wellfield House	53
Lanchester Hostel	32
Essington House	29
Fines Park House	29
Horndale House	24
Tall Trees	24
Mount Pleasant Grange	24
Walker Drive Home	21
Premiere Lodge	21
Hylton House	13
Cleves Ferye House	13
Skerne Lodge	13
Greenbank	6
Arran Walk	3
Heathway Community Homes	3

Table 2.1 The Number of Cases Living in Each Type of Home

other than the case. Forty nine percent were with the mother, which represents 78% of the instances in which the case lived in the family home. A further 13% were with another family member; 28% were with staff and 1% was with a female carer in a family placement scheme. For 9% of the interviews the case was the respondent. Table 2.2 shows the relationship of the respondents to the 'cases'.

As contact was made only a week prior to the intended interview there was, as time progressed, a significant delay between first contact by County Hall and first contact by me. It was therefore not surprising that individuals often had no recollection of having received a letter from Durham County Council; either they had not received a letter that was sent or they had forgotten about it. When this was the case more time was given to explaining why I had called and if necessary showing a copy of the letter sent by County Hall. However in all instances the research contact began by explaining what the research entailed, verifying willingness to participate, giving reassurances of confidentiality and answering any queries that the respondents had. If necessary a further visit was arranged. This was seldom necessary and most interviews were completed on my first visit.

The interview was structured using a questionnaire designed for completion by the interviewer with either the case him/herself, a parent or other relative, or care staff, depending on whether the case lived independently, at home with parents or other family, or in a staffed residential home. The questions were designed to elicit information about the case. Respondents were asked each question in a fixed order and the answers were recorded and rated by the interviewer as appropriate. Where the interview was conducted with the case as

RESPONDENT	NUMBER OF CASES
Mother of case	42
Stepmother	1
Father	7
Brother	1
Sister	1
Wife	1
Female carer in family placement scheme	1
Case	8
Staff of staffed home	24

Table 2.2 The Relationship of the Respondent to the Case

respondent the wording of the questions was altered appropriately and the questions on social skills were omitted (see section 2.6 on questionnaire).

Where the case was present an endeavour was made to include him/her in the interview, but the answers recorded were those given by the respondent. Information over and above the answers was recorded: this included significant comments made at the time. Following each interview short notes were made on the home, hospitality, cooperation and attitude of the respondent. This practice provided interesting information which would not have been available otherwise. The interviews lasted from about 20 minutes to one and a half hours. This variation depended on the respondents: on the extent to which they elaborated on the basic answers and offered information over and above that required.

Respondents were generally friendly, hospitable and cooperative. I was often invited to return. There was only one exception, and this was probably due to factors unrelated to my visit. The interview was nevertheless completed and the required data obtained.

The number of people present at the interview varied but seldom exceeded 2 or 3 people. One exception was when there were 5 members of the family present. During this interview it was necessary to direct the questions at one main respondent, the mother of the case, in order to maintain some control over the direction of the interview.

The interview relied on the respondents' knowledge about the abilities and day to day activities of the case. Where the case lived at home

with relatives this was not a particular problem. However, where they lived in a staffed home difficulties arose. These were as follows:

1) The size of some staffed homes inevitably limited the amount of contact staff had with any particular individual.

2) Staff work in shifts and, as a result, were not always on duty when case went out.

3) Staff were not always involved in day care and may have little or no contact with staff from day centres. It was sometimes necessary to check individual records to answer certain questions particularly those concerned with reading and writing.

## 2.6 The Questionnaire

The interview schedule consisted of 29 questions designed to collect information in the following areas: basic descriptive data on both the respondent and the case; the degree of dependence of the case; the kinds of occupational activities that they engaged in; the kinds of leisure activities that they participated in; and particular problems that the respondent had about case (see Appendix 3 for the questionnaire).

The basic descriptive data included: respondent's name, address and relationship to case (questions 1 and 4); age, sex, date of birth and address of the case (questions 2 and 3); and household characteristics (questions 5 and 6).

The questions on the degree of dependence of the case (questions 7 to 16) were taken from the dependency rating scale of Kushlick, Blunden and Cox (1973). Its aim is to obtain information on the level of

skills possessed by people with a mental handicap. Referred to as the Wessex Mental Handicap Scale, it is one of the most well known dependency rating scales available and is widely used in planning mental handicap services. For example Humphreys, Lowe and Blunden (1983) used a modified version of the Wessex scales in their long term evaluation of services for people with a mental handicap living in Cardiff.

It was originally designed for a large scale survey in Wessex to collect data on people with a mental handicap from those concerned with their day to day care, principally the parents of those living at home or the nursing and hospital staff of those living in hospital or residential care. The schedule, an example of which is given in Appendix 4, consists of 20 questions divided into 2 scales: the Social and Physical Incapacity (SPI) scale which rates level of continence, ambulance and presence of disruptive behaviours; and the Speech, Self Help and Literacy (SSL) scale which rates the level of speech, self help (feeding, washing and dressing) and literacy (reading, writing and counting). The scales use a 3 point rating system to answer each question: a score of 1 indicates a high degree of incapacity, 2 a moderate degree of incapacity and 3 no incapacity. The exception is the question on speech where a 4 point rating is used: a score of 4 indicates partly verbal ('can talk but does not'), 3 verbal ('sentences and normal'), 2 partly verbal ('odd words only') and 1 non-verbal. Speech is additionally classified for those rated as 'verbal' according to whether or not speech can be understood, although this is not included in the overall SSL rating. Using these ratings people can be categorised into High, Medium or Low dependency.

A number of studies have looked at the inter-rater reliability of the Wessex scales. As only some of the items from the Wessex scales were used in this research only those ratings relevant to these items will be quoted. Kushlick et al (1973), using percentage reliability, found inter-rater agreements of 92% for mobility, 82% for speech, 78% for literacy, and 76% for total SSL score. May, Hallett and Crowhurst (1982) looked at reliability using 'weighted kappa' (Cohen, 1968), a more sophisticated reliability assessment that takes chance association into account. They found a 'weighted kappa' of 68%. They did not quote reliability figures for the individual items. Palmer and Jenkins (1982) investigated inter-rater reliability in residential and non-residential settings. Reliability for each item was calculated using 'weighted kappa'. (Table 2.3 gives the obtained values of Kappa). They concluded that "the 'Wessex classification' is an instrument of modest but not negligible reliability" and that "it is usable for large scale surveys but that in the assessment of individual clients it must be treated with great caution."

The Wessex has been criticised as being too institution-orientated, and not giving an adequate indication of individual needs (Cubbon, 1987). However the advantages are that it is quick and easy to administer, supported by short but explicit notes of guidance and requiring little or no training. The questions are framed in terms of behaviour which can be assessed as objectively as possible. The results are simple to interpret and relate in practical terms to the degree of dependency.

As I was concerned with obtaining an overall picture of those with a mental handicap living in the community and not with a detailed

WEIGHTED KAPPA VALUES

	Residential		Non-Residential	
	Adults	Children	Adults	Children
Wessex Items				
Speech	.71	.73	.78	.78
Counting	.62	.67	.89	.77
Walk by Self	.77	.72	.84	.61
Writing	.52	.63	.83	.78
Dressing	.62	.69	.69	.74
Washing	.63	.72	.52	.67
Walk with Aid	.61	.59	.80	.57
Reading	.59	.40	.73	.75
Vision	.77	.56	.56	.48
Feeding	.52	.55	.59	.54
Hearing	.50	.56	.42	.48

Table 2.3 The Values of 'Weighted Kappa' Obtained by Palmer and Jenkins (1982) for Individual Items on the Wessex Schedule

assessment of individual cases, the Wessex was suitable particularly because of the above advantages. It was possible to select those items of relevance to this project and disregard those not relevant. In addition to this, the Wessex is currently being used in a project at Newton Aycliffe hospital, County Durham. Using the same schedule presents the opportunity for making cross comparisons between hospital and community populations.

The items chosen from the Wessex were those which I felt were of relevance to a person's ability to participate in activities outside the home and to make use of community facilities. They included the questions on vision, hearing, speech (including clarity), walking by self and with aid, feeding, dressing, washing, reading writing and counting. The same scoring system was used but the items were rephrased so that they were in question form rather than as statements of ability as on the original schedule.

As previously reported the questionnaire was designed for completion by an interviewer with a parent or carer. However in 8 interviews the case was the respondent. Nathan, Millham, Chilcutt and Atkinson (1980) conducted a study in which the adaptive behaviour skills of adults with a mental handicap were evaluated for 10 behavioural subdomains of the AAMD Adaptive Behaviour Scale (ABS), a schedule for rating the adaptive behaviour of people with a mental handicap. The study included 17 mildly and 17 moderately mentally handicapped clients. Each client was assessed in 4 ways: by a trained staff counsellor, by the client him/herself, by the client's best friend, and by a trained observer. When the ratings were made by the adult with a mental handicap the language was simplified and the questions required only a

yes/no response. The ratings made by the first 3 of the above methods were compared with the ratings made when the behaviour of the mentally handicapped client was observed by a trained observer under controlled conditions. The results indicated that the ratings of the adults with a mild mental handicap were more frequently exactly the same as those obtained by direct observation than were those obtained from the staff counsellors. Nearly 60% of the adaptive behaviour ratings agreed with the behavioural observation assessment when the informant for the ABS was mildly mentally handicapped. For trained staff there was perfect agreement between adaptive behaviour assessment and behavioral observation for only 44% of the ratings. The authors concluded that "the mildly mentally retarded adult person is as fully capable as a counsellor of evaluating his/her performance on many adaptive behaviour dimensions".

The above study provides justification for including the ratings made by adults who are mildly mentally handicapped of their own adaptive behaviour. However as the present study is concerned with a random sample of cases with all degrees of mental handicap it was necessary to include the ratings made by a third party. As in the Nathan et al study when the case was used as the respondent the questions were simplified and rephrased. For example the question on vision, "How well is (case) able to see?" was changed to "Do you have any problems with your sight?". A similar change was made with hearing. The question on speech was omitted. The questions on self help were also omitted. As the case was living independently it could be assumed that these skills were present. I felt that to ask the questions would have been insensitive. The questions on literacy were changed from, "Is (case) able to read (write or count)" to "Are you able to read (write

or count)".

The questions relating to occupational activities, questions 19 to 22, and those relating to leisure activities, questions 24 to 26, were partly based on the 'Nightingale project' undertaken at Newton Aycliffe hospital: a mobility study looking at the daily activities of people with a mental handicap within a hospital environment (Dagnan, 1990). This was modified and extended for use with people living in the community. The aim was to obtain information on the range of occupational and leisure activities that cases engaged in, the modes of travel used, and with whom they travelled.

The term 'occupational activities' is used to refer to those activities which are undertaken during the working week. It covers a variety of activities, including those considered as work, education, training and other activities which occur on a regular weekly basis.

Obtaining data on occupational activities was not particularly problematic. Respondents were merely asked about the place/places that the case attended regularly during the week. Data were additionally obtained on the timing, number of hours and days attended. In addition to this respondents were asked how case travelled to each activity, and with whom.

Data on leisure and social activities were obtained in a similar way. These activities include all those not included in the definition of occupational activities. The data were necessarily retrospective and therefore had several limitations. Obtaining the data depended upon the assumption that the respondent was familiar with the activities of

the case and therefore could answer the questions. This proved to **cause** greater difficulty for those living in staffed homes than for those living in family homes or independently, for the reasons stated previously. Therefore the data obtained on leisure activities from the staffed homes can only give some indication of what the cases did during a specified period. The questions also required the respondent to recall events that had occurred in the past. Converse and Presser 1986 quote, "If researchers were guided by a concern for valid descriptive data, they would focus on the current, the specific, the real" (Turner and Martin, 1984). Although it would be desirable to obtain a day to day account of the activities of people with a mental handicap (as did the Nightingale project) this was not possible given the nature of the research and the limited time and resources available. In only one staffed home were the daily activities of each of the 3 residents recorded and the resulting information was extensive. However this was the exception. A solution to this was to narrow the time period of interest to the 2 weeks immediately prior to the interview. Providing cues in the form of a list of possible places and activities was also a strategy used to assist in recall (question 25). The data obtained on leisure activities also included timing, how case travelled and with whom.

In order to gain a more precise picture of what a person with a mental handicap does on one particular day, respondents were asked about the places that **the** case went to on the day prior to the interview. This again included where, timing, mode of travel and with whom (question 23).

Questions 28 and 29 referred to any particular anxieties that the respondent had when **the** case was out and what, if any, were the major

problems facing him/her. Where the case was the respondent the questions were rephrased appropriately.

Each questionnaire was edited shortly after the interview, and the data transferred onto an SPSSx data file.

## 2.7 Pilot Study

A short pilot study involving 10 cases was carried out in order to determine the adequacy of the questionnaire. Following this a number of amendments were made to the questionnaire. Shopping was added to the list of social activities as it became apparent that some cases went out shopping but respondents did not think it was important enough to mention. For many people with a mental handicap this is an enjoyable activity and one which often enables them to come into contact with non-handicapped people.

One particular concern, which became apparent after the first few interviews, was the method of recording. It was necessary to complete the questionnaire during the interview which involved splitting my attention between writing and listening. To overcome this I explained that it was important to complete the questionnaire at that time to ensure accuracy and to ensure that no important information was lost.

## CHAPTER THREE

### Results

#### 3.1 Introduction

The main focus of this chapter is on the range of occupational and leisure activities engaged in by a group of people with a mental handicap living in County Durham. The type of activities included under these terms will be described at the beginning of the appropriate sections. The results are mainly descriptive. They begin with an account of the abilities of the cases selected, followed by an account of their activities, which includes information on place, time spent away from home, how and with whom they travelled. A statistical comparison is made between cases from staffed and cases from unstaffed homes, in terms of their abilities and their activities.

#### 3.2 Abilities

The abilities rated were those which were considered important to taking part in activities outside the home. They were sensory capacity, ability to walk, self care and skills of reading writing and counting.

##### 3.2.i Vision and hearing

Table 3.1 gives the ratings of vision and hearing. As can be seen the

		HEARING			
		Deaf (or almost)	Poor	Normal	
VISION	Blind (or almost)			3	3
	Poor	1	2	2	5
	Normal		2	76	78
		1	4	81	86

Table 3.1 Ratings of Vision and Hearing

majority, 76 cases, were rated as having normal vision and hearing. Only 10 cases had some impairment in either vision, hearing or both.

### 3.2.ii Mobility

By combining the ratings from question 10a, "Can (case) walk with help?" and question 10b, "Can (case) walk by him/herself?", a total mobility score was obtained. Cases were subsequently rated as fully mobile if their total score from the two questions was 6; partly mobile if their total score was 4 or 5; and non mobile if their total score was 2 or 3.

Figure 3.1 shows that 79 cases were rated as fully mobile. As with vision and hearing only a minority were rated as having mobility problems.

### 3.2.iii Speech

As figure 3.2 shows 72 cases were described as being able to speak normally and in sentences.

For the 72 cases with no speech impairment clarity of speech was additionally assessed. Figure 3.3 shows the number of cases rated at each level on clarity of speech. As can be seen 62 cases were rated as intelligible to everyone. Ten could be understood by the respondents and close acquaintances but strangers found their speech more difficult to understand. There were no instances in which speech could not be understood by respondents or close acquaintances.

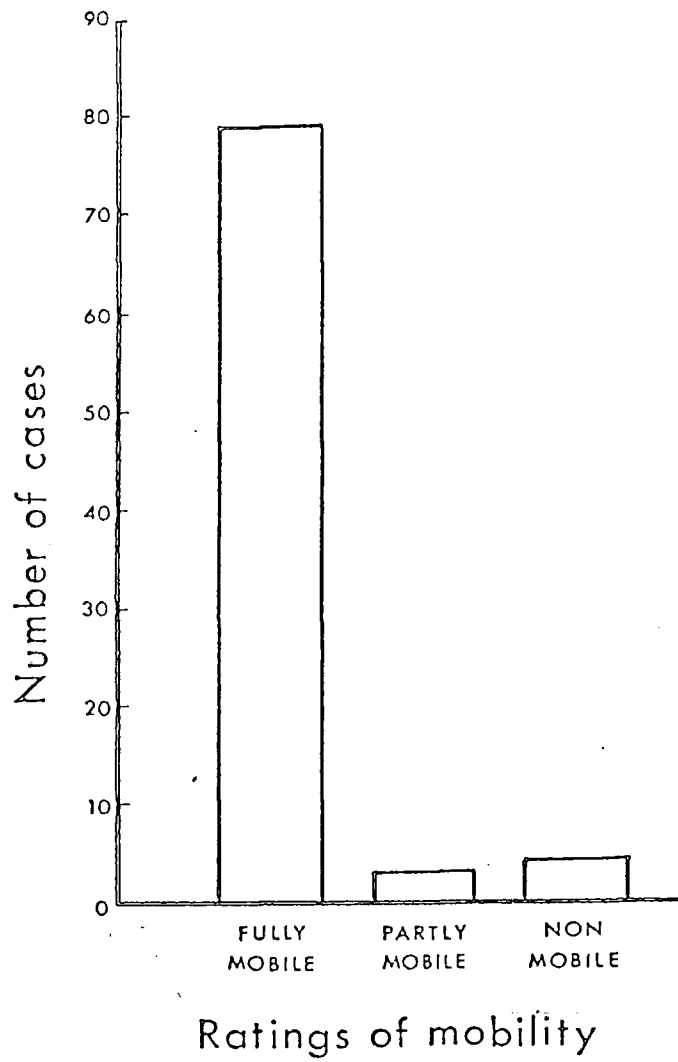


Figure 3.1 The Mobility Ratings for all Cases

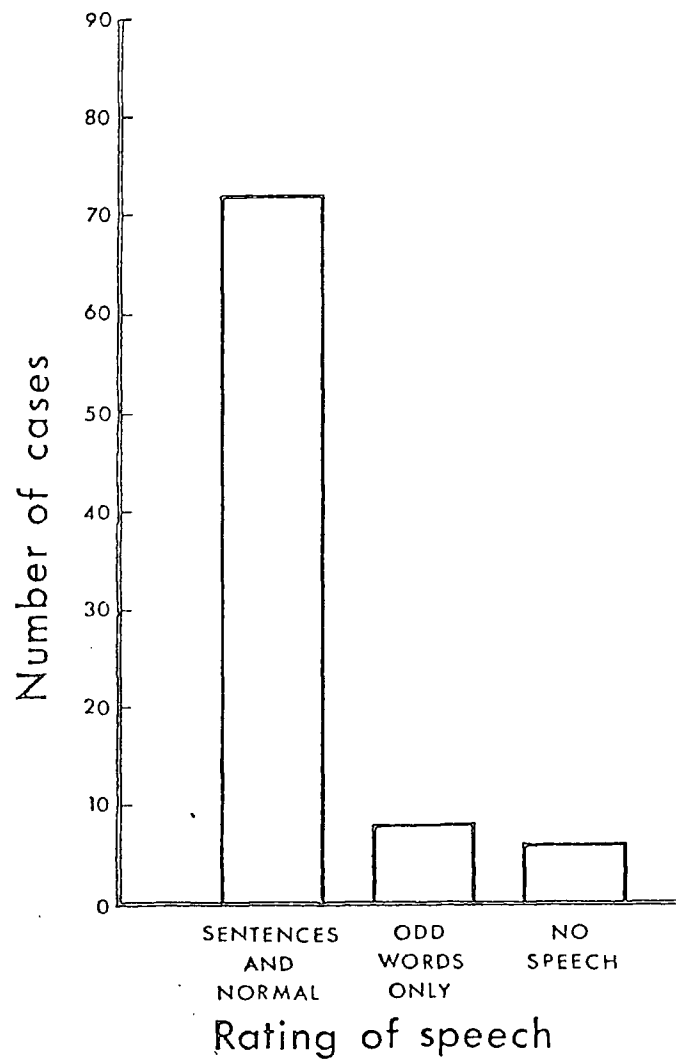


Figure 3.2 The Speech Ratings for all Cases

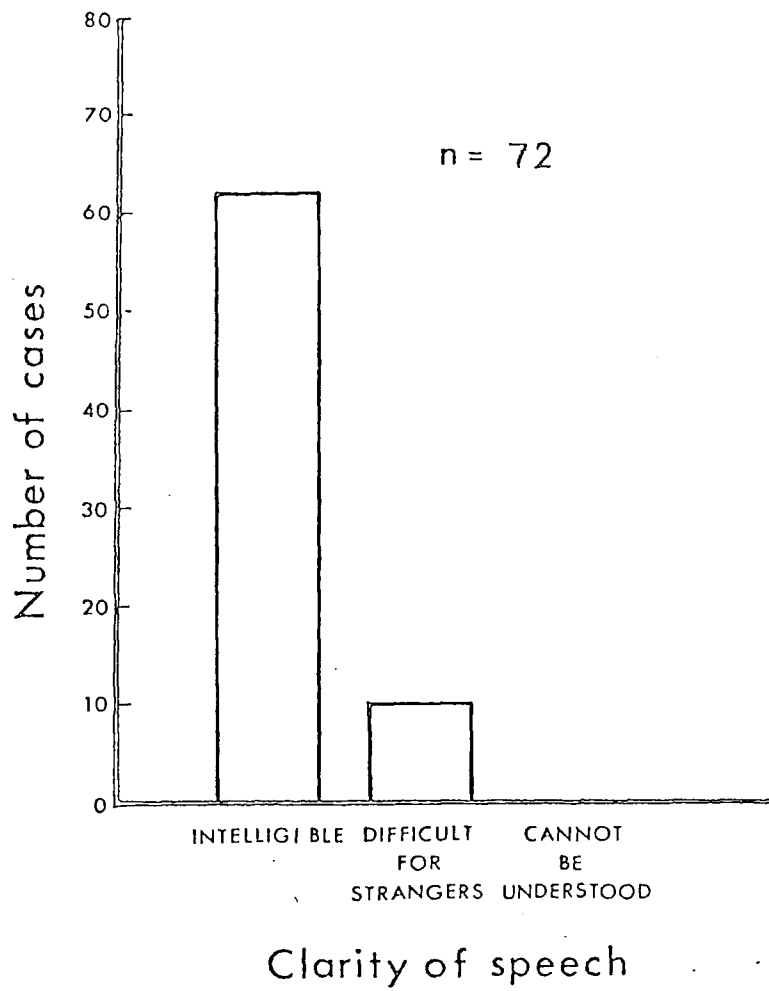


Figure 3.3 The Clarity of Speech Ratings for the 72 Cases Rated as 'Sentences and Normal' on the Question 9

For the 13 cases who had speech problems, no rating was made of their ability to understand what was said to them, as there was no relevant question on the Wessex schedule.

#### 3.2.iv Selfhelp Skills

The basic skills of washing, dressing and feeding were chosen to indicate the extent to which cases could take care of their personal needs. A composite score was calculated by combining the ratings of ability to feed, wash and dress. Cases were subsequently given a selfhelp rating of either 'not able', 'partly able' or 'able'.

As previously mentioned in interviews where the case was the respondent, the questions referring to self help were not asked. Therefore as 8 interviews were with the case, only 78 cases were rated.

As figure 3.4 shows 61 of the 78 cases rated were able to take care of all of their personal needs independently. Only 9 were rated as needing full assistance.

#### 3.2.v Educational Skills

Figures 3.5, 3.6 and 3.7 show the number of cases rated at each level of ability on reading writing and counting. They show that 27 cases were able to read at least simple books and newspapers, 16 could write, and 33 could understand money values and were capable of coping with everyday money transactions. In some cases this understanding was limited only to familiar purchases.

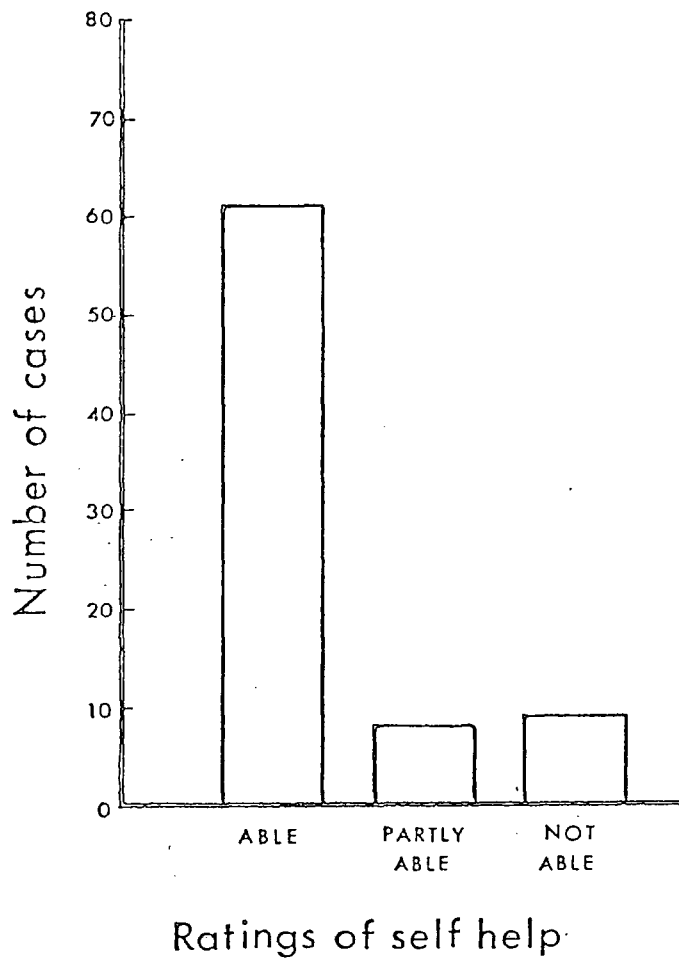


Figure 3.4 The Ratings of Selfhelp Skills for the 78 Cases Rated

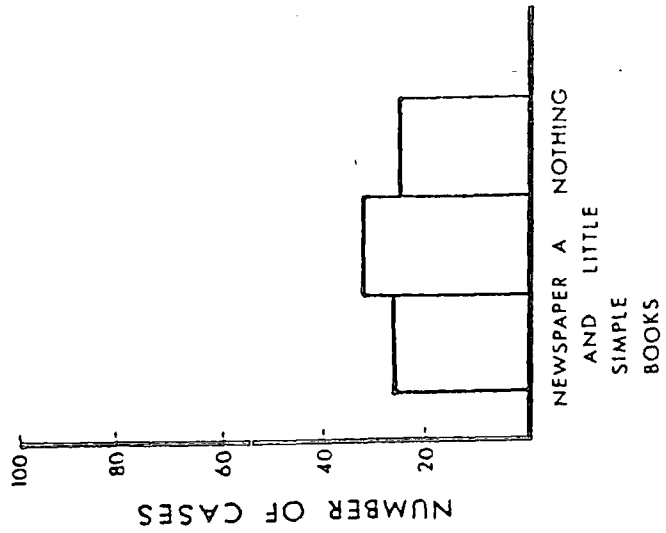


Figure 3.5 Ratings of Reading for all Cases

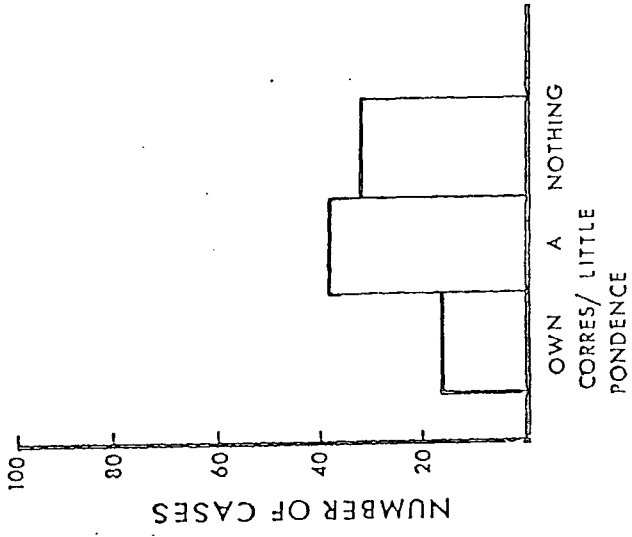


Figure 3.6 Ratings of Writing for all Cases

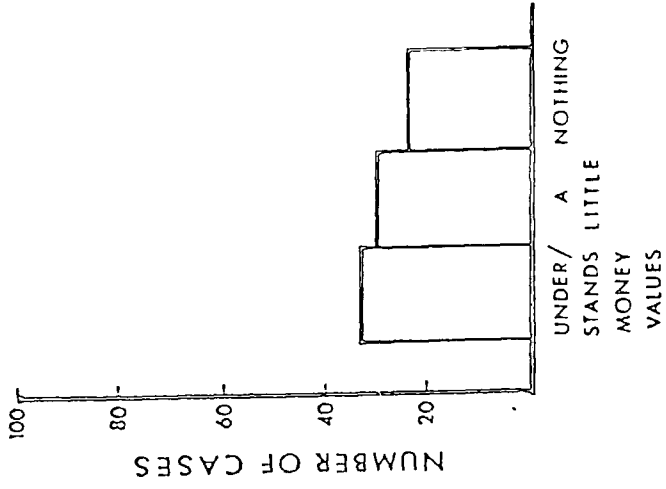


Figure 3.7 Ratings of Counting for all Cases

A total score for literacy was additionally obtained by combining the scores from the questions on reading, writing and counting. A total score of 3, 4 or 5 indicated 'not literate', a total score of 6 or 7 indicated partly literate and 8 or 9 literate. Figure 3.8 shows that only 21 cases were rated as literate; 35 cases were rated as not literate.

### 3.3 Characteristics of Cases by Home Setting

To determine whether there were any differences in the characteristics of cases living in different home settings further analyses were carried out. The analyses were based upon the classification described in Chapter 2 (staffed home and unstaffed home).

There was a statistically significant difference in the ages of cases in the 2 types of home. Those from staffed homes were significantly older than those from unstaffed homes ( $t=3.97$ ,  $p<0.01$ ). The mean age of cases from staffed homes was 42 years ( $sd=12$ ) compared with a mean age of 30 years ( $sd=12$ ) for cases from unstaffed homes.

There were no significant differences in the proportion of clients rated at each ability level on vision ( $\chi^2=2.1$ ,  $p=0.4$ ), hearing ( $\chi^2=0.4$ ,  $p=0.8$ ), mobility ( $\chi^2=2.1$ ,  $p=0.3$ ), or literacy ( $\chi^2=3.4$ ,  $p=0.2$ ).

The results from the 78 cases on selfhelp skills show that a higher proportion of cases from staffed homes were able to take care of their own personal needs, with 96% of those from staffed homes compared with

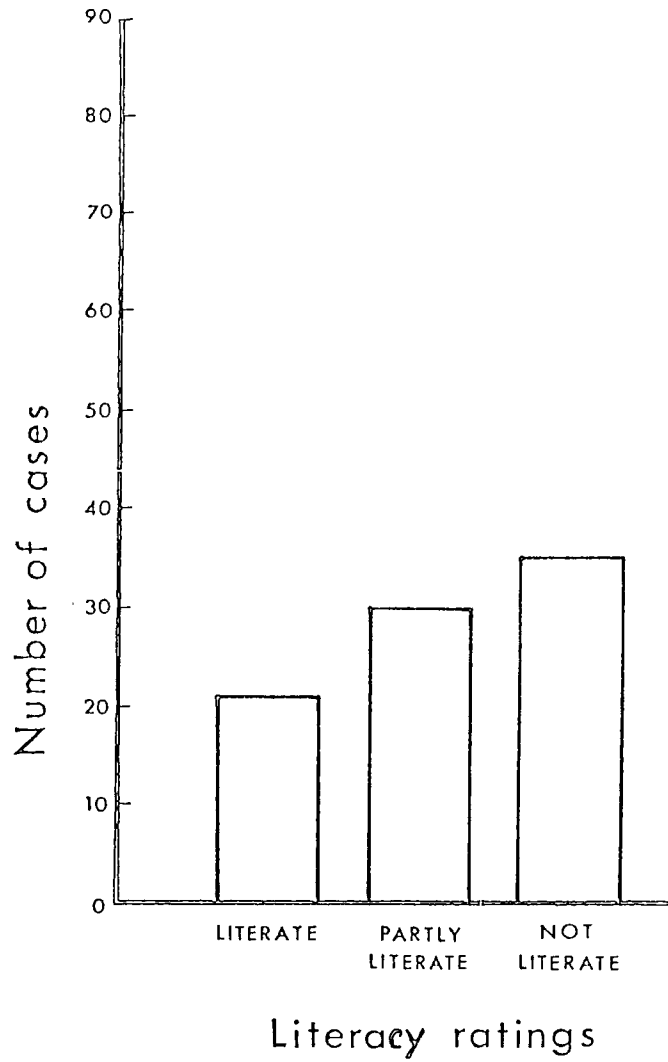


Figure 3.8 The Ratings of Literacy for all Cases

70% of those from unstaffed homes able to do so (chi-square=6.6, p=0.04). Table 3.2 shows the number of cases from each home setting rated at each level. This includes 54 cases living in unstaffed homes and 24 living in staffed homes.

For the 8 interviews where the case was the respondent, all of whom were living in unstaffed homes, a rating of 'able' was assumed. When these are included in the analysis the significance is reduced, with 96% of those in staffed homes compared with 74% of those in unstaffed homes able to take care of their personal needs (chi-square=5.4, p=0.07). When those with severe visual or mobility problems were removed from the analysis, the proportions able to take care of their own personal needs increased to 100% for staffed and 81% for unstaffed homes.

### 3.4 Occupational Activities

For the purpose of this study occupational activities are defined to include those activities which are undertaken during the working week (Monday to Friday). They include activities which can be considered as training, education or work and other activities which occur on a regular weekly basis. For example attendance at an Art centre 1 day a week will be classed as an occupational activity.

#### 3.4.i Attendance at Occupational Activities

Seventy-one cases (83 per cent) attended some type of occupational activity during the working week. Fifteen cases did not.

SELFHELP RATINGS

	Able	Partly Able	Not Able	
Staffed home	23		1	24
Unstaffed home	38	8	8	54
				78

chi-square=6.6, p=.04.

The table does not include the data from the interviews where the case was the respondent

Table 3.2 The Selfhelp Ratings of Cases from Staffed and Unstaffed Homes.

As figure 3.9 shows of the 71 attending occupational activities, 50 attended an ATC, 12 were still at school and 6 attended other activities in an art centre, a leisure centre and a day centre other than an ATC. Only 6 cases were in paid employment. These figures include 4 people who attended 2 different activities a week.

#### 3.4.ii Timing of Occupational Activities

Of the 71 attending occupational activities the majority, 65, attended 5 days a week. Only 6 attended on 4 days or less. Figure 3.10 shows the proportion of cases from staffed and unstaffed homes attending on either 5, 4, 3, 2 or 1 days per week.

The average number of hours a week spent in one or more activities was 32 (sd=6), with a range of 5 to 45 hours.

#### 3.4.iii Travel to Occupational Activities

This section gives the results on the mode of travel used by cases to travel to and from their usual occupation.

As figure 3.11 shows, 61 of the 71 cases attending occupational activities used a means of transport that was specifically provided either by the place of attendance (ie ATC) or by the staffed home. Of the 50 people attending an ATC, 47 travelled by specially provided transport. Only 4 people travelled by public transport for at least part of the journey. Ten people walked either all or part of the way to or from their destination.

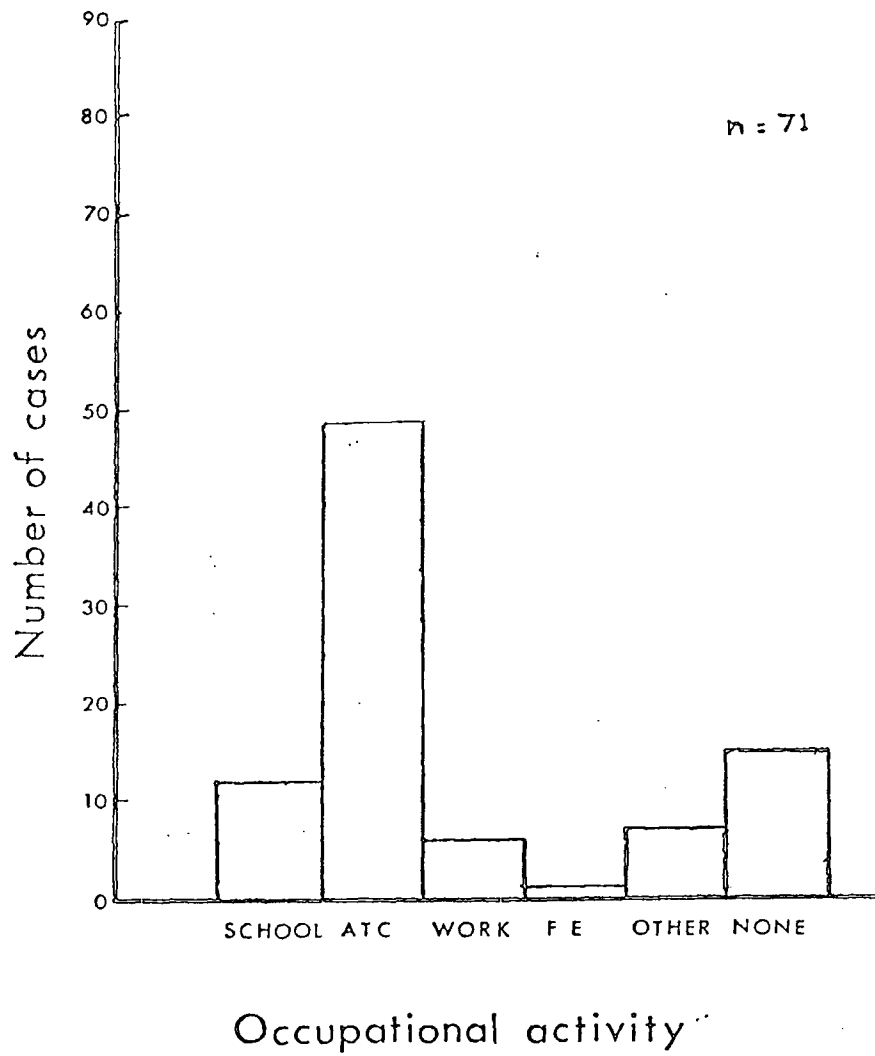


Figure 3.9 The Number of Cases Attending Each Type of Occupational Activity

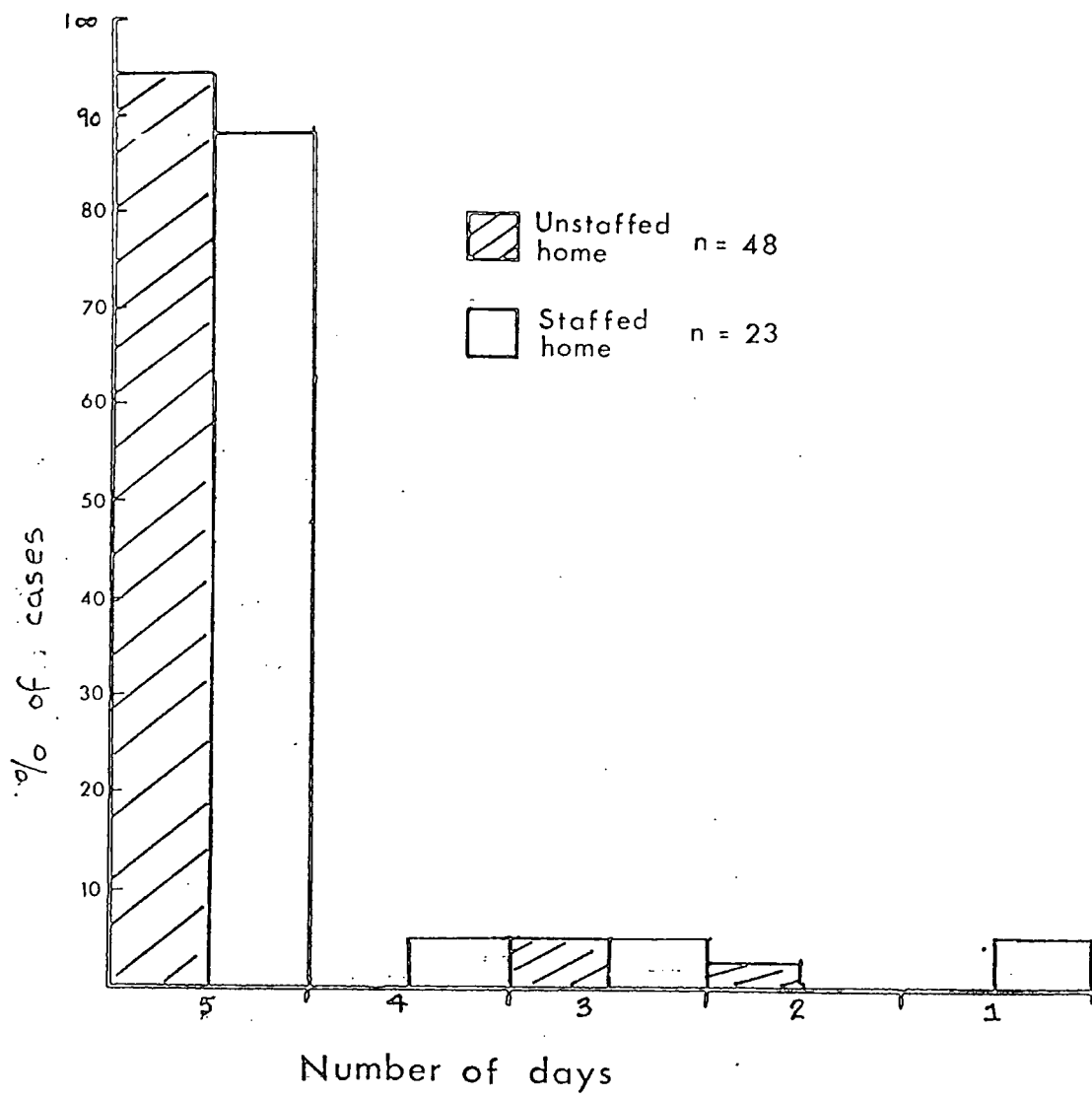


Figure 3.10 The Proportion of Cases from Staffed and Unstaffed Homes Attending Occupational Activities on 5, 4, 3, 2 or 1 day per week.

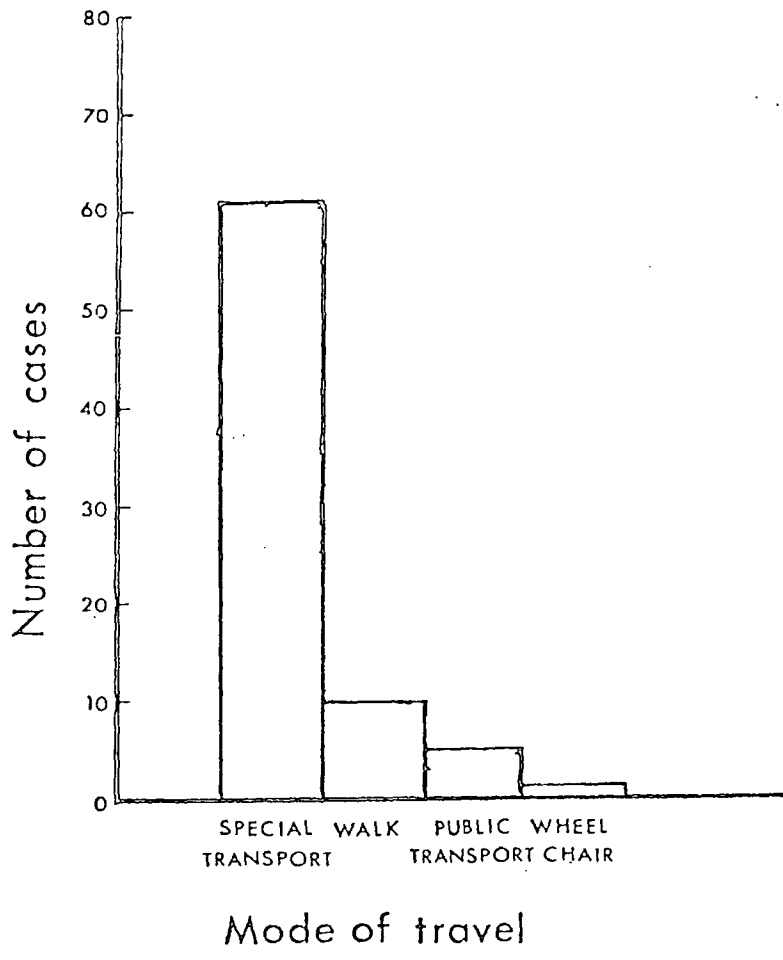


Figure 3.11 The Mode of Transport Used by Cases to Travel to Occupational Activities

#### 3.4.iv With Whom Cases Travelled

Data were obtained on whether case travelled alone or accompanied to their usual occupation.

The results show that 57 cases were always accompanied. Only 9 people were reported as travelling alone all the way and 8 travelled alone for part of the journey.

#### 3.5 Attendance at Occupational Activities by Home Setting

Again using the classification of staffed and unstaffed homes it is possible to ask, does attendance at an occupational activity differ between the 2 types of home setting?

Figure 3.12 shows the percentage from staffed and unstaffed homes attending each type of activity. Table 3.3 gives the numbers from each home setting attending any occupational activity. As can be seen only one man from staffed homes did not attend an occupational activity. Interestingly this man was aged 63 years. Fourteen cases from unstaffed homes did not attend occupational activities. Their average age was 36 years.

Table 3.4 gives the number of males and females from each home setting attending occupational activities. Table 3.5 gives the mean age of cases from the different home settings attending occupational activities.

Comparing the proportion of cases from staffed and unstaffed homes

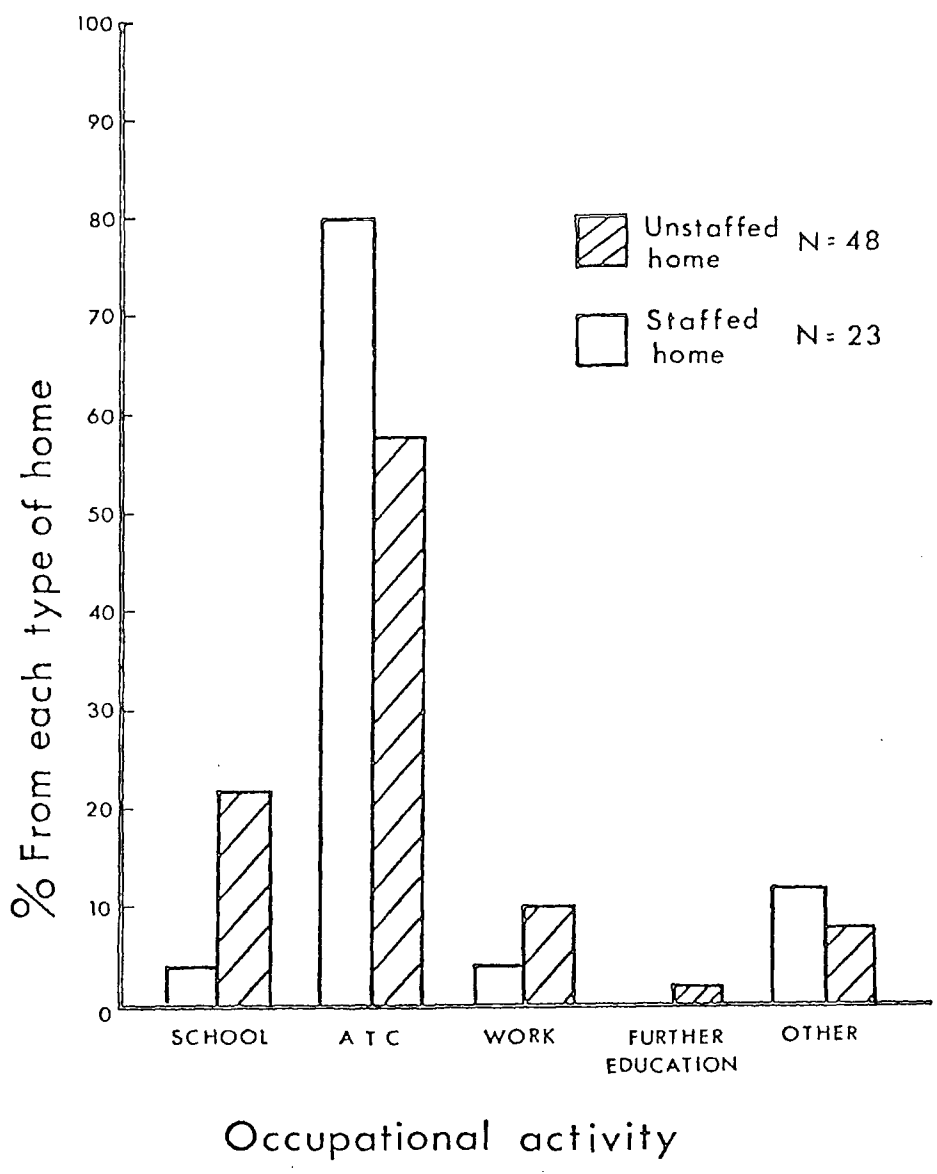


Figure 3.12 The Percentage of Cases from Staffed and Unstaffed Homes Attending Each Occupational Activity

ATTENDANCE AT OCCUPATIONAL ACTIVITIES

	Yes	No
Staffed	23	1
Unstaffed	48	14

Table 3.3 The Number of Cases Attending Occupational Activities from Staffed and Unstaffed Homes

ATTENDANCE AT OCCUPATIONAL ACTIVITIES

	Yes	No
Staffed		
Male	15	1
Female	8	0
Unstaffed		
Male	29	4
Female	19	10

Table 3.4 Number of Males and Females From Each Home Setting Attending Occupational Activities

ATTENDANCE AT OCCUPATIONAL ACTIVITIES

	Yes	No
	Mean Age (years)	Mean Age (years)
Staffed	41	63
Unstaffed	28	37

Table 3.5 The Mean Age Of Cases From Staffed and Unstaffed Homes Attending Occupational Activities

attending an occupational activity shows that those living in staffed homes were more likely to attend (chi square=4.07,  $p<.05$ ). This difference is, however, only just statistically significant, perhaps partly due to the rather small number in the staffed homes.

Additional data on staffed homes were available from the mobility study of the Aycliffe Project already referred to on page 44. Cases for this project were those who had moved from hospital to the community within the past 2 years. The cases were not defined in exactly the same way in my own study but the results can nevertheless be cautiously combined.

Data from 18 cases living in staffed homes were available. Of these, 16 attended an occupational activity and 2 did not. The places attended were similar (A.T.C., work, arts centre, technical college and a meeting place for people with a mental handicap). When the two data sets were combined the number of cases living in staffed homes increased to 42. Table 3.6 presents the combined data. An analysis of the combined data confirms that a higher proportion of people living in staffed homes attend day activities, 93 per cent of those living in staffed homes compared with 77 per cent of those living in unstaffed homes (chi square= 4.36,  $p<.05$ ). It appears therefore that home setting is an important predictor of attendance at occupational activities.

Why is it that people from staffed homes are more likely to attend a day activity?

There is a significant difference in the ages of cases from staffed

ATTENDANCE AT OCCUPATIONAL ACTIVITIES

	Yes	No
Staffed Home	39	3
Unstaffed Home	48	14

Table 3.6 Attendance at Occupational Activities by Home Setting (including Data from the Newton Aycliffe Project (n=104))

and unstaffed homes (page 50). The average age of cases from staffed homes was 42 years compared with an average age of 30 years for cases from unstaffed homes ( $t=3.97$ ,  $p<0.01$ ). However there is no significant difference in the ages of cases from the whole group who do and who do not attend occupational activities ( $t=-1.56$ ,  $p=0.1$ ). The mean age of those who attend occupational activities from staffed homes was 41 years and from unstaffed homes was 28 years (table 3.5). The mean age of those who do not attend occupational activities from staffed homes was 63 years and from unstaffed homes was 37 years (table 3.5). In so far as there is a difference younger people were more likely to attend.

In fact, the age difference between the staffed and unstaffed homes to some extent disguises the attendance rates from staffed and unstaffed homes. The two variables can be combined in a single analysis, using age and type of home to predict to attendance (or non attendance) at occupational activities.

A logistical regression analysis was carried out using GLIM, with age entered as a variable and type of home as a factor (coded 1=unstaffed, 2=staffed), and using the probability of attending an occupational activity as the outcome variable, after transformation to a logit;

$$\text{logit } p = \ln \left( \frac{p}{1-p} \right)$$

The estimates (with their standard errors) were:

$$\begin{array}{r} 3.189 \quad (0.90) \quad -0.06041 \quad (0.02451) \quad \text{age} \\ \qquad \qquad \qquad +2.708 \quad (1.140) \quad \text{home type.} \end{array}$$

The effect of age is opposite in sign to the effect of home type. Both coefficients are greater than twice their standard errors. Therefore age and home setting have a significant effect upon attendance at an

occupational activity.

As reported in a previous section the only other difference in the characteristics of cases from staffed and unstaffed homes was in their selfhelp skills. However there is no significant difference in the selfhelp skills of those who attend and those who do not attend occupational activities (chi-square=0.5, p=0.8).

Those with difficulties in walking independently or those with severe visual impairments may be among those less likely to be accommodated in day care centres, given the limited number of places available. However as already shown there is no significant difference in the mobility (chi square=2.132, p=0.3) or the visual capacity (chi square=2.076, p=0.4) of those living in staffed and unstaffed homes. To determine if these factors are important to day care attendance, those who were rated as blind or almost on question 7, and as either non ambulant or only partly mobile on question 10, were excluded. A total of 7 cases were excluded using these criteria; 2 from staffed homes and 5 from unstaffed homes. Although the statistical significance is reduced, a higher proportion of those from staffed homes still attend occupational activities; 95 per cent in staffed homes compared with 77 per cent from unstaffed homes (chi square=3.63, p=0.0567). As the proportion attending activities remains higher for the staffed homes even with 7 excluded the difference cannot be attributed to visual or mobility handicaps, though they may make some contribution to it.

A logistical regression analysis was again carried out using GLIM as above, but with these 7 cases were removed. The estimates (with their

standard errors) were:

3.529 (0.90) -0.06897 (0.02638) age  
+2.768 (1.161) home type.

Both coefficients were again greater than twice their standard errors. These results show that when both age and type of home are taken into account both have a statistically significant effect upon attendance at an occupational activity.

### 3.6 Occupational Activities on the Day Prior to the Interview

The previous sections on occupational activities refer to data collected on activities engaged in each week. This section presents the results obtained from question 23, "Could you briefly tell me where (case) went yesterday?", which focuses on all the activities outside of the home on the day prior to the interview.

Only 4 people did not go out that day: 3 lived with their parents and 1 lived in a staffed home. The rest engaged in a variety of both occupational and leisure activities. This section however concerns only occupational activities as already defined in section 3.4.

#### Activities Attended

Sixty three cases attended an occupational activity. Figure 3.13 shows the number of cases attending each type of activity. The majority attended an ATC on that day.

#### How Cases Travelled

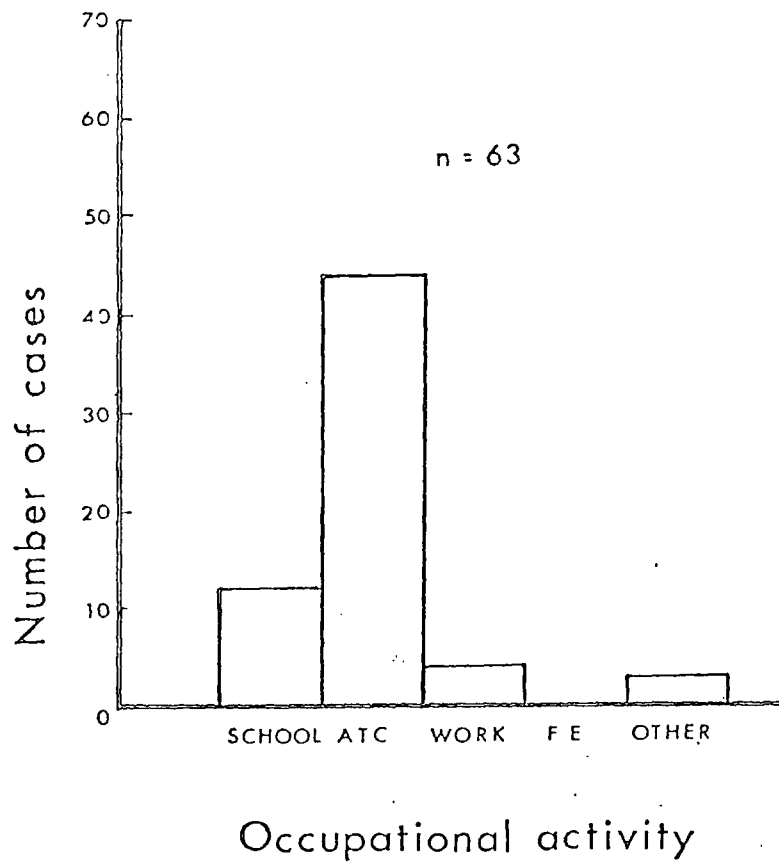


Figure 3.13 The Number of Cases Attending Each Occupational Activity on the Day Prior to the Interview

Of the 63 cases attending occupational activities, 55 used specially provided transport, 7 walked and only 1 person used public transport.

#### With Whom Cases Travelled

Of the 63 cases attending occupational activities on the day prior to the interview, 55 were accompanied by others on the bus travelling to the same destination and 2 were accompanied by staff of the staffed home in which they lived. Only 6 travelled alone on that day.

### 3.7 Leisure Activities

The next section of the questionnaire was specifically concerned with identifying out of home leisure activities and interests and also places visited. Leisure activities include all those other activities not included in the definition of occupational activities. This covers activities occurring during the weekday, in the evenings and at weekends and includes such activities as shopping, babysitting, and walking. It also includes activities engaged in during the day if the case did not attend any occupational activities. Places visited include the hairdressers, local attractions and the cinema

#### 3.7.i Interests and Hobbies

The results show that 43 cases had some interest or hobby. Gardening, sport, swimming, music, pubs, horse riding, walking and shopping were among the interests or hobbies mentioned. Only 3 people mentioned an interest in clubs such as Gateway which are specifically for people with a mental handicap.

### 3.7.ii Activities Engaged in and Places Visited

As discussed in the previous chapter (page 45) there are a number of difficulties associated with obtaining data retrospectively. In an attempt to minimise these, data were collected on leisure activities engaged in during the 2 week period immediately prior to my visit.

Seven cases were reported as not participating in any leisure activities or visiting any places outside the home during the 2 week period immediately prior to my visit. Six of the 7 cases lived in unstaffed homes and 1 lived in a staffed home.

Shopping and visits to friends or relatives were the activities that the highest number of people were said to participate in. Table 3.7 shows that of the 79 cases, 55 were recorded as going shopping on at least one occasion during the 2 week period and 43 were recorded as visiting friends or relatives on at least one occasion.

The minimum number of activities recorded was 1 and the maximum was 7.

A more detailed examination of leisure activities shows that the total number of leisure activities or visits recorded for the 79 cases was 230 (table 3.8). Again the most frequently engaged in activity was shopping. Often these shopping expeditions were only short trips to the local shop but which were nevertheless included because of their importance to the individual. This was followed by visits to either friends or relatives. 'Other visits' as shown in table 3.8 were the fourth most frequently mentioned. They covered a wide range of

	Staffed Home		Unstaffed Home		
	n=23		n=56		n=79
	N	%	N	%	N
Leisure Activity					
Gateway Club etc	4	17	14	25	18
Pub/Social Club	10	43	21	37	31
Other Clubs	2	9	10	18	12
Dance/Disco	2	9	4	7	6
Cafe/Restaurant	2	9	5	9	7
Theatre/Cinema	4	13	1	4	5
Visit Friends/Relatives	11	43	32	57	43
Shopping	20	87	35	63	55
Other Visits	10	43	18	32	28

Table 3.7 The Number of Cases from Staffed and Unstaffed Homes Engaging in Each Leisure Activity Listed

Leisure Activity	Staffed Home		Unstaffed Home		
	n=68		n=162		N
	N	%	N	%	
Gateway Club etc	4	6	21	13	25
Pub/Social Club	10	15	21	13	31
Other Clubs	2	3	10	6	12
Dance/Disco	2	3	2	1	4
Cafe/Restaurant	2	3	10	6	12
Theatre/Cinema	6	9	2	1	8
Visit Friends/Relatives	11	16	36	22	47
Shopping	22	32	42	26	64
Other Visits	9	13	18	11	27
Total Number of Occasions					230

Table 3.8 The Number of Occasions that Each Leisure Activity was Engaged in by Cases from Staffed and Unstaffed Homes

activities and included trips to the swimming baths, arts and craft centres, pantomimes, adult literacy class, library, weight watchers club, local attractions such as Sunderland illuminations and Durham Cathedral, music lesson, soft play area, hairdressers, also fishing and day trips. Attending Gateway clubs or other such clubs for people with a mental handicap was, interestingly, only the fifth most frequently mentioned activity. Visits to 'cafe or restaurant', 'dance or disco', and 'theatre and cinema' were the least often mentioned.

### 3.7.iii Travel to Leisure Activities

Table 3.9 shows the number of occasions that each mode of transport was used when travelling to the activities or places referred to in the previous section.

On 95 occasions cases walked to their destination. Often this was only a short walk to the local shop. On 53 occasions they were taken by car. On 39 occasions specially provided transport was used.

### 3.7.iv With Whom Cases Travelled

Table 3.10 shows the number of occasions on which cases were accompanied and by whom. On 82 occasions cases were accompanied by family members and on 66 occasions they were alone. 'Others' refers to other people on the bus, usually specially provided transport and not public transport. 'Other residents' and 'staff of staffed homes' applies only to those from staffed homes.

During a 2 week period 15 cases from unstaffed homes were with family

MODE OF TRANSPORT	Staffed Homes		Unstaffed Homes		
	n=68		n=162		N
	N	%	N	%	
Walk	29	43	66	40	95
Public Transport	14	21	17	10	31
Special Transport	15	22	24	15	39
Car	5	7	48	30	53
Taxi	0	0	1	1	1
Other	5	7	6	4	11
					230

Table 3.9 Mode of Transport Used by Cases from Staffed and Unstaffed Homes to Travel to Leisure Activities

Accompanied by	Staffed Homes		Unstaffed Homes		
	n=68		n=162		
	N	%	N	%	N
Alone	20	29.5	46	28	66
Family	4	6	78	48	82
Friends	1	1	22	13.5	23
Neighbour	0	0	4	2.5	4
Others on the Bus	2	3	12	7	14
Other Residents	21	31	0	0	21
Staff of Staffed Home	20	29.5	0	0	20
					230

Table 3.10 The Number of Occasions on which Cases were Accompanied and by Whom

members and 11 cases from staffed homes were with staff members for all their leisure activities. Forty-one cases never went out alone to a leisure activity or a place outside of the home; 10 from staffed homes and 31 from unstaffed homes.

### 3.8 Leisure Activities by Home Setting

Table 3.7 (referred to on page 59) gives the proportion of cases from staffed and unstaffed homes engaging in each activity on at least one occasion. The figures quoted are a percentage of the number engaging in leisure activities at all from each setting and not of the total number of people from each. The figures shown are therefore a percentage of 23 for staffed homes and 56 for unstaffed homes.

### 3.9 Leisure Activities on the Day Prior to the Interview

As mentioned in section 3.6 (page 57), information was obtained on activities engaged in on the day prior to the interview. This section gives the results of other activities, leisure activities and places visited not already referred to in section 3.6

#### Leisure Activities and Places Attended

On the day prior to the interview 36 cases engaged leisure activities. <sup>In</sup> Fifteen cases attended an occupational activity and engaged in one leisure activity, and 2 attended an occupational activity and engaged in 2 leisure activities. Nineteen cases did not attend an occupational activity, of these 12 engaged in one leisure activity, 6 in 2 leisure activities and 1 in 3 different leisure activities. A total of 46

separate leisure activities were recorded and these are shown in figure 3.14

Figure 3.15 shows the various modes of travel used. As can be seen on the majority of occasions cases walked.

Figure 3.16 Shows the people with whom cases travelled. On 22 occasions cases travelled alone and on 10 occasions cases were with a family member.

### 3.10 Problems and Anxieties

Questions 28 and 29 referred to anxieties that the respondent had about case when he/she was out and about. Table 3.11 gives the number of respondents from staffed and unstaffed homes mentioning each type of problem. The most frequently mentioned problems for cases from staffed homes were behaviour problems and for cases from unstaffed homes were traffic and crossing roads.

Fifty four respondents indicated that there were no particular problems or anxieties: 10 from staffed homes and 44 from unstaffed homes. (One of the main reasons could be that many did not go out alone and when they did it was usually in the company of other non-handicapped people). Thirty seven of the 54 respondents specifically said that there were no particular anxieties or problems because case seldom or never went out alone. Two quotes, both from mothers underline the attitude of many carers. One mother said of her 23 year old son " he is always in good hands". Another mother said of her 24 year old daughter "she is always with adults". Such comments

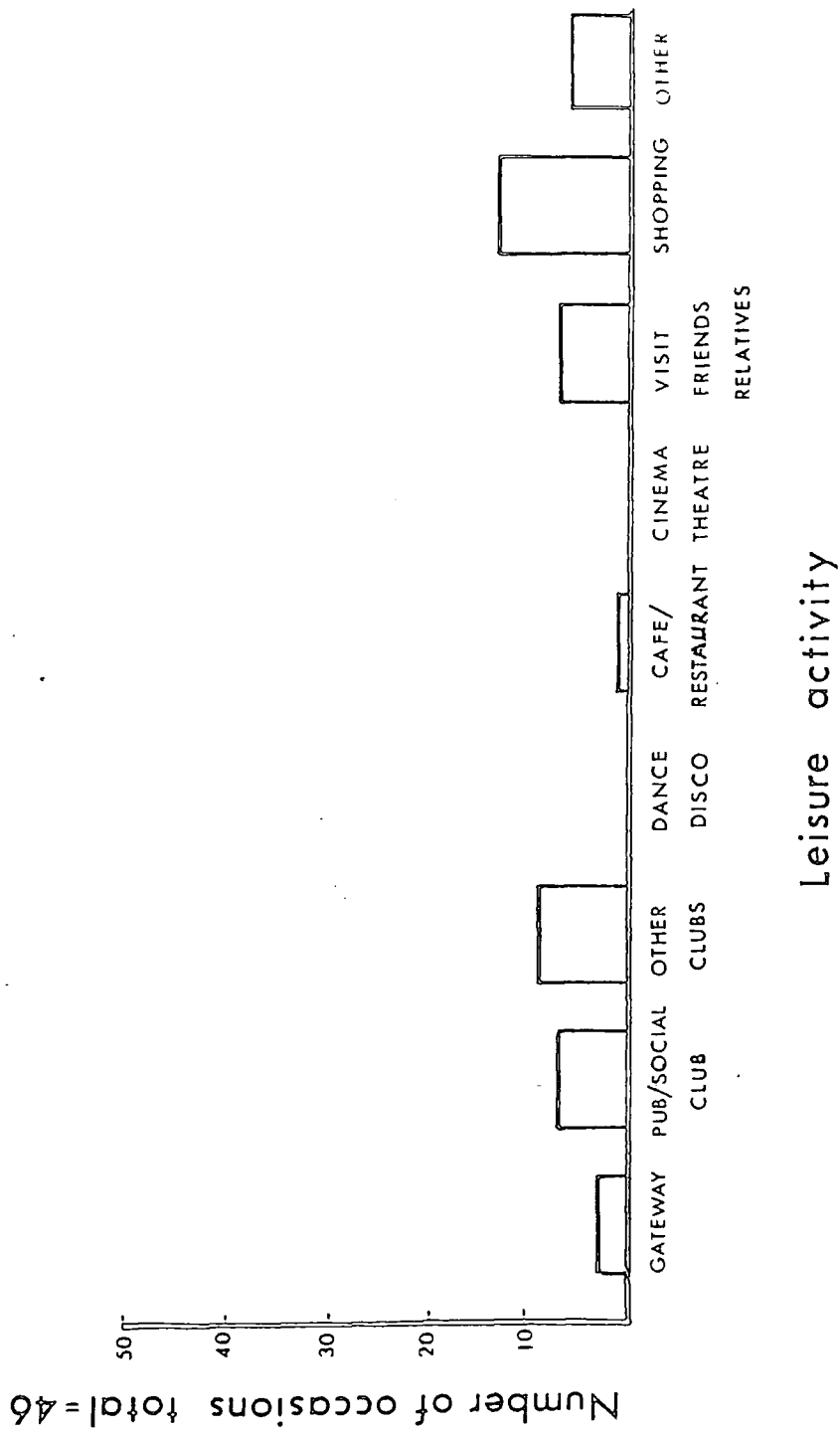


Figure 3.14 Leisure Activities on the Day Prior to the Interview

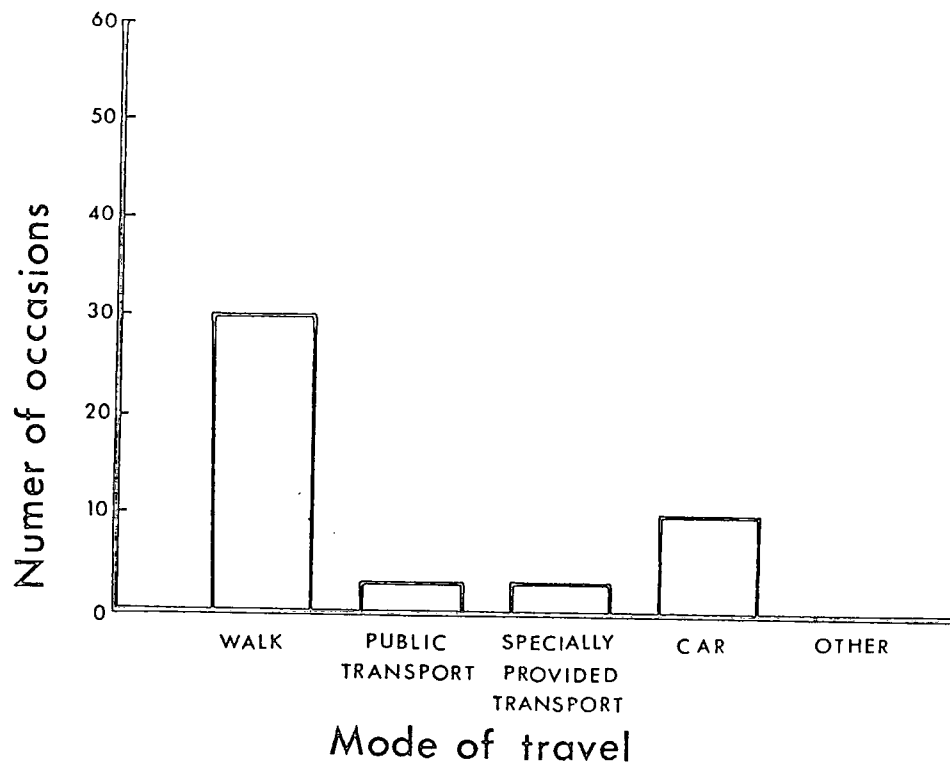


Figure 3.15 The Mode of Transport Used to Travel to Leisure Activities on the Day Prior to the Interview

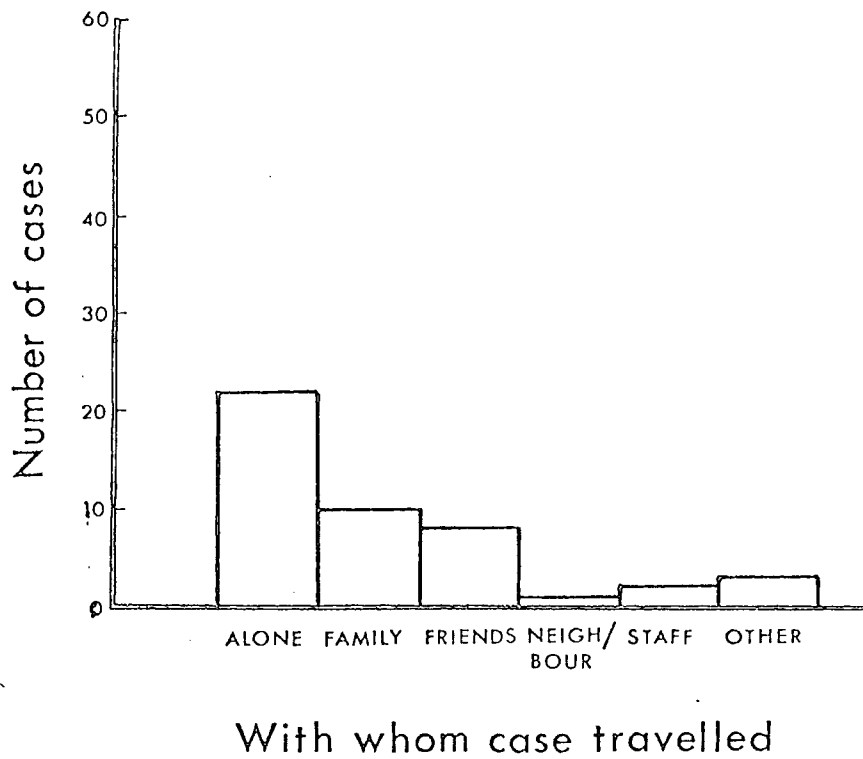


Figure 3.16 The People with Whom Cases Travelled on the Day Prior to the Interview

MENTIONED BY (number of respondents)

	Staffed Homes		Unstaffed Homes		
	n=24		n=62		N
	N	%	N	%	
Mobility	0	0	2	3	2
Selfcare	0	0	1	2	1
Reaction of other people	0	0	9	14	9
Road Safety	4	17	12	19	16
Health	2	8	8	13	10
Getting Lost	1	4	4	6	5
The Opposite Sex	0	0	4	6	4
Behaviour	5	21	3	5	8
Speech and Communication	1	4	2	3	3
Lack of Money Values	0	0	1	2	1
None	10	42	44	71	54

Table 3.11 Number of Respondents from Staffed and Unstaffed Homes Mentioning Each Problem

will be considered in more detail in the discussion. A staff member of a staffed home commented that of 20 residents, only 6 were able to go out alone.

### 3.11 Case Studies

Throughout this chapter results have been given which refer to the sample as a whole and which refer to people as cases. In order to reintroduce these cases as individual people and to give a realistic picture of their lives in the community, the remainder of this chapter consists of a narrative account of 8 individual cases, 4 from staffed homes and 4 from unstaffed homes. These are essentially brief sketches of the lives of real people. Names have been changed to preserve anonymity.

#### George (aged 32 years)

George lives alone in a 2 bedroom council house. He takes care of all his own personal needs, does his own shopping, cooking and cleaning. He was married for "1 year and 10 months", but the marriage ended in divorce. He has no problems with his vision, hearing, speech or mobility. He said he could read and write only a little and that he frequently required help from a community nurse to deal with his mail. However he had no problems understanding money values.

George was in full time employment with Mencap, a charitable organisation for people with a mental handicap. He usually travelled to work by specially provided transport but on occasions he would travel by push bike.

Although George lives independently, much of his life revolves around services for people with a mental handicap. When asked what he had done during the previous 2 weeks he mentioned 7 different activities or places visited. Three of them involved activities organised by societies for people with a mental handicap. On these occasions he would use the specially provided transport. The other activities included shopping, visiting friends and relatives. His interest was woodwork.

Joyce (aged 33 years)

Joyce lives at home with her mother only. She has no physical problems. However she can only read and write a little and has no understanding of money values. She attended school for only a short while and was then educated at home by her mother who believed that teaching her daughter the difference between right and wrong was more important than teaching educational skills.

Joyce is an example of a young woman whose life appears to be centred around the home and her mother. She enjoys music and watching TV. Although Joyce is quite able and can do most things for herself she does not attend any occupational activities during the weekday and only went out of the house during a 2 week period to go to the local shop. Friends do not appear to feature in her life. Contacts with people outside of the home were usually mother's friends or other family members. This combined with her mother's ill health meant that Joyce led a fairly sheltered and isolated life.

Paul (aged 27 years)

Paul lives at home with his parents. He has no sensory or mobility problems and is quite able in self care and reading, writing and understanding money values. His parents, to quote them, "have taken terrific risks with him". They have encouraged and supported him in his attempts to be independent in travel when out of the home. Paul is able to travel alone and to use public transport including trains and buses. His parents were extremely proud of him , commenting on his artistic ability. His interests included classical music, playing the piano, weaving and origamy.

Paul attends a day centre for people with a mental handicap on 5 days a week. He walks alone to the centre each day. During a 2 week period he engaged in a number of activities including shopping, visiting a cafe, attending a classical music concert at an art centre and attending piano lessons. On all occasions he travelled alone either walking, by public transport or by push bike. However friends did not appear to feature in his life. At no point during the interview did Paul's parents mention him going out with a friend.

Graham (aged 46 years)

Graham lives at home with his parents. He has a brother, also with a mental handicap, who is living at home. Graham has some difficulty in washing himself and is unable to read, write or understand money values. He never goes out alone and in 46 years he has never been left alone in the home. His parents regard him as a child and spoke of a local fair as being for "the children themselves". They also mentioned

that Graham believed in Santa Claus.

Graham attends an ATC on 5 days a week and is taken there and back by specially provided transport. During a 2 week period shopping with his father was the only activity mentioned. Again friends were not mentioned during the interview. He was interested in darts and football.

James (aged 27 years)

James lives in a staffed home with 13 other people with a mental handicap. He spent most of his childhood at home with his parents. It became apparent during the interview that the staff members did not know a great deal about James and had to refer to the records before they were able to answer some of the questions.

James has no sensory , mobility or selfcare problems but can only read, write and count a little. He attends an ATC on 5 days a week and travels by specially provided transport. He never goes out alone and during a 2 week period the only leisure activity mentioned was an organised trip to a local attraction with other residents from the staffed home, including staff members. He had no interests or hobbies outside the home.

During the interview James was present and he appeared quiet and shy. He appeared to have no contact with either family or friends outside the staffed home.

Keith (aged 31 years)

Keith lives in a staffed home with 24 other people with a mental handicap. Though he is slightly deaf in one ear he has no problems with sight, mobility or self care. He can read and write a little and has a limited understanding of money values.

Keith is one of the few who work. He attends an ATC on 2 days a week and for the remaining 3 days works on a community rural aid programme, bookbinding. He uses several modes of travel including walking, public transport and specially provided transport. During a 2 week period he went to a local pub with others residents of the staffed home in which he lived and to a local shop alone. Apart from these 2 activities no others were mentioned. There was also no mention of Keith going out with friends apart from those people with whom he lived. He frequently goes out alone. His interest outside of the home was visiting the local pub.

Sean (aged 49 years)

Sean lives in an ordinary house with 2 other men with a mental handicap. The home is however a staffed home managed by the NHS. The staff do not stay overnight. Prior to living in an ordinary house he lived first in a large hospital for people with a mental handicap and then in a community home with several other people also with a mental handicap. He has no physical problems and is independent in self care. He can read and write a little and can understand money values.

Sean leads a fairly busy life. He attends an ATC on 2 days a week and on a further 2 days attends a local art centre. He travels alone or

with others from his home by public transport. During a 2 week period Sean was recorded as engaging in 7 different activities. These included visiting friends, going to a folk club, going to the swimming baths and the cinema, attending adult literacy classes and doing his own shopping. His interest is in folk music and is a member of a band at the art centre.

Roger (aged 33 years)

Roger lives in staffed home with 28 other people with either a physical handicap, a mental handicap or both. Prior to this he lived in a large hospital for people with a mental handicap. One of the difficulties with Roger's present home is that it accommodates people both with and without a mental handicap. According to one member of staff, this causes problems in that people without a mental handicap feel stigmatised because they live with people with a mental handicap.

Roger is severely physically disabled and is unable to walk. He has no sensory or selfcare problems. He can read and write a little but is unable to count. He attends a Spastics Society day centre on 5 days a week and travels with other residents from the staffed home by specially provided transport.

Roger's interests include swimming and listening to pop music. Though he is severely physically disabled and is confined to a wheelchair when out, he frequently goes out alone. During a 2 week period he was recorded as engaging in 5 different activities. These included going to the swimming baths with other residents, visiting his brother, going to the library, the local shop and the local pub. For the last 3

activities he went alone in his wheelchair. This involved negotiating pavements and kerbs and crossing roads.

When out Roger places himself at risk. However this is viewed by one member of staff as important for development since people with a mental handicap "should face the same kinds as risks as everyone else". Although the staff are concerned about Roger when he is out they do not impose limits upon him. Roger's life is enriched as a result of this attitude combined with his "love of socialising".

## CHAPTER FOUR

### Discussion

The study reported in this thesis sought to make a contribution to current knowledge of the characteristics and activities of people with a mental handicap living in the community. Data were obtained on a group of people with a mental handicap living in County Durham.

This chapter aims to discuss the problems experienced when collecting the data and to discuss the results obtained. The following sections briefly summarise the main findings and where appropriate compare them to the those of previous research workers referred to in chapter one.

#### 4.5 Methodology

The study was conducted within the constraints of time and resources. This inevitably limited the number of people interviewed and restricted the detail and reliability of the data gathered. A number of problems were apparent in the way the data were collected.

Information on the characteristics of the sample of the cases chosen was obtained by interviewing a main carer. As already stated this was less problematic in interviews with parents or other family members who may have greater opportunities to observe the behaviour to be rated. Even then there is a danger that parents may be over

optimistic about what their son or daughter is able to do. However when the respondent was a staff member of a staffed home it was sometimes necessary to check records, particularly to answer the questions relating to reading, writing and counting. The other ratings on the Wessex were less problematic, as they included skills which were more readily observable in everyday living. According to Nathan, Millham and Atkinson (1980), whose study was discussed more fully in chapter 2 (pages 42-43), asking a third party to rate the skills involves relying on informants who have varying opportunities to observe the person with a mental handicap. Judgements may be biased by that person's personal reaction as well as by his/her limited observation of the behaviour under study. One alternative to the method used would have been direct observation. This method however was impossible given the constraints. In addition one can question whether it is justifiable to use observational procedures to study people in their own homes. Another alternative would be to use the people with a mental handicap as informants on what they can do. For 8 interviews this is what occurred. However had this method been used as the only means to collect data the study would have then been limited to those who were mildly mentally handicapped or to those who were able to respond in the manner required. This study was concerned with a random sample of people with varying degrees of mental handicap.

A further problem was that the data on activities were collected retrospectively. The data obtained on occupational activities referred to activities that occurred regularly and often on a daily basis throughout the year: similar to the employment of many non-handicapped people. However the data on leisure activities or places visited during the 2 weeks immediately prior to the interview can only give an

indication of what the cases did in their leisure time. Little can be said about the variability of this data over an extended period. This could be investigated by repeated interviews over an extended period. Alternatively data could be collected in the form of a diary kept for a short period of time. Investigating leisure activities is an important area for further research because of the relevance to social integration.

#### 4.1 Abilities

The data obtained on the abilities of the cases selected for inclusion in the study revealed that the majority were independent in the skill areas rated by the Wessex scales; 77% were able to wash, dress and feed themselves independently (figure 3.4). Only a minority needed full assistance. The majority had no additional physical handicaps; 89% had normal vision and hearing (table 3.1), 90% were able to walk without any assistance (figure 3.1) and 84% had normal speech (figure 3.2). This positive picture of the characteristics of a sample of people with a mental handicap living in the community is consistent with that given by Cheseldine and Jeffree (1981) for adolescents in Manchester and by McConkey, Walsh and Mulcahy (1982) for adults in Dublin.

As regards educational skills, McConkey, Walsh and Mulcahy (1982) found that 50% were able to write their own name and 50% could understand money values. However in this study only 38% could understand money values and were capable of coping with everyday money transactions. A further 31% could read at least simple books and newspapers, but only 19% were recorded as able to write (figures 3.5,

3.6, 3.7). A low level of educational skills may in some cases have been due to a lack of opportunity to acquire them. According to one mother, her daughter was "born too early" and did not benefit from the 1970 Education Act which gave every child the right to education regardless of severity of handicap. Another example is that of Joyce, (described in the case studies) who was educated at home by her mother rather than at a school with trained teachers.

Previous studies on the characteristics of people with a mental handicap have not differentiated between staffed and unstaffed homes. In this study the sample was divided into those who lived in staffed homes and those who lived in unstaffed homes. Statistical analyses were carried out in order to determine whether there were any significant differences in the characteristics of the cases from each. The only statistically significant difference found was in self care skills. Ninety six percent of cases from staffed homes were rated as 'able' on the Wessex scales compared with 70% from unstaffed homes. Given the available data this difference could not be accounted for. One tentative hypothesis is that formal carers as a result of training have a greater understanding of the philosophy and goals of normalisation than do parents and other informal carers. They may encourage and support the individual towards greater independence. Alternatively, it might be due to selection policies of the staffed homes.

Data were not collected on IQ as this information was not readily available and would have been difficult to obtain. In addition to this, the aim of the study was to provide data on ability to participate in activities outside of the home.

#### 4.2 Occupational Activities

The results on occupational activities show that those from staffed homes were more likely to attend an occupational activity. A logistical regression analysis indicated that this was a result <sup>of</sup> the age of the cases and the type of home setting in which they lived (section 3.5). Although McConkey, Walsh and Mulcahy (1982) did not compare staffed and unstaffed homes they did find that in a sample in which 91% lived at home, 54% were at home most of the day.

The current study also showed that the majority of those who did engage in occupational activities attended an ATC (either full or part time). This included 91% of those living in staffed homes and 60% of those living in unstaffed homes attending occupational activities. Raynes and Sumpton (1987) found that 100% of those from hostels and only 76% of those living in parental homes were involved in activities which were described as training. They did not however exclusively refer to ATCs. Humphreys, Lowe and Blunden (1984) found that 62% of those who were living at home and who were attending some form of day care attended an ATC. McConkey, Walsh and Mulcahy (1982) in contrast found that only 21% of their sample attended a long term sheltered work shop and 7% attended a short term training centre. However their study was conducted in Southern Ireland and provision of day care may differ. For example McConkey, Naughton and Nugent (1983) comment that all those attending training centres in Dublin city had to find their own way there, whereas in the U.K. transport is usually provided. This may account for the finding referred to above that 54% of the sample remained at home most of the day (McConkey et al, 1982). The authors do

not however discuss this as a possible factor contributing to day care attendance. Travelling to and from activities presents difficulties for people with a mental handicap and for their carers.

Only 6 people out of 71 attending occupational activities were in paid employment, 5 of whom lived in unstaffed homes. This confirms previous findings (McConkey, Walsh and Mulcahy, 1982; Raynes and Sumpton, 1987; Donegan and Potts, 1988) that few people with a mental handicap are employed. As a result they are denied the benefits of work, both social and financial. Studies eliciting the views of people with a mental handicap have shown that work or getting work is important (Scheerenberger and Felsenthal, 1977; Flynn and Saleem, 1986).

The picture which emerges from this and from other work is that for many people with a mental handicap their working life consists of attending the local ATC, with little opportunity for paid employment. ATCs are essentially safe and protected environments, assuring company and contact with others. However they are structured settings which specifically provide activities for people with a mental handicap. This ensures that those attending spend most of the week in the company of paid-staff and other people with a mental handicap, and not with other non-handicapped people. The concept of normalisation envisages integration socially as well as physically into the mainstream of ordinary life. Giving people with a mental handicap the opportunity to work alongside people without handicaps will aid this process, and enable them to see themselves as valued members of a community taking responsibility for their own daily survival. As mentioned in chapter one (pages 13-14) effective solutions can be found, but they require imagination and resources.

### 4.3 Leisure Activities

The investigation of leisure activities was confined to a sample period of 2 weeks immediately prior to the interview. The findings show that though some led fairly active lives, others did not. For example Sean who lived in a staffed home with 2 other men with a mental handicap engaged in 7 different activities over the 2 week period. Joyce, however, who lived at home with her mother, was recorded as not going out of the home over the 2 week period (both Sean and Joyce are described in the case studies). A few individuals were actively encouraged to be independent, for example Sean and Paul (see the case studies). Some, like Joyce, were cocooned in an isolated environment, reliant upon others to provide leisure activities or to take them out of the home.

The cases from this study engaged in a variety of leisure activities, of which the most popular was shopping; 55 people went shopping on at least one occasion during a 2 week period. This included 20 cases (87%) from staffed homes and 35 cases (63%) from unstaffed homes (table 3.7). Previous research has also shown that shopping is a popular activity of people with a mental handicap (Cheseldine and Jeffree, 1981; Humphreys, Lowe and Blunden, 1984). Related to this is the finding of McConkey, Naughton and Nugent (1983) that local shop-keepers, bus conductors and chemists were the 3 groups of people with whom over 50% of the people with a mental handicap in their study had recent contact during the month prior to their being interviewed. In many instances in the current study these shopping trips consisted of a short walk to the local shop and back. However

although these quick trips to the local shops may give some opportunity for brief encounters with non-handicapped people they may not permit more extended contact.

After shopping, visiting friends or relatives and going to the pub or social club were the next most popular activities. Forty three cases were recorded as visiting friends or relatives (table 3.7). This included 43% of those from staffed homes and 57% of those from unstaffed homes. A more detailed examination revealed that 29 people visited relatives, 5 visited friends of the family and only 9 people visited a friend of their own. Previous studies have suggested that many of the leisure activities of people with a mental handicap are passive and solitary (eg Tyne, 1978; Cheseldine and Jeffree, 1981; McConkey, Walsh and Mulcahy, 1981) . However in this study 31 cases were recorded as visiting a pub or social club during a 2 week period, 20 men and 11 women. This included 43% from staffed homes and 37% from unstaffed homes. Again looking more closely at this finding, 23 people were in the company of either family members or other carers (including staff); 6 went alone; and only 2 went with a friend. In so far as a high number of these activities were in the company of family or other carers, the findings do seem to confirm those of previous studies, in that many of the leisure activities of people with a mental handicap living in the community are family or carer centred, with friends rarely featuring as companions.

Attending a Gateway or other club for people with a mental handicap was only the fifth most popular activity, with 18 cases mentioning this as a leisure activity. Some reported that they used to go but stopped either because they did not like it, or for some other reason

not mentioned. For 4 of the 18 attending a Gateway, or other club for people with a mental handicap, this was their only leisure activity during a 2 week period. These clubs are usually run by voluntary or paid members of the public and membership consists of people with a mental handicap. As previously mentioned social integration into the mainstream of ordinary life is an important goal of normalisation. Providing special facilities for people with a mental handicap to occupy themselves goes against this goal. Furthermore the provision of leisure activities in large groups can in itself be a barrier to integration with non-handicapped people (Wertheimer, 1983). People with a mental handicap need the opportunity to meet and mix with non-handicapped people of their own age (providing that this is what they wish to do) with less emphasis on the use of special leisure facilities and more encouragement to use ordinary existing community leisure facilities.

As reported above, some of the cases in the current study were highly dependent on staff and family for their leisure activities. For some cases their leisure activities were wholly family or carer centred: 11 cases from unstaffed homes were with family members for all of their leisure activities during a 2 week period and 11 cases from staffed homes were with staff members for all of their leisure activities during a 2 week period. Of the total number of leisure activities recorded, 44% were in the company of family or staff of the staffed homes. Previous studies have also shown that many people with a mental handicap are dependent on family members for their leisure (Cheseldine and Jeffree, 1981, 1982; McConkey, Walsh and Mulcahy, 1981; McConkey, Naughton and Nugent, 1983). For only 10% of the activities in the current study was a friend mentioned as companion. This confirms

earlier findings (McConkey Walsh and Mulcahy, 1981, 1982; McConkey, Naughton and Nugent, 1983; Humphreys, Lowe and Blunden, 1984) that friends do not play an important part in the leisure pursuits of people with a mental handicap.

When considering leisure activities for people with a mental handicap it should not be assumed that they all have similar social interests. Although some may wish to share much of their social lives with other handicapped people, to take this as an assumption may lead to segregation in their social lives even though they may be physically integrated within a residential area. It is important to consider each person's individual needs. Atkinson (1983) in a survey of 50 people with a mental handicap found that they had a wide and ordinary range of activities. She concluded that "it is clear that different people (with a mental handicap) enjoy doing different things". This study also showed that the interests and activities of people with a mental handicap vary. Given the opportunity and encouragement many can develop active social lives. However the findings of this study, and those of previous studies, have shown that for people with a mental handicap, friends are not often companions in leisure activities. It may be that in addition to providing the opportunity to participate in a wide variety of leisure activities many people with a mental handicap may need help to make acquaintances and develop friendships.

Obtaining information on the leisure activities of people with a mental handicap is an important step in monitoring the progress of community care. However it is also important to find out from those with a mental handicap their views on leisure time activities, and the types of leisure activities that they are interested in.

#### 4.4 Travel

Travel was not looked at separately, but it is of such importance in attending activities, occupational or leisure, outside the home that it will be looked at separately in this section. In retrospect it is an area which could have received more examination. Travel skills are essential for independent functioning. People without the skills to move around the community independently will be perceived and responded to as dependent individuals. Some may never be able to travel independently either because of the severity of the mental handicap or because of physical handicaps. However for others travelling independently may be a possibility if opportunities and adequate training are given. Research has shown that people with even severe mental handicap can learn travel skills (e.g. Page, Iwata and Neef, 1976; Matson, 1980; Marchetti, McCartney, Drain, Hooper and Dix, 1983; Michie and Lindsay, 1987). Roger, referred to in the case studies illustrates how someone with a severe physical handicap can travel independently even though this may be limited to travelling within the vicinity of the home.

Specially provided transport was the most popular mode of travel used by cases in the present study, whether this was travelling to an occupational activity or to a leisure activity. Sixty one cases used specially provided transport to travel to an occupational activity (figure 3.11) and on 39 occasions (from a total of 230 occasions) to travel to a leisure activity (figure 3.9). Twenty nine cases (37%) were recorded as using public transport to travel either to an occupational activity or to a leisure activity. Of these 12 travelled

alone; of whom 4 lived in staffed homes, 5 in the family home and 3 lived alone. The remaining 17 cases using public transport were accompanied either by other family members or by staff. Again research has shown that even those with a severe mental handicap can be taught to use public transport.

Research on the travel skills of people with a mental handicap is limited. Cheseldine and Jeffree, in their study of the leisure time of teenagers with a mental handicap aged between 13 and 19 years, reported that the majority were dependent on their family or special transport to take them out of the home, with 93% unable to catch a familiar bus on their own and 42% never going further than their own cul-de-sac without an adult. McConkey et al (1982) on the other hand reported that 64% of the males and 47% of the females were travelling independently or using community facilities alone. However the age range of their sample was 15 to 64 years. Neither study looked at the ways in which the people in their sample travelled to day activities or to leisure activities. McConkey, Naughton and Nugent (1983) comment that all those attending training centres in Dublin city have to find their own way there, but McConkey et al (1981, 1982) did not explore whether this had an effect on the attendance rates at the training centres, how people travelled to the centres or whether any difficulties were experienced in travelling.

That many people with a mental handicap lack independent mobility presents a problem both for themselves and for their carers. For example one father mentioned that a particular problem with his 33 year old daughter was transport and the cost of transport. She rarely went out alone. When she did go out her parents had to travel with her

and either remain or return to collect her. This placed limitations both on her and on her parents. As the results have shown, in many instances this difficulty was overcome by providing special transport. But the use of special transport often means long journeys which take away from time spent in other activities. In addition to this it perpetuates the 'school atmosphere' which detracts from adult independence. Time restrictions are placed on the family like those imposed by having children in primary schools, with the important difference that these restrictions can last a lifetime.

The current study showed that 37 cases (43%) rarely or never went out alone and 41 (52%) of the 79 cases recorded as going out during a 2 week period did not go out alone. Wandsworth (1976) in a study canvassing the views of people with a mental handicap in South London found that 60% of the sample never went anywhere by themselves; of these 64% said they would like to. That many do not go out alone again imposes restrictions and limitations particularly on family or informal carers. As in the case of Joyce this may mean spending a lot of time mixing with the parents or with the parents' generation.

The above restrictions provide a framework in which the people with a mental handicap and their carers led their lives: always having to make arrangements. If someone is unable to or does not travel alone for other reasons, related either to lack of ability or to lack of opportunity, they are dependent upon others to take them out and as a result are dependent upon others to provide activities outside the home.

#### 4.5 General

This section concerns information that was recorded at the end of each interview. This includes comments made by the respondents, which often revealed how they perceived the person with a mental handicap.

Although all the cases in the study lived in homes which were located in a community setting, one comment made by a respondent who was a staff member of a staffed home illustrates that there was perhaps little contact with that community. This respondent said "(Staffed home) is supposed to be in the community, but there is little contact. Activities are usually organised by and centre around (staffed home)". Simply locating a person in an ordinary community does not ensure that they become part of that community. It is important that some social interaction with other members of that community takes place.

That some carers tended to be overprotective became apparent over the course of the study. This may be related to the way they perceive people with a mental handicap. As mentioned in the case of Graham (see case studies) many are seen as children who are in need of protection. Allowing them to take risks is unacceptable. Several references to the cases were made which suggested this childlike status. These included referring to the cases as boys, girls, children and kids and referring to their activities as play. Although these references were most likely unintentional or were made with the best of intentions, they cannot help people with a mental handicap feel 'grown up', or help others perceive them as adults. How independent a person with a mental handicap can become depends not only upon potential but also upon the extent to which they are encouraged. Cheseldine and Jeffree (1981) found that restrictive parents were a major reason for young adults

failing to adapt to community life. That many people with a mental handicap remain children in the eyes of their carers has a significant effect upon how they achieve greater independence commensurate with their adult status. For many people with a mental handicap their "potential remains untested and they live within the limited expectations imposed upon them " (Wertheimer, 1981). This attitude is understandable given the vulnerability of many people with a mental handicap and it is difficult to criticise parents and other caregivers for it, but this attitude does not facilitate normalisation. The degree to which this kind of attitude limited the activities of cases from the present study is not known and is an area for further study. Paul (see case studies) had parents who took "terrific risks" (their words) with him. He was given the opportunity to travel alone with the help and support of his parents. As a result he led a fairly active life albeit one in which friends did not seem to feature.

Even though the emphasis in the study was upon people with a mental handicap living in various settings it is important to say something of the effect upon the family. The discussion has already referred to the limitations imposed by lack of independent travel skills. However some parents despite frequently heavy demands placed upon them gain a great deal of personal happiness and satisfaction from being with the handicapped person. The lives of 2 families in the present study were totally dominated by their severely handicapped sons but the experience was for them a positive one. One family referred to their severely handicapped son as a "blessing" and the other referred to their son as an "angel".

A number of respondents in the present study had experienced some sort

of rejection and hostility from others. One family felt bitter about the lack of help and support that they had received, particularly from other family members, and had withdrawn into a world consisting mainly of parents and son. Nine respondents said that their anxieties were related to the response of other people, particularly when this involved staring and overt hostility.

If more people with a mental handicap are to remain in the community then these issues need to be tackled. Parents and other carers need help and advice in order to allow their handicapped charges to develop to their full potential. Ways of increasing public acceptance of and reducing hostility towards people with a mental handicap are also needed. Sandler and Robinson (1981) review research studies on the effects of contact and information upon attitudes towards people with a mental handicap.

#### 4.6 Implications of the Study

A number of factors have been identified throughout this study which may account for the limitations sometimes placed on the lives of some people with a mental handicap. In addition to this a number of areas have been highlighted for further research.

Although the principle of normalisation is the philosophy guiding service development in the field of mental handicap, there appears to be little research on the extent to which parents or families are aware of and understand these developments. If the aim of the community care initiative is to keep people with a mental handicap in the community and wherever possible to keep them at home with their

families, then the families awareness of these issues needs to be raised. It is important that they understand how they can unconsciously restrict activities, and how their attitudes may become a barrier to the acquisition of skills necessary to participate in daily survival and in a wide range of activities. Combined with this is the need for more formal resources to help parents and other carers cope with the "daily grind" (Bayley, 1973) of caring for people with a mental handicap.

This study has, amongst other things, pointed to the importance of travel for people with a mental handicap. The potential hazards that naturally exist in the community pose a danger to the safety of people with a mental handicap and may curtail access to a wide range of activities (Nihira and Nihira, 1975). However research has shown that people with a mental handicap can learn independent travel skills. The present study has also shown that given the opportunity some can become independent in travel.

Other areas needing further research include investigating the differences in self care skills and attendance rates at occupational activities between those from staffed and unstaffed homes; the opportunities available for employment; leisure activities; the attitude of parents and other caregivers to people with a mental handicap; and the attitude of the public towards people with a mental handicap.

The results reported from 86 cases, are, as far as practicable, a random sample from the mentally handicapped population of County Durham as recorded on the Social Services Register. The register

provides a much better basis than any previously available, for sampling in a controlled way from this population. As the register improves and is updated its further use in research of this kind is to be greatly encouraged.

Appendix 1 Reasons Why Some of the People Included in the Initial Target Sample Were Not Interviewed.

NUMBER OF CASES	REASON FOR NOT BEING INTERVIEWED
7	The case did not want to participate.
5	The case had moved out of the area.
7	The case had moved, but there was no forwarding address.
5	The address given was incorrect.
13	The case was not known at the address given.
2	There were serious doubts as to whether the case was mentally handicapped.
1	A decision was made by the interviewer not to proceed due to anticipated difficulties in the interview. (A decision which, with the benefit of hindsight and experience, was wrong).
1	The case could not be contacted.

Appendix 2 Composition of Households

Composition of Household	Number of Cases
Both parents only	18
Both parents and 1 sibling	7
Both parents and 2 siblings	4
Both parents and 3 sibling3	1
Both parents and grandfather	1
Mother only	10
Mother and 1 sibling	1
Mother, 1 sibling and grandfather	1
Mother and 2 siblings	1
Mother and 3 siblings	1
Mother and adult male	2
Father only	3
Brother and sister-in-law	1
Sister, brother-in -law and nephew	1
Uncle	1
Wife	1
Independent own home (alone)	6
Independent own home (with others)	2
Staffed homes	24

Appendix 3 The Questionnaire

Interviewer ..... Editor.....  
(red pen)

Today's Date (as 16JUN67)  
Time (use 24 hr clock)

Col 2 

--	--	--	--	--	--	--	--	--	--

  
10 

--	--	--	--	--	--	--	--	--	--

 13 

--	--	--	--	--	--	--	--	--	--

 8

FILE RS CAT 1  
Line 1

1. Respondent's Surname .....

Forename .....

Address .....

Telephone number .....

2. Client's Surname .....

Forename .....

Address .....

ID 15 

--	--	--	--

 17

3. Client's Date of Birth (as 16JUN67)

Age last birthday —

Sex (1 = male; 2 = female)

19 

--	--	--	--	--	--	--	--	--	--

 25

27

4. WHAT IS YOUR RELATIONSHIP TO (client)?

- (mother) = 1
  - (father) = 2
  - (brother) = 3
  - (sister) = 4
  - (other) = 5
- (specify)

29

5. CAN YOU TELL ME THE NUMBER OF PEOPLE LIVING IN YOUR HOUSEHOLD? (include respondent and client).

Adult male over 16 31  
Adult female over 16 32  
Children 25  
Total 37

6. CAN YOU TELL ME THE RELATIONSHIP OF THE OTHER MEMBERS OF YOUR HOUSEHOLD TO (client). (exclude respondent).

(code: mother = 1; father = 2; brother = 3; sister = 4; other = 5).

Name Relationship to Client

1.....	39
2.....	41
3.....	42
4.....	45
5.....	47
6.....	49
7.....	51

Can I now ask you how well (client) is able to see, hear, speak and walk.

Line 2

7. HOW WELL IS (client) ABLE TO SEE? (assess as with spectacles, if worn).

Code as follows:

- Blind or almost = 1
- Poor vision = 2
- Normal vision = 3

2

6. HOW WELL IS (CLIENT) ABLE TO HEAR? (assess as with hearing aid if worn)

Code as follows:  
Deaf or almost = 1  
Poor hearing = 2  
Normal hearing = 3

4

Can I now ask you about (client's) use of language.

9. IS (CLIENT) ABLE TO SPEAK? (regardless of clarity)

Code as follows:  
Never a word = 1  
Odd words only = 2  
Sentences and normal = 3  
Can talk but does not = 4

6

If the answer to q.9 is 'sentences and normal', is his/her speech:  
Difficult for you or other close acquaintances to understand, impossible for strangers? = 1

Easily understood by yourself and other close acquaintances, but difficult for strangers? = 2

Clear enough to be understood by anyone? = 3

3

Can I now ask you how well (client) is able to get around, with or without help.

10. CAN (CLIENT) WALK:

Code as follows:  
a) With help? (from another person or appliances)  
Not at all = 1  
Not upstairs = 2  
Upstairs and elsewhere = 3

10

b) By him/herself?

Not at all = 1  
Not upstairs = 2  
Upstairs and elsewhere = 3

12

I would like to ask you some questions about how well (client) is able to do things for him/herself.

11. IS (CLIENT) ABLE TO FEED HIM/HERSELF?

Code as follows:  
'Not at all' - needs to be fed = 1  
'With help' - occasional assistance; food has to be cut; requires a job; = 2  
'Without help' - eating; without undue mess; in a reasonable length of time if left alone; without food being specially prepared. = 3

14

12. IS (client) ABLE TO WASH HIM/HERSELF?

.....  
Code as follows:  
'Not at all' - needs to be washed. = 1

'With help' - washes him/herself with assistance; if male and needs to be shaved. = 2

'Without help' - washes adequately and completely without assistance. = 3

16

13. IS (client) ABLE TO DRESS HIM/HERSELF?

.....  
Code as follows:  
'Not at all' - Needs to be dressed. = 1

'With help' - Unable to manage fastenings; unable to tie shoelaces. = 2

'Without help' - puts on clothing; fastens them reasonably well without any assistance. = 3

18

I would like to ask you some questions about (client) reading, writing and counting skills.

14. IS (client) ABLE TO READ?

.....  
Code as follows:  
'Nothing' if unable to read or recognise own name = 1

'A little' if can read or recognise all or part of own name. = 2

'Newspapers &/or books' if able to read and understand a newspaper or simple book. = 3

20

15. IS (client) ABLE TO WRITE?

.....  
Code as follows:  
'Nothing' if unable to write his/her own name or is only able to copy it. = 1

'A little' if can at least write his/her own name without copying it. = 2

'Own correspondence' if able to write brief letters without help. = 3

22

16. IS (CLIENT) ABLE TO COUNT?

.....  
.....

Code as follows:

'Nothing' if unable to count, or, even if able to count up to 5 or 10 cannot make use of it at all. = 1

'A little' if able to recognise small values, eg. would be able to sort out 3 spoons or 4 plates or 5 cups. = 2

'Understands money values' if able to make small purchases at a shop and give/receive correct change.

= 3

24

Can I now ask you about (client's) activities and interests outside the home.

Line 3

17. DOES (CLIENT) ATTEND ANY OF THE FOLLOWING?

- 1. School (1 = yes; 2 = no) 2
  - 2. A.T.C. (1 = yes; 2 = no) 4
  - 3. Work (1 = yes; 2 = no) 6
  - 4. Further education (1 = yes; 2 = no) 8
  - 5. Other care (1 = yes; 2 = no) 10
- (Specify)

.....

IF (client) attends any of the above ask questions 18 to 23 for each place. Use separate sheets. (Number each sheet 1 - 5 as above)



YESTERDAY?

(If yesterday was Saturday or Sunday refer to Friday.)

(Use a separate sheet for each place)

Day? (Mon = 1; Tues = 2; Wed = 3; Thurs = 4; Fri = 5).

Where did he/she go? .....

.....

What time did he/she depart and return?

(use 24 hr clock)

Departed  
Returned


How did he/she get there?

.....

Walk

(1 = yes; 2 = no)

Public Transport (1 = yes; 2 = no)

Taxi/Minibus (1 = yes; 2 = no)

Car (1 = yes; 2 = no)

Other (1 = yes; 2 = no)

(Specify)


Did (client) go alone?

(1 = yes; 2 = no)

If not, was he/she accompanied:

Part of the way? = 1

All of the way? = 2

Who accompanied him/her?

.....

I would now like to ask you some questions about (client's) social activities, outside of the home.

24. DOES HE/SHE HAVE ANY SPECIAL INTERESTS OR HOBBIES OUTSIDE OF THE HOME?

(1 = yes; 2 = no)

If YES, please give brief details.

.....

Can I now ask you about (client's) social activities outside the home during the past 2 weeks?

25. HAS HE/SHE :

been to; 1. a Gateway Club etc.? (1 = yes; 2 = no)

2. a Pub/social club? (1 = yes; 2 = no)

3. Other clubs (youth, sports etc.)?

(1 = yes; 2 = no)

(specify)

.....

4. a Dance/Disco? (1 = yes; 2 = no)

5. a Cafe/restaurant? (1 = yes; 2 = no)

6. the Theatre/Cinema? (1 = yes; 2 = no)

or: 7. Visited friends/relatives?

(1 = yes; 2 = no)

8. Shopping (1 = yes; 2 = no)

9. Other visits outside the home?

(1 = yes; 2 = no)

(specify)

.....

If so, ask the following for each place. Use separate sheets. (Number each sheet 1-B as above).

Did he/she go?

For each sheet: Gateway club etc = 1; Pub/social  
= 2; Other clubs = 3; Dance/Disco = 4; Cafe/  
Restaurant = 5; Theatre/Cinema = 6; Visited relatives/  
Friends = 7; Shopping = 8; Other visits = 9).

.....  
.....  
.....  
.....

At what time did he/she depart and return?

(24 hr clock)

Departed  
Returned


How did he/she get there?

- Walk (1 = yes; 2 = no)
  - Public Transport (1 = yes; 2 = no)
  - Taxi/Minibus (1 = yes; 2 = no)
  - Car (1 = yes; 2 = no)
  - Other (1 = yes; 2 = no)
- (specify)


Did (client) go alone?

(1 = yes; 2 = no)

If not:

Was he/she accompanied:

Part of the way? = 1  
All of the way? = 2

Who accompanied him/her?

.....  
.....  
.....

26. HAS (CLIENT) BEEN TO THE ABOVE PLACE ON PREVIOUS

OCCASIONS?

(1 = yes; 2 = no)

If so:

Does he/she go regularly?

(specify ie. weekly, fortnightly, monthly).

(1 = yes; 2 = no)



Appendix 4 An Example of the Wessex Schedule

CONFIDENTIAL

FAMILY NAME .....

DAY		MON		YEAR	
10	12	14			

CHRISTIAN NAME .....

CASE NO 

--	--	--	--

  
2

Grade: 1. Mentally Handicapped  
2. Severely Mentally Handicapped  17

INITIALS 

--	--

  
7

3. Not Known  
(Please enter appropriate code in Box)

WARD (if applicable)

INCAPACITIES, PLEASE ENTER APPROPRIATE CODE (e.g. 1, 2, 3 or 4) IN BOXES PROVIDED

- |                     |               |                 |                         |                             |
|---------------------|---------------|-----------------|-------------------------|-----------------------------|
| a. WETTING (Nights) | 1. Frequently | 2. Occasionally | 3. Never                | <input type="checkbox"/> 19 |
| b. SOILING (Nights) | 1. Frequently | 2. Occasionally | 3. Never                | <input type="checkbox"/> 21 |
| c. WETTING (Days)   | 1. Frequently | 2. Occasionally | 3. Never                | <input type="checkbox"/> 23 |
| d. SOILING (Days)   | 1. Frequently | 2. Occasionally | 3. Never                | <input type="checkbox"/> 25 |
| e. 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' for walk with help)
- |                    |                    |                   |                             |                             |
|--------------------|--------------------|-------------------|-----------------------------|-----------------------------|
| f. WALK BY HIMSELF | 1. Not at all      | 2. Not upstairs   | 3. Upstairs & elsewhere     | <input type="checkbox"/> 29 |
| g. FEED HIMSELF    | 1. Not at all      | 2. With help      | 3. Without help             | <input type="checkbox"/> 31 |
| h. WASH HIMSELF    | 1. Not at all      | 2. With help      | 3. Without help             | <input type="checkbox"/> 33 |
| i. DRESS HIMSELF   | 1. Not at all      | 2. With help      | 3. Without help             | <input type="checkbox"/> 35 |
| j. VISION          | 1. Blind or Almost | 2. Poor           | 3. Normal                   | <input type="checkbox"/> 37 |
| k. HEARING         | 1. Deaf or Almost  | 2. Poor           | 3. Normal                   | <input type="checkbox"/> 39 |
| l. SPEECH          | 1. Never a word    | 2. Odd words only | 3. Sentences & Normal       | <input type="checkbox"/> 41 |
|                    |                    |                   | 4. Can talk but doesn't     |                             |
| m. READS           | 1. Nothing         | 2. A little       | 3. Newspaper &/or Books     | <input type="checkbox"/> 43 |
| n. WRITES          | 1. Nothing         | 2. A little       | 3. Own correspondence       | <input type="checkbox"/> 45 |
| o. COUNTS          | 1. Nothing         | 2. A little       | 3. Understands money values | <input type="checkbox"/> 47 |

SPEECH IF THIS PERSON TALKS IN SENTENCES IS THE SPEECH (Enter appropriate code in Box)

CODE

- Difficult to understand even by close acquaintances. Impossible for Strangers?
- Easily understood by close acquaintances. Difficult for strangers?  49
- Clear enough to be understood by anyone?

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