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PEOPLE WITH LEARNING DIFFICULTIES LIVING IN  
COMMUNITY HOMES - THEIR VIEWS  
AND THE QUALITY OF THE SERVICE

BY

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## A B S T R A C T

Services for people with learning difficulties are currently moving from predominantly institutional facilities to community based services. The two studies addressed this major change by assessing the views of the users and using a number of quality of service measures.

Study I investigated twenty-one people who had left hospitals in Leicestershire. An assessment of each person was completed which included the views of users and carers and quality of service measures. The majority of users expressed a preference for their community placement. In addition, it was found that their measured views were not statistically associated with any quality of service measure. It was decided to investigate this finding further in Study II by using a different methodological approach.

Study II used an innovative methodology emphasising outcome measures and involving six detailed case studies of people living in community residential services. These all addressed the same set of questions by the systematic collection and analysis of in-depth, objective information. An important advantage of this methodology was that it enabled a number of processes to be identified, which were not detectable using large sample techniques.

It was found that certain features of service style, such as systematic allocation of domestic tasks, were powerful influences over the amount of time that people participated in these activities. Time spent in integrated settings used by the general public was influenced by factors such as having an active link in the community, e.g., a person to visit. Users in Study II expressed greater dissatisfaction than those in Study I, and some people wanted to move to places offering greater independence. Factors were identified which influenced this viewpoint, including knowledge of alternative residential placements.

Guidelines for practice are offered. Recommendations are made for case study designs which will enable processes to be identified. Suggestions are given for implementation and feedback within services, and for targets to be achieved.

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## TERMINOLOGY

Throughout the research, care and consideration has been given to the terms and language used. The following terms have been chosen:

### 1. People with learning difficulties

Many people who have been labelled "people with mental handicaps" reject that label and prefer "people with learning difficulties. One woman who participated in the second study stated clearly her dislike of the term "mental handicap". The term "people with learning difficulties" has been selected in order to respect these wishes.

### 2. Service users and people who live in a house/home/hostel

These terms have been used because they are more accurate descriptions than "residents" or "clients".

### 3. Challenging behaviours

The term "challenging behaviours" has been chosen in preference to "problem or inappropriate behaviour". The continued use of the term "problem or inappropriate behaviour" implies the person is a problem, whilst in contrast the term "challenging behaviour" places the challenge with service providers to try to meet and individual's needs.

Challenging behaviour has been defined as: "behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities" (Emerson et al 1987).

### 4. Integration

Integration refers to people with learning difficulties being present in places not predominantly designed for use by people with disabilities, and where the majority of people present do not have a learning difficulty or other major disability.

## Chapter I

### INTRODUCTION

## Deinstitutionalisation

"Deinstitutionalisation" is the term used to describe the movement of people from institutional forms of care, often hospital based, to other apparently superior environments. At its most basic this process simply involves the relocation of people from one setting to another. At its more sophisticated, a systematic attempt is made to reverse the deleterious effects of living in large groups, enforced isolation from normal society, restricted life opportunities, and restricted personal choice (Allen 1989).

The process of people leaving hospitals has a history as long as the institutions themselves (Lakin, Bruinincks and Sigford, 1981). As long ago as 1919, Fernald described a follow-up study reporting the success of people discharged from hospital. The deinstitutionalisation movement developed during the 1960's. Motives before this time are not well documented, but there is a suggestion that economic factors were important (Allen, 1989).

Emerson (1985) argued that the origins of the policy lie in the social, political and economic changes of the 1960's and the civil rights movement that began in that era. A consumer movement had rapidly grown in size and strength (Roos, 1983, Scheerenberger, 1983) and provided a powerful lobby for community services. They were helped by the growing awareness of the negative aspects of institutional care (e.g., Goffman, 1961) and by the escalating costs of hospital services (Bachrach, 1981). Practical and ethical concerns about institutional forms of care were reinforced by a series of enquiries into hospital services in the United Kingdom (Martin, 1984), and by a succession of legal actions in North America (Landesman and Butterfield, 1987). Alternative models of care (e.g., Wolfensberger, Nirje, Olshansky, Perske and Roos, 1972; Wolfensberger 1980, 1983a) offered a symbolic ideological underpinning to the growing social movement. So a timely combination of factors resulted in both planned and actual changes in services.

Community facilities aimed to provide the support necessary to effect the assimilation of people with learning difficulties into mainstream society. This process of supported physical and social integration was to provide the mechanism that would enable people with learning difficulties to experience the autonomy, choices, freedoms, dignity, respect and independence afforded to more valued members of society. These experiences are considered to be important features of an individual's overall life quality (Novak, 1980). Hence, Emerson (1985) stated:

"the essential goal of the deinstitutionalisation movement was, and remains, nothing less than the reversal of the devaluation experienced by retarded persons as members of a deviant social group".

In practice, services vary in the degree to which they subscribe to this statement. Emerson argued that the success or failure of deinstitutionalisation can only be appropriately evaluated through an understanding of these goals and processes with their implicit values.

Butler and Bjaanes (1978) suggested three basic assumptions which underlay the shift in policy from institutional to community care for people with learning difficulties. These were:

- \* that total institutions have failed to increase the competence of the people living in them and may have detrimental effects on the development of their social skills
- \* that an environment providing "normal social contact" and the potential for "normal social integration" has a positive "normalising" effect on people with learning difficulties, and,
- \* that community care facilities provide relative "normal" environments and therefore have a "normalising" effect on people with learning difficulties.



Bachrach and Lamb (1982) suggested that in common with other social protests, deinstitutionalisation proceeded from a philosophy whose assumptions - and outcomes - remain largely untested. However, there is now a considerable literature regarding the effects of the policy on service users - see Chapter III.

A major force influencing the deinstitutionalisation movement was the demonstration that all people with learning difficulties were capable of learning. Important research studies showed that many adults living in large facilities had considerable abilities (O'Connor and Tizard, 1951, 1956) and confirmed that people with severe learning difficulties were capable of learning (Clarke and Hermelin, 1955). A behavioural teaching technology developed and included a clear demonstration that a wide variety of skills could be taught. For example, Cullen (1976) demonstrated that an errorless learning procedure could be used to teach colour discrimination and other skills, and was more effective than trial-and-error approaches. This concern for the potential of people with learning difficulties influenced policy, particularly the 1971 White Paper and led to policies emphasising development of alternative community settings. In addition, skill acquisition became a primary criterion for evaluation.

One of the most powerful influences on thinking about services for people with learning difficulties was (and is) the work of Professor Tizard and his colleagues. The Brooklands study (Tizard, 1964) reported on the findings of an experimental unit, where children with severe learning difficulties were treated on the principles developed in residential nurseries for children, rather than on medical and nursing lines. The scheme was very successful and it became clear that many of the children's problems arose from previous emotional deprivation and lack of one-to-one relationships. The children made "marked and significant" gains in intelligence and language ability. These findings had a major influence on the 1971 White Paper.

The inadequacies of the majority of existing services were clearly demonstrated by hospital enquiries, e.g., Howe Report, 1969, Report of the Committee of Enquiry in the Normansfield hospital, 1978. Similarly, Morris (1969) in a study of thirty-five hospitals found low standards and intermittent squalor in a low-prestige service that lacked energy and coherence. Dr. Morris's conclusions were blunt: much of the difficulty in administering hospitals stems from adopting a clinical model for institutions, whose primary purpose is socio-therapeutic. Hospitals tended to be run for their own bureaucratic ends, not to serve the individual needs of patients.

At about the same time, as the negative characteristics of hospitals were being reported, findings of the Wessex experiment demonstrated that alternative service provision was possible. This work directly supported the findings of the Brooklands study. Felce, Kushlick and Smith (1983) summarised the outcome of the Wessex experiment which took place in the 1960's and 1970's. The experiment involved five homes, four for children and one for adults and are now termed the Wessex locally based hospital units. The units were designed to be smaller than traditional hospital wards, were located within a residential community, and had an operational policy which was intended to give care staff the autonomy and guidance needed to implement various principles of high quality care, i.e., to avoid block treatment, rigidity of routine, social distance and depersonalisation. Four units were purpose built with twenty-five places and one was a converted house. The evaluation of the new style service demonstrated the feasibility of the locally based hospital units for people with learning difficulties. The results for children were almost unequivocal: superior outcomes were achieved at no greater revenue cost. The findings for adults were less conclusive, but still demonstrated the feasibility of the other services. For example, it was found that children in the locally based hospital units were engaged in activities to a greater extent, received more family contacts, were recorded as having fewer episodes of illness and injury and gained more skills than a control group of children living in a hospital villa.

The research demonstrating that a different style of service to traditional hospital villas was a realistic option, influenced policies, in particular the 1971 White Paper: Better Services for the Mentally Handicapped. This included ideas such as the provision of a wide range of residential services, that health authorities can provide small-scale domestic facilities, that there should be an end to segregation and physical distance from families and the local community, and there should be an extension of the development of domestic environments and personalised and individualised services. Subsequent government circulars and legislation encouraged the development of community-based alternative facilities. However, change has been very slow.

The fourth report of the National Development Team identifies some factors contributing to the slow pace of change in alternative residential environments to the long-stay hospitals. The reasons include the 1982 restructuring of the health districts that were neither coterminous with local authority social services departments, nor local education authorities. The same restructuring created health districts over half of which did not have any services for people with learning difficulties. Some District Health Authorities may have believed that care in the community was the province of social service departments. Also, awareness of the range of financial options may be less common than one could expect. Raynes, Sumpton and Flynn (1987) suggested that the slowness of transfer to community service reflects local authorities unwillingness to develop alternative provision without financial assurances. Clearly, the combination of these administrative constraints has impeded the change that could have taken place.

#### Community Care - Policies

The policy of community care can be traced back to the Royal Commission on Mental Illness and Mental Deficiency of 1954-57, which considered the problem of outdated mental hospitals and recommended the "development of community care", as a duty of local authorities in relation to Section 28 of the National Health Service Act. This recommendation was supported in the Mental Health Act, 1959, which emphasised the importance of providing services alternative to hospitals within the community.

The 1971 White Paper to the Royal Commission provided, for the first time ever, a planned strategy on community care. The overall concern of the White Paper was with the movement of people from hospital into the community and with increasing the support given to families. During the 1970's groups were set up, such as the National Development Group and the Warnock Committee that reported in favour of taking more positive action to integrate people with learning difficulties into the community. Malin (1987) suggested that this was an era of positive policy discrimination towards services for people with learning difficulties, yet in practice few real alternatives to institutions, such as hospitals, hostels, training centres, schools were offered (Malin, Race and Jones, 1980).

Other major events in the 1970's included reorganisation of both health and local authorities, which provided opportunities to revise structures in line with current needs. The Education Act, 1970, by providing entitlement to education for all children regardless of handicap, set off a movement concerned with the closer integration of special education with ordinary school education. In addition, a Committee was set up to investigate the pattern of training appropriate to caring for people with learning difficulties, which reported in 1979 (The Jay Committee, 1979, Vol. I). Its recommendations in many ways surpassed its basic remit - a new 'model of care' was proposed which emphasised the need for a service geared to enhancing the social status of people with learning difficulties.

From 1971 to the present, DHSS policy on providing community-based services has changed in substance (Malin, 1987). There have been specific changes in, for example, the role of the long-term hospital. The 1971 White Paper, Better Services for the Mentally Handicapped (DHSS, 1971) recommended the provision of suitable substitute homes (for children and adults) which would either be a hospital 'if the person required special medical, nursing or other skills', or a local authority establishment 'for all others' (para. 158). In the 1980 review of progress, the DHSS claimed that 'it was likely that the White Paper overestimated the number of hospital places for adults (para. 2.47). The following year Care in the Community (DHSS 1981) estimated that 'about 1500 mentally handicapped people at present in hospital

could be discharged immediately if appropriate services in the community were available' (para. 3.1), and furthermore that most people needing long-term care 'should be looked after in the community' (para. 1.1). Since 1981, DHSS policy has been to support the planned closure of most long-stay hospitals and provide a range of suitable alternative care within the community commensurate with individual client needs.

The House of Commons Select Committee on Social Services into Community Care (1985) supported the policy for community care, but stated that it cannot be drawn up overnight, nor is it cheap. The committee recommended that hospital provision should not be reduced without demonstrably adequate services being provided beforehand; and nobody should be discharged from hospital without a practical individual care plan. However, as Bosenquet (1985) argued, it fails to deal with the central question: can the system actually be tuned to deliver community care?

Malin (1987) argued that a variety of factors are relevant to future policies:

- \* the way ahead now seems more in terms of the build up of local services through much closer co-operation between health and local authorities
- \* a greater role is being played by the voluntary sector in terms of service provision
- \* greater emphasis is now put on the role of the local authority as service-initiator
- \* service planners and providers have become more sensitive and aware of the values and principles that underpin services clients receive.

## The Griffiths Report - Community Care: Agenda for Action (1988)

The Griffiths Report (1988) - community care, covered services for people with learning difficulties, elderly, people with physical disabilities, and people with mental health problems. A detailed review of the proposals and their implications is outside the scope of this research report, and has been completed by other authors, e.g., Ovretveit (1988). Some of the central points of the report will be outlined.

The main proposals include:

- a) A Minister of State in DHSS, responsible for community care.
- b) Local Social Services Authorities should assess the community care needs for their locality; assess individual's needs; arrange the delivery of care to individuals - but not primarily as direct providers, but acting as the organisers and purchasers of services.
- c) Local Social Services Authorities should assess the need for residential care.
- d) Central Government should arrange for the necessary transfer of resources between Central and Local Government to match the defined responsibilities.
- e) Health Authorities should continue to be responsible for medically required community health services, including any necessary input into assessing needs and delivering packages of care.

Griffiths view was that social services should start from an understanding of the needs of an individual or client group and encourage many different ways of meeting need by stimulating a mixed economy of care, and in this way increase consumer choice and power. However, he did not propose a 'lead authority' (para. 32), nor favour 'a major transfer of responsibilities' (para 5.3). One theme of the

report was the need to establish accountability and financial mechanisms from the top (a Minister for community care) to the bottom ('a budgetary approach'), where realistic policies can be related to known levels of finance, and where provision of finance will require evidence of seeking out value for money. Griffiths did not comment on the total level of finance available. A major shortcoming of the proposals is the failure to recognise and address the problems of interprofessional working relationships in the community or issues concerning the management of professionals. However, a particularly positive feature of the proposals is the involvement of consumers in planning and delivery of services. Full implementation of the proposals will require a major transformation of the organisation, culture and political structures of local government.

#### The White Paper: Caring for People, 1989

The White Paper, Caring for People, set out the Government's proposals for improving community care. It complemented the proposals in the White Paper, Working for Patients. Taken together, the two White Papers set out how the Government believes Health and Social Services should develop over the next decade.

The Government proposes to make a number of changes in the way social care is delivered and funded.

1. Local Authorities are to become responsible, in collaboration with medical, nursing and other interests, for assessing individual need, designing care arrangements and securing their delivery within available resources.
2. Local Authorities will be expected to produce and publish clear plans for the development of community care services, consistent with the plans of Health Authorities and other interested agencies.
3. Local Authorities will be expected to make maximum use of the independent sector.

4. New funding arrangements will be available for those seeking public support for residential and nursing home care from April 1991.
5. Applicants with few resources of their own will be eligible for the same levels of income support and housing benefit whether they are living in their own homes or in independent residential or nursing homes.
6. Local Authorities will be required to establish inspection and registration units at arm's length from the management of their own service, which will be responsible for checking on standards in both their own homes and in independent residential care homes.
7. There will be a new specific grant to promote the development of social care for people with serious mental health difficulties.

So, it is clear that the Local Authority becomes responsible for securing the delivery of social care and this would appear to contrast with the Griffiths Report (1988). The White Paper distinguished between social care and health care and suggested that the needs of most people with learning difficulties are largely for social rather than health care (para. 2.14). In addition, clear support was given for people leaving hospitals (para. 2.14).

The White Paper placed an emphasis on achieving high standards of care (Chapter 5). The recommendations included inspection of residential homes (para. 5.17) and the Government recommended that common standards should apply across all sectors. It was proposed that special emphasis be given to assessing the quality of care provided and the quality of life of residents, as well as physical conditions (para. 5.24). In addition, the White Paper stated that the field of community care was a particularly rich one for research, and that the successful record of research of the past will continue to be needed (para. 5.28). Further discussion of the White Paper is outside the scope of this chapter and the main points are summarised by Millar and Sheldon (1989).



## Rationale for the Current Research

It is suggested that within the current situation of policy discussion and planning aimed at deinstitutionalization and community care, evaluation of services is particularly pertinent. The White Paper, *Caring for People*, (1989) has clearly stated the value of such research, and emphasised the importance of assessing quality of care and quality of life of people living in residential care. The research studies outlined in chapters 5 and 6 address the issue of evaluation of quality of service and place particular emphasis on the views of people living in community services. In addition, methodological issues of measurement are central to the studies. Before describing the studies, chapter two considers the issue of Quality of Life which is often cited as a reason to support community based services; and chapter three reviews the literature on outcome studies.

## Changes during the Course of the Research

During the course of the research, major changes have occurred both nationally and locally. Study I took place during 1986. Since this time, the Health Service has undergone a major reorganisation with the introduction of Griffiths management. Within Leicestershire, one hospital (33 beds) closed and two are planned for closure in 1990/91, and an expansion of resources in the private and voluntary sectors has taken place. During 1989, both the Health Service and Local Authority agreed a set of Service Principles which are broadly consistent with O'Brien's (1987) work - see Chapter II. In addition, the White Paper, *Caring for People*, is offering clear support for non-institutional services.

## CHAPTER II

### Literature Review

### QUALITY OF LIFE

## QUALITY OF LIFE

### Introduction

The term 'Quality of Life' has been used increasingly in recent years in the planning of services for people with disabilities. It is frequently argued that people with learning difficulties who leave large institutions will "enjoy a better quality of life in the community". The development of the concept Quality of Life and its application is likely to play a major role in the development of and changes to the delivery of services in the coming decade (Brown, 1988). Brown (1988) suggested that perhaps the most critical aspect will be the direct role that clients and sponsors (usually parents) play in this process.

The term Quality of Life is complex and ill-defined. It has obvious relevance to the evaluation of services. However, it is important to distinguish between the quality of care and quality of life. Quality of care may be viewed as a measure of the input to a service, whilst quality of life is an output measure. Good quality of care can lead to a good quality of life, but clearly this is not always the case. The quality of a person's life is influenced by many other variables than the quality of the service received. Brown (1988) stated that quality of life is an integrated and flexible process. It is a global concept and not just something happening at one point in time.

The measurement of quality of life relates to both subjective and objective criteria and includes aspects of external behaviour, personal perception and descriptions of the environment (Brown, 1988). Individuals have different wishes and different perceptions of personal fulfillment, although there are common elements from individual to individual, e.g., physical health. The views that a person has about him or herself the enjoyment an individual experiences and the problems that he or she faces, help to make up this quality. Brown (1988) suggested that quality of life is, in essence, a phenomenon which recognises, regardless of level of disability, the personal needs and perceptions of each individual, which necessarily leads to changes in

service delivery. Whitaker (1989) argued that the factors that determine quality of life for a person with a profound learning difficulty are the same ones that determine quality of life for people with lesser disabilities.

The concept of quality of life raises a number of questions and dilemmas for services. What a person thinks or feels represent important quality of life statements and may be unrelated to the nature of their disability. However, institutional services do not regularly ask the people experiencing the services, their views. In addition, it is difficult for services to decide when another person needs to become responsible for ensuring that quality of life is maintained, e.g., for a person who has difficulty expressing their own views.

#### Definition of Quality of Life

Milbrath (1982) defined quality of life as the fulfillment of one's values, goals, aspirations and needs. One measure of quality of life is viewed as the discrepancy between a person's achieved and his or her unmet needs and desires. The larger the gap between what a person has and what he or she wants and needs, the poorer the quality of their life. A similar view was given by Bigelow, Brodsky, Stewart and Olsen (1982) who viewed quality of life as consisting of a state of satisfaction for the individual and his/her meeting of the performance requirements of his or her environment.

Quality of life has also been described as the ability to meet one's perceived needs and includes the ability to increasingly have control over one's environment regardless of the original baseline (Brown, MacFarlane and Bayer, 1988). Within such a definition, it is apparent that personal perception may change over age and that perception may be influenced by a range of factors relating to experience. Brown et al (1988) recommended that any definition relating to quality of life in terms of perceived needs should take into account the individual's range of environmental experience. This has particular relevance to people whose range of experiences may be very limited, e.g., by living in institutions for many years.

Landesman (1986a) requested that the A.A.M.D. (American Association of Mental Deficiency) considered assuming a leadership role in defining the terms Quality of Life and Personal Life Satisfaction. Rosen (1986) considered that the problem is not merely definition of the term quality of life, but also one of entitlement, i.e., what minimal advantages are persons with learning difficulties entitled to, both as human beings and as individuals with disabilities?

#### Dimensions of Quality of Life and Measurement

Comparative studies to measure the quality of life have followed three major orientations: social indicators, measures of life satisfaction and more direct approaches. Social indicators, e.g., availability of services, can be measured objectively, but they present a rather narrow indicator of quality of life of a community. A major problem is that social indicators provide no information about individuals within a group. Attention has been given to the assessment of subjective or perceived quality of life in order to provide information on both individuals and communities (Andrews & Withey, 1976, Campbell, Converse & Rodgers, 1976, Hall, 1976, Atkinson, 1978, Andrews & McKennell, 1980, Campbell, 1981, Zautra & Reich, 1983). These measures are influenced by cognitive and affective factors such as an individual's aspirations, values and immediate feeling states (McKennell & Andrews, 1983).

The third approach assesses quality of life on the basis of a person's behaviour in response to the environment or environments in which the behaviour occurs (Evans, Burns, Robinson and Garrett, 1985). There is obviously an interaction between the affective, cognitive and behavioural components of quality of life. For example, Andrews and McKennell argued that actions (behaviours), feelings (affect) and values (cognitions) all interact to determine a person's perceived well being or quality of life.

Evans et al (1985) developed a Quality of Life Questionnaire which was designed to measure a person's behaviour in response to a number of ecological domains that affected him/her. The domains selected were: general wellbeing, interpersonal relations, organizational activity, occupational activity and leisure and recreational activity. A concurrent validation study indicated that there was a moderate correlation between Life Satisfaction ratings and Quality of Life scale scores. Evans et al (1985) argued that this is evidence for the view expressed by authors such as Zautra and Reich (1983), that functional or rewarding and enriching life experiences are necessary in order for an individual to report a high level of perceived life satisfaction or subjective wellbeing.

Researchers (Byrne & Cunningham, 1987, Brown et al, 1988) contend that both subjective and objective measures are valuable in determining a person's quality of life. The measurement of quality of life is, therefore, multi-dimensional across various life domains and is interactional. Quality of life includes, but is not equivalent to, the person's life satisfaction, his or her happiness and sense of control.

Milbrath (1982) conceptualised quality of life as the result of two major classes of variables: a) values, goals and aspirations and b) lifestyles. In Milbrath's model, factors at the personal level affect and are in turn affected by the factors at the community level. He suggested that personal and societal learning is the main dynamic in this interaction process.

Blunden (1988) identified four major dimensions along which quality of life is often judged. He emphasised that these dimensions were not mutually exclusive or independent: changes in one dimension may well influence another. The dimensions were:

1. Physical wellbeing

This can be defined as the ability to use one's own body in as effective a way as possible. This encompasses good health and fitness and the absence of disability.

## 2. Material wellbeing

Quality of life within our own Western culture is often judged in terms of material wellbeing. Great emphasis is placed on material aspects of life: income, housing, means of transport, and other possessions.

## 3. Cognitive wellbeing

One way of looking at this is whether the person has a positive interpretation or 'story' about their life, which they tell both to themselves and to others. It is often assumed that the cognitive aspects of wellbeing are the real dependent variables; if the other dimensions are satisfactory, then the person has a high degree of life satisfaction. This is not the case. People can be healthy, materially well off, but very dissatisfied with their life. Although there is a correlation between cognitive wellbeing and other aspects of quality of life, it is not a simple relationship.

## 4. Social wellbeing

This fourth dimension of quality of life is often neglected, particularly within services for people with disabilities. O'Brien (1987) has identified important aspects of social wellbeing which are particularly relevant within services:

- \* Community Presence: refers to the basic ability of a person to live in the company of other valued human beings.
- \* Choice: includes the opportunity to make small everyday choices, as well as major decisions about where to live, who to live with.
- \* Competence: refers to the ability and opportunity to perform basic skills in areas such as communication, self care, mobility.

- \* Respect: groups of people who are perceived as 'different' from the rest of society, often become treated as second class citizens.

The net result of a high level of social wellbeing is that the person enters into a series of valued relationships with others. They have a network of friends, relatives, colleagues and acquaintances and enjoy a mutually rewarding set of interactions with these people. It is suggested that O'Brien's aspects of social wellbeing offers a useful framework for the evaluation of services.

The work of Andrews and Withey (1976) and Campbell (1981) has investigated the quality of life and sense of wellbeing in America. Andrews and Withey identified concerns which are related to general wellbeing. The concern measures were: oneself and one's personal life (e.g., health), family, relations with other people, economic, local area, larger society and other (e.g., religion). They found that perceived general wellbeing was a single phenomenon to which the concern measures are related. Within the American population, most people felt quite positive about their lives, a few people felt very negative and a few very positive. Perceived general well-being was associated with socioeconomic status.

Campbell (1981) argued that a sense of wellbeing depends on the satisfaction of three basic kinds of need: the need for having, e.g., material successes of life; the need for relating e.g. social support, marriage, and the need for being - this is difficult to measure and refers to the image people have of themselves, including self-evaluation and their sense of influencing their own fate. Campbell found that when total populations were considered the relationship between the objective conditions of life, e.g., economic status, marital status, and experiences of wellbeing was relatively weak. He suggested that people whose feeling of wellbeing was negative, e.g., unemployed, disabled, have failed to achieve some expectation which society highly values. If this is so, then people with learning difficulties are likely to have a negative feeling of wellbeing, as currently they achieve few of society's values, e.g., paid employment, marriage.



Stanley and Roy (1988) used Campbell's life domains to evaluate the quality of life of people leaving hospital using standards set by the local community. They identified eleven items as being important to people and then obtained ratings of relevance, frequency and satisfaction from the local community. Staff then rated people living in a group home. It is suggested that this approach is a useful innovation, particularly by using standards that are local. This implies that each geographical area may have to participate in a similar local validation study.

#### Quality of Life Index: Schalock, Keith, Hoffman and Karan (1989)

Schalock et al (1989) described a Quality of Life Index that can be used either as an outcome measure or as the criterion for the goodness-of-fit between persons and their environments. The Quality of Life Questionnaire contains 28 criterion-referenced items that reflect three aspects of a person's quality of life: environmental control, social interaction and community utilization. The questionnaire was designed to be used easily by staff to assess, monitor and so improve a person's quality of life. The questionnaire has been standardised primarily on people with disabilities living in services in Nebraska. Inter item correlations averaged .83 and inter-rater reliabilities .83. The index was found to differentiate between three vocational or residential models for 419 persons receiving these services. Consistent significant differences were found among groups, suggesting a more successful quality of life outcome for those persons in more "normal" environments. The authors outline a number of cautions. Firstly, that the work on the Quality of Life Index has primarily been done with persons with mild/moderate learning difficulties, and so items provide little variability in response for people with a more severe learning difficulty. Numerous factors were found to contribute to a person's Quality of Life Index, not just programmatic intervention. In addition, the criterion for goodness-of-fit between persons and their environments was found to be most appropriate to

living rather than work environments. Despite these issues, it is considered that the Quality of Life Index developed by Schalock and his colleagues offers a valuable contribution to the measurement of quality of life.

#### Parmenter's (1988) Model of Quality of Life

Parmenter (1988) argued that symbolic interaction theory was a useful framework in which to develop a quality of life model. Fundamental to a symbolic interactionist viewpoint is the principle that human experiences are mediated by interpretation (Bogdan and Kugelmass, 1984). Another basic tenet is that the 'self' arises and is maintained in a symbolic and interactive context, e.g., we come to know what we are through others' response to us.

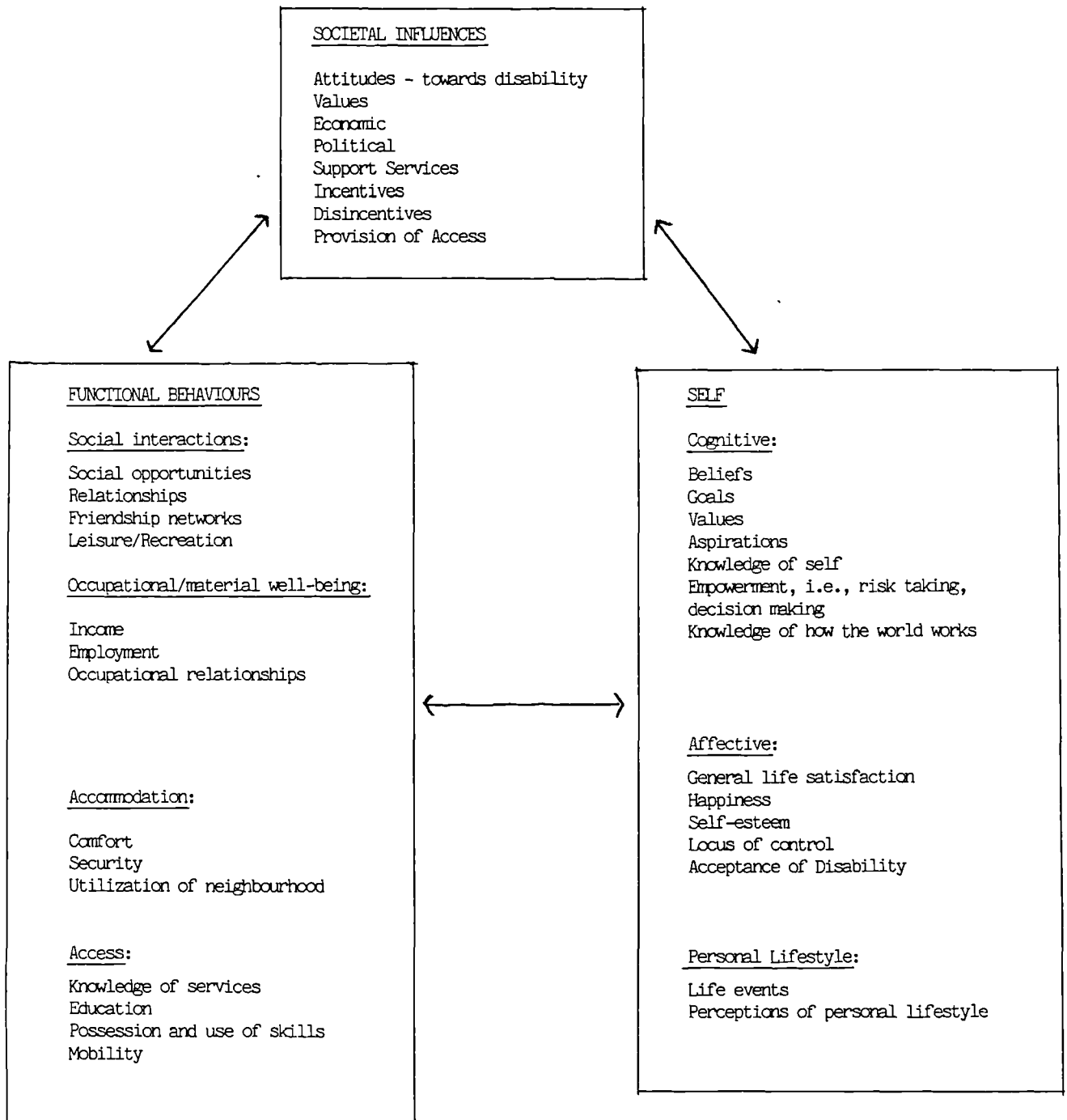
Parmenter's model is based within a symbolic interactionist/ecological theoretical framework and was influenced by the work of both Evans et al (1985) and Milbrath (1982). Parmenter's model is primarily concerned with people with physical disabilities. However, it is considered that the model is also of value when considering people with a learning difficulty.

The model includes three major components: an individual's perception of self; an individual's behaviour in response to ecological demands; and responses that the settings might make to an individual. The model accommodates the interactions that would occur between each of these components. The model is outlined in Figure 1.

It is considered that parmenter's model includes the important elements of a quality of life model. However, the model lacks validation and adequate evaluation designs. It is suggested that the model offers a valuable contribution and is a useful starting point for evaluation of the outcome of services.

Figure 1

PARMENTER'S MODEL OF QUALITY OF LIFE OF  
PEOPLE WITH DISABILITIES



A. Ager (1988) developed the Life Experiences Checklist (L.E.C.). The development of the LEC is set within the tradition of normalisation (O'Brien & Tyne, 1981, Wolfensberger, 1983a). So, the range of experiences enjoyed by an individual is seen as an important variable influencing the expectation that society has of that individual and the development of their social competence. The LEC was, therefore, developed as a means of gauging for any individual the extent to which they enjoy experiences common to many other members of the population. As a measure of quality of life, it clearly concerns itself centrally with the activities and experiences of a person, and only tangentially with their subjective wellbeing.

Items were chosen to include a broad range of life experiences. The checklist has five major themes:

1. Home, e.g., my home is well decorated.
2. Leisure, e.g., I visit friends or relatives for a meal at least once a month.
3. Relationships, e.g., I have several close friends.
4. Freedom, e.g., I can spend time by myself in privacy, when I want to.
5. Opportunities, e.g., local shops are a short walk away.

This measure of quality of life, in common with others, has the difficulty of deciding which experiences are valued. The LEC has not attempted to eliminate this bias, but rather to clarify the nature and extent of the bias. This is achieved by the normative data which found that the majority of items of the LEC were experienced and presumably enjoyed by a clear majority of the general public. The normative data was collected in a study involving the completion of self-rated LEC's by 409 householders in the general population of Leicestershire. The

LEC may be useful in providing a valuable picture of quality of life facilitated by a service. It is suggested that some caution should be exercised as the findings are likely to be influenced by the bias of individual preferences outlined above. However, the normative data of the LEC provides a very useful source of information on the experiences of the general population.

## SUMMARY

The term Quality of Life is complex and difficult to define. Milbrath (1982) offers a definition, i.e., Quality of Life is the fulfillment of one's values, goals, aspirations and needs. Other writers, particularly Brown (1988) emphasise that Quality of Life includes both subjective and objective criteria. This presents a particular difficulty for services for people with learning difficulties. People with severe learning difficulties are usually unable to express their values, aspirations and subjective views, in an easily understood way. Secondly, people who have lived in segregated services for any length of time are likely to have little objective information on which to base their views. This is not to deny the value of these views, but to recognise the real difficulties of measurement.

Parmenter's model includes many of the important elements of a Quality of Life model. However, the model gives no guidelines for measurement, e.g., measuring beliefs, goals and aspirations is likely to be extremely difficult and may not lead to a helpful clarification of the important issues in service design and delivery. Measurement of Quality of Life using an index, e.g., Schalock et al (1989), Ager (1988), may also be of limited practical value, because the overall index does not clearly differentiate between the components making up a total score on an index. It is suggested that the elusive term, Quality of Life, is best addressed by defining components that can be measured, e.g., it may be of use to develop a scale measuring opportunities, and a different scale to measure the physical

environment. This would enable service managers and planners to identify relative strengths and weaknesses within their services. A range of outcome measures could be developed and O'Brien (1987) has clarified some of the most relevant issues that need to be measured. Differentiation of components of Quality of Life that can be measured objectively may be more helpful than building complex frameworks.

## Chapter III

### Literature Review

#### OUTCOME OF COMMUNITY SERVICES

## INTRODUCTION

This chapter reviews the literature on the outcome of community based services. The review is organised into the following sections:

1. The Development of Evaluation in Britain.
2. Issues to be Addressed by Outcome Studies.
3. Success of Community Placements.
4. The Views of Service Users.
5. Activity Levels.
6. Integration.
7. Characteristics of Residential Environments.
8. Adaptive Behaviour.
9. Additional Indicators of Quality of Life.
10. Summary.
11. Implications of the Literature for the Research Studies.

Methodological issues will be discussed within the relevant sections.

### 1. THE DEVELOPMENT OF EVALUATION IN BRITAIN

Evans, Beyer and Todd (1988) outlined the development of evaluation of services in Britain. Initially evaluation approaches primarily concentrated on the quantitative assessment of service availability and use of services, e.g., estimating need among particular groups. Generally this approach does not involve any evaluation of the quality of service offered.



Evaluative research in the 1960's started to concentrate on residential establishments. Evans et al (1988) suggested that this shift could possibly be linked to wider social and economic trends in the 1960's, and a negative reaction to institutions, both buildings and professionals. The dissatisfaction with institutional provision culminated with the enquiries into mental handicap hospitals which began in the late 1960's (e.g., DHSS, 1969). Evaluators then started to express concern about the assumption that institutions were a unitary phenomenon, with no differences within or between them. Raynes, Pratt and Roses (1979) suggested that comparative studies had shown that institutions varied in the quality of service offered. The thrust of evaluative research was then aimed at comparing institutions, presumably with the goal of bringing all institutions up to a superior standard - but not using a comparison with the expectations and values of wider society. So, evaluative research (e.g., King, Raynes and Tizard, 1971) examined establishments in terms of the presence of negative features, e.g., depersonalisation, block treatments, rather than examining the rationale for such establishments.

In the early 1970's, residential services attempted both to reduce their size and the size of groupings within a service. The new developments were often accompanied by large scale evaluation projects, e.g., Wessex Locally Based Hospital Units, and by new initiatives in evaluation.

The influence of behavioural psychology became evident in evaluation within the field of learning difficulties. The use of the concept of engagement (Risley and Cataldo, 1973) as an observational measure and as a means of assessing 'purposeful activity' became common when assessing day services and residential services (e.g., Porterfield and Blunden, 1978).

Evaluation research looked at skill acquisition as it was recognised that people with learning difficulties could learn new skills given the right conditions, e.g., errorless learning techniques. This trend was evident in the number of studies using the Adaptive Behaviour Scale (Nihira, Foster, Shellhaas and Leland, 1974). In using such an approach the focus of the 'problem' is seen as the person, who needs to learn a new set of skills.

In the late 1970's, it became increasingly acceptable to state that institutions were detrimental to those living in them. At the same time, the ideology of normalisation (Wolfensberger, 1974) came to the attention of services, and offered a new direction to service planners. The philosophy of normalisation also provided a new value base for the evaluation of services, e.g., Program Analysis of Service Systems P.A.S.S. (Wolfensberger and Glenn, 1973).

It can be seen that evaluation began to assess change in terms of standards that would be acceptable to wider society. The philosophy of normalisation began to be evident in the types of behaviour to be monitored. Observational measures concentrated on age appropriate activities and use of community facilities (Humphreys, Lowe and Blunden, 1983; Evans, Todd, Blunden, Porterfield and Ager, 1987). Evaluative research began to focus on community settings as these developed.

Evans, Beyer and Todd (1988) pointed out that the most recent development in evaluation has been a concern with 'life satisfaction' indices. Interviews have been used to assess aspects of satisfaction. Heal and Chadsey-Rusch (1985) and Conroy and Bradley (1985) compared satisfaction in large institutions and small scale community living. Evaluation has recently become more concerned to ascertain the views of consumers (Lowe, de Paiva and Humphreys, 1986).

Evans, Beyer and Todd (1988) identified the phases through which service evaluation has passed. The progression has been towards a concern with the quality of services offered and increasingly with an emphasis on the experience of service users. They argued that it is not a valid method of evaluation to assess the life experiences of service users purely in terms of the extent to which they are better than those experienced in services which were considered detrimental.

## 2. ISSUES TO BE ADDRESSED BY OUTCOME STUDIES

Emerson (1985) suggested that there are two basic and overlapping issues that must be addressed by outcome studies in which investigators are concerned with the effectiveness of the social policy of deinstitutionalisation. These are:

- a) What impact does living "in the community" have upon the quality of life of people with learning difficulties?
- b) Do the processes employed in community-based services reflect the sociocultural values implicit in the movement's aims, goals and processes?

Evans, Beyer and Todd (1988) suggested that there are dangers in using deinstitutionalisation as a basis for evaluation. First there are questions about the motives behind the policy and how it is being implemented. Second, the majority of people with learning difficulties live outside institutions. Third, the evaluation of deinstitutionalisation has frequently resulted in a narrow approach to evaluation, with the effects of moving out of the institution being the focus of the analysis. In addition, Evans, Beyer and Todd pointed to the dangers of evaluation research being associated with organisations responsible for service delivery.

Evaluation needs to be based on criteria which relate to wider societal values, rather than criteria based within the culture of service delivery. The philosophy of normalisation offers a framework for evaluation research. Nirje (1969) defined the major problem of those dependent on services as being segregation from ordinary opportunities and experiences. Kebbon (1982) operationalised normalisation as a three component model where normal living conditions provide the access needed for a 'good quality of life', access being a necessary but not sufficient condition for this outcome. To obtain a good quality of life the access must be turned into actual utilization of the opportunities offered.

Normal living conditions -> leading a normal life -> good quality of  
(access) (utilization) life

Evans, Beyer and Todd (1988) suggested that identifying outcomes using this approach remains controversial, particularly in relation to their indices of life quality, for which they have adopted largely psychological measures to examine such areas as "commitment", "self realisation" and "confidence". An additional problem with this approach is that it does not take account of person's own view of their lifestyle and the services they receive.

Emerson and Pretty (1987) identified three principles from their interpretation of normalisation which are of relevance to evaluation practice:

1. A person's experience, behaviour and status are determined by the environments in which they live. Alternatives to institutional residences should, therefore, reflect the values of a wider culture in their practices and procedures.
2. Full participation in the life of the community is both a right and a need of people at significant risk of devaluation.
3. The essential objectives of community living are to enhance the quality of life experiences of people whose status has been significantly devalued.

This approach to evaluation is not fundamentally based on the values of service delivery, but rather on an analysis of the relationship between people with learning difficulties and the communities in which they live.

A further issue for evaluation to address is the use of the information within services and planning. Emerson (1985) suggested that questions should be relevant to the agendas of policy makers, and that results should be accessible to service planners. A fundamental problem for research has been its failure to influence outcome. Evans and Blunden (1984) and Humphreys and Blunden (1987) suggested a collaborative approach to evaluation which can produce valid and useful

data to both researchers and services. They argued that the utilization of research findings can only be achieved by reducing the distance between researchers and practitioners.

### 3. SUCCESS OF COMMUNITY PLACEMENTS

Studies have attempted to identify factors associated with "successful" placements. A major difficulty has been that the concept of a successful placement is ill-defined and varies from one study to the next. Crawford, Aiello and Thompson (1979) in a review of studies found that the criteria for success included remaining out of an institution, increases in functional skills and decreases in non-functional behaviours, and parental classification of success. Remaining out of an institution is the most widely used definition of success in studies, but it is suggested that this offers a very narrow perspective. Predictions of success are doubtful given the great variety in community programmes and variety in the quality of care (Molony and Taplin, 1988).

There have been few clearly agreed predictors of success. The exception is the finding that unacceptable client behaviour leads to placement failure, i.e., re-admission (Moen, Bogen and Aanes, 1975; Heal, Sigelman and Switzky, 1978; Pagel and Whiting, 1978; Sigelman, Novak, Heal and Switzky, 1980; Schalock, Harper and Carver, 1981; Intagliata and Willer, 1982). Estimates of re-admission rates have varied from 10% for people admitted to group homes (Reagen, Murphy, Hill and Thomas, 1980), 9-56% (Thiel, 1981), and 16% (Schalock, Harper and Genung, 1981). McCarver and Craig (1974) in a review of 44 studies found 74% of people remained in community services. Crawford, Aiello and Thompson (1979) concluded that demographic features and pre-discharge functional behaviour were only inconsistently related to community success, and that environmental factors were an important influence on the behaviour of people in community settings. Jacobson and Schwartz (1983) in a study of over 6,000 adults found that people in jeopardy of placement failure had higher IQ's, fewer mobility

problems and greater independence skills than other group home residents. They also evidenced more challenging behaviours and unmet mental health service needs than people not in jeopardy of placement failure. Vitello, Atthowe and Cadwell (1983) found that in general higher functioning residents were placed in less restrictive community settings. Schalock and Lilley (1986) found that success, i.e., remaining in a placement, was associated with a higher score on a Quality of Life Questionnaire (covering environmental control, social interaction and community integration).

Both Crawford, Aiello and Thompson (1979) and Landesman-Dwyer (1981) urged that the concept of "successful" placement is reconsidered and that research should concentrate more on factors associated with longer-term community adaptation. Atkinson (1988) found adaptation to life outside institutions was associated with personal qualities, personal friendships, social contacts and day-time activities.

#### 4. THE VIEWS OF SERVICE USERS

The opinions of people with learning difficulties are increasingly being sought by practitioners and planners. While studies involving the views of service users are still very much in their infancy, researchers have begun to recognise the importance and value of including users' views in research about their lives and their services (e.g., Edgerton, 1967; Edgerton and Bercovia, 1976; Edgerton, Bolliger and Herr, 1984; Conroy and Bradley, 1985; Emerson, 1985; Lowe and de Paiva, 1988). People with learning difficulties are best placed to describe their own situation, their personal experiences and their feelings (Wynngaarden, 1981).

Conroy and Bradley (1985) in their five year study of the closure of a large institution, aimed to address the feelings of the people themselves. Pre- and post consumer interviews were undertaken using a standardised questionnaire. The people who moved were found to have

more positive views about where they lived, their beliefs about how the staff felt about them, and how they felt about the other residents. People who had not left the institution were also re-interviewed, and although no significant changes were found, there was a tendency for them to be more dissatisfied with the living environment. At second interviews, a sharply reduced inconsistency rate was found, which suggests some doubts concerning the validity of responses. These findings confirm those of Edgerton (1967), Scheerenberger and Felsenthal (1977), McDevitt, Smith, Schmidt and Rosen (1978), Kielhofner (1981), Sugg (1987), that most people prefer a community placement to a hospital placement. In addition, Beswick, Leeming, Taylor, Kemp and Monk (1988) found that people living in community services show a more favourable response to their living situation, life-style and the people around them. Stanley and Roy (1988) found people living in a group home were significantly more satisfied than those living in hospital; satisfaction scores were close to those of people without disabilities in the community.

Sugg (1987) found that a closer analysis of people's reports reveals areas of dissatisfaction, i.e., a desire for more autonomy and privacy, a concern about a loss of friends after moving and dissatisfaction with day care arrangements. Williams (1986) pointed out that many people are extremely critical of existing services. It is considered that some of the more negative views may only be identified after a period of time living in the community, or/and if the interviewer has met the person over a period of time. Birenbaum and Re (1979) interviewed forty-two adults over a four year period of living in the community. They found that over half the group wanted to live elsewhere and at the fourth interview they were not reluctant to complain, e.g., about fighting. However, in contrast, Edgerton, Bollinger and Herr (1984) met fifteen people with mild learning difficulties, after they had been living in the community for twenty years. They described the people in their study as being very hopeful, confident and independent, despite ill health and stressful life events. In addition, over the years they had become less dependent on others, previously described as their benefactors.

Heal and Chadsey-Rusch (1985) developed the Lifestyle Satisfaction Scale which covers the areas of: leisure, location, staff and services, and is administered by interview. The scoring of the questions contains adjustments for acquiescence. They compared the lifestyle satisfaction of people living in flats and people living in a large fifty-eight bed service. People living in the flats varied considerably in their ability and desire to explore their local community, but they had more opportunity to do so. In contrast, the people living in the larger facility had very regulated activity schedules. They found that people living in the flats had higher lifestyle satisfaction scores and they concluded that this finding is consistent with the view that satisfaction is positively correlated with less restrictive settings. Seltzer (1981) found a positive relationship between feelings of satisfaction and relevant aspects of the residential environment, e.g., satisfaction was related to cleanliness of the house ( $r = 0.377$ ;  $p < 0.01$ ). These studies suggest that satisfaction is related to the service offered.

Some studies have identified the importance of personal freedom for people living in community services (McDevitt, Smith, Schmidt and Rosen, 1978). Lowe, de Paiva and Humphreys (1986) found that people living in NIMROD accommodation reported liking their personal freedom, e.g., being able to come and go as they pleased, and owning items (i.e., having money to spend and having their own bedroom). Cattermole, Jahoda and Markova (1988) interviewed people who had left their family home to move to residential hostels and reasons for leaving included to gain more freedom and learn new skills. Flynn (1986b) reported a number of features associated with satisfaction, e.g., when homes are in a good state of repair, if people are not victimised, if they have extensive household facilities, if their days are structured, if they have few changes of home, and if they live alone. Booth, Booth and Simons (1989) met eight people who were leaving hostels to move to houses and flats. They found that important positive aspects for the people were increases in their choice, privacy, freedom control and integration. However, problems were derived from the people they lived with and supported them, e.g., the staff were viewed as too strict and domineering. In addition, they



sometimes complained of loneliness and boredom. Reservations and positive features of the move were different for families and staff, e.g., families were concerned that their relative may be vulnerable.

Bogden and Taylor (1982) reported a rare autobiographical account of two people who had left institutions. They both had disliked living in an institution, and give examples of abuse and dehumanization, e.g., involuntary sterilization. They found benefits in leaving hospital, of having freedom, privacy, spending money, meeting new people and doing household tasks. However, they did miss the people they had known in the institution.

Recent studies have shown an increasing trend to include the views of service users (Lowe, de Paiva and Humphreys, 1986). All the studies have focussed on people who can answer questions with relative ease, and so may be described as comparatively able. Considerable problems are likely to remain in obtaining the views of people with a more severe learning difficulty.

#### Methodological Issues - Views of Service Users

Sigelman, Budd, Spanhel and Schoenrock (1981b) raised the question of whether or not the assumption can be made that what people with learning difficulties say in response to questions is valid. The literature on survey research suggests that obtaining valid information from anyone can be troublesome (Bradburn and Sudman, 1979; Sudman and Bradburn, 1974). People with learning difficulties are very likely to have difficulty with expressive and receptive communication, and so obtaining valid information is likely to be even more problematic.

Sigelman and her colleagues have addressed the issue of response validity in a number of studies (Sigelman and Werder, 1975; Sigelman, Novak, Heal and Switzky, 1980; Sigelman, Budd, Spanhel and Schoenrock, 1981a; Sigelman et al 1981b; Sigelman et al 1981c; Sigelman, Budd, Winder, Schoenrock and Martin, 1982) and have given particular

attention to acquiescence bias. The tendency towards acquiescence, responding affirmatively to questions regardless of their content is most common among younger and less educated respondents in the general population (Lenski and Leggett, 1960; Wells, 1963), and previous researchers found that people with learning difficulties are particularly susceptible to acquiescence (Gerjuoy and Winters, 1966; Rosen, Floor and Zisfein, 1974). Sigelman et al found acquiescence bias to be a significant problem and point to the dangers of relying on yes-no questions, despite the fact they yield high response rates. They suggest including embedded questions as a check for acquiescence in interviews, e.g. item-reversal techniques, asking questions that demand a "no" answer, or including an independent measure of response validity (e.g., from files or reports of carers). Acquiescence may act as a cover for difficulty in answering questions, as an automatic answer strategy, and as a means of obtaining social approval.

Sigelman et al (1982) found that open-ended questions were difficult for many people to answer, and supplementary questions with clarifying examples and probes for additional information only exacerbated response bias. Sigelman et al (1981a) found that the use of pictures in conjunction with either-or questions tended to increase responsiveness and overcome the slight bias towards choosing the last of the two options that characterised answers to verbal either-or questions. Many of these problems outlined by Sigelman and her colleagues were less pronounced for people with mild learning difficulties. Sigelman et al also found that responsiveness was increased for all types of questions after two askings. Wyngaarden recommended the use of simply-phrased open-ended questions and suggested that interviewers should be allowed to re-phrase questions, while maintaining the original content, in order to spark a response. In addition, it is important to recognise that parents, carers and other informants are by no means immune from response effects themselves, judging from the survey research literature. (Sigelman et al 1981c).

Research interviews should be natural, unobtrusive and unthreatening interactions (Taylor and Bogdan, 1981). A relaxed and conversational style is preferable, with as little structure as possible and minimum formality (Wyngaarden, 1981). The favoured setting for research interviews has been the person's own home (Malin, 1981; Flynn, 1986a). It may help to find out in advance about people's communication skills, and take steps to cope with these situations where these skills are known to be limited (Flynn, 1986a). A tape recorder reduces the amount of writing required and can make interviews seem less of a test situation (Edgerton and Bercovici, 1976; Flynn, 1986a). Wyngaarden (1981) recommended that interviews should start with easy questions to build up the person's confidence, and difficult or upsetting questions should come in the middle or towards the end. In addition, Atkinson (1988c) recommended that research interviewers acknowledge potential areas of difficulty, i.e., respondent's perception of the research (of its purpose and implications, the need for feedback, some respondents may be concerned to please the researcher). If projects are planned carefully these difficulties can be overcome.

Whilst issues of interviewing present challenges to researchers, Heal and Chadsey-Rusch identified an additional problem. The concept of "happiness" is very difficult to define in operational terms, and perhaps impossible to describe in anything other than subjective and value laden terms.

Some of the studies outlined above have paid particular attention to the methodological issues, e.g., Conroy and Bradley (1985) and Heal and Chadsey-Rusch (1985); Flynn (1986b); Lowe and de Paiva (1988). The interview schedules of Conroy and Bradley and Lifestyle Satisfaction Scale (LSS) both have checks for acquiescence bias, either in the scoring or in the question design. In addition, the LSS had inter rater reliability ranging from 0.60 - 0.95 and test-retest reliability for the total scale of 0.74. However, relatively few studies involve meeting people a number of times and sometimes (e.g., Conroy and Bradley, 1985) single meetings only occur at each stage of the research. It is felt to be likely that there is a limit to how true a picture people will be prepared to give in a single meeting.

In summary, the literature suggests that people with learning difficulties can give valid answers to questions, and can express views on many aspects of their lives. However, it is particularly important for researchers to be aware of the methodological issues, and to use checks for acquiescence bias.

## 5. ACTIVITY LEVELS

Increased activity levels are often hypothesised as likely outcomes of deinstitutionalisation, and are closely related to changes in adaptive functioning. Studies investigating activity levels have used two main approaches: observation and diary record keeping. These will be discussed separately.

### A. Observational Studies

#### Direct Observation

Direct observation of behaviour has been used as a method of evaluation of residential services for people with learning difficulties. The approach assesses the quality of client's lives by observing how they spend their time and whether they participate in opportunities available within a setting. It examines the quality of care of the setting by assessing to what extent opportunities for appropriate activity exist and are realised (Felce, 1986). Risley and Cataldo (1973) have suggested that the notion of appropriate engagement has a widespread commonsense appeal. They stated: "The extent and direction of engagement with the physical and social environment appears to be an almost universal indication of the quality of a setting for people". The definition of client engagement included: interacting with another; interacting with materials, e.g., household materials; attending/interacting in a group activity.

## Studies of Client Engagement in Houses, Community Units and Institutions

Studies of client engagement in houses, community units and institutions have involved people with severe and profound learning difficulties. There have been few investigations of people with mild and moderate learning difficulties.

Mansell, Jenkins, Felce and de Kock (1984) found that people living in a small domestic house spent on average 46% of the time engaged in purposeful occupation (range 22 - 69%). In this study, domestic activity represented 27 - 65% of engagement. This study suggested that even in "pioneering" services, people with severe learning difficulties spend half their time disengaged.

Studies comparing engagement levels in houses and institutions have generally found higher engagement levels in houses/flats than institutions (Rawlings 1985a; Felce, de Kock and Repp, 1986; Thomas, Felce, de Kock, Saxby and Repp, 1986). Felce et al (1986) made two comparisons, firstly between a group of people in a small home and a comparable group in an institution, and secondly between the latter group when in the institutions and after having moved to a small home. They found that greater engagement in activity was shown in the small homes than in the institutional settings for each category observed. Clients in two small homes were observed to be in leisure, personal, domestic and formal program activities for 51% and 56% of the time. The average in institutions was 23%, with personal (mainly eating the evening meal) the only significant category for most subjects. McHatton, Collins and Brookes (1988) found an increase in engagement following a move from a ward to a flat within an institution.

Thomas et al (1986) conducted observations of client activity of 50 adults, in matched groups of ten, drawn from two institutional wards, two 25-place community units and two small houses. They found that appropriate client engagement was extremely low in the institutional settings (3% non-social, 1% social), higher in the large community units (11% non-social, 1% social) and highest in the small

homes (40% non-social, 7% social). These findings suggest that engagement is higher in small houses than both larger community services and institutions.

#### Studies of Interaction with Staff/Carers

Felce et al (1987) in a large study of ninety adults living in houses, larger community units and wards found that when subjects behaved appropriately, such behaviour was three times more likely to be encouraged by staff in small houses than large community units and institutions. This result was supported by that of Thomas et al (1986). In addition, Felce et al (In Press) found that staff in small homes and larger community units showed greatest discrimination in their giving of attention than institutional staff. Felce et al (In Press) found no simple linear relationship between client engagement and staff:client ratios. They concluded that improvement was found when the client group size was reduced.

Repp, Felce and de Kock (1987) found that staff have low rates of interaction with people with learning difficulties. A disproportionate number of staff interactions tend to occur with a relatively small number of people, particularly those perceived as being more intelligent or less disruptive and more participative. Interaction was improved by structured settings, small teaching groups, and involving staff in decision making.

Felce et al concluded from their studies within small houses that a high quality service was not determined by a single variable but rather the combined interaction of many variables. Their studies pose two challenges. Firstly, can these findings be replicated in services in a larger scale and, secondly, can they be maintained over a long period of time. Recently, evidence has been found that beneficial effects of projects can be maintained over a long period of time. Blunden and Evans (1988) reported that "activity period" procedures were maintained over six years, despite staff changes.

## Methodological Issues in Direct Observation

The methodology used by the studies outlined above has varied in terms of the amount/length of observations, type of recording procedures and behaviour categories used. For example, Felce et al (1986) used video recordings over a three hour period for each subject, which were later analysed using a continuous real-time data collection procedure. In contrast, Mansell et al (1984) collected data over five days for eleven hours a day. There is no evidence available as to the minimum number of hours of observation necessary to give a representative picture of a person's activities. However, the studies have generally paid careful attention to inter-observer reliability, e.g., Thomas et al (1986), established inter-observer agreement using video tapes prior to the study as 82%, and during the study agreement was found to be 91%, 87% and 87%.

Some studies have used portable computers to collect data, e.g., Epson HX-20. Typically, a programme will be used which designates one key for each observational category, and an additional key starts the recording session and the internal clock. Schinke and Wong (1977) reviewed the advantages and disadvantages of electronic coding devices. Advantages were that precise chronology of behaviour could be recorded, duration of behaviour was measured, multiple behaviours were recorded and the equipment was portable. However, such equipment can be subject to mechanical failure, operator error and is expensive. The successful use of portable computers as a method of collecting data in a variety of settings has been demonstrated by the above studies.

Direct observation is a time consuming method of finding out how service users spend their time. It gives a clear picture of the activities that people participate in, and alternatives such as diaries have been shown to be unreliable (Evans, Todd, Blunden, Porterfield and Ager, 1987). Some authors have claimed that direct observation can be intrusive in small settings and there are increased problems in reactivity (Kazdin, 1979) and sampling adequacy (Mansell, 1985). Bratt and Johnston (1988) tested for re-activity effects to observations by comparing staff-resident interactions under 'covert' and 'overt'

conditions and found no difference. Felce (1986) suggested that time must be invested to find out what really happens to clients in services.

#### B. Activity Patterns - Diary Data

Some studies have also looked at what people do in services by the use of diaries and activity pattern data. Evans et al (1987) asked a primary carer to complete a diary for each participant for one week before the move and one week in the post move phase of the study. Three of the four participants moved to a staffed house as part of the NIMROD service. For two of the participants an increase was found in the amount of time spent doing domestic activities, and a decrease in recreational activities, e.g., watching TV. All three women who moved were found to spend more time in social activities, i.e., talking to fellow residents and staff. For the women who remained in hospital there were few recorded changes. Although the changes were not dramatic, they did highlight some benefits of moving to a smaller setting. Beswick, Leeming, Taylor, Kemp and Monk (1988) found similar results in a follow-up study of people leaving hospitals in Derbyshire, i.e., people living in the community spend more hours a week in constructive activity than those in hospital. O'Neill, Brown, Gordon, Schonhorn and Greer (1981) found that such changes were maintained over two and a half years.

#### Methodological Issues - Diary Data

The approaches used to collect information on activities has included the use of diaries and structured interviews with carers (O'Neill et al 1981). However, there is an important problem with the reliability of diary data. Evans et al (1987) found that agreement on a person's location recorded by diary data and observational data can vary from 45% - 87% and agreement on location and activity varied between 33% - 76%. If only small differences are found, then such data has to be treated with extreme caution. Joyce, Mansell and Gray (1989)



compared the results of structured diaries of activities with direct observation. They found agreement ranged from 41% - 72% and suggested that great caution is needed in using diaries as a source of evaluative data.

## 6. INTEGRATION

Emerson and Pretty (1987) stated that full participation in the life of the local community is both a right and a need of people at significant risk of devaluation. So, evaluation practice needs to address the extent to which people with learning difficulties participate in their local community whilst living in residential services. Felce (1988) suggested that a framework for sharing in the patterns and conditions typical of community life includes:

1. Living in a local community: maintaining familial ties.
2. Using local amenities.
3. Gaining acceptance.
4. Developing friends and a social life based on integrated pursuits.

### a) Living in a local community: maintaining familial ties

Maintenance of family links is an explicit recommendation of British national policy (e.g., DHSS 1971, 1972, 1977) and is also advocated by other concerned bodies (e.g., CMH 1975). Many variables have been investigated for their correlation with the extent of family involvement including level of resident ability (D'Onofrio, Robinson, Isett, Roszkowski and Spreat, 1980), presence of physical disabilities and parental characteristics (Burrows, Posewark and Gillette, 1968). However, the most consistently implicated factor as an obstacle to contact is the distance relatives must travel between home and

residence (Campbell, 1968; Burrows et al, 1968; McKeown, Cross and Keating, 1971; Dalgleish, 1985). De Kock, Felce, Saxby and Thomas (1988) compared the rate of family and friendship contact experienced by the residents of two houses serving adults with severe and profound learning difficulties from local catchment areas, with the rate that the majority of these individuals had experienced previously when in institutional care and with rates experienced by two comparable groups of residents living in larger units which also served local catchment areas. Residents in institutions were found to have an annual rate of 11 contacts on average per year, which rose to 40 after transfer to houses, and this was not significantly more than residents of larger units, also serving a local catchment area. Studies by Firth and Short (1987) and Felce, Lunt and Kuchlick (1980) supported the finding that locally based services support family contacts being maintained.

#### b) Using Local Amenities

Extensive use of local amenities may not always follow as a consequence of siting a service in the community. De Kock et al (1988) also investigated community contact in the study outlined above. Adults living in small homes used local amenities significantly more than they did when living in an institution (the frequency rose from 7 visits a year to 254 visits), and this was significantly more than residents living in larger units. The people living in small houses visited shops (140 trips), visited a public house, cafe or restaurant (48 visits), and participated in 31 outings for cultural and leisure purposes. The study indicated that factors other than location were important to the access residents had to local resources. The authors suggested that the factors involved were the emphasis that the houses placed on involving people in all aspects of daily living, the absence of a 'hotel' service, i.e., no catering staff, and having a devolved budget. These factors made shopping trips possible and essential. Other studies have found that adults and children living in community services have greater access to the community than people living in hospital (Firth and Short, 1987; Campbell, 1968). Raynes, Sumpton and Flynn (1987) found that less than 50 per cent of people living in hospital had visited shops, pubs or cafes, for at least a month prior

to data collection. This was in contrast to the people surveyed who were living in a hostel, more than 50 per cent of whom had visited such venues during the previous month, and 88 per cent of whom had also visited a club. People living in private or voluntary residential services, or with parents, showed a greater variation in activities than those resident in hospital, but less variation than people living in hostels. Across all settings, the use of community facilities, such as public transport, banks and cinemas, was low. Crapps and Stoneman (1989) found people living in family care situations visited leisure facilities, fast food and shops at least once a week, but rarely went unsupervised.

Saxby, Thomas, Felce and de Kock (1986) in an observation study of ten adults with severe learning difficulties found substantive participation in shopping averaged 29% and in cafes, restaurants or pubs averaged 36%. Contact with the public did occur and was considered sufficient at the casual acquaintance level. It was, nonetheless, restricted and hardly extensive enough to be the basis of friendship. Donegan and Potts (1988) reported that while people were knowledgeable about local facilities, they failed to use them. The authors suggested that while people had the skills necessary to cope with the demands of everyday life, they lacked the skills to be able to develop new social relationships. Social skills training is hence very important (Atkinson, 1985). Bratt and Johnson (1988) found that a group of young adults who had left hospital, went out more, but there was little evidence of integration. They account for this finding by the project being "second generation".

#### c) Gaining Acceptance

Felce (1988) viewed social integration as a two way affair and therefore saw the opportunities available to handicapped citizens as dependent in part on how they are perceived by their fellow citizens. A number of studies of public attitudes towards integration have concerned the decision to provide local residential services (e.g., O'Connor, 1976; Kastner, Reppucci and Pezzoli, 1979; Lubin, Schwartz, Zigman and Janicki, 1982. Felce (1988) summarised these studies as

showing that: (1) attempts to prepare communities for future residential services are likely to have little positive effect and can generate opposition; (2) opposition in practice can arise from individuals who have shown positive attitudes hypothetically; (3) actual experience of people with learning difficulties is important in shaping attitudes; (4) positive experiences shape positive attitudes and therefore there is an argument in favour of structuring contact to be successful more than for promoting contact per se and (5) opposition to community residences prior to opening moderates to acceptance or indifference following the actual experience.

Saxby et al (1986) investigated the degree of acceptance of people living in houses by gaining the views of people who had contact with them. A short questionnaire was administered in a ten-minute structured interview to managers/proprietors and staff of cafes, pubs and shops used regularly by the residents. The opinions gained showed that the level of use that residents had was highly acceptable to those working in the shops and amenities visited. The degree of acceptance was clearly demonstrated in the study, e.g. by comments such as "I think it's great, I really do. Keep it up". House staff had made efforts to improve the appearance of people in the houses, to encourage participation and group sizes were kept small. The questionnaire results confirmed positive experiences.

#### d) Developing Friends and a Social Life Based on Integrated Pursuits

Research on developing friends and a social life based on integrated pursuits for people with learning difficulties is less optimistic. De Kock et al (1988) and Firth and Short (1987) emphasised that the social and community lives of the people they studied were largely dependent on their immediate family and staff. Malin (1983) found that unofficial support for people living in group homes, e.g., from friends, neighbours and relatives, was very limited.

McConkey, Naughton and Nugent (1983) in a survey of 160 adults demonstrated that most individuals had a limited range of community contacts and these usually occurred on their own or with their family.

Friends rarely featured as companions. Flynn (1987) and Malin (1982) in studying group homes found individuals who were lonely and with limited social contacts. Crapps and Stoneman (1989) found a high proportion of people living in family care services who had no recent contact with friends. McConkey, Walsh and Mulcahy (1981) investigated the leisure time of 200 adults living at home. They found that the majority of activities were solitary and passive, e.g., watching TV, listening to music, and nearly half the sample did not take part in any activity outside the family. These results are similar to those of Cheseldine and Jeffree (1981) with regard to adolescents with learning difficulties. Some examples are available which have intended to overcome this problem, e.g., organised volunteers (Salzberg and Langford, 1981) and teaching leisure skills (Jeffree and Cheseldine, 1984).

Defining friendship presents problems. People with learning difficulties with a history of restricted social contact, may apply the term 'friend' to people whose relationship with them would not usually be judged by other people to be sufficient to be called friendship. However, these relationships are valued by the individuals concerned and should not be viewed as unimportant.

#### Methodological Issues - Integration

Measurement of maintaining familial ties, the use of community amenities and friendship has usually involved an event counting procedure, e.g., contact with families, visits to shops. Some studies have used data kept routinely (e.g., Felce et al 1980), and others have involved residential staff in special data collection exercises and some have used structured interviews with staff, e.g., Firth and Short (1987). There is little information available on the reliability and validity of the different approaches. It would seem likely that a specially mounted data collection exercise is preferable, and may overcome problems of inadequate recall. De Kock et al (1988) undertook a limited reliability check by noting community excursions taking place when in the houses to collect other data. Apart from this example, few

studies have paid attention to the reliability of their measures. Although the definition of friendship is problematic, Felce (1988) suggested that this was academic as the extent of social relationships outside the family and staff was so restricted.

Measures of gaining community acceptance have usually involved survey methodology. McConkey (1988) recommended that more 'person-centred' approaches need to be developed, e.g., Repertory Grid techniques. Methodology in this area will not be reviewed in further detail as measuring community acceptance was not an aim of the research studies.

## 7. CHARACTERISTICS OF RESIDENTIAL ENVIRONMENTS

### A. Service Models

Evaluating the extent to which services use practices consistent with the principles of normalisation (or, social role valorisation, Wolfensberger, 1983a) is considered central to socially relevant evaluation practice (Emerson and Pretty, 1987). Wolfensberger (1983b) developed a range of evaluation instruments of which PASS or Program Analysis of Service Systems (Wolfensberger and Glenn, 1973) has received wide attention. Methodological issues concerning PASS are discussed below.

Direct attempts to measure the effect of adherence to the principle of normalisation are limited. Eyman, Demaine and Lei (1979) found PASS scores were significantly associated with positive change in adaptive behaviour for specified types of residents. Older residents, with mild learning difficulties, improved in all aspects of adaptive behaviour in conjunction with positive ratings on items dealing with comfort, deployment of staff, access to the home, local proximity of services and blending with the neighbourhood. One factor, related to administrative control and structure, was negatively related to adaptive behaviour, and the authors account for this by the time taken

by staff to complete and participate in the administrative structure. Eyman, Borthwick-Duffy and Sheehy (1987) found PASS 3 scores on the items dealing with administration of the service and proximity and access were moderately associated with improvements in adaptive behaviour, while proximity and access were related to decreases in challenging behaviour. Fiorelli and Thurman (1979) studied four adults before and after a move from an institution to a community placement and used measures including PASS 3. They found significant differences between the two settings, and client behaviour and client-staff interaction varied as a function of the living environment. The positive behaviour change was not great. Sandler (1981) found that people with severe learning difficulties benefited from a move to a more normalised environment and showed improvements in active leisure and positive social behaviour. Conroy and Bradley (1985) in their large scale study of the closure of Pennhurst institution found a positive relationship between the overall normalisation rating of a residence and the adaptive behaviour gains of the residents. In addition, Hull and Thompson (1980), using a multiple-regression analysis, found 35% of the variance in adaptive functioning was accounted for by environmental variables, primarily those related to normalisation.

A few studies have used PASS ratings and found differences between institutional and community services (Fiorelli and Thurman, 1979 Conroy and Bradley, 1985). Williams (1986) outlined the results of using PASS to look at service quality in 52 different residential services for adults with learning difficulties. Traditional wards in hospital were of very inferior quality, attaining only 9% of the total possible score. Among services gaining higher PASS scores were more recent developments in service design, utilising ordinary housing. Highest scores were received in houses where people without disabilities lived with people with learning difficulties. So, total PASS scores can discriminate between different types of service. Caution must be exercised with these findings, as the results were those obtained by teams of students on introductory PASS workshops. However, Webb, Wells and Hornblow (1986) found that normalisation scores of hospital and community services overlapped and higher PASS scores were not always associated with an increase in adaptive behaviour.

Other studies using normalisation instruments devised by Wolfensberger and his colleagues are reviewed by Flynn (1980). These have tended to concentrate on the instrument's structure, rather than its relationship to outcomes.

Some studies have also measured resident management practices, e.g., using the Scale of Management Practices, King and Raynes (1968). Hemming, Lavender and Pill (1981) found environmental changes in management practices and staff-resident interaction improved for people transferred from large institutions to new small units. Quality of life improved for the majority of residents on most indices. Studies using the Residential Management Survey (RMS) found differences between institutional services and community services (McClain, Silverstein, Hubbell and Brownlee, 1977; Conroy and Bradley, 1985;).

Allen (1989) summarised the present research findings. The only clear overall finding was that there appears to be as much variation in terms of outcomes within particular models (for example, staffed houses) as there was between different models (for example, staffed houses and hospital (Vitello, 1984; Raynes, Johnson, Sumpton and Thorp, 1987)).

#### Methodological Issues - Service Models

Determining the impact of residential environments upon the lifestyle of service users is dependent on two issues: the development of a valid system for classifying residential settings and the measurement of important characteristics of these settings (Landesman-Dwyer, 1985). Both these issues are presenting methodological difficulties for research at present.

Classifying residential settings is complex as a result of the diversity of services included under umbrella terms such as "community living development" and "community services". This problem has been addressed by workers producing a system for classifying environments in



relation to service user outcomes (Butler and Bjaanes, 1977; Moos, Gauvain, Lemke, Max and Mehren 1979; Hill and Lakin, 1986). Landesman-Dwyer (1985) provided a review of available systems. Landesman (1986b) suggested a classification system which takes into account service structure, service function and historical origins. Clearly a classification system needs to be developed which will allow comparisons to be made across studies and reduce errors arising from inappropriate grouping of heterogeneous facilities. Allen (1989) was doubtful that a categorization system can be developed to encompass all models of community care.

Characteristics of service settings have been assessed in studies by the use of instruments such as PASS (Wolfensberger and Glenn, 1975) and Resident Management Survey (RMS). PASS is used to assess the extent to which a service is using approaches consistent with the philosophy of normalisation. PASS requires a team of three or more trained evaluators and at least three days to complete the 50 items. Clearly this approach is expensive, time consuming and labour intensive. Short forms have been developed, e.g., Flynn and Heal (1981) but trained evaluators are still required. So, it is considered that the widespread use of this approach is impractical. In addition, Landesman-Dwyer (1985) argued that PASS attempts to measure the environment in absolute terms rather than in ones specific to the individual and so was not useful. She suggested that the person x environment interaction must be acknowledged in operational terms. Conroy and Bradley (1985) used the Resident Management Survey (RMS) in a large scale study. They found the change from hospital to community services was so extreme that the RMS ceased to be of value, and that as an 'environmental' instrument it was sensitive to the characteristics of people present in the setting. Conroy and Bradley expressed concern over the reliability of environmental measures. Many studies using PASS (e.g., Eyman, Demaine and Lei, 1979; Fiorelli and Thurman, 1979) did not consider reliability issues and rely on the training of the evaluators.

An alternative approach has been developed by L. Davies - The Aspects of Daily Living Checklist (ADLC - Davies, 1985). This is a set of scales designed to cover a range of factors which have a key influence on an individual's quality of life. Two scales are relevant to the assessment of residential environments: Privacy and Environments. The purpose of the ADLC is to evaluate differences in the quality of people's lives resulting from organisational factors rather than the person's disability. Limited reliability and validity data is available. It is considered that the approach of using different scales to assess differing aspects of a service may be useful. The ADLC has been used to compare costs of different service models (Davies, 1987).

## B. Environmental Variables

Various environmental factors have been considered to influence the outcome of services. In particular, the size, location and appearance of a service have been studied.

It is generally assumed that smaller services will offer a better quality of service. Balla (1976) found considerable variation in the quality of care in small community based services. Landesman-Dwyer (1981) reviewed the literature and concluded that within a given type of residential setting, size per se was not related to the quality of care offered, and some small family-style services were evaluated as being more restrictive than the larger board-and-care settings. Depersonalising practices were more frequently found in institutions (Baroff, 1980). Landesman-Dwyer, Stein and Sackett (1978) found more positive social behaviours in larger facilities, i.e., 18-20 residents and Sackett and Landesman-Dwyer (1977) found a higher percentage of dyadic behaviour in homes with 9-17 residents than smaller homes with 6-8 residents. Similarly, Landesman-Dwyer and Sackett (1980) found people in larger facilities, i.e., up to 20 people, engaged in more social behaviour with peers, and were more likely to have intense reciprocal friendships than those in smaller facilities. So, there may be some evidence that very small groupings may not facilitate

interaction. However, Landesman-Dwyer, Berkson and Romer (1979) studied affiliation and friendship patterns among people living in group homes. Residents in large homes affiliated more extensively with others, but intense relationships were as likely in small as in large homes.

Roteqard, Hili and Bruinincks found size to be a significant predictor of positive treatment environments when controlling for staff job satisfaction and resident ability and small community facilities offered the more positive treatment environments. Willer and Intagliata (1981) found people living in smaller residences displayed more gains in self-care skills. Overall, it is considered that the research studies support the conclusion of Allen (1989) that within a given particular type of establishment, the size itself is not related to measures of quality of care.

Laurendeau, Blanchet and Coshan (1984) refer to programmes that aimed at improving life inside institutions. Reduction in group size has led to improvements (Gilbert and Hemming, 1979; Witt, 1981). Tyerman and Spencer (1980) found that people given more private space demonstrated an increase in activity and a decrease in stereotyped behaviour. However, McHatton, Collins and Brookes (1988) found that a move from a ward to a flat within the hospital was followed by increased participation in activities, but no change in participation in community life. Landesman-Dwyer (1983) reported a comparison between traditional wards and new living units. Although differences were found in the environments (as measured by King, Raynes, Tizard, Resident Management Scale), the behaviour of most residents did not alter significantly.

Locating residential services in residential areas with good access to local facilities was considered important (Wolfensberger and Thomas, 1983). Butler and Bjaanes (1978) found that services located in more urban areas did provide more community contact, but Landesman-Dwyer (1981) concluded there was no substantial evidence to support the notion that this was a general trend. Rawlings (1985b) found no evidence of any benefit of locating an ordinary house in an ordinary

street for people with severe learning difficulties. The most important factors to enable use of local facilities were the availability of staff, followed by access to petty cash and transport. External appearances of buildings may have an impact on service users (Dalglish, 1983; Atkinson, 1988a). Hostels that do not merge naturally into the community influence the neighbours' views of its occupants.

Allen (1989) pointed out that a common error in designing community programmes has been to concentrate on the residential component, to the relative exclusion of other service elements such as day and leisure activities. Raynes, Sumpton and Flynn (1987) found that across all types of residence studied, only a small number of people were engaged in day-time occupations that involved employment; the vast majority of people spent their day-time in day centres or similar environments.

#### Methodological Issues - Environmental Variables

The discussion of methodological issues of service models applies equally to the measurement of environment variables. The difficulties of classifying residential settings is particularly relevant when considering the issue of size; for example, no clear definition exists of a "small group size".

#### C. Typology of Residential Settings

It is evident from the review of the literature of service models and environmental variables that residential settings cannot be classified according to simple dichotomies, e.g., large-small, hospital-community. Landesman (1986b) suggested that the current classification system and nomenclature was confusing and potentially dangerous. She concluded that the scientific knowledge base for understanding the ways in which home environments influence the development of individuals and their behaviour, will not develop without the use of objective and standardised means for selecting, categorising, describing, and evaluating residential environments.

Landesman (1986b) proposed a home classification system involving four variables: aetiology (how the home came into existence); major purpose or goals; anticipated duration (short-versus long-term home); nature of the relationships among home members/participants. She suggested that ideally any given home could be correctly classified, even though a considerable range of expression will exist within a given home type. However, as Landesman (1986b) pointed out, the utility of the proposed typology cannot yet be evaluated.

Janicki (1981) emphasised that only a few empirical studies have attempted to identify the variables associated with settings that affect change. Janicki and Reynolds (1979) have identified three constructs for identifying and analysing community residences: the residence environment, the rehabilitative intent and the management system. These three factors are connected by a single philosophical strand: normalisation. Janicki (1981) identified factors which promote the highest development of independence and competence behaviours, and summarised these findings within the above three constructs. For example, within the construct, the residence environment, there were more gains in residents' skills in homes with between six and fourteen people, than homes with fewer or greater numbers of people. The literature concerning rehabilitative intent suggested that a high degree of programme intensity, when coupled with a sound behaviour methodology, seemed to produce greater learning of new behaviours. Also, when residence staff were comfortable with their own feelings towards disability and correspondingly exerted a high degree of effort, residents developed more appropriately. The research has not yet fully analysed management practices, but indicated that administrative practices that promote a resident centred environment, also produced a more normative home, with greater resident gain. Future research in management practices is necessary.

Felce (1988) also has argued that future research should investigate how resident behaviour is affected within different residential systems. It is likely to be false to assume that high quality outcomes will be assured by correctly determining a few key variables in the service structure. Felce (1988) outlined three defining features of housing programmes for people with learning

difficulties. Orientation referred to the objectives to which a programme aspires. Structure included the relatively permanent features of the residential environment that are decided upon in the initial planning. Procedures were the training and operational systems that guide staff performance. This is likely to be useful as a basis for a classification system in the future. It has the value of differentiating between the relatively fixed features of a service, i.e., the structure, and those that are operational features, i.e., the procedures.

The complex nature of the social ecologies of residential facilities for people with learning difficulties is demonstrated clearly in the study by Felce et al (In Press). The study investigated the relationship of staff:client ratios and client behaviour. It was found that when one or two staff were together, improvements in the level of staff interaction and client adaptive functioning occurred as the client group decreased in size and the staff size remained constant. Similarly, Felce (1989) suggested that quality cannot be assured by getting a few factors correct, e.g., size, professional grouping, resident grouping, philosophy. Felce (1989) outlined a housing project in which many features were included to develop a high quality service. These features involved procedures to carry out individual planning, planning for individual engagement, individual teaching, monitoring experience and progress and responses to challenging behaviours.

It is clear that future research needs to investigate the effect of different residential systems on outcomes for users. It is likely that this could be best achieved by the use of a classification system within research. The suggestions of features outlined by Felce (1989) and Janicki (1981) may be helpful.

#### D. Participant Observation

Bercovici and Edgerton and their colleagues developed an approach to evaluate the outcome of community services which they described as participant observation. The approach involved a researcher and assistant regularly and actively being present in the residential

environment, interacting with staff and residents and recording their observations. They argued that the prolonged and regular presence of the researchers enabled people to behave as they normally do, without self-consciousness. Participant observation also usually included open-ended interviewing, video-taping, audio-taping and reading documents about the subjects.

Examples of participant observation studies were reported by Bercovici (1981), (1983). A large study was carried out of 85 people living in group homes of varied sizes: small - less than ten people; medium - eleven to twenty-one people and large - over twenty-one people. They found institution-orientated practices prevailed regardless of size, and the quality of environments varied from facility to facility. People had few choices and there were restrictions regarding privacy, possessions and access to facility resources. Interactions between care givers and residents revealed devices to reduce the social status of residents. They found evidence of social distance between staff and residents, e.g., eating separately and little conversational interaction. Generally, people were denied opportunities for socio-sexual relationships. Smaller services were likely to be more rigid regarding daily routines such as meals, bedtime, bathing and housekeeping. Block treatment occurred at meal times and medicals. In a study of ten group homes in the Los Angeles area, it was found that people were isolated in many ways from larger society and the community placement way of life contained many elements of a sub-culture.

The above findings contrast in some ways with the more positive findings of other studies, e.g., the work of Felce and his colleagues. However, the studies were generally not carried out in 'pioneering' services, planned to overcome institutional and devaluing practices. Bercovici's work confirmed that many factors are necessary to provide a good quality service, not merely location outside an institution.

## Methodological Issues - Participant Observation

Participant observation developed from approaches used by social anthropologists. Bercovici (1983) argued that other large scale quantitative research does not tell us about community care. Research has isolated discrete variables and not looked at the total environment that people live in. As Edgerton, Bollinger and Herr (1984) pointed out, participant observation has certain advantages. It views what people do, as well as what they say they do, and looks at the meaning of activities for them.

The problems of the approach are that it is extremely time consuming and costly, e.g., at least a year is recommended. The data collected is massive, complex and sometimes contradictory. Clearly the approach is likely to be open to bias and subjectivity, as defined codes of behaviour are not used. Whilst recognising the advantages of the approach, it is concluded that this does not offer a realistic option for regular evaluation of services. It is suggested that methodology should recognise that a number of visits are necessary to collect accurate information that is not biased by novelty effects, but that defined categories are essential.

### 8. ADAPTIVE BEHAVIOUR (Skills)

Changes in adaptive behaviour have frequently been used as an outcome measure of deinstitutionalisation (Emerson, 1985). Skill mastery alone is considered a rather limited outcome measure (Seltzer, 1981) and Emerson (1985) suggested that other outcome measures should be considered, e.g., client satisfaction, social and personal relationships and activity patterns.

Studies have generally found that people leaving institutions to move to community services have shown gains in adaptive behaviour (Close, 1977; Schroeder and Henes, 1978; Smith, Glossop and Kushlick, 1980; Willer and Intagliata, 1981; Conroy, Efthimiou and Lemanowitz, 1982; Eyman and Arnt, 1982; Kleinberg and Galliagan, 1983; Felce, de Kock and Repp, 1986; Beswick et al 1988). Increases in adaptive



behaviour were reported for self-care skills (e.g., Smith, Glossop and Kushlick, 1980), social behaviours (e.g., Close, 1977) and domestic activities (Beswick et al 1988). Hemming (1986) demonstrated that an improvement in skills was maintained over time. Kleinberg and Galligan (1983) in a study of 20 people moving from a large institution to three community units suggested that the improvement in adaptive behaviour found represented behaviour already in a person's repertoire, rather than new learning. Some studies (Tyerman and Spencer, 1980) have shown that improvements in the physical environment within an institution can produce similar changes, but these changes may be less substantial than those observed in people with similar levels of disability upon moving to small community homes (Landesman and Butterfield, 1987). McHatton, Collins and Brookes (1988) found an increase in a range of skills following a move from a ward to a flat within the hospital; whilst Tyerman and Spencer (1980) found poorer self-care skills in a normalised physical environment.

Adaptive behaviour gains are not an inevitable outcome of deinstitutionalisation. Rawlings (1985a) found no significant differences in the development of self-care skills between a matched control group living in hospital and a group living in small houses outside the hospital. However, Rawlings (1985a) used the Vineland Social Maturity Scale which may not be sensitive to change for a group of people with severe learning difficulties. Hemming, Lavender and Pill (1981) found that people with IQ scores over 50 who left wards described as allowing relative freedom, showed little or no change in adaptive behaviour. In addition, when improvements in adaptive behaviour occurred, they may fade over time (Hemming, Lavender and Pill (1981). Willer and Intagliata (1981) suggested that structured individual planning is an important feature in the development of gains in adaptive behaviour.

## Methodological Issues

Reviewers (Heal, Sigelman and Switzky, 1978; Emerson, 1985; Haney, 1988; Allen, 1989) have observed that studies in this area have a number of methodological weaknesses. Rating scales are sometimes the only measure used and there is a relative absence of studies using observational measures. Few studies are longitudinal and not all use control groups. Ethical considerations tend to preclude randomised selection of study participants, but this may restrict inferences that can be made.

### 9. ADDITIONAL INDICATORS OF QUALITY OF LIFE

Emerson (1985) proposed that there were a number of different indicators of quality of life which could meaningfully be employed to study the effects of deinstitutionalisation. These included social and demographic characteristics relating to housing, employment, health, education, leisure and environment, as well as measures of community participation, power and autonomy. Data regarding such measures are limited and not encouraging. Common findings are that people with learning difficulties living in the community are often poor, have restricted access to and control over their own money, have restricted access to their place of residence and experience problems in obtaining help from generic services. (Gollay, Freedman, Wynqaarden and Kurtz, 1978; Halpern, Close and Nelson, 1986; Raynes, Sumpton and Flynn 1987; Donegan and Potts, 1988). Kishi, Teelucksingh, Zoller, Park-Lee and Meyer (1988) in one of the few studies using a non-disabled control group, found that people with learning difficulties in general had less choice than other citizens; the degree of available choice being related to degree of learning difficulty - people with a more severe learning difficulty had less choice.

## Methodological Issues

Methodology in this area is not well established. Interviewing service users has been used (Gollay et al, 1978; Halpern et al, 1986) and Halpern et al (1986) paid careful attention to training interviewers. Donegan and Potts (1988) used the Quality of Life Questionnaire (Cragg and Harrison, 1984), but offered no information on validity or reliability. Clearly, this is an area where methodology needs to be developed.

### 10. SUMMARY: EVALUATION OF COMMUNITY SERVICES

The following conclusions can be drawn from the literature:

- A. There have been few clearly agreed predictors of success (i.e., remaining in the placement), but challenging behaviour can lead to re-admission to an institution.
- B. Service users generally prefer community placements to hospital placements. Closer analysis reveals areas of dissatisfaction.
- C. Personal freedom is highly valued by most service users.
- D. Quality of service may be associated with reported satisfaction- but few studies have investigated this relationship.
- E. Clear guidelines for interviewing people with learning difficulties now exist and there is evidence that valid views can be assessed.
- F. Few studies have included the views of service users.
- G. Generally higher activity levels have been found in small, domestic style services, than in larger units or institutions.
- H. Locally based services support family contacts.

I. Increased use of community amenities is a possible, but not inevitable outcome of deinstitutionalisation.

J. Opposition to residences prior to opening moderates to acceptance or indifference following actual experience. People with learning difficulties were highly acceptable to proprietors of community facilities.

K. Social relationships are usually confined to carers, family and people with disabilities.

L. Considerable variation in outcomes is not only likely between different service models, but also within different facilities based on the same model.

M. Research needs to use objective and standardised methods for categorising, describing and evaluating residential environments. Quality is unlikely to be assured by getting a few key factors correct.

N. Services receiving higher scores on a measure of normalisation were likely to be associated (but not always) with positive outcomes, e.g., gains in adaptive behaviour.

O. Smaller services do not necessarily offer a better quality of service.

P. People leaving institutions generally show gains in adaptive behaviour, but this is not an inevitable outcome.

Q. People with learning difficulties living in the community are generally poor, have limited control over their own money, have restricted access to their place of residence, and experience problems in gaining access to generic services. Studies in this area are few.

R. The current methodology available for evaluation research has a number of limitations, e.g., no clear system of classification of environments exists; current measures of normalisation are extremely time consuming; measures do not always clearly differentiate between

different features of a service such as opportunities and the physical environment; no measure of choices offered is available. In addition, many measures have limited information on reliability and validity.

S. Simply relocating people with learning difficulties into community settings is unlikely to have any lasting positive effect on their quality of life.

T. Research has concentrated on 'pioneering' services/pilot studies and replication of findings needs to be demonstrated.

## 11. IMPLICATIONS OF THE LITERATURE FOR THE RESEARCH STUDIES

### Study I

A. Previous definitions of 'successful' placements have usually only involved remaining in the placement. It is suggested that this definition should include the person's views of the placement, i.e., wishing to remain and carers' view of the placement.

B. Few studies have included the views of service users.

C. Satisfaction has been found to be associated with the quality of service offered. The number of studies investigating the association is very small, i.e., two.

### Study II

A. Most studies that have included the views of service users have only met respondents once.

B. Studies have generally measured quality of service or views of service users, but not both together.

C. Observational studies have predominantly involved people with severe and profound learning difficulties.

D. Observational studies within small, domestic houses are still few, and most concern 'pioneering' services/pilot studies.

E. Studies reporting frequent use of community facilities involve 'pioneering' services/pilot studies.

F. Few studies have compared outcomes in small, domestic services and alternative community services.

## CHAPTER IV

### STUDY I

## INTRODUCTION TO THE STUDIES

All the subjects in Study I and two subjects in Study II, lived in Leicestershire. A brief description of services in Leicestershire and the approach of the hospital to discharging people will be given.

### a) Services in Leicestershire

Leicestershire District Health Authority is the largest health district in England and Wales (population 865,000). The majority of both Health Authority and Local Authority services could be described as traditional, i.e., large hospitals and local authority hostels. Hospital services were beginning to consider alternative forms of service provision, e.g., staffed houses, but planning was in the very early stages when Study I began (i.e., 1986) - with the exception of one staffed house which opened in 1984. Community teams were planned, but not operational. Day Services consisted of traditional local authority day centres, with the number of places varying from 45 to 260; and hospital day services offered occupational and industrial therapy. Few alternative day services were available, e.g., a small house for domestic activities for approximately six people.

It is also relevant that the Health Service underwent a change in management structure in 1985 following the Griffiths report. In addition, local authority services were reorganised in 1987 into five divisions across the City and County.

The major provision of residential care is outlined as follows:

#### 1. Hospital

In 1984, i.e., just before Study I commenced, a total of 738 hospital beds were available.

Four large hospitals: 296 beds, 126 beds, 96 beds and 87 beds.

Two hospitals: 54 beds and 33 beds.

Two hospital hostels and community unit: 22 beds and 24 beds.



In addition, towards the end of 1984, the hospital's first staffed houses opened - a pair of semi-detached houses in the County for eight people.

## 2. Local Authority

In 1985, Social Services had seven hostels across the County which varied in size from twelve places to thirty-five places. A new hostel opened in 1986 which offered places to twenty-six people. From 1986, a total of 176 places were available in hostels.

A branch of Social Services called the Community Accommodation Project (CAP) had been set up, which offered a domiciliary support service using ordinary housing, with staffing support varying according to need. Service users were all tenants in their own houses. At the end of 1985, CAP offered a service to: seven people living in two houses with twenty-four hour support staff; and twenty-two people in houses with support varying from twenty hours to one hour a week. People living in a service which is a joint project between the Health Service and CAP are included in Study I. No new developments took place within CAP for people with learning difficulties between 1985 and 1988.

## 3. Private Services

The private sector represents an expanding service within Leicestershire. Services consist of registered and unregistered homes, where all places are funded by DHSS payments. Homes with four or more people are required to be registered with the Local Authority. In 1985 services included:

- a) Registered homes: 11 homes existed offering a service to 106 clients at a cost of £140 p.w.
- b) Non-registered homes: 25 homes existed offering a service to 48 clients at a cost of £55 p.w.

#### 4. Voluntary Services

Overall, voluntary services were not a major provider of residential care during the period of the research. The first MENCAP staffed houses opened in Leicestershire in 1988. Housing Associations were involved with a small number of unstaffed houses, flats, etc., e.g., Guideposts Trust Supported Group Home.

##### b) Hospital Policy for the Discharge of People to Community Care

In 1985, hospital services in Leicestershire had no policy on discharge that had been formally agreed with the management board. A policy was being developed, but was "informal" - see Appendix 1.

A Boarding-out Officer post existed within the hospital Social Work department. The role of the boarding-out officer was to "match" people with learning difficulties to suitable accommodation within the private sector, i.e., registered and unregistered homes. Multi-disciplinary teams identified people who were considered suitable to leave hospital. If the boarding-out officer could find a suitable placement, then a number of tasks were undertaken, including introductory visits, informing relatives. Following the move to a new placement, the person's hospital bed was retained for six weeks.

Hospital services were making other efforts, with the long-term aim of people leaving hospital. Two "training areas" were identified, where people spent time learning domestic tasks, e.g., shopping, leisure activities and also an informal assessment of compatibility was made.

## STUDY I - AIMS

The study had 4 main aims:

1. To assess, within one calendar year, the outcome of people moving from hospital to live in community placements. The success of the moves was evaluated to take into account three features:
  - a) The views of the service users.
  - b) The views of the carers.
  - c) The permanence of the placement.
2. To evaluate the assessment approach to measuring the outcome of placements. The assessment approach included the following three factors:
  - a) Views of the service user.
  - b) Views of the carer.
  - c) Quality of service measures, e.g., opportunities, physical environment support services, friendships.
3. To identify whether the views of service users were associated (statistically) with the Quality of Service measures, i.e., the physical environment opportunities support services, friendships.
4. To identify the cause of the return of any service users to hospital, from their placement in the community.

## HYPOTHESES

1. Service users' views would be associated with the Quality of Service measures. So, a positive correlation would be found between the positive views of service users and high scores on the following sections of the assessment: physical environment, support services, opportunities, preparation and friendships.
2. People with learning difficulties who return to hospital do so because of their challenging behaviour

## METHOD

### 1. Initial contact with subjects

An introductory letter was sent to the carers in the new placement (see Appendix 2). The letter outlined briefly the reasons for the research project and summarised the practical implications of participation, e.g., time required. The letter gave an assurance that the information collected would be confidential and also that there was no implication that the person was experiencing difficulties in their new placement. The carer and the person with learning difficulties were asked to consider participating in the research. About 7-14 days after sending each letter, the placement was contacted by telephone. Any doubts or questions were clarified and confidentiality was assured. The person with learning difficulties and carer were asked if they would agree to meet one of the researchers. If the person with learning difficulties expressed any reluctance to participate, then it was agreed at this stage that they would not be involved in the study. So, from the initial stage of contact the wishes of the person with learning difficulties was considered to be of great importance.

### 2. Subjects

#### a) Identification

People with learning difficulties who had left hospital services in Leicestershire during 1985 were identified from hospital discharge records. People included in the research were those who had moved to live in any non-hospital placements, and for whom the service could have been able to plan the move and prepare the person. People with learning difficulties were not included in the project if:

- the person discharged him/herself, so allowing no opportunity for preparation
- the person returned to his/her parental home, e.g., after a temporary care stay

- the person went to another hospital, e.g., a hospital in mental health services.

b) Details of subjects - age, length of time in placement, etc.

A total of 21 subjects participated in the research. During 1985, 25 people with learning difficulties left hospital to live in alternative placements. The carers of one person could not be traced - the person having moved a second time - and one person was not included as he had discharged himself. Two people refused to meet the researchers. In both cases the refusals were given after having received the introductory letter. One person stated that he/she wanted no reminders or contact with the hospital, the experiences whilst in hospital had been so unhappy. The second person had returned to live in hospital, and was hoping to return to her placement outside hospital and did not wish to discuss these issues. In both cases the individuals' wishes were respected and so they did not participate in the study.

The average age of subjects was 45 years (range 21-72 years). Twelve of the subjects were men and nine were women. The assessments were completed on average 13 months after leaving hospital (range 9 months - 17 months). The subjects had lived in hospital for 26 years on average (range 3-59 years) before moving to their community placement.

c) Subjects who returned to hospital

Two of the subjects who left hospital had returned at the time the assessment was being undertaken. Both of these people were met in their hospital placements. In addition, information about their community placements, including the reasons for the return to hospital, was collected by interview with care staff in the community placements.

d) Assessment of Skills

Carers were requested to complete an assessment of skills of each subject. The assessment chosen was by E. Whelan and B. Speake - Scale for Assessing Coping Skills. The reason for this choice of assessment was that it was in common usage in Leicestershire. The assessment form was left with the carer at the end of the visit with the request to complete this and forward it to the researcher. In eleven cases carers did not return the assessment and reminders were sent.

Table 1 below summarises the number of subjects who were credited as being independent on specified areas of the checklist.

Table 1 Summary of Assessment of Skills

Number of Subjects Credited as Independent in Specified Skills

Skill area	Items Credited	Number of subjects
Dressing	A-D	20
Use of toilet	A-D	19
Food and drink preparation	A-C	3
Washing-up	A-C	6
Community knowledge	A-C	7
Shopping	A-C	5
Communication	A-C	10
Money	A-C	5
Friendships	A-C	6
Sexual knowledge	A-C	6

A copy of the assessment and a summary of the total scores of the subjects are available in Appendices 3 and 4 respectively.

### 3. Placements

The placements that people with learning difficulties moved to were varied in terms of size, etc. Eleven people moved to Social Services establishments. (Elderly persons' homes - 3; staffed group homes - 4; hostel for people with learning difficulties - 3; hostel for recovering mentally ill - 1). In addition, 10 people moved to private homes - registered and unregistered.

### 4. Consent procedures

Careful attention was given to consent procedures. It was considered very important that people had full knowledge of the implications of participating in the research, e.g., "the type of questions asked", etc. Consent was requested from both the person with learning difficulties and their carer.

The consent procedures involved:

- a) Agreeing to meet the researchers after receiving the initial letter.
- b) Consent was requested at the beginning of the visit.  
The person with learning difficulties was asked if he/she would agree to talk to the researcher and it was explained that this would involve talking about where he/she was living, what he/she did, etc. Similarly, carers were asked if they would agree to participate after being given more information about the assessment approach. Confidentiality was assured to both the subject and the carer.
- c) Some interviews were tape-recorded for the purpose of calculating reliability. Particular care was taken to explain the process to the person. The recording method was demonstrated, i.e., a short piece of tape was recorded and played back to the person. It was clearly stated that the tape would be taken away at the end of the session.

## 5. Researchers

The data was collected by two researchers - the author and a psychology graduate. The psychology graduate accompanied the author on two assessment visits and then undertook one assessment herself whilst being observed by the author. Following feedback and discussion, the psychology graduate undertook the remaining assessments alone. Particular care and discussion was given to the procedures of collecting the data and scoring categories. Subjects were assigned randomly to each of the researchers with the exception of four subjects whom the author had met previously. In these cases, the psychology graduate undertook the assessments.

## 6. Assessment - Outcome of Community Placements

Study I aimed to assess the outcome of community placements by measuring the views of service users, their carers and quality of service measures, i.e., opportunities, physical environment, support services and friendships. In devising the measures for Study I, the work outlined in Chapter III was influential in their design, in particular, the PASSING Manual (Wolfensberger and Thomas, 1983), West Midlands CMH Quality of Life Checklist (Cragg and Harrison, 1984) and the Life Satisfaction Scale (Heal and Chadsey-Rusch, 1985). A further aim of the assessment was that it should take no longer than 3 hours 30 minutes to complete. It was considered that a brief assessment would be much more likely to be used by other services in the future. The assessment was completed by interview with service users, carers, and some items by observation in the service.

The Assessment: Outcome of Community Placements had the following sections:

- Person's view of the placement
- Carer's view of person's suitability for placement
- Carer's view: challenging behaviour and social behaviour
- Physical environment
- Support services
- Opportunities
- Friendships
- Preparation for the move
- Special requirements.



A copy of the assessment is available in Appendix 5 and the nine sections of the assessment instrument are described as follows:-

A) Person's views of the placement

The section 'person's view of the placement' consisted of twenty-five questions. All the questions involved at least one sub-question which continued the same topic as the main question.

The questions were concerned with:

Current living situation	-	5 questions
Food	-	1 question
Bedroom	-	1 question
Activities - spare time and within the home	-	6 questions
Friendships - within the home and at work	-	5 questions
Carers	-	3 questions
Rules	-	1 question
Pets	-	1 question
Money	-	1 question
Neighbourhood	-	1 question

The questions were chosen to include areas that were most likely to be influenced by the residential placement. In addition, the areas were similar to some of those identified by Andrews and Withey (1976) as major life concerns for Americans. Andrews and Withey (1976) identified the following clusters of items of life concerns:- self, family, other people, economic aspects, job, house, costs, local area, larger society, religion and beneficence. The questions included in the assessment were those that had a greater degree of psychological closeness to the person in their placement as opposed to concerns about society.

## Format of questions

The range and type of questions were designed to maximise the validity of the answers given. The questions took the following forms:

Yes-no questions	-	12
Yes-no questions with a negative item confirmation	-	3
Open-ended questions	-	8
Either/or questions	-	2

Open-ended questions and either/or questions were included in the interview assessment because, although these questions are more difficult for people with learning difficulties to answer, the answers are more valid than yes/no questions (Sigelman et al, 1982, 1981). A large number of yes/no questions were asked because they are the easiest type of question to answer. The interview assessment was hence designed to be applicable to as broad a range of people with learning difficulties as possible.

Sigelman et al (1981) found that acquiescence bias is particularly likely to occur in response to yes/no questions. Acquiescence bias was identified by varied methods - firstly every question had a number of sub-questions - answering "yes" to every sub-question indicated the possibility of acquiescence bias. In addition, three yes/no questions involved a sub-question requiring a negative answer to confirm the yes answer to the first question.

Example: Q5	Do you want to carry on living here?
Sub-question	Is there somewhere else you would rather live?

It is acknowledged that a person could have in mind an 'ideal' placement, but prefer to remain in their current placement in the short-term. All the subjects were encouraged to expand on their answers if they preferred to.

## Scoring the questions

The scoring for the questions took the following basic approach:

Score 3	-	Positive view of the topic
Score 2	-	Undecided, mixed views
Score 1	-	Negative view
A	-	Answers "yes" to all questions - including acquiescence bias
*	-	No response, incoherent, now known.

Six of the questions required a named example to score 1, 2 or 3. All the named examples were simple, e.g., to name a friend when discussing friendships. These features of the scoring system were introduced to clarify the validity of all answers.

### B) Carer's views of the placement for the person

This section of the assessment approach was designed to assess the carer's overall view of the suitability of the placement for the person. The definition of suitable referred to meeting the person's needs, as viewed by the carer. It consisted of four questions, but the fourth question had nine sub-questions each of which was scored separately. So, in total there were twelve items scored. The questions asked generally whether, in the carer's view, the placement was suitable for the person and asked about the suitability of specific features of the placement, e.g., the other people living there, leisure activities.

Each of the items were scored using the following categories:

Score 3	-	Suitable
Score 2	-	Mixed, neither suitable nor unsuitable
Score 1	-	Unsuitable
Score *	-	Unknown, not applicable.

C) Carer's views of the placement for the person - challenging behaviour and social behaviour

(1) Challenging behaviour

The carer was asked whether the person had presented any of a list of fifteen challenging behaviours or difficulties within the last month. The behaviour specified ranged from 'aggression' and withdrawal, to those that may have less immediate impact of a service, e.g., complaints of feeling ill/tired, complaints about the service. The fifteen selected behaviours were designed to identify potential problems, but also indicate that the person may dislike the placement or be under stress.

Each item was scored twice. Firstly, the frequency of the behaviour was recorded and, secondly, the perception of the carer as to whether or not the behaviour had presented a problem. Hence, a person could be reported, for example, to be spending long periods alone, but this may not have presented a problem within the service.

The scoring was as follows:

Frequency:

Score 2	-	has not occurred within the last month
Score 1	-	has occurred within the last month
Score *	-	not known.

Perceived problem:

Score 2	-	not a problem (whether occurred or not)
Score 1	-	is considered a problem
Score *	-	not known.

## (2) Social behaviour

The purpose of this sub-section of the assessment was to identify social behaviours which could occur within a placement. Nine items were asked and in contrast to the previous sub-section, all the items were positive behaviours, e.g., offer of help in the house.

The items were scored using the following three point scale:-

- Score 3 - yes, satisfactory
- Score 2 - does so, but with a reminder
- Score 1 - no, improvement required
- Score \* - not known, no opportunity. (note this).

## D) Physical environment

The aim of this section of the assessment approach was to assess the physical environment. The section consisted of sixteen items (ten scored by observation and six assessed by interview with the carer). The items included the degree of privacy, state of repair and whether a person had their own bedroom. Most items had clear definitions and scoring categories, e.g., counting the number of personal items on display in a bedroom.

The items were scored using a three point scale. The highest scores (3) were given to the most valued options, the lower score to the least valued option (1). In addition, three items required that the person had a choice in order to have the highest score, e.g., living room furniture was required to be domestic, but also that the person had chosen some of the furniture in order to achieve the highest score of 3.

E) Support services for the person in their placement

This section of the assessment approach was designed to assess the degree of support services that the person had in their placement. The section consisted of eleven items which included asking about the staffing levels within the placement, visiting professionals, day services. One item asked whether the staffing in the home and visiting the home was considered appropriate to the needs of the person.

The majority of items were scored using a three point scale. A score of 3 was given to the greatest degree of support service; 1 was given for the least support services, and 2 was given for services between these extremes.

F) Opportunities available and undertaken within the placement

This section was designed to assess the opportunities available and undertaken by the person within the placement. Opportunities to participate in the following areas were assessed: cooking, shopping and use of money, clothes, leisure activities and learning new skills. A total of fifteen items were asked and included questions concerning whether further opportunities to participate could be easily organised. Items were all scored using a three point scale which was similar to the scoring of the Physical Environment section, i.e., a score of 3 was given to the most valued option.

G) Friendships

This section of the assessment was designed to assess a person's friendships - within and outside the placement - and close personal friendships. For example, questions were asked about who the person's friends were, if the person had a close friend with whom he/she could discuss a problem if they invited friends home. A total of eight items were asked. Scoring involved using a three-point scale, e.g., a score of (3) was given for the greater the number of friendships.

#### (H) Preparation for the move into community

The aim of this section was to assess the preparation that the person had experienced before their move into the community. The questions asked about the extent to which the person was involved in the decision to move, number of visits, assessment and training, familiarity with the other people in the placement, etc. A total of nine items were asked. Scoring involved a three point scale, e.g., a score of (3) was given to items when the person had a high degree of preparation.

#### I) Special requirements identified

A total of six questions asked about special requirements that a person may have, e.g., for a quiet environment, space, carer's time to discuss personal difficulties, carer's time because of behaviour, help/time of other people and other requirements. The items were scored using a three point rating scale. A score of (3) was given if the person had this requirement; (2) was given if the person sometimes had this requirement and (1) was given if the person did not have this requirement.

### 7. The Assessment Procedure

The assessment procedure was undertaken in the subject's placement/home. Following the consent procedures, the assessment approach was undertaken in three stages:

### First stage

The researcher asked to be shown around the placement/home by the subject. The researcher specifically asked to see certain areas, e.g., kitchen, living room(s), bedroom, bathroom. The privacy of the person with learning difficulties was always acknowledged, i.e., private areas such as the bedroom were only entered with the person's permission. It was regularly found that the person would invite the researcher into other people's bedrooms. The researcher discouraged this by stating, for example: "This is someone else's bedroom and private - I don't think that I will go in". The majority of items of the Physical Environment scale were observed during the placement/home. The researcher had a "mental list" of items to be noted. Immediately following the visit, the Physical Environment scale was completed.

### Second stage

The subject was interviewed by the researcher in private. During the interview, the section of the assessment the "Person's view of the Placement" was completed.

### Third stage

The carer was interviewed in private by the researcher. During the interview, the remaining sections of the assessment were completed, e.g., carer's views of the suitability of the placement for the person, etc.

The procedure allowed the researcher to become familiar with the person whilst viewing the placement/home. This enabled a rapport to develop between them and also the researcher was able to identify the person's typical response style within a general discussion.



The assessment approach lasted on average between 2 hours 30 minutes to 3 hours. The first stage usually took about 30 minutes; the second stage varied, typically lasting about 30 minutes, and the third stage took 1 hour to 1 hour 30 minutes. Before stage one commenced, time was taken to explain the assessment approach and ask for consent.

#### 8. Reliability of the Assessment: Outcome of Community Placements

The inter-rater reliability of the Assessment: Outcome of Community Placements was calculated by tape recording seven of the twenty-one assessments. Interviews were recorded after the consent was obtained from the person with learning difficulties and his/her carer-see consent procedures for full details. The tape recordings were transcribed and each of the assessments were then re-scored by a psychology graduate. Percentage agreement was then calculated as follows:

$$\% \text{ agreement} = \frac{\text{total number of items agreed}}{\text{total number of items}}$$

Table 2 below summarises the reliability of the assessment.

Table 2  
Percentage Inter-Rater Reliability of the Assessment  
- Outcome of Community Placements

	Mean Percentage	Range
Total assessment	84%	71% - 94%
Sections		
Person's views	83%	68% - 96%
Carer's view of placement	92%	75% - 100%
Carer's view of placement - challenging behaviour	91%	67% - 100%
Carer's view of placement - social behaviour	91%	78% - 100%
Support services	74%	55% - 91%
Opportunities	82%	67% - 93%
Friendships	84%	50% - 100%
Preparation	71%	40% - 90%
Special needs	94%	60% - 100%
Physical environment	82%	71% - 100%

The reliability of the Physical Environment section of the assessment was calculated on only six items of the section. These six items were those that could be asked verbally or which required checking by questioning. So, the items that were scored by observation only were not included. The reliability of all the other sections involved all the items within a section.

Two sections of the assessment had a reliability below 80%. The reliability of the section Support Services was found to be 74%. Five of the seven reliability assessments were below 80%. This score was considered to be accounted for by two reasons. Firstly, there were only 11 questions, so any disagreement had a large effect on a percentage agreement score. Secondly, it was found that scores for two questions were regularly found to disagree (questions 9 and 10). Both these questions involve stating whether the person with learning difficulties contacted a specified person if upset or in an emergency. The lack of agreement suggested these questions were difficult to score or answers were unclear.

The section of the assessment on Preparation was found to have a reliability of 71%. The section consisted of only ten questions, so all disagreements would have a large effect on a percentage agreement score. In addition, scores for three questions were regularly found to disagree (questions 2, 3 and 4). These questions asked about multi-disciplinary teamwork, assessment and preparation/training prior to the move. In many cases, answers to these questions were uncertain, as the information was not always easily available. It is felt that this uncertainty is reflected in the low percentage agreement.

#### 9. Discussion - The Assessment: Outcome of Community Placements

The assessment of users' views was found to present few difficulties to complete, i.e., all users were co-operative. The checks for acquiescence bias, etc., were considered positive features of the approach, but were recorded for four people only. The responses of three people were recorded as acquiescence bias for one or two questions only, whilst a fourth person's responses were recorded as acquiescence bias for sixteen questions. However, it was unclear why so few critical comments were made by users. It was possible that the use of a single questionnaire did not enable people to comment critically.

The main difficulties were that researchers only met the person once and so there was insufficient opportunity to "get to know" each other. In addition, an alternative approach was required for the five people who were unable to answer many of the questions. Also, some questions were infrequently answered by many people, e.g., a question concerning the rules in a placement.

The assessment of the carers' views of the outcome was found to present few practical problems, e.g., it was easy to complete. However, one major issue arose. It was found that carers offered few critical comments on the placement, e.g., the placement was usually reported to be suitable in the most ways. As discussed above, carers

may be unlikely to be critical of their own placement or indeed be unaware of the shortcomings of a placement. It is felt that the value of some of these views for the service user needs to be questioned.

Some of the quality of service measures were found to differentiate between the various aspects of different services, e.g., the Physical Environment Scale and the Opportunities Scale. Two major problems were noted. Firstly, it was considered a disadvantage to have included issues concerning choices within most sections; it would be more appropriate to have a separate section on choices. Secondly, most of the measures were not supported by observations. Also, some information was difficult to collect, i.e., the Preparation section. In order to attempt to complete parts of the Preparation section, case notes were read, e.g., to find a record of multi-disciplinary meetings.

## RESULTS

### 1. Spearman RHO Correlations

The results of the Assessment - Outcome of Community Placements were analysed using Spearman RHO correlations. Correlations were calculated between each section of the assessment and all the other sections. The mean scores are shown in Table 3A and 3B, the standard deviations are in Table 3C, and the Spearman Rank correlations are in Table 3D.

#### A. Person's views of the placement

The most striking feature of the results of this section of the assessment was the small variation between subjects reports and the high degree of satisfaction. This made it more difficult to look for correlations.

Twenty-one people were interviewed. Five people's responses were scored as: not applicable, no response or acquiescence bias for more than half the questions. So, the results are a summary of the responses of sixteen people only.

TABLE 3A

## MEAN SCORES FOR EACH SUBJECT: ASSESSMENT - OUTCOME OF COMMUNITY PLACEMENTS

Subject	Person's Views	Carer's View of Person's Suitability	Challenges	Social Behaviour	Physical Environment	Opportunities	Support Services	Friendships	Preparation	Special Requirements
1	2.61	2.91	3.8	3	2.31	1.93	2.44	2.57	2.22	1.33
2	2.68	2.83	3.8	2.33	2.31	2.33	2.44	2.86	2.44	1
3	2.79	2.92	3.87	2.89	2.75	1.93	2.78	2.38	2.3	1
4	0	3	3.8	2.38	2.63	2.29	2.22	1.88	2.1	1.17
5	2.59	2.58	3.73	1.67	2.56	2.27	2.33	1.88	2	1
6	2.96	3	3.67	2.67	2.81	1.73	2.38	2.14	2.3	1.33
7	2.5	2.92	3.8	2.33	2.38	1.8	2.7	1.75	2.3	1.33
8	3	3	3.87	2.56	2.57	2	2.63	1.63	2.4	1.33
9	2.23	3	3.53	2	2.56	2.2	2.6	1.29	2.4	1.33
10	2.61	3	3.87	3	2.38	1.73	2.25	1.29	2.33	1
11	2	2.83	3.2	1.83	2.69	2.33	2.6	1.63	1.9	1.33
12	2.81	3	4	2.33	2.63	1.8	2.67	1.75	2.6	1
13	2.87	3	3.93	2.63	2.38	1.87	2.5	2	2.2	1
14	2.86	3	3.67	3	2.38	2.33	2.5	1.86	2.1	1.33
15	0	2.92	3.87	2.56	2.75	3	2.5	1.57	2.9	1
16	0	3	3.87	2.56	2.88	3	2.3	1.57	2.9	1
17	3	2.92	3.93	2.75	2.75	3	2.5	1.57	2.9	1
18	2.83	2.17	4	3	2.31	1.87	2.38	1.33	2.2	1
19	2.8	2.75	3.86	3	2.5	2.8	2.6	2.63	2.5	1.33
20	2.95	2.5	2.4	1.56	2.69	2.13	2.8	1.43	2.6	2.33
21	0	1.83	3	2	2.75	2.27	2.4	1.25	2.1	2.2

TABLE 3B

MEAN SCORES OF EACH SECTION OF ASSESSMENT:  
 OUTCOME OF COMMUNITY PLACEMENTS - STUDY I

Variable:	pview	cview	challenges
Sample size	16	21	21
Average	2.69313	2.81333	3.68905
Standard deviation	0.270868	0.308745	0.384881

Variable:	social	physical	opport
Sample size	21	21	21
Average	2.47857	2.57	2.21952
Standard deviation	0.454646	0.183248	0.418981

Variable:	support	friends	prep
Sample size	21	21	21
Average	2.50095	1.8219	2.36619
Standard deviation	0.164314	0.463989	0.286783

Variable:	special
Sample size	21
Average	1.25429
Standard deviation	0.370885

WHERE: pview = person's views.  
 cview = carer's view  
 challenges = challenging behaviours  
 social = social behaviours  
 physical = physical environment  
 opport = opportunities  
 support = support services  
 friends = friendships  
 prep = preparation  
 special = special requirements

TABLE 3C

STANDARD DEVIATIONS FOR EACH SUBJECT: ASSESSMENT - OUTCOME OF COMMUNITY PLACEMENTS

Subject	Person's Views	Carer's View of Person's Suitability	Challenges	Social Behaviour	Physical Environment	Opportunities	Support Services	Friendships	Preparation	Special Requirements
1	0.72	0.30	0.56	0	0.79	0.88	0.88	0.79	0.83	0.52
2	0.69	0.39	0.56	0.87	0.70	0.90	0.88	0.38	0.88	0
3	0.41	0.29	0.35	0.33	0.45	0.88	0.67	0.92	0.82	0
4	0	0	0.41	0.74	0.5	0.83	0.83	0.99	0.88	0.41
5	0.71	0.67	0.46	0.87	0.51	0.70	0.71	0.83	1	0
6	0.21	0	0.49	0.71	0.40	0.88	0.92	0.69	0.82	0.82
7	0.78	0.29	0.41	0.71	0.62	0.77	0.67	1.04	0.82	0.52
8	0	0	0.35	0.73	0.45	0.85	0.74	0.92	0.84	0.52
9	0.75	0	0.83	0.87	0.63	0.86	0.84	0.49	0.70	0.52
10	0.78	0	0.52	0	0.81	0.96	1.03	0.49	0.87	0
11	0.88	0.39	0.86	0.98	0.48	0.90	0.84	0.74	0.99	0.52
12	0.60	0	0	0.71	0.62	0.77	0.71	1.04	0.70	0
13	0.34	0	0.26	0.52	0.72	0.99	0.93	0.82	0.92	0
14	0.47	0	0.72	0	0.62	0.90	0.85	0.90	0.88	0.52
15	0	0.29	0.35	0.73	0.58	0	0.85	0.79	0.32	0
16	0	0	0.52	0.73	0.34	0	0.95	0.79	0.32	0
17	0	0.29	0.26	0.46	0.58	0	0.85	0.79	0.32	0
18	0.48	0.83	0	0	0.87	0.99	0.92	0.52	0.92	0
19	0.5	0.62	0.36	0	0.52	0.56	0.84	0.74	0.85	1.52
20	0.22	0.67	0.63	0.88	0.48	0.99	0.63	0.79	0.70	1.03
21	0	0.83	0.04	0.87	0.45	0.70	0.67	0.71	0.99	1.10

TABLE 3D

SPEARMAN RANK CORRELATIONS - ASSESSMENT OUTCOME OF COMMUNITY  
PLACEMENTS - STUDY I

	pomn	cvmn	cvpmn	sbmn	pemn	opmn
pomn	1.0000 ( 16)	.1923 ( 16)	.2580 ( 16)	.2457 ( 16)	.2675 ( 16)	-.2028 ( 16)
	1.0000	.4563	.3177	.3412	.3001	.4322
cvmn	.1923 ( 16)	1.0000 ( 21)	.2797 ( 21)	.2282 ( 21)	.1752 ( 21)	-.2045 ( 21)
	.4563	1.0000	.2111	.3074	.4332	.3604
cvpmn	.2580 ( 16)	.2797 ( 21)	1.0000 ( 21)	.5162 ( 21)	-.0761 ( 21)	-.1299 ( 21)
	.3177	.2111	1.0000	.0210	.7337	.5614
sbmn	.2457 ( 16)	.2282 ( 21)	.5162 ( 21)	1.0000 ( 21)	-.2545 ( 21)	-.1215 ( 21)
	.3412	.3074	.0210	1.0000	.2551	.5870
pemn	.2675 ( 16)	.1752 ( 21)	-.0761 ( 21)	-.2545 ( 21)	1.0000 ( 21)	.2710 ( 21)
	.3001	.4332	.7337	.2551	1.0000	.2256
opmn	-.2028 ( 16)	-.2045 ( 21)	-.1299 ( 21)	-.1215 ( 21)	.2710 ( 21)	1.0000 ( 21)
	.4322	.3604	.5614	.5870	.2256	1.0000
ssmn	.0969 ( 16)	-.0829 ( 21)	-.0505 ( 21)	-.2208 ( 21)	.0833 ( 21)	-.0833 ( 21)
	.7075	.7108	.8214	.3235	.7097	.7097
fmn	.1010 ( 16)	.0510 ( 21)	.0543 ( 21)	.2429 ( 21)	-.2514 ( 21)	-.0105 ( 21)
	.6956	.8194	.8081	.2774	.2609	.9627
prmn	.2633 ( 16)	.1794 ( 21)	.3836 ( 21)	.0688 ( 21)	.3124 ( 21)	.2343 ( 21)
	.3078	.4223	.0863	.7582	.1623	.2948
srmn	.1065 ( 16)	-.2017 ( 21)	-.7653 ( 21)	-.2510 ( 21)	.0840 ( 21)	-.0459 ( 21)
	.6799	.3671	.0006	.2617	.7072	.8372

Coefficient (sample size) significance level

pomn = person's opinions  
 cvmn = carer's view  
 cvpmn = challenges  
 sbmn = social behaviour  
 pemn = physical environment  
 opmn = opportunities  
 ssmn = support services  
 fmnn = friendships  
 prmn = preparation  
 srmn = special requirements



It was found that none of the Spearman RHO correlations reached significance. The correlation with the carer's view of the person's suitability for the placement was 0.19 ( $p = 0.46$ ), so there was little association between the person's views of the placement and the carer's views of the person's suitability for the placement.

People's opinions of their community placement were very positive. A summary of the people expressing positive views to specific topics is given in Table 3E below.

Table 3E  
Summary of People's Views - Study I  
Number of people expressing positive views on specified topics

Topic	Number of people
Liking the placement (Q1)	14
Preference for community placement (Q4)	14
Wish to remain in community placement (Q5)	13
Enjoy helping in the house/hostel (Q8)	11
Enjoy weekend activities (Q10)	14
Enjoy spare-time activities (Q11)	14
Sufficient to do in spare time (Q12)	6
Liking the other people living in the house/hostel (Q14)	7
Having friends at college, day centre, etc. (Q15)	4
No desire to have more friends (Q16)	8
Having friend of the opposite sex (Q17)	7
Liking carers (Q19)	14

#### B. Carer's views of person's suitability for the placement

It was found that none of the Spearman Rho correlations reached a significance level of below 0.05. Carers reported that sixteen of the people were suited to their individual placements and they were happy in the placement.

#### C. Carer's views - challenging and social behaviour

The reports of challenging behaviours and social behaviours were analysed separately. The carer's view of the presence of social behaviours was correlated with the absence of challenging behaviours (correlation = 0.52,  $p = 0.02$ ). Also, the absence of challenging behaviours was correlated with the absence of special requirements (correlation = 0.77,  $p = 0.0006$ ). So, carers reported that people without challenging behaviours had more social behaviours and few special requirements.

Twelve people were reported to have presented no major challenging behaviours during the month prior to the interviews, i.e., their scores were all 3 or 4 on each item of the scale. Four people only were reported to be 'aggressive'

A number of 'social behaviours' were reported to be absent in varying frequencies. Some people were reported to take insufficient care of their physical appearance (6 people); many people took little interest in the house (10 people).

#### D. Physical environment

It was found that none of the Spearman Rho correlations reached a significance level of below  $p = 0.05$ . Table 3F outlines the number of services receiving the highest scores on specified items.

Table 3F

## Summary of Quality of Service Measures

Number of services receiving the highest scores on specified items of the quality of service measures

	No.
Physical Environment	
Person has own bedroom, chosen. Q1	11
Personal possessions on display in bedroom. Q2	19
Degree of privacy. Q4	16
Domestic furniture in living areas, chosen. Q5	1
Domestic kitchen equipment. Q7	15
Comfortable and clean. Q8	17
No conspicuous details outside. Q10	12
Available equipment. Q11	21
No rooms locked, requiring permission to enter. Q12	15
Available space to be alone. Q13	12
Easy access to local shops. Q15	21
Support Services	
Carers present 24 hours a day. Q1	21
Professionals visit the house twice weekly. Q2	1
Staffing appropriate to needs. Q3	19
Support staff meet twice a year to review progress. Q6	15
Full-time day placement (if under 65 years old). Q7	15
Familiar person available to talk to if upset. Q10	15
Opportunities	
Preparing cooked food, twice a week. Q1(a)	5
Using own money to buy essential. Q2(b)	3
Washing own clothes. Q3(b)	7
Leisure activities outside house, more than once a week	
Q4(a)	14
Meeting people without disabilities. Q4(c)	7
Individual plan. Q5(a)	11
Friendships	
Has two or more friends. Q1	8
Arrange to meet friend. Q2	4
Close friend of opposite sex. Q3	5
Knew people in placement. Q4	10
Invited friends to house. Q7	3
Preparation	
Person fully involved in the decision to leave hospital. Q1	12
Complete assessment. Q3	7
Preparation - including experience in new service. Q4	5
Visits to new service. Q5	15
Compatibility considered. Q8	12

#### E. Support Services

It was found that none of the Spearman Rho correlations reached a significance of below  $p = 0.05$ . Table 3F outlines the number of services receiving the highest scores on specified items of the Support Services section of the assessment.

#### F. Opportunities

None of the Spearman Rho correlations reached a significance level below  $p = 0.05$ . Table 3F outlines the number of services receiving the highest scores on specified items of the Support Services section of the assessment.

#### G. Friendships

None of the Spearman Rho correlations reached a significance level of 0.05 or below, between the scores on the friendships section of the assessment and the other sections. Table 3F outlines the number of services receiving the highest scores on specified items of the Friendships section of the assessment.

#### H. Preparation

None of the Spearman Rho correlations were found to reach a significance level of  $p = 0.05$  or below. Table 3F outlines the number of services receiving the highest scores on specified items of the Preparation section of the assessment.

## I. Special requirements

It was found that the absence of challenging behaviours was correlated with the absence of special requirements (correlation = .77,  $p = 0.0006$ ). So, carers reported that people presented more challenging behaviours if they had special requirements. Three people only were reported to have special requirements on a regular basis.

## 2. Further Analysis of the Data

In order to investigate Hypothesis I further, it was decided to analyse the data in disaggregated form. Each section of the assessment was divided into sub-sections. In addition, seven people's responses were removed from the analysis because of the number of their questions with "no answer" scored. It was considered necessary to remove subjects five and eight who had eight and twelve responses not scored, since, when summarising the data in a disaggregated form, items not scored could have a greater effect (i.e., within a sub-section) than in the previous analysis. Items not scored were given a mid-point score of two, but for each subject a maximum of three items was not scored. So, the data analysis in disaggregated was undertaken with fourteen subjects.

Each section of the assessment was divided as outlined below. In addition, when a question had no score given, this was allocated the mid-point score point.

### A. Person's Views of the Placement

This section was divided into:

Overall view of current placement	- Questions 1,2,3,4,5,7,13,22,23
Views of activities	- Questions 8,9,12,25
Views of friendships	- Questions 14,15,16,17,18
Views of carers	- Questions 19,20,21,24.

No variance was found in the replies to questions 6,10 and 11 and these were not included in the analysis.

B. Carer's Views of Person's Suitability for the Placement

This section was divided into:

Carer's views of placement - Questions 1,2,3,4H,4I.

Carer's views of activities - Questions 4C,4D,4E.

Carer's views of friendships - Questions 4A,4F.

Carer's views of carers (time) - Question 4B.

No variance was found in the replies to question 4G and this was not included in the analysis.

C. Carer's Views of Challenging and Social Behaviours

This section was divided into:

Carer's views of challenging behaviours - Questions 1A to 10.

Carer's views of social behaviours - Questions 2A to 2I.

D. The Physical Environment

This section was divided into:

Personal - Questions 2,3,5,6,12,16.

Privacy - Questions 1,4,13,14.

Equipment and repair - Questions 7,8,9.

Outside location - Question 10.

No variance was found in the responses to questions 11 and 15 and these were not included in the analysis.

E. Support Services

This section was divided into:

Support services (primarily) within the placement:

Questions 3,6,9,10.

Support services, external

Questions 2,5,7,8,11.

No variance was found in the responses to questions 1 and 4 and these were not included in the analysis.

F. Opportunities

This section was divided into:

- |                           |                       |
|---------------------------|-----------------------|
| Cooking                   | - Questions 1A to 1C. |
| Shopping and use of money | - Questions 2A to 2D. |
| Clothes                   | - Questions 3A to 3C. |
| Leisure                   | - Questions 4A to 4D. |
| Learn new skills          | - Question 5.         |

G. Friendships

This section was divided into:

- |   |                    |
|---|--------------------|
| Close friendships                             | - Questions 3,8.   |
| Friendships outside the service               | - Questions 2,6,7. |
| Friendships (primarily) within<br>the service | - Questions 1,4,5. |

H. Preparation

This section was divided into:

- |                       |                         |
|-----------------------|-------------------------|
| Person's involvement  | - Questions 1,4,5.      |
| Compatibility         | - Questions 7,8.        |
| Preparation (general) | - Questions 2,3,6,9,10. |

I. Special Requirements

This section was not sub-divided. The total scores excluded responses to questions 5 and 6 as these showed no variance/had no responses.

Correlations

Full details of all the correlations are available in Table 4A. Those that reached a significance level or below  $p = 0.05$ , or close to this level, are discussed below. It is understood that having done ninety-six correlations, some would be likely to be significant by chance. Nevertheless, it is useful to note these as possible pointers for future research.

TABLE 4A

## SPEARMAN RANK CORRELATIONS (DISAGGREGATED DATA)

	Person's Views Current	Activity	Friend	Carer	
Current/Activity/ Friend/Carer	1.0000 ( 14) 1.0000	1.0000 ( 14) 1.0000	1.0000 ( 14) 1.0000	1.0000 ( 14) 1.0000	Where:
Place	-.3099 ( 14) .2639	-.3153 ( 14) .2556	.2184 ( 14) .4310	-.5168 ( 14) .0624	C.Activity = Carer's Views: Activity C.Friend = Carer's Views: Friendships
C.activity	.1731 ( 14) .5324	.1862 ( 14) .5019	.3279 ( 14) .2371	.1519 ( 14) .5840	C.Carers = Carer's Views: Carers Challenge = Carer's Views: Challenging
C.Friend	-.3671 ( 14) .1857	-.2622 ( 14) .3445	-.0227 ( 14) .9348	-.4474 ( 14) .1067	Social = Carer's Views: Social Behaviour
C.Carers	-.5169 ( 14) .0623	-.2609 ( 14) .3469	-.1039 ( 14) .7080	-.5319 ( 14) .0552	Place = Carer's Views: Placement
Challenge	.0794 ( 14) .07747	.1259 ( 14) .6499	.2939 ( 14) .2893	.0665 ( 14) .8105	
Social	.4480 ( 14) .1062	.1846 ( 14) .5057	.2606 ( 14) .3473	.0247 ( 14) .9291	

Coefficient (sample size) significance level



TABLE 4A

## SPEARMAN RANK CORRELATIONS (DISAGGREGATED DATA)

	Person's Views Current	Activity	Friend	Carer	
Pe.Personal	-.2378 ( 14)	-.1812 ( 14)	.3290 ( 14)	-.1583 ( 14)	
	.3913	.5136	.2355	.5682	Where:
Pe.Privacy	.1797 ( 14)	.2097 ( 14)	-.3142 ( 14)	.0420 ( 14)	Pe.Personal = Physical Environment: Personal
	.5170	.4497	.2573	.8796	Pe.Privacy = Physical Environment: Privacy
Pe.Equip	.0000 ( 14)	-.0048 ( 14)	.4329 ( 14)	-.3021 ( 14)	
	1.0000	.9862	.1185	.2761	Pe.Equip = Physical Environment: Equipment
Pe.Outside	-.3865 ( 14)	.0988 ( 14)	.2175 ( 14)	.0591 ( 14)	Pe.Outside = Physical Environment: Outside
	.1634	.7217	.4329	.8311	SS.Within = Support Services: Within Service
SS.Within	-.1125 ( 14)	.1370 ( 14)	-.2937 ( 14)	-.1762 ( 14)	
	.6849	.6212	.2896	.5253	ss.Outside = Support Services: Outside
SS.External	.1545 ( 14)	.0333 ( 14)	-.1481 ( 14)	.0765 ( 14)	
	.5774	.9043	.5933	.7828	

Coefficient (sample size) significance level

TABLE 4A

## SPEARMAN RANK CORRELATIONS (DISAGGREGATED DATA)

	Person's Views Current	Activity	Friend	Carer	
Current/Activity/ Friend/Carer	1.0000 ( 14) 1.0000	1.0000 ( 14) 1.0000	1.0000 ( 14) 1.0000	1.0000 ( 14) 1.0000	Where:
OP.Cook	.1389 ( 14) .6166	.1590 ( 14) .5664	.0457 ( 14) .8691	.2149 ( 14) .4384	OP.Cook = Opportunities: Cooking OP.Shop = Opportunities: Shopping OP.Clothes = Opportunities: Clothes OP.Leisure = Opportunities: Leisure OP.New = Opportunities: New Skills
OP.Shop	.1259 ( 14) .6499	-.1012 ( 14) .7153	-.5059 ( 14) .0682	.2159 ( 14) .4364	
OP. Clothes	.3035 ( 14) .2738	.0117 ( 14) .9662	-.0958 ( 14) .7298	-.0778 ( 14) .7792	
OP.Leisure	-.3223 ( 14) .2451	-.2828 ( 14) .3079	-.3559 ( 14) .1994	-.0996 ( 14) .7195	
OP.New	.1810 ( 14) .5140	-.0799 ( 14) .7732	.0000 ( 14) 1.0000	.4074 ( 14) .1418	

Coefficient (sample size) significance level

TABLE 4A

## SPEARMAN RANK CORRELATIONS (DISAGGREGATED DATA)

	Person's Views Current	Activity	Friend	Carer	
FR.Close	.3199 ( 14)	.3938 ( 14)	.1223 ( 14)	.1975 ( 14)	Where:
	.2487	.1556	.6594	.4764	FR.Close
FR.Outside	.1689 ( 14)	.3822 ( 14)	.2423 ( 14)	.2705 ( 14)	FR:Outside
	.5427	.1681	.3822	.3294	FR:Within
FR.Within	-.1391 ( 14)	.1322 ( 14)	.3772 ( 14)	-.1252 ( 14)	Preppers
	.6161	.6337	.1738	.6517	Preparation:
Preppers	.2668 ( 14)	.1599 ( 14)	.1371 ( 14)	.6218 ( 14)	Person's involvement
	.3360	.5643	.6211	.0250	Preparation:
Precompat	-.1918 ( 14)	.0980 ( 14)	.2307 ( 14)	-.0426 ( 14)	Compatibilty
	.4893	.7239	.4054	.8778	Perparation: general
Preprep	.0749 ( 14)	.1721 ( 14)	-.1678 ( 14)	.1067 ( 14)	Special requirements
	.7872	.5349	.5451	.7005	
Special	.0985 ( 14)	.1079 ( 14)	-.1593 ( 14)	-.1038 ( 14)	
	.7224	.6971	.5656	.7081	

Coefficient (sample size) significance level

a) Significant

It was found that the person's views of carers was correlated with the person's involvement in preparation (correlation = + 0.6218,  $p = 0.025$ ). So, users reported more positive views of carers (i.e., liking staff, finding staff helpful, rules were acceptable, knew a person to contact if upset - staff member), when they had been more involved in the move (i.e., involved in the decision to move, preparation/training took place and an overnight stay).

The questions involving the greatest variation in scores were (person's views): having someone to contact if upset, liking the rules and (preparation) the degree of training/preparation, having an overnight stay, being involved in the decision to move. Caution should be exercised in interpreting the responses to the question involving rules, as six responses were not scored and given a score of two for the analysis.

b) Close to Significance

Although the following results did not reach statistical significance, it was likely that if the correlations had been corrected for tied scores (which was not possible), more of the results may have reached significance.

(1) It was found that the person's views of carers was correlated (negatively) with the carer's views of carers, i.e., staff time. (Correlation = -0.5319,  $p = 0.0552$ ) but this did not reach statistical significance. So, users reported positive views of carers, when carers reported that the amount of staff time was unsuitable for that person. The questions involving the greatest variation in scores were (person's views) having someone to contact if upset and liking the rules. The variation in the scores of the carers views of carers was due to two people's scores which were both below the maximum available score.

(2) The person's overall views of their current placement was correlated negatively with the carers views of carers (i.e., staff time) (correlation = - 0.5169,  $p = 0.0623$ ) - but this did not reach statistical significance. So, users reported positive overall views of their placement, when carers reported that the amount of staff time was

unsuitable for that person. The question involving the greatest variation in scores (person's views) concerned views on pets. However, the variation in the scores of the carers views of carers was accounted for by two peoples scores which were both below the maximum available score.

(3) It was found that the person's views of carers was correlated negatively with the carers overall views of the placement (correlation = -0.5168,  $p = 0.0624$ ) - but this did not reach statistical significance. So, users reported more positive views of carers, when carers viewed the placement as less suitable. The questions involving the greatest variance in scores were (person's views) having someone to contact if upset and liking the rules and (carer's views of placement) suitability of the placement in the long-term.

(4) It was found that the person's views of friendships was correlated negatively with opportunities to go shopping and to use money (correlation = -0.5059,  $p = 0.0682$ ) - but this did not reach statistical significance. So, people reported more positive views of friendships, when they had less opportunity to go shopping and use money. The questions involving the greatest variance in scores were (person's views) having friends at the Day Centre, wishing for more friends and (opportunities) frequency of shopping and ease of organising further opportunities.

The inter-correlations of the sub-scales are given in Appendix 9B. Approximately half of these correlations were significant at/below  $p = 0.05$  (i.e., nine out of a total of nineteen correlations). This suggested that the disaggregation of the data was necessary.

### 3. Comparison of the Quality of Service Measures for the Subjects with the Highest and Lowest Satisfaction Scores

The results of the Quality of Service measures were compared for the two least satisfied subjects and two most satisfied subjects. Two subjects only (nine and eleven) had reported that they did not like where they lived and wanted to move. Their mean scores on the section of the Assessment - Person's Views - were the lowest (mean scores 2.23

and 2 respectively). In comparison, subjects six and twenty had the two highest scores on the section of the assessment - Person's Views (mean scores 2.96 and 2.95 respectively), and both subjects had replied to the majority of questions.

The Quality of Service measures have been divided into the scores in the "high" range, "mid"-range and "low" range. The "high" range scores include the highest five scores, the "low" range scores include the lowest five scores, and the "mid"-range scores involve all the remaining scores.

Table 4B below summarises the Quality of Service scores for most and least satisfied subjects.

Table 4B. Quality of Service Scores for Subjects  
Scoring Highest and Lowest on the Person's Views Scale

	Most Dissatisfied		Most Satisfied	
	Subject 9	Subject 11	Subject 6	Subject 20
Physical				
Environment	Mid-range	Mid-range	High	Mid-range
Opportunities	Mid-range	Mid-range	Low	Mid-range
Support				
Services	Mid-range	Mid-range	Low	High
Friendships	Low	Mid-range	High	Low
Preparation	Mid-range	Low	Mid-range	High
Total high scores	0	0	2	2
Total Mid-range scores	4	4	1	2
Total low scores	1	1	2	1

## THE HYPOTHESES

### Hypothesis I

Service users' views would be associated with the Quality of Service measures.

1. When the data was analysed in disaggregated form, it was found that people reported more positive views of carers when they had been more involved in the move ( $r = + 0.6218$ ,  $p = 0.025$ ). In addition, four correlations came close to significance: people reported positive views of carers, when carers reported the amount of staff time was unsuitable for the person ( $r = - 0.5319$ ,  $p = 0.0552$ ); and people reported more positive overall views of their placement, when carers reported that the amount of staff time was unsuitable for the person ( $r = - 0.5169$ ,  $p = 0.0623$ ). People reported more positive views of carers, when carers viewed the placement as less suitable ( $r = - 0.5169$ ,  $p = 0.0624$ ). People reported more positive views of friendships when they had less opportunity to go shopping and use money ( $r = - 0.5059$ ,  $p = 0.0682$ ).

2. When the results of the Quality of Service measures were compared for the two least satisfied and the two most satisfied subjects, it was found that the two subjects who had the highest scores on the Person's Views scale (complete scale) had some Quality of Service measures within the "high" range. In contrast, the two subjects with the lowest scores on the Person's Views scale had no Quality of Service measures in the "high" range. This finding should be treated with caution, due to the small numbers of subjects involved.

3. It may be concluded that there was some support for Hypothesis I.

### Hypothesis II

People with learning difficulties who return to hospital, do so because of their challenging behaviour.

Hypothesis II was supported. The two people who returned to hospital did so because of their challenging behaviour. In one case, mental health issues were also relevant. Caution must be exercised in this conclusion, due to the small numbers of people involved.

## Feedback to Services

Written feedback was sent to each person and their carer who had participated in Study I. No comments were received. A copy of this feedback is available in Appendix 10.

## INDIVIDUAL CASES

### Subject 20 - Returned to Hospital: Pseudonym, Brenda

#### Introduction

Brenda was 50 years old at the time of the researcher's visit. She had left an NHS twenty-four bed unit to move into a privately run domestic house with three other people with learning difficulties. Approximately two months after her move to her community placement, she was admitted to an NHS twenty-bed unit.

Brenda's return to hospital was a re-admission. She had originally left the 24-bedded hospital unit just over two years earlier and moved to her community placement. Due to continued problems with her behaviour in the community setting, she was admitted to the same hospital unit for a period of assessment and treatment. She returned to her community placement, but was re-admitted to the same hospital unit approximately two months later.

#### Person's Views

Brenda reported that she left her community placement because she had caused trouble and upset other people in the placement. She stated that at the time of her difficulties she had received help from the woman who ran the private house, but that she had received no other help. She was clear in her views that she wished to return to this community placement.



## Carer's Views

### a) Reasons for return

The main reason for Brenda's return to hospital care was reported to be schizophrenia. She required care for twenty-four hours a day because, for example, she kept the household awake as she imagined men were on the roof. In addition, she was described as being cruel to another woman who lived in the same house. She suffered from extreme feelings of guilt, believing that her mother had died because she was so wicked. She had, on occasions, left the house alone and had nearly been run over in the road.

When Brenda had first come to her community placement, she was described as rather depressed, but her schizophrenia was under control. However, she gradually deteriorated and her carer noted changes in her behaviour. In addition, Brenda started to have epileptic fits (previously unknown). A brain scan at this time indicated a slow growing tumour - which the carer was unaware of prior to Brenda coming to live with her. However, the carer believed that this had been identified prior to the move.

Her carer emphasised that they had wanted Brenda to stay living with them. Brenda was taking medication for her schizophrenia, but no p.r.n. medication was available.

### b) Support Services

The carer reported that she had requested visits from a community nurse and social worker. She described the community nurse as "very good", but had little support from the social worker. She felt that Brenda should have possibly seen a psychiatrist and/or a psychologist, but these services were not specifically requested nor offered. It was considered that different medication could have helped.

c) Possible prevention of return to hospital

The carer felt that one factor that had contributed to the problems was Brenda's relationship with another woman in the house. The two women had known each other well in hospital before coming to live in their community placement and they had been described as friends. However, the carer felt that these two women disliked each other intensely and Brenda had tried to encourage the other woman to leave. Hence, the carer felt that these two women should not have left hospital together to go to the same community placement.

In addition, the carer felt that different medication could have prevented admission. Also, it was reported that Brenda needed more "dominant" people around her.

d) Future

The carer felt that Brenda could live in a community placement again - but not to return to this placement. She suggested that Brenda may be more suited to being the only person in a placement, i.e., not with other people with learning difficulties - this would avoid her jealousy of other people receiving attention.

Follow-up

Brenda remained in the NHS unit to which she returned for five months. After this she moved to a different unit of similar size. Nursing reports soon after her return refer to paranoid symptoms and after six months she was described as wandering in the street. Approximately 18 months later, the unit where she was living was planned to undergo major changes as a result of a hospital closure. At this time, Brenda and six other people from the same unit all moved to a staffed house. A few months after this move, she was admitted to a hospital ward for treatment of depression and a month later she returned to the staffed house.

## Past history

Brenda had been admitted to hospital in 1979 following her mother's death. Her mother died of a C.V.A., but Brenda blamed herself for her mother's death. Brenda had a history of mental health problems prior to admission. She had been admitted to a mental health unit where she was diagnosed as schizophrenic. In 1980, she went to live in a group home, but only remained for four days. The reasons for her return were unclear.

Some difficulty was found in tracing Brenda's history. Hence, clear dates and reasons for actions were not available in case notes.

## Summary

1. The cause of Brenda's return was her behaviour and mental health.
2. Two possible reasons are suggested for the cause of her return. Firstly, the placement was given inaccurate information regarding a friendship and past health. Secondly, support services did not offer an active treatment package for her mental health difficulties (if this had been possible).
3. Brenda clearly wished to return to her community placement.
4. Brenda had a long history of similar mental health difficulties.

Individual case      Subject 21 - Returned to Hospital: Pseudonym,  
Jeffrey

Introduction

Jeffrey was 30 years old at the time of the researcher's visit. He had left an NHS 24-bed ward on the site of an 88-bed hospital to move to a domestic house with three other people with learning difficulties managed by Social Services. Approximately three months after his move to the community placement, he was admitted to the hospital he had previously left - but to another ward. He was then moved to a different hospital about four weeks later.

Person's Views

Jeffrey's views were difficult to assess due to his communication difficulties. His usual means of communication involved the use of Makaton signs. Before asking Jeffrey any questions, he was asked (using Makaton signs) to choose between two activities. The interviewer had been informed of his preferences by care staff and one activity offered was one that Jeffrey was reported to clearly prefer to the other activity. Jeffrey chose the activity he preferred so demonstrating that he had understood the choice offered. He then participated in the activity for a short time. This approach had been discussed with his speech therapist.

Jeffrey was then asked (using Makaton signs) four questions from the section of the assessment "Person's Views". His answer to the question "Did you like living in the house?" was the most clear of his responses. When asked this question, in addition to using Makaton signs, a picture of a house was presented that was very similar to the house he had lived in. His response included: repeated smiling, pointing to the picture and the Makaton sign for sleeping. His responses to other questions were unclear.

It was considered that his responses indicated that he had a positive view of living in the house. However, it cannot be assumed that he would like to return.

## Carer's views

### a) Reason for return to hospital

Jeffrey was reported to have presented the following challenging behaviours whilst living in the house. He banged his head, slapped his face and hit the carers and other people living in the house. The driver who took Jeffrey to the day centre refused to take him because Jeffrey had grabbed his neck whilst driving. The frequency of the behaviours had gradually increased during the three months of his stay. He was reported to be hitting other people approximately every other day towards the end of the placement. Various approaches to managing his behaviour had been attempted with limited success.

Jeffrey was considered to be having a detrimental effect on everyone in the house. Carers were having to spend much of their time with him. The atmosphere in the house was described as tense - and this was felt by carers to be the result of Jeffrey's behaviour. The above behaviours led to him returning to hospital.

### b) Support services

Various support services were requested: psychology, speech therapy and a hearing test. Although the services were received, they were felt to be too slow in responding and not all the carers were informed of recommendations.

### c) Possible prevention of return to hospital

It was considered that Jeffrey had little in common with the other people he lived with. So the assessment of compatibility with the others had been inaccurate prior to leaving hospital. Although the people in the house had lived together previously, they were not friends with each other.

His carer also felt that the group of carers required more training in the use of Makaton signs and in the understanding of his behaviour. The advice offered in these areas was too late to prevent admission. In addition, there had been some disagreement amongst the various disciplines as to whether or not Jeffrey should be admitted to hospital.

d) The future

Jeffrey was considered to be suited to living in an ordinary house, but with carers who knew him well and who understood his communication difficulties. Also he needed to live with other people with learning difficulties that he would like to live with. In addition, Jeffrey may require a house with more space than the house he had lived in.

Follow-up

Four weeks (approximately) after his return to hospital, Jeffrey was moved to another hospital unit. Nursing reports from this ward stated that Jeffrey kicked and "head butt" carers. These challenging behaviours occurred about three times a week. The situations in which the behaviour took place included : on return from the day centre; if carers did not understand his requests; if he was denied a request; if he lost something; when relatives visited. When these behaviours occurred, Jeffrey was usually asked to sit in an empty room alone (called a Time-out room) or to sit alone in his bedroom until he calmed down. Carers felt that Jeffrey should still eventually live in a house in the community if his challenging behaviours reduced. If his behaviour did not change in the near future, a house was still considered appropriate - but with a high staffing ratio, and the house may need to be large and detached.

## Past History

Jeffrey had lived in the same hospital ward for about three years before he left to move into a house in the community. Challenging behaviours were reported to have occurred and to be similar to those presented in the house. However, the frequency was low and the behaviour was easily managed. Previously, Jeffrey had lived in a different hospital unit and again some challenging behaviours were reported, but were easily managed.

## Summary

1. The reason for Jeffrey's return to hospital was the challenging behaviour that occurred.
2. Further reasons for Jeffrey's return to hospital were identified by carers, e.g., the incompatibility between Jeffrey and the other people he lived with, the carers' lack of knowledge of Makaton. Jeffrey's communication difficulties were considered to be extremely important.
3. Jeffrey had a history of similar challenging behaviour and frequency after admission was similar to that occurring in the community placement.
4. Jeffrey reported positive views of his community placement-although caution must be exercised in interpreting his responses, due to the few questions he answered.
5. Practical suggestions were made by carers as to ways of developing a suitable community placement for Jeffrey in the future, e.g., a larger detached house, more carers familiar with offering a service to people with challenging behaviours.

## DISCUSSION

### 1. The views of the service users

The views of service users were found, on first analysis, to not be associated (statistically) with any of the quality of service measures. This failure to establish an association was due to the data showing little variance since the majority of people expressed similar views, i.e., liking the placement.

The data was then analysed in disaggregated form and an association between users' views and quality of service measures was established. This finding would support previous research that people's satisfaction is related to the service offered (Seltzer 1981; Heal and Chadsey-Rusch 1985).

It was found that users reported more positive views of carers when they had been more involved in the move. It may be that greater involvement in the move established a better relationship with carers, but also carers who value the views of users, may be more likely to involve them in the move. Clearly, this finding has a practical implication, i.e., to involve users in the move, but carers may need to support this actively.

In addition, some correlations of the disaggregated data came close to significance. Although these findings are discussed, they should be treated with caution, since they did not reach a significance level of  $p = 0.05$ . Firstly, it was found that users reported positive views of carers when carers reported that the amount of staff time available was unsuitable for that person. This finding is in agreement with some previous research. Felce et al (in press) found no simple linear relationship between staff:client ratios and engagement. So, a tentative conclusion may be that users perceived no clear benefits when carers did have more time available. Secondly, it was found that users reported more positive overall views of their placement when carers reported that the amount of staff time was unsuitable for the person. It is suggested that the explanation for this association is similar to the previous findings, i.e., users do not always perceive clear



benefits when carers have more time available. A third finding was that users reported more positive views of carers, when carers viewed the placement as less suitable for the person (in the long-term). A likely explanation for this finding is that carers who were able to see the negative aspects of the service may be carers with whom users were more able to establish supportive relationships. Finally, an association was found between users positive views of friendships and having fewer opportunities to go shopping and use money. Possibly people placed a greater emphasis on friendships when they were able to go out shopping less often.

Further analysis of the data compared the results of the Quality of Service measures for the most satisfied and least satisfied people. Caution must be exercised, since the numbers of subjects involved were small (i.e., two most satisfied and two least satisfied). It was found that the most satisfied people had some Quality of Service measures in the "high range"; but the least satisfied people had no scores in the "high range". This finding suggested that users who were most satisfied were in services offering a higher quality of service and this was reflected across a range of outcome measures, e.g., support services, friendships, physical environment and preparation. It may be concluded that people's views were influenced by the quality of service received. This relationship may not always be a simple association between two factors, and possibly the quality of service influences more extreme views to a greater extent.

The views of service users were found in the majority of cases to be positive towards their placement. Thirteen people wanted to remain in their placement and fourteen people preferred it to living in hospital. However, five people were unable to answer many of the questions and so their views cannot be included in this summary. Among the few questions answered by this group of five people, the answers suggested positive views. Such answers need to be treated with caution as it is possible that this group were most likely to demonstrate acquiescence bias.

A few areas of dissatisfaction were also found. Five people expressed a desire to have more to do and six people would like to have more friends. These findings were consistent with previous research (Sugg, 1987).

It was considered somewhat surprising that the majority of service users offered such similar views of the placements. A variety of reasons can be suggested to account for this finding:

A. Some reasons may relate to the measurement approach itself. People were met once only and so may be unlikely to reveal their true views and reluctant to criticise their placement. A desire to be viewed positively by the interviewer may also account for a tendency to give positive views. In addition, the phrasing of the questions could influence the answers given.

B. People's views are influenced by their knowledge of other services and their own perceived ability and/or opportunity to create any change in their placement. So many people who took part in the study had lived in hospital for many years and hence their knowledge of services outside traditional hospitals, hostels, etc., was limited.

C. It is considered possible that any service outside hospital was viewed positively by the people in the study. Perhaps most service users had the view that "anywhere is better than hospital". This would be consistent with the finding of Bogden and Taylor (1982) that people disliked living in hospital.

The finding that the majority of service users expressed positive views about their placement is consistent with previous studies. The Pennhurst Longitudinal Study (1985) found that the majority of people who left hospital expressed satisfaction verbally with the place where they lived. Various studies (Edgerton 1967, Scheerenberger and Felsenthal 1977, McDevitt, Smith, Schmidt and Rosen 1978, Kielhofner 1981 and Sugg 1987) found that most people prefer a community placement to a hospital placement.

## 2. Carers views

The first analysis did not demonstrate a clear association (statistically) between the views of service users and carers, nor between carers views and the Quality of Service measures. The failure to establish an association was due to the data demonstrating little variance, i.e., carers offered positive views, and so did users.

When the data was analysed in disaggregated form, some associations between carers views and users views came close to a significance level of  $p = 0.05$ . It should be stressed that the findings should be treated with caution, since the significance levels achieved were not below  $p = 0.05$ . It was found that when carers reported that the amount of staff time available was unsuitable for the person, users reported more positive views of both their carers and the overall placement. As discussed above, it is suggested that users may not always perceive clear benefits when carers have more time available. In addition, when carers viewed the placement as less suitable in the long-term, users offered more positive views of carers. It was felt that this could be explained by carers who were able to see the negative aspects of the service, being more likely to develop supportive relationships with users.

Carers reported that sixteen of the people were suitable and happy in their placements. Only five people were reported to be either unsuitable and/or unhappy and two of these people returned to hospital. In most cases a specific reason could be given, e.g., the other people in the placement.

Generally, carers reported that individual features of a placement, e.g., the other people, the situation, were suitable for a person. However, it is considered unlikely that many carers would criticise openly the service they offered. In addition, it may be that carers were not aware of the way in which the service was unsuitable for a person.

Carers reported fewer challenging behaviours if people had few special requirements and if people demonstrated greater social behaviours (correlated significantly). The finding that people with greater social behaviours present few challenges is to be expected as the two classes of behaviour are incompatible. In addition, the association between challenging behaviours and special requirements is likely to be accounted by the time that carers may need to spend with people with challenging behaviours.

### 3. Quality of service

The initial analysis of the data demonstrated no association (statistically) between the views of users and Quality of Service measures. This failure to establish an association was due to the data showing little variance, as the majority of people expressed similar views, i.e., liking the placement.

However, it was found that the two people who had the highest scores on the Person's Views Scale had some Quality of Service scores within the "high" range. In contrast, the two people with the lowest scores on the Person's Views Scale had no Quality of Service measures in the high range. Both groups had scores in the "mid-range" and the "low" range. This suggests that people who were most satisfied were in services offering a higher quality, but this was reflected across a range of outcome measures, i.e., support services, friendships, physical environment and preparation. No "high" scores on the Opportunities scale were found for either the most nor the least satisfied people. Caution must be exercised with the findings as the number of people was small.

In addition, when the data was analysed in disaggregated form, some association was found between the person's views and Quality of Service measures. People reported more positive views of carers when they had been involved in the move. This finding was discussed above, and it has been suggested that carers who offered greater involvement in the move valued the views of users more, but also the involvement could have established a better relationship between user and carer.

An association was found (but not statistically significant) between users' positive views of friendships and having fewer opportunities to go shopping and use money. It was suggested that friendships may become more significant when people went out less often.

Some of the quality of service measures were found to vary considerably. So, the physical environment scores showed a variation. The size of the services visited varied, e.g., from a hostel for elderly people (thirty-eight places) to a four-bed staffed house. Some consistent features were noted, e.g., all services had all the basic equipment and in the majority of cases people had been unable to choose furniture. The disaggregated data suggested that the degree of privacy varied considerably. Similarly, the opportunities offered by services varied. A variety of approaches were identified towards the amount of cooking, caring for clothes that service users undertook within a placement. Some more consistent features were found, e.g., all people chose their own clothes, and three people only used money to buy essential goods - these three people were among the least independent of the group in terms of their current knowledge of using money. Also, many services reported they could organise more opportunities.

The measures on the section Support Services showed less variation. All services offered twenty-four hour presence of carers and in twenty cases there were few visiting professionals. Nineteen services considered overall that their staffing levels were adequate.

Collecting the information for the section on Preparation presented difficulties, e.g., some of the information was not readily available. On average, most people had left hospital only thirteen months before the data was collected. It is suggested that one reason why the information was difficult to collect was due to poor communication and co-ordination between services. In addition, collecting data retrospectively may always be more problematical. The data indicated that preparation was more often inadequate, followed no clear pattern and suggested that there was no policy or minimum criteria for preparation in operation. This may be a likely consequence of a relative new area of work for hospital services.

The section on friendships was included as a quality of service measure since services can organise to offer people more opportunities for making and maintaining friendships. This is not to deny personal characteristics of the desire for friends and the ability to make friends. The definition of friendships was an issue which emerged. Service users often reported carers as friends. Carers reports of friendships were considered difficult to interpret. People who spend time together in services may not be true friends, but merely are in the same services. However, it was clear that five people had friends with a member of the opposite sex, and only four people arranged to meet friends outside services. Clearly this could represent a contrast to friendship patterns of people without disabilities.

#### 4. Service users who returned to hospital

Two people returned to live in hospital from their placements in the community. In both cases, the return was reported to be due to their behaviour. The behaviour of the woman who returned was described as being attributed in part to mental health problems. Both people were reported by carers to be unsuited to their community placement. Information on both people after they returned to hospital indicated that their behaviour did not significantly improve. The finding that the return was due to their behaviour is supported by previous studies (Moen, Bogen and Aanes, 1975; Heal, Sigelman and Switzky 1978; Pagel and Whiting 1978; Sigelman, Novak, Heal and Switzky 1980; Schalock, Harper and Carver 1981; Intagliata and Willer 1982). Caution should be exercised with this finding as the number of people involved is small.

It is suggested from the reports that they were unsuitable for their community placement need to be questioned. In addition, it was clear that one woman wished to return to her community placement whilst the second person's views were more difficult to ascertain.

Two issues arose in both cases which could have influenced the outcome for the two people who returned. In both cases, the preparation stage had failed to identify the difficulties of compatibility which arose within the community placements. Also, where difficulties occurred, support services were either too slow to respond and/or failed to do so in an effective manner. The disruption to the two people's lives after their return to hospital is worthy of note, i.e., the number of changes in their placements.

#### 5. Outcome of placements

The majority of placements (71% i.e., fifteen of the twenty-one placements) were found to be successful. Success was defined as the service user offering a positive report of the placement, carers viewing the person as being happy and suitable and the person remaining in the placement. This finding would appear to compare favourably with some previous work, e.g., McCarver and Craig (1974) in a review of forty-four studies, found 74% of people remained in community services.

Thirteen of the people interviewed gave positive views of the placement, i.e., they liked the placement, preferred it to hospital and wanted to remain. It was difficult to assess the views of five people as they could not answer more than half of the questions. It was decided to assume that these incomplete reports were positive - there was no evidence to the contrary and the reports offered were positive, though incomplete. So, a total of eighteen people were considered to have positive views of the placement.

Carers reported that sixteen people were both happy and suited to their placements. This group of sixteen included one person who expressed some mixed views. So, fifteen people gave positive views of the placement and were reported by carers to be happy and suited to the placements. All fifteen people remained in the placement.

## SUMMARY OF FINDINGS

The following conclusions can be drawn from Study I:

1. Fourteen of the service users reported liking their community placement and stated a preference for this placement rather than a previous hospital placement. A striking feature of the results was the small variation in the reports given and the high degree of satisfaction expressed.
2. It was found that services users reported more positive views of their carers when they had been more involved in the move. In addition, four other associations between user views and carers views and Quality of Service measures came close to (but did not achieve) a probability of  $p = 0.05$ .
3. The most satisfied users were in services offering a higher Quality of Service on varied measures, but in contrast, the least satisfied users were in services where no Quality of Service measures were in the "high" range.
4. Service users (sixteen) were able to express their views and these views could be assessed objectively.
5. Service users views were influenced by their view that "anywhere is better than hospital" and by their limited knowledge of other services. In addition, their reported views may have been influenced by the approach of a single meeting only.
6. Five service users expressed a desire to have more to do and six people reported that they would like more friends.
7. Carers gave positive reports of the outcome of placements in sixteen cases.
8. Carers reported that the majority of features of individual placements were suitable for service users. Carers may not be aware of way(s) in which a service is unsuitable.



9. Carers reported that people with few challenging behaviours had few special requirements and demonstrated greater social behaviours.

10. Three service users only used money to buy essential goods and these people were among the least independent of the group in terms of their knowledge of money.

11. The people who returned to hospital did so because of their challenging behaviours. In one case, a person's return was also influenced by their mental health. Their return to hospital highlighted service deficiencies: responding to the challenging behaviours within a community setting and poor preparation, particularly in assessing compatibility. Two people out of the twenty-one people in the study returned to hospital.

12. Fifteen of the twenty-one placements met the criteria for a successful outcome, i.e., remaining in the placement, the service user giving a positive report of the placement and the carer viewing the person as being happy and the placement being suitable.

## CHAPTER V

### STUDY II

### M E T H O D O L O G Y

## DEVELOPMENT OF THE DESIGN OF STUDY II

Study I was a survey based approach to investigating the outcome of community services. This approach had identified few major differences between services, i.e., the views of service users were broadly similar and few correlations between different factors had reached a significant level of probability. In addition, when differences between services were identified it was not possible to identify why the differences had occurred. It is suggested that there is no simple link between factors, e.g., the physical environment, preparation and the views of the users. Repetition of a survey based approach was considered unlikely to lead to a greater understanding of the influence of specific factors of service delivery on the views of service users.

One of the major aims of the Study II was to overcome the limitations of Study I. The major disadvantages of Study I were considered to include: the single visit only to the service and the absence of clear data on people's activities. It may be difficult to overcome these disadvantages with a design involving a large number of people if resources are limited to a single researcher.

When designing Study II, the possibility of a comparative study was considered. This would involve a small number of people before and after a move from hospital, together with a control group. However, such a comparative study was not feasible for the author within local services. The main disadvantage was the dependence needed on local service developments. In practice, these new developments were relatively few in number and timing was unpredictable. In addition, many studies (see Chapter Three) have undertaken comparative studies with considerably more resources than were available for the present research.

A single case study was also considered. This approach has been recommended by researchers, e.g., Bromley (1986), and has often been used to investigate treatment effects, e.g., Browning and Stover (1971), Wilson (1987). Yin (1989) has outlined situations in which a

case study is advantageous, i.e., when a "how" or a "why" question is being asked. It was acknowledged that single case study design would be revealing, but it would be difficult to generalise the outcome from a single person and it would be unlikely to influence practice.

In addition, the literature reveals some clear gaps:

1. Many studies have involved 'pioneering' services, i.e., not developed as part of on-going attempts to change services without resources for evaluation.
2. Services have often not been evaluated using a broad range of measures and including user views.
3. Evaluation has not concentrated on the processes leading to outcome, and this may be impractical if studies involve large numbers.

It was decided to use a methodology that differs from usual research practice. This involves studying a small number of people to a depth by which processes may be identifiable and with an emphasis on the use of objective measures. The design involved assessing the quality of service and views of six people in six different community services. The researcher was aware that such a design may fall between the advantages of a single case study (i.e., detailed information on outcome and processes for a single person) and a survey approach (i.e., a broad range of outcome data for a number of people). It was decided that given the complexity of research in the area, i.e., the number of factors involved, that this was a risk worth taking. It was planned to overcome the potential difficulties of the design by developing a system to analyse commonalities and differences across the six subjects.

The methodology developed an approach of asking the same questions (see below) of each of the six subjects. Clear and objective measures were used to attempt to answer these questions. So, it is argued that the design required a high degree of scientific rigour and analysis.

The use of the questions was intended to identify commonalities and differences across the subjects and so clarify the processes involved in specified outcomes. Where commonalities are found, there exists a prima facie case to proceed towards practice guidelines and further research. A clear advantage of this design is the potential for the generalisation of results and practical applications.

## THE QUESTIONS ADDRESSED

### Question 1

What are the subjects' views of their residential service and do they wish to remain? What features are influencing their views?

### Question 2

What do the subjects do in the evenings in their residential service? What processes are influencing what they are doing?

### Question 3

What is the quality of the physical environment of the services?

### Question 4

Do all the subjects have friends and how are these maintained?

### Question 5

What decisions do the subjects participate in?

### Question 6

How much time do the subjects spend in integrated settings and what were the processes involved in their presence in integrated settings?

These questions will be addressed for each subject by the use of objective measures. For each question standard criteria are applied- see the discussion of the findings for each subject. This process will enable similarities and differences across the subjects to be identified, and also the processes leading to different outcomes.

## AIMS

The aims of Study II were:

- A. To assess the quality of service and views of six people living in community services.
- B. To identify the similarities and differences between the services.
- C. To offer an interpretation for the reasons and processes involved in the outcome.
- D. To compare the outcome of three small domestic style services and three larger community services.
- E. To evaluate the outcome measures.

## METHOD

### 1. Initial contact with the service and identification of subjects

Services outside Leicestershire were contacted initially by a telephone conversation with their line manager or person familiar with local services. This was then followed immediately by a letter enclosing a copy of the "Summary of Methodology" - see Appendix 11. The purpose of the Summary of Methodology was to outline briefly what the project involved, i.e., the measures to be collected, the design of services that the researcher wished to visit, and brief criteria for

the subjects of the study. Following this, the researcher was given the addresses of potentially suitable services and the names of the Home Leader/Officer-in-Charge. Within Leicestershire, contact was made directly by telephone to the Manager/Owner, and Officer-in-Charge of the service. Any questions asked by line managers were fully answered and usually concerned confidentiality, privacy of service users and reasons for the research.

During initial discussions with managers or home leaders, the following requests were made:

a) Services

The researcher asked to meet people living in staffed houses, preferably with 24 hour staffing and to meet people living in larger "community units/adapted houses". It was requested that the larger services had 10 or more people living there and preferably had 24 hour staffing.

b) Subjects

The following criteria were used in selecting participants. They should:

- have lived in their present placement for 12 months or longer
- be able to answer questions, e.g., stating whether he/she enjoys living in the placement, to name friends, etc.
- be aged between 19-55 years.

Typically, after meeting the Home Leader/Officer-in-Charge and outlining details of the project and answering questions, the Home Leader suggested a person who met the criteria outlined above and who would be likely to enjoy such a project. If this occurred, the researcher began to introduce the consent procedures. In addition, the permission of the other people living in the house/hostel was sought. The researcher explained to the other service users that she would be visiting and what the project involved - including watching what the subject did. Users were asked if they objected in any way.

An alternative approach was for the researcher to meet everyone living in the house/hostel and ask who would like to participate in the project (i.e., be the subject), including brief details of the criteria. This gave an opportunity to ask if the other people living there had any objections to the project. In practice, this approach was only possible if the house/hostel had regular meetings scheduled and so the approach was implemented in two places only. In all cases, once a subject had been identified as being potentially interested in the project, the introduction of the consent procedures began.

Few problems were encountered in identifying services and subjects to participate in the project. In one hostel, two people wanted to be subjects and this was decided by tossing a coin (!) (at the carer's suggestion). In another placement, one person initially expressed an interest in the project, but changed her mind; she informed the other people in the house about the project and another person enthusiastically expressed a desire to participate. In one house contacted, the owners (not the service users) stated that they did not wish to be involved in the study, giving the reason that they were moving house and felt they had little privacy anyway. In addition, one manager described a service as being in a 'temporary crisis' and felt it was an unsuitable time to participate in a project. It is emphasised that the researcher did not influence the selection of the subjects in any way, and merely supplied the above criteria.



## 2. Subjects

### a) Background details

Brief details of each of the subjects' background were collected by interview with the carer. In some cases, the subject was present during the interview. Further background details are available in Appendix 12, and are outlined for each subject in Chapter VI.

### b) Adaptive Behaviour Scale Scores

Table 5 gives a summary of scores on selected items for each subject. The scores did not take account of items influenced by a lack of opportunity. For example, the three subjects who did not wash and iron their clothes (item 45) had little or no opportunity to do so. A copy of an A.A.M.D. Adaptive Behaviour Scale is available in Appendix 13.

Table 5

Summary of Scores on the Adaptive Behaviour Scale. Items credited for each subject - Selected Items only.

I T E M S	S U B J E C T S					
	1	2	3	4	5	6
8. Prepares and completes bathing unaided.	+	-	+	+	+	+
18. Goes a few roads from home without getting lost.	+	-	+	+	+	+
20. Answers telephone appropriately.	+	-	+	+	+	-
28. Uses money, not checking change correctly.	+	+	+	+	+	+
30. Goes to a shop for a specified item.	+	-	+	+	+	-
32. Writes or prints ten words.	-	+	-	+	+	-
35. Sometimes uses complex sentences containing because, but, etc.	+	+	+	+	+	-
37. Recognises 10 or more words by sight.	-	-	-	+	+	+
38. Understands instructions referring to the order in which things must be done.	+	+	+	*	+	+
41. Counts 10 or more objects.	-	+	+	+	+	-
42. Tells the time correctly to the minute.	-	+	-	+	+	-
44. Cleans room well.	+	+	+	+	-	-
45. Washes and irons clothing.	+	-	+	+	-	-
47. Prepares an adequate complete meal (may use canned/frozen food).	+	-	+	+	-	-
49. Washes dishes well.	+	+	+	+	+	+
57. Organises leisure time on a complex level.	-	-	-	-	-	-
63. Interacts with others in activity or group game.	+	+	+	-	-	-
<hr/>						
+	=	Item credited.				
-	=	Item not credited.				
*	=	Item not completed.				

### 3. Services

Full details of each service are described within each individual case study in Chapter VI. In summary, the subjects lived in the following services:

- A. One NHS staffed house where a total of four people lived.
- B. An extended house, privately owned, where twelve people lived (and having one short-term care bed).
- C. One 24-bed unit, run by a local authority. The building consisted of four modern bungalow-style units.
- D. A house for three people, run by a local authority.
- E. A house where four people lived, that was owned privately.
- F. A local authority hostel where twelve people lived.

### 4. Consent procedures

The researcher considered that consent procedures were particularly important, as the project involved spending a considerable amount of time with each subject, watching the person and talking about their views. The consent procedures were designed to enable the subject to give informed consent. The procedures involved:

#### a) The subject's consent

The subject's consent was requested after both the researcher and carer had explained what the project involved, i.e., as outlined in the Summary of Methodology. In addition, a demonstration of the computer was given. The subject was asked to sign or place a mark on a form stating that the project and measures had been explained and he/she agreed to participate. Typically, final consent was not requested until the second or sometimes the third visit.

b) Carer's consent

A carer in each service was asked to give their consent to the subject participating in the project. The carer was present during all initial discussions with the subject concerning the project. The carer was also asked to sign a form stating that he/she had read the Summary of Methodology and agreed to the subject's participation. The carer was always a person who had known the subject for a least 6 months and in most cases considerably longer.

c) Person outside the service

A person outside the service was contacted by letter asking for their agreement to the subject participating in the study. A copy of the Summary of Methodology was included in the letter. The person had to have known the subject over a period of at least a year. Subjects were asked to suggest a person for the researcher to contact. Two subjects proposed their brothers-other subjects proposed their parents, their friend, their I.P. worker, and a friend of the family.

When a person was contacted by letter he/she was invited to telephone the researcher to ask for further details. The researcher was contacted once only. The nature of the enquiry was to ask if the person could refuse to reply to questions.

As outlined in the section "Initial contact with the service and identification of the subjects", the researcher informed the other people in the service about the project, and asked for their agreement.

5. Researcher

All the data were collected by the author.

## MEASURES USED IN STUDY II

The measures were designed to give a detailed evaluation of a placement for use with a small number of service users. The measures were devised to overcome the limitations of the measurement approach of Study I, e.g., the second study included observational measures and meeting the service user over a period of time.

The measures used in Study II included:

1. The views of service users. These were measured using two approaches:
  - a) Service Users Interview Questionnaire - adapted from the Consumer Interview Questionnaire, Institute for Survey Research, Temple University. Conroy and Bradley, 1985.
  - b) A number of interviews with service users, when specific topics were discussed.
2. Observations of the Service Users activities.
3. The following questionnaires were completed:
  - a) Physical Environment Scale.
  - b) Opportunities Scale.
  - c) Friendships Scale.
  - d) Decision Making Scale.
4. Diary records of the service users activities.
5. Carers were asked for brief details of:
  - a) The service user's past history.
  - b) Staffing levels and qualifications.
  - c) Contact with neighbours.
  - d) Finance supporting the placement.

Each of the measures 1-4 above are described in detail as follows:

# 1. The Views of Service Users

Before commencing any interviews, it was explained that all information given by subjects would be confidential and not shared with carers.

The views of service users were assessed using two approaches:

## A. Service Users Interview Questionnaire

This was an adapted form of the Consumer Interview Questionnaire, Institute for Survey Research, Temple University. Conroy and Bradley 1985. The questionnaire consisted of two parts: (a) the Emotional Labelling Interview and (b) the Service User's View of the Service. The two parts of the questionnaire were given at separate times as outlined in the procedure. A copy of the questionnaire is available in Appendix 14.

The Service User's Interview Questionnaire consisted of 21 questions (4 with sub-questions). The questions were concerned with the following topics:

Placement (view of placement and future and past placements)	5 questions
Day-time occupation	4 questions
Friendships	4 questions
Happiness	3 questions
Carers	2 questions
Visits and visitors	2 questions
Future wishes	1 question
Illness	1 question
Leisure time	1 question
Additional information	1 question
Question to interviewer	1 question

The questions were designed to maximise the validity of the answers and took the following forms:

Yes-no questions:	15
Information only:	3
Open-ended questions:	6
Either/or questions:	1

As in Study I, the questionnaire was intended to be applicable to a wide range of people with learning difficulties. So, a number of yes-no questions were included because they are the easiest type of question for people with learning difficulties to answer.

Five questions were included which cross-checked the answers to previous questions. For example, questions 1 and 13 both asked if the person liked living in the placement. Other topics that had questions which cross-checked the answers were: the carers, future placements and happiness. Usually, the questions which cross-checked a previous answer used different wording and phrasing.

#### Scoring

The answers were categorised as follows:

Positive view  
Mixed views  
Negative view  
Don't know  
No answer

The replies to the open-ended questions were written down in a brief note form.

## Emotional Labelling Section

This was designed to identify the extent to which the person comprehended the concept of positive and negative feelings, e.g., happiness, sadness. The section consisted of nine questions. The first question asked the person to identify a task and a sequence, when three pictures of a man making tea were presented. The following four questions also used either a single picture or a sequence of three pictures and the person was asked to identify the task and the emotion of a person in the picture. For example, one set of pictures showed a boy falling off a bicycle and lying hurt on the road - the person was asked to describe what had happened and how the boy felt. In preparing these materials, efforts were made to choose clear pictures of adults. It was found to be difficult to obtain clear pictures of "sad adults" and so some pictures of children in accidents were included.

The second part of the Emotional Labelling Section used five "smile button faces". The person was asked to identify the happy and the sad face. If these responses were correct, the person was asked to choose which face was most like how he/she felt about living in the placement, the other people living there, the carers and the day services. This part was also a cross-check for the main part of the questionnaire.

The Service Users Interview Questionnaire was used in a pilot form before use in Study II. The questionnaire was completed with seven people living in hospital accommodation and the interviewers were two psychology undergraduates. On the basis of feedback from this pilot study, adaptations were made to the Consumer Interview Questionnaire-Conroy & Bradley (1985). The adaptations are outlined in Appendix 15.

## B. Interviews

Service users were interviewed on a least six occasions when a total of twenty topics were covered. The topics included:

- . The home placement - including activities, carers and peers.
- . Day placement(s) - including activities, staff and peers.



- . Friendships - within home placement, day placement and others.
- . Leisure activities - segregated and integrated.
- . Previous and future placements.
- . Visits and visitors.
- . Shopping, food and clothes.

Each topic was discussed at least twice to enable the researcher to obtain a view of the consistency over time of the person's responses. A summary sheet of each interview was completed by the researcher during the interview and in order to prevent writing many details during the interview, the summary sheet was finished after the interview. A copy of the summary sheet is available in Appendix 16.

Interviews were always conducted in a private place and were tape-recorded, with the person's agreement. If the person showed any doubts about the use of the tape-recorder, the interviews were not recorded. One person only disliked the sessions being tape recorded and his wishes were complied with.

The general style of the interview involved the use of open-ended questions about the topics outlined above. In addition, the subjects were encouraged to talk about recent events, e.g., what did you do this weekend? The length of time spent discussing each topic varied considerably and was, to a large extent, determined by the wishes of the subjects. So, if a person wished to discuss one topic at length, this took place. In particular, people's views of each topic were requested, e.g., whether or not they liked their Day Service. Subjects were encouraged to add topics that they chose to discuss. The researcher recognised that some topics may be sensitive for the person, and if the person did not wish to discuss a topic, their wishes were respected. In addition, the interviewer gave details of herself, e.g., interests, where she lived. The overall style of the interviews was flexible, but also had a structure.

## 2. Observations of Service Users Activities

Service users were observed in their everyday activities using a portable computer - Bondwell 8. Continuous recording was undertaken for periods varying from about 10 minutes to 50 minutes. Each person was observed for a minimum of 10 hours over at least six evenings, and an attempt was made to observe part of every weekday evening, from a Monday to Friday. The length of each recording period was usually determined by factors such as the activity, e.g., a mealtime was always treated as a separate period, the person leaving the room for more than a few minutes, the observation session ending. Usually, three recording periods took place during an evening: before meals, during meals and after meals.

Observations commenced soon after the person had returned from their Day Service and always ended by 7.00 p.m. This time of the afternoon/evening was chosen because it gave service users the opportunity to participate in many domestic and leisure activities, but also was considered the least invasive time, e.g., service users had sufficient time to go out afterwards. The time period usually included a mealtime. Generally, observations were only carried out in public areas, e.g., living room, kitchen, etc., and never occurred outside the service. Sometimes observations took place in a person's bedroom with their consent, if a large proportion of their activities occurred in the bedroom, e.g., listening to music, changing the bed linen.

The categories of behaviour were adapted from those used by Thomas, Felce, de Kock, Saxby and Repp (1986) and are outlined in Appendix 17. The categories included:

1. Four categories of engaged behaviour: leisure, personal, domestic, TV.
2. Three categories of social interaction: peers, carers, visitors.
3. Neutral behaviour.

4. Three categories of challenging behaviour: Communication, aggression, other, i.e., stereotyped behaviours.

In the case of the engaged behaviours, interaction and challenging behaviours, more than one category at a time could be recorded. So, a person could be recorded as cooking and interacting at the same time. However, the neutral category could not be recorded with another category. In addition, a key was reserved for out of sight, i.e., when the person left the room briefly, or could not be seen. Watching TV was recorded separately within the engaged behaviours, so that this could be identified from other leisure activities. For the purpose of summarising the data, the % total engaged, included the social interaction categories.

Before observations commenced, a minimum of two trial observations took place. These observations were not included in the data. During these trial observations, explanations were given to the service user about the categories used and general use of the computer. Carers and other people living in the service were also given explanations on request. Service users were offered copies of the computer print-out together with explanations.

## Reliability

The reliability of the observations was assessed from three pieces of video film. Both the researcher and a second observer rated the same pieces of video film. The second observer was a Clinical Psychologist or a psychology graduate. The videos used were taken in different settings to the research settings, but included similar situations to those observed, e.g., domestic settings. It was considered too intrusive to take a video film in the research settings in addition to asking for co-operation with the other measures. Also, it was felt to be advantageous for both the observers of the video films to be equally unfamiliar with the people and settings in the film.

Reliability was calculated using the methodology proposed by Thomas et al (1986). Agreement occurred when both observers recorded the same category of behaviour and when the behaviour commenced and ended within the same 5 seconds. A disagreement therefore constituted an occasion when one observer coded a behavioural event as occurring and the second observer either differed by more than 5 seconds, or did not indicate its occurrence. Thomas et al (1986) argued that this method is particularly rigorous. Percentage reliability was then calculated as follows:

$$\begin{aligned} \% \text{ reliability} &= \frac{\text{Number of observations agreed}}{\text{Total number of observations}} \times 100 \end{aligned}$$

Reliability was calculated on three occasions:

#### Reliability I:

Reliability was calculated using a 15 minute piece of film and was undertaken at the same time as Subject I was being observed. The film showed a man in a lounge with carers and other people and was taken in a staffed house. The reliability was found to be 84.6%.

#### Reliability II:

Reliability was calculated using a 15 minute piece of film taken in a staffed house. The film showed a man, a carer and others preparing a meal. The reliability was found to be: 78.9%. Reliability II was undertaken just after Subject II had been observed.

#### Reliability III:

Reliability was calculated using a 15 minute piece of film and was undertaken after all the observations had been completed. The film showed a man and a carer in a kitchen making scones, in a hospital setting. The reliability was found to be: 83.6%.

### 3. Questionnaires

Four questionnaires were completed for each subject. Questionnaires were completed by interview jointly with the subject and a carer who had known the subject for at least six months. The questionnaires were:

- A. The Physical Environment Scale: This was the same as that used in Study I, with the minor alteration to remove the issue of choice in the scoring. A copy of this measure is available in Appendix 18.
- B. The Opportunities Scale: This was the same as that used in Study I.
- C. The Friendships Scale: This was the same as that used in Study I.
- D. The Decision Making Scale: The scale consisted of 21 questions about how decisions were made effecting the subject. The decisions included those that could be taken every day, e.g., what to eat, but also included decisions taken less often, e.g., a person coming to live in the service. The responses were scored according to the degree to which the service user participated in the decision, e.g., a score 'A' was given to items when the service user made the decision him/herself, whilst a score 'D' was given when no choice was available, e.g., the decision was made externally by managers. A copy of this measure is available in Appendix 19.

## Reliability

### a) Inter-Rater Reliability

The inter-rater reliability of the questionnaires was found to range from 82% Decision Making questionnaire to 93% Physical Environment scale. The reliability of the three questionnaires used in both studies was slightly higher in this study. Details of the method of calculation are in Appendix 20. Percentage reliability was chosen in order to be consistent with the reliability measures of the observations.

### b) Test-Retest Reliability

Test-retest reliability was found to range from 65% Friendships questionnaire to 97% Physical Environment questionnaire. Typically, there was a 6-8 week interval between completion of the questionnaires. Within this time interval, some genuine changes took place, e.g., in friendships for one woman. The test-retest reliability of the Decision Making Scale (68%) was influenced by one very low reliability score (33%), and it was felt that this carer and subject were unclear about how decisions were made. The test-retest reliability of the Opportunities Scale (77%) was considered to be due to carers and subjects changing their reports and perceptions of opportunities available as a result of the project. Further details and method of calculation are in Appendix 20.

## 4. Diary Records

Diary records were kept for three weeks. A carer usually completed the records, always with the subject's knowledge. In one case the records were kept by the subject.

The records requested that the following information was recorded:

### a) The person's activities.

- b) Where the activity took place.
- c) With whom the person was when the activity occurred.
- d) How long the activity lasted.

It was requested that every activity lasting a quarter of an hour or more was written down. It was emphasised that if the subject was unoccupied this should be recorded as such. When the person attended their day service(s) the name of the service only was recorded. If the carer was uncertain what the person had been doing, it was requested that the carer ask the subject. The researcher suggested that the records were completed at the end of each morning, afternoon and evening. A copy of the Daily Diary sheet is available in Appendix 21.

Before the diary records were recorded, an explanation was given to carers together with an example of a completed Daily Diary sheet and a list of some possible activities. During visits to the service, the Daily Diary was checked and any queries answered. For the purpose of analysis, the diary data was summarised into categories and these are outlined in Appendix 22.

#### Agreement with other Measures

##### a) Agreement with Observations

The agreement was calculated between the diary records and the observations, completed on the same evenings and within the same time period. The agreement was found to range between 43.7% to 63.2%. A high proportion of the disagreement (69%) was accounted for by carers not recording when a person was "doing nothing" or "talking/interacting with carers and/or peers". Additional details are available in Appendix 23.

b) Agreement with Questionnaires

The diary data for each subject was compared with three items of the Opportunities questionnaire: the frequency of cooking, shopping and leisure. The frequency of going out, i.e., leisure agreed for all the subjects, but the frequency of cooking disagreed for two subjects, and the recordings of shopping disagreed for four subjects. With one exception, the disagreement was due to the questionnaires overestimating the frequency of shopping and cooking. Further details are available in Appendix 24.

Procedure: Study II

Following the consent procedures, the data were collected in the following stages:

Stage I

During Stage I, the four questionnaires were completed jointly with the carer and the subject. This usually took about one hour only.

Stage II

The diary was introduced to the service and explanations given to the carer and subject. During this stage the observational data was collected. The observations were undertaken over a period of at least two weeks, and usually three, i.e., until 10 hours of data were available. This procedure allowed the diary data and observational data to overlap, enabling agreement to be calculated.

Stage III

The interviews with the subject were completed over a period of about three weeks. This time period allowed the subject to discuss experiences during this period with the researcher. In addition, it was ensured that the diary data was completed.



#### Stage IV

The questionnaires first completed in Stage I were undertaken in the same way. The purpose was to assess reliability of the questionnaires over time. In addition, the carer was asked for brief information concerning the person's background history, staffing, funding and contact with neighbours.

Prior to each stage, the subject and carer were reminded of the next stage. This was considered particularly important when the observational data was complete and the interviews were soon to begin. The detailed information and preparation that took place during the consent procedures (see Method - Study II) were considered valuable and enabled the measures to be collected in the above manner.

#### Discussion of Measures - Study II

The Service User's Interview Questionnaire was found to be a useful introduction to assessing a person's views and gave the subjects an overview of questions to be discussed in more detail. The cross-checking of questions and the Emotional Labelling section of the Questionnaire were very useful. These features enabled the researcher to be confident of the validity of the person's views. A negative aspect of the Emotional Labelling section was that it closely resembled a test - and this was an approach which the research had deliberately avoided. The open-ended interviews which were conducted over at least 6 meetings were considered very valuable at identifying the subject's views. The subjects made some critical statements of the service received which it was felt to be unlikely to have occurred if the researcher had not already been familiar to the subjects.

The observational measures gave an accurate picture of a small part of the subject's day. The reliability of the measure was considered adequate and ranged from 78% - 84%. The collection of 10 hours of data was found to be sufficient because the subject's nature of activity did not vary considerably across sessions. Usually

variation in activity was due to a rota, e.g., washing-up or illness, and these events would be identified in the diary data. It was considered most important to conduct at least two trial sessions of collecting data. This enabled all the service users in a service to become accustomed to the presence of the researcher and time to ask questions about the procedure. One doubt about the observational measures was that the researcher was always unclear whether the subject fully comprehended the data analysis when explained.

The diary data was found to give an overall picture of a subject's life-style over a three week period. This enabled an attempt to be made at a measure of integration - of community participation and community presence. However, the data did not agree with the observations (43%-63% agreement), e.g., the carers rarely recorded that the subject was "doing nothing" - which the observational data identified. It was considered likely that major events in the day and evening, e.g., going out, were recorded. Very few problems were encountered when asking carers to complete the daily diary - on only two days were the diaries not completed (both in the 'larger' services). One subject only expressed some concern when asked by carers for information to complete the diaries.

The four questionnaires were found to offer useful comparisons between services (see Results, Study II). However, when completing the Opportunities Questionnaire, carers and subjects sometimes reported that people did activities, e.g., cooking, more often than the diary records would suggest. In addition, responses to both the Decision Making and Friendships Questionnaires showed some differences over time when comparing replies at the beginning and the end of the contact with each subject - approximately a 6-8 week period. It may be reasonable that friendships change over time, but less likely that the decision making processes would alter. It is suggested that the differences found over a period of time by the Friendships Scale, could be viewed as supporting the validity of the measure. When completing the Decision Making questionnaire, it was noted that carers and subjects were sometimes unclear about how decisions were taken. In spite of

these limitations, it was felt that the Decision Making questionnaire was a valuable addition to the measures, since no other practical approach was available to use to assess this aspect of a person's lifestyle.

The subjects, carers and other service users offered no objections to the data collection process. One subject did ask for the tape recorder not to be used as he felt his voice sounded strange (this wish was obviously agreed to). The use of the computer and the tape recorder were welcomed by the subjects (with the exception reported above). The subjects, other service users and carers were very interested in the computer, and often were familiar with computers, usually due to attending computing courses at colleges of further education. It is suggested that the use of the computer added to the status of the measurement approach and so contributed to the co-operation given.

At the end of the contact with each service, the subject and carer were asked their views of the project and measures used. Four of the subjects were very positive about the project and reported that they had enjoyed it greatly. Two subjects gave positive views, but to a lesser degree, e.g., reporting that they liked the project and found it "all right". The subjects made comments such as "it was useful to talk things over with someone ... it helped". All carers gave positive views of the project and in three cases offered very clear examples of how it helped the subjects e.g. to express their views and talk to someone. The researcher concluded that the design of the measures and procedure had not been an inappropriate invasion of privacy.

The most difficult part of the study was leaving the subjects at the end of a contact with a service. In four cases it was evident that the researcher's visits would be missed and this was clearly stated to the researcher.

## CHAPTER VI

### STUDY II

### R E S U L T S

## INTRODUCTION

The results are presented as a series of individual case studies. Background details are outlined for each person, followed by the findings on each measure. The questions addressed by the research, outlined in Chapter V, are then discussed within the individual cases.

### INDIVIDUAL CASES:

Subject 1 - Pseudonym - Paul

#### 1. Background Details

Paul was a 35 year old man. At age 13 years, he was admitted to a large hospital for people with learning difficulties. Twenty years later, he moved to another hospital. Paul had left this hospital 18 months before the research began to move to a staffed house. Two carers worked in the house in the hospital grounds and then in the staffed house. Whilst living in hospital, Paul presented challenging behaviours, i.e., shouting and throwing chairs across the ward on most mornings. Paul had a physical disability (one leg was shorter than the other) which prevented him from walking long distances. Paul attended a Day Centre five days a week.

#### 2. Service

Paul lived in a 3 storey semi-detached house in a residential area on the outskirts of a large city. He lived with three other people with learning difficulties. There was no sign or evidence outside the house that it was a service for people with learning difficulties. The house was well decorated inside and outside. Most furniture was of good quality with the exception of some furniture brought from the hospital.

The hospital was managed by the District Health Authority. Five carers were in post, one with nursing qualifications and two had extensive experience of working in hospitals. The less experienced carers were attending an in-service training course.

Paul had moved to live in the service with three other people from the same hospital. Paul had acquired more practical skills than his peers, e.g., he had learnt more cooking and verbal skills.

### 3. Findings

#### a) Views

##### (1) Service User's Interview Questionnaire

Paul gave positive responses to all the questions, i.e., he liked his present placement; wished to remain; liked his carers, has friends but would like more friends; has visitors and visits others; is usually happy and likes his day service. He may like to leave his residential service if possible in the future. He suggested that he would like to live with his sister - see below. His spare time activities included TV and going to evening classes.

Paul gave correct answers to items 1-5 of the Emotional Labelling section. All his answers to items 6-9 of the Emotional Labelling section confirmed his views expressed in the interviews and questionnaire. A summary of the questionnaire is available in Appendix 25.

##### (2) Interviews:

A summary of the interviews is given in Appendix 26.

### Present Placement

- The features of the house that Paul liked were: his bedroom (being able to be alone) and choosing what to eat.
- He liked all the household activities, e.g., cooking, hoovering, TV.
- He stated that the people he lived with were his friends, but he reported more than one incident of behaviour of a woman in the house that annoyed him.
- He described his carers as his friends.

### Past and Future Placements

- Paul preferred his present placement to his previous hospital placement.
- He missed aspects of his previous life in hospitals - friends and carers.
- He had been frightened and nervous of leaving hospital.
- He was clear he wanted to stay in his present placement - he viewed living with his sister as unlikely to be possible.

### Friendships

- Paul described his carers and people he lived with as friends.
- He discussed a close friend (a woman) that he would like to marry. They met only at the Day Centre and his carers were unaware of the friendship.

### Day Services

- Paul had friends at the Day Centre and enjoyed all the activities.

### Leisure Activities

- Paul stated he would like to go out more often.
- He enjoyed all his leisure activities - drama class, Gateway Club, shopping, going to a local pub.
- He had positive experiences of integrated settings. One incident had occurred when a taxi driver could not understand Paul's address. However, Paul returned home after a telephone call to his house. (This information was confirmed by carers when completing the Questionnaires - with Paul's prior agreement).

### Visits and Visitors

- Paul was visited by his sister every 2 months approximately.

### Other Issues

- Paul gave very positive views of owning his own car.

### Reliability

The majority of his views were consistent, although occasionally he expressed some indifferent views, e.g., "it's all right".



b) Client Activity: Observational Measures

Table 6 below outlines the percentage of time recorded in each category of behaviour both before and after meals, and within meals. The raw data are available in Appendix 27.

Table 6

Summary of Observations - Paul

	<u>Before and After Meals</u>	<u>Within Meals</u>
Total time of observations:	8.83 hours	1.89 hours
Number of evenings data collected:	7	5
Percentage time recorded in each category of behaviour:		
% Leisure	0.88	-
% Personal	2.10	54.45
% Domestic	8.88	4.35
% TV	47.24	14.99
% Interaction with visitors	0.57	0.87
% Interaction carers	14.72	23.74
% Interaction peers	1.91	3.57
% Neutral	24.46	12.79
% Challenging	0.05	-
% Time recorded in engaged behaviour (i.e., 100% - neutral - challenging behaviours)	75.49	87.21

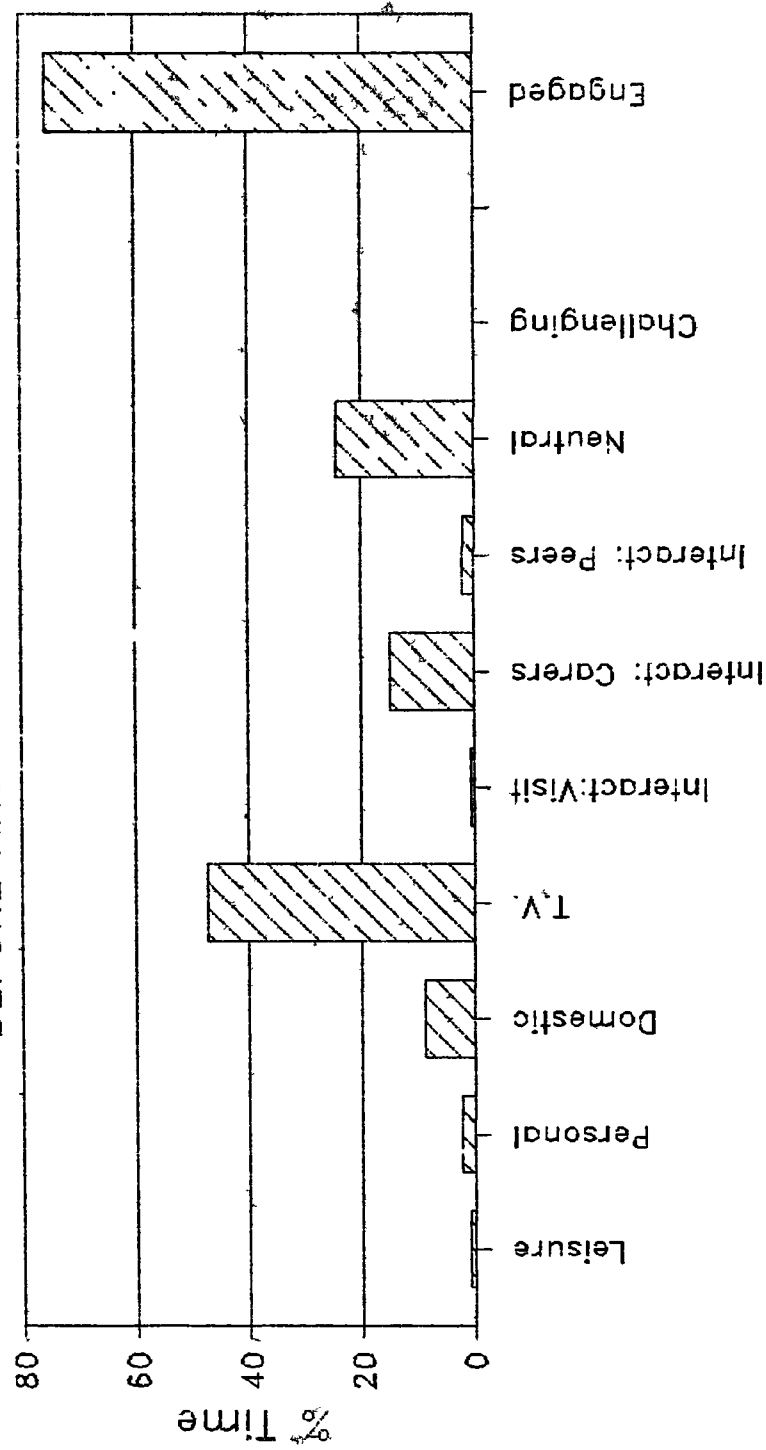
A summary of the observations, before and after meals, is shown in Figure 2.

Important features were:

- \* The relatively long periods spent watching TV
- \* Little time was spent in domestic activities
- \* Interaction with carers and peers was considerably higher at mealtimes than before and after meals
- \* Challenging behaviours rarely occurred

Figure 2

# SUMMARY OF OBSERVATIONS: BEFORE AND AFTER MEALS PAUL



Total time of observations: 8.38 hours  
Number of evenings data collected: 7

Categories

c) Questionnaires

Table 7 below summarises the questionnaire data. Full details are available in Appendix 28.

Table 7  
Summary of Questionnaires - Paul

<u>Questionnaire</u>	<u>Possible Scores for</u>	<u>No. Items</u>	<u>Examples of Item</u>
Physical Environment	Most valued feature present	13	Own bedroom; furniture domestic; well-decorated house.
	Mid-point	2	Domestic bedroom furniture; private room to meet friends.
	Least valued feature present.	1	Pets not discussed.
Opportunities	High degree of opportunity	11	Preparing snacks; shopping; clothes care; leisure
	Mid-point	3	Cooking hot food; access to money.
	Little opportunity	1	Uses pocket money only.
Friendships	Greatest number of friendships	3	Has 2 friends; knew people in house before move; friend of opposite sex.
	Mid-point	1	Inviting friend/relative to house.
	Few friendships	4	Meeting friends; making new friends.
Decision	Person makes decision	9	Friends; bed-time; TV; going out.
	Carers and person take decision	5	Living in house; who to live with; money.
	Carers take decision	5	Bedroom; person leaving the house.
	No choice available	1	Furniture in bedroom.
	Not scored.	1	Choosing a pet.

Important features were:

- \* High quality physical environment.
- \* Opportunities to shop, prepare snacks, etc., but Paul had little control over major expenses.
- \* Paul has friends and knew people in the house before he moved; less opportunity to make new friends.
- \* Paul takes decisions on a daily basis and would be involved in a new person coming to live in the house.

e) Additional Information

Financial: Paul received £159 p.w. DHSS allowance and £150 p.w. was sent to the Housing Association. His personal spending money was £9 p.w.

Neighbours: Paul had little contact with his neighbours - they sometimes talked over the fence. Neighbours expressed ill feeling initially, but this was now resolved.

This information is available in Appendices 31 and 32.

A summary of these findings is given in Table 9 - Individual Profile - Paul.

d) Diary Data

Appendices 29 and 30 contain summaries of the diary data. The main findings of Paul's diary data may be summarised in the table below:

Table 8  
Summary of Diary Data - Paul

Time	%	Hours
Out of residential service weekdays (15)	23.8	26.2
Out of residential service weekends (6 days at weekends)	7.5	5.2
Time in integrated settings, weekdays (15)	2.0%	2.2
Time in integrated settings, weekends (6 days at weekends)	1.7%	1.2

Categories recorded above 10% of time:

Weekdays:	TV	34.1%
	Self-care	15.2%
	Segregated clubs	13.9%
Weekends:	TV	42.7%
	Sitting	16.7%

Main features of the data were:

- \* During the weekdays, Paul went out, but predominantly to segregated settings.
- \* He went out very little at the weekends.
- \* His main activities were watching TV, going to segregated clubs and settings.
- \* His only integrated activities were shopping, walking (to a segregated club!).

TABLE 9  
INDIVIDUAL PROFILE - PAUL

Age: 35 years

Service: Staffed house - total 4 people.

	<u>NEGATIVE OUTCOME</u>	<u>POSITIVE OUTCOME</u>
VIEWS	Annoyed by one woman in house.	Wished to stay. Liked his car, bedroom and having choices
ACTIVITIES WITHIN THE HOUSE	Spent little time doing domestic activities (9%), leisure activities (1%).	Spent long periods watching TV (47%). Interacted often with carers (14%). Few challenges (0.05%) were observed.
PHYSICAL ENVIRONMENT		Well-decorated house, own bedroom, domestic furniture. No signs outside.
OPPORTUNITIES	Used pocket money only.	Prepared snacks. Shopping regularly.
FRIENDS	Few opportunities to meet friends and make new friends.	Has friends. Knew people in house before he moved.
DECISION MAKING	No choice was available of bedroom furniture. Having a pet in the house was not discussed.	Participated in decisions concerning: bedtime, TV, going out, who would come to live in the house, moving to the house.
ACTIVITIES	Goes out little at weekends. (5 hours) Goes to integrated settings (3.4 hours).	Goes out in the week (26 hours) to segregated settings.

## Questions

Each of the questions will be discussed with reference to a standard set of criteria.

### Question 1

What were Paul's views of his service and did he wish to remain? What factors were influencing his views?

### Outcome

#### 1.1 Did Paul like his service?

Paul gave positive views of his placement and he clearly preferred this to living in hospital. In particular, he liked his bedroom and choosing what to eat.

#### 1.2 Did Paul want to remain in the service?

Paul wanted to continue to live in his current service, both in the short-term and long-term. Initially he expressed an interest in living with his sister, but on discussion he felt that this was unlikely to be possible.

### Influencing factors

#### 1.3 Physical environment

Paul's service offered a high quality, physical environment, e.g., well decorated, domestic style furniture. It is considered that it was probable that the physical environment was of a higher quality than his previous ward environment.

#### 1.4 Bedroom

Paul had his own bedroom and he stated that he liked this feature of the service.

#### 1.5 Activities within the house

Paul reported that he liked all the household activities, e.g. cooking, Hoovering and he enjoyed watching TV.

#### 1.6 Activities outside the house

Paul enjoyed all his leisure activities, e.g., drama class, shopping. He stated that he would like to go out more often.

### 1.7 Carers

Paul liked all his carers and viewed them as his friends.

### 1.8 Peers within the house

Paul described the people he lived with as his friends. However, he reported that one woman 'annoyed' him, specifically when she had urinated in his bedroom and had eaten raw food from the deep freezer.

### 1.9 Other friendships

Paul had friendships outside the house, i.e., at the Day Centre. In particular, he had a close friendship with a woman at the Day Centre and carers were unaware of this relationship.

### 1.10 Involvement in decision making

Paul had been involved in the decision to come and live in the house. He participated in many everyday decisions.

### 1.11 Knowledge of other services

It was considered that Paul had little access to information of other services.

### 1.12 Other features

Paul gave very positive reports of his car and clearly was very proud of this possession. He described leaving hospital, which he found very frightening. He liked his day services.

### Comments

It was clear that Paul liked his present service and wanted to stay. His views were positive on all the proposed influencing factors. He did give mixed views concerning one woman he lived with, i.e., that she annoyed him. So, although he did complain about her behaviour, it is suggested that whilst living in hospital, he probably would have been expected to tolerate more frequent and intense challenging behaviours of others.



## Question 2

What did Paul do in the evenings in his residential service? What processes were influencing what he did?

### Outcome

#### 2.1 Leisure activities

Paul spent very little time in leisure activities.

#### 2.2 Domestic activities

Paul participated little in domestic activities (9%), although he clearly enjoyed these.

#### 2.3 TV

Paul spent long periods watching TV (47%) and enjoyed this activity.

#### 2.4 Interaction

Interaction with peers was moderate, but increased during mealtimes. Interaction with carers was high, particularly within meals.

#### 2.5 Challenging behaviour

Very little challenging behaviour occurred.

#### 2.6 Level of engagement

Paul's overall level of engagement was reasonably high (75% outside meals and 87% within meals).

### Influencing Factors

#### 2.7 View and Preferences

Paul had consistently stated that he enjoyed all household activities, e.g., cooking, Hoovering and watching TV. This was supported by his co-operation when asked to help in the kitchen (noted during the observations).

#### 2.8 Allocated jobs/rota

Paul had no clearly allocated jobs within the household.

## 2.9 Activity of carers

Carers prepared many of the meals and did the clothes washing. When carers did not prepare a meal independently, Paul was often involved. One carer reported that she did not feel that it was fair to expect people to prepare their own food after being out all day. No clear encouragement was offered to participate in leisure activities.

## 2.10 Group size

Interaction with both carers and peers was higher during mealtimes, i.e., when all the group were together. Interaction with carers was high outside mealtimes and was noted to occur usually when Paul was in the kitchen preparing a meal with a carer, or when watching TV with a carer. Discussion was usually about the activity. Peer interaction outside meals was low and two reasons were felt to account for this: peers sometimes were not present and peers did not always respond to an attempt to initiate a conversation.

## 2.11 Length of mealtime

Mealtimes lasted for about 25 minutes on average. Carers ate their meal with the group.

## 2.12 Aims of the service

These were not clear to the researcher. It was considered unlikely that high participation in domestic activities was an aim, as neither Paul nor the other people were regularly encouraged in this activity.

## Comments

The major influences over Paul's activities were considered to be his own initiation of activity (i.e., TV) and group size (i.e., influencing interaction). In addition, the absence of specified jobs and clear aims resulted in carers not consistently encouraging him to participate in domestic activities.

### Question 3

What is the quality of the physical environment?

#### 3.1 Quality of decor

Paul's service offered a high quality of decor and was in a good state of repair. A wide range of household appliances were available.

#### 3.2 Privacy

The house offered reasonable privacy to Paul, e.g., his bedroom was large enough for some spare time activities. However, there was no allocated private area to meet friends and relatives.

#### 3.3 Access

The house was within easy access of shops and local services.

#### 3.4 Bedroom

Paul had his own bedroom which he stated he liked.

#### 3.5 Pets

Pets were not present and had not been discussed.

#### 3.6 Features of larger services

Paul's bedroom furniture was somewhat institutional. It had come from the hospital in an effort to cut the cost of setting up the house. No other features of larger services were present, i.e., other furniture was domestic, possessions were left downstairs, no sign was outside and there was no locked office/room.

### Comment

The service offered a high quality physical environment as measured by the features identified above. The lack of a private area to meet friends was difficult to overcome in a domestic house. Carers planned to replace the bedroom furniture when possible.

#### Question 4

Does Paul have friends and how are these maintained?

##### 4.1 Carers

Paul reported that his carers were his friends.

##### 4.2 People within service

Paul reported that the people living within the service were his friends and he had known them before moving to the service.

##### 4.3 Friends outside the service

Paul had friends that he met at his Day Service.

##### 4.4 Close friend

Paul reported that he had a close friend of the opposite sex.

##### 4.5 Relationship difficulties

None reported.

##### 4.6 Opportunities to meet outside services (i.e., segregated services)

Paul met other people at his Day Service and other activities. However, he did not arrange to meet them outside services. He had made no new friends outside services.

#### Comment

Paul had friends. His social network included only people with learning difficulties and their carers. So, friendships were maintained within services.

## Question 5

What decisions does Paul participate in?

### 5.1 Everyday Decisions (i.e., decisions taken every day, or at least every week)

Paul took part in all everyday decisions (that the questionnaire investigated - total 10), with the exception of deciding who visited the house. So, Paul chose how to spend his free time, what to eat, what to spend his pocket money on.

### 5.2 Infrequent Important Decisions

Paul participated in six major decisions (total investigated - 11). So, he did not decide if someone left the service, nor his bedroom, nor decor. The item on pets was not scored, as pets had not been discussed. However, Paul had participated in the decision to come and live in the service.

### 5.3 Meetings

Paul did not participate in any pre-arranged meetings on a regular basis, at which issues were discussed before decisions were made.

## Comment

Paul participated in most everyday decisions and some infrequent major decisions.

## Question 6

How much time did Paul spend in integrated settings and what were the processes involved in his presence in integrated settings?

### 6.1 Time out of the Residential Service

Paul spent over 31 hours (in 3 weeks) out of his residential service - not including time spent at the Day Service. He spent more time out during the week than at weekends.

## 6.2 Time in Integrated Settings

During a three week period, Paul spent just over three hours in integrated settings and this involved going shopping and walking (to a segregated club). So, the majority of the time that he spent out of the house was in segregated clubs, e.g., Gateway.

## Influencing Factors

### 6.3 Desire to go to Integrated Settings

Paul stated that he would like to go out more often. He enjoyed his activities in integrated settings. He had experienced one difficult situation in public, i.e., in the taxi (see Section 3(a)), but this had not led him to be reluctant to go to integrated settings.

### 6.4 Large Group Trips, i.e., everyone in the service going out together.

Paul did not always go out with the people he lived with - he went to leisure clubs without them.

### 6.5 Active Links with the Community

Paul's sister lived in the same city. However, she visited him approximately every two months and so she was not viewed as an active link with the community. No other links were identified.

### 6.6 Need for Help from Carers

Paul did require help from carers when out of the service. He was unable to walk long distances due to his physical disability.

### 6.7 Aim of the Service

It remained unclear whether integration was an aim of the service. However, Paul's peers in the house did not visit integrated settings. In addition, carers sometimes did the shopping without any of Paul's group being present.

#### Comment

Paul spent little time in places predominantly used by the general public, although he did go out regularly. It is suggested that the main reasons accounting for this were: his need for help outside the service, integration was unlikely to be a clear aim of the service and he had no active links within the community. His car was clearly not being used to its full potential.

#### Postscript

Paul was visited 18 months after the last research visit had taken place. The purpose was to give feedback to Paul and his carers about the major findings of Study II - See Appendix 33.

Little had changed in Paul's life. Two members of staff had left, he was planning to get a new car and had had a holiday. No other changes or major events had occurred.

Subject\_2 - Pseudonym: Patricia

## 1. Background Detail

Patricia was a 40 year old woman. She had lived at home with her mother until her mother died, approximately 17 months before she participated in the research project. Patricia then moved to her current service with no prior visits as preparation for the move. She did know many of the people living in the service as a result of attending a local club. At the time of her move, she started to attend a local Day Centre. She had not attended a Day Centre, nor school, while her mother had been alive.

## 2. Service

Patricia lived in a large extended house on the outskirts of a large city. Twelve people lived in the service and there was one temporary care bed. The house was set back from a busy main road and had an obvious extension and large sign with the Christian name of a young woman living in the service. Parked in the drive was a minibus with the name written on the side. All the decor of the house was of very high quality, e.g., co-ordinating Sanderson duvet covers and curtains.

The house was managed by the man who planned the service and he had appointed a person-in-charge. The service had 6 full-time staff and an additional person on the weekends. The house had many volunteers coming from a local club. The service was influenced by a strong religious commitment.

The other people living in the service had a range of learning difficulties, including some people with a greater disability than Patricia. The service also involved a few people who, in common with Patricia, could continue a clear conversation.



### 3. Findings

#### a) Views

##### (1) Service User's Interview

Patricia stated that she liked her present placement and wanted to remain. However, she would like to leave if she could in the future and live in a cottage with a friend. She offered mixed views of her carers, i.e., liking some staff, but not others. She has friends, but would like more. Patricia sometimes had visitors and sometimes visited others. In addition, she liked her Day Service. Her spare time activities included doing her homework and cleaning and she felt she had enough to do in her spare time. She reported that she usually felt happy.

Patricia gave correct answers to items 1-5 of the Emotional Labelling section. All answers to items 6-9 of the Emotional Labelling section confirmed her views expressed in the interviews and the questionnaire. A summary of the questionnaire is available in Appendix 25.

##### (2) Interviews

A summary of the interviews is available in Appendix 26.

##### Present placement

- Patricia liked her home and all the activities, e.g., Hoovering, laying the table, etc.
- She liked everyone she lived with; one woman upset her.
- She liked most of her carers; she stated that she "could not stand" one carer - she was bossy.

### Past and Future Placements

- Patricia missed both her parents and previous family home.
- She was very clear that she wanted to live in a small cottage (near her present placement) with her close friend.

### Friendships

- Patricia viewed as her friends all the people she lived with and the couple who had set up the service.
- She spoke at length about her close friend (a man). She stated that she would like to marry him. She had discussed this with carers, who had replied that this "was stupid". Her close friend was very important to her, despite frequent disagreements.

### Day Services

- Patricia liked attending the Day Centre - the activities and the instructors.

### Leisure Activities

- Patricia enjoyed all her leisure activities - integrated and segregated.
- She often reported that she would like to go out shopping more often.
- No difficulties had been reported in integrated settings. (This was confirmed by carers when completing the Questionnaires - with Patricia's prior agreement).

### Visits

- Patricia liked all visitors to the service.
- She wanted to maintain contact with friends of her family.

### Other\_Issues

- Patricia had greatly enjoyed shopping with her mother in the past.
- The man who had set up the service was very important to her.
- She made frequent references to religion.

### Reliability

Patricia gave consistent reports on the majority of topics.

### b) Client Activity: Observational\_Measures

Table 10 below outlines the percentage of time recorded in each category of behaviour, both before and after meals, and within meals. The raw data are available in Appendix 27.

Table 10

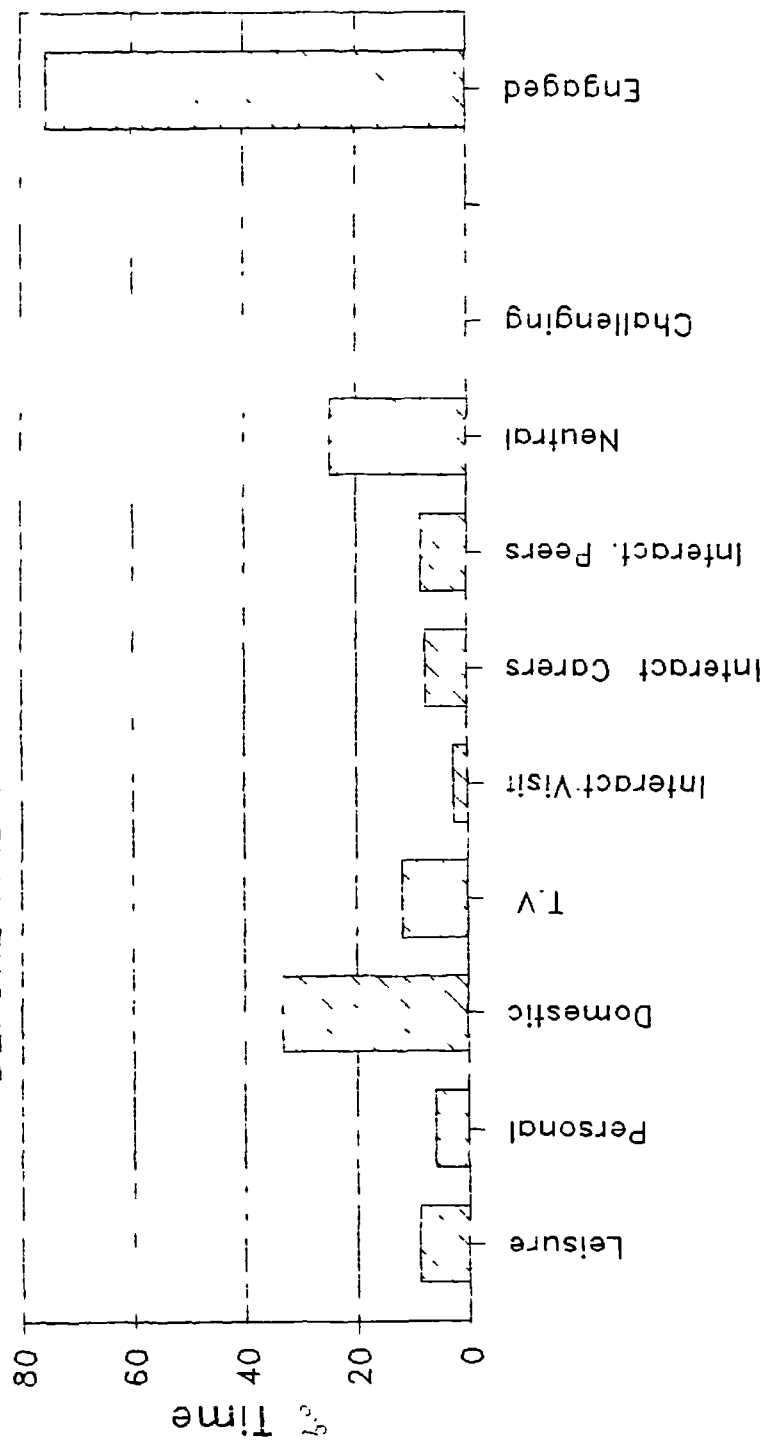
## Summary of Observations - Patricia

	Before and After Meals	Within Meals
Total time of observations	7.25 hours	4.13 hours
Number of evenings data collected	7	7
Percentage time recorded in each category of behaviour:		
% Leisure	8.92	-
% Personal	5.99	65.10
% Domestic	33.21	8.58
% TV	11.86	-
% Interaction with Visitors	2.68	0.07
% Interaction with Carers	7.51	3.71
% Interaction with Peers	8.19	4.84
% Neutral	24.69	17.99
% Challenging	0	0
% Time recorded in engaged behaviour (i.e., 100% - neutral - challenging behaviours)	75.31	82.01

A summary of the observations, before and after meals, is shown in Figure 3.

FIGURE 3

# SUMMARY OF OBSERVATIONS BEFORE AND AFTER MEALS PATRICIA



Total time of observations: 7.25 hours  
Number of evenings data collected: 7

Categories

Important features of this data were:

- \* Patricia spent long periods in domestic activity, although this was very repetitive and always involved laying and clearing the table.
- \* Patricia participated in some leisure activities, but watched less TV than some other subjects.
- \* Interaction with peers was high when compared with the other subjects. Interaction with carers was neither particularly high nor low.
- \* Interaction reduced substantially during mealtimes.
- \* Challenging behaviours were not observed.

c) Questionnaires

The table below summarises the questionnaire data. Full details are available in Appendix 28.

Table 11

Summary of Questionnaires - Patricia

<u>Questionnaire</u>	<u>Possible Scores for Each Item</u>	<u>No. Items Receiving This Score</u>	<u>Examples of Item</u>
Physical Environment	Most valued feature present	11	Own bedroom; privacy; domestic furniture; state of repair.
	Mid-point	4	Domestic equipment; details outside; locked room; personal possessions downstairs.
	Least valued feature present.	1	Pets.
Opportunities	High degree of opportunity.	7	Cold snacks; clothes; leisure service.
	Mid-point.	6	Cooking hot food; shopping; spare time activities.
	Little opportunity.	2	Use of money; washing clothes.
Friendships	Greatest number of friendships.	4	Has friends; has friend of opposite sex; has made friends.
	Mid-point	3	Meeting friends; inviting friends; knowing others in the service.
	Few friendships.	1	Friend to discuss problems with.
Decision Making	Person makes decision	5	Bedroom; bedtime; clothes; visitors.
	Carers and person	5	Jobs; special friend; TV; bathing; money.
	Carers take decision	8	Other people living in service; decorations; food; smoking/drinking; when to go out.
	No choice available	2	Living in service; attending Day Centre.
	Not scored	1	Pets.

Important features were found to be:

- \* Many features of the physical environment were of a high quality; but there was a locked office, little domestic equipment in the kitchen and signs outside.
- \* Patricia was able to prepare cold snacks and drinks on a regular basis. Many opportunities were more limited: shopping, cooking hot food, washing clothes and use of money.
- \* Patricia has friends and a friend of the opposite sex, but she had few opportunities to make new friends, invite them home. She knew the other people in the service before moving, but not well.
- \* Patricia participated in many everyday decisions. She had no choice of where to live, nor what to do in the daytime. Carers decided many important issues, e.g., who lived in the service, food, decorations.

d) Diary Data

Appendices 29 and 30 contain summaries of the diary data. The main findings of Patricia's diary data are summarised in the table below:

Table 12

Summary of Diary Data - Patricia

<u>Time</u>	<u>%</u>	<u>Hours</u>
Out of residential service weekdays (15)	16	18.6
Out of residential service, weekends (6 days at weekends)	25.7	16.0
Time in integrated settings, weekdays (15)	-	-
Time in integrated settings, weekends (6 days at weekends)	11.2	7

Categories Recorded Over 10% of Time

Weekdays:	Self-Care	20.3%
	Domestic	31.2%
	TV	10.0%
Weekends:	Self-Care	16.0%
	Domestic	29.7%
	TV	19.8%
	Segregated Clubs	10.4%

The main features of the data were:

- \* Patricia spent time out of the residential service both during the week and weekends.
- \* Patricia spent very little time in integrated settings, i.e., only 7 hours in three weeks - going to Church, for a meal, and to visit friends.
- \* Her main activities, apart from self-care, were domestic activities, TV and visiting segregated clubs.



e. Additional Information

Financial: Patricia received DHSS benefit of £150 p.w.

Neighbours: The neighbours send Christmas cards and two neighbours visit at Christmas. One neighbour objected when the service was planned and now only complains if cars are parked on the road.

This information is also available in Appendices 31 and 32.

A summary of all of the findings is given in Table 13 - Individual Profile.

TABLE 13

INDIVIDUAL PROFILE - PATRICIA

Age: 40 years.

Service: Extended house: total 12 people and one short-term care bed.

	<u>NEGATIVE OUTCOME</u>	<u>POSITIVE OUTCOME</u>
VIEWS	Wanted to leave in the future and live with a close friend. Disliked one carer.	Liked her home and activities, e.g. hoovering, laying table. Liked most people she lived with and most carers.
ACTIVITIES WITHIN THE HOUSE	Domestic activities repetitive. Less TV than some other subjects (11.9%). Interaction reduced substantially at meal times. Long meals.	Spent long periods in domestic activities (33%). Some leisure activities (8.9%). High interaction with peers (8.2%) - the close friend.
PHYSICAL ENVIRONMENT	Locked room; sign present outside; non-domestic kitchen.	Own bedroom, privacy available and good quality decor.
OPPORTUNITIES	Used pocket money only. Did not wash own clothes.	Prepared cold snacks. Leisure opportunities out of the service.
FRIENDS	No friend to discuss problems with. Rarely invites friends home.	Has friends. Close friend (a man).
DECISION MAKING	No choice re living in service, attending a Day Service.	Chose bedroom, bed time, clothes to wear, visitors.
ACTIVITIES	Very limited time in integrated settings (7 hours in 3 weeks).	Spent long periods out of the service (34.6 hours in 3 weeks).

## Questions

Each of the questions will be discussed with reference to a standard set of criteria.

### Question 1

What are Patricia's views of her service and does she wish to remain? What features may be influencing her views?

## Outcome

### 1.1 Did Patricia like her service?

Patricia reported that she liked her placement and all the activities, e.g., laying the table, Hoovering. She did describe her feelings of distress concerning her parents' death and she missed the family home.

### 1.2 Did Patricia want to remain in her service?

Patricia was clear that in the long-term she wanted to leave and live with her close friend. She stated she would like to live in a nearby cottage. The cottage she was referring to was a smaller service which had been set up by the owner of her present service. So, she had a clear view of where she would like to live and who with. Her knowledge of the other service was not extensive, but she had visited and knew some of the staff. Her carers were not aware of her wishes to leave.

## Influencing Factors

### 1.3 Physical environment

The majority of features of the physical environment were of a high standard, e.g., the decor and the house were well maintained. Some features of larger services were present, e.g., a locked room, a sign outside, large kitchen equipment. It was likely that the physical environment would not have been to the same quality as her previous family home.

#### 1.4 Bedroom

Patricia had her own bedroom which she clearly liked. She had had the opportunity to choose her bedroom as it was part of a new extension to the house.

#### 1.5 Activities within the service

Patricia liked all the activities within the house, i.e., laying the table, Hoovering and the hobbies organised by the service.

#### 1.6 Activities outside the service

Patricia reported that she liked all her activities outside the service - both the segregated clubs and activities and the integrated activities, e.g., Church, going for a meal. However, she stated that she would like to go out shopping more often.

#### 1.7 Carers

Whilst Patricia reported that she liked her carers, there was one carer that she "could not stand". Her reason for disliking the carer so much was that she was "bossy" and she was often telling Patricia what to do. Patricia gave very positive reports of the man who had set up the service. She viewed all the carers as her friends.

#### 1.8 Peers within the house

Patricia liked everyone she lived with and viewed them as her friends. One woman annoyed her because of the noise she made.

Patricia spoke at length about her close friend (a man) who lived in the service. He was very important to her, despite frequent disagreements and upsets. Patricia felt that she would like them to be married. She had discussed this with her carers who had replied that this "was stupid".

#### 1.9 Other friendships

Patricia had no other active friendships out of the service.

#### 1.10 Involvement in decision making

Patricia had had no other choice of where to live after her mother's death. She participated in many everyday decisions, although not all, e.g., what to eat, when to go out.

#### 1.11 Knowledge of other services

Patricia's knowledge of alternative styles of living came from her family home and having some information on another service.

#### 1.12 Other features

Patricia made frequent references to religion. She liked her day services.

#### Comment

Patricia liked her service, but had clear views about wanting to leave in the future. Her wish to leave was considered to be influenced by her close friendship, knowledge of a possible alternative and a clear dislike of one carer.

#### Question 2

What did Patricia do in the evenings in her residential service?  
What processes were influencing what she did?

#### Outcome

##### 2.1 Leisure activities

Patricia participated in some leisure activities (9%), for example craft work.

##### 2.2 Domestic activities

Patricia spent long periods in domestic activities (33%) and this always involved laying the table, clearing the table, Hoovering the dining room and sometimes loading the dishwasher.

### 2.3 TV

Patricia spent some time watching TV (12%), but this was less than some subjects.

### 2.4 Interaction

Interaction with peers was high, but this reduced at mealtimes. Some interaction with carers occurred, but this reduced at mealtimes.

### 2.5 Challenging behaviours

These did not occur.

### 2.6 Level of engagement

Patricia's overall level of engagement was reasonably high (75% outside meals and 82% within meals).

## Influencing Factors

### 2.7 Views and Preferences

Patricia reported that she liked all the activities within the house, both domestic and leisure.

### 2.8 Allocated jobs/rota

Patricia had a clearly allocated task of laying and clearing the table and she was proud of this task.

### 2.9 Activity of carers

Carers performed the majority of other household tasks, e.g., cooking, care of clothes. Encouragement to participate in leisure activities was given.

### 2.10 Group size

Interaction reduced substantially during mealtimes. Some carers (not all) ate with the group. Peer interaction (outside meals) was higher than for other subjects. Much of this took place with her close friend, e.g., when clearing the table, talking together in the kitchen and to a limited extent with another person.

### 2.11 Length of mealtimes

Mealtimes were quite long (about 35-40 minutes). Some carers ate separately and some ate with the group.

### 2.12 Aims of the service

These remained somewhat unclear to the researcher. Patricia had domestic tasks to perform, but the other people did not.

### Comments

Patricia's activities were considered to be influenced by having clear tasks allocated and interaction was high in very small group situations, e.g., when two/three people only were together. Also, encouragement by carers to participate in leisure activities took place. Her high participation in household activities masked the repetitive nature of the activity. However, she clearly took great pride in the tasks.

### Question 3

What is the quality of the physical environment?

#### 3.1 Quality of decor

Patricia's service offered a particularly good quality of decor and was in a good state of repair. A wide range of household appliances were available.

#### 3.2 Privacy

The service offered a very good degree of privacy, e.g., a room was available to meet friends and her bedroom was large enough for some spare time activities.

#### 3.3 Access

The service was within easy access of shops and local services.

#### 3.4 Bedroom

Patricia had her own bedroom.

### 3.5 Pets

Pets were not present, and had not been discussed.

### 3.6 Features of larger services

Four features of larger services were present: non-domestic kitchen equipment, a notice outside, a locked room, and a few personal possessions were on display downstairs.

#### Comment

The service offered Patricia a high quality physical environment, except that a number of features of larger services were noted.

#### Question 4

Does Patricia have friends and how are these maintained?

#### 4.1 Carers

Patricia viewed some of her carers as her friends, particularly the couple who had set up the service.

#### 4.2 People within the service

Patricia viewed all the people that she lived with as her friends. She did not know them well before moving to the service, but had met them.

#### 4.3 Friends outside the service

Patricia knew people at her Day Services.

#### 4.4 Close friend

Patricia had a close friendship with a young man living in the service. She hoped that they could marry, but on discussion carers had not supported this idea.

#### 4.5 Relationship difficulties

Patricia had great difficulties in her relationship with her friend. She was sometimes very distressed - usually when he ignored her or was annoyed with her.



#### 4.6 Opportunities to meet outside services (i.e., segregated services)

Patricia rarely made arrangements to meet people outside services.

#### Comments

Patricia had friends including a close friend. She had relationship difficulties with her close friend. Her social network included only people with learning difficulties and their carers. So, friendships were maintained within services.

#### Question 5

What decisions did Patricia participate in?

##### 5.1 Everyday Decisions

Patricia took part in most everyday decisions - seven out of the ten investigated. She did not decide what to eat, whether to go out and who to do activities with. She decided, for example, when to bath, go to bed and what to do in her spare time.

##### 5.2 Infrequent Important Decisions

Patricia participated in few important but infrequent decisions, e.g., she had not decided to come and live in the service, nor did she participate in deciding who she should live with. She had chosen her bedroom, her clothes and a special friend.

##### 5.3 Meetings

Patricia participated in no pre-arranged regular meetings at which issues were discussed before decisions were taken.

#### Comment

Patricia participated in most everyday decisions, but few important infrequent decisions.

#### Question 6

How much time did Patricia spend in integrated settings and what were the processes involved in her presence in integrated settings?

##### 6.1 Time out of the Residential Service

Patricia spent over 34 hours out of the residential service during a three week period.

##### 6.2 Time in Integrated Settings

Patricia spent 7 hours (in three weeks) in integrated settings. These activities involved going to Church, out for a meal and a visit to a friend.

#### Influencing Factors

##### 6.3 Desire to go to Integrated Settings

Patricia enjoyed going out, including going to integrated settings. She stated that she wanted to go out more often.

##### 6.4 Large Group Trips, i.e., everyone in the service going out together

Patricia often went out with everyone living in her service. This did not always occur, e.g., she went shopping with a carer only.

##### 6.5 Active Links with the Community

Patricia had no active links with the community. She visited friends infrequently.

##### 6.6 Need for Help from Carers

Patricia was not able to go out alone, e.g., she could not cross roads without help and carers considered that she would get lost if he was by herself.

#### 6.7 Aim of the Service

It was unclear whether integration was an aim of the service. Patricia's peers did not regularly attend integrated settings. Shopping was predominantly done by carers alone.

#### Comment

Patricia spent little time in settings used predominantly by the general public, although she went out regularly. It is suggested that the main reasons accounting for this were her need for help outside the service; integration was not a clear aim of the service; she had no links with the community; and often went out with everyone living in her house.

#### Postscript

Patricia was visited approximately 18 months after her participation in the research project was ended. The purpose was to give feedback to Patricia and her carers about the major findings in Study II - see Appendix 33. She had had a summer holiday and had started a part-time college course. There were no plans reported concerning her moving to live in another service with her friend.

## Subject 3 - Pseudonym Janet

### 1. Background Details

Janet was a 40 year old woman. At the age of 28 she had been admitted to a large hospital for people with learning difficulties. She stayed there for 9 years and about 2 years 6 months before the research commenced, she had moved to her current community placement. Janet's sister lived locally and she visited her sister regularly. Whilst in hospital, Janet had presented challenging behaviours, e.g., biting her hand, smacking her face and pulling her hair. She attended a Day Centre five days a week.

### 2. Service

Janet lived in a community based service in a small town. The service was situated up a short driveway which was clearly marked with a large sign. The building appeared to be very different from the surrounding houses. It was a modern bungalow-style unit. The service was for 24 people with learning difficulties (including a short-stay unit) and Janet lived with a group of six people. The unit was split into four living areas and there was a common hallway and people from the different living areas visited each other. The service had a clearly marked office and enquiry point.

The service was managed by the Local Authority, Social Services Department. There were 6 staff in post for the unit where Janet lived, but there was an establishment of 8 posts. Two carers had a CQSW qualification, one was a trained nurse and one was an art therapist. Three carers were graduates. The unit did not have a staff hierarchy, but the service had a manager and deputy manager.

The people living in Janet's unit had a range of learning difficulties. Another woman in the unit could continue a clear conversation with Janet but she was considerably younger.

### 3. Findings

#### a) Views

Janet stated clearly that she did not like her present placement and she did not wish to remain. She would like to leave when possible and live in a flat or bungalow alone. She did like the carers in her service. Janet did not have many friends, but would like more friends. She did have visitors and did visit others. She disliked her day service. She sometimes felt happy. Her spare time activities included cleaning and shopping.

Janet gave correct answers to items 1-5 of the Emotional Labelling section. Responses to items 6-9 confirmed replies to the questionnaire and information given in the interviews. The majority of her replies to 'check' questions within the questionnaire agreed, but Janet was unclear about being happy - sometimes she was happy, but at other times she was upset and unhappy with her placement. A summary of the questionnaire is available in Appendix 25.

#### b) Interviews

A summary of the interviews is available in Appendix 26.

##### Present Placement

- Janet described her placement as "all right", but clearly wanted to leave.
- She liked the domestic activities in the placement.
- She did not like the other people she lived with.
- She liked her carers; she did not like the policy of discouraging friendships with carers.

- For one week, she and another woman went to live independently in another part of the unit. She liked living more independently and liked the freedom, but had found the stay stressful initially.

#### Past and Future Placements

- Janet discussed the difficulties that she had had leaving hospital, e.g., she missed the people, the staff, helping the old ladies, etc.
- She had wanted to leave hospital - and she did not want to return.
- She was clear that she wanted to live in a bungalow on her own - it was important to have her freedom.

#### Friendships

- Janet had a close and long-term friendship with a woman at the Day Centre.
- She had had a close friendship with a man, but she was upset that she had not seen him for 2 months.

#### Day Services

- Janet disliked the Day Centre - the work was boring and the people got on her nerves.
- She would like to do voluntary work or have a job, or go to college.

#### Leisure Activities

- Janet enjoyed all her activities - segregated and integrated.
- She was very enthusiastic about shopping with her sister and activities undertaken with carers - e.g., visits to the pub.

- No difficulties were reported in integrated settings. (This was confirmed with carers when completing the Questionnaires with Janet's prior agreement.

#### Visits

- Janet met her sister every weekend - an event she greatly enjoyed.

#### Other Issues

- Janet did not like being referred to as "mentally handicapped" - preferring to be described as a "lady with a learning difficulty".
- She was a member of a local "People First" group.

#### Reliability

Janet was consistent on all topics.

#### b) Client Activity: Observational Measures

Table 14 below outlines the percentage of time recorded in each category of behaviour both before and after meals, and within meals. The raw data is available in Appendix 27.

Table 14

## Summary of Observations - Janet

	Before and After Meals	Within Meals
Total time of observations:	8.39 hours	1.39 hours
Number of evenings data collected:	8	6
Percentage time recorded in each category of behaviour:		
% Leisure	0.77	3.07
% Personal	4.41	58.46
% Domestic	30.42	3.65
% TV	8.87	-
% Interaction with visitors	1.03	0.26
% Interaction carers	10.22	5.22
% Interaction peers	2.22	3.12
% Neutral	47.09	25.59
% Challenging	-	
% time recorded in engaged behaviour (i.e., 100% - neutral - challenging behaviours)	52.91	74.41

A summary of the observations, before and after meals, is shown in Figure 4.

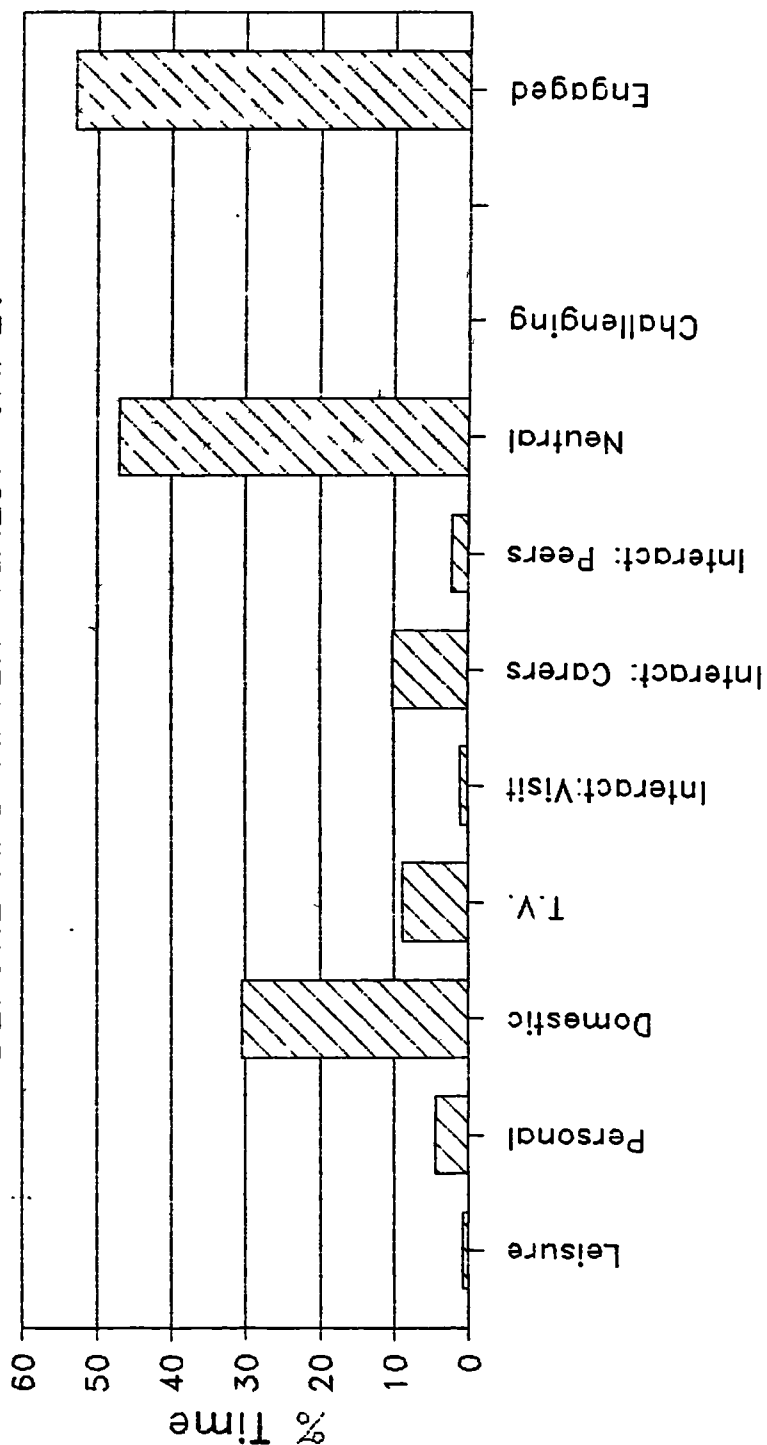
Important features were:

- \* Considerable periods were spent in domestic activities.
- \* Little time was spent in leisure activities or watching TV.
- \* Long periods were spent doing nothing.
- \* Interaction with carers was reasonably high outside meal times and reduced considerably during meal times; interaction with carers was higher than interaction with peers.
- \* Meal times were short in duration.



Figure 4

# SUMMARY OF OBSERVATIONS: BEFORE AND AFTER MEALS: JANET



Total time of observations: 8.39 hours  
Number of evenings data collected: 8

Categories

c) Questionnaires

The table below summarises the questionnaire data. Full details are given in Appendix 28.

Table 15  
Summary of Questionnaires - Janet

<u>Questionnaire</u>	<u>Possible Scores for For Each Item</u>	<u>No. Items Receiving This Score</u>	<u>Examples of Item</u>
Physical Environment	Most valued feature present	10	Own bedroom; comfortable; good state of decor; no locked rooms.
	Mid-point	5	Not all furniture domestic; kitchen equipment not domestic; few items on display; no private area.
	Least valued feature present	1	Conspicuous details outside.
Opportunities	High degree of opportunity	11	Preparing cold food; access to money; care of clothes; leisure outside and within service.
	Mid-point	3	Cooking hot food; shopping, buying essential goods.
	Little opportunity	1	Difficult to organise more cooking.
Friendships	Greatest number of friendships	4	Has 2 friends; made new friend; friend to discuss problems.
	Mid-point	1	Inviting a friend.
	Few friendships	3	Arrange to meet friend; close friend; knew people in placement.
Decision Making	Person makes decision	14	Bedroom; bedroom furniture; TV; bath time; who to spend time with; bedtime; spending money.
	Carers and person take decision	4	Living in service; person coming to live in service; decoration; household jobs.
	Carers take decision	2	Person leaving service; day time activities.
	No choice available	1	Pets.
	Not scored	-	

Important features were:

- \* The physical environment had many positive features, but included clear examples usually found in larger institutions.
- \* Opportunities existed to shop and spend her own money, but cooking hot food was more difficult to organise regularly.
- \* Janet had friends and had made new friends in the service but had a close friendship, did not arrange to meet friends, and had not known people in the placement before moving.
- \* Janet participated in the majority of everyday decisions, but she was not involved in the decision of a person leaving the service, nor her day time activities.

d) Diary Data

Appendices 29 and 30 contain summaries of the diary data. The main findings of Janet's diary data are summarised in Table 16 below.

Table\_16

Summary of Diary Data -- Janet

Time	%	Hours
Out of residential service, weekdays (15)	17.9	17.2
Out of residential service, weekends (6 days at weekends)	17.5	12.3
Time in integrated settings, weekdays (15)	14.0	13.5
Time in integrated settings, weekends (6 days at weekends)	17.5	12.3

Categories Recorded Over 10% of Time

Weekdays	TV (19.9%) Domestic (15.0%) Self-care (13.7%)
Weekend	TV (23.3%) Domestic (20.6%) Shopping (13.2%) Self-care (12.9%) Sitting (10.1%)

The main features of the data were:

- \* Janet spent considerable periods out of the service.
- \* Janet spent over 25 hours (in 3 weeks) in integrated settings - shopping, going to pub, walking, evening class.
- \* Her main activities were recorded to be: watching TV, domestic activities, self-care, sitting and going shopping. (The high proportion of time spent watching TV does not agree with the observational data).

e) Additional Information

Financial: Janet received Severe Disability Allowance of £41.20 per week. £32.90 was given to the service for board and lodgings and she received £8.30 per week pocket money.

Neighbours: One neighbour had given some rhubarb and a few Christmas cards were received. Neighbours had objected before the service opened. A petition was raised and it was claimed that the water would be infected. Complaints ceased after the service opened.

This information is also available in Appendices 31 and 32.

A summary of all the findings is given in Table 17 - Individual Profile.

TABLE 17  
INDIVIDUAL PROFILE - JANET

Age: 40 years.

Service: 24 bed unit - group of 6.

	<u>NEGATIVE OUTCOME</u>	<u>POSITIVE OUTCOME</u>
VIEWS	Disliked present placement. Wanted to leave. Disliked other people in service.	Liked carers.
ACTIVITIES WITHIN THE HOUSE	Long periods doing nothing (47%). Little time spent watching TV (9%), or in leisure activities (1%).	Long period of domestic activity (30%). Interaction with carers outside meal times (10%).
PHYSICAL ENVIRONMENT	Conspicuous details outside. Furniture - not all domestic.	Well-decorated; own bedroom; no locked doors.
OPPORTUNITIES	Could not organise more cooking. Shopping - not often in a week.	Prepared cold food. Care of clothes.
FRIENDSHIPS	Does not meet friends outside service. No close relationship.	Has two friends. Made new friends in service. Close friend.
DECISION MAKING	Not involved in decision if person leaves the service, nor day placement.	Participates in everyday decisions.
ACTIVITIES		Considerable periods outside service; and in integrated settings (25 hours in 3 weeks).

## Questions

Each of the questions will be discussed with reference to a standard set of criteria.

### Question 1

What are Janet's views of her service and does she wish to remain?  
What features may be influencing her views?

### Outcome

#### 1.1 Did Janet like her service?

Janet initially stated that she did not like her placement, but during further interviews described it as "all right". At no time did she say she liked living there. She liked the domestic activities and her carers, but disliked the people that she lived with.

#### 1.2 Did Janet want to remain in the service?

Janet did not want to remain in the residential service. She wanted to live in a flat or bungalow alone. Her carers were aware of her wishes and were helping her to plan towards this move.

### Influencing factors

#### 1.3 Physical environment

Janet's service offered a high quality physical environment, e.g., well decorated and in a good state of repair. Some features of larger services were present, e.g., not all equipment was domestic, a sign was outside. It was considered that the environment was likely to be of a higher quality than her previous hospital ward.

#### 1.4 Bedroom

Janet had her own bedroom which she liked and she had many personal possessions on display. She spent long periods alone in her bedroom.

1.5 Activities within the service

Janet enjoyed all the activities within the service, e.g., cooking, cleaning, TV.

1.6 Activities outside the service

Janet enjoyed all the activities outside the service, both integrated and segregated. In particular, she enjoyed shopping with her sister and going to the pub with carers.

1.7 Carers

Janet reported that she liked all her carers. However, the service had a policy of not encouraging friendships between carers and service users, e.g., the people were persuaded not to put their arms around carers. Janet disliked this policy.

1.8 Peers within the service

Janet did not like the other people in her group within the residential service.

1.9 Other friendships

Janet had a close, long-term friendship with another woman at the Day Centre. She had had a close friendship with a man who had attended her People First group. She was upset as she had not seen him for two months.

1.10 Involvement in decision making

Janet participated in the decision to come and live in the service and in all everyday decisions.

1.11 Knowledge of other services

Janet had access to knowledge of other services through attendance at People First group - where it is likely that such issues would have been discussed. In addition, she met her sister regularly and could also recall her family home.

### 1.12 Other features

Janet saw her sister every weekend, which she enjoyed. She disliked her day services and felt that she would like to do voluntary work or go to college. Janet also discussed the difficulties that she had had leaving hospital, although she had wanted to leave.

### Comments

Janet's dislike of her service and desire to leave were considered to be influenced by her dislike of the people she lived with, and a knowledge of alternatives. Her choice of where to live would involve a greater degree of independence.

### Question 2

What did Janet do in the evenings in her residential service?  
What processes were influencing what she did?

### Outcome

#### 2.1 Leisure activities

Janet spent little time (less than 1%) participating in leisure activities.

#### 2.2 Domestic activities

Janet participated in varied domestic activities (30%) for long periods and enjoyed these.

#### 2.3 TV

Janet spent a moderate amount of time watching TV (9%), but this was considerably less than some of the other subjects.

#### 2.4 Interaction

Interaction with carers was high outside mealtimes, but reduced considerably within meals. Interaction with peers was moderate, both within and outside mealtimes.



## 2.5 Challenging behaviours

These did not occur.

## 2.6 Level of engagement

Engagement outside meals was low (53%), i.e., Janet spent long periods doing nothing.

## Influencing factors

### 2.7 Views and preferences

Janet enjoyed all the activities within the service and particularly liked household activities.

### 2.8 Allocated jobs/rota

A rota was used for all household tasks and so Janet had clearly allocated jobs.

### 2.9 Activity of carers

Carers were consistent in their encouragement to the group to participate in domestic activities.

### 2.10 Group size

Interaction with carers was high when Janet was participating in a domestic activity with a carer. Interaction reduced when the group size increased at mealtimes. Peer interaction varied little according to group size.

### 2.11 Length of mealtimes

Mealtimes were short, e.g., 14 minutes. All carers ate with the group.

### 2.12 Aims of the service

One clear aim of the service was to encourage people to participate in domestic activities. Great effort was made by carers to maintain this aim.

## Comments

Janet's high participation in domestic activities was clearly an aim of the carers and the use of a rota helped to achieve this aim. High interaction with carers was influenced by the group size and a dyad situation was most likely to achieve this.

## Question 3

What is the quality of the physical environment?

### 3.1 Quality of Decor

Janet's service offered a high quality of decor and was in a good state of repair. A wide range of household appliances were available.

### 3.2 Privacy

The service offered reasonable privacy. However, a sleeping-in room for carers was available for Janet to meet friends.

### 3.3 Access

The service was within easy access of shops and local services.

### 3.4 Bedroom

Janet had her own bedroom and a wide range of personal possessions.

### 3.5 Pets

Pets were not present, but this had been discussed.

### 3.6 Features of larger services

Five features of larger services were present: some bedroom furniture and some living area furniture were non-domestic; few possessions were on open display downstairs; the kitchen area did not contain all domestic equipment and a large sign was seen outside.

#### Comment

The service offered Janet a good quality of physical environment, except that five features of larger services were noted.

#### Question 4

Does Janet have friends and how are these maintained?

##### 4.1 Carers

Janet liked her carers, but disliked the policy of the unit of discouraging friendships. It was unclear whether she viewed them as friends but she did not name them as friends.

##### 4.2 People within the service

She did not report them as her friends.

##### 4.3 Friends outside the service

Janet had a friend at the Day Centre and also a friend that she met at her People First group.

##### 4.4 Close friend

Her two friends outside the service were close friends. She had known her woman friend at the Day Centre for a long time. She had not seen her friend (a man) at the People First group for two months.

##### 4.5 Relationship difficulties

None.

##### 4.6 Opportunities to meet outside services (i.e., segregated services)

Janet did not make arrangements to meet friends outside services (except at the People First group - see above).

#### Comment

Janet had friends outside the residential service, but she did not make regular arrangements to meet them. Her social network involved only people with learning difficulties, despite her desire for "a friend without disabilities". Her friendships were maintained within segregated settings.

#### Question 5

What decisions did Janet participate in?

##### 5.1 Everyday Decisions

Janet participated in all everyday decisions investigated, i.e., ten.

##### 5.2 Infrequent Important Decisions

Janet participated in most infrequent, important decisions, e.g., to come and live in the service, other people coming to live in the service, decor. She was not involved in decisions concerning a person leaving the service, pets and whether to attend a Day Service.

##### 5.3 Meetings

The group met each week and discussed issues important to them. Decisions concerning, for example, the rota were discussed and views listened to within this meeting.

#### Comment

Janet participated in all everyday decisions and most infrequent, but important decisions. The regular meetings facilitated this process.

## Question 6

How much time did Janet spend in integrated settings and what were the processes involved in her presence in integrated settings?

### 6.1 Time out of the Residential Service

Janet spent just over 29 hours out of the residential service, during a three week period - excluding time spent in day services.

### 6.2 Time in Integrated Settings

During a three week period, Janet spent just over 25 hours in integrated settings: shopping, going to a pub, walking and an evening class.

## Influencing Factors

### 6.3 Desire to go to Integrated Settings

Janet liked going out, including going to integrated settings. She was very enthusiastic about shopping with her sister and going to a pub.

### 6.4 Large Group Trips, i.e., everyone in the service going out together.

Janet rarely went out with everyone else in her group and on one occasion actively avoided such a trip.

### 6.5 Active Links with the Community

Janet visited her sister every week and so had active links with the community.

### 6.6 Need for Help from Carers

Janet required no help from carers in public settings and often went out alone.

### 6.7 Aims of the Service

It remained unclear whether integration was an aim of the service. Janet was encouraged by carers to be present in integrated settings, but it was unclear whether other members of her group were encouraged to the same extent. Shopping was often completed by a member of the group, with or without a carer.

#### Comment

Janet spent long periods out of the service in integrated settings. The reasons accounting for this included her ability to go out alone and her active link with the community. In addition, her activities were encouraged by carers.

#### Postscript

Janet was visited about fifteen months after the last meeting with her had taken place. The purpose of the meeting was to give feedback to Janet and her carers about the major findings in Study II - see Appendix 33. She was planning to move to live in another bungalow within the unit, with a person who was currently living in her group. The aim was for them to live more independently. However, the other person was someone Janet had previously stated had irritated her. In addition, Janet had done some voluntary work but had disliked it and so left. The researcher was struck by the turnover of staff, i.e., only one staff had remained that was present during the research project.

## Subject 4 - Pseudonym Stephen

### 1. Background Details

Stephen was a 21 year old man. He had lived with his family and then moved to a large community service for people with learning difficulties. He had moved to his present placement, a small flat, 18 months before the project began. Stephen was reported to have sworn frequently in the past, but this had reduced recently. He attended a Day Centre one day a week, college three days a week and a community house one day a week.

### 2. Service

Stephen lived in a semi-detached house in a predominantly residential area - there was a factory close-by. The house was indistinguishable from other houses, although in slightly better condition. The house was divided into three self-contained flats. Stephen and two other men with learning difficulties lived in one flat; a person with a learning difficulty lived in another flat and a carer (from another service) lived in the third flat.

The service was managed by the Local Authority, Social Services department. The flat was staffed by two full-time carers - who were present for 2 hours early in the morning and between 4-6 hours in the evenings and for 10 hours at the weekends. One carer had a teaching qualification and the second carer was on an in-service training course. A flat meeting was attended every fortnight by an area manager, Social Services. The staff establishment for the flat was 3 full-time carers.

The two other men that Subject 4 lived with could continue a clear conversation with him. They were considerably older (i.e., early and mid forties) than Subject 4. He had known one of the men whilst living in a large community based service.

## Findings

### a) Views

#### 1. Service Users Interview Questionnaire

Stephen stated clearly that he disliked his present placement and did not want to stay. He would prefer to live in another flat with other people. He had mixed views of his carers, i.e., he liked one, but not the other. Stephen had friends, but would like more friends. He visited others and sometimes had visitors. He liked his day services. He liked his spare time activities: watching TV, visiting a close friend. He felt he had enough to do in his spare time. He did not usually feel happy.

Stephen gave correct answers to items 1-5 of the Emotional Labelling section. All his replies to items 6-9 of the Emotional Labelling section confirmed views expressed in the questionnaire and interviews. The majority of the 'check' questions agreed views expressed, but he was inconsistent in his replies to questions about being happy - initially he stated he was sad, but then that he was happy, but unhappy about living in his current service. A summary of the questionnaire is available in Appendix 25.

#### 2. Interviews

A summary of the interviews is available in Appendix 26.

##### Present Placement

- Stephen regularly reported an intense dislike of one of his carers, whilst liking a second carer.
- He expressed mixed views of his placement.



- He expressed mixed views of the men he lived with, stating that he got annoyed with one man.
- He liked the majority of activities, but disliked cooking in the evenings.

#### Past and Future Placements

- Stephen had liked his previous placement (in a larger community unit), but wanted to leave.
- He felt sad about leaving his family home.
- He would like to move to another flat, and during later discussions said he would like the flat to be near a close friend.

#### Friendships

- Stephen discussed his close friendship with a woman - they met most evenings and weekends.
- He named one other person as a friend.

#### Day Services

- Stephen disliked the Day Centre - he disliked the instructors and other people who attended.
- He liked college and attending a Community House.
- He wanted to leave his Day Service and get a job.

### Leisure Activities

- Stephen disliked staying in the flat in the evening.
- He visited his close friend in the evenings and weekends.
- No difficulties in integrated settings were reported. (This was confirmed by carers when completing the Questionnaires. Stephen had agreed to discussing this with carers).

### Visits and Visitors

- Stephen received visits from his social worker - he found these helpful.

### Other Issues

- Stephen gave positive reports of the meetings he attended, e.g., I.P. meetings, fortnightly meetings in the flat.

### Reliability

- Some of Stephen's reports were influenced by events immediately prior to the meetings, e.g., a disagreement with one carer. Otherwise, his reports were consistent.

### b) Client Activity

Table 18 below outlines the percentage of time recorded in each category of behaviour, both before and after meals, and within meals. The raw data are available in Appendix 27.

Table 18  
Summary of Observations: Stephen

	Before and After Meals	During Meals
Total time of observations:	8.73 hours	1.40 hours
Number of evenings data collected	8	8
Percentage time recorded in each category of behaviour:		
% Leisure	11.16	0.16
% Personal	6.35	59.70
% Domestic	38.18	18.97
% TV	7.33	1.05
% Interaction - visitors	7.80	0.48
% Interaction - carers	18.36	18.23
% Interaction - peers	4.35	9.63
% Neutral	20.29	5.78
% Challenging	0.07	-
% time recorded in engaged behaviours (i.e., 100-neutral - challenging)	79.64	94.22

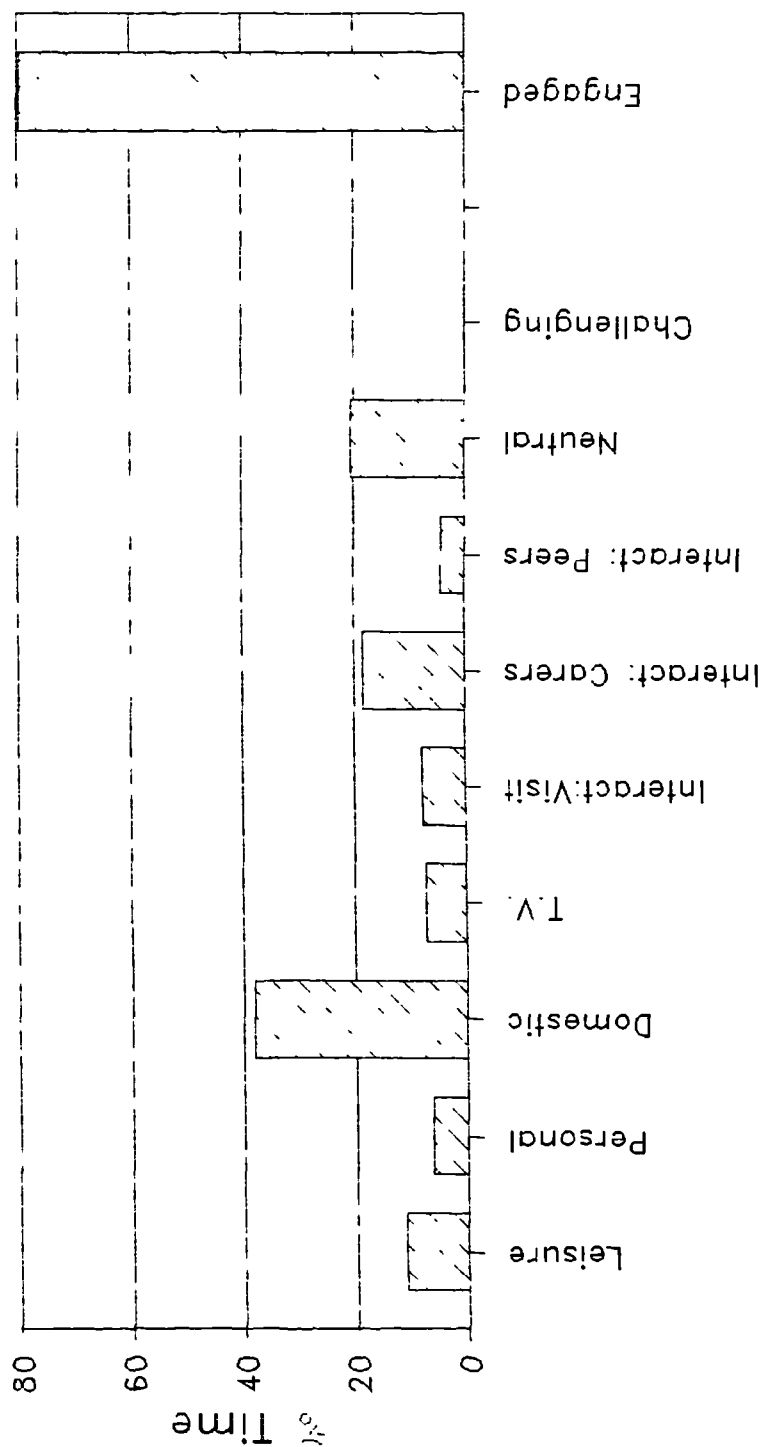
A summary of the observations, before and after meals, is shown in Figure 5.

The important features were:

- \* Stephen spent considerable time in varied domestic activities.
- \* He spent some time in leisure activities, e.g., listening to music, phoning his friend.
- \* Interaction with carers was considerably higher than with peers; interaction with peers increased during meals.
- \* Mealtimes were short in duration.
- \* Few challenging behaviours were observed.

Figure 5

# SUMMARY OF OBSERVATIONS BEFORE AND AFTER MEALS. STEPHEN



Total time of observations: 8.73 hours  
Number of evenings data collected: 8

Categories

c) Questionnaires

The table below summarises the questionnaire data. Full details are available in Appendix 28.

Table 19  
Summary of Questionnaires: Stephen

<u>Questionnaire</u>	<u>Possible Scores for Each Item</u>	<u>No. Items Receiving This Score</u>	<u>Examples of Item</u>
Physical Environment	Most valued factor present	13	Own bedroom; possessions on display; all domestic furniture and equipment; all locked rooms; no signs.
	Mid-point	2	Privacy available; room not available to meet friends.
	Least valued feature present	1	Pets not discussed.
Opportunities	High degree of opportunity	10	Cooking hot food; shopping x 2 p.w; pays for essentials; care of clothes; I.P.
	Mid-point	1	Range of spare time activities.
	Little opportunity	4	Preparing cold snacks; no more opportunities to shop/cook; meeting people.
Friendships	Greatest number of friendships	6	Has friends; meets friends; close relationship; knew people in service.
	Mid-point	1	Inviting friend to flat.
	Few friendships	1	Friends to discuss problems with.
Decision Making	Person makes decision	14	Bedroom; decoration in bedroom; who to do things with; TV; bedtime; going out; spending money; day-time activities.
	Carers and person	6	Living in service; other people coming to live/leaving the service; downstairs furniture; jobs; bath time.
	Carers take decision	0	-
	No choice available	1	Pets now allowed in tenancy agreement.
	Not scored	0	

The important features were found to be:

- \* The quality of the physical environment was very high, but privacy was limited by space available within the flat.
- \* Opportunities were present for cooking, shopping, care of clothes and some further opportunities could not be organised.
- \* Stephen had friends and a close friendship. He did not often invite a friend home, or have friends to discuss problems with.
- \* Stephen participated in nearly all decisions - everyday decisions and less frequent important decisions.

d) Diary Data

Appendices 29 and 30 contain summaries of the diary data. The main findings of Stephen's diary data are summarised in the table below:

Table 20

Summary of Diary Data - Stephen

Time	%	Hours
Out of residential service, weekdays (15)	36.9	40.0
Out of residential service, weekends, (6 days at weekends)	49.0	36.5
Time in integrated settings, weekdays (15)	29.5	32.0
Time in integrated settings, weekends, (6 days at weekends)	49.0	36.5

Categories Recorded Over 10% of Time

Weekdays:	Visits to friend	(15.5%)
	Domestic	(15.5%)
	Self-care	(13.5%)
	Public Transport, walking	(10.5%)
Weekends:	Visits to friend	(38.9%)
	TV	(12.4%)

The main features of the data were:

- \* Stephen spent considerable periods out of the residential setting, both at weekends and during the week.
- \* He spent long periods in integrated settings, particularly visiting his close friend.
- \* His main activities, apart from self-care were: visiting his close friend, domestic activities, using public transport and walking and watching TV.

Visiting his close friend, a woman with learning difficulties, was classified as integrated because she lived in her family home, which was not designed predominantly for use by people with disabilities, and her parents were usually present, i.e., other people without disabilities).

e) Additional Information

Financial: Stephen received a DHSS allowance of £39.10 p.w. His rent was paid directly by DHSS. £13 p.w. was set aside for food. £7 p.w. for electricity and £10 p.w. for savings. He received £9.10 p.w. pocket money.

Neighbours: The immediate neighbours were very friendly and talked over the garden fence. There were few other neighbours. No complaints had ever been made concerning the existence of the service.

This information is also available in Appendices 31 and 32.

A summary of all the findings is given in Table 21 - Individual Profile.

TABLE 21

INDIVIDUAL PROFILE - STEPHENAge: 21 years.Service: Flat with two men.

	<u>NEGATIVE OUTCOME</u>	<u>POSITIVE OUTCOME</u>
VIEWS	Disliked placement. Wanted to leave. Strong dislike of one carer.	Liked one carer.
ACTIVITIES WITHIN THE FLAT	Watched less TV than most subjects (7%).	Spent long periods in varied domestic activities (38%). High interaction carers (18%). Few challenging behaviours (0.07%).
PHYSICAL ENVIRONMENT	Sufficient privacy not available.	All domestic furniture and equipment. No locked doors. No signs outside.
OPPORTUNITIES	Few opportunities to meet new people. More opportunities to cook, shop could not be organised.	Cooking hot food. Shopping x 2 p.w. Care of clothes. Pays for essentials.
FRIENDSHIPS	No friend to discuss problems with.	Has friends. Meets friends regularly. Has a close friendship.
DECISION MAKING		Involved in majority of discussions - everyday and major decisions.
ACTIVITIES		Long periods out of the residential service. Long periods spent in integrated settings.



## Questions

Each of the questions will be discussed with reference to the standard set of criteria.

### Question 1

What are Stephen's views of his service and does he wish to remain? What features may be influencing his views?

### Outcome

#### 1.1 Did Stephen like his service?

Initially, Stephen stated that he disliked his residential service, but during later interviews he offered mixed views of living in the flat. He regularly reported an intense dislike of one carer, whilst liking another carer. He expressed mixed views of the men he lived with. He liked the majority of activities within the flat.

#### 1.2 Did Stephen want to remain in the service?

Stephen was clear that he would like to move to live in another flat. He wanted to live with other people and near to a close friend. His carers were aware of his desire to leave.

### Influencing factors

#### 1.3 Physical environment

The physical environment of Stephen's flat was to a high standard, e.g., decor and state of repair. In addition, there were no features of larger services present. Privacy was somewhat limited, as the flat was small. The physical environment was of a similar standard to his previous service, but there had been features of larger services.

#### 1.4 Bedroom

Stephen had his own bedroom which he liked. Although small, he had many possessions in his room.

1.5 Activities within the flat

Stephen liked the majority of activities within the flat, e.g., cooking, cleaning. He disliked cooking in the evenings.

1.6 Activities outside the flat

Stephen disliked staying in the flat in the evenings. He visited his close friend in the evenings and weekends. He enjoyed these activities.

1.7 Carers

Stephen repeatedly reported that he disliked one of his carers. Another man in the service stated he also disliked this carer. The reasons for the dislike were that the carer was always telling Stephen what to do next. The other carer was liked by Stephen.

1.8 Peers within the flat

Stephen expressed mixed views of the men he lived with. He was annoyed by one man who was sometimes upset and crying. He did not go out with either of the men.

1.9 Other friendships

Stephen had a close friendship with a young woman that he had met at his day service. They met most evenings and weekends. Sometimes there were clear difficulties between them, e.g., she would refuse to meet him for no clear reason. In addition, he had another friend at the Day Centre.

1.10 Involvement in decision making

Stephen was involved in the decision to live in the flat and with all everyday decisions.

1.11 Knowledge of other services

It was considered likely that Stephen had some knowledge of other living arrangements, for example, from his family home. In addition, carers had discussed Stephen leaving and where he could live.

### 1.12 Other features

Stephen gave positive reports of his I.P. meetings and flat meetings. He also discussed feeling sad about leaving his family home. He disliked the day centre and wanted to leave. However, he liked attending college and a community house.

#### Comments

Stephen's dislike of his service and wish to leave were considered to be greatly influenced by his dislike of one carer. In addition, he did not particularly like the people he lived with, and he had some knowledge of possible alternatives.

#### Question 2

What did Stephen do in the evenings in his residential service?  
What processes were influencing what he did?

#### Outcome

##### 2.1 Leisure activities

Stephen spent a moderate amount of time in leisure activities (11%), i.e., phoning his friend and listening to music. These activities were initiated by Stephen.

##### 2.2 Domestic activities

Stephen participated in a variety of domestic activities, e.g., cooking, washing-up, clothes washing, and these continued for long periods (38%).

##### 2.3 TV

Stephen spent a moderate amount of time watching TV (7%).

##### 2.4 Interaction

Interaction with carers was high outside and within mealtimes. Interaction with peers was moderate outside mealtimes.

## 2.5 Challenging behaviours

These occurred very infrequently.

## 2.6 Level of engagement

Stephen's overall engagement in activities was high, both outside and within meals.

## Influencing factors

### 2.7 Views and preferences

Stephen enjoyed the majority of activities within the flat, and was particularly pleased with some of the cleaning tasks. He disliked cooking in the evenings.

### 2.8 Allocated jobs/rota

A rota was used for most household tasks - cooking, washing-up, cleaning the main areas of the flat. Some tasks, i.e., personal washing and cleaning the bedroom, were arranged on a more flexible basis.

### 2.9 Activity of carers

Carers were consistent in their encouragement to the group to participate in domestic activities.

### 2.10 Group size

Interaction with carers was high, both within mealtimes and outside mealtimes. Interaction was particularly likely to occur during meal preparation, i.e., when Stephen was with a carer only. Interaction with peers increased considerably during mealtimes. This increase was accounted for by the fact that usually at least one of his peers would leave the flat immediately after the evening meal.

### 2.11 Length of mealtimes

Mealtimes were short, e.g., 10 minutes only. Carers and the group always ate together.

## 2.12 Aims of the service

It was clear to the researcher that one aim of the service was to encourage all of the group to participate in all domestic activities.

### Comments

Stephen's high participation in domestic activities was clearly an aim of the service and the rota helped to achieve this aim. High interaction with carers was influenced by the many occurrences of undertaking an activity with the guidance of a carers and the small group size.

## Question 3

What is the quality of the physical environment?

### 3.1 Quality of care

The flat offered a good quality of decor and was in good repair. A wide range of household appliances were available.

### 3.2 Privacy

The flat was rather small and so this influenced privacy. No room was available to meet friends and Stephen's bedroom was small.

### 3.3 Access

The flat offered good access to shops and public facilities.

### 3.4 Bedroom

Stephen had his own bedroom.

### 3.5 Pets

Pets had not been discussed, but were not allowed in the tenancy agreement.

### 3.6 Features of larger services

None.

#### Comment

The flat offered a high quality physical environment and no features of larger services were present. Privacy was limited.

#### Question 4

Does Stephen have friends and how are these maintained?

##### 4.1 Carers

Stephen viewed one carer as a friend and disliked the second carer. He reported that his tutor at College was a friend.

##### 4.2 People within the service

Stephen had mixed views of the men he lived with, but did name them as his friends. He had known the men before moving to live in the service.

##### 4.3 Friends outside the service

Stephen had two friends outside the service: one was his close friend.

##### 4.4 Close friend

Stephen had a close friend - a woman. They had known each other for several months and regularly met at her family home. They attended the same Day Centre together.

##### 4.5 Relationship difficulties

Stephen did express some difficulties with his close friend, e.g., sometimes she did not wish to meet him and she did not reciprocate his presents.

##### 4.6 Opportunities to meet outside services (i.e., segregated services)

Stephen regularly met a close friend outside the services. He sometimes invited her to the flat.

#### Comment

Stephen had friends. His social network included only people with learning difficulties. His friendships were initiated within services, but were maintained outside (and within services).

#### Question 5

What decisions did Stephen participate in?

##### 5.1 Everyday Decisions

Stephen participated in all the everyday decisions investigated (i.e., 10).

##### 5.2 Important Infrequent Decisions

Stephen participated in all important decisions, except whether to have a pet. Pets were not allowed in the tenancy agreement. Stephen had decided to live in the flat, who would live in the flat and the decor.

##### 5.3 Meetings

Meetings took place in the flat every fortnight. These meetings discussed issues before decisions were taken.

#### Comment

Stephen took place in all everyday decisions and important, infrequent decisions (with only one exception). The regular meetings were likely to facilitate this process.

#### Question 6

How much time did Stephen spend in integrated settings and what were the processes involved in his presence in integrated settings?

##### 6.1 Time out of the Residential Service

Stephen spent over 76 hours out of the residential service during a three week period - excluding time spent at day services.

## 6.2 Time in Integrated Settings

Stephen spent over 68 hours in integrated settings. These activities included visiting a friend, using public transport, shopping, walking and going to a pub.

## Influencing Factors

### 6.3 Desire to go to Integrated Settings

Stephen liked to go out to all his activities. No difficulties were reported in public settings.

### 6.4 Large Group Trips i.e., everyone in the service going out together

Stephen did not go out with the other men in his flat.

### 6.5 Active Links with the Community

Stephen visited his friend regularly, i.e., about five times a week. She lived with her family and could be viewed as an active link in the community. His friend was a young woman with learning difficulties.

### 6.6 Need for Help from Carers

Stephen needed no help from carers in public settings.

### 6.7 Aims of the Service

The service supported Stephen in all his visits to integrated settings. In addition, the two men he shared his flat with spent time in integrated settings. Shopping was always completed by at least one member of Stephen's group and a carer.

## Comment

Stephen spent long periods in integrated settings. The reasons accounting for this included his link with the community (his friend) and his ability to go out without help. In addition, carers clearly supported his presence in public settings.



## Postscript

Stephen was visited about fifteen months after the last meeting had taken place. The purpose of the meeting was to give feedback to Stephen and his carers about the major findings of Study II - see Appendix 33. Stephen had a new close friend; his previous friend's family had moved out of the area. He had met his new friend at a work centre (sheltered work experience). He had left the Day Centre and now attended the work centre. The member of staff he had so disliked had left. No clear plans existed for him to leave, but he still wanted this, although he was now less emphatic.

Subject 5 - Pseudonym: Keith

## 1. Background Details

Keith was a 24 year old man. He had lived with foster parents for most of his childhood. Five years before the research project began, he moved to live in his current placement. He had attended three different one year day placement training schemes. He left one scheme after threatening someone with a knife and then, following a shoplifting offence, he started to attend a day placement in a hospital for people with learning difficulties. At the time of the project, Keith continued to attend the hospital day placement for four days a week and college one day a week.

## 2. Service

Keith lived in a large Victorian terrace house in a residential area of a large city. He lived there with three people with learning difficulties. The area was described as "rough" by his carers as cars were regularly broken into. The house was decorated and furnished to a high standard. A variety of animals - 4 cats and 3 dogs - lived in the house.

The house was owned and managed by two carers. In addition, part-time workers were asked to work varied hours in the week. The staffing establishment totalled a 110 hour week and in addition the owners slept in the house overnight. One of the owners had a Special Needs Teaching Certificate and the second owner was studying for an Advance Certificate in Psychology and Behavioural Studies.

The three other people with learning difficulties that Keith lived with were able to carry on a good conversation with him. The two women living in the house were considerably older than Keith.

### 3. Findings

#### a) Views

##### (1) Service Users Interview

Keith reported that he liked his present placement and wanted to stay (in the short-term). However, he would like to leave eventually and live in a similar house with friends.

Keith liked his carers. He did not have many friends and would like more friends. He had no visitors and sometimes visited others. He liked his Day Services. He stated that in the future he would like to work in the market. He felt that he had enough to do in his spare time and enjoyed going to night classes. He usually felt happy.

Keith gave correct answers to items 1-5 of the Emotional Labelling section. All the answers to items 6-9 of the Emotional Labelling section confirmed views expressed in the questionnaire and interviews. All the 'check' questions agreed views stated in the interview. A summary of the questionnaire is available in Appendix 25.

##### (2) Present Placement

A summary of the interviews is available in Appendix 26.

- Keith liked many features of his placement, including household activities, particularly meeting friends and relatives of his carers.
- He viewed taking his own decisions, e.g., when to go out, as very important.
- He gave mixed views of the people he lived with - one woman annoyed him.

- He gave very positive reports of his carers, but viewed them as "in charge".
- He agreed with the policy that the carers had a separate sitting room and ate separately.

#### Past and Future Placements

- Keith had liked living with foster parents, but disliked childrens' homes.
- He had not discussed his views of the future with his carers, i.e., to live in a house with two friends.

#### Friendships

- Keith discussed two friends he saw currently and one person he had known in the past.

#### Day Services

- Keith liked his hospital Day Service and college course, but would now like to leave and get a job.

#### Leisure Activities

- Keith spent all of his time out of the house in integrated settings - which he enjoyed, e.g., visiting the market.
- He had been teased in public, but was happy to return to the same situation. (This was confirmed by carers when completing the Questionnaires. It had been agreed with Keith to discuss this topic with carers).

#### Visits and Visitors

- Keith would like to have visitors.

## Other Issues

- Keith liked being out with his carer, e.g., shopping, and would like to do this more often.
- He would like to travel more.

## Reliability

Keith's views were consistent during all the interviews.

### b) Client Activity: Observational Measures

Table 22 below outlines the percentage of time recorded in each category of behaviour, both before and after meals and within meals. The raw data are available in Appendix 27.

Table 22

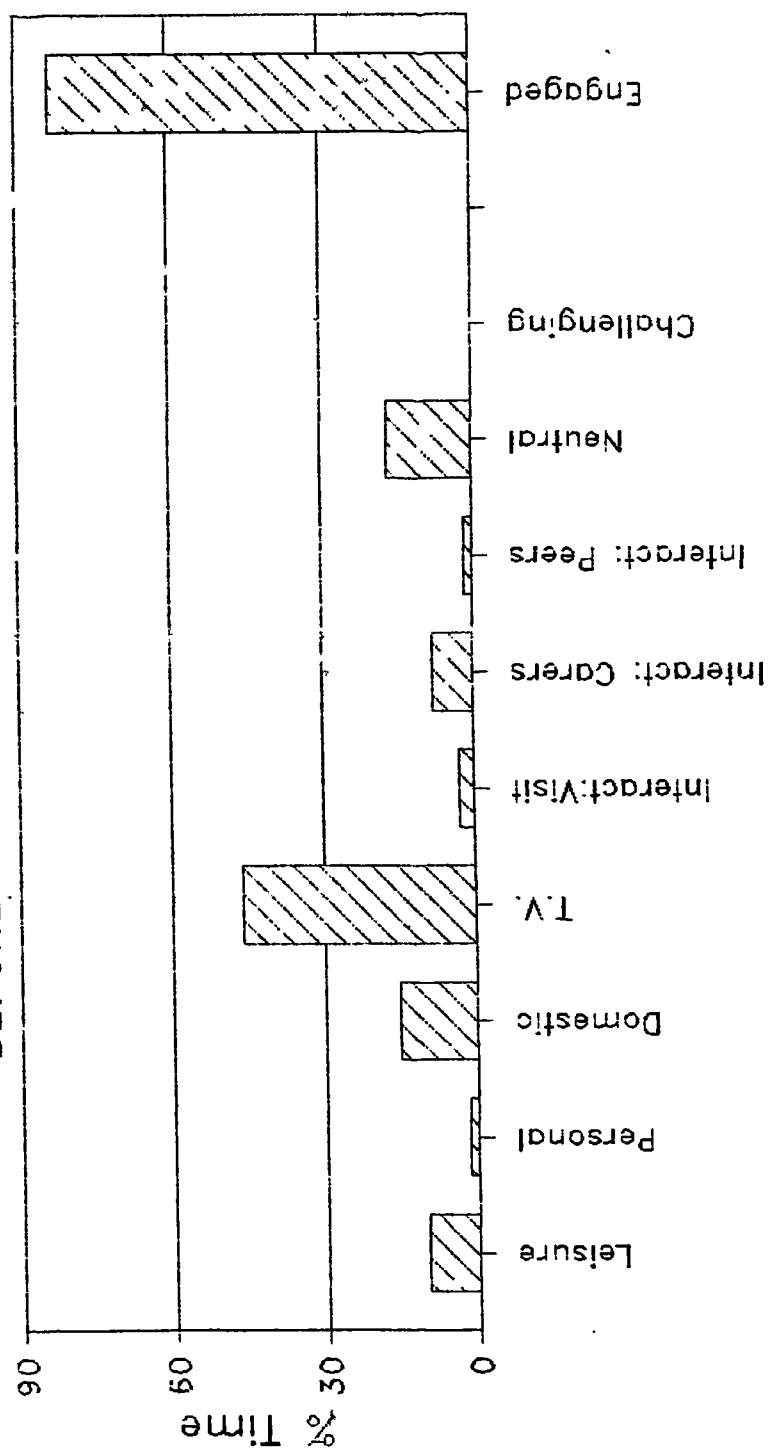
#### Summary of Observations - Keith

	Before & After Meals	Within Meals
Total time of observations:	9.21 hours	1.78 hours
Number of evenings data collected:	10	9
Percentage time recorded in each category of behaviour:		
% Leisure	9.88	-
% Personal	1.42	69.07
% Domestic	14.97	3.45
% TV	46.03	-
% Interaction with visitors	2.88	3.35
% Interaction with carers	7.98	14.60
% Interaction with peers	1.61	2.45
% Neutral	16.86	15.71
% Challenging	-	-
% time recorded in engaged behaviour (i.e., 100% - neutral - challenging behaviours)	83.14	84.29

A summary of the observations before and after meals is shown in Figure 6.

FIGURE 6

# SUMMARY OF OBSERVATIONS: BEFORE AND AFTER MEALS: KEITH



Total time of observations: 9.21 hours  
Number of evenings data collected: 10

Categories

Important features of this data were:

- \* Keith spent long periods watching TV.
- \* He spent relatively little time doing domestic activities when compared with some other subjects.
- \* Interaction with carers was considerably higher than interaction with peers.
- \* Interaction with carers increased at mealtimes.
- \* Mealtimes were relatively short.
- \* Keith spent some time participating in leisure activities.

c) Questionnaires

The table below summarises the questionnaire data. Full details are available in Appendix 28.

Table 23  
Summary of Questionnaires - Keith

<u>Questionnaire</u>	<u>Possible Score For Each Item</u>	<u>No. Items Receiving This Score</u>	<u>Examples of Items</u>
Physical Environment	Most valued feature present	10	All furniture and equipment domestic, high standard of decor, personal possessions on display, no signs.
	Mid-point	6	Shared bedroom, privacy in bedroom, locked room, space to be alone/ meet people; pets not discussed.
	Least valued feature	0	-
Opportunities	High degree	12	Cooks hot snack x 2 p.w., shopping x 2 p.w., could care for clothes, goes out every week.
	Mid-point Little opportunity	- 3	- Uses pocket money only; does not wash own clothes; no clear aims.
Friendships	Greatest number of friendships	5	Has 2 friends; meets friends; close friend; made new friends.
	Mid-point	2	Does not invite friend home; no friend to discuss problems with.
	Few friendships	1	Did not know people in the service.
Decision Making	Person makes decision	10	Who to do things with; TV; special friend; bath; bed; clothes; spare time activities; visitors.
	Carer and person	5	Others living in service; jobs in house; day service; smoking/ drinking.
	Carers take decision	3	Decoration; food; pets.
	No choice available	3	To live in service; bedroom; decoration in bedroom.
	Not scored	-	-

Important features were found to be:

- \* The majority of features of the physical environment were of high quality, but Keith shared a bedroom and little privacy was available. One room was locked.
- \* Keith was reported to have many opportunities to cook, shop and participate in leisure activities. He only used pocket money and did not wash his own clothes.
- \* Keith had some friends and met them on a regular basis. He did not invite friends home, nor did he have a friend to discuss problems with.
- \* Keith participated in many everyday decisions and some important, less frequent decisions, e.g., who lived in the service. However, he did not decide to come to live in the service, nor the decoration and food.



d) Diary Data

Appendices 29 and 30 contain summaries of the diary data. The main findings of Keith's diary data are summarised in the table below:

Table 24

Summary of Diary Data - Keith

Time	%	Hours
Out of residential service, weekdays (15)	42.7	56.1
Out of residential service, weekends (6 days at weekends)	37.0	32.5
Time in integrated settings, weekdays (15)	42.7	56.1
Time in integrated settings, weekends (6 days at weekends)	37.0	32.5

Categories Recorded Over 10% of Time

Weekdays:	Walking, public transport	28.7%
	Self-care	24.6%
	TV	13.3%
Weekends:	TV	19.7%
	Sitting	18.2%
	Self-care	16.5%
	Shopping	12.5%

The main features of the data were:

- \* Keith spent considerable periods out of his residential service.
- \* Keith spent all his time in integrated settings, when out of the service.
- \* His main activities in integrated settings included use of transport, shopping, evening class, voluntary work and going to Church.

e) Additional Information

Financial: Keith's service received DHSS allowance of £160 p.w.

Neighbours: When the group initially moved in, neighbours did not state any views. Then the Council displayed a notice concerning a change of use of the house and neighbours asked questions, but no clear complaints were made.

This information is also available in Appendices 31 and 32.

A summary of all the findings is given in Table 21 - Individual Profile.

TABLE 25

INDIVIDUAL PROFILE - KEITH

Age: 24 years.

Service: Domestic house with three other people.

	<u>NEGATIVE OUTCOME</u>	<u>POSITIVE OUTCOME</u>
VIEWS	Would like to live in a different house with his friends. Mixed views of peers.	Liked placement. Liked the activities and the carers. Liked taking own decisions.
ACTIVITIES WITHIN THE HOUSE	Relative little time in domestic activities (15%). Low peer interaction (2%).	Long periods watching TV (46%). High interaction with carers within meals (15%). Leisure (10%).
PHYSICAL ENVIRONMENT	Shared bedroom - influenced privacy. Locked room.	High quality decor. All domestic equipment, furniture.
OPPORTUNITIES	Did not wash own clothes. Used pocket money only.	Cooking twice a week. Shopping twice a week.
FRIENDSHIPS	Did not invite friends home. No friend to discuss problems with.	Had friends and met friends. Close friend.
DECISION MAKING	Did not choose any decoration, nor bedroom, nor pets.	Participated in most everyday decisions and important, less frequent decisions.
ACTIVITIES		Spent long periods out of the service (over 88 hours in 3 weeks). All this time was in integrated activities.

## Questions

Each of the questions will be discussed with reference to a standard set of criteria.

### Question 1

What are Keith's views of his service and does he wish to remain? What features may be influencing his views?

### Outcome

#### 1.1 Did Keith like his service?

Keith reported that he liked his present placement. He liked many features of his placement including household activities and particularly meeting friends and relatives of his carers. He gave very positive views of his carers, but mixed reports of the people he lived with.

#### 1.2 Did Keith want to remain in the service?

Keith was clear that he would like to leave in the future and live with two men that he knew from his day service. He would like to live in a similar house. His carers were not aware of his hope to leave eventually.

### Influencing factors

#### 1.3 Physical environment

The physical environment was of a high standard, e.g., decor and state of repair. One room was locked and was an office. Carers and service users had separate lounges and sometimes ate separately. Keith agreed with this policy. It is likely that the quality of the physical environment was not substantially different from his previous placement with foster parents.

#### 1.4 Bedroom

Keith shared his bedroom with another man. He did not describe this man as a friend. Keith had limited privacy, e.g., the other man spent long periods in the bedroom and there was no alternative private area/room for Keith to meet friends, visitors.

#### 1.5 Activities within the house

Keith reported that he liked all the household activities, e.g., feeding the pets. He was particularly proud of organising and clearing the rubbish.

#### 1.6 Activities outside the house

Keith liked all his activities outside the house, e.g., the voluntary work at the market, evening classes. He particularly liked being out shopping with his carer and he stated that he would like to do this more often. Also, he would like to travel more.

#### 1.7 Carers

Keith gave very positive reports of his carers. He viewed them as "in charge", but he did not object to this situation.

#### 1.8 Peers within the house

Keith gave mixed views of the people he lived with. One he liked; a second woman annoyed him by talking for long periods and worrying about her health. The other man in the house sometimes annoyed him by defecating in the bed.

#### 1.9 Other friendships

Keith discussed two friends he had, that he currently met at the day service and hoped to live with eventually. He had another friend in the past but they had lost contact. In addition, he knew many people, e.g. at the market.

#### 1.10 Involvement in decision making

Keith had not been involved in the decision to move to the house - his mother had decided this. Keith participated in many everyday decisions, e.g., his spare time activities and he valued his participation in decision making. He did not participate in some important decisions, e.g., his bedroom, choice of food and decoration.

#### 1.11 Knowledge of other services

It was considered likely that Keith had knowledge of other services. He had discussed with other people where they lived. Also, Keith had many acquaintances and knew where they lived.

#### 1.12 Other features

Keith liked his day service at the hospital, although he wanted to leave and get a job. He did not discuss his lack of contact with his mother and this was respected by the researcher, i.e., questions were not asked on this topic.

#### Comments

Keith liked his placement and reported many positive features that he appreciated, e.g., his carers. However, he clearly wanted to leave in the future. His desire to leave was considered to be influenced by his preference to live with his friends and a knowledge of possible alternatives.

#### Question 2

What did Keith do in the evenings in his residential service?  
What processes were influencing what he did?

#### Outcome

#### 2.1 Leisure activities

Keith spent a moderate amount of time participating in leisure activities (10%), e.g., writing notes.

## 2.2 Domestic

Keith spent a moderate amount of time participating in domestic activities (15%) when compared with other subjects. His household activities included organising the dustbins and the rubbish and feeding the pets. He enjoyed these activities.

## 2.3 TV

Keith spent long periods watching TV (46%).

## 2.4 Interaction

Interaction with carers was moderate and far greater than with peers. Peer interaction was moderate (when compared with other subjects). Both carer and peer interaction increased at mealtimes.

## 2.5 Challenging behaviours

These did not occur.

## 2.6 Level of engagement

Keith's engagement in activities was high, both outside meals and within meals.

## Influencing factors

### 2.7 Views and Preferences

Keith liked all the household activities and was particularly proud of organising the rubbish.

### 2.8 Allocated jobs/rota

Keith was allocated specified jobs, i.e., feeding the pets and organising the rubbish. He sometimes offered to wash-up.

### 2.9 Activity of carers

Carers prepared all main meals, did all clothes care and some washing-up.

#### 2.10 Group size

Interaction with both carers and peers increased during mealtimes. This was accounted for by the finding that when watching TV, carers were rarely present and often only one of his peer group.

#### 2.11 Length of mealtimes

Mealtimes were short, e.g., 14 minutes. Carers were present, but did not eat and had a cup of coffee with the group.

#### 2.12 Aims of the service

The aims were unclear, e.g., other members of the group had no allocated household activities.

#### Comments

Keith spent long periods watching TV and this was initiated by himself. He participated in some domestic activities and these were predominantly tasks allocated to him. Interaction clearly increased when all the group (four people) and carers were together, i.e., mealtimes.

#### Question 3

What is the quality of the physical environment?

##### 3.1 Decor

The quality of the decor and the standard of repair of the house was to a very high standard. A wide range of household appliances were available.

##### 3.2 Privacy

The house offered reasonable privacy, but there was no area for Keith to be alone or to meet friends. Also, he shared a bedroom.



### 3.3. Access

The house gave Keith good access to all local shops and services.

### 3.4 Bedroom

Keith shared a bedroom.

### 3.5 Pets

Pets were present, but had not been discussed. Keith did not object to their presence.

### 3.6 Features of larger services

One feature of larger services was present: there was an office, which was kept locked.

### Comment

The house offered a high standard of physical environment. Privacy was somewhat limited, particularly as Keith shared a bedroom. Only one feature of larger services was found to be present.

## Question 4

Does Keith have friends and how are these maintained?

### 4.1 Carers

Keith gave very positive reports of his carers, but viewed them as "in charge", and not as friends.

### 4.2 People within the service

Keith did not view them as his friends. He did not know them before moving to live in the service.

### 4.3 Friends outside the service

Keith had two friends and he met them at his day service.

### 4.4 Close friend

Keith had a close friend, but they met infrequently, e.g., once/twice a year.

#### 4.5 Relationship difficulties

None reported.

#### 4.6 Opportunities to meet outside services (i.e., segregated services)

Keith met his friends out of the service (but not those from his Day Service). In addition, he had a range of acquaintances that he met at his voluntary work.

#### Comment

Keith had a small number of friends. His social network included people with learning difficulties, but also people without disabilities. He met people within services, but also in other settings.

#### Question 5

What decisions did Keith participate in?

##### 5.1 Everyday Decisions

Keith participated in all everyday decisions, except that he did not choose what to eat.

##### 5.2 Infrequent, Important Decisions

Keith participated in some important decisions - six out of eleven investigated. He did not decide to live in the service, nor any decor in the house.

##### 5.3 Meetings

No regular, pre-arranged meetings took place in the house.

#### Comment

Keith participated in all except one everyday decisions and some less frequent, important decisions.

## Question 6

How much time did Keith spend in integrated settings and what were the processes involved in his presence in integrated settings?

### 6.1 Time spent out of the Residential Service

Keith spent over 88 hours in three weeks out of his residential service - excluding time spent in his day services.

### 6.2 Time in Integrated Settings

During a three week period, Keith spent over 88 hours in integrated settings, i.e., all his time out of the service was in integrated settings. His activities included various forms of voluntary work, using public transport, walking, shopping, attending an evening class and going to Church.

## Influencing Factors

### 6.3 Desire go to Integrated Settings

Keith enjoyed all his activities in integrated settings. His single experience of being teased had not influenced his views.

### 6.4 Large Group Trips, i.e., everyone in the service going out together

Keith went out alone. In one case only was he accompanied to Church by another woman in the service.

### 6.5 Active Links with the Community

Keith had clear active links with the community in the form of his voluntary work, e.g., he knew people at the market and he was offered the work to do.

### 6.6 Need for help from Carers

Keith required no help from carers in public places. The majority of the time he went out alone, unaccompanied.

## 6.7 Aims of the Service

It remained unclear whether integration was an aim of the service. Carers supported Keith in his presence in integrated settings, but there was less evidence of the other people in his house spending considerable periods in integrated settings. Carers usually completed the shopping without being accompanied by a member of the group.

### Comment

Keith spent all his time in integrated settings when out of the service. This was accounted for by Keith's ability to go out alone, his links in the community, i.e., his voluntary work. It remained somewhat unclear whether integration was an aim of the service. In addition, Keith clearly enjoyed all his activities in public settings.

### Postscript

Keith was visited about eight months after the last meeting had taken place. The purpose of the meeting was to give feedback to Keith and his carers about the major findings of Study II - see Appendix 33. He had recently changed his day services - he had left his hospital day placement and was attending a sheltered work placement where the main activity was gardening. He had enjoyed a good summer holiday. Keith lived in the same house - one man had left and no-one new had come to live in the service.

1. Background Details

Andrew was a 24 year old man. He lived at home until age 13 years when he went to live at Dr. Barnardo's. At age 18 years, he moved to his current placement. He had lived with his twin brother until he left Barnardo's. His twin brother was considered unsuitable for the placement - on visits he banged his head against the wall and attacked staff. Andrew's father visited him every alternate weekend. He attended a Day Centre four days a week and college one day a week.

2. Service

Andrew lived in a hostel in a market town with eleven other people. The hostel was a large building and clearly not a domestic house when viewed from the entrance at the rear of the building. The front of the building was not as large and did blend with a house next door. A notice on the front gate stated "Forthcoming events ...". The hostel was close to a railway line, the Day Centre, offices and houses. The hostel was reasonably well decorated.

The hostel was owned and managed by Social Services. It was staffed by 4 co-ordinators, 2 care staff, 2 part-time cooks (30 hours per week), 3 part-time domestics (40 hours per week) and a part-time clerk (20 hours per week). One co-ordinator had a teaching qualification, one had a degree, and one was a nurse, trained to work with people with learning difficulties.

The eleven other people with learning difficulties living in the hostel were of widely varied ages and degree of learning difficulty. Three people in the hostel could continue a good conversation with Andrew.

### 3. Findings

#### a) Views

##### (1) Service User's Interview

Andrew reported that he liked his present placement and wanted to remain in the short-term). He would like to leave in the future if possible and live in a house "like my mum's". He gave mixed reports of his friends, i.e., who they were, but was clear that he would like more friends.

He reported that he had visitors and that he visited others. In his spare time he played music and he felt that he had enough to do. He liked his Day Service, but reported that he "did nothing there". He was usually happy.

Andrew gave correct answers to items 1-5 of the Emotional Labelling section. The majority of his replies to items 6-9 confirmed replies to questionnaire and information given during interviews. His reports on the people he lived with were inconsistent, i.e., his reply to item 7 of the Emotional Labelling was that he was unhappy about the people that he lived with. All his responses to the 'check' questions in the questionnaire confirmed views stated. A summary of the questionnaire is available in Appendix 25.

##### (2) Interviews

A summary of the interviews is available in Appendix 26.

##### Present Placement

- Andrew liked his placement - the town and the activities in the hostel.
- He liked the carers and the people he lived with.

- He preferred to be alone, particularly if listening to music.

#### Past and Future Placements

- Andrew had liked his previous placement at Dr. Barnardo's.
- He gave mixed reports of the future, stating he would like to live in a flat/house - but later said he did not want to discuss the future.

#### Friendships

- Andrew named carers and one person at the hostel as his friends.
- He named a volunteer and Day Centre instructor as friends.

#### Day Services

- Andrew stated that he "did nothing" at the Day Centre- but he named activities.
- He clearly preferred college to the Day Centre.

#### Leisure Activities

- Andrew enjoyed most of his activities - particularly shopping.
- He disliked the noise at one club.
- He reported no difficulties in integrated settings. (This was confirmed by carers when completing the Questionnaires, by prior agreement with Andrew).

### Visits

- Andrew met his father on alternate weekends.
- He stated he would like to visit his twin brother.

### Other Issues

- Andrew was interested in clothes and wanted a new coat for Christmas.

### Reliability

- Andrew was consistent on most topics, with the exception of future placements.

### b) Client Activity: Observational Measures

Table 26 below outlines the percentage of time recorded in each category of behaviour, both before and after meals, and within meals. The raw data are available in Appendix 27.

Table 26  
Summary of observations - Andrew

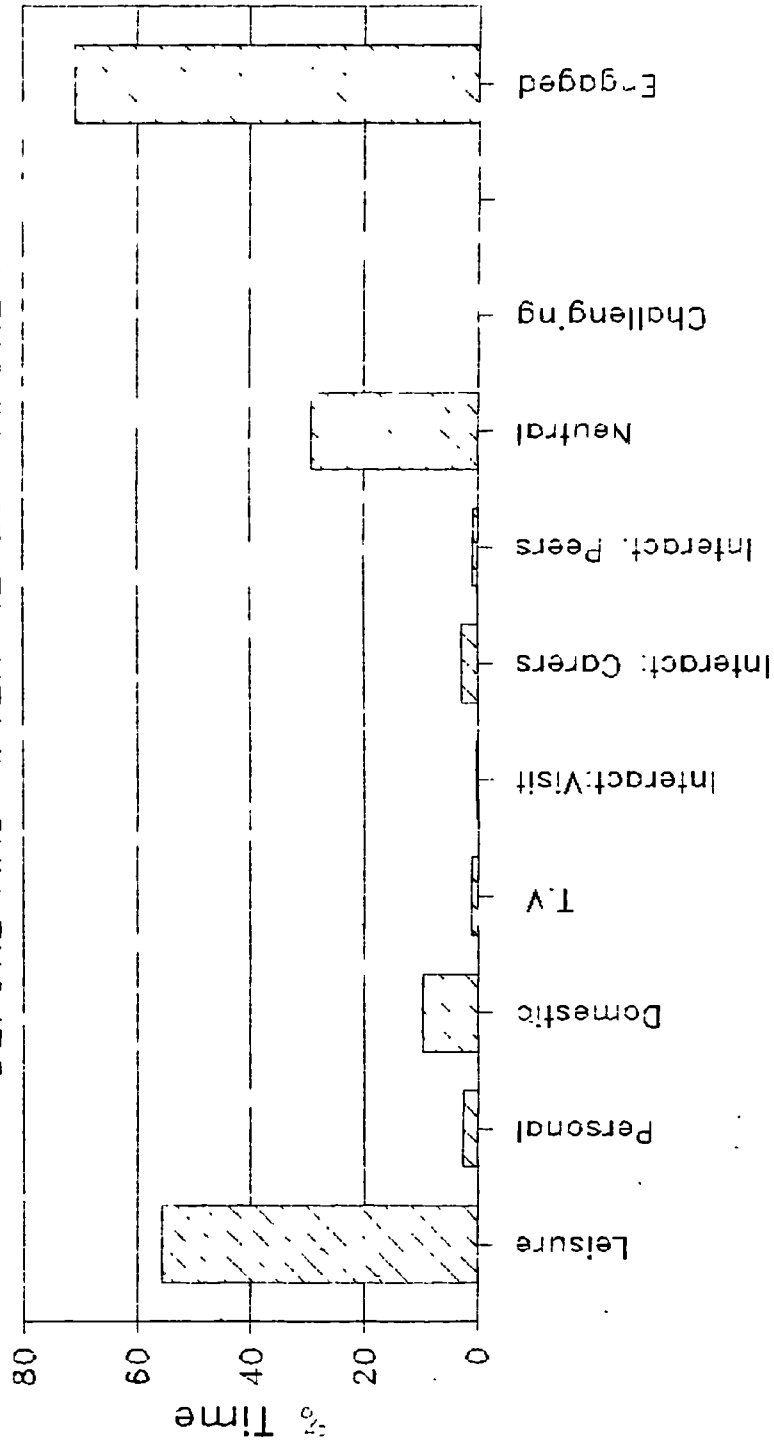
	<u>Before and</u> <u>After Meals</u>	<u>Within</u> <u>Meals</u>
Total time of observations:	6.21 hours	5.38 hours
Number of evenings data collected:	8	7
Percentage time recorded in each category of behaviour:		
% Leisure	55.67	0.22
% Personal	2.61	44.64
% Domestic	9.64	5.01
% TV	1.09	-
% Interaction with visitors	0.18	0.23
% Interaction with carers	2.74	2.52
% Interaction with peers	0.73	0.34
% Neutral	29.07	46.51
% Challenging	-	-
% time recorded in engaged behaviour (i.e., 100% - neutral - challenging behaviours)	70.93	53.49

A summary of the observations, before and after meals, is shown in Figure 7.



FIGURE 7

# SUMMARY OF OBSERVATIONS. BEFORE AND AFTER MEALS. ANDREW



Total time of observations: 6.21 hours  
Number of evenings data collected: 8

Categories

Important features of the data were:

- \* Paul spent long periods in leisure activities (55.7%). In practice, the majority of this time was spent in his room alone listening and dancing and singing to tapes - always the same two or three tapes. Some of the leisure activities involved group activities - e.g., preparing Halloween decorations.
- \* Little time was spent in domestic activities (9.6%) or watching TV (1.1%).
- \* Interaction with carers was low (2.7%), but interaction with peers was less (0.7%).
- \* Mealtimes were relatively long.
- \* Time spent doing nothing was quite high (29.1%).

c) Questionnaires

The table below summarises the questionnaire data. Full details are available in Appendix 28.

Table 27  
Summary of Questionnaires - Andrew

<u>Questionnaire</u>	<u>Possible Scores for Each Item</u>	<u>No. Items Receiving This Score</u>	<u>Examples of Item</u>
Physical Environment	Most valued feature	8	Items displayed in bedroom, well decorated, good repair, no locked room, close to shops.
	Mid-point	6	Shares bedroom, limited privacy, some furniture, institutionalised, personal items not displayed, sign outside.
	Least valued feature present	2	Institutional bedroom furniture and kitchen equipment.
Opportunity	High degree of opportunities	8	Cooking cold snacks, shopping, clothes, leisure activities, meeting others.
	Mid-point	5	Could not organise more cooking, care of clothes; washes some clothes, some aims set.
	Little opportunity	2	Cooking hot meals; uses pocket money only.
Friendships	Greatest number of friendships	6	Had friends, met friends, close friend.
	Mid-point	0	
	Few friendships	2	Did not know people in service; no friend to discuss problems with.
Decision Making	Person makes decisions	7	TV, bath, friends, bedtime, how to spend time, spending pocket money, pets.
	Carers and person	6	Bedroom, decoration, going out, clothes, smoking/drinking.
	Carers take decision	5	To live in service, people leaving, jobs, food, visitors.
	No choice available	3	New person to live in house, furniture, day services.
	Not scored	-	

Important features were found to be:

- \* Many features of the physical environment were of a high quality, e.g., well decorated; several institutional features were present, e.g., institutional equipment.
- \* Opportunities were available, for example, shopping and leisure activities. Few opportunities were available to cook hot food and use money for essentials.
- \* Had several friends and met them regularly; no friend to discuss problems with.
- \* Participates in many everyday decisions, but not all and few important, less frequent decisions.

d) Diary Data

Appendices 29 and 30 contain summaries of the diary data. The main findings of Andrew's diary data are summarised in the table below:

Table 28

Summary of Diary Data - Andrew

Time	%	Hours
Out of residential service, weekdays (15)	12	14.6
Out of residential service, weekends (6 days at weekends)	18	14.6
Time in integrated settings, weekdays (15)	0.9	1.0
Time in integrated settings, weekends (6 days at weekends)	2.8	2.3

Categories Recorded Over 10% of Time

Weekdays:	Self-care	31.2%
	Leisure (within home)	19.2%
	TV	12.4%
	Clubs, segregated	10.6%
Weekends:	Self-care	29.3%
	Leisure (within home)	24.8%
	Travel - minibus	15.2%

The main features of the data were:

- \* Andrew spent time out of the residential service both at weekends and during the week.
- \* Andrew spent little time in integrated settings, i.e, just over three hours in three weeks. Activities in integrated settings included walking, shopping and going to the pub.
- \* His main activities, apart from self-care were leisure within the home, watching TV, attending segregated clubs and travelling in the minibus.

e) Additional Information

Financial: The costs were unknown and paid by the Local Authority. He received pocket money of £11.50 p.w.

Neighbours: There was little contact with immediate neighbours. Local people were reported to help, e.g., mending a bicycle cheaply. No complaints had been received, but a group from the hostel had been asked not to visit one local pub.

This information is available in Appendices 31 and 32.

A summary of all the findings is given in Table 29 - Individual Profile.

TABLE 29  
INDIVIDUAL PROFILE - ANDREW

Age: 24 years

Service: Local Authority Hostel; total 12 people.

	<u>NEGATIVE OUTCOME</u>	<u>POSITIVE OUTCOME</u>
VIEWS	-	Liked placement. May want to remain in future (?uncertain). Liked carers and other people.
ACTIVITIES WITHIN THE HOSTEL	Little time in domestic activities (9.6%) or watching TV (1.1%). Little interaction with carers (2.7%) or peers (0.7%).	Long periods in leisure activities (44.7%).
PHYSICAL ENVIRONMENT	Institutional bedroom furniture and kitchen equipment. Limited privacy.	Well decorated and good state of repair. No locked room.
OPPORTUNITIES	Cooking hot meals. Uses pocket money only. Could not organise more cooking nor care or clothes.	Cooking cold snacks. Shopping Leisure activities.
FRIENDSHIPS	Did not know others in service. No friend to discuss problems with.	Has friends, including close friend. Meets friends.
DECISION MAKING	Participates in few major decisions, e.g., who to live with, day services.	Participates in many everyday decisions, e.g., TV, bath, bedtime.
ACTIVITIES	Very little time in integrated settings (i.e., over 3 hours in 3 weeks).	Spent long periods out of the residential service (i.e., over 25 hours in 3 weeks).

## Questions

Each of the questions will be discussed with reference to a standard set of criteria.

### Question 1

What are Andrew's views of his service and does he wish to remain? What features may be influencing his views?

### Outcome

#### 1.1 Did Andrew like his residential service?

Andrew liked his residential service. He liked the town he lived in and all the activities in the hostel. He liked his carers and the people he lived with.

#### 1.2 Did Andrew want to remain in the residential service?

Andrew gave mixed reports of where he would like to live in the future. In the short-term, he wanted to remain at the hostel. Initially, he stated that in the long-term future he would like to live in a flat/house "like my mum's". In later interviews, he stated that he did not want to discuss this topic and his wishes were complied with. The interviewer considered that it was probable that discussing the future caused Andrew some anxiety and that he was uncertain about his wishes for the future.

### Influencing Factors

#### 1.3 Physical Environment

The physical environment was of a reasonable standard, e.g., decor, good state of repair. Some features of larger services were present, e.g., institutional bedroom furniture and kitchen equipment, a sign outside. It is considered that the quality of the physical environment varied little from his previous placement in Dr. Barnardo's.

#### 1.4 Bedroom

Andrew shared his bedroom with another young man. Andrew did report that this man was a friend. The bedroom was reasonably large. Andrew had somewhat limited access to privacy, i.e., he had no private area to meet friends and relatives. If he wished to be alone in his bedroom, he was likely to be interrupted.

#### 1.5 Activities within the Hostel

Andrew enjoyed all the activities within the hostel, e.g., listening to music, washing-up. He preferred to listen to music whilst alone in his bedroom.

#### 1.6 Activities Outside the Hostel

Andrew enjoyed most of the activities outside the hostel, particularly shopping. He disliked the noise at one club.

#### 1.7 Carers

Andrew liked his carers and viewed them as his friends.

#### 1.8 Peers within the Hostel

Andrew stated that he liked all the people that he lived with and he viewed them as his friends.

#### 1.9 Other Friendships

Andrew named a volunteer and a Day Centre instructor as his friends.

#### 1.10 Involvement in Decision Making

Andrew had not been involved in the decision to come to live in the hostel - carers had decided. Andrew was involved in many everyday decisions, but not all, e.g., jobs to do, food.



#### 1.11 Knowledge of other Services

The extent of Andrew's knowledge of other services was difficult to ascertain. He knew that his twin brother lived in a house, but he did not know where this was. He did not discuss or describe where any other people lived. It was felt to be unlikely that he had a good knowledge of other services.

#### 1.12 Other Features

Visits from his father were very important. He stated that he would like to meet his twin brother. Andrew reported that he did little at the Day Centre and preferred college.

#### Comments

Andrew clearly liked his placement. He gave positive responses to most topic areas and had no major complaints. His views concerning the future were unclear.

#### Question 2

What did Andrew do in the evenings, in his residential service?  
What processes were influencing what he did?

#### Outcome.

##### 2.1 Leisure Activities

Andrew spent long periods participating in leisure activities (56%). This consisted predominantly of listening and dancing to a small selection of cassette tapes, alone in his bedroom.

##### 2.2 Domestic

Andrew participated little in domestic activities (10%) when compared with other subjects. When he did a household task, it was always washing-up.

##### 2.3 TV

Andrew spent very little time watching TV (1%).

#### 2.4 Interaction

Interaction with carers and peers was low, although slightly higher for carers. Peer interaction reduced during mealtimes.

#### 2.5 Challenging Behaviours

None took place.

#### 2.6 Level of Engagement

Andrew's level of engagement in activities was reasonably high outside mealtimes (71%), but low within mealtimes (53%).

### Influencing Factors

#### 2.7 Views and Preferences

Andrew liked all the activities in the hostel, both leisure and household. He was proud of the washing-up that he did.

#### 2.8 Allocated jobs/rota

Andrew did participate in washing-up when it was his turn on the rota. Due to the group size, this only occurred once a week. Other tasks did not have a rota.

#### 2.9 Activity of Carers

Carers prepared all food and did most clothes care for the group. They encouraged leisure and craft opportunities by offering these activities and results were openly on display.

#### 2.10 Group Size

Interaction with carers varied little during and outside mealtimes. Peer interaction reduced within meals. However, all interaction was relatively low, as Andrew spent much time alone in his bedroom.

#### 2.11 Length of Mealtimes

Mealtimes were relatively long, e.g., 45 minutes and carers all ate with the group.

## 2.12 Aims of the Service

It was clear that carers wanted to encourage leisure activities and achieved this aim for some people in the service. Carers stated they wanted people to participate in more domestic activities, but this was not possible - the kitchen equipment was designed for large scale catering and also the hostel had catering staff.

## Comment

Andrew's long periods spent in leisure activities were both an aim of the service, but also initiated often by Andrew. The time spent alone in his bedroom resulted in low levels of interaction with others (substantially lower than other subjects). The large group situation at mealtimes did not lead to more interaction. Domestic activities were encouraged by a rota, but opportunities to participate were few, e.g., once a week to wash-up.

## Question 3

What is the quality of the physical environment?

### 3.1 Quality of Decor

The hostel was well decorated and in a good state of repair. A wide range of household appliances were available.

### 3.2 Privacy

Privacy was rather limited; there was no area where Andrew could be alone or meet friends (apart from his bedroom).

### 3.3 Access

The hostel offered good access to local shops and services.

### 3.4 Bedroom

Andrew shared a bedroom.

### 3.5 Pets

Pets had been discussed and were present.

### 3.6 Features of Larger Services

Five features of larger services were noted: bedroom furniture and some furniture in living areas were not domestic, a sign was present outside, personal items were not displayed downstairs and kitchen equipment was all of a large scale catering design. The hostel had an office, but this was not locked.

#### Comment

Andrew's hostel offered a reasonable quality of physical environment. However, privacy was somewhat limited and there were a number of features more often found in larger services.

#### Question 4

Does Andrew have friends and how are these maintained?

##### 4.1 Carers

Andrew viewed his carers as his friends.

##### 4.2 People within the Service

Andrew viewed the people he lived with as his friends. He did not know them before moving to the service.

##### 4.3 Friends outside the Service

Andrew met people that he regarded as friends outside his residential service, e.g., at the Day Centre and at clubs.

##### 4.4 Close Friendship

Andrew reported that he had a close friendship. (This was reported when completing the questionnaires and referred to a woman that had left the service).

##### 4.5 Relationship Difficulties

None reported.

#### 4.6 Opportunities to meet outside Services (i.e., segregated services)

Andrew did not meet his friends out of the services, i.e., he met friends at segregated clubs and day services only.

#### Comment

Andrew's social network involved people with learning difficulties and his carers. His friendships were maintained within services.

#### Question 5

What decisions did Andrew participate in?

##### 5.1 Everyday Decisions

Andrew participated in most everyday decisions, i.e., seven out of ten questions investigated. He did not decide what to eat, what jobs to do in the service, nor who visits the service.

##### 5.2 Infrequent, Important Decisions

Andrew participated in some important decisions, i.e., six out of eleven questions investigated. He did not decide to live in the service, nor did he participate in decisions regarding other people coming to live in or leaving the service.

##### 5.3 Meetings

No regular, pre-arranged meetings took place in the hostel.

#### Comment

Andrew participated in most everyday decisions and some infrequent, important decisions.

## Question 6

How much time did Andrew spend in integrated settings and what were the processes involved in his presence in integrated settings?

### 6.1 Time out of the Residential Service

Andrew spent over 29 hours out of the residential service during a three week period - excluding time spent at day services.

### 6.2 Time in Integrated Settings

During a three week period Andrew spent over three hours in integrated settings and this involved shopping, a visit to the pub and a walk. So, the majority of time out of the hostel was in segregated settings.

## Influencing Factors

### 6.3 Desire to go to Integrated Settings

Andrew enjoyed most of his activities out of the residential service - in particular he liked to go shopping. He did complain about the noise in one (segregated club) he attended.

### 6.4 Large Group Trips (i.e., everyone in the service going out together)

The majority of Andrew's activities (out of the service) were undertaken with a number of other people who lived in his residential service.

### 6.5 Active Links with the Community

Andrew had no active links within the community. His father visited him every two weeks but they did not usually go out together and so his father was not actively helping Andrew to be present in the community.

### 6.6 Need for Help from Carers

Andrew was viewed by carers as unable to go out alone, e.g., he needed help to cross roads with safety. Carers were aiming to teach Andrew to cross a road.

#### 6.7 Aim of the Service

It was unclear whether integration was an aim of the service. Carers did organise trips to the pub, but these usually involved everyone from the service going together. Similarly, shopping trips, for clothes, were arranged. However, all food was purchased by carers independently, i.e., without the involvement of Andrew or a member of his group.

#### Comment

Andrew spent very little time in integrated settings, despite his reports of enjoying such activities. It is suggested that this finding can be accounted for by Andrew's need for help from carers in public settings and an absence of an active link in the community. In addition, the service was not clear that integration was an aim.

#### Postscript

Andrew was visited about one year after the last meeting had taken place. The purpose of the meeting was to give feedback to Andrew and his carers about the major findings of Study II - see Appendix 33. Few changes had taken place within the service, although some carers had left. Andrew had started a different college course which he was enjoying. Andrew had been considered to live in a newly developing project, which involved living with three other people in a house, but with only a few hours practical support each week. Andrew had not been accepted for the project, as it was felt by carers that he would need more practical support than this project was able to offer.

## CHAPTER VII

### STUDY II

### D I S C U S S I O N



## Discussion of the Findings of Study II

The discussion will address each of the questions responded to individually in the case studies. The main aim of the chapter is to identify similarities and differences across the six subjects and so to indicate the processes which have led to specified outcomes.

### Question 1

What were the views of the subjects of their residential service and did they wish to remain? What factors may be influencing their views?

The following discussion refers to Table 30.

#### 1.1 Views of the Service

Four people liked their service and two people expressed dislike and very mixed views of their residential service. The two people who expressed mixed views wanted to leave. Strong influencing factors in their negative views were their reports of either a carer or/and the other people in the service.

The people who liked their service reported a variety of features that were important to them: their bedroom, having choices and freedom, the activities, the carers, the town. So, a variety of factors influenced the outcome of positive views.

TABLE 30

SUMMARY OF SUBJECTS' VIEWS AND INFLUENCING FACTORS

	<u>Paul</u>	<u>Patricia</u>	<u>Janet</u>	<u>Stephen</u>	<u>Keith</u>	<u>Andrew</u>
<u>Outcome</u>						
Liked service	✓	✓	x, ✓	x, ✓	✓	✓
Wanted to remain (long-term)	✓	x	x	x	x	?
<u>Influencing Factors</u>						
Physical environment	✓	✓	✓	✓	✓	✓
Improved physical environment	✓	x	✓	N.C.	N.C.	N.C.
Own bedroom	✓	✓	✓	✓	x	x
Activities within service	✓	✓	✓	✓, x	✓	✓
Activities outside service	✓, x	✓, x	✓	✓	✓	✓, x
Carers	✓	✓, x	✓, x	x, ✓	✓	✓
Peers within house	✓, x	✓, x	x	x, ✓	x, ✓	✓
Additional friendships	✓	0	✓	✓	✓	✓ - carers
Participation in decision to live in service	✓	x	✓	✓	x	x
Participated in many everyday decisions	✓	✓	✓	✓	✓	✓
Knowledge of other services	x	✓	✓	✓	✓	x
Other features	✓	N/A	✓, x	✓, x	✓	✓

Key:    ✓    - positive  
           x    - negative, complaint stated, alternative/addition requested  
           0    - does not happen, exist  
           N/A   - not applicable  
           N.C. - no change  
           ?    - uncertain view

## 1.2 Did the subjects wish to remain in their Residential Service?

Four subjects did not wish to stay in the service in the future. One person wanted to remain and one did not want to discuss the topic at length. The researcher had not anticipated that so many people would want to leave their service!

In two cases, carers were aware that the person wanted to leave and were helping the person aim towards a move. Carers in two services did not know that the person wanted to leave! In all cases, people wanted to move towards greater independence and two people had identified other people to live with.

## Influencing Factors

### 1.3 Physical Environment

All of the subjects lived in a good quality physical environment. It was considered that the physical environment was not a major factor in influencing views for these subjects, particularly those that expressed a wish to leave.

However, it may be that if the physical environment had been of poor quality, complaints may have been made. This study could not investigate this possibility.

In Paul's situation, the physical environment may have contributed towards his positive view of the service, e.g., he commented on his bedroom. In addition, his move to the house was likely to have involved a major improvement in the quality of his physical environment - to a greater degree than most of the other subjects.

### 1.4 Bedroom

Two people shared a bedroom. Neither complained about this feature of the service. However, it did restrict their potential access to privacy.

### 1.5 Activities within the Residential Service

All the subjects liked the activities within the houses/hostels. In most cases they were proud of their household skills. Stephen did complain about having to do so much cooking. Household activities were likely to contribute towards positive views of the service.

### 1.6 Activities outside the Residential Service

All the subjects liked their leisure activities outside the service. Two people, Paul and Patricia, wanted to go out more often. Andrew complained of the noise in one leisure activity. It was considered that the activities contributed towards positive views of the service.

### 1.7 Carers

Carers were considered to be a major contributing factor towards a person's view of their residential service. Stephen and Patricia had a major dislike for a carer which was likely to be influencing their wish to leave. Also, Janet's view that carers were not encouraging friendships was important to her. Positive views of carers also contributed in a major way towards positive views of the service. Such strong negative views of some carers had not been anticipated by the researcher.

### 1.8 Peers within the House

Most of the subjects expressed mixed views of their peer group. Five people reported some complaints, always concerning the behaviour of others. This was another finding that had not been anticipated. Negative views of the other people were considered to be a major influencing factor for Janet particularly.

## 1.9 Other Friendships

Five people reported important friendships outside of the service. Despite difficulties in some of these relationships, they were considered to be important features in influencing views of the residential service, but only when the friend was identified as a possible person to live with.

## 1.10 Involvement in Decision Making

Some subjects viewed involvement in decision making as important features of the service. However, this did not have a major influence on outcome - both the subjects who disliked their service were involved in the decision to live in the service and in everyday decisions. Hence, people with learning difficulties also need the right to change their mind!

## 1.11 Knowledge of Other Services

This was considered to be a major influence over people's desire to leave the service: all four people who wanted to leave had access to knowledge of other services. Access had been gained from previous family home, discussion of other developing services, relatives, People First group and close friends. The two people who did not want to leave or were uncertain had less access to this information, possibly because they had been in services for longer and/or had less access to integrated settings.

## 1.12 Other Features

Other features were important to service users but were unlikely to be major influencing factors. Day services were important and were disliked by two people. Paul was very proud to own a car. Andrew valued his visits from his father. Distress over leaving hospitals and the death of parents were often topics that subjects wanted to discuss.

## Comparison with the Literature

The findings broadly support the existing literature. Williams (1986) pointed out that many users are critical of services and Sugg (1987) found that on close analysis people's reports revealed areas of dissatisfaction. The number of people expressing a wish to leave their service is consistent with Birenbaum and Re (1979) who found over half of a group of forty-two adults wanted to move.

The criticisms of two staff are supported by Booth, Booth and Simons (1989) who found that staff were viewed as too strict and domineering. The importance of personal freedom is consistent with both Lowe, de Paiva and Humphreys (1986) and Cattermole, Jahoda and Markova (1988). In general, previous research has not highlighted the negative views of the behaviour of other users. It is likely that previous research has not investigated this aspect of user views. However, it was clear that other people living in the service had an important influence on user views.

## Summary and Comments

A. Four of the six people who participated in Study II wanted to leave their residential service. Two people had mixed views or disliked their current service. The desire to leave was influenced by a combination of the following features:

- \* Dislike of the behaviour of the people living in the service.
- \* Dislike of a carer.
- \* Knowledge of alternative living arrangements.
- \* Identified friend(s) to live with.

Two or more of these features were present for each person who wanted to leave. In all cases, people wanted to move towards greater independence.

B. Other features of services influenced views, but not sufficiently to override the wish to leave. These features were the physical environment, activities within and outside the service, friendships and involvement in decision making.

C. Some of the findings were not anticipated before the study commenced. These include:

- \* Two people disliking/having very mixed views of their service and four people wanting to leave.
- \* Strong negative views of a small number of carers.
- \* Most people complained about the behaviour of others.

In addition, the researcher was influenced by the number of sad stories that some people reported, e.g., the stress involved in leaving hospital, the death of parents and difficulties with friendships. In retrospect, it was felt that the people who participated in the study may have had insufficient opportunity to discuss such topics.

## Question 2

What did the subjects do in the evening in their residential services? What processes were influencing what people did?

The discussion refers to the information summarised in Table 31.

## Outcome

### 2.1 Leisure Activities

Andrew was the only person to spend long periods in leisure activities (56%), and much of this time was spent listening and dancing to one/two particular cassette tapes. It was clear that he enjoyed this activity, but it was very repetitive. However leisure activities were an aim of his service, although he initiated much of this himself.

Patricia, Stephen and Keith participated in some leisure activities (9% - 11%) and these were initiated usually by themselves. However, some craft activities were organised by carers for Patricia. Paul and Janet participated little in leisure activities (less than 1%).

TABLE 31

SUMMARY OF ACTIVITIES AND INFLUENCING FACTORS

<u>Outcome</u>	<u>Paul</u>	<u>Patricia</u>	<u>Janet</u>	<u>Stephen</u>	<u>Keith</u>	<u>Andrew</u>
Leisure Activities	Low	Moderate	Low	Moderate	Moderate	High
Domestic Activities	Low	High	High	High	Moderate	Low
TV	High	Moderate	Moderate	Moderate	High	Low
Interaction) - peers outside )	Moderate	High	Moderate	Moderate	Moderate	Low
meals ) - carers	High	Moderate	High	High	Moderate	Low
Challenging behaviours	Low	None	None	Low	None	None
Level of engagement outside meals	High	High	Low	High	High	High
<u>Influencing Factors</u>						
Views and preferences	Positive	Positive	Positive	Mixed	Positive	Positive
Allocated jobs/rota	No	Yes	Yes	Yes	Yes	Yes
Activity of carers	Prepared meals	Prepared meals	Encouraged meal pre- paration	Encouraged meal pre- paration	Prepared meals	Prepared meals
Group size ) - peers	Increased	Reduced	Little change	Increased	Increased	Reduced
Interaction) within ) - carers	Increased	Reduced	Reduced	No change	Increased	No change
meals						
Mealtimes - carers & group together	Yes	Not all	Yes	Yes	Present - did not eat	Yes
Clear aims	Not identified	Not Identified	Yes	Yes	Not Identified	Identified

NB: The ratings of high, moderate and low within a category of behaviour took account of:

- Ranking of activity level across subjects, e.g., the highest activity level is described as "high".
- Overall activity levels of a category of behaviour, e.g., most interaction with peers was below 5% but some of these scores are described as moderate.



## 2.2 Domestic Activities

Three people - Patricia, Janet and Stephen - spent long periods in domestic activities (range 30% - 38%). Keith spent some time participating in household tasks (15%). All four people had domestic tasks allocated to them - either by use of a rota or by specifying the jobs. In two of these services, meal preparation was always done by the group with the guidance of carers. When carers prepared meals, the outcome was either that a person performed long repetitive tasks, i.e., laying a table, or overall participation in domestic activities reduced.

Paul and Andrew participated little in domestic tasks (9% and 10% respectfully). In Paul's case the physical environment gave the opportunity for participation, but carers were inconsistent in their encouragement. Andrew's opportunities were significantly reduced by the size of service, i.e., only once a week was he able to wash-up and domestic staff were specifically employed to do the cooking of meals.

## 2.3 TV

Keith and Paul watched TV for long periods (45% and 46% respectfully). They enjoyed this activity and living in a house with a small lounge (i.e., not a hostel size room) was likely to encourage this activity. Janet and Stephen watched some TV (7%-12%) and Andrew watched little TV (1%). Both Stephen and Andrew preferred other activities, i.e., going out (Stephen) and listening to music (Andrew). Patricia and Janet liked TV, but the larger services, with larger sitting areas, were less likely to encourage the activity.

## 2.4 Interaction

Interaction with peers (outside meals) was generally not a high frequency activity (range less than 1% to 8%). Patricia's interaction with peers was the highest (i.e., 8%) and this involved usually talking to her close friend or another friend in

the service. Interaction with peers was usually with the same people within any one service, i.e., in large services, people did not interact with everybody. Peer interaction increased substantially in small services (i.e., 3-4 people) at mealtimes; whilst in larger services interaction reduced or did not change at mealtimes. Much interaction with peers took place in groups of two/three, participating in the same task.

Interaction with carers was higher (sometimes substantially) than interaction with peers for all but one person - Patricia (range 3% -18% outside meals). This often occurred whilst a person was doing a task with a carer. Interaction with carers increased during meals in two of the smaller services (i.e., 3-4 people) and either reduced or did not change in the larger services.

## 2.5 Challenging Behaviours

The occurrence of challenging behaviour was extremely infrequent. Four people were observed not to participate in any challenging behaviours. The incidences that occurred included swearing, pinching a peer on the arm and throwing a waste paper basket. In every case it was clear that the person concerned was annoyed by another person/event. Carers expressed few concerns about challenging behaviour, despite the background history of four subjects.

## 2.6 Level of Engagement

Five subjects had a high level of overall engagement in activities, i.e., over 70% outside meals. Janet, by contrast, spent long periods doing nothing and her overall engagement was 53%. All three subjects in small services (i.e., 3-4 people) had higher levels of engagement than those in the larger services, although the differences were not substantial.

Within meals, five subjects had high levels of engagement - over 74%. Andrew's engagement within meals was lower - 53%. This was accounted for by the long mealtime, during which he had little to do when he had finished eating. Again, engagement was higher in the smaller services (3-4 people) than in the larger; differences were not substantial.

## Influencing Factors

### 2.7 Views and Preferences

All the subjects liked household tasks and leisure activities. Some subjects were very proud of their achievements in the household. Stephen did complain of cooking every evening.

### 2.8 Allocated Jobs/Rota

In five services people were either allocated jobs or there was a rota for household tasks. Tasks were always completed as expected. The approach of using a rota/allocating specified tasks was the major influence on engagement in most household tasks. Paul and Andrew participated little in household tasks. In Paul's service there were no tasks clearly allocated to him. Andrew's service used a rota, but only for washing-up and his turn came only once a week.

### 2.9 Activity of Carers

The activity of carers was a major influence over the activity of all the subjects, e.g., if a carer offered or encouraged an activity the person participated. In only two services, Janet's and Stephen's, carers did not prepare meals themselves, but encouraged the group to prepare their own meal with guidance as required. Janet and Stephen both spent long periods in varied domestic activities.

In services where the group size was larger, i.e., Patricia's and Andrew's, meal preparation on a regular basis may have been difficult to organise. However, for Keith and Paul it was considered that there were lost opportunities in this area.

## 2.10 Group Size

Comparison of interaction levels within mealtimes and outside mealtimes found some interesting results. In the smaller services, i.e., 3-4 people living together, interaction was very likely to increase at mealtimes. This was accounted for by all the group being present in contrast to outside mealtimes when some people went out or were in their bedrooms. Interaction in the larger services was much more likely to reduce at mealtimes since large groups are less conducive to high interaction by all group members.

It was consistently noted by the researcher that interaction was most likely to occur when people were in groups of two or three participating in the same/similar task, e.g., household tasks. This accounted for the finding that interaction with carers was more likely to be higher in the smaller services - because opportunities to participate in a task together occurred more frequently. In addition, it was found that in larger services, the subjects predominantly interacted with only a small number of other people, i.e., not with all of the group.

## 2.11 Mealtimes

Carers were all present throughout mealtimes in five services - although in one service the carer did not eat, but had a cup of coffee. In Patricia's service some carers ate with the group whilst others did not. Interaction with carers increased in two services (the smaller ones) within meals, reduced in two and did not change in two. So, unless the group size is small, i.e., four or less, carers' presence is not a major factor in influencing the

level of interaction. Carers eating with the group may be valuable for other reasons, e.g., modelling of behaviour and equalizing power relationships.

The length of mealtimes varied considerably from 10 minutes to 45 minutes. The long mealtime in Andrew's service influenced the amount of time he had nothing to do.

## 2.12 Aims of the Service

Aims were clearly identified in three services, i.e., to participate in household activities and (in one service) in leisure activities. These aims were clearly being put into practice. In the other three services, aims were unclear to the researcher. However it was considered that all services wanted people living in them "to be happy".

## Comparison with the Literature

This study found that most people were engaged in activities for about 70% of their time outside mealtimes. So, engagement was higher than in previous studies, e.g., Mansell, Jenkins, Felce and de Kock (1984) found engagement of about 46%. However, previous research has involved people with severe learning difficulties, whilst in this study users had mild/moderate learning difficulties. Study II found no clear difference in engagement levels between different sizes of service which has been reported in previous research, e.g., Rawlings, 1985a. This study was not designed to investigate specifically different sizes of services, and as only six services were involved, it is suggested that no clear conclusions can be drawn.

The study clearly supported the findings of Felce et al (1987) that a high quality service was determined by a number of variables and not by a single factor. Study II has identified some of these features and has clearly added to the existing literature. In addition, the study identified the influence of group size on interaction levels, which is consistent with the findings of Felce et al (1987).

## Summary and Comments

A. The following features of services were found to be powerful influences of people's activities, particularly in relation to household activities:

- \* allocating tasks or having a rota of tasks
- \* activity of carers; if carers prepare a meal, users have lost this opportunity
- \* clear aims that are put into practice.

In combination, these features were a powerful influence over participation in varied domestic activities. Such activities were usually enjoyed and a source of pride to the subjects.

B. Two people living in small domestic style services did not participate to a high degree in household activities. Both Paul and Keith were able and motivated to participate more and there were no practical difficulties, i.e., there was a small, domestic kitchen. The absence of clear aims and the activity of carers accounted for this lack of participation. In addition, in Paul's case, the value judgments of some carers were relevant, i.e., "it is not fair to prepare a meal after returning from work".

C. Andrew's low degree of participation in domestic activities was accounted for by the activity of carers and absence of aims and a kitchen fitted with catering style equipment. In another larger service, Patricia participated in household tasks, but these were long and repetitive.

D. Group size was a clear influence on interaction levels. Interaction was highest in small groups at mealtimes (i.e. four people and a carer) or when people were in groups of two/three participating in a task. Group size was a stronger influence on interaction than the presence of carers at mealtimes, e.g., in larger groups. In addition, people in larger services interacted predominantly with only a small number of the group. So, there was no evidence that large groups encouraged friendships.

E. Interaction with peers was generally a low frequency activity. Interaction with carers was usually higher than with peers and again demonstrates the importance of carers to people with learning difficulties.

F. Most people's overall participation in tasks was high, i.e., over 70% outside mealtimes. Engagement levels were higher in the smaller services (both within and outside mealtimes), but differences were not substantial when compared with the larger services.

G. Some activities were predominantly initiated by the subjects themselves - specifically watching TV and some leisure activities. Watching TV varied considerably - from 1% to 47% of observed time, as did leisure activities (varied from 71% to 56% of observed time). The physical environment of a small service was more likely to encourage watching TV when a person wished to do so.

### Question 3

What was the quality of the physical environment of the services?  
The discussion refers to Table 32.

#### 3.1 Quality of Decor

All services offered high quality decor and were in a good state of repair. All had a wide range of household appliances available.

#### 3.2 Privacy

Two services (both larger services) offered very good privacy, e.g., there was an area/room allocated to meet visitors which would not involve disturbing others. The four other services did not have this facility. Subjects did not complain about the lack of a specific area to be alone. Possibly, as people generally had few visitors, this was not an important feature.

TABLE 32

SUMMARY OF PHYSICAL ENVIRONMENTS OF SERVICES

	<u>Paul</u>	<u>Patricia</u>	<u>Janet</u>	<u>Stephen</u>	<u>Keith</u>	<u>Andrew</u>
Quality of decor	Good	Good	Good	Good	Good	Good
Privacy	No area to meet friends	Good	Good	No area to meet friends	No area to meet friends	No area to meet friends
Access	Good	Good	Good	Good	Good	Good
Own Bedroom	Yes	Yes	Yes	Yes	No	No
Pets	Not discussed	Not discussed	Discussed - not present	Not discussed	Not discussed	Discussed - present
Features of larger services	One	Four	Five	None	One	Five



### 3.3 Access

All services had good access to shops and all local facilities.

### 3.4 Own Bedroom

Four subjects had their own bedrooms and two people shared. The two men who shared bedrooms, Keith and Andrew, did not complain about this feature of their service.

### 3.5 Pets

Pets had not been discussed in four services - but were present in one. Two services had decided to discuss pets and one of these services had a pet. No major disagreements or difficulties arose around the issue of pets in services.

### 3.6 Features of Larger Services

All of the larger services, i.e., Patricia's, Janet's and Andrew's, had at least four features that are more often found in larger style services, i.e., institutional furniture, catering style kitchen equipment, few/no possessions on open display downstairs, notices outside, a locked room/office. By contrast, the smaller style services had a maximum of one such feature present. Users did not complain about such features in services.

## Comparison with the Literature

Little previous research has specifically addressed the quality of the physical environment. In the past, the physical environment has often been measured as part of the overall service, e.g., a measure of normalisation. It is suggested that if residential environments are to be classified, then measuring the structure and physical environment as a separate feature is helpful.

The findings supported the previous research, e.g., Balla (1976) and Landesman-Dwyer (1981) that within a given service style, quality of care varies and this includes the physical environment. In addition, the findings that more "institutional" features were present in larger services is consistent with Baroff (1980) who found that depersonalising practices were more frequently found in institutions.

#### Summary and Comments

- A. All subjects lived in services with good quality decor and easy access to facilities.
- B. Some subjects shared a bedroom, had somewhat less access to privacy, but did not offer negative comments about these features.
- C. Pets had not always been discussed in services, but there was no evidence of disagreements occurring.
- D. Larger services had more features usually found in large (institutional) services, than the small domestic style services. Subjects did not complain about these features.

#### Question 4

Did the subjects have friends and how were these maintained?

The following discussion refers to Table 33.

##### 4.1 Carers Viewed as Friends

Four people viewed carers as friends. In Janet's service, she felt friendships with the carers had been discouraged and she did not like this approach. Staff at college/day services were reported to be friends by two people. Keith liked his carers, but did not view them as friends, but as 'in charge'.

TABLE 33

SUMMARY OF FRIENDSHIPS

	<u>Paul</u>	<u>Patricia</u>	<u>Janet</u>	<u>Stephen</u>	<u>Keith</u>	<u>Andrew</u>
Carers (viewed as friends)	Yes	Yes	No	Yes	No	Yes
People within service	Yes	Yes	No	Yes	No	Yes
Friends outside the service	Yes	Yes	Yes	Yes	Yes	Yes
Close friendship	Yes	Yes	Yes	Yes	Yes	Yes
Relationship difficulties	No	Yes	No	Yes	No	No
Meeting outside services	No	No	No	Yes	Yes	No
Knew people in service before living there	Yes	Not well	No	Yes	No	No

#### 4.2 People within the Service

Four people viewed the other people living in the service as their friend. The two people who did not view the other people in the service as friends had not known the people before coming to live in the service.

#### 4.3 Friends outside the service

All the subjects had friends outside the residential service. These friends were often within day services. Janet expressed a desire for a friend 'without disabilities'.

#### 4.4 Close Friendship

All the subjects reported a close friendship. However, some people did not always meet their close friend very often. In one case, carers did not know the relationship existed. Two people were considering marriage. Pauline was very clear in her desire to marry her close friend, but her carer had told her she 'was stupid'.

#### 4.5 Relationship Difficulties

Two people had clear difficulties within their close relationships. These difficulties had a major effect on their lives. Distress was caused in situations such as a close friend ignoring a person, or not wishing to meet without offering a reason.

#### 4.6 Meeting outside Services

Two people only met friends/acquaintances regularly outside services, e.g., at voluntary work and visiting a friend's house.

#### 4.7 Knew people in service before Living in Service

Two people knew well the other people living in their service before living in the service - in both cases they had lived in (previous) services together. Patricia had met the people in her service, but had not known them well.

#### Comparison with the Literature

In part, the findings support previous research, e.g., de Kock et al (1988) and Firth and Short (1987) found that social lives were largely dependent on family and staff. In this study, friendships were predominantly with other users and carers were often reported to be friends. However, unlike previous work, e.g., Flynn (1987) and Malin (1982), users in this study could not be described as lonely. This difference could be accounted for by all users in Study II living in staffed accommodation and not in unstaffed or minimally staffed services.

#### Summary and Comments

A. All the subjects had friends, i.e., they were not lonely in their community settings. Friendships were considered to be very important to all the subjects.

B. Friendships were predominantly with people with disabilities. One person expressed a desire for a friend 'without disabilities'.

C. Friendships were usually made and maintained within segregated settings - only two people met friends/acquaintances outside services.

D. People who knew the other people they lived with before living in the service were more likely to view them as friends - but this finding was not consistent.

E. Some close friendships involves stress for people with disabilities. One person was very clear in her desire to marry, but received no support from carers.

F. The concept of friendship was unclear to some subjects, e.g., four subjects viewed carers as friends. Relationships with carers were very important to all the subjects. Most services offered no guidance to subjects, for example discussing the features of friendships, acquaintances, strangers and carers.

#### Question 5

What decisions did the subjects participate in?

The following discussion refers to Table 34.

##### 5.1 Everyday Decisions

The questionnaire, Decision Making, investigated ten everyday decisions including what to eat, when to go to bed and what jobs to do. Most subjects participated in all/the majority of everyday decisions.

##### 5.2 Infrequent, Important Decisions

The questionnaire, Decision Making, investigated eleven important but infrequent decisions. These ranged from whether to live in the service, other people coming to/leaving the service, to decisions involving choosing what clothes to buy and decor. Stephen and Janet participated in most/all of these decisions. In contrast, Patricia was only involved in three such decisions and the other three subjects were all involved in six of such decisions. So, there was a wide range of involvement in infrequent decisions.

##### 5.3 Meetings

Only two services had regular meetings at which users and carers discussed issues before decisions were made. These services both offered the greatest involvement in decision making. So, it is suggested that such meetings facilitate decision making, particularly of infrequent decisions.

TABLE 34

SUMMARY OF DECISION MAKING

	<u>Paul</u>	<u>Patricia</u>	<u>Janet</u>	<u>Stephen</u>	<u>Keith</u>	<u>Andrew</u>
Number of everyday decisions participated in (total 10)	9	7	10	10	9	7
Number of infrequent decisions participated in (total 11)	6	3	8	10	6	6
Meetings	No	No	Yes	Yes	No	No

## Comparison with the Literature

Little previous research has investigated users participation in decision making. In one of the few studies, Kishi et al (1988) found that people with learning difficulties in general had less choice than other citizens, and the degree of choice being related to the degree of learning difficulty. The finding that participation in infrequent decisions varied is consistent with this previous research.

## Summary and Comments

A. All subjects were involved in most everyday decisions. Participation in infrequent important decision varied more.

B. The two services where regular meetings took place offered the greatest participation in decisions, particularly of infrequent, important decisions. It is suggested that the meetings facilitated the process of a person being involved in decisions.

C. It was considered that most decision making was an informal process and was almost invariably initiated by carers.

## Question 6

How much time did the subjects spend in integrated settings and what were the processes involved in a person being present in integrated settings?

The following discussion refers to Table 35.

## Outcome

### 6.1 Time out of the Residential Service

The amount of time that the subjects spent out of the residential service varied considerably - from 29 to 88 hours in a three week period. So, all the subjects spent at least nine hours a week out of the service, and some considerably more. (This time was in addition to attending Day Services).



TABLE 35

SUMMARY OF TIME SPENT IN INTEGRATED SETTINGS

<u>Outcome</u>	<u>Paul</u>	<u>Patricia</u>	<u>Janet</u>	<u>Stephen</u>	<u>Keith</u>	<u>Andrew</u>
Time out of the residential service (in a 3 week period)	31 hrs.	34 hrs.	29 hrs.	76 hrs.	88 hrs.	29 hrs.
Time in integrated settings (in a 3 week period)	3 hrs.	7 hrs.	25 hrs.	68 hrs.	88 hrs.	3 hrs.
<u>Influencing Factors</u>						
Wish to go to integrated settings	Yes	Yes	Yes	Yes	Yes	Yes
Large group trips	Mixed	Majority	Rarely	No	No	Majority
Active links	No	No	Yes	Yes	Yes	No
Help required	Yes	Yes	No	No	No	Yes
Aim of the service	Unclear	Unclear	Supported Integration	Yes	Unclear	Unclear

## 6.2 Time in Integrated Settings

The amount of time spent in integrated settings varied considerably, i.e., between 3 and 88 hours in three weeks. The subjects could be clearly divided into two groups: three people spent the majority of time integrated setting when out of the service whilst three people spent the majority of their time in segregated settings.

## Influencing Factors

### 6.3 Wish to go to Integrated Settings

All the subjects enjoyed their activities in integrated settings. Two people had experienced difficulties in public places, e.g., teasing, but these had been managed by carers and had not influenced people's views in the longer term.

### 6.4 Large Group Trips i.e., going out with everyone in the residential setting

The three people who spent long periods in integrated settings were less likely to go out regularly in a large group. The people who spent the majority of time out of the residential service within segregated settings usually went out with the other people from the service.

### 6.5 Active Links with the Community

The three people who spent long periods in integrated settings all had an active link in the community, e.g., a relative/friend visited regularly, or a person participated in voluntary work. In contrast, the three people who spent the majority of their time in segregated settings had no such active links with the community.

## 6.6 Help required

The three people who spent long periods in integrated settings required no help in public places and often went out alone. In contrast the people spending considerable periods of time in segregated settings required help, e.g., to cross roads with safety.

## 6.7 Aims of the Service

The influence of the clarity of the aims of the service was difficult to ascertain. Whilst no services were actively opposing integration, only two services gave active support, e.g., by expecting people to do their own shopping (with help if required). The two people in services supporting integration did spend long periods in such settings.

## Comparison with the Literature

The findings of the study clearly support previous research, e.g., de Kock et al (1988) found that factors other than location were important to the access residents had to local resources. This study found factors influencing time spent in integrated settings, e.g., the degree of help required by users. De Kock et al (1988) did not identify this as a factor, but clearly different influencing factors could be relevant across a range of services.

Overall, the findings of Study II support Felce (1989) that quality cannot be assured by getting a few factors correct. The outcomes for users are clearly influenced by various factors, as outlined by the analysis in reply to questions two and six. The explanation for the variety of quality of care in community services found by Balla (1976) becomes clear as an understanding of the factors involved emerges. It is considered that Study II has significantly contributed to the understanding of the influencing factors on outcomes for users.

## Summary and Comments

A. All the subjects spent long periods out of their residential service. Three subjects spent the majority of this time in integrated settings whilst three subjects spent their time (almost entirely) in segregated settings.

B. All the subjects liked activities in integrated settings and had experienced very few difficulties with the general public.

C. The following factors were identified as influencing whether or not people spent time in integrated settings:

- \* Having an active link in the community: this was present for all those spending long periods in integrated settings.
- \* requiring no help: all those spending the majority of their time in integrated settings required no practical help in public places.
- \* Absence of large group trips: the people spending long periods in integrated settings did not do so with other people living in their residential service.

The influence of the clarity of the aims of the service was difficult to ascertain, but when services did actively support integration this outcome did occur.

## Additional Issues

In addition to investigating the six questions discussed above, three other issues may be commented upon: overall service quality, TV and a comparison with the general public.

## 1. Overall Service Quality

The above findings have demonstrated that in some of the services opportunities were wasted. This was particularly clear in the two staffed houses, where engagement in domestic activities was low, i.e., 9% and 15%, but in terms of the physical environment, staffing levels and motivation of users, far greater engagement could have been achieved, e.g., 30% engagement in non-repetitive activities was found in the largest service in the study. In addition, the repetitive nature of the engagement was not acknowledged nor clearly considered by services, e.g., Andrew spent long periods listening to the same tapes.

Possibly the most obvious example of a missed opportunity was the ownership of a car by a person who then only spent three hours a week in integrated settings. Three subjects spent very little time in integrated settings, but enjoyed these activities and it is considered very likely that more opportunities could have been organised within their current staffing resources.

In addition, it was found that the majority of friendships and relationships were developed and maintained within segregated settings, e.g., most people rarely met friends in integrated settings. Two users disliked a carer within their services, and this had a major impact on them not to remain living in the service.

The majority of services within the study could be described as being reasonably well resourced. The missed opportunities discussed above need to be addressed if community based services are to offer a substantially different style of service from previous large, institutional services.

## 2. TV

Paul was recorded as watching TV for 66 hours during a three week period. Although this may appear to be an excessive length of time, it is less than the average adult person who watches 26 hours of TV a week (40th Edition, Britain - An Official Handbook, 1988). So, all the subjects watch less TV than the average adult in Britain.

### 3. Comparison with the General Population

Appendix 34 shows a comparison of the results of the measures used in Study II with the findings of a general population sample. Items have been selected from the Life Experiences Checklist (A. Ager, 1988 - Draft Version) for which information is available for the six subjects using the data collected, i.e., questionnaires and daily diary data. The percentages quoted for the general population are taken from a study involving the completion of self-rated Life Experiences Checklists by 409 householders in the East Midlands, across urban, suburban and rural settings.

It is found that the six subjects in Study II were more likely to have some positive life experiences than the general population. For example, the subjects were more likely to live in a well decorated home, to attend a club every month (although a segregated club), to have several friends (see discussion of friendships) and to choose what to do in their spare time. In addition, the subjects were far more likely to be learning a new skill. It could be considered doubtful whether such an emphasis on skill teaching for adults in their late thirties and early forties is a valued activity.

There are a range of life experiences that the subjects in the study were less likely to have than the general population. The subjects were less likely to have their own bedroom (or share with a partner); to be married or have a steady partner; to meet friends or relatives out of the house; to choose where to live and how the house is decorated; to use public transport regularly and to cook meals. These differences suggest three major areas where services are failing to offer the same opportunities as the general population enjoy. The first area involves people participating actively in major life decisions; the second involves close relationships with the opposite/same sex and friendships and the third concerns using the same facilities as the general public. It is considered that community services need to address these issues as a priority.

## Summary of Findings - Study II

The following is a summary of the main findings of the study. These have emphasised the similarities and differences across the six subjects, with particular reference to the processes involved.

### 1. Views

#### A. Some findings regarding views had not been anticipated:

- \* Two people expressed mixed views and a dislike of their service and four people wanted to leave. Their choice was always to move towards a placement offering greater independence, and two people had identified other people to live with.
- \* Although carers were often viewed as friends, some strong negative views of a small number of carers were expressed.
- \* Most people complained about the behaviour of others.

#### B. The desire to leave a service was influenced by a combination of the following factors:

- \* Dislike of the behaviour of people living in the service.
- \* Dislike of a carer.
- \* Knowledge of alternative living arrangements.
- \* Identified friend(s) to live with.

#### C. Other features of services influenced views, but not sufficiently to overcome the wish to leave. These features were: the physical environment, activities within and outside the service, friendships and involvement in decision making. These features were usually viewed positively by the subjects.

## 2. Activities

A. Most people participated in activities for relatively long periods during the evening, e.g., engagement was usually about 70% outside meals. Engagement levels were slightly higher in the smaller services -but differences were not substantial.

B. Certain features of a service were found to be powerful influences over people's activities, particularly in relation to household tasks. These were:

- \* Allocating tasks/having a rota of tasks.
- \* Activity of carers, i.e., carers doing the activity/encouraging users to complete the activity.
- \* Clear aims that are put into practice.

In combination, these features were found to be a powerful influence over participation in varied domestic activities. However, activities such as watching TV and some leisure activities were predominantly initiated by the person themselves.

C. Group size was a clear influence on interaction levels. Interaction was highest in small groups at mealtimes (e.g., four people and a carer), or when people were in groups of 2-3 participating in a task.

D. Everyone in the study watched less TV than the average adult in Britain.

## 3. Physical Environment

A. All the people in the study lived in services with good quality decor and easy access to facilities.



B. Some people shared a bedroom and had somewhat less access to privacy, but did not offer any complaints of these features.

C. The larger services had more features of institutional services, e.g., an office, a sign outside, but no complaints were made of these features.

#### 4. Friendships

A. All the people in the study had two or more friends, i.e., they were not lonely in their community settings.

B. Friendships were predominantly with people with disabilities and were usually made and maintained within segregated settings. Some people viewed carers as friends.

C. Some close friendships involved considerable stress for people with learning difficulties.

#### 5. Decisions

A. All the people in the study were involved in most everyday decisions. Participation in infrequent important decisions varied to a greater extent.

B. Regular meetings within a service facilitated the process of a person being involved in decisions. It was considered that most decision making was an informal process, and was almost invariably initiated by carers.

## 6. Integration

A. All the people in the study liked their activities in integrated settings and experienced few difficulties with the general public.

B. All the people spent reasonably long periods out of the house/residential service. Three people spent the majority of such time in integrated settings, whilst three people remained in segregated settings.

C. The following factors were identified as influencing whether or not people spent long periods in integrated settings:

- \* Having an active link in the community, e.g., a person to visit
- \* Requiring no help from carers
- \* Absence of large group trips.

The influence of a clear aim of integration was more difficult to ascertain.

## 7. Overall Service Quality

It was found that in some services opportunities were wasted. For example, in two staffed houses participation in domestic activities was considerably lower, than in a much larger service.

## 8. Comparison with the General Population

A. Whilst the subjects all enjoyed some life experiences to a greater extent than the general public, e.g., to live in a well decorated home, there were a range of life experiences which they were less likely to experience, e.g., to be married or have a steady partner.

B. It is suggested that community services need to address the following issues as a priority: participation in major life decisions, close relationships with the opposite/same sex, using the same facilities as the general public.

## CHAPTER VIII

## C O N C L U S I O N S

## INTRODUCTION

The concluding chapter aims to cover the following areas:

### 1. Methodology

The research studies have made a valuable contribution to the methodology used in outcome studies and this will be discussed. Recommendations for case studies are outlined.

### 2. Monitoring and Feedback of Community Services

The research can offer some practical guidelines for monitoring and feedback of community services.

### 3. Practice Guidelines

Study II enabled some clear guidelines for practice to be identified and these may be valuable for services to consider.

### 4. Views of Service Users

Both of the research studies placed a high emphasis on the views of service users and the main findings will be outlined.

### 5. Personal Experiences

The research studies left some lasting impressions on the researcher and these will be discussed.

## 1. METHODOLOGY

### a) Advantages of the Methodology used in the Studies

Study II used an innovative research methodology involving a number of case studies. These all addressed the same set of questions by the systematic collection and analysis of in-depth information. This was found to be particularly relevant in the area of community services where there are a large number of factors to be studied and interaction between factors is likely to occur.

A major advantage of the methodology used in Study II was that it has enabled a number of processes to be identified. So, for example, the in-depth information and systematic analysis enabled the identification of factors which led to the outcome of people participating in a number of varied household tasks. Also, it became clear that most factors may not be operating in isolation, e.g., the size of a service alone may not consistently lead to any major changes in activities for people living in a residential service. Studies which simply measure factors before and after a move are unlikely to identify these processes. Since policies are clearly stating that the majority of people with learning difficulties should not live in institutional care, it is considered that investigating the processes leading to specified outcomes is a particularly valuable area of research. Questions regarding processes are of equal importance to users, carers, managers and planners alike.

An additional advantage of the methodology was that it enabled a large amount of detailed information to be organised to identify useful findings. This was only possible by asking the same questions for each subject using the same methodology and looking at specific factors which may be influencing the outcome. For example, within each service, when attempting to answer the questions "what do people do in the evening?", firstly, observations identified the activities people participated in, and then the influence of carer behaviour, a rota, etc., was discussed for each person. It was clear that without this structure and rigour within the methodology, potentially useful findings would be 'lost' within the volume data.

A particularly valuable feature of Study II was that it concentrated on measuring outcomes of the service, e.g., what people do, their views, where they spend time. This is considerably more useful than approaches that only investigate inputs to the service. For example, three people in Study II lived with 3-4 people in houses/flats, but their activities in the evening varied considerably, i.e., the amount of time spent in household activities. However, the inputs to the service are similar, i.e., group size, ordinary housing. A second example is that of Paul, who had a car, but went out very little at the weekends. Although the 'input' to the service appeared very positive, i.e., the car, this had little influence on outcome. There are a number of intervening features and processes which lead to such varied outcomes for users. So, it considered that future studies should concentrate on outcome measures. These should include what people do, where they spend time, i.e., integrated/segregated settings, views of users, user participation in decision making and social relationships.

Before commencing Study II, it was considered that there was a risk attached to using this methodological approach, e.g., it would not give the breadth of information that a survey would offer, nor the details of a single case study. It was clear that the advantages of the methodology of Study II outweighed these potential risks. It would be very unlikely that an isolated single case study could have offered the practice guidelines (discussed later in this chapter).

One weakness of Study II was the measurement of social relationships. In retrospect, it was found that the use of a questionnaire combined with asking the person about their friends, had highlighted the issue of the definition of a friend, i.e., who is a friend? Some people with learning difficulties clearly continued to confuse friends and acquaintances. Whilst accepting that these relationships may be of value to those concerned, it is recommended that further work needs to involve a clarification of definitions of friends and acquaintances.

The survey approach used in Study I clearly gave the impetus to the need to design Study II. Study I found few major differences between services, and when differences were identified, it was not possible to give any reasons for these. In addition, it is significant that the views of the users of the services appeared to differ considerably within the two studies. This finding is discussed in more detail later in the chapter, but it is considered that the difference may in part be accounted for by the different methodology used in the two studies. The people in the second study had spent time with the interviewer before any attempt was made to ask their views of the service and it was very probable that the familiarity with the interviewer enabled the person to report negative views in addition to positive views.

The use of the observational measures, questionnaires and diaries and the information on reliability has highlighted some important issues which are relevant for the future. In particular, the low agreement of the diary data (43% to 63%) with other measures, was a cause of concern. The agreement was calculated by a comparison with the observational data, and the majority of the disagreement (69%) was accounted for by carers not recording a person doing nothing, nor interaction. So, it was considered very likely that major events, e.g., going out, were recorded. However, future research should address the agreement of different types of measures with diary records. The use of questionnaires highlighted further measurement issues. Inter-rater reliability was acceptable (i.e., over 80%) for all the questionnaires used in the second study, but test-retest reliability was low for the Friendships Questionnaire (65%) and the Decision Making Questionnaire (68%). Friendships are likely to change and so the test-retest reliability could also be viewed as assessing validity, and this would suggest the questionnaire identified real changes that had occurred. A comparison of parts of the Opportunities Questionnaire with diary data suggested quite major overestimation of events, e.g., how often a person goes shopping within a week. These findings suggest that questionnaires should not be used in isolation, as the only measure to evaluate quality of service/outcome. Asking



views of service users and observational measures were found to have few measurement problems, e.g., the reliability of the observations was acceptable, but both were time consuming. It is most important that researchers and those monitoring services are aware of these issues. The research has offered additional practical information concerning these measurement issues.

#### b) The Way Forward

It is suggested that future research could use the approach of the methodology of Study II and apply this in a wide range of community residential services. The methodology involved a number of case studies that collected in-depth information, used a number of measures and analysed the data systematically, with reference to the same set of questions. A number of cumulative projects would add to the findings of Study II. This could be achieved by asking the same questions (e.g., what do people do in the evenings and what influences these activities) in a range of services. In order to achieve this, it would be necessary to investigate methods which are less time consuming and could be maintained as part of a regular monitoring and feedback service.

Future use of the measures may depend upon less time being required for their completion. The features of the measures that were time consuming were the number of interviews, the number of observation sessions, the analysis of the diaries and the time required "to get to know the people" in the service and offer explanations. It was considered that the latter feature was likely to be essential if processes are to be identified. So, two to three visits to a service are necessary if people are to understand what is involved and to be prepared to offer information - which may include criticisms of their service. The number of interview sessions and observation sessions could be reduced since usually information was being repeated and sometimes was being used as a confirmation and check only. In addition, the observations could be simplified to using a recording

form and recording main activities only, e.g., domestic activities, leisure, watching TV, and not recording detailed interaction. Similarly, diary records could ask for less information and record major activities only. Clearly, further work needs to investigate such possible modifications to the measures.

c) Recommendations: Data Collection for Case Studies

It is suggested that case studies require consideration of the questions to be addressed, the method of data collection and analysis.

1) Clarification of Questions to be Answered:

It is particularly important to be clear and precise about the questions to be answered. Questions that are considered most relevant include:

- a) What do users do within their residential service?
- b) How much time do users spend in integrated settings?
- c) What decisions and choices are available to users?
- d) What are the users views of their service?
- e) What social contacts does the user have?

2) Data Collection to Answer the above Questions

a) Introduction to service

This phase involves getting to know a user and becoming familiar with the service. A full explanation of the measures and practical implications of participation need to be given before consent is requested. Time should be spent in the service, e.g., two evenings before any data is collected, and could involve participating with users during mealtimes, household and leisure activities.

b) Questionnaires

The questionnaires on Decision Making and Friendships are to be completed with the person and a carer (who has known the person for a least three months). These can be completed after the introduction.

c) Observation of the Users Activities

Two introductory sessions are required for the user and other people to become accustomed to this form of data collection. Following this, data should be collected on five consecutive weekdays for 1 hour 30 minutes after the person has returned from their daytime activities. Observations could involve recording events within the following categories: household activities, leisure activities, personal activities (in public areas), and interactions that continue for longer than one minute.

d) Diary Recording

Diaries should be kept by carers over a two week period and commencing after the introduction to a service. Carers would be asked to record on a daily basis:

- \* major activities within the household, within the categories of household, leisure and personal activities
- \* activities out of the household, i.e., where visited and with whom
- \* visits and visitors, e.g., family, professionals.

The diary may be in the form of a daily checklist and looked at on each visit. Major activities refer to those that continue for 15 minutes or longer. Particular attention needs to be given to clarify whether activities out of the household are in segregated or integrated settings.

#### e) User Views

Users should be met after the observations have been completed. Interviews may include a range of "yes-no" and 'open-ended' questions. Topics need to be covered more than once as a check on the reliability and validity of views. It is recommended that topics include: views of the present service; features liked and disliked; carers; other users; friendships; views of past placement and preferences; activities within and outside the service; preference for future placements. Some users may find the number of topics too great and the issue of preference complex. In this case it is suggested that specified topics and questions are selected.

#### 3) Analysis of Data

The analysis of the data needs to be completed with reference to the questions. The data should systematically be used to answer each question by referring to a number of possible influencing factors. Outcome and influencing factors should be considered for each question. Some examples are given in Table 36.

Table 36

Outcome and Influencing Factors for each Question  
(Examples)

Question	Outcome	Influencing Factors
1. User Activities	Number of household activities.	Carer completion of task. Allocated jobs/rota.
2. Integrated Settings	Time in integrated settings	Aims and philosophy of service. Large group activities
3. Decision Making	Decisions participated in	Aims and philosophy of service House meetings.
4. User Views	Wish to remain in present service	Knowledge of other services. Views of carers and peers.
5. Social Contacts	Number and range of contacts	Regular contact with a person without disabilities. Time in integrated settings.

Table 36 gives examples of outcome and influencing factors. More factors are available in Chapter VI and were used when analysing the individual cases. This form of analysis requires that the researcher uses more than one form of data to answer a question, e.g., the question on Integrated Settings involves the use of diary data and user views. In addition, it may not always be necessary to have such a clear split between outcome and influencing factors. For example, when considering the amount of time spent in integrated settings, large group activities may be both an outcome and an influencing factor. This method of analysis can help the researcher to make recommendations for practice within a service.

## 2. MONITORING AND FEEDBACK OF COMMUNITY RESIDENTIAL SERVICES

The White Paper: Caring for People (1989) recommended that the Local Authority will be required to establish inspection and registration of residential care homes. The White Paper emphasised achieving high standards of care and that common standards should apply across all services. It was proposed that emphasis will be given to assessing the quality of care provided and quality of life of residents as well as physical conditions. This latter recommendation requires the measurement of outcomes for the users, rather than inputs which services have traditionally attempted to measure.

The current research has practical implications for monitoring residential services, as recommended by the White Paper. It is considered that monitoring would be more effective if clear and practical feedback was offered to services, e.g., concerning processes which lead to different outcomes for users. Monitoring is likely to be most useful when it forms part of a self-evaluation by a service. Landesman (1988) suggests that one of the best ways to prevent institutionalisation is to encourage service providers and recipients to evaluate the service on their own. The individuals involved in the self-appraisal should be able to shape the process, for ultimately they will be implementing any changes. It is important for any monitoring approaches to be negotiated with the service and for the service to be clear about the outcomes being assessed.

In the previous section, proposals were made for reducing the time required to collect the information. One option is to collect a minimum amount of data for a number of people in a residential service, on an on-going basis. Data collection is more likely to be practical and to have greater reliability if it is in the form of a diary, which records only major activities, e.g., visits from the service, household and leisure activities within the service. The aim of this data is to investigate the outcomes, what people do and where they spend their time. Combined with this, it is necessary to spend time in the service and collect more detailed data on one individual (chosen at random).

Time spent initially in the service could involve explaining the process to users and staff, and giving time to answer questions and simply spending time with people, joining in their lifestyle. At this stage, it may also be useful to complete questionnaires, e.g., decision making and friendships. After this initial time is over, e.g., after four/five evenings, observation data can be completed and this could involve less complex observations than used in Study II- for example, a more detailed form of the diary kept by carers. Following this, users are asked their views of the service.

The approach of collecting in-depth information could be completed in about two weeks in services where six or fewer people live. In larger services, it may be necessary to complete diaries on a small sample of people only. The above approach retains many of the advantages of the design of Study II and would enable practical feedback to be given to services. A procedure would need to be clarified for dealing with sensitive issues, e.g., complaints about carers. The approach outlined above maintains the emphasis on measuring the outcomes of the service, specifically the following:

- \* the views of service users
- \* what people do in the evenings
- \* the amount of time spent in integrated settings
- \* participation in decision making
- \* social relationships.

Stating clearly the outcomes to be measured is more likely to be useful than attempting to measure "quality of life" which as a concept remains poorly defined.

The cost of implementation of a monitoring and feedback service depends on the size and number of services to be included. Maintaining an on-going diary system would involve few additional resources and could, in part, replace current record keeping systems. Feedback and the collection of in-depth information would require staffing. The effectiveness of the approach in terms of improving services may depend on the quality of feedback.

### 3. PRACTICE GUIDELINES

The research has identified a number of practical issues which it may be useful for services to address. These will be discussed within the following sections:

- \* taking account of the views of users of the service
- \* operational management of services
- \* size of the service
- \* implementation of practice guidelines.

#### a) Taking account of the views of users of the service

Users require a mechanism through which their views can be clearly stated. The majority of people in Study II had seriously considered wishing to leave their service, but their carers were not always aware of this. Two people whose carers did know of their preferences, both had actively participated in an Individual Planning process. It is likely that this process led to discussions about a person's future and so had highlighted their views of a service. In addition, it is suggested that having a person outside the service who discusses issues may help to identify preferences to leave or stay. Such approaches require time and skills and are likely to lead to pressure on services to deliver alternatives. In addition, direct carers must be aware of the process of asking users their views and support such a process.

One factor found to influence the views of people in Study II was their knowledge of services and alternative living arrangements. Services need to consider the issue that offering people more information about alternative styles of living may increase their dissatisfaction. Users have a right to such information and often actively participate in acquiring information, e.g., self-advocacy groups. Carers need to be aware that helping people to gain information and make informed decisions is likely to increase dissatisfaction with current services.



A most important practical issue was found to be that of user views of carers. Although complaints about carers were few, when they occurred they had a major impact upon user views. It is very important that users are enabled to state these views and that their concerns are acted upon. However, such situations need to be treated with great care and sensitivity for both the user and the carer. One practical approach may be for a person outside the service to act in the role of a negotiator and counsellor in such a situation. In addition, such difficulties may be avoided (or reduced) by involving users in the appointment of direct care staff.

A similar issue for services was found to be user views of the behaviour of the other people in the service. Users were usually prepared to state their complaint openly to carers, but it was likely that carers were not considered (by users) to respond clearly. Overt management programmes using procedures such as 'time out' may be undignified for those involved and are not suggested as a widespread practical approach for many situations. However, acknowledgment of the behaviour, discussion and reassurance for the other people in a service are likely to be beneficial, particularly when combined with positive programming. This process was found to work particularly well in one service by the use of regular house meetings, where such issues were openly discussed and the implementation of management approaches including positive programming. In addition, users could be encouraged to play an active role in the selection of other people living in the service.

In summary, the research suggests that services need to consider the following issues for practice:

- a) A mechanism is required for users to state their views of a service, e.g., a preference to leave, dislike of a carer or peer, and a person outside the service may be required to act in the role of an advocate.
- b) Approaches for management of challenging behaviour need to be discussed and acknowledged with users, e.g., within regular house meetings.

c) Services need to encourage users to gain more information about alternative services, but to recognise that this may lead to increased dissatisfaction with current services.

d) Users who are able to express their views verbally should be encouraged to participate in the selection process for carers and for other people living in the service.

b) Operational issues

Study II highlighted many issues that can be grouped together as operational features of services. In some cases, the policies of a service remained somewhat unclear, even after spending long periods in services, e.g., was a service actively encouraging use of integrated settings or was this merely fortunate when it occurred? It is felt to be inadequate to leave outcomes in such a vague fashion, and it is likely that in these situations the value judgments of direct carers become influential. So, it is suggested that services need to be very clear about their goals and the outcomes that are expected. Merely writing these in an Operational Policy is probably ineffective, although it may be a practical starting point. It is suggested that a far greater active role for operational managers is necessary combined with training for direct carers. Guidelines and possible methods for achieving specific outcomes will be discussed in turn.

i) Activities

Firstly, the research investigated processes that lead to users being involved in activities. Involvement in household activities was found to be influenced by factors including allocating tasks/having a rota, the activity of carers and putting clear aims into practice. A rota may not be an approach to use in all services, but selectively and only with the involvement of users. A danger of using a rota is that it can easily become regimented in its application which should be avoided in community settings. However, some approach is required in a service to ensure that users are encouraged to participate to household

tasks. For example, this may be a discussion with users about the tasks, or a rota, or allocation of specified tasks. Different approaches are likely to suit different users and services. An important influence over participation was found to be the activity of the carers. So, it is recommended that it is clearly stated to carers that they do not do the household activities but enable the users to complete the tasks, with help as required. It is the role of 'senior' carers and managers to model this approach and ensure that this policy is put into practice. In addition, it may be necessary to discuss the value judgments of carers, e.g., that users are tired on return from the Day Centre and so should not prepare their own food. Study II found that users enjoyed household activities and were able to participate actively. Only in one case, where a person was doing considerable amounts of food preparation, were any complaints received - and this issue of the degree of participation expected can be discussed and clarified with each person. Users were proud of their achievements in domestic activities, and participation gave satisfaction and self-respect. In some services, the size of service may be a limiting factor on participation, and this is discussed below.

Many leisure activities were initiated by users themselves, especially watching TV. When leisure activities are becoming repetitive for a person, e.g., listening to music for long periods alone, it is recommended that carers offer alternatives that are age-appropriate and offer users a choice. The only alternatives that were offered during the study were crafts and making decorations (it was doubtful whether the latter was age-appropriate). Users initiated some leisure activities, e.g., writing notes and a diary. Services need to investigate additional interests within the house/hostel, e.g., card games, board games, hobbies, magazines (such as those about gardening, motor cars), indoor plants, dress making, cake making. The people who participated in Study II could (with help) become involved with such activities, but there was no evidence of this choice being available.

## ii) Friendships

A further area of practice that the research investigated was that of friendships. Clearly this is a complex area, but there are some basic points that services could start to consider. Firstly, some of the subjects were confused about "who is a friend?" and viewed carers and acquaintances as "friends". One service was addressing this by emphasising that carers were not friends and discouraged touching by users. This caused distress to the user (who participated in the research), possibly because apart from one relative she had few friendships. Overall, it is considered misleading to continually not help users to distinguish between friends, carers and acquaintances. It is suggested that in conjunction with explanations about different relationships, there is a need to help people to make and maintain friendships.

A further practice issue concerning friendships was found to be that of clear difficulties in close relationships, which were having a major impact on those concerned. It is suggested that people could be offered a counselling service by carers to help to identify their difficulties and consider options. Such problem solving skills are difficult for people with learning difficulties, unless they are offered active support.

In addition, it was found that some people in Study II did not often meet friends/acquaintances outside the service. Friendships with non-disabled people were rare, but requested by one person. These are two areas where carers need to place an emphasis. For example, if a person living in a residential service is known to be friends with another person, then carers could help the two people to arrange to meet. Friendships with people without disabilities is probably the most difficult of these issues for services to address successfully. However, if people do not come into contact with people without disabilities, friendships will never develop, so presence in integrated settings becomes a major aim. Finally, it is particularly important for carers to recognise the importance of friendships in people's lives.

### iii) Decision Making

The research found that in services where users were most actively involved in less frequent decisions, e.g., where to live, meetings took place. These "house" meetings gave a clear opportunity to discuss decisions and choices such as where to go on holiday. So, it is suggested that regular meetings can help users to participate in taking decisions.

However, it was likely that often decisions were taken on an informal basis. Carers need to be aware of this process, and regularly, i.e., daily, help users to participate. Such approaches also need to be emphasised in operational policies and induction training.

### iv) Integration

Study II found that the amount of time that users spent in integrated settings varied considerably. Since all users gave very positive reports of time spent in integrated settings, e.g., shopping, it is suggested that carers should be setting this as a clear aim and priority of a service. However, in most services it remained unclear whether or not integration was an aim. Presence in community settings is usually recommended as an important aim of a service and is essential if any acquaintances with non-disabled people are to be made and maintained.

Study II suggested that various actions on the part of carers are likely to help to achieve integration for users. Firstly, large group trips need to be avoided and this may have implications for staffing levels. Secondly, it was clear that particular attention should be given to people who are unable to go out alone, e.g., because they are unable to cross a road independently. A need was identified for carers to support people in integrated settings and to teach skills that would enable a person to go out alone/as a member of a pair. Thirdly, having a

clear and active link with the community, contributed towards people spending time in integrated settings. Such links may be difficult for carers to develop, but emphasis could be given to taking opportunities, e.g., by supporting contacts with relatives and friends.

Finally, it was found that people who spent longer periods in integrated settings were more likely to participate in certain activities, i.e., shopping, use of public transport, voluntary work, going to an evening class, church and a pub. These are particularly important activities for carers to consider, e.g., how do people travel and how is the shopping organised? If carers do the shopping, this is an opportunity that is lost for users to be present in an integrated setting, as well as the opportunity to use money. So, it is suggested that carers need to encourage users to participate regularly in the shopping, integrated leisure activities (e.g., evening class) and to use public transport.

In summary, the research suggests that services need to consider the following operational issues for practice:

- a) Clear expectations regarding outcomes, which are written in an operational policy and emphasised by managers.
- b) Activities: Clear mechanisms need to be developed for encouraging participation, e.g., specified tasks, a rota, daily discussions. Carers need to be aware of the influence of their actions. Efforts need to be developed to offer a wider range of leisure activities.
- c) Friendships: Users need clear support and help with difficulties in close relationships. Greater attention is required to meeting friends outside services and meeting people without disabilities. Clarification of relationship roles is also necessary.

d) Decision making: Regular 'house' meetings are likely to help people to participate in infrequent decisions, but carers also need to be aware of the informal process of much decision making.

e) Integration: This needs to be clearly stated as an aim of services. Large group trips should be avoided and an emphasis given to supporting people in integrated settings who are not able to go out independently. In addition, developing active community links is useful and participating in certain activities increased opportunities for integration, e.g., shopping, use of public transport.

c) Size of service

The size of the service was found to have less influence on outcome than was expected. However, size did affect certain practices and it is considered particularly important that planners are aware of these. The following practices and outcomes were influenced by size:

Group size was found to have an effect on interaction levels. In smaller services, i.e., 3-4 people living together, interaction increased at mealtimes, but in contrast in larger services, interaction decreased. It was noted that interaction was most likely to occur when people were in pairs or a group of three participating in a task, e.g., a household task. This was consistent with the finding that interaction with carers was more likely to be higher in the smaller services. So, if services wish to increase the opportunities for interaction, group size should be decreased. In addition, it was found that most interaction between users occurred between a small number of people only, so that large groups were unlikely to encourage more interaction and friendships.

A further practice issue concerned the range of tasks offered. In larger groups, it was found that people were more likely to participate in a narrow range of tasks, e.g., laying the tables and clearing the tables and to repeat these tasks every day. Clearly offering a wide range of household tasks, such as meal preparation, can be more difficult in larger services because of the large nature of any task. So, in order to offer a wide range of household activities, group size should be small, e.g., 3-6 people.

Larger services were found to be more likely to have features which could be described as institutional. The features included institutional furniture, catering style kitchen equipment, few/no possessions on open display downstairs, notices outside, a locked room/office. Smaller services were less likely to have these features, but it is suggested that planners and managers need to take active steps to avoid their presence. These features can emphasise the difference in power relationships, e.g., locked rooms, and may reduce opportunities, catering equipment is more difficult to learn to use, and some features are likely to encourage the public to view people with learning difficulties as different, e.g., a notice outside.

In summary, the size of a service has the following implications for practice:

- a) Small groups are required to achieve higher interaction.
- b) Small groups are more likely to encourage a wider range of tasks.
- c) Smaller services are less likely to have "institutional features".
- d) Implementation of Practice Guidelines

Services need to seriously consider how to implement the practice guidelines. It is suggested that a variety of methods may be required if services are to practice these approaches over a long period of time. These may include:



i) Operational Policy

An operational policy which states objectives clearly is necessary. The effect of a policy is likely to be influenced by the extent to which all involved with the service are familiar with the contents. The policy will need to be discussed by all direct care staff, managers and users.

The contents of an operational policy will require that the following topics are included:

- \* a mechanism for user views to be expressed, e.g., reviews with the support of an advocate, regular house meetings
- \* user participation in activities, e.g., specified tasks, a rota
- \* participation in integrated activities
- \* supporting friendships
- \* user participation in decisions, e.g., regular house meetings
- \* user participation in the selection of carers and other users.

It is likely that these topics will be in addition to other such as finance, staffing levels. The use of advocates suggested above can refer to involving other professionals from outside the service, e.g., members of a community team.

## ii) Clarity of Objectives

It is most important that services are clear about their objectives and that these are regularly discussed amongst all carers. One role of an operational manager is to ensure that these objectives are being achieved, or, if not, why and what measures can be taken to overcome constraints. Services may need to consider their objectives (which cover the same topics as suggested for inclusion in the operational policy). Objectives could include:

- \* users views are acknowledged and influence events
- \* users participate in all domestic activities
- \* users spend time in integrated settings
- \* users are supported in friendships and relationships
- \* users participate in decisions.

These objectives can then be added to by individual services, but using clear language which enables both users and carers to know what "to do" in a range of situations.

## iii) Monitoring and Feedback

Regular monitoring and feedback to a service is an additional method of encouraging a review of outcomes achieved. It is suggested that this takes the form outlined in section two of this chapter, i.e., a minimum data set in the form of a diary, in combination with more detailed information on one individual.

The value of such feedback is that it can be used within the service to compare the outcomes achieved with the aims of the service. This form of feedback can be used in a constructive manner which will influence day-to-day practices within any service.

#### iv) In-Service Training

In-service training is of importance if the practice guidelines are to be implemented. It is recommended that this should not be limited to an induction programme, but needs to be on-going. It is suggested that the following topics are necessary:

- \* discussion of the operational policy
- \* review of the aims and objectives of the service
- \* review of outcomes achieved
- \* management of challenging behaviours.

In addition, the aims and objectives and operational policy are likely to necessitate a range of additional topics that are often covered in induction courses and packages such as the E.S.C.A.T.A. package: Bringing People Back Home, Participation in Everyday Activities (developed in collaboration with South East Thames Regional Health Authority). These may include: helping people to participate in everyday activities, teaching strategies, planning the day.

#### v) Planning Services

The findings have clear implications for planning future services. In practice at the planning stage, planners are most likely to consider structural and permanent factors such as the size of the service, location, the physical environment and staffing levels. The findings of Study II have demonstrated that whilst these are the important factors, they can have less influence on outcomes for users than may usually be realised - see (c) above for a discussion of the impact of the size of services. If factors, such as staffing levels, are incorrect, then this places obvious limits on outcomes for users. However, even when all these structural factors are correctly planned, outcomes for

users may not be as positive as can be achieved in less than ideal circumstances. It is suggested that at the planning stage, considerably more attention is given to the operational features such as the aims of the service, day-to-day operation of the service. It may be helpful to consider planning in terms of structural and permanent features, operational features and outcomes for users. The permanent and operational features can be planned with specific outcomes in mind, e.g., to achieve high engagement in household activities, a service requires domestic style kitchen equipment, no kitchen staff, but also this needs to be a clear aim and a mechanism in place to achieve this.

#### vi) Funding of the Implementation

The majority of the above recommendations require little additional funding, but need some re-direction of current resources. For example, the role of a manager would need to allow time for the development of an operational policy and discussion of outcomes. It is anticipated that a monitoring and feedback service would require funding.

### 4. VIEWS OF USERS

An important feature of both Study I and Study II was the emphasis given to the views of users of the service. It was clear from both studies that users can express their views and these can be assessed objectively. However, interviewers need to pay attention to acquiescence bias and use strategies such as repeating questions in a different format. Such interviewing approaches were used with success in both studies.

Study I found that the majority of users preferred their community placement to living in hospital. The users did not wish to return to hospital, and it was considered that many people felt that anywhere was better than living in hospital. It remains unclear how much knowledge these people could have of alternative residential services in the community. They had all left hospitals within the last year (approximately) and also some people had lived in hospitals for many

years. So, it is possible that a lack of knowledge of alternatives influenced some people's views. In summary, Study I would suggest a high level of satisfaction with community placements.

Study II found a far greater degree of dissatisfaction. Four out of six people wanted to leave their residential service at some time in the future. Two people expressed a dislike/mixed views of their service. The desire to leave was influenced by a number of factors:

- \* Dislike of the behaviour of other people living in the service.
- \* Dislike of a carer.
- \* Knowledge of alternative living arrangements
- \* Identified friend(s) to live with.

Two or more of these features were present for each person who wanted to leave. The first feature, dislike of the behaviour of others, was also reported by one man who wanted to remain in his service. The number of complaints and people wanting to leave had not been anticipated before the study began. It is particularly important that none of the people who wished to leave wanted to go or return to an institutional service nor to a larger service. In all cases, people wanted to move towards greater independence and two people had identified other people to live with.

There is a major difference between the findings of Study I and Study II. Study I found the majority of people had positive views of community residential services, whilst Study II found a high degree of dissatisfaction. Two main reasons are suggested to account for this finding. Firstly, the methodology of the two studies was different. In Study II, the subjects had met the researcher several times before any interviewing took place and a series of interviews took place. It considered that this approach is much more likely to identify criticisms. It is less likely that people will discuss their dislike of a service during a single interview with an unknown person.

Secondly, it is probable that more people in Study II had information about alternative styles of living, e.g., two people had lived in a family home until a few years before the study and had clear recollections of this, two people belonged to a People First group. So, it is suggested that the differences in the views expressed in the two studies can be explained.

The research indicated that it is likely that there is a high degree of dissatisfaction among people in community settings. It is likely that as people with learning difficulties gain more information about alternative services and styles of living, their satisfaction will decrease. Expectations are more likely to be raised by increased information and unless met, dissatisfaction will be the outcome for some people. In the current situation of services changing, but very slowly, it is felt that this is an issue that managers and service personnel need to acknowledge. It is possible that the dissatisfaction could become an impetus to change as people's rights become more accepted.

Both studies met people who predominantly could express their views verbally. It is a drawback of the research that no-one participated who was unable to express their views verbally. Although the people in both studies had individual preferences, there was some consistency over features liked and disliked. Most people liked leisure activities and going out, involvement in decision making and a good quality physical environment; also, friendships were very important. People often reported disliking the challenging behaviour of others when this directly affected them, and carers who attempted to control or tease users. So, there is some general consistency over features that are liked or cause distress. Future studies need to address methods of establishing the views of people who communicate non-verbally, e.g., noting reactions and behaviour in a range of situations may help to identify views.

## 5. FINAL NOTE - PERSONAL EXPERIENCES

The researcher's predominant memory of the research is that of the sad stories, and the many unresolved issues for people. In particular, the two people in Study II who had very much wanted to leave and a year later plans remained either vague and uncertain or possibly not consistent with their preferences. Also, there was a woman whose life had been dramatically altered by the death of a parent and she continued to miss her regular shopping trips. In spite of such difficulties, all the people remained outwardly cheerful for much of the time, and the impression gained was of resignation to their situation, but with some remainder of hope.

The researcher was struck by the power of carers. Decisions and everyday actions could clearly be influenced by carers. The potential power became evident when one woman discussed marriage and was told that this was stupid of her. This caused her considerable distress, but she felt unable to clearly contradict the views of her carers.

A great personal advantage of the studies was the opportunity to meet people in various services without a clinical task to complete. This allowed the researcher to spend time with people in the role of an acquaintance and to complete a project together. This highlighted the differences between the researcher's lifestyle and that of people living in services, e.g., weekend activities were sometimes very repetitive in services, the small income of users and the unfulfilled hopes. In addition, the research offered an opportunity to talk to many direct carers. Whilst all carers acknowledged the advantages of a residential service in the community, they experienced a number of difficulties, e.g., inconsistent practices among carers, loneliness at night in a house, complaints about day services and other services and professionals and staff turnover. It was likely that some of these difficulties influenced the welcome given by all services to the research visits, e.g., sometimes carers felt isolated and the research project was a welcome diversion!

The researcher has developed and changed her views considerably about outcome measures of residential services. This process has been continuing throughout the course of the studies. The outcome of the first study led to the conclusions that single visits and interviews may not give a true picture and similarly the use of questionnaires alone did not clearly differentiate between services, nor could clear outcomes be assessed. The methodology used in Study I was useful to gain an overall picture of numbers in services, how long people remained, the size of a service. The second study emphasised the time required to gain useful outcome measures and the benefits gained from time given to collecting observational data and interviewing users. Also, it was concluded that the diary was a practical means of assessing integration. The researcher was also somewhat disappointed by the lack of clear aims in most services.

Before starting the second study, the researcher had a number of reservations, e.g., invasion of privacy, use of a computer in a house. These concerns were unfounded. Also, it was pleasantly surprising that most people approached wanted to participate in the project. On the visits, the researcher was warmly welcomed and, contrary to initial expectations, leaving a service was the most difficult part of the research.

It is the view of the researcher that this field of research requires more work, and the White Paper has highlighted this need. In particular, the work on processes within services may be of particular long-term benefit to investigate. It is hoped that the research will be an inspiration to others who share the same interest in pursuing high quality services.



## SUMMARY OF CONCLUSIONS

The main topics discussed are:

1. The use of multiple case studies is outlined. An important feature of the methodology was that each case study addressed the same set of questions and involved the systematic collection and analysis of objective and in-depth data. A major advantage was found to be that processes and influencing factors could be identified. The approach of measuring outcomes for service users was valuable and suggestions of relevant outcomes are made.
2. Recommendations are made for the future use of case studies in research into the outcome of community services. Relevant questions are suggested, together with methods of data collection including introduction to a service, questionnaires, observations, recording of activities and interviewing users. An approach to analysing the data is outlined which involves considering the questions asked, the outcome and influencing factors. Future research using this methodology would add further information about the processes that influence outcomes.
3. Recommendations are made for monitoring and feedback of community residential services as recommended by the White Paper: Caring for People (1989). This involves the use of a minimum data set, combined with more detailed data collection for one individual within a service.
4. The research studies identified a number of practical issues for services to address and these are outlined. These include a mechanism through which users views can be stated and acknowledged, clarification of the outcomes of the service, processes that lead to user involvement in activities and decisions supporting friendships and participation in integrated settings. The influence of the size of a service is discussed.
5. An important feature of both studies was the emphasis given to the views of the users of the service. It was found that users were able to express their views and that these could be assessed objectively. Study I found that the majority of users preferred their community

placement to living in hospital and suggested a high level of satisfaction with community placements. In contrast, Study II found a far greater degree of dissatisfaction. Four out of six people wished to leave their residential service at some time in the future, and they wanted to move towards greater independence. Reasons for the different findings are discussed.

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## A P P E N D I C E S

GLENFRITH UNITPolicy for Discharge of Residents to Community Care

For the purpose of this document, Community Care encompasses Group Homes, Local Authority Compatible Units, Landladies, Local Authority Units, Private Health Care Establishments, and Community Units and Units provided by Voluntary Agencies.

1. The decision as to the suitability of the resident for discharge will be the responsibility of the multidisciplinary care team. The team, which will consist of medical, nursing and social work members, and any other professional deemed necessary, will make this decision in cognisance of all available reports and date.
2. In identifying a suitable place for discharge, due regard must be given not only to maintaining but enhancing the resident's quality of life. Such things as retaining personal contact with friends and the accessibility of the future placement for residents' relatives, should be considered.
3. Once it is agreed that a resident is ready for discharge, the team will appoint named members of staff to ensure that the preparation goes smoothly. The tasks these staff will perform will include:
  - a. Notifying and consulting with relatives
  - b. Arranging suitable residential, day care and/or occupation
  - c. Assessing need for and arranging any support services which may be required, including multidisciplinary support and financial help.
  - d. Liaising with proposed care agency and identifying a future key worker.
  - e. Forwarding patient transfer form and any other information which may be required.
4. On discharge the R.M.O. or his/her agent will forward a discharge letter to the new medical practitioner. The residential care worker will provide a picture of care needs.
5. For all community discharges, the "home bed" will be retained for a period of six weeks. If, during this period, the placement proves unsuccessful the resident will be returned to the pre-discharge placement. If, towards the end of the six week period, there is doubt as to the success of the placement, the new care agency may apply to the multidisciplinary team for a time extension.
6. At the end of the six week trial period, or any subsequent extension, if the placement is thought to be satisfactory, the home bed will not be available. Should there be any subsequent failure of the placement, the hospital will attempt to provide the service thought necessary through existing mechanisms.

# LEICESTERSHIRE HEALTH AUTHORITY

## THE GLENFRITH UNIT

Leicester Frith Hospital  
Stretton Hall Hospital  
Gorse Hill Hospital  
Mountsorrel Hospital

Kibworth Hall Hospital  
Montrose Court  
Stoneygate

Leicester Frith Hospital  
Groby Road  
Leicester LE3 9QF

Telephone (STD 0533) 872231

Our ref AH/MSL

ext. 3168

Your ref

Dear

I am undertaking research in the area of people with learning difficulties leaving large living environments, e.g., hospitals, to live in small community situations. There have been few investigations of people with learning difficulties living in community based environments and the need for such work is evident. In order to complete the research, I have registered for a Ph.d and so have discussed the planning and design of the research with my supervisors.

I would appreciate your help in completing the research and I would like to visit yourself and Mr/Ms \_\_\_\_\_. I usually talk to you both separately and we discuss your opinions about the placement - the positive opportunities offered, any difficulties encountered, support services, etc. I anticipate the visit would last about 2 hours 30 minutes.

Before my visit, I would like to reassure you that this does not imply that Mr/Ms \_\_\_\_\_ should change his/her placement, nor does it indicate that any problems exist. In addition, all the discussions are confidential.

May I suggest I telephone you in the next few days to discuss the possibility of arranging a time for me to visit. If you and/or Mr/Ms \_\_\_\_\_ would rather not participate in the research, please contact my secretary or myself on the above number.

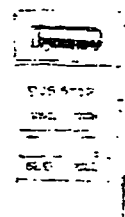
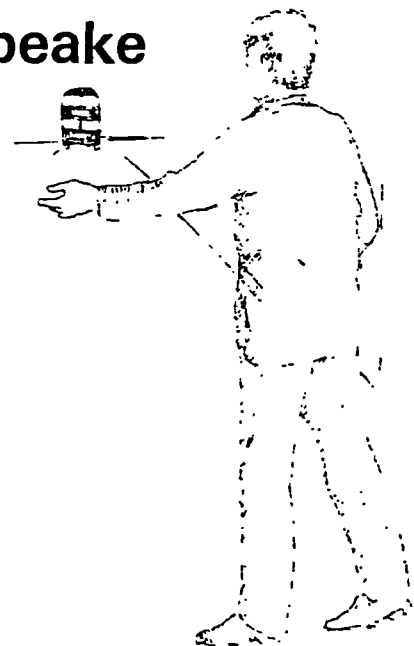
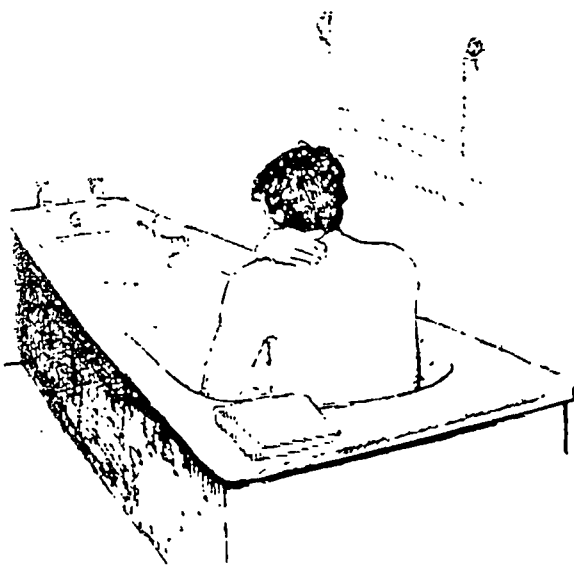
Thank you for your help.

Yours sincerely,

Angela Holland,  
Clinical Psychologist

# Scale for Assessing Coping Skills

Edward Whelan & Barbara Speake





# Scale for Assessing Coping Skills

PAGE 1

	1	2	3	4	5	6	7
	Can do without help or super- vision	Can do but only with help or super- vision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opport- unity to do this
<b>SELF HELP</b>							
<b>1. Selection of clothing</b>							
(a) Selects own clothes from drawer or wardrobe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Chooses clothing and footwear suitable for weather conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Chooses clothing and footwear appropriate to occasion (eg. work, party)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Shows personal preferences and awareness of fashion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Locates clothing/footwear shops or departments and knows own sizes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>2. Undressing/dressing</b>							
(a) Removes simple articles of clothing (e.g. socks, underwear)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Puts on simple articles of clothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Removes garments requiring unbuttoning or unzipping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Puts on garments requiring buttoning, zipping, tying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Completely dresses self, in sensible sequence (e.g. does not put shoes on before socks)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3. Use of toilet</b>							
(a) Recognises when needing toilet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Uses toilet by self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Flushes toilet and adjusts dress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Leaves toilet clean, fit for others to use. (Ladies: disposes of sanitary materials properly)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Uses public conveniences, knows difference between ladies and gents, can operate coin mechanism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE

	1 Can do without help or super- vision	2 Can do but only with help or super- vision	3 Cannot yet do	4 Do not know whether he can do this	5 Uses the ability an adequate amount	6 Does not use this an adequate amount	7 There is no opport unity do thi
<b>4. Personal hygiene</b>							
(a) Washes hands and face when needed, after toilet, before meal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Takes bath or shower when needed. Uses deodorants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Cleans teeth properly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Washes hair properly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Changes underwear and socks regularly. (Ladies: Copes with menstruation appropriately)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>5. Grooming and appearance</b>							
(a) Cleans and cuts nails	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Blows nose and uses handkerchief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Shaves (if necessary) Ladies: under arms, and legs if necessary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Combs or brushes hair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Visits barbers/hairdressers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>6. Care of clothing</b>							
(a) Puts clothes away, hangs them up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Cleans and polishes shoes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Knows when clothes need laundering/dry cleaning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Irons simple articles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Carries out simple repairs, stitching on patch, buttons, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 3

	1 Can do without help or super- vision	2 Can do but only with help or super- vision	3 Cannot yet do	4 Do not know whether he can do this	5 Uses the ability an adequate amount	6 Does not use this an adequate amount	7 There is no opport- unity to do this
<b>7. Food and drink preparation</b>							
(a) Makes hot drinks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Can assemble ingredients, open tins, packets, or bottles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Prepares vegetables for cooking, shells peas, peels potatoes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Follows simple recipe or instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Selects correct oven temperature and monitors cooking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8. Setting (and clearing) table</b>							
(a) Places mat, salt and pepper etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Sets simple place: correctly positions knife, fork, spoon, glass	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Places serving dishes and serving utensils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Clears away, taking care with breakables	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Clears cloth, shakes, wipes down table	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>9. Table habits</b>							
(a) Uses knife, fork and spoons appropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Serves food and drink to self in reasonable quantity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Pours out liquids with care, no spilling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Considers others, passes salt, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Eats unoffensively, mouth closed, no spilling, at correct speed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 4

	1	2	3	4	5	6	7
	Can do without help or super- vision	Can do but only with help or super- vision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opport- unity to do this
<b>10. Washing up</b>							
(a) Dries items and puts away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Prepares dishes for washing, clearing food scraps into bin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Prepares bowl or sink, correct water temperature and amount of washing up liquid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Washes greasy dishes thoroughly, top and bottom, no breakages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Washes cups, saucers, cutlery and glassware, taking care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>11. Making the bed</b>							
(a) Strips bed down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Puts pillowcases on pillows	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Tucks bedclothes in at sides	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Puts bedclothes on in right order	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Pulls sheets straight, avoids wrinkles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>12. Tidying room</b>							
(a) Tidies things away in proper place, games in cupboard, books on shelf etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Dusts surfaces	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Sweeps/vacuums carpet, also under the bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Cleans window(s) and mirror(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Decorates walls, reflecting personal interests (posters, certificates, beer mats, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 5

	1	2	3	4	5	6	7
	Can do without help or supervision	Can do but only with help or supervision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opportunity to do this
<b>13. Leisure at home</b>							
(a) Decides how to spend own time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Occupies self for short periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Selects favourite TV or radio programme(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Plays indoor games, dominoes, cards, table-tennis, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Engages in a creative hobby or interest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>14. First aid and health</b>							
(a) Shows awareness of danger and exercises caution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Knows how to obtain appropriate help in emergency, fire-brigade, police, ambulance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Treats simple injuries, and minor ailments, cuts, headaches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Takes simple health precautions, changing wet clothes, attention to weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Seeks medical help when required and takes medicine reliably	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>5. Community knowledge</b>							
(a) Can find own street and house, knows name and number	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Knows neighbourhood and can find way around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Observes safety rules when crossing road	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Knows location and function of community services, shops, Post Office, bank, library, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Asks directions and knows what to do if lost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 6

	1	2	3	4	5	6	7
	Can do without help or supervision	Can do but only with help or supervision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opportunity to do this
<b>16. Local transport</b>							
(a) Recognises correct bus stop and bus number for intended journey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Can state destination and pay fare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Alights at correct stop	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Travels alone on the bus behaving appropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Can plan a bus journey to a place never previously visited by bus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>17. Shopping</b>							
(a) Goes errand with note or shopping list	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Locates items, or asks assistant for help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Recognises difference between self service and other shops, behaves and pays appropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Shops for regular items, e.g. groceries, comparing prices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Shops for personal items, e.g. clothing, checking sizes, style, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>Eating out</b>							
(a) Knows difference between self-service and waiter service cafe or restaurant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Selects meal and drink and takes tray, cutlery etc. as required (in self-service cafe)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Orders from a menu, keeping to meals which can be afforded	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Observes table habits acceptable to public eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Locates pay-desk, or pays waiter. Avoids overtipping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 7

## OCIAL ACADEMIC 9. Communication

	1	2	3	4	5	6	7
	Can do without help or supervision	Can do but only with help or supervision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opportunity to do this
(a) Makes wants known by gesture, sounds, or simple language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Follows spoken instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Can say own name and address	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Uses whole sentences, speaking clearly and distinctly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Explains feelings so that others can understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## J. Reading

(a) Recognises letters of the alphabet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Reads important words, such as 'danger', 'exit', 'toilet'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Can 'sound out' new words, using knowledge of letter sounds	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Reads with understanding, e.g. uses newspaper to get information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Reads books, magazines, etc. for pleasure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## I. Writing

(a) Writes signature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Prints name, age, address	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Fills in printed forms, coupons, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Writes simple sentences, when dictated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Writes letters or messages which are easily understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 8

	1	2	3	4	5	6	7
	Can do without help or supervision	Can do but only with help or supervision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opportunity to do this
<b>22. Number</b>							
(a) Counts by rote up to 10 -	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Recognises and names numbers 1 to 10	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Counts by rote and recognises numbers between 10 and 50	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Counts and recognises numbers with three or more digits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Recognises and names fractions and decimal parts, (e.g. 12½p, 98.4 degrees)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>23. Use of number</b>							
(a) Has ordinal concept of number: knows which of two numbers is bigger	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Can use number scale when measuring or weighing self or goods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Adds or subtracts single numbers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Adds or subtracts numbers with two or more digits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Can do simple multiplication and division	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>24. Telling the time</b>							
(a) Tells time to nearest hour, using clock or watch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Tells time to nearest ½ hour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Tells time to nearest minute	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Sets a clock, e.g. alarm clock, to a given time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Uses 24 hour system, e.g. in reading a time-table	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



# Scale for Assessing Coping Skills

PAGE 9

	1	2	3	4	5	6	7
	Can do without help or supervision	Can do but only with help or supervision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opportunity to do this
<b>4. Concept of time</b>							
(a) Knows days of week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Associates certain times with daily activities, eg. rise at 8.0 am, lunch at 1.0 pm.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Knows months of year and order of seasons	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Can plan events in advance, using calendar or timetable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Estimates passage of time fairly well (eg. $\frac{1}{2}$ hr. ago)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5. Money</b>							
(a) Recognises and names coins	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Recognises and names notes: £1. 00, £5.00, £10.00 and so on	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Understands equivalence of coins (2 x 5p equals 10p)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Understands equivalence of coins and notes (2 x 50p equals £1)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Can add coins together to reach a specified amount, and can check change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>7. Use of money</b>							
(a) Makes purchases with coins or notes and checks change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Offers reasonable amount of money, where possible (eg. not a £5 note for a packet of chewing gum)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Compares prices on goods before purchase	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Spends money without over-spending, can follow a simple budget - avoids debt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Saves up for desired items (has bank account or post office savings account, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 10

	1 Can do without help or super- vision	2 Can do but only with help or super- vision	3 Cannot yet do	4 Do not know whether he can do this	5 Uses the ability an adequate amount	6 Does not use this an adequate amount	7 There is no opport- unity to do this
<b>28. Colour recognition and use</b>							
(a) Can name and match primary colours (red, yellow, blue) and black and white	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Can name and match secondary colours (orange, green, purple)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Can name and match intermediary shades (grey, pink)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Responds appropriately to colour signs, traffic lights, for example	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Avoids colour schemes which clash (e.g. red and orange)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>INTERPERSONAL</b>							
<b>29. Personal knowledge</b>							
(a) Knows full name, address, sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Knows age and birthday and telephone number (where appropriate)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Knows nationality, name of country, and religion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Can name and describe members of immediate family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Has fairly realistic idea of own strengths and limitations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>30. Conversation</b>							
(a) Uses basic social conversation, 'Hello', 'good morning', 'how are you' etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Relates experiences, recent events, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Talks about subjects of interest to person concerned	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Seeks other person's advice or opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Knows when someone is getting bored and brings conversation to an end, or changes topic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

PAGE 11

	1	2	3	4	5	6	7
	Can do without help or supervision	Can do but only with help or supervision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opportunity to do this
<b>31. Social graces</b>							
(a) Says 'please' and 'thank you'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Greets others in appropriate way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Takes turn, waits patiently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Knocks on doors before entering, or excuses self, where appropriate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Can take hint when someone wants to leave or wants privacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>32. Friendships</b>							
(a) Generally tries to get along with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Shares or lends possessions with discretion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Shows warmth or affection, kindness and sympathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Keeps in touch with friend, remembers birthday, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Considers friends' feelings, offers help where possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>33. Leisure - group activities</b>							
(a) Enjoys being in the company of others, going to party, dance or disco	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Attends a club or social centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Goes to cinema, theatre, sporting or athletic event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Takes part in team games	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Takes part in drama, concert, amateur theatrical, band or choir	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Scale for Assessing Coping Skills

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	1	2	3	4	5	6	7
	Can do without help or supervision	Can do but only with help or supervision	Cannot yet do	Do not know whether he can do this	Uses the ability an adequate amount	Does not use this an adequate amount	There is no opportunity to do this
<b>34. Telephone</b>							
(a) Answers phone and correctly identifies self. Holds simple conversation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Calls appropriate person to phone, or takes simple message	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Dials and obtains a required number (written down) and asks for person concerned	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Uses a call-box for well-known numbers, including emergency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Uses a telephone directory with some success	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>35. Responsibility</b>							
(a) Aware of rules and the need to keep them (safety, honesty, punctuality, hygiene, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Accepts criticism where appropriate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Anticipates the consequence of own actions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Accepts blame for own mistakes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Shows concern for the safety or welfare of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>							
<b>36. Sexual knowledge and behaviour</b>							
(a) Aware of differences between men and women	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Understands own sexual development, pubic hair, breasts, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Knows how babies are conceived and born, in context of love and marriage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Aware of birth control, dangers of venereal disease, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Behaves with responsibility and respect in relations with opposite sex (not over affectionate, or promiscuous)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### Appendix 4

##### Subjects' Scores on the Assessment: Scale for Assessing Coping Skills - E. Whelan and B. Speake

The assessments were scored as follows:

Items scored:	Subject can do without help	-	Score 2
Items scored:	Subject can do with help	-	Score 1
Items scored:	Subject cannot yet do	-	Score 0
Items scored:	Don't know, no opportunity, not completed	- -	Given no score.

In addition, to total scores, the number of items given no score and the number of items where no opportunity was available, are given. Scores are summarised separately for each section of the assessment, i.e., self-help, social academic, and interpersonal skills.

Score on the Assessment: Scale for Assessing Coping Skills  
E. Whelan and B. Speake

Subjects	Total: Self- Help	Not Scored	No Opp.	Total: Social Academic	Not Scored	No Opp.
1	74	4	15	22	1	1
2	157	4	0	77	10	0
3	82	6	0	60	1	1
4	98	1	0	10	1	0
5	119	3	2	57	3	2
6	71	0	0	15	0	0
7	84	8	27	23	0	0
8	97	0	11	11	0	0
9	78	14	5	11	3	0
10	90	2	3	31	0	0
11	126	21	0	62	14	0
12	69	8	5	4	0	0
13	101	24	9	84	8	0
14	128	1	1	17	0	0
15	99	1	0	6	1	0
16	78	0	0	10	0	0
17	72	1	1	6	0	0
18	73	42	18	68	4	0
19	162	9	2	92	4	0
20	169	3	1	97	1	0
21	115	14	11	23	26	0

Subjects	Total Interpersonal	Not Scored	No Opp.
1	39	7	2
2	69	3	0
3	54	0	0
4	32	6	0
5	37	1	1
6	24	0	0
7	34	4	5
8	35	0	0
9	15	8	0
10	28	0	5
11	44	16	0
12	15	7	0
13	47	10	0
14	52	0	0
15	10	0	0
16	5	0	0
17	20	0	0
18	59	6	0
19	78	1	0
20	51	11	0
21	10	7	0

RESEARCH PROJECT -ANGELA HOLLAND  
ASSESSMENT - OUTCOME OF COMMUNITY PLACEMENTS.

Name:

Address:

D.O.B.

Date of Visit:

Interviewer:

Staff Member:

Length of time known to client:

Placement:

Number of people:

Number of staff:

Agency:

Previous Placements:

Length of time at this placement:

PERSON'S VIEWS OF PLACEMENT:

SCORES

- 1) Do you like living here?  
Is this a nice place to live?  
  
 \* - Not known, incoherent, no answer.  
 1 - No.  
 2 - Indifferent, mixed, accepts "it's all right"  
 3 - Yes, with/without a reason \_\_\_\_\_
  
- 2) What do you like about living here?  
If no example given ask: "Are the people friendly?"  
  
 \* - Not known, incoherent, no answer.  
 A - Replies "yes" to both questions,  
     but no examples given - acquiesce.  
 1 - Nothing liked.  
 2 - Uncertain; replies yes to example -  
     no further example given.  
 3   Person gives own example of feature(s) liked \_\_\_\_\_
  
- 3) What do you not like about living here?  
If no example given ask: "Is it too noisy here?"  
  
 \* - Not known, incoherent, no answer.  
 A - replies "yes" to both questions - acquiesce  
 1 - One or more features disliked. Answer to  
     example given not included.  
 2 - Uncertain; replies "yes" to example,  
     no further example given.  
 3 - Nothing disliked. \_\_\_\_\_
  
- 4) Where did you live before?  
Do you like it better here (name place) or  
 prefer it there (name place)?  
  
 \* - Not known, incoherent, no answer.  
 A - Answers "yes" to both questions.  
 1 - Clear preference for previous placement.  
 2 - Uncertain, indifferent, no clear preference.  
 3 - Clear preference for present placement. \_\_\_\_\_
  
- 5) Do you want to carry on living here?  
Is there somewhere else you would rather live?  
  
 \* - Not known, incoherent, no answer.  
 A - Yes, to both questions.  
 1 - No, wishes to move, need not name place.  
 2 - Uncertain, indifferent.  
 3 - Yes, to first question, wishes to remain. \_\_\_\_\_

SCORES:



- 6) Do you enjoy the food here?  
What did you eat for \_\_\_\_\_(state last meal at home/hostel)?  
Was this nice.  
Do you like most of the food? (Ask if replies suggest mixed preferences).

\* - Not known, incoherent, no answer.  
A - Yes to three questions.  
1 - No to first question, dislikes majority of food.  
2 - Uncertain, indifferent, mixed preferences.  
3 - Yes to first question - no examples of food required. Enjoys majority of food. \_\_\_\_\_

- 7) Do you have your own bedroom?  
Do you like your bedroom?

\* - Not known, incoherent, no answer.  
A - Yes to both questions, but shares a bedroom.  
1 - Dislikes bedroom.  
2 - Uncertain, indifferent. Likes bedroom but would prefer own room or to share, (does not at present).  
3 - Yes, likes bedroom. \_\_\_\_\_

- 8) Do you help in the house/hostel?  
What do you do to help? If no example given, ask "Do you help with the washing up?"  
Do you enjoy helping in the house?

\* - Not known, incoherent, no answer, no opportunity. Does not help in house/hostel.  
A - Answers yes to all questions.  
1 - Dislikes helping in house.  
2 - Uncertain, indifferent.  
3 - Yes - additional example not required. \_\_\_\_\_

- 9) What do you do in the daytime (during the week).  
If not activity named ask:  
"Do you go to a Day Centre?  
Do you stay at home?"  
Do you like it there?

\* - Not known, incoherent, no answer.  
A - Answers yes to all questions or answers yes to suggested placements, but does not attend.  
1 - Dislikes day placement.  
2 - Uncertain, indifferent, mixed.  
3 - Yes, likes day placement. \_\_\_\_\_

SCORE: \_\_\_\_\_

- 10) What do you do at the weekends?  
What do you do in the evenings?  
Do you enjoy this?  
If no activities named ask:  
Do you go shopping.  
Do you go to the pub?  
Do you visit friends?  
Do you enjoy this?
- \* - Not known, incoherent, no answer.
  - A - Answers yes to all questions.
  - 1 - Dislikes majority of spare-time activities.
  - 2 - Uncertain, indifferent, mixed - likes some activities not others.
  - 3 - Likes the majority of activities - need not name activities.
- 11) What did you do last night when you returned from the Day Centre/yesterday (if this was Saturday or Sunday).  
Did you enjoy it?
- \* - Yes to both questions.
  - 1 - Disliked activity.
  - 2 - Uncertain, indifferent, mixed.
  - 3 - Yes, enjoyed activity.
- 12) Do you have enough to do in your spare time?  
Are there other things you would like to do?  
Would you like to go out more often?
- \* - Not known, incoherent, no answer.
  - A - Answers yes to all questions.
  - 1 - Yes would like to have more activities to do.  
- need not give example.
  - 2 - Indifferent, uncertain, mixed.
  - 3 - No.
- 13) Do you like the neighbourhood/area around here?  
Is this a nice neighbourhood\/  
Can you think of a neighbourhood that you would like better?
- \* - Not known, incoherent, no answer.
  - A - Answers yes to all questions.
  - 1 - No - dislikes neighbourhood, no example of alternative required.
  - 2 - Indifferent, uncertain, mixed.
  - 3 - Yes - likes neighbourhood.

SCORES:

- 14) Do you like the other people here?  
Do you have any friends here?  
Can you tell me the name of one of your friends?
- \* - Not known, incoherent, no answer, no name of friend given. Not applicable - only person in placement.
  - A - Answers yes to all questions.
  - 1 - No friends.
  - 2 - Indifferent, uncertain, likes everyone.
  - 3 - Yes, gives example of friend (exclude staff, relatives)

- 15) Do you have any friends at the Day Centre, College etc?  
Can you tell me the name of one of your friends at the Day Centre, College etc?
- \* - Not known, incoherent, no answer, no name of friend given.
  - A - Answers yes to both questions.
  - 1 - No friends.
  - 2 - Indifferent, uncertain, mixed likes everyone.
  - 3 - Yes, names of friend (include instructors at Day Centre).

- 16) Would you like to have more friends?

- \* - Not known, incoherent, no answer.
- 1 - Yes, would like to have more friends.
- 2 - Uncertain, indifferent.
- 3 - No desire for more friends.

- 17) Do you have a boyfriend/girl friends?  
If yes ask:  
What is his/her name?  
Do you like each other?  
Where does he/she live?  
If no ask:  
Would you like a boyfriend/girl friend.

- \* - Not known, incoherent, no answer.
- \* - Has no boyfriend/girlfriend and does not want to.
- A - Has a boyfriend/girlfriend does not name person.
- 1 - Has no boyfriend/girlfriend and would like to.
- 1 - Has a boyfriend/girlfriend and stated dislike.
- 2 - Has a boyfriend/girlfriend, - indifferent.mixed feelings.
- 3 - Has a boyfriend/girlfriend and are happy together \_\_\_\_\_

SCORES

18) Would you prefer to live with other friends/people or alone?

Who would you like to live with?

- \* - Not known, incoherent, no answer.
- A - Yes, but does not name person.
- 1 - Yes, names others to live with/alone.
- 2 - Uncertain, indifferent.
- 3 - No wishes to stay with present group.

19) Do you like the staff (in the home)?

How do you get on with them?

- \* - Not known, incoherent, no answer.
- A - Yes to all questions.
- 1 - Dislikes staff - predominant view.
- 2 - Uncertain, indifferent, mixed.
- 3 - Yes, likes staff.

20) Do the staff help you?

What do they do to help you?

Do you think the staff help you enough?

- \* - No known, incoherent, no answer.
- A - Yes to all questions.
- 1 - Dissatisfied - staff do not help.
- 2 - Uncertain, indifferent, mixed.
- 3 - Satisfied, staff help person sufficiently.  
(example not required).

21) Are there any rules in the house/hotel?

For example, do you have to be in bed by 11.00 p.m. during the week?

What are the rules in the house/hostel?

Do you like the rules?

- \* - No known, incoherent, no answer, no example given.
- A - Yes to all questions.
- 1 - Dislikes the rule(s) (exclude example provided).
- 2 - Uncertain, indifferent, mixed.
- 3 - Likes the rules.

22) Are there any pets? (in the home).

If yes ask: do you like the pets?

What are the pets?

If no ask: would you like a pet?

- \* - Not known, incoherent, no answer.
- A - Yes to all questions.
- 1 - If pets, dislikes/would like a pet (if none).
- 2 - Indifferent, uncertain, mixed.
- 3 - If pets likes/it no pets does not want any.

SCORE:

- 23) How much money do you have to spend each week?  
What do you spend your money on?  
Do you have enough money or too much?

\* - Not known, incoherent, no answer.  
A - Yes to all questions.  
1 - Clear dissatisfaction and wish for more money.  
2 - Mixed, indifferent, uncertain.  
3 - Satisfied e.g. "I have enough for what I want." \_\_\_\_\_

- 24) If you are upset about something, what do you do?  
Who do you talk to?

\* - No answer, incoherent.  
A - Answers yes to both questions.  
1 - Does not know what to do. No-one to contact.  
2 - Uncertain. Vague suggestion. Impractical idea.  
3 - Clear person to contact, appropriate action. \_\_\_\_\_

- 25) Are there other things you would like to do while  
living here?  
Are there any new things you would like to learn?  
If one activity is mentioned, ask if there are any  
others.

\* - No answer, not known, incoherent.  
A - Answers yes to all questions.  
1 - Names two or more things to do.  
2 - One further activity only reported. Uncertain  
indifferent.  
3 - No further activities reported. \_\_\_\_\_

#### Summary of Scores:

Number of questions scored	*	-
"	"	"
"	"	"
"	"	"
"	"	"

A	-
1	-
2	-
3	-

Total: \_\_\_\_\_  
\_\_\_\_\_

CARER'S VIEW OF THE PLACEMENT FOR THE PERSON.

SCORES:

1. In your opinion is this placement suitable for Mr/Mrs \_\_\_\_\_ at present?

3 - Suitable.  
2 - Neither suitable nor unsuitable.  
1 - Unsuitable.  
\* - Unknown. Not applicable

\_\_\_\_\_

2. Do you feel this placement is suitable in the long term (e.g. after two years).

Score as for Q.1.

\_\_\_\_\_

3. How 'happy' do you think Mr/Mrs \_\_\_\_\_ is living here?

3 - Happy.  
2 - Not clearly happy or unhappy.  
1 - Unhappy.  
\* - Unknown.

\_\_\_\_\_

4. How suitable are the following features of the placement for Mr/Mrs \_\_\_\_\_.

Score as for Q.1.

Other people in placement.

\_\_\_\_\_

Staff time.

\_\_\_\_\_

Day-time occupation e.g. Day Care.

\_\_\_\_\_

Occupation within the home e.g. domestic tasks.

\_\_\_\_\_

Space time activities - leisure etc.

\_\_\_\_\_

Making new friends (both sexes).

\_\_\_\_\_

Geographical situation - distance from shops amenities.

\_\_\_\_\_

Visitors - privacy etc.

\_\_\_\_\_

Integration with community - neighbours visiting etc.

\_\_\_\_\_

To be completed with a member of staff who has known the person for at least 3 months.

Note if person is reported to be "very suitable, happy" or very "unsuitable, unhappy".

CARER'S VIEWS OF THE PLACEMENT

CHALLENGING/SOCIAL BEHAVIOUR:

1. CHALLENGING BEHAVIOUR: Score each item as follows:-

A. Frequency:

- 2 - Not occurred during the last (1) month.
- 1 - Has occurred during the last (1) month.
- \* - Not known.

B. Perceived Problems:

- 2 - Not a problem (whether occurred or not).
- 1 - Is considered a problem.
- \* - Not known.

SCORES:

A. Frequency B. Perceived Problem:

- |   |       |       |
|---|-------|-------|
| A. Aggression:(include verbal and physical, but state which/both. Note whether aggression has occurred or threatened only).             | _____ | _____ |
| B. Withdrawn (e.g. avoids interaction with others, quiet etc).  | _____ | _____ |
| C. Moodiness (e.g. sometimes pleasant and helpful, at other times not so, with no reason. Do not confuse with unco-operative (D) below. | _____ | _____ |
| D. Unco-operative (e.g. does not follow requests within a person's ability - consistently so; do not confuse with moodiness).           | _____ | _____ |
| E. Demanding (e.g. regularly telling/ asking staff and/or peers for help).  | _____ | _____ |
| F. Crying e.g. excessive length for situation, or for no reason.  | _____ | _____ |
| G. Easily upset e.g. becomes distressed for little/no reason.   | _____ | _____ |
| H. Weight loss/gain. (State whether gain/loss).   | _____ | _____ |
| I. Sleep disturbance.   | _____ | _____ |

SCORES:  
A: Frequency: B: Perceived  
Problem:

- |    |   |       |       |
|----|---|-------|-------|
| J. | Complains of feeling ill/tired.                           | _____ | _____ |
| K. | Complains about situation - house,<br>people, staff etc., | _____ | _____ |
| L. | Spends long period alone e.g. in<br>bedroom.              | _____ | _____ |
| M. | Asks to move to another house/placement.                  | _____ | _____ |
| N. | New 'problems' i.e. not known in past -<br>describe.      | _____ | _____ |
| O. | Other problem(s) (describe)                               | _____ | _____ |



2. SOCIAL BEHAVIOUR WITHIN HOME:

Score the items as follows:-

- 3 - Yes - satisfactory.
- 2 - Does so with reminder.
- 1 - No. improvement required.
- \* - Not known, no opportunity.
- \* - If clear choice not to, score \*, make a note.

SCORES:

- |   |       |
|---|-------|
| A. Takes care over physical appearance  | _____ |
| B. Shows interest in house - items in house pictures, etc.,   | _____ |
| C. Shows visitors around house (downstairs) garden etc.,  | _____ |
| D. Offers visitors tea, coffee etc.,  | _____ |
| E. Guests visit house (include family).<br>(within last 3 months, do not include people who visit as part of their work). | _____ |
| F. Complies with routine of household e.g. going to Day Centre etc.,  | _____ |
| G. Offers to help in house.   | _____ |
| H. Undertakes activities with others in home.   | _____ |
| I. Communicates/interacts with peers in placement.  | _____ |

## PHYSICAL ENVIRONMENT

SCORES:

PART (A) To be completed by observation during interview.

1. Does Mr./Mrs.\_\_\_\_\_ have their own bedroom? (requires confirmation of choice by staff). \_\_\_\_\_

Score: 3 - Yes, by choice. Also 3 if clearly prefers to share.

2 - Yes, decided by staff. Also score 2 if shared and decided by staff.

1 - No, - considered to prefer own room.

2. Are personal possessions openly on display in the bedroom e.g. posters, ornaments, make-up, radio etc., \_\_\_\_\_

Score: 3 - At least 3 items on open display.

2 - 1-2 objects on display.

1 - None on display.

3. Is the bedroom furniture domestic or "institutional" i.e. individualised bedspread/duvet, wardrobe etc., \_\_\_\_\_

Score: 3 - Some items chosen by Mr/Mrs.\_\_\_\_\_ e.g. duvet cover, pictures - all of domestic type.

2 - All items domestic but none chosen by Mr/Mrs.\_\_\_\_\_

1 - Some items "institutionalised" or not individualised.

Comment on what influenced your choice.

4. Does the home have an appropriate degree of privacy. \_\_\_\_\_

Score: 3 - Bathroom, toilet have locks, bedroom doors cannot be seen through, bedroom large enough for table and chair.

2 - Some privacy available.

1 - Little privacy.

Comment on what influenced your choice:

5. Is the furniture in the living areas varied and domestic i.e. not institutionalised. \_\_\_\_\_

Score: 3 - Furniture all varied and attractive i.e. settees, easy chairs which could be bought in local shops. Some items chosen by group.

2 - Some furniture is varied, attractive and domestic. None chosen by group.

1 - Majority of furniture institutionalised.

Comment on what influenced your choice

SCORES:

6. Are some small household items and personal possessions openly display in downstairs rooms or do rooms have an "institutional" appearance. e.g. over-tidiness etc., \_\_\_\_\_

Score: 3 - Items displayed in all rooms e.g. posters, plants, magazines.

2 - Items displayed but some have an institutional appearance.

1 - All rooms have an institutional appearance.

Comment on what influenced your choice:

7. Does the kitchen have domestic equipment or is some "institutional". i.e. industrial size cooker, extra large teapot etc., - note cooker, cupboards, fridge teapots, geyser. \_\_\_\_\_

8. Is the house "comfortable" and reasonably clean. e.g. are there carpets and curtains in all rooms except kitchen and bathroom, warmth of house, noise level \_\_\_\_\_

Score: 3 - Comfortable in every way.

2 - Comfortable in most ways - but identified deficiency.

1 - Not comfortable.

Comment on what influenced your choice.

9. Is the house in a "good state of repair" - decoration, furniture. \_\_\_\_\_

Score: 3 - Yes.

2 - Needs some improvements - not major.

1 - No.

Comment on what influenced your choice.

10. Are there any conspicuous details outside the house that would indicate that "handicapped" people live there e.g. a reference to NHS/Social Services, design of building etc., \_\_\_\_\_

Score: 3 - No.

2 - One identified detail.

1 - Yes, more than one.

Comment on what influenced your choice.

PART (B) To be completed by asking Carers.

SCORES:

11. How many items of equipment are available in the house: e.g. fridge, deep freeze, colour T.V. radio, cassette player, Hoover, iron, washing machine, telephone, garden, heaters in all rooms. \_\_\_\_\_

Score: 3 - 7+  
2 - 3 - 6  
1 - 3 or less

12. Are there any rooms which are locked/require permission to enter? \_\_\_\_\_

Score: 3 - None.  
2 - One room (state room \_\_\_\_\_)  
1 - More than one room (state room \_\_\_\_\_)

13. Is there available space for someone to be alone if they wish/need to be. \_\_\_\_\_

Score: 3 - Yes, an area is identified.  
2 - Yes, but this may require another person/activity to be disrupted.  
1 - No.

14. Is there a room which is private where Mr/Mrs. \_\_\_\_\_ can meet his/her relatives/friends etc., \_\_\_\_\_

Score: 3 - Room identified which would not be used by others at the time of visit (exclude bedroom).  
2 - Room identified (include bedroom). Room may be used by others e.g. lounge people leave when visitor arrived.  
1 - No room identified.  
Comments.

SCORES:

15. How far away are the local shops, leisure places e.g. swimming baths, pub. \_\_\_\_\_

Score: 3 - Easy access - short bus journey e.g.  
15 - 20 minutes.  
2 - Some places require a longer bus journey.  
1 - All require a long journey.

16. Has Mr/Mrs. \_\_\_\_\_ got any pets?  
If yes, did Mr/Mrs choose to have a pet?  
If no, has Mr/Mrs.been asked if he/she would like a pet. \_\_\_\_\_

Score: 3 - Yes, has a pet by choice.  
2 - No, has no pet by choice.  
2 - Pet(s) are present - but not by choice of person.  
1 - Pet not present and have not been discussed.  
Comments:

NOTE: If any features are influenced significantly by the other people living in the placement.

SUPPORT SERVICES FOR PERSON IN PLACEMENT:

SCORE:

1. Are Carers/landlady present in the house/hostel: \_\_\_\_\_

Score: 3 - 24 hours a day.  
2 - Daytime - every day of week.  
1 - Daytime - part-time only.

2. Staff/professionals visiting the house: \_\_\_\_\_

Score: 3 - Visits occur more than twice a week.  
(all visitors except parents).  
2 - Visits occur once/twice a week.  
1 - Visits occur less than once a week.

State who visits e.g. CN. SW. and frequency.  
Visit involves remaining half an hour at least.

3. Is the staffing in the home and visiting the home considered appropriate to the needs of the person. \_\_\_\_\_

Score: 3 - Yes - definitely appropriate.  
2 - No - some change required, slightly too many staff/too few. Changes needed involve a member of staff for an increase/decrease of 16 hours a week or less only.

4. What do Carers in house do: \_\_\_\_\_

e.g. Domestic tasks.  
budgeting.  
collect rent.  
counselling about personal problems  
gardening.  
visiting together for shopping.  
discussing social security benefits.  
skills training.  
ensuring "no problems exist"  
others \_\_\_\_\_

Score: 3 - 5+ of the above.  
2 - 2+ of the above.  
1 - 1-2+ of the above.

SCORE: \_\_\_\_\_

5. What do visiting professionals do: \_\_\_\_\_

e.g. Domestic tasks.  
budgeting.  
collect rent.  
counselling about personal problems.  
gardening.  
visiting town together for shopping.  
discussing social security benefits.  
skills training.  
ensuring "no problems exist"  
others \_\_\_\_\_

Score: 3 - 5+ of the above.  
2 - 2+ of the above.  
1 - 1-2 of the above.

6. Do all "support staff" meet regularly to review Mr/Mrs. \_\_\_\_\_ progress? \_\_\_\_\_

Score: 3 - All support workers meet at least twice a year.  
2 - Meetings held - but usually only when problems have occurred, or less than twice a year.  
1 - No meetings have been held.

7. Has Mr/Mrs. \_\_\_\_\_ a day time placement? \_\_\_\_\_

Score: 3 - Yes full time.  
2 - Yes part time.  
1 - No.  
\* - N/A not considered appropriate.

8. Is the day-time placement considered appropriate for Mr/Mrs. \_\_\_\_\_ (e.g. activities undertaken at Day Centre, company etc)? \_\_\_\_\_

Score: 3 - Yes.  
2 - Partially suitable.  
1 - No.

Describe factors influencing choice:

SCORES:

9. Who does Mr/Mrs. \_\_\_\_\_ contact in an emergency? \_\_\_\_\_

- Score:
- 3 - Person(s) is clearly identified and means of contact.
  - 2 - Person identified, means of contact unclear.
  - 1 - No - one person(s) identified.

10. Who does Mr/Mrs. \_\_\_\_\_ talk to if he/she is upset. \_\_\_\_\_

- Score:
- 3 - person/persons who are regularly available and who know him/her well. (staff).
  - 2 - No - one person is chosen - who ever is about (carer/resident). Waiting period necessary.
  - 1 - No- one/always relies on another resident.

11. List persons involved with Mr/Mrs. \_\_\_\_\_

- A - Nursing staff.
- B - Community nurse.
- C - Social Worker.
- D - Residential staff - Social Services.
- E - Speech Therapy.
- F - O.T.
- G - Physiotherapist.
- H - Psychologist.
- I - Psychiatrist.
- J - Volunteer.
- K - Advocate.
- L - Parent.
- M - Other.



OPPORTUNITIES AVAILABLE AND UNDERTAKEN WITHIN THE PLACEMENT:

What opportunities does Mr/Mrs. \_\_\_\_\_ have in the following areas (appropriate help can be given):

SCORE:

1. Cooking:

- a) How often does Mr/Mrs. \_\_\_\_\_ prepare his/her own cooked food (include snack on toast). \_\_\_\_\_

Score: 3 - More than twice a week.  
2 - One/Twice a week.  
1 - Less than once a week.

- b) How often does Mr/Mrs. \_\_\_\_\_ prepare a cold snack (e.g. cereals, sandwiches etc.). \_\_\_\_\_

Score: 3 - Every day.  
2 - More than twice a week.  
1 - Twice a week or less.

- c) Could Mr/Mrs. \_\_\_\_\_ undertake more cooking than he/she is doing. \_\_\_\_\_

Score: 3 - Yes, opportunities exist, and are actively encouraged.  
2 - Yes, more opportunities could be organised.  
1 - Would be difficult to organise in the present environment.

Specify the opportunities available which are not undertaken:

2. Shopping and Use of Money:

- a) How often does Mr/Mrs. \_\_\_\_\_ go shopping \_\_\_\_\_

Score: 3 - Twice a week or more. (Including single purchases at corner shop etc.)  
2 - Once a week approximately.  
1 - Less than once a week.

- b) To what extent does Mr/Mrs. \_\_\_\_\_ use his own money. \_\_\_\_\_

Score: 3 - Pays for all items etc. electricity, with help e.g. with budgeting.  
2 - Buys food (i.e. some essentials), with help e.g. with budgeting.  
1 - Uses pocket money only.

SCORES:

- c) If new clothes, or other items are required -  
outline the access to money. \_\_\_\_\_

Score: 3 - Withdraws money from bank/savings  
account (with/without help). No  
delay (less than a week).  
2 - Staff obtain money - items bought  
with/by Mr/Mrs \_\_\_\_\_.  
1 - Items are bought/obtained by staff.

- d) Could Mr/Mrs. \_\_\_\_\_ go shopping more often,  
or use money more often. \_\_\_\_\_

Score: 3 - Yes, opportunities exist and are  
actively encouraged.  
2 - Yes, more opportunities could be  
organised.  
1 - Would be difficult to organise in  
the present environment.

3. Clothes:

- a) To what extent does Mr/Mrs. \_\_\_\_\_ choose his/her  
own clothes. \_\_\_\_\_

Score: 3 - All clothes are bought with Mr/Mrs. \_\_\_\_\_  
and chosen by him/her.  
2 - Some clothes (not all) are bought with  
Mr/Mrs. \_\_\_\_\_ and are chosen by him/her.  
1 - No clothes, only one/two items in the last  
6 months are bought with Mr/Mrs. \_\_\_\_\_.

- b) Does Mr/Mrs. \_\_\_\_\_ wash his/her own clothes and care  
for them e.g. put them away. \_\_\_\_\_

Score: 3 - Majority of washing is done by/with  
Mr/Mrs. \_\_\_\_\_.  
2 - Some washing may be done by staff, some by  
Mr/Mrs. \_\_\_\_\_.  
1 - No.

- c) Could Mr/Mrs. \_\_\_\_\_ care for his/her clothes, choose  
the clothes more often than he/she is doing? \_\_\_\_\_

Score: 3 - Yes, opportunities exist and are actively  
encouraged.  
2 - Yes, more opportunities could be organised.  
1 - Would be difficult to organise in the present  
environment.

Specify the opportunities available which are not undertaken:

4. Leisure Activities:

SCORES:

- a) How often does Mr/Mrs. \_\_\_\_\_ go for visits outside the home; include visits to cinema, restaurant, swimming, 'window' shopping, staff's family. Exclude attending Day Centre, single purchase at local shops. \_\_\_\_\_

List places visited in last two weeks:

- Score: 3 - More than once a week.  
2 - Every week/fortnight.  
1 - Less than once a fortnight.

- b) What spare time activities are regularly undertaken by Mr/Mrs. \_\_\_\_\_ e.g. Television, radio, card games, gardening, walks, swimming, sewing, collecting items \_\_\_\_\_ etc.

List:

- Score: 3 - Activities (more than 2 of the above/others in the last 2 weeks).  
2 - Organised activities (more than 2 of the above/others in the last 2 weeks) with other handicapped people only.]  
1 - Organised activities (one/two of the above /others) with other handicapped people.

- c) How often does Mr/Mrs. \_\_\_\_\_ meet/mix with other people?  
Meeting includes attending a club, visiting friends (not relatives) neighbours etc. \_\_\_\_\_

List:

- Score: 3 - Meets other people (should include non-handicapped people)  
2 - Meets other people (include handicapped people), every week - a month. Exclude attendance at Day Centre.  
1 - Meets other people less than once a month.

- d) Could Mr/Mrs. \_\_\_\_\_ join in more leisure activities than he/she is doing? \_\_\_\_\_

- Score: 3 - Yes, opportunities exist and are actively encouraged.  
2 - Yes, more opportunities could be organised.  
1 - Would be difficult to organise in the present environment.

Specify the opportunities available which are not undertaken:

5. Learning New Skills:

SCORE

- a) What plans are there for Mr/Mrs. \_\_\_\_\_ to learn new skills.

\_\_\_\_\_

- Score:
- 3 - Individual plan is being followed and covers more than two areas of development. Includes consideration of long-term future.
  - 2 - Individual aims are being followed - not necessarily covering various areas nor considering the future.
  - 1 - No clear individual aims exist.

FRIENDSHIPS:

SCORE

1. List people who could be described as a friend of Mr/Mrs. \_\_\_\_\_

Friends - undertake activities together e.g. go out together choose to sit together etc.,

List: Name.

Score: 3 - Has two or more friends.  
2 - Has one friend.  
1 - Has no friends.

2. How often does Mr/Mrs. \_\_\_\_\_ arrange to meet his/her friends and where do they meet. \_\_\_\_\_

Score: 3 - Meets a friend(s) every week (exclude if only met at work).  
2 - Meets a friend(s) every month (exclude if only met at work)  
1 - Meets friends less than every month/only meet at work.  
\* - N/A - has no friends.

3. Has Mr/Mrs. \_\_\_\_\_ a friend of the opposite sex. with whom he/she has a "special relationship" and who could be described as a girl/boy friend? \_\_\_\_\_

Must have known each other a month.

Score 3 - Yes, appears to be a "happy relationship"  
2 - Yes. Not a "happy relationship".  
1 - No.

4. Before moving did Mr/Mrs. \_\_\_\_\_ know any people in the new placement? Where they friendly? \_\_\_\_\_

Score: 3 - Yes, familiar, trained together, lived in past together for long time.  
2 - Slightly familiar. e.g. attends same Day Centre.  
1 - No.  
\* - Not known.

SCORE:

5. Has Mr/Mrs.\_\_\_\_\_ made new friends within this placement? (Included on list or Q.I.) \_\_\_\_\_

Score: 3 - Yes.  
2 - "Gets on" with everyone, no-one specific.  
1 - No/does not "get on" with all other people.

6. Has Mr/Mrs.\_\_\_\_\_ made new friends outside the placement. e.g. at Day Centre, since moving to new placement. \_\_\_\_\_

Score: 3 - Yes.  
2 - No-one specific "gets on with everyone"  
1 - No/"does not" get on with many people.  
\* - Not known.

7. Has Mr/Mrs.\_\_\_\_\_ invited a friend/relation/acquaintance to the house/hostel, etc? \_\_\_\_\_

Score: 3 - Yes - at least once a month.  
2 - Occasionally,  
1 - Never.  
\* - Not known.

8. Has Mr/Mrs.\_\_\_\_\_ a friend with whom he/she would discuss problems. \_\_\_\_\_

Score: 3 - Yes,- always discusses problems with a friend.  
2 - Yes - sometimes discusses with a friend.  
1 - No.

PREPARATION FOR THE MOVE INTO THE COMMUNITY:

SCORE

1. To what extent was Mr/Mrs. \_\_\_\_\_ involved in the decision that he/she move to live in the community. \_\_\_\_\_

- Score:
- 3 - Person was fully involved at every stage e.g. person asked to move visited different possible placements themselves.
  - 2 - Person was involved, but not fully e.g. visited one possible placement, given opportunity to refuse placement.
  - 1 - Person involved, but to a lesser extent than 2 above/not involved.

2. Was a multi-disciplinary team involved in the initial decision that Mr/Mrs. \_\_\_\_\_ would leave hospital. \_\_\_\_\_

- Score:
- 3 - Four disciplines (or more) involved in decision (e.g. at a meeting).
  - 2 - Two/three disciplines involved in decision.
  - 1 - One discipline only involved in decision.

3. What form of assessment was completed before Mr/Mrs. \_\_\_\_\_ left hospital. \_\_\_\_\_

- Score:
- 3 - A skills assessment checklist and a report from every environment the person visits e.g. Day Centre. Must include a report from visits to the community e.g. for shopping.
  - 2 - An assessment was completed but incomplete - must include at least two features outlined for score of 3.
  - 1 - No assessment/assessment only contains one feature outlined for score of 3.

4. What training/preparation did Mr/Mrs \_\_\_\_\_ receive before leaving hospital. \_\_\_\_\_

- Score:
- 3 - Part of the preparation took place in the new environment e.g. shopping familiarisation, with neighbourhood. Preparation was planned for individual e.g. I.P.P. and covered a period of more than one month.
  - 2 - Preparation planned according to individual's needs. Did not involve training/preparation in new environment. Training covered period of more than a month.
  - 1 - Preparation brief, unplanned. All group activities, little account taken of individual needs.

SCORE:

5. How many times did Mr/Mrs. \_\_\_\_\_ visit his/her new placement before the final decision to move was taken? \_\_\_\_\_

Score: 3 - Two visits or more, and an overnight stay.  
2 - Two or more visits.  
1 - One visit only.

6. Did staff/caretakers in the new placement visit the person and staff in the previous placement, prior to the move? \_\_\_\_\_

Score: 3 - Two visits or more (each of half an hour minimum).  
2 - One visit (half an hour minimum).  
1 - No visits.

7. Did Mr/Mrs. \_\_\_\_\_ know anyone in the new placement prior to the move - including staff or peers. \_\_\_\_\_

Score: 3 - Yes, knows one/two people (or more) well. e.g. lived together, known for more than 3 months.  
2 - Yes, knew one/two people - but not very well. e.g. had not lived together or not known for more than 3 months.  
1 - No.  
Comment if people were friends etc.,

8. To what extent was 'compatibility' with other people living in the house, taken into account when preparation for the move was taking place? \_\_\_\_\_

Score: 3 - 'Matching' process took place i.e. consideration for how person would 'get on' with every other person in house. Full account taken of findings.  
2 - Some account taken, but could have been more complete/little account taken of findings.  
1 - Not taken into account.

9. Was the length of preparation period considered 'appropriate' for the person? \_\_\_\_\_

Score: 3 - Yes, correct length of time  
2 - No, somewhat too long/short but caused no stress.  
1 - No. Delays/speed required caused stress to person.



SCORE:

10. Did a member of staff involved in the move e.g. social worker visit Mr/Mrs. \_\_\_\_\_ after the move?

\_\_\_\_\_

Score:     3 - Three or more visits in the first  
             3 months of the placement.  
             2 - One/two visits in the first 3 months  
             of the new placement.  
             1 - No visit in the first 3 months of the  
             new placement.

## SPECIAL REQUIREMENTS IDENTIFIED:

SCORE

1. Requires staff time because of behaviour  
(more time than other people require).

---

Score: 3 - Yes, and is a problem.  
2 - Sometimes, but not a problem.  
1 - No.  
\* - Not known.

2. Requires staff time to discuss personal problems.  
(more time than other people require).

---

Score: 3 - Yes, and this is a problem.  
2 - Sometimes, but not a problem.  
1 - No.  
\* - Not known.

3. Demands time/help from other residents.

---

Score: 3 - Yes, and this is a problem.  
2 - Sometimes, but not a problem.  
1 - No.  
\* - Not known.

4. Needs a quiet environment.

---

Score: 3 - Yes, all the time.  
2 - Sometimes, e.g. is upset.  
1 - No.  
\* - Not known.

5. More space than the other people need.

---

Score: 3 - yes.  
2 - Sometimes, e.g. if upset.  
1 - No.  
\* - Not known

6. Other - identify.

---

FOLLOWING THE MOVE TO A NEW PLACEMENT:

ILLNESS REPORTED AFTER MOVE:

CHANGE IN MEDICATION:

APPENDIX 6

Raw Data - Study I  
Person's View of Placement

		Question:																									
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	
Subject:																											
1	3	2	3	3	3	3	3	3	3	3	3	3	2	3	3	N/A	1	1	3	3	2	*	3	3	1	3	3
2	3	3	3	3	3	3	3	3	3	3	3	3	1	3	3	3	1	3	3	3	3	3	3	3	3	3	3
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14	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
15	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
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20	3	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
21	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3

A = Acquiescence Bias  
N/A = Not Applicable  
\* = No Answer, Not Known

Carer's View of Person's Suitability for the Placement

		Question:														
		1	2	3	4A	B	C	D	E	F	G	H	I			
Subject:	1	3	3	3	2	3	*	3	3	3	3	3	3	3	3	3
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## APPENDIX 6

## APPENDIX 6

Subject:	1A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	2A	B	C	D	E	F	G	H	I
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21	2	2	4	4	2	2	4	4	2	4	4	4	*	2	2	3	2	2	2	1	3	3	3	1

Physical Environment

APPENDIX 6

Question:

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

Subject:

1	2	3	3	3	1	2	1	3	1	3	2	3	2	3	2
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12	3	3	3	2	3	3	3	3	3	3	3	2	2	3	1
13	3	1	2	3	2	3	3	2	2	3	3	3	3	3	2
14	2	3	2	3	2	3	2	3	1	3	3	3	2	3	2
15	3	3	3	3	2	3	3	3	3	3	3	3	2	3	1
16	3	3	3	3	3	3	3	3	3	3	3	3	2	3	3
17	3	3	3	3	2	3	3	3	3	3	3	3	3	3	2
18	2	3	3	3	1	1	3	3	1	3	2	3	3	3	2
19	3	3	2	3	2	3	2	2	2	3	2	3	3	3	2
20	3	3	2	3	2	3	3	3	2	3	3	2	3	3	2
21	2	3	3	3	2	3	3	3	3	3	3	2	2	3	3

Support Services

APPENDIX 6

Question:

	1	2	3	4	5	6	7	8	9	10	11
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Subject:

1	3	1	3	3	1	2	*	3	3	3	4
2	3	1	3	3	N/A	3	3	2	3	1	2
3	3	1	3	3	N/A	3	3	3	3	3	3
4	3	1	2	3	N/A	2	3	1	3	2	4
5	3	1	3	3	N/A	2	3	2	2	2	7
6	3	1	3	3	1	3	N/A	N/A	2	3	4
7	3	1	3	3	2	3	3	3	3	3	3
8	3	1	3	3	2	3	*	*	3	3	5
9	3	1	3	3	1	3	3	3	3	3	2
10	3	1	3	3	1	1	N/A	N/A	3	3	4
11	3	1	3	3	1	3	3	3	3	3	3
12	3	1	3	3	N/A	3	3	3	3	2	2
13	3	1	3	3	1	3	*	*	3	3	1
14	3	1	3	3	1	2	3	3	3	3	2
15	3	1	3	3	1	3	3	2	3	3	4
16	3	1	3	3	1	3	3	1	3	2	2
17	3	1	3	3	1	3	3	2	3	3	1
18	3	1	3	3	*	1	2	*	3	3	3
19	3	1	3	3	1	3	3	3	3	3	7
20	3	3	3	3	1	3	3	3	3	3	5
21	3	1	2	3	2	3	3	2	3	2	3



## APPENDIX 6

Question:

Subject:	1A	B	C	2A	B	C	D	3A	B	C	4A	B	C	D	5A
1	1	1	2	3	1	3	2	3	1	2	2	3	3	1	1
2	3	3	1	3	1	3	2	3	1	1	3	3	3	3	2
3	1	1	2	2	1	3	1	3	2	2	3	3	3	1	1
4	2	3	3	3	1	3	1	3	2	2	2	3	3	3	3
5	1	3	3	3	1	3	2	3	2	3	3	1	2	2	2
6	1	1	3	1	1	3	3	2	1	3	2	2	3	3	1
7	1	1	1	2	1	2	2	3	1	1	3	2	2	3	2
8	1	1	3	3	1	2	3	3	1	2	3	1	3	3	2
9	1	1	2	2	1	3	2	3	3	3	3	2	3	3	1
10	1	1	1	3	1	3	3	3	1	3	1	3	3	2	1
11	1	1	3	2	1	3	3	3	2	3	3	3	3	2	1
12	1	1	2	1	1	2	3	3	1	2	3	2	2	3	1
13	1	1	1	1	1	3	3	3	2	1	3	3	3	1	1
14	2	1	1	3	1	3	1	3	3	3	3	3	3	1	1
15	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
16	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
17	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
18	1	1	1	1	1	3	3	3	1	2	2	3	3	3	1
19	3	3	3	3	2	3	1	3	3	3	3	3	3	3	3
20	1	3	3	3	1	3	3	3	3	3	1	3	3	3	1
21	2	3	2	3	1	2	2	3	2	2	3	3	2	2	3

Friendships

Question:

1 2 3 4 5 6 7 8

Subject:

1 3 \* 3 1 3 2 3 3  
2 3 3 3 3 \* 2 3 3  
3 3 3 1 3 3 3 2 1  
4 3 1 3 1 2 3 1 1  
5 2 3 2 1 2 3 1 1  
6 2 N/A 1 3 2 3 2 2  
7 3 1 1 1 3 3 1 1  
8 3 1 1 1 2 3 1 1  
9 1 N/A 1 1 2 2 1 1  
10 1 N/A 1 1 2 2 1 1  
11 2 1 1 3 2 2 1 1  
12 3 1 1 1 3 3 1 1  
13 2 \* 1 3 3 2 1 2  
14 2 \* 3 1 3 2 1 1  
15 1 N/A 1 3 2 2 1 1  
16 1 N/A 1 3 2 2 1 1  
17 1 N/A 1 3 2 2 1 1  
18 2 \* 1 2 1 \* 1 1  
19 3 3 3 1 2 3 3 3  
20 1 \* 1 3 2 1 1 1  
21 1 1 1 3 1 1 1 1

Preparation

1 2 3 4 5 6 7 8 9 10

2 3 2 1 3 1 2 3 3 3  
3 3 1 1 3 \* 3 3 2 3  
3 1 1 2 2 3 3 2 3 1  
3 3 2 2 3 1 2 1 3 1  
2 3 1 1 3 3 1 \* 3 1  
3 1 2 1 2 3 3 3 2 3  
2 3 1 2 3 2 1 3 3 3  
2 3 2 1 3 3 1 3 3 3  
2 3 3 2 2 3 1 3 3 2  
3 3 3 2 3 1 1 2 \* 3  
3 3 1 1 1 1 3 3 1 2  
2 3 3 2 3 3 1 3 3 3  
3 3 1 1 3 1 3 2 2 3  
2 3 2 1 3 2 1 3 3 1  
3 3 2 3 3 3 3 3 3 3  
3 3 3 3 3 3 3 3 2 3  
2 3 3 3 3 3 3 3 3 3  
3 3 2 1 3 1 1 2 3 3  
3 3 3 3 3 1 2 1 3 3  
3 3 1 2 3 3 2 3 1 1  
1 3 3 3 2 3 3 3 1 1

Special Requirements

1 2 3 4 5 6

2 2 1 1 1 1  
1 1 1 1 1 1  
1 1 1 1 1 1  
1 1 1 2 1 1  
1 1 1 1 1 1  
1 1 1 3 1 1  
2 2 1 1 1 1  
1 1 1 2 1 2  
2 2 1 1 1 1  
1 1 1 1 1 1  
1 2 1 1 1 2  
1 1 1 1 1 1  
1 1 1 1 1 1  
2 2 1 1 1 1  
1 1 1 1 1 1  
1 1 1 1 1 1  
1 1 1 1 1 1  
1 1 1 1 1 2  
3 3 3 \* 3 3  
3 3 3 1 3

# APPENDIX 7

## MEAN SCORES - STUDY I

Subject	Person's Views	Carer's View of Person's Suitability	Challenges	Social Behaviour	Physical Environment	Opportunities	Support Services	Friendships	Preparation	Special Requirements
1	2.61	2.91	3.8	3	2.31	1.93	2.44	2.57	2.22	1.33
2	2.68	2.83	3.8	2.33	2.31	2.33	2.44	2.86	2.44	1
3	2.79	2.92	3.87	2.89	2.75	1.93	2.78	2.38	2.3	1
4	0	3	3.8	2.38	2.63	2.29	2.22	1.88	2.1	1.17
5	2.59	2.58	3.73	1.67	2.56	2.27	2.33	1.88	2	1
6	2.96	3	3.67	2.67	2.81	1.73	2.38	2.14	2.3	1.33
7	2.5	2.92	3.8	2.33	2.38	1.8	2.7	1.75	2.3	1.33
8	3	3	3.87	2.56	2.57	2	2.63	1.63	2.4	1.33
9	2.23	3	3.53	2	2.56	2.2	2.6	1.29	2.4	1.33
10	2.61	3	3.87	3	2.38	1.73	2.25	1.29	2.33	1
11	2	2.83	3.2	1.83	2.69	2.33	2.6	1.63	1.9	1.33
12	2.81	3	4	2.33	2.63	1.8	2.67	1.75	2.6	1
13	2.87	3	3.93	2.63	2.38	1.87	2.5	2	2.2	1
14	2.86	3	3.67	3	2.38	2.33	2.5	1.86	2.1	1.33
15	0	2.92	3.87	2.56	2.75	3	2.5	1.57	2.9	1
16	0	3	3.87	2.56	2.88	3	2.3	1.57	2.9	1
17	3	2.92	3.93	2.75	2.75	3	2.5	1.57	2.9	1
18	2.83	2.17	4	3	2.31	1.87	2.38	1.33	2.2	1
19	2.8	2.75	3.86	3	2.5	2.8	2.6	2.63	2.5	1.33
20	2.95	2.5	2.4	1.56	2.69	2.13	2.8	1.43	2.6	2.33
21	0	1.83	3	2	2.75	2.27	2.4	1.25	2.1	2.2

APPENDIX 8

STANDARD DEVIATIONS - STUDY I

Subject	Person's Views	Carer's View of Person's Suitability	Challenges	Social Behaviour	Physical Environment	Opportunities	Support Services	Friendships	Preparation	Special Requirements
1	0.72	0.30	0.56	0	0.79	0.88	0.88	0.79	0.83	0.52
2	0.69	0.39	0.56	0.87	0.70	0.90	0.88	0.38	0.88	0
3	0.41	0.29	0.35	0.33	0.45	0.88	0.67	0.92	0.82	0
4	0	0	0.41	0.74	0.5	0.83	0.83	0.99	0.88	0.41
5	0.71	0.67	0.46	0.87	0.51	0.70	0.71	0.83	1	0
6	0.21	0	0.49	0.71	0.40	0.88	0.92	0.69	0.82	0.82
7	0.78	0.29	0.41	0.71	0.62	0.77	0.67	1.04	0.82	0.52
8	0	0	0.35	0.73	0.45	0.85	0.74	0.92	0.84	0.52
9	0.75	0	0.83	0.87	0.63	0.86	0.84	0.49	0.70	0.52
10	0.78	0	0.52	0	0.81	0.96	1.03	0.49	0.87	0
11	0.88	0.39	0.86	0.98	0.48	0.90	0.84	0.74	0.99	0.52
12	0.60	0	0	0.71	0.62	0.77	0.71	1.04	0.70	0
13	0.34	0	0.26	0.52	0.72	0.99	0.93	0.82	0.92	0
14	0.47	0	0.72	0	0.62	0.90	0.85	0.90	0.88	0.52
15	0	0.29	0.35	0.73	0.58	0	0.85	0.79	0.32	0
16	0	0	0.52	0.73	0.34	0	0.95	0.79	0.32	0
17	0	0.29	0.26	0.46	0.58	0	0.85	0.79	0.32	0
18	0.48	0.83	0	0	0.87	0.99	0.92	0.52	0.92	0
19	0.5	0.62	0.36	0	0.52	0.56	0.84	0.74	0.85	1.52
20	0.22	0.67	0.63	0.88	0.48	0.99	0.63	0.79	0.70	1.03
21	0	0.83	0.04	0.87	0.45	0.70	0.67	0.71	0.99	1.10

## Spearman Rank Correlations - Study I

	pomn	cvmn	cvpmn	sbmn	pemn	opmn
pomn	1.0000 ( 16) 1.0000	.1923 ( 16) .4563	.2580 ( 16) .3177	.2457 ( 16) .3412	.2675 ( 16) .3001	-.2028 ( 16) .4322
cvmn	.1923 ( 16) .4563	1.0000 ( 21) 1.0000	.2797 ( 21) .2111	.2282 ( 21) .3074	.1752 ( 21) .4332	-.2045 ( 21) .3604
cvpmn	.2580 ( 16) .3177	.2797 ( 21) .2111	1.0000 ( 21) 1.0000	.5162 ( 21) .0210	-.0761 ( 21) .7337	-.1299 ( 21) .5614
sbmn	.2457 ( 16) .3412	.2282 ( 21) .3074	.5162 ( 21) .0210	1.0000 ( 21) 1.0000	-.2545 ( 21) .2551	-.1215 ( 21) .5870
pemn	.2675 ( 16) .3001	.1752 ( 21) .4332	-.0761 ( 21) .7337	-.2545 ( 21) .2551	1.0000 ( 21) 1.0000	.2710 ( 21) .2256
opmn	-.2028 ( 16) .4322	-.2045 ( 21) .3604	-.1299 ( 21) .5614	-.1215 ( 21) .5870	.2710 ( 21) .2256	1.0000 ( 21) 1.0000
ssmn	.0969 ( 16) .7075	-.0829 ( 21) .7108	-.0505 ( 21) .8214	-.2208 ( 21) .3235	.0833 ( 21) .7097	-.0833 ( 21) .7097
fmn	.1010 ( 16) .6956	.0510 ( 21) .8194	.0543 ( 21) .8081	.2429 ( 21) .2774	-.2514 ( 21) .2609	-.0105 ( 21) .9627
prmn	.2633 ( 16) .3078	.1794 ( 21) .4223	.3836 ( 21) .0863	.0688 ( 21) .7582	.3124 ( 21) .1623	.2343 ( 21) .2948
srmn	.1065 ( 16) .6799	-.2017 ( 21) .3671	-.7653 ( 21) .0006	-.2510 ( 21) .2617	.0840 ( 21) .7072	-.0459 ( 21) .8372

=====  
Coefficient (sample size) significance level

pomn = person's opinions  
 cvmn = carer's view  
 cvpmn = challenges  
 sbmn = social behaviour  
 pemn = physical environment  
 opmn = opportunities  
 ssmn = support services  
 fmn = friendships  
 prmn = preparation  
 srmn = special requirements

## APPENDIX 9A

	ssmn	fmn	prmn	srnm
pomn	.0969 ( 16) .7075	.1010 ( 16) .6956	.2633 ( 16) .3078	.1065 ( 16) .6799
cvmn	-.0829 ( 21) .7108	.0510 ( 21) .8194	.1794 ( 21) .4223	-.2017 ( 21) .3671
cvpmn	-.0505 ( 21) .8214	.0543 ( 21) .8081	.3836 ( 21) .0863	-.7653 ( 21) .0006
sbmn	-.2208 ( 21) .3235	.2429 ( 21) .2774	.0688 ( 21) .7582	-.2510 ( 21) .2617
permn	.0833 ( 21) .7097	-.2514 ( 21) .2609	.3124 ( 21) .1623	.0840 ( 21) .7072
opmn	-.0833 ( 21) .7097	-.0105 ( 21) .9627	.2343 ( 21) .2948	-.0459 ( 21) .8372
ssmn	1.0000 ( 21) 1.0000	.0609 ( 21) .7855	.2748 ( 21) .2190	.3237 ( 21) .1478
fmn	.0609 ( 21) .7855	1.0000 ( 21) 1.0000	-.1384 ( 21) .5360	-.1120 ( 21) .6165
prmn	.2748 ( 21) .2190	-.1384 ( 21) .5360	1.0000 ( 21) 1.0000	-.2270 ( 21) .3100
srnm	.3237 ( 21) .1478	-.1120 ( 21) .6165	-.2270 ( 21) .3100	1.0000 ( 21) 1.0000

INTER-CORRELATIONS OF SUB-SCALES (DISAGGREGATED DATA): STUDY I

	current	activity	friend	carers
current	1.0000 ( 14)	.5117 ( 14)	.4884 ( 14)	.5666 ( 14)
	1.0000	.0651	.0782	.0411
activity	.5117 ( 14)	1.0000 ( 14)	.2442 ( 14)	.4092 ( 14)
	.0651	1.0000	.3787	.1401
friend	.4884 ( 14)	.2442 ( 14)	1.0000 ( 14)	.2679 ( 14)
	.0782	.3787	1.0000	.3340
carers	.5666 ( 14)	.4092 ( 14)	.2679 ( 14)	1.0000 ( 14)
	.0411	.1401	.3340	1.0000

---

	place	cactivity	cfriend	ccarers
place	1.0000 ( 14)	-.1370 ( 14)	.3016 ( 14)	.5786 ( 14)
	1.0000	.6214	.2768	.0369
cactivity	-.1370 ( 14)	1.0000 ( 14)	.5374 ( 14)	.1296 ( 14)
	.6214	1.0000	.0527	.6402
cfriend	.3016 ( 14)	.5374 ( 14)	1.0000 ( 14)	.7557 ( 14)
	.2768	.0527	1.0000	.0064
ccarers	.5786 ( 14)	.1296 ( 14)	.7557 ( 14)	1.0000 ( 14)
	.0369	.6402	.0064	1.0000

---

	challenge	social
challenge	1.0000 ( 14)	.2722 ( 14)
	1.0000	.3263
social	.2722 ( 14)	1.0000 ( 14)
	.3263	1.0000

Coefficient (sample size) significance level

Appendix 9B continued

	pepersonal	peprivacy	peequip	peoutside
pepersonal	1.0000 ( 14) 1.0000	-.4073 ( 14) .1419	.6204 ( 14) .0253	.6955 ( 14) .0122
peprivacy	-.4073 ( 14) .1419	1.0000 ( 14) 1.0000	-.1631 ( 14) .5565	-.4621 ( 14) .0957
peequip	.6204 ( 14) .0253	-.1631 ( 14) .5565	1.0000 ( 14) 1.0000	.5179 ( 14) .0619
peoutside	.6955 ( 14) .0122	-.4621 ( 14) .0957	.5179 ( 14) .0619	1.0000 ( 14) 1.0000

---

	sswithin	ssexternal
sswithin	1.0000 ( 14) 1.0000	.4884 ( 14) .0782
ssexternal	.4884 ( 14) .0782	1.0000 ( 14) 1.0000

---

	opcook	opshop	opclothes	opleisure	opnew
opcook	1.0000 ( 14) 1.0000	.3211 ( 14) .2469	.4382 ( 14) .1141	.3161 ( 14) .2544	.2750 ( 14) .3213
opshop	.3211 ( 14) .2469	1.0000 ( 14) 1.0000	.0776 ( 14) .7795	.0069 ( 14) .9801	.0229 ( 14) .9342
opclothes	.4382 ( 14) .1141	.0776 ( 14) .7795	1.0000 ( 14) 1.0000	.3380 ( 14) .2230	.1256 ( 14) .6506
opleisure	.3161 ( 14) .2544	.0069 ( 14) .9801	.3380 ( 14) .2230	1.0000 ( 14) 1.0000	.5817 ( 14) .0360
opnew	.2750 ( 14) .3213	.0229 ( 14) .9342	.1256 ( 14) .6506	.5817 ( 14) .0360	1.0000 ( 14) 1.0000

Coefficient (sample size) significance level.



Appendix 9B continued

	frclose	froutside	frwithin
frclose	1.0000 ( 14) 1.0000	.6357 ( 14) .0219	.2536 ( 14) .3605
froutside	.6357 ( 14) .0219	1.0000 ( 14) 1.0000	.3530 ( 14) .2031
frwithin	.2536 ( 14) .3605	.3530 ( 14) .2031	1.0000 ( 14) 1.0000

---

	preppers	prepcompat	preprep
preppers	1.0000 ( 14) 1.0000	-.2855 ( 14) .3033	.3521 ( 14) .2042
prepcompat	-.2855 ( 14) .3033	1.0000 ( 14) 1.0000	-.5884 ( 14) .0339
preprep	.3521 ( 14) .2042	-.5884 ( 14) .0339	1.0000 ( 14) 1.0000

Coefficient (sample size) significance level

WHERE

Person's views of Current Placement	=	Current
Person's Views of Activities	=	Activity
Person's Views of Friendships	=	Friend
Person's Views of Carers	=	Carer
Carer's Views: Placement	=	Place
Carer's Views: Activity	=	C.Activity
Carer's Views: Friendships	=	C.Friend
Carer's Views: Carers	=	C.Carers
Carer's Views: Challenging	=	Challenge
Carer's Views: Social Behaviour	=	Social
Physical Environment: Personal	=	Pe.Personal
Physical Environment: Privacy	=	Pe.Privacy
Physical Environment: Equipment	=	Pe.Equip
Physical Environment: Outside	=	Pe.Outside
Support Service: Within	=	SS.Within
Support Service: External	=	SS.External
Opportunities: Cooking	=	OP.Cook
Opportunities: Shopping	=	OP.Shop
Opportunities: Clothes	=	OP.Clothes
Opportunities: Leisure	=	OP.Leisure
Opportunities: New Skills	=	OP.New
Friendships: Close	=	FR.Close
Friendships: Outside	=	FR.Outside
Friendships: Within	=	FR.Within
Preparation: Person's Involvement	=	Preppers
Preparation: Compatibility	=	Prepcompat
Preparation: Preparation	=	Preprep.
Special Requirements	=	Special

SUMMARY OF THE RESEARCH PROJECT

PEOPLE WITH LEARNING DIFFICULTIES LEAVING HOSPITAL

INTRODUCTION

A number of research projects have been undertaken, which have investigated people with learning difficulties living in a variety of environments. Researchers have reported findings concerning skill acquisition, transition shock, evaluation of services, friendships, costs etc. The majority of writers recommend that the policy of deinstitutionalisation is in urgent need of evaluation. Clear evidence of the negative features of institutions exists e.g. segregation, group practices etc., but it is less clear what services in alternative settings should aim for, and what leads to a "successful community placement".

The present study aimed to attempt to investigate the factors that lead to a successful placement both from the person's viewpoint and that of his/her carer's. So, for example, is the person's satisfaction with a placement related to friendships, opportunities, support services (or combinations of these factors)? In addition, the study considered the reasons why people returned to hospital, were the reasons always related to "challenging behaviours"?

HOW THE STUDY WAS UNDERTAKEN

All the people who had left hospitals for people with learning difficulties in Leicestershire in 1985 were contacted and asked if they would agree to participate in the study. A total of 21 people and their carers agreed to take part. The majority of this group of people lived in Social Services hostels and group homes, and private registered and unregistered homes. Two people had returned to hospital. The average age of the people was 45 years (range 21-72 years). On average, people had left hospital 13 months earlier.

Information was collected by structured interviews in the person's home (for two people, a hospital had become their home). All the interviews were conducted in private and an assurance of confidentiality and a brief explanation of the purpose of study were given. In the early stages of the visit, the person was asked if they would show the researcher around their home - this brief tour served the purposes of "getting to know the person", their style of communication and also to see the home environment. The person was then interviewed alone, and, finally, a carer was interviewed. It was requested that the carer had known the person for at least 3 months. Questions were asked about the following areas: the person's satisfaction; carer's view of the suitability of the placement; "challenging behaviours"; social behaviour, physical environment, support services; opportunities, e.g., to participate in domestic activities; friendships; preparation, e.g., assessment procedures, visits, etc.; special requirements.

## Findings:

The findings are presented in a manner which maintains the confidentiality of all those people who contributed. Any difficulties in collecting the information are referred to under the relevant section.

### 1. Person's Opinions

- Five people were unable to answer many of the questions, so results are based on the information from 16 people only.
- Majority of people liked where they were living and wanted to stay.
- Positive reports were given about the activities, carers, helping in the home, neighbourhood, money, etc.
- Many people wanted more to do in their spare time.
- Many people said they would like more friends.
- No significant association was found with any of the other factors.

### 2. Carer's Views of the Placement

- The majority of people were felt to be suited to their placements.
- Specific reasons could be given if the placement was considered unsuitable, e.g., the amount of carer's time required.

### 3. Challenges Presented

- few "challenging" behaviours were reported
- some people were described as sometimes being demanding, moody, etc.
- significant associations were found between the absence of problems and the absence of special requirements, and with the presence of a greater degree of social behaviours; so carers reported that people who presented with few 'challenging' behaviours had more social behaviours and fewer special requirements.

#### 4. Social Behaviour

- The majority of people took sufficient care of their appearance, undertook activities with others in the house.
- Some people showed little interest in the home.
- Many people needed to be reminded to offer a drink to visitors.
- A significant association was found between this measure and the absence of challenging behaviours, so carers reported a greater degree of social behaviours for people who had few challenging behaviours.

#### 5. Physical Environment

- Majority were pleasant and 'homely'.
- Most people had their own bedroom (not always chosen by the person).
- Most furniture was of a 'domestic' type (but not usually chosen by the person).
- Often no place to be alone, except bedroom or interrupting others.
- Some houses had a locked area.
- Some placements had a specific reference outside the house.
- No significant association was found with other factors.

#### 6. Support Services

- All the people lived in situations in which carers were present 24 hours a day.
- Staffing levels were considered appropriate in most cases.
- Few people were visited regularly by other professionals.
- No significant association was found with other factors.

#### 7. Opportunities

- Varied across different settings.
- Most people went shopping regularly.
- A few people regularly prepared hot food.
- All people chose their own clothes.

- Few people organised their own money (except pocket money).
- Many people mixed regularly with people without learning difficulties.
- No significant association was found with the other factors.

#### 8. Friendships

- Many people knew other people in the placement before they moved.
- Some people were reported to have two or more friends.
- Few people invited friends to the house.
- Few people had a friend with whom they could discuss problems.
- No significant association was found with the other factors.

#### 9. Preparation

- Problems were found in obtaining this information; sometimes carers did not have the information.
- The majority of people visited their placement at least twice before moving.
- For many people the assessment undertaken was incomplete.
- Most people had little preparation/training in the new placement.
- The above information concerning preparation should be treated with caution, due to the difficulties in collecting the information.
- No significant association was found with the other factors.

#### 10. Special Requirements

- Few were reported.
- People who returned to hospital were considered to have special requirements.
- The absence of special requirements was associated with the absence of challenging behaviours.

## CONCLUSIONS

The majority of people gave positive reports of their placements outside hospital. Some dissatisfaction was expressed about friendships and spare time activities. The study did not identify any (statistically significant) factors involved in "successful" placements from the person's viewpoint

Carers reports of the placements were also largely positive. Carers reported that people with greater social behaviours had fewer "challenging behaviours" and fewer special requirements. The physical environment of services and opportunities varied considerably.

Overall, few "challenging behaviours" were reported. Both the people who returned to hospital presented such problems, but expressed positive views of their placement outside hospital.

Angela Holland,  
Clinical Psychologist

AH/MSL  
5.3.87.

Research Project - Summary of Methodology

Subjects

It is planned that six people with learning difficulties in six different services will be the subjects of the research:

The people who participate in the research should:

1. Have lived in their present placement for 18 months.
2. Be able to answer questions, e.g., to name their friends, state whether he/she enjoys living in their present placement.
3. Be aged between 19-55 years.

Services

Subject will be living in 6 different services. The services will be of two types: (3 people living in each type of service)

1. Staffed houses - preferably 24 hour staffing.
2. Larger "community units/houses" - 10 or more places and preferably having 24 hour staffing.

Measures

a) Collected by the researchers:

1. Clients' views:

- a) Modified version of the Consumer Interview Questionnaire (Conroy and Bradley, 1985).
- b) Meetings on 6 occasions - using open-ended questions on a series of topics. These meetings will be tape-recorded.

2. Client activity:

Observational data using a portable computer will be collected for 1 hour 30 mins. in the evening, e.g., starting at tea/supper-time 5.00 p.m. and continuing until 6.30 p.m. Data will be collected on 8 consecutive weekdays. Observations will generally not be conducted in private areas, e.g., bathrooms, toilets, bedrooms.



b) Collected by interview with care staff:

Four short questionnaires will be completed by interview with care staff:

1. Physical environment (part of questionnaire only).
2. Choices available.
3. Opportunities - available and potential.
4. Friendships.

In addition, an Adaptive Behaviour Scale will be completed on each subject before participation. If this has been completed within the last 6 months, the whole ABS need not be repeated.

c) Collected by care staff:

Diary data on each subject will be completed for 3 weeks - specifying what the person has done, where, with whom, approximate duration, etc.

#### Consent Procedures

The project involves both "getting to know" the person in detail, their preferences, lifestyle, etc., and includes observation for approximately 12 hours for each person. So, it is felt that attention must be given to consent procedures. Consent will be required from 3 sources:

1. The person - including an explanation of the interviews, tape recordings and observations.
2. Direct care staff - e.g., a keyworker who knows the subject well.
3. Relative - if in regular contact.  
If no relative is in regular contact, then an alternative person may be approached. This person should know the subject, but not be a direct care staff, e.g., Social Worker, Psychologist, etc.

#### Period over which measures will be collected

It is estimated that the researcher(s) will be in contact with each service for six weeks approximately.

AH/MSL  
6.10.87.

Past History of the Subjects in Study II

Paul

1. Age: 35 years.

2. Previous placements

Paul was admitted to a large hospital for people with learning difficulties when he was 13 years old. The hospital was described as having large dormitories.

He moved to another hospital 20 years later. This hospital also had large dormitories.

3. Current links with family

Paul's parents were both dead. His mother had died nearly 5 years before the research project started, whilst his father had died only 1-2 months before the researcher met Paul.

4. Other information

No information was available on his school history.

Before leaving hospital, Paul and the other people living in the staffed house had all lived together in a house in the grounds of the hospital. The group had started to attend a Day Centre and to participate in domestic tasks, etc. Two carers who currently worked in the staffed house, were involved in the house in the hospital grounds.

A committee in the hospital decided who would leave hospital.

Whilst living in hospital, Paul had regularly argued with a "friend" - he shouted and threw chairs around the ward on most mornings. The behaviour resulted in threats of having no cigarettes and sometimes the threats were put into practice.

Patricia

1. Age: 40 years.

2. Previous placements

Patricia had lived with her mother until her mother died, when she moved to her current service. She had lived in the service for about 17 months.

3. Current links with family

Both her parents are dead.

She occasionally visits an old friend of the family.

4. Other information

Patricia did not attend school, nor a Day Centre, while her mother was alive. This was at the request of her mother.

Patricia did not visit the service prior to her move.

Patricia knew most of the people living in the service before her move. She had met them regularly at a local voluntary club.

Appendix 12 contd ...

Janet

1. Age: 40 years.

2. Previous placements

Janet had lived with parents until age 28 years.

She moved to live in a large hospital for people with learning difficulties, where she remained for about 9 years.

She had lived in her present placement for about 2 years 6 months.

3. Current links with family

Janet's father had died. She felt that her father had been very good to her.

She had no contact with her mother.

She was in regular contact with her sister. She visited her sister every weekend and her sister lived nearby.

4. Other information

Janet had been frightened during her stay in hospital.

In hospital she used to bite her hands, pull her hair and smack her face.

In her present placement, few challenging behaviours occurred - she sometimes swore.

She had attended a Day Centre from home and hospital.

Appendix 12 contd ...

Stephen

1. Age: 21 years.

2. Previous placement

Stephen lived at home until he went to live in a large community service. The length of time he remained there is unknown.

Stephen had been in his present placement for 18 months.

3. Current links with family

He visited his family infrequently, i.e., less than once a month.

His father hit him at home.

4. Other information

He sometimes swore at his carers, but had reduced during the time he lived in his present service.

Appendix 12 cont ...

Keith

1. Age: 24 years.

2. Previous placements

Keith lived in a children's home and was then fostered at the age of 6 years.

After leaving school, he spent one year on a residential course run by MENCAP in Somerset.

He left his foster parents five years before the research project began to live in his current placement.

3. Current links with family

Keith sees his foster parents about 3-4 times a year.

He has no current contact with his mother, whose last known address was in Scotland.

4. Other information

After leaving school he attended two courses in addition to the course in Somerset. He went to a Special Needs course for one year and a YTS course also for a year.

He then attended a Day Centre, but left after he threatened someone with a knife.

He was accused of shoplifting and taken to court. He then attended a day service based in a large hospital for people with learning difficulties.

Andrew

1. Age: 24 years.

2. Previous placements

Andrew lived with his parents as a young child. When he was 8 years old his mother left home.

At age 13 years, he went to live at Barnardo's children's home, together with his twin brother.

At age 18 years he moved to live in his present placement, but without his twin brother. During visits to the service, his twin brother hit his head against the wall and attacked staff and was considered unsuitable.

3. Current links with family

Andrew is visited on alternate weekends by his father and sometimes his twin brother comes with the father.

Andrew sees his mother less frequently.

Andrew went to his father's wedding, but not his mother's.

4. Other information

Andrew's twin brother had recently moved to a (private) group home.

Andrew had completed a bronze Duke of Edinburgh award.

He had his first holiday abroad in 1988.

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The second type of item asks you to check ALL statements which apply to the person. For example:

<b>[4] Table Manners</b>		
(Check ALL statements which apply)		
Swallows food without chewing	<input type="checkbox"/>	8-number checked =  <b>6</b>
Chews food with mouth open	<input checked="" type="checkbox"/>	
Drops food on table or floor	<input type="checkbox"/>	
Uses napkin incorrectly or not at all	<input checked="" type="checkbox"/>	
Talks with mouth full	<input type="checkbox"/>	
Takes food off others' plates	<input type="checkbox"/>	
Eats too fast or too slow	<input type="checkbox"/>	
Plays in food with fingers	<input type="checkbox"/>	
None of the above	<input type="checkbox"/>	
Does not apply, e.g., because he or she is completely dependent on others (If checked, enter "0" in the circle to the right.)		

In the example above, the second and fourth items are checked to indicate that the person "chews food with mouth open" and "uses napkin incorrectly." In scoring, the number of items checked, 2, is subtracted from 8, and the item score, 6, is entered in the circle to the right. Most items do not, however, require this subtraction; instead, the number checked can be directly entered as the score. The statement "None of the above," which is included for administrative purposes only, is not to be counted in scoring here.

Some items may deal with behaviors that are clearly against local regulations, (e.g., use of the telephone), or behaviors that are not possible for a person to perform because the opportunity does not exist, (e.g., eating in restaurants is not possible for someone who is bedridden). In these instances, you must still complete your rating. Give the person credit for the item if you feel absolutely certain that he or she can and would perform the behavior without additional training had he or she the opportunity to do so. Write "AR" for "Against Regulations" or "HNO" for "Has No Opportunity" next to the rating made in these cases. These notations will not affect the eventual scoring of that item, but will contribute to the understanding and interpretation of the person's adaptive behavior and environment.

Please observe the following general rules in completing the Scale:

1. In items which specify "with help" or "with assistance" for completion of task, these mean with *direct physical assistance*.
2. Give the person credit for an item even if he or she needs verbal prompting or reminding to complete the task unless the item definitely states "*without prompting*" or "*without reminder*."

This Scale is prepared for general use. Therefore, some of the items may not be appropriate for your specific setting, but please do try to complete all of them.

## PART ONE

### I. INDEPENDENT FUNCTIONING

#### A. Eating

##### [1] Use of Table Utensils (Circle only ONE)

- |  |   |
|--|---|
| Uses knife and fork correctly and neatly               | 6 |
| Uses table knife for cutting or spreading              | 5 |
| Feeds self with spoon and fork - neatly                | 4 |
| Feeds self with spoon and fork - considerable spilling | 3 |
| Feeds self with spoon - neatly                         | 2 |
| Feeds self with spoon - considerable spilling          | 1 |
| Feeds self with fingers or must be fed                 | 0 |

☐

##### [2] Eating in Public (Circle only ONE)

- |   |   |
|---|---|
| Orders complete meals in restaurants            | 3 |
| Orders simple meals like hamburgers or hot dogs | 2 |
| Orders soft drinks at soda fountain or canteen  | 1 |
| Does not order at public eating places          | 0 |

☐

##### [3] Drinking (Circle only ONE)

- |   |   |
|---|---|
| Drinks without spilling, holding glass in one hand          | 3 |
| Drinks from cup or glass unassisted - neatly                | 2 |
| Drinks from cup or glass unassisted - considerable spilling | 1 |
| Does not drink from cup or glass unassisted                 | 0 |

☐

##### [4] Table Manners (Check ALL statements which apply)

- |  |       |  |
|--|-------|--|
| Swallows food without chewing  | _____ | 8-number checked = <input type="radio"/> |
| Chews food with mouth open   | _____ |  |
| Drops food on table or floor   | _____ |  |
| Uses napkin incorrectly or not at all  | _____ |  |
| Talks with mouth full  | _____ |  |
| Takes food off others' plates  | _____ |  |
| Eats too fast or too slow  | _____ |  |
| Plays in food with fingers   | _____ |  |
| None of the above  | _____ |  |
| Does not apply, e.g., because he or she is bedfast, and/or has liquid food only (If checked, enter "0" in the circle to the right) | _____ |  |

ADD

1-4

☐

A. Eating

B. Toilet Use

##### [5] Toilet Training (Circle only ONE)

- |  |   |
|--|---|
| Never has toilet accidents                       | 4 |
| Never has toilet accidents during the day        | 3 |
| Occasionally has toilet accidents during the day | 2 |
| Frequently has toilet accidents during the day   | 1 |
| Is not toilet trained at all                     | 0 |

☐

#### [6] Self-Care at Toilet

(Check ALL statements which apply)

- |   |       |
|---|-------|
| Lowers pants at the toilet without help | _____ |
| Sits on toilet seat without help        | _____ |
| Uses toilet tissue appropriately        | _____ |
| Flushes toilet after use                | _____ |
| Puts on clothes without help            | _____ |
| Washes hands without help               | _____ |
| None of the above                       | _____ |

☐

B. Toilet Use

ADD

5-6

☐

#### C. Cleanliness

##### [7] Washing Hands and Face

(Check ALL statements which apply)

- |                                  |       |
|----------------------------------|-------|
| Washes hands with soap           | _____ |
| Washes face with soap            | _____ |
| Washes hands and face with water | _____ |
| Dries hands and face             | _____ |
| None of the above                | _____ |

☐

##### [8] Bathing (Circle only ONE)

- |   |   |
|---|---|
| Prepares and completes bathing unaided                        | 6 |
| Washes and dries self completely without prompting or helping | 5 |
| Washes and dries self reasonably well with prompting          | 4 |
| Washes and dries self with help                               | 3 |
| Attempts to soap and wash self                                | 2 |
| Cooperates when being washed and dried by others              | 1 |
| Makes no attempt to wash or dry self                          | 0 |

☐

##### [9] Personal Hygiene

(Check ALL statements which apply)

- |  |       |
|--|-------|
| Has strong underarm odor   | _____ |
| Does not change underwear regularly by self  | _____ |
| Skin is often dirty if not assisted  | _____ |
| Does not keep nails clean by self  | _____ |
| None of the above  | _____ |
| Does not apply, e.g., because he or she is completely dependent on others. (If checked, enter "0" in the circle to the right.) | _____ |

☐


##### [10] Tooth Brushing (Circle only ONE)

- |  |   |
|--|---|
| Applies toothpaste and brushes teeth with up and down motion | 5 |
| Applies toothpaste and brushes teeth                         | 4 |
| Brushes teeth without help, but cannot apply toothpaste      | 3 |
| Brushes teeth with supervision                               | 2 |
| Cooperates in having teeth brushed                           | 1 |
| Makes no attempt to brush teeth                              | 0 |

☐

[11] **Menstruation** (Circle only ONE)  
(For males, Circle "no menstruation")


No menstruation	5
Cares for self completely for menstruation without assistance or reminder	5
Cares for self reasonably well during menstruation	4
Helps in changing pads during menstruation	3
Indicates pad needs changing during menstruation	2
Indicates that menstruation had begun	1
Will not care for self or seek help during menstruation	0

C Cleanliness ADD 7-11 

**D. Appearance**


[12] **Posture** (Check ALL statements which apply)


Mouth hangs open	_____
Head hangs down	_____
Stomach sticks out because of posture	_____
Shoulders slumped forward and back bent	_____
Walks with toes out or toes in	_____
Walks with feet far apart	_____
Shuffles, drags, or stamps feet when walking	_____
Walks on tiptoes	_____
None of the above	_____
Does not apply, e.g., because he or she is bedfast or non-ambulatory (If checked, enter "0" in the circle to the right)	_____

8-number checked = 

[13] **Clothing** (Check ALL statements which apply)

Clothes do not fit properly if not assisted	_____
Wears torn or unprompted clothing if not prompted	_____
Rewears dirty or soiled clothing if not prompted	_____
Wears clashing color combinations if not prompted	_____
Does not know the difference between work shoes and dress shoes	_____
Does not choose different clothing for formal and informal occasions	_____
Does not wear special clothing for different weather conditions (raincoat, overshoes, etc.)	_____
None of the above	_____
Does not apply, e.g., because he or she is completely dependent on others (If checked, enter "0" in the circle to the right)	_____


7-number checked = 

D. Appearance ADD 12-13 

**E. Care of Clothing**

[14] **Care of Clothing**  
(Check ALL statements which apply)


Wipes and polishes shoes when needed	_____
Puts clothes in drawer or chest neatly	_____
Sends clothes to laundry without being reminded	_____
Hangs up clothes without being reminded	_____
None of the above	_____

E. Care of Clothing ENTER 14 

**F. Dressing and Undressing**


[15] **Dressing** (Circle only ONE)

Completely dresses self	5
Completely dresses self with verbal prompting only	4
Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help	3
Dresses self with help in pulling or putting on most clothes and fastening them	2
Cooperates when dressed by extending arms or legs	1
Must be dressed completely	0




[16] **Undressing at Appropriate Times**  
(Circle only ONE)


Completely undresses self	5
Completely undresses self with verbal prompting only	4
Undresses self by unfastening (unzipping, unbuttoning, unsnapping) clothes with help and pulling or taking them off with verbal prompting	3
Undresses self with help in unfastening and pulling or taking off most clothes	2
Cooperates when undressed by extending arms or legs	1
Must be completely undressed	0



[17] **Shoes** (Check ALL statements with apply)

Puts on shoes correctly without assistance	_____
Ties shoe laces without assistance	_____
Unties shoe laces without assistance	_____
Removes shoes without assistance	_____
None of the above	_____




F. Dressing and Undressing ADD 15-17 

**G. Travel**

[18] **Sense of Direction** (Circle only ONE)

Goes a few blocks from hospital or school ground, or several blocks from home without getting lost	3
Goes around hospital ground or a few blocks from home without getting lost	2
Goes around cottage, ward, or home alone	1
Gets lost whenever leaving own living area	0



[19] **Public Transportation**

(Check ALL statements which apply)

- Rides on train, long-distance bus or plane independently \_\_\_\_\_
- Rides in taxi independently \_\_\_\_\_
- Rides subway or city bus for unfamiliar journeys independently \_\_\_\_\_
- Rides subway or city bus for familiar journeys independently \_\_\_\_\_
- None of the above \_\_\_\_\_

G. Travel

ADD  
18-19



H. Other Independent Functioning

[20] **Telephone** (Check ALL statements which apply)

- Uses telephone directory \_\_\_\_\_
- Uses pay telephone \_\_\_\_\_
- Makes telephone calls from private telephone \_\_\_\_\_
- Answers telephone appropriately \_\_\_\_\_
- Takes telephone messages \_\_\_\_\_
- None of the above \_\_\_\_\_



[21] **Miscellaneous Independent Functioning**  
(Check ALL statements which apply)

- Prepares own bed at night \_\_\_\_\_
- Goes to bed unassisted, e.g., getting in bed, covering with blanket, etc. \_\_\_\_\_
- Has ordinary control of appetite, eats moderately \_\_\_\_\_
- Knows postage rates, buys stamps from Post Office \_\_\_\_\_
- Looks after personal health, e.g., changes wet clothing \_\_\_\_\_
- Deals with simple injuries, e.g., cuts, burns \_\_\_\_\_
- Knows how and where to obtain a doctor's or dentist's help \_\_\_\_\_
- Knows about welfare facilities in the community \_\_\_\_\_
- None of the above \_\_\_\_\_



H. Other Independent Functioning

ADD  
20-21



I. INDEPENDENT FUNCTIONING ADD  
TRIANGLES A-H



II. **PHYSICAL DEVELOPMENT**

A. **Sensory Development**  
(Observable functioning ability)

[22] **Vision** (With glasses, if used)  
(Circle only ONE)

- No difficulty in seeing \_\_\_\_\_
- Some difficulty in seeing \_\_\_\_\_
- Great difficulty in seeing \_\_\_\_\_
- No vision at all \_\_\_\_\_

3  
2  
1  
0



[23] **Hearing** (With hearing aid, if used)  
(Circle only ONE)

- No difficulty in hearing \_\_\_\_\_
- Some difficulty in hearing \_\_\_\_\_
- Great difficulty in hearing \_\_\_\_\_
- No hearing at all \_\_\_\_\_

3  
2  
1  
0



A. Sensory Development

ADD  
22-23



B. **Motor Development**

[24] **Body Balance** (Circle only ONE)

- Stands on "tiptoe" for ten seconds if asked \_\_\_\_\_
- Stands on one foot for two seconds if asked \_\_\_\_\_
- Stands without support \_\_\_\_\_
- Stands with support \_\_\_\_\_
- Sits without support \_\_\_\_\_
- Can do none of the above \_\_\_\_\_

5  
4  
3  
2  
1  
0



[25] **Walking and Running**  
(Check ALL statements which apply)

- Walks alone \_\_\_\_\_
- Walks up and down stairs alone \_\_\_\_\_
- Walks down stairs by alternating feet \_\_\_\_\_
- Runs without falling often \_\_\_\_\_
- Hops, skips or jumps \_\_\_\_\_
- None of the above \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



[26] **Control of Hands**  
(Check ALL statements which apply)

- Catches a ball \_\_\_\_\_
- Throws a ball overhand \_\_\_\_\_
- Lifts cup or glass \_\_\_\_\_
- Grasps with thumb and finger \_\_\_\_\_
- None of the above \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



[27] Limb Function

(Check ALL statements which apply)

- Has effective use of right arm \_\_\_\_\_
- Has effective use of left arm \_\_\_\_\_
- Has effective use of right leg \_\_\_\_\_
- Has effective use of left leg \_\_\_\_\_
- None of the above \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



B. Motor Development

ADD  
24-27




II. PHYSICAL DEVELOPMENT

ADD  
TRIANGLES A-B



[31] Purchasing (Circle only ONE)

- Buys all own clothing 5
- Buys own clothing accessories 4
- Makes minor purchases without help (candy, soft drinks, etc.) 3
- Does shopping with slight supervision 2
- Does shopping with close supervision 1
- Does no shopping 0



B. Shopping Skills

ADD  
30-31



III. ECONOMIC ACTIVITY

ADD  
TRIANGLES A-B



III. ECONOMIC ACTIVITY

A. Money Handling and Budgeting

[28] Money Handling (Circle only ONE)

- Uses banking facilities independently 4
- Makes change correctly but does not use banking facilities 3
- Adds coins of various denominations, up to one dollar 2
- Uses money, but does not make change correctly 1
- Does not use money 0



[29] Budgeting

(Check ALL statements which apply)

- Saves money or tokens for a particular purpose \_\_\_\_\_
- Budgets fares, meals, etc \_\_\_\_\_
- Spends money with some planning \_\_\_\_\_
- Controls own major expenditures \_\_\_\_\_
- None of the above \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



A. Money Handling and Budgeting

ADD  
28-29




B. Shopping Skills

[30] Errands (Circle only ONE)

- Goes to several shops and specifies different items 4
- Goes to one shop and specifies one item 3
- Goes on errands for simple purchasing without a note 2
- Goes on errands for simple purchasing with a note 1
- Cannot be sent on errands 0

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



IV. LANGUAGE DEVELOPMENT

A. Expression

[32] Writing (Circle only ONE)

- Writes sensible and understandable letters 5
- Writes short notes and memos 4
- Writes or prints forty words 3
- Writes or prints ten words 2
- Writes or prints own name 1
- Cannot write or print any words 0



[33] Preverbal Expression

(Check ALL statements which apply)

- Nods head or smiles to express happiness \_\_\_\_\_
- Indicates hunger \_\_\_\_\_
- Indicates wants by pointing or vocal noises \_\_\_\_\_
- Chuckles or laughs when happy \_\_\_\_\_
- Expresses pleasure or anger by vocal noises \_\_\_\_\_
- Is able to say at least a few words (Enter "6" if checked, regardless of other items.) \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



None of the above \_\_\_\_\_

[34] Articulation (Check ALL statements which apply--if no speech, check "None" and enter "0" in the circle)

- Speech is low, weak, whispered or difficult to hear \_\_\_\_\_
- Speech is slowed, deliberate, or labored \_\_\_\_\_
- Speech is hurried, accelerated, or pushed \_\_\_\_\_
- Speaks with blocking, halting, or other irregular interruptions \_\_\_\_\_
- None of the above \_\_\_\_\_

4-number checked =

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



[35] Sentences (Circle only ONE)

- Sometimes uses complex sentences containing "because," "but," etc  
Asks questions using words such as "why," "how," "what," etc  
Speaks in simple sentences  
Speaks in primitive phrases only, or is non-verbal

3  
2  
1  
0

[36] Word Usage (Circle only ONE)

- Talks about action when describing pictures  
Names people or objects when describing pictures  
Names familiar objects  
Asks for things by their appropriate names  
Is non-verbal or nearly non-verbal

4  
3  
2  
1  
0

A Expression → ADD 32-36 →

B. Comprehension

[37] Reading (Circle only ONE)

- Reads books suitable for children nine years or older  
Reads books suitable for children seven years old  
Reads simple stories or comics  
Reads various signs, e.g., "NO PARKING," "ONE WAY," "MEN," "WOMEN," etc  
Recognizes ten or more words by sight  
Recognizes fewer than ten words or none at all

5  
4  
3  
2  
1  
0

[38] Complex Instructions

(Check ALL statements which apply)

- Understands instructions containing prepositions, e.g., "on," "in," "behind," "under," etc  
Understands instructions referring to the order in which things must be done, e.g., "first do—then do—"  
Understands instructions requiring a decision: "If—, do this, but if not, do—"  
None of the above

—  
—  
—

B. Comprehension → ADD 37-38 →

C. Social Language Development

[39] Conversation

(Check ALL statements which apply)

- Uses phrases such as "please," and "thank you"  
Is sociable and talks during meals  
Talks to others about sports, family, group activities, etc  
None of the above

—  
—  
—

[40] Miscellaneous Language Development

(Check ALL statements which apply)

- Can be reasoned with  
Obviously responds when talked to  
Talks sensibly  
Reads books, newspapers, magazines for enjoyment  
Repeats a story with little or no difficulty  
Fills in the main items on application form reasonably well  
None of the above

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C. Social Language Development → ADD 39-40 →

IV. LANGUAGE DEVELOPMENT → ADD TRIANGLES A-C →

V. NUMBERS AND TIME

[41] Numbers (Circle only ONE)

- Does simple addition and subtraction  
Counts ten or more objects  
Mechanically counts to ten  
Counts two objects by saying "one . two"  
Discriminates between "one" and "many" or "a lot"  
Has no understanding of numbers

5  
4  
3  
2  
1  
0

[42] Time (Check ALL statements which apply)

- Tells time by clock or watch correctly to the minute \_\_\_\_\_
- Understands time intervals, e.g., between "3 30" and "4 30" \_\_\_\_\_
- Understands time equivalents, e.g., "9 15" is the same as "quarter past nine" \_\_\_\_\_
- Associates time on clock with various actions and events \_\_\_\_\_
- None of the above \_\_\_\_\_

[43] Time Concept  
(Check ALL statements which apply)

- Names the days of the week \_\_\_\_\_
- Refers correctly to "morning" and "afternoon" \_\_\_\_\_
- Understands difference between day-week, minute-hour, month-year, etc. \_\_\_\_\_
- None of the above \_\_\_\_\_

V. NUMBERS AND TIME ADD 41-43  

VI. DOMESTIC ACTIVITY

A. Cleaning

[44] Room Cleaning (Circle only ONE)

- Cleans room well, e.g., sweeping, dusting and tidying 2
- Cleans room but not thoroughly 1
- Does not clean room at all 0

[45] Laundry (Check ALL statements which apply)

- Washes clothing \_\_\_\_\_
- Dries clothing \_\_\_\_\_
- Folds clothing \_\_\_\_\_
- Irons clothing when appropriate \_\_\_\_\_
- None of the above \_\_\_\_\_

A. Cleaning ADD 44-45  

B. Kitchen

[46] Table Setting (Circle only ONE)

- Places all eating utensils, as well as napkins, salt, pepper, sugar, etc., in positions learned 3
- Places plates, glasses, and utensils in positions learned 2
- Places silver, plates, cups, etc., on the table 1
- Does not set table at all 0

[47] Food Preparation (Circle only ONE)

- Prepares an adequate complete meal (may use canned or frozen food) 3
- Mixes and cooks simple food, e.g., fries eggs, makes pancakes, cooks TV dinners, etc. 2
- Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc. 1
- Does not prepare food at all 0

[48] Table Clearing (Circle only ONE)

- Clears table of breakable dishes and glassware 2
- Clears table of unbreakable dishes and silverware 1
- Does not clear table at all 0

B. Kitchen ADD 46-48  

C. Other Domestic Activities

[49] General Domestic Activity

(Check ALL statements which apply)

- Washes dishes well \_\_\_\_\_
- Makes bed neatly \_\_\_\_\_
- Helps with household chores when asked \_\_\_\_\_
- Does household tasks routinely \_\_\_\_\_
- None of the above \_\_\_\_\_

C. Other Domestic Activities ENTER 49  

VI. DOMESTIC ACTIVITY ADD TRIANGLES A-C  

VII. VOCATIONAL ACTIVITY

[50] Job Complexity (Circle only ONE)

- Performs a job requiring use of tools or machinery, e.g., shop work, sewing, etc. 2
- Performs simple work, e.g., simple gardening, mopping floors, emptying trash, etc. 1
- Performs no work at all 0

**[51] Job Performance**

(Check ALL statements which apply)

(If "0" is circled in item 50, check "None of the above" and enter "0" in the circle)

Endangers others because of carelessness \_\_\_\_\_ 4-number checked =  
Does not take care of tools \_\_\_\_\_  
Is a very slow worker \_\_\_\_\_  
Does sloppy, inaccurate work \_\_\_\_\_  
None of the above \_\_\_\_\_

**[52] Work Habits**

(Check ALL statements which apply)

(If "0" is circled in item 50, check "None of the above" and enter "0" in the circle)

Is late from work without good reason \_\_\_\_\_ 5-number checked =  
Is often absent from work \_\_\_\_\_  
Does not complete jobs without constant encouragement \_\_\_\_\_  
Leaves work station without permission \_\_\_\_\_  
Grumbles or gripes about work \_\_\_\_\_  
None of the above \_\_\_\_\_

VII VOCATIONAL ACTIVITY → ADD 50-52 → 

**VIII. SELF-DIRECTION**

**A. Initiative**

**[53] Initiative (Circle only ONE)**

Initiates most of own activities, e g , tasks, games, etc \_\_\_\_\_ 3  
Asks if there is something to do, or explores surroundings, e g , home, yard etc \_\_\_\_\_ 2  
Will engage in activities only if assigned or directed \_\_\_\_\_ 1  
Will not engage in assigned activities, e g , putting away toys, etc \_\_\_\_\_ 0

**[54] Passivity**

(Check ALL statements which apply)

Has to be made to do things \_\_\_\_\_ 6-number checked =  
Has no ambition \_\_\_\_\_  
Seems to have no interest in things \_\_\_\_\_  
Finishes task last because of wasted time \_\_\_\_\_  
Is unnecessarily dependent on others for help \_\_\_\_\_  
Movement is slow and sluggish \_\_\_\_\_  
None of the above \_\_\_\_\_  
Does not apply, e g , because he or she is totally dependent on others (If checked, enter "0" in the circle to the right)

A. Initiative → ADD 53-54 → 

**B. Perseverance**

**[55] Attention (Circle only ONE)**

Will pay attention to purposeful activities for more than fifteen minutes, e g , playing games, reading, cleaning up \_\_\_\_\_ 4  
Will pay attention to purposeful activities for at least fifteen minutes \_\_\_\_\_ 3  
Will pay attention to purposeful activities for at least ten minutes \_\_\_\_\_ 2  
Will pay attention to purposeful activities for at least five minutes \_\_\_\_\_ 1  
Will not pay attention to purposeful activities for as long as five minutes \_\_\_\_\_ 0

**[56] Persistence**

(Check ALL statements which apply)

Becomes easily discouraged \_\_\_\_\_ 4-number checked =  
Fails to carry out tasks \_\_\_\_\_  
Jumps from one activity to another \_\_\_\_\_  
Needs constant encouragement to complete task \_\_\_\_\_  
None of the above \_\_\_\_\_  
Does not apply, e g , because he or she is totally incapable of any organized activities (If checked, enter "0" in the circle to the right)


B. Perseverance → ADD 55-56 → 


**C. Leisure Time**

**[57] Leisure Time Activity**

(Check ALL statements which apply)

Organizes leisure time on a fairly complex level, e g , plays billiards, fishes, etc \_\_\_\_\_  
Has hobby, e g , painting, embroidery, collecting stamps or coins \_\_\_\_\_  
Organizes leisure time adequately on a simple level, e g , watching television, listening to phonograph, radio, etc \_\_\_\_\_  
None of the above \_\_\_\_\_

C. Leisure Time → ENTER 57 → 

VIII SELF-DIRECTION → ADD TRIANGLES A-C → 

**IX. RESPONSIBILITY**

**[58] Personal Belongings (Circle only ONE)**

Very dependable--always takes care of personal belongings \_\_\_\_\_ 3  
Usually dependable--usually takes care of personal belongings \_\_\_\_\_ 2  
Unreliable--seldom takes care of personal belongings \_\_\_\_\_ 1  
Not responsible at all--does not take care of personal belongings \_\_\_\_\_ 0



[59] **General Responsibility** (Circle only ONE)

- Very conscientious and assumes much responsibility--makes a special effort; the assigned activities are always performed 3
- Usually dependable--makes an effort to carry out responsibility, one can be reasonably certain that the assigned activity will be performed 2
- Unreliable--makes little effort to carry out responsibility, one is uncertain that the assigned activity will be performed 1
- Not given responsibility, is unable to carry out responsibility at all 0

IX. RESPONSIBILITY → ADD 58-59 →

X. **SOCIALIZATION**

[60] **Cooperation** (Circle only ONE)

- Offers assistance to others 2
- Is willing to help if asked 1
- Never helps others 0

[61] **Consideration for Others**  
(Check ALL statements which apply)

- Shows interest in the affairs of others \_\_\_\_\_
- Takes care of others' belongings \_\_\_\_\_
- Directs or manages the affairs of others when needed \_\_\_\_\_
- Shows consideration for others' feelings \_\_\_\_\_
- None of the above \_\_\_\_\_

[62] **Awareness of Others**  
(Check ALL statements which apply)

- Recognizes own family \_\_\_\_\_
- Recognizes people other than family \_\_\_\_\_
- Has information about others, e.g., job, address, relation to self \_\_\_\_\_
- Knows the names of people close to him, e.g., classmates, neighbors \_\_\_\_\_
- Knows the names of people not regularly encountered \_\_\_\_\_
- None of the above \_\_\_\_\_

[63] **Interaction With Others** (Circle only ONE)

- Interacts with others in group games or activity 3
- Interacts with others for at least a short period of time, e.g., showing or offering toys, clothing or objects 2
- Interacts with others imitatively with little interaction 1
- Does not respond to others in a socially acceptable manner 0

[64] **Participation in Group Activities**  
(Circle only ONE)

- Initiates group activities (leader and organizer) 3
- Participates in group activities spontaneously and eagerly (active participant) 2
- Participates in group activities if encouraged to do so (passive participant) 1
- Does not participate in group activities 0

[65] **Selfishness**  
(Check ALL statements which apply)

- Refuses to take turns \_\_\_\_\_
- Does not share with others \_\_\_\_\_
- Gets mad if he does not get his way \_\_\_\_\_
- Interrupts aide or teacher who is helping another person \_\_\_\_\_
- None of the above \_\_\_\_\_
- Does not apply, e.g., because he or she has no social interaction or is profoundly withdrawn. (If checked, enter "0" in the circle to the right.) \_\_\_\_\_
- 4-number checked =

[66] **Social Maturity**  
(Check ALL statements which apply)

- Is too familiar with strangers \_\_\_\_\_
- Is afraid of strangers \_\_\_\_\_
- Does anything to make friends \_\_\_\_\_
- Likes to hold hands with everyone \_\_\_\_\_
- Is at someone's elbow constantly \_\_\_\_\_
- None of the above \_\_\_\_\_
- Does not apply, e.g., because he or she has no social interaction or is profoundly withdrawn. (If checked, enter "0" in the circle to the right.) \_\_\_\_\_
- 5-number checked =

X. SOCIALIZATION → ADD 60-66 →

SERVICE USERS INTERVIEW QUESTIONNAIRE

(Adapted from: The Consumer Interview Questionnaire. Institute for Survey Research, Temple University. Conroy and Bradley, 1985).

Respondent's Name:

Respondent's Address:

Interviewer:

Date:

Duration of Interview:

## EMOTION LABELLING INTERVIEW

1. Show the 3 pictures of the gentleman making tea.  
Present the pictures in a random order and ask "Can you put these pictures in the right order, so they show what the man is doing?".

If the order is incorrect, arrange the pictures in the correct order and then ask the following questions:

- a) What is the man doing in the pictures?
- b) What is the man doing? - pointing to each picture in order.

If the order is correct - ask the above questions.

Score: 2 - perceives task and sequence  
1 - perceives task only  
0 - does not perceive task or sequence,  
e.g., says "man or cup", with no connection between  
the two ideas.

Repeat this with a different set of pictures if you are uncertain about the reliability of the answer.

2. Show the picture of the lady knitting.  
Ask: "What is the lady doing? How does she feel?".

Score: 2 - perceives action and emotion, e.g., she is knitting  
and is happy  
1 - labels the emotion  
0 - incorrectly labels the emotion. No answer.

3. Show the picture of the girl crying.  
Ask: "What is the girl doing? How does she feel?".

Score: 2 - perceives action and emotion, e.g., she is crying and  
is upset/sad  
1 - labels the emotion: she is sad  
0 - incorrectly labels the emotion. No answer.

4. Show all the 3 pictures of the girl opening a present (in the correct order).

Ask: "Look at all these pictures and tell me what is happening.  
How does she feel?".

Score: 2 - perceives sequence and emotion, e.g., "the girl  
opened a parcel/present and felt happy/pleased".  
1 - correctly labels the emotion.  
0 - incorrectly labels the emotion. No answer.

5. Show the three pictures of the boy falling off his bicycle (in the correct order).

Ask: "Look at these pictures and tell me what is happening.  
How does the boy feel?".

Score: 2 - perceives sequence and emotion, e.g., "the boy fell off his bicycle and he is upset/sad/hurt."  
1 - correctly labels the emotion  
0 - incorrectly labels the emotion. No answer.

6. Show the 5 "Smile button faces". Leave them within reach of the respondent.

Ask: Which is the happy face? Which is the sad face?

If correct, then ask:

Which one is most like how you feel about living here?

Most happy      5      4      3      2      1      least happy

7. Which one is most like how you feel about the other people living here?

Most happy      5      4      3      2      1      least happy

8. Which one is most like how you feel about the nurses/staff here?

Most happy      5      4      3      2      1      least happy

9. Which one is most like how you feel about the Day Centre?

Most happy      5      4      3      2      1      least happy.

## QUESTIONS CONCERNING CONSUMER'S VIEWS OF THE SERVICE

May I now ask you some questions about yourself?

1. a) Do you like living here?

Yes	1
In between, sort of, mixed, always	2
No/bad	3
Don't know	8
No answer	9

b) Have you ever liked anywhere else? If yes, ask for the name of the placement/home address.

Yes - other institution	1
Yes - name	2
No	3
Don't know	8
No answer	9

2. Do you want to carry on living here?

Yes	1
Sort of, unsure	2
No	3
Don't know	8
No answer	9

3. Do you like the nurses/staff who work here?

Yes	1
Sort of, unsure	2
No	3
Don't know	8
No answer	9

4. a) Do you have any good friends - people you like a lot?

Yes	1
Unsure	2
No (go to Q.5)	3
Don't know	8
No answer	9

b) Who are they?/what are their names?

5 or more	1
A few 3-5	2
A couple 1-2	3

c) Would you like to have more friends?

Yes	1
Sort of, may be, etc.	2
No	3
Don't know	8
No answer	9

5. Do you have one special friend, someone you spend a lot of time with? Do you mind me asking who?

Yes	1
Sort of, may be, etc.	2
No	3
Don't know	8
No answer	9

6. a) Do you have any visitors? Who?  
(Check non-professionals)

Yes	1
Sometimes	2
No	3
Don't know	8
No answer	9

b) Do you ever go to visit anyone?  
(Check non-professionals)

Yes	1
Sometimes	2
No	3
Don't know	8
No answer	9

7. Most of the time are the staff/nurses nice or not nice?

Unpleasant	1
Both, some of each, etc.	2
Nice	3
Don't know	8
No answer	9

8. Are you usually happy or sad?

Happy	1
In between	2
Sad	3
Don't know	8
No answer	9

9. Are you ill much?

Yes	1
In between	2
No	3
Don't know	8
No answer	9

10. If you had one wish, what would you wish for?

.....

.....

.....

.....

11. Where do you go during the daytime? Probe for as much detail as possible about activities, etc.

.....

.....

.....

.....

12. Do you learn a lot there?

Yes	1
Sometimes	2
No	3
Don't know	8
No answer	9

13. Do you like it there?

Yes	1
In between, sort of, a little	2
No	3
Don't know	8
No answer	9

14. Do you earn any money there? (If attends Day Centre)

Yes	1
Not much, a little, etc.	2
No	3
Don't know	8
No answer	9

15. Are you happy? Are you sad?

Sad	1
In between	2
Happy	3
Don't know	8
No answer	9

16. What do you do in your spare time?  
Do you have enough to do?

.....

.....

.....

.....

17. If you could, would you like to leave here and live somewhere else?

Yes	1
In between, uncertain	2
No - go to question 18	3
Don't know	8
No answer	9

18. What kind of place would you like to go to?

.....

.....

.....

.....

19. Are you ever sad?

Yes	1
In between, some of the time	2
No, not usually	3
Don't know	8
No answer	9



20. Is there anything else you would like to tell me?

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

21. Are there any questions you would like to ask me?

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

Thank you very much for talking to me.

## APPENDIX 15

Adaptations to the Consumer Interview Questionnaire - Conroy and Bradley, 1985

The following is a summary of the adaptations:

1. The front sheet was altered, e.g., consent was asked for all the measures of the study before any part of the project was completed.
2. The order of the questions was changed slightly to keep a natural flow of conversation.
3. American language was removed, e.g., "mean" was altered to "not nice".
4. When asking about close friends of the opposite sex, further permission was asked and the terms 'girlfriend' and 'boyfriend' were not used, but rather 'a special friend'.
5. Two questions were removed. These concerned contact with family and returning to Pennhurst.
6. Some questions were added. These included asking about spare time and leisure time, visitors and having more friends. In addition, people were asked to name friends.
7. Within the emotional labelling interview part of the questionnaire, all the examples and materials were different. Two questions involving the use of the smiling faces were removed, e.g., how do the carers feel about you?

INTERVIEWS SUMMARY

## TOPICS

Category	Topic	Emotion (positive/ negative - if stated
1.	Home placement	
2.	Within home activities	
3.	Peers - living at home	
4.	Carers - at home	
5.	Day placement	
6.	Peers in day placement	
7.	Staff - day placement	
8.	Friendships	
9.	Activities - day placement	
10.	Activities - leisure - segregated	

Category	Topic	Emotion
11.	Activities - leisure - integrated	.
12.	Shopping	.
13.	Food (state where)	.
14.	Clothes	.
15.	Visitors	.
16.	Visits - segregated	.
17.	Visits - integrated	.
18.	Previous placements	.
19.	Future placements	.
20.	Other	.

Observation Categories - Study II

Engaged behaviour

A. Leisure

- Participating in any leisure activity (except TV), e.g., looking at a book, playing a card game, knitting, etc.
- Getting ready to participate in a leisure activity.
- Clearing away leisure materials.
- Talking on the telephone to a friend.
- Stroking pets, picking up pets.
- Writing notes, writing in diary, completing work from Day Centre.

B. Personal

- Participating in a personal activity, e.g., eating, washing hands.
- Clearing up or getting ready to participate in a personal activity, e.g., collecting a sponge bag.

C. Domestic

- Participating in housework as demonstrated by a motor activity, e.g., cooking, washing clothes, opening windows, etc.
- Getting ready to or clearing up after domestic activities, e.g., collecting cleaning materials.
- Looking for lost items, reading rota of household activities.

D. Television

Eyes directed at TV, when TV is switched on.

An appropriate engagement was considered to have ceased when the task had been clearly completed or when the person had become passive for 5 seconds.

## Social Interaction

### A. Interacts with peer

- Client speaks to, looks at, gestures to, listens to, touches another peer who is reciprocally interacting, i.e., there must be visible or verbal evidence of another person being involved in the interaction.

### B. Interacts with Staff/Carers

- Client speaks to, looks at, gestures to, listens to, touches a member of staff/carer who is reciprocally interacting, i.e., there must be visible or verbal evidence of the member of staff being involved in the interaction.

### C. Interacts with other

- Client speaks to, looks at, gestures to, listens to, touches a person other than a staff member or client, e.g., a visitor, who is reciprocally interacting, i.e., there must be visible or verbal evidence of the other person being involved in the interaction.

## Neutral Behaviour

### A. Neutral Behaviour

- Passive: sitting, lying, standing without purposeful gross motor activity - includes asleep, eyes closed, but awake, looking that does not constitute an interaction, just holding materials, e.g., a book.
- Ambulation: walking/wandering to no known purpose, i.e., it is not clearly in the context of an engagement category.
- Smoking: moving cigarette or pipe to or from mouth, lighting cigarette or pipe, having a cigarette or pipe in mouth.
- Unpurposeful: minor self manipulation, e.g., fiddling with buttons, picking at clothing, nailbiting, talking quietly to self, manipulating materials to no apparent purpose.

## Challenging behaviour

### A. Communication

- Inappropriate communication such as shouting, verbal threats, swearing, giggling out of context, crying when asked to do something, pushing/pulling someone against their will, pestering, etc.

### B. Aggression

- Any act that harms or potentially could harm another person, e.g., hitting someone.
- Any act that directly harms or could potentially harm the person exhibiting the behaviour, e.g., hitting self.
- Any behaviour which damages or could potentially damage property (e.g., throwing but not breaking a dish), or which overturns or disarranges property.

### C. Other

Other challenging behaviour other than those listed above, e.g., public masturbation, incontinence, self-stimulation, e.g., continuous loud groaning.

Note: Self-stimulation and self-manipulation:

Self-stimulation which is likely to be obvious to others and intrusive to others, e.g., continuous pacing, should be rated as inappropriate.

Self-manipulation of a minor nature, e.g., fiddling with clothes, should be rated as neutral.

PHYSICAL ENVIRONMENT

Score

## PART A

To be completed by observation during interview.

1. Does Mr/Ms \_\_\_\_\_ have their own bedroom?  
 Score: 3. Yes/shares with special friend.  
           2. Shares with one other person.  
           1. Shares with 2 or more people. \_\_\_\_\_
  
2. Are personal possessions openly on display in the bedroom, e.g., posters, ornaments, make-up, radio, etc?  
 Score: 3. At least 3 items on open display.  
           2. 1-2 objects on display  
           1. None on display. \_\_\_\_\_
  
3. Is the bedroom furniture domestic or "institutional", i.e., individualised bedspread/duvet, wardrobe, etc?  
 Score: 3. All items domestic and individualised.  
           2. Most items domestic and individualised - allow up to 2 exceptions.  
           1. Some items "institutional" or not individualised. \_\_\_\_\_  
 Comment upon what influenced your choice:
  
4. Does the house have an appropriate degree of privacy?  
 Score: 3. Bathroom, toilet have locks, bedroom doors cannot be seen through, bedroom large enough for table and chair.  
           2. Some privacy available.  
           1. Little privacy. \_\_\_\_\_  
 Comment on what influenced your choice.
  
5. Is the furniture in the living areas varied and domestic, i.e., not institutionalised?  
 Score: 3. Furniture all varied and attractive, i.e., settees, easy chairs which could be bought in local shops.  
           2. Some furniture is varied, attractive and domestic.  
               Allow up to two exceptions.  
           1. Majority of furniture institutionalised. \_\_\_\_\_  
 Comment on what influenced your choice.



6. Are some small household items and personal possessions openly displayed in downstairs rooms, or do rooms have an "institutional" appearance, e.g., over-tidiness, etc.

Score: 3. Items displayed in all rooms, e.g., posters, plants, magazines.  
2. Items displayed, but some have an institutional appearance.  
1. All rooms have an institutional appearance.

Comment on what influenced your choice: \_\_\_\_\_

7. Does the kitchen have domestic equipment or is some 'institutional', i.e., industrial size cooker, extra large teapot, etc. - note cooker, cupboards, fridge, teapots, geyser.

Score: 3. All equipment is domestic.  
2. Some items are domestic - one/two non-domestic.  
1. More than 2 items are not domestic.

Comment on what influenced your choice: \_\_\_\_\_

8. Is the house "comfortable" and reasonably clean, e.g., are there carpets and curtains in all rooms except kitchen and bathroom, warmth of house, noise level.

Score: 3. Comfortable in every way  
2. Comfortable in most ways - but identified deficiency  
1. Not comfortable.

Comment on what influenced your choice: \_\_\_\_\_

9. Is the house in a "good state of repair" - decoration, furniture:

Score: 3. Yes  
2. Needs some improvements - not major  
1. No.

Comment on what influenced your choice: \_\_\_\_\_

10. Are there any conspicuous details outside the house that would indicate that "handicapped" people live there, e.g. a reference to NHS/Social Services, design of building, etc.

Score: 3. No  
2. One identified detail  
1. Yes - more than one.

Comment on what influenced your choice: \_\_\_\_\_

## PART B

To be completed by asking staff.

11. How many items of equipment are available in the house: e.g., fridge, deep freeze, colour TV, radio, cassette player, Hoover, iron, washing machine, telephone, garden, heaters in all rooms.

Score: 3. 7+  
2. 3-6  
1. 3 or less. \_\_\_\_\_

12. Are there any rooms which are locked/require permission to enter?

Score: 3. None  
2. One room (state room \_\_\_\_\_)  
1. More than one room  
(state rooms \_\_\_\_\_)

13. Is there available space for someone to be alone if they wish/need to be?

Score: 3. Yes - an area is identified  
2. Yes - but this may require another person/ activity to be disrupted.  
1. No. \_\_\_\_\_

14. Is there a room which is private where  
Mr/Ms \_\_\_\_\_ can meet his/her relatives/friends  
etc?

- Score:
3. Room identified which would not be used  
by others at the time of visit  
(exclude bedroom)
  2. Room identified (include bedroom). Room  
may be used by others, e.g., lounge,  
people leave when visitor arrived.
  1. No room identified.

Comments: \_\_\_\_\_

15. How far away are the local shops, leisure places, e.g.,  
swimming baths, pub?

- Score:
3. Easy access - short bus journey,  
e.g., 15-20 minutes
  2. Some places require a longer bus journey
  1. All require a long journey.

16. Has Mr/Ms \_\_\_\_\_ got any pets?  
Did Mr/Ms \_\_\_\_\_ choose whether or not to have a pet?

- Score:
3. Yes - has his/her own pet. No pets by  
person's choice.
  2. Pet(s) are present in the house
  1. Pets not present and have not been  
discussed/pets are present against  
person's choice.

Comments: \_\_\_\_\_

Note if any features are influenced significantly by the other people  
living in the placement.

DECISION MAKING

Items are to be completed by interviews with carers and service users separately. Note any differences in answers.

Scoring

- A    -    Mr/Ms \_\_\_\_\_ currently make this decision themselves, with information and help from carers if needed.
  
- B    -    Carers and Mr/Ms \_\_\_\_\_ currently make this decision together.
  
- C    -    Carers decide for Mr/Ms \_\_\_\_\_.
  
- D    -    No choice is available for either carers or Mr/Ms \_\_\_\_\_ i.e., decision is made externally by managers or decision made in the past.

\* \_\_\_\_\_ Not known, not applicable.

## Decision Making

1. Who decided that Mr/Ms \_\_\_\_\_ should come and live here?

Score:    A    B    C    D    \*

2. Does Mr/Ms \_\_\_\_\_ decide (together with the other people in the house) when and if someone has to leave the house, to live elsewhere? If this situation has not arisen, score procedure that would be followed, and note that this has not taken place.

Score:    A    B    C    D    \*

3. Does Mr/Ms \_\_\_\_\_ choose a new person to live in the house (together with the other people in the house)? If this situation has not arisen, score procedure that would be followed and note that this has not taken place.

Score:    A    B    C    D    \*

4. Did Mr/Ms \_\_\_\_\_ choose which bedroom he/she should have? (NB: choice of bedroom includes whether to have his/her own room or to share).

Score:    A    B    C    D    \*

5. Did Mr/Ms \_\_\_\_\_ choose the decoration and furniture in his/her own bedroom?  
(NB: scoring refers to a minimum of 2 items)

Score:    A    B    C    D    \*

6. Did Mr/Ms \_\_\_\_\_ choose the furniture/decoration downstairs (together with the others in the house)?  
(NB: scoring refers to a minimum of 2 items)

Score:    A    B    C    D    \*

7. Does Mr/Ms \_\_\_\_\_ decide what jobs to do, e.g., housework, shopping?  
(NB: if rota exists, state this and score according to the method used to devise the rota)

Score:    A       B       C       D       \*

8. Does Mr/Ms \_\_\_\_\_ decide who to do things with? e.g., who to go out with, etc?

Score:    A       B       C       D       \*

9. Is Mr/Ms \_\_\_\_\_ free to choose a special friend, partner?

Score:    A       B       C       D       \*

10. When Mr/Ms \_\_\_\_\_ chooses to watch TV, does he/she choose the programme, together with the other people living in the house?

Score:    A       B       C       D       \*

11. Does Mr/Ms \_\_\_\_\_ choose when to have a bath?

Score:    A       B       C       D       \*

12. Does Mr/Ms \_\_\_\_\_ choose when to go to bed?  
(NB: scoring can refer to weekends only, if this differs from weekdays)

Score:    A       B       C       D       \*

13. Does Mr/Ms \_\_\_\_\_ choose when to go out, e.g., for a walk, to the shops, etc?

Score:     A     B     C     D     \*

14. Does Mr/Ms \_\_\_\_\_ choose how to spend his/her money?  
(NB: if access only is possible to pocket money)

Score:     A     B     C     D     \*

15. Does Mr/Ms \_\_\_\_\_ choose what to do in his/her spare time?

Score:     A     B     C     D     \*

16. Does Mr/Ms \_\_\_\_\_ choose his/her own clothes?

Score:     A     B     C     D     \*

17. Does Mr/Ms \_\_\_\_\_ choose his/her own food, together with the other people living in the house?

Score:     A     B     C     D     \*

18. Does Mr/Ms \_\_\_\_\_ choose whether or not to have a pet in the house, together with the other people living there?

Score:     A     B     C     D     \*

19. Does Mr/Ms \_\_\_\_\_ choose whether or not to attend a Day Service, college, etc.?

Score:     A     B     C     D     \*

20. Does Mr/Ms \_\_\_\_\_ choose who can visit the house - together with the other people in the house?

Score:     A     B     C     D     \*

21. Does Mr/Ms \_\_\_\_\_ choose whether or not people may smoke/drink alcohol in the house - together with the other people in the house?

Score:     A     B     C     D     \*



## RELIABILITY OF QUESTIONNAIRES - STUDY II

a) Inter-Rater Reliability

The inter-rater reliability was calculated from tape recordings of the interviews during which the questionnaires were completed. The tape-recordings were transcribed and the questionnaires were re-scored by a Psychology graduate - but not the same person as had completed this task in Study I. % agreement was then calculated. The tape-recordings were undertaken with six subjects and their carers for the questionnaire Decision Making, but with only five subjects and their carers for the other three questionnaires. The questionnaires were completed twice for each subject, i.e., at the beginning and the end of the contact with a service. The inter-rater reliability calculations are based on the second completion of the questionnaire.

Percentage Inter-Rater Reliability of the Questionnaires

<u>Questionnaire</u>	<u>Mean %</u>	<u>Range</u>
Physical Environment Scale	93%	83% - 100%
Opportunities Scale	88%	64% - 100%
Friendships Scale	92%	75% - 100%
Decision Making Scale	82%	71% - 95%

All the Inter-Rater Reliabilities of the Questionnaire were found to be over 80% on average. The reliability of the Decision Making Scale was felt to be accounted for by two reasons. Firstly, some carers and subjects genuinely found it difficult to be clear about how some decisions were reached, e.g., to come and live in a service. Secondly, replies to question 17 (concerning choice of food) were often found to disagree.

b) Test-Retest Reliability

Test-retest reliability was calculated by comparing the scores of the questionnaires completed at the beginning of the contact with a service and those completed at the end of the contact with the service. Again, the Decision Making Questionnaire was completed twice for all six subjects, whilst the other Questionnaires were completed twice for five subjects only. Typically, there was a 6-8 week interval between completion of the questionnaire. Table \* below summarises the test-retest reliability.

Table - Percentage Test-Retest Reliability of the Questionnaires

<u>Questionnaire</u>	<u>Mean %</u>	<u>Range</u>
Physical Environment Scale	97%	83% - 100%
Opportunities Scale	77%	64% - 86%
Friendships Scale	65%	50% - 87%
Decision Making Scale	68%	33% - 86%

The test-retest reliability of the Physical Environment Scale was considered acceptable. The lower reliability over time of the Friendships Scale was accounted for by genuine changes over time in the friendships people had. The lowest reliability on the Friendships Scale (50%) referred to the friendships of a woman where it was known that these had changed within the timescale of the project. The mean reliability of the Decision Making Scale was influenced by one low score of 33%. It is possible that this carer and subject found the questionnaire particularly difficult - in addition, the carer was the least experienced of all the carers. The reliability over time of the Opportunities Scale (77%) was less easily accounted for. It is unlikely that opportunities changed within the timescale of the project, and more likely that carers' perceptions and reports of opportunities available varied as a result of the project.

DAILY DIARY

Guidelines for completion

- 1) Please complete the diary at the end of each day. It may be easier to complete it at the end of every morning, afternoon and evening.
- 2) Please record for every hour:
  - a) The main activities undertaken. The attached sheets give some examples of activities which may be undertaken within the house, and also in the community.

It is particularly important to also record if no activities were undertaken - this may be reported as "unoccupied".
  - b) Where the activity was undertaken, e.g., visiting room, kitchen day centre, pub, cinema, etc.
  - c) With whom the activities were undertaken, e.g., named person, other people in the house, with general public.

It is important to state whether or not members of the general public were present.
  - d) How long each activity lasted - to the nearest quarter of an hour.
- 3) It is very important not to leave gaps - it is difficult to identify what a person has been doing if it has not been recorded within a short period.

(An example of a completed Daily Diary is attached to help to clarify the method of completion).

Many thanks for completing the Daily Diary.

Angela Holland

## DAILY DIARY

### Use of Community Facilities

Please record whether Mr/Mrs \_\_\_\_\_ used any of the following facilities. Record this on the daily diary sheet.

#### a) Shopping

1. Corner shop
2. Supermarket
3. Chemist
4. Post Office
5. Clothes shop
6. Shoe shop.

#### b) Services

1. Doctor
2. Dentist
3. O.P. appointment
4. Church
5. Public bus
6. Car
7. Train
8. Taxi
9. Restaurant
10. Cafe
11. Pub
12. Take-away meal
13. Hairdresser
14. Bank/Building Society
15. Launderette
16. Library.

#### c) Leisure

1. Cinema
2. Theatre
3. Museum
4. Watching live sport
5. Playing sport
6. Club
7. Evening adult education
8. Park
9. Bingo
10. Dancing, disco.

#### d) Away from home visits

1. Visit another person's home (not staff)
2. Overnight stay
3. Holiday

## DAILY DIARY

Use of facilities within the house

Please record whether Mr/Mrs \_\_\_\_\_ undertook any of the following activities during the day.

Please record these on the daily diary sheet.

### A. Self-care

1. Dressing, undressing
2. Bathing, showering
3. Washing hair
4. Toilet (if longer than 5 minutes)
5. Time in bathroom, e.g., washing hands, cleaning teeth
6. Eating meal
7. Drinking coffee/tea - if not part of a meal.

### B. Cookery

1. Preparing a drink, hot or cold
2. preparing a cold snack
3. Preparing a hot snack/meal
4. Washing-up.

### C. Cleaning

1. Dusting, hoovering own bedroom
2. Making bed
3. Dusting, hoovering downstairs living areas
4. Cleaning kitchen
5. Cleaning bathroom/toilets
6. Clearing up/cleaning up outside.

### D. Care of clothes

1. Washing clothes by hand
2. Washing clothes - use of machine
3. Hanging clothes to dry
4. Ironing
5. Putting clothes away in drawers, hanging them up.

### E. Leisure

1. Watching TV
2. Playing cards, board games, etc.
3. Sewing, knitting, embroidery, etc.
4. Listening to/playing music, radio
5. Talking to friends - must be clear evidence of a conversation
6. Yoga, relaxation exercises
7. Painting, drawing, etc.
8. Reading, magazines/books.

F. Outside the house

1. Gardening
2. Clearing up, sweeping, etc.

G. Minor repairs and maintenance

1. Decorating
2. Changing light bulb, etc.

H. Care of pets

1. Feeding
2. Grooming, cleaning.

I. Work brought home

1. From Day Centre (specify)
2. From College (specify).

Angela Holland,  
Principal Clinical Psychologist

AH/MSL  
18.3.88.

EXAMPLEDAILY DIARY

Name:

Address:

Date:

<u>Time</u>	<u>Activities</u>	<u>Where</u>	<u>With Whom</u>	<u>Duration</u>
<u>Morning</u> 7.00-8.00	GETTING UP, DRESSING GETTING BREAKFAST EATING	BEDROOM KITCHEN / DINING ROOM	ALONE GROUP	$\frac{1}{2}$ HOUR $\frac{1}{2}$ HOUR
8.00-9.00	WAITING DAY CENTRE BUS	SITTING ROOM BUS	GROUP GROUP	$\frac{1}{4}$ HOUR $\frac{1}{2}$ HOUR
9.00-10.00	DAY CENTRE	DAY CENTRE	DAY CENTRE	↑ ↓
10.00-11.00	"	"	"	
11.00-12.00	"	"	"	
<u>Afternoon</u> 12.00-1.00	"	"	"	
1.00-2.00	"	"	"	
2.00-3.00	"	"	"	↓
3.00-4.00	"	"	"	
4 -5.00	PREPARE CUP OF TEA DRINKING TEA SITTING UNOCCUPIED	KITCHEN " SITTING ROOM	B. IN KITCHEN " B	$\frac{1}{4}$ HOUR $\frac{1}{2}$ HOUR
<u>Evening</u> 5.00-6.00	PREPARE TEA / SUPPER EATS	KITCHEN "	STAFF GROUP & STAFF	$\frac{1}{2}$ HOUR $\frac{1}{2}$ HOUR
6.00-7.00	WATCHES TV SITTING UNOCCUPIED	SITTING ROOM "	ALONE "	$\frac{1}{2}$ HOUR 1 HOUR
7.00-8.00	VISITS PUB	PUB	GROUP & PUBLIC	1 HOUR
8.00-9.00	WATCHING TV	SITTING ROOM	GROUP	1 HOUR
9.00-10.00	BATH GOES TO BED	BATHROOM BEDROOM	ALONE ALONE	$\frac{1}{2}$ HOUR $\frac{1}{2}$ HOUR

DAILY DIARY

Name:

Address:

Date:

<u>Time</u>	<u>Activities</u>	<u>Where</u>	<u>With Whom</u>	<u>Duration</u>
<u>Morning</u>				
7.00-8.00				
8.00-9.00				
9.00-10.00				
10.00-11.00				
11.00-12.00				
<u>Afternoon</u>				
12.00-1.00				
1.00-2.00				
2.00-3.00				
3.00-4.00				
4.00-5.00				
<u>Evening</u>				
5.00-6.00				
6.00-7.00				
7.00-8.00				
8.00-9.00				
9.00-10.00				



Categories of Behaviour - Diary Data

<u>Category of Behaviour</u>	<u>Examples Recorded</u>
Self-care	Getting up, dressing, eating, drinking, bathing, washing, going to bed.
Domestic	Cooking, washing-up, clearing and laying table, changing sheeting, clothes washing.
Leisure within the house	Reading, listening to music, craft, keep fit.
TV	TV
Sitting	Sitting, sitting alone in bedroom.
Talking	Talking to peers, carers, visitors.
Clubs, classes - segregated	Gateway Club, evening classes (segregated), Clubs (segregated).
Waiting to travel	Waiting to travel.
Travel minibus	Travel minibus.
Public transport, walking	Taxis, car, walking to destination, bus.
Shopping	Shopping.
Leisure integrated	Pub, evening class (integrated), meal out, walking.
Voluntary work	Unpaid work, e.g., for Mencap, car boot sale, market.
Church	Church.
Visit to friends	Visit to friends (but not in services).
Visitors	Visitors to service.
Phone	Talking on the telephone.
House meeting	Meeting in house.

DIARY RECORDS - Agreement with Observations

The agreement was calculated between the diary records and the observations completed on the same evening and within the same time period. The number of evenings when both measures were completed varied for each subject (range 3-9 evenings), due to the date when the diary could be commenced, e.g. after a staff meeting had taken place to explain the procedures, and also because of occasional difficulties operating the computer. If the same category of activity was written in the diary as was observed to occur within the same period, this was counted as an agreement. So, if the category 'domestic' had been recorded by observation and 'washing-up' was written in the diary within the same time period, this was counted as an agreement. Observations of less than 5% duration of a single observation period were not included as they were considered to be too short a duration for carers to record. For the purpose of the calculations, the time period was identified as the total time during which observations were recorded during an evening, e.g., 1 - 1hr 30 mins. So, each time period could include a mealtime and the time before and after the meal. A single observation refers to one of the observations within the time period. typically, three observations would be made in one evening/afternoon.

Using this approach, it was found that the diary records agreement ranged from 43.7% to 63.2%. The low agreement was largely accounted for by the omission of the neutral and interaction categories from the diary records. Few activities (8) were recorded in the diary, but not observed. The lowest agreement was found for the records kept by the subject himself, but this was not substantially different from the agreement of the other diary records.

Table Agreement of Diary Records with Observations

<u>Subject</u>	<u>Number of Evenings - diary &amp; Observations were both completed</u>	<u>Number of Observational Categories recorded</u>	<u>Number agreed with Diary</u>	<u>% Agreement</u>
1	4	19	12	63.2
2	7	40	20	50.0
3	4	18	8	44.4
4	9	58	31	53.4
5	3	16	7	43.7
6	6	21	10	47.6

Table Summary of Activities not Recorded in Both the Diary and by Observation

<u>Subject</u>	<u>Activities not recorded in Diary but recorded by Observation</u>			<u>Activities not Observed but recorded in the Diary</u>
	<u>Neutral</u>	<u>Interactions</u>	<u>Other</u>	
1	3	2	2	0
2	7	12	1	2
3	3	3	4	4
4	6	12	9	0
5	1	2	6	0
6	5	2	4	2
TOTAL	25	33	26	8

% of disagreements accounted for by not recording neutral and interaction activities in the diary: 69% (58/84).

## AGREEMENT DIARY DATA AND QUESTIONNAIRE: OPPORTUNITIES

The agreement between the diary data and the questionnaire Opportunities was calculated. Only three questions of the Opportunities questionnaire were considered and these concerned how often each subject cooked, went shopping and went out to a leisure activity. The table below outlines the agreement.

## Agreement between Diary Data and Questionnaire: Opportunities

Question:	Cooking	Shopping	Leisure	Comments
Subject 1	✓	X	✓	Questionnaire overestimates shopping by one shopping trip a week.
Subject 2	✓	X	✓	Questionnaire overestimates shopping by one shopping trip a week.
Subject 3	X	✓	✓	Questionnaire underestimates cooking by once a week.
Subject 4	✓	✓	✓	
Subject 5	X	X	✓	Questionnaire overestimates cooking by twice a week and shopping by once a week.
Subject 6	✓	X	✓	Questionnaire overestimates shopping by twice a week.

## RAW DATA - STUDY II

## Service User's Interview Questionnaire - Subject 1: Paul

Questions	Scores
1.a) Liking the placement	1
1.b) Names previous placement	1
2. Wants to continue to live in placement	1
3. Likes carers/staff	1
4.a) Has friends	1
4.b) Has 5 or more friends	1
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	1
6.b) Visits others	1
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	3
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	3
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	✓
19	✓

## Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Don't know
- Q.11 Where do you go in the day-time?  
Reply: Day Centre.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Hoovering, washing-up; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Live with my sister.
- Q.20 Is there anything else you would like to tell me?  
Reply: No.
- Q.21 Are there any questions you would like to ask me?  
Reply: What do you do?

## Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed.

## Additional Information

Complaint about another person in the house not helping.

## RAW DATA - STUDY II

## Service User's Interview Questionnaire - Subject 2: Patricia

Questions	Scores
1.a) Liking the placement	1
1.b) Names previous placement	2
2. Wants to continue to live in placement	1
3. Likes carers/staff	2
4.a) Has friends	1
4.b) Has 5 or more friends	1
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	2
6.b) Visits others	2
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	1
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	✓
19	✓

## Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Anything.
- Q.11 Where do you go in the day-time?  
Reply: Day Centre - help with shopping, went out shopping on Saturday.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Anything - cricket, homework; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Another cottage.
- Q.20 Is there anything else you would like to tell me?  
Reply: Friend's birthday soon, mother's illness, father's death, likes where she's living.
- Q.21 Are there any questions you would like to ask me?  
Reply: That's all.

## Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed. Q.9 repeated

## Additional Information

None

RAW DATA - STUDY IIService User's Interview Questionnaire - Subject 3: Janet

<u>Questions</u>	<u>Scores</u>
1.a) Liking the placement	3
1.b) Names previous placement	1
2. Wants to continue to live in placement	3
3. Likes carers/staff	1
4.a) Has friends	2
4.b) Has 5 or more friends	3
c) Would like more friends	1
5. Has a special friend	3
6.a) Has visitors	1
6.b) Visits others	1
8. Is usually happy	2
9. Is often ill (Score 1 = illness)	2
12. Learns a lot a Day Services	1
13. Likes Day Service	3
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	/
15 = agree	unhappy here
19 = agree	gets upset

Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Move into own house.
- Q.11 Where do you go in the day-time?  
Reply: Day Centre - packing, reading and writing.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Cleaning, shopping; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Flat/bungalow on my own.
- Q.20 Is there anything else you would like to tell me?  
Reply: Not really.
- Q.21 Are there any questions you would like to ask me?  
Reply: Will I (the researcher) work around here?

Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed.

Additional Information

Gets upset with other people she lives with.  
Dislikes the Day Centre because it's for disabled people.  
Would like more friends that are not disabled.

APPENDIX 25 contd ...

RAW DATA - STUDY II

Service User's Interview Questionnaire - Subject 4: Stephen

Questions	Scores
1.a) Liking the placement	3
1.b) Names previous placement	2
2. Wants to continue to live in placement	3
3. Likes carers/staff	3 & 1
4.a) Has friends	1
4.b) Has 5 or more friends	1
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	2
6.b) Visits others	1
8. Is usually happy	3
9. Is often ill (Score 1 = illness)	3
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	x
19	✓

Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: None.
- Q.11 Where do you go in the day-time?  
Reply: College 3 days a week - car mechanics, community house.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Go to girlfriend every evening; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Move to a flat with other people.
- Q.20 Is there anything else you would like to tell me?  
Reply: No.
- Q.21 Are there any questions you would like to ask me?  
Reply: No.

Emotional Labelling

- Q. 1-5 All correct.  
Q. 6-9 All confirmed.

Additional Information

None.



RAW DATA - STUDY IIService User's Interview Questionnaire - Subject 5: Keith

<u>Questions</u>	<u>Scores</u>
1.a) Liking the placement	1
1.b) Names previous placement	2
2. Wants to continue to live in placement	1
3. Likes carers/staff	1
4.a) Has friends	1
4.b) Has 5 or more friends	3
c) Would like more friends	1
5. Has a special friend	3
6.a) Has visitors	3
6.b) Visits others	2
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	3
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	✓
19	✓

Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Work full-time on the market sweeping or selling flowers.
- Q.11 Where do you go in the day-time?  
Reply: Hospital (Day Service) 4 days a week; college one day a week - reading and writing.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: TV, night-classes, car boot sale; yes, but could fit more in.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Similar house/flat, with friends.
- Q.20 Is there anything else you would like to tell me?  
Reply: Not really.
- Q.21 Are there any questions you would like to ask me?  
Reply: Not really.

Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed.

Additional Information

None.

## APPENDIX 25 contd ...

RAW DATA - STUDY IIService User's Interview Questionnaire - Subject 6: Andrew

<u>Questions</u>	<u>Scores</u>
1.a) Liking the placement	1
1.b) Names previous placement	1
2. Wants to continue to live in placement	1
3. Likes carers/staff	1
4.a) Has friends	1
4.b) Has 5 or more friends	2
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	1
6.b) Visits others	1
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	2
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	/
15 = agree	/
19 = agree	/

Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Christmas.
- Q.11 Where do you go in the day-time?  
Reply: Day Centre - does nothing; college on Monday-computers.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Play music; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: House, like mum's.
- Q.20 Is there anything else you would like to tell me?  
Reply: No.
- Q.21 Are there any questions you would like to ask me?  
Reply: Don't know.

Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed, except re people he lives with.

Additional Information

None.

Summary of Person's Views: Subject 1 - PaulIntroduction

The following is a summary of the views expressed by Paul during six interviews. The interviews were carried out as outlined in the Method. Paul always readily agreed to come to the interviews and after the first two meetings he set up the tape recorder himself.

1. Present placement

Paul stated consistently that he liked his present home, i.e., in the house. The features that he liked (his suggestions) were his bedroom - being able to be alone - his alarm clock and the food, particularly choosing what to eat. He stated that he liked participating in cooking, washing-up, hoovering, playing snooker and watching TV. The programmes that he enjoyed most on TV were: Eastenders; Blockbusters and Coronation Street.

Paul's views about the people he lived with were mixed. He stated that he liked them and that they were his friends. He named one woman that he liked in particular, but he reported that the second woman "moaned and got on his nerves". In addition, he described an incident in which the second woman had urinated in a waste-paper basket in his bedroom - which he clearly disliked. The woman that he expressed a preference for tended to be quiet.

Paul reported that he liked all the carers. One older male carer was preferred, but all carers were described as friends. However, he stated that they did not help him, but he was unclear about exactly what help he needed or would like.

## 2. Past and future placements

Paul stated that he preferred his present placement to his previous hospital placement. The main reason that he gave was the food. However, he also clearly missed aspects of his previous life in hospital. Specifically, he reported whilst in hospital he had liked the staff, one particular male friend and the outings in the minibus to the pub. He understood why his close male friend could not leave hospital with him - Paul described him as "naughty". He stated (on direct questioning) that he had liked living with a large number of people. He described being nervous and frightened of leaving (although, following the move, he was not nervous). Also, he stated that he does not now think about the hospital. However, he was clear that he wanted to remain in his present placement in the future.

## 3. Friendships

Paul described all the carers and the three other people living in the house as his friends. In addition he reported that three other people who attended his drama class were his friends.

During later meetings he talked about a woman friend whom he had met at the Day Centre. He described her as a close friend that he liked to spend time with and stated that he would like to marry her. He reported that he would like to see more of her, but that they had not visited each other's home, nor did his carers know about the friendship. It remained unclear exactly how long they had known each other, but he estimated a month.

#### 4. Day Service

Paul stated that he liked the Day Centre he attended, although on some occasions he expressed some indifferent views e.g., "it's all right". He was able to name friends at the Day Centre and described his instructor as a friend. He liked all the activities, i.e., making shears, playing football and talking. He expressed a particular preference for a trip to the pub. He reported that a person was leaving the Day Centre and that he would miss him - but he did not know where the person was going to.

#### 5. Leisure activities

##### a) Segregated

Paul described attending a drama class. He stated that he liked this class and the teacher and that he had three friends there. He did not report what he did during the class, but said that they drank coffee.

He also attended a Gateway Club every week, and had recently been to a Gateway disco. He said that he enjoyed the club and the disco, although he reported that he did nothing there.

##### b) Integrated

Paul clearly enjoyed visiting a pub to have a drink and he stated (on direct questioning) that he did not talk to members of the public whilst there, i.e., he talked with carers and the other people he lived with. He enjoyed going shopping, e.g., for food, clothes, etc. Paul was very positive about visits to his sister and an ex-home leader's house - neither of these had occurred for some months.

He reported one occasion in which he had experienced difficulties: the taxi driver did not understand his address, but he returned home after a 'phone call.

#### 6. Visits

Paul was visited by his sister (approximately every 2 months) which he said was "all right". A friend of one of the carers visited the house, and he was described by Paul as "his mate", but on closer questioning he stated that they did no activities together. In addition, he described the neighbour next door as friendly and she had borrowed a camera from Paul. It is understood that these latter two visitors were infrequent.

#### 7. Other issues

Paul was very positive about his car and frequently talked about this, emphasising that it was his. In addition, he reported that he missed the previous home leader who had left 2-3 months previously. He consistently stated (on questioning) that he would like to go out more at the weekends, e.g., to the pub and that he would like to attend more classes.

#### Reliability of the information

Overall, it was considered that the above information was reliable. Paul usually gave similar descriptions and responses to each of the above topics. However, it was noted that on some occasions, although his responses were positive, he tended to be somewhat indifferent stating, for example, "it is all right". This applied to most of the topics, except those where he was clearly very positive, e.g., his car, going out, etc.

Person's Views - Subject 2 - PatriciaIntroduction

The following is a summary of the views expressed by Patricia. The interviews were carried out as in the method. Patricia always came readily for the interviews, but she did request on two occasions that the meetings take place in a public area. These requests were refused and an explanation of the importance of privacy was given. However, Patricia was waiting to meet the interviewer in a private room for the last two interviews - before the interviewer had had an opportunity to suggest meeting.

Patricia asked for her close friend to hear the tape recordings. These requests were agreed to, but the tape was replayed for no more than 5 minutes and a "neutral" piece of tape was chosen, i.e., where no clear views were expressed and information exchange took place that the gentleman friend was very likely to be aware of, e.g., activities at the Day Centre. Again, the importance of privacy was emphasised.

Patricia regularly stated "now, I said it, it's in there" (the recorder). The interviewer was concerned that she may believe that change could occur as a result of the interviews. It was repeated to Patricia that no change would be influenced by the research project.

1. Present Placement

Patricia regularly stated that she liked her home, and referred to it as "my home now". She reported that she liked helping, particularly with the hoovering, cleaning the mats and the table. She especially enjoyed participating in these activities with her close friend. She was very pleased with her bedroom.

Patricia said that she liked everyone that she lived with. However, she stated that one woman had upset her, and another made too much noise - but they were still friends. In particular, she spoke at great length about her fondness for her close friend (a man) who also lived in the service.

She gave mixed views about her carers. Some of the carers she reported that she liked, e.g., the woman who worked part-time and washed her clothes. However, one carer in particular, she stated that she "couldn't stand her"; that she was bossy, and hoped that she would leave. In addition, a carer that had recently left had also been disliked.

## 2. Past and Future Placements

Patricia had lived with her parents until their death and then moved to live in the present service. She very much missed both her parents, the family home and her previous friends. This topic was discussed twice only, as it always caused her distress.

Patricia had clear views about the future which she repeated on more than one occasion. She wanted to leave her present placement and live in a small cottage nearby with her close friend.

## 3. Friendships

Patricia reported that the people she lived with were all her friends - see above. She considered that the couple who had set up and developed the service where she lived were her special friends. She regularly said how "good they are to me" and that they buy her clothes, etc. She reported having friends at the Day Centre, but also that she disliked one woman that attended.

Patricia spoke at length about her close friend (a man) who lived in the same placement, and attended the same Day Centre. She regularly expressed her fondness for him, stating that she wanted to marry him. She had told the man who had developed the service of her hopes, but she stated that he had replied that this was "stupid". At present, she was afraid to discuss her wish to marry with her other carers. However, she also reported that she was often very upset with her gentleman friend, and that they argued, etc., which often resulted in her crying.



#### 4. Day Service

Patricia consistently said that she liked attending the Day Centre. She particularly enjoyed going shopping, but she also liked other activities, e.g., snooker, PE, basketball, table tennis, sewing, writing, etc. Patricia liked the food at the Day Centre and the tea breaks. However, she felt that the Day Centre had changed, but she was unclear in what way.

Patricia particularly liked the instructors at the Day Centre, describing them as her friends. However, during one discussion she stated that she was an instructor at the Day Centre, but in the following discussion said she attended the Day Centre and was not an instructor - that she had been "muddled" previously.

#### 5. Leisure Activities

##### a) Segregated

Patricia described a variety of leisure activities that she enjoyed that took place within her current placement, e.g., snooker, a craft night, keep fit, etc. In addition, she reported that she liked to go out to a disco, reading class, to a mass and for walks with people from her placement. She had friends at her evening reading class that she liked to meet.

##### b) Integrated

Patricia very much enjoyed going shopping with the man who had developed the service. She liked to go swimming at the local baths - but did not talk to other people there. In addition, she had enjoyed going to a local fish and chip restaurant - but was disappointed that they had not been recently. She also liked to go to church. She reported that she would like to go out more often into the nearby city to shop, etc. No difficulties had been experienced in integrated settings.

#### 6. Visits

Patricia was visited by her cousin and in the past was visited by a friend, but the latter visits had ceased. She was very positive about visits to the house by the man who had developed the service. Two volunteers also visited the service. She was positive about all these visitors.

Patricia had recently paid a brief visit to friends of her family. She was very interested in maintaining these contacts. She expressed a desire to meet her close friend's parents in the future.

#### 7. Other Issues

Patricia talked about shopping in the town with her mother in the past - an activity that she had greatly enjoyed. she expressed some interest in clothes and liked all her clothes. In addition, she was proud of a trophy she had won recently.

She was not pleased about the man who had developed the service going away on holiday. Patricia had been offered the opportunity of going away on holiday to France, with a group from the Day Centre. During one visit she said she did not want to go, but on a subsequent visit was pleased to be going.

Patricia frequently made reference to her religion, initially stating the date, etc., of her confirmation. All the people she lived with and her carers were of the same religion.

#### Reliability of the information

The above information was considered reliable. On most topics Patricia gave consistent and clear responses and also had definite views of her likes, dislikes and events that upset her. Occasionally, she was inconsistent, e.g., her initial statements of being an instructor at the Day Centre and her views about her holiday. Her explanation was that she was sometimes "muddled".

Person's Views - Subject 3 - JanetIntroduction

The following is a summary of the views of Janet. The interviews were all carried out as outlined in the method. She was always very keen for the interviews to take place, and eagerly went to find out which rooms were free for us to meet in, e.g., the staff sleeping-in room. After each interview she wished to hear part of the tape recording replayed and listened with interest. She commented that she "sounded disabled on the tape". At the end of the project she reported that she "had enjoyed my company and enjoyed someone listening to her problems".

Present placement

Janet reported rather mixed views about her placement and usually described it as "all right". She stated that when she came to her current placement it was with the aim that she would eventually move, which was in accord with her wishes.

Janet stated that she liked doing the cleaning, washing-up, shopping and cooking. Whilst out shopping she reported that she did not talk to other people.

She felt that the other people that she lived with were not her friends, and she did not like them. She regularly stated that "they get on my nerves". She described one woman she lived with as "carrying on, to get attention". She reported that one person was "all right, until he got going" and that a second man was "all right". She complained that the others did not do any cooking, and was very pleased when one woman made the sandwiches one evening.

Janet reported that she liked her carers, in particular her keyworker. She did not like the policy of discouraging friendships with her carers, e.g., she was discouraged from putting her arms around carers. She preferred her current carers - social workers - to nurses in her previous placement, although she stated that she did not understand what they all did. She liked the Individual Planning

approach - people talked to her about the future. She disliked the policy of carers of discouraging her helping other people at the Unit - as she felt she would have enjoyed this.

During the period of the project, Janet and another younger woman went to live independently in a separate part of the unit, for one week. Carers visited briefly in the evenings. She reported being very nervous about the week, and about whether they would get on all right. She clearly preferred it to living in the main part of the centre, because she had her freedom. She particularly liked being able to come and go without telling her carers. She decided that she did not want to live with the other woman permanently. She enjoyed her week - especially the cooking. At the end of the week, she reported that she cried when she left.

## 2. Past and future placements

Janet had left a large hospital to come to her present placement. She had lived there for a number of years and stated that she had found it hard to leave. In particular she said she "missed one of the patients in the hospital". She had particularly enjoyed helping the old ladies in the hospital and liked to help the night staff. She described the staff in the hospital as very nice and more friendly than in her present placement. She reported that she used to be violent in the hospital but that after seeing the psychologist she had no more problems. Although she had liked it in the hospital, she clearly stated that she did not want to stay there and die there; nor did she wish to return there. Her sister had wanted her to leave, to move closer to where she lived.

Janet was very clear about her wishes for the future. She stated that she would like to live in a bungalow on her own. She felt that she would not be nervous living alone. She was clear that it was important to have her freedom back, the freedom that she had had as a child. Janet had considered the possibility of living with a man friend - see below - but she felt that he did not really want this.

### 3. Friendships

Janet reported having a close and long-term friendship with a woman at the Day Centre. Unfortunately, they were unable to meet outside work because the woman lived alone with a sick relative. She used to have a close friendship with a man friend who regularly visited her. She was upset because he had not come for approximately two months. In addition, she also reported another friendship with a woman at the Day Centre.

She reported that the people she lived with were not her friends. She would like to consider her carers her friends. She stated that she would like a friend "without disabilities".

### 4. Day Service

Janet attended a Day Centre. She described the Day Centre as being split into two parts - one part was a factory unit, where the activities included packing, e.g., childrens post office sets and taking things off moulds.

She stated that she disliked the Day Centre and wanted to leave. She found the work boring and the other people got on her nerves, e.g., joking about the instructors. She felt that it was wrong, that when she helped in the Special Care Unit the instructors discussed people in front of her. Overall, she found the instructors very helpful.

She felt that in the future she would like to do voluntary work or have a job, e.g., helping in a local community house. She also wanted to go to college to do nursing or social work with the aim of working with people with a learning difficulty. However, her friend had advised her that she may be unable to become a nurse. She had a friend who had left the Day Centre and now works in a large supermarket and Janet hoped that something similar could be possible for her.

## 5. Leisure activities

### a) Segregated

Janet reported attending an education class every week where she did reading and writing. She enjoyed this, but had found her previous tutor more helpful than her current tutor. She also attended a Tuesday group every week which she enjoyed. This consisted of a small group of local people with learning difficulties who met and arranged social outings.

Janet had interests and activities that she participated in within her placement, e.g., listening to the radio (The Archers in particular), watching films on the TV. Her favourite television programme was Songs of Praise and she often 'arranged' supper-time on Sundays so she could see this programme. Most of these activities she undertook alone. She had recently refused to go on a day trip with the other people she lived with. She enjoyed cooking for herself. In addition, she reported that she sometimes liked to sit and think and joke by herself.

### b) Integrated

Janet was very enthusiastic about shopping with her sister and going to darts with her sister. Both of these activities occurred every week. In addition, she was very positive about some activities that she had undertaken with carers, e.g., visiting the pub when a carer left, visiting a carer's house, badminton, etc. Some of these activities were not recent, but recalled with clear pleasure by Patricia. No difficulties were reported in integrated settings.

## 6. Visits

Janet met her sister every weekend - an event that she greatly enjoyed. She reported being visited by her social worker for her Individual Plan. In addition, she had in the past been visited regularly by a friend (a man) and was distressed that this had now ceased without explanation.

## 7. Other issues

Janet was very clear in her view that she did not like being referred to as 'mentally handicapped'. Her clear preference was for being described as a "lady with a learning difficulty". She was a member of a local People First group and had participated in writing a letter jointly with other members of the group to the local press. The letter concerned the issue of sterilization.

Janet felt that she "was getting better". She was pleased that she could now read and write her own name. Also, she was not keeping her own drug chart.

### Reliability

The information given by Janet was considered very reliable. She was extremely consistent in all her reports.

PERSONS VIEWS - SUBJECT 4 - STEPHENIntroduction:

The following is a summary of the views of Stephen. The interviews were all carried out, as outlined in the method.

Stephen was reluctant for the interviews to take place on three occasions. He asked to wait and then agreed to participate in the interviews. Immediately before two interviews Stephen had been complaining and annoyed about events within the flat, and it was considered likely that this influenced his willingness to come to the interviews, and his views stated within the interviews. He always expressed an interest in when the researcher would visit again.

Stephen asked that the last three interviews would not be tape-recorded. These wishes were complied with. The following summary is taken from the tape recordings of the first interviews, and brief notes taken during and after the remaining interviews. He stated that "he sounded daft" on the tape recordings.

Present Placement.

Stephen expressed some mixed views of his present placement. He stated that "it was alright" and that he had wanted to come to this placement. However, on one occasion he stated that he disliked living there.

Stephen had very clear views about the carers in placement. He liked one of the carers and found her helpful, and also he liked his Linkworker. (The Linkworker worked in another larger service, and was identified as the person Stephen could go to if he had any difficulties). Stephen clearly and repeatedly stated that he disliked one of his carers.



His dislike of the carer was intense at times. e.g. when he threatened to hit him. Stephen reported that when this carer was present: "that he could not do anything" and that the carer "got on his nerves". Stephen repeatedly stated that "he was not daft". Stephen had discussed his views of this carer with his Linkworker some months earlier - but the situation clearly had not been resolved.

Stephen had mixed views of the two other men that he lived with. He reported that "they were alright". On one occasion he stated that he disliked one of the men. Also, Stephen stated that he got annoyed with the second man, when he (the second man) was upset.

Stephen reported that he liked many of the activities within the flat. He liked getting his breakfast, shopping, and cleaning. In addition, he liked the quiet environment, and the food. He stated that he disliked cooking in the evenings, and preparing the Sunday lunch.

#### Past and Future Placements:

Stephen stated that he would like to leave his present placement and move to his own flat. During the initial discussions he was uncertain about whether he would like to share the flat with someone - and he had no clear ideas whom he would like to share with. During later discussions he reported that he would like the flat to be close to a friend (see below).

Stephen had previously lived at a larger service - 24 beds (approx.). Although he had wanted to leave there, he stated that he had liked it there, and he liked the carers and the other people living there.

Before Stephen lived at the larger service, he had lived at home, with his family. He had not wanted to leave home but had left because he swore frequently. He felt sad about leaving home. He saw his parents sometimes and got on well with them. He did not see his brothers nor sisters (total 10) but was not bothered about this.

### Friendships:

Stephen had a long standing friendship with a woman (with learning difficulties) and they met every evening and at weekends. He sometimes felt upset with her - he stated that he would buy her present, but she bought him nothing. He also reported that another man who lived alone was a friend. Stephen named one of his carers as a friend, and the men he lived with, and his tutor at college.

### Day Services:

Stephen attended three different day services during the week. He attended a local College of F.E. which he stated that he liked. He had been there for two years and one of the main activities was car mechanics. In addition, he also attended a Community House, where he participated in reading skills etc., He reported that he like the Community House. For one day a week, he went to a Day Centre. He stated clearly that he disliked this, - he disliked the instructors and the other people who attended. He considered that there were too many people there. Whilst at the Day Centre, he reported that he chopped wood.

Stephen wanted to leave the above Day Services - as soon as possible. He wanted to get a job e.g. gardening, or in a warehouse, or building (which he had done at College).

### Leisure Activities:

Stephen disliked staying in the flat during the evenings and weekends. - he considered this was boring.

#### a) Segregated:

Stephen usually attended a group for people with learning difficulties, which met every week. He reported that he enjoyed this group. Whilst at the group he play snooker and darts. His close friend attended and so did the men that he lived with.

b) Integrated:

Stephen visited his close friend every evening and at weekends. He stated that he enjoyed these visits. They went into the town shopping together on Saturdays which he also like to do. Occasionally he had been to local disco, which he had also enjoyed. He reported no difficulties in integrated settings.

Visits:

Stephen was visited by his social worker. He reported that he liked the visits, as his social worker was helpful. He received no other visitors, not did he regularly visit others - apart from the above.

Other Issues:

Stephen was looking forward to a holiday with the Day Centre. Also, he was very keen to write in his diary every evening.

Stephen reported that whilst living at home he participated in a lot of sport e.g. rugby, cricket, squash. He used to attend a local leisure centre with his brother, and although he had enjoyed this, he no longer wanted to continue.

Stephen had recently had an I.P. meeting and a H.A.L.O. assessment meeting. He reported that both of the meetings "were good" and discussed what he wanted to do. In addition, he expressed positive views about the meetings held in the flat every fortnight.

Reliability:

It was found that Stephen presented some mixed views on some topics e.g. where he lived. In addition, it was clear to the researcher that some of his statements were influenced by what had happened immediately before the interview e.g. when he was annoyed by a carer.

Overall, it was considered that his reports were reliable, but influenced by the above factor.

PERSON'S VIEWS - SUBJECT 5 - KEITHIntroduction

The following is a summary of the views of Keith. The interviews were all carried out as outlined in the method. Keith always came very willingly to the interviews.

1. Present Placement

Keith reported that he liked his present placement. There were many features of the placement that he liked, e.g., cleaning, washing-up, clearing up the rubbish, cooking when the carers were out. In particular, he liked meeting and getting to know the friends and relatives of the carers. He expressed very positive views about going out and helping people, e.g., at a local MENCAP function. He stated that the house was an alternative to living in hospital and "was the same way as living in the hospital grounds". It was very important to Keith to take his own decisions about when to go out. He considered that you get out and about more if you live in a house than a hospital.

Keith described the other three people living in the house as his friends. He reported that he got on well with the other man in the house and that he "did not bother him too much". He felt he got on well with one of the women in the house, but that she was "snappy". He complained about the second woman in the house: "she moans and groans ... I get sick of her moaning ... she's a pain".

Keith gave very positive reports of both his carers. He described them as generous, kind and having good manners. He perceived the carers as "being in charge of the house". He found both his carers helpful and one was described as giving him more practical information. Sometimes he felt that one of the carers "nagged him", e.g., to tidy his room and empty the cat litter tray.

The carers and people with learning difficulties had separate sitting rooms and ate separately. Keith agreed with this feature of the organisation. He stated that he did not want to share his sitting room with the carers - he felt there was more privacy in having separate sitting rooms. He agreed with eating separately, stating this was practical and saved time.

## 2. Past and Future Placements

Keith reported that at age 4 years he had left his family home to live in a children's home and then, when 11 years old, he went to live with foster parents. He had been distressed at going to live in children's homes and found it noisy. He reported being happy with his foster parents and felt that he got on well. When he was 19 years old, he left his foster parents to move into private care. He stated that he and his foster parents looked at two private services and Keith felt that he would prefer his present placement because he could have tea and coffee when he wanted.

Keith had a clear view on where he would like to live in the future. He stated that he would like to live with two men that he knows and meets on most days at the hospital day service. He was very clear that he did not want to live with a woman. He stated that he would like to live in a house the same size as the present house, but close to the hospital. He had discussed this with one of his friends who felt it was a good idea; he had not mentioned it to carers. Keith thought that he could manage without the help of carers, but he had not discussed this with his friend. He reported that he wanted to make his own decisions about where to live and to have more time to go out.

## 3. Friendships

Keith reported that he had two friends that he knew well and spent time with in the hospital day service. They had known each other for 6 years. He also reported that he had had a friend at a previous day centre and does not see him now. He stated that he does not miss his old friends, but that he "knows about 1,000 people". However, he also felt that he would like more friends. He met neither of his friends from the day service outside work. He had a close friend, but they met infrequently.

#### 4. Day Services

Keith spent four days a week in a hospital day service and one day a week at college. Whilst at the hospital, Keith mowed the lawns, cut flowers and picked potatoes. He stated that he liked the activities. He liked some of the people at the hospital, but not all. He felt that some of the staff were helpful, but some were "grumpy". Keith stated that when he started at the hospital day service three and a half years ago, he had wanted to come, but was given no choice. He gave no explanation as to why he commenced attending a hospital day service. Keith felt that he would now like to leave the hospital day service. His choice of day-time activity would be selling flowers on the market.

During the one day a week at college, he attended a course for people with learning difficulties. He participated in reading, writing and going shopping, e.g., to compare prices. He liked the course and felt that he helped the tutor. He found the tutors at college to be helpful and polite, but one was "snappy".

Keith also described his previous day placements. He had completed a one year farming course in Somerset which he had enjoyed and wanted to continue (but was unable to). He then attended an Introduction to Work course for 3 months (in Leicestershire). He then moved to a day centre where he did a variety of activities, e.g, day work, using a loom and also work experience in an Elderly Person's Home. The day centre closed due to lack of funding. In addition, he reported that he had sold flowers on the market, which he had enjoyed and would have continued, but the man employing him was sent to prison.

#### 5. Leisure

##### Integrated Activities

Keith spent all his leisure time when out of the house in integrated settings. During his holidays, every Thursday evening and on Saturdays, he chose to go to the market where he worked as a volunteer, collecting and organising the rubbish. He enjoyed this activity very much and knew many people to talk to at the market. He did on one occasion have some vegetables thrown at him by a market trader. Keith was unclear of the cause of this event, but was advised

by his carer not to carry a briefcase to the market. Keith stated: "people take it out on someone like me". This incident had not altered his obvious pleasure at going to the market.

Keith reported that he enjoyed helping people, e.g., at a local City Show. He had helped at three other local events in the last few months, e.g., a car boot sale for MENCAP. He always attended events as a volunteer.

Keith had two additional evening activities which he attended regularly. He attended an Adult Basic Education course, where he learned computing. He enjoyed this and found the tutors helpful. He also went to a local Neighbourhood Centre where he did some reading and writing. He found this course very enjoyable and stated that the tutors were very helpful and that he knew everyone in the group.

Every Sunday, Keith went to church with one of the women he lived with. He helped at the church by ringing the bell and giving out hymn books. He enjoyed going to church.

Keith stated that he particularly liked long distance travel on buses and trains. He did this rarely, e.g., once a year for a holiday and would like to do this more often, but found that he was often busy.

#### 6. Visits and Visitors

Keith had no visitors, but would like to have. He visited his parents infrequently - the last visit was two months ago.

#### 7. Other Issues

Keith stated that he liked to go to the Cash and Carry with his carers. This happened infrequently and he would like to go more often. He stated that he liked to be out with his carer. He had enjoyed spending 5 hours on a Saturday sorting out the cellar after shopping.

Keith enjoyed cooking and would like to do more. He liked the food in the placement. He had little interest in clothes and preferred to wear jeans and a T-shirt. He stated that he would like to do his own washing.

## Reliability

It was considered that Keith's account was very reliable and he was consistent in his views during all the interviews. He may have omitted a few facts, e.g., why he attended a hospital day centre. It was accepted as his right to omit these facts for the purpose of the research.



Person's Views - Subject 6 - AndrewIntroduction

The following is a summary of the views of Andrew. The interviews were all carried out as outlined in the Method. Andrew always came very willingly to the interviews.

1. Present placement

Andrew reported that he liked his present placement. He stated that he liked the town where he lived and being situated near to a railway. Andrew likes to watch television in the hostel (the news, Howard's Way), listen to music and to do the washing-up - he said he would like to do more washing-up.

Andrew reported that he liked the other people he lived with, and mentioned one of the other men living in the hostel that he liked. When asked if the other people were his friends, he replied "Yes". He also stated that he preferred to be alone, particularly if he was listening to music.

Andrew liked all the carers in the hostel. He viewed them as his friends. On one occasion he did say that he disliked one carer because she "told him off if his slippers had a hole in them". Otherwise, he consistently gave positive reports of all the carers.

2. Past and future placements

Andrew described living at Dr. Barnardo's as being "all right". He liked living with his twin brother there and he liked all his carers at Dr. Barnardo's.

Andrew gave mixed reports of the future. On one occasion he stated that he would like to live in a house. He also reported that he would like to live in a flat with a woman who used to live at the hostel. He had visited her flat a few months earlier and wished to go again. During one meeting, he said that he would like to live with the

staff. However, on one occasion he clearly said that he did not want to talk about future placements, without giving a clear reason. His wish was agreed to. He clearly stated that he wanted to stay in his present placement in the short-term, but not forever.

### 3. Friendships

When asked to name friends, Andrew always gave the names of carers at the hostel. In addition he named day centre instructors and the manager as his friend. He also reported that he liked a volunteer that visited the hostel on Saturdays. He only named one of the people that he lived with as being a friend. He reported that the woman who had moved from the hostel was a friend.

### 4. Day Services

Andrew attended a day centre very close to the hostel 4 days a week. When asked what he did at the day centre, his usual reply was "nothing". However, he did give some reports of some activities he did at the day centre: playing tapes and records, swimming, woodwork, cookery and pottery. He stated that he liked going swimming and cooking and liked the majority of activities, but found the workshop too cold.

Andrew went to a local college one day a week. Whilst at college he practiced with computers and learnt road crossing skills. In addition, he had recently been Christmas shopping with the college, visiting the nearby town. Andrew was very clear in his preference for college in comparison to the day centre. In addition, he liked the tutor at college.

## 5. Leisure

### A. Integrated activities

Andrew had been on two recent visits to Peterborough shopping. He enjoyed both the visits, although on one occasion he did not buy anything. One weekend he went with all the other people from the hostel to a local pub where he bought a pint of beer. He consistently gave very positive reports of these activities, and reported no difficulties in integrated settings.

### B. Segregated activities

Andrew said that he enjoyed watching TV, particularly programmes on aeroplanes, sitting on the swing and riding his bicycle around the car park. He had enjoyed a recent disco at the hostel and attending a bonfire party. One evening a week he went to a local Gateway Club where he listened to music and drank pop - he enjoys visiting this Club. In contrast, he stated that he disliked attending one club because he had had a headache due to the loud music (the club was held at a local prison).

## 6. Visits and visitors

Andrew was visited on alternate weekends by his father. On occasions, his twin brother accompanied his father. He stated that during the visits he and his father sat in his bedroom whilst he ate Opal Fruits. Andrew said that he would like to visit his twin brother in his new group home. Towards the end of the researcher's visits, Andrew had written and asked his twin brother if he could visit him. In addition, he reported that several months ago (date unknown), he visited an aunt and was taken by a Social Worker.

Andrew was asked if he missed living with his twin brother. He stated that he did not miss his twin brother and explained that his brother had disliked the hostel.

## 7. Other issues

Andrew gave both positive reports of the food at the hostel and the food at the college and the day centre. He said he was interested in clothes and would like a new coat, shoes and jumper for Christmas. His cousin had recently had a new baby - a relative of his father's second wife. He stated that he liked babies and that the baby was "all right".

## 8. Reliability

It was considered that the majority of Andrew's account was reliable and he was consistent in many of his views during all the interviews. One issue where his views were considered unclear was that of future placements. During the initial interviews he gave various examples of alternative placements he would eventually like to live in. However, towards the end of the interview, he stated that he did not wish to discuss this any more. The researcher considered that one possible reason for his choice not to discuss this topic was that he found it stressful. He was very willing to discuss all other topics.

DAILY DIARY

Guidelines for completion

1) Please complete the diary at the end of each day. It may be easier to complete it at the end of every morning, afternoon and evening.

2) Please record for every hour:

a) The main activities undertaken. The attached sheets give some examples of activities which may be undertaken within the house, and also in the community.

It is particularly important to also record if no activities were undertaken - this may be reported as "unoccupied".

b) Where the activity was undertaken, e.g., visiting room, kitchen day centre, pub, cinema, etc.

c) With whom the activities were undertaken, e.g., named person, other people in the house, with general public.

It is important to state whether or not members of the general public were present.

d) How long each activity lasted - to the nearest quarter of an hour.

3) It is very important not to leave gaps - it is difficult to identify what a person has been doing if it has not been recorded within a short period.

(An example of a completed Daily Diary is attached to help to clarify the method of completion).

Many thanks for completing the Daily Diary.

Angela Holland

## DAILY DIARY

### Use of Community Facilities

Please record whether Mr/Mrs \_\_\_\_\_ used any of the following facilities. Record this on the daily diary sheet.

#### a) Shopping

1. Corner shop
2. Supermarket
3. Chemist
4. Post Office
5. Clothes shop
6. Shoe shop.

#### b) Services

1. Doctor
2. Dentist
3. O.P. appointment
4. Church
5. Public bus
6. Car
7. Train
8. Taxi
9. Restaurant
10. Cafe
11. Pub
12. Take-away meal
13. Hairdresser
14. Bank/Building Society
15. Launderette
16. Library.

#### c) Leisure

1. Cinema
2. Theatre
3. Museum
4. Watching live sport
5. Playing sport
6. Club
7. Evening adult education
8. Park
9. Bingo
10. Dancing, disco.

#### d) Away from home visits

1. Visit another person's home (not staff)
2. Overnight stay
3. Holiday

## DAILY DIARY

Use of facilities within the house

Please record whether Mr/Mrs \_\_\_\_\_ undertook any of the following activities during the day.

Please record these on the daily diary sheet.

### A. Self-care

1. Dressing, undressing
2. Bathing, showering
3. Washing hair
4. Toilet (if longer than 5 minutes)
5. Time in bathroom, e.g., washing hands, cleaning teeth
6. Eating meal
7. Drinking coffee/tea - if not part of a meal.

### B. Cookery

1. Preparing a drink, hot or cold
2. preparing a cold snack
3. Preparing a hot snack/meal
4. Washing-up.

### C. Cleaning

1. Dusting, hoovering own bedroom
2. Making bed
3. Dusting, hoovering downstairs living areas
4. Cleaning kitchen
5. Cleaning bathroom/toilets
6. Clearing up/cleaning up outside.

### D. Care of clothes

1. Washing clothes by hand
2. Washing clothes - use of machine
3. Hanging clothes to dry
4. Ironing
5. Putting clothes away in drawers, hanging them up.

### E. Leisure

1. Watching TV
2. Playing cards, board games, etc.
3. Sewing, knitting, embroidery, etc.
4. Listening to/playing music, radio
5. Talking to friends - must be clear evidence of a conversation
6. Yoga, relaxation exercises
7. Painting, drawing, etc.
8. Reading, magazines/books.

F. Outside the house

1. Gardening
2. Clearing up, sweeping, etc.

G. Minor repairs and maintenance

1. Decorating
2. Changing light bulb, etc.

H. Care of pets

1. Feeding
2. Grooming, cleaning.

I. Work brought home

1. From Day Centre (specify)
2. From College (specify).

Angela Holland,  
Principal Clinical Psychologist

AH/MSL  
18.3.88.



EXAMPLEDAILY DIARY

Name:

Address:

Date:

<u>Time</u>	<u>Activities</u>	<u>Where</u>	<u>With Whom</u>	<u>Duration</u>
<u>Morning</u>				
7.00-8.00	GETTING UP, DRESSING EATING BREAKFAST EATING	BEDROOM KITCHEN / DINING ROOM	ALONE GROUP	$\frac{1}{2}$ Hour $\frac{1}{2}$ Hour
8.00-9.00	WAITING DAY CENTRE BUS	SITTING ROOM BUS	GROUP GROUP	$\frac{1}{4}$ Hour $\frac{1}{2}$ Hour
9.00-10.00	DAY CENTRE	DAY CENTRE	DAY CENTRE	↑ ↓
10.00-11.00	"	"	"	
11.00-12.00	"	"	"	
<u>Afternoon</u>				
12.00-1.00	"	"	"	
1.00-2.00	"	"	"	↓
2.00-3.00	"	"	"	
3.00-4.00	"	"	"	
4 - 5.00	PREPARE CUP OF TEA DRINKING TEA	KITCHEN "	B. IN KITCHEN "	$\frac{1}{4}$ Hour $\frac{1}{2}$ Hour
<u>Evening</u>				
5.00-6.00	SITTING UNOCCUPIED PREPARE TEA / SUPPER EATS	SITTING ROOM KITCHEN "	B STAFF GROUP & STAFF	$\frac{1}{2}$ Hour $\frac{1}{2}$ Hour
6.00-7.00	WATCHES TV SITTING UNOCCUPIED	SITTING ROOM "	ALONE "	$\frac{1}{2}$ Hour 1 Hour
7.00-8.00	VISITS PUB	PUB	GROUP & PUBLIC	1 Hour
8.00-9.00	WATCHING TV	SITTING ROOM	GROUP	1 Hour
9.00-10.00	BATH GOES TO BED	BATHROOM BEDROOM	ALONE ALONE	$\frac{1}{2}$ Hour $\frac{1}{2}$ Hour

DAILY DIARY

Name:

Address:

Date:

<u>Time</u>	<u>Activities</u>	<u>Where</u>	<u>With Whom</u>	<u>Duration</u>
<u>Morning</u>				
7.00-8.00				
8.00-9.00				
9.00-10.00				
10.00-11.00				
11.00-12.00				
<u>Afternoon</u>				
12.00-1.00				
1.00-2.00				
2.00-3.00				
3.00-4.00				
4.00-5.00				
<u>Evening</u>				
5.00-6.00				
6.00-7.00				
7.00-8.00				
8.00-9.00				
9.00-10.00				

Categories of Behaviour - Diary Data

<u>Category of Behaviour</u>	<u>Examples Recorded</u>
Self-care	Getting up, dressing, eating, drinking, bathing, washing, going to bed.
Domestic	Cooking, washing-up, clearing and laying table, changing sheeting, clothes washing.
Leisure within the house	Reading, listening to music, craft, keep fit.
TV	TV
Sitting	Sitting, sitting alone in bedroom.
Talking	Talking to peers, carers, visitors.
Clubs, classes - segregated	Gateway Club, evening classes (segregated), Clubs (segregated).
Waiting to travel	Waiting to travel.
Travel minibus	Travel minibus.
Public transport, walking	Taxis, car, walking to destination, bus.
Shopping	Shopping.
Leisure integrated	Pub, evening class (integrated), meal out, walking.
Voluntary work	Unpaid work, e.g., for Mencap, car boot sale, market.
Church	Church.
Visit to friends	Visit to friends (but not in services).
Visitors	Visitors to service.
Phone	Talking on the telephone.
House meeting	Meeting in house.

DIARY RECORDS - Agreement with Observations

The agreement was calculated between the diary records and the observations completed on the same evening and within the same time period. The number of evenings when both measures were completed varied for each subject (range 3-9 evenings), due to the date when the diary could be commenced, e.g. after a staff meeting had taken place to explain the procedures, and also because of occasional difficulties operating the computer. If the same category of activity was written in the diary as was observed to occur within the same period, this was counted as an agreement. So, if the category 'domestic' had been recorded by observation and 'washing-up' was written in the diary within the same time period, this was counted as an agreement. Observations of less than 5% duration of a single observation period were not included as they were considered to be too short a duration for carers to record. For the purpose of the calculations, the time period was identified as the total time during which observations were recorded during an evening, e.g., 1 - 1hr 30 mins. So, each time period could include a mealtime and the time before and after the meal. A single observation refers to one of the observations within the time period. typically, three observations would be made in one evening/afternoon.

Using this approach, it was found that the diary records agreement ranged from 43.7% to 63.2%. The low agreement was largely accounted for by the omission of the neutral and interaction categories from the diary records. Few activities (8) were recorded in the diary, but not observed. The lowest agreement was found for the records kept by the subject himself, but this was not substantially different from the agreement of the other diary records.

Table Agreement of Diary Records with Observations

<u>Subject</u>	<u>Number of Evenings - diary &amp; Observations were both completed</u>	<u>Number of Observational Categories recorded</u>	<u>Number agreed with Diary</u>	<u>% Agreement</u>
1	4	19	12	63.2
2	7	40	20	50.0
3	4	18	8	44.4
4	9	58	31	53.4
5	3	16	7	43.7
6	6	21	10	47.6

Table Summary of Activities not Recorded in Both the Diary and by Observation

<u>Subject</u>	<u>Activities not recorded in Diary but recorded by Observation</u>			<u>Activities not Observed but recorded in the Diary</u>
	<u>Neutral</u>	<u>Interactions</u>	<u>Other</u>	
1	3	2	2	0
2	7	12	1	2
3	3	3	4	4
4	6	12	9	0
5	1	2	6	0
6	5	2	4	2
TOTAL	25	33	26	8

% of disagreements accounted for by not recording neutral and interaction activities in the diary: 69% (58/84).

## AGREEMENT DIARY DATA AND QUESTIONNAIRE: OPPORTUNITIES

The agreement between the diary data and the questionnaire Opportunities was calculated. Only three questions of the Opportunities questionnaire were considered and these concerned how often each subject cooked, went shopping and went out to a leisure activity. The table below outlines the agreement.

## Agreement between Diary Data and Questionnaire: Opportunities

Question:	Cooking	Shopping	Leisure	Comments
Subject 1	✓	X	✓	Questionnaire overestimates shopping by one shopping trip a week.
Subject 2	✓	X	✓	Questionnaire overestimates shopping by one shopping trip a week.
Subject 3	X	✓	✓	Questionnaire underestimates cooking by once a week.
Subject 4	✓	✓	✓	
Subject 5	X	X	✓	Questionnaire overestimates cooking by twice a week and shopping by once a week.
Subject 6	✓	X	✓	Questionnaire overestimates shopping by twice a week.

## RAW DATA - STUDY II

## Service User's Interview Questionnaire - Subject 1: Paul

Questions	Scores
1.a) Liking the placement	1
1.b) Names previous placement	1
2. Wants to continue to live in placement	1
3. Likes carers/staff	1
4.a) Has friends	1
4.b) Has 5 or more friends	1
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	1
6.b) Visits others	1
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	3
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	3
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	✓
19	✓

## Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Don't know
- Q.11 Where do you go in the day-time?  
Reply: Day Centre.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Hoovering, washing-up; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Live with my sister.
- Q.20 Is there anything else you would like to tell me?  
Reply: No.
- Q.21 Are there any questions you would like to ask me?  
Reply: What do you do?

## Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed.

## Additional Information

Complaint about another person in the house not helping.

## RAW DATA - STUDY II

## Service User's Interview Questionnaire - Subject 2: Patricia

Questions	Scores
1.a) Liking the placement	1
1.b) Names previous placement	2
2. Wants to continue to live in placement	1
3. Likes carers/staff	2
4.a) Has friends	1
4.b) Has 5 or more friends	1
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	2
6.b) Visits others	2
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	1
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	✓
19	✓

## Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Anything.
- Q.11 Where do you go in the day-time?  
Reply: Day Centre - help with shopping, went out shopping on Saturday.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Anything - cricket, homework; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Another cottage.
- Q.20 Is there anything else you would like to tell me?  
Reply: Friend's birthday soon, mother's illness, father's death, likes where she's living.
- Q.21 Are there any questions you would like to ask me?  
Reply: That's all.

## Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed. Q.9 repeated

## Additional Information

None



# APPENDIX 25 contd ...

## RAW DATA - STUDY II

### Service User's Interview Questionnaire - Subject 4: Stephen

Questions	Scores
1.a) Liking the placement	3
1.b) Names previous placement	2
2. Wants to continue to live in placement	3
3. Likes carers/staff	3 & 1
4.a) Has friends	1
4.b) Has 5 or more friends	1
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	2
6.b) Visits others	1
8. Is usually happy	3
9. Is often ill (Score 1 = illness)	3
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	x
19	✓

### Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: None.
- Q.11 Where do you go in the day-time?  
Reply: College 3 days a week - car mechanics, community house.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Go to girlfriend every evening; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Move to a flat with other people.
- Q.20 Is there anything else you would like to tell me?  
Reply: No.
- Q.21 Are there any questions you would like to ask me?  
Reply: No.

### Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed.

### Additional Information

None.

RAW DATA - STUDY IIService User's Interview Questionnaire - Subject 5: Keith

<u>Questions</u>	<u>Scores</u>
1.a) Liking the placement	1
1.b) Names previous placement	2
2. Wants to continue to live in placement	1
3. Likes carers/staff	1
4.a) Has friends	1
4.b) Has 5 or more friends	3
c) Would like more friends	1
5. Has a special friend	3
6.a) Has visitors	3
6.b) Visits others	2
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	3
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	✓
15	✓
19	✓

Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Work full-time on the market sweeping or selling flowers.
- Q.11 Where do you go in the day-time?  
Reply: Hospital (Day Service) 4 days a week; college one day a week - reading and writing.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: TV, night-classes, car boot sale; yes, but could fit more in.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: Similar house/flat, with friends.
- Q.20 Is there anything else you would like to tell me?  
Reply: Not really.
- Q.21 Are there any questions you would like to ask me?  
Reply: Not really.

Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed.

Additional Information

None.

## APPENDIX 25 contd ...

RAW DATA - STUDY IIService User's Interview Questionnaire - Subject 6: Andrew

<u>Questions</u>	<u>Scores</u>
1.a) Liking the placement	1
1.b) Names previous placement	1
2. Wants to continue to live in placement	1
3. Likes carers/staff	1
4.a) Has friends	1
4.b) Has 5 or more friends	2
c) Would like more friends	1
5. Has a special friend	1
6.a) Has visitors	1
6.b) Visits others	1
8. Is usually happy	1
9. Is often ill (Score 1 = illness)	2
12. Learns a lot a Day Services	1
13. Likes Day Service	1
14. Earns money at Day Service	1
17. Would like to leave (residential services) if he/she could	1
Check questions: 7 = agree	(
15 = agree	/
19 = agree	/

Open-Ended Questions

- Q.10 If you had one wish, what would you wish for?  
Reply: Christmas.
- Q.11 Where do you go in the day-time?  
Reply: Day Centre - does nothing; college on Monday-computers.
- Q.16 Where do you go in your spare time? Do you have enough to do?  
Reply: Play music; yes.
- Q.18 What kind of place would you like to go to? (to live)  
Reply: House, like mum's.
- Q.20 Is there anything else you would like to tell me?  
Reply: No.
- Q.21 Are there any questions you would like to ask me?  
Reply: Don't know.

Emotional Labelling

- Q. 1-5 All correct.
- Q. 6-9 All confirmed, except re people he lives with.

Additional Information

None.

Summary of Person's Views: Subject 1 - PaulIntroduction

The following is a summary of the views expressed by Paul during six interviews. The interviews were carried out as outlined in the Method. Paul always readily agreed to come to the interviews and after the first two meetings he set up the tape recorder himself.

1. Present placement

Paul stated consistently that he liked his present home, i.e., in the house. The features that he liked (his suggestions) were his bedroom - being able to be alone - his alarm clock and the food, particularly choosing what to eat. He stated that he liked participating in cooking, washing-up, Hoovering, playing snooker and watching TV. The programmes that he enjoyed most on TV were: Eastenders; Blockbusters and Coronation Street.

Paul's views about the people he lived with were mixed. He stated that he liked them and that they were his friends. He named one woman that he liked in particular, but he reported that the second woman "moaned and got on his nerves". In addition, he described an incident in which the second woman had urinated in a waste-paper basket in his bedroom - which he clearly disliked. The woman that he expressed a preference for tended to be quiet.

Paul reported that he liked all the carers. One older male carer was preferred, but all carers were described as friends. However, he stated that they did not help him, but he was unclear about exactly what help he needed or would like.

## 2. Past and future placements

Paul stated that he preferred his present placement to his previous hospital placement. The main reason that he gave was the food. However, he also clearly missed aspects of his previous life in hospital. Specifically, he reported whilst in hospital he had liked the staff, one particular male friend and the outings in the minibus to the pub. He understood why his close male friend could not leave hospital with him - Paul described him as "naughty". He stated (on direct questioning) that he had liked living with a large number of people. He described being nervous and frightened of leaving (although, following the move, he was not nervous). Also, he stated that he does not now think about the hospital. However, he was clear that he wanted to remain in his present placement in the future.

## 3. Friendships

Paul described all the carers and the three other people living in the house as his friends. In addition he reported that three other people who attended his drama class were his friends.

During later meetings he talked about a woman friend whom he had met at the Day Centre. He described her as a close friend that he liked to spend time with and stated that he would like to marry her. He reported that he would like to see more of her, but that they had not visited each other's home, nor did his carers know about the friendship. It remained unclear exactly how long they had known each other, but he estimated a month.

#### 4. Day Service

Paul stated that he liked the Day Centre he attended, although on some occasions he expressed some indifferent views e.g., "it's all right". He was able to name friends at the Day Centre and described his instructor as a friend. He liked all the activities, i.e., making shears, playing football and talking. He expressed a particular preference for a trip to the pub. He reported that a person was leaving the Day Centre and that he would miss him - but he did not know where the person was going to.

#### 5. Leisure activities

##### a) Segregated

Paul described attending a drama class. He stated that he liked this class and the teacher and that he had three friends there. He did not report what he did during the class, but said that they drank coffee.

He also attended a Gateway Club every week, and had recently been to a Gateway disco. He said that he enjoyed the club and the disco, although he reported that he did nothing there.

##### b) Integrated

Paul clearly enjoyed visiting a pub to have a drink and he stated (on direct questioning) that he did not talk to members of the public whilst there, i.e., he talked with carers and the other people he lived with. He enjoyed going shopping, e.g, for food, clothes, etc. Paul was very positive about visits to his sister and an ex-home leader's house - neither of these had occurred for some months.

He reported one occasion in which he had experienced difficulties: the taxi driver did not understand his address, but he returned home after a 'phone call.

#### 6. Visits

Paul was visited by his sister (approximately every 2 months) which he said was "all right". A friend of one of the carers visited the house, and he was described by Paul as "his mate", but on closer questioning he stated that they did no activities together. In addition, he described the neighbour next door as friendly and she had borrowed a camera from Paul. It is understood that these latter two visitors were infrequent.

#### 7. Other issues

Paul was very positive about his car and frequently talked about this, emphasising that it was his. In addition, he reported that he missed the previous home leader who had left 2-3 months previously. He consistently stated (on questioning) that he would like to go out more at the weekends, e.g., to the pub and that he would like to attend more classes.

#### Reliability of the information

Overall, it was considered that the above information was reliable. Paul usually gave similar descriptions and responses to each of the above topics. However, it was noted that on some occasions, although his responses were positive, he tended to be somewhat indifferent stating, for example, "it is all right". This applied to most of the topics, except those where he was clearly very positive, e.g., his car, going out, etc.

Person's Views - Subject 2 - PatriciaIntroduction

The following is a summary of the views expressed by Patricia. The interviews were carried out as in the method. Patricia always came readily for the interviews, but she did request on two occasions that the meetings take place in a public area. These requests were refused and an explanation of the importance of privacy was given. However, Patricia was waiting to meet the interviewer in a private room for the last two interviews - before the interviewer had had an opportunity to suggest meeting.

Patricia asked for her close friend to hear the tape recordings. These requests were agreed to, but the tape was replayed for no more than 5 minutes and a "neutral" piece of tape was chosen, i.e., where no clear views were expressed and information exchange took place that the gentleman friend was very likely to be aware of, e.g., activities at the Day Centre. Again, the importance of privacy was emphasised.

Patricia regularly stated "now, I said it, it's in there" (the recorder). The interviewer was concerned that she may believe that change could occur as a result of the interviews. It was repeated to Patricia that no change would be influenced by the research project.

1. Present Placement

Patricia regularly stated that she liked her home, and referred to it as "my home now". She reported that she liked helping, particularly with the hoovering, cleaning the mats and the table. She especially enjoyed participating in these activities with her close friend. She was very pleased with her bedroom.

Patricia said that she liked everyone that she lived with. However, she stated that one woman had upset her, and another made too much noise - but they were still friends. In particular, she spoke at great length about her fondness for her close friend (a man) who also lived in the service.



She gave mixed views about her carers. Some of the carers she reported that she liked, e.g., the woman who worked part-time and washed her clothes. However, one carer in particular, she stated that she "couldn't stand her"; that she was bossy, and hoped that she would leave. In addition, a carer that had recently left had also been disliked.

## 2. Past and Future Placements

Patricia had lived with her parents until their death and then moved to live in the present service. She very much missed both her parents, the family home and her previous friends. This topic was discussed twice only, as it always caused her distress.

Patricia had clear views about the future which she repeated on more than one occasion. She wanted to leave her present placement and live in a small cottage nearby with her close friend.

## 3. Friendships

Patricia reported that the people she lived with were all her friends - see above. She considered that the couple who had set up and developed the service where she lived were her special friends. She regularly said how "good they are to me" and that they buy her clothes, etc. She reported having friends at the Day Centre, but also that she disliked one woman that attended.

Patricia spoke at length about her close friend (a man) who lived in the same placement, and attended the same Day Centre. She regularly expressed her fondness for him, stating that she wanted to marry him. She had told the man who had developed the service of her hopes, but she stated that he had replied that this was "stupid". At present, she was afraid to discuss her wish to marry with her other carers. However, she also reported that she was often very upset with her gentleman friend, and that they argued, etc., which often resulted in her crying.

#### 4. Day Service

Patricia consistently said that she liked attending the Day Centre. She particularly enjoyed going shopping, but she also liked other activities, e.g., snooker, PE, basketball, table tennis, sewing, writing, etc. Patricia liked the food at the Day Centre and the tea breaks. However, she felt that the Day Centre had changed, but she was unclear in what way.

Patricia particularly liked the instructors at the Day Centre, describing them as her friends. However, during one discussion she stated that she was an instructor at the Day Centre, but in the following discussion said she attended the Day Centre and was not an instructor - that she had been "muddled" previously.

#### 5. Leisure Activities

##### a) Segregated

Patricia described a variety of leisure activities that she enjoyed that took place within her current placement, e.g., snooker, a craft night, keep fit, etc. In addition, she reported that she liked to go out to a disco, reading class, to a mass and for walks with people from her placement. She had friends at her evening reading class that she liked to meet.

##### b) Integrated

Patricia very much enjoyed going shopping with the man who had developed the service. She liked to go swimming at the local baths - but did not talk to other people there. In addition, she had enjoyed going to a local fish and chip restaurant - but was disappointed that they had not been recently. She also liked to go to church. She reported that she would like to go out more often into the nearby city to shop, etc. No difficulties had been experienced in integrated settings.

#### 6. Visits

Patricia was visited by her cousin and in the past was visited by a friend, but the latter visits had ceased. She was very positive about visits to the house by the man who had developed the service. Two volunteers also visited the service. She was positive about all these visitors.

Patricia had recently paid a brief visit to friends of her family. She was very interested in maintaining these contacts. She expressed a desire to meet her close friend's parents in the future.

#### 7. Other Issues

Patricia talked about shopping in the town with her mother in the past - an activity that she had greatly enjoyed. she expressed some interest in clothes and liked all her clothes. In addition, she was proud of a trophy she had won recently.

She was not pleased about the man who had developed the service going away on holiday. Patricia had been offered the opportunity of going away on holiday to France, with a group from the Day Centre. During one visit she said she did not want to go, but on a subsequent visit was pleased to be going.

Patricia frequently made reference to her religion, initially stating the date, etc., of her confirmation. All the people she lived with and her carers were of the same religion.

#### Reliability of the information

The above information was considered reliable. On most topics Patricia gave consistent and clear responses and also had definite views of her likes, dislikes and events that upset her. Occasionally, she was inconsistent, e.g., her initial statements of being an instructor at the Day Centre and her views about her holiday. Her explanation was that she was sometimes "muddled".

Person's Views - Subject 3 - JanetIntroduction

The following is a summary of the views of Janet. The interviews were all carried out as outlined in the method. She was always very keen for the interviews to take place, and eagerly went to find out which rooms were free for us to meet in, e.g., the staff sleeping-in room. After each interview she wished to hear part of the tape recording replayed and listened with interest. She commented that she "sounded disabled on the tape". At the end of the project she reported that she "had enjoyed my company and enjoyed someone listening to her problems".

Present placement

Janet reported rather mixed views about her placement and usually described it as "all right". She stated that when she came to her current placement it was with the aim that she would eventually move, which was in accord with her wishes.

Janet stated that she liked doing the cleaning, washing-up, shopping and cooking. Whilst out shopping she reported that she did not talk to other people.

She felt that the other people that she lived with were not her friends, and she did not like them. She regularly stated that "they get on my nerves". She described one woman she lived with as "carrying on, to get attention". She reported that one person was "all right, until he got going" and that a second man was "all right". She complained that the others did not do any cooking, and was very pleased when one woman made the sandwiches one evening.

Janet reported that she liked her carers, in particular her keyworker. She did not like the policy of discouraging friendships with her carers, e.g., she was discouraged from putting her arms around carers. She preferred her current carers - social workers - to nurses in her previous placement, although she stated that she did not understand what they all did. She liked the Individual Planning

approach - people talked to her about the future. She disliked the policy of carers of discouraging her helping other people at the Unit - as she felt she would have enjoyed this.

During the period of the project, Janet and another younger woman went to live independently in a separate part of the unit, for one week. Carers visited briefly in the evenings. She reported being very nervous about the week, and about whether they would get on all right. She clearly preferred it to living in the main part of the centre, because she had her freedom. She particularly liked being able to come and go without telling her carers. She decided that she did not want to live with the other woman permanently. She enjoyed her week - especially the cooking. At the end of the week, she reported that she cried when she left.

## 2. Past and future placements

Janet had left a large hospital to come to her present placement. She had lived there for a number of years and stated that she had found it hard to leave. In particular she said she "missed one of the patients in the hospital". She had particularly enjoyed helping the old ladies in the hospital and liked to help the night staff. She described the staff in the hospital as very nice and more friendly than in her present placement. She reported that she used to be violent in the hospital but that after seeing the psychologist she had no more problems. Although she had liked it in the hospital, she clearly stated that she did not want to stay there and die there; nor did she wish to return there. Her sister had wanted her to leave, to move closer to where she lived.

Janet was very clear about her wishes for the future. She stated that she would like to live in a bungalow on her own. She felt that she would not be nervous living alone. She was clear that it was important to have her freedom back, the freedom that she had had as a child. Janet had considered the possibility of living with a man friend - see below - but she felt that he did not really want this.

### 3. Friendships

Janet reported having a close and long-term friendship with a woman at the Day Centre. Unfortunately, they were unable to meet outside work because the woman lived alone with a sick relative. She used to have a close friendship with a man friend who regularly visited her. She was upset because he had not come for approximately two months. In addition, she also reported another friendship with a woman at the Day Centre.

She reported that the people she lived with were not her friends. She would like to consider her carers her friends. She stated that she would like a friend "without disabilities".

### 4. Day Service

Janet attended a Day Centre. She described the Day Centre as being split into two parts - one part was a factory unit, where the activities included packing, e.g., childrens post office sets and taking things off moulds.

She stated that she disliked the Day Centre and wanted to leave. She found the work boring and the other people got on her nerves, e.g., joking about the instructors. She felt that it was wrong, that when she helped in the Special Care Unit the instructors discussed people in front of her. Overall, she found the instructors very helpful.

She felt that in the future she would like to do voluntary work or have a job, e.g., helping in a local community house. She also wanted to go to college to do nursing or social work with the aim of working with people with a learning difficulty. However, her friend had advised her that she may be unable to become a nurse. She had a friend who had left the Day Centre and now works in a large supermarket and Janet hoped that something similar could be possible for her.

## 5. Leisure activities

### a) Segregated

Janet reported attending an education class every week where she did reading and writing. She enjoyed this, but had found her previous tutor more helpful than her current tutor. She also attended a Tuesday group every week which she enjoyed. This consisted of a small group of local people with learning difficulties who met and arranged social outings.

Janet had interests and activities that she participated in within her placement, e.g., listening to the radio (The Archers in particular), watching films on the TV. Her favourite television programme was Songs of Praise and she often 'arranged' supper-time on Sundays so she could see this programme. Most of these activities she undertook alone. She had recently refused to go on a day trip with the other people she lived with. She enjoyed cooking for herself. In addition, she reported that she sometimes liked to sit and think and joke by herself.

### b) Integrated

Janet was very enthusiastic about shopping with her sister and going to darts with her sister. Both of these activities occurred every week. In addition, she was very positive about some activities that she had undertaken with carers, e.g., visiting the pub when a carer left, visiting a carer's house, badminton, etc. Some of these activities were not recent, but recalled with clear pleasure by Patricia. No difficulties were reported in integrated settings.

## 6. Visits

Janet met her sister every weekend - an event that she greatly enjoyed. She reported being visited by her social worker for her Individual Plan. In addition, she had in the past been visited regularly by a friend (a man) and was distressed that this had now ceased without explanation.

## 7. Other issues

Janet was very clear in her view that she did not like being referred to as 'mentally handicapped'. Her clear preference was for being described as a "lady with a learning difficulty". She was a member of a local People First group and had participated in writing a letter jointly with other members of the group to the local press. The letter concerned the issue of sterilization.

Janet felt that she "was getting better". She was pleased that she could now read and write her own name. Also, she was not keeping her own drug chart.

### Reliability

The information given by Janet was considered very reliable. She was extremely consistent in all her reports.



PERSONS VIEWS - SUBJECT 4 - STEPHENIntroduction:

The following is a summary of the views of Stephen. The interviews were all carried out, as outlined in the method.

Stephen was reluctant for the interviews to take place on three occasions. He asked to wait and then agreed to participate in the interviews. Immediately before two interviews Stephen had been complaining and annoyed about events within the flat, and it was considered likely that this influenced his willingness to come to the interviews, and his views stated within the interviews. He always expressed an interest in when the researcher would visit again.

Stephen asked that the last three interviews would not be tape-recorded. These wishes were complied with. The following summary is taken from the tape recordings of the first interviews, and brief notes taken during and after the remaining interviews. He stated that "he sounded daft" on the tape recordings.

Present Placement.

Stephen expressed some mixed views of his present placement. He stated that "it was alright" and that he had wanted to come to this placement. However, on one occasion he stated that he disliked living there.

Stephen had very clear views about the carers in placement. He liked one of the carers and found her helpful, and also he liked his Linkworker. (The Linkworker worked in another larger service, and was identified as the person Stephen could go to if he had any difficulties). Stephen clearly and repeatedly stated that he disliked one of his carers.

His dislike of the carer was intense at times. e.g. when he threatened to hit him. Stephen reported that when this carer was present: "that he could not do anything" and that the carer "got on his nerves". Stephen repeatedly stated that "he was not daft". Stephen had discussed his views of this carer with his Linkworker some months earlier - but the situation clearly had not been resolved.

Stephen had mixed views of the two other men that he lived with. He reported that "they were alright". On one occasion he stated that he disliked one of the men. Also, Stephen stated that he got annoyed with the second man, when he (the second man) was upset.

Stephen reported that he liked many of the activities within the flat. He liked getting his breakfast, shopping, and cleaning. In addition, he liked the quiet environment, and the food. He stated that he disliked cooking in the evenings, and preparing the Sunday lunch.

#### Past and Future Placements:

Stephen stated that he would like to leave his present placement and move to his own flat. During the initial discussions he was uncertain about whether he would like to share the flat with someone - and he had no clear ideas whom he would like to share with. During later discussions he reported that he would like the flat to be close to a friend (see below).

Stephen had previously lived at a larger service - 24 beds (approx.). Although he had wanted to leave there, he stated that he had liked it there, and he liked the carers and the other people living there.

Before Stephen lived at the larger service, he had lived at home, with his family. He had not wanted to leave home but had left because he swore frequently. He felt sad about leaving home. He saw his parents sometimes and got on well with them. He did not see his brothers nor sisters (total 10) but was not bothered about this.

b) Integrated:

Stephen visited his close friend every evening and at weekends. He stated that he enjoyed these visits. They went into the town shopping together on Saturdays which he also like to do. Occasionally he had been to local disco, which he had also enjoyed. He reported no difficulties in integrated settings.

Visits:

Stephen was visited by his social worker. He reported that he liked the visits, as his social worker was helpful. He received no other visitors, not did he regularly visit others - apart from the above.

Other Issues:

Stephen was looking forward to a holiday with the Day Centre. Also, he was very keen to write in his diary every evening.

Stephen reported that whilst living at home he participated in a lot of sport e.g. rugby, cricket, squash. He used to attend a local leisure centre with his brother, and although he had enjoyed this, he no longer wanted to continue.

Stephen had recently had an I.P. meeting and a H.A.L.O. assessment meeting. He reported that both of the meetings "were good" and discussed what he wanted to do. In addition, he expressed positive views about the meetings held in the flat every fortnight.

Reliability:

It was found that Stephen presented some mixed views on some topics e.g. where he lived. In addition, it was clear to the researcher that some of his statements were influenced by what had happened immediately before the interview e.g. when he was annoyed by a carer.

Overall, it was considered that his reports were reliable, but influenced by the above factor.

The carers and people with learning difficulties had separate sitting rooms and ate separately. Keith agreed with this feature of the organisation. He stated that he did not want to share his sitting room with the carers - he felt there was more privacy in having separate sitting rooms. He agreed with eating separately, stating this was practical and saved time.

## 2. Past and Future Placements

Keith reported that at age 4 years he had left his family home to live in a children's home and then, when 11 years old, he went to live with foster parents. He had been distressed at going to live in children's homes and found it noisy. He reported being happy with his foster parents and felt that he got on well. When he was 19 years old, he left his foster parents to move into private care. He stated that he and his foster parents looked at two private services and Keith felt that he would prefer his present placement because he could have tea and coffee when he wanted.

Keith had a clear view on where he would like to live in the future. He stated that he would like to live with two men that he knows and meets on most days at the hospital day service. He was very clear that he did not want to live with a woman. He stated that he would like to live in a house the same size as the present house, but close to the hospital. He had discussed this with one of his friends who felt it was a good idea; he had not mentioned it to carers. Keith thought that he could manage without the help of carers, but he had not discussed this with his friend. He reported that he wanted to make his own decisions about where to live and to have more time to go out.

## 3. Friendships

Keith reported that he had two friends that he knew well and spent time with in the hospital day service. They had known each other for 6 years. He also reported that he had had a friend at a previous day centre and does not see him now. He stated that he does not miss his old friends, but that he "knows about 1,000 people". However, he also felt that he would like more friends. He met neither of his friends from the day service outside work. He had a close friend, but they met infrequently.

#### 4. Day Services

Keith spent four days a week in a hospital day service and one day a week at college. Whilst at the hospital, Keith mowed the lawns, cut flowers and picked potatoes. He stated that he liked the activities. He liked some of the people at the hospital, but not all. He felt that some of the staff were helpful, but some were "grumpy". Keith stated that when he started at the hospital day service three and a half years ago, he had wanted to come, but was given no choice. He gave no explanation as to why he commenced attending a hospital day service. Keith felt that he would now like to leave the hospital day service. His choice of day-time activity would be selling flowers on the market.

During the one day a week at college, he attended a course for people with learning difficulties. He participated in reading, writing and going shopping, e.g., to compare prices. He liked the course and felt that he helped the tutor. He found the tutors at college to be helpful and polite, but one was "snappy".

Keith also described his previous day placements. He had completed a one year farming course in Somerset which he had enjoyed and wanted to continue (but was unable to). He then attended an Introduction to Work course for 3 months (in Leicestershire). He then moved to a day centre where he did a variety of activities, e.g, day work, using a loom and also work experience in an Elderly Person's Home. The day centre closed due to lack of funding. In addition, he reported that he had sold flowers on the market, which he had enjoyed and would have continued, but the man employing him was sent to prison.

#### 5. Leisure

##### Integrated Activities

Keith spent all his leisure time when out of the house in integrated settings. During his holidays, every Thursday evening and on Saturdays, he chose to go to the market where he worked as a volunteer, collecting and organising the rubbish. He enjoyed this activity very much and knew many people to talk to at the market. He did on one occasion have some vegetables thrown at him by a market trader. Keith was unclear of the cause of this event, but was advised

by his carer not to carry a briefcase to the market. Keith stated: "people take it out on someone like me". This incident had not altered his obvious pleasure at going to the market.

Keith reported that he enjoyed helping people, e.g., at a local City Show. He had helped at three other local events in the last few months, e.g., a car boot sale for MENCAP. He always attended events as a volunteer.

Keith had two additional evening activities which he attended regularly. He attended an Adult Basic Education course, where he learned computing. He enjoyed this and found the tutors helpful. He also went to a local Neighbourhood Centre where he did some reading and writing. He found this course very enjoyable and stated that the tutors were very helpful and that he knew everyone in the group.

Every Sunday, Keith went to church with one of the women he lived with. He helped at the church by ringing the bell and giving out hymn books. He enjoyed going to church.

Keith stated that he particularly liked long distance travel on buses and trains. He did this rarely, e.g., once a year for a holiday and would like to do this more often, but found that he was often busy.

#### 6. Visits and Visitors

Keith had no visitors, but would like to have. He visited his parents infrequently - the last visit was two months ago.

#### 7. Other Issues

Keith stated that he liked to go to the Cash and Carry with his carers. This happened infrequently and he would like to go more often. He stated that he liked to be out with his carer. He had enjoyed spending 5 hours on a Saturday sorting out the cellar after shopping.

Keith enjoyed cooking and would like to do more. He liked the food in the placement. He had little interest in clothes and preferred to wear jeans and a T-shirt. He stated that he would like to do his own washing.

Person's Views - Subject 6 - AndrewIntroduction

The following is a summary of the views of Andrew. The interviews were all carried out as outlined in the Method. Andrew always came very willingly to the interviews.

1. Present placement

Andrew reported that he liked his present placement. He stated that he liked the town where he lived and being situated near to a railway. Andrew likes to watch television in the hostel (the news, Howard's Way), listen to music and to do the washing-up - he said he would like to do more washing-up.

Andrew reported that he liked the other people he lived with, and mentioned one of the other men living in the hostel that he liked. When asked if the other people were his friends, he replied "Yes". He also stated that he preferred to be alone, particularly if he was listening to music.

Andrew liked all the carers in the hostel. He viewed them as his friends. On one occasion he did say that he disliked one carer because she "told him off if his slippers had a hole in them". Otherwise, he consistently gave positive reports of all the carers.

2. Past and future placements

Andrew described living at Dr. Barnardo's as being "all right". He liked living with his twin brother there and he liked all his carers at Dr. Barnardo's.

Andrew gave mixed reports of the future. On one occasion he stated that he would like to live in a house. He also reported that he would like to live in a flat with a woman who used to live at the hostel. He had visited her flat a few months earlier and wished to go again. During one meeting, he said that he would like to live with the

staff. However, on one occasion he clearly said that he did not want to talk about future placements, without giving a clear reason. His wish was agreed to. He clearly stated that he wanted to stay in his present placement in the short-term, but not forever.

### 3. Friendships

When asked to name friends, Andrew always gave the names of carers at the hostel. In addition he named day centre instructors and the manager as his friend. He also reported that he liked a volunteer that visited the hostel on Saturdays. He only named one of the people that he lived with as being a friend. He reported that the woman who had moved from the hostel was a friend.

### 4. Day Services

Andrew attended a day centre very close to the hostel 4 days a week. When asked what he did at the day centre, his usual reply was "nothing". However, he did give some reports of some activities he did at the day centre: playing tapes and records, swimming, woodwork, cookery and pottery. He stated that he liked going swimming and cooking and liked the majority of activities, but found the workshop too cold.

Andrew went to a local college one day a week. Whilst at college he practiced with computers and learnt road crossing skills. In addition, he had recently been Christmas shopping with the college, visiting the nearby town. Andrew was very clear in his preference for college in comparison to the day centre. In addition, he liked the tutor at college.



## 7. Other issues

Andrew gave both positive reports of the food at the hostel and the food at the college and the day centre. He said he was interested in clothes and would like a new coat, shoes and jumper for Christmas. His cousin had recently had a new baby - a relative of his father's second wife. He stated that he liked babies and that the baby was "all right".

## 8. Reliability

It was considered that the majority of Andrew's account was reliable and he was consistent in many of his views during all the interviews. One issue where his views were considered unclear was that of future placements. During the initial interviews he gave various examples of alternative placements he would eventually like to live in. However, towards the end of the interview, he stated that he did not wish to discuss this any more. The researcher considered that one possible reason for his choice not to discuss this topic was that he found it stressful. He was very willing to discuss all other topics.

Raw Data - Observations of Subjects - Study IINotes:

1. All the figures given are in seconds.
2. Totals and % are given for each category of behaviour.
3. Data before and after meals is summarised separately from data within meals.
4. The categories of behaviour are:

Q	-	leisure
W	-	personal
E	-	domestic
S	-	TV
I	-	interaction with visitors
O	-	interaction with carers
P	-	interaction with peers
A	-	neutral
Ch	-	challenging behaviours
M	-	out of sight
5. The total time a subject was observed is given at the end of the column marked 'total' and this figure has been adjusted for time out of sight.

## SUMMARY OF OBSERVATIONS - Subject 1

## APPENDIX 27

Before and After Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
Before:											
SI-20	2136	-	107	1204	-	38	776	109	225	-	-
SI-30	1922	-	-	13	1553	-	63	5	258	-	-
SI-50	3177	-	293	735	1459	17	697	16	153	-	-
SI-70	442	-	-	4	-	9	101	54	263	-	-
After:											
SI-10	2080	48	-	169	1156	16	154	55	442	-	-
SI-11	1898	12	-	-	1170	-	79	84	486	-	-
SI-22	937	20	-	-	626	-	20	11	222	-	-
SI-40	2871	25	-	-	1749	-	266	50	705	-	-
SI-41	3001	114	-	8	2187	-	19	17	611	-	-
SI-52	1717	-	-	-	51	34	1212	29	360	-	-
SI-60	3058	-	138	-	1997	9	113	31	770	-	-
SI-61	3644	-	11	19	1002	38	398	55	2053	14	-
SI-70	1784	26	84	286	794	3	331	3	382	-	-
SI-71	1515	22	-	241	514	7	215	56	453	-	-
Total		267	633	2679	14,258	171	4444	575	7383	14	-
%	30.182 = 503.03 mins. = 8.38 hours	0.88	2.10	8.88	47.24	0.57	14.72	1.91	24.46	0.05	-

During Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
SI-22	1001	-	695	90	-	-	198	61	93	-	-
SI-31	2262	-	1378	23	-	24	566	117	459	-	-
SI-51	1799	-	486	63	1019	5	168	16	166	-	-
SI-60	545	-	188	18	-	25	245	29	92	-	-
SI-70	1192	-	955	102	-	5	437	20	60	-	-
Total	6799	-	3702	296	1019	59	1614	243	870	-	-
%	= 113.31 mins. = 1.89 hours	-	54.45	4.35	14.99	0.87	23.74	3.57	12.79	-	-

Before and After Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
Before:											
S3-10	1912	-	-	1612	-	4	107	97	179	-	34
S3-20	4162	27	112	748	-	28	311	159	2463	-	280
S3-30	2526	58	-	340	51	-	636	5	1537	-	49
S3-40	4838	-	308	2196	689	48	608	53	1145	-	352
S3-50	4589	-	177	543	1190	18	578	142	1873	-	219
S3-60	3535	-	9	1291	-	6	43	25	2051	-	104
S3-70	2327	-	60	964	-	41	112	-	1048	-	135
After:											
S3-32	1303	-	442	-	738	56	8	47	251	-	-
S3-62	2411	-	200	1492	-	69	355	85	514	-	28
S3-62/72	3142	149	-	-	12	31	246	39	2260	-	406
S3-81	1134	-	24	-	-	11	84	19	902	-	70
Total	30202	234	1332	9186	2680	312	3088	671	14223	-	1677
%	8.39	0.77	4.41	30.42	8.87	1.03	10.22	2.22	47.09	-	

During Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
S3-11	1070	155	432	9	-	13	110	41	320	-	-
S3-31	879	-	557	29	-	-	76	42	165	-	-
S3-41	751	-	265	9	-	-	34	30	335	-	56
S3-51	730	-	503	4	-	-	18	17	177	-	-
S3-61	693	-	446	64	-	-	13	19	141	-	19
Se-80	1090	-	741	69	-	-	12	8	151	-	102
Total	5036	155	2944	184	-	13	263	157	1289	-	177
%	1.39	3.07	58.46	3.65	-	0.26	5.22	3.12	25.59	-	-

## SUMMARY OF OBSERVATIONS - Subject 4

## APPENDIX 27

Before and After Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
Before:											
S4-10	2582	-	79	2115	-	280	220	31	46	4	275
S4-20	2156	-	15	1591	12	50	333	175	177	-	109
S4-30	1260	80	163	587	-	56	231	29	133	-	75
S4-50	2260	125	-	79	224	127	12	183	1029	-	478
S4-60	3117	810	28	1424	16	30	1637	44	163	-	339
S4-80	2579	10	185	861	43	48	787	190	609	-	141
S4-81	635	375	91	-	199	64	-	-	9	-	-
S4-90	5337	366	107	1339	-	1414	212	65	1923	-	146
After:											
S4-12	1267	27	-	356	16	68	359	27	411	-	-
S4-32	3456	247	289	1621	325	19	515	191	460	-	172
S4-41	3364	758	600	246	972	80	561	129	360	-	194
S4-52	648	205	-	-	15	120	-	87	213	-	-
S4-62	2444	99	89	1422	108	50	466	94	308	-	32
S4-71	2445	357	345	47	374	20	327	64	468	-	689
S4-84	601	49	5	314	-	27	113	59	70	17	64
Total:	31437	3508	1996	12002	2304	2453	5773	1368	6379	21	2714
%	8.73	11.16	6.35	38.18	7.33	7.80	18.36	4.35	20.29	0.07	

During Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
S4-11	680	-	145	521	-	3	130	46	-	-	-
S4-21	457	-	319	6	-	1	52	109	31	-	-
S4-31	665	-	618	24	-	-	28	83	16	-	-
S4-40	691	8	272	113	53	5	288	-	33	-	24
S4-51	648	-	439	103	-	-	71	51	6	-	-
S4-61	672	-	595	11	-	-	165	29	2	-	-
S4-70	521	-	281	23	-	-	56	89	112	-	-
S4-82	725	-	337	154	-	15	128	78	91	-	-
Total	5035	8	3006	955	53	24	918	485	291	-	24
%	1.40	0.16	59.70	18.97	1.05	0.48	18.23	9.63	5.78	-	-

## SUMMARY OF OBSERVATIONS - Subject 5

## APPENDIX 27

Before and After Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
Before											
S5-20	1373	454	-	157	-	76	293	-	427	-	24
S5-30	849	516	-	9	280	2	-	-	2	-	19
S5-40	879	75	-	-	767	-	-	11	21	-	-
S5-50	888	297	37	-	375	-	-	-	181	-	-
S5-60	4299	238	6	-	3354	21	381	48	234	-	7
S5-70	3505	457	-	21	2489	81	30	37	215	-	180
S5-80	5456	557	-	1200	1859	114	697	53	642	-	496
S5-90	4765	-	12	126	3562	17	-	104	778	-	153
S5-100	3769	-	64	906	1056	18	284	22	246	-	1211
After											
S5-12	1174	22	28	910	-	330	21	44	-	-	-
S5-32	643	258	-	-	370	-	-	-	6	-	-
S5-42	759	-	159	157	-	-	119	17	273	-	64
S5-52	-	-	-	-	-	-	-	-	-	-	-
S5-62	1344	73	-	216	517	7	83	10	186	-	266
S5-72	2917	240	-	34	-	45	549	1	1619	-	427
S5-82	1462	-	16	195	625	101	-	71	453	-	-
S5-92	1974	88	149	1032	-	142	187	116	304	-	68
Total	33141	3275	471	4963	15254	954	2644	534	5587	-	2915
%	9.21	9.88	1.42	14.97	46.03	2.88	7.98	1.61	16.86	-	

During Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
S5-11	844	-	514	66	-	133	73	46	29	-	-
S5-21	812	-	761	31	-	49	67	-	5	-	-
S5-31	912	-	881	-	-	6	149	-	-	-	-
S5-41	745	-	619	24	-	-	125	47	-	-	100
S5-51	1297	-	492	-	-	25	117	-	720	-	-
S5-61	432	-	227	-	-	-	19	11	169	-	-
S5-71	679	-	500	2	-	-	110	21	72	-	-
S5-81	159	-	108	42	-	-	-	25	6	-	-
S5-91	631	-	326	56	-	2	276	7	6	-	-
Total	6411	-	4428	221	-	215	936	157	1007	-	100
%	1.78	-	69.07	3.45	-	3.35	14.6	2.45	15.71	-	

## SUMMARY OF OBSERVATIONS - Subject 6

## APPENDIX 27

Before and After Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
Before											
S6-80	3680	2863	-	-	-	9	231	15	676	-	70
S6-81	2000	1110	-	-	-	-	77	4	706	-	199
S6-90	806	-	551	-	214	-	-	3	82	-	-
After											
S6-11	2329	2010	29	17	-	-	-	-	242	-	-
S6-31	2285	655	3	1015	-	22	-	29	348	-	233
S6-40	2936	1243	-	-	30	-	-	13	1620	-	-
S6-51	3414	2773	-	-	-	3	9	6	587	-	-
S6-61	3827	1251	-	-	-	3	280	47	2137	-	197
S6-71	1307	-	-	1124	-	3	2	45	95	-	91
S6-92	643	542	-	-	-	-	13	1	8	-	77
Total	22360	12447	583	2156	244	40	612	163	6501	-	867
%	6.21	55.67	2.61	9.64	1.09	0.18	2.74	0.73	29.07	-	

During Meals

File	Total	Q	W	E	S	I	O	P	A	Ch	M
S6-10	3169	-	1667	96	-	5	136	18	1246	-	-
S6-20	3000	-	980	106	-	12	45	1	1853	-	-
S6-30	2527	-	971	298	-	22	156	-	1075	-	-
S6-50	3055	42	816	54	-	-	5	3	2123	-	-
S6-60	2866	-	1700	92	-	-	51	5	981	-	-
S6-70	2569	-	1640	191	-	5	33	38	647	-	11
S6-91	2206	-	877	134	-	-	62	-	1089	-	-
Total	1 381	42	8651	971	-	44	488	65	9014	-	-
%	5.38	0.22	44.64	5.01	-	0.23	2.52	0.34	46.51	-	-

RAW DATA - QUESTIONNAIRES  
STUDY II - RAW DATA: PHYSICAL ENVIRONMENT

Subjects	Q	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Subject 1		3	3	2	3	3	3	3	3	3	3	3	3	3	2	3	1
Subject 2		3	3	3	3	2	2	3	3	3	2	3	2	3	3	3	1
Subject 3		3	3	2	3	2	2	2	3	3	1	3	3	3	2	3	3
Subject 4		3	3	3	2	3	3	3	3	3	3	3	3	3	2	3	1
Subject 5		2	3	3	2	3	3	3	3	3	3	3	2	2	2	3	2
Subject 6		2	3	1	2	2	2	1	3	3	2	3	3	2	3	3	3

STUDY II - RAW DATA: OPPORTUNITIES

Subjects	Q	1A	1B	1C	2A	2B	2C	2D	3A	3B	3C	4A	4B	4C	4D	5
Subject 1		2	3	3	3	1	2	3	3	3	3	3	3	3	3	2
Subject 2		2	3	3	2	1	2	2	3	1	3	3	2	3	3	2
Subject 3		2	3	1	2	2	3	3	3	3	3	3	3	3	3	3
Subject 4		3	1	1	3	3	3	1	3	3	3	3	2	1	3	3
Subject 5		3	3	3	3	1	3	3	3	1	3	3	3	3	3	1
Subject 6		1	3	2	3	1	3	3	3	2	2	3	2	3	3	2



## SUMMARY (IN MINUTES) OF DATA RECORDED DURING THREE WEEK (15 weekdays and 6 days of three weekends)

	SELF-CARE	DOMESTIC	LEISURE AT HOME	TV	SITTING	TALKING	CLUBS, CLASSES, SEGREGATED	WAITING TO TRAVEL	TRAVEL - MINIBUS	PUBLIC TRANSPORT, WALKING	SHOPPING	LEISURE - INTERESTS, e.g. PUB, CLASS	VOLUNTARY WORK	CHURCH	VISITS TO FRIENDS, etc.	VISITORS	PHONE	HOUSE MEETING	GAPS/EXCESS (+)	AVERAGE WAKING DAY *
Subject 1	1005	573	75	2254	250	513	920	127	520	130	-	-	-	-	-	-	-	-	243	7hrs 2mins
Subject 2	1410	2170	495	720	120	-	545	415	570	-	-	-	-	-	-	-	-	-	515	7 hrs 44mins
Subject 3	795	865	10	1150	410	240	225	-	-	24	325	460	-	-	-	160	-	395	720	6hrs 25mins
Subject 4	880	990	-	490	285	125	480	95	-	685	225	-	-	-	1010	-	93	95	1050	7hrs 14mins
Subject 5	1935	253	60	1050	465	450	-	-	-	2265	60	480	562	-	-	-	-	-	300	8hrs 45mins
Subject 6	2290	415	1415	910	270	210	775	115	40	5	5	50	-	-	-	-	-	-	840	7hrs 44mins
Subject 1	246	360	285	1724	675	265	200	-	40	-	70	-	-	-	-	-	-	-	170	12hrs
Subject 2	600	1110	270	740	30	-	390	90	150	-	-	240	-	90	90	-	-	-	+60	9hrs 11mins
Subject 3	545	870	160	985	425	205	-	-	-	-	560	180	-	-	-	15	-	120	160	11hrs 45mins
Subject 4	380	315	-	555	230	60	-	60	-	75	300	75	-	-	1740	-	25	-	660	12hrs 26mins
Subject 5	870	300	-	1040	960	-	-	-	-	510	660	120	480	180	-	-	-	-	150	14hrs 38mins
Subject 6	1425	305	1205	300	390	145	-	30	740	-	-	135	-	-	-	-	-	-	185	13 hrs 30mins

\*Excludes time in Day Services

WEEKDAYS

WEEKENDS

STUDY II  
DAILY DIARY DATA - SUMMARY

% Time Recorded in each Category during three weeks (15 weekdays and 6 days of three weekends)

	SELF-CARE	DOMESTIC	LEISURE - WITHIN HOUSE	TV	SITTING	TALKING	CLUBS, CLASSES SEGREGATED	WAITING TO TRAVEL	TRAVEL MINIBUS	PUBLIC TRANS- PORT; WALKING	SHOPPING	LEISURE - INTERFACED, e.g. PUB, CLASS	VOLUNTARY WORK	CHURCH	VISITS TO FRIENDS, etc.	VISITORS	PHONE	HOUSE MEETING	GAPS/ EXCESS (+)	AVERAGE WAKING DAY *
<u>WEEKDAYS</u>	Subject 1	15.2	8.7	1.1	34.1	3.8	7.8	13.9	1.9	7.9	2.0	-	-	-	-	-	-	-	3.6	7hr 21min
	Subject 2	20.3	31.2	7.1	10.3	1.7	-	7.8	6.0	8.2	-	-	-	-	-	-	-	-	7.4	7hr 44min
	Subject 3	13.7	15.0	0.2	19.9	7.1	4.2	3.9	-	-	0.4	5.6	8.0	-	-	2.8	-	6.8	12.4	6hr 25min
	Subject 4	13.5	15.2	-	7.5	4.4	1.9	7.4	1.5	-	10.5	3.5	-	-	15.5	-	1.4	1.5	16.2	7hr 14min
	Subject 5	24.6	3.2	0.8	13.3	5.9	5.7	-	-	-	28.7	0.8	7.1	-	-	-	-	-	3.8	8hr 45min
	Subject 6	31.2	5.6	19.2	12.4	3.7	2.9	10.6	1.6	0.5	0.1	0.1	0.7	-	-	-	-	-	11.4	7hr 44min
<u>WEEKENDS</u>	Subject 1	6.1	8.9	7.1	42.7	16.7	6.6	5.0	-	1.0	-	1.7	-	-	-	-	-	-	4.2	12hr
	Subject 2	16.0	29.7	7.2	19.8	0.8	-	10.4	2.4	4.1	-	-	-	2.4	2.4	-	-	-	+1.6	9hr 11min
	Subject 3	12.9	20.6	3.8	23.3	10.1	4.9	-	-	-	-	13.2	4.3	-	-	0.4	-	2.8	3.7	11hr 45min
	Subject 4	8.5	7.0	-	12.4	5.1	1.3	-	-	-	1.7	6.7	1.7	-	38.9	-	0.6	-	14.8	12hr 26min
	Subject 5	16.5	5.7	-	19.7	18.2	-	-	-	-	9.7	12.5	2.3	3.4	-	-	-	-	2.9	15hr 38min
	Subject 6	29.3	6.3	24.8	6.2	8.0	3.0	-	0.6	15.2	-	-	2.8	-	-	-	-	-	3.8	13hr 30min

\* Excludes time at Day Services

FINANCIAL INFORMATION

The following details were given by carers:

Subject 1

- Received DHSS allowance £159 per week.
- Personal spending money was £9 per week.
- £150 per week was sent to the Housing Association.

Subject 2

- Received DHSS benefit £150 per week.

Subject 3

- Received Severe Disability Allowance, £41.20 per week.
- £32.90 was given to the service for board and lodgings.
- She received £8.30 per week pocket money.

Subject 4

- Received DHSS allowance £39.10 per week.
- His rent was paid direct by DHSS.
- He received £9.10 per week pocket money.
- £13 per week was set aside for food, and £7 for electricity and £10 for savings.

Subject 5

- He received DHSS allowance £160 per week.

Subject 6

- The costs were unknown and paid by the local authority.
- He received pocket money of £11.50.

Contact with Neighbours

The following information was given by carers:

Subject 1

- Little contact with neighbours - sometimes talk over the fence.
- Some ill feeling expressed initially, now resolved.

Subject 2

- Neighbours send Christmas cards.
- Two neighbours visited at Christmas.
- One neighbour objected initially - complains if cars parked on road.

Subject 3

- One neighbour gave rhubarb, a few Christmas cards were received.
- Initial objections were made. A petition was raised and it was claimed that the water would be infected. The complaints ceased after the opening of the service.

Subject 4

- The immediate neighbours are very friendly and talk over garden fence.
- There are few other neighbours.

Subject 5

- When the group moved in, the neighbours did not notice.
- The Council placed a notice concerning a change of use of the house and then the neighbours asked questions.

Subject 6

- There is no contact with immediate neighbours.
- Local people help, e.g., mend a bicycle cheaply.
- No problems/complaints have been received.
- The group were asked not to visit one local pub.

INFORMATION FOR PEOPLE WHO TOOK PART  
IN THE RESEARCH PROJECT (STUDY II)

PEOPLE WITH LEARNING DIFFICULTIES LIVING IN COMMUNITY  
PLACEMENTS - THEIR VIEWS AND THE QUALITY  
OF THEIR SERVICE

Angela Holland,  
Leicestershire.

September 1989

## SUMMARY

During 1988, I met six people with learning difficulties in their homes. I found that:

1. Everyone was able to give clear views about their lifestyles.
2. Most people liked where they lived and enjoyed their freedom and making choices. However, some complaints were made about the other people living in the houses, and in a few cases staff were disliked.
3. Some people wanted to leave their present home eventually, and had plans which were well thought out and always involved greater independence.
4. The household activities that people participated in during the evenings was influenced by allocating tasks/having a rota of tasks; by whether carers performed household tasks or encouraged people to do such tasks themselves; and by having participation as a clear aim.
5. Everyone liked their time spent in settings used by the general public and they experienced few difficulties. Time spent in these places was influenced by having a person or place to go to, being able to go out alone, and not going out in a large group.
6. Most people had many experiences that were similar to other members of the general public, but they were less likely to participate in major life decisions, e.g., where to live, to have close relationships and friendships, and to use the same facilities.

Further details are available overleaf.

## Introduction

During 1988, I met six people living in six different places in Leicestershire, Nottinghamshire and Derbyshire. Three people lived in small houses/flats (with 2-3 other people), and three lived in larger services, e.g., with eleven people. Information was collected both from the people living in houses or hostels, and also from their carers. This included:

- \* Questionnaires completed: Physical Environment, Opportunities, Friendships and Decision Making.
- \* Diaries: completed for three weeks.
- \* Watching people, e.g., doing housework, looking at TV.
- \* Meeting people in private to discuss their views of, e.g., where they live, the other people.

## Aims of the Project

The aim of the project was to investigate a range of issues including: people's views of their service, their activities within the house/hostel, the quality of the physical environment, friendships, participation in decisions and time spent in settings used by the general public. In addition, the project aimed to identify the reasons for some outcomes, e.g., what influenced what a person did in the evenings in the house/hostel?

## Findings

The following is a summary of the main findings. No information is given which is considered private and confidential, e.g., no-one is named.

### 1. Views

- \* Most people liked their service, including features such as the activities, having choices and freedom.
- \* Some complaints were made, usually about the behaviour of others, and occasionally about carers.

- \* Some people wanted to leave eventually and move to a placement offering greater independence. Such plans were usually well thought out. The wish to leave was influenced by knowledge of alternatives, dislike of another person/carer, an identified friend to live with.

## 2. Activities

- \* Most people participated in activities for relatively long periods during the evening. These included watching TV, household activities and leisure activities.
- \* Participation in activities, particularly household activities, was influenced by allocating tasks/having a rota; carers encouraging a person to complete the activity themselves with guidance; having a clear aim to participate in household activities.
- \* Interaction was highest in small groups at mealtimes (e.g., four people and a carer) or when people were in groups of 2-3 participating in a task.

## 3. Physical Environment

- \* All the people in the study lived in services with good quality decor, and easy access to facilities.
- \* People did not dislike sharing a bedroom, nor did they complain about having limited access to privacy.

## 4. Friendships

- \* All people had two or more friends.  
Friendships were predominantly with people with disabilities and were maintained in services.

## 5. Decisions

- \* People participated in most everyday decisions. Participation in infrequent decisions varied more.
- \* Regular meetings may have helped some people to be involved in more decisions.



6. Time Spent in Settings Used by the General Public

- \* Everyone liked their activities in integrated settings and experienced few difficulties with the general public.
  
- \* The amount of time spent in integrated settings was influenced by having a person or place to go to; being able to go out alone; going out individually and not in a large group.

7. Comparison with the General Public

- \* People had many experiences in common with the general public. However, they were less likely to be married or have a steady partner, and were less likely to participate in major decisions, e.g., where to live, nor to use the same facilities.

Comparison of the Results (Study II) with the percentage of a general population sample enjoying specific life experiences. From: Life Experiences Checklist. A. Ager (1988)

Specified item from the Life Experiences Checklist	% General Population	1	2	SUBJECT			
				3	4	5	6
<u>Home:</u>							
Home is well decorated.	73	+	+	+	+	+	+
Have own bedroom/share with partner only.	88	+	+	+	+	-	-
<u>Leisure:</u>							
Go to cafe/restaurant for a meal at least once a month.	34	-	+	1)	-	-	+
Go to club, class or meeting at least once a month.	35	+	+	+	+	+	+
Go out to meet friends or relatives e.g. at pub, in someone's home at least once a week.	70	-	+	2)	+	-	-
<u>Relationships:</u>							
Have several close friends.	78	+	+	+	+	+	+
Married or have a steady partner. 3)	70	-	+	-	+	-	-
<u>Freedom:</u>							
Help to choose how home is decorated.*	84	-	-	+	+	-	-
Chose to live in present house.*	76	+	-	+	+	-	-
Choose what to do in spare time.	89	+	+	+	+	+	+
<u>Opportunities:</u>							
Travel by car or public transport at least once a week.	91	+	-	-	+	+	-
Cook meals with help, once a week.	78	+	+	+	+	-	-
Do some jobs in the home.	94	+	+	+	+	+	+
Being taught a new skill.	23	+	+	+	+	-	+

\* Scoring includes deciding jointly with carers.

1) Goes to pub, but not known if this was for a meal.

2) Goes out with sister regularly.

3) Scores are taken from interviews - steady partner only credited if known to the subject for more than one month.