Measuring Quality of Life: Developing a Questionnaire to Measure Satisfaction With Lifestyle of People with an Intellectual Disability.

By Penny Kent

University of Adelaide

February 1990

CONTENTS

A "Resident Satisfaction Questionnaire" was developed to measure the "quality of life" of people who were or had been residents of a large institution for intellectually disabled people. Quality of life was defined as satisfaction with lifestyle in seven areas of life - residential placement, work placement, leisure time, financial status, interpersonal relationships, physical health and self-esteem. Questions were devised for each of these seven areas of life, resulting in a 136-item questionnaire. In Study 1 the test-retest and internal consistency of the seven scales were measured. Thirty-one persons with an intellectual disability, ranging in age from 18 years 10 months to 50 years 2 months, and residing in institutional settings, community group homes and an intermediate setting, participated in the study. Twenty unreliable items, including 13 items from one scale with poor internal consistency, were deleted from the Resident Satisfaction Questionnaire. In study 2 a staff questionnaire was developed as a means of measuring the external validity of the Resident Satisfaction Questionnaire. It consisted of one scale utilising subjective ratings by staff of resident satisfaction and three scales using objective items to measure the degree of

responsibility, autonomy, and decision making allowed residents. The test-retest reliability of the staff questionnaire was found to be good but its inter-rater reliability was less satisfactory. Unreliable items were deleted and the score from this questionnaire was then correlated with the score from the Resident Satisfaction Questionnaire. Correlations between the objective scales of the staff questionnaire and self-expressed satisfaction were greater than those between the subjective scale of the staff questionnaire and self-expressed satisfaction. In Study 3, the revised Resident Satisfaction Questionnaire was presented to 61 intellectually disabled persons - 30 in an institutional setting; 11 in an intermediate location providing training for eventual community placement; and 20 persons living in group homes in the community. The level of expressed satisfaction within the community was generally found to be higher than for the institutional or intermediate groups but was significantly higher in only two areas (residential placement and interpersonal relationships). Expressed satisfaction was found to be negatively related to the number of other people in the residential setting, to the presence of an additional handicap, and to the presence of

a behaviour problem. Study 4 involved a group of 17 intellectually disabled persons living in a residential setting provided by a different agency to that in the first studies. Satisfaction in this group was compared with the results obtained for the institutional, intermediate , and community groups in Study 3. Again, those in community settings expressed greater satisfaction than those in the institutional or intermediate areas, with significant differences in expressed satisfaction associated with residential placement, and interpersonal relationships. Factor Analysis suggested that only a general factor of satisfaction accounted for group differences.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university and that; to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

I consent to the thesis being made available for photocopying and loan if applicable if accepted for the the award of the degree.

To Peter and my parents

I wish to thank the following people:

My supervisor, Dr Ted Nettelbeck, for his patience over the long years it took to complete this; Dr Don Tustin for being a sympathetic boss and supporting and encouraging me during the work on my thesis; the residents and staff of Minda Inc. and Balyana who willing gave their time to complete the questionnaires; Brenton; and most of all my husband, without whose support and constant encouragement this thesis may never have been completed.

CHAPTER ONE

INTRODUCTION

The care of persons with an intellectual disability has changed over the course of time. This change has been closely linked with changes in care afforded to people with psychiatric disorders, as it is only in relatively recent times that people with intellectual and psychiatric disorders have been separated from each other, in terms of both diagnosis and treatment. Prior to the eighteenth century, it was generally expected that the family would care for its disabled members (Craig and McCarver, 1983), so that people with disabilities tended to live within their local communities and to be supported by them. However, not all such people were cared for by their families and many became destitute. The earliest form of accommodation for destitute persons who could not provide for themselves was provided in work houses or almshouses, which first came into being during the sixteenth century. Workhouses and almshouses also came to be used to provide accommodation for people with psychiatric disturbances and intellectual disabilities, although no treatment was provided and the living conditions in many such places were commonly very bad (Scheerenberger, 1983).

During the eighteenth century institutions known as lunatic asylums were founded, on the assumption that psychiatric disturbance in the individual might be modified or even eradicated by providing the mentally ill person with a refuge from the stresses and strains of society. This period has been called the "Moral Treatment Era" (Shepherd, 1984) because the general model for treatment adopted was a humane and individualised approach (Gottesfeld,1979). Asylums or retreats developed during this time tended to be small and to dispense with the harsh treatments (e.g. mechanical restraints, chaining) that had previously sometimes existed in the workhouses and almshouses. Similarly, the care of people with an intellectual disability began to change as educators gradually adopted an approach to the education and training of people with intellectual disabilities which assumed that, if appropriate procedures were applied, then the effects of intellectual deficiencies might be alleviated.

The first schools for children with intellectual (and other) disabilities began to come into existence in the mid nineteenth century. These schools began as small teaching establishments which had the aim of curing, or at least ameliorating, the condition of intellectual disability, through individualised training programmes. The early educators (among them Séguin and Güggenbuhl) were influenced by the work of Itard, in France. While attempting to educate a young feral boy, Itard had developed a number of innovative teaching techniques (Lane, 1977) and some of

these techniques were later used in the instruction of deaf, blind and intellectually disabled children.

However, the new schools also followed a trend that was developing in the field of accommodation for people with psychiatric disorders. Growing numbers of clients were admitted to the asylums and individualised care, which was the basis on which the institutions had been founded, became increasingly difficult to implement. As the asylums increased in size and became overcrowded, conditions within them began to deteriorate and they tended to become less therapeutic and more custodial. This trend eventually led to widespread disillusionment with the early hopes held for curing mental illness through institutional means (Shepherd,1984).

Similarly, as educators began to realise that they could not cure intellectual disability and that, despite training, many of their students would continue to need lifelong care, the early hopes of the founders for the effectiveness of the schools faded. As a consequence the schools became more custodial in nature, with reduced emphasis on training and on the possibility of integrating intellectually disabled students within the community at large. These developments prompted one of the pioneers of institutions, S.G. Howe, to urge in 1866 that as many of the institutions as possible should be dispensed with (Braddock and Heller, 1985). Howe felt that institutions had already begun to depart from their original pedagogical aims and had become too custodial. However, concern like Howe's in some quarters not withstanding, institutions continued to grow in

size and number. During the early years of the twentieth century the Eugenics movement further contributed to the trend for institutions to become custodial places, since this movement was in part established with the aim of "protecting" society from those with an intellectual disability (Craig and McCarver, 1984). At least in some quarters, it came to be believed that people with intellectual disabilities were a menace to society, it being held that they bred more rapidly than nondisabled persons and passed on defective genes to their offspring, so that the average level of ability in the general population would gradually become reduced. Such fears contributed to the development of institutions in order to segregate those with intellectual disabilities from society; within such institutions, the sexes were separated to prevent procreation.

Particularly in the past two decades, however, the broad philosophy underpinning the provision of services to people with intellectual disabilities has changed again. Families are now once again encouraged to care for their handicapped children at home, but with help and support from community services. Where such an arrangement is not possible and a child is placed in an institution, then the predominant change in the direction of policy regarding residential services for those with an intellectual disability has been away from large centralised facilities towards small community-based facilities (Pratt, Luszcz and Brown, 1980; Willer and Intagliata, 1981; Zigler and Balla, 1977). Today, modern institutions care predominantly for

those with more severe disabilities who, without the aid of modern medical technology, would not have survived one hundred years ago (Craig and McCarver, 1984; Scheerenberger, 1982). The population of residential institutions in the United States of America (USA), Europe and Australia is tending now towards older residents, who are more profoundly intellectually disabled, and who have been diagnosed as having organic disorders and/or behaviour problems (Eyman, Borthwick, and Tarjan, 1984).

In the USA this change in direction of the provision of services was in part spurred on during the 1960s by the formation of parent lobby groups (Emerson, 1985, Heal, Sigelman and Switzky, 1978) that were aided by research demonstrating the detrimental effects of long periods of institutionalisation (such as decrease in IQ and retarded developmental growth), as well as by the viability of alternative models of care derived from the Normalisation Principle. This principle has been expressed in a number of different ways but, essentially, it holds that means which are as culturally normative as possible should be used to establish or maintain behaviours which are as culturally normative as possible (Wolfensberger, 1972). Followers of the Normalisation Principle argue that residence within the community provides a more developmentally stimulating and "normalised" living situation for a person with an intellectual disability than institutional placement; and that therefore people requiring support or supervision should be placed in community rather than in institutional settings.

Two other models (The Developmental Model and the Principle of the Least Restrictive Alternative) have also been influential in the movement towards deinstitutionalisation. The Developmental Model suggests that people with an intellectual disability progress through the same levels of development as people without an intellectual disability, but at a much reduced rate and perhaps to a reduced extent ultimately. The Principle of Least Restrictive Alternative suggests that treatment or habilitation services should be provided in the least restrictive placement or with the least restrictive methods. These models will be explained further in following sections.

In some instances, in recent times, deinstitutionalisation has been accelerated by the public exposure of deplorable conditions which have been found to exist in some institutions (e.g. Blatt and Kaplan, 1966) and also by court decisions to close unsatisfactory institutions (e.g. Wyatt vs Stickney, 1972). Some social historians have argued that the movement to deinstitutionalise was aided by the social climate of the 1960s and 1970s, when considerable attention was paid to individual human rights (Willer and Intagliata, 1984), because deinstitutionalisation reflected a concern for the rights of people with an intellectual disability and was therefore consistent with the prevailing social climate. In addition to claiming that deinstitutionalisation would increase the independence and quality of life of the people concerned, proponents of the Normalisation Principle have also claimed that it would

ultimately be cheaper to maintain services under the circumstances recommended, thereby making the proposal attractive to administrators and to government funding bodies (Willer and Intagliata, 1984).

However, this impetus towards deinstitutionalisation and community care has generated its own concerns about the quality of care available to intellectually disabled people residing in community facilities. Researchers in the USA who have studied the placements of clients who have been moved from institutions into the community have warned of the need to be aware about where such people have been placed and under what circumstances. Thus, it has been noted that many intellectually disabled persons have been transferred to Nursing Homes, or other settings not all that different from the institutions from which they came (Edgerton, 1975; Willer and Intagliata, 1984) and some settings used have been far worse than the original institutions (Edgerton, 1975). Another claim is that many people have not, in fact, been deinstitutionalised but, instead merely transferred between institutions (Novak, 1980).

Although institutions in Australia tend not to develop to the large sizes of institutions in the USA, there has been an impetus towards deinstitutionalisation in Australia also, resulting in the placement of people with intellectual disabilities into community settings. With this increased emphasis on community placement has come an interest in the evaluation of such placements. It seemed likely that, just as institutions have been shown to vary in the care

provided, (e.g. McCormick, Balla and Zigler, 1975) community-based facilities may also vary in care practices (e.g. Birenbaum and Re, 1979; Eyman, Demaine and Lei, 1979). The effects of community placement need to be studied since, although the placement of clients in institutions has been criticised due to its potential to produce adverse consequences, it is also important to demonstrate objectively that improvements have been made in the quality of life of people with intellectual disabilities who have been moved into the community (Thompson and Carey, 1980). Clients must be shown to benefit from community placement before such living placements can be accepted as better models than institutional placements for the provision of care to intellectually disabled people. For the move to deinstitutionalise to gain wide community acceptance, it is therefore necessary to demonstrate that the quality of life for intellectually disabled people placed in the community is better than among those remaining in the institution - or at least that those placed in community settings are no worse off.

In an attempt to evaluate the value of community placements, researchers have focussed on "placement success" which has been measured in terms of several variables, including the length of time for which a person with an intellectual disability remains in the community (e.g. Schalock, Harper and Carver, 1981; Intagliata, Crosby and Neider, 1981; Willer and Intagliata,1981); the social competence and independence achieved by the deinstitutionalised person, based on clinical judgement and

client interview (e.g. Edgerton and Bercovici, 1976); and by behavioural and personality dimensions (e.g. Mc Devitt, Smith, Schmidt, and Rosen, 1978; Seltzer, Sherwood, Seltzer and Sherwood, 1981; Willer and Intagliata, 1981). Other studies have focussed on changes to adaptive behaviour following relocation (e.g. Eyman, Demaine and Lei, 1979; Eyman, Silverstein, McLain and Miller, 1977; Hull and Thompson, 1980, 1981); the use made of community resources by deinstitutionalised persons (e.g. Reiter and Levi, 1980; Willer and Intagliata, 1982); characteristics defining the environment of the home in which the deinstitutionalised person has been placed (e.g. Baker, Seltzer and Seltzer, 1974; Pratt, Luszcz and Brown, 1980; Rotegard, Hill and Bruininks, 1983); and the degree of normalisation of the community placement (e.g. Flynn, 1975).

Research in the area of deinstitutionalisation has consistently shown that the quality of care provided for individuals in community settings and thus placement "success" can vary widely in terms of the environment, the use made of community resources by residents and the degree of freedom allowed residents (Edgerton, 1975). Research has also demonstrated that placements in community facilities have sometimes been more restrictive than previous institutional placements; and that care practices in group homes have not necessarily been superior (Balla, 1976; Edgerton, 1975; Scheerenberger, 1974; Willer and Intagliata, 1984). Furthermore, the available data do not indicate that residents of group homes necessarily participate more in

community activities as the length of time spent in a community placement increases (Okolo and Guskin, 1984).

The results of research, which have come primarily from the USA, have led investigators to caution that placement in community facilities does not guarantee normalisation or that the residents will necessarily become better integrated within the community, nor that residents are necessarily better off than they were in an institutional placement (Butler and Bjaanes, 1977; Moreau, Novak and Sigelman, 1980; Willer and Intagliata, 1982). It is sometimes assumed that people in a community placement are, as a result of that placement, part of the community and that people living within an institution are not (Wing and Olsen, 1979). There is also the risk that notions of "normal" (as in "normal neighborhood") could lead to the isolation of persons with intellectual disabilities in settings which are physically normal (i.e. which are not purpose built and which look like other houses in the street) but which, despite this, do not provide opportunities for normal social interaction within an appropriate peer group (O'Connor, 1983).

Others have cautioned against interpreting or judging, from a middle class bias, the lifestyle of persons with intellectual disabilities (Penney, 1977). Edgerton (1975) states that "[intellectually disabled people whom] we have focussed on seldom come from 'middle class' families; those that are did not themselves attend college; nor have they established a comfortable pattern of middle class living" (1975, p. 137). However, many of those who are responsible for making decisions that affect the lives of these people

typically do come from middle class backgrounds. This middle class bias, on the part of the decision-makers, can be reflected in their choices of goals for more normalised community living (such as selecting houses in middle class neighborhoods, expecting a high standard of dress and cleanliness on the part of the person with an intellectual disability and so on).

Normalisation should not be judged by middle class standards of speech, dress, hygiene, nutrition, or even recreation, since there are a number of different but culturally acceptable lifestyles within society (Edgerton, 1975). All the studies above have examined placement success in terms of objective outcomes and none has examined success from an individual's point of view. Whilst it is important to have objective measures of placement outcome, it is perhaps more important that the success of a given placement is evaluated from the perspective of the individual and what is best for that person (Moreau et al., 1980), rather than from a purely theoretical point of view.

Residents involved in deinstitutionalisation often have little say in what happens to them and are rarely consulted about where they want to live and with whom they would choose to live. Rather, they are placed in situations because other people who have been given the responsibility for making these decisions feel that a particular location is best (Seltzer, 1984). In such circumstances it is particularly important that the people involved are studied in order to find out how they feel about where they live and work. However, there are many difficulties inherent in

determining the feelings of intellectually disabled people. It is perhaps because there is such a low emphasis on the rights of intellectually disabled people, to make choices about their own lifestyles, that there has been little emphasis on research to develop means for studying the effect that community living has on the people involved, in terms of satisfaction with their placement and other aspects of their lives.

This lack of research into the feelings of intellectually disabled people has been recognised and in recent years there has been a call to attempt to measure the personal satisfaction of intellectually disabled people with their particular circumstances (e.g. Peck, Blackburn and White-Blackburn, 1980; Landesman, 1986) in an attempt to measure their quality of life. As much as possible, quality of life should be ascertained from the viewpoint of the individual - his/her personal preferences, needs, and capabilities - rather than from the perspective of the researcher. (For example, as pointed out by Landesman-Dwyer (1981), the researcher should not ask "Would I like to live here?" but should ascertain whether the individual concerned likes to live in that place). However, there are as yet very few studies that have attempted to look at the degree of satisfaction that people with intellectual disabilities express about their own lifestyles.

This thesis provides an account of an attempt to develop a questionnaire, designed to measure placement success in terms of the satisfaction that people with an intellectual disability express about their lives. The

following sections will outline in greater detail the history of institutionalisation, the recent research that has been undertaken into the effects of institutionalisation, the major factors which have influenced the deinstitutionalisation movement, research into the effects on intellectually disabled people following placement within the community, and research into the measurement of the quality of life of deinstitutionalised intellectually disabled people.

1.1 An Historical Perspective

Prior to the 1800s, there is little literature regarding the care of people with intellectual disabilities. There is some evidence that early man may have killed, at birth, many children with visible intellectual or physical disorders, although there is also evidence that some tribes cared for and protected their handicapped children (Scheerenberger, 1983). There are references made to "those without reason" in Greek and Roman literature, the Bible, Talmud, and Koran, but there is no evidence that any specific efforts were made to provide shelter, protection or training for them (Kanner, 1964). Such writings as there are suggest that supernatural explanations were heavily relied on as explanations of the cause for mental disorder.

By about 400 B.C., at the time of Hippocrates, diseases were given labels and inferred to have organic causes (Rimm and Somervill, 1977). However, there was no clear definition of what mental disorder or intellectual disability was and generally no clear recognition of the intellectually disabled as a separate category requiring a distinctive form of care (Shepherd, 1984).

During the latter part of the Middle Ages (fourteenth to sixteenth centuries) supernatural explanations again became the accepted explanation as to the cause of intellectual and other disabilities and such people were seen as demons. Martin Luther (1483-1546), who is generally regarded as an enlightened reformer during that period, is quoted as saying of a severely disabled child "I should take this child to the Moldau River and drown him"

(Scheerenberger, 1983, p. 32). He believed that mentally handicapped children were changelings who were possessed by the devil and had no soul. This belief was widespread and many intellectually disabled people were executed as witches during the witch hunts of the sixteenth century (Gottesfeld, 1979).

Although it is likely that those with serious malformations or defects died at an early age during the Middle Ages, due to the lack of an appropriate medical technology, many of those with mildly disabling conditions survived. Care of such people with mental disorders, and who had not been labelled as witches, lay with the family. Mostly they were ignored and lived within their own local communities, others became court jesters or fools (Kanner, 1964; Scheerenberger, 1983). Local authorities cared only for those who had no-one else to care for them or who were violent at home (Gottesfeld, 1979).

During the late sixteenth century, specialised institutional care for people with disabilities began with the establishment of St. Mary of Bethlehem ("Bedlam") in London. Many other persons with mental disorders were still incarcerated in alms houses and jails where no attention was given to treatment (Baumeister, 1970). People with intellectual disabilities and psychiatric disorders were included in the same category as the poor and in England were held to be within the ambit of the Elizabethan Poor Law Act of 1601. This meant that they were either supported at home by a payment made to them or to the family, or they

were taken into the workhouses. However, conditions in workhouses were generally harsh (Shepherd, 1984).

Towards the end of the eighteenth century the attitude that the disabled were subhuman and abnormal gradually changed and people began to believe that mental disorders were caused by changing social conditions and historical development (Gottesfeld, 1979). New forms of treatment reflected the humanitarian view of the times and the harsh treatments that had previously existed in lunatic asylums were dispensed with by some of the more progressive administrators: (for example, Philippe Pinel removed the chains from inmates at the Bicêtre, a Paris hospital).

This change in attitude towards those with mental disorders also had an effect on the care and treatment of people with intellectual disabilities. An example of this is the work of Itard with the "Wild Boy of Aveyron". Victor (the name given to the boy by Itard) was believed to have been abandoned at the age of two or three, and had grown up in the wild. He was eleven or twelve when found naked by villagers and was taken to Itard in Paris a year later.

Itard believed that sensory perceptions and concept formation based upon associations provided the basis for the development of intelligence. He attempted, by means of educational principles, to apply such stimuli to Victor and thus to educate him (Balthazaar and Stevens, 1975). This approach was contrary to the beliefs of many of the intellectuals of the time who believed that Victor had been left in the woods because he was intellectually disabled and

not that he was disabled as a result of being abandoned in the woods.

Itard spent five years teaching Victor to recognise objects and to respond to social affection from people. Although Itard then ended Victor's training, disillusioned that he had not made more progress, Itard had begun a new approach to education that was focussed on the individual and adapted to developing needs and abilities. Itard later used many of the techniques that he had developed with Victor when teaching deaf and intellectually disabled children to speak. Some of the techniques that he developed form the basis of some modern instructional techniques (e.g. shaping and fading) (Lane, 1977).

Despite Itard's disillusionment, others continued to believe that intellectual handicap could be cured. Edouard Séguin was a student of Itard and in the 1830s he set out to prove that children with intellectual disabilities were educable, establishing a training hospital in Paris for intellectually disabled children. Güggenbuhl, in Switzerland, also believed that children with intellectual disabilities were educable and he began the first training school for intellectually handicapped children in 1840. Both Güggenbuhl and Séguin believed in "physiological education" and both claimed success for their methods, although Güggenbuhl later came under criticism because his clients were not cured and visitors to the school claimed to find it in a disgusting state (Kanner, 1964; Scheerenberger, 1983).

Séguin believed that "feeblemindedness" was due to a weakness of the nervous system. He believed that the intellectually disabled had latent abilities which could be stimulated by special training (Gelder, Gath and Mayou, 1983) and that systematic training of the senses and muscles would lead to improvement in intellectual functioning. Séguin's educational methods included physical exercises, and tasks of increasing difficulty. His methods were very influential, especially in the USA, to which country he moved in 1850 and began establishing schools employing his techniques.

The founders of the first schools were highly optimistic. Their main aims were to cure intellectual handicap and to return students to the community as self-sufficient members (Dybwad, 1964). These schools usually had only a few clients (10-12 pupils), had high pupil to staff ratios and each child had an individualised intensive training programme. The schools also tended to accept only those with a reasonable prognosis of response to treatment (Novak and Berkeley, 1984). Their founders warned against accepting "incurables" (the severely handicapped, the epileptic, the insane, and hydrocephalic children) (Baumeister, 1970; Lazerson, 1975). Great claims were made by the sponsors of these schools regarding their success. Séguin claimed to have "improved and made happy and more healthy idiots", some to the level where they could not be distinguished from young men and women without handicaps (Bright, 1981, p. 9). He claimed that "idiots have been improved, educated and even cured" and that "not 1 in 1,000

had been entirely refractory to treatment" (Scheerenberger, 1983, p. 56).

However, this optimism about the amelioration of intellectual disability began to fade as it became obvious to the educators that they were unable to cure intellectual disability and that, despite training, their students still had residual disabilities. Despite the fact that some educators had more realistic expectations with respect to ameliorating the condition of intellectual disability (e.g. "more of a man and less of a brute", Kanner, 1964), many educators felt that they were not succeeding and that the schools were returning many students to the community "unfit and unprepared" (Baumeister, 1970, p. 9).

As the superintendents of the schools began to realise that their pupils were not being cured, and that many would continue to need care throughout their lives, reluctance to release their pupils increased. As a consequence of wishing to keep their clients where they were safe from harm, schools began to grow in size and within about twenty years (approximately 1870-1890), schools had grown in number from 10-12 pupils to hundreds. Most schools also had waiting lists.

Once it became obvious that many of the students would need lifelong care, the notion of the school as a training establishment lost support. Schools, which previously had made no allowance for long-term care, became residential institutions to provide lifelong care (Baumeister, 1970; Kanner, 1967; Novak and Berkeley, 1984). The desire of most superintendents changed from returning the students to the

community to protecting them from the cruelties of society and to benefit them by being with their own kind (Enkin, 1979).

By the 1880s the attitude towards the intellectually handicapped had undergone another change. The attitude had changed from that of protecting the person with the intellectual disability from society, within a benevolent or charitable approach, to that of protecting society from the dangers of intellectually handicapped people. Intellectually disabled people were no longer seen as "innocents" but, as a class, they had become undesirable and were even sometimes viewed as evil (Scheerenberger, 1983). With the advent of the eugenics movement there was alarm in some quarters about the damage to society that was occurring by allowing intellectually disabled people to remain in the community.

One of the influential founders of training schools for the intellectually disabled in the mid-1880s in the USA, Walter Fernald, used such statements to describe intellectually disabled people as "a dangerous element in the community", "potential criminal" and so on (Balthazaar and Stevens, 1975). In 1912 he claimed that the "feeble-minded are a parasitic, predatory class, never capable of self-support or managing their own affairs.....They cause unutterable sorrow at home and are a menace and a danger to the community" (Scheerenberger, 1983, p 157).

Fernald's pronouncements added much weight to the growing "evidence" of the dangers of intellectual

disability to the community. Other studies which further added to the disheartening picture were the pseudoscientific studies of the Jukes (Dugdale, 1877) and Kallikak families (Goddard, 1912). These studies represented attempts to show that intellectual disability and criminality were linked and inherited.

The development and widespread use of intelligence tests showed how numerous "mental defectives" were (Baumeister, 1970) and, combined with the belief that mental defect was hereditary and that the "feebleminded" bred more rapidly than normal, led to the belief that society was threatened (Kanner, 1964). To attempt to prevent the spread of intellectual disability, calls for lifelong institutionalisation of persons with an intellectual disability were made, as was the prohibition of marriage of intellectually disabled people. Many states in the USA passed compulsory sterilisation laws for people with intellectual and other disabilities, such as epilepsy (Scheerenberger, 1983).

At the same time as institutions were developing in the USA in the mid-19th century, institutions for persons with intellectual disabilities were also developing in England. These institutions were mainly charitable and the present notion that the intellectually handicapped are a "burden of charity" is attributable to the charity model developed in Britain (Bright, 1981). These institutions were also segregated from society and the sexes were segregated within them. With the introduction of the Lunacy Acts of 1890 and 1891, these institutions also became more concerned with the

protection of society (Wing, 1979). The Mental Deficiency Act of 1913 also helped to increase the number of intellectually disabled people in residential care. The act, which made local authorities responsible for the provision "of confinement of the morally and intellectually defective" (Gelder et al., 1983, p. 704), resulted in an increase in the number of residents of institutions or hospitals from 6,000 in 1916 to 50,000 in 1939 (Gelder et al., 1983).

In Australia, institutions developed along similar lines to those in England. Minda Incorporated, which opened in 1898 and which has provided most of the settings for the studies reported in this thesis, was one of the first private institutions in Australia and it was the first to provide a school for children with intellectual disabilities. Prior to the establishment of Minda, care for people with intellectual disabilities in South Australia was provided in the psychiatric hospital where no education was provided. Minda, too, was selective in the children whom it accepted for training and only those who were considered "trainable" were admitted.

However, despite the fact that Minda prided itself on its modern methods of care, the attitude that the intellectually disabled were a danger to the community persisted until the late 1940s, as is evidenced by the following comment: "Very few people outside the medical profession and psychologists realise the gravity of the problem of the mentally deficient, its relation to crime and to the multiplication of the unfit in the community" (Note

1). Minda's philosophy at that time was to provide "permanent-care colonies to make the lives of these children happy and safeguard the community" (Note 1). The founders of Minda believed that it would be cruel to allow the "feeble-minded" to be exposed to a hostile society and that society needed to be protected from the "feeble-minded" who may "propagate their kind by marriage" (Note 1). Segregation from the community was encouraged and residents were not allowed to mingle freely in the community.

The eugenics alarm was eventually dispersed by the recognition that intellectual handicap can be caused by a variety of factors, with or without inheritance, and that the intellectually handicapped were a heterogeneous group with respect to level of disability, personality, presence of a behaviour disorder and so on. The advent of genetic, biochemical, and sociological studies of the causes of intellectual handicap gradually resulted in the previous speculations about intellectual disability being dispelled (Kanner, 1964).

Although some historians have painted a grim picture of the development of institutions into custodial and inhumane places, not all institutions were so. There were some early programmes that served as models of care, education and training and would do so even under today's standards (Rosen,M, 1984). Some were established to train and return the intellectually disabled to the community and in many cases did (e.g. The Training School for the Imbecile Youth of Scotland, Primrose, 1977).

Although Minda's organisers had the attitude that society needed to be protected from the "feeble-minded", its founders strove to make the institution as little like an institution as possible. There were no uniforms and each child had his/her own clothes. Work or schooling was greatly encouraged as were games which developed the senses. It was each staff member's duty "to make Minda a healthy and happy home" (Note 1). It is unlikely that Minda was unique in its approach to the care of the intellectually disabled and thus to categorise all such facilities as inhumane is inaccurate.

In addition, the concept that admission to an institution was the sole answer to the problem of intellectual disability was abandoned by even the early leaders of the field. At no time has more than approximately 3% of the total intellectually disabled population of the USA resided within institutions (Scheerenberger, 1981). Even Fernald, who originally supported the image of the mentally defective as dangerous, later changed his mind, acknowledging that there were good and bad 'feeble-minded' (Scheerenberger, 1983) and in 1919 he advocated alternatives to institutional care (Scheerenberger, 1981).

Furthermore, although some institutions had policies which were based on legal commitments and release, with those "escaping" from care being caught and returned by police (Baumeister, 1970), there has always been a flow of population through the institutions. For example, in 1926 the discharge rate from institutions for intellectually

disabled people in the USA was 6%. This compares favourably with the discharge rate of approximately 10%, reported by institutions in the USA for the Financial Year 1978-1979. In 1926 fewer people were transferred between institutions or other forms of residential settings than is currently the case (Scheerenberger, 1982). The main difference between the two groups discharged in 1926 and 1978-79 is that there were more people with mild intellectual disabilities released in the earlier years (Scheerenberger, 1981), probably because there were more mildly intellectually disabled people within the institutional system at that time.

Despite the fact that deinstitutionalisation as a goal was a visible concept in the 1950s (Scheerenberger, 1983), the current movement towards deinstitutionalisation began following the exposure, in the 1960s, of the dehumanising conditions that existed in some of the institutions in the USA. Deinstitutionalisation as a movement became strong in the 1970s. The proponents of deinstitutionalisation based their beliefs on studies which showed the deleterious effects of institutionalisation (on IQ growth, adaptive behaviour growth and personality) and upon the principles of Normalisation, Developmental Model, and the Principle of the Least Restrictive Alternative, referred to above and to be discussed in detail in sections to follow. In other instances the movement towards deinstitutionalisation was spurred on by public opinion and parental pressure groups as well as by court decisions to close institutions. A more

in-depth discussion of these influences is presented in the following sections.

1.2 The Effects of Institutionalisation

Many studies have examined the effect of institutionalisation on the performance and development of people with intellectual disabilities. Some have indicated that the behaviour of institutionalised intellectually disabled people is in part due to the experience of institutionalisation and is not determined by intellectual handicap alone (Balla, Butterfield and Zigler, 1974; Balla and Zigler, 1975; Burkhart and Seim, 1979; Klaber, Butterfield and Gould, 1969). However, the results of studies examining the effects of institutionalisation on intellectually disabled people are variable and do not always support the notion that institutions are necessarily detrimental to the well-being of intellectually disabled people (Rosen, Clarke and Kivitz, 1977). Most studies have tended to focus on changes in IQ and developmental growth, as well as on personality variables, as measures of the effects of institutionalisation. These studies are reviewed below.

IQ Changes and Developmental Growth

Some studies have found decreases in the IQ of persons with an intellectual disability following institutionalisation. For example, Zigler and Williams (1963) studied 49 children with a mean age of 10.6 years and mean mental age of 6.2 years. These children were part of a sample of 60 who had been tested three years previously. It was found that while the IQ of four of the children had increased, and for six remained the same, the IQ of 39 of the children decreased

between the time when they entered the institution and the time of the second testing. The authors found that the magnitude of the decrease was not related to the preinstitutional histories of the children but that the initial decrease in IQ was related to the child's motivation to perform for social reinforcement (i.e. as social deprivation, as a result of institutionalisation increased, the desire of the child to interact with the experimenter overrode the desire of the child to be correct in the testing situation). Zigler and Williams concluded that the change in IQ reflected this change in motivation for social interaction rather than an actual change in the child's intellectual potential.

Clarke and Clarke (1954), on the other hand, found contradictory results. They studied 59 intellectually disabled children and adults who had been admitted to hospitals in England. The sample was tested initially and again two years later, using the Wechsler Adult Intelligence Scale. It was found that about 15% of residents in the sample had dropped up to 7 IQ points. However, overall, there was a significant increase in mean IQ of 6.5 points . Clarke and Clarke (1954) found that age was not closely related to change in IQ but that initial IQ was, with those who had lower initial IQs showing a slight tendency to make larger gains than those with higher initial IQs. It was also found that those who had come from backgrounds characterised by neglect, poverty, poor parental attitude,or crime were mainly those who had made the larger IQ increments; (average increment of 9.7 points compared to 4.1

points for those from less disadvantaged backgrounds). IQ growth was found to continue for up to five years after being admitted to an institution (Clarke, Clarke, and Reiman, 1958). However, since there was no relationship between length of institutionalisation and IQ growth, it seemed likely that changes were due to removal from an adverse environment, rather than because of entry into a relatively better one.

Other studies have also found increases in IQ when longitudinal research designs have been used. Zigler, Butterfield and Capobianco (1970) followed up the children involved in the 1963 study of Zigler and Williams, eight years after the initial testing on IQ measures, and 10 years after admission to an institution. Zigler et al. found that the drop in IQ reported in the Zigler and Williams (1963) study had levelled off and that some of the children had shown an increase in IQ over their admission IQ level. This time a relationship between preinstitutional social deprivation and IQ change was found and, as for the findings of Clarke and Clarke (1954), those who showed an increase in IQ were more likely to come from highly deprived backgrounds.

Balla and Zigler (1975) also found that IQ gains by children could be maintained and continue to show improvement for up to six years after admission to an institution. Gains were found to be related not only to the preinstitutional history of the child but also to the nature of the child's disability. Children diagnosed as nonfamilially intellectually disabled, with the disability

due to organic conditions, showed no differences in IQ between testings, whereas familial cases showed improvement. History prior to institutionalisation was found to be of importance in determining the amount of IQ growth for those diagnosed as familially retarded. Those from backgrounds which were determined by the authors to be highly depriving made more gains initially than those who came from less deprived backgrounds, although the latter group nonetheless showed growth after three years of institutionalisation.

Primrose (1977) found that there was no demonstrable decrease in IQ after 35 to 50 years following admission to an institution, a result contrary to what some would have expected. He studied 24 residents of a hospital in Scotland whose files contained an IQ test that had been completed 35 to 50 years previously, finding a remarkable level of stability in the results at retesting. In addition, Primrose studied 57 children who were tested twice between 1968 and 1975, using an unspecified intelligence test. It was found that the average increase in IQ was from 57.2 to 63.4, similar to the 6.5 points found by Clarke and Clarke (1954). Children who had been admitted as a result of expulsion from school due to unruly behaviour improved in IQ results, as well as behaviour. Primrose concluded that the mere change from a bad environment to one more suited to the needs of the person with an intellectual disability may result in higher IQ scores. Although the increase in IQ noted in Primrose's study could have been due to increased test familiarity, and not to actual growth in IQ, the main

implication of this work is that a lengthy period within an institution does not necessarily result in a lowered IQ.

In a study of 85 nonhandicapped children in 13 nursery groups, Tizard (1975) did not find any evidence of gross retardation in verbal or performance IQ as a result of placement in a home for children. The children ranged in age from 2 to 4 years of age, with most being admitted before 12 months of age. Scores on both a verbal and nonverbal measure of intelligence were average, indicating that the nursery experience was not causing intellectual disability. However, it was found that there were large differences between the verbal scores of the children in different nurseries. Those who lived in nurseries rated as more autonomous and had a higher mean language comprehension score than those living in less autonomous nurseries. In addition, there was a difference in the quality of verbal interaction between staff and children in the different locations. In autonomous nurseries the staff made more informative and less directive remarks to the children and read to the children more often and these activities were related to the mean language comprehension score of the children.

Other studies, related more to the learning of intellectually disabled children, have found that the learning performance of institutionalised intellectually disabled children is inferior in a social situation, due to the child paying more attention to the experimenter than to the task. Harter, Brown and Zigler (1971) compared the performance of nonintellectually disabled children,

intellectually disabled children living at home, and institutionalised intellectually disabled children, matched for mental age, on a three-choice discrimination task. Overall, being admitted to an institution did not affect the ability of the children to perform the task but children in the institution performed poorly under a condition where social reinforcement was given because they paid more attention to the experimenter who was giving them praise, rather than to the task at hand. It was assumed that the children in the institution had been deprived of social interaction and thus were distracted from the task.

Other studies have also found that intellectually disabled people in institutions are more responsive to social reinforcement than intellectually disabled people not in institutions (Zigler, Hogden and Stevenson, 1958), which has been taken as an indication that institutions provide a socially depriving environment. However, further research has shown that the effect of placement in an institution on social responsiveness varies according to the preinstitutional history of the child (Zigler, Balla and Butterfield, 1968). Zigler et al. found that, at three weeks after admission to an institution, children who came from highly deprived backgrounds showed greater responsiveness to social reinforcement than those who had come from less deprived backgrounds. However, this relationship was not evident on follow-up three years later, although there were differences between the high deprived subjects and low deprived subjects in the time spent on the task in the first and second testings. The authors

concluded that social deprivation results in heightened motivation for social reinforcement but that this is affected by the child's previous history. Being admitted to an institution has a differential effect on residents, with those children having poor preinstitutional histories finding the experience of institutionalisation less depriving than those with good preinstitutional histories. Zigler, Butterfield and Capobianco (1970) also found that children from less deprived backgrounds found institutionalisation more depriving and that this effect was still evident up to 10 years after being admitted to an institution.

However, Blair and Fox (1973) did not find intellectually disabled children in an institution to be distracted by social reinforcement during performance of a two-choice discrimination task. They studied 60 intellectually disabled children in an institution, who were divided into six groups matched for sex, chronological age (CA), mental age (MA), diagnosis and length of time spent in the institution. Blair and Fox examined the effect of various forms of reward, including social reinforcement, on performance. They did not find that the subjects performed less well under social conditions than under any of the other conditions. However, the institutionalised group were not compared with a noninstitutionalised group, as in the Harter et al. (1971) study.

Some studies have found that length of time spent in an institution is related to the level of adaptive behaviour shown by children. For example, Burkhart and Seim (1979)

studied 40 children with an average MA of 4years 4months, who had been rated on the Adaptive Behaviour Scale - revised edition (Fogelman, 1975). The children were then divided into eight groups controlling for MA, CA, and percentage of life spent in an institution. It was found that those children who had spent more time in an institution received lower adaptive behaviour scores, and that this was not related to the MA of the child. Burkhart and Seim assumed that this increase in dependency was related to the lack of appropriate adult models in the institution. However, the study was not longitudinal and thus it is difficult to relate the dependency of those who had spent more time in the institution to institutionalisation alone. In addition, no measurement of the institutional environment with respect to staff numbers, training provided or role modelling by staff, was provided.

Such factors are important because it has been shown that staff in some institutions do not spend much time on training programmes. For example, Viet, Allen and Chinsky (1976) found that only 5% of staff time was spent on formal training. In addition, the interactions between staff and clients in the institution under investigation were mostly initiated by staff and were characterised by lack of affect. Such environments may not be conducive to the developmental growth of intellectually disabled people. However, if an appropriate environment is provided, then growth can occur in institutional settings. This is demonstrated by a study by Mitchell and Smeriglio (1969), who found that stimulation provided by staff was important in producing changes in the

adaptive behaviour of moderately and severely intellectually disabled children. Mitchell and Smeriglio studied two groups of 25 such children who either had had no special teaching or had received special teaching for three years in an institution which catered for 220 children. It was found that those who had received special training had improved in development at the same rate as would have been predicted by their preadmission Social Quotients (as measured by the Vineland Social Maturity Scale; Doll, 1953). However, of those children who had received only the routine care provided in this institution, only two children showed any gain, while 22 showed a decline in adaptive behaviour. Overall, the group that did not receive special education training showed a significant decrease in Social Quotient of 10.64 points.

Mitchell and Smeriglio also found that the initial level of development of the child was an important criterion for whether or not further development occurred. Those children who were initially high in social competence showed more subsequent development than those who were initially lower in social functioning and who showed a marked tendency to decline subsequently. The tendency to decline was unaffected by whether or not the child received special training. Thus, those who were high-functioning to begin with benefitted more from a stimulating environment, whereas those who were low-functioning apparently found the institutional experience to be detrimental to their development, whether or not special training was provided.

In a similar study, Mayhew, Enyart and Anderson (1978) observed the effects of reinforcement on the social behaviour of 18 institutionalised adolescent females who were severely to profoundly intellectually disabled . The residents spent most of the day sitting in a day room where no formal skills training or recreational programmes were provided. Using an ABAB design, Mayhew et al. found that the social behaviour of the residents increased and decreased as social reinforcement of behaviours was presented or withdrawn. The data suggested that the social responses of institutionalised intellectually disabled residents may undergo extinction due to the failure of staff to reinforce them. This conclusion was consistent with the results of a previous study (Dailey, Allen, Chinsky, and Veit, 1974). The implication of these results is that if staff were to be trained to respond to the social behaviour of residents, then the institutional experience need not be so socially depriving.

Thus, the results of research into the effects of institutionalisation on IQ and developmental growth have shown that although institutionalisation may have negative consequences, this is not always so and institutions can provide environments in which growth may occur. The results of these studies indicate that institutionalisation can have varying effects on an individual, depending on a number of different variables. One such variable is the preinstitutional history of the child, with those children coming from deprived backgrounds showing increases in IQ and finding the experience of institutionalisation less

depriving than those coming from less deprived backgrounds who show, at least initially after admission, a decrease in IQ. Another important variable is the initial level of skill development of the child at admission. Those with low developmental levels may find the experience of institutionalisation negative, regardless of whether or not specialised training programmes are provided. Characteristics of the residential environment, such as the provision of formal skills training programmes, having flexible routines, and positive resident-staff interactions are also important in determining the levels of skill development which children in institutions achieve.

Other studies, discussed below, have examined the effects of institutionalisation on personality variables.

Personality Variables:

Research on the effects of institutionalisation on the personality development of persons with an intellectual disability has shown similarly diverse results as those studies on IQ and developmental growth.

Children with intellectual disabilities in institutions have been found to be wary of interaction with adults. Shallenberger and Zigler (1961) measured the length of time spent on two presentations of the same boring task as utilised in the studies on social deprivation by 20 intellectually disabled children, matched for MA with 20 nonintellectually disabled children. It was predicted that those who showed wariness of adults would spend longer on the second presentation than the first and that those who

were not wary would become satiated with the task and spend less time on the second presentation. The results showed that the intellectually disabled group spent longer on the second task, indicating a wariness to interact with the experimenter. Shallenberger and Zigler felt that, in contrast to the effects of preinstitutional history on the desire for increased interaction, wariness of adults was a product of institutional experience, since the scores were related to length of institutionalisation.

However, Balla, McCarthy and Zigler (1971) found that increased wariness of adults was not an inevitable consequence of institutionalisation as they had supposed and that wariness was related to a number of variables. In their study of 27 children, with mental ages ranging from 5.9 years to 13.0 years, Balla et al. found that older children from deprived homes were more wary than those not from deprived homes and that those who were institutionalised at an early age were less wary than those who were institutionalised later in life. It was also found that those younger children who had regular visits with parents and relatives were less wary than those who received fewer visits. However, older children who were in regular contact with their families were more wary. Thus, it is difficult to conclude that the institution alone is responsible for greater wariness of intellectually disabled children in institutions.

It has been claimed that intellectually disabled children in institutions have low self-esteem, causing them to set lower standards for themselves (Zigler, Balla, and

Watson, 1972). Zigler et al. (1972) studied the performance of 118 intellectually disabled children, younger normal children and older normal children, either living at home or in institutional settings, on two scales designed to measure self-image. They found that intellectually disabled children in institutions showed a greater disparity between ideal self-image and real self-image than noninstitutionalised intellectually disabled children. Children in institutions, with and without an intellectual handicap, also had significantly lower ideal self-image scores than did children not in institutions. The authors concluded that children in institutions set lower standards for themselves as well as having poor self-image.

Tizard (1975) studied the behaviour of 2-year-old children without intellectual disabilities in residential nurseries and found that abnormalities of development were related to aspects of the environment rather than to the experience of residence in the nursery. She found that children in nurseries where there was limited contact with strangers, multiple caretaking so that no relationships could readily develop between staff and children as no one staff member was assigned to look after a child, and constant staff changes showed greater abnormalities of behaviour (e.g. excessive shyness, excessive clinging and diffuse attachments), than was found among those children in nurseries in which staff practices fostered the development of social relationships.

Institutionalisation has not always been found to have deleterious effects and, for some, has led to an increase in

problem-solving ability (Yando and Zigler, 1971); and a decrease in verbal dependency and imitativeness plus an increase in behavioural variability (Balla et al., 1974). It has also been shown that age at admission, the number of outside visits, length of institutionalisation and number of parental visits can affect the development of negative reaction tendencies (or wariness of adults) among children. For example, Balla, McCarthy and Zigler (1971) found that children institutionalised at an early age, but who both received and went on many visits with family and friends, were less wary than other children admitted to the institution at a later age but who also had contact with their families.

In addition, it has been found that intellectually disabled adolescents in institutions have less need for or dependence on approval from others, as characterised by greater conformity and susceptibility to persuasion, than intellectually disabled adolescents living in the community. Talkington and Riley (1978) studied 150 adolescents (50 normal, 50 institutionalised intellectually disabled, and 50 noninstitutionalised intellectually disabled adolescents) and found that the intellectually disabled adolescents showed a greater need for approval than the normal adolescents. However, contrary to expectation, the community-based sample of intellectually disabled adolescents showed a greater need for approval than the adolescents with intellectual disabilities in the institution. The authors felt that intellectually disabled adolescents living in the community may be living in a more

competitive environment than those in the institution and that the community provides fewer opportunities for meeting need approval than the institution. In addition, within the institution, peers with less ability are available for comparison and thus adolescents in institutions could have a more favourable view of themselves than those living in the community, who often have to compare themselves with more able peers. This could well lead to them having a lower concept of themselves.

It has often been found that differing institutional climates have differential effects on residents (Balla, Butterfield and Zigler, 1974, Klaber, Butterfield and Gould, 1969), and that the same institution can have different effects depending on the preinstitutional history of the child (Balla, Butterfield and Zigler, 1974; Zigler, Butterfield and Capobianco, 1970; Zigler and Williams, 1963).

In an effort to determine the institutional characteristics that could lead to the differential effects on residents, studies of demographic features (e.g. size, number of residents, daily cost per residents, attendant resident ratio etc) have been undertaken. In general, it has been shown that these factors are not determinants of differences in the behaviour of residents and the type of care received by them (Baroff, 1980).

In order to understand the differential effects that institutions have on their residents, McCormick, Balla and Zigler (1975) felt that it was necessary to look beyond institutional size and other demographic variables to the

socio-psychological characteristics of the institution in question. Using a questionnaire developed by King, Raynes and Tizard (1971), they measured resident management practices (the rigidity of routines, whether residents were managed together as a group, whether privacy was allowed residents and the extent to which staff interacted with residents outside formal activities). McCormick et al. (1975) found that there was no relationship between resident management practices and the number of children in each living group, resident-staff ratio, or the level of handicap of the residents. The studies of King et al. (1971) and McCormick et al. (1975) were the first to look at the quality of care received by residents in institutions. These studies will be reviewed in greater detail in the following chapter.

In summary, the effects of living within an institution on the behaviour and personality of intellectually disabled residents are not clear and studies have not consistently shown that the effects of institutions are negative. However, studies that showed detrimental effects of institutionalisation were the ones which have been emphasised by supporters of the deinstitutionalisation movement.

1.3 The Normalisation Principle

The Normalisation Principle has played an important role in the development of community-based services for people with intellectual disabilities (Mesibov, 1976). It is a model which has been used both to provide a technology and an ideology (a means and an end) for both improving and evaluating services to the intellectually disabled (Hull and Thompson, 1981).

The model was initially developed by Bank-Mikkelson and Nirje in relation to service delivery to people with intellectual disabilities in Denmark and Sweden, the concepts involved subsequently being articulated by Nirje (1969), published in the USA. Since then, the model has been transformed and modified in the USA, largely as a consequence of the writings of Wolfensberger (1972; 1975), and the principle of normalisation has become one of the most widely quoted concepts internationally in the field of intellectual disability, and in other human service areas (Perrin and Nirje, 1985). Although Wolfensberger's model of Normalisation differs from that of Nirje in a number of ways, Wolfensberger's model is the one most commonly applied in the United States and Australia and it is discussed below. This is followed by a review of criticisms that have been levelled at the normalisation principle, especially at Wolfensberger's version.

Wolfensberger's Normalisation

To Wolfensberger, the Principle of Normalisation is a "systematic formulation of how to maximise the likelihood

that people who have been defined as deviant (devalued) become socially valued or re-valued" (Wolfensberger, 1977, p. 1).This is attempted through "the utilisation of means which are as culturally normative as possible in order to establish/maintain personal behaviors and characteristics which are as culturally normative as possible" (Wolfensberger, 1972, p. 28).

In a later explanation of his view of normalisation Wolfensberger states that applying this principle involves:

a) the use of culturally valued means so that people can live culturally valued lives;

b) the use of culturally normative means to offer intellectually disabled people life conditions that are at least as good as those of average citizens; and, as much as possible, enhancing and supporting the behaviour, appearances, experiences, status, and reputation of intellectually disabled people;

c) the use of means that are as culturally normative as possible in order to establish, enable, or support behaviours, appearances and interpretations that are as culturally normal as possible. (Wolfensberger, 1980).

Wolfensberger goes on to say that the normalisation principle applies at the following levels:

Cultural Normativeness: The roles, expectations, forms of address, labels, environments, social services, rhythms of the day, the week, and year, should all be typical in nature.

Developmental Expectations: The developmental growth of individuals, regardless of their level of impairment, should be emphasised.

Integration of Activities: Opportunities, activities, and services should be as physically and socially integrated as possible because culturally normative opportunities are denied to intellectually disabled people when they are segregated from the rest of the community.

Integrity of Program Models: A service systems model for the provision of services to people with an intellectual disability should be based on the needs of those individuals. The service itself should also be the most normative means of meeting those needs. (Janicky, Castellani, and Norris, 1983).

Basically, however, Wolfensberger has emphasised that the ultimate concern of proponents of the normalisation principle is "the maintenance or attainment of nondeviant behavior" (Wolfensberger, 1977, p. 13).

Criticisms of the Normalisation Approach as an ideology

A major criticism levelled at the normalisation principle, particularly as developed by Wolfensberger, concerns the problem of defining the term "normative behaviour". According to Wolfensberger (1972) "normative behaviour" means "usual", "typical", or "conventional" behaviour. In other words, normal is taken to mean what most people do rather than to have moral connotations about what most people think should be normal. However, when this concept is examined more closely the definition is not as simple as

it would first appear. Briton (1979) suggests that what is really meant by normative behaviour is behaviour that is "expressly regarded as acceptable or appropriate behaviour in retarded people by the population at large" (Briton, 1979, p. 5). This interpretation is somewhat different from Wolfensberger's original definition. Under Briton's interpretation of "normative behaviour", the behaviour of people with intellectual disabilities has to be modified, not so that it meets general societal standards but so that it meets society's expectations about how people with intellectual disabilities should ideally behave. Thus, under this interpretation, nonmarital sex and homosexuality, while quite common in general society, would probably not be seen as appropriate behaviours for intellectually disabled people to engage in.

Even Wolfensberger himself does tend to set different standards for intellectually disabled people than for "normal" people. For example, he has stated that a person with an intellectual disability should not work with animals, or that a male should not wear his hair long, or that a middle-aged man should wear a tie even in circumstances where it is "normal" not to do so (Wolfensberger and Glenn, 1975). His position is perhaps consistent with the aim of improving the image of people with intellectual disabilities and avoiding an image of deviancy, rather than "normalcy" as described by Nirje. However, the imposition of such standards can constrict people in making individual choices about what they will do. Wolfensberger's assessment instrument (Programmed Analysis

of Service Systems - PASS), which by his own admission is concerned with programme structures and not the feelings of individuals (Wolfensberger and Glenn, 1975), would downgrade a program which did not encourage its clients to conform to such standards as mentioned above. This is despite the fact that, by not forcing clients to conform to such standards, the service system may be respecting the personal preference of the people whom it serves (Perrin and Nirje, 1985). Where a conflict arises between an individual's choice and more appropriate or "normalised" behaviour then, according to Wolfensberger, more normalised behaviour should take priority (Wolfensberger, 1980).

Wolfensberger's approach also makes the assumption that "normal" is right and the only way to be. However, according to Mesibov (1976), "doing what others are doing is not necessarily doing what is right or what gives one dignity or satisfaction. To aspire to the uncertainties, anxieties, and isolation of the average person in our rapidly changing, highly mobile society is to set one's goals unnecessarily low" (1976, p. 31).

What has tended to happen too often in the application of the Normalisation Principle is that people have overlooked the qualifying phrase "as normal as possible". As people with an intelectual disability are heterogenous it indicates that what is possible for some is not possible for others (Begab, 1975). It is dangerous to give the principle the status of a philosophical absolute.

Others have argued that the aim of normalisation should not be to define normal in terms of either organisational

conditions of everyday life (as in Nirje's approach) or in terms of normal behaviour (as in Wolfensberger's approach). Rather, the aim should be to take "abnormality" as a negatively valued concept, and align it with the institution, rather than with the individual with an intellectual disability. Beckey (1982) has argued that it is only by linking abnormality with the institutions (and thus making them negatively valued) that alternatives to institutions will become the only placements that can be positively valued.

Nirje takes issue with Wolfensberger, claiming that by integration he (Nirje) meant "to be able to be allowed to be yourself among others" (Nirje, 1975,p. 67). He did not mean that a person's behaviour should be manipulated so as to "pass" for normal. Nirje claims that imposing overly restrictive standards of behaviour that tend to be more conservative or that deny people the right and the chance to choose for themselves (for example, a lifestyle that is judged inappropriate according to Wolfensbergers's instrument by PASS) is not consistent with his original concept of Normalisation (Nirje, 1985). In fact, he goes so far as to say that there are so many differences between his and Wolfensberger's approach that "contrary to Wolfensberger's claim, [Wolfensberger's version of normalisation] cannot be considered as a refinement, reformulation, or operationalisation of the principle" (Perrin and Nirje, 1985).

Another claim of normalisation, namely that integration will improve public attitudes to people with intellectual

disabilities, has not been proved (Mesibov, 1976). To some this is not surprising, given that many attempts to integrate other minority groups, especially in the USA, have also met with failure (Briton, 1979). Although Wolfensberger links normalisation with the movements of other minority groups (e.g. blacks, homosexuals), his process of normalisation of intellectually disabled people does not follow the same approach taken by other minority groups to integration. Normalisation stresses reduction of perceived deviancy through integration into the community (i.e. not congregating people with disabilities together) and normalisation of deviant behaviour, whereas other minority groups do not seek to hide their differences. Rather, these minority groups claim that their rights are being denied without having to hide or deny their uniqueness or change their behaviour (Briton, 1979; Perrin and Nirje, 1985). The normalisation approach is also different to the direction taken by self-help groups of people with intellectual disabilities who have started to demand the services that they need to compete and participate in society on an equal footing (Perrin and Nirje, 1985).

In addition, it has not been shown that deviance is reduced by contact with others. Some researchers have claimed the opposite, in that those in regular contact with 'deviants' are sometimes stigmatised as 'deviant' (Thomas, 1978). Goffman (1963) also claims that there is a tendency for stigma to spread from the stigmatised individual to close others and he claims that this "courtesy stigma" is avoided rather than sought. This would tend to negate

Wolfensberger's view that there is a reduction in perceived deviancy if the "deviant" interacts with more socially valued people.

Another difficulty with the normalisation approach is its tendency to deny the ways in which people with an intellectual disability differ from nonhandicapped people. Although the behaviour of a person with an intellectual disability may be made less obvious, the underlying reduction in cognitive functioning will remain. The slowness of behaviour and thinking that results from poor cognitive functioning will become obvious to a nondisabled person during interaction (Briton, 1979). To deny that such people are different is to deny the fact that those with an intellectual disability do need extra help in many aspects of their daily lives (Mesibov, 1976). The normalisation approach may therefore tend to overlook the fact that intellectually disabled people, despite the fact that their behaviour may have been made more "normal", will still be able to perceive that they are different (i.e. that they are limited in the skills that they can learn and the things that they can do) and that this self-perceived difference can cause frustration and unhappiness (Briton, 1979).

This point also gives rise to another concern about the normalisation approach. As it is so concerned with minimising the contact between people with disabilities and against congregation of intellectually disabled people (to reduce public recognition of intellectual handicap as a deviance) it tends to deny contact with others who share this disability (Rhoades and Browning, 1977). This in a

sense could be seen as doing the same thing that proponents of the deinstitutionalisation approach criticised institutions for doing - hiding people away from the view of society (Schwartz and Allan, 1974). Prevention of congregation of people with an intellectual disability may deny them access to important peer relationships with people who share their frustrations and with whom they can most easily relate. Friendships with nonintellectually disabled people will possibly only be of a limited nature and may not be truly satisfactory for either (Briton, 1979).

This denial of contact with people who share a common problem is also different from the way that other minority groups function. These groups give their members support in dealing with a society which discriminates against them. It may be that there will always be discrimination against those who have an intellectual disability as there seems to be an inbuilt bias in society against difference in general and against those whose intellectual abilities are significantly lower than average (Briton, 1979). Major attitude changes are needed before society accepts people with intellectual disabilities as equal members (Thurman and Gable, 1976). In the meantime, reducing access of people with intellectual disabilities to a peer group may be denying them access to a valuable source of friendship and support.

The concern that Wolfensberger has had with minimising deviancy can lead to an emphasis on the appearance rather than the reality of normalisation. For example, Wolfensberger and Glenn (1975) stated that a person with an

intellectual disability and with a hearing impairment should not wear an obvious hearing aid even if this is the only way in which the impairment can be corrected. Similarly, any place which provided handgrips or other special aids to assist with the mobility or increased independence of clients would receive low scores in an evaluation which used Wolfensberger and Glenn's rating scale, PASS. However, Nirje's original concept of normalisation incorporated the acceptance of the group with their handicap, (Perrin and Nirje, 1985) and in a later version of their evaluation procedure - Programmed Analysis of Service Systems Implementation of Normalisation Goals - (PASSING) - Wolfensberger and Thomas (1980) recanted on the earlier position against the provision of aids.

Criticism of the Normalisation Principle as a Technology

A major criticism of the normalisation approach as a technology is that follow-up studies of intellectually disabled people released to community placements have not necessarily shown such clients to be well adjusted to community living. Rather, researchers have noted that some follow-up studies of intellectually disabled people released from institutions, who successfully work, pay bills, and stay out of trouble, have nonetheless shown these people to be socially isolated, lonely, uncomfortable in social situations, economically frustrated, and generally unhappy (Rosen, Clarke and Kivitz, 1977). These authors insist that it should be acknowledged that not all aspects of a "normal" environment are necessarily of benefit to the socialisation

of people with intellectual disabilities. Aspiration, or being forced to conform to middle-class, white standards may lead to frustration and unhappiness in the lives of the people whose living situations are supposed to be improved.

Another criticism of normalisation is that there is little empirical evidence providing support for the approach. Normalisation is not easily measured or validated and Wolfensberger tends to present his approach as a 'fait accompli' (Heal and Laidlaw, 1980; Mesibov, 1976) and not requiring validation. Often, discussions about the effectiveness of normalisation as a technology have relied on the fact that suggestions sound reasonable or make good common sense (Hull and Thompson, 1981). Flynn (1975), with his study of 102 systems of service delivery rated on PASS (measuring degree of adherence to normalisation as defined by Wolfensberger), was one of the first to examine the concept of normalisation as operationalised in PASS. Flynn found that average service quality was little better than the minimally acceptable level of PASS but that community services received better ratings than institutional services.

However, measuring the degree of adherence to the principle is different from measuring the principle itself and its usefulness for improving service to people with intellectual disabilities (Mesibov, 1976). Measuring adherence to a principle tends to beg the question since the assumption is made that the principle is, "by its very nature the most desirable approach possible" (Roos, 1972, p 14). Roos goes on to say that action based on this

assumption is based on faith as opposed to empirical evidence. Measuring adherence to a principle also denies the possibility that other approaches, which are not necessarily in line with the normalisation principle, may benefit people with intellectual disabilities and provide them with satisfactory lifestyles. The concept of normalisation as proposed by Nirje, however, did not advocate only one model of service provision (Perrin and Nirje, 1985). Rather, Nirje supported the concept of a range of different types of services dependent on individual needs and abilities. Thus, normalisation could be applied as well to improve conditions and programs within an institutional setting.

In addition, PASS (Wolfensgberger's instrument) has been criticised on a number of different grounds. A major criticism by Demaine, Silverstein and Mayeda (1980) concerns its scoring system which yields potentially misleading information. As scores provided by the raters are both positive and negative, then the impact of some items may be reduced by the summing of positive and negative scores. Demaine et al. also felt that the instrument is difficult to use and that the potential for error in adding positive and negative scores is great, pointing out that the instrument was designed to be used by a team of raters who have to agree on ratings. The procedure used is time consuming, elaborate and costly which, as these authors have suggested, may explain why little research has been done with the instrument.

Further, PASS does not necessarily return results consistent with the structure suggested by Wolfensberger. Thus, Demaine et al. (1980) studied 98 residential facilities, ranging in size from six or fewer clients to greater than 50 clients, examining environmental normalisation, as measured by PASS. Factor Analysis suggested six factors, as opposed to the two factors that Wolfensberger and Glenn (1975) proposed, the first assessing compliance with normalisation and the other five factors relating to administrative policies, physical location of service, and the comfort and functional nature of the physical setting.

Another criticism of normalisation is that, whilst the principle itself is not easily evaluated, some of its underlying assumptions are, and the research evidence does not always support these (Roos, 1972). For example, the normalisation principle predicts that the more normal the available opportunities for experience, then the more normal behaviour will become (Olshansky, 1972). Thus, facilities which receive a high score on PASS (i.e. which provide normalising environments) should also show a greater degree of developmental growth in their clients. However, according to Demaine et al. (1980) currently available research does not find this, suggesting that the normalisation factor is not necessarily related to client development.

For example, Eyman, Demaine, and Lei (1979) studied the adaptive behaviour, in a three-year longitudinal study, of 245 mildly to profoundly intellectually disabled residents

in 98 community homes (87 family-care homes and 11 board and care homes). Although some aspects of PASS were positively associated with positive changes in adaptive behaviour for specified types of residents, some aspects were negatively correlated. Age and level of retardation were highly related to both the initial score and average annual gain on the Adaptive Behaviour Scale (ABS; Nihira, Foster, Shellhaas, and Leyland, 1974), with older and more mildly intellectually disabled residents improving far more than the younger or more severely intellectually disabled residents, regardless of where they lived. Using a Path Analysis to control for age, level of intellectual disability, and initial level of development, Eyman et al. correlated the change in development with PASS facility ratings. They found that characteristics of the service system (administrative policies, environmental blending of the facility with the neighborhood, location and proximity of services to the community, and comfort and appearance of the home) were related to positive growth in adaptive behaviour. However, there was one exception. Progress in adaptive behaviour was negatively related to ideology-related administration, indicating that a low score on activities such as education of the public and manpower development was significantly related to gain in adaptive behaviour, regardless of the personal characteristics of the residents. It was also noteworthy that there was no relationship between the PASS factor of adherence to normalisation principles and developmental changes in any of the adaptive behaviour domains.

Others have argued that development does not occur merely by placement in community settings. Thompson and Carey (1980) claimed that the improvement in skill level of eight severely and profoundly intellectually disabled young women after two years placement in a community group home was more related to the individualised programming provided in the group home than to the normalised environment and that, without the provision of such structured environments, residents moved from institutions to group homes did not necessarily demonstrate growth in independent living skills. In other words, development does not occur merely by placement in community settings. The environment has to be structured so that development will take place.

In addition, whilst positive relationships between normalised environments and increase in adaptive behaviour have been found, individual characteristics such as IQ and the presence of behaviour problems have also been found to be related to adaptive functioning (Hull and Thompson, 1980). In addition, negative relationships between a normalised environment and adaptive functioning have also been found to exist.

Hull and Thompson (1980) measured the skills of 369 persons residing in 144 residential facilities, using the Personal Routines, Community Awareness and Social Maturity domains of a revised version of the Adaptive Functioning Index (Marlett, 1977). In addition, they measured the residential environment, using a scale based on PASS. It was found that quality of the physical environment was negatively related to adaptive functioning; (i.e. residents

who lived in homes which had high scores on quality of the physical environment had lower scores on the measure of adaptive functioning). It was also found that residents in houses which received low scores on the adequacy of community resources, and where staff addressed residents in an inappropriate or a demeaning manner, received higher adaptive functioning scores. The authors were unable to explain these negative relationships.

Similar negative relationships were found in another study by the same authors (Hull and Thompson, 1981). They found a negative relationship between the measure of the normalisation of the environment and maladaptive behavior of residents. A higher level of self-abuse occurred among residents who lived in homes that were characterised by good environmental normalisation. Those residences with older populations were more normalised than those with younger residents. Residences where a high number of clients had lived in an institution for lengthy periods had lower normalisation scores than those whose clients had only lived in an institution for a short time. Size of the residence was also found to be related to environmental normalisation with larger residences being less normalised than smaller residences. O'Connor (1976) also found that size of the facility was related to normalisation of the environment, with community homes of more than 21 residents providing reduced opportunities for normalised living.

Other research has failed to show that residents living in community placements live in normalised environments or are integrated within the community. For example, O'Connor

(1976) studied 105 community homes in the USA, ranging in size from one to 10 residents to more than 21 residents. She found that greater than 50% of residents in the study were living in nonnormalised facilities. O'Connor also found that many residents did not use community activities for leisure and many who did, did so in segregated programmes.

Another criticism of the normalisation approach is the confusion that arises over its use as an ideology or a technology. From an ideological perspective, any procedure may be used to achieve normative behaviour, and this is what Nirje intended, as long as ethics were observed (Perrin and Nirje, 1985). According to Wolfensberger, however, only normative techniques should be used. However, as pointed out by Aanes and Haagenson (1978), it has not been demonstrated that normalised environments and techniques will automatically result in normalised behaviour; a service delivery system should be evaluated not on how it achieved a particular goal but on whether or not that goal was successfully reached (Aanes and Haagenson, 1978; Roos, 1972). For example, behaviour modification technology may be successful in changing the behaviour of people with intellectual disabilities but applying these methods involves the use of techniques or specially designed environments that may not appear to be "normal" or "homelike". This may be especially so with respect to those with severe and profound intellectual disabilities. The normalisation approach does not differentiate between levels of intellectual disability but rather advocates normal

patterns of living for all. There can also be a conflict when allowing intellectually disabled people to make choices. If people express a preference for a particular food, music, or item of clothing, then a behavioural approach would allow that choice to be respected. However, if that choice was not "normal" then the normalisation approach would suggest denying the person with an intellectual disability the freedom of choice, in favour of developing the "normal" pattern (Roos, 1970)

Finally, there is the criticism that normalisation is not oriented towards individual clients but it deals with the provision of systems of service. It is assumed that the individual benefits because the system is sound and that, conversely, individuals suffer where the system does not meet certain standards. However, it is felt by some that the real issue should be the effect of the service system on the individual and that the target for measurement or evaluation should be the individual (Landesman-Dwyer, 1981; Mesibov, 1976). It has been suggested that a more appropriate means of evaluating a system may be to measure the effect that the system has on promoting positive self-thoughts rather than on normal behaviour or environments. Another way of evaluation may be to measure individual development, so as to compare the effectiveness of alternative service systems (Mesibov, 1976).

Thus, there are warnings in the literature against accepting normalisation at face value, along with the assumption that the provision of a normative environment will automatically benefit individuals. The danger in

accepting this is that desirable support systems may not be seen as necessary and may therefore not be provided. As some authors have argued, providing conditions as close as possible to mainstream society should include the consideration of individual needs, including those for special services and support (Baker, Seltzer and Seltzer, 1974). Still others have argued that there is a need to consider individual needs and avoid forced conformity, since the unthinking application of principles could have as much a detrimental effect on an individual's life as a positive effect (Pankhurst and Pankhurst, 1982).

There is a continual danger that programming based on the values/perceptions of planners will not be in the best interests of the intellectually disabled people for whom the programmes are implemented (Lakin, Bruininks, and Sigford, 1981). This concern prompted Elliot (1978) to caution that we should not " in the pursuit of our own dogma [..] inflict a way of life on a fellow human being who happens to be handicapped" (cited by Baranyay, 1981). It is important that we should not impose onto those with an intellectual disability whatever happens to be the philosophy of the day, as they may not want to change. If there is no evidence, or at best contradictory evidence, to show that movement towards more independent living will lead to a better lifestyle than that previously enjoyed, then administrators have a moral obligation not to force change upon those with disabilities. Rather, individuals should be allowed to make their own choices and have those choices respected, even if

such decisions do not conform to the current philosophy of care.

The Developmental Model:

Other philosophical models which have been influential in determining the direction of services to intellectually disabled people have been consistent with the normalisation principle and in many ways complement it. One of these is the Developmental model. This model has also been influential in advocating that treatment and training should be provided to intellectually disabled people in community, as opposed to institutional, settings. The Developmental Model is based on the right to education, and the right to develop and function at whatever level is possible (Hogan and McEachron, 1980; Klapper, 1970), with the consequential assumption that every person must receive active treatment (Crosby, 1980). The Developmental Model is based on the following beliefs:

1) That development continues throughout life
2) That development progresses in a sequential, orderly and predictable manner.
3) That development does not occur unless the environment is suitable (Note 2).

The model recognises that each child or adult with an intellectual disability is in a continual state of change (Packer and Wright, 1983) and that each individual has a capacity to learn, grow and develop, regardless of the severity of the disability (Note 3). In order to develop appropriate behaviours and reduce inappropriate behaviours

in people with an intellectual disability, those responsible for their care need to have an expectation, based on an individual assessment of needs, that such persons can change. Once needs are established, then individual training programmes need to be developed within an appropriate environment (Note 2). An appropriate environment is defined by Hogan and MacEachron (1980) as one which has individualised assessments and service delivery plans, is integrated within the community, has service delivery hours that meet consumer needs, avoids overprotection of the individual and allows for some risk taking.

Service delivery plans, which should continue to be developed by carers throughout an individual's lifespan, should emphasise developing skills which will help clients to gain more control over their environment, which includes other people and themselves. The plans should also contain goals which will lead to increasingly complex behaviours and should consist of goals which would increase human qualities (Note 3). These human qualities are seen as; the ability to determine one's own goals and the strategies to accompany them; and spontaneity, enthusiasm, initiative and so on (Packer and Wright, 1983). The goals of any programme should be appropriate to the age of the person and should also specify the use of age-appropriate materials (Norton, 1983).

The goals of the developmental model are consistent with the principle of normalisation since they suggest that services to people with intellectual disabilities should

provide programmes which enhance the development and behaviour of the clients and thus enhance their image and acceptability to the community. The principle of providing training is also linked in with the principle of least restrictive alternative.

The Least Restrictive Alternative:

This principle arose from court decisions on the right of people with intellectual disabilities to education and treatment (Katz-Garris, 1976). The principle implies that there needs to be a balance between the amount of freedom that is given to residents and the degree of protection that they need (Packer and Wright, 1983). In other words, education or training should be given in an environment which does not unnecessarily restrict the person's freedom but it should not also endanger the person's well being.

The landmark decision in the USA was the Wyatt vs. Stickney case of 1972 (Cohen, 1976). This class action suit was brought against the Alabama Department of Mental Hygiene in 1970, alleging that the state had failed to provide proper treatment for the residents of a state institution for people with intellectual disabilities (Willer, Scheerenberger, and Intagliata, 1980). The challenge was based on the due process clause of the Constitution of the USA, which states that when an individual is deprived of liberty then that deprivation should be the minimum possible to achieve the end which is being used to justify the deprivation (Sprague and Baxley, 1978). The interpretation of the Wyatt vs. Stickney decision is that a balance must be

found between the amount of freedom that is given to a resident and the degree to which the resident is protected (Packer and Wright, 1983).

The Wyatt vs. Stickney decision stated that the following should apply: that people should move from more restrictive to less restrictive environments; that residents should be moved from larger to smaller facilities; that residents should be moved from larger to smaller units and from group to individual residences. It also stated that people should progress from segregated to community settings and from dependent to independent living (Cohen, 1976). This decision formalised many of the arguments put forward by proponents of the normalisation principle. Since then, further court decisions have emphasised the following: that all people with intellectual disabilities have basic rights that must be recognised; that residential institutions should serve a select population and return as many residents as possible to their home community; that each resident should have his/her needs met on an individual basis; that restraints, certain aversive stimuli and the use of behaviour controlling medication should be restricted; and that the residential institution should provide a humane physical and psychological environment (Willer, Sheerenberger, and Intagliata, 1980).

With respect to deinstitutionalisation, the courts in the USA have decreed that no borderline or mildly intellectually disabled person should be admitted to an institution unless that person suffers from a psychiatric or emotional disorder or is dangerous to him/herself or others.

Under such circumstances a person may be admitted to an institution but only after all other less restrictive resources had been explored. Once admitted, a person should stay in the institution no longer than is necessary but at the same time should not be indiscriminately returned to the community (Willer et al., 1980).

As indicated, the normalisation principle, the developmental model and the principle of least restrictive alternatives have been influential in the movement away from institutionalisation towards community placement. It is assumed by proponents of these models that developmental growth can occur only in normalised environments and that people placed in community settings lead better and less restricted lives than people in institutional settings. However, this movement towards community living has generated its own concern. At times it has appeared that many people with intellectual disabilities were being placed in community settings that were no better than the institutions from which they came, merely to satisfy the requirements of law. Research has shown that not all deinstitutionalised clients are living in normalised environments, nor that they are well integrated in the community.

Despite the problems with the normalisation principle and contradictory results, the approach, or at least community placement seems valid. However, if, as supporters of the deinstitutionalisation movement suggest, community placement is beneficial to people with intellectual disabilities, then this must be demonstrated. It must be

shown that the quality of life of people with an intellectual disability has been improved by placement in the community. However, rather than measure the success of a community placement in terms of a system's adherence to a particular principle, a different measure of success is needed - one that will take into account the effect of community placement on the individual. In this respect measuring the satisfaction of an individual with his/her lifestyle may be better than measuring success in terms of objective measures such as adherence to a principle or behavioural competence. This thesis is an attempt to measure the differences in quality of life between people with an intellectual disability in institutional and community settings. The following chapter outlines previous research into the quality of life of intellectually disabled people in community placements. It also contains a discussion of the development of the model, based on this research, used in this thesis to measure quality of life.

CHAPTER TWO

STUDIES RELATED TO QUALITY OF LIFE

During the past two decades, following the impact of the Normalisation movement, parent lobby groups, and legal decisions to close institutions, many people with intellectual disabilities have been transferred from institutions to community placements. However, as noted by Butler and Bjaanes (1978), it has often been assumed that placement of an intellectually disabled person in a community facility is equivalent to providing a normalising environment, without carefully assessing the skills and other training programmes available within the community homes and the extent of use of community resources. In other words, placement in community facilities has sometimes been based on the assumption that community facilities provide a relatively more normal environment than institutional settings and that they are therefore more conducive to personal development and normalisation (Butler and Bjaanes, 1974). However, this assumption has not always been supported by research which has addressed this issue. For example, it has sometimes been found that community residential facilities can be equivalent to mini-institutions (Edgerton, 1975; Moen and Aanes, 1979; S.Roos, 1978), that the quality of life of those moved into the community is sometimes impoverished and unsatisfying

(Parnicky, 1977), and that some large institutions which allow residents to move freely in the community can provide more nearly normal experiences than can many large, traditional institutions or alternative care facilities that become mini-institutions (Edgerton, 1975).

Researchers have been interested in studying the lives of persons with an intellectual disability, both within institutions and following their release to community placements. Many of the studies have claimed to be studying the "quality of life" of individuals in particular settings. However, researchers have used many and varied definitions of quality of life, most of which can be divided into the following areas:

(i) the climate of the residential placement in terms of the way in which residents are managed and the nature of staff-resident interactions;

(ii) changes in the adaptive behaviour of individuals following placement in community settings;

(iii) integration and the use of community resources by intellectually disabled persons;

(iv) personal variables, such as satisfaction with lifestyle, which characterise disabled persons in different residential settings.

However, it can be argued that these studies of quality of life could be seen to focus on two different outcomes - objective and subjective. Those studies which have examined characteristics of the residential climate, changes in adaptive behaviour, and use of community resources (ie (i), (ii) and (iii), above), can be seen to be studying objective

characteristics of the environment. When evaluating facilities, these aspects are important as they relate to the quality of care that a person receives; i.e. they examine what happens to the individual in a specific placement. However, the reactions of intellectually disabled people to what happens to them and how they feel about living in a specific situation are also important considerations when evaluating the value or success of a particular placement and few researchers have examined this subjective aspect of quality of life. The results of studies into the objective and subjective aspects of the quality of life of people with intellectual disabilities living in the community, and in institutional settings, will be presented below, as well as a more detailed description of the definition of quality of life.

2.1 Objective Considerations: Quality of Care

Characteristics of the Residential Climate:

Researchers have tended to use the residential unit as the basis for research and comparison. However, comparison of the effects of different residences is difficult because there are no widely accepted definitions of the terms "institution" and "group home". Many researchers have used the same labels to apply to residences which are, in fact, very different (Heal and Laidlaw, 1980). For example, the term "institution" has been used to describe facilities which have ranged in size from 50 to 5000 residents and studies which have examined "group homes" have looked at facilities ranging in size from accommodating 4 to 80 people

(e.g. Seltzer and Seltzer, 1977). There are other variables that differ between residences but "residential climate" is a broad term that includes most factors of the social environment and interpersonal factors (Heal and Laidlaw, 1980).

There have only been a few scales developed to measure and classify residential climates. The first of these, the Resident Management Practices Scale (RMPS), was developed in England by King and Raynes (1968a). The scale measured whether resident-care practices were resident-oriented or institution-oriented in four dimensions (based on Goffman, 1961) of rigidity of routine, block treatment of residents, depersonalisation of residents and social distance between residents and staff. These are explained in more detail below :

(i) Rigidity of Routine: This scale measures the ability of management practices to take into account individual differences between residents or special circumstances. Institution-oriented practices reflect inflexible routines.

(ii) Block treatment of residents: This scale measures the degree to which residents are managed together as a group before and after routine activities (such as eating or bathing). Institution- oriented practices reflect little individualised treatment.

(iii) Depersonalisation of residents: This scale measures the degree of privacy and opportunities for self-expression and initiative allowed residents. Institution- oriented practices reflect no such provision whereas resident-oriented practices reflect the opposite.

(iv) Social distance between staff and residents: This scale measures the degree to which staff and residents are separated. Institution-oriented practices reflect the separation of resident and staff activities so that there are separate areas specifically for staff or resident use and the extent to which interaction between residents and staff is limited to purely specific formal activities. Resident-oriented practices reflect the sharing of living space and interaction between residents and staff in functionally diffuse and informal situations. (King and Raynes, 1968b).

Using the RMPS, or modified versions of this scale, researchers have assessed different types of residences and have found that care practices in institutions are generally more institution-oriented than care practices in community placements (Dalgleish, 1983; Howell and May, 1980; King, Raynes and Tizard, J., 1971; and McCormick, Balla and Zigler, 1975). However, it has also been found that care practices between group homes can vary (Pratt, Luszcz and Brown, 1980), that institutional wards can also vary in management practices (Hemming, Lavender and Pill, 1981), and that units in institutions can provide similar care to community-based facilities (Howell and May, 1980).

The variation found in care practices ~~found~~ has led researchers to investigate variables ~~which~~ that affect resident management practices; specifically size of the living unit, and level of disability.

A study by King et al. (1971) found that size of the unit was unrelated to management practices and similar

results were found by Howell and May (1983). In contrast, other studies have shown that size of the living unit is related to management practices, with large units having more institution-oriented care than smaller units (Hemming, Lavender and Pill, 1981; McCormick et al., 1975; Zigler, Balla and Kossan, 1986). However, results of studies examining the effects of size on management practices may have varied because there has been no account taken of the nature of the population being studied in each unit (e.g. level of intellectual disability of the clients).

The level of disability of the residents may be a factor that affects the type of management practices applied because, although King et al. (1971) found no association between level of disability of residents and management practices, other studies have found such a relationship. Howell and May (1980) studied three hostels and 27 wards in three hospitals in England. They found that care practices did not differ greatly between the hospital and hostel settings in units which cared for mildly and moderately intellectually disabled people. However, severely intellectually disabled people received more institution-oriented care and this was not related to the size of the units or the level of staffing. Overall, the hospital units were rated as more institution-oriented but this may possibly be accounted for by the fact that the hospital units tended to cater for more severely disabled people. Dalgleish (1983) also found that hospitals were more institution-oriented in care practices than hostels administered by local authorities but that this was

accounted for by the fact that the hospitals catered for a more severely disabled population.

It has been assumed by critics of institutions that institutions, by their very nature, do not change and thus will continue to provide more institution-oriented care than community units. However, Hemming, Lavender and Pill (1981) have suggested that this need not be the case. Using the RMPS, Hemming et al. studied two groups of residents - those located in seven institutional wards and those transferred from the seven wards to smaller units in the grounds of the hospital. Although it was found that the smaller units provided more resident-oriented care it was also found that, over the two-year period during which this research was conducted, there was a significant decrease in institution-oriented practices in the main institution. Thus, institutions are not necessarily unchanging monoliths and they can be modified to provide better residential climates over time.

McClain, Silverstein , Hubbel and Brownlee (1975) used another instrument (The Characteristics of the Treatment Environment Scale, CTE) in their research on care practices in residential settings. In addition to a modified version of the RMPS, McClain et al. used the CTE which was originally developed for use within psychiatric hospitals. The CTE consists of 72 items to which a respondent is asked to indicate on an 11-point scale how true or false each statement is, with respect to his/her unit in the hospital. The scale results in measurement within two factors; Autonomy and Activity. Items characterising the activity

factor assess whether residents are encouraged by staff and provided with opportunities to participate in a variety of activities. Items characterising the Autonomy scale assess whether staff members encourage residents to use initiative in the responsible management of their affairs.

McClain et al. studied 43 living units within an institution catering for 1,800 residents. They found that both the CTE and RMPS measures of the residential climate could discriminate between ward programmes with different emphases (such as those wards with an emphasis on maintaining the medical stability of residents or those concerned with behaviour modification) but could also discriminate between wards within the same programme, reflecting that management practices can vary within an institutional setting and between wards which were designed to provide similar environments. Scores on the scales were not related to staff characteristics such as age or length of employment. As the two measures (RMPS and CTE) were sensitive to differences in treatment environments, McClain et al. felt that the measures could be used for determining the differential effects of various residential settings upon intellectually disabled people.

One way of doing this is to compare the developmental growth of residents in different residential climates. In a longitudinal study to examine the effects of community placement on adaptive behaviour, Eyman, Silverstein, McClain and Miller (1977) used these two measures of the environment (CTE and RMPS). Eyman et al. examined the adaptive behaviour growth of 1,649 institutionalised residents and

296 residents in community settings for from two to three years, using a version of the Adaptive Behaviour Scale (ABS; Nihira, Foster, Shellhaas and Leyland, 1974). The community settings included foster homes, board and care homes, and also a convalescent hospital. Results showed that positive adaptive behaviour changes did occur over time and that these tended to be related to age (with younger people developing more than older people), level of retardation (with more profoundly intellectually disabled residents making less progress) and facility (with residents within community facilities making more progress). However, the finding that residents in community homes made more gains than those in the institutional setting was confounded by the fact that residents in community facilities tended to be younger and higher functioning to begin with. The results also showed that the characteristics of the environment, as measured by the RMPS and the CTE, were moderately related to adaptive behaviour growth, with those resident in facilities characterised by higher scores on these measures making more positive gains.

It is possible that the level of adaptive behaviour of residents may influence the type of care received. In a study using nine items from the CTE, Rotegard, Hill and Bruininks (1983) compared 236 residential facilities of five sizes (1-4 residents, 5-8 residents, 9-15 residents, group homes of 16-63 residents, and public residential facilities of 64+ residents, with one having more than 400 residents). They found that as size of the facility increased beyond 16 residents, the facility became less homelike on physical

measures. Residences with 5-8 places scored better on the activity and autonomy factors of the CTE than residences of smaller or larger numbers, although there was no significant difference between the public and community facilities per se. Using a stepwise regression analysis, Rotegard et al. found that a facility's autonomy and activity score was best explained by the adaptive behaviour level of residents and next by the size of the unit. Resident staff ratios were also important. Eyman and Arndt (1982) also found that environmental quality was associated with initial levels of adaptive behaviour, which suggested that adaptive behavioural competence may determine the types of environment provided, or at least determine the quality of the environment.

Similar results were found by Eyman and Widaman (1987) in a study of the developmental growth of 30,749 intellectually disabled people in California. They found that institutionalised intellectually disabled clients declined in cognitive growth over four years, as compared to residents in community settings, but that this was due to fact that the institutions catered for more dependent and frail populations. Therefore, it is possible that lower scores on measures of the quality of the environment attributed to institutional settings could be due to the lower abilities of the residents, rather than to the size of the institution.

It has also not been demonstrated that resident-oriented care practices necessarily lead to positive changes in adaptive behaviour, especially in those

studies which have examined the effects of different residential placements on severely disabled children. Such studies which have related resident care practices to changes in adaptive behaviour have shown that residences which avoided institution-oriented practices, as measured by the RMPS and CTE, did not necessarily provide conditions under which their clients made progress or did not regress (Eyman and Arndt, 1982; Whatmore, Durward and Kushlik, 1975), or that there is an increase in more appropriate behaviour following relocation. For example, Eyman and Widaman (1987) found that maladaptive behaviour increased among clients placed in foster care homes and this was thought to be related to a high rate of movement from foster home to foster home; (over 10% of the sample had not remained in the same placement).

Use of the CTE and RMPS as measures of the treatment environment, especially with respect to severely disabled populations, has been criticised on a number of grounds. Firstly, some of the practices measured by the scales do not seem to be related to factors which would encourage developmental progress, and the scales thus lack sensitivity to staff practices directly affecting individual clients. Secondly, scores on both scales are related to whether or not residents have the skill to perform the particular item in question. In situations where intellectually disabled people do have these skills (i.e. mildly and moderately intellectually disabled client groups) but are restricted by management practices, the instruments are useful in detecting restrictive practices. However, low scores in

residential units catering for severely or profoundly intellectually disabled clients may merely be reflecting that the clients do not have the skills to perform the item, rather than restrictive staff practices. This possibility has led Eyman et al. (1982) to question the appropriateness of using these measures of environmental quality with severely intellectually disabled populations, because they measure socialisation experiences that are beyond the skill level of severely disabled clients.

Other measures of the environment have been developed for use with psychiatric populations. In his study of 29 psychiatric hostels, Apte (1968) sought to distinguish the social elements between the environments provided by hostels and hospitals. His Hospital-Hostel Practice profile had two scales which measured restrictive-permissive practices and the degree of responsibility expected by staff from the resident. He found that hostels were less restrictive than hospitals, although they varied and some were more restrictive than others. Many hostels still practiced institutional routines (e.g. locking clients out if they came back later than 11p.m., restricting availability of drinks, and forcing the wearing of certain clothing). His research showed that, even for psychiatric patients, placement in the community is not necessarily placement in a more normal or less restrictive environment than that experienced in the institution.

Moos (1973) listed six characteristics of the environment which he felt related to human functioning (ecological, behaviour, organisational structure, collective

characteristics of others in the environment, psychosocial characteristics and organisational climate, and reinforcement analyses of the environment). Based on these, he developed a number of scales for use within prisons, community placements, and family environments (Moos, 1975). His scales were developed with psychiatrically ill or criminal populations but they have been used with intellectually disabled clients in family care and natural family placements. The Family Environment Scale has 10 categories for environmental climate, constructed from 100 true-false items and this scale has been used with intellectually disabled people.

Willer and Intagliata (1981) used this instrument, along with the Community Oriented Programmes Environment Scale, also developed by Moos, in their study of the adjustment of 338 individuals transferred to community placements from five institutions in the USA. The clients had been in community placements (either foster family care, natural family, board and care homes, or nursing homes) for at least two years since release. Willer and Intagliata found that skill level after two years was best predicted by the skill level of the client when entering the community; and that there was essentially no improvement in self-care skills in either foster-care or community placements (Willer and Intagliata, 1982). However, the results also showed that the social environment of the setting was important in predicting skill development and behaviour. Environments where the care-provider was over-protective did not encourage growth and those where freedom to express feelings

was allowed, rather than punished, were environments that had the most success in controlling behaviour problems. Residents in homes where there were structured programmes also showed more development. Thus, it was shown that the quality of care in community facilities varied, whether in family homes or group residences.

A review of the literature with respect to residential climate of care facilities has thus shown that care practices can vary between institutions and small group homes. However, care practices within small group homes or community-based facilities can also vary and the research has shown that care in community facilities is not necessarily better or a guarantee of individualised care. In some instances the quality of the residential climate in some institutions is as good as care practices in some group homes, although in general, the outcome favours small community placements. Studies disagree as to whether the size and type of institution affect the quality of the residential climate, whether the quality of the residential climate has any effect on the behavioural competencies of the residents, and whether the behavioural competencies of the clients affect the nature of the management practices provided.

The research available has shown that it cannot be concluded that small size and community location are a guarantee of normal or better residential environments than can be provided by institutional environments but that the community placements generally score better than institutional placements.

Studies of Changes in Adaptive Behaviour

As part of an evaluation of community and residential services many authors have focussed on changes in adaptive behaviour that occur when residents move from larger to smaller residential facilities. As will be seen in what follows, in contrast to claims made by proponents of the normalisation movement, the results of these studies do not prove unequivocally that movement from larger to smaller facilities necessarily results in an improvement in adaptive behaviour.

Some investigators have found that the incidence of adaptive behaviour increases following transfer from larger institutions to smaller units (Aanes and Moen, 1976; Gilbert and Hemming, 1979; Hemming, Lavender and Pill, 1981; Kleinberg and Galligan, 1983; MacEachron, 1983; Schroeder and Henes, 1978; Thompson and Carey, 1980; Conroy, Efthimiou and Lemanowicz, 1982). However, while these studies have shown that growth in adaptive behaviour can occur following change in placement, not all studies have provided unequivocal evidence that such growth is extensive or that gains are maintained over time.

Studies which have investigated changes in adaptive behaviour following relocation to community units have found that most development occurs within the first few months (up to nine months) following transfer. After that time scores either become stable or decline (Locker, Rao, and Weddell, 1983; Kleinberg and Galligan, 1983; Schroeder and Henes, 1978), or sometimes return to baseline level after two years (Hemming, Lavender and Pill, 1981). Some researchers have

claimed that the positive changes that occurred initially represented manifestations of skills already in the residents' repertoire before transfer and that the new environment offered new opportunities to use those skills, rather than that the residents learned new skills (Kleinberg and Galligan, 1983). The decline in skill level found after the initial gain has, in some instances, been related to loss of staff morale (Hemming, Lavender and Pill, 1983).

It has been shown that placement in the community is no guarantee that skills either develop or are maintained. For example, Malin (1983) studied 20 residents who had been living in the community, two years after an initial assessment. He found that, while over half the residents in group homes had improved on six scales of the Adaptive Behaviour Scale (ABS), one quarter or more had deteriorated on 10 of the scales of the ABS. Other researchers have also found no change or negative changes in adaptive behaviour following relocation to small units.

Silverman, Silver, Sersen, Lubin and Schwartz (1986) studied the adaptive competence of two groups of profoundly mentally retarded and physically impaired residents in New York. A repeated assessment was made at 12 months. The first sample of 101 residents lived in a hospital for the developmentally disabled. The second group of 74 residents lived at 12 community- based homes, each of 3-10 residents. The community sample tended to have slightly higher skills than the hospital sample, most of whom were non-ambulatory and severely impaired. Using the Minnesota Developmental Programming System Behavioural Scales and the abbreviated

form of the scale (MDPS-AF, Joiner and Krantz, 1979) Silverman et al. found that percent competence scores in the specialty hospital group increased over time, although significant change was found only for eating behaviours. For the community residents, overall competence declined slightly over time, although the decline was not statistically significant. There was no evidence that smaller programmes in the community were any better than the larger specialty hospitals in promoting gains or preventing deterioration in levels of adaptive behaviours. It was found that musculo-skeletal impairments and factors relating to the nature of systematic and intensive training programmes, such as whether there were specific treatment goals as part of an individual programme plan, were more important than the size of the residential facility.

Similarly, Aninger and Bolinsky (1977) found that 18 intellectually disabled adult residents moved from a private residential facility to community units did not show improvement six months after placement in skills measured by Part I of the ABS. Although six months was a short follow-up time, previous research has suggested that most gains occur by nine months, so that it could be expected that some gains should have been detected after six months, if gains were going to be made. However, no comparison was made with a control group remaining in the institution. Given that there was no change, it would also have been of interest to know whether the training programmes in the institution and the intermediate residence had been compared, since it has been found by others that the

presence of specific training goals is related to development of skills, regardless of type of placement (Eyman, Silverstein, McClain and Miller, 1977).

Even where studies have shown positive gains in adaptive behaviour following relocation, these changes have not necessarily been marked or significant. For example, MacEachron (1983) studied two groups of randomly selected residents; those moving to 15 smaller units within the campus of the institution (n=160), and those remaining in 14 of the large institutional units (n=129). Using ratings on the ABS 12 months after relocation, MacEachron found that all of the 15 groups moved to the smaller units had higher adaptive behaviour scores than the groups remaining in the institutional units, although the difference was statistically significant for only 7 of the 15 groups. It was found that the strongest predictor of improved adaptive functioning was IQ but characteristics of the environment (e.g. small-sized units, home-like architecture, resident-oriented management practices) remained significant after the effect of IQ had been controlled by analysis of covariance.

Similar results were found by Gilbert and Hemming (1979), in relation to psycholinguistic skills. Nine months after transfer to smaller units, the transferred group had made more gains than a control group remaining in the institution. However, the gains were significant for only one of the sub-scales of the Illinois Test of Psycholinguistic Abilities. Other studies have also shown that, while improvement following relocation to community

placement does occur, such growth is not necessarily marked nor across all areas of adaptive behaviour (Kushlik, 1975; Aanes and Moen, 1976).

The results of the above study, and other studies of changes in adaptive behaviour following relocation, have shown that changes in adaptive behaviour appear to be related to the initial IQ of the intellectually disabled people being transferred (Hemming et al., 1981, Kushlick, 1975). For example, Hemming et al. (1981) studied residents transferred from a large institution to smaller units, located in the grounds of the institution. Hemming et al. found that higher functioning residents (IQs above 50) who had come from less restrictive institutional wards decreased their participation in culturally normative activities and did not significantly change their abilities. Both groups (i.e. IQ greater and less than 50) attained their peak improvement nine months after transfer, although the improvements were not maintained two years later.

Cohen, Conroy, Frazer, Snellbecker, and Spreat (1977) also found that residents of a large institution moved to a smaller, but non-community based facility showed variable gains, depending on their initial level of functioning. Cohen et al. studied 92 male and female subjects ranging in age from 10 to 42 years, who were rated on the ABS immediately following relocation and again six to eight weeks following relocation. For two groups of clients (average IQ less than 20, and average IQ 35), there was significant change over time on five and six of the 23 domains of the ABS, respectively.

When results for higher and lower functioning residents were compared, it was found that residents with the highest adaptive behaviour scores initially showed a pattern of lowered functioning with respect to independent activity, economic activity, language development and withdrawal domains of the ABS. However, these residents did show an improvement with respect to the anti-social behaviour scale. The comparison group (which had not been relocated) made significant gains in only two of the ABS domains (domestic activity and self-direction). Compared to the comparison group, members of the higher functioning group were more withdrawn and suffered setbacks in language development. In contrast, those residents whose functioning was generally lower increased in domestic activity, self-direction and responsibility. They also showed decreases in three of the maladaptive behaviour domains.

The authors claimed that there was evidence of a "relocation syndrome" for the higher functioning clients but not for the lower functioning clients, for whom it had been expected. [Heller (1984), in a survey of the literature, found that a relocation syndrome comprising increased mortality rate, increase in medical problems, and emotional, behavioural and mental health changes, existed in people with severe intellectual disabilities following movement to a different facility]. Cohen et al. stated that increased performance following transfer was of interest to people working with the very severely handicapped. However, the length of follow-up time was not great and it would have been interesting to investigate whether this change was

maintained over a longer period of time, since other research has shown that initial gains are frequently not maintained beyond about 12 months.

Maladaptive behaviour, which according to proponents of the normalisation movement would be expected to decrease following transfer to small units, has sometimes been shown to increase (Hemming, Lavender and Pill, 1981, Kleinberg and Galligan, 1983). This has also been related to the IQ level of the transferred residents, with those with lower IQs (less than 20) showing increases in maladaptive behaviour and those with higher IQs decreasing maladaptive behaviour following relocation (Kleinberg and Galligan, 1983).

Although Hemming et al. (1981) found an increase in the prescription of medication for the purpose of controlling behaviour following transfer to a smaller location, Horten (1982) found a contrary result. At a three-year follow-up, medication prescribed to control behaviour had been reduced for those moved to community placements. The level of medication prescribed to those remaining in the institution had also decreased but the decrease was not as substantial as was found in the community group. However, confounding the results of this study was the change to residential care workers specially trained in behaviour modification techniques, who replaced the previous psychiatric nurses, and which occurred during the three-year period. At the same time, the service changed from a medical model of service provision to a more behavioural model. Thus, it is not possible to attribute the changes found as being due to the move to smaller facilities alone.

In addition, it has not been demonstrated that living in community placements, with normalised environments, leads to positive gains in adaptive behaviour, or that positive growth can occur only in community placements. For example, little relationship was found between a group home's PASS rating scores and clients' adaptive behaviour scores. In fact, in one study, the group home where clients made the most gains received one of the lowest PASS ratings (Schroeder and Henes, 1978). Another study, comparing the change in adaptive behaviour of a group transferred to small units and those remaining in institutional units, found that some of the changes that occurred in the institutional residents did not differ significantly from changes in the transferred residents (Hemming et al., 1983). This indicates that transfer to a small unit does not necessarily mean that adaptive behaviour will increase more than it would have, had the client remained in the institution.

The use of adaptive behaviour as a criterion for measuring change has been criticised by some. Repp and colleagues (Repp, Barton, and Brulle, 1986; Felce, de Kock, and Repp, 1986) have claimed that studies focussing only on changes in adaptive behaviour represent a narrow way of examining the changes that occur when residents move from one placement to another. Instead, they support the use of observational measures to measure changes in the behaviour of residents. Felce, Kock, and Repp (1986) studied the adaptive behaviour and observed behaviour changes found for 12 severely and profoundly intellectually disabled persons, six in group homes and six controls in institutional

settings, who then moved to community placements. Felce et al. found that residents of the group homes received markedly higher rates and longer durations of staff interactions, and this outcome was not entirely related to the higher level of staffing found in the group homes. Clients in the group homes showed greater engagement in activities (including leisure, personal, domestic and formal programme activities) than the institutionalised clients, and all persons in the control group improved their level of adaptive functioning (as measured by the ABS) when transferred to community settings. However, Felce et al. cautioned against claiming differences were due to placement in community-based residences. The residences had been designed to encourage resident interaction with the environment and the staff had been specially trained to increase client participation. However, since the study involved only 12 clients, caution is warranted about generalising the results to similar client groups.

The major critics of institutions presume that positive changes in adaptive behaviour within institutions are prevented from occurring because of the very nature of institutions. However, individuals with an intellectual disability do develop when placed in institutions (Butler and Bjaanes, 1977) and some researchers have argued that institutional care is more appropriate for some severely intellectually disabled people (Ellis, Balla, Estes, Warren, Meyers, Hollis, Isaacson, Palk, and Siegel, 1981).

Schwartz and Allen (1974) found that adaptive behaviour could improve within large institutions. They studied

residents of a residential training centre who had been rated on the Adaptive Behaviour Checklist (Allen, Cortazzo, & Adamo, 1970) and its revised edition (Schwartz, Allen, & Cortazzo, 1974) for three (N=699) or four (N=414) consecutive years. Schwartz and Allen found that the residents made continued improvement in their total scores and that these changes were statistically significant. Gilbert and Hemming (1979) also found that matched controls remaining in an institutional setting improved in psycholinguistic skills, although the gains were not quite as large as the gains made by a comparison group transferred to smaller units.

Thus, a review of the literature relating to the changes in behaviour of residents moved from larger to smaller facilities has not shown that improvements are necessarily linked to the change in size of the placement. It has been shown that changes in adaptive behaviour may be related to IQ, and to adaptive behaviour prior to placement and that adaptive behaviour does not improve unless specialised programming is provided. Moreover, movement to less institutionalised settings has sometimes resulted in increases in maladaptive behaviour and with increases in the prescription of anti-psychotic medication.

In addition, there have been many methodological flaws in the studies to date of change in adaptive behaviour, and these make generalisation difficult. Some studies have failed to collect data in a pre-release location, while others have collected data at only one point in time, or have not involved comparison groups. Again, others have

used small sample numbers, and while some studies have shown that improvement does occur following placement, long-term (greater than one year) evidence of change has frequently not been provided.

The use of changes in adaptive behaviour as the only criterion for the success of placements within the general community has been debated. Some researchers feel that this approach is too narrow and that a social policy aimed at enhancing the quality of life of individuals should not be evaluated by counting the number of behaviours in an individual's repetoire. A more comprehensive evaluation, including environmental variables (such as the use of leisure time and of community facilities) and individual variables (such as happiness and satisfaction), needs to be made (Seltzer, 1981; Seltzer, Sherwood, Seltzer, and Sherwood, 1981). Studies which have examined these aspects of the lives of deinstitutionalised intellectually disabled people are discussed in the following sections.

Use of Community Facilities and Social Interaction

The study of social supports available to people with an intellectual disability involves the examination of social interactions of intellectually disabled people, both within their home and with their families and the surrounding communities (O'Connor, 1983). The results of research in these areas have differed and many studies have shown that intellectually disabled people living in the community lead isolated and lonely lives, rarely interacting outside a disabled peer group (Atkinson, 1985; Baker, Seltzer, and Seltzer, 1974; Butler and Bjaanes, 1977). Reiter and Levi (1980) have warned against accepting that integration necessarily results in a positive outcome and even optimal location of an adequate community facility does not necessarily result in individuals being better integrated than when they were living in the institution (Moreau, Novak and Sigelman, 1980). The results of various studies on the use of community facilities and socialisation are outlined in greater detail below.

Berkson and his colleagues (Berkson and Romer, 1980; Romer and Berkson, 1980a, 1980b; Romer and Berkson, 1981; Berkson, 1981; Heller, Berkson and Romer, 1981) studied the interaction patterns of 304 intellectually disabled people, both at their workplace and in their residences. Using naturalistic observation techniques, they found that informal socialising was an important aspect of the lives of intellectually disabled adults. In general, clients who were physically attractive, desired affiliation, and whose activities involved interactions with peers who were less

intellectually disabled, affiliated more extensively and intensively with peers. Berkson et al. found that intelligence was only weakly related to sociability. Heller, Berkson and Romer (1981) found that social interaction occurred during about one-third of the time for which people were in their residences. They also found that socialisation increased with time and with familiarity with the setting. Those clients who were later placed in the settings suffered disruption to their friendship patterns and tended to affiliate with people whom they had known prior to placement. The results of this research led the authors to state that group placements may be preferable, because such arrangements were less likely to result in social isolation when clients first entered a strange situation.

Landesman-Dwyer, Berkson and Romer (1979) studied the social behaviour of 208 intellectually disabled people in 18 group homes, ranging in size from five people to 20 people. Individuals spent most of their time alone, next most with one other peer and successively less with two or more peers. Residents in the larger homes affiliated more extensively with others and intense relationships were as likely to develop there as in small homes. It was shown that merely putting people in small groups did not necessarily create social relationships. Other findings revealed that social interaction between the residents (affiliation) was more a consequence of the size of the home, the average intelligence of people in the group home, the ratio of males to females in the group home, and the homogeneity of the

residents' backgrounds than of personal characteristics of sex and intelligence; (i.e. more intense relationships occurred in homes with a higher proportion of female residents, people in homes with older clients were less social, and clients in group homes with others who shared a similar prior living history socialised more). The number of residents in a home was also found to affect the interaction patterns of residents (Landesman-Dwyer, Sacket and Kleinman (1980), with residents in larger homes (up to 20 people) engaging in more social behaviour, particularly with peers, and being more likely to have a best friend and form broader social relationships than residents in smaller homes (6-8 residents). Residents in facilities of intermediate size (9-17 residents) had the greatest amount of peer interaction.

Studies of the use of facilities by intellectually disabled people living in the community have found variable results. Some studies have shown that residents in community placements do not use community facilities a great deal (Bercovici, 1981; Edgerton, 1976; Gollay, Freedman, Wyngaarden and Kurtz, 1978), whereas others have demonstrated active use of community resources (Atkinson, 1985; Schalock, Harper and Carver, 1981; Willer and Intagliata, 1981). Wide variation between types of community placements have been found in the use by residents of community resources (Baker, Seltzer and Seltzer, 1974; Pratt, Luszcz and Brown, 1980), although studies which have compared the use of community resources by institution-based and community-based residents have generally shown that the

community-based residents make more use of community resources (Ericsson, Lerman and Nielson, 1985; Pratt, Luszcz and Brown, 1980).

Even use of community resources for leisure activities by intellectually disabled people living in community placements has sometimes been shown to be limited. Many researchers have found that passive recreational activities, such as watching TV, are more frequently engaged in than any other (Chesseldine and Jeffree, 1981; Craft and Craft, 1979; Gollay et al., 1978; Kregel, Wehman, and Marshall, 1986; McDevitt, Smith, Schmidt and Rosen, 1978; Malin, 1983). Even if a wide variety of social activities were engaged in, many involved other disabled people rather than nondisabled members of the wider community. (Gollay et al., 1978; Baker et al., 1977; O'Connor, 1976). O'Connor (1976) found that 15% of the residents had no activities based on community resources. Similarly, Ericsson et al. (1985) found that 19% of the residents in community units did not use facilities in the community, although this was better than the 75% of residents in institutional settings who did not use community facilities. However, no study has compared the use of community facilities by intellectually disabled people and nonhandicapped people in community settings, so that it is not possible to determine if the low use of community facilities by people with an intellectual disability is less than that of a similar, but nonhandicapped, population.

Where studies have shown that residents of community units do use community resources, it has often been the case

that interaction with the community is minimal and that many disabled people operate as observers, rarely interacting with people outside their own network of disabled peers or support workers. For example, Atkinson (1985) surveyed 50 intellectually disabled men and women aged between 29 and 74, discharged to a variety of independent living situations in England. She found that, although many of the people studied spent time in the neighborhood and local community, most were only observers and there were few instances of interactions with nonhandicapped people. Similar results were found by Schalock, Harper and Carver (1981) and by Gollay et al. (1978), who found that whilst residents did use community facilities extensively and had friends, few of these friends were people other than disabled peers, families, or staff. Thus, while the residents in these studies may have used community facilities they were not socially integrated within the community. In contrast, Kregel, Wehman, Seyfarth, and Marshall (1986), studied the extent of community integration among 300 mildly to moderately-severely handicapped ex-residents of a state school, finding that 59% of the residents did report that they spent the majority of their free time with persons with no identified disabilities.

Lack of contact with friends or relatives is another factor that has been shown to be a problem with residents living in the community. It has been found that a proportion of residents of both institutions and group homes have little contact with relatives or friends and lead very socially isolated lives, although the residents in the

community have generally been noted to have more interaction with friends and relatives (Ericsson et al., 1985). For example, Willer and Intagliata (1981) studied 229 intellectually disabled individuals living in group homes and foster family care in the USA. They found that only about 50% of the residents studied had contact with friends and only about 40% had contact with their natural families. Similar studies have also found that intellectually disabled people living in the community, either at home with their families, or in community residential facilities, are socially isolated, have few friends, and interact mainly with other intellectually disabled people in specially organised groups and are thus not truly integrated within the community (Atkinson, 1985; Chesseldine and Jeffree, 1981; Edgerton, 1975; Flynn and Saleem, 1986; Gollay, Freedman, Wyngaarden and Kurtz, 1978; Mc Devitt et al., 1986; O'Connor, 1976; Schalock, Harper and Carver, 1981; Schalock and Lilley, 1986). Many deinstitutionalised residents retain strong ties to friends and staff at the institution from which they came and spend many hours travelling back to visit them (Baker et al., 1974).

Loneliness is a much commented upon feature of the lives of intellectually disabled people living in the community, possibly due to their social isolation and limited contact with friends. Muehlenberger (1974) found that profound loneliness characterised the 10 discharged residents he followed. This loneliness began in their pre-institutional lives, persisted throughout their time in an institution and continued beyond their leaving the

institution. Similarly, Malin (1983) found that friendships were few and that contact with neighbours was minimal for the 20 intellectually disabled residents he followed for two years after placement in community settings .

Schalock and Lilley (1986) followed-up 85 deinstitutionalised intellectually disabled people after 8-10 years in the community. Schalock and Lilley personally interviewed these persons, finding that many were lonely and had fragile support systems. They were socially isolated, their main interactions being with staff members or other intellectually disabled residents in the same community settings. Few interacted with nonhandicapped peers or were accepted as equal members of local community groups. Similar results were found by Gollay et al. (1978) who surveyed 440 deinstitutionalised intellectually disabled people living in the community. Gollay et al. found that, although a wide variety of social activities were engaged in, few involved nondisabled peers. Loneliness was a problem reported by many of the groups studied.
In addition to loneliness, depression may also be a common problem for many intellectually disabled adults living in the community. For example, Prout and Schaeffer (1985) studied self-report measures of depression among 21 mildly intellectually disabled adults living in community residences but who were not attending any psychiatric clinic. Using three different self-report measures they found that there was strong agreement between the measures with 52% of the residents scoring in the range considered to be clinically significant and 48% in the significant problem

range. On two of the three measures the intellectually disabled group scored significantly higher than did nonintellectually disabled adults.

In a study of 181 people with an intellectual disability living in, or about to live independently in the community, Edgerton (1986) found that many reported either anxiety or depression which was often associated with low self-esteem or frustrating life circumstances. Thus, adults living in the community may suffer psychological disorders which may be due to living in socially isolated circumstances.

Various research has shown that the social isolation of residents in group homes is sometimes due to the following factors: age of residents, with older residents using community resources less than younger residents (Willer and Intagliata, 1982); residents lacking the skills to use public transport (Chesseldine and Jeffree, 1981; O'Connor, 1976); the managers of facilities not allowing or teaching the residents to use community facilities (Bercovici, 1981); staff or parents being reluctant to allow outside visitors into the home (Bercovici, 1981; Birenbaum and Re, 1979; Chesseldine and Jeffree, 1981; Flynn and Saleem, 1986) and not allowing free access to telephones within the facility (Bercovici, 1981); geographical isolation of the facility (Bercovici, 1981); and unfavourable location of facilities in socially depressed neighborhoods, so that residents fear for their safety when leaving the facility (Bercovici, 1981; Birenbaum and Re, 1979). However, Birenbaum and Re (1979) have stated that in many ways the lifestyles of people with

an intellectual disability in the community are no different to those of marginally employed or unemployed persons, whose income limits many excursions; and that fear that some disabled residents have about moving in the community at night is similar to that experienced by many city dwellers.

One problem with many of the studies examining use of community resources is that they have done so at one particular point in time. However, it may be expected that use of community resources will increase as residents become familiar with the community in which they live and this result has been found when longitudinal studies have been employed. Edgerton and Bercovici (1976) followed up 30 of an original sample of 48 intellectually disabled residents released from an institution into community placements. Although the original study found residents did not use community resources highly, five years later it was found that use of community resources had improved.

Nonetheless, a contrasting result was found by Birenbaum and Re (1979) who re-examined the use of community resources by former residents of institutions for people with intellectual disabilities four years after the initial study. Birenbaum and Re found that, contrary to their expectation, greater familiarity with the wider environment did not occur with the passage of time and that the residents led very socially restricted lives, despite the fact that they had easy access to public transport. Similarly, Bercovici (1981) found that, despite living in the community for five or more years, many of the residents in his study showed a general lack of familiarity with even

the most commonplace aspects of community life. The residents of these facilities did not perceive themselves as living in the normal community. Although a longitudinal approach was not employed by Bercovici, many of the residents had lived in the community for the same length of time as those in the Edgerton and Bercovici (1976) study and could thus have been expected to have become familiar with their environment.

When, however, residents are asked about how they feel about their placements, only very few do not like where they live or express a desire to return to the institution (Gollay et al., 1978; O'Connor, 1976). Intellectually disabled people living at home with parents were an exception to this. Flynn and Saleem (1986) found that eight out of 12 people living with their parents were not satisfied and wanted to move to more independent living situations.

Marital status also seems to affect satisfaction that intellectually disabled people living in the community express with their placement, with married people tending to express less dissatisfaction and to report feeling lonely less often than single people (McDevitt, Smith, Schmidt, and Rosen, 1978). Craft and Craft (1979) studied 45 married couples where one or both partners had an intellectual disability. They found that, although there was wide variation in the social life of the couples, most had limited contact with people other than family (21 pairs). However, none of the couples talked about being bored or having difficulty passing time, and many acknowledged that

marriage had brought them a contentment that they had not had as single people.

As indicated, research has shown that intellectually disabled people living in the community do not necessarily use community facilities to a great extent. Even if they do, many do not interact with others outside their peer group and few are truly integrated into the community-at-large. It may be that intellectually disabled people living and working in the community are like many other community dwellers who tend to spend their leisure time most often with friends from work, from the place where they live and from previous places of residence (Baker et al., 1974).

There is evidence, then, that placement in the community does not, by itself, produce greater participation by intellectually disabled people in the life of the community. Many intellectually disabled people living in the community are not well integrated within it and tend instead to socialise with other intellectually disabled people or care-workers. However, this may be a matter of personal preference; the establishment of organisations by intellectually disabled people (such as People First in the USA and Reinforce, Ipswich in Australia) does suggest that this may be the case. In other words, the low interaction between people with intellectual disabilities and nondisabled peers may be a matter of choice on the part of people with an intellectual disability. People with intellectual disabilities may choose to form a group with other such disabled people because of the social support

which that group can provide (due to sharing similar needs and experiences), rather than because of reduced opportunities to have normal friends (O'Connor, 1983).

In many respects, the establishment of socialisation and friendship patterns among disabled persons which are restricted to people found in living and work environments does not differ from the circumstances of many people in the community who are marginally employed or unemployed and thus lack the financial resources to pay for leisure activities. Restricting travel to weekends is also a common pattern for many residents of inner-city areas who are fearful of travelling alone (Birenbaum, 1980; Birenbaum and Re, 1979).

There are those who would attempt to remedy the social isolation of intellectually disabled individuals in group settings by removing them from such placements and placing them individually in the community. However, it should be remembered that there is little evidence that public acceptance of normalisation "has gone so far that [intellectually disabled people] would be welcomed or even tolerated in most non-deviant circles" (O'Connor, 1976). Moreover, there is research to suggest that placing intellectually disabled people individually in the community is detrimental to their lives. In a study of deinstitutionalised individuals, Seltzer and Seltzer (1978) found that people with intellectual disabilities who lived alone tended to become isolated and lonely, often lived on meager incomes, and came into contact with serious social problems. These authors claimed that it was better for intellectually disabled people who had not developed

adequate social networks, to live with others in a semi-independent setting.

When moving disabled people to the community one should be aware that integration is not a necessary result. It may be that for some who enjoy social activities, movies and other planned activities within the institution, independent living in the community may not be sufficient (Begab, 1975). Others may not wish to live in the community independently because the prospect of living on marginal incomes, being forced to live in sub-standard rooming houses, with the possibility of social problems, is too overwhelming (Seltzer and Seltzer, 1977). People with intellectual disabilities may prefer to live in semi-independent or sheltered settings and should not be penalised for doing so, even though proponents of the normalisation principle would argue that they should be made to live up to their potential for independent living because that is more socially desirable behaviour. Many researchers have defined positive outcomes in terms of behaviour change, use of community resources, use of leisure time and so on. If, however, the principle of normalisation is to be taken seriously, then it is important that the attitude of people with intellectual disabilities to their life circumstances and placements be examined (Edgerton and Bercovici, 1976).

Those studies which have asked disabled people living in the community how they feel have found that, while many may be living lifestyles that would not necessarily be aspired to by the researchers, most were happy with their lives. It is thus important to develop a measure which will

examine satisfaction with one's lifestyle from an individual's point of view. Development of such a measure is important as there are many conflicting results on quality of life when the residences themselves are rated, or other measures of positive outcome are used (Lakin, Bruininks, and Sigford, 1981). Studies which examine quality of life from a subjective viewpoint may provide useful information on how to measure placement success, as it has been argued by some that satisfaction with lifestyle is an integral part of quality of life. Studies of subjective aspects of quality of life and their applications to people with intellectual disabilities are examined in greater detail in the following section.

2.2 Subjective Considerations: Quality of Life

Definition:

The term "quality of life" first emerged as a concept in sociological literature ten to fifteen years ago (Szalai and Andrews, 1980). However, despite the fact that the term has existed for some time and there are constant demands to improve the "quality of life" of people in the community, there is not yet an accepted definition of the term, and nor is there any consensus on how it should be measured or fostered (Solomon, Bauchaichi, Denisov, Hankiss, Mallman, and Millbrath, 1980).

Various attempts have been made at defining the concept. It has variously been defined as: personal satisfaction, happiness, or well being (Andrews and Withey, 1976); an inclusive concept which covers all aspects of living as it is experienced by the individual (Solomon et al., 1980); the more or less "good" or "satisfactory" character of people's lives (Szalai and Andrews, 1980); an evaluation of the gratification which people derive from the degree to which their material and mental needs are actually satisfied (Bestuzhev-Lada, 1980); and as a global sense of well-being which depends on personal characteristics and objective and subjective factors (Lehman, 1983).

It has been stated that a person's existential state, well-being, and satisfaction with life is determined by subjective factors and objective factors (Andrews and Withey, 1976; Blishin and Atkinson, 1980; Szalai and Andrew, 1980). The objective considerations termed "exogenous factors" by Szalai and Andrews (1980) include wages, housing

etc., whereas subjective considerations ("endogenous factors") are the person's perception and assessment of the objective considerations and of him/herself (Szalai and Andrews, 1980). The interaction of the objective and subjective factors determines the quality of life.

When looking at the quality of life of people in the community, many studies have examined only the objective areas, such as housing conditions (Bestuzhev-Lada, 1980; Verwayen, 1980), quality of clothing, food and physical environment (Bestuzhev-Lada, 1980), population variables such as social status, mobility, health, education and participation in the community (Zapf, 1980), or mortality rates, per capita Gross National Product, life expectancy, homicides and so on (Scheer, 1980).

However, looking at the subjective perceptions of individuals to gain a measure of general life satisfaction is another way of measuring the quality of life (Blishin and Atkinson, 1980; Craft and Craft, 1979; Lehman, 1983). Various researchers have looked at satisfaction as a measure of the quality of life but the same areas of satisfaction have not always been examined. Indicators of quality of life have been variously defined as satisfaction with family and interpersonal relationships (Bestuzhev-Lada, 1980; Hedley, Dubin, and Traveggia, 1980; Minor, Bradburn and Schaeffer, 1980); with leisure (Hedley et al., 1980; Minor et al., 1980; Scheer, 1980); financial situation (Blishin and Atkinson, 1980; Minor et al., 1980); and with employment (Bestuzhev-Lada, 1980; Hedley et al., 1980; Minor et al., 1980). The main areas that are considered important in

determining a good quality of life have been more broadly defined as including remaining alive and healthy, having a suitable place to live, enjoying leisure time, and receiving an education that provides preparation to face the problems of life (Scheer, 1980), or as the availability of means for the satisfaction of human needs (McCall, 1975).

Minor, Bradburn and Schaeffer (1980) considered that, although the number of domains that potentially contribute to life satisfaction is endless, there are seven domains that cover the major domains in which individuals seek satisfaction, for North Americans at least. Four of these domains (interpersonal relationships, especially familial and marital; leisure activities; financial status; and work situation) are significant aspects of all adult lives and Minor et al. considered that these areas make the major contribution to overall satisfaction ratings. However, three other domains (residential environment; affective states; and physical health) were also felt to be important.

Minor et al. sampled 4,883 North Americans (USA) from various socioeconomic status levels and from a variety of employment areas. They found that the seven domains accounted for 30% of the variance in life satisfaction and that the largest correlation coefficients between the satisfaction factor and the domains were the variables for satisfaction with leisure, finances and work. These seven variables were found not to define independent life areas and their contributions to the structure of life satisfaction were not unique. The authors proposed that the model was able to explain variation in life satisfaction by

"combinations of evaluations in specific life domains" (Minor et al., 1980, p. 130). In other words, they sought to explain differences in life satisfaction by differences in the scores received on each of the domains rather than by comparing a score on a specific domain with its evaluation; (i.e. such as the nature of work performed and satisfaction with work). In this way the authors felt that the structure of life satisfaction should be generalisable across the USA population.

Andrews and Withey (1976) felt that a person's own perception of well-being was a reasonable measure of quality of life as the promotion of well-being is a central goal of most modern societies. They surveyed 5,422 individuals in the USA, in six surveys over one and a half years. Using a structured interview, Andrews and Withey asked respondents to rate on a seven-point scale how they felt about various areas of their lives. They found that people could and did divide their lives into domains which, although these were not isolated, were " separate enough to be identified and evaluated as a distinguishable part of life" (Andrews and Withey, 1976, p.11). The domains found were: marriage; health and physical condition; friends; job; religious faith; local government and neighborhood. Andrews and Withey found that the best predictor variables of overall well-being were feelings about self-efficacy, family, money, amount of fun, house/apartment, national government, job, health, spare time activities, things to do with families, consumer index, and time to do things. All these things accounted for 50% of the variance in overall well-being.

Andrews and Withey found that sex, race, age, education, family income, and family life-cycle stage were poor predictors of well-being. Thus, it is important to measure the subjective feelings of people, since purely objective measures of their living conditions may not adequately reflect their feelings about life.

Other large studies of feelings of satisfaction have found that feelings about life as a whole can be related to specific life domains, such as national government, work, non-working activities, marriage, family life, friendships, health and physical condition (Campbell, Converse and Rogers, 1976) and financial situation (Blishin and Atkinson, 1980; Campbell et al., 1976). Blishin and Atkinson (1980) found that age and income independently did not have much significance for satisfaction. However, there was a larger relationship between income and satisfaction with present financial situation.

Applications of Quality of Life: Studies of Community Placements:

Improvement of quality of life is seen as important, both for the so-called "normal" population and for those with physical, intellectual, or emotional difficulties. However, the majority of research into the outcome of placement of people with intellectual disabilities from institutions to community has been into variables which are more properly regarded as population variables, or objective measures of quality of life. It is also important to measure the quality of life of an individual from the individual's point

of view (Landesman-Dwyer, 1981, Schalock, Harper and Carver, 1981), rather than from an external viewpoint only. There has been little research that has addressed the subjective factors, or life satisfaction, of deinstitutionalised people (Seltzer, 1981; Seltzer, Sherwood, Seltzer, and Sherwood, 1981) and yet life satisfaction is perhaps the most important outcome measure of residential placement (Heal and Laidlaw, 1980; Lehman, 1983; Zusman and Slawson, 1981). An individual measure of satisfaction has advantages over other methods of evaluation as there have been conflicting research outcomes from quality of life studies which involve objective factors, such as when the residences themselves are rated (Lakin, Bruininks, and Sigford, 1981).

When objective and subjective factors have been measured, high correlations between them have been found. For example, Lehman, Ward and Linn (1982) studied the quality of life, using both subjective and objective measures, of 278 psychiatric patients, ranging in age from 18 years to 65 years, living in board and care homes . Lehman et al. found a high correlation between the two kinds of measures. For example, they found that those residents who had rooms of their own, or somewhere to go for privacy, and who had social relationships within the home were more satisfied with their lives than those who did not. Interestingly, Lehman et al. found that those who had more autonomy and more leisure activities were not more satisfied than those who had less autonomy or fewer leisure activities. This, it should be noted, is contrary to the

prediction that would follow from the principle of normalisation.

A single subjective or objective measure alone does not adequately explain all the variance in well-being. Lehman (1983) found that objective factors (including living situation, family, social, social relationships, leisure, work, safety, finances and health) could explain about 49% of the variance in the global well-being of ex-psychiatric patients. However, when the person's own view (their satisfaction with life) was added, this figure doubled, indicating that it is important to include both objective and subjective factors when evaluating quality of life.

Blau (1977) studied psychiatric patients and asked them to select variables which they felt were of importance in determining the quality of life. The patients selected ten variables: working, leisure, eating (enjoying food), sleeping, social contact, earning, loving, environment and self-acceptance. Blau then used these variables to develop a self-report, Likert-type scale which could be used to measure perceived changes in a person's quality of life as he/she progressed through treatment.

A few researchers have examined satisfaction with life from the viewpoint of people with intellectual disabilities who have been placed from institutions into community settings. Using a field-observation method, Edgerton and Bercovici (1976) followed up 30 cases (from an original sample of 48) who had left the institution ten years previously. Edgerton and Bercovici found that the people they studied had a vital interest in enjoying life and that

recreational interests, leisure time, friends and family dominated their lives more than interests in work, worry about the stigma of being handicapped, or "passing" as "normal". Edgerton and Bercovici also found that 12 were happier than they had been ten years ago, seven were about the same, six were less happy, and one was not sure. When 13 of this group were studied again ten years later (Edgerton, Bollinger and Herr, 1984), these individuals were still determined to enjoy life and felt that they could manage. Based on tape-recorded interviews and field notes, the researchers rated each individual on a 7-point scale in the areas of life satisfaction, social competence, life stress, relative dependence on benefactors, quality of life, and degree of improvement in life circumstances over the last ten years. They found that for five in the sample, satisfaction with lifestyle was rated as poor, with more bad than good aspects, one person was given an ambivalent rating and three were given good life satisfaction ratings, and four had excellent or wonderful ratings.

The results of the Edgerton and Bercovici study also showed that community adjustment was relatively independent of vocational success and that therefore people's success in the community should not be judged on the basis of whether they are employed or not, nor on how competent they are. Edgerton and Bercovici found that competence and independence were less vital to the people that they studied than a sense of confidence and a subjective sense of well-being, which often differed from the observer's judgement.

Similarly, McDevitt, Smith, Schmidt and Rosen (1978) found that subjective criteria were more important than overt behaviours. In a study of 18 people with mild to borderline intellectual disabilities living in the community, they found that the residents could not have been said to have adjusted to community life purely on the grounds of behavioural competencies (e.g. many had limited knowledge of their financial status and how to budget, few took part in community activities or used community resources, most had few social interactions and were more isolated than would have been expected in a nonhandicapped population). However, in terms of their personal satisfaction they had adjusted well and none of the people interviewed wished to return to the institution.

In their study of 45 handicapped couples, Craft and Craft (1979) also found that, in social and material terms, the quality of life experienced by many of the couples was not enviable. However, many were satisfied with their lifestyles. Similarly, Passfield (1983) found that, although the intellectually disabled people he studied reported some negative aspects about their current living situation, there was a general satisfaction with their home. These results reinforce the view that, when evaluating the lifestyle of a person with an intellectual disability, it is important to look at his/her viewpoint, rather than imposing the subjective rating of the researcher as to how good the lifestyle appears to be.

However, although residents may express general satisfaction with their current residential placement, there

is sometimes also a desire to change one's living accommodation. For example, 25% of the residents in the Passfield study wanted to move to another place, although they had expressed satisfaction with the current placement; a variety of reasons were given, including wanting to live more independently and missing friends. Birenbaum and Re (1978) found similar results when they restudied a group of 42 ex-residents of an institution, from an original group of 63, who had remained in the community for four years. It was found that attitudes to community placement had remained favourable but that dissatisfaction was mentioned more readily during these later interviews. Things complained about included fighting among residents and lack of independence. Nonetheless, even if residents were not fully satisfied with their living arrangements or fellow residents, they felt at home. However, despite feeling at home, 57% wanted to move from where they lived, with about half of these wanting to move to more independent settings.

Kregel, Wehman, Seyfarth, and Marshall (1986) studied 300 young adults living in the community with respect to satisfaction with placement. Over three-quarters of the residents responded to a multiple-choice question regarding satisfaction as being very satisfied or somewhat satisfied with their lives. Fifteen percent were dissatisfied and 4% were very dissatisfied with their lives, the most frequently reported problems being lack of work skills, transportation problems and lack of money. Other reported problems included loneliness, lack of leisure activities,

difficulties in making friends, inappropriate behaviour, and health problems.

Similar problems were reported by ex-residents of a state school studied by Gollay, Freedman, Wyngaarden and Kurtz (1978). The most frequently mentioned aspect of residential living concerned social relationships with other people, with more than 80% disliking the people with whom they lived. The next most frequently mentioned aspect was the degree of freedom and independence, and then social and recreational interests. Gollay et al. found that 90% of those remaining in the community liked their current living situation; (the 10% dissatisfaction rating was consistent with an 8.2% dissatisfaction rating reported by a national census of the US population in 1975). However, satisfaction with living placement was not incongruent with wanting to move on, as more than 33% of the residents interviewed said that they would prefer to live elsewhere, usually in a more independent setting.

Seltzer and Seltzer (1978) studied 70 mild to borderline intellectually disabled people who had been living in the community for four years in a wide range of placements, on aspects related to satisfaction with work and residential placements. Satisfaction was found to vary between placements, with the most satisfied living in independent apartments and the least satisfied among those who had returned to the institution. The latter group also tended to have more behaviour problems than those who had remained in the community. The relationship between type of placement and satisfaction was not linear, in that those in

semi-independent living apartments were not as highly satisfied as the researchers expected, while those in foster homes were more satisfied than the researchers expected. This led Seltzer and Seltzer to the conclusion that amount of independence given to residents is not the sole criterion for satisfaction. Satisfaction with the physical setting was the single most important criterion used by the intellectually disabled adults in evaluating the relative desirability of their residences. Those who lived in houses that were kept clean and in good condition, who were given more responsibility for household tasks, and who participated in more community activities, were most satisfied with the physical setting. Most of the residents interviewed were satisfied with their work places, although successful workers in workshops felt that they were underpaid. Of those who were unemployed, some were bored but all but one said that their lives were better in the community as compared to the institution.

Seltzer (1981) also found that there was a positive relationship among the members of his sample between feelings of satisfaction and relevant aspects of the residential environment. Satisfaction with in-house responsibilities was higher when formal skill training was provided by staff and satisfaction with autonomy was higher when the actual autonomy afforded in the residential environment was high. Only satisfaction with social relationships was not related to aspects of the residential environment. Intagliata, Crosby and Neider (1981) also

found that satisfaction with the community was drawn from relationships with other people.

Halpern, Nave, Close and Nelson (1986) studied 257 moderately to borderline intellectually disabled clients in community placements. They proposed a four-dimensional model of evaluation of community adjustment. This included three objectively measured factors - social support or safety (minor or major abuse and social support), occupation (employment status, income after housing, integration with non-intellectually disabled people), and residential environment (access to services, residential comfort, neighborhood quality), as well as the subjective measure of satisfaction (programme satisfaction, self-satisfaction, overall satisfaction). Halpern et al. measured overall satisfaction with a 40-item questionnaire which assessed satisfaction with the four proposed life domains (employment status, residential environment, support and safety, and self-satisfaction). A factor analysis revealed that the questions loaded onto the four proposed domains and that the level of association between the factors was quite low. The only exception to this was the satisfaction factor which correlated significantly with residential environment (.41) and with support/ safety (.61). Halpern et al. felt that research could continue to refine measures in each domain and this would simplify the task of outcome measurement.

However, there are problems with many of the studies or questionnaires used to date. Few present reliability or validity data or show that they have taken into account the difficulties involved in interviewing intellectually

disabled people when constructing the questionnaire. (This issue will be discussed in more detail in the following chapter). Rather researchers use the questionnaire as part of the research without first investigating its psychometric properties.

One exception to this is the Heal and Chadsey-Rusch (1985) survey of satisfaction among former residents of institutions now living in the community. Heal and Chadsey-Rusch interviewed 38 residents living in apartments and an intermediate care facility that cared for 58 people. They used a 50-item Residential Satisfaction Scale that had been used by previous researchers. After testing for test-retest and inter-rater reliability the scale was modified to a 29-item scale called the Lifestyle Satisfaction Scale. This scale also includes a sub-scale designed to measure acquiescence (a tendency to say "yes" regardless of question content). The scale consists of four sub-scales: Community Satisfaction (nine items), Friends and Free Time Satisfaction (six items); Satisfaction with Services (seven items), and General Satisfaction (five items). A single Job Satisfaction item is also included.

Heal and Chadsey-Rusch found that the four major subscales had such high inter-correlations that they could not be said to be measuring greatly different constructs. However, their intercorrelations were much less than their reliabilities, suggesting that the subscales had some uniqueness and were not merely measuring the same thing. Heal and Chadsey-Rusch also found, when comparing facility types, that the apartment dwellers were more satisfied with

their facility and community environment and their general lifestyle than those in intermediate care facilities. The residents did not differ in their satisfaction with friends, community services, their jobs, or in their acquiescence. Heal and Chadsey-Rusch felt that they had established the reliability and validity of the scales but their sample was small and heterogeneous and further research with a larger and wider group of people is needed.

Seltzer, M. (1984) has also studied the satisfaction of intellectually disabled people in the community, using a demonstrably reliable questionnaire. Seltzer was concerned to measure the subjective experience of work not available by way of observational measures, since she considered this to be an important component of satisfaction. Each subject was interviewed using the Job Description Index, modified from a self-report measure to a structured interview requiring "Yes", "No" or "Not Sure" answers. In addition to the questionnaire, sample members were asked to respond to several open-ended questions and to rate their overall satisfaction on a five-point scale (which consisted of representational drawings of five faces ranging from a scowl to a broad smile). Seltzer found that sample members who experienced downward mobility (i.e. who had previously held competitive jobs but were now unemployed) were less satisfied than those who were not downwardly mobile. In addition, it was found that sample members who were more satisfied with their tasks at work were more self-confident and felt that leisure time activities were more satisfying. Those who were more dissatisfied with their tasks at work

were more likely to say that they wanted competitive jobs. Task dissatisfaction was the major aspect related to seeking other employment. More communication between employer and employee was found to be related to a higher degree of satisfaction with supervision.

Setzer also examined the relationships between satisfaction with co-workers and satisfaction with pay with other aspects of the lives of those participating in the study. She found that those who were satisfied with their co-workers seemed to be happier in general, more self-confident and optimistic, liked their housemates more, and were more successful in their residential placements than those who were not satisfied with their co-workers. It seemed that those who were more satisfied had better social skills. With respect to satisfaction with pay, those who were more competent workers tended to feel that their pay was too low, while those who were less competent were more satisfied with their pay. It was also found that overall satisfaction was related to satisfaction with tasks, satisfaction with co-workers, and satisfaction with supervisors, but was not related to satisfaction with pay and with promotional opportunities. Thus, the most important things related to work satisfaction included the content of the work and the interpersonal climate of the work setting.

The fact that the subjective satisfaction of the persons being studied often differs from an observer's judgement about how well a person is managing, leads to a dilemma as to whose assessment (in terms of community

adjustment) should be valued most - that of the observer/evaluator, or that of the individual. Edgerton and Bercovici (1976) felt that a dilemma had been posed because researchers' criteria of adjustment tend to emphasise competence and independence while the intellectually disabled people themselves emphasise personal satisfaction.

Edgerton (1975) stated that it should be remembered that there are many culturally acceptable lifestyles in society and people with intellectual disabilities usually establish one that is satisfying to them. The tendency to impose a rigid view, that there is only one culture and that normalisation should be judged by middle class standards, is faulty. People with intellectual disabilities do not necessarily come from middle class backgrounds or live middle-class lifestyles and they should not then be rated on how well their current placement or lifestyle adheres to middle-class standards of what is acceptable (Edgerton, 1975). If the principle of normalisation is to be taken literally, then the views of people with intellectual disabilities should be given greater weight when evaluating whether or not the placement is satisfactory than personal competencies, or objective measures of the environment.

The present study, to be described in Chapter 3, is an attempt to develop a questionnaire that can be used to measure the satisfaction of people with intellectual disabilities with their lifestyle. The questionnaire has been designed to be suitable for use with people who are either living semi-independently in the community or who are still living within an institutional setting. Previous

research has shown that while many intellectually disabled people living in the community may be living in impoverished circumstances, many are happy with their current residential placements, although they tend to report difficulties such as arguments with other residents in the placement and with making friends. Few researchers have compared the satisfaction levels of former residents of institutions, now living in the community, with a comparable group of people still living within an institution. With the current emphasis on movement of people from institutions to community placements, it is important to test whether those living in the community are indeed more satisfied than those remaining in the institution. This research was designed to test whether, in fact, former residents of an institution living in the community are more satisfied than those remaining in the institution. The community units were developed by the institution to be small, homelike, and integrated into the community and the "success" of these placements will be tested in terms of the satisfaction level of the residents. It was predicted that those in the smaller community placements would be more satisfied than those remaining in the institution. The development of the questionnaire and the model of quality of life upon which it has been based will be presented in the following chapter.

CHAPTER THREE

CONSTRUCTING THE QUESTIONNAIRE

Studies examining the Quality of Life of nondisabled populations have demonstrated that relevant variables fall into two broad areas; i)objective factors that are observable and easily measured; and ii)subjective factors that are measured by self-report. Applying these two concepts to the literature on Quality of Life with intellectually disabled people, it can be seen that such studies also fall into one or other of the two broad areas. Thus, there are those studies that have measured changes in adaptive behaviour, quality of the residential climate, use of community resources and so on - i.e. studies that have examined the objective, or observable component of Quality of Life; and there are those that have looked at how the person him/herself feels about his/her life - i.e studies that have examined the subjective component of Quality of Life. However, the bulk of the research is concerned with the first area and very few studies have investigated the subjective aspect of the Quality of life of people with an intellectual disability living in either community or institutional settings. While it is important to study the objective factors, it is equally important to examine a person's subjective feelings in order to develop a measure of "success" of a given program at the level of the individual (Landesman, 1986). For the purpose of this study

the subjective factor is taken to mean the individual's satisfaction with his/her particular lifestyle - meaning satisfaction with: residential placement; work placement; use of leisure time; financial status; interpersonal relationships; physical health; and with him/herself (self-esteem).

These seven areas conform to the model proposed by Minor, Bradburn and Schaeffer (1980) to explain the Quality of Life of nondisabled persons. Minor et al. considered interpersonal relationships (especially familial and marital relationships), leisure activities, financial status and work situation to be significant aspects of all adult lives, with three other domains of residential environment, affective states and physical health also being seen as influential in determining judgements about life satisfaction. These broad areas are applicable to persons with intellectual disabilities, with only minor modification required to the content of the areas to make them more applicable to the lifestyles and living situation of people with an intellectual disability.

When devising the questionnaire to measure the seven aspects of satisfaction with life it proved necessary to divide the seven scales into sub-areas. With respect to the residential placement scale, the literature review showed that social ~~realtionships~~ relationships in the home, privacy, autonomy within the home, and location of the home could affect satisfaction. The scale was therefore divided into the sub-areas for satisfaction with; the physical environment of the house, both externally and internally; social aspects of

the house lived in; the staff with whom residents had daily interactions; in-house responsibilities for tasks of daily living; and the rules and restrictions that existed in the house.

With respect to employment, research reviewed has shown that satisfaction with work placement could be determined by satisfaction with the physical aspects of the building and working conditions in the building, satisfaction with the tasks under taken at work, satisfaction with interactions with other workers and staff, and satisfaction with the amount of pay received for work.

Leisure time generally consists of two parts; general leisure time after work and on weekends; and holidays from work and the satisfaction with Leisure Time scale was therefore divided accordingly.

Satisfaction with financial status has generally been seen in the literature as general satisfaction with the amount of money available to be spent and the way that one spent it.

Regarding interpersonal relationships, the literature review showed that satisfaction with relationships with other people with whom one shared accommodation, satisfaction with relationships with friends; and satisfaction with relationships with one's family were important sub-areas.

Satisfaction with physical health and self-esteem were not divided into smaller categories but were treated as general scales when devising the questionnaire.

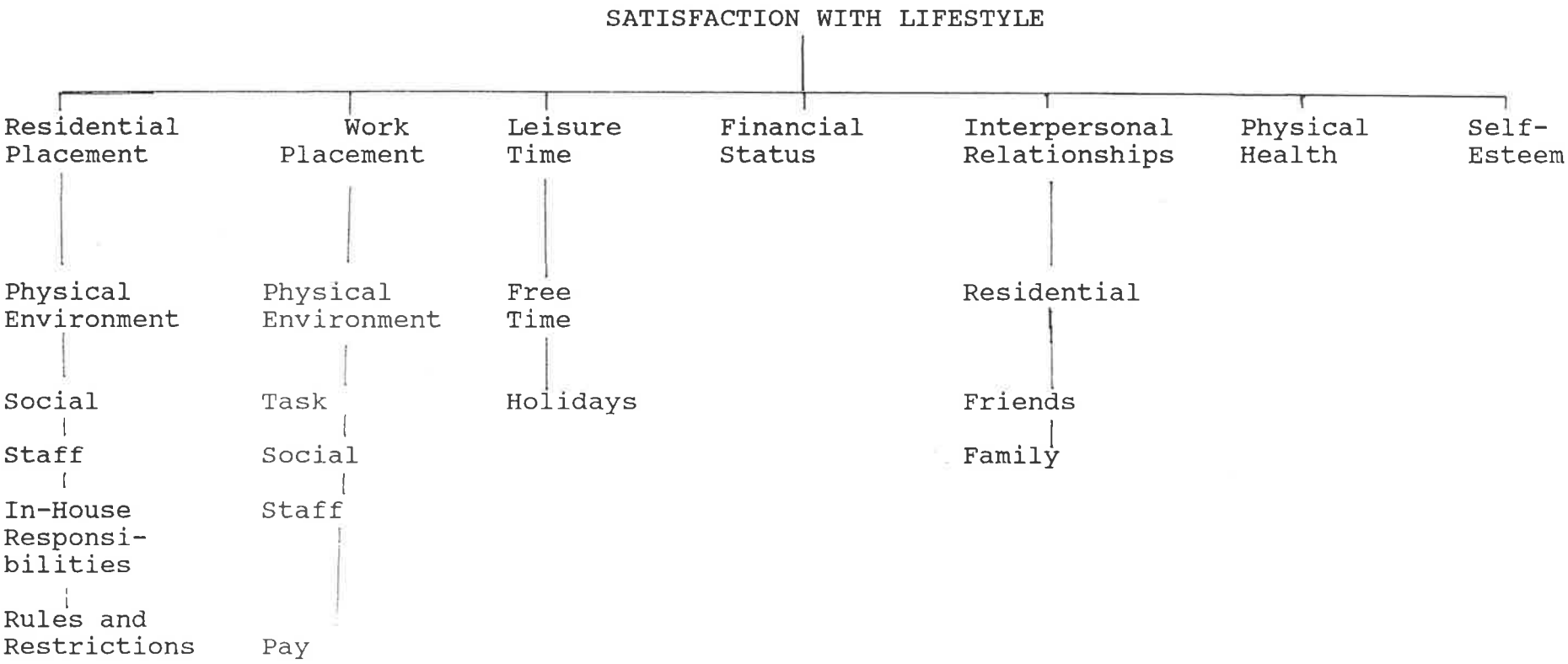
The model of Quality of Life adopted for the purpose of this study is presented in Figure 1. Details about the development of the Resident Satisfaction Questionnaire follow.

Selection of Response Format:

The selection of the response format is especially important when interviewing people with an intellectual disability. According to Wyngaarden (1981), who interviewed 440 former residents of institutions in the US, people with intellectual disabilities are valid sources of information and, in any case, in some instances they are the only appropriate source. They are the only ones who can tell how satisfied they are with their particular lifestyle and an investigation into the adequacy of community placements would be of limited value without the inclusion of the views of the people under study (Flynn, 1986). However, while people with an intellectual disability are increasingly being involved in decision making and being encouraged to speak for themselves, it is important that the validity of their responses be examined (Sigelman, Budd, Spanhel, & Schoenrock, 1981a).

Issues that are relevant to the interviewing of nondisabled populations are as relevant to interviewing people with an intellectual disability. It has been shown that children or adults with low intellect or of low educational background are particularly susceptible to response biases. For example, Rosen, Clark and Kivitz (1977) found that children with an intellectual disability

Figure 1: Model of Satisfaction with Lifestyle



displayed more acquiescent and compliant behaviour than nonintellectually disabled children of the same age. Even persons from good educational backgrounds may tend to acquiesce on particular types of questionnaires. For example, Ray and Pratt (1979) found that Australian Army conscripts and officers were susceptible to acquiescence on a measure of Conservatism. Although the sample was homogeneous, which may have contributed to the low internal reliability scores that were found (Feather,1980), this homogeneity did not rule out entirely the possibility of some acquiescent response set affecting the outcome.

Before formulating a questionnaire, literature examining the effect of types of questions on the responsiveness and reliability of people with an intellectual disability was reviewed. Sigelman and his colleagues (Sigelman, Budd, Spanhel and Schoenrock, 1981a; Sigelman, Budd, Spanhel, and Schoenrock, 1981b; Sigelman, Budd, Winer, Schoenrock, and Martin, 1982; Sigelman, Schoenrock, Spanhel, Hromas, Winer, Budd, and Martin, 1980; Sigelman, Schoenrock, Budd, Winer, Spanhel, Martin, Hromas, and Bensberg, 1983; Sigelman, Schoenrock, Winer, Spanhel, Hromas, Martin, Budd, and Bensberg, 1981; Sigelman, Novak, Heal and Switzky, 1980) have examined the responses of intellectually disabled people to a variety of different types of questions. Their studies have involved, in total, 180 community and institutionally based children and adults ranging from profound to mild levels of intellectual disability. A summary of results follows, from studies examining the use of four different types of questions;

Yes/No, Either/Or, Multiple Choice and Open-ended Questions.

Yes/No Questions:

Yes/No questions were found by Sigelman et al. (1983) to be the easiest type of question for intellectually disabled people to answer (with the exception of some questions which required subjective responses). Yes/No questions required little in the way of verbal behaviour on the part of the person, other than a nod or shake of the head, and could thus be used with people having poor language skills. Test-retest reliability of these questions was high, with the same response being made a week apart. However, the predominant type of response consistency (or reliability) was found to be answering "yes" both times (8 of the 12 questions), leading the researchers to conclude that the test-retest reliability may have been inflated by a bias towards a positive response. Thus, high reliability is not necessarily evidence that the response was valid, in the sense that such responses may not agree with responses to the same questions from significant others (i.e. a parent or caregiver) (Sigelman, Schoenrock, Winer, Spanhel, Hromas, Martin, Budd, and Bensberg, 1981a). To examine this issue Sigelman et al. (1981a) looked at the consistency of responding to alternative questions on the same topic and compared the responses with information provided by significant others.

There are two problems with using these approaches to validity. One is that people may respond consistently but still not reveal the truth; and the other is that lack of

agreement with an external person cannot necessarily be taken to indicate that the intellectually disabled person is wrong. However, both measures will provide some evidence of response validity.

The researchers found that there was poor consistency between responses to oppositely worded questions on the same topic and that many of the subjects' responses did not match with the responses of significant others. They felt that acquiescence negated the value of Yes/No questions and showed that a number of subjects, especially in the severely intellectually disabled group, agreed to questions which were clearly incorrect (e.g. respondents gave "Yes" answers to such questions as: "Are you Chinese?", "Are you a school bus driver?"). Sigelman et al. (1981a) concluded that acquiescence was most influential when the person failed to understand the question, or when the correct answer was not known. However, the researchers also found that acquiescence was not always found on yes/no questions. Sigelman et al. (1983) also found that intellectually disabled people are more likely to acquiesce when "yes" is consistent with the socially desirable response but not when "no" appears to be socially desirable. Acquiescence was found to be related to IQ, with those with lower IQ scores acquiescing more than those with higher IQs, but it was no more likely in institutional than community samples (Sigelman et al., 1980). Despite the difficulties encountered with the use of yes/no questions, it has been argued that such questions can be used if adequate checks for acquiescence (such as oppositely worded items

scattered throughout the questionnaire and asking questions that should properly be answered "no") are built into the interview (Heal and Chadsey-Rusch, 1985; Sigelman et al., 1983).

Either/Or Questions:

Although either/or questions do not result in obvious acquiescence, as is evident with yes/no questions, a form of response bias can affect the answers. Sigelman et al. found a tendency for respondents, especially severely intellectually disabled respondents, to choose the last alternative presented. However, they also found that responses to these questions in the either/or format were confirmed more by significant others than was the case with yes/no questions, leading to the conclusion that responses by intellectually disabled people to either/or questions are more valid than those to yes/no questions. Either/or questions were also slightly harder for intellectually disabled people to answer than yes/no questions, in that fewer people were able to respond, but the either/or format was easier than multiple choice or open-ended questions.

Multiple Choice Questions:

Sigelman et al. asked respondents multiple choice questions with two different answer formats. Questions were either associated with discrete alternatives (e.g. "Do you live in a house, an apartment building, a trailer house, or a duplex") or questions required quantitative responses (e.g. "How many friends do you have: a lot, some , not many, or

none?"). The researchers found that questions in both formats were as difficult to answer as open-ended questions. In addition they found that agreement between the respondents and significant others was good for the discrete alternative questions (77.9%) but so low for the quantitative questions (24%) as to make their validity for obtaining information from intellectually disabled people highly questionable. The use of multiple-choice questions was therefore not recommended in research with intellectually disabled people.

Open-Ended Questions:

Sigelman, Budd, Winer, Schoenrock and Martin (1982) asked respondents open-ended questions that required factual and non-factual answers. They found that open-ended questions were unanswerable by many persons and that supplementing such questions with clarifying questions and probes for additional information only served to increase response biases and a tendency to over-report. Sigelman et al. (1983) found that when open-ended questions were used, agreement rates between significant others and the respondents were low, even on factual statements, although outcome varied according to the type of question asked, with questions involving time, money and number concepts being most difficult. When looking at the results of questions which asked respondents what they would like to do or learn, the researchers found that most agreement between the respondent and significant others was because both the client and the significant other did not mention a

particular category. These types of open-ended questions were found to yield little information.

In addition to the results presented above, Sigelman et al. (1983) found that many of the respondents could not provide basic factual information, such as name, birth date, and address. They found that people living in the community were no more likely to agree with significant others than those living in institutions but that those with higher IQs were more likely to agree with significant others than those with lower IQs. However, this relationship was not strong enough to be able to allow the researchers to predict in advance which intellectually disabled persons' responses would be valid.

This research has obvious implications for the response format chosen in the present study. For the Resident Satisfaction Questionnaire to have general use as an evaluation tool it should be useable with as wide a range of people with an intellectual disability as possible. The yes/no format is the easiest type of format to answer and would therefore increase the range of persons able to be interviewed. Either/or questions pose a difficulty in the present context, since to provide two responses for each question would considerably lengthen the questionnaire and it was anticipated that this would lead to problems of poor concentration on the part of the respondents. In addition, it is very difficult to generate true alternatives to questions that involve attitudes (Sigelman et al., 1983). Thus, it was decided to use yes/no questions as the format in this questionnaire. Some open-ended questions were

included, as described below, but only to provide information additional to that sought by other means, and responses to these were not analysed statistically or included in the score on the questionnaire. However, the difficulties with the yes/no format were recognised and steps were taken to reduce response bias. Following the recommendations of Heal and Chadsey-Rush (1985) and Sigelman et al. (1983), an introductory section with questions designed to check for inappropriate responding (i.e. questions which required the respondent to give a "no" answer to be correct) was included. In addition, a number of oppositely worded questions were scattered throughout the questionnaire, as a further check on those who passed the initial screening.

Development of the Resident Satisfaction Questionnaire (RSQ):

As developed, the RSQ consisted of five introductory questions designed to test a tendency to acquiesce, followed by 139 Yes/No questions subdivided into seven scales which probed the individual's satisfaction with residential placement, work placement, leisure time, financial situation, interpersonal relationships, physical health and self-esteem. (The RSQ is presented as Appendix 1).

Introductory Questions:

To pass the introductory section, the respondent was required to give his/her name correctly and to correct enquiries made by the tester that were in error in some way (e.g. "Is today .....(the wrong day)?). The interviewer

also asked the respondent a clearly incorrect question to test the strength of acquiescence (e.g. "Are you Chinese"?). If respondents failed to pass this section the interview was not continued.

Residential Placement:

Eight questions (1-8) dealt with the physical aspects of the house, examining satisfaction with the neighbourhood, the house lived in, personal space in the house and feelings of safety. A further eight questions (9-16) dealt with the social aspects of living in a residential situation. These examined satisfaction with people with whom the accommodation was shared, the number of people in the house, and opportunities for privacy. Questions 17 to 24 dealt with the resident's perception of the staff who worked in the home, specifically satisfaction with the help received and relationships with staff. Questions 25 to 31 dealt with in-house responsibilities - whether there were enough, whether people liked carrying them out, or if such responsibilities took up too much time. Questions 32 to 39 dealt with the resident's perceptions of the rules and restrictions that applied - whether there were too many, if frequent orders came from other people, and how much freedom the resident had to make decisions.

Of the 39 questions, items 1, 10, 11, 15, 19, 22, 28, 31, 32, 34, and 38 came from Seltzer and Seltzer (1978), with the others being devised by the author. At the end of the "Yes/No" questions there were eight open-ended questions, with four (questions 40, 41, 42, and 44) coming

from Seltzer and Seltzer (1978) and the others developed by the author.

Following the open-ended questions, five cartoon-type faces depicting feelings ranging from very happy to very unhappy, were presented, from among which the residents had to select the one that represented how they felt about living where they were. These faces and the instructions associated with them were adapted from Seltzer and Seltzer (1978) and are illustrated below in Figure 2.

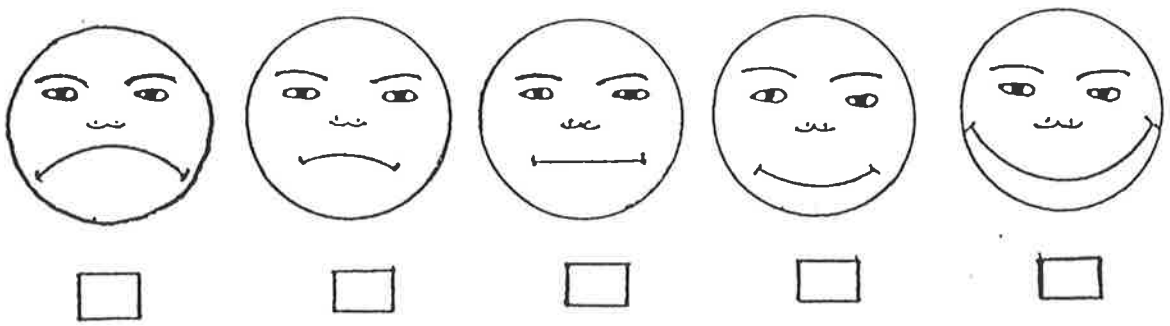


Figure 2: Illustration of cartoon faces of feelings.

Work Placement:

Six questions (1-6) dealt with the workers' satisfaction with the physical aspects of the work environment - the place and building in which they worked. Questions 7 to 12 dealt with tasks that workers were expected to do - whether the jobs done were satisfying and interesting and if the person would rather be doing other jobs. Questions 13 to 17 examined the workers' feelings about the people they worked with - whether they liked them and how well they got on with them. Questions 18 to 23 examined the workers' perceptions

of the staff who worked with them; how much they liked the staff, how much the staff helped them, how easy they were to get along with and whether they taught the workers enough. The last four questions (24 to 27), examined how the workers' felt about pay received and specifically whether they received enough money for the work that they did.

At the end of the Yes/No questions there were three open-ended questions (questions 28 to 30). Items 3, 4, 5, 9, 10, 15, 21, 24, 25, 29, came from Seltzer and Seltzer (1978), with the other items being devised by the author. Another set of five faces followed this section, the instructions for which related to how the person felt about the place where they were working.

Leisure Time:

Questions dealt with how the person felt about his/her use of leisure time. Questions 1 to 7 dealt with the use of spare time - whether there was enough of it and whether residents did enough things in their spare time. Questions 1, 3, 4, and 7 were adapted from Seltzer and Seltzer (1978) with the others devised by the author.

Questions 8 to 13, devised by the author, dealt with use of leisure during holidays from work. The questions examined whether residents felt that they had enough holidays from work and if they did enough things in them. The five faces were again presented, with instructions relating to the use of leisure time.

Financial Status:

Questions dealt with how satisfied the residents were with their financial situation - whether they felt that they had enough money to spend, and to what extent they were satisfied with their level of involvement in decisions in how they spent their money. Question 8 came from Seltzer and Seltzer (1978), the other ten questions being developed by the author. The five faces were presented, with the instructions now related to satisfaction with financial status.

Interpersonal Relationships:

Nineteen questions in this section tested satisfaction with three different sets of relationships: Questions 1 to 7 dealt with the people with whom he/she lived with, whether these people were trusted and if the resident would choose to live with them again. Questions 8 to 14 were aimed at relationships with friends, whether he/she had enough friends and was able to spend sufficient time with them. Questions 15 to 19 dealt with perceptions about relationships with family - how often members of the family were seen and whether the respondent wished to see more of them.

Questions 1, 2, 3, 9, 11, and 15 in this scale came from the Seltzer and Seltzer (1978) questionnaire, with the others suggested by results of research encountered in the literature review.

The five faces were not presented at the end of this scale nor the following two scales, because the format was

not readily consistent with the use of these scales.

Physical Health:

Questions dealt with satisfaction with physical health, whether he/she felt well most of the time, whether the respondent worried about getting sick and whether any fears or worries existed. The questions in this section were suggested by the review of the literature.

Self Esteem:

The questions in this section were designed to a measure the respondent's self esteem and were adapted from the Self-Evaluation Scale (Cautela, Cautela, & Esonis, 1983).

Scoring the Resident Satisfaction Questionnaire:

Items were scored 1 if the answer was positive and 0 if the answer was negative, or if the respondent could not give a satisfactory answer to the question, or did not know the answer. The total for each scale was the sum of scores on all items in that scale. Totals were transformed into percentage scores to permit comparisons across scales. An overall satisfaction rating on the RSQ was obtained by adding the scores received for all items and dividing the number by the total of number of items in the questionnaire. However, due to the structure of the questionnaire, this procedure varied for two scales - the Residential Placement Satisfaction scale and the Satisfaction with Interpersonal Relationships scale, since some of the items were used as an internal measure of consistency of responding. Percentage

scores were adjusted to account for duplication.

Although there were other items within each scale that were used to measure consistency of responding, these were reworded versions and it cannot be demonstrated that these two forms of the question were exact opposites. Therefore, the scores for these items were included in the total score of the scale. The items used to calculate consistency of responding, in addition to the six items above, are listed below:

Residential Placement Scale	- Items 1 & 3, 9 & 15, 18 & 22, 25 & 30, and 33 & 37
Work Placement Scale	- Items 1 & 3, 8 & 10, 13 & 16, 22 & 23. and 24 & 27.
Leisure Time	- Items 1 & 3, and 10 & 13
Financial Status	- Items 1 & 3
Interpersonal Relationships	- Items 1 & 4. and 8 & 11,
Physical Health	- Items 1 & 2
Self-Esteem	- Items 8 & 13

Consistency of responding was measured using two different formats. In the first, respondents had to answer both forms of the question with the same response (i.e. Yes/Yes or No/No). However, because a person could be consistent but still show acquiescence, a second format was used in which, respondents had to reverse the direction of the response required. Thus, in one version of such a question a "Yes" response indicated a positive response but in the second version of the same question the direction had been reversed

so that a "No" response was required to maintain consistency.

The Development of the Staff Questionnaire:

The staff questionnaire was developed to gain an independent measure of residents' satisfaction and of the degree of responsibility, autonomy, and decision making afforded residents in their particular accommodation. (The Staff Questionnaire is presented as Appendix 2)

The first section of the questionnaire dealt with staff perceptions about the satisfaction of residents who were being interviewed. Two (or in one case, three) questions were developed to measure staff responses in each of the seven areas covered by the Resident Satisfaction Questionnaire.

These were:

Satisfaction with Residential Placement	- Questions 3 & 4
Satisfaction with Work Placement	- Questions 5 & 6
Satisfaction with Leisure Time	- Questions 8 & 9
Satisfaction with Financial Status	- Questions 10 & 11
Satisfaction with Interpersonal Relationships	- Questions 12,13, 14 & 19
Satisfaction with Physical Health	- Questions 15 & 16
Satisfaction with Self-Esteem	- Questions 17 & 18

In addition, questions 1, 2 and 7 measured overall satisfaction.

Staff rated the resident's perceived satisfaction on a five point scale, ranging from very dissatisfied (-2) to very satisfied (+2), with a neutral rating scored 0. Scores

from the two items in each section were added together and a total score on all the subjective items was calculated. Scores from each of the seven sections and the total score were then correlated with the appropriate sub-scale on the Resident Satisfaction Questionnaire.

The second section of the Staff Questionnaire was involved objective items, in order to examine the degree of responsibility, autonomy, and decision making permitted by staff to residents, as outlined below.

Responsibility for performing household tasks was measured by Scale 20. For the 18 items in this section staff indicated if each task was performed by the resident alone, by the resident with assistance, or by staff alone.

Degree of autonomy afforded residents was measured by Scale 21, consisting of 25 items. Staff stated whether residents were allowed to do the items listed at any time, only with staff permission or at certain times, or not at all.

Degree of decision making that the residents were allowed in the running of the household was measured by Scale 24, a 30-item scale. Staff indicated if the person alone made the decisions, if decisions were made by the resident in consultation with others, or if they were made by staff alone.

All three scales were adapted from a study by Packer and Wright (1983), although the scoring system differed slightly, each scale being scored on a three-point rating. A score of 2 indicated that the resident performed the item alone; that no restrictions on the resident on that item

existed; or that the person alone made the decision for that item. A score of 1 indicated that the resident performed the item with some assistance; required staff permission to perform an item listed; or that decisions were made in consultation with other residents or staff. A score of 0 indicated either that the item was performed by staff alone; that the resident was not allowed to perform the item at all; or that the decision for that item was made by staff alone. A total score for each scale was obtained by summing scores for individual items.

A member of staff familiar with the resident(s) in question completed a questionnaire for each of the residents in the study. Thus, scores for an individual were calculated with respect to satisfaction with lifestyle (the score on the RSQ), satisfaction as perceived by staff, and for the degree of responsibility, autonomy and decision making afforded the person.

Sections dealing with responsibility, decision making, and autonomy were adapted from the study by Packer and Wright (1983) but those authors did not report reliability coefficients. Furthermore, the scales were considerably altered from their original presentation, including the development of the new first section, and needed to be shown to be reliable in their new form. The issue of the reliability of the staff questionnaire will be addressed in Study 2.

CHAPTER FOUR

ESTABLISHING RELIABILITY

The results of two studies are presented. The first estimated the test-retest and inter-rater reliability Resident Satisfaction Questionnaire (RSQ). The second study examined the test-retest and inter-rater reliability of the Staff Questionnaire. Results from the Staff Questionnaire and RSQ were compared to examine the external validity of the latter.

STUDY 1

METHOD

Participants

Participants were residents of a residential organisation caring for intellectually disabled adults. Thirty-three residents were initially selected to participate but two did not satisfactorily respond to the questions designed to test for inappropriate acquiescence, as described in Chapter 3, and were not further interviewed. Of the 31 remaining 19 lived in an institutional setting, six on a farm in a setting regarded by the residential administrators as intermediate between institutional and community living, and

six in group homes in the community.

The institutional setting is located on the beach front in one of the popular seaside suburbs of Adelaide, the capital of South Australia and a medium-sized city (population 1 million). The institution's campus is surrounded by the local community, is close to local shops and easily accessed by public transport. At the time of the study (1987) the setting provided accommodation for 500 people in 15 single-storey houses, with the number of residents in each house ranging from 14 people to a maximum of 32 people. Participants from the institutional setting were 11 males and 8 females, ranging in age from 18 years 10 months to 36 years 8months (mean=26 years 8 months, SD=5 years 8 months).

The intermediate setting is a unit, supervised for 24 hours each day, for 16 people living and working on a farm. The farm is located in a popular hillside suburb, is no more than 45 minutes drive from the centre of the city, and is surrounded by community housing and new real-estate subdivisions which are occurring on farm land recently sold for property development. However, although not isolated from the community, the farm is some distance from local shops and public transport to the area is irregular. Four males and two females took part in the study from this setting. Ages ranged from 30 years 10 months to 50 years 2 months (mean=36 years 9 months, SD=7 years 8 months).

The group homes are scattered throughout the community within a radius of 10 kilometre from main campus of the institution. Each home caters for 4 or 5 people who live

semi-independently. Staff are in attendance for about 60 hours per week to supervise morning and evening activities but are not present at night. The amount of supervision received by each house varies, this being determined by staff responsible for administering the programme of community placement. There were 6 participants from the group homes, of whom 2 were female and 4 male and whose ages ranged from 28 years 7 months to 46 years 6 months (mean=36 years 1 month, SD=5 years 10 months). Descriptive data for the three groups are summarised in Table 1 below.

All of the individuals participating in the study had been assessed as intellectually disabled prior to their admission to the institution. The assessments were done by either the state agency responsible for the care of people with an intellectual disability or the state children's hospital. Because the assessments had been done, in some cases many years previously, and by another organisation, IQ

TABLE 1: Description of Sample

	N			
Sample	Total	Male	Female	Mean Age
Institutional Setting	19	11	8	26yr 8m
Intermediate Setting	6	4	2	36yr 9m
Community Home Setting	6	4	2	36yr 1m

scores were not available on all of the participants files. The general level of intellectual disability at admission had been recorded as presented in Table 2 below.

There was a significant difference between the groups with respect to age ($F=9.44$, $N=31$, $p<.01$), with participants from the institutional setting being younger.

There was no difference between the samples with respect to sex ($F<1.0$). There was no difference bewteen the groups with respect to IQ ($\chi^2=.24$, $df=2$, $p.0.05$), with most respondents falling in the mild and moderate ranges.

Participants left their places of residence during the day - for employment in various supported (i.e. sheltered) settings, for all but four, aged between 18 and 21 years of

TABLE 2: IQ Level

Sample	Borderline (71-85)	Mild (56-70)	Moderate (36-55)	Severe (<35)
Institutional Setting	1	9	9	0
Intermediate Setting	0	3	2	1
Community Home Setting	0	3	3	0

age, who attended a Special School, located on the grounds of the institutional property but administered separately by the State Education Department of South Australia. Thirteen of the participants were employed in the Activity Therapy Centres (ATCs) of the residential organisation.[1] Eleven of the participants were employed in a variety of independent work stations located on the main campus of the residential organisation or on the farm. Residents in these positions usually worked with a minimal amount of staff supervision or on complicated machinery and received a higher rate of remuneration for such work. These positions included domestic work, working on the farm (in the dairy, piggery, egg sheds, market garden, etc.), maintenance work on the buildings and property, and the laundry. The remaining three participants worked in a craft co-operative which, although attached to the Special School, was run as a work place for students who had graduated from the school.

At the craft co-operative workers made a variety of items, from wooden goods through to woven textiles. Income for the workers in this area came from goods that were sold to the public, and the amount received might vary from week to week depending on the sales.

1. These ATCs provide supported employment for up to 100 people in large buildings, with clients working mainly on contract work - like cutting wires for motor vehicle transmissions, assembling medical specimen containers and packaging parts for sprinkler systems.

Procedure

Participants were asked by institutional staff if they wished to take part in the study. If they agreed, the author negotiated a time for an interview, to be held generally in the evening after the person had returned home from work. Participants were interviewed individually using the RSQ described in Chapter 3 and presented in Appendix 1. This was designed to evaluate satisfaction with: (i) residential placement, (ii) work placement, (iii) leisure time activities, (iv) financial status, (v) interpersonal relationships, (vi) physical health and (vii) self-esteem. Most interviews were conducted in private in the participant's house, usually in a lounge room. However, if no quiet or private place was available in the house then the interview was conducted in an office located on the institutional grounds. This was necessary for only seven of the participants from the institutional setting.

Each participant was read the following instructions, adapted from Packer and Wright (1983):

> " I am here today to talk to you about the work I am doing and to ask you to help me with this work. I am interested in talking to you and other people who live here about where you live and if you are happy with the way that you are living. I am asking these questions because I want to find out what is good about the place, as well as what might be bad about it, and to find out what you want. This will help the people who run these places know how they can be made better.

> This is not a test. There are no right or wrong answers to the questions. I just want to find out how you feel about things. I will not tell anyone what you tell me unless you want me to.
>
> If you would rather not talk to me you can say so now. If there are any questions that you do not want to answer, then that is alright, just let me know. If you want to ask me questions then stop whenever you want and ask them." None of the participants elected not to continue with the interview.

During the interview the 136 items in the RSQ were read to the participant, the interviewer ticking the "Yes", "No", or "Not Sure" boxes according to the response. If the participant did not appear to understand the question it was repeated. If the participant still did not understand the question, it was paraphrased. If, after this, the participant appeared not to understand the question then the interviewer ticked a "Not Sure" response. If an answer contradicted a previous response then the question was repeated (following Heal and Chadsey-Rusch, 1985).

After the interview the interviewer thanked the participant for his/her time and left. Participants were interviewed again approximately seven days later, using the same questionnaire. The longest time between interviews was fourteen days in one case who had gone away on a camp.

RESULTS

Item Test-Retest Reliabilities:

Reliability of the individual items in the RSQ was examined by calculating the proportion of agreement between answers to the same item on the two testing occasions. However, it cannot be assumed that by chance alone agreement on each occasion would be 50%, especially as high agreement might be obtained by people responding "yes" on both occasions. For this reason, the statistic Kappa was calculated, as a means of determining how much a given agreement figure exceeds what can be expected on the basis of chance. Chance probability was calculated from the marginals of the 2x2 contingency table summarising the outcome on the two occasions. The kappa statistic ranges from -1 to 1, a negative kappa indicating that disagreement is more likely than one would expect by chance, a kappa around zero indicating that agreement is not different from what would be expected by chance, and a large positive kappa indicating consistency beyond chance probability. A large kappa is very difficult to obtain when a question leads to a very high proportion of "Yes" responses on both occasions because the odds of agreement by chance are high. An illustration of the calculation of kappa, using the results from item 2 of the Residential Placement Scale is illustrated in Appendix 3.

Criteria for Inclusion in Questionnaire:

According to Sigelman, Schoenrock, Budd, Winer, Spanhel, Martin, Hromas, and Bensberg (1983), the Kappa statistic should not be used as the ultimate criterion of reliability. If an item has a high proportion of agreement this indicates that there is high reliability and that individuals are saying the same thing on both testing occasions, irrespective of kappa. If high proportion of agreement is also associated with a high Kappa then this result can be regarded as conclusive. Similarly, where there is both low proportion of agreement and a low Kappa, then the usefulness of the item should be questioned. For the purpose of this study, those questions which showed proportion of agreement of .75 or more were accepted, while those questions which received proportion of agreement scores of .64 or below were deleted from the questionnaire. Items with between .65 and .74 proportional agreement were scrutinised closely and then, depending on the kappa score, were either accepted or rejected. Results are presented below for each section of the questionnaire.

The Residential Placement Scale:

The item proportion agreement and Kappa statistics for the Residential Placement Scale are presented in Table 3. Proportion agreement ranged from .52 to 1. Two items (12 and 18) were excluded from the scale on the basis that they had proportion agreement scores that were below .64. Items 14 and 22 had agreement scores between .64 and .75 and were deleted from the questionnaire because of low kappa scores.

TABLE 3: Test-Retest reliability for satisfaction with residential placement

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
1. Do you like the area you live in?	90%	0%	.90	
2. Do you feel safe in this suburb?	81%	13%	.94	.78*
3. Is it a nice area to live in?	100%	0%	1	
4. Is your house a nice place to live in?	94%	0%	.94	
5. Do you like your bedroom?	100%	0%	1	
6. Do you feel safe in this house?	87%	6%	.93	.61*
7. Would you rather live in a different area?	68%	19%	.87	.67**
8. Would you rather live in a different house?	74%	16%	.90	.71**
9. Are the people you live with nice people?	97%	0%	.97	
10. Do too many people live here?	35%	48%	.83	.66***
11. Do you have enough chance to be alone if you want to be alone?	81%	6%	.87	.41
12. Would you rather more people lived here?	26%	29%	.55	.12
13. Would you rather be living by yourself?	71%	19%	.90	.73***
14. Would you rather less people lived here?	55%	16%	.71	.31
15. Do you like the people you live with?	94%	0%	.94	
16. Would you rather live with someone else?	77%	13%	.90	.67**
17. Do you like the staff who work here?	100%	0%	1	
18. Do you get criticised unfairly by staff	13%	39%	.52	.09
19. Do the staff here help you with your problems?	77%	0%	.77	
20. Do the staff here make you do too much?	10%	65%	.75	.32
21. If you had a problem would the staff here help you?	97%	0%	.97	
22. Do you think the staff pick on you?	3%	71%	.74	.07
23. Are the staff here hard to get along with?	19%	52%	.71	.36*

cont..../

Table 3 cont...

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
24. Would you like the staff here to teach you more things?	90%	0%	.90	
25. Do you like to do jobs around the house?	100%	0%	1	
26. Do you have enough jobs to do?	81%	0%	.81	
27. Does doing your jobs take up too much time?	6%	77%	.83	.43*
28. Do your jobs make you feel useful?	48%	29%	.77	.54**
29. Do you have too many jobs here?	16%	74%	.90	.71**
30. Do you mind doing.....? (eg laundry)	0%	97%	.97	
31. Would you rather have someone else do the jobs for you all the time?	13%	71%	.84	.51*
32. Are there too many rules around here?	23%	52%	.75	.47*
33. Do you have the freedom to do what you want?	81%	13%	.94	.78**
34. Do other people tell you what to do too much?	16%	61%	.77	.43*
35. Are you allowed to make up your mind about the things that you want to do?	87%	0%	.87	
36. Do you want the staff to tell you what to do more often?	32%	61%	.93	.85***
37. Can you do what you want to when you want to?	84%	10%	.94	.74**
38. Can you go out whenever you want to?	90%	0%	.90	
39. Can you go out without telling staff where you are going?	6%	84%	.90	.52

* p<0.05, ** p<0.01, *** p<0.001

Item 23 (proportion agreement was .71) was retained because it had a significant kappa score.

Following removal of the four items referred to, a total score for the scale was obtained by adding scores for each of the items. An item was scored 1 if the response was in a positive direction and 0 if the item was answered in a negative direction. Test-retest correlation for the residential placement scale, with the four unreliable items removed, was high (Pearson $r = .80$, $N=31$, $p<0.001$).

Six pairs of questions in this scale (items 1 and 3, 12 and 14, 9 and 15, 18 and 22, 25 and 30, and items 35 and 37) tested the internal consistency of responding. Responses were considered consistent if both items in that pair were in the appropriate direction; for example answering both "Do you like the area you live in?" and "Is it a nice area to live in?" with either a "Yes" or "No" response on both questions. (Two pairs of items (items 12 and 14 and items 18 and 22) were excluded previously because of low test-retest reliability and low consistency; 40% and 55% respectively. This may have been due to the use of qualitative concepts. Previous research has shown that intellectually disabled people do have difficulty with qualitative concepts such as more or less. Items 18 and 22 were also questions that required a reversal response.).

Responses to all pairs were highly consistent; items 1 and 3, 96%; items 9 and 15, 96%; items 25 and 30, 99%; and items 35 and 37, 84%. Although these items could be answered consistently by people who were acquiescing, no check for this was possible since the two pairs of items

requiring that direction of responding be reversed were found to be unreliable.

There were apparent inconsistencies in responding to individual items. High positive responses to item 1 ("Do you like the area you live in?") item 3 ("Is it a nice area to live in?") and item 4 ("Is your house a nice place to live in?") appear contradictory with high positive responses to item 7 ("Would you like to live in a different area?") and item 8 ("Would you like to live in a different house?"). However, previous research by O'Connor (1976) has shown that residents can be satisfied with their current placement and still wish to live elsewhere, so the finding that residents in this study were satisfied with their residence but still wished to live elsewhere is not necessarily contradictory.

The Work Placement Scale:

Table 4 shows the proportion agreement and Kappa scores for the items in the Work Placement Scale. Five items in this scale fell into the range between .65 and .74 proportion agreement, but only item 23 was deleted because kappa was not significant. The overall test-retest reliability of the corrected total score for the scale was acceptable ($r=.63$, $N=31$, $p<0.001$).

Again, there were some inconsistencies in the results with the responses to items 24 ("Do you get paid enough money for working?") and 27 ("Do you get paid enough money for the work you do?") appearing inconsistent with the response to item 25 ("Do you get paid less than you are worth?"). During the interviews it appeared that some

TABLE 4: Test-Retest reliability for satisfaction with work placement

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
1. Do you like the place where you work?	90%	3%	.93	.46
2. Is it a nice building to work in?	87%	3%	.90	.38
3. Is it a nice place to work?	87%	3%	.90	.38
4. Do you have to stand on your feet too much	35%	39%	.74	.48**
5. Do the days seem too long at work?	16%	58%	.74	.59*
6. Would you rather be working somewhere else?	52%	29%	.81	.60***
7. Do you like the jobs that you do at work?	90%	3%	.93	.46
8. Do you think that your work is interesting?	84%	3%	.87	.28
9. Does your job make you feel useful?	42%	29%	.71	.42**
10. Is your work boring?	19%	55%	.74	.53**
11. Do you have enough to do at work?	81%	10%	.91	.64*
12. Would you rather be doing different jobs?	48%	29%	.77	.52**
13. Do you like the people you work with?	94%	0%	.94	
14. Are the people you work with ever not nice to you?	29%	42%	.71	.43**
15. Do the people you work with talk too much?	39%	48%	.87	.74***
16. Are the people you work with nice people?	94%	0%	.94	
17. Would you rather be working with different people?	55%	23%	.78	.51**
18. Do you like the staff at work?	94%	3%	.97	.67
19. Do the staff at work help you when you need it?	90%	0%	.90	
20. Do the staff at work pick on you?	10%	81%	.91	.63*
21. Do the staff at work tell you when you are doing a good job?	90%	3%	.93	.63*
22. Do the staff at work teach you enough?	77%	10%	.87	.52*
23. Do you want the staff at work to teach you more things?	68%	7%	.74	.17

cont.....

Table 4: cont...

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
24. Do you get paid enough money for working?	74%	7%	.81	.36
25. Do you get paid less than you are worth?	78%	0%	.78	
26. Do you think your pay is bad?	11%	67%	.78	.37
27. Do you get paid enough for the work you do?	78%	15%	.93	.77**

* p<0,05, ** p<0.01, *** p<0.001

of the participants had difficulty with the concept of "less than you are worth" and the high "yes" agreement may have been acquiescence, due to a failure to understand the question.

Five sets of questions had been designed as measures of internal consistency (items 1 and 3, 8 and 10, 13 and 16, 22 and 23, and items 24 and 27). Items 1 and 3, 13 and 16, and items 24 and 27 were answered highly consistently (99%, 97% and 95% respectively). Two of the pairs (items 8 and 10 and items 22 and 23) had opposite wordings, requiring a "yes" response on one item to be paired with a "no" response on the other item. Both were answered with poor consistency (26% in both cases). It may have been that participants had particular difficulty with item 23, because the quantitative concept of "more" was required.

The Leisure Time Scale:

Proportion agreement and kappa scores for the Leisure Time scale are presented in Table 5. Six of the items had proportion agreement between .65 and .74 and of these, five were excluded on the basis of low kappa scores (Items 2, 3, 5, 8, and 10). Again some of the difficulty experienced may have been due to the use of quantitative concepts in items 2, 3, and 8.

After removing the unreliable items, the reliability of the total scale score remained low ($r=0.28$, $N=31$, $p=0.06$) and this scale has not been subsequently included in the revised RSQ.

TABLE 5: Test-Retest reliability for satisfaction with leisure time

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
1. Do you have enough to do in your spare time?	13%	65%	.78	.63***
2. Do you have enough spare time?	68%	6%	.74	.21
3. Would you like to do more things in your spare time than you do now?	65%	6%	.71	.12
4. Do you wish you had more spare time to do things?	87%	3%	.90	.38
5. Is it easy to find things to do in your spare time?	68%	6%	.74	.21
6. Are you ever bored?	26%	42%	.68	.37**
7. Do you want someone to show you more things to do in your spare time?	61%	19%	.80	.52**
8. Do you have enough holidays from work?	64%	10%	.74	.28
9. Do you do enough things in your holidays from work?	81%	10%	.91	.63*
10. Are your holidays from work boring?	6%	61%	.67	.08
11. Do you wish that there were no holidays from work?	6%	90%	.96	.75*
12. Would you like more holidays from work?	87%	3%	.90	.38
13. Do you do interesting things in your holidays from work?	74%	10%	.84	.47*

* p<0.05, ** p<0.01, ** p<0.001

The Financial Status Scale:

Proportion agreement for items in the financial scale ranged from .77 to .97 and, as shown in Table 6, all items conformed to criteria for retention. Overall test-retest reliability was statistically significant ($r=0.52$, $N=31$, $p<0.001$) though only moderate.

There were some inconsistencies in responses to item 9 ("Should you make more decisions about what you will do with your money?") and item 10 ("Would you like someone to show you how to look after your money better?"), with 71% of respondents feeling that they should not make more decisions about what they do with their money, yet 77% indicated that they would like to be shown how to look after their money better. However, most participants agreed that they decided how to spend their money, so that it is perhaps not too surprising that they did not want to make more decisions about the way in which their money was spent. Despite the fact that participants decided how to spend their money, they still sought to learn to manage their money better. This is consistent with the finding that 48% of the participants stated that they ran out of money before their next pay.

The only pair of items designed to measure internal consistency of responding - item 1 ("Do you have enough money to spend?") and item 3 ("Would you like to have more money to spend?") showed low consistency(15%). It is possible that these questions are not exact opposites, however, and it may not be incongruent to be satisfied with the amount of money that one has but still to desire more

TABLE 6: Test-Retest reliability for satisfaction with financial status

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
1. Do you have enough money to spend?	84%	3%	.87	.24
2. Do you spend too much money?	13%	71%	.84	.52*
3. Would you like to have more money to spend?	90%	6%	.96	.75*
4. Do you have enough money to buy the things that you need?	87%	10%	.97	.85**
5. Do you have enough money to go out when you want to?	84%	3%	.87	.28
6. Do you run out of money before your next pay?	48%	39%	.87	.93***
7. Do you decide how to spend your money?	81%	6%	.87	.41*
8. Do you spend your money the way you want to?	71%	6%	.77	.26
9. Should you make more decisions about what you will do with your money?	6%	71%	.77	.21
10. Would you like someone to show you how to look after your money better?	77%	13%	.90	.68**
11. Do you have enough money to buy special things when you want to?	84%	0%	.84	

* p<0.05, ** p<0.01, *** p<0.001

disposable income.

The Interpersonal Relationships Scale:

Proportion agreement, ranging from .68 to 1, and kappa scores for the Interpersonal Relationships scale are presented in Table 7. All items in this scale met the retention criteria. The test-retest reliability for the total scale score was moderately significant ($r=.63$, $N=31$, $p<0.001$).

Again, there were some inconsistencies in responding. Item 8 ("Do you have enough friends?") and item 11 ("Would you like to have more friends?") were oppositely worded questions designed to be used as a measure of internal consistency of responding. However, most participants responded "yes" to both questions, indicating poor consistency. It is possible that the two questions are not exact opposites and that it is therefore not inconsistent to respond "yes" to both questions; or that the respondents had difficulty with the concepts enough and more, leading to a tendency to say "yes".

Questions 1 and 4 were also measures of internal consistency of responding and were responded to consistently 100% of the time. However, whilst respondents were highly consistent this does not rule out the possibility of acquiescence as the answers did not require a reversal.

TABLE 7: Test-Retest reliability for satisfaction with interpersonal relationships

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
1. Do you like the people you live with?	100%	0%	1	
2. If you were to move would you live with them again?	39%	35%	.74	.5**
3. Can you trust the people you live with?	84%	3%	.87	.28
4. Are the people you live with nice people?	100%	0%	1	
5. Do the people you live with get you into trouble?	26%	42%	.68	.37*
6. Are the people you live with ever not nice to you?	26%	48%	.74	.43**
7. Would you rather be living with someone else?	71%	13%	.84	.52*
8. Do you have enough friends?	87%	6%	.93	.62*
9. Do you spend enough time with your friends?	6%	81%	.87	.43
10. Is it hard to find friends?	52%	39%	.91	.81***
11. Would you like to have more friends?	81%	3%	.84	.24
12. Do you feel lonely a lot of the time?	42%	39%	.81	.62***
13. Do you go out with your friends when you want to?	90%	6%	.96	.61*
14. Do you choose your friends?	97%	0%	.97	
15. Do you see your family?	87%	6%	.94	.62*
16. Would you like to see more of your family?	90%	3%	.94	.47
17. Do you like visiting your family?	90%	0%	.90	
18. Would you like your family to visit you more often?	94%	0%	.94	
19. Can you visit your family whenever you want to?	55%	23%	.78	.50**

* $p<0.05$, ** $p<0.01$, *** $p<0.001$

The Physical Health Scale:

Proportion agreement and kappa scores for the Physical Health scale are presented in Table 8. Agreement ranged from .81 to 1 and all items reached the criteria for retention. The test-retest reliability for the total scale score was acceptable and statistically significant ($r=.65$, $N=31$, $p<0.001$).

The two questions designed to measure consistency of responding (Item 1 - "Do you feel sick often?" and item 2 - "Do you feel healthy most of the time?") acted well as incompatible statements, with most respondents showing consistency (94%), thus indicating that acquiescence does not necessarily occur all the time.

The Self Esteem Scale

Table 9 shows the proportion agreement and kappa scores for the Self Esteem Scale. Proportion agreement ranged from .61 to 1. Two items (Item 6 - "Do you feel that sometimes you are no good at all?" & item 9 - "Do you feel that your life is not very useful?") failed to meet criteria for retention. It may have been that respondents had difficulty with the double negative involved in both questions.

The two questions designed to check consistency of responding (item 8 - "Do you feel that you are a happy person?" and item 13 - "Do you feel that you are sad most of the time?") were answered appropriately (97%). The test-retest reliability for the corrected total scale score was moderately significant ($r=0.59$, $N=31$, $p<0.001$).

TABLE 8: Test-Retest reliability for satisfaction with physical health

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
1. Do you feel sick often?	3%	97%	1	1
2. Do you feel healthy most of the time?	94%	0%	.94	
3. If you are sick is there someone to look after you?	84%	10%	.94	.74**
4. Do you worry about being sick?	16%	71%	.87	.64**
5. If you are sick can you take time off work?	74%	6%	.80	.26
6. When you are sick can you go to a doctor?	100%	0%	1	
7. Do you like the doctor that you go to?	90%	3%	.93	.46
8. Can you trust the doctor that you go to?	87%	6%	.93	.61*
9. Do you want to change your doctor?	19%	71%	.90	.74***
10. Do you have problems that worry you a lot	26%	55%	.81	.58***
11. Is there anything that you are afraid of?	19%	68%	.87	.67***

* P<0.05, ** p<0.01, ** p<0.001

TABLE 9: Test-Retest reliability for satisfaction with self-esteem

Question	Yes/ Yes	No/ No	Proportion Agree	Kappa
Do you feel that				
1.....you can be proud of yourself?	94%	0%	.94	
2.....everything you do goes wrong?	16%	55%	.71	.36*
3.....when you do something you do it well?	87%	3%	.90	.38
4.....there are lots of good things about you?	81%	0%	.81%	
5.....you can do things as well as most people?	87%	3%	.90	.38
6.....sometimes you are no good at all?	23%	39%	.61	.20
7.....you are a useful person to have around?	45%	26%	.71	.41**
8.....you are a happy person?	97%	3%	1	1
9.....your life is not very useful?	42%	19%	.61	.17
10....you can do anything if you really try?	94%	3%	.97	.67
11....you are a good person?	100%	0%	1	
12....you can handle most problems?	90%	3%	.90	.46
13....you are sad most of the time?	3%	90%	.93	.46
14....most people like you?	97%	0%	.97	
15....people are hard to get along with?	35%	35%	.70	.40**
16....you like the way you look?	77%	10%	.87	.54*

* p<0.05, ** p<0.01, ***p<0.001

Overall Satisfaction:

The overall average satisfaction score was calculated by adding all the scores on each individual item retained in each scale and dividing by the total number of items. Test-retest reliability of the corrected scale total was high ($r=0.78$, $N=31$, $p<=0.001$). As a measure of construct validity, the extent to which the sub-scales correlated with the total score was measured. Pearson coefficients were high for the Residential Placement, the Work Placement, Interpersonal Relationships, and Self-Esteem Scales ($r=0.68$, $N=31$, $p<0.001$; $r=.72$, $N=31$, $p<0.001$; $r=0.68$, $N=31$, $p<0.001$; $r=0.63$, $N=31$, $p<0.001$ respectively) but moderate for the Financial Status and Physical Health Scales ($r=0.42$, $N=31$, $p<0.01$; $r=0.51$, $N=31$, $p<0.01$ respectively).

Internal Reliabilities:

To measure the internal consistency of the six retained scales, Cronbach's alpha was applied, using the SPSSX subprogramme RELIABILITY (SPSS Inc., 1986). The internal consistencies of each scale (i.e. with those items already identified as unreliable removed) on both occasions are presented in Table 10. As can be seen the alpha measure for internal consistency ranged from .41 to .80 on the first administration and from .37 to .87 on the second. On the first administration, alpha ranged from moderate - for the Interpersonal Relationships Scale, Financial Status Scale, the Physical Health Scale and the Self-Esteem Scale - to good - for the Residential Placement scale and Work Placement Scale. On the second administration, alpha

coefficients for the Interpersonal Relationships Scale and the Physical Health Scale were moderate, and good for the Residential Placement Scale, Work Placement Scale, Financial Status Scale, and Self-Esteem Scale. These results are interpreted as indicating that the scales have an acceptable degree of internal consistency.

The Five Faces Scores:

As previously indicated, at the end of each of the residential, work, leisure and financial satisfaction scales, participants were asked to indicate how they felt about their situation on a scale represented by five "cartoon-type" faces. These ranged in appearance from very unhappy to very happy, with the centre face being neutral.

TABLE 10: Internal Consistencies for the Satisfaction Scales

Scale	Cronbach's Alpha	
	First Administration	Second Administration
Residential Placement Scale	.59	.61
Work Placement Scale	.80	.87
Interpersonal Relationships Scale	.47	.37
Financial Status Scale	.53	.65
Physical Health Scale	.42	.51
Self-Esteem Scale	.41	.66

The test-retest reliability of the five faces scores was examined and the results are presented in Table 11. [As outlined above, the leisure time scale was deleted from the questionnaire because of poor test-retest reliability.] As can be seen, the test-retest correlations on the five faces were statistically significantly reliable for the three

TABLE 11: Test-retest reliability of the Five faces score and correlation with satisfaction scales.

	r
Test-Retest correlation of the Five Faces score	
Residential Face	.42**
Work Face	.77***
Financial Face	.38**

Correlation of Five Faces score with Satisfaction Scale Score

	First Administration.	Second Administration.
Residential Placement	.13	.16
Work Placement	.49**	.76***
Financial Status	-.15	-.17

* = p<.05, ** = p<.01, ***= p<.001

remaining sets of five faces, although the coefficients for the residential faces and the finance faces were small. In these two instances the test-retest reliabilities for the faces score was less than the test-retest reliability for the total score for the scale, indicating that the global measure of satisfaction may not be as stable a measure of satisfaction as that obtained from the scale.

The correlations between the score on the five faces and the score on the relevant satisfaction scale are also presented in Table 11. As can be seen, only satisfaction with work placement correlated significantly with the face score: it may therefore be that the global measure of satisfaction and the items in the various scales are not measuring the same thing. However, because subjects' ratings were reliable, the five faces were retained in the next study to see if increasing the number of participants would improve the correlations.

Summary:

Reliability of the seven scales making up the RSQ was measured in two ways. Firstly, test-retest reliability of individual items was found to range from .52 to 1, with the majority being above .75. To be retained in the scales, an item required .75 agreement or more, or lie between .65 and .74 supported by a significant kappa coefficient. In total, only 12 items (4 from the Residential Placement Scale, 1 from the Work Placement Scale, 5 from the Leisure Time Scale, and 2 from the Self-esteem Scale) were deleted because of poor individual test-retest reliabilities,

indicating a high consistency of responding between testing occasions. Secondly, test-retest reliability of the total score on each of the seven scales was examined. Only one - the leisure time scale - was found to have less than acceptable test-retest reliability and this scale was therefore eliminated from further analyses. Test-retest reliabilities for the other six scales ranged from moderate to good.

However, it is possible that these test-retest reliabilities were inflated by acquiescence since there was not an equal balance of questions that required "yes" and "no" answers to receive a positive score. That some inconsistency in responding occurred is evident from an examination of the pairs of questions that were used as measures of consistency. In the main, those questions requiring opposing answers to be consistent were poorly answered, with most respondents providing "yes" answers on both items. However, acquiescence did not occur on all questions. It seems probable that inconsistency occurred on questions which participants had difficulty understanding like ones which involved quantitative concepts. It is also possible that the questions were not interpreted as exact opposites and inconsistency occurred because respondents responded to the pairs as different questions. Measuring consistency of responding was also affected by low test-retest reliability of some of the paired items requiring opposite responses.

The internal consistency of the scales (Cronbach's alpha) ranged from moderate to good . In addition, the

external validity of the scale was tested by correlating scores received on each of three of the scales with a rating of satisfaction for each scale made by the respondent, based on the presentation of five cartoon-type faces. Although the respondents ratings were moderately reliable on test-retest, correlation between the total score on the scale and the score on the five faces was significant for only the Work Placement Scale. Thus it seems likely that, for the other two satisfaction scales, these were not measuring the same construct as the "faces" procedure.

Content validity was not examined but the argument for content validity is made on the basis of the steps followed in developing the items. Nunnally (1967) claims that there are two major standards for ensuring content validity; these are a representative collection of items and a sensible method of test construction. It is argued that these conditions have been met in the construction of the questionnaire as a large area of literature was searched and a model was developed that was based on models used for measuring quality of life in nondisabled populations.

CHAPTER FOUR continued

STUDY 2

The aim of this study was to test the reliability of the staff questionnaire and to provide a form of external validation for the Resident Satisfaction Questionnaire (RSQ).

METHOD

Participants:

Twenty one staff members (7 males and 14 females) who worked with the residents in their house completed the questionnaires, as described in Chapter 3. Apart from staff in the community houses, staff had either undergone, or were undergoing, a three-year training course in intellectual disability, entitling recipients to registration with the Nurses Board of South Australia. Staff in the community houses were part-time, and had completed an in-service training course run by the institution.

Procedure

A staff member in the house where the resident lived and who knew the resident well was given the questionnaire (Appendix 2) to complete it in his/her own time but as soon as possible. Approximately one week after the questionnaire had been completed and returned, the staff member was asked to complete the same questionnaire again. This allowed for measurement of the test-retest reliability of the scale. In addition, a different staff member, who was familiar with the resident, was asked to complete the questionnaire, which

allowed for the measurement of the inter-rater reliability of the scale.

RESULTS

Subjective Scale: Items 1-19.

Items 1-19 dealt with staff perceptions about the satisfaction of the residents who were being interviewed as part of the study and formed the subjective part of the staff questionnaire. The results of test-retest and inter-rater reliability are presented below.

Test-Retest Reliability:

The test-retest reliabilities were calculated for Items 1-19, the subjective items of the scale, using both percent agreement and also Pearson Product Moment Correlation Coefficients (These are more appropriate for these rating scales than Kappa which is appropriate only for dichotomously rated scales). Results are presented in Table 12. As can be seen, percent agreement for the items ranged from 46% to 80%. Pearson correlations ranged from .39 to .87, with all correlations significant at the .01 level. This indicates acceptable reliability within staff when making subjective judgements about a resident's satisfaction with aspects of his/her lifestyle.

TABLE 12: Test-retest and Inter-rater agreement for Staff Questionnaire Items 1-19.

Question	Test-retest N	Test-retest Percent Agree	Test-retest r	Inter-Rater N	Inter-Rater Percent Agree	Inter-Rater r
1. In general, how happy do you think this person is with his/her life?	35	80	.54**	28	64	.38
2. In general, how happy do you think this person is?	35	74	.59**	28	63	.25
3. How happy do you think this person is with his/her residential placement?	35	74	.79**	28	64	.56**
4. How well placed do you think this person is in this house?	35	60	.53**	27	56	.16
5. How satisfied is this person with his/her current work placement?	35	65	.60**	27	70	.48*
6. How well placed is this person in his/her current work placement?	35	77	.47**	27	56	-.11
7. How satisfied do you think this person is with his/her lifestyle?	35	77	.39*	28	61	.0

cont....

TABLE 12 cont.....

Question	Test-retest N	Test-retest Percent Agree	Test-retest r	Inter-Rater N	Inter-Rater Percent Agree	Inter-Rater r
8. How bored does this person get?	35	60	.53**	28	64	.48**
9. How well does this person occupy him/herself on holidays from work?	35	54	.61**	28	39	.18
10. How satisfied do you think this person is with his/her financial affairs?	33	76	.70**	27	59	.53*
11. How well does this person manage his/her financial affairs?	30	73	.72**	27	44	.09
12. How many friends does this person have?	35	74	.77**	28	50	.35
13. How lonely do you think this person is?	35	57	.56*	28	50	.35
14. How often does this person visit his/her family?	35	54	.82**	28	43	.85**
15. How well physically is this person?	35	77	.72**	28	50	.34
16. How often does this person complain of feeling unwell?	35	46	.47**	28	72	.77**

cont....

TABLE 12 cont.....

Question	Test-retest N	Test-retest Percent Agree	Test-retest r	Inter-Rater N	Inter-Rater Percent Agree	Inter-Rater r
17. How high is this person's level of self-esteem?	35	72	.74**	28	61	.62**
18. How much do you think this person likes the way he/she looks?	35	74	.65**	28	43	.19
19. How many visits, letters, phone calls has this person had with any members of his/her immediate family during the past 12 months?						
a. Visited a family member	35	71	.87**	26	58	.81**
b. Family member visited person	35	60	.83**	28	50	.48*
c. Person wrote or phoned family	35	72	.86**	27	59	.65**
d. Family wrote or phoned person	35	54	.83**	28	54	.69**

* = p,0.01, ** = p<0.001

Inter-Rater Reliability:

Inter-rater reliabilities for items 1-19 are also presented in Table 12. As can be seen the percent agreement rates ranged from 39% to 72%. This measure is very strict, since to get a perfect score the two raters have to agree on the same score and Pearson correlation coefficient is a more lenient measure of the relation between the two scores. However, as can be seen, reliability on this measure ranged from -.11 to .81 and only 11 of the 22 items had coefficients that were significant. Thus staff did not always agree with each other on subjective ratings of a person's feelings. This may be due to staff seeing each resident for a different amount of time; and some staff completing the questionnaire may not have known the resident for as long as the other staff member completing the form, or may have seen the resident under different circumstances.

The subjective items were to be divided into sub-scales (as discussed in Chapter 3) to correlate with the seven satisfaction ratings of the RSQ. However, since a number of the items in this section had to be deleted, this was not possible and a composite score was instead calculated from items which had significant test-retest and inter-rater reliabilities. Eight items (items 3, 5, 8, 10, 14, 16, 17,& 19 - a,b,c,d) had significant test-retest and inter-rater reliabilities at the .01 level. Four had inter-rater reliabilities that were significant at the .05 level (Items 1, 12, 13, and 15) and significant test-retest reliabilities. Thus a total of 12 items were accepted for further analysis.

Objective Scales: Scales 20, 21, 24:

The three scales in this section were concerned with the measurement of objective items in order to examine the degree of responsibility, autonomy, and decision making permitted by staff to residents. Initially, each scale consisted of three response categories and Percent Agreement was calculated. However, whilst test-retest reliability was adequate for each scale, inter-rater reliability turned out to be very poor, resulting in the elimination of many of the items. This may have arisen because staff interpreted questions differently (as the questionnaires were completed by staff without the author present); or it could reflect different work practices on the part of staff in the houses.

However, the strictness of the method used to measure reliability may have led to the less than desirable results (i.e. for agreement to be scored staff had to tick exactly to same category). Given this, the results were analysed in a slightly different format. The tables of these results are presented as Appendix 4. Instead of the three response categories (for example, "Staff only", "Person with assistance" and "Person alone", as in Scale 20) two response categories were established. The first category of "Staff Only" was retained (the 0/0 column in the previous Tables which are presented as Appendix 4) and the other two combined to make a single category of "Assistance". Following recoding, proportion agreement figures for each question were again calculated. In addition, the statistic Kappa was calculated, there now being a 2x2 contingency table. These results are included in the summary tables

TABLE 13: Staff Questionnaire Scale 20 Test-Retest and Inter-Rater Reliabilities - Revised.

Question	Test-Retest		Inter-Rater	
	Proportion Agree	Kappa	Proportion Agree	Kappa
In your situation, who has the most responsibility for the following:				
1. Cleaning the bedroom	.98	.37	.93	.5*
2. Serving own meals	.86	.63**	.61	-.05
3. Preparing meals	.83	.64***	.66	.08
4. Food Shopping	.82	.64***	.68	.33*
5. Washing clothes etc	.94	.86***	.61	
6. Mending clothes	.77	.46**	.57	.02
7. Banking money from work/pension	.97	.94***	.85	.65**
8. Spending money	1		1	
9. Deciding how much money to save each week	.97	.90***	.71	-.07
10. Maintenance of the grounds	.77	.54***	.68	.42**
11. Setting the table	.89	.54*	.79	
12. Doing the dishes	.92	.53*	.86	
13. Shopping for supplies for the house	.97	.94***	.71	.38*
14. Paying bills	.94	.85***	.71	.42*
15. Cleaning living rooms	.86	.62**	.83	.35
16. Cleaning dining rooms	.88	.57*	.86	.42
17. Cleaning the kitchen	.80	.35*	.86	.62**
18. Making sure all tasks are performed as necessary	.94	.86***	.68	.32*

presented. For this reorganisation, the same criteria used for acceptance of results from the RSQ. That is, items which had a .75 or more proportion agreement were accepted, regardless of kappa scores. Where proportion agreement lay between .65 and .74 items were accepted if there was a significant kappa score, otherwise they were rejected.

Scale 20

This scale was developed to measure responsibility for performing household tasks and consisted of 18 items.

As can be seen from Table 13, all items met test-retest criteria for acceptance. However, items 2, 3, 5, 6, and 9 had poor inter-rater reliability and were not retained for further analysis. A total score was calculated by allocating a score of 0 to responses in the "Staff only" category and a score of 1 to responses in the "Assistance" category and the reliability of this total score tested by Pearson Product Moment Correlation. Both the test-retest coefficient and the coefficient for inter-rater reliability were acceptable ($r=.57$, $N=27$, $p=.001$).

Scale 21:

This 22-item scale was designed to measure degree of autonomy afforded to residents. Results are presented in Table 14. Rather than the "Staff only" and "Assistance" categories the categories "Not at all and "Allowed" were used. Items 2, 8, 16, 20, and 23 were rejected since they failed to meet the criterion on either test-retest or inter-rater reliability. The reliability of the total score

TABLE 14: Staff Questionnaire - Scale 21, Test-Retest and Inter-Rater Reliabilities.

Question	Test-Retest Proportion Agree N=35	Test-Retest Kappa	Inter-Rater Proportion Agree N=28	Inter-Rater Kappa
Is ..... allowed to:				
1. Invite visitors for a meal	1		1	
2. Have a pet	.84	.55**	.63	.29*
3. Go out alone	.94	.45*	.89	
4. Stay up late on week nights #	.83	.19	.93	
5. Stay up late on weekends	1		1	
6. Stay out late on week nights*	.79		.96	
7. Stay out late on weekends	.97		.97	
8. Get up late on weekdays *	.73	.53***	.50	-.06
9. Get up late on weekends *	1		1	
10. Stay out overnight	.90	.60*	.82	
11. Make him/herself a snack	1		.96	
12. Watch TV	1		1	
13. Make him/herself a drink	1		1	
14. Use the telephone	1		1	
15. Withdraw money from his/her bank account	.86	.63**	.82	.44*
16. Drink alcohol in the house	.80	.46*	.79	.16
17. Drink alcohol outside the house*	.74	.38*	.79	.16
18. Invite a boy/girlfriend home	.97		1	

cont.....

TABLE 14 cont....

Question	Test-Retest Proportion Agree	Test-Retest Kappa	Inter-Rater Proportion Agree	Inter-Rater Kappa
19. Leave his/her room untidy *	.97%	.94***	.36	.66***
20. Stay home without a medical reason	.71	.31	.72	.26
21. Keep a key to the house	1	1***	.85	.71**
22. Decorate his/her room	.86		1	
23. Lock his/her room from the inside	.94	.85***	.61	.07
24. Lock the bathroom from the	.97	.93***	1	1***
25. Lock the toilet from the inside	1	1***	.89	.72***

N=31 Test-Retest, N=27 Inter-Rater
* N=34 Test-Retest

was calculated for both test-retest and inter-rater reliability. Both coefficients were good ($r=.78$, $N=31$, $p<.001$, and $r=.69$, $N=27$, $p<.001$ respectively) indicating that the scale, in its revised form, has an acceptable degree of reliability.

Scale 24:

The degree of decision making allowed the resident in running the household was measured by this 30-item scale. Results are presented in Table 15. In this instance the "Staff Only" category was retained and the "Assistance" category was replaced by "Decided". As can be seen all but item 19 in the test-retest meet the criteria of either .75 or more proportion agreement or between .65 and .74 with a significant kappa score.

Use as External Validation

Composite total scores were calculated for each of the scales from the Staff Questionnaire in order to compare them with RSQ results. For the subjective ratings (Items 1-19), a total score was calculated by taking the average of the ratings from both test-retest and inter-rater scores. Total scores for each of the three objective rating scales (Scales 20, 21, and 24) were calculated, as explained previously, by adding the score received on each of the items retained. The total score used for comparison here was an average of the ratings from both test-retest and inter-rater scores. The subjective score (Items 1-19) and the scores from the three objective scales were then correlated with the scores

TABLE 15: Staff Questionnaire - Scale 24, Test-Retest and Inter-Rater Reliabilities.

Question	Test-Retest Proportion Agree N=35	Test-Retest Kappa	Inter-Rater Proportion Agree N=28	Inter-Rater Kappa
In your situation who is most involved in deciding the following:				
1. What he/she will do on the weekends	1		1	
2. Where to go on his/her holidays	.91		.97	
3. What time to take a shower	.97		1	
4. What time to go to bed	.97		1	
5. What time meals are served	.94	.88***	.86	.68***
6. What the daily menu is	.92	.84***	.82	.63***
7. What food to buy for the house	.98	.96***	.82	.64*
8. What time to get up in the morning	.83	.62***	.93	.79***
9. What the rules of the house will be	.86	.72***	.67	.33*
10. Who he/she will share a room with	.89	.54*	.82	
11. When the house needs to be painted	.86	.65***	.71	.17
12. Whether a particular staff member should be fired	.86		.75	
13. How much money he/she should save each week	.83	.32	.86	
14. When staff have days off	1		.93	
15. Whether a particular resident is admitted	.95	.75***	.57	
16. How he/she spends his/her money	1		1	
17. When staff take holidays	1		.93	
18. Whether a particular staff member will be assigned to the house	1		.89	

cont....

Table 15 cont....

Question	Test-Retest Proportion Agree N=35	Test-Retest Kappa	Inter-Rater Proportion Agree N=28	Inter-Rater Kappa
19. When he/she takes his/her holidays	.69	.14	.86	.26
20. When to punish bad behaviour	.77	.44**	.50	-.02
21. How to punish bad behaviour	.68	.58***	.53	
22. What he/she will do weeknights	.94		1	
23. What equipment to buy for the house	.85	.70***	.83	.63***
24. When he/she is ready to move out of the house	.86	.72***	.57	.04
25. What time household tasks are done	.89	.78***	.74	.40*
26. What he/she wears	1		1	
27. What leisure activities he/she will participate in *	1		1	
28. What clothes he/she buys	.95	.87***	.68	
29. Choose whether or not to go to go to work (i.e. be unemployed)	.80	.54**	.79	.28
30. Choose what his/her job (occupation) will be	.94	.71**	.89	

*N=34 Test-Retest reliability

on each of the sections in the RSQ (which were the averages of scores on both testing occasions). Results are presented in Table 16.

As can be seen, very few of the correlations were significant and those that were were only of moderate significance. The composite subjective score of staff rated satisfaction was significantly correlated with only one of the Resident Satisfaction scales. Satisfaction with Residential Placement was significantly negatively related to the subjective rating of the person's satisfaction by staff ($r=-.41$, $N=31$, $p<.001$) indicating that those people that staff rated as well satisfied were more likely to express lower satisfaction. Why this result occurred is not clear.

The objective scales of the Staff Questionnaire were more correlated with the RSQ scales than the subjective score (Items 1-19). The degree of responsibility allowed a person was moderately correlated with satisfaction with financial status ($r=.31$, $n=31$, $p<.05$), satisfaction with interpersonal relationships ($r=.38$, $N=31$, $p<.01$), and overall satisfaction ($r=.35$, $N=31$, $p<.05$). The degree of autonomy allowed an individual did not correlate with satisfaction, whereas the degree of decision making allowed a person was related to expressed satisfaction. Degree of decision making allowed is correlated with satisfaction with work placement ($r=.34$, $N=31$, $p<.05$), satisfaction with financial status ($r=.28$, $N=31$, $p=.06$), satisfaction with interpersonal relationships ($r=.37$, $N=31$, $p<.05$), and overall satisfaction ($r=.33$, $N=31$, $p<.05$). This indicates

TABLE 16. Correlation of Subjective and Objective questions from Staff Questionnaire with Scores from the Resident Satisfaction Questionnaire

	Subjective (Items 1-19)	Scale 20 (Responsibility)	Scale 21 (Autonomy)	Scale 24 (Decision Making)
Residential Placement	-.41**	.16	.02	.10
Work	.21	.35	.26	.34*
Financial Status	.12	.31*	.23	.28*
Inter-Personal Relationships	.16	.38**	.27	.37*
Physical Health	-.09	-.14	.07	.09
Self Esteem	-.09	.05	-.18	-.03
Overall Score	-.02	.35*	.20	.33*

that objective factors in an individual's environment can affect an individual's expressed satisfaction.

However, since the subjective score (Items 1-19) from the Staff Questionnaire did not correlate with the RSQ (other than in a negative direction on residential placement), there is obviously some discrepancy between self-rated satisfaction (i.e. the score obtained from the RSQ) and satisfaction as rated by another (i.e. Items 1-19 from the Staff Questionnaire). This does not mean, however, that the self-rated satisfaction of the participants should be discounted. In fact, as the objective ratings were correlated to some extent with self-rated satisfaction this indicates that staff ratings of satisfaction are less reliable measures of satisfaction than self-ratings.

A Oneway Analysis of Variance was conducted to examine differences between placements in the degree of responsibility (Scale 20), autonomy (Scale 21) and autonomy (Scale 24) allowed the residents and staff ratings of resident satisfaction. It was expected that, as the intermediate and group home settings were designed to encourage the development of independence and responsibility, residents in these settings would be allowed greater freedom, autonomy and decision making responsibilities than residents in the institutional setting. The means and standard deviations for the three placements are presented in Table 17.

There were significant differences between placements with respect to the degree of responsibility allowed ($F = 6.11$, df 2,28, $p < .01$); the degree of autonomy allowed to the

TABLE 17: Means and Standard Deviations of Staff Ratings on the Staff Questionnaire by Placement

Placement	N	Mean	SD
Item 1-19 (Subjective score)			
Institutional setting	19	15.35	7.03
Intermediate setting	6	22.67	5.20
Group Home setting	6	14.33	3.83
Scale 20 (Responsibility)			
Institutional setting	19	8.37	3.77
Intermediate setting	6	11.83	.41
Group Home setting	6	12.67	3.04
Scale 21 (Autonomy)			
Institutional setting	19	17.42	2.04
Intermediate setting	6	21.33	3.77
Group Home setting	6	20.17	.98
Scale 24 (Decision Making)			
Institutional setting	19	14.68	3.07
Intermediate setting	6	19.67	4.63
Group Home setting	6	18.00	.63

residents (F=7.94, df 2,28 ~~N=31~~, p<.01); and degree of decision making allowed (F=6.76, df 2,28 ~~N=31~~, p<.01). In all cases those in the institutional placements received the lowest scores. Scheffé post-hoc tests revealed significant differences between the groups (at the .05 level) with the institutional placements receiving significantly lower scores than the group home placement on the responsibility scale (Scale 20), and significantly lower scores than the intermediate setting on both the autonomy and decision-making scales (Scales 21 and 24). The results of these analyses show that the institutional residents are allowed less responsibility, less decision making, and less autonomy than residents in either the group homes or the intermediate settings.

There was also a significant difference between the groups with respect to the staff ratings of satisfaction (Items 1-19 of Staff Questionnaire), with those in the intermediate settings receiving higher scores than those in the institutional or group home placements (F=3.48, df 2,28 ~~N=31~~, p<.05). However, a Scheffé post hoc analysis failed to reveal any differences between the groups at the .05 level.

Given that there were differences between the placements in the objective ratings, and that the objective ratings are related to expressed satisfaction, it could be predicted that those in the institutional settings would be less satisfied than those in the intermediate and group home placements. This difference was also predicted on the basis of the literature review. A Oneway Analysis of Variance was conducted but there were no significant differences between the groups with expressed satisfaction in any of the areas.

Summary:

The staff questionnaire was designed to measures both staff ratings of resident satisfaction and objective ratings of the degree of autonomy, responsibility and decision making allowed residents. Initial analysis revealed difficulties with inter-rater reliabilities. However, a less strict method of calculating percent agreement improved reliability ratings so that scores could be calculated for staff rated resident satisfaction (subjective measure) and for the degree of autonomy, decision making, and responsibility allowed residents (objective measures). These measures were then compared to residents' self-rated satisfaction, as obtained from the RSQ. Self-rated satisfaction was correlated with the objective measures from the staff questionnaire but not with the subjective measure, suggesting that objective factors in an individual's life may affect satisfaction. It also indicates that staff may not be good judges of residents' satisfaction. The correlation with the objective measures gives some support to the external validity of the RSQ.

Following this work, two further studies were conducted to examine the external validity of the RSQ. The results of these are presented in the following chapter.

CHAPTER FIVE

ESTABLISHING VALIDITY

This chapter presents the results of Studies 3 and 4, the aim of which was to examine the external validity of the Resident Satisfaction Questionnaire (RSQ). First, the numbers of participants in each placement setting was expanded beyond those participating in Study 1, in order to determine if there were any differences between the three settings (institutional, intermediate, and community group home) with respect to expressed satisfaction with lifestyle. On the basis of the literature review, it was predicted that those people residing in the community would be more satisfied than those in the institutional or intermediate settings. In addition, satisfaction scores were correlated with other measures, such as presence and extent of behaviour problem, whether additional handicaps were present, age, etc., in order to examine further the external validity of the questionnaire. In Study 4, an additional group of intellectually disabled people, living in a supervised community setting provided by another agency, was studied in order to test the generalisability of conclusions drawn from Study 3. On the basis of the literature review of satisfaction studies with intellectually disabled people living in the community, it was predicted that satisfaction in this group would be similar to that found in the

community group home group.

STUDY 3

METHOD

Participants

An additional 31 participants were interviewed and the data obtained incorporated with data from Study 1. Eleven of the additional participants interviewed were from the institutional setting, making a sample from this setting of 30 participants. There were 18 males and 12 females ranging in age from 18 years 10 months to 43 years (mean = 27 years 10 months, SD= 6 years 2 months). The length of time spent in residence at the institution ranged from six months to 14 years 7 months (mean = 5 years 8 months, SD= 5 years 2 months).

An additional six residents were interviewed from the intermediate setting. The final sample therefore comprised 11 participants (7 males, and 4 females). Ages ranged from 29 years 10 months to 50 years 2 months (mean = 34 years 10 months, SD= 5.98). The members of this group had been in their current placement for an average of 5 years (range 1 year 2 months to 13 years, SD= 3 years 7 months).

The community group home sample was increased to 20 participants by the addition of 14 participants. (One additional participant was excluded because she failed to meet the criteria for internal consistency). This sample then comprised 10 females and 10 males with ages ranging from 23 years to 46 years 6 months (mean = 32 years 9

months, SD=6 years 3 months). Participants of this group had been resident at their current placements for an average of 2 years 4 months (range 2 months to 5 years 6 months, SD=1 year 6 months). Descriptive data are summarised in Tables 18 and 19.

There were no significant differences between the groups with respect to sex ($F < 1.0$). However, there was a significant difference between the group with respect to age ($F=6.79$, df 2,58 ~~N=61~~, $p<0.01$), the residents of the institutional sample being younger than the other samples. There was also a significant difference between the groups with respect to length of time in current placement, with those in the community group homes having been in their placements a shorter period of time than the other two groups ($F= 5.40$,

TABLE 18: Description of Sample

Sample	N	Male	Female	Mean Age	Mean Time in Residence
Institutional setting	30	18	12	27yr 10m	5yr 8m
Intermediate setting	11	7	4	34yr 10m	5 yrs
Community Group Home Setting	20	10	10	32yr 9m	2yr 4m

TABLE 19: IQ Level

Sample	Borderline	Mild	Moderate	Severe
Institutional Setting	3	12	15	0
Intermediate Setting	1	6	3	1
Community Group Home Setting	0	13	7	0

df 2,58
~~N= 61~~, $p<0.01$). There was no difference between the groups with respect to IQ ($\chi^2=.63$, df=2, $p>0.05$).

Procedure

A procedure similar to that used in Study 1 was followed for this study, except that instead of the initial 136 item version of the RSQ used previously, the modified version was read to the additional participants. Scores for participants in Study 1 were corrected for the questions that had been removed from the original questionnaire.

The additional participants in this study were interviewed on the one occasion only. Instead of completing the Staff Questionnaire, the staff were asked to complete, for each individual, the Behaviour Assessment Scale (BAS), which is a scale designed to measure the severity of behaviour disorders (Note 4). This scale was also completed for those people who had participated in the first study.

STUDY 4

The aim of this study was to compare RSQ results from the previous studies with those from a sample of intellectually disabled adults who were not part of the services provided by the agency involved in the previous studies and who were functioning at a slightly higher level of independence and higher level of intellectual functioning than participants in the previous studies. In effect, therefore, the present study explored the general utility of the RSQ across a wider range of abilities than previously obtained. As both the

community groups were in similar situations of training for independent living, it was predicted that satisfaction in the new group would be the same as in the community houses, with both these higher than in the other two groups.

METHOD

Participants:

An additional 17 adults with an intellectual disability participated. All were residents at an independent living accommodation complex provided by an agency that also provided supported employment. The aim of programmes organised at both the supported employment placement and the independent living accommodation is to provide rehabilitation to people with disabilities arising both through intellectual or physical disabilities. At the time of the interview, there were 52 residents in the independent living complex, which had originally been established along the lines of a motel. The residents either had physical disabilities or were borderline to mildly intellectually disabled. Each person had his/her own room. Although the complex had originally been established as a motel, services that are traditionally supplied by motels (e.g. servicing of rooms), were provided only to those who were unable to do these things for themselves. Most of the people who participated in this study were expected to do their own washing and clean their own rooms. Meals were provided in a central dining room but residents were

expected to help tidy up following the meal.

The 8 male and 9 female participants from this setting ranged in age from 16 years 6 months to 59 years ($\bar{X}$=33years 4 months, SD=13years 9 months) and were of moderate to borderline intellectual disability (exact IQ scores were not available on the resident's file at the motel but the category of disability resultant from intelligence testing was recorded on the file). Tables 20 and 21 provide descriptive data on the sample, as compared to the groups in studies 1 to 3.

There were some differences between the groups with respect to age ($F=2.97$, df 3, 75 ~~N=76~~, $p<0.05$), with those in the institutional setting being younger than the other groups; and with respect to time spent in current placement ($F=3.69$,

TABLE 20: Description of Sample

Sample	N	Male	Female	Mean Age	Mean Time in Residence
Institutional setting	30	18	12	27yr 10m	5yr 8m
Intermediate setting	11	7	4	34yr 10m	5yr
Community Group Home setting	20	10	10	32yr 9m	2yr 4m
Independent Living Complex	17	8	9	33yr 4m	3yr 4m

TABLE 21: IQ Level

Sample	Borderline	Mild	Moderate	Severe
Institutional Setting	3	12	15	0
Intermediate Setting	1	6	3	1
Community Group Home Setting	0	13	7	0
Independent Living Complex	5	12	0	0

df 3,68
~~N=72~~, p,0.05). Those in the community group homes and the Independent Living Complex had spent less time in their placements, reflecting the transient nature of these settings (i.e. the settings were designed to have a flow through of people. As residents moved to more independent settings, their places were taken by new people).

There was a difference between the groups with respect to IQ (X^2=10.12, df=3, p<0.05), with the new group functioning at a higher IQ level than the previous groups, with all of the participants falling into either the mild or borderline categories.

RESULTS

The means and standard deviations for the groups in the two studies, on each of the six satisfaction scales in the modified version of the RSQ, are presented in Table 22. Results of the Oneway Analyses of Variance are presented below for each satisfaction scale.

Satisfaction with Residential Placement:

It was predicted that members in the community group home would be satisfied with the quality of their lives than people in either the intermediate setting or the institutional setting. Analysis revealed that there were significant differences between the groups with respect to expressed satisfaction with residential placement (F= 4.89,

df 2,58
~~N=61~~, p<0.01).

TABLE 22: Group means and standard deviations for satisfaction scores on various scales of the RSQ.

	Mean	SD
Residential Placement:		
Institutional setting	72.73	9.78
Intermediate setting	69.9	12.54
Community Group Home setting	80.35	9.26
Independent Living Complex	88.35	7.34
Work Placement:		
Institutional setting	78.10	14.38
Intermediate setting	72.82	18.63
Community Group Home setting	78.10	13.25
Independent Living Complex	83.06	13.34
Financial Status:		
Institutional setting	61.07	18.50
Intermediate setting	63.0	20.21
Community Group Home setting	69.25	19.28
Independent Living Complex	64.35	25.47
Interpersonal Relationships:		
Institutional setting	61.50	12.86
Intermediate setting	68.18	14.82
Community Group Home setting	71.2	13.35
Independent Living Complex	74.35	11.32
Physical Health:		
Institutional setting	84.10	13.30
Intermediate setting	89.36	9.71
Community Group Home setting	83.35	10.23
Independent Living Complex	86.35	11.83
Self Esteem:		
Institutional setting	86.30	9.27
Intermediate setting	84.45	12.87
Community Group Home setting	88.00	9.65
Independent Living Complex	89.29	7.05
Overall Satisfaction:		
Institutional setting:	73.70	8.20
Intermediate setting:	71.45	12.62
Community Group Home setting	78.00	9.65
Independent Living Complex	82.59	9.69

Scheffé post hoc analyses confirmed significant differences, at the 0.05 level, between the intermediate setting and the community group home settings, with the community groups being more satisfied than the intermediate group; and between the institutional and community groups, again with the community group being more satisfied. The difference between the institutional and intermediate settings was not significant.

A significant difference was also found between the groups when the additional independent living setting was added ($F=12.52$, ~~N=78~~ df 3, 74, $p<0.001$). A Scheffé post-hoc test revealed that there were significant differences (at the .05 level) between the intermediate setting and the group home and independent living settings; and between the institutional setting and the independent living complex. This was reflected in the responses to some of the questions in this scale.

For example, those in the motel sample were more satisfied with the area in which they lived as fewer wished to live in an other area (17%) compared to those in the intermediate, institutional and group home samples (73%, 63%, and 30% respectively). None in the motel sample felt that staff were hard to get along with whereas 36% in the intermediate setting, 20% in the institutional setting and 25% in the community group home setting felt that staff were hard to get along with. In addition, all in the motel sample felt that they had enough freedom to do what they wanted, whereas only 73% in the intermediate sample, 83% in the institutional sample and 85% in the community group home

sample felt that they had enough freedom.

This outcome indicates that the community groups expressed greater satisfaction with residential placement (which included such aspects as the physical location of the group homes, the other residents in the house, the staff who worked in the houses, the in-house responsibilities, and the rules and restrictions that were imposed) than groups in the institutional and intermediate settings.

Satisfaction with Work Placement:

There was no significant difference between the groups with respect to expressed satisfaction with work placement in either of the studies ($F<1.0$ in Study 3 and $F=1.13$ ~~N=78~~ df 3, 73, $p>0.05$ in Study 4). This result was not surprising since many of the participants in fact worked in the same work areas so that there was no great difference in the type of work placement attended by residents in the different placement settings.

Satisfaction with Financial Status:

It was predicted that the community group home sample would be more satisfied than the other groups as they were in receipt of a pension and thus had more disposable income than the other two groups, whose only source of finances came from the money they received from working (about $7 - $20 a week). However, although the results were in the predicted direction (i.e. with the community group home sample members expressing more satisfaction than the intermediate and institutional samples), difference between

the groups was not significant (F= 1.13, df 2,58 ~~n= 61~~, p>0.05). There were some differences in responses to individual questions. For example, fewer of the participants in the community setting (50%) said that they ran out of money before their next pay compared to the institutional (57%) and intermediate (73%) settings. In addition, more of the community sample felt that they made enough decisions about their use of money (45%) than the institutional (20%) and intermediate (27%) settings.

There was no significant difference between the groups with respect to satisfaction with financial status in Study 4 (F<1.0).

Satisfaction with Interpersonal Relationships:

There was a significant difference between the groups with respect to satisfaction with interpersonal relationships in Study 3 (F= 3.35, df 2,58 ~~N= 61~~, p<0.05). However, a post hoc analysis (Scheffé) revealed that no two groups were statistically significantly different at the 0.05 level. However, in Study 4, the significant difference between the groups held and Scheffé analysis revealed a significant difference between the institutional setting and the independent living complex (at the 0.05 level). The differences between the groups can be highlighted with some responses to the questions in this scale.

For example, fewer in the institutional sample trusted the people that they lived with (73%), as compared with the intermediate (91%), group home (95%) and independent living complex (89%) samples. In addition, more in the

institutional sample felt that the people they lived with got them into trouble (60% compared with 27% for the intermediate, 35% for the group home and 11% for the independent living complex samples) and were not nice to them (77% compared with 55% in the intermediate, 45% in the group home and 39% in the independent living complex samples).

Interestingly, loneliness, which has been reported in the literature as a problem experienced by many intellectually disabled people living in the community, was also a problem for the respondents in this survey. However, more of the residents in the institutional and intermediate settings responded "Yes" to the question "Do you feel lonely a lot of the time?" (55% and 53% respectively), than those in the group home or independent living complex settings (45% and 39% respectively).

In addition, with respect to relationships with families, fewer of the institutional residents reported that they saw their families (83%) than the intermediate (100%) and community settings (90%), but not the independent living setting (83%). The results were consistent with the tendency for more of the institutional sample to report that they could not visit their families whenever they wanted to and wanted to see more of them. However, those in the independent living setting felt that they could see their families when they wanted to, but did not want to see more of them, indicating that this group had more difficulties than the other groups in their relationships with families.

Satisfaction with Physical Health:

Although some in the community samples indicated that when they were sick they had no-one to look after them (25% and 44% in the community group homes and independent living settings respectively, compared with 7% from the institutional sample and 0% from the intermediate sample), and that they had problems that worried them a lot (60% in the community group home compared with 33% for the independent living, 30% for the institutional and 27% for the intermediate settings, differences between the three groups in terms of expressed satisfaction with physical health were not significant in either Study 3 or 4 ($F<1.0$ in both studies).

Satisfaction with Self-Esteem:

The community samples expressed higher satisfaction in the area of self-esteem than the institutional and intermediate settings, with many feeling that they were useful people to have around (94% in the independent living and 80% in the community group home settings, compared with 63% for the institutional setting and 73% for the intermediate setting), although fewer of the community sample liked the way they looked (83% and 80% in the independent living and community group home samples respectively) compared to the institutional or intermediate settings (93% and 91% respectively). However, the difference between the groups with respect to expressed satisfaction on the self-esteem scale was not statistically significant ($F<1.0$ in both studies 3 and 4).

Overall Satisfaction:

An index of overall satisfaction was computed by adding the scores received on all the items and dividing the sum by the total number of items. In Study 3 the intermediate sample expressed lower satisfaction than the institutional or community group home settings suggesting that this setting was not meeting the needs of its residents. This suggestion is supported by the responses to some of the questions in this scale. For example, 91% of participants in the intermediate sample indicated that they would like to live in another house (compared with 35% of participants in the community group homes and 65% of institutional participants). When asked where they wanted to live many (in the intermediate sample) indicated that they would like to move on to more independent living situations. Fewer of the participants in the intermediate setting (82%) felt that their house was a nice place to live in, compared with 100% of participants in the institutional and community group home settings.

However, although the residents in the community group homes expressed slightly higher satisfaction than the residents of the intermediate or institutional setting the difference was not statistically significant ($F= 1.99$, ~~N=61,~~ df 2,58 $p>0.05$).

In Study 4, the independent living setting had the highest overall satisfaction score and the difference between the groups was significant ($F=5.04$, ~~N=78,~~ df 3,74 $p<0.01$). A Scheffé post-hoc analysis revealed significant differences (at the 0.05 level) between the institutional setting and

the independent living complex; and between the intermediate and independent living settings.

Summary:

Overall, the results indicate that the RSQ is capable of discriminating between the groups examined here, with participants in the independent living complex expressing greater satisfaction than those in the institutional and intermediate settings but not, as predicted, than those in the community group home setting. The fact that overall satisfaction in the independent living complex is not significantly higher than that for the community group home setting, suggests that the outcome is not entirely the consequence of brighter individuals being better adjusted.

The results are consistent with the prediction that living in the community, in semi-independent to independent settings at least, leads to greater satisfaction than placement in an institutional or intermediate setting. However, this difference is almost entirely the consequence of satisfaction/dissatisfaction with residential placement (consisting of physical aspects of the house, social aspects, staff , in-house responsibilities, and rules and restrictions) and interpersonal relationships (consisting of satisfaction with the people lived with, friends, and family).

Correlation of Expressed Satisfaction with Five Faces Score: Correlations between satisfaction scales and the score obtained from the judgements about the mood portrayed in the

five faces were made, as in the previous study. There were three scales where the faces were presented following the yes/no questions (residential placement, work placement and financial status) and the results are presented in Table 23 below. As can be seen, in both studies, correlations were weak but statistically significant for two of the three scales. The correlations between work placement satisfaction and the five faces score for that scale were the only correlations that were not significant, which is the reverse of the situation in Study 1, where the work correlation was the only significant correlation.

The correlations do suggest that the rating on the five faces and the satisfaction score are in part measuring the same concept (i.e. participants who express a high satisfaction with residential placement, leisure time and financial status do choose one of the happy faces on the five faces scale).

Table 23: Correlation of Satisfaction Scores with Score of Five Faces.

Satisfaction Scale	r	N
Study 3:		
Residential Placement	0.32**	61
Work Placement	0.13	61
Financial Status	0.23*	61
Study 4:		
Residential Placement	0.32**	78
Work Placement	0.17	78
Financial Status	0.29**	78

* $p < 0.05$ ** $p<0.01$

Other Comparisons:

In an attempt to further validate the questionnaire a number of other comparisons were made, as outlined below.

Satisfaction by place of employment

Previous research has suggested that type of work placement may affect satisfaction. For example, Seltzer and Seltzer (1978) found that those who were competitively employed were more satisfied than those in sheltered workshops, who had once been competitively employed, and unemployed people who had also once been competitively employed.

All participants were employed, except one, but none was in competitive employment. The various work stations were therefore categorised into three groups. In Study 3, group 1 comprised 25 people and consisted of those people who were employed in the Activity Therapy Centres ((ATCs) as described in Chapter 4) or who were still at the Special School (also described in Chapter 4). Group 2 comprised 8 people who were at the Craft Co-operative (described in Chapter 4) or in Supported Employment. Clients working in Supported Employment require less supervision and training, and perform work that requires greater skills than clients at ATCs. For example, clients may work on assembling furniture or other items which are sold to the public and receive a higher rate of pay than clients in the ATCs. Group 3 comprised 27 people who were employed in a variety of independent work stations, also previously described in Chapter 4.

Oneway Analyses of Variance were conducted on the satisfaction scores for the six areas of the RSQ, as well as the overall satisfaction, by the type of work placement (Means and Standard Deviations are presented in Appendix 5). It was found that there was no significant difference between the groups (Activity Therapy group, Supported Employment, and Independent work stations) with respect to expressed satisfaction with residential placement ($F= 1.07$, df 2,57 ~~N= 61~~, $p>0.05$), or work placement ($F<1.0$).

There were significant differences between the groups in expressed satisfaction with financial status ($F=3.89$, df 2,57 ~~N=60~~, $p<0.05$) and interpersonal relationships ($F=4.62$, df 2,57 ~~N=60~~, $p<0.01$), those in independent workstations being more satisfied than those in supported employment (Scheffé $p<.05$) on both occasions

There were no differences between the groups in expressed satisfaction with physical health ($F<1$), self-esteem ($F= 1.29$, df 2,57 ~~N= 60~~, $p>0.05$) and overall satisfaction ($F= 1.75$, df 2,57 ~~N= 60~~, $p>0.05$).

In Study 4, the sample consisted of 29 participants in the ATC group, 17 in the supported employment group and 31 in Independent workstation positions.

There was a tendency for the supported employment group to express more satisfaction with their residential placement than either persons occupying independent workstation positions or the members of the ATC group but the difference was not significant ($F=1.24$, df 2,74 ~~N=77~~, $p=>0.05$). There was no significant difference between the groups with respect to satisfaction with work placement ($F < 1$).

The participants in the ATC and independent workstation positions expressed greater satisfaction with financial status than participants in the supported employment positions and this difference was approaching significance (F=2.92, df 2,74 ~~N=77~~, p=0.06).

The independent workstation participants expressed slightly higher satisfaction with respect to interpersonal relationships than the participants in the supported employment or ATC positions but this difference was not statistically significant (F=1.22, df 2,74 ~~N=77~~, p>0.05). There was no difference between the groups with respect to expressed satisfaction with physical health (F < 1), self-esteem (F < 1), or overall satisfaction (F < 1).

These results are similar to the results obtained in Study 3 and show that type of work placement may affect expressed satisfaction, although differences were significant in only two of the areas (financial situation and interpersonal relationships). However, it was not unexpected that there would be no differences with respect to satisfaction with residential placement as there was fairly even distribution across work locations of residents from each residential setting.

Comparison of satisfaction scores with presence of an additional handicap

For the participants in Study 3, information was available on whether an additional handicap was present. It was predicted that those with additional handicaps, either physical, medical, or sensory, would be less satisfied than

those who did not have such handicaps. Participants were divided into two groups - those who had physical, medical or sensory disabilities (such as epilepsy, hemiplegia, deafness or blindness, N=16) and those who did not (N=45) (Means and Standard deviations are presented in Appendix 5). There were no differences between the groups with respect to satisfaction with residential placement ($t= 1.26$, $N= 61$, $p>0.05$), work placement ($t= 1.48$, $N=60$, $p>0.05$), financial status ($t= 1.20$, $N=61$, $p>0.05$), physical health ($t= 1.57$, $N=61$, $p>0.05$), or self-esteem ($t=.97$). However, there were significant differences between the groups with respect to satisfaction with interpersonal relationships ($t=2.35$, $N=61$, $p<0.05$) and overall satisfaction ($t=1.97$, $N=61$, $p<0.05$), with those people with additional handicaps being less satisfied in both instances.

The results confirm the prediction that the presence of an additional handicap does have some effect on the degree of expressed satisfaction, most particularly with interpersonal relationships, thus providing further evidence of the RSQ's validity. It may be that the presence of an additional handicap such as epilepsy, which was common amongst those with handicaps, affects interpersonal relationships either by reducing the number of friends that a person has or by restricting the frequency or freedom of contact, especially if seizures are frequent. Overall, people with additional handicaps expressed less satisfaction with their lifestyle than those without handicaps.

Comparison of satisfaction by presence of a behaviour problem:

Previous research has shown that people with an intellectual disability and who exhibit behaviour problems are the most likely to have been returned to placements within an institutional setting, and to have expressed less satisfaction with their previous placement, compared to those without behaviour problems (Seltzer and Seltzer, 1978). A comparison of satisfaction scores was therefore made, for participants in Study 3, between those who had very low scores on the BAS (BAS < 2, N= 13), those who had very high scores (BAS > 20, N= 9) and those who fell in between the two scores (N= 39). It was predicted that those with behaviour problems would express less satisfaction than those who did not have behaviour problems (Means and Standard Deviations are presented in Appendix 5).

Oneway Analyses of Variances showed that the difference between the groups with respect to expressed satisfaction with residential placement was in the predicted direction (i.e. those with behaviour problems being less satisfied than those without behaviour problems and those in-between) and was close to significance (F= 2.87, df 2,58 ~~N=61~~, p=0.06). There was no difference between the groups with respect to expressed satisfaction with work placement (F<1), or self-esteem (F<1). There was a significant difference between the groups with respect to satisfaction with financial status (F= 4.00, df 2,58 ~~N=61~~, p<0.05), with a Scheffé post-hoc analysis (0.05) revealing significant differences between those those with severe behaviour problems and those

rated as in-between and those with very low scores on the behaviour problem scale. The difference between the groups on satisfaction with interpersonal relationships was in the predicted direction (with those with behaviour problems being less satisfied) and was close to significance ($F=2.43$, df 2,58 ~~N=61~~, $p=0.10$).

There was a significant difference between the groups with respect to satisfaction with physical health ($F=4.02$, df 2,58 ~~N=61~~, $p<0.01$), with a significant difference between those with severe behaviour problems and those in-between (Scheffé, 0.05 level). There was also a significant difference with respect to overall satisfaction ($F=3.6$, df 2,58 ~~N=60~~, $p<0.05$) with those with behavior problems having lower overall satisfaction scores than those without behaviour problems. A Scheffé analysis revealed that there was a significant difference between those with severe behaviour problems and those in-between.

Thus, it can be seen that the presence of a behaviour problem does affect to some extent expressed satisfaction, most particularly in the areas of financial status, interpersonal relationships, physical health and the overall satisfaction score, with those with severe behaviour problems expressing significantly less satisfaction than those without such severe problems. The fact that the questionnaire is reflecting this lower satisfaction on the part of participants with behaviour problems adds further validity to the questionnaire.

Correlations:

Measures of satisfaction from the various scales of the questionnaire (residential placement, work placement, financial status, interpersonal relationships, physical health, and self-esteem) including the overall satisfaction score, were correlated with age, number of other residents in the house, length of time in current placement, and score on the Behaviour Assessment Scale. It was expected that age would not affect satisfaction; that satisfaction would be negatively related to the number of people living in a house and score on the Behaviour Assessment Scale; and that satisfaction would be positively related to length of time in placement.

Previously it has been shown that the placement groups were significantly different with respect to age (with the institutional sample having the younger members). However, as age was correlated with only one of the satisfaction scales in Study 3 and three in Study 4, it was felt that this difference did not confound the results presented in the previous section. In Study 3, age was weakly correlated with satisfaction with interpersonal relationships ($r= 0.24$, $N= 61$, $p<0.05$), suggesting that the older participants expressed more satisfaction with interpersonal relationships than the younger participants. This is perhaps not surprising, because older people tend to have formed more settled and stable friendships than younger people. In Study 4, age was again weakly correlated with satisfaction with interpersonal relationships ($r=.21$, $N=76$, $p<0.05$) and, in addition, with satisfaction with financial status ($r=.34$,

N=76, p<0.01). Age was also weakly correlated to overall satisfaction (r=.20, N=76, p<0.05). In general, it was confirmed that age did not affect satisfaction.

The number of other residents in the location was negatively correlated with all of the scales in Study 3 but outcome was only significant for two of the satisfaction scales and the overall satisfaction score. The number of other residents in the living situation was weakly negatively correlated with satisfaction with residential placement (r = -0.33, N= 61, p<0.01), which suggests that the greater the number of other people in the living accommodation unit, the lower the expressed satisfaction is with the placement. There was also a significant negative correlation between expressed satisfaction with interpersonal relationships and the number of other people living in the house (r= -0.37, N= 61, p<0.001), suggesting that those participants in houses with higher numbers of others sharing the accommodation were less satisfied with interpersonal relationships than those in accommodation where there were fewer people. This is partly reflected in the responses to some of the items in that scale, as fewer of the institutional sample (who lived in accommodation shared with the highest number of others) felt that they could trust the people that they lived with (73% compared with 91% in the intermediate setting and 95% in the community group home setting). More of the institutional sample responded that the people with whom they lived got them into trouble (60% in the institutional sample compared with 27% in the intermediate setting and 35% in the

community group home setting) and were not nice to them (63% compared with 55% in the intermediate setting and 25% in the community setting). More of the institutional sample would rather be living with someone else (77%) than was so in the intermediate setting (55%) or in the community setting (45%).

The correlation between the number of other residents in the house and financial satisfaction approached significance ($r= -0.19$, $N=61$, $p=0.07$) but was only a very weak relationship. There was also a weak but significant negative correlation between numbers in the house and the overall satisfaction score ($r=-0.25$, $N=61$, $p<0.05$), which confirmed that the higher the number of other people with whom the participants had to share accommodation, the lower the overall expressed satisfaction. In Study 4 none of the correlations were significant.

The negative correlations with the number of other people in the house follows from the fact that participants in the institutional sample live in houses with the largest number of people and it was the institutional sample which showed significantly less expressed satisfaction in the areas of residential placement, interpersonal relationships and overall satisfaction. This suggests that satisfaction could be related to living unit size and that satisfaction could be increased by decreasing the number of people in living units.

There were no significant correlations between the length of time spent in current placement and satisfaction on any of the scales in Study 3 and only one scale in Study

4 (satisfaction with financial status) was weakly correlated with time in current placement ($r=.21$, $N=72$, $p<0.05$). However, it would be interesting to conduct longitudinal studies of participants who move from one setting to another, to measure any changes in expressed satisfaction that may occur over time.

For participants in Study 3, the score on the Behaviour Assessment Scale (BAS) was negatively correlated with all the scales, confirming that the higher the score (i.e. the greater the degree of behaviour problem) the lower the expressed satisfaction, but correlations were significant for only three of the scales. There was a significant negative correlation between score on the BAS and expressed satisfaction with financial status ($r= -0.35$, $N= 58$, $p<0.01$), suggesting that as the degree of behaviour problem increases then expressed satisfaction with financial status decreases.

There was a significant relationship between BAS score and expressed satisfaction with interpersonal relationships ($r=-0.26$, $N=58$, $p<0.05$), suggesting that the more marked the degree of behaviour problem, the less satisfaction there is with interpersonal relationships. This may be because a person with a behaviour problem may have few friends due to his/her anti-social behaviour or may have difficulty in making friends due to poor interpersonal skills.
A weak but significant negative relationship existed between the score on the BAS and overall satisfaction ($r=-0.28$, $N=58$, $p<0.05$), suggesting that those participants with higher degrees of behaviour problems tend to be less

satisfied with their overall lifestyles than those participants with fewer or no behaviour problems, although the trend is only a weak one. The relationship between expressed satisfaction and presence of a behaviour problem was also reflected in the oneway analyses of variances which showed that people with behaviour problems were significantly less satisfied in the areas of financial situation, interpersonal relationships, physical health and overall satisfaction. It is recognised, however, that all of the correlations obtained are weak and show only weak trends, with few accounting for more than 10% of shared variance. This is due to the difficulty of obtaining reliable results from people with an intellectual disability when using scales of this kind. However, the results do show that there is a weak trend for participants rated as having behaviour problems to express less satisfaction than those who are not so rated, and for people living in accommodation with greater numbers of others to express less satisfaction than those living in accommodation with fewer people.

Satisfaction by Admission to an Institution:

As previous research reviewed in Chapter 2 has shown, the effects of institutionalisation can last for many years. It was therefore of interest to see if admission to an institution has an effect on expressed satisfaction, regardless of current placement.

Oneway Analyses of Variance were conducted on two groups, those who had never been admitted to an institution

(N=16) and those who had a history of institutional placement (N=61) (Means and Standard Deviations presented in Appendix 5). It was found that there were significant differences between the groups with respect to satisfaction with residential placement ($F=15.39$, ~~N=77~~ df 1,75, $p<0.001$), with those who had never been admitted to an institution expressing greater satisfaction with their residential placement ($\bar{X}=86.56$, $SD=7.23$) than those who had been admitted to an institution ($\bar{X}=75.0$, $SD=11.05$). Those who had never been admitted to an institution also expressed more satisfaction with their interpersonal relationships ($\bar{X}=73.5$, $SD=13.11$) than those who had been admitted to an institution ($\bar{X}=65.97$, $SD=13.57$) ($F=3.96$, ~~N=77~~ df 1,75, $p<0.05$). They also expressed greater satisfaction overall than those who had been admitted to an institution ($F=6.50$, ~~N=77~~ df 1,75, $p<0.01$).

There were no significant differences between the groups with respect to satisfaction with work placement ($F=1.89$, ~~N=76~~ df 1,74, $p>0.05$), financial status ($F=2.01$, ~~N=77~~ df 1,75, $p>0.05$), or physical health ($F < 1$).

Inter Scale Correlations:

Relationships between the scales were examined using the Product Moment Correlation Coefficient. A matrix is presented in Table 24, and as can be seen, the scales are generally related to each other with the exception of the Physical Health Scale which correlated with only one other scale - Residential Placement. It would therefore seem that the scales tend to measure general satisfaction rather than

satisfaction with individual aspects of life satisfaction. Construct validity of the test was supported by the fact that all sub-scales of the questionnaire were significantly correlated with the total score.

Factor Analysis:

A Factor Analysis was conducted using the Principal Axis Factoring technique. Only one factor with an eigen value greater than one was extracted and all of the variables loaded on this factor, which accounted for 45.6% of the variance. The highest loading variables were satisfaction with Residential placement (.71) and satisfaction with Interpersonal relationships (.70) indicating that these are the two most important factors in satisfaction with lifestyle. The other loadings on the factor were Self-esteem (.63), Work Placement (.59), Financial Status (.47) and Physical Health (.41) (Further data presented in Appendix 5). These results indicate that the questionnaire is measuring a general factor of satisfaction, rather than the seven individual components as originally proposed.

Summary:

The questionnaire has been found to discriminate between groups with respect to expressed satisfaction to a limited degree, and it has been shown that placement in a community setting leads to greater expressed satisfaction than placement in an institutional or intermediate setting. This may be related to the lower number of residents in the community settings or to the greater degree of freedom and

independence allowed to the residents in community settings. It has also been shown that work placement may also affect expressed satisfaction in the areas of interpersonal relationships and financial status, with persons in independent workstation positions expressing greater satisfaction than people in ATCs or supported employment. The effect of placement in an institution can also affect expressed satisfaction with those who have or had been admitted to an institution expressing lower satisfaction than those who have never been admitted to an institution.

The general utility of the questionnaire across a broader range of abilities was tested and the results remained consistent with the previous studies. The additional independent living group studied was functioning at a higher intellectual level than the previous groups studied but, despite this, these participants did not express greater satisfaction than the community group of Studies 1 and 3, indicating that satisfaction is not necessarily related to higher intellectual functioning. However, while the results of these studies support the external validity of the RSQ, strong differences or relationships were not found and thus validation is only weak.

TABLE 24: Inter-Scale Correlations

	Residential Placement	Work Placement	Financial Status	Interpersonal Relationships	Physical Health	Self-Esteem	Overall Score
Residential Placement		.36***	.31**	.52***	.31**	.50***	.76***
Work Placement			.33**	.41**	.22*	.42***	.72***
Financial Status				.45***	.26*	.16	.63***
Interpersonal Relationships					.24*	.40***	.74***
Physical Health						.32**	.43***
Self-Esteem	.61***						
Overall Score							

* P<.05, ** p<.01, *** p<.001.

CHAPTER SIX

CONCLUSIONS

A review of the literature on the care of people with an intellectual disability showed that there is an increasing trend away from care in large institutions to care in smaller community units. With this trend has come a need to evaluate the success of such community placements in order to demonstrate that the quality of life of people with an intellectual disability has been enhanced, or at least not made worse, by placement in the community. In the main, evaluative studies have focussed on measuring success in terms of objective factors such as the use of community resources, increases in adaptive behaviour, or adherence to the principle of Normalisation. It was shown that outcomes of such research have varied and that community placements have not always been shown to be superior to institutional placements. It was argued that, while objective measures of placement success are important, it is also important to measure success from the viewpoint of an individual and that a measure of client satisfaction with lifestyle was needed.

This study aimed to develop a measure of client satisfaction from an individual's point of view. To this end, a model of satisfaction, based on a model used by sociologists for measuring the satisfaction of people without handicaps, was developed. Satisfaction with lifestyle was felt to consist of satisfaction in seven areas (residential placement, work placement, use of leisure time, financial status, interpersonal relationships, physical health and self-esteem). The Resident Satisfaction Questionnaire (RSQ) was then developed to measure satisfaction with these life areas.

The reliability of the RSQ was measured in two ways. The test-retest reliability of individual items and scale totals was established. In total 12 items and one scale were removed from the RSQ due to low test-retest reliabilities. The remaining scales had test-retest reliabilities that ranged from moderate to good. However, a problem was found to exist with acquiescence, which may have inflated the reliabilities. Despite the fact that an attempt had been made to control for acquiescence by using a screening test before proceeding with the questionnaire, the use of paired items scattered throughout the questionnaire revealed that a degree of acquiescence had occurred. However, acquiescence did not occur on all paired questions and inconsistency of responding may have occurred a) because respondents had difficulty with quantitative concepts that were involved in the pairs or b), where the question was reversed, the respondents did not interpret the questions as exact opposites of each other.

Despite the problems with acquiescence it was felt that the test-retest reliability of the questionnaire was adequate. Future research could improve the questionanire by: a) examining a more stringent means of screening for acquiescence prior to administering the questionnaire; b) balancing the number of positively and negatively worded questions. One problem which existed with the questionnaire was a lack of balance between positive and negatively worded questions (i.e. most questions were worded in such a way that a "yes" response received a positive score), thus leading to potential problems with acquiescence. It is recommended that future research in this area should try to have a better balance with questions requiring both positive and negative answers to receive a positive score; c) continued use of pairs of questions requiring reversed responding scattered throughout the questionnaire as another means of controlling for acquiescence. These questions would best be in the form of "Are you a happy person" vs "Are you a sad person" rather than in the form of questions which utilise concepts as "more", "less", "enough" as these types of questions were shown to be problemmatic for people with an intellectual disability to answer. Respondents who failed to answer these questions consistently could be excluded from analysis.

The internal consistencies of each of the scales was measured using Cronbach's alpha and were found to range from moderate to good. Content validity was argued on the basis of the method used in developing the questionnaire. In addition an attempt was made to measure the external

validity of the questionnaire using cartoon-type faces to represent satisfaction. Although respondents were moderately reliable on test-retest, the ratings of satisfaction on the cartoon-type faces did not correlate well with the satisfaction scores on the RSQ. It is felt that the cartoon faces may have been influenced by social desirability as respondents generally pointed to the happy faces, perhaps expecting that this was what the interviewer wanted.

In order to measure the criterion-related validity of the RSQ, a Staff Questionnaire was developed that attempted to measure both subjective ratings of resident satisfaction, as perceived by staff, and objective measures of degree of responsibility, autonomy, and decision-making allowed residents. Difficulties were experienced with the inter-rater reliabilities of this questionnaire, indicating that staff did not agree between themselves as to how satisfied residents were or how much influence the residents had on their lives. This may have been due to the fact that different staff do indeed engage in different practices within a house or that staff are not as reliable a source of information as the residents themselves. To some extent the differences may have arisen because the questionnaire was left with the staff and not presented by an interviewer, thus leading to possible differences in interpretation of the questionnaire. It is recommended that, if the questionnaire is utilised in future research, it be presented by an interviewer. Although difficulties were experienced with the staff questionnaire, a combined score

was calculable and was correlated with the results of the RSQ. It was found that staff rated satisfaction did not correlate with expressed satisfaction of the resident but that self-rated satisfaction correlated with objective factors indicating that degree of autonomy, responsibility and decision-making allowed residents may affect life satisfaction. It also indicated that staff may not be good judges of resident satisfaction. This supports the view that it is important to consult the person, despite the difficulties that may be encountered in doing so, when evaluating how satisfied a person with an intellectual disability is with his/her lifestyle. The results gave some support to the criterion-related validity of the RSQ.

The number of respondents interviewed and the range of intellectual disability was expanded in two final studies to test the construct validity of the questionnaire. Firstly, a study was conducted to compare the residential alternatives to determine the extent to which the RSQ discriminated among them. On the basis of the literature review it was predicted that institutional residents would be less satisfied than residents in the community and the results did, to some degree support this hypothesis. However, the difference was almost entirely due to satisfaction/dissatisfaction with residential placement and interpersonal relationships.

In general, the RSQ was shown to be capable of discriminating between placement settings and that satisfaction was related to a number of other factors in a person's life such as the number of other people living in

the unit, presence of additional handicap and so on. However, relationships found were not strong and thus support for the validity of the questionnaire was only weak.

Secondly, construct validity was examined by testing the degree to which the seven sub-scales of the questionnaire correlated with the total score. In all cases the correlations were highly significant. Finally, factor analysis was conducted which revealed that only one general factor of satisfaction was being measured by the questionnaire, rather than the seven sub-scales as had been proposed.

Despite the problems encountered with acquiescence, it is felt that obtaining degree of satisfaction from the people most affected by placement in community settings (i.e. the residents themselves) is still important. In this respect, it is felt that the RSQ could be useful as part of an evaluation into the success of a given placement. Satisfaction over time was not examined and future research could examine longitudinal changes in satisfaction, prior to replacement and at intervals after relocation.

APPENDIX 1

RESIDENT SATISFACTION QUESTIONNAIRE

Name:.....

Address:.....

Date of Interview:.....

I am here today to talk to you about the work that I am doing and to ask you to help me with this work. I am interested in talking to you and to other people here about where you live and if you are happy with the way you are living. I am asking these questions because I want to find out what is good about the place as well as what is bad about it, and to find out what you want. this will help the people who run these places know how they can be made better.

This is not a test. there are no right or wrong answers to the questions. I just want to find out how you feel about things. I will not tell anyone what you tell me unless you want me to.

If you would rather not talk to me you can say so now. if there are any questions that you do not want to answer, then that is alright, just let me know. if you want to ask me any questions as we go through then stop me whenever you want and ask them.

1. What is your name?
2. Is today (wrong day)?
3. Is it raining/sunshining outside today?
4. Is this..... (wrong address)?
5. Are you Chinese?

RESIDENTIAL PLACEMENT

Physical

		YES	NO	NOT SURE
1.	Do you like the area (suburb) you live in?			
2.	Do you feel safe in this suburb (area)?			
3.	Is it a nice area to live in?			
4.	Is your house a nice place to live?			
5.	Do you like your bedroom?			
6.	Do you feel safe in this house?			
7.	Would you rather live in a different area?			
8.	Would you rather live in a different house? Where?.....			

Social

9.	Are the people you live with nice people?			
10.	Do too many people live here?			
11.	Do you have enough chance to be alone if you want to be alone?			
12.	Would you rather more people lived here?			
13.	Would you rather be living by yourself?			
14.	Would you rather less people lived here?			
15.	Do you like the people you live with?			
16.	Would you rather live with someone else? Who?.....			

..../3.

Staff

		YES	NO	NOT SURE
17.	Do you like the staff who work here?			
18.	Do you get criticised unfairly by staff?			
19.	Do the staff here help you with your problems?			
20.	Do the staff here make you do too much?			
21.	If you had a problem, would the staff here help you?			
22.	Do you think the staff pick on you?			
23.	Are the staff here hard to get along with?			
24.	Would you like the staff here to teach you more things? What?.....			

In- House Responsibilities

25.	Do you like to do jobs around the house?			
26.	Do you have enough jobs to do?			
27.	Does doing your jobs take up too much time?			
28.	Do your jobs make you feel useful?			
29.	Do you have too many jobs here?			
30.	Do you mind doing the..... (laundry etc.)			
31.	Would you rather have someone else do the jobs for you all the time?			

..../4.

Rules and Restrictions

	YES	NO	NOT SURE
32. Are there too many rules around here?			
33. Do you have enough freedom to do what you want?			
34. Do other people tell you what to do too much?			
35. Are you allowed to make up your mind about the things you want to do?			
36. Do you want the staff to tell you what to do more often?			
37. Can you do what you want to when you want to?			
38. Can you go out whenever you want to?			
39. Can you go out without telling the staff where you are going?			

General

40. Is this the right place for you to be living? Why?

41. Is this place better than the last place you were living? Why?

42. What do you like best about living here?

43. Is there anything that you do not like about living here?

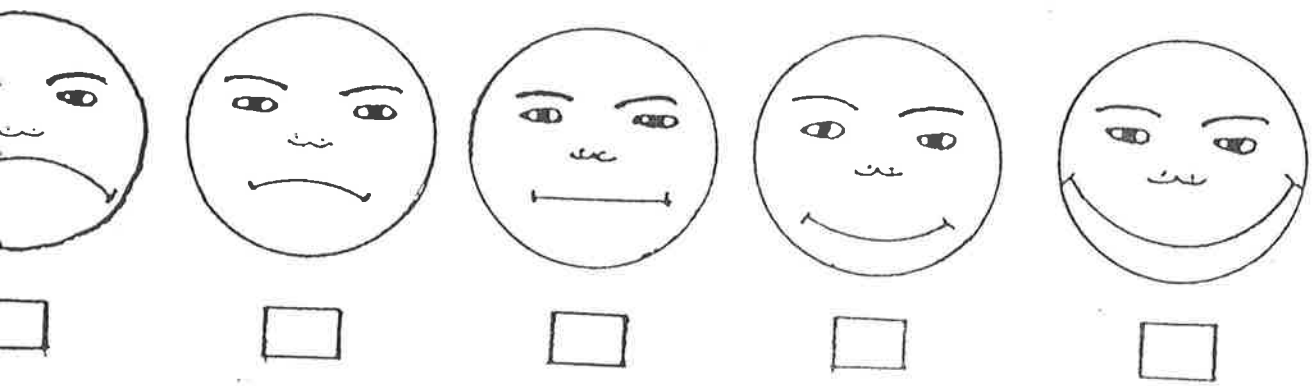
44. Do you think that you have been taught all the things that you need to do to do well here?

45. Is there anything that you would like to learn that you are not being taught?

46. Is it better or worse living here than at Minda? (For ex-residents)

47. Would you rather be living in the community or Minda?

48. Here are five faces. One has a very big smile (point) which means that he is <u>very</u> happy, one has a big frown (point) which means he is <u>very</u> unhappy. One has a little smile (point) which means he is happy, one has a little frown (point) which means he is sad, and one has no smile and no frown (point) which means that he is not happy and not sad. Point to the face which best tells how you feel most of the time about where you live, including the house you live in, the people you live with, the jobs you do, the rules, and the staff.



..../6.

WORK PLACEMENT

Physical

	YES	NO	NOT SURE
1. Do you like the place where you work?			
2. Is it a nice building to work in?			
3. Is it a nice place to work?			
4. Do you have to stand on your feet too much?			
5. Do the days seem too long at work (ie like they will never end)?			
6. Would you rather be working somewhere else? Where?.....			

Task.

7. Do you like the jobs (tasks) that you do at work?			
8. Do you think your work is interesting?			
9. Does your job make you feel useful?			
10. Is your work boring?			
11. Do you have enough to do at work?			
12. Would you rather be doing different jobs? What?.....			

..../7.

Social

		YES	NO	NOT SURE
13.	Do you like the people you work with?			
14.	Are the people you work with ever not nice to you?			
15.	Do the people you work with talk too much?			
16.	Are the people you work with nice people?			
17.	Would you rather be working with different people? Who?.....			

Staff

18.	Do you like the staff at work?			
19.	Do the staff at work help you when you need it?			
20.	Do the staff at work pick on you?			
21.	Do the staff at work tell you when you are doing a good job?			
22.	Do the staff at work teach you enough?			
23.	Do you want the staff at work to teach you more things? What?.....			

Pay

24.	Do you get paid enough money for working?			
25.	Do you get paid less than you are worth?			
26.	Do you think your pay is bad?			
27.	Do you get paid enough for the work you do?			

..../8.

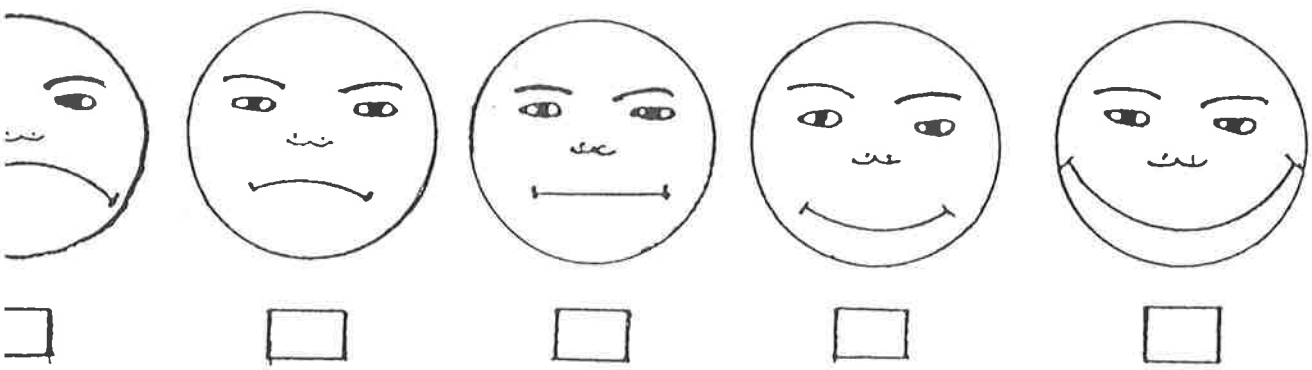
General

28. Is ..... the right place for you to be working? Why?

29. What do you like best about working there?

30. Is there anything that you do not like about working there?

31. Here are the five faces again. One has a very big smile (point) which means he is very happy, and one has a very big frown (point) and he is very unhappy. One has a little smile (point) which means he is happy, one has a little frown (point) and he is unhappy, and one has no smile and no frown (point) which means he is not happy and not unhappy. Point to the face which best tells how you feel about where you work, including the people you work with, the staff there, the money you get, and the type of job you do.



..../9.

LEISURE TIME

Free Time

1. Do you have enough to do in your spare time? (ie when you are not working or doing your jobs)
2. Do you have enough spare time?
3. Would you like to do more things in your spare time than you do now?
4. Do you wish you had more spare time to do things?
5. Is it easy to find things to do in your spare time?
6. Are you ever bored?
7. Do you want someone to show you more things to do with your spare time?

   What?.....

	YES	NO	NOT SURE
1.			
2.			
3.			
4.			
5.			
6.			
7.			

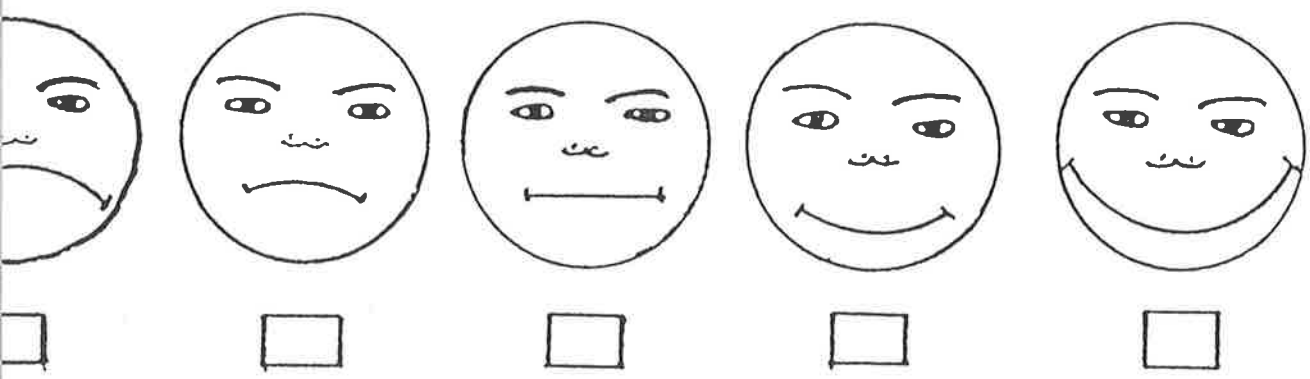
Holidays

8. Do you have enough holidays from work?
9. Do you do enough things in your holidays?
10. Are your holidays from work boring?
11. Do you wish that there were no holidays from work (ie that you worked all year)?
12. Would you like more holidays from work?
13. Do you do interesting things in your holidays from work?

8.			
9.			
10.			
11.			
12.			
13.			

..../10.

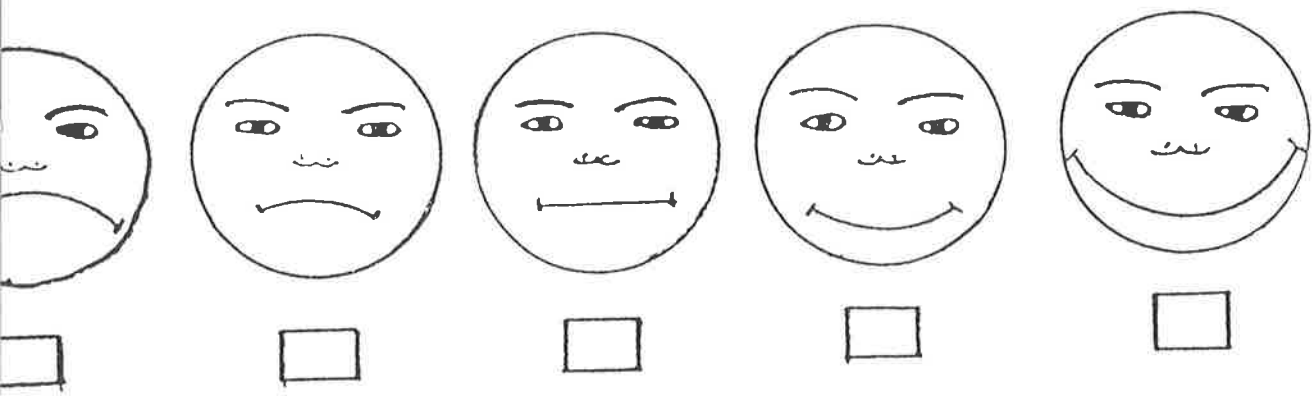
14. Here are the five faces again. There is the one with the very big smile (point) and there is the one with the very big frown (point). The rest are in-between. Point to the one that best tells how you feel most of the time about your spare time, including the things that you do in your spare time, how much spare time you have, and your holidays from work.



INANCIAL STATUS

	YES	NO	NOT SURE
1. Do you have enough money to spend?			
2. Do you spend too much money?			
3. Would you like to have more money to spend?			
4. Do you have enough money to buy the things that you need?			
5. Do you have enough money to go out when you want to?			
6. Do you run out of money before your next pay?			
7. Do you decide how to spend your money?			
8. Do you spend your money the way you want to?			
9. Should you make more decisions about what you will do with your money?			
10. Would you like someone to teach you how to look after your money better?			
11. Do you have enough money to buy special things when you want to?			

12. Here are the five faces again. Here is the one with the big smile (point) and here is the one with the big frown (point). The rest are in-between. Point to the one which tells how you feel most of the time about the amount of money you have, including the way you spend it.



INTERPERSONAL RELATIONSHIPS

		YES	NO	NOT SURE
Residential				
1.	Do you like the people you live with?	1.		
2.	If you were to move, would you live with them again?	2.		
3.	Can you trust the people you live with?	3.		
4.	Are the people you live with nice people?	4.		
5.	Do the people you live with get you into trouble?	5.		
6.	Are the people you live with ever not nice to you?	6.		
7.	Would you rather be living with someone else? Who?.....	7.		
Friends				
8.	Do you have enough friends?	8.		
9.	Do you spend enough time with your friends?	9.		
10.	Is it hard to find friends?	10.		
11.	Would you like to have more friends?	11.		
12.	Do you feel lonely a lot of the time?	12.		
13.	Do you go out with your friends when you want to?	13.		
14.	Do you choose your friends?	14.		
Family				
15.	Do you see your family?	15.		
16.	Would you like to see more of your family?	16.		
17.	Do you like visiting your fgamily?	17.		
18.	Would you like your family to visit you more often?	18.		
19.	Can you visit your family whenever you want to?	19.		

PHYSICAL HEALTH

		YES	NO	NOT SURE
1.	Do you feel sick often?			
2.	Do you feel healthy most of the time?			
3.	If you are sick, is there anyone to look after you?			
4.	Do you worry about being sick?			
5.	If you are sick, can you take time off work?			
6.	When you are sick can you go to a doctor?			
7.	Do you like the doctor that you go to?			
8.	Can you trust the doctor that you go to?			
9.	Do you want to change your doctor (ie go to a different doctor)?			
10.	Do you have problems that worry you a lot? What?.....			
11.	Is there anything that you are afraid of? What?.....			

..../14.

SELF ESTEEM

Now I am going to ask you some questions about how you feel about yourself.

Do you feel that:

1.....you can be proud of yourself?

2.....everything you do goes wrong?

3.....when you do something you do it well?

4.....there are lots of good things about you?

5.....you can do things as well as most people?

6.....sometimes you are no good at all?

7.....you are a useful person to have around?

8.....you are a happy person?

9.....your life is not very useful?

10.....you can do anything if you really try?

11.....you are a good person?

12.....you can handle most problems?

13.....you are sad most of the time?

14.....most people like you?

15.....people are hard to get along with?

16.....you like the way you look?

	YES	NO	NOT SURE
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			
15.			
16.			

APPENDIX 2

INDIVIDUAL PROFILE

Name of resident:.....

Name of staff member:.....

Address of group home/placement:.....

Date : .../../...

Please answer the following questions about.....

(please circle the response which you feel best describes the person)

1. In general, how happy do you think this person is with his/her life?

Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

2. In general, how happy do you think this person is?

Very Unhappy	Unhappy	Neut al	Happy	Very Happy

3. How happy do you think this person is with his/her current residential placement?

Very Unhappy	Unhappy	Neutral	Happy	Very Happy

4. How well placed do you think this person is in this house?

Very Badly Placed	Badly Placed	Neutral	Well Placed	Very Well Placed

5. How satisfied is this person with his/her current work placement?

Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

..../2.

6. How well placed is this person in his/her current work placement?

Very Badly Placed	Badly Placed	Neutral	Well Placed	Very Well Placed

7. How satisfied do you think this person is with his/her lifestyle?

Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

8. How bored does this person get?

Very Bored	Bored	Neutral	Not Very Bored	Not at all

9. How well does this person occupy him/herself on holidays from work?

Very Badly	Badly	Neutral	Well	Very Well

10. How satisfied do you think this person is with his/her financial affairs?

Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

11. How well does this person manage his/her money?

Very Badly	Badly	Neutral	Well	Very Well

12. How many friends does this person have?

None	Very Few	About Average	A Few More Than Average	Lots

13. How lonely do you think this person is?

Very Lonely	Lonely	Neutral	Not much	Not at all

14. How often does this person visit his/her family?

Never	Rarely	Seldom	Often	Frequently

15. How well physically is this person?

Very Unhealthy	Unhealthy	Average	Healthy	Very Healthy

16. How often does this person complain of feeling unwell?

Very Often	Often	Seldom	Rarely	Never

17. How high is this person's level of self-esteem?

Very Low	Low	Average	High	Very High

18. How much do you think this person likes the way he/she looks?

Greatly Dislikes	Dislikes	Neutral	Likes	Likes a Lot

19. How many visits, letters, phone calls has this person had with any members of his/her immediate family during the past twelve months?

	Never	Once Only	2-6 Times	7-12 Times	>12 Times
a. Visited a family member					
b. Family member visited person					
c. Person wrote or phoned family					
d. Family wrote or phoned person					

..../4.

20. In your situation, who has the most responsibility for the following:

		..... Alone	..... with Assistance*	Staff Only
1.	Cleaning the bedroom			
2.	Serving own meals			
3.	Preparing meals			
4.	Food shopping			
5.	Washing clothes etc.			
6.	Mending clothes			
7.	Banking money from work/pension			
8.	Spending money			
9.	Deciding how much money to save each week			
10.	Maintenance of the grounds			
11.	Setting the table			
12.	Doing the dishes			
13.	Shopping for supplies for the house			
14.	Paying bills			
15.	Cleaning living rooms			
16.	Cleaning the dining room			
17.	Cleaning the kitchen			
18.	Making sure all tasks are performed as necessary			

* Assistance may be from other residents or staff.

Please make any comments that you feel necessary regarding the above.

1. Is..... allowed to:

		At any Time	Only with staff permission/ at certain times	Not at all
.	Invite visitors for a meal	1.		
.	Have a pet	2.		
.	Go out alone	3.		
.	Stay up late on week-nights	4.		
.	Stay up late on weekends	5.		
.	Stay out late on week-nights	6.		
.	Stay out late on weekends	7.		
.	Get up late on week-days	8.		
.	Get up late on weekends	9.		
0.	Stay out overnight	10.		
1.	Make him/herself a snack	11.		
2.	Watch TV	12.		
3.	Make him/herself a drink	13.		
4.	Use the telephone	14.		
5.	Withdraw money from his/her bank account	15.		
6.	Drink alcohol in the house	16.		
7.	Drink alcohol outside the house	17.		
8.	Invite a boy/girlfriend home	18.		
9.	Leave his/her room untidy	19.		
0.	Stay home from work without a medical reason	20.		
1.	Keep a key to the house	21.		
2.	Decorate his/her room	22.		
3.	Lock his/her room from the inside	23.		
4.	Lock the bathroom from the inside	24.		
5.	Lock the toilet from the inside	25.		

..../6.

'lease make any comments that you feel are necessary in relation to the above.

2. What time is this person expected to be home by if they go out at night?
(Please specify if this is different on weekends)

3. What time is this person expected to be in bed?
(Please specify if this is different on weekends)

..../7.

24. In your situation, who is most involved in deciding the following:

		..... Alone	..... with other residents &/or staff	Staff Only
1.	What he/she wiill do on weekends			
2.	Where to go on his/her holidays			
3.	What time to take a shower			
4.	What time to go to bed			
5.	What time meals are served			
6.	What the daily menu is			
7.	What food to buy for the house			
8.	What time to get up in the morning			
9.	What the rules of the house will be			
10.	Who he/she will share a room with			
11.	When the house needs to be painted			
12.	Whether a particular staff member should be fired.			
13.	How much money he/she should save each week.			
14.	When staff have days off			
15.	Whether a particular resident is admitted			
16.	How he/she spends his/her money			
17.	When staff take holidays			
18.	Whether a particular staff person will be assigned to the house			
19.	When he/she takes his/her holidays			
20.	When to punish bad behaviour			
21.	How to punish bad behaviour			
22.	What he/she will do on weeknights			
23.	What equipment to buy for the house			
24.	When he/she is ready to move out of the house			
25.	What time household tasks are performed			
26.	What he/she wears			

..../8.

24. ...../cont.

	..... Alone	..... with other residents &/or staff	Staff Only
27. What leisure activities he/she will participate in			
28. What clothes he/she will buy			
29. Choose whether or not to go to work (ie to be unemployed)			
30. Choose what his/her job (occupation) will be			

Please make any comments that you feel are necessary in relation to the above.

APPENDIX 3

Illustration of the calculation of the statistic Kappa.

Sample Contingency Table.

Do you feel safe in this suburb (area)?

First Administration	Second Administration: Yes	Second Administration: No	
Yes	.81	.03	.84
No	.03	.13	.16
	.84	.16	

The proportion of agreement obtained is .81 + .13 = .94. Chance level is calculated from the marginals of the two cells which represent agreement. The chance probability of a "yes-yes" result is .71 (.84 x .84) while the chance probability of a "no-no" combination is .02 (.16 x .16), resulting in the proportion of agreement expected by chance as .73 (.71 + .02). Kappa is calculated as:

$$k = \frac{\text{p obtained - p by chance}}{\text{1 - p by chance}}$$

[Where k = Kappa, p obtained = proportion obtained, p by chance = proportion obtained by chance)

For this example,

$$k = \frac{.94 - .73}{1 - .73} = .78$$

This indicates that 78% of the cases represent agreement beyond that one would expect on the basis of chance. The statistical significance of kappa can be determined by the calculation of a standard error term:

$$ko = \frac{\text{p by chance}}{\sqrt{N(1 - \text{p by chance})}}$$

[where ko = standard error of Kappa, N = sample size]

$$ko = \frac{.73}{\sqrt{31(1 - .73)}} = .30$$

$$\underline{z} = \frac{k}{ko} = \frac{.78}{.30} = 2.6 \ (p < .01)$$

Please make any comments that you feel are necessary in relation to the above.

22. What time is this person expected to be home by if they go out at night?
(Please specify if this is different on weekends)

23. What time is this person expected to be in bed?
(Please specify if this is different on weekends)

Staff Questionnaire Scale 20: Test-Retest and Inter-Rater Reliabilities Revised.

Question	Test-Retest A	Test-Retest B	Inter-Rater A	Inter-Rater B
In your situation, who has the most responsibility for the following:				
1. Cleaning the bedroom	9%	89%	4%	89%
2. Serving own meals	21%	65%	4%	57%
3. Preparing meals	29%	54%	7%	59%
4. Food Shopping	32%	50%	21%	47%
5. Washing clothes etc	29%	65%	7%	54%
6. Mending clothes	51%	26%	46%	11%
7. Banking money from work/pension	37%	60%	21%	64%
8. Spending money	0%	100%	0%	100%
9. Deciding how much money to save each week	18%	79%	0%	71%
10. Maintenance of the grounds	34%	43%	32%	36%
11. Setting the table	9%	80%	0%	79%
12. Doing the dishes	6%	86%	0%	86%
13. Shopping for supplies for the house	38%	59%	21%	50%
14. Paying bills	54%	40%	46%	25%
15. Cleaning living rooms	17%	69%	7%	76%
16. Cleaning dining rooms	11%	77%	7%	79%
17. Cleaning the kitchen	9%	71%	18%	68%
18. Making sure all tasks are performed as necessary	29%	65%	18%	50%

A= Staff Only rated on both occasions
B= Assistance given or performs task alone rated on either occasion.

Staff Questionnaire Scale 21: Test-Retest and Inter-Rater Reliabilities Revised.

Question	Test-Retest A	Test-Retest B	Inter-Rater A	Inter-Rater B
	N=35		N=28	
Is ..... allowed to:				
1. Invite visitors for a meal	0%	100%	0%	100%
2. Have a pet	65%	19%	37%	26%
3. Go out alone	3%	91%	0%	89%
4. Stay up late on week nights #	3%	80%	0%	93%
5. Stay up late on weekends	0%	100%	0%	100%
6. Stay out late on week nights*	0%	79%	0%	96%
7. Stay out late on weekends	0%	97%	0%	97%
8. Get up late on weekdays *	32%	41%	14%	36%
9. Get up late on weekends *	0%	100%	0%	100%
10. Stay out overnight	9%	81%	0%	82%
11. Make him/herself a snack	0%	100%	0%	96%
12. Watch TV	0%	100%	0%	100%
13. Make him/herself a drink	0%	100%	0%	100%
14. Use the telephone	0%	100%	0%	100%
15. Withdraw money from his/her bank account	17%	69%	11%	71%
16. Drink alcohol in the house	14%	66%	4%	75%
17. Drink alcohol outside the house*	12%	62%	4%	75%
18. Invite a boy/girlfriend home	0%	97%	0%	100%
19. Leave his/her room untidy *	38%	59%	36%	47%
20. Stay home without a medical reason	14%	57%	11%	61%
21. Keep a key to the house	57%	43%	46%	39%
22. Decorate his/her room	0%	86%	0%	100%
23. Lock his/her room from the inside	68%	26%	50%	11%
24. Lock the bathroom from the inside	66%	31%	64%	36%
25. Lock the toilet from the inside	29%	71%	21%	68%

N=31 Test-Retest, N=27 Inter-Rater
* N=34 Test-Retest
A = Not at all, B = Only with staff permission/ at certain times /or At any time.

Staff Questionnaire Scale 24: Test-retest and Inter-rater Reliabilities Revised.

Question	Test-Retest A	Test-Retest B	Inter-Rater A	Inter-Rater B
	N=35		N=28	
In your situation who is most involved in deciding the following:				
1. What he/she will do on the weekends	0%	100%	0%	100%
2. Where to go on his/her holidays	0%	91%	0%	97%
3. What time to take a shower	0%	97%	0%	100%
4. What time to go to bed	0%	97%	0%	100%
5. What time meals are served	40%	54%	25%	61%
6. What the daily menu is	49%	43%	46%	36%
7. What food to buy for the house	49%	49%	43%	39%
8. What time to get up in the morning	26%	57%	18%	75%
9. What the rules of the house will be	43%	43%	21%	46%
10. Who he/she will share a room with	9%	80%	0%	82%
11. When the house needs to be painted	66%	20%	64%	7%
12. Whether a particular staff member should be fired	86%	0%	75%	0%
13. How much money he/she should save each week	6%	77%	0%	86%
14. When staff have days off	100%	0%	93%	0%
15. Whether a particular resident is admitted	86%	9%	57%	0%
16. How he/she spends his/her money	0%	100%	0%	100%
17. When staff take holidays	100%	0%	93%	0%
18. Whether a particular staff member will be assigned to the house	100%	0%	89%	0%
19. When he/she takes his/her holidays	6%	63%	4%	82%

cont..../

Staff Questionanire Scale 24: Test-retest and Inter-rater Reliabilities Revised cont.

Question	Test-Retest A	Test-Retest B	Inter-Rater A	Inter-Rater B
	N=35		N=28	
20. When to punish bad behaviour	60%	17%	36%	14%
21. How to punish bad behaviour	51%	17%	39%	14%
22. What he/she will do weeknights	0%	94%	0%	100%
23. What equipment to buy for the house	34%	51%	29%	54%
24. When he/she is ready to move out of the house	40%	46%	21%	36%
25. What time household tasks are done	40%	49%	18%	54%
26. What he/she wears	0%	100%	0%	100%
27. What leisure activities he/she will participate in *	0%	100%	0%	100%
28. What clothes he/she buys	24%	71%	0%	68%
29. Choose whether or not to go to go to work (i.e. be unemployed)	19%	61%	7%	72%
30. Choose what his/her job (occupation) will be	9%	85%	0%	89%

*N=34 Test-Retest reliability
A Staff only,
B = Person with other residents and/or staff or Person alone

Staff Questionnaire Scale 20: Test-Retest and Inter-Rater Reliabilities

Question	Test-Retest 0/ 0	1/ 1	2/ 2	Percent* Agree	Inter-Rater 0 / 0	1/ 1	2/ 2	Percent* Agree
In your situation, who has the most responsibility for the following:								
1. Cleaning the bedroom	9	14	57	80	4	11	43	57
2. Serving own meals	21	15	35	71	4	4	32	39
3. Preparing meals	29	43	-	72	7	48	-	56
4. Food Shopping	32	41	3	77	21	39	4	64
5. Washing clothes etc	29	12	47	88	7	-	39	47
6. Mending clothes	51	14	9	74	46	7	-	54
7. Banking money from work/pension	37	40	3	80	21	50	-	71
8. Spending money	-	47	29	77	-	32	14	46
9. Deciding how much money to save each week	18	50	15	82	-	36	14	50
10. Maintenance of the grounds	34	29	3	66	32	21	4	57
11. Setting the table	8	11	57	77	-	4	39	43
12. Doing the dishes	6	26	46	77	-	11	18	29
13. Shopping for supplies for the house	38	53	3	94	21	43	4	68
14. Paying bills	54	31	-	86	46	21	-	68
15. Cleaning living rooms	17	9	51	77	7	14	29	50
16. Cleaning dining rooms	11	20	54	86	7	14	29	50
17. Cleaning the kitchen	9	14	51	74	18	4	29	50
18. Making sure all tasks are performed as necessary	29	47	18	94	18	36	4	57

* % Agree is the sum of totals in preceding columns.

0 = Staff only 1= Person with assistance 2 = Person alone

Staff Questionnaire Scale 21: Test-Retest and Inter-Rater Reliabilities.

Question	Test-Retest 0/0	1/1	2/2	Percent Agree	Inter-Rater 0/0	1/1	2/2	Percent Agree
	N=35				N=28			
Is ..... allowed to:								
1. Invite visitors for a meal	0	40	57	97	0	29	29	75
2. Have a pet	65	13	7	84	37	11	7	56
3. Go out alone	3	57	23	83	0	36	21	57
4. Stay up late on week nights #	3	49	14	66	0	57	7	64
5. Stay up late on weekends	0	20	63	83	0	11	61	72
6. Stay out late on week nights*	0	65	9	74	0	82	0	82
7. Stay out late on weekends0		69	20	89	0	61	7	68
8. Get up late on weekdays *	32	38	3	74	14	32	0	46
9. Get up late on weekends *	0	18	59	76	0	11	61	72
10. Stay out overnight	9	61	0	70	0	68	0	68
11. Make him/herself a snack	0	37	46	83	0	21	50	71
12. Watch TV	0	0	83	83	0	0	96	96
13. Make him/herself a drink	0	29	63	92	0	21	75	96
14. Use the telephone	0	34	51	86	0	32	46	79
15. Withdraw money from his/her bank account	17	40	6	63	11	46	14	71
16. Drink alcohol in the house	14	54	6	74	4	68	4	75
17. Drink alcohol outside the house*	12	41	12	65	4	39	14	57
18. Invite a boy/girlfriend home	0	40	54	94	0	21	32	55
19. Leave his/her room untidy *	38	41	12	91	36	39	0	75
20. Stay home without a medical reason	14	57	0	71	11	61	0	72
21. Keep a key to the house	57	0	31	89	46	4	32	82
22. Decorate his/her room	0	20	43	63	0	25	64	89
23. Lock his/her room from the inside	68	3	21	9	50	0	7	57
24. Lock the bathroom from the inside	66	0	29	94	36	0	36	100
25. Lock the toilet from the inside	29	3	43	74	21	4	50	75

N=31 Test-Retest, N=27 Inter-Rater * N=34 Test-Retest

0 = Not at all, 1 = Only with staff permission/ at certain times, 2 = At any time.

Staff Questionnaire Scale 24: Test-Retest and Inter-Rater Reliabilities.

Question	Test-Retest 0/0	1/1	2/2	Percent Agree	Inter-Rater 0/0	1/1	2/2	Percent Agree
	N=35				N=28			
In your situation who is most involved in deciding the following:								
1. What he/she will do on the weekends	0	51	34	86	0	32	14	46
2. Where to go on his/her holidays	0	66	6	71	0	71	4	75
3. What time to take a shower	0	20	54	74	0	21	36	57
4. What time to go to bed	0	34	43	77	0	32	29	61
5. What time meals are served	40	40	0	80	25	54	0	79
6. What the daily menu is	49	45	0	93	46	36	0	82
7. What food to buy for the house	49	49	0	97	43	39	0	82
8. What time to get up in the morning	26	20	6	51	18	57	7	82
9. What the rules of the house will be	43	43	0	86	21	46	0	68
10. Who he/she will share a room with	9	63	3	74	0	50	4	54
11. When the house needs to be painted	66	20	0	86	64	7	0	71
12. Whether a particular staff member should be fired	86	0	0	86	75	0	0	75
13. How much money he/she should save each week	6	43	11	60	0	32	14	46
14. When staff have days off	100	0	0	100	93	0	0	93
15. Whether a particular resident is admitted	86	6	0	91	57	0	0	57
16. How he/she spends his/her money	0	57	17	74	0	38	18	57
17. When staff take holidays	100	0	0	100	93	0	0	93
18. Whether a particular staff member will be assigned to the house	100	0	0	100	89	0	0	89
19. When he/she takes his/her holidays	6	57	0	63	4	75	0	79
20. When to punish bad behaviour	60	17	0	77	36	14	0	50

cont.....

Staff Questionnaire Scale 24: Test-Retest and Inter-Rater Reliabilities cont.

Question	Test-Retest 0/ 0	1/ 1	2/ 2	Percent Agree	Inter-Rater 0/ 0	1/ 1	2/ 2	Percent Agree
	N=35				N=28			
21. How to punish bad behaviour	51	17	0	69	39	14	0	54
22. What he/she will do week nights	0	26	37	63	0	25	46	71
23. What equipment to buy for the house	34	51	0	86	29	54	0	82
24. When he/she is ready to move out of the house	40	43	3	86	21	36	0	57
25. What time household tasks are done	40	46	0	86	18	46	0	64
26. What he/she wears	0	34	54	89	0	18	39	57
27. What leisure activities he/she will participate in *	0	38	32	71	0	32	29	61
28. What clothes he/she buys	24	62	9	94	0	54	0	54
29. Choose whether or not to go to go to work (i.e. be unemployed)	19	36	19	74	7	54	0	61
30. Choose what his/her job (occupation) will be	9	67	12	88	0	68	0	68

*N=34 Test-Retest reliability

0 = Staff only,
1 = Person with other residents and/or staff, 2 = Person alone

APPENDIX 5

Satisfaction with Lifestyle by Place of Employment
Means and Standard Deviations. N=60.

Group	N	Mean	SD
Satisfaction with Residential Placement			
Activity Therapy Centre	25	73.12	11.66
Supported Employment	8	72.25	8.60
Independent Work Station	27	77.00	10.65
Satisfaction with Work Placement			
Activity Therapy Centre	25	75.20	13.79
Supported Employment	8	78.75	12.53
Independent Work Station	27	78.44	16.44
Satisfaction with Financial Status			
Activity Therapy Centre	25	66.32	16.82
Supported Employment	8	49.00	20.20
Independent Work Station	27	68.22	17.23
Satisfaction with Interpersonal Relationships			
Activity Therapy Centre	25	64.52	13.43
Supported Employment	8	56.13	10.45
Independent Work Station	27	71.04	12.77
Satisfaction with Physical Health			
Activity Therapy Centre	25	84.52	13.12
Supported Employment	8	85.38	10.69
Independent Work Station	27	85.67	10.67
Satisfaction with Self-Esteem			
Activity Therapy Centre	25	87.60	8.60
Supported Employment	8	81.25	9.57
Independent Work Station	27	87.11	11.33
Overall Satisfaction			
Activity Therapy Centre	25	74.48	8.74
Supported Employment	8	69.75	5.99
Independent Work Station	27	76.85	11.29

Satisfaction with Lifestyle by Place of Employment
Means and Standard Deviations. N=77.

Group	N	Mean	SD
Satisfaction with Residential Placement			
Activity Therapy Centre	29	75.48	12.80
Supported Employment	17	80.59	11.18
Independent Work Station	31	78.39	10.59
Satisfaction with Work Placement			
Activity Therapy Centre	29	75.97	13.35
Supported Employment	17	79.24	13.63
Independent Work Station	31	80.32	16.23
Satisfaction with Financial Status			
Activity Therapy Centre	29	67.86	17.02
Supported Employment	17	54.71	21.24
Independent Work Station	31	67.35	20.48
Satisfaction with Interpersonal Relationships			
Activity Therapy Centre	29	66.31	13.33
Supported Employment	17	65.88	14.72
Independent Work Station	31	71.00	12.74
Satisfaction with Physical Health			
Activity Therapy Centre	29	85.17	12.73
Supported Employment	17	85.18	13.10
Independent Work Station	31	85.77	10.07
Satisfaction with Self-Esteem			
Activity Therapy Centre	29	87.86	8.51
Supported Employment	17	86.24	9.38
Independent Work Station	31	86.97	10.71
Overall Satisfaction			
Activity Therapy Centre	29	75.83	8.55
Supported Employment	17	76.35	8.25
Independent Work Station	31	77.81	11.27

Satisfaction with Lifestyle by Presence of a Behaviour Problem. Means and Standard Deviations.

Group	N	Mean	SD
Satisfaction with Residential Placement			
Low BAS	13	72.31	11.82
In-Between	39	77.03	10.48
High BAS	9	68.44	7.60
Satisfaction with Work Placement			
Low BAS	13	75.46	10.60
In-Between	39	78.54	15.65
High BAS	8	73.00	16.65
Satisfaction with Financial Status			
Low BAS	13	68.77	13.20
In-Between	39	66.15	17.11
High BAS	9	48.44	27.45
Satisfaction with Interpersonal Relationships			
Low BAS	13	69.31	9.54
In-Between	39	66.80	14.43
High BAS	9	57.00	14.51
Satisfaction with Physical Health			
Low BAS	13	86.15	10.78
In-Between	39	86.62	11.66
High BAS	9	75.00	9.84
Satisfaction with Self-Esteem			
Low BAS	13	84.77	8.35
In-Between	39	87.79	10.00
High BAS	9	83.56	7.21
Overall Satisfaction			
Low BAS	13	75.00	7.19
In-Between	39	76.36	10.28
High BAS	9	68.22	6.70

Satisfaction with Lifestyle by Presence of an Additional Handicap. Means and Standard Deviations.

Group	N	Mean	SD
Satisfaction with Residential Placement			
No Additional Handicap	45	75.76	11.16
Additional Handicap	16	71.82	9.38
Satisfaction with Work Placement			
No Additional Handicap	44	78.82	13.85
Additional Handicap	16	72.50	16.61
Satisfaction with Financial Status			
No Additional Handicap	45	65.84	18.23
Additional Handicap	16	59.19	21.15
Satisfaction with Interpersonal Relationships			
No Additional Handicap	45	68.29	13.39
Additional Handicap	16	59.13	13.42
Satisfaction with Physical Health			
No Additional Handicap	45	86.20	11.61
Additional Handicap	16	80.88	11.79
Satisfaction with Self-Esteem			
No Additional Handicap	45	87.27	9.67
Additional Handicap	16	84.44	10.97
Overall Satisfaction			
No Additional Handicap	45	76.13	9.74
Additional Handicap	16	70.69	8.76

Factor Analysis Results - Principal Axis Factoring

Variable	Factor	Eigen Value	Percent of Variance
Residential Placement	1	2.735	45.6
Work Placement	2	.903	15.0
Financial Status	3	.808	13.5
Interpersonal Relationships	4	.661	11.0
Physical Health	5	.462	7.7
Self-Esteem	6	.431	7.2

Factor Matrix

	Factor 1
Residential Placement	.71
Work Placement	.70
Financial Status	.63
Interpersonal Relationships	.59
Physical Health	.47
Self-Esteem	.41

Satisfaction with Lifestyle by Admission to an Institution. Means and Sttandard Deviations.

Group	N	Mean	SD
Satisfaction with Residential Placement			
Admitted	61	75.10	11.23
Never Admitted	16	86.69	7.01
Satisfaction with Work Placement			
Admitted	61	77.03	15.16
Never Admitted	16	82.63	11.26
Satisfaction with Financial Status			
Admitted	61	65.61	18.70
Never Admitted	16	57.50	25.10
Satisfaction with Interpersonal Relationships			
Admitted	61	65.97	13.57
Never Admitted	16	73.50	13.11
Satisfaction with Physical Health			
Admitted	61	84.95	12.87
Never Admitted	16	86.50	10.39
Satisfaction with Self-Esteem			
Admitted	61	85.72	9.82
Never Admitted	16	91.69	5.84
Overall Satisfaction			
Admitted	61	74.98	9.54
Never Admitted	16	81.63	8.13

Note 1: **Fifty Years of Sympathetic Care and Practical Service.** Printed by the Board of Management of Minda Home Incorporated on the occasion of the Jubilee Anniversary of Minda Home Inc. December 1948. Printed by The Advertiser Printing Office, Adelaide, 1948.

Note 2: Le Breton, J. The Intellectually Handicapped Person, Accommodation and the Developmental Model. Paper presented at the Symposium on Accommodation for the Disabled, Candberra, ACT, 1982.

Note 3: Accreditation Council for Services for Menatlly Retarded and other Developmentally Delayed Persons **Standards For Services for Developmentaly Delayed Individuals.** Chicago, Ill.: Joint Commission on the Accreditation of Hospitals, 1978.

Note 4: Tustin, R.D., Kent, P.A., Bond, M. and Haskill, S. Assessing Severity and Types of Behaviour Disorder. Paper submitted for publication, December, 1987

REFERENCES

Aagnes, D. and Haagenson, L. Normalisation: Attention to a Conceptual Disaster. Mental Retardation, 1978, 16, 55-56.

Aaanes, D and Moen, M. Adaptive Behaviour Changes of Group Home Residents. Mental Retardation, 1976, 14, 36-49.

Allen, R.M., Cortazzo, A.D., and Adamo, C.C. Factors in an Adaptive Behaviour Checklist for Use With Retardates. The Training School Bulletin, 1970, 63, 144-157.

Andrews, F.M. and Withey, S.B. **Social Indicators of Well-Being: American's Perceptions of Quality of Life.** Plenum Press, New York, 1976.

Aninger, M., and Bolinsky, K. Levels of Independent Functioning of Retarded Adults in Apartments. Mental Retardation, 1977, 15, 12-14.

Apte, R,Z. **Halfway Houses: A New Dilemma in Institutional Care.** Occasional Papers in Social Administration NO. 27, 1968.

Atkinson, D. With Time to Spare: The Leisure Pursuits of People With Mental Handicaps. Mental Handicap, 1985, 13, 139-140.

Baker, B.L., Seltzer, G.B., and Seltzer, M.M. **As Close as Possible: Community Residences for Retarded Adults.** Little-Brown and Company, Boston, 1974.

Balla, D.A. Relationship of Institution Size to Quality of Care: A Review of the Literature. American Journal of Mental Deficiency, 1976, 81, 117-124.

Balla, D.A., Butterfield, E.C. and Zigler, E. Effects of Institutionalisation on Retarded Children: A Longitudinal, Cross-Institutional Investigation. American Journal of Mental Deficiency, 1974, 78, 530-549

Balla, D.A., McCarthy, E. and Zigler, E. Some Correlates of Negative Reaction Tendencies in Institutionalised Retarded Children. Journal of Psychology, 1971, 79, 77-84

Balla, D.A., Styfco, S.J. and Zigler, E. Use of the Oppositional Concept and Outerdirectedness in Intellectually Average, Familial Retarded and Organically Retarded Children. American Journal of Mental Deficiency, 1971, 75, 663-680.

Balla, D.A., and Zigler, E. Preinstitutional Social Deprivation, Responsiveness to Social Reinforcement, and IQ Change in Institutionalised Retarded Individuals. American Journal of Mental Deficiency, 1975, 80, 228-230.

Balthazaar, E.E. and Stevens, H.A. **The Emotionally Disturbed Mentally Retarded: A Historical and Contemporary Perspective.** Prentice-Hall, Englewood Cliffs N.J., 1975.

Baranyay, E. **Towards a Full Life: Provisions for Mentally Handicapped Adults.** MENCAP, London, 1981.

Baroff, G.B. On Size and the Quality of Resiential Care: A Second Look. Mental Retardation, 1980, 18, 113-117.

Baumeister, A.A. The American Residential Institution: its History and Character. In Baumeister, A,A, and Butterfield, E.C. **Residential Facilities for the Mentally Retarded.** Aldine Publishing Co. Chicago, 1970.

Becky, D. Normalisation's Theoretical Status and Future Residential Models. Australian and New Zealand Journal of Developmental Disabilities, 1982, 8,97-104.

Begab, M.J. The Mentally Retarded and Society: Trends and Issues. In Begab, M.J. and Richardson, S.A. (eds) **The Mentally Retarded and Society: A Social Science Perspective.** University Park Press, 1975.

Bercovici, S. Qualitative Methods and Cultural Pespectives in the Study of Deinstitutionalisation. In Bruininks, R.H., Meyers, C.E., Sigford, B.B. and Lakin, K.C. (eds) **Deinstitutionalisation and Community Adjustment of Mentally Retarded People.** AAMD Monograph, 1981.

Berkson, G. Social Ecology of Supervised Community Facilities for Mentally Disabled Adults: V Residence as a Predictor of Social and Work Adjustment. American Journal of Mental Deficiency, 1981, 86, 39-42.

Berkson, G and Romer,D. Social Ecology of Supervised Community Facilities for Mentally Disabled Adults: I

Introduction. American Journal of Mental Deficiency, 1980, 85, 219-228.

Bestuzhev-Lada, I.V. Way of Life and Related Concepts as Parts of A System of Social Indicators. In Szalai, A and Andrews, F.M. **The Quality of LIfe: Comparative Studies.** SAGE Studies in International Sociology, SAGE Publications, London, 1980.

Birenbaum, A. Social Integration of the Developmentaly Disabled in the Community. In Cohen, H,J., Kliger, D., and Eisler, J. (eds) **Urban Community Care for the Developmentaly Disabled.** Thomas, Springfield, Illinois, 1980.

Birenbaum, A. and Re, M.A. Resettling Mentally Retarded Adults in the Community - Almost Four Years Later. American Journal of Mental Deficiency, 1979, 83, 323-329.

Blair, J.R. and Fox, B. Effects of Differential Reinforcement Procedures on Discrimination Learning by Institutionalised Mentally Retarded Children. Psychological Reports, 1973, 33, 447-450.

Blatt, B. and Kaplan, F. **Christmas in Purgatory.** Boston, Allyn and Bacon, 1966.

Blau, T. Quality of Life: social indicators and criteria of change. Professional Psychology, 1977, 8,464-473.

Blishin, B and Atkinson, T., Anglophone and Francophone Differences in Perceptions of Quality of Life in Canada. In Szalai, A and Andrews, F.M. (eds) **The Quality of Life: Comparative Studies.** SAGE Studies in International Sociology, SAGE Publications, London, 1980.

Braddock, D. and Heller, T. The Closure of Mental Retardation Institutions II: Implications. Mental Retardation, 1985, 23, 222-229.

Briton, J. Normalisation: What of and What For? Australian Journal of Mental Retardation, 1979, 5, 224-229.

Bright, J. **The Law and Persons with Handicap: Vol 2: Intellectual Handicaps.** Adelaide Government Printer, 1981.

Burkhart, G. and Seim, R. The Effects of Institutionalisation on Retardates Social Independence. Journal of Mental Deficiency Research, 1979, 23, 213-217.

Butler, E.W. and Bjaanes, A.T. A Typology of Community Care Facilities and Differential Normalisation Outcome. In Mittler, P.(ed) **Research to Practice in Mental Retardation: Vol 1 Care and Intervention.** University Park Press, Baltimore, 1977.

Campbell, A.C., Converse, P.E. and Rogers, W.L. **The Quality of American Life: Perceptions, Evaluations, and Satisfactions.** Russel-Sage Foundation, New York, 1976.

Cautela, J.R., Cautela, J. and Esonis, S. **Forms for Behaviour Analysis with Children.** Research Press, Illinois, 1983.

Chesseldine, S.C. and Jeffree, D.M. Mentally Handicapped Adolscents: Their Use of Leisure. Journal of Mental Deficiency Research, 1981, 25, 49-59.

Clarke, A.D.B. and Clarke, A.M. Cognitive Changes in the Feebleminded. British Journal of Psychology, 1954, 45, 173-179.

Clarke, A.D.B., Clarke, A.M., and Reiman, S. Cognitive and Social Changes in the Feebleminded - Three Further Studies. British Journal of Psychology, 1958, 49, 144-151.

Cohen, M. The Right to Treatment. In Wortis, J. (ed) **Mental Retardation and Developmental Disabilities: An Annual Review.** Grune and Stratton, New York, Vol VIII, 1976.

Cohen, H., Conroy, J.W., Frazer, D.W., Snellbecker, G.E. and Spreat, S. Behavioural Effects of Institutional Relocation of Mentally Retarded Residents. American Journal of Mental Deficiency, 1977, 82, 12-18.

Conroy, J., Efthimiou, J., and Lemanowicz, J. A Matched Comparison of the Developmental Growth of Institutionalised and Deinstitutionalised Mentally Retarded Clients. American Journal of Mental Deficiency, 1982, 86, 581-587.

Craft, A. and Craft, M. **Handicapped Married Couples.** Routledge and Kegan Paul, London, 1979.

Craig, E.M. and McCarver, R.B. Community Placement and Adjustment of Deinsitutionalised Clients: Issues and Findings. In Ellis, N.R. and Bray, N. **International Review of Research in Mental Retardation** . Academic Press, Florida, Vol 12, 1984.

Crosby, K.G. Implementing the Developmental Model. In Gardener, J.F., Long, L., Nichols, R., and Iagulli, D.M. (eds) **Program Issues in Developmental Disabilities: A Resource Manual for Surveyors and Reviewers.** Paul H Brooks, Baltimore, 1970.

Dailey, W., Allen, G.J., Chinsky, A.J. and Viet, S.W. Attendant Behaviour and Attitudes Toward Institutionalised Retarded Children. American Journal of Mental Deficiency, 1974, 78, 586-591.

Dalgleish, M. Assessments of Residential Environments for Mentally Retarded Adults in Britain. Mental Retardation, 1983, 21, 204-208.

Demaine, G.C., Silverstein, A.B., and Mayeda, T. Validation of PASS 3: A First Step in Service Evaluation Through Environmental Assessment. Mental Retardation , 1980, 18, 131-134.

Doll, E.A. **Measurement of Social Competence.** Cirole Press, Minn: American Guidance Services, 1953.

Dugdale, R. **The Jukes: A Study in Crime, Pauperism, Disease and Heredity.** N.Y. G.P. Putnam, 1877.

Dybwad, G. **Challenges in Mental Retardation.** Columbia University Press, N.Y., 1964.

Edgerton, R.B. Issues Relating to the Quality of Life among Mentally Retarded Persons. In Begab, M.J. and Richardson, S.A. (eds) **The Mentally Retarded and Society: A Social Science Perspective.** University Park Press, Baltimore, 1975.

Edgerton, R.B. Alcohol and Drug Use by Mentally Retarded Adults. American Journal of Mental Deficiency, 1986, 90, 602-609.

Edgerton, R.B. and Bercovici,S.M. The Cloak of Competence: Years Later. American Journal of Mental Deficiency, 1976, 80, 485-497.

Edgerton, R.B., Bollinger, M. and Herr, B. The Cloak of Competence: After Two Decades. American Journal of Mental Deficiency, 1984, 88, 345-351.

Ellis, N.R., Balla, D., Estes, O., Allen-Warren, S. Meyers, C.E., Hollis, J., Isaacson, R.L., Palk, B.E., and Siegel, P.S. Common-sense in the Rehabilitiation of Mentally Retarded Persons: A Reply to Menaloscino and Magee. Mental Retardation, 1981, 18, 221-225.

Ellis, N.R., Bostick, G.E., Moore, S.A. and Taylor, J.J. A Follow-Up of Severely and Profoundly Mentally Retarded Children After Short-Term Institutionalisation. Mental Retardation, 1981, 19, 31-35.

Emerson, E.B. Evaluating the Impact of Deinsitutionalisation on the Lives of Mentally Retarded People. American Journal of Mental Deficiency , 1985, 90, 277-288.

Enkin, M.I. Deistitutionalisation and Institutional Reform in British Columbia. British Columbia Journal of Special Education, Summer, 1979, 3, 133-146

Ericsson, K., Lerman, B., and Nilsson, I. Mentally Handicapped Persons' Participation in the Community: The Role of Institutional and Integrated Services. Australia and New Zealand Jourrnal of Developmental Disabilities, 1985, 11, 83-90.

Eyman, R.K. and Arndt, S. Lifespan Development of Institutionalised and Community Based Mentally Retarded Residents. American Journal of Mental Deficiency, 1982, 86, 342-350.

Eyman, R.K., Borthwick, S.A. and Tarjan, G. Current Trends and Changes in Institutions for the Mentally Retarded. In Ellis, N.R. and Bray, N.W. (eds) **International Review of Research in Mental Retardation.** Academic Press, Florida, Vol 12, 1984.

Eyman, R.K., Demaine, G.C. and Lei, T. Relationship Between Community Environments and Resident Changes in Adaptive Behaviour: A Path Model. American Journal of Mental Deficiency, 1979, 83, 330-338.

Eyman, R.K., Silverstein, A.B., McClain, R. and Miller, C. Effects of Residential Settings on Development. In Mittler, P. (ed) **Research to Practice in Mental Retardation: Vol 1 Care and Intervention.** University Park Press, Baltimore, 1977.

Eyman, R.K. and Widaman, K.F. Life-span Development of Institutionalised and Community-Based Mentally Retarded Adults Revisited. American Journal of Mental Deficiency, 1987, 91, 559-569.

Feather, N. Conservation , Acquiesence and the Effects of Sample Heterogeneity. Australian Journal of Psychology, 1980, 32, 11-16.

Felce, D., de Koch, V., and Repp, A. An Eco-Behavioural Analysis of Small Community-Based Houses and Traditional Large Hospitals for Severely and Profoundly Mentally Handicapped Adults. Applied Research In Mental Retardation, 1986, 7, 393-408.

Flynn, M.C. Adults who are Menatlly Handicapped as Consumers: Issues and Guidelines for Interviewing. Journal of Mental Deficiency Research, 1986, 30, 369-386.

Flynn, M.C. and Saleem, J.K. Adults Who are Mentally Handicapped and Living with Their Parents: Satisfaction and Perceptions Regarding their Lives and Circumastances. Journal of Mental Deficiency Research, 1986, 30, 379-387.

Flynn, R.J. **Assessing Human Service Quality with PASS2: An Empirical Analysis of 102 Service Program Evaluations.** National Institute on Mental Retardation, Ontario, 1975.

Fogelman, G.J. (ed) **AAMD Adaptive Behaviour Scale Manual: 1975 Revised Edition.** Washington D.C. American Association on Mental Deficiency, 1975.

Gelder, M., Gath, D., and Mayou, R. **Oxford Textbook of Psychiatry.** Oxford Universiity Press, Oxford, 1983.

Gilbert, K.A. and Hemming, H. Environmental Change and Psycholiinguistic Ability of Mentally Retarded Adults. American Journal of Mental Deficiency, 1979, 83, 453-459

Goddard, H. **The Kallikak Family: A Study in the Heredity of Feeblemindedness.** N.Y. Macmillan, 1912.

Goffman, E. **Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.** Doubleday and Co., London, 1961

Goffman, E. **Stigma: Notes on the Management of Spoiled Identity.** Penguin, Middlesex, 1963.

Gollay, E., Freedman, R., Wyngaarden, M. and Kurtz, N.R. **Coming The Community Experiences of Deinstitutionalised Mentally Retard People.** Abt Books, Cambiridge, Massachusetts, 1978.

Gottesfeld, H. **Abnormal Psychology: A Community Mental health Perspective.** Science Research Associates, Chicago, 1979.

Gunzberg, H.C.. **The PAC Manual** (3rd Edition) London, NSMHC, 1975.

Halpern, A.S., Nave, G., Close, D.W., and Nelson, D. An Empirical Analysis of the Dimensions of Community Adjustment for Adults with Mental Retardation in Semi-Independent Living Programmes. Australia and New Zealand Journal of Developmental Disabilities, 1986, 12, 147-157.

Harter, S., Brown, L. and Zigler, E. Discrimination Learning in Retarded and Non-Retarded Children as a Function of Task Difficulty and Social Reinforcement. American Journal of Mental Deficiency, 1971, 76, 275-285.

Heal, L.W. and Chadsey-Rusch, J. The Lifestyle Satisfaction Scale (LSS): Assessing Individuals' Satisfaction with Residence, Community Setting, and Associated Services. Applied Research in Mental Retardation, 1985, 6, 475-490.

Heal, L.W. and Laidlaw, T.J. Evaluation of Residential Alternatives. In Novak, A.R. and Heal, L.W. (eds) **Integration of Developmentally Disabled Individuals into the Community.** Paul H. Brooks, Baltimore, 1980.

Heal, L.W., Sigelman, C.K., and Switsky, H.N. Research on Community Residential Alternatives for the Mentally Retarded. In Ellis, N.R. **International Review of Research in Mental Retardation.** Academic Press, Florida, Vol 9, 1978.

Hedley, R.A., Dubin, R., and Traveggia, T.C. The Quality of Working Life, Gender and Occupational Status: A Cross-National Comparison. In Szalai, A. and Andrews, F.M. **The Quality of Life: Comparative Studies SAGE Studies in International Sociology.** SAGE Publications, London, 1980.

Heller, T. Social Disruption and Residential Relocation of Mentally Retarded Children. American Journal of Mental Deficiency, 1982, 87(1), 48-55.

Heller, T. Issues in Adjustment of Mentaly Retarded Individuals to Residential Relocation. In Ellis, N.R. **International Review of Research into Mental Retardation.** Academic Press, Florida, Vol 12, 1984.

Heller, T., Berkson, G. and Romer, D. Social Ecology of Supervised Community Facilities for Mentally Disabled Adults: VI Initial Social Adaptation. American Journal of Mental Deficiency. 1981, 86, 43-49.

Hemming, H., Lavender, T., and Pill, R. Quality of Life Of Mentally Retarded Adults Transferred from Large Institutions to New Small Units. American Journal of Mental Deficiency. 1981, 86, 157-169.

Hogan, M.F. and McEachron, M.E. **Plan Evaluation Guide: A Guide Planning, Management, and Evaluation of Community Based Service Systems.** National Institute on Mental Retardation, 1980.

Horten, I. A New Caring Model Reduces Need for Drug Therapy for Intellectually Handicapped Persons. Australian and New Zealand Journal of Developmental Disabilities, 1982, 8, 219-225.

Howell, H.H. and May, A.E. Resident-Care Practices in the County of Somerset, England. American Journal of Mental Deficiency, 1980, 84, 393-396.

Hull, J.T. and Thompson, J.C. Predicting Adaptive Functioning of Mentally Retarded Persons in Community Settings. American Journal of Mental Deficiency, 1980, 85, 253-261.

Hull, J.T. and Thompson, J.C. Factors Contributing to Normalisation in Residential Facilities for Mentally Retarded Persons. Mental Retardation, 1981, 19, 69-73.

Intagliata, J., Crosby,N. and Neider, L. Foster Family Care for Mentally Retarded People: A Qualitative Review. In Bruininks, R.H., Meyers, C.E., Sigford, B.B., and Lakin, K.C. (eds) **Deinstitutionalisation and Community Adjustment of Mentally Retarded People.** AAMD Monograph, 1981.

Janicky, M.P., Castellani, P.J. and Norris, R.G. Organisation and Administration of Service Delivery Systems. In Matson, J.L. and Mulick, J.A. (eds) **Handbook of Mental Retardation.** Pergamon, New York, 1983.

Joiner, L. and Kranz, G. **The Assessment of Behavioural Competence of Developmentally Disabled Individuals: The MDPS.** Minneapolis: University of Minnesota, College of Education, 1979.

Kanner, L. **A History of the Care and Study of the Mentally Retarded.** Charles C Thomas, Springfield Ill, 1964.

Katz-Garris, L. The Right to Education. In Wortis, J. (ed) **Mental Retadation and Developmental Disabilities: An Annual Review.** Grune and Stratton, N.Y. Vol 1, 1970.

King, R.D. and Raynes, N.V. a) Patterns of Institutional Care for the Severely Subnormal. American Journal of Mental Deficiency, 1968, 72, 700-709.

King, R.D. and Raynes, N.V. b) An Operational Measure of Inmate Management in Residential Institutions. Social Science and Medicine, 1968, 2, 41-53.

King, R.D., Raynes, N.V. and Tizard, J. **Patterns of Residential Care: Sociological Studies in Institutions for Handicapped Children.** Routledge and Kegan Paul, London, 1971.

Klaber, M.M., Butterfield, E.C. and Gould, L.J. Responsiveness to Social Reinforcement Among Institutionalised Retarded Children. American Journal of Mental Deficiency, 1969, 73, 890-895.

Klapper, Z.S. Developmental Psychology in Wortis, J. **Mental Retardation and Developmenatl Disabilities: An Annual Review.** Grune and Stratton, New York, Vol 1, 1970.

Kleinberg, J. and Galligan, B. Effects of Deinstitutionalisation on Adaptive Behaviour of Mentally Retarded Adults. American Journal of Mental Deficiency, 1983, 88, 21-24.

Kregel, J., Wehman, P., Seyforth, J. and Marshall, K. Community Integration of Young Adults with Mental Retardation: Transition from School to Adulthood. Education and Training of the Mentally Retarded, 1986, 21, 35-42.

Kushlick, A. Epidemiology and Evaluation of Services for the Mentally Handicapped. In Begab, M.J. and Richardson, S.A. **The Mentally Retarded and Society: A Social Science Perspective.** University Park Press, Baltimore, 1975.

Lakin, C., Bruininks, R.H., and Sigford, B.B. Early Perspectives on the Community Adjustment of Mentally Retarded People. In Bruininks, R.H., Meyers, C.E., Sigford, B.B., and Lakin, K.C. (eds) **Deinstitutionalisation and Community Adjustment of Mentally Retarded People.** AAMD Monograph 4, 1981.

Landesman, S. Quality of Life and Personal Satisfaction: Definition and Measurement Issues. Guest Editorial American Journal of Mental Deficiency, 1986, , 141-143.

Landesman-Dwyer, S. Living in the Community. American Journal of Mental Deficiency, 1981. 86, 223-234.

Landesman-Dwyer, S., Berkson, G., and Romer, D. Affiliation and Friendship of Mentally Retarded Residents in Group Homes. American Journal of Mental Deficiency, 1979, 83, 571-580.

Landesman-Dwyer, S., Sacket, G.P., and Kleinman, J.S. Relationship of Size to Resident and Staff Behaviour in Small Community Residences. American Journal of Mental Deficiency, 1980, 85, 6-17.

Lane, H. **The Wild Boy of Aveyron.** Granada, London, 1977.

Lazerson, M. Educational Institutions and Mental Subnormality: Notes on Writing a History. In Begab, M.J. and Richardson, S.A. **The Mentally Retarded and Society: A Social Science Perspective.** University Park Press, Baltimore, 1975.

Lehman, A.F. The Well-Being of Chronic Mental Patients: Assessing Their Quality of Life. Archives of General Psychiatry, 1983, 40, 369-373.

Lehman, A.F., Ward, N.C. and Linn, L.S. Chronic Mental Patients: The Quality of Life Issue. American Journal of Psychiatry, 1982, 139, 1271-1276.

Locker, D., Rao, B., and Weddell, J.M. The Impact of Hostel Care on Mentally Handicapped Adults. Mental Handicap, 1983, 11, 100-103.

MacEachron, A.E. Institutional Reform and Adaptive Functioning of Mentally Retarded Persons: A Field Experiment. American Journal of Mental Deficiency, 1983, 88, 2-12.

McCall, S. Quality of Life. Social Indicators Research, 1975, 2, 229-248.

McLain, R.E., Silverstein, A.B., Hubbell, M., and Brownlee, L. The Characterisation of Residential Environments Within a Hospital for the Mentally Retarded. Mental Retardation, 1975, 13, 24-27.

McCormick, M., Balla, D. and Zigler, E. Resident-Care Practices in Institutions for Retarded Persons: A Cross-Institutional, Cross-Cultural Study. American Journal of Mental Deficiency, 1975-76, 80, 1-17.

McDevitt, S.C., Smith, P.M., Schmidt, D.W. and Rosen, M. The Deinstitutionalised Citizen: Adjustment and Quality of Life. Mental Retardation, 1978, 16, 22-24.

Malin, N. **Group Homes for Mentally Handicapped People.** Department of Health and Social Security, London, Her Majesty's Stationary Office, 1983.

Marlett, N.J. **Adaptive Functioning Index Standardisation Manual.** Calgary: The Vocational and Rehabilitation Research Institute, 1977.

Mayhew, G.L., Enyart, P. and Anderson, J. Social Reinforcement and the Naturally Occurring Social Responses of Severely and Profoundly Retarded Adolescents. American Journal of Mental Deficiency, 1978, 83, 164-170.

Mesibov, B.B. Alternatives to the Principle of Normalisation. Mental Retardation, 1976, 14, 30-32.

Minor, M.J., Bradburn, N.M. and Schaeffer, N.C. The Structure of Life Satisfaction: A Comparative Analysis Across Social Groups. In Szalai,A. and Andrews,F.M. (eds) **The Quality of life: Comparative Studies.** SAGE Studies in International Sociology, SAGE Publications, London, 1980.

Mitchell, A.C. and Smeriglio, V. Growth in Social Competence in Institutionalised Mentally Retarded Children. American Journal of Mental Deficiency, 1969, 74, 666-673.

Mittler, P. **Research to Practice in Mental Retardation Vol 1: Care and Intervention.** University Park Press, Baltimore, 1977.

Moen, M.G., and Aanes, D. Eclipse of the Family Group Home Concept. Mental Retardation, 1979, 17, 17-19.

Moos, R.H. Conceptualisations of Human Environments. American Psychologist, 1973, 28, 652-665.

Moos, R.H. **Evaluating Treatment Environments: A Social Ecologic Approach.** John-Wiley and Sons, New York, 1974.

Moreau, F.A., Novak, A.R. and Sigelman, C.K. Physical and Social Integration of Developmentally Disabled Individuals into the Community. In Novak, A.R. and Heal, L.W. (eds) **Integration of Developmentally Disabled Individuals Into the Community.** Paul H Brooks, Baltimore, 1980.

Muehlberger, C.E. The Social-Psychological Experience of Adult Former Residents of a State School for the Mentally Retarded. Mental Retardation, 1974, 12, 23.

Nihira, K., Foster, R., Shellhaas, M., and Leland, H. **AAMD Adaptive Behaviour Scale.** Washington, D.C. American Association on Mental Deficiency, 1974.

Nirje, B. The Normalisation Principle and its Human Management Implications. In Kugel, R.B. and Wolfensberger, W. **Changing Patterns in Residential Services of the Mentally Retarded.** Washington, D.C. President's Committee on Mental Retardation. 1969.

Norton, P. Providing Day Services for Profoundly Handicapped Adults. Mental Handicap, 11, 1983, 5-6.

Novak, A.R. Backlash to the Deinstitutionalisation Movement. In Novak, A.R. and Heal, L.W. (eds) **Integration of Developmentaly Disabled Individuals Into the Community.** Paul H. Brookes, Baltimore, 1980.

Novak, A.R. and Berkeley, T.R. A Systems Approach to Deinstitutionalisation Policies and Research. In Ellis, N.R. and Bray,N.W. **International Review of Research in Mental Retardation.** Academic Press, Florida, Vol 12, 1984.

O'Connor, G. Social Support of Mentally Retarded Persons: Presidential Address. Mental Retardation, 1983, 21, 187-196.

O'Connor, G. **Home is a Good Place: A National Perspective of Community Resididential Facilities for Developmentally Disabled Persons.** Monograph of the AAMD, No2, 1976.

Okolo, G. and Guskin, S. Community Attitudes Toward Community Placement of Mentally Retarded Persons. In Ellis,N.R. and Bray, N.W. **International Review of Research In Mental Retardation.** Academic Press, Florida, Vol 12, 1984.

Olshansky, S. Changing Vocational Behaviour Through Normalisation. In Wolfensberger, W. **Normalisation: The Principle of Normalisation in Human Services.** National Institute on Mental Retardation, York University Campus, 1972.

Packer, J. and Wright, J. **I Like Where I Live: An Evaluation of Models of Group Home Living.** Department of Rehabilitation Planning, Department of Social Security, Candberra, 1983.

Pankhurst, F. and Pankhurst, J. **Evaluation, Standards and Accreditation of Government Subsidised Services for Handicapped People: Part 1.** Fred and Eleanor Schonell Educational Research Centre, Department of Education, University of Queensland, 1982.

Parnicky, J.J. Pathways Toward Independence for Institutionalised Moderately Retarded Adults. In Mittler, P. (ed) **Research to Practice in Mental Retardation Vol 1: Care and Intervention.** University Park Press, Baltimore, 1977.

Passfield, D. What Do You Think of It So Far?: A Survey of 20 Priory Court Residents. Mental Handicap, 1983, 11, 97-99.

Peck, C.A., Blackburn, T. and White-Blackburn, G. Making it Work: A Review of the Empirical Literature on Community Living Arrangements. In Appollini, T, Cappucilli, J. and Cooke, T.P. (eds) **Achievemnts in Residential Services for Persons with Disabilities: Towards Excellence.** University Park Press, Baltimore, 1980.

Penney, R.K. A Broad View of the Quality of Life for the Intellectually Handicapped. Paper presented at the Annual Conference of the Australian Association of Mental Retardation, Perth, 1977.

Perrin, B. and Nirje, B. Setting the Record Straight: A Critique of Some Frequent Misconceptions of the Normalisation Principle. Australia and New Zealand Journal of Developmental Disabilities, 1985, 11(2), 69-74.

Pratt, M.W., Luszcz, M.A. and Brown, M.E. Measuring Dimensions of the Quality of Care in Small Community Residences. American Journal of Mental Deficiency, 1980, 85, 188-194.

Pratt, M.W., Raynes, N.V., and Roses, S. Organisational Characteristics and Their Relationship to the Quality of Care in Mittler, P. (ed) **Research to Practice in Mental Retardation Vol 1: Care and Intervention.** University Park Press, Baltimore, 1977.

Primrose, D.A. Asylum. In Mittler, P (ed) **Research to Practice Mental Retardation Vol 1: Care and Intervention.** University Park Press, Baltimore, 1977.

Prout, H., and Schaefer, B. Self-Reports of Depression by Community-Based Mildly Mentally Retarded Adults. American Journal of Mental Deficiency, 1985, 90, 220-222.

Ray, J.J. and Pratt, G.J. Is the Influence of Acquiesence on "Catchphrase" Type Attitude Scale Items Not so Mythical After All? Australian Journal of Psychology, 1979, 31, 73-78.

Reiter, S. and Levi, A.M. Factors Affecting Social Integration of Non-institutionalised Mentally Retarded Adults. American Journal of Mental Deficiency, 1980, 85, 25-30.

Repp, A., Barton, L.E., and Brulle, A.R. Assessing a Least Restrictive Educational Environment Transfer Through Social Comparison. Education and Training of the Mentally Retarded, 1986, 21, 54-61.

Rhoades, C. and Browning, P. Normalisation at What Price? Mental Retardation, 1977, 15, 24.

Rimm, D.C. and Somervill, J.W. **Abnormal Psychology.** Academic Press, New York, 1977.

Romer, D. and Berkson, G. Social Ecology of Supervised Community Facilities for Mentally Disabled Adults: II Predictors of Affiliation. American Journal of Mental Deficiency, 1980, 85, 229-242 (a)

Romer, D. and Berkson, G. Social Ecology of Supervised Community Facilities for Mentally Disabled Adults: III Predictors of Social Choice. American Journal of Mental Deficiency, 1980, 85, 243-252 (b).

Romer, D. and Berkson, G. Social Ecology of Supervised Community Facilities for Menatlly Disabled Adults: IV Characteristics of Social Behvaviour. American Journal of Mental Deficiency, 1981, 86, 28-38.

Roos, P. Normalisation, De-humanisation, and Conditioning - Conflict or Harmony? Mental Retardation, 1970, 8, 12-14.

Roos, P. Reconciling Behaviour Modification Procedures with the Normalisation Principle. In Wolfensberger, W. **Normalisation: The Principle of Normalisation In Human Services.** National Institute on Mental Retardation, Toronto, 1972.

Roos, S. The Future of Residential Services for the Mentally Retarded in the United States: A Delphi Study. Mental Retardation, 1978, 16, 355-356.

Rosen,M. Preserving our Institutional Roots. Education and Training of the Mentally Retarded, 1984, 19, 1-4.

Rosen, M., Clark, G.R., and Kivitz, M.S. **Habilitation of the Handicapped: New Dimensions in Programs for the Developmentally Disabled.** University Park Press. Baltimore, 1977.

Rotegard, L.L., Hill, B.K., and Bruininks, R.H. Environmental Characteristics of Residential Facilities for Mentally Retarded Persons in the United States. American Journal of Mental Deficiency, 1983, 88, 49-56.

Schallenberger, P. and Zigler, E. Rigidty, Negative Reaction Tendencies, and Cosatiation Effects in Normal and Feebleminded Children. Journal of Abnormal and Social Psychology, 1961, 63(1), 20-26.

Schalock, R.L., Harper, R,S. and Carver, G. Independent Living Placement: Five Years Later. American Journal of Mental Deficiency, 1981, 86, 170-177.

Schalock, R.L. and Lilley, M.A. Placement from Community-Based Mental Retardation Programs: How well do clients do after 8 to 10 Years? American Journal of Mental Deficiency, 1986, 90, 669-676.

Scheer, L. Experience With Quality of Life Comparisons. In Szalai, A. and Andrews, F.M. (eds) **The Quality of Life: Comparative Studies.** SAGE Studies in International Sociology, SAGE Publications, London, 1980.

Scheerenberger, R.C. A Model for Deinstitutionalisation. Mental Retardation, 1974, 12, 3-7,

Scheerenberger, R.C. Deinstitutionalisation: Trends and Difficulties. In Bruininks, R.H., Meyers, C.E., Sigford, B.B. and Lakin, K.C. (eds) **Deinstitutionalisation and Community Adjustment of Mentally Retarded People.** AAMD Monograph 4,1981.

Scheerenberger, R.C. Public Residential Facilities, 1981: Status and Trends. Mental Retardation, 1982, 20, 210-215.

Scheerenberger, R.C. **A History of Mental Retardation.** Paul H Brookes, Baltimore, 1983.

Schroeder, S.R. and Henes, C. Assessment of Progress of Institutionalised and Deinstitutionalised Retarded Adults: A Matched Control Comparison. Mental Retardation, 1978, 16, 147-148.

Schwartz, B.J. and Allan, R.M. Measuring Adaptive Behaviour: The Dynamics of a Longitudinal Approach. American Journal of Mental Deficiency, 1974, 79, 424-433.

Schwartz, B.J., Allen, R.M., and Cortazzo, A.D. Factors in the Adaptive Behaviour Checklist Revisited and Revised. The Training School Bulletin, 1974, 70, 248-254.

Seltzer, G. Community Residential Adjustment: The Relationship Between Environment, Performance and Satisfaction. American Journal of Mental Deficiency, 1981, 85, 624-630.

Seltzer, M.M. Patterns of Job Satisfaction Among Mentally Retarded Adults. Applied Research in Mental Retardation, 1984, 5, 147-159.

Seltzer, M.M. and Seltzer, G.B. Community Living: Accommodation and Vocations. In Mittler, P. (ed) **Research to Practice in Mental Retardation Vol 1: Care and Intervention.** University Park Press, Baltimore, 1977.

Seltzer, G.B. and Seltzer, M.M. **Context For Competence: A Study of Retarded Adults Living and Working in the Community.** Educational projects Inc, Cambridge Massechussets, 1978.

Seltzer, M.M., Sherwood, C.C., Seltzer, G.B., Sherwood, S. Community Adaptation and the Impact of Deinstitutionalisation. In Bruininks, R.H., Meyers, C.E., Sigford, B.B. and Lakin, K.C. (eds) **Deinstitutionalisation and Community Adjustment of Mentally Retarded People.** AAMD Monograph, 1981.

Shallenberger, P. and Zigler, E. Rigidity, Negative Reaction Tendencies and Cosatiation Effects in Normal and Feebleminded Children. Journal of Abnormal and Social Psychology, 1961, 63, 20-26.

Shepherd, G. **Institutional Care and Rehabilitation.** Longman, New York, 1984.

Shepps, R. and Zigler, E. Social Deprivation and Rigidity in the Performance of Organic and Familial Retardates. American Journal of Mental Deficiency, 1962, 67, 262-268.

Sigelman, C.K., Budd, E.C., Spanhel, C.L., and Schoenrock, C.J. When in Doubt Say Yes: Acquiescence in Interviews with Mentally Retarded Persons. Mental Retardation, 1981, 19, 53-58 (a).

Sigelman, C.K., Budd, E.C., Spanhel, C.L. and Schoenrock, C.J. Asking Questions of Retarded Persons: A Comparison of Yes/No and Either/Or Formats. Applied Research In Mental Retardation, 1981, 2, 347-357 (b).

Sigelman, C.K., Budd, E.C., Winer, J.L., Schoenrock, C.J. and Martin, P.W. Evaluating Alternative Techniques of Questioning Mentally Retarded Persons. American Journal Of Mental Deficiency, 1982, 86, 511-8.

Sigelman, C.K., Novak, A.R., Heal, L.W., and Switzky, H.N. Factors that Affect the Success of Community Placement. In Novak, A.R. and Heal, L.W. (eds) **Integration of Developmentally Disabled Individuals into the Community.** Paul H. Brooks, Baltimore, 1980.

Sigelman, C.K., Schoenrock, C., Spanhel, C., Hromas, S., Winer, J., Budd, E. and Martin, P. Surveying Mentally Retarded Persons: Responsiveness and Response Validity in Three Samples. American Journal of Mental Deficiency, 1980, 84, 479-84.

Sigelman, C.K., Schoenrock, C.J., Winer, J.L., Spanhel, C.L., Hromas, S.G., Martin, P.W., Budd, E.C., and Bensberg, G.J. Issues in Interviewing Mentally Retarded Persons: An Empirical Investigation. In Bruininks, R.H., Meyers, C.E., Sigford, B.B., and Lakin, K.C. (eds) **Deinstiutionalisation and Community Adjustment of Mentally Retarded People.** AAMD Monograph No. 4.,1981c

Sigelman, C.K., Schoenrock, C.J., Budd,E.C., Winer, J.L., Spanhel, C.L., Martin,P.W., Hromas, S. and Bensberg, G.J. **Communicating with Mentally Retarded Persons: Asking Questions and Getting Answers.** Research and Training Centre in Mental Retardation, Texas Tech University, Texas. 1983.

Silverman, W.P., Silver, E.J., Sersen, E., Lubin, R.A., and Schwartz, A.A. Factors Related to Adaptive Behaviour Changes Among Profoundly Mentally Retarded, Physically Disabled Persons. American Journal of Mental Deficiency, 1986, 90, 651-658.

Solomon, E.S., Bouchauchi, N., Denisov, V., Hankiss, E., Mallman, C.C. and Milbrath, L.W. UNESCO's Policy-Relevant Quality of Life Research Program. In Szalai, A. and Andrews, F.M. **The Quality of Life: Comparative Studies.** SAGE Studies in International Sociology, SAGE Publications, London, 1980.

Sprague, R.L. and Baxley, G.B. Drugs for Behaviour Management, with Comment on Some Legal Aspects. In Wortis, J. (ed) **Mental Retardation and Developmental Disabilities: An Annual Review.** Grune and Stratton, N.Y., Vol X, 1978.

Szalai, A. and Andrews, F.M. **The Quality of Life: Comparative Studies SAGE Studies in International Sociology.** SAGE Publications. London, 1980.

Talkington, L.W. and Riley, J. Comparison of Retarded and Non-Retarded Adolescents on Need Approval. Psychological Reports, 1978, 33, 39-42.

Thomas, D. **The Social Psychology of Childhood Disability.** Methuen and Co., London, 1978.

Thompson, T and Carey, A. Structural Normalisation: Intellectu and Adaptive Behaviour Change in a Residential Setting. Mental Retardation, 1980, 18, 193-197.

Thurman, S.K. and Gable, R.A. Mental Retardation Services: Socia Traps and Social Fences. Mental Retardation, 1976, 14, 16-18.

Tizard, B. Varieties of Residential Nursery Experience. In Tizard, J., Sinclair, I., and Clarke, A. **Varieties of Institutional Experience.** London, Routledge and Kegan Paul, 1975.

Verwayen, M. The Specification and Measurement of the Quality of Life in OECD Countries. In Szalai, A. and Andrews, F.M. (eds) **The Quality of Life: Comparative Studies.** SAGE Studies in International Sociology, SAGE Publications, London, 1980.

Viet, S.W., Allen, C.J., and Chinsky, J.M. Interpersonal Interactions Between Institutionalised Retarded Children and Their Attendants. American Journal of Mental Deficiency, 1976, 80, 535-542.

Whatmore, R., Durward, L. and Kushlick, A. Measuring the Quality of Residential Care. Behaviour Research and Therapy, 1975, 13, 227-236.

Willer, B. and Intagliata, J. Social-Environmental Factors as Predictors of Adjustment of Deinstitutionalised Mentally Retarded Adults. American Journal of Mental Deficiency, 1981, 86, 252-259

Willer, B. and Intagliata, J. Comparison of Family Care and Group Homes as Alternatives to Institutions. American Journal of Mental Deficiency, 1982, 86, 588-595.

Willer, B. and Intagliata, J. An Overview of the Social Policy of Deinstitutionalisation. In Ellis, N.R. and Bray, N.W. **International Review of Research in Mental Retardation.** Academic Press, Florida, Vol 12, 1984.

Willer, B., Scheerenberger, R.C., and Intagliata, J. Deinstitutionalisation in Mentally Retarded Persons. In Novak, A.R. and Heal, L.W. (eds) **Integration of Developmentally Disabled Individuals Into the Community.** Paul H. Brooks, Baltimore, 1980.

Wing, J.K. Trends in the Care of the Chronically Mentally Handicapped. In Wing, J.K. and Olsen, R. (eds) **Community Care for the Mentally Disabled.** Oxford University Press, Oxford, 1979.

Wing, J.K. and Olsen, R. Principles of the New Community Care. In Wing, J.K. and Olsen, R. (eds) **Community Care for the Mentally Disabled.** Oxford University Press, Oxford, 1979.

Witt, S.J., Increase in Adaptive Behaviour Level After Residence in an Intermediate Care Facility for Mentally Retarded Persons. Mental Retardation, 1981, 19, 75-79.

Wolfensberger, W. **Normalisation: The Principle of Normalisation Human Services.** National Institute on Mental Retardation, Toronto, 1972

Wolfensberger, W. The Normalisation Principle and some Major Implications to Architectural and Environmental Design. In Bednar, M.J. (ed) **Barrier-Free Environments.** Dowden, Hutchinson and Ross, Stroudsgerg PA., 1977.

Wolfensberger, W. The Definition of Normalisation: Update, Problems, Disagreements and Misunderstandings. In Flynn, R.J. and Nitsch, K.E. (eds) **Normalisation, Social Integration and Human Services.** Uni Park Press, Baltimore, 1980.

Wolfensberger, W. and Glenn, L. **PASS3: A method for the quantitative evaluation of human services.** Handbook, 3rd edition, National Institute on Mental Retardation, 1975.

Wolfensberger, W. and Thomas, S. **PASSING: A Method for Evaluating the Quality of Human Services in Terms of Principles of Normalisation.** Training Institute for Human Service Planning, Leadership and Change Agency, New York, 1980, experimental edition.

Wyngaarden, M. Interviewing Mentally Retarded Persons: Issues and Strategies. In Bruininks, R.H., Meyers, C.E., Sigford, B.B. and Lakin, K.C. (eds) **Deinstitutionalisation and Community Adjustment of Mentally Retarded People.** AAMD Monograph, 1981.

Wyatt vs Stickney et al. Civil Action No.3195-N, Adequate Habilitation for the Mentally Retarded. District Court of the United States for the Middle District of Alabama, Northern Division, February 28, 1972.

Yando, R. and Zigler, E. Outerdirectedness of Problem Solving of Institutionalsised and Non-Institutionalised Normal and Retarded Children. Developmental Psychology, 1971, 4, 277-288.

Zapf, W. The SPES Social Indicators System in Comparative Perspective. In Szalai, A and Andrews, F.M. **The Quality of Life: Comparative Studies.** SAGE Studies in International Sociology, SAGE Publications, London, 1980.

Zigler, E. Research on Personality Structure in the Retardate. In Ellis, N.R. (ed) **International Review of Research in Mental Retardation.** Academic Press, N.Y., Vol 1, 1976.

Zigler, E., and Balla, D. The Social Policy Implications of a Research Program on the Effects of Institutionalisation on Retarded Persons. In Mittler, P. (ed) **Research to Practice in Mental Retardation Vol 1: Care and Intervention.** Univerity Park Press, Baltimore, 1977.

Zigler, E., Balla, D. and Butterfield, E.C. A Longitudinal Investigation of the Relationship Between Preinstitutional Social Deprivation and Social Motivation in Institutionalised Retardates. Journal of Personality and Social Psychology, 1968, 10, 437-445.

Zigler, E., Balla, D. and Kossan, N. Effects of Institutionalisation on Responsiveness to Social Reinforcement, Wariness, and Outerdirectedness Among Low-MA Residents. American Journal of Mental Deficiency, 1981, 91, 10-17.

Zigler, E., Balla, D. and Watson, N. Developmental and Experimental Determinants of Self-Image Disaparity in Institutionalised and Noninstitutionalised Retarded and Normal Children. Journal of Personality and Social Psychology, 1972, 23, 81-87.

Zigler, E., Butterfield, E.C. and Capobianco, F. Institutionalisation and Effectiveness of Social Reinforcement: A Five and Eight Year Follow-up Study. Developmental Psychology, 1970, 3, 255-263.

Zigler, E., Butterfield, E.C. and Goff, G. A Measure of Social Deprivation for Institutionalised Retardates. American Journal of Mental Deficiency, 1966, 70, 873-885.

Zigler, E., Hogden, L. and Stevenson, H.W. The Effect of Support and Non-support on the Performance of Normal and Feebleminded Children. Journal of Personality, 1958, 26, 106-122.

Zigler, E., and Williams, J. Institutionalisation and The Effectiveness of Social Reinforcement: A Three Year Follow-up Study. Journal of Abnormal and Social Psychology, 1963, 66, 197-205.

Zusman, M.D. and Slawson, M.R. Service Quality Profile: Development of a Technique for Measuring Quality of Mental Health Services. Archives of General Psychiatry, 1972, 27, 692-698.