The Habilitation of Mentally Retarded Adults

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University of Cape Town

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ABSTRACT

The history of the care of the mentally retarded in Western civilization is outlined, including the care of the mentally retarded in South Africa. Difficulties in the definition and assessment of mental retardation are indicated and problems in present day institutional care are considered: specific reference is made to the characteristics of institutionalization, and to the role of institutions in the future. Pre-discharge training within the institutional setting is discussed, with particular emphasis on the curriculum of such training programmes, training methods, and the role of transitional facilities. This is followed by a critical review of prognostic and follow up studies of retarded persons discharged into the community, and a consideration of the concepts of "success" and "normalization".

An experimental study was conducted to evaluate the specific training programme (ASAT) in operation at Fernhill Care & Rehabilitation Centre. The degree of improvement shown after six months by those participating in the programme was compared with a control group. The experimental and control groups were matched on age, IQ and length of institutionalization. The living skills of the mentally retarded subjects were assessed on the ten areas covered by the ASAT Schedules, an assessment procedure previously designed for the assessment of such skills. Significant improvement was found in the two areas of finance and measurement only, and no clear trends emerged relating either age, IQ or length of institutionalization to the degree of improvement shown. Possible reasons for the lack of measured improvement in the other areas of skills are outlined. The need for systematic revision of the assessment procedure itself is indicated and the possible effects of the institutional environment upon the retention and learning

of skills is discussed. Recommendations for increasing the efficacy of the training programme within the institutional setting are put forward and suggestions are made for easing the transition from institutional to community living.

A detailed investigation of the lives of discharged persons already living in the community was carried out to assess the suitability of the content of the ASAT programme as a preparation for discharge. It was found that none of the subjects was living completely independently and that this was largely due to the restricting circumstances in which they had been placed, rather than lack of potential. The content of the training programmme was found to be relevant to community life except for the omission of training in employment practices and the use of leisure time. It is suggested that greater consideration be given to the achievement of maximum levels of functioning for those discharged rather than simply being discharged into "protective" settings. It is concluded that many mentally retarded persons are well able to speak for themselves and that greater effort should be made to ascertain their views.

CHAPTER ONE

HISTORY OF THE CARE OF THE MENTALLY RETARDED

The mentally retarded person has always been present in all societies, although the terms used to describe "mental retardation" have changed from generation to generation. How the problem of mental retardation has been approached and what "solutions" have been attempted is very much a function of the prevailing Zeitgeist and has thus varied accordingly. It is not possible to predict what the attitudes to mental retardation will be in the future but it is possible to outline some of the historical trends which have contributed to present contemporary perspectives.

The Pre-Christian Era

Care of those considered defective is a fairly recent phenomenon in the history of Western civilization and is in marked contrast to the attitudes of earlier times. In the ancient civilizations of Greece and Rome the mentally retarded were scorned and persecuted, being thought of as cursed of the gods and thus to be denied all human rights and priveleges. It is alleged that in ancient Rome parents of deaf, blind or retarded children would throw their children into the Tiber so that they would not have to support them (Rosen, Clarke, & Kivitz, 1976) and, in Sparta they were exposed to the death peril. If they survived they were tolerated for diversion and amusement, a blind imbecile having been mentioned in this regard by Seneca.

The Beginnings of Caring

The dawn of Christianity brought with it the first beginnings of caring for the mentally retarded. In the time of Constantine Magnus, the then Bishop of Myra (later to be called St. Nicholas) cared for retarded children. The Institutes of Justinian provided caretakers for imbeciles and the deaf and dumb; at least one Byzantine nunnery undertook to care for the sick and idiotic. During the dark ages quite variable practices appear to have prevailed in Europe, the retarded being sometimes favoured as innocents or persecuted as witches. In Medieval times the retarded were regarded as "les enfants du Bon Dieu" and wandered through the streets unmolested, being viewed as mysteriously connected with the unknown and thus treated with superstitious reverence. According to Doll (1962) imbeciles in twelfth century England were even awarded legal status as wards of the King. A similar regard for the retarded was found in the Orient, in some American Indian tribes, and in the writings of Confucious, Zoroaster and the Koran.

In the time of the Reformation superstition still prevailed, but now Luther and Calvin denounced the retarded as "filled with Satan" (Barr, 1904/1973, p. 26) and thus they were treated extremely harshly. Throughout this early period there was no understanding of the condition of mental retardation or any co-ordinated plan for dealing with it. The first known glimmer of modern concepts is found in a legal definition of idiocy in "New Natura Brevium" of 1534 by Sir Anthony Fitz-Herbert which combines a number of aspects to be found in present day terminology:

> And he shall be said to be a sot (i.e. simpleton) and idiot from his birth, is such a person who cannot account or number twenty pence, nor can tell who was his father or mother, nor how old he is etc., so as it may appear that he hath no understanding or

> reason what shall be for his profit nor what for his loss. But if he hath such understanding, that he know and understand his letters, and do read by teaching or information of another man, then it seemeth he is not a sot nor a natural idiot. (Fitz-Herbert, cited in Doll, 1962, p. 23.)

In 1775 Wolfgang Hofer, court physician at Vienna, gave the first scientific description of cretinism. In the same period at Bicetre in Paris, St. Vincent de Paul and his Confrerie de Charite gathered together the children of the city (homeless, abandoned, retarded) in what Barr (1904/1973) considered the "first intimation of organised effort" (p. 26). Half a century earlier, Juan Pablo Bonnet working in Spain had developed a system for the education of the deaf which was to have a far reaching influence on the education of the mentally retarded.

New Ideas in the Eighteenth Century

As mentioned earlier, attitudes and approaches to the mentally retarded cannot be considered without reference to the prevailing philosophies of that particular era in history. In the latter half of the eighteenth century and the first half of the nineteenth century many revolutionary ideas in all areas of human thought were being debated. The roots of some of these ideas can be found in the Renaissance concern with observation and scientific inquiry and a revitalised interest in education and humanitarianism. While Galileo and Newton attempted to understand nature using empirical means, Descartes, Leibnitz, Hobbes and Locke, among others, attempted to study man.

The equality of man

According to Crissey (1975) the previous historical epoch could be characterised by preordination -- men were born to nobility or serfdom and acquiesced to "the will of God". The revolutionary idea of men being created equal did not only have implications for government but for all social institutions. The recognition of the political rights of the individual was accompanied by a recognition of each human being's rights as a person. This type of thinking was to have extensive consequences for all types of previously disadvantaged persons -- the blind, deaf, those in slavery and the mentally retarded.

Because of the belief that men should govern themselves, there was an increased emphasis on, and a critical appraisal of, education. Locke, Rousseau, Sicard and others challenged the worth of lecture, memorization amd recitation and focused on practical experience. (Although as early as 1657 Comenius had advocated education in harmony with human nature and suggested basing the curriculum on the "living book of the world" rather than dead papers (Doll, 1967).) Rousseau, according to Barr (1904/1973), stood as "the acknowledged herald of reform in education" (p. 23) with his book "Emile". Rousseau advocated, inter alia, an education based on nature and the use of natural interest as a guide to teaching. Rousseau himself was greatly influenced by the work of Pereire who "although he did not work with the mentally retarded, his contributions to the philosophy and methodology of their education can hardly be overestimated" (Doll, 1962, p. 24).

Pereire

Pereire made great advances in applying the idea that deaf mutes could be taught to communicate with others. He demonstrated the results of his work at the Academy of Sciences in Paris in 1749 and the sight of a deaf mute reading and speaking caused a sensation. Many famous men, including Buffon, Diederot and Rousseau came to

observe his lessons, and so the principles which Pereire formulated for the teaching of the deaf have since become the basis for the education of the retarded: scientific observation, the use of the case history, adapatation of methods to suit the individuality of the pupil, sensory substitution and sensory reinforcement, progress through developmental sequences, education in terms of social needs and the principle of proceeding from the known to the unknown (Doll, 1967). Pereire's influence was extremely far reaching but it's most immediate impact was on Itard who undertook the first recorded attempt to educate a mentally retarded child.

The First Teachers

Itard

Itard, at the age of twenty five, was physician at the Institution for Deaf Mutes in Paris when Victor, aged eleven or twelve years, was found in the woods near Aveyron. He was thought to have been abandoned at the age of two or three years and his social contact had been minimal since that time. He crawled on all fours and exhibited many other animal like behaviours. Victor was handed over to Bonnterre, a naturalist, who brought him to Paris. Phillippe Pinel, on examining the child, considered that he was "an incurable idiot, inferior to domestic animals" (Kanner, 1974, p. 13) but Itard could not accept Pinel's prognosis of irreversibility and believed that the boy's deficiency was due to the absence of appropriate sensory stimuli (Balthazar & Stevens, 1975). He thus undertook to systematically supply these stimuli and hoped to provide Victor with ideas through the repetition of sensations. Apart from Pereire's work with the deaf, Itard was also strongly influenced by the sensationist psychology of the time, particularly the views of his contemporary, Condillac. Condillac's sensationism arose from the philosophy of the British Associationists, particularly Locke. Locke attempted to demonstrate the

rationality of man and to relate this rationality to simpler associative laws of the mind. According to Locke, ideas derive from experience, and observation supplies understanding with the materials of thinking. Condillac, however, considered sensations alone to be the basis of all mental life without presupposing any laws of association. "The faculties of our mind are but our sensations transformed" and "all simple ideas are the result of sensation alone" (Barr, 1904/1973, p. 33).
Placing motivation first, Itard proceeded to teach Victor in terms of the point of view and needs felt by the child, using the now common method of moving from the familiar to the unfamiliar. He analysed failure in learning in terms of readiness, exercising skills and wants that appeared to be underdeveloped. He moved from wide to narrow differences, from the simple to the complex, eliminating distractions and reinforcing one sense with another (Doll, 1967).

After five years of intensive work Itard considered that he had failed in his objective of completely socialising Victor, even though the Academy of Sciences applauded the fact that Victor had undergone some remarkable changes. He had learned to recognise objects, identify letters of the alphabet, make "relatively fine" sensory discriminations and "preferred the social life of civilization to an isolated existence in the wild". Kanner (1974) quotes the Academy of Sciences as follows:

> The Academy, moreover, cannot see without astonishment how he could succeed as far as he did, and think that to be just to Monsieur Itard, and to appreciate the real worth of his labours, the pupil ought to be compared only with himself . . . consider the distance separating his starting point from that which he has reached; and by how many new and ingenious modes of teaching this gap has been filled." (p. 16).

Itard knew nothing of the different degrees of mental retardation and failed to see that in actual fact he had demonstrated the educability of the mentally retarded. His methods embodied much of what is today known as behaviour modification (Crissey, 1975) and his pupil, Edouard Seguin, in refining and elaborating his methods, provided such a comprehensive approach to the education of the mentally retarded that he laid the bases for almost all future developments.

Seguin

In his work with the mentally retarded, Seguin was not only influenced by his teacher, Itard, but also by the beliefs of a movement known as the St. Simonians. They advocated the rise of a French republic based on the greatest good for the greatest number and were "striving for a social application of the principles of the gospel, for the most rapid elevation of the lowest and poorest by all means and institutions, mostly by free education" (Kanner, 1974, p. 35). Thus Seguin was convinced that education was a universal right, that society had an obligation to improve the lot of all of its members and that the mentally retarded were among the neediest.

In 1837, encouraged by Itard, Seguin attempted to educate a retarded boy. Much progress was made in eighteen months so Seguin opened a private school in Paris. He was so successful that in 1842 he was made director of the school for the mentally retarded at the Bicetre. However, with the coming to power of Napoleon, Seguin saw the end of personal freedom in France and emigrated to America in 1850.

In 1846 Seguin published a text book outlining his method. "According to this method, education is the ensemble of the means of developing harmoniously and effectively the moral, intellectual and physical capacities, as functions, in man and mankind" (Kanner, 1974, p. 35). Seguin's method was not a system, it was a series of

principles and techniques to be applied to the individual child in terms of observed progress and was firmly grounded in current physiology, humane philosophy and practical ingenuity. His methodology was based on the stimulation of the central nervous system by active involvement of the muscles and senses. He arranged the sensory modalities in a sequence from motion, through the lower senses, to vision, and suggested that each be developed in isolation and in reciprocal ways, stressing the fundamental nature of touch. "He utilised orderly progressions from passive to active, from sensation to perception, from the gross to the refined, from observation to comparison, from attention to imitation, from patterned activity to spontaneity" (Doll, 1967, p.177). Seguin also advocated teaching in context and used daily living situations as a basis for instruction.

Seguin's work was the inspiration for many workers with the retarded, particularly in America and England. By 1876 there were twelve institutions in America and Seguin had been actively associated with the establishment of the first four. In that year the Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons was formed with Seguin as chairman, and the permanence of the institution as a means of care for the mentally retarded was established.

Guggenbuhl

At the same time as Seguin was outlining his methods, Guggenbuhl in Switzerland and Saegert in Berlin developed their own systems for educating the retarded in terms of sensori-motor beginnings and socio-vocational goals. Guggenbuhl had been influenced by the sight of a cretin praying at a wayside shrine and wondered if more could have been achieved with intensive training. In 1842 he established an institution for cretins at Abendberg which served as a model for institutions in Germany, Austria, Britain, Holland and Scandinavia. Guggenbuhl travelled widely and was heralded as one who had given new life to the cretins. Unfortunately, he

did not deny this exaggerated claim and gradually fell into disrepute as the cretins were not "cured". An inspection by the British minister to Berne produced an unfavourable report of conditions at Abendberg, and Guggenbuhl died in disgrace in 1863. In spite of this, Barr (1904/1973) points out "that he in a comparatively narrow sphere, should have worked out and foreshadowed the colony plan of the large institutions of today is as marvellous as it is admirable" (p. 40), and Kanner (1974) concludes his chapter on Guggenbuhl by commenting that he "must be acknowledged as the indisputable originator of the idea and practice of institutional care for feebleminded individuals" (p. 30).

Attempts At Classification

A milestone in the understanding of mental retardation as a separate condition came when Esquirol, a contemporary of Seguin's, distinguished mental retardation from insanity in 1838. He defined idiocy as arrested or imperfect development, incurable and based upon defects in the structure of the brain visible on autopsy: he considered imbecility to be similar but less severe. According to Doll (1962), Binet credited Esquirol with being the first to recognise that the lack in both types was primarily intellectual rather than sensory. Other advances in the field of classification were made by Down in England, who distinguished three major groups of idiocy -- congenital, developmental and accidental. In 1866 he outlined the features of what is today known as Down's syndrome. Down's classification was superceded by that of Ireland who in his text book "On Idiocy and Imbecility" published in 1877 described twelve subclassifications of mental retardation -- genetous idiocy, microcephalic idiocy, eclampsic idiocy, epileptic idiocy, hydrocephalic idiocy, paralytic idiocy, traumatic idiocy, inflammatory idiocy, sclerotic idiocy, syphilitic idiocy, cretinism and idiocy by deprivation (Kanner, 1974).

This was the first well organised, medically orientated text book on mental retardation and thus mental retardation was no longer considered a unitary concept as had been the case previously.

The teachings of Itard and Seguin and others set an optimistic tone to the study and investigation of mental retardation. This optimism was enhanced by hopeful early nineteenth century considerations regarding general education, the rise of experimental science, the belief that it would find solutions to human problems, the resurgence of Christianity as a social force and the political upheavals of the time.

The Era of Institutional Expansion

Institutions were originally conceived as training schools for education and release, but by 1876 there was evidence of some toning down of Seguin's original optimism and a new conception of the custodial role of the institution. In 1878 Wilbur announced the opening of a genuinely custodial branch of the Syracuse School in New York to cope with the serious problem of women of child bearing age. In 1894 the Rome State Custodial Asylum was also estasblished in New York. The number of institutions throughout Europe and America increased dramatically and as they grew in size there was less emphasis on training and a new concern with economy of operation. This resulted in the use of residents as labourers to reduce costs and the establishment of many farm colonies. The increased numbers of mentally retarded persons sent to institutions reflected the considerably different attitudes in society which arose at this time compared with the early nineteenth century. This change in attitude and approach can be linked to a number of developments in many other fields.

The Eugenics Movement

The "Eugenics Movement" as it came to be known had its beginnings in the 1890's and reached its peak in the 1920's. In 1900 Mendel's laws of inheritance were re-discovered and this gave new impetus to the study of the inheritance of intellectual ability. De Vries' description of mutations made it possible to conceptualise changes in species not as slight variations but as drastic alterations. Social class differences were studied and greater urbanization made the socially unacceptable more visible. Studies of plants and animals provided evidence of unfavourable strains and this was thought to also apply to man.

As a result of these new areas of investigation, not only mental health but also criminality, social conformity and other traits were ascribed to inheritance. Numerous studies were put forward as "evidence" of these "facts" -- the most notable being the study of the Kallikak family by Goddard in 1910. In this he "proved" that retardation and degeneracy were inherited and irreversible and concluded that:

> feeblemindedness is hereditary and transmitted as surely as any other character. We cannot successfully cope with these conditions until we recognise feeblemindedness, and its hereditary nature, recognise it early, and take care of it. In considering the question of care, segregation through colonization seems in the present state of our knowledge to be the ideal and perfectly satisfactory method (Goddard, cited in Kanner, 1974, p. 132).

Fernald, the superintendent of Massaschusetts School for the Feebleminded was extremely influential and his views provide a good reflection of the attitudes

prevailing at the time, i.e. that mental retardation was not only unfortunate but it was actually to be feared. In 1893 Fernald stated that "the brighter class of the feebleminded with their weak will power and deficient judgment, are easily influenced for evil and are prone to become vagrants, drunks and thieves" (Fernald, cited in Balthazar & Stevens, 1975, p. 24). By 1912 Fernald was even stronger in his condemnation:

> The feebleminded are a parasitic predatory class never capable of self support or of managing their own affairs. They cause unutterable sorrow at home and are a menace and danger to the community. Feebleminded women are almost invariably immoral and if at large usually become carriers of venereal disease or give birth to children who are as defective as themselves . . . Every feebleminded person, especially in the high grade is a potential criminal needing only the proper environment and opportunity for the development and expression of his criminal tendencies (Fernald, cited in Rosen et al., 1977)

By the turn of the century the mentally retarded were regarded as a menace from which society had to be protected and such negative attitudes had far reaching effects on institutions and the nature of the treatment that retarded persons received. Institutions became larger and larger as more people were confined for a lifetime; in fact in the 1890's Kerlin and Knight, both superintendents, were advocating the value of large institutional populations to permit efficient classification! The growth of these very large institutions also gave rise to a certain type of institutionalization (contributing to further deficiencies in personality and behaviour), the consequences of which are still apparent today. The eugenics alarm was also responsible for the application of sterilization laws to the

retarded. The first laws were passed in Indiana in 1907 and by 1917 sterilization was a customary provision for parole in California; it was also available to mentally retarded persons outside the institution at the request of their families.

Intelligence testing

Another development which contributed greatly to this period of pessimism regarding the retarded was the advent of intelligence testing. A recent evaluation of the effects of this milestone in psychology by JenKins and Patterson (1961, cited in Wolf, 1964) considers that "probably no psychological innovation has had more impact on the societies of the Western world than the development of the Binet-Simon scales" (p. 762). That impact can be clearly seen in the case of the mentally retarded.

Binet was a member of a French commission investigating the education of retarded children and was faced with the problem of selecting retarded children for special classes. It was necessary to provide a method which would discriminate objectively between those who were unmotivated, poorly taught or mentally retarded. Binet believed that the basis of intelligence could be found in the process of judgment and that attention and memory could serve as useful indicators. Binet and Simon had also noted developmental stages in language, judgment and varying aspects of behaviour which the average child tended to reach at about the same time. On the basis of these observations they drew up, in 1905, a number of test items ranging from simple to difficult; in 1908 these were revised and classified according to age, and the term "mental age" was introduced to represent that age level at which not more than one item was failed. The Binet-Simon scale was translated by Goddard in 1911 and was further perfected and standardised by Terman in 1916. Terman was the first to introduce the intelligence quotient (IQ), utilising the suggestion by

Stern in Germany that the level of relative retardation was more important than the level of absolute retardation, or mental age (Luckey, 1967).

In view of the criticism and controversy that IQ tests have generated it is necessary to point out that Binet regarded his scale as tentative and always remained highly critical of it. In no way did he consider it to be a total indicator of developmental status and maintained that careful observation of individuals, intensively and over time, was the only satisfactory basis for understanding general principles of development. However, for practical purposes the intelligence test quickly became the primary, and in some cases, the sole criterion for identifying and classifying retardation, in spite of Binet's own view that "retardation is an idea related to a host of circumstances that must be kept in mind when judging each particular case" (Wolf,1973, cited in Crissey, 1975, p. 803). Initial research results with the new instrument were interpreted in the light of the heredity/genetic view of retardation and thus the concept of the "fixed IQ" was uncritically accepted.

Conflicting Trends: 1910-1950

Kanner (1974) describes the period from 1910 to 1935 as a "lull" (p. 141), with gradually increasing numbers of institutions, special classes and the administration of the Binet-Simon scales to tens of thousands of children. However, there are a number of developments during that time which are worthy of note.

Although the use of the concept of mental age had been accepted so quickly, it was not long before this was under suspicion as a basis for classification. Goddard had suggested that an M. A. of twelve years should be the cut off point for the classification of feeblemindedness but the use of this criterion with the Army Alpha

test in 1917 produced the statistic that 47,3 per cent of the men drafted for service were feebleminded! Ultimately this finding provided the impetus for better standardization procedures for IQ tests with adult populations through the efforts of Terman, McNemar and Wechsler.

The subsiding of the eugenics alarm

There was increased understanding of the non-genetic determinants of retardation, e.g. organic causation and the influence of the environment (Doll, 1962) and this, coupled with the pioneering studies of the effects of stimulation, eventually demolished the myth of the constancy of the IQ (Rosen et al., 1976). However, it was a considerable time before the results of these studies had any effect on the widespread use of IQ tests.

In 1915 Fernald had been the first to establish travelling clinics to assist with training and treatment of those mentally retarded persons not residing in institutions, and these clinics can be viewed as the fore-runners of the child guidance clinics which were established later. In 1919 Fernald published the results of a follow up study of persons who had been discharged from Waverley, an institution in Massachusetts, usually without official appproval, and he was astonished at his own results. He found a far greater success rate than he expected, showing that some mentally retarded persons could make a satisfactory adjustment to the community without becoming drunkards, criminals or prostitutes.

The eugenics alarm also began to be dispersed by the gradual recognition of the diversity of conditions leading to retardation, thus invalidating many earlier studies, and even Fernald, who had been so strong and adamant in his condemnation in 1912, could, only twelve years later in his presidential address to the American Association for Mental Deficiency, attack "the legend of the feebleminded" and the

"twin ogres of heredity and criminality" as "far too sweeping . . . generalizations and deductions" (cited in Rosen et al., 1976, p. xx). Contradictory trends arose at this time because, although in some instnaces there was revival of earlier educational principles, the institutions were still considered the treatment of choice for many retarded perons.

Binet's central theory of retardation as intellectual deficiency in judgment was qualified by investigations of individual variation based upon sensory defects, special abilities and disabilities, temperamental pattern and environmental deprivation. There was a decade of work with form boards, mazes, puzzles and picture completion tests by Norsworthy, Goddard, Knox, Healy and Patterson. There was also increasing interest in personality structure, social competence, borderline diagnosis and delinquency with increased attention to the scientific evaluation of non-intellectual aspects of behaviour (Doll, 1962). In 1921 Porteus devised a social rating scale, in 1925 Gesell developed a developmental scale for the pre-school child and 1935 saw the introduction of Doll's Vineland Social Maturity Scale which has been used extensively since its inception, particularly for the assessment of the retarded.

Scientific advances

In the field of science many advances were made during this time. In 1929 Murphy and Doll related mental retardation to maternal pelvic irradiation, and in 1932 Doll, Phelps and Melcher outlined the implications of birth injury for retardation (Doll, 1962). The study and theory of heredity underwent extensive revision: as early as 1912 Davenport and Danielson had suggested that inherited retardation involved a combination of traits rather than a Mendelian character; in 1925 Jennings pointed out the complexity of the combinations of genes and their chemical interactions; and in 1936 Jervis suggested the biochemical hereditary basis of a number of conditions

characterised by both the genetic behaviour of Mendelian recessivity and the lack of specific enzymatic action (Doll, 1962). A milestone in the biochemical approach to mental retardation occurred in 1934 with the discovery by Folling in Norway of phenylketonuria as a metabolic disturbance which could be reversed by proper dietary control. Gradually mental retardation became a legitimate field of research in the biological sciences and there was a slow revival of interest by the medical profession.

Although definite advances were made in the twenties and thirties, the Depression and World War II were distracting factors. The resumption of normal activity after the war brought in a new generation of professionals in the area of mental retardation who were largely unacquainted with the accomplishments of their predecessors and also by the late forties there were the ever increasing demands of parents, impatient with the inadequacy of immediate help and frequently unaware of available resources. More money became available, particularly from private funds and, according to Doll (1962), much time was wasted in ill-conceived programmes before old truths were re-discovered. The efforts of the parents of retarded children in America led to the formation of the National Association for Retarded Children in 1950 and by 1959 it had a membership of 50,000.

There was continuing evidence of the satisfactory adjustment of retarded persons leaving institutions in the twenties and thirties, and many residents of institutions were discharged during the war to work in factories because of the severe manpower shortage. The success of these people contibuted considerably to the deinstitutionalization trends which were to arise in the 1960's.

Current Developments

Writing in 1962, Doll considered the most important current developments in the field of mental retadation to be: the revival of anatomical and biochemical research, advances in the study of sensory deprivation, the application of the principles of Freudian psychology, special interest in the severely retarded and vocationally trainable, and increasing co-operation between various disciplines, parents and administrators. To these must be added the dramatic swing away from institutional care to attempts to integrate the retarded into the mainstream of the community. These attempts were particularly stimulated in America by the President's Panel on Mental Retardation which, in 1962, set definite targets for the reduction of institutional populations. "Few social reversals have occurred as quickly" (Crissey, 1975, p. 806) and inevitably friction, obstacles and hostility have occurred. Although the changes are taking place with the best of intentions, "good intentions are treacherous paving stones" (Crissey, 1975, p. 806) and many people have been discharged without the provision of sufficient community services. Very recently this has resulted in a backlash against the desirability of deinstitutionalization as a policy and much disagreement.

"Thus have the mentally retarded progressed from total rejection by society, through imprisonment and grudging acceptance, through a century of devoted care by a handful of professionals and philanthropists, to emerge as a major concern of the welfare state" (Doll, 1962, p. 61). As mentioned at the beginning of this chapter, attitudes to the mentally retarded cannot be separated from the prevailing Zeitgeist and the era of "Civil Rights" has had its impact on equal opportunites for all kinds of minority groups, including the retarded. In spite of this, our present methods and philosophies are not drastically different from the previous century and "the newest methods, perhaps unawares, revamp the devices of Seguin and Goddard

in terms of modern statistics" (Doll, 1967, p. 181). There is much to be gained from a study of past endeavours, "only so can the mistakes, successes and learnings of the past be winnowed and incorporated into progressive advances" (Doll, 1967, p. 181).

The Care of the Mentally Retarded in South Africa

Since most of the literature on the history of the care of the mentally retarded is written from an American or European perspective, it was felt that this historical review would not be complete without an attempt to describe the development of care for the retarded in South Africa.

Colonial times

Barr (1904/1973) makes mention of a separate department for retarded children at the Grahamstown Insane Asylum, and this appears to be the first reference to a place specifically for the care of the retarded in South Africa. When Europeans first settled in South Africa the retarded were either kept with their families or, if unmanageable, were kept with those considered mentally ill. No distinction was made between retardation and mental illness, and belief in possession by demons was common. In the time of the Dutch East India Company and the government of the Cape by the British the insane were housed at either the ordinary hospital, the slave lodge or on Robben Island in very poor conditions. There were no attempts at any kind of treatment and it was a considerable time before the humanitarian ideas of Europe filtered through to South Africa.

From 1845 all mental patients were kept on Robben Island and this resulted in people being sent there from all parts of the country. This practice continued until

1913 when a Select Committee of Parliament recommended that the institution there be closed down and the patients transferred to the mainland. However, direct admissions still continued and it was not until 1920 that it was finally closed.

The establishment of Mental Health Societies

In 1912 the Child Life Protection Society in Cape Town held a Baby Week exhibition and drew attention to the shortcomings of "mental hygiene" in South Africa. Amongst other things, they mentioned in their leaflet that "above and below the great mass of average persons are types for whom special provision needs to be made" (cited in Minde, 1975b, p. 1717). They exhibited some of the then recent findings concerning mental retardation, including the discovery and testing of types and the influence of heredity. This was followed in 1913 by a "drawing room meeting" at which a committee of fifteen members was elected to become the "Committee for Mental Hygiene and Care of the Feebleminded". One of the resolutions passed was that "this meeting desires steps to be taken for raising funds to develop a scheme for the care, protection and training of feebleminded persons" (cited in Minde, 1975b, p. 1717). At the first annual meeting in 1914 the committee decided to make representations to the government on the necessity for a Mental Deficiency Act. A similar society was founded in Johannesburg in 1917 and by 1920 there were five mental health societies and a number of child welfare societies in South Africa. At this time psychiatric services were the responsibility of the Department of the Interior which requested that a central body be formed to represent the interests of all the different societies and this resulted in the formation of the South African National Council for Mental Hygiene in 1920. In 1916 the Mental Disorders Act was passed, unifying the control of mental hospitals in South Africa under a Commissioner for Mental Hygiene and making provision for the certification, care and supervision of the mentally retarded and mentally ill.

Enthusiasm in the 1920's

The 1920's was a period of great activity in the field of mental retardation. In 1921 the first government institution for the retarded (Alexandra) was opened and this was followed by Witrand in 1923. Dunston, the moving force behind the 1916 Act and the first Commissioner for Mental Hygiene, was very enthusiastic and, amongst other things, initiated surveys of the mentally retarded in South Africa. In 1927 Fick standardised the Stanford-Binet Revision Scale for use in South Africa and from then it became the standard scale in use. The Minister of the Interior appointed an interdepartmental committee in 1928 "to inquire generally into the position in the Union with regard to mentally retarded, mentally defective and psychopathic children and young persons" (cited in Minde, 1975b, p. 1719). The subsequent report was detailed and far reaching and among the recommendations were: the provision of special schools and classes, the appointment of educational psychologists, the assumption of the responsibility for the training of teachers for special schools and for all educable children by the Department of Education, and the assumption of responsibility for ineducable children by the Department of the Interior.

Another departmental committee was appointed in 1936, this time "to consider and investigate the conditions at present prevalent in the mental hopitals and institutions for the feebleminded in the Union" (cited in Minde, 1975a, p. 408). One of its most important recommendations that was carried out was the provision of out-patient clinics, but many other recommendations were ignored.

The Van Wyk Commission

The inadequacy of facilities for the mentally retarded stimulated the South African National Council for Mental Health to take an increasing interest in the mentally retarded and in 1960 a National Division for the Mentally Handicapped Child was

created. This body was instrumental in obtaining a per capita grant-in-aid in respect of day centres for White retarded children and applied strong pressure on the government to appoint a committee of inquiry into the care of retarded children. A committee was eventually appointed in 1965 but its report, dealing only with White children, was not released to the public until 1969. Some of the most important recommendations of the Van Wyk Commission were as follows: clinics for genetic investigation and counselling be introduced, State accommodation for the retarded be increased, private welfare organisations should form a national body to represent their interests, State institutions to be modernised, training of children between six and eighteen years be compulsory unless the child is considered untrainable, and the care, accommodation and employment of trainable adults be placed under the Department of Social Welfare. In addition many generous subsidies towards, for example, buildings, furniture and staff salaries were introduced.

In an attempt to co-ordinate the work of organisations in the field of mental retardation the National Division for the Mentally Handicapped Child, which had been dormant since 1965, was re-established, its terms of reference amended to provide for the membership of organisations which were not mental health societies, and the specialisation in the child was abandoned. This division was extremely active in the first half of the 1970's as organisations needed guidance with many aspects of the implementation of the Van Wyk Commission's recommendations.

Mental Health Act, 1973

In 1970 a commission of inquiry was appointed to inquire into the Mental Disorders Act of 1916 and the desirability of re-organising the mental health services. This led to the Mental Health Act of 1973 which, although it deals mainly with psychiatric patients, does make the provision of training facilities in institutions and licensed homes for retarded children compulsory. It further recommends that mentally

retarded patients should not be kept in psychiatric wards and introduces a new category, patients by consent, which has proved very useful in the case of mentally retarded patients.

This brief review may seem to indicate that the retarded in South Africa are well provided for, but unfortunately most of these provisions relate to a small segment of South Africa's mentally retarded -- those of the White population group. In a publication by the National Council for Mental Health (1981) only three Care and Rehabilitation Centres are listed which admit non-White residents and the total number is exceedingly small compared with the existing need. Fortunately, many day centres have been set up, mainly under the auspices of non-governmental organisations, but they cannot provide all the facilites required, and at present Blacks who are mentally retarded constitute over five per cent of the population at non-White mental hospitals. It is to be hoped that the government will exert its energies to redress this imbalance in the very near future.

CHAPTER TWO

THE ASSESSMENT OF MENTAL RETARDATION

Chapter One outlined how the problem of mental retardation has been approached at various times throughout history. Before continuing with material more directly related to the present study it is necessary to consider the definition of mental retardation and, more specifically, its assessment. A detailed examination of the problems of assessment is not attempted here and a number of issues are simply presented without extensive discussion. It was felt that some reference to these particular aspects of mental retardation could not be omitted since they determine to a great extent who is classified as mentally retarded at the present time. Although brief, this chapter is presented separately because it is not considered to be an integral part of any of the topics outlined in subsequent chapters.

The Cultural Basis of Mental Retardation

According to Brooks and Baumeister (1977), mental retardation is first and foremost a social-cultural phenomenon. A layman will recognize that an individual is not behaving according to the community rules of normality, and this awareness will exist independently of a culture's attempt to formalise the concept of mental retardation. What is construed as "retarded behaviour" will vary between cultures and also be affected by a society's tolerance at a particular time. "That which the society views as retarded behaviour is the first and only 'true' criterion for defining retarded behaviour" (Brooks & Baumeister, 1977, p. 408). O'Connor and Tizard (1956)

classify retardation into two main types; those who would be retarded in any society at any time and those who in a less intellectually centred society would have no trouble in attaining equality.

Formal classification

Although the informal criteria for mental retardation may be socially maladaptive behaviours, the formal criteria are much more explicit. Clarke and Clarke (1974) outline three criteria of retardation; social incompetence, educational retardation and IQ, but none can be considered completely reliable by itself. The standards of what constitutes social competence are arbitrary and differ between societies, within a society in different areas or social classes, and at varying points of time. Educational retardation has never been used as a sole criterion but is commonly used as a supporting factor. School failure is often what first brings the mildly retarded child to the attention of a professional person, but IQ is the most commonly used formal classification of mental retardation. It is probable that a diagnosis of retardation will be made if the IQ score falls more than two standard deviations below the mean. It must be noted that the categories of mild, moderate and severe retardation refer to intelligence testing only even though they may be commonly applied to retarded persons' behaviour in other situations. Gunzburg (1970) indicates that such testing only refers to functioning at the time, it is usually biased in favour of academic ability and provides little indication of social potential. Other problems with the measurement of intelligence are that the IQ is liable to some degree of measurement error, the same IQ on different tests may not mean the same thing and intellectual growth over long periods of time does not necessarily proceed in a constant fashion.

Assessment

Clark (1974) warns against confusing diagnosis with assessment, mentioning that, although both involve the eliciting of information, signs and symptoms, diagnosis is a descriptive process defining a relatively clearly delineated present condition in terms of aetiology, family history, signs and symptoms. Assessment, however, is a much more comprehensive activity relating the client and his behaviour to present and future events and circumstances and owing nothing to the medical model of illness and cure. The initial question which should precede any assessment activity is, "assessment for what?" as "the types of data gathered greatly influence and in a sense even limit or restrict the types of recommendations or conclusions which can be derived" (Gardner, 1971, p. 145).

Until recent years, the IQ test has been the assessment procedure most often used. Although this has come under considerable criticism, if administered carefully with due attention to all the qualitative factors, instead of just a score, it can provide a great deal of valuable information. However, it is unsatisfactory to use this as the only measure of retardation and recently there have been attempts to include other dimensions.

Adaptive behaviour

In recognition of the limitations of the IQ as a sole means of classification the American Association on Mental Deficiency proposed in 1961 that the diagnosis of mental retardation must rest upon deficiencies along two general dimensions -- measured intelligence and adaptive behaviour. "Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behaviour" (Heber, 1961, p. 499). Adaptive behaviour refers to the success of the individual in adapting to the natural and social demands of his environment. The Adaptive

Behaviour Scale designed by Nihira, Foster, Shellhaas and Leland and published in 1969 was an attempt to measure adaptive behaviour and was based on the individual's ability to adapt to environmental demands. It focused on the areas of independent functioning, personal responsibility and social responsibility. However, although the significance of adaptive behaviour in diagnosis and programming has been accepted, "Knowledge concerning the specific attributes of adaptive behaviour and their developmental implications is not yet well developed" (Nihira, 1976, p. 215).

Although the measurement of adaptive behaviour appears to hold promise as a tool in the assessment of mental retardation, at the present time its application has many difficulties. Heber's comments in 1962 (cited in Leland, Shelhaas, Nihira & Foster, 1967) would appear to still hold. "Because of the imprecision of these norms and standards of behaviour, intelligence test performance will remain as the most important and heaviliy weighted of the criteria used. In spite of obvious limitations, the individual intelligence test remains the most objective and best single assessment technique currently available" (p. 368). This may sound extreme but with a far greater emphasis on the qualitative aspects of testing, a de-emphasis on its labelling function, the use of testing as a basis for further training rather than an end in itself, and an awareness of all the factors that can influence test performance, IQ tests can play a valuable role in the assessment of mental retardation.

CHAPTER THREE

INSTITUTIONS AND INSTITUTIONALIZATION

It must be noted that this chapter is only concerned with state institutions for the mentally retarded as this was felt to be the area most relevant to the present study. Mentally retarded persons have been, and continue to be, cared for in a variety of settings apart from institutions and it is not implied that aspects of institutional life described here will necessarily be found in other types of care.

As mentioned in Chapter One, the first institutions of the 1850's were viewed as temporary boarding schools with training as their first priority. They were usually very small, situated in the community, and only those children who were considered suitable for training were admitted, most being later returned to live in the community. Gradually the term "school" was replaced by the term "asylum" and for various reasons, outlined previously, the trends of isolation, enlargement and economization arose. By the 1920's institutions were extremely large, usually very isolated and many undesirable practices had arisen in the treatment of the mentally retarded residents. As Baumeister and Butterfield (1970) point out, "like any social institution it (the institution) can only be construed as "good" or "bad" in relation to society's values" (p. v). The general view at the beginning of the century that the retarded were a menace from which society had to be protected was certain to give rise to attitudes and practices that differed greatly from today's attitudes in the present human rights era. Unfortunately, many institutions have not moved with the times and this has led to institutions for the retarded being denounced as inhuman, evil, degrading and viewed in a negative light. These negative views may

misrepresent some institutions which are administered along more modern lines but "many of our institutions still operate in the spirit of 1925 when inexpensive segregation of a scarcely human retarded individual was seen as the only feasible alternative to combat a social menace" and "still function as if this view were still held" (Wolfensberger, 1976, p. 69).

One may wonder why, with so much rapid change in all other areas of life in the twentieth century, institutions for the retarded have not changed very much. Various reasons can be considered, each of which has contributed to the maintenance of the status quo. Professionals had indoctrinated the public for thirty years as to the dangers of mental retardation and only a prolonged campaign of attitude modification would have changed public opinion. Much pessimism had been generated, so more professionals became involved in other areas of mental health rather than retardation. The depression stifled progress in the social services and World War II diverted attention from any possible reforms. It was not until 1950 that there was a "new look" at mental retardation. Although those factors can all be considered to have contributed to the maintenance of institutions until 1950, even today institutions are widespread. Large, older institutions are still being enlarged, new institutions are still being built (often in inconvenient locations), admission procedures are often uncritical and the practices of fifty years ago are still continuing. Roos (1970) considers that institutions for the retarded are in danger of becoming extinct unless they adapt to the changes occurring in the field of mental retardation, but it seems more likely that they will exist until there are sufficient alternative services.

Types of Institutions

In Western civilization institutions have been created to deal with many different areas of life and for very different purposes. Barton (1973) outlines the different types of institutions as follows:

1) Institutions established for the care of people who are both incapable and harmless; for example, homes for the blind, aged or orphaned.

2) Places established to care for people unable to care for themselves and who are an unintentional threat to the community; for example, tuberculosis sanatoria, leprosia and mental hospitals.

3) Places established for persons intentionally dangerous to the community; for example, prisons and concentration camps. (These differ from other institutions since the welfare of the inmates is not the primary or immediate issue).

4) Institutions established to pursue some technical task; for example, army barracks or boarding schools.

5) Places established as retreats from the world or training centres for the religious; for example, abbeys or monasteries.

In spite of the widely differing natures and purposes of these varied institutions, there are a number of features which predominate in any institution to a far greater extent than in the outside world: the inmates tend to sleep, play and work in the same place, and each phase of the individual's daily activity is carried out in the company of a large number of others, all of whom are treated more or less alike and required to do the same thing together. In addition, all phases of a day's activity or idleness are tightly scheduled and pre-arranged, the whole circle of activities being imposed from above through a system of explicit formal rulings and body of officials.

Total institutions

Goffman (1958, cited in Wing, 1962) calls certain segregated communities "total institutions" and considers that they have a number of features in common. The staff and inmates have fundamentally different points of view, there is great social distance between them, and they may come to perceive each other in terms of narrow stereotypes rather than as individuals. The amount of contact with non-institutional life is strictly rationed and considered a privelege. Even the smallest detail in the life of an inmate may be decided for him and social experience is drastically altered as previous social roles no longer apply. The normal activities of the outside world are no longer practised and relationships with the outside world are reduced to a minimum. Many of the conditions described above apply particularly to institutions for the mentally ill and the mentally retarded and it is obvious that prolonged exposure to these abnormal conditions will affect the individual in many ways. In the institution itself, the effect of these conditions is the production of a pattern of culture (attitudes, behaviours and values) so different from the pattern of culture in the rest of the community that adaptation to life "outside" can be extremely difficult. The effects of these conditions on the the individual have been outlined in recent years as a set of symptoms in their own right, separate from the original symptoms that may have brought the person into the institution. The syndrome is commonly known as "institutionalism" or "institutionalization" and, although "there is a dearth of research data bearing upon the exact nature of institutional effects upon personality and behaviour" (Rosen, Floor & Baxter, 1973, p. 21), certain recognisable characteristics can be outlined.

Institutionalization

According to Wing (1962) the term "institutionalization" can be used to describe any behaviour which is evoked in the individual by the social pressures of an institution. These behaviours have been described in detail in many novels and descriptive works but, because of the methodological problems involved, very few studies have involved the systematic collection of empirical data. In spite of this, it is generally accepted that institutionalization is a separate syndrome which, if not recognised as such, can confound the aims and achievements of any programme aimed at preparing a person for discharge. All too often institutional programmes reinforce the behaviour required for institutional life which is of very little help when dealing with the outside world.

The institutionalized personality

A number of factors can be said to contribute to the development of the "institutionalized personality" -- the social pressures to which an individual is exposed after admission, the degree of resistance or susceptibility to institutional pressures which the individual possesses and the length of time the person is exposed to these pressures (Wing, 1962). If a person is very resilient and is not in the institution for very long it is probable that the effects will be few and short lived. However, if a person is more susceptible and confined for a long period of time the effects will be deeply embedded and very difficult to alter should his circumstances change.

Barton (1973) considers institutionalization to be a more or less "constant psychiatric syndrome" (p. 15) in hospitals for the mentally ill and the mentally retarded. The syndrome is characterised by apathy, lack of initiative, loss of interest particularly in things and events not immediately personal or present,

submissiveness, often no expression of resentment at harsh or unfair orders, lack of interest in the future, deterioration in personal habits, conduct and standards, loss of individuality, and a resigned acceptance that things will go on as they are, indefinitely and inevitably. Not every resident or patient will show these symptoms to the same degree but until recent years they were considered to be an integral part of the illness or condition. (For example, the latter stages of deterioration in schizophrenia, or the condition of mental retardation.)

With reference to the mentally retarded, it has been well documented that intellectual level alone cannot predict the success of those discharged into the community and many other variables appear to be important. Rosen et al. (1973) identified a number of personality and behavioural characteristics in persons discharged from an institution -- lowered self esteem and related motivational deficits, conditioned helplessness, acquiescence to authority, other inappropriate behaviours and sexual inadequacies. None of these deficits is a necessary concommitant of retardation but can be seen as the end product of living in an environment structured to produce such behaviour. When research is conducted on the characteristics of retardates, investigators should now be aware of these other variables and in fact, environmental factors such as increased attention for dependence, tantrums and other undesirable behaviours can be clearly identified. Ideally, identification of these factors should be only the first step, the next step being alterations and improvements to the institutional environment itself, but that is a much more difficult proposition.

Investigations concerning the features of institutionalization as a specific personality syndrome are fairly recent, while previous research has concentrated on changes that could be more easily measured. Some areas of investigation have been IQ variability, social deprivation, and self esteem.

IQ variability

Anastasi (1968) considers that "an IQ is an expression of an individual's ability level at a given point in time, in relation to his age norms" (p. 211) and there has been considerable research on the constancy of the IQ in normal populations. Husen (1951, cited in Anastasi, 1968) and Sontag, Baker and Nelson (1958, cited in Anastasi, 1968) found intelligence test performance to be remarkably stable over a ten year period. It is considered that there is increasing stability of the IQ with increasing age and this has been accounted for by various factors: intellectual development is a cumulative process and a growing consistency would emerge simply because earlier acquisitions constitute an increasing proportion of total skills and knowledge as age increases (Anastasi, 1968). In addition, not only does the individual retain his prior learning but such prior learning provides tools for subsequent learning experiences, thus the more progress made at any one time the better an individual is able to profit from later experiences.

The IQ is considered to be a fairly reliable estimate of a person's present level of intellectual functioning, and, as mentioned previously, in most instances it is used as the most important determinant in screening and classifying the mentally retarded. Although many problems have been ackowledged both with the administration of IQ tests and their reliability over time, a number of studies have indicated a significant change in the IQ of retardates after admission to an institution. Clarke and Clarke (1954) and Clarke, Clarke and Reiman (1958) found that over half their sample showed gains in IQ of eight points or more at ages when mental growth is assumed to have ceased. Further study of the results indicated that the greatest change occurred in those with the lower initial IQ and whose background prior to entry into the institution had been severely deprived. The length of time in the institution was not associated with the increases in IQ,

suggesting that changes were more the effect of removal from a very adverse environment than of entry into a good one. These results indicate that the mentally retarded from poor social conditions may benefit from admission to a institution even at a relatively late age, although there are obviously limits to the change which can occur. The finding of IQ increases was supported in a study by Rosen, Stallings and Nowakwiska (1968) who, when testing the reliability and stability of the WAIS and the WISC for the retarded, also found a strong tendency for the adult IQ to increase (mainly PIQ) when change did occur. However, for each study that has found IQ increases after institutionalization there are others which indicate IQ decreases, for example, Zigler and Williams (1963) and Butterfield and Zigler (1970).

Social deprivation

Many arguments have been advanced to account for the variability of these studies. Most investigators have inferred that changes in IQ have reflected actual change in cognitive functioning and whether IQ increased or decreased depended on the differing levels of stimulation in the two environments (pre-institutional and institutional). However, this emphasis on cognitive functioning ignores the fact that intelligence test performance is determined by a variety of factors, particularly motivation and achievement, as well as cognitive processes. Zigler and Williams (1963) found that the magnitude of their subjects' decreases in IQ was positively related to the magnitude of their desire to interact with adults. It would appear logical that the degree to which the institutional environment would be experienced as socially depriving would depend to a considerable extent on the pre-institutional environment. If a child came from a background that was only mildly deprived he would probably experience greater social deprivation in the institution than the child who had a severely deprived pre-institutional background. Thus, the child from the mildly deprived background would have a heightened motivation for social reinforcement which could interfere with performance in the testing situation. This

heightened motivation for social reinforcement could become a major feature of the child's interactions with his enironment. A hypothesis which is supported by studies using a satiation type of game. Institutionalized retarded children were found to play the game longer than normal children (matched on M.A.) and also longer than non-institutionalized retarded children (Green & Zigler, 1962), thus indicating that their greater persevrance was a product of their particular environmental conditions rather than their intellectual level. The variability of the results of the studies investigating IQ change indicates that the effects of institutionalization on individuals may differ markedly depending on their pre-institutional history and that different institutions may have different effects.

<u>Self esteem</u>

Frequently institutions are condemned automatically as being "bad" without regard for the possible advantages to the individual of living in a "sheltered" environment. A person's self concept develops from, inter alia, their success or failure in dealing with their environment, and a number of studies (Green & Zigler, 1962; Rosen, Diggory &Werlinsky, 1966) have indicated that residential care is more conducive to optimism and self confidence than non-sheltered community experience. Institutions for the retarded provide a set of demands and expectations that differ from the non-institutional environment, and protection, encouragement, training and more realistic standards for performance may well heighten self esteem. This is not to suggest that all retarded persons should reside in institutions but simply to indicate how much care must be taken when evaluating institutional life.

In summary, "very few statements can be made in the form of generalizations about the effects of hospital care on subnormals" (MacKay, 1974, p. 65), but with reference to children, Klaber's (1970) assessment would appear to be valid. "The apparent conclusions that can be drawn on institutional rearing are: 1) institutional child

rearing is generally less conducive to child growth and development than normal home care; 2) some institutional environments are less harmful to child growth and development than others" (p. 65). Institutionalization cannot be regarded as a homogenous variable or automatically equated with social deprivation. Critical social interactions are not constant from one institution to another and this may in some way account for the many inconsistent findings in research with institutionalized retardates. It is clear that institutions do differ in many ways, apart from concrete variables such as, the size of buildings, numbers in a ward, staff/resident ratio, etc., but it is not clear what specific aspects of the social-psychological environment give rise to the different personality and behaviour patterns in the residents themselves. It has even been suggested that all the important factors may be a consequence of the quality rather than the form of institutional per se. It is obvious that a great deal of detailed research needs to be done adn tizard (1972) suggests that "the major contribution to our knowledge of, and treatment for, the mentally handicapped over the next two or three decades will come through studies of institutions" (p. 15).

Institutions of the Future

In recent years there has been widespread condemnation of institutions for the mentally retarded, particularly in America, and strong recommendations that institutions as such be demolished. This viewpoint is shown in such comments as: "the continuation of institutionalization of the mentally retarded has no premise or conceptual base . . . institutionalization or 'warehousing' of any form is a national disgrace" (Granger, 1972, p. 6). Thurman and Thiele (1973) advocate "the immediate termination of all institutional facilities for mentally retarded individuals". There are many comments in a similar vein but it would seem that, although one would not

advocate the continuation of many present day practices, it is necessary to be realistic, to "avoid thinking in Utopian terms and seeking solutions which completely depart from present day reality" (Gunzburg, 1973, p. 47). It is also essential to make efforts to help those in institutions at present because "while patients may be judged not to need hospital care, it by no means follows that in all cases they could be discharged, particularly after long periods in an institution" (McKeown & Teruel, 1970, p. 117), and indeed it would often not be a kindness to do so. White and Wolfensberger (1969) maintain that "we cannot just modify or patch up these monstrosities" (p. 6), and "it can be argued, on the basis of history, that large institutions may be temporarily reformed from time to time , but that such places tend to revert to their ideal type, namely that of the total institution" (Tizard, 1972, p. 15). In spite of many pessimistic viewpoints it is most likely that finances will not permit "instant community services" no matter how desirable these might be, and that institutions, with considerable changes in attitudes and practices, could contribute substantially more to the development and advancement of their residents. After all, what makes an institution is not simply buildings or numbers of people but the philosophy prevailing within it.

Obstacles to institutional change

There are many obstacles to institutional change, one of the most important being the fact that most institutions are run in terms of a "medical model", presumably suited to the care of the sick but certainly not for the lifelong development of mentally retarded persons. Gunzburg (1973) points out that "typical institutional practices persist because they are part of a "hospital myth" where the environment has to conform to a particular verbal concept -- hospital -- irrespective of the actual needs" (p. 49). The use of this model affects all aspects of institutional life, for example, obsession with cleanliness, regimentation and ward administration,

staff in uniform, little possibility of spontaneous action, and interactions which are often less than human. A recent study (McCormick, Balla & Zigler, 1975) found that care practices in Scandinavia were more resident oriented than in America and attributed this in a large part to the differences in training of personnel. In Scandinavia a three year child development course must be completed and very few units are supervised by nurses. In Sweden only 5,8% of mentally retarded people are cared for in the special facilities of a hopital based on the medical model (Grunewald, 1974). King, Raynes and Tizard (1971, cited in McCormick et al., 1975) concluded that living units staffed by people trained in child care were more resident oriented than those whose staff were untrained or who were nurses. These studies indicate that a specific type of training for institutional personnel could have a direct effect on the resident care practices employed and that specific training as a nurse is not required. Many people who advocate reforms in the care of the retarded clamour for more money and staff to be allocated, but these studies also provided empirical evidence that the amount of money spent, the number of aides per resident, and the number of professional staff cannot predict resident care practices. Increasing expenses and personnel does not guarantee a better quality of life for residents; it is the underlying attitudes of staff and their daily interactions with residents which differentiate between an "institution" and a "communal home".

Possible re-organisation

Changes in institutions need to be made at a number of levels if they are to fulfill a new role as special training environments for normal living. The methods of administration need to be reformed and authority delegated. Ideally, the institution could be divided into a number of semi-autonomous units with staff having far greater responsibility for planning and organisation, as well as the day to day running of the unit. Institutional personnel could be given the responsibility

(under some type of supervision) of preparing a person for discharge or of maximising his potential for normal living, without having to leave it to the "expert" or expecting it to be achieved by the resident attending some form of training programme twice a week. Staff could have a far greater "stake" in their residents' welfare but this would mean that movement of staff from place to place would have to be drastically reduced. These innovations would need a greater flexibility in management practices and also wholesale "normalization" of institutional wards. Without certain concrete changes, such as lockers for private possessions and private toilet facilities, any attempts at training for normal living would be doomed, or at least extremely difficult. Each informal learning situation could be deliberately programmed and manipulated so that the residents could practise normal living skills in as many situations as possible. However, none of these changes is possible if the staff still consider the residents to be "patients" or the institution to be an "institution" instead of a special training environment.

The institution and the community

The institution could also drastically alter its relationship with the community and assume a role of leadership in the development of community treatment alternatives for the retarded. It could provide educational programmes as models for the same services in the community, training for community personnel and in many ways provide an impetus for community services. Research could be an integral part of the institution, increasing contact with neighbouring universities and establishments for higher education and in all ways assisting in the training of students in many disciplines. The result would be two-fold: greater contact with the community for the institution and its residents, and a new generation of professionals in many areas having knowledge and experience of mental retardation.

These are just some of the ways in which an institution could improve its tarnished image and assume a new role in the care and training of the mentally retarded. "There is no doubt that an institutional framework has the potential for giving the subnormal person the essential training for normal life, and even though we have misused this tool in the past, the tool itself is more pliable than tradition and practice have allowed so far" (Gunzburg, 1973, p. 59).

CHAPTER FOUR

PREPARATION FOR DISCHARGE

As mentioned briefly in Chapter One, the 1960's were notable for the rise of a systematic policy of deinstitutionalization. This involved a revival of the philosophy of habilitation which had first appeared in the mid-nineteenth century. Rosen, Clark and Kivitz (1977) define habilitation as "a process by which professional services are utilized to help a disabled individual make maximum use of his capacities in order that he might learn to function more effectively" (p. 3). "Habilitation" would seem to be a more appropriate term than the more commonly used "rehabilitation", as rehabilitation implies the restoration of the individual to some earlier level of functioning. In the case of the mentally retarded habilitation is normally to levels of functioning never previously attained.

The achievement of habilitation goals necessitates the establishment of systematic and effective training programmes at all levels. This chapter is concerned with pre-discharge training programmes in an institutional setting, specifically for the habilitation of mentally retarded adults so that if possible they can live independent or partially independent lives in the community. Vocational training and training for the more severely retarded will not be discussed. It must be emphasised that, no matter how comprehensive the curriculum of a training programme, it will have great difficulty in meeting its objectives if the total environment in which the retarded resident lives is not conceived of as a total habilitation environment, i.e. if it is not normalised and normalising, as has been mentioned in the previous chapter.

The participant in the training programme must have at least some minimum opportunities for practising and reinforcing the skills that he is learning.

Principles of Training Programmes

The developmental model

The establishment of any kind of training programme is the logical consequence of the application of the "developmental model" to the mentally retarded. This assumes that a) every person is capable of learning and development, b) human beings develop in a sequential and predictable way, c) the rate and direction of development can be influenced by systematic training, and d) certain conditions must be met for training to be maximally effective (Crosby, 1976). These principles can be applied when considering training for any level of retardation. However, individual rates of development differ, so the goals that should be set for an individual depend on the developmental level that he has already acquired and his specific developmental needs. This means that developmental programmes should be tailored to the individual as far as possible.

Objectives

As well as the application of the developmental model, there are certain principles applicable to all training programmes which, if adhered to, can contribute greatly to the success of any programme. Specific objectives must be expressed in behavioural terms so that all observers can understand the objectives and agree on whether or not they have been achieved. Too often objectives are expressed in unclear terms, for example, "to reduce disruptive behaviour", "to improve manual dexterity", and are therefore impossible to measure. This often results in the staff responsible for training becoming discouraged because progress cannot be measured, whereas if

objectives were stated in clear behavioural terms such as, "is able to pull off his socks", progress could be clearly observed.

Objectives for a programme must be ordered so as to reflect sequential and progressive development with new objectives being built on earlier ones. Objectives should be short range, with each contributing to the achievement of long term goals. In addition to providing measurable objectives, each training programme must include a clear description of the methods to be used to achieve them so that all staff implement the programme in a consistent fashion and so it can be evaluated or modified if necessary.

Assessment

Before any training can begin it is essential that the current status of the resident and the next level to which his development is to be facilitated is determined. This requires the use of one or more of the scales of adaptive behaviour covering the areas that are appropriate for the individual. The aim of assessment is not to predict how well a resident will do but to determine whether the centre can build a programme suited to his needs. Unfortunately IQ tests are still routinely administered at most institutions and these are of very little help in planning a training programme. There is still a great emphasis on the "labelling" function of testing and assessment instead of a realisation of its great value in terms of planning programmes to aid future development. To be most useful, the behaviours or skills measured by the scale should be broken down into small steps and these steps arranged in developmental sequence or order of difficulty. The scale should ideally be suitable for administration by ward personnel rather than specially trained professionals but, although the scale may be scored by the ward staff, a psychologist's evaluation is essential in describing the individual's current developmental status in terms of specific behaviours and skills, indicating what

skills should next be acquired, and suggesting methods for attaining those objectives. Assessments should not be a once and for all occurrence but used at regular intervals to monitor progress and re-assess goals.

Pre-discharge Programme Curriculum

Gunzburg (1968, cited in Faulkner, 1979) maintains that the aim of a pre-discharge programme should be to achieve a minimum of occupational, social and personal competence which will enable adjustment to community demands on varying levels. Programmes should be designed for the acquisition of functional skills which will be transferable to community situations, enabling the handicapped person to be more effective and competent in his living and working environment.

Practical skills

Education and training of the retarded should be practical and realistic and focus on all areas of daily living. There is general agreement in the literature on what should be included in a pre-discharge curriculum but there appears to be very little empirical evidence to support it. Faulkner (1979) considers that training should take place in the following skill areas: vocational, social-academic, residential and home living, recreational and leisure, physical care, personal development, and social competence. Comprehensive pre-discharge training has been seen as the combination of various "service areas" (Wilkie, Kivitz, Clark, Byer & Cohen, 1968) -- pre-industrial training experience, specific trade training, counselling and guidance, community work programmes (the resident living in the institution but working "outside") and adult education for community living. An institution able to offer all these services would be fortunate indeed and most appear to concentrate on training for daily living. Wilkie et al.(1968) consider the following areas of social

functioning to be critical in community adjustment: social sight vocabulary, the use of money, measurement, time, the use of the post office and bank, the use of the newspaper, completion of job application forms, use of the telephone, and public transport. Competence in these areas would appear to represent a minimum level of community functioning but would certainly not guarantee successful adjustment.

Social skills

Follow up research on those discharged into the community (to be discussed in detail in the following chapter) has indicated that it is not intellectual level or vocational skills which prevent successful adjustment in the community but rather social and emotional factors. Zisfein and Rosen (1973) feel that this is understandable considering the relative lack of clarity about the social, emotional, and personality needs and training procedures, compared with specific job skills, and relevant training in these areas is far more difficult to achieve. It must be remembered that once an individual has been institutionalized he is handicapped for other reasons apart from his intellectual deficits: he has been denied normal community living experiences, and the institution itself forces the learning of institutionally adaptive but community maladaptive behaviours which can often interfere with the goals of a training programme. Although personality and social deficits are more difficult to change, their amelioration must be part of the training programme, either in specific social skills training or dealt with when appropriate within the training programme in general.

The importance of research

Ideally, findings from follow up studies of those discharged into the community should be integrated into the training programme, but all too often this is not the case and the curriculum is a "hit and miss" affair. Gelman (1970) describes a programme where students were responsible for taking out a resident into the

community and reporting on their behavioural deficits. The main problems encountered were: inability to make a decision when given several alternatives, inability to handle a restaurant menu, difficulty in making small talk, inability to respond to questions about interests, difficulty in pinpointing future goals, distortion and boasting about past exploits, need for structure and to be told what to do, lack of self confidence (for example, reluctance to pay a cashier or operate lifts), and perfect manners which were sometimes over done. This type of information is invaluable and allowed those planning the training programme to adapt their activities accordingly. Often specific deficits will not be revealed until the resident is actually in the community, so as much community contact and experience as possible is a pre-requisite for a successful programme.

Thus, the curriculum of a pre-discharge training programme must contain training in all the practical elements for independent living but, even more importantly, attention must be given to counteracting the effects of institutionalization by the learning of appropriate social skills and planned community exposure. To achieve this the programme cannot be rigid but must be sufficiently flexible and adaptable to meet the needs of the participants as they are revealed.

Methods of Training

Groups

Initially it might be thought that giving a resident individual attention would be the best way of achieving training objectives. This may be the case when teaching concrete skills, such as calculating change, but, apart from the fact that institutions in general are too large for this to be feasible, group techniques have been found to be more suitable for improving social deficits and personal relationships (Boruchow

& Esplanade, 1976; Zisfein & Rosen, 1973). A skilled trainer can use the group to improve and change an individual's behaviour even if the group happens to be learning to prepare a meal or use a telephone. Improvement in social functioning should be a continuous process throughout the programme (ideally within the institutional environment too) and not just during the hour which the timetable indicates is reserved for social skills training. Having established that pre-discharge training will usually take place in groups it is necessary to indicate some of the methods by which skills could be taught.

Concrete experience

"Generally speaking people learn best through concrete experiences. Therefore, any opportunity for the teacher of the mentally retarded to change an abstract idea into a concrete experience should be taken" (Sniff, 1973, p. 3). This should be the "golden rule" for the teaching of as many skills as possible. It requires considerably more effort on the part of the trainer and the allocation of more money and resources but results will be achieved far more quickly and with far more generalizability than if teaching is limited to a "classroom type" of procedure. Almost all of the required skills can be taught in a concrete fashion -- actual money must always be used, real meals prepared, actual use made of public transport and other facilities, articles bought from shops etc. Boruchow and Espenshade (1976) even mention the use of more advanced residents to teach those less skilled, particularly in the use of public transport. This idea may have its drawbacks but it is still essential for residents to be given greater responsibility and to be encouraged to venture into the community unsupervised while participating in the training programme. Extra-institutional activities without supervision imply trust on the part of those in authority (Fitzpatrick, 1956) and are essential if self confidence is to be fostered. It also allows problems to be pinpointed, difficulties to be discussed, further practice if required then fresh attempts made. These

principles have been found to stimulate the learning of concrete skills, but the specific teaching of social skills is much more controversial and problematic. The two methods most often attempted are modelling and role play (also known as behaviour rehearsal).

Modelling

> Modelling procedures, particularly as utilized in laboratory contexts, have been consistently demonstrated to be an effective, reliable and, relative to other learning procedures, rapid technique for both the development of new responses and the strengthening or weakening of previously acquired responses. Yet in spite of the sheer number, diversity and robustness of such successful demonstrations of the modelling interventions, their systematic use and evaluation in clinical contexts has been minimal (Goldstein, Martens, Hubben, Belle, Schaaf, Wiersma, & Goedhart, 1973, p. 31).

Laboratory research has indicated that modelling takes place most often when the model is of high status, powerful, competent, of the same age and sex as the observer, and when the model is rewarded for his actions (Bandura, 1965; Burstein, Stotland & Zander, 1961; Grusec & Mischel, 1966; Meichenbaum, 1971). Goldstein et al. (1973) found that modelling did increase independent responses from psychiatric patients and it would seem that this method could be of considerable value in the training of the retarded. However, results in the use of modelling with retardates has been mixed. Fechter (1971), investigating whether behaviours towards a doll shown on a videotape would be modelled, found that specific behaviours were not modelled but rather the mood shown on the screen appeared to produce a similar mood in the viewers, but this was also differentially related to differences in

personality. Gibson, Lawrence and Nelson (1976) found that the most effective training procedure for retarded subjects comprised modelling, instructions, and feedback and that modelling alone was the least effective procedure.

It would seem that for subjects of average intelligence modelling is an effective procedure but, in training the retarded, modelling combined with instructions and feedback appears to be necessary. As Bandura (1970, cited in Kazdin, 1974) has pointed out, modelling refers to the cognitive and representational processes which guide behaviour rather than the mode through which modelling information is transmitted, and in the case of the retarded it would seem logical that their cognitive and representational processes would be assisted with instructions and feedback. A number of studies point out the value of using normal models on videotape as a method of instruction in social skills and it would appear that this aid to training could be extremely valuable.

Role play

Role play has been used extensively in behavioural research and the treatment of interpersonal dysfunction but its validity is surprisingly unclear (Bellack, 1978). The lack of research into "one of the most promising, yet least studied, of the available behaviour therapy approaches" (McFall, 1970, p. 295) can be attributed to a number of factors: it is complex, unsystematic and unstandardized compared with other techniques; it is typically applied to classes of behaviour which are not sufficiently specific; and it is difficult to obtain reliable and objective measures of the behaviours treated. In spite of this, a number of studies have shown improvements after treatment in various types of subjects, usually with reference to assertive behaviour and, since this is considered to be a noticable deficit in the mentally retarded, this method would appear to have potential for social skills training.

Ideally, in vivo observation is presumed to be the best method for obtaining information about a person's social functioning but in many instances this is either uneconomical or impractical. The alternative is to use analog situations which are assumed will elicit responses that are parallel to the in vivo behaviour. Persons with social deficiencies are given direct training in more efficient and effective alternative behaviours, mainly through the use of response rehearsal, modelling and therapist coaching. However, this procedure makes a number of assumptions which have not been empirically verified. It is not certain whether people respond to the simulated interactions in the same way as they would respond in a natural setting and results showing improvement after treatment have often only measured this improvement in simulated settings. For improved functioning to be shown it must be demonstrated that specific in vivo changes have occurred and that these behaviours can be generalized to a number of different situations. Assessment of outcome should place a greater emphasis on response patterns rather than individual components of behaviour. Change in individual components only might not result in improved functioning if the critical combinations of stimuli are not present.

It also cannot be assumed that all persons can role play effectively, i.e. behave in a natural manner. Affleck (1975) has pointed out the importance of social cognition in the interpersonal behavioural repertoires of the retarded. Role taking necessitates the ability to recognise and co-ordinate the perspectives of self and other during social interactions, and Affleck considers that there is a direct association between role taking ability and social competence. This has direct relevance for the use of role play techniques with the mentally retarded. It could be assumed that mentally retarded persons would find role playing even more difficult than a person of average intelligence and more difficult to act "naturally" in a simulated situation which they have to imagine. Bellack (1978) criticises role play techniques on the grounds that they narrow the person's focus and limit the range of alternative

responses. In the natural environment the person must attend to a much broader range of interpersonal cues, has many more alternative responses, and must consider the potential consequences of his actions.

Modelling and role play are just two methods which can be considered for improving the social skills deficits of the mentally reatrded. Both have drawbacks and neither can be an effective substitute for real life encounters. It would seem that the most useful approach would be a combination of all methods. Residents could be given opportunities for interaction in the community, these could be discretely observed, discussed in a role play session, alternatives suggested, modelled and practised, and then the resident given further opportunities for the use and practice of new behaviours. Training procedures must be flexible and much depends on the individual responsible for the training. It is an area in which there is a dearth of relevant research so the trainer need not be hesitant about trying different methods and choosing the combination which seems to be most effective. However, a note of caution is sounded by Stacy, Doleys and Malcolm (1979) who point out that training retarded adults to be more assertive in the community is not without its dangers. Mentally retarded persons generally experience difficulty in discrimination tasks, and so it is possible that the acquisition of assertive behaviour may be over generalized and misapplied, to the disadvantage of the individual. Thus training must include discrimination in the application of new social skills, particularly assertive behaviour. In spite of this possibility, social skills training must not be ignored as absence of social skills has been found to be the main source of failure in community placement.

Difficulties in Effective Training

Evaluating the effectiveness or otherwise of a pre-discharge programme is extremely important but there are many factors which combine to make this a very difficult undertaking. Ideally, effectiveness would be assessed through detailed follow-up of those discharged and careful monitoring of their successes and failures. However, in many instances this is not practically feasible, either through lack of personnel or because those in authority are not aware of its importance. If the person responsible for pre-discharge training does not have access to this kind of research he/she must be even more aware of the obstacles to be found within the institution itself which can interfere with the eventual outcome of training.

Staff

Wilkie et al. (1968), describing the development of a habilitation programme within an institution, found three distinct categories of staff: 1) those amenable to programme alteration and direction, 2) those who through direction could be assisted in modifying their approach to support and contribute to the new programmes, and 3) those who were so rigid in their concepts that they were unable to adjust to the proposed changes. It would seem that this is likely to be the case in all institutions and that the objectives of a pre-discharge programme could be subtly sabotaged by certain kinds of staff. There may be very little to be done about this, but it is essential that the trainer be aware of possible resistance and the possibility of "lip service" to preparation for discharge instead of whole hearted conviction. Certain kinds of staff will make the trainer's job more difficult in that they prevent the institution itself from operating as a total habilitation environment.

Those in authority and those responsible for finance also need to have a conviction as to the value of pre-discharge programmes. There is a limit to what the trainer can do without adequate facilities or resources and these will be diverted to other projects unless there is a commitment to the goals of the programme from those "above". Grossman and Rowitz (1974) point out that many services compete for available money and that the demand for the accountability of the programmes usually comes from external sources who are concerned about costs. Unless the pre-discharge programme has a "champion" at high level it may be difficult to obtain the necessary funding.

Characteristics of the trainees

When selecting residents to participate in a pre-discharge programme a number of factors must be bourne in mind. One of the most difficult is that a person who is rated low within the institution may be successful outside it (Fitzpatrick, 1956) and vice versa. Good institutional behaviour does not guarantee effective behaviour in the community. Crnic and Pym (1979) found that the resident's motivation to work towards independent living as a goal was the most important factor. Behavioural skills were necessary but not sufficient to ensure a successful transition. Often those selected for training are those considered to be more intelligent than others but this is not necessarily the most important variable.

It is not always possible to determine in which skills the resident needs most training until he/she is living in the community. It is often the case that residents can acquire and perform skills while under supervision but are unable or unmotivated to perform the same skills without supervision. Zisfein and Rosen (1974) found that, although their trainees knew the right things to say about signing a document or lending money, only a few minutes later all of them signed a document and over

half offered money. This can be extremely disappointing and supports the need for "trial discharges" or half way houses where it can be seen how the resident will behave when unsupervised.

Other psychological factors, in addition to motivation, can have a tremendous effect on the effectiveness of training. Residents often become anxious and frightened when the time for discharge draws near and this can result in regression to pre-training levels of behaviour (Crnic & Pym, 1979). It is essential to realise that this is normal, since by being discharged the resident may well lose most of his friends. If the move was gradual, possibly with the resident working outside the institution first, then severe anxiety would be less likely to occur. If it does occur it can usually be overcome with individual counselling and support.

Assessment of progress

It is often very easy for the trainer who works with the residents every day to see progress in a fairly short space of time, but unfortunately this is not sufficient when programmes have to be justified in terms of money and resources allocated. Ideally, objective measures of progress should be used to demonstrate that the programme is effective, and to provide, where possible, detailed follow-up of those discharged.

Some assessments of behavioural skills are available; for example, the Independent Living Screening Test (Schalock, 1975, cited in Crnic & Pym, 1979), and the Progress Assessment Charts by Gunzburg. An assessment of this type should be administered before a resident begins the programme and at regular intervals throughout. However, assessment of social skills and personality traits is much more difficult as adequate precision in measurement remains to be devéloped. Zisfein and Rosen (1974), in evaluating the effects of a personal adjustment training

programme designed to improve the traits postulated to comprise the "institutional personality" found that, in spite of clinical impressions and anecdotal reports, change could not be measured with objective indices when the residents exposed to the programme were compared with a control group. They attributed this to the insufficient sensitivity and unreliability of the specific measures employed, and advocated evaluation based on demonstrable behavioural change. It would appear, in the light of present deficiencies in the assesssment of social functioning, that this is the only feasible method. Assessment of progress in this area would have to take the form of observation of the individual's behavioiur in specific concrete situations. Behaviour in contrived settings is not necessarily an accurate reflection of behaviour in the "real world".

Transitional Facilities

The gap between institutional living and independent living is very wide indeed, and no matter how thorough and comprehensive the pre-discharge training it cannot be a substitute for real life experience. To give the individual every chance to eventually adjust to independent living, some kind of transitional living arrangements are required.

Half way houses

The idea of a half way house is to provide a transitional living situation between a more structured situation, like an institution, and more independent livin g. However, as Pankratz (1975) points out, it must be more than merely a living situation away from the institution; it must also be half way in terms of vocational adjustment, social living and psychological support. Ideally it would be supportive only insofar as the resident needed assistance and would gradually encourage more

self determination. The psychological and social environment in a half way house is more important than the physical environment and there have been investigations which showed that these facilities can become "mini-institutions". Apte (1968, cited in Pankratz, 1975) found that 15 out of 25 "transitional hostels" for the mentally ill had a more restricitve social environment than the least restrictive hospital ward.

Continued training

The biggest gap in training in the institution is practical experience, and in a half way house exposure to and experience dealing with everyday problems could enable many persons to gain further independence. However, exposure alone is not training, and may be of little value without guidance and feedback. It is necessary for experience to be gained in a series of carefully graded steps and utilized for training purposes. Mulvihill (1978) maintains that this necessitates setting up training situations which include an element of calculated risk, presenting a real challenge to the trainer. Perske (1972, cited in Kokaska, 1974) contends that denying an individual exposure to normal risks commensurate with his level of functioning delays the development of responsibility. A positive self concept cannot thrive under conditions which by their very nature and structure convey the covert message that a person is incapable.

If training is not continued in the half way house, there is a real possibility that the residents will not move towards greater independence. In a study using the AAMD Adaptive Behaviour Scale with persons who had lived in a transitional facility for six months Aninger and Bolinsky (1977) found no increase in independent behaviours as measured by the scale and only one of the subjects expressed any desire to live independently.

There are many different ways in which a half way house for the retarded could be staffed and managed. Collins and Rodman (1974) outline a scheme whereby a house contains six to eight residents and house staff of one married couple and a single person to act as relief. Staff are responsible for the operation of the house, financial management and to help the residents function independently. However, no matter what "rules and regulations" are laid down, the ability of a half way house to provide a stepping stone to greater independence and responsibility depends entirely on the attitudes and behaviour of the staff concerned.

CHAPTER FIVE

LIFE IN THE COMMUNITY

The American term "deinstitutionalization" when used with reference to the mentally retarded is generally thought of as the discharge of such persons from institutions to a more independent life in the community. However, according to Scheerenberger (1977) deinstitutionalization actually encompasses three inter-related processes -- a) prevention of admission by finding and developing alternative community methods of care and training, b) return to the community of all residents who have been prepared through habilitation programmes to function adequately in appropriate local settings and, c) the establishment and maintenance of a responsive residential environment which protects human and civil rights. It is essential that the community is prepared and has the services for those who are discharged. Too often individuals are discharged without the necessary services being available and in America this has been the main factor in the "deinstitutionalization backlash" (Payne, 1976) in public opinion, as well as causing increased difficulties for those discharged. An adequate community support structure must provide at least three types of support -- a variety of residential options; services such as day care centres, training, sheltered employment, recreation, counselling, information and referral services and transportation; and preventive and early intervention services to reduce the likelihood that a person needs to be removed from the community (Gollay, Freedman, Wyngaarden & Kurtz, 1978).

The absence of many of these services has not prevented large numbers of people from being discharged and, since Fernald's classic work in 1919, there have been

numerous studies concerning the postinstitutional placement of retarded persons. Although "the literature concerning the postinstitutional adjustment of the mentally retarded is replete with inconclusive and contradictory findings " (McCarver & Craig, 1974, p. 194), it is possible to divide the studies into three main types: 1) prognostic studies -- those done in an attempt to establish variables which would predict the success or failure of those discharged, 2) simple follow up studies -- using no prediction variables but simply finding out how the discharged persons were faring in the outside world and 3) comparative studies -- these are distinguished by some attempt to compare the retardate's achievement in the community to some other relevant group but these are relatively rare because of the question of what constitutes a suitable control group.

Prognostic Studies

Prognostic studies can either be truly predictive or, as is most often the case, retrospective. In retrospective studies data is collected at the time of follow up from available records rather than before discharge. The major interest is in determining indices available either before or during the habilitation programme which can predict some later criterion of success or failure.

Predictor variables

Although it has been recognised by most researchers that success in community placement is not the function of a single variable but rather a complex of factors, including individual differences in skill, personality, and environmental conditions, this has not prevented many discrete variables from being evaluated. The variables to which investigators have most often directed their attention fall into three main groups -- 1) formal test measures, such as intellectual functioning, sensory and

motor characteristics, and personality; 2) factors relating to background history, including school training and work histories, personal characteristics, familial and community environment, and residential history; 3) ratings of observed behaviour, including work samples and general behaviour samples. Within these broad classifications hundreds of variables have been recorded and many have shown some relationship to some criterion variable under some set of conditions but there is still no systematic organisation of data which is useful for practical applications.

Shafter (1957) examined the predictive merit of 66 characteristics drawn from the categories of family, psychological data, education, work record, pre-admission residence, and behaviour within the institution. He found 12 institutional behavioural characteristics to be useful in predicting successful placement. Krishel (1959) investigated 15 variables related to the institutional period of the educable retarded child and related three to success in community placement. Jackson and Butler (1963) attempted to predict community success from age, intelligence, academic achievement, length of institutionalization, and early environmental conditions. They concluded that the major factors underlying successful community placement were age, verbal intelligence and early environment as defined by residence with parents in early childhood, and a mixed urban-rural pre-admission environment. As in the other studies, the level of prediction was not high. Rosen, Kivitz, Clark and Floor (1970) attempted to evaluate 29 variables, including measures of intelligence, perceptual-motor abilities, academic achievement, motivation, work potential, and social adjustment, as predictors of 22 criteria measures of community adjustment. It was found that tests of perceptual-motor abilities and behavioural ratings of employment potential showed the highest number of significant relationships with criteria, but these results were not validated in two further replications of the original study (Rosen, Floor & Baxter, 1972).

Problems in prognostic studies

Many factors contribute to the limited reliability and generalizability of the predictive studies in spite of their number. There is a great diversity in the types of variables that have been evaluated in any single study and this, together with the different methods of statistical analysis applied, makes it impossible for any definite conclusions to be drawn.

Many of the studies purporting to show relationships of predictors to criterion variables have treated prediction in a systematic rather than a historical frame of reference, and measured predictors and criteria within the same time period on a given sample rather than over a time interval. Cobb (1972) illustrates the unsatisfactory nature of this kind of study by citing the work of Stephens (1964) who obtained a set of "predictor" factors for subjects whose training and job placement had already occurred, and then concluded, on the basis of the results, that the particular battery of tests could be used to screen candidates for habilitation. This assumptioin is unwarranted without validation over time and across training, but unfortunately is typical of many studies in the literature. In general, the comparison of test and other data between groups whose success or failure has already been established does not constitute a reliable guide to the selection of those who will subsequently succeed.

It is also impossible to compare the results of different studies when there is no uniformity in the selection of criteria, particularly in the definition of what constitutes successful adjustment. According to Cobb (1972), terms such as "success" or "failure" are meaningless unless the referent variables are specified, and with sufficient clarity so as not to be ambiguous. If prediction research is to continue it must attempt to sort out the many possible criteria for success or failure in social adjustment, define them operationally in terms of appropriate methods of

measurement, establish the empirical relationship among them and relate these clusters of normative behaviour to specific social environments. It must be determined what kinds of success, in what kinds of social situations is being investigated. According to Rosen (1967), however, without behavioural norms for persons discharged from institutions the level of adjustment cannot be evaluated. Until a better understanding of the meaning of adequate or poor adjustment has been developed, predictive studies will be limited by a vague and ambiguous criterion.

The problems in prognostic studies are further complicated because of the questionable stability of the predictor measures over time and the effects of any intervening experience which is bound to occur. Cobb (1972) concludes that "the absence of longitudinal studies relating predictive measures to coherent theories of development makes most of the attempts at scientific prediction of the status of the retarded of dubious value" (p. 13).

Follow Up Studies

Tizard (1974) maintains that longitudinal studies of the mentally retarded cannot be interpreted unless they take into account a number of factors -- a) biological differences between retardates functioning at a higher level compared with those at the lower levels, b) differences between "pathological", "clinical" or "organic" retardates on the one hand and "aclincal", "endogenous" or "subcultural" retardates on the other, c) the distinction beteen low intelligence and mental retardation, d) the epidemiology of mental handicap, in particular the systematic biases which result when generalizations from data relating to samples of diagnosed or "ascertained" cases of retardation are applied to retarded persons not so ascertained. Although studies carried out since 1919 have become more

sophisticated, there are no studies which take all these factors into account and, according to Esgrow (1978), "we seem to have as many definitions for follow up as Eskimos have for snow" (p. 7). In spite of this, the most consistent finding of all follow up studies is that a high proportion of retarded adults achieve satisfactory adjustment by whatever criteria are employed.

Early studies

Fernald's study of 646 persons who escaped or were discharged from Waverley School from 1890-1914 was the first significant follow up study. It was a landmark in that it undertook to study the characteristics of both males and females who made successful adjustment with those who did not, thus establishing a methodology which was to become increasingly popular. Fernald's main finding was that the chief difference was in the amount of supervision and support provided by family and friends.

Although the early studies had many flaws and limitations, the prevailing negative opinions at the beginning of the century were such that little support could be obtained for any type of pre-discharge training or for the research that could prove it to be necessary. The first step was to establish that the retarded could succeed in community life at all. It was not until the manpower demands of World War II provided demonstrations of the employability and success of retardates in the community that this view gained some acceptance.

Reasons for failure

Follow up studies of many different kinds have been conducted in recent years. Eagle (1967) summarised the studies of the previous 25 years and this yielded a sample of 7436 with an overall failure rate of 39,6%. In the period 1960-1965, of the 1830 placements reported in the literature, 52% were classified as failures.

Shafter (1954, cited in Eagle, 1967) expresses great concern about this high rate of failure and the fact that most studies seem to gloss over it. "Most articles would have one believe that all is wonderful, no problems arise and that patients live happily ever after . . . Such a picture is not only unrealistic but dangerous. Honest research cannot be carried on, and then the lay public starts to expect miracles of complete and perfect rehabilitation" (p. 233). A study of the literature would appear to support Shafter's concern. There are extremely few attempts to utilize the information gained in follow up studies to improve pre-discharge training and thus decrease the failure rate.

A number of studies outline the reasons for failure but most do not indicate how this could be averted. Moen, Bogen and Aanes (1975) found that the most common reasons for return to the institution were aggressive behaviours and inappropriate personal habits. Taylor (1976) found that the reasons for failure in group homes were untrustworthy behaviour, poor money management, poor number and time concepts, and hyperactive tendencies. Schalock and Harper (1978) found the reasons for return to be inappropriate behaviour and the need for additional training. Windle, Stewart and Brown (1961), in a review of previous studies of the failure of discharged residents, maintain that the differences in studies are related to the variations in types of persons and leave conditions studied and that there can be no consistency in findings until at least these gross factors are controlled. Different processes operate in the different kinds of leave placements to produce failure. Although Windle et al. made these observations in 1961, more recent studies show no improvement and the same inconsistencies apply.

What Constitutes Successful Adjustment?

The definition of what constitutes "success" in community placement is an extremely complex issue and thwarts any attempt to combine information from different studies into a meaningful whole. Many investigators have construed "success" or "failure" in terms of dichotomised variables, such as returning to the institution, having employment, being married, showing no criminal behaviour, and lack of illness. If these criteria are used, then studies over the past fifty years have indicated that a high proportion of those identified as mildly retarded "disappear" into the general population and are "successful". However, "to regard the return to the community as 'success' and placement in a hospital or institution as 'failure' leads to the reactionary and absurd conclusion that the fewer beds there are available for the mentally disordered the better a country's health service" (Tizard, 1974, p. 239).

Societal demands

Success in the community is closely related to society's tolerance and expectations, and in modern society demands are continually rising. Skaarbrevik (1971), in a follow up study of those discharged from vocational training schools in Norway, points out that technological development has decreased the opportunities for retarded people to find work which they can accomplish and thereby earn their own living. In addition, the urbanization of society makes social life more difficult, thus hampering the interaction of retarded persons. He takes the uncommon view that the solution of such problems is as much political as academic since approaches supporting the "illness" concept of retardation have diverted attention from a discussion of mild retardation being a result of changes in societal demands. At the mild level, the effects of mental retardation are also highly confounded with the effects of social class, cultural deprivation and socio-economic pressures. The

relative contributions of constitutional, as opposed to environmental, factors to success and failure are unknown.

Middle class bias

Apart from the dichotomised variables mentioned previously, there have been other attempts to define "success". However, without exception, these have all been by the researcher himself or by people who would normally be classified as middle class. One of the few studies recognising the multivariate nature of success (Stephens, Peck & Veldman, 1968) used as criteria the judgments of ten expert workers in the field of mental retardation and from these selected 80 variables as measures of success. Subjecting these variables to factor analysis did not produce neat contextual groupings, rather they were highly inter-related and not always in positive ways, thus indicating that success is indeed a highly complex process. Other studies have used a "critical incident" technique for reporting on community success or participation but again the ratings of what constitutes a "critical incident" have always been from the perspective of the investigator or some other person in authority (Goroff, 1967; Nihira & Nihira, 1975a; Nihira & Nihira, 1975b). Most professionals may well have a middle class bias and implicitly expect retarded persons to attain certain levels of behaviour even though many of the working class population do not.

Rating scales, usually devised by a particular investigator, have also been used to rate those discharged on many variables. They are problematic in their degree of reliability, the possible influence of halo-effects, the discrepancies when ratings are made by those experienced in working with the retarded and those inexperienced (Bower & Switzer, 1962, cited in Cobb, 1972), as well as the same problem of the "judgments" being from the observer's rather than the retarded person's point of view.

Wolfson (1970) maintains that it is time for workers with the retarded "to relinquish the paternalistic and sometimes omnipotent attitude and cease to demand conformity to a rigid pattern of behaviour from those under their care" (p. 23). Edgerton (1974) makes mention of the apparent requirement of super-normality before being allowed to be ordinarily normal. There is a widespread tendency on the part of "normal" persons to construe the everyday problems of retarded persons as "problems of retarded persons" instead of ordinary every day problems. Such labelling can set in motion a self fulfilling prophecy such that the retarded person in the community may see himself as a failure with reference to some particular criteria yet feel successful within himself. Edgerton (1974) points out that retarded people can develop a situationally specific definition of self, i.e. retarded behaviour in the presence of social workers, etc. and coping behaviour when unsupervised. The incompetence of retardates varies with time and place so a person's degree of "success" cannot be evaluated without a knowledge of change and circumstance. A person may succeed in one area of life and not in others and this is likely to change the longer he is in the community.

Community Life from the Retardate's Point of View

In the hundreds of studies which have been conducted on the postinstitutional placement of those discharged into the community, almost none have been concerned with what the retarded people themselves have thought and felt about their lives. An exception to this is Edgerton's study (1967) in which 48 discharged persons were contacted and, through participant observation and indirect interviews averaging 17 hours per person, information was collected regarding the quality of the residential environment, aspects of making a living, sex, marriage, use of leisure time, reliance on benefactors and concern with stigma.

Stigma

The results of this study provide a fascinating account of life in the community from the retarded person's viewpoint. There are too many findings to report in detail here but mention must be made of the importance of "passing" for Edgerton's subjects. Their lives were devoted to "passing" as normal and denying that they were retarded. None of them felt that they should have been in an institution at all and made various excuses for why they had been there in the first place. An admission of mental retardation was totally unacceptable but, according to Edgerton, the masquerade was only able to continue through the connivance of normal persons. In fact Edgerton judged that "in general, the ex-patient succeeds in his efforts to sustain a life in the community only as well as he succeeds in locating and holding a benefactor" (1967, p. 204).

All the discharged persons reported a period of "release shock" and also difficulties in reading, writing, use of numbers and money management. They also found it difficult to find jobs because of the need to lie about their past but the need to work was extremely important -- "I've just got to get a job like other people" (Edgerton, 1967, p. 65). Marriage and finding a mate were also considered normalizing events.

None of the persons interviewed considered themselves a failure no matter how desperate their life circumstances and none had any desire to return to the institution. However, Edgerton concluded by emphasising the finding that these persons owed the success of their adjustment more to the availability of non-retarded benefactors than to any measurable skill, attitude, training or experience. (It is of interest that this finding is similar to that of Fernald's study in 1919.)

The passage of time

Edgerton and Berovici (1976) then compared the circumstances of 30 of the original 48 persons 12 years later to examine what effect the passage of a considerable length of time had had on their adaptation and to attempt to predict who among the original 48 would have improved, remained static or deteriorated in their community adjustment. These predictions were found to be correct for less than half the sample and when correct it was often for the wrong reason. This illustrates the difficulties involved in predicting community adjustment (even when the original cohort had already been in the community for an average of six years) and that the most confident predictions were often wrong.

It was found that the lives of the majority of the 30 persons had been characterised by major fluctuations, even more extreme than those experienced by "normal" persons (although longitudinal studies with a suitable control population have not yet been carried out) and that this instability had not lessened with time. Edgerton and Berovici attribute this to the fact that people who have been institutionalized have so few reliable resources that can stabilize them in times of crisis that the loss of a job or a benefactor can precipitate a major change in their level of adaptation. It appeared that the retarded persons had only a tenuous control over their life circumstances compared with persons who can control some essential aspects of their lives through job security, savings and networks of friends.

In this second follow up study only five persons gave any indication that the issue of passing and stigma was still a major concern, thus indicating that however deleterious labelling may be, its effects are not permanent. Also in 1972-73 benefactors appeared to play a far less important role in all respects and it was no longer possible to say that the adaptive success of these persons was primarily a function of their ability to locate and maintain benefactors. This may have been

brought about by a lesser need for benefactors or by a lesser availability of them but it is also possible that another 12 years of experience in the community had reduced the need for assistance in every day problems.

Changes were also reflected in the need to work which had been very strong in 1960-61. Money was still considered very important but work had been relegated to an instrumental role and was no longer character defining as previously. Those receiving welfare payments expressed no eagerness to return to work.

According to Edgerton and Berovici (1976) what dominated the retarded persons' lives in 1972-73 was a vital interest in enjoying life -- recreation, hobbies, leisure, friends and family, not work, stigma or "passing", and most people said that they were as happy or happier than 12 years earlier. Happiness was not found to be a function of employment or even of material circumstances.

Success

Edgerton based his evaluation of success on the two basic criteria of competence and independence but in attempting to ascertain how the 30 people in the follow up study assessed their own adaptation a very different view emerged. Confidence appeared to be more important than competence and a subjective sense of well being more important than independence. Persons whom the interviewers had considered to be unchanged since 1960-61 said that they were happier and the specific reasons why a person considered his life to be happier or not were extremely diverse.

Edgerton's studies were discussed at length because they appear to represent an essential type of research which is all too rare in the present literature and they point out conclusively how complex research in this area is. Researchers have relied on "experts" to define adequate adjustment or "success" but it appears that

persons who have been institutionalized develop their own collective and individual views on what constitutes success. Workers have been concerned with helping "them" to live in accordance with "our" standards but "whose assessment of success shall we value most, ours or theirs?" (Edgerton & Berovici, 1976, p. 496). Almost nothing is known about the retarded person's evaluation of his own adjustment and it is time "to consider them as individuals with varied personalities and capacities for self determination, who are prone to various levels of adjustment" (Wolfson, 1970, p. 22) rather than as a collective group who must be normalized to a certain set of standards.

The discharge of retarded persons into the community without being able to reliably predict success involves a considerable amount of risk but this risk would be lessened if information from detailed studies of those already in the community were carried out and the findings incorporated into pre-discharge training. There can be no guarantee that an individual will always succeed in all aspects of community life at all times but the retarded person must be given the right to try and to fail if necessary because "without learning to deal with it (failure) they cannot take their place in society as independent and self sufficient people" (Esgrow, 1978, p. 8).

The Dilemma of Normalization

The reader will have noticed a seeming paradox in this chapter. On the one hand, the need for specialized community services to be available before the discharge of retarded persons into the community has been expressed; on the other, evidence was put forward that many retarded persons "disappear" into the general population and are "absorbed", thus specialized services would not appear to be necessary. This is an example of the dilemma of normalization.

Normalization as a principle

"The normalization principle draws together a number of lines of thought on social role, role perceptions, deviancy and stigma that have their origins in sociology and social psychology" (Granger, 1972, p. 6). It refers to a cluster of ideas, methods and experiences originating in the Scandinavian countries and which is now enjoying extreme popularity in America. In practical terms it means "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Nirje, 1969, p. 181). Wolfensberger (1972) proposes that the definition of normalization be further refined to "the utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible" (p. 28). This recognises that the normalization principle is culturally specific and Wolfensberger maintains that "normative" should have statistical connotations. As a principle it sounds ideal but it is deceptively simple and the philosophy of treating those who are "abnormal" as "normal" has aroused heated controversy.

Normalization and training

The normalization principle and training are in a sense contradictory because "normal" people do not receive intensive training, except in a few specialized areas of their choice. Normative procedures are designed for people who are normal and they may tend to stabilise the retarded in the retarded state instead of making them more normal. Skills learned easily by the normal person may be learned with difficulty or not at all by the retarded subjected to normative procedures. According to Throne (1975), if more normal lives for the retarded are indeed the ends sought, then specialized procedures are always the prescription of choice. "Regardless of etiology the developmental rates of the retarded may be speeded up through conditions that are extraordinary" (Throne, 1975, p. 23). For retarded

persons to achieve their maximum potential it is not sufficient that they are simply "exposed" to a normal environment; a far greater degree of competence will be achieved with intensive training in particular areas.

Present society

According to Schwartz (1977), "we have failed to examine the capacity of retarded persons to adapt to the pressures of this highly industrialised and competitive society" (p. 38), and the policies of normalization and deinstitutionalization have reflected "fanciful wishes rather than sound reality" (p. 38). The assessment of a retarded person's success in society has been mainly on the basis of being able to maintain himself independently and the ability to meet societal demands for social and personal responsibility. Although these are no doubt important criteria of functioning, they represent minimum levels which are not typically applied to non-retarded populations. They also do not necessarily represent "good adjustment".

Wolfensberger (1972) considers that "normative" should have statistical connotations but "doing what others are doing is not necessarily doing what is right or what gives one dignity and satisfaction" (Mesibov, 1976, p. 31). There are many things which are statistically common in our present society but which would not necessarily be construed as right. To slavishly advocate doing what others are doing precludes striving for more enduring goals and "to aspire to the anxieties, uncertainties and isolation in our rapidly changing, highly mobile society is to set one's goals unnecessarily low" (Mesibov, 1976, p. 31).

Normalization also stresses mainstreaming and integration for the elimination of apparent deviance. The mark of success is societal integration (although it has been shown that simply putting people together does not necessarily reduce hostility or

mistrust) and the congregation of mentally retarded individuals is discouraged. Rhoades and Browning (1977) ask the price of this integration and whether physical integration does not mean personal isolation. People who are perceived as deviant often seek out each other (for example, Alcoholics Annonymous and the Little People) to provide a mutual exchange of trust and empathic understanding. If normalization is carried out, opportunities for retarded persons to mix are restricted or discouraged thus perhaps denying them the opportunity of meaningful peer relationships. Schwarz (1977) maintains that "at no place have we ever given proper recognition for their need for group identification, with the possible exception of Camp Hill" (p. 39). Normalization is only possible within a setting providing security, a means of achieving self esteem, real friends and a common level of achievement, not "in a society that is basically alien and for whom the ideals are essentially unattainable" (Schwarz, 1977, p. 39).

Mental health

If one is concerned about the quality of life and a subjective sense of well being, there is a great deal which cannot be predicted from information about a person's practical life circumstances. "People living in different life circumstances express different patterns of well being and these patterns reflect the peculiar quality of the situation they live in " (Campbell,1976, p. 122).

According to Schwarz (1977), the more the retarded are confronted with the stimulation, stresses, competitiveness, and the high economic and social levels of present society, the more their defence mechanisms will be imposed upon, creating a less healthy mental state. Gunzburg (1972, cited in Rosen & Kivitz, 1973) makes mention of the specific personality deficits of the retarded:

> Do we perhaps tend to forget that the handicapped are also emotionally immature, unstable, insecure, anxious, inadequate, that they are easily disturbed, tend to vegetate, to collapse in the face of difficulty and show little confidence in their admittedly meagre abilities? . . . there is nothing to suggest that sizable and significant weaknesses in his personality make up will not still remain after transplanting him to new, more normal but also more demanding conditions (p. 64).

It is difficult to define what is meant by a well adjusted retarded person. Often criteria such as, remaining out of prison, being obedient, having employment are used, but these are only minimum criteria and are not meaningful if one is concerned with mental health. If the view is taken that "basically the personalities of mildly retarded persons differ very little from the so-called normal people" (Wolfson, 1970, p. 22), then there is no reason at all why current conceptions of mental health should not be applied to the retarded. Mesibov (1976) cites Mahoney's (1975) "cognitive ecology" as an alternative to normalization. Programmes and placements would be evaluated on the degree to which they enhance self esteem and the goal would be having positive feelings about oneself. This would represent a more enduring value structure than simply a desire to be "normal".

What is the solution to the dilemma of normalization? It is obviously desirable that retarded persons live their lives in an environment which is as "normal" as possible, but this cannot be at the expense of the intensive training required for them to reach their potential. "Normalization is not a substitute for sound criteria of personal and social adjustment" (Rosen & Kivitz, 1973, p. 64), and individual differences among retardates as well as between retarded and non-retarded populations should dictate the application of the normalization principle. With

reference to those considered suitable for discharge into the community, it is essential that training concentrate on improving self esteem and the ability to be oneself irrespective of what is statistically "normal". Recognition of the individuality of each retarded person should be the guide line: some will need supportive services all their lives whereas others will naturally merge into the mainstream of society. Integration should not be forced because of a specific government policy, rather the possibility of community life should always be available.

CHAPTER SIX

THE PRESENT STUDY: METHOD AND RESULTS

This study was undertaken to evaluate the pre-discharge training programme at present in operation at Fernhill Care & Rehabilitation Centre. This training programme and its accompanying assessment procedures (see Appendices A & B) were devised by Prof. V. M. Grover and Dr. N. S. Egnal and have been in existence for four years. The programme is commonly known as ASAT (Assessment Schedules and Adult Training) and during the last four years many residents have participated in the programme and a number have been discharged into the community. It was felt that the effectiveness, or otherwise, of the programme needed to be empirically established, both in terms of the degree of learning shown by the participants and the relevance of its content to the life circumstances of those discharged. Although, as Gunzburg (1974) indicates, "the effectiveness of such a programme can only be assessed in an 'academic' manner because the final success or failure of the programme can be evaluated only by reference to changes in the mentally subnormal's life pattern and the assistance it is able to give in non-institutional situations" (p. 247), it is still essential that objective evaluation takes place, not only to assess the residents' progress but also to highlight deficiencies in the programme itself which may not promote the development of the participants.

The programme is based on the skills outlined in the ASAT schedules and consists of training in areas of practical skills, such as cooking, self care, the use of money etc. with the addition of role play, sex education and community outings. Training is in small tutorial groups with a maximum of six participants and instruction is given by

one nursing assistant. The role play and sex education groups are given by the occupational therapist and psychometrist respectively (see Appendix A for actual timetable). Training takes place in a small room adjacent to one of the wards and at the present time a kitchen is being established in the premises of the occupational therapist, solely for the ASAT programme.

It was felt that a detailed investigation of those mentally retarded persons actually living in the community to establish areas of success and failure and to ascertain something of their "quality of life" would indicate whether in fact the ASAT schedules do contain skills relevant to community living. On the basis of the information regarding the retarded persons' actual experience in the community it would be possible to indicate whether any changes or additions to the ASAT schedules needed to be made.

Method

Subjects

All residents at Fernhill who were thought to have an IQ greater than 50, who were under 55 years old but over 19 years old and had not previously participated in the ASAT programme were ascertained. Their IQ was tested, information on age and length of institutionalization was obtained and from that sample two matched groups were drawn up. The range and mean of each group's age, IQ and length of institutionalization, as well as the correlations between the groups is shown in Table 1.

Table 1

Summary statistics for Age, IQ, and Length of Institutionalization (LOI) for Experimental and Control Groups

		Experimental Group		Control Group
Age:	range	22 - 55		23 - 55
	mean	40,44		40,94
	st. dev.	10,13		9,99
	correlation		0,91	
IQ:	range	50 - 85		50 - 82
	mean	65,75		67,06
	st. dev.	10,29		9,63
	correlation		0,93	
LOI: (years)	range	6 - 42		5 - 42
	mean	21		19,81
	st. dev.	10,88		10,65
	correlation		0,93	

The experimental group consisted of eight males and seven females and the control group five males and 10 females but no attempt was made to match the groups on sex as this was not considered to be an important variable.

Subjects for the follow up part of the study consisted of as many as could be contacted who were known to have been discharged from Fernhill and placed in the community. This resulted in a total of 12 males and 21 females. Details of their age, length of institutionalization and length of time in the community are shown in Table 2. Of those discharged, 16 had apparently had no specific pre-discharge training, five had received some training when the ASAT programme was in its early stages and 12 had participated in the ASAT programme in its present form. Considering the aims of the present research, i.e. obtaining a picture of the lives of retarded persons in the community, it was felt that these dissimilarities in pre-discharge training were not important.

Table 2

Summary statistics for Age, Length of Institutionalization (LOI) and Time in the Community for discharged residents

		Males	Females
Age:	range	28 - 49	24 - 68
	mean	39,91	43,67
	st. dev.	6,7	9,85
LOI:	range	4 - 37	6 - 55
(years)	mean	19,1	22,2
	st. dev.	10,1	14,2
Time in	range	1 - 13	1 - 12
Community:	mean	3,67	2,62
(years)	st. dev.	3,11	2,29

Tests used

IQ was assessed using the Ravens Coloured Matrices. Although this has obvious limitations it has "great value as a screening device where estimates of general visual/perceptual reasoning level are concerned" (Clark, 1974, p. 417). In terms of the number of residents that needed to be assessed at Fernhill it would not have been possible from a time point of view to administer a more comprehensive IQ test. Previous scores on residents' files were mostly out of date and generally unreliable. It is also generally accepted that standard IQ tests, particularly for retarded persons, are verbally and academically loaded, thus the Matrices "to the subnormal, are refreshingly free of verbal or 'educational' content" (Clark, 1974, p. 417). The colour element is merely a device to secure the attention of less intelligent subjects and Philips and Bannon (1968, cited in Clark, 1974) have indicated that the Coloured Matrices differentiate very well in the lower ranges of ability. Vincent and Cox (1974) found a correlation of r = 0,85 with WAIS fullscale scores and commented that the Matrices were "devoid of many factors often cited as limitations of IQ testing" (p. 302). Stacy and Gill (1954) quote r = 0,86 with the Stanford-Binet in a study

using the Coloured Matrices with retarded persons and Orme (1961) quotes r = 0,93 between the Coloured Matrices and the WISC, also with retarded persons.

The experimental group and the control group were assessed on the ASAT schedules (see Appendix B) at the beginning of the study and after six months. A search of the literature had indicated a dearth of assessment procedures for assessing the living skills of retarded persons. None except the ASAT schedules were available in South Africa, and the schedules had been used at Fernhill for four years. They cover ten specific areas of skills, as shown in Table 3, and each of the schedules is scored independently.

Table 3

The ASAT Schedules

Schedule I	Personal appearance and physical condition
Schedule II	Emotional stability
Schedule III	Communication
Schedule IV	Care of living quarters and possessions
Schedule V	Simple food preparation and consumption
Schedule VI	Appreciation and avoidance of hazards
Schedule VII	Simple units of measurement
Schedule VIII	Simple finance
Schedule IX	Use of community facilities
Schedule X	Work attitudes and behaviour at work

The assessments were carried out by a nursing assistant who had had considerable experience in the use of the schedules. Information on the resident's behaviour and skills is obtained from a number of sources - ward staff, personal observation and the resident himself - then the schedules are scored accordingly.

The schedules arose from experience with retarded persons being discharged who were not able to cope, and the question was formulated, "What behaviour patterns, skills and knowledge are pre-requisite if the retarded person is to have a reasonable

chance of enjoying a relatively independent and productive life?" (ASAT, 1980, p. 2). The "answers" form the core of the ASAT schedules (Grover, 1981, personal communication). Although the reliability of these schedules had not been empirically demonstrated, a reading of them indicated high face validity. The areas covered and the questions asked were generally of a very practical nature and it was expected that they would exhibit high reliability. (The question of reliability will be considered in greater detail in the Discussion section.)

Follow up questionnaires for landladies and employers had already been designed as part of ASAT so it was decided to use these as a base and simply add a little more detail (see Appendices C and D). However, interviews with the discharged persons themselves had never been conducted and a search of the literature reveled no "standard questionnaire". It was recognised that interviews with retarded persons could present unique problems so it was decided to correspond with those authors who had published research in this field (of whom there are not many!). Dr. M. Rosen provided a copy of the Elwyn Community Adjustment Evaluation Form (1976) which is used for follow up studies of those discharged from Elwyn Institute, Pennsylvania. This was designed for use in America and was extremely detailed so it was felt that certain alterations had to be made for use in this particular study. The revised version (Appendix E) included information on living accommodation, personal finances, vocational history, leisure time, social and emotional adjustment and marriage (if applicable) and consisted of both open ended and closed questions.

Procedure

Two groups of 15 residents matched on age, IQ and length of institutionalization were drawn up. From each pair, one was randomly assigned to the experimental group and the other to the control group. The groups were matched on these three variables because it was felt that either one or all might contribute to the degree of

improvement shown. Both groups were assessed on the ASAT schedules before the experimental group began the programme and again after six months. The assessments were carried out by two nursing assistants who were blind as to whether a particular subject belonged to the experimental or the control group. It was thought that those who participated in the programme would show a greater improvement than those who did not. The design of this part of the study was thus a 2 x 2 design comprising two groups, experimental and control, which were assessed on two occasions. Using pre and post test scores, two way analyses of variance (ANOVAS) were conducted for each of the schedules to ascertain if the experimental group as a whole had improved more than the control group and in which particular areas (Kirk, 1968; Winer, 1971). Because the same subjects were assessed on factor B (pre and post test scores) this necessitated a repeated measures design.

Information on residence and employment was obtained for as many persons as possible who had been discharged from Fernhill into the community (N = 33). Questionnaires were sent to landladies and employers and detailed structured interviews of approximately two hours duration were conducted with the discharged persons themselves. Replies to certain categories of information were tabulated but this was not possible for certain types of more qualitative information.

Results

Experimental and control groups

As mentioned previously, two way analyses of variance (ANOVAS) were conducted for each of the schedules. Factor A consisted of two levels, the experimental group and the control group. Factor B consisted of two levels, pre and post test scores.

A summary of the ANOVA summary tables can be found in Table 4 and the means and standard deviations in Table 5.

Table 4

Summary of ANOVA summary tables for differences between experimental and control groups (factor A), differences between pre and post tests (factor B) and their interaction.

Schedule	F(A)	MS(swg)	F(B)	F(AB)	MS(B x swg)
I	0,35	0,50	4,41*	1,36	0,35
II	0,23	2,11	19,19**	0,39	1,23
III	0,37	29,88	12,61**	4,34*	5,13
IV	1,20	1,94	18,22**	0,03	0,77
V	1,15	14,10	18,86**	1,98	5,14
VI	0,00	31,66	0,93	0,01	12,97
VII	0,11	21,46	8,30**	12,40**	1,69
VIII	1,31	5,30	2,84	5,17*	3,58
IX	0,47	8,06	8,37	0,00	2,66
X	2,11	16,12	1,40	0,07	4,44

Degrees of freedom for each F ratio are 1 and 24.
* Significant at p = 0,05.
** Significant at p = 0,01.

Table 5

Means and S.D.'s of experimental and control groups
on the ASAT Schedules

	Experimental group				Control group			
	Pre-test		Post-test		Pre-test		Post-test	
Schedule	Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
I	11,00	0,04	10,46	1,13	10,92	0,28	10,77	0,56
II	7,39	0,77	6,23	1,64	7,78	0,56	6,23	1,74
III	18,69	3,28	15,15	4,67	18,31	4,25	17,38	4,41
IV	21,00	1,15	19,92	1,26	21,38	0,77	20,38	1,39
V	11,77	3,03	15,38	2,87	11,54	4,27	13,38	1,66
VI	27,92	4,41	28,77	2,95	27,77	6,56	28,85	4,26
VII	8,70	3,30	11,00	3,08	10,38	3,50	10,15	3,69
VIII	5,62	1,85	7,69	2,78	6,08	1,98	5,77	1,64
IX	6,38	1,98	7,69	2,46	5,85	2,48	7,15	2,30
X	22,15	2,64	21,31	2,14	20,38	3,69	19,85	4,00

The important results from Table 4 are the significant interaction effects on Schedules III, VII and VIII. An analysis of Simple Main Effects (SME) was then carried out to further analyse these interaction effects (see Table 6). This analysis was carried out according to procedures laid out by Kirk (1968), in particular the SMEs of factor A (differences between experimental and control groups) at each level of factor B were tested using MS (within cells) as an estimate of experimental error variation.

Table 6

Summary of SME analyses

Schedule	F(A at B1)	F(A at B2)	MS(w cell)	F(B at A1)	F(B at A2)	MS(B x swg)
III	0,06	2,20	17,26	18,53**	1,26	5,13
VII	1,83	0,47	11,58	23,48**	0,23	1,69
VIII	0,36	6,23*	4,44	8,98**	0,20	3,58

Degrees of freedom for F ratios of A are 1 and 48.
Degrees of freedom for F ratios of B are 1 and 24.
* Significant at p = 0,05
** Significant at p = 0,01.

It can be seen that for Schedules III, VII and VIII the experimental group (A1) changed significantly from the pre (B1) to post (B2) test assessments while the control group (A2) showed no such change. Interestingly, this change was a deterioration on Schedule III but an improvement on Schedules VII and VIII.

For the schedules in which there were no significant interaction effects (see Table 4) it may be seen that there were no overall differences between the experimental and control groups for the pre and post test scores taken together (insignificant factor A F ratios), while on Schedules I, II, IV, V and IX both groups changed significantly on post test (Significant factor B F ratios). In the case of Schedules I, II and IV this change was in fact a deterioration and in the case of Schedules V and IX change constituted an improvement.

"Improvement scores" (pre test score subtracted from post test score) were calculated for each subject in the experimental group on each schedule and these were correlated in turn with age, IQ and length of institutionalization (the correlation matrix can be found in Appendix E). To ascertain the relationship between the degree of improvement shown and the independent variables of age, IQ

and length of institutionalization, 10 multiple linear regressions were calculated. A summary of these results is shown in Table 7.

Table 7

Summary table of regression statistics for experimental group.

Schedule	Beta weights Age	IQ	Inst.	R^2	F
I	0,07	0,00	0,10	0,02	0,82
II	-0,74	0,58	0,87	0,60	5,45*
III	-0,33	0,53	0,12	0,33	1,77
IV	-0,46	0,03	0,40	0,13	0,55
V	-0,29	0,15	0,37	0,08	0,32
VI	-0,39	-0,10	-0,26	0,36	2,03
VII	0,16	-0,74	-0,37	0,52	3,95*
VIII	-0,06	0,15	0,09	0,02	0,08
IX	-0,67	0,33	0,34	0,33	1,79
X	-0,72	0,20	0,74	0,36	2,07

Degrees of freedom for each F ratio are 3 and 11.
* Significant at $p = 0,05$.

Of the 10 multiple linear regressions conducted, two obtained significant F ratios. Student's t-tests were conducted on their regression coefficients to establish which variables contributed significantly to the prediction. The results of the t-tests are shown in Table 8.

Table 8

Student's t-tests for regression coefficients

	Age	IQ	Inst.
Schedule II	-2,90*	2,91*	3,37*
Schedule VII	0,58	-3,41*	-1,29

Degrees of freedom for t-test are 11.
* Significant at p = 0,05

The two significant F ratios obtained in the regression analyses were for Schedules II and VII. An examination of the regression coefficients for these two schedules indicated that on Schedule II IQ and length of institutionalization predicted improvement and age predicted deterioration, while for Schedule VII only IQ predicted deterioration.

Information regarding discharged persons

Information from questionnaires and interviews cannot be completely captured by a neat statistical analysis and, in attempting to integrate the information obtained, it is unavoidable that some details will be omitted. The aim of this part of the research was to obtain as comprehensive a picture of retarded persons' lives in the community as possible, with particular reference to areas of difficulty, areas of success and issues relating to their "quality of life", with the intention of suggesting improvements or alterations to the ASAT programme, if indicated. Additional information which could not be easily tabulated is contained in the Discussion section, whereas relating the findings to the present ASAT programme is discussed in the Recommendations and Conclusions section.

Types of residence. Of the 33 persons contacted three were married couples

(i.e. six subjects) and of these, two couples had their own council house and one couple lived in a boarding house. The single subjects lived in a variety of settings, as shown in Table 9.

Table 9

Types of residence for single subjects (N=27)

Boarding house	12
Hostel	8
Group home	5
Rented room	1
Family	1

Only four of those interviewed expressed any dissatisfaction with their place of residence, and in each case the unhappiness was connected with the other people in the house. When asked why they were happy where they were, eight commented on the amount of freedom they had to do as they liked, six commented on the good food and eight commented on the "goodness" of the landlady.

Employment. All except one of the subjects interviewed was in some form of employment although only four were employed on the open labour market (see Table 10).

Table 10

Types of employment of discharged persons (N=33)

Service Products	12
Fernhill	11
Teacher's aides	4
Shampoo assistant	1
Lawn mower servicing	1
Labourer	1
Security guard	1
Housewife	1
Unemployed	1

Of the four employed in "outside" jobs, three expressed themselves as being very satisfied with their work but one (employed as a labourer by South African Railways) was about to resign because of ridicule from other workers. Of those working at Service Products (sheltered employment) six were very satisfied with their work, two were very dissatisfied and four were moderately satisfied, apart from feeling that the money was too low. None of those attending Fernhill during the day (in the industrial therapy or handicrafts sections, unpaid) were dissatisfied with that arrangement, although two considered themselves only moderately satisfied and one wanted to work at Service Products because she could earn more money. Three of those working as teacher's aides at the day centre situated in the grounds of Fernhill were very satisfied with their work but one would prefer to work at Service Products.

Finance. The income of discharged persons ranged from R5-00 per week "pocket money" from the social worker (the rest of the finances being administered by the social worker) to R65-00 per week for the man employed as a security guard to administer himself. Only nine subjects were reported as being fully independent in their financial affairs. Six persons had no savings at all but only 13 had their own savings accounts (see Table 11).

Table 11

Methods of saving of discharged persons

Own savings account	13
No savings	6
Mother saves for him/her	5
Savings in room	4
Social worker saves for him/her	3
Landlady saves for him/her	2

Leisure time. Table 12 gives some indication of the major ways in which those interviewed spend their leisure time. The most common activities appeared to be watching television, listening to the radio, doing some form of handwork, for example knitting or crocheting, and attending church every Sunday. In addition to those activities listed in Table 12, two persons wrote letters regularly, one went fishing, one attended Karate, one made furniture and one repaired electrical appliances. In general, spare time activities were extremely varied and only four persons reported that they had no hobbies. One person made model aeroplanes, another made models from clothes pegs, one person went to Muizenberg every weekend to swim and talk to the other ladies sitting beside the sea and two persons had budgerigars.

Table 12

Use of leisure time by discharged persons

Radio	28
Televsion	26
Handwork	21
Church: weekly	21
Reading: magazines	19
newspapers	13
books	12
Cinema	12
Membership of a club	9
Visiting family	7
Shopping	7
Walking	6
Visiting friends	5
Swimming	4
Making models	3
Library	2
Gardening	2
Budgerigars	2
Discos	2
Sports events	1

Social relationships. Although it was not possible to ascertain the quality of the social relationships of those interviewed, it was possible to ascertain the number of such relationships. Landladies' and employers' reports on the friendships of those discharged can be seen in Table 13.

Table 13

Landladies' and employers' reports of friendships of discharged persons

	Landladies	Employers
Some friends	11	17
No friends	10	8
Boy/girl friend only	7	3
One friend only	5	3

Information obtained from the discharged persons themselves was more detailed and

perhaps a more accurate reflection of their social relationships. Table 14 indicates the number of respondents who answered in the affirmative to questions on the topics listed.

Table 14

Self reports of social relationships of discharged persons

New friends since leaving Fernhill	23
Visits friends	18
Wants more friends	18
Often feels lonely	15
Has contact with neighbours	15
Mixes mainly with new friends	13
Friends visit	10

As can be seen a large number of persons did not appear to have any contact with friends apart from the people they met at their place of work and more than half of those interviewed wished they had more friends.

CHAPTER SEVEN

DISCUSSION

This chapter consists of two parts: a discussion of the results pertaining to the effectiveness of the ASAT programme and a discussion of the information regarding the lives of discharged persons in the community. Relating information concerning those in the community to the present ASAT programme and outlining proposals for possible change can be found in Chapter Eight.

Effectiveness of the ASAT programme

The results failed to show that the group who participated in the training programme improved, as a whole, more than a group of matched controls when re-assessed on the ASAT schedules after six months. The only two areas in which significant improvement was shown by the experimental group were "Simple units of measurement" (Schedule VII) and "Simple finance" (Schedule VIII). The results otherwise showed no particular pattern: a deterioration on post test occurred on four of the schedules for both groups (Schedules I, II, III & IV), an improvement on two of the schedules for both groups (Schedules V & IX) and no significant changes in either direction on the remaining two schedules (Schedules VI & X). There are a number of reasons which could account for both the lack of improvement shown on some schedules and the apparent deterioration shown on others.

Type of training

The results could reflect the type of training given. At present the training is carried out by one nursing assistant and it is quite possible that she may be more effective in the teaching of measurement and finance than in other areas. She has no supervision at all with reference to her methods of teaching so she may have evolved a method of teaching measurement and finance that is particularly good. The importance of objectives in training has been discussed previously (Chapter Four) and, although the contents of the ASAT schedules provide guidelines for the content of the programme, specific objectives in the daily organisation of the programme are not systematically laid down. The content of each particular "subject" on the timetable is completely at the discretion of the nursing assistant. This represents a considerable degree of responsibility and, considering that she has had no formal training at all, it is quite possible that certain areas of training will be emphasised at the expense of others.

One does not need much in the way of concrete facilities to practise the skills of measurement and finance but, as has been mentioned previously, "any opportunity ... to change an abstract idea into a concrete idea should be taken" (Sniff, 1973, p. 3). Unfortunately, the facilities at Fernhill for the training of skills in a practical way have been extremely limited (although they are being greatly improved at the present time), and, even had the trainer wished to teach a particular skill in a practical fashion, in some instances this was simply not possible. This could certainly have contributed to the lack of improvement shown in those areas requiring practical training, such as many of those skills indicated in Schedule V.

Generalization of learning

Those participating in the programme may have been able to master certain skills while actually in the training situation but may have had insufficient opportunity for

those skills to be practised and generalized. This would mean that learning would not be carried over to new situations and improvements would not be shown when later assessments were administered.

Chapter Three dealt extensively with the uniqueness of institutional life and its effects on personality, and many researchers have commented on the difficulties this poses for the learning of "normal" behaviours. The aims of training programmes will continue to be at variance with those of the institution for as long as the institution does not operate as a "normalising training environment" (Gunzburg, 1973, p. 58). Although considerable progress is being made in this direction and real advances have been made, there is still considerable disparity between behaviours expected while the resident is actually attending the programme and behaviours expected in the ward. On the one hand, the programme is attempting to prepare the resident for more independent living and, on the other hand, simply organising the daily living for almost 50 residents simultaneously in one ward makes it impossible for each resident to behave independently. The consequences of this for the generalization of training can be illustrated by some examples of ward routine: all meals are served at specific times (supper at 4.30p.m.) and there are no opportunities for the residents to contribute to their preparation; residents' laundry is done for them (although in the female "hostel" ward there is provision for the washing of underwear); there are two baths in each bathroom, with no partition, thus making privacy impossible; there are, on average, 12 beds per dormitory, with no partitions, and although the residents have their own locker beside the bed their clothes are kept separately; residents are not allowed to be responsible for their own medication. Fixed ward routines are necessary for the management of large numbers of people by a small staff and the examples are given simply to indicate how difficult it can be for the residents, especially if they have lived in the institution for a long time, to generalize any skills learned in the training

programme to their daily life in an institutional environment. This could have affected the assessment of some of the skills outlined in Schedules IV and VI.

Ceiling of ability

It is possible that those participating in the programme had already reached their ceiling of ability in many areas (apart from the areas of measurement and finance) and that even if learning did take place it was not of sufficient magnitude to be reflected in the scores on the schedules. Although the existence of a training programme implies the application of the developmental model (the belief that every person is capable of learning and development, and that this development can be influenced by systematic training; vide Chapter Four), there can be no guarantee that such development takes place during the ASAT programme, nor that there is any potential for further development for individual residents. Gunzburg (1974) states that at present there are "no reliable means of stating with any degree of certainty whether a particular mentally handicapped person is underfunctioning in a particular area of social competence because there is no way of assessing his social potential" (p. 250). However, anecdotal reports of changes and improvements were received, even if such changes were not reflected in the assessments.

In addition, the ASAT schedules themselves have a limited ceiling and, if residents were scoring near the ceiling on pre test, it would not be possible for much improvement to be shown.

The reliability of the ASAT schedules

Although the ASAT schedules had been in use [ ] for four years prior to the start of this study, their reliability had not been established and this present study was the first to utilize them for research purposes. A reading of them had revealed a highly relevant content and it was thought that the type of information

required by the schedules would yield a high degree of reliability. As mentioned previously, the schedules evolved from practical experience to meet an existing need and were considered as prototypes rather than precise psychometric instruments. It would have taken a great deal of time and personnel resources to produce a more sophisticated scientific instrument and meanwhile the residents would have continued to be trained and discharged in a haphazard manner. In addition, it was considered essential, in view of the shortage of professional staff, that the assessment procedure be suitable for administration by "non-expert" members of staff.

On a general level it would seem important that the reliability of the schedules be established in a systematic way. It is suggested that the pre and post assessments of the control group in this particular study can offer some guidelines in this regard, although they are obviously not a substitute for a study dealing specifically with reliability. The correlations between the pre and post test scores for each schedule are shown in Table 15.

Table 15

Correlations of pre and post test scores of control group

Schedules	Correlations
I	0,887*
II	0,695*
III	0,696*
IV	0,319
V	0,415
VI	0,550
VII	0,923*
VIII	0,109
IX	0,764*
X	0,655*

*significant at the 0,01 level

From this it would appear that some schedules could be distinctly more reliable than others; Schedules I, II, III, VII, IX and X appeared to show a reasonably high degree of reliability but for Schedules IV, V, VI and VIII a poorer degree of reliability was indicated. This possibility of some variability in the reliability of the schedules would certainly affect the results of the present study.

The purposes for which the ASAT schedules can be used encompass almost all areas of adult training (ASAT, 1980, p. 3). However, although it is stated that "results properly obtained on the schedules will provide a precise objective assessment of the individual's present level of functioning in significant tasks and behaviours" (ASAT, 1980, p. 3), experience in the administration of these schedules in the present study has indicated a number of problems which may prevent such a "precise, objective assessment" from being obtained. In general, problems arise in the need for subjective judgment (which can vary from person to person), a lack of clarity in how information is to be obtained, ambiguous phrasing and occasional ambiguity in scoring. A more detailed evaluation of the schedules is given in Appendix G. Any of these problems could affect the reliability of the schedules and thus the outcome of this particular study.

Prediction of improvement

It was hypothesised that one or more of the variables of age, IQ and length of institutionalization would be related to the degree of improvement shown by the experimental group on post test. However, in view of the lack of improvement shown in the ANOVA analyses for the majority of the schedules, it was unlikely that any significant relationship would be indicated by the regression analyses. In fact the regression analyses showed no general correlation between the three predictor variables and the degree of improvement, although statistically significant predictions for improvement were found for Schedules II and VII.

The two significant results are difficult to interpret as no similar relationships for the other schedules were indicated. Schedule II reflects emotional stability and positive relationships between IQ and length of institutionalization were shown as well as an inverse relationship to age. It is possible to postulate that those who were younger at the commencement of the programme became more emotionally stable after participating in the programme for six months and that the higher the person's IQ and length of institutionalization the more pronounced this improvement. However, these possible relationships cannot be supported by evidence from any other source and as such can only be considered suggestive.

It is also difficult to draw any conclusions from the inverse relationship between IQ and degree of improvement shown in Schedule VII in view of the lack of similar trends for the other schedules. It could be suggested that those having a lower IQ may not previously have had the benefit of systematic teaching and thus may have improved to a greater extent than those with higher IQ's who are more likely to have had some earlier schooling. However, if this had been a strong trend it would also

have been reflected in the other regression analyses. Further studies would have to be carried out to ascertain whether in fact age, IQ or length of institutionalization conclusively affect the degree of learning shown by the participants of the training programme.

Life in the community

Gaining an insight into the lives of those retarded persons living in the community was a fascinating experience and it is difficult to summarise and integrate such complex data. Each person's individuality was striking and each person's life unique in its own way. However, none of those contacted could be said to be living a completely independent life and the existence of specific "benefactors" was clearly shown. It is of interest that this finding parallels that of Edgerton's first study (1967).

Residence

The majority of the subjects lived in boarding houses or hostels, offering no opportunities for the application or learning of domestic skills or domestic budgeting. Even the two married couples who had their own council houses were closely supervised by a social worker or relative. Those living in a group home were closely supervised by a community sister [illegible] but this was the only instance in which any systematic training towards greater independence seemed to be occurring. Most subjects appeared very dependent on their landlady ("a mother in a million") and in response to the question "When you are upset about something, do you have someone with whom you can talk things over?", 17 indicated that their landlady would be the person of choice, five mentioned a social worker and only four a friend.

Some boarding houses were homes for a number of ex-residents and it is felt that this may be a distinct disadvantage for making new friends. However, this arrangement could certainly be considered preferable to living alone.

Employment

Only four of those contacted were working in the open labour market. The majority worked at sheltered employment or attended Fernhill during the day. It is felt that the latter is a particularly unsatisfactory arrangement as it maintains close contact with Fernhill and discourages the making of new friends. Ideally "outside" employment should be obtained before discharge, the person working "outside" but staying at Fernhill, thus easing the transition into the community and breaking the bonds with Fernhill more gently. Very few of those attending Fernhill during the day had made any new friends since discharge and this situation showed little likelihood of change.

Only two of those employed had found their jobs independently. Fernhill had found employment for 16 and a social worker for two. It was apparent from the interviews that the great majority of subjects would not think of attempting to find another job even if they were dissatisfied with their present position. As discussed in Chapter Five, success in the community cannot be reliably predicted, but it is felt that being engaged in a suitable and satisfying occupation can be a contributory factor.

With reference to the type of employment suitable for retarded persons, Goldberg (1975, cited in Faulkner,1979) maintains that "we have established an expectancy cycle which perpetuates low levels of success and low functional employment capabilities" (p. 14). However, to a great extent, levels of performance are a function of the opportunities and training provided and, although 13 of those

contacted were considered by their work supervisors to have potential for further training, in no instance was further training actually being carried out. It would seem that a considerable amount of research needs to be undertaken to ascertain at what employment levels these people could function and what particular types of jobs might be suitable. The possibility that the potential of these persons is not being realised is further supported by the fact that for 27 of those contacted their work supervisors had no complaints at all about their work habits (attendance, punctuality, reliability, persistence and conformity to rules), thus indicating that many may be able to cope with the pressures of the open labour market.

Finance

In present day terms, "income" was extremely low, ranging from R5-00 per week for "pocket money" to R65-00 per week for the man employed as a security guard. Landladies reported that only nine subjects were fully independent in their financial affairs, while the others all needed some degree of supervision with five being reported as being totally dependent. Only seven persons paid their rent themselves although 13 had their own savings accounts. Eight persons owed money (unsually on clothing accounts) and six had no savings. In spite of their limited financial resources, 21 of those interviewed described themselves as very satisfied with their money and possessions and only one described himself as dissatisfied. Their attitudes can be summed up as follows: "I've got to be grateful for what I've got", "It's alright for a start", "I never complain, just take it like it is".

This lack of independence in finance represents a very unsatisfactory state of affairs, but what is greater cause for concern is that no training towards greater independence is occurring (except for those in the group home). Most persons appeared satisfied with the status quo and instances of dissatisfaction were rare. As discussed in Chapter Four, continued training after discharge necessitates an

element of calculated risk, and in the area of finance it would appear that very few of those in authority are prepared to allow discharged persons the opportunity to administer their own disability grants. There are a number of reasons for this situation: the majority of social workers and landladies do not consider themselves "responsible" for training; teaching someone to handle money responsibly is a very time consuming activity; and there may simply be ignorance on the part of those concerned that mentally retarded people could be capable of managing their financial affairs more independently. Whatever the reasons, such lack of experience in the management of money effectively prevents the transition to more independent living arrangements. That development to a higher level of independence in financial matters is possible is suggested by the number of persons who have their own savings accounts and the reporting of successful management of "pocket money".

Transport

Discharged persons appeared to be extremely competent in the use of public transport and 20 of those interviewed used the train to go to and from their place of work every day. Three persons used a bicycle and this appeared to be a very valued possession, giving the owners increased feelings of independence. None of those interviewed expressed any problems with the use of public transport and some travelled extensively at weekends all over the Cape Peninsula.

Personal appearance and care of living quarters

There were eight complaints by the landladies of unsatisfactory appearance but comments on all the others were along the lines of "always neat and tidy". Having one's own room seemed very important to all those interviewed and there were very few reports that rooms were untidy. Generally landladies' comments were extremely favourable: "she is very proud of her room and it is one of the best in the hostel", "beautifully kept", "spotlessly clean", "very clean and always tidy", "always

immaculate". This concern with one's own room is perhaps understandable in the light of having shared a ward with so many others at Fernhill and the great majority of those interviewed were extremely proud of their room, especially of the accessories they had bought themselves.

Domestic skills

Even though most of those contacted had received some form of training in the preparation of meals etc. before discharge, 20 had no opportunity to practise domestic skills in their present living situations. All of those interviewed made their own tea and coffee and many wanted to learn how to be more competent in the kitchen. However, apart from one instance, no further training or experience was occurring. A landlady said of one of her boarders "I'm afraid to allow her to cook" but the consensus of opinion was that most had potential but simply no opportunities. As mentioned in the discussion of finance, this lack of training effectively prevents the transition to a more independent living situation.

Leisure time

Table 12 indicated the variety of ways in which the discharged persons spend their leisure time. Many activities were solitary and social functions (apart from church) appeared to be relatively rare in their lives. Church attendance was extremely regular for 21 of those interviewed and it is possible that this is because regular church attendance is encouraged at Fernhill, thus it would not present a new venture but rather a continuation of well established habits. It certainly appeared to be an extremely important part of their lives and to give considerable satisfaction.

Only two people were members of "normal" clubs, seven others being members of the club at the hostel. Attendance at "public functions", for example, seeing films or

attending a sports event, was low. It is suggested that discharged persons would initially have to be specifically encouraged to try new activities. While a small number of those discharged went swimming or to discos, the great majority stayed at home, did some handwork and watched television in the evenings. However, it appeared that everyone enjoyed having the freedom to come and go more or less as they pleased even if their activities were not "adventurous".

It is difficult to comment on the use of their leisure time without knowledge of the use of leisure time by a relevant control group. Although their use of leisure time may appear unsatisfactory when judged by middle class standards, it is quite possible that with reference to those in the lower socio-economic groups it may be perfectly acceptable. None of those interviewed was dissatisfied with their leisure time and only three considered themselves moderately satisfied.

<u>Social relationships</u>

"Data on social activities and relationships are difficult to collect and interpret" (Gollay et al., 1978, p. 93) and in this study it was only possible to ascertain the amount and type of social relationships which existed in the lives of the discharged persons but not the quality of those relationships.

Landladies' and employers' reports of friendships of discharged persons were shown in Table 13 but it was felt that interviews with the discharged persons themselves were perhaps a more accurate reflection of their social life. Although 23 persons indicated that they had made new friends since they were discharged , only 13 of those contacted mixed mainly with new friends, the others only had contact with ex-residents. Only 15 of those interviewed had any contact with their neighbours (usually just saying "hello") and those in the group home appeared

to experience actual hostility from their neighbours: "they don't speak to us", "when you greet them they look the other way".

Visiting friends was a common activity for 18 discharged persons but only 10 persons had anyone who ever came to visit them. Although the majority indicated that they would like more friends and half described themselves as often lonely (one man said "I have not actually got friends"), no-one appeared to know how to attempt to make new friends. When asked "What keeps you from making new friends?" a number of those interviewed appeared almost fearful of anyone new: "I must trust them, they can be bad company", "they can lead you to bad places", "friends cause trouble", or otherwise just generally lacking in confidence: "I am too hesitant", "I'm too shy to visit", "I don't know what they would think about me". Others considered that their actual living circumstances prevented them from having more friends: "the landlady doesn't like them to stay too long", "I wouldn't ever take a friend home".

As mentioned previously, there were three married couples amongst those interviewed (six persons) and none reported any difficulties in the marital relationship. There were two other couples with steady relationships (four persons), two had boyfriends at Service Products, two had boyfriends from "outside" and one had a girlfriend at Fernhill. For those who had a steady relationship it appeared to be the most important aspect of their lives, and 14 persons indicated that they would like to be married one day even if they did not have a boyfriend/girlfriend at the moment: "I would like to meet a decent man".

The general impression gained was of a very limited number of social relationships and a high degree of loneliness, particularly at weekends. It did not seem that anyone was actually trying to increase their social relationships or had any idea of

how to do so, although most were dissatisfied with the present situation. Again, it is difficult to comment without reference to a relevant control group but it is possible that in today's society loneliness and a limited number of meaningful relationships might be extremely common.

Stigma

One of the central findings of Edgerton's first study (1967) was the importance of "passing" for his subjects and their perceived feelings of stigma. Although this concern was not manifested by all the subjects in this present study, a considerable number did have very strong feelings about having spent part of their lives at Fernhill and the necessity of keeping this fact a secret from others.

In response to the question "Do you ever feel you would rather be back at Fernhill?" only one of those interviewed said that at times she did (she had been discharged after a period of 55 years). Everyone else said that they would not and six were particularly adamant: "never". When asked about how they felt about "being from Fernhill" 14 subjects said that they did not mind but all the others indicated that it upset them considerably: "I'm upset to think I was ever a patient", "it's bad, others think that you're off your head", "it upsets me a lot", "I don't like to talk about it", "I feel embarrassed", "I feel guilty, sorry I was put there", "it makes me unhappy", "horrible". However, when asked "Does it bother you that you used to live at Fernhill?" only 12 replied in the affirmative and 27 said that most of their friends knew that they had been at Fernhill. Of the five persons that said that most of their friends did not know that they came from Fernhill, four considered that if their friends did know they would treat them differently: "they would if they knew", "they think you don't know anything", "people might call me stupid".

Only four of those interviewed said openly that they had been at Fernhill because of their retardation: "I was backwards", "I was retarded", "I had a fall and lost my memories". If any of the others did feel that they had been at Fernhill because of their retardation they did not admit it. Instead, all kinds of reasons were given and each appeared to be sincerely belived: "my mother put me there to keep me out of trouble", "I came because of the headaches", "I went out with too many men", "I was naughty and had a baby", "my sister was meant to come and fetch me but she never came", "so I could be trained", "my father thought I needed protection", "I was sent from the children's home", "the welfare took me because I was alone at home", "I stole some money", "my stepmother put me there because I didn't have a job". This finding of subjects not admitting their retardation parallels that of Edgerton's study (1967).

Concern with possible stigma was evident in response to the question of whether they would tell anyone they met that they had been at Fernhill. Only six of those interviewed said that they would tell anyone and three said that they might tell a friend: "only people I could trust otherwise they could make a fool out of me", "only friends, other people might be suspicious that I was an inmate". The remainder of the subjects were all adamant that they would never tell anyone: "I would never say, they will say we come from a mad place", "I would keep it a secret otherwise people wouldn't be nice to you", "it's better not to say anything", "people think that you are mental", "people outside know what place this is and think bad about it", "I wouldn't tell anyone, they would ask me about it".

<u>Problems experienced by discharged persons</u>

Of those interviewed, 21 maintained that they had learnt enough at Fernhill to live "outside". Of those who did not feel that they had learnt enough, four wished they had learnt more about money, two wished they had learnt more about cooking, one

wished she had learnt to read, one wished he had been taught to control his temper, one woman said "they did not tell me about sex", and one person complained generally that "they didn't say what it was like, I was frightened to come out at first".

Only nine persons had had no problems that they felt they could not handle and only seven persons said that there were no things or situations that they were afraid of. Problems that the subjects felt they were unable to handle were mainly in the areas of social skills: "arguments with the people at work", "the girls at Service Products say that I'm a welfare because I come from Fern", "the other people in the house picked on me", "I can't get on with my parents", "some people at Service Products called me stupid". In all these cases the problems had been handled either by the social worker or the landlady. Reports of practical problems were surprisingly rare: one person reported problems with money, one reported a road accident, another had been assaulted, one reported that she did not know how to vote and one that she did not know how to change her lodgings.

There were many varied situations and things that those interviewed reported being afraid of. Nine reported that they were frightened of going out at night, two said that they were frightened of being alone, two were frightened of losing their temper, two said they were frightened of being followed when walking by themselves, one was afraid of the noises and machines at her place of work and two were frightened of the "skollies" at the station or in the subway.

Almost all of those interviewed were most anxious to assure the interviewer that they could manage very well even though they may have had problems in the beginning. The question "If you were to give advice to a resident who wants to leave, what would you say?" was considered to be an indirect way of

ascertaining what was of greatest importance to those interviewed without being perceived as a threat to their own competence. Answers to this question appeared to reflect their own anxieties as well as their own optimism and sense of achievement. Three persons gave advice on the dangers of being robbed, six persons mentioned not lending money, eight persons commented on the dangers of traffic, ten persons said that behaving oneself and not arguing was important, four mentioned the dangers of going out at night and two the dangers of going out with men. In addition, there was a prevailing attitude that a person leaving should be thankful to be "out": "they must be glad not to be locked up", "it's nice to be outside", "the world is'nt as bad as everyone says", and a realisation that although things might be difficult at first it is possible to manage: "they must try it out so they can stand on their own feet, you must fight for yourself", "it's much nicer out of Fern, it might be difficult at first but they will learn to cope", "they must get used to being out", "they must just act normal, not like Fern people".

The problems reported by the discharged persons themselves were far less than had been anticipated and although their lives have a large number of unsatisfactory elements seen from a certain perspective, "whose assessment of success shall we value most, ours or theirs?" (Edgerton, 1976, p. 496).

CHAPTER EIGHT

CONCLUSIONS AND RECOMMENDATIONS

Gunzburg (1974), in an evaluation similar to the first part of the present study, comments that:

> monitoring an active training programme which has grown out of habilitation needs and is subject to many unpredictable and non-measurable interferences in the form of frequent staff changes, trainees being absent, different staff management practices, emotional disturbances etc., can never take the form of tidy and convincing laboratory research (p. 263).

However, in spite of this, it is still considered that regular assessments of progress, in particular analyses of successes and failures, are essential for any training programme and that such objective results can be used as guidelines for the future. It must be stressed that the purpose of this study was not to criticise those who have been instrumental in the organising of the training or to denigrate the considerable progress which has been made [Fernhill] up to the present time: rather, it is hoped that this study may be of assistance in the continuation of such progress for the benefit of as many residents as possible. Much has been achieved so far, residents have been discharged and are coping, but areas in which greater improvement seems possible have been indicated in this study and it is felt that the efficacy of the programme could be improved.

Evaluation of the ASAT programme was the principle aim of this study and it was felt that appraisal of its actual content (and thus the ASAT Schedules on which it is based) could best be achieved by an investigation of the lives of those discharged persons actually living in the community. Therefore, this chapter will begin with a consideration of those persons' lives, relate this to the contents of the programme and schedules and finally, put forward recommendations as to how the implementation of the programme could be improved so that maximum learning takes place.

Discharged Persons in the Community

It is to Fernhill's credit that 21 of those interviewed considered that they had learnt a sufficient amount while at Fernhill to live "outside". Only 12 of those had actually participated in the ASAT programme so it is suggested that some learning also takes place in the ordinary ward and therapy situations. Subjects reported surprisingly few instances of "problems" with which they were not able to cope and the majority of these were in the area of personal relationships. At first glance this may appear to be a very satisfactory state of affairs. However, a consideration of the actual living situations of these people prevents the automatic acceptance of that conclusion.

As discussed in Chapter Five, "normalization" does in fact present a dilemma. On the one hand there is a sense of progress having been made because these people are no longer living in an institution, but on the other hand, none of those interviewed was living what could be called a "normal", "independent" life. It is therefore necessary to examine the aims of the policy of discharge into the community (a policy which is of comparatively recent origin in South Africa).

If the approach is that any discharge represents "progress" then one could be satisfied with the present situation. However, if the approach is to maximise the potential of those who have the capacity to live in the community, this has not been realised for the majority of those contacted in the present study. It is suggested that it is not simply the <u>number</u> of those discharged that is important but rather their <u>level of functioning</u> after discharge. It is felt that many of those interviewed had the potential to be functioning at a higher level than at present but that this was prevented to a considerable extent by their restricting circumstances. These restricting circumstances include having their financial affairs administered for them, having no opportunities for the practice or learning of domestic skills, and living in environments which could be considered as "protective" rather than actively encouraging greater independence. This automatically ensures that the people concerned never confront certain types of problem situations simply because of their "protected" circumstances.

In discussing the content and implementation of the ASAT programme the view will be taken that the maximum number of opportunities should be given for persons to demonstrate their capabilities and that discharge would be to situations offering greater independence than the majority of those found in the present study. This does not assume that everyone will succeed but simply that progress cannot be achieved if opportunities are not specifically created.

Content of the ASAT Programme/Schedules

As mentioned previously, the programme is based on the skills outlined in the schedules. However, a perusal of the timetable indicates that only particular areas have been mentioned specifically: education (measurement and finance), cooking, self

care, role play, sex education, sight reading and community outings. In view of the lack of direct supervision given to the nursing assistant responsible for training, it is understandable that training in some of the skills mentioned in the schedules may be omitted, although it must be stressed that she manages the programme extremely competently and is very enthusiastic. It is felt that the ASAT assessment Schedules do cover almost all the skills required for independent functioning in the community even though they are not necessarily being taught in the present programme. However, it is felt that some useful additions could be made which might assist in the transition from institutional to community life.

Employment

The ASAT Schedules make no reference to the obtaining of employment. Although Schedule X refers to attitudes and behaviour at work, this refers to a supervisor's report rather than the resident's own knowledge of employment and work habits. It is felt that specific training and exposure to particular types of employment needs to be given (perhaps on a trial basis "outside" for half a day per week). Residents need to be taught methods of obtaining employment and general employment practices, for example, pay slips, what to do if one is sick, working hours etc. Perhaps ex-residents could be invited to discuss their own experiences at work and visits to different work places arranged.

This recommendation assumes that jobs are actually available but in practice finding suitable jobs can be extremely difficult. Although the occupational therapist and social worker at Fernhill have made strenuous efforts to find work for discharged persons, they have many other responsibilities and cannot give the amount of time required to ascertain suitable places of employment. If finance was available, one staff member could be solely responsible for job liason. Unfortunately this is unrealistic at the present time even though the benefits would be enormous.

Leisure time

The ASAT programme timetable includes "hobbies" on a Friday afternoon. This performs a valuable function in teaching residents different forms of handwork and interviews with discharged persons indicated that almost all occupied some of their time in this way. However, this is not the only way to spend one's leisure time and it is felt that further emphasis needs to be given to the use of leisure time in the programme and schedules. Although Schedule IX deals with the use of community facilities, the use of facilities for leisure is only cursorily mentioned (Question 2 ii). It is felt that particular attention needs to be given to leisure time activities, particularly those involving other members of the public. The nursing assistant at present pays considerable attention to modes of transport, use of the post office, etc. but not to such activities as going to the cinema, sporting events etc. Confidence in these areas will only be improved by actual attendance, particularly unsupervised.

In general, it is felt that, apart from the two areas mentioned above, the ASAT Schedules cover most of the skills required for community living even though many of those interviewed were not practising some of these skills because of their circumstances. In addition, in a number of areas the contents of the schedules are not being "translated" into the contents of the programme. This is hindered, inter alia, by lack of direct supervision, lack of facilities, insufficient finance and problems stemming from the accepted patterns of daily life at Fernhill.

Implementation of the ASAT Programme

The present study indicated that the only areas in which significant improvement was shown for those participating in the programme for a period of six months were

"units of measurement" (Schedule VII) and "simple finance" (Schedule VIII). This would seem to indicate that progress in other areas was not sufficient to be shown when subjects were re-assessed on the ASAT Schedules. Although the schedules themselves could be problematic (as mentioned in Chapter Seven and Appendix G), it is felt that if improvements had been of a sufficient magnitude they would still have been reflected in the scoring of the schedules. Thus it would appear that in certain areas learning was either not taking place at all or to a very limited extent. Possible reasons for this were given in Chapter Seven: type of training, generalization of learning, and ceiling of ability.

Ceiling of ability

It is not possible to state accurately at the beginning of training if someone has reached their ceiling in a certain skill and this conclusion can only be reached after the maximum number of opportunities have been presented and levels of achievement reliably assessed over a period of time. Thus, with reference to the actual implementation of the ASAT programme, no resident should be automatically excluded from participation because it is assumed that his ceiling of ability has already been reached. This assumption cannot be made until he has been presented with all the opportunities the programme offers and reliably assessed before participation and at regular intervals throughout. Although ceiling of ability cannot be predicted, it is felt that alterations to the actual training given, increases in opportunities for the generalization of learning and greater ease in the practical admininstration of the programme could dramatically increase the degree of improvement shown in many areas.

Methods of training

As mentioned previously, the nursing assistant at present responsible for the programme has received no systematic training. Although she has achieved a great

deal under often difficult conditions, because she has evolved her own methods she is generally lacking in confidence. It is felt that some systematic training is essential both to improve the actual methods used and to increase the trainer's self confidence. Particularly it is felt that objectives need to be clarified and specifically laid down (as discussed in Chapter Four) and supervisory/feedback meetings be held on a regular basis. It would also be beneficial if her designation could be changed to "social trainer" instead of "nurse", if at all possible, as this would free her from much of the "red tape" that surrounds administration in the nursing profession and clarify her role in the eyes of other members of staff.

> It is probably not realized sufficiently often how much the selection of a particular teaching approach is determined by the fact that the framework within which the teaching has to function is so narrowly defined by rules and regulations that nothing else but a very limited classroom approach with emphasis on academic education appears possible. (Gunzburg, 1974, p. 266.)

In addition, it is considered that 30 residents is too great a number to participate in the programme simultaneously unless there are increases in staff and facilities. There would be a greater likelihood of progress being made if residents were able to attend the programme more "intensively". At present, each participant receives training for approximately eight hours per week in total but this is in "odd sessions" of usually an hour at any one time. It is felt that attendance for two full days per week, for example, would be far more beneficial and enable much more to be achieved in a shorter period of time.

Opportunities for generalization of learning

It is not necessary to re-iterate the need for increased facilities because the management at Fernhill is well aware of this problem and improvements are steadily being made. However, no matter how excellent the facilities are for the programme, generalization of learning will not be possible if certain behaviours that are required while participants are attending the programme are not required in the ward.

It is strongly recommended that wards become actively involved in training in a systematic fashion to complement and aid in the achievement of the goals of the ASAT programme. This is not to suggest that wards do not carry on any training at the moment but at the present time there is very little communication or co-operation between the programme and the ward. Ideally "the wards themselves should become social education centres where systematic work is carried out in the natural conditions of the trainee's own permanent living unit" (Gunzburg, 1974, p. 249). This may sound very ambitious and impractical but a beginning could be possibly be made by allocating a small section of the ward to those participating in the programme so that they could practise independent living skills under the guidance of the ward sister and in co-operation with the programme co-ordinator. If, for example, only six persons from that ward were participating in the programme they could be allowed to prepare their own meals in the ward kitchen, do their own washing and ironing and be responsible for the complete domestic organisation of their part of the dormitory. It is predicted that great strides could be made in a very short time if such opportunities were provided and independent living skills were actively encouraged. This would particularly affect the learning of many of the skills outlined in Schedules IV, V and VI.

Practical administration of the programme

Problems of administration always arise when provision has to be made for so many residents (Fernhill has a population of just under 1 000), overall responsibility is to the State, and professional staff changes occur with depressing frequency. The ASAT programme has been affected by these "facts" in a number of ways but it is felt that with greater rationalization in organisation a number of problems could be overcome, thus contributing to the greater impact of the programme.

Finance. At the present time, the system of funding the ASAT programme is not generally understood. Although it appears that money is available, the "channels" through which it is available and the methods by which "supplies" can be obtained are somewhat ambiguous. It is recommended that ASAT have its own separate budget and that there be as few restrictions as possible on the ways in which the money can be spent. However, this recommendation will be impractical if one person or one particular department is not made specifically responsible for the administration of that budget.

Personnel. The ASAT programme has been nominally under the auspices of the Psychology Department with the occupational therapist being heavily involved. In view of the number of staff changes which occur and the resulting lack of clarity, this has led to a very unsatisfactory situation, with considerable confusion existing as to "who is responsible for what". This has particularly affected the nursing assistant who has been uncertain as to whom she is responsible.

It is recommended that, if possible, one person be appointed as ASAT co-ordinator and given clear areas of responsibility. It is felt that the person does not have to have specific training in any particular discipline but rather should be committed to the aims of the ASAT programme and be of a tactful disposition. It is possible that

this role could be combined with that of "liason officer" for those discharged so that an overall perspective could be gained (training in the institutional setting and actual experience of the difficulties of transition from the institution to community living). At the present time, once a person is discharged they are "handed over" to an "outside" agency who then becomes responsible for them. This results in a lack of knowledge regarding the process of transition for those discharged and any systematic continuation of previous training is not possible. Further, there is no opportunity for feedback into the training programme to give it greater relevance to the actual problems of living "outside".

It is felt that if one person was responsible for the administration of the ASAT programme instead of a "department" then a far greater level of efficiency in administration could be established.

Freedom of movement. If independent living skills are to be actively encouraged, it is essential that life be made as "normal" as possible. This involves, inter alia, the opportunities for outings without supervision. Many residents have "ground parole" and a few have "town parole" but discussions with nursing staff revealed great unease and uncertainty as to the question of responsibility for residents in these circumstances. It is felt that clarification of this issue and greater freedom of movement for those involved in the programme could contribute greatly to the learning of appropriate behaviours in the community and to increased feelings of confidence and self esteem for the residents. (As noted in Chapter Four, these feelings cannot be fostered in situations which do not imply trust on the part of those in authority.) This relates specifically to some of the skills mentioned in Schedules VI and IX.

Communication with nursing staff. As mentioned in Chapter Four, it is possible for the aims of a training programme to be "subtly sabotaged" by ward staff and this has been noted in some instances at Fernhill. It is felt that the dissemination of information throughout Fernhill regarding the aims and achievements of the ASAT programme is essential and that the co-operation and assistance of the nursing staff should be actively sought. This could be done by actually involving them in training, as outlined above, and although the problem is unlikely to be eliminated, it is felt that mutual co-operation and understanding could certainly be improved.

Although it cannot be stated with certainty what effects alterations in the practical administration of the ASAT programme would have on the degree of learning shown by the residents, it is felt that in general a firmer foundation would be established, enabling all those concerned to operate with greater certainty and assurance.

The Need for Transitional Facilities

The previous section has outined some possible ways in which the effectiveness of the ASAT programme could be increased within the institutional setting. However, even if these changes were made, it is felt that a direct change from Fernhill to independent living would be too large a step for many residents. The need for transitional facilities in general was discussed in Chapter Four and this study has indicated that in many instances the residences of the discharged persons were in fact operating in many ways like a half way house, even if they were not designated as such. In one sense it is admirable that landladies and hostel supervisors should feel so responsible for these discharged persons. On the other hand, as mentioned

previously, almost no further training was taking place; the landladies and supervisors viewed their roles as being ones of care and support rather than of training for increased independence.

It is felt that ideally Fernhill should have its own half way house, both to complement and extend the training given in the ASAT programme and to ensure that maximum levels of independence are achieved. It should function not as the end result of training in the ASAT programme but as the next stage on the road to community living. Thus it would be possible for residents to practise living skills already learned but also to have systematic training in greater independence and the gradual assumption of greater responsibility for their own affairs, particularly administering their own finance.

Retarded Persons as Informants

Very few studies of retarded persons have used retarded persons themselves as sources of information. Gollay et al. (1978) comment that "mentally retarded persons are able to speak for themselves -- accurately and poignantly" (p. 158), and similarly Edgerton (1976) notes that "we should listen to retarded persons when they tell us about their lives" (p. 498). The retarded persons interviewed in this study were remarkably verbal and able to talk about their own circumstances realistically. Although the interviewing of retarded persons concerning so many aspects of their lives was approached with a certain degree of trepidation this proved to be completely unfounded. In terms of future research and practice, it is felt that these people as sources of information should not be underestimated and that greater effort at all levels could be made to ascertain their views, both those living in the community and at Fernhill itself.

It must be realised that going into the community is a process and even though these people were interviewed at one point in this process it is highly unlikely that their lives will remain static, in spite of their limited circumstances. Edgerton (1976) found many changes in his subjects after ten years and it is felt that a further follow up of the persons contacted in this study could be extremely valuable.

Concluding Comments

The habilitation of mentally retarded adults so that they can live more independent lives in the community would appear to be an extremely desirable goal in spite of the many problems and uncertainties encountered. The attainment of habilitation goals requires not only specific training to that end but also reliable methods to assess the effectiveness of such training.

It is felt that the ASAT Schedules could play a vital role in the habilitation process, but in their present form their use involves many problems, both for the monitoring of training at Fernhill and for future research. The inadequacy of present methods of assessing the living skills of retarded persons is acknowledged by Gunzburg (1974) when discussing the evaluation of a training programme using his P-A-C assessment procedure. However, he considers that:

> as an interim measure, until better standardized and more sensitive instruments become available, which can be used generally and not only by the initiated, the P-A-C and P-E-1 should serve the purpose of drawing attention to areas in need of remedial action (p. 270).

This same comment could be made with reference to the ASAT Schedules, but reliable assessment procedures will not "become available" unless time, personnel and finance are specifically allocated for that purpose. The instrument of assessment emerged as one of the major problems encountered in the present study and it would seem that future research in this area would inolve considerable difficulties unless prior attention was given to making the ASAT Schedules as reliable and objective as possible.

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APPENDIX A

The ASAT Programme Timetable

The ASAT Programme Timetable

Day	Time	Activity
Monday	8.00 - 9.00	Education (A)
	9.00 - 10.00	Education (B)
	10.00 - 11.30	Cooking (C)
	1.00 - 2.00	Selfcare Men (A)
	2.00 - 3.00	Ward Round
	3.00 - 4.00	Selfcare Men (B)
Tuesday	8.00 - 9.00	Education (C)
	9.00 - 10.00	Education (E)
	10.00 - 11.30	Cooking (D)
	1.00 - 4.30	Outings
Wednesday	8.30 - 9.30	Roleplay I/Sex Education II
	9.30 - 11.0	Cooking (A)
	11.00 - 11.30	Sight reading
	1.00 - 2.00	Selfcare Women (A)
	2.00 - 3.00	Sport
	3.00 - 4.00	Selfcare Women (B)
	4.00 - 4.30	Sight reading
Thursday	8.00 - 9.00	Education (D)
	9.00 - 10.00	Roleplay II/Sex Education III
	10.00 - 11.30	Cooking (B)
	11.00 - 11.30	Sight reading
	1.00 - 4.30	Outings
Friday	8.00 - 9.00	Education (D)
	9.00 - 10.00	Roleplay III/Sex Education I
	10.00 - 11.30	Cooking (E)
	1.00 - 2.00	Hobbies Women
	2.00 - 3.00	Hobbies Men
	3.00 - 4.00	Tidy up

Note: Residents were divided into five groups (A, B, C, D & E) for Education and Cooking, three groups (I, II & III) for Roleplay and Sex Education and two groups each (A & B) for men and women for Selfcare.

APPENDIX B

The ASAT Schedules

THE DIVISION FOR THE MENTALLY RETARDED

(S.A. NATIONAL COUNCIL FOR MENTAL HEALTH)

ASSESSMENT SCHEDULES AND ADULT TRAINING FOR THE MENTALLY RETARDED (A.S.A.T.)

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ASSESSMENT SCHEDULES AND ADULT TRAINING FOR THE RETARDED (ASAT.)

The assessment schedules and related training programmes for Adults are intended primarily for use in residential institutions for the mentally retarded. They can also be used in day training centres and extra-mural training groups for adolescents and adults and can provide a guide for parents who have a retarded family member living at home.

The ruling principle underlying ASAT is the developmental one which, briefly stated, asserts that potential for advance and improvement is often present in spite of intellectual limitations but that such potential will be realised only if the right conditions are provided. This does not imply that, even with the best training, a high level of intellectual functioning will ever be attained. It must be recognised that the retarded adult is never likely to be capable of abstract thinking, deductive reasoning, complex planning or creative flexibility in the face of changing circumstances.

The developmental principle is, however, diametrically opposed to the too commonly held supposition that the preclusion of almost any kind of further learning, unnecessary inefficiency in concrete daily tasks and living skills, and markedly unacceptable behaviours are the inevitable concomitants of the low intelligence and hence unmodifiable.

Conditions which prevent the realisation of potential in the mentally retarded adult are :-

1. Unsuitable domestic/residential conditions which fail to provide models of "normal" living.

11. Low expectations on the part of personnel and too ready acceptance and tolerance of unwarranted subnormal or abnormal behaviour.

111. Lack of a planned policy by which improvement is carefully observed and reinforced through such rewards as privilege and promotion.

1V. Experiential deprivation; lack of meaningful and directed exposure to suitable real life situations.

V. Absence of continued systematic training and education for living, after the "school" years.

It need hardly be mentioned that adult training is intended to be the logical extension of well planned programmes in the pre-school and school years. Where these have been almost totally lacking, adult training will be made extremely difficult.

A comprehensive adult training scheme must take cognisance of all the points mentioned if it is to achieve the desired results. Although regular systematic training in small tutorial groups (Point V above) will be the nuclsus of the Adult Education programme, this alone will not be effective.

ASAT was planned in response to experience which showed that mentally retarded adults discharged from a residential institution into the community on the basis of insuffcient and insufficiently defined criteria frequently found themselves unable to cope and ran into difficulties of various kinds.
To extend and refine these criteria, the question was formulated :-
<u>What behaviour pattens, skills, and knowledge are pre-requisite if the retarded adult is to have a reasonable chance of enjoying a relatively independent and productive life ?</u>

Since the retarded individual finds it difficult, inter alia, to generalise, to recognise common features in somewhat dissimilar situations, to learn as spontaneously as the better endowed from mere exposure to experiences, it is

2/.........

necessary to itemise in considerable detail those concrete tasks which are likely to face him in a broad spectrum of daily living situations. ASAT is thus made up of ten separate schedules each comprising a number of quite specific goals, attainment or lack of attainment of each of which can be objectively scored.

After proper training some individuals could be expected to reach or even exceed the ceiling on all schedules. Individuals reaching such a level would be considered to have a good chance of living and working outside a protected institutional setting provided some supervision and guidance in dealing with complex problems is available. However, training should certainly not be confined to those who are judged likely to attain this highest level of competence but should be instituted too for those for whom a considerably lower level of attainment can realistically be expected. Any advance, the acquisition of any of the skills detailed can help to make the individual more acceptable, more independent and enable him to lead a more meaningful life even if it is to be spent within an institutional or semi-protected setting.

PURPOSES FOR WHICH ASAT SHOULD BE USED.

1. For directing the attention of planning authorities and relevant personnel to the meaning and nature of and need for adult education of the retarded.

2. For placement, promotion and discharge.

Results properly and carefully obtained on the Schedules will provide a precise objective assessment of the individual's present level of functioning in significant tasks and behaviours. Such assessments will allow useful and realistic judgements to be made with regard to such matters as:-

- 1. Readiness for discharge into the open community and open work market.
- 11. Readiness for discharge into semi-sheltered living and working conditions.
- 111. Readiness for promotion to a pre-discharge training programme.
- 1V. Readiness for promotion to a higher ward or unit.

3. For pinpointing gaps in essential knowledge, skills and experience and planning suitable training to rectify such deficiencies.

4. For evaluating the effects of training strategies and introducing changes where these are considered necessary.

5. For guidance of parents, adult centres supervisors and group leaders undertaking continued training of post-school retarded persons.

THE TUTORIAL GROUPS

The nucleus of the Adult Education programme will be training in small tutorial groups which will meet with the tutor for regular sessions over a continous period. The number of weekly sessions, the length of sessions and the exact number of students in a group cannot be definitely prescribed as conditions and circumstances will vary from one institution or setting to another. Such factors as the total number of residents considered at all capable of adult education, the availability of tutors and the kinds of work programmes in which residents are engaged will have to be considered. The length of a session will depend, too, on whether it takes the form of a discussion/demonstration/exercises on the spot or an outing into the community to learn about and practise the use of community facilities.

The members of any one tutorial group should be carefully selected, should be fairly homogeneous with regard to their general level of intelligence, ability to

3/.......

learn and degree of literacy, and language medium should be considered. With the possible exception of one or two specific areas of training, a group should consist of members of both sexes. Once a group has been selected and found to work well as a group, it should be maintained as such since a great deal of inter-member support arises, tolerance and respect for one another are developed, confidence is fostered and members become co-teachers with the tutor.

Important principles to be observed in tutorial groups.

1. Students should be treated as adults, not children. It must be made clear to them that they are engaged in adult education, not school instruction, and that adult behaviour is expected.

2. Whereever possible the matter in hand should be presented as a problem solving situation since in this way students reveal the extent or lack of their knowledge and understanding and hence provide the proper starting point for instruction. Characteristic of many mentally retarded adults is the unevenness of performance with unexpectedly high peaks and dismal lows.

3. Concrete aids must be used at all times and new knowledge referred to real life, not abstract or unknown situations. Training on the job should be undertaken wherever and whenever possible.

4. In the acquisition of new skills, power (ability to do the job properly) rather than speed must be stressed, especially in the initial stages.

5. The tutor must carefully analyse each task to be mastered into a number of finely graded component parts or steps and ensure that each step is mastered before proceeding to the next.

6. Frequent repetition is required but to avoid boredom and encourage transfer this should be done in slightly varied ways.

7. Unwarranted criticism, sarcasm or mockery are totally out of place and students must quickly be shown that such behaviour towards another's ignorance or mistakes is forbidden. Every effort must be made to show that each student has his strengths as well as his weaknesses.

8. Every opportunity must be taken to underline and hence reinforce any form of desirable behaviour by such remarks as: "I liked the way Joan did ......"; "Adrian explained that well"; "Peter showed good manners by ....".

9. A written, dated record of each session should be made immediately after the session. This will detail material covered, particular difficulties en - countered, significant behaviours of each member and matters which have arisen which will have to be dealt with in future sessions.

In a large institution the whole adult education programme should be planned and supervised by a well qualified co-ordinator who will also assist and guide tutors. Tutors themselves can be drawn from a variety of professional disciplines, for instance, nurses, occupational therapists, psychologists and teachers, while the use of suitable volunteers from the community should not be overlooked.

INTRODUCTION TO THE SCHEDULES, THEIR OBJECTIVES AND SOME SUGGESTED TRAINING STRATEGIES

SCHEDULE 1 Personal appearance and physical condition:

(a) Body Management and physical skills.

One of the most fundamental tasks of any training programme for the mentally

retarded is to assist the individual to gain awareness and control of his body and its functions and to hold and move his body and dispose his limbs in ways which are "normal" and socially acceptable.

The bizarre postures and mannerisms, the unacceptable ways of sitting, the hanging head, shuffling gait and other abnormalities frequently observed in institut - ions for the retarded are not always the result of organic damage but often stem from poor training, lack of correction and insufficient awareness of the physical self.

Improved body awareness and management are not only ends in themselves but provide the foundation for progress in other areas. New physical skills can be mastered once normal posture and better understanding of body parts have been achieved. Self asteem is fostered and an interest in appearance, personal hygiene and clothing can be developed. The individual can then be more readily taken into the community for exposure to new learning experiences.

Suggested Training Strategies:

Physical exercises and games including music and movement; use of full length mirrors; body image exercises; behaviour rehearsal; group judgement and group discussion; skill training in using tools and implements.

(b) Personal hygiene.

The main objective here is the achievement of a clean and neat appearance, the acceptance of responsibility for personal hygiene, and the establishing of personal habits which render the individual reasonably acceptable to others.

Suggested training Stratagies:

Establishing desirable toilet habits by consistant and regular repetition; providing domestic conditions in which personal hygiene is easy to practise (clearly, absence of toilet paper and of personal toilet articles, removal of taps from basins and similar practices make the exercise of personal hygiene almost impossible) use of full length mirrors; group judgement and group discussion; training in specific skills e.g. hair washing, nail filing, oral hygiene.

SCHEDULE 11 Emotional Stability:

The main objective here is to assist the individual to give up primitive, infantile ways of expressing his feelings; to gain some control over his impulses; to develop some degree of frustration tolerance and to refrain from delinquent behaviours to gain his ends.

Correct behavioural responses will have to be developed more incidentally in this area than in some of the areas covered by other Schedules. Every group session, no matter what the specific training being undertaken, will provide opportunities to deal with interpersonal relationships and responses to such things as failure, correction, mild teasing or disappointment, and to point out both desirable and undesirable behaviours. Group outings will also provide opportunities for the practice of self control and acceptable manners as well as for the observation of the behaviour, both good and bad, of other members of the community. Where language ability allows, group discussion can be held on such topics as: "What makes you very angry?" or "What would you do if X did so and so to you?". Simple behaviour rehearsal based on specific emotion-evoking situations can be practised. In connection with Section 5 of this Schedule, simple sex education is essential.

The level of attainment on Schedule 11 is very important. Even when there is high competence on other Schedules, a very low rating (i.e. a preponderance of "No" checks) on Schedule 11, will have to be heavily weighted in making decisions about placement and promotion.

SCHEDULE 111 Communication:

One of the more difficult training goals here is to develop some appreciation of the purposes of and conventions regarding spoken language. Whereas items 1 and 3 in Schedule 111 refer respectively to the actual levels of ability to understand the spoken word and to utter the spoken word, items 2 and 4 refer to the ways in which these skills (if present) are used. The distinction is an important one and scoring must be undertaken with great care. Some of the goals to be attained in this particular respect are: attentive listening, awaiting ones turn to speak, avoiding rudely interrupting another, gaining confidence in speaking in a group, formulating questions, learning to take part in conversation rather than hogging the talk to draw attention to oneself, and the use of common courteous conventions e.g. "Please, May I, Thank You."

While some of these goals may appear to be beyond the capacity of the retarded individual, experience with tutorial groups has clearly shown that considerable advances can be made in these skills if the right kind of training is introduced.

Training in oral communication will not, ofcourse, be limited to special occasions but will be an important aspect of every group session no matter which Schedule is being dealt with; outings will be used to learn new words to encourage discussion of experiences and where possible to read notices, names and the letters.

Where some reading and writing ability exist, these skills should be used and developed in practical settings, e.g. Steps in carrying out a task, such as making tea, listing items to pack for a weekend; making a shopping list. Other training strategies would include use of tape recorder both for attentive listening, and for recording and play back of student's speech, reading etc; simple language games; role playing; use of model telephone (or preferably real telephone which can be disconnected) to give and receive messages, make enquires and the like.

SCHEDULE 1V Care of Living quarters and possessions:

SCHEDULE V Simple food preparation and consumption:

These two Schedules are concerned particularly with assisting the individual to make the transfer from a setting in which all ordinary domestic tasks are done for him to one in which he has to accept a considerable degree of responsibility for carrying out himself.

Training in these areas will be virtually impossible in the outmoded type of large institution characterised by forty or more bedded wards without individual lockers and wardrobes, where the keeping of personal possessions and clothing is not permitted, where all services such as kitchens, laundries, sewing rooms are highly centralised and where there is no access to kitchenette and laundrette facilities.

Where conditions are more suitable, training should almost entirely "on the job" with specific practical training in correct methods of carrying out certain tasks and repeated practice. Simple explanations of reasons for doing things in certain ways must be given.

SCHEDULE V1 Appreciation and Avoidence of Hazards:

The main objective here is the safeguarding of the person and possessions of the retarded individual who is to accept a considerable degree of responsibility for his own welfare or who can live in a family or hostel setting without being a real hazard to life and property.

Some of the content of Schedule V1 will have been touched upon and seen in practical application in the course of covering Schedules IV & V which should precede it, but Schedule V1 brings all hazards together in a systematic way and includes certain items which might otherwise have been overlooked.

As far as possible, training should be in the real life situation, for instance item (1) Road Safety must be practised in this way, but in some other instances such

strategies as discussion, demonstration, behaviour rehearsal can be effectively used.

SCHEDULES V11 Simple Units of Measurement:

V111 Simple Finance:

1X Use of Community Facilities:

These three Schedules are concerned with skills and knowledge which lead to a better understanding of the wider environment and an increased ability to deal with it meaningfully, both for greater independence and a fuller life.

Since Schedule V11 has as its objective the achievement of a knowledge and understanding of the ways in which common aspects of the envornemnt are measured and expressed quantitatively, training in this area lays the foundation for and should precede the introduction of certain of the areas in Schedules V111 and 1X.

Training Strategies for Schedule V11

While the teaching here will more closely resemble "class room" instruction, it must be kept very concrete and based on situations which are of interest to and within the experience of the student. Use of students own body as reference point a.g. height, mass, number of digits and other personal measures such as span of hand, length of foot; learning to use tape or other measure (metres,centimetres) and scales (both bathroom and kitchen types) for weighing large and small quantities. Use of student's own physical capacities such as mass able to be lifted, reach of arms, length of stride, rate of walking. Use of significant times and dates in student's routines and life; use of calendar, large clock face for telling time.

Meaningful counting, seriation exercises, discrimination exercises; judging quantities (height, length,mass etc) and verifying by measurement.
Use of common food containers, packets, bottles and practical exercises based on these.

Reading and writing of figures.

Training Strategies for Schedule V111

Here again, some sections will have to be taught in a "class room" type situation but even in this setting can be made more realistic by basing exercises on catalogues from stores or full page newspaper advertisements such as inserted in the daily press by supermarkets. Real money should be used in all such exercises. Outings in which there is actual shopping and a certain amount of window shopping should be carried out.

Training Strategies for Schedule 1X

Dealing as it does with an understanding of and ability to use community facilit - ies, training in this area must be carried out essentially by actual familiarisation with the various institutions and services listed. The nature and amount of activity planned for one outing with any particular group will, of course, depend on the extent of previous experience. For one group a walk to a public park and a period spent in the park may be all that can at first be managed. For another, a journey by train to a nearby suburb or town, with a visit to a store and practice in using the escalators and public toilets may not be too ambitious as a starting point.

SCHEDULE X Work Attitudes and Behaviour at Work:

The emphasis in this Schedule is almost entirely upon assessment to help to determine in what kind of working environment (if any) the individual may be placed with some expectation of success. As its title implies, it is concerned not so much with work skills as with the more general quality of being able to adapt to and fit into a working routine and regular work setting.

The tutor, who has come to know his group members, will be in a position to evaluate some of the qualities listed but should not depend entirely on this judgement since behaviour and attitudes in a work situation may be rather different from those in the close personal and supportive tutorial group. Hence reports from Supervisors of work carried out inside or outside the residential institution are very necessary.

Although specific training in tutorial groups is not envisaged for this area, yet it is evident that constant opportunities will arise during the whole training programme for referring to and trying to develop some of the desirable work behaviours and attitudes mentioned.

THE SCHEDULES

l.	Personal Appearance and Physical Condition
ll.	Emotional Stability
lll.	Communication
lV.	Care of Living Quarters and Possessions
V.	Simple Food Preparation and Consumption
Vl.	Appreciation and Avoidance of Hazards
Vll.	Simple Units of Measurement
Vlll.	Simple Finance
lX.	Use of Community Facilities
X.	Work Attitudes and Behaviour at Work

Read the following instructions carefully:

Check each item in every schedule. Use the answer sheet provided.

Where there are only two possible responses to an item, Yes ..... No,

Yes receives a score 1

No receives a score 0

This is the case in all Schedules except for some items in Schedules lll and X

Schedules lll and X

In these two Schedules some items require more finely graded scoring, namely: 0 1 2 3 or 0 1 2

In such cases the score to be given precedes each grading.

Example from Schedule lll.

1. Understands spoken language. 0 Not at all, 1 To a very limited extent,

   2 For most practical purposes, 3 Well.

Here there are four grades of ability, the corresponding scores being 0 1 2 3. If there are only three grades as in Item 2 of this Schedule, then the respective scores are 0 1 2.

A.S.A.T. Scoring and Rating Sheet

THE SCHEDULES

Name: .... D.O.B. ....

Age: .... Sex: .... Present Placement: ....

Date of Assessment: .... Language Medium: ....

Diagnosis: ....

Current Status: ....

Reasons for Evaluation: ....

Mental Age or I.Q. level: ....

Date of First Admission: ....

Summary of Evaluation: (See Table 1A)

		Level
I	Personal Appearance and Physical Condition	A B C D
II	Emotional Stability	A B C D
III	Communication	A B C D
IV	Care of Living Quarters and Possessions	A B C D
V	Simple Food Preparation and Consumption	A B C D
VI	Appreciation and avoidance of Hazards	A B C D
VII	Simple Units of Measurement	A B C D
VIII	Simple Finance	A B C D
IX	Use of Community Facilities	A B C D
X	Work Attitudes and Behaviour at Work	A B C D

Comments, Conclusions, and Recommendations: ....

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Signature of Evaluator: ....

....

SCHEDULE I

yes (1) no (o)

PERSONAL APPEARANCE AND PHYSICAL CONDITION

1.	Is physical appearance sufficiently normal not to cause repulsion, undue attention or ridicule ?	yes	no
	If no, specify abnormal features		
	....		
2.	Is free from physical handicap, physical health condition or extreme frailty which, if present, would place at special risk	yes	no
	If no, specify disability		
3.	Has the necessary strength, co-ordination and agility to cope with ordinary physical tasks e.g. moving freely, lifting, reaching, carrying	yes	no
	If no, specify disability		
4.	Is free from severely handicapping, uncorrectable visual or auditory defect	yes	no
	If no, specify defect		
5.	Has the necessary dexterity to carry out manual move - ments e.g. use of implements and tools, household tasks etc	yes	no
6.	Is the body held and managed in such a way as to avoid undersirable postures and abnormal physical mannerisms?	yes	no
	If no, specify abnormalities		
	....		
7.	Does the appearance and condition indicate the exercise of personal cleanliness, e.g. face, neck, nails, teeth, hair?	yes	no
8.	Is personal hygiene attended to without supervision?...	yes	no
9.	Is clothing neat and clean?............................	yes	no
10.	Is there an understanding of appropriate dress for occasion and weather?	yes	no
11.	Is free from unacceptable personal habits e.g. nose picking, drooling	yes	no

SCHEDULE I

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SCHEDULE 11

Yes (1) no (o)

EMOTIONAL STABILITY

1. Is the general behaviour sufficiently normal not to cause repulsion, fear, avoidance, damage to self or others, or conflict with the law .... yes no

If no, specify abnormality.........................

2. If free from psychiatric condition(other than retardation) which is present, would place at special risk.................................. yes no

If no, specify condition and indicate whether it can be controlled by suitable medication ....

....

3. Is able to handle strong negative feelings, e.g. anger,disappointment without resorting to behaviour which would:-

i Damage other persons i.e.any form of physical assault

ii Damage possessions of others i.e. breaking,throwing away, concealing.

iii Damage self i.e. self-mutilation,suicidal attempts

iv Damage own possessions i.e. tearing clothes, breaking objects.

v Be otherwise socially unacceptable i.e.screaming, cursing, tantrums .... yes no

If no, specify unacceptable behaviour........

....

4. Is able to handle strong positive feelings e.g. delight joy without resorting to highly implusive and in-appropriate behaviour such as: -

i Indiscriminate hugging and kissing

ii Wild physical movement,leaping,rushing around.

iii Shrieking and other unacceptable vocal expression.

.... yes no

If no, specify unacceptable behaviour.....

....

5. Is able to limit the expression of sexual impulses i.e. to refrain from: -

i Indiscriminate sexual advances to opposite sex.

ii Indiscriminate sexual advances to same sex.

iii Self stimulation in public.

iv Exhibiting self in public.

v. Over-readiness to respond to sexual advances by others.................................... yes no

If no, specify unacceptable behaviour......

....

....

SCHEDULE II (Cont.)

		yes (1)	no(o)
6.	Can accept minor upsents and irritations...........	yes	no
	If no, specify usual reaction		
	....		
7.	Will tend to seek aid/advice from suitable person when in trouble	yes	no
8.	Is free from a record of habitual:-		
	i) Dishonesty i.e. pilfering, stealing.		
	ii) Telling falsehoods, lying.		
	iii) Trouble making i.e.deceitfulness,blaming others, fostering bad behaviour.		
	....	yes	no
	If no, specify unacceptable behaviour..............		
	....		

SCHEDULE II

....

....

....

....

....

....

SCHEDULE III

COMMUNICATION

yes (1) no (o)

1. Understands spoken language. (Mark one)

0 not at all, 1 To a very limited extent, 2 for most practical purposes, 3 Well 0 1 2 3

2. Listens attentively with awareness of expected conventions (Mark one)

0 No awareness, 1 Fair awareness, 2 Good awareness 0 1 2

3. Communicates verbally (speaks) (Mark one)

0 Not at all, 1 To a very limited extent, 2 For most practical purposes, 3 Well 0 1 2 3

4. Uses speech with awareness of expected conventions (Mark one)

0 No awareness, 1 Fair awareness, 2 Good awareness.......... 0 1 2

5. Is speech (if present) intelligible to everyone .... yes no

6. Refrains from habitual swearing and other socially unacceptable language or unacceptable sounds if no speech present......... yes no

7. Able to read (Mark one)

0 not at all, 1 A few sight words only e.g. Ladies, danger, 2 Simple material with understanding, 3 Well 0 1 2 3

8. Able to read figures accurately e.g. 10 centimetres, No 23.... yes no

9. Communicates by writing. (Mark one)

0 Not at all, 1 A few isolated words/Figures, 2 Very simple notes/messages, 3 For most practical purposes.. 0 1 2 3

10. Can use private (home or familiar) telephone to give, receive messages .... yes no

11. Is free from handicapping speech defect e.g. severe stuttering.

If No, specify defect. .... yes no

12. Where speech is absent or extremely limited through some special condition (other than severe retardation) e.g. deafness, aphasia, is there ability to make needs known through gestures, signs ? (Mark one)

0 Special condition present, not able to make needs known, 1 Special condition present but able to make needs known, 2 Not applicable, no such special condition present 0 1 2

....

SCHEDULE IV

CARE OF LIVING QUARTERS AND PERSONAL POSSESSIONS

		yes (1)	no (o)
1.	Is completely free from wetting/soiling bed..............	yes	no
2.	Is free from other unacceptable toilet habits e.g. soiling clothes, room etc	yes	no
3.	Simple rules of cleanliness and hygiene in room/s		
i	Understands need for airing room, openeing windows.......	yes	no
ii	Understands disposal of refuse, use of w.p.b., ash tray, dust bin. Does not hoard rubbish, stale food, empty food contain - ers in room	yes	no
iii	Is capable of cleaning own room, sweeping, dusting, tidying.	yes	no
iv	Makes own bed, changes linen, towels at suitable intervals..	yes	no
v	Washes hair brush/comb when necessary	yes	no
vi	Is hygienic in public bathroom and toilet	yes	no
4.	Storage of clothes and possessions.		
i	Hangs suits, frocks in wardrobe	yes	no
ii	Packs clean underwear etc. neatly in drawers..............	yes	no
iii	Keeps shoes in suitable place..........................	yes	no
iv	Keeps toilet articles, face cloth, towel, toothbrush etc. in suitable place	yes	no
5.	Cleanliness and repair of clothes.		
i	Understands disposal of soiled garments, laundry arrangements	yes	no
ii	Is capable of washing and drying of washable garments, simple ironing	yes	no
iii	Is capable of cleaning shoes and use of clothes brush.....	yes	no
iv	Understands use of dry cleaners, type of garment to be taken there	yes	no
v	Understands use of shoe repairer, recognises need for shoe repairs	yes	no
vi	Is capable of small repairs or knows where to seek help e.g. buttons, tears, etc....................................	yes	no
6.	Safety and conventions.		
i	Refrains from smoking in bed	yes	no
ii	Exercises care with electrical appliances, heater	yes	no
iii	Conforms to rules of house, punctuality at meals, use of radio, entertaining	yes	no

SCHEDULE IV: ....

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SCHEDULE V

SIMPLE FOOD PREPARATION AND CONSUMPTION

			yes (1)	no (o)
1.	i	Understands control of heat, turning on, increasing, reducing, switching off, use of electric kettle.....................	yes	no
	ii	Understands heating (dry) and boiling fast and simmering, knows when liquid is boiling understands boiling over.....	yes	no
2.		Understands use of cooking utensils, and implements e.g. plastic and china cannot be placed on hot stove, kettles, pots must contain liquid before being heated; use of tin opener; avoid burning, cutting self	yes	no
3.		Keeping/storing of food:		
	i	Understands what are suitable containers for various commodities	yes	no
	ii	Understands need for keeping certain foods in refrigerator.	yes	no
	iii	Recognises need for cleanliness in handling and storing food	yes	no
	iv	Recognises when food/drink is stale and knows when it is unsafe to consume foods...................................	yes	no
	v	Avoids storing cleaning and other toxic materials with food stuffs...	yes	no
4.		Meal making:		
	i	Can make tea, coffee or other beverage.....................	yes	no
	ii	Can boil eggs, hard soft, understands timing...............	yes	no
	iii	Can deal with raw fruit/vegatables, peeling and washing	yes	no
	iv	Can prepare sandwiches and wrap suitably..................	yes	no
	v	Can prepare simple breakfast/supper e.g. cereal, egg	yes	no
	vi	Can lay a table or tray properly	yes	no
	vii	Can wash and dry cutlery, dishes..........................	yes	no
	viii	Can prepare most vegetables for cooking	yes	no
5.		Has elementary idea of food values e.g. fruit, vegetables, whole wheat bread	yes	no
6.		Has acceptable table manners	yes	no

SCHEDULE V.

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SCHEDULE VI

yes (1) no (o)

APPRECIATION AND AVOIDANCE OF HAZARDS

			yes	no
1.	Road Safety			
	i	Understands use of traffic lights:Discriminates red/green..	yes	no
	ii	Practices correct road crossing in absence of traffic lights	yes	no
	iii	Knows correct side of road to use in absence of pavements..	yes	no
2.	Burns			
	i	Tests washing and bath water	yes	no
	ii	Shows care in handling pots on stove,in oven and irons.....	yes	no
	iii	Avoids over exposure to sun	yes	no
3.	Cuts			
		Handles sharp tools and implements with proper care	yes	no
4.	Fire			
	i	Avoids putting or throwing down lighted cigarettes.........	yes	no
	ii	Refrains from lighting fires in open places...............	yes	no
	iii	Knows inflammable liquids - petrol,paraffin,cleaning fluids	yes	no
	iv	Switches off electrical equipment,irons,kettles,heaters....	yes	no
	v	Avoids drying garments etc.close to electric or open fire..	yes	no
	vi	Cools hot appliances e.g.irons, before putting away........	yes	no
5.	Poisons			
	i	Can read: "Poison, Not to be taken"	yes	no
	ii	Understands stale food/drink can be poisonous..............	yes	no
	iii	Understands that water from certain sources should not be drunk	yes	no
	iv	Refrains from taking pills/medicines other than given by a responsible person..	yes	no
	v	Understands that wild berries,mushrooms can be poisonous...	yes	no
	vi	Refrains from putting toxic substances in unlabelled containers	yes	no
6.	Electricity			
	i	Undertands that electricity can kill......................	yes	no
	ii	Understands that switch should be off before inserting/ removing appliance......................................	yes	no
	iii	Knows location and function of Main Switch................	yes	no
7.	Alcohol			
	i	Knows difference between soft and alcoholic drinks.........	yes	no
	ii	Knows causes and obvious indications of drunkenness........	yes	no
	iii	Has been free from "drinking" behaviour....................	yes	no

....

SCHEDULE VI (Cont.)

			yes(1)	no(o)
8.	Theft and Burglary			
	i	Understands need for locking doors, windows, cupboards.......	yes	no
	ii	Understands need for keeping valuables/moneys safely at home/work	yes	no
	iii	Understands danger of pickpockets, bag snatchers..........	yes	no
9.	Assualt and Accident			
	i	Avoids going out alone at nights..........................	yes	no
	ii	Avoids frequenting unsafe places, day or night............	yes	no
	iii	Avoids accepting lifts/invitations indiscriminately........	yes	no
	iv	Avoids inviting strangers into home......................	yes	no
10.	Water			
		Understands danger of drowning, avoids taking risks.........	yes	no
11.	General			
	i	Capable of very simple first-aid, washing and band-aid for small cuts etc.	yes	no
	ii	Immediate reporting of any accident/injury to superior.....	yes	no

SCHEDULE VI

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SCHEDULE VII

yes(1) no(o)

SIMPLE UNITS OF MEASUREMENT

1. Number

		yes(1)	no(o)
i	Counts with understanding up to and including 10............	yes	no
ii	Counts with understanding up to and including 20............	yes	no
iii	Counts by tens up to and including 100	yes	no
iv	Understands the 3 positions,units,tens,hundreds.............	yes	no
v	Understands symbols, and meaning of $\frac{1}{2}$, $\frac{1}{4}$	yes	no
vi	Can read and write numbers up to and including 999..........	yes	no
vii	Understands ordinal positions e.g. 1st,2nd,3rd	yes	no

2. Time

		yes(1)	no(o)
i	Can tell time accurately from clock within 5 minutes........	yes	no
ii	Knows time of regular routines, e.g.meals, transport, work hours..	yes	no
iii	Knows with understanding: days of week,months of the year, seasons of year,number of weeks and days in month, months in year..	yes	no
iv	Can use Calendar: knows date, day, months, year.............	yes	no
v	Has realistic appreciation of duration of 1hr, $\frac{1}{2}$hr, $\frac{1}{4}$hr, 5 minutes...	yes	no

3. Length, Height, Distance

	yes(1)	no(o)
Knows with understanding i.e. can compare,judge and relate to one another; 1 Kilometre, 1 Metre, 1 Centimetre	yes	no

4. Mass

	yes(1)	no(o)
Knows with understanding: 1 Kilogram., $\frac{1}{2}$ K., 250 grammes,100 g.	yes	no

5. Capacity

	yes(1)	no(o)
Knows with understanding: 1 litre, $\frac{1}{2}$ litre.......................	yes	no

6. Grasps relationship between time and distance: e.g.how long it

	yes(1)	no(o)
would take to walk, 1 Kilometre; travel a certain distance by bus etc	yes	no

7. Personal details

	yes(1)	no(o)
Knows the following: Own height, mass, own age, date of birth; shirt, dress, shoe sizes;home address and telephone number; address and telephone number at work	yes	no

SCHEDULE VII:

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SCHEDULE VIII

yes(1) no(o)

SIMPLE FINANCE

1.	Recognises all coins and notes up to and including R10 note...	yes	no
2.	Understands relationship of one denomination to another e.g. 2 x 50c = R1	yes	no
3.	Can calculate and check simple change..........................	yes	no
4.	Understands price and quantity symbols e.g. 2 Kg for 55c	yes	no
5.	Understands in which shops various commodities can be bought..	yes	no
6.	Has some realistic grasp of value of commodities..............	yes	no
7.	Buys only for cash..	yes	no
8.	Avoids borrowing and lending money..........................	yes	no
9.	Understands need for safe custody of money....................	yes	no
10.	Understands need for safe retention of receipts..............	yes	no
11.	Can manage a Post Office savings account......................	yes	no
12.	Can plan prudent use of money, e.g. pays basic sums such as boarding fees first, saves something each pay day for future use	yes	no

SCHEDULE VIII:

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SCHEDULE IX

yes (1) no (o)

USE OF COMMUNITY FACILITIES

Is there sufficient knowledge and experience with the following facilities to allow use of them if and when required ? Check each:

1. Public Transport
   - i Location of and procedure in station and on train............... yes no
   - ii Location of and procedure at bus stops and in bus............... yes no
   - iii Use of lifts and escalators................................... yes no
2. Recognition of and proper conduct in:
   - i Public toilets including toilets in large stores............... yes no
   - ii Places of recreation e.g. cinemas, parks......................... yes no
   - iii Eating places e.g. cafes, can manage self service.............. yes no
   - iv Public telephone booths.. yes no
   - v Relevant religious institution.................................. yes no
3. Recognition and use of letter boxes................................ yes no
4. Recognition of police station and policemen, nature of help available .... yes no
5. Proper behaviour in streets - avoid gaping, loud talking, undesirable comments, blocking path by walking 3 or 4 abreast.............. yes no
6. Recognition of Post Office and understanding of main services available there... yes no
7. Knows location of and how to use relevant Welfare or Mental Health Society when in need.. yes no

SCHEDULE IX:

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SCHEDULE X

yes(1) no (o)

WORK ATTITUDES AND BEHAVIOUR AT WORK

1\. i Work experience (Mark one)

0 none, 1 less than 3 months, 2 at least three months 0 1 2

ii Nature of work (Mark one)

0 No work, 1 unskilled repetitive, 2 better than unskilled 0 1 2

2\. Are reports from Supervisor/s (Mark one)

0 Unsatisfactory, 1 fairly satisfactory, 2 satisfactory 0 1 2

3\. Has been retained in job/work situation.................... Yes no

If no, give reason/s for dismissal.........................

4\. Attitude to persons in authority.

i Able to understand and carry out instructions.......... yes no

ii Understands whose instructions must be obeyed........... yes no

iii Can take correction or reprimand from authority......... yes no

5\. Relationship with fellow workers.

i Can co-operate with others to carry out task .... yes no

ii Is free from behaviour which would make group inclusion difficult.. yes no

If no, specify difficulty...................................

6\. General work attitudes (mark one for each quality)

i	Punctuality	0 Poor	1 Fair	2 Good	0 1 2
ii	Attendance	0 Poor	1 Fair	2 Good	0 1 2
iii	Reliability	0 Poor	1 Fair	2 Good	0 1 2
iv	Persistence	0 Poor	1 Fair	2 Good	0 1 2
v	Conformity to rules	0 Poor	1 Fair	2 Good	0 1 2

7\. Potential for further work training (Mark one)

0 Extremely limited, unlikely to adapt or learn new skills

1 Fair, will probably adapt and respond to certain training

2 Good, should adapt well and definitely benefit from training

0 1 2

GUIDE FOR SCORING AND RATING ON A.S.A.T.

Complete the appropriate section of the Scoring and Rating Sheet page Two by making a pencil stroke through the obtained score for each item.
Add all the scores for the Schedule and write the result next to Total.
Enter the ten totals in the correct boxes in Table 1 A which appears at the bottom of the Scoring Sheet.
Refer to Table 1 B by means of which each Schedule Total you have entered in Table 1 A can be given a Rating Level (A, B, C, D,).
Enter these Rating Levels in the correct boxes in Table 1 A.

Table 1 A is now complete. It provides the data for:

- i An overall Rating Level
- ii Recommendations for appropriate placement (See Table 2).
- iii Required further training in all or some areas,
- iv A baseline when reassessment is done after training.

Complete all items for identifying data, name, age etc. scoring sheet (Page one).
Circle the appropriate Level Rating in the Summary of Evaluation for each section on the scoringsheet page one. Refer to Table 1 A.

This provides a graphic display of the overall functioning level of the person.

Refer to Table 2 for guidelines as to placement recommendations.

TABLE I B

For determining the Rating Level for each Schedule Total

Schedule	Maximum	A	B	C	D
I	11	11 to 9	8 to 7	6 to 5	4 to 0
II	8	8	7	6	5 to 0
III	23	23 to 20	19 to 13	12 to 7	6 to 0
IV	22	22	21 to 18	17 to 14	13 to 0
V	18	18 to 17	16 to 12	11 to 5	4 to 0
VI	35	35	34 to 31	30 to 25	24 to 0
VII	17	17 to 14	13 to 11	10 to 3	2 to 0
VIII	12	12 to 11	10 to 7	6 to 3	2 to 0
IX	13	13	12 to 10	9 to 4	3 to 0
X	24	24 to 21	20 to 15	14 to 10	9 to 0

Table I B reflects four different levels of functioning, namely A B C D and each level corresponds to a particular kind of setting in which the individual, at this point in his development and training, is likely to have a reasonable chance of success. These four settings are described in Table 2 .

ASAT Scoring and Rating Sheet

Schedule I

Item	Score
1	1 0
2	1 0
3	1 0
4	1 0
5	1 0
6	1 0
7	1 0
8	1 0
9	1 0
10	1 0
11	1 0

Total

Schedule II

Item	Score
1	1 0
2	1 0
3	1 0
4	1 0
5	1 0
6	1 0
7	1 0
8	1 0

Total

Schedule III

Item	Score
1	3 2 1 0
2	2 1 0
3	3 2 1 0
4	2 1 0
5	1 0
6	1 0
7	3 2 1 0
8	1 0
9	3 2 1 0
10	1 0
11	1 0
12	2 1 0

Total

Schedule IV

Item	Score
1	1 0
2	1 0
3i	1 0
3ii	1 0
3iii	1 0
3iv	1 0
3v	1 0
3vi	1 0
4i	1 0
4ii	1 0
4iii	1 0
4iv	1 0
5i	1 0
5ii	1 0
5iii	1 0
5iv	1 0
5v	1 0
5vi	1 0
6i	1 0
6ii	1 0
6iii	1 0

Total

Schedule V

Item	Score
1i	1 0
1ii	1 0
2	1 0
3i	1 0
3ii	1 0
3iii	1 0
3iv	1 0
3v	1 0
4i	1 0
4ii	1 0
4iii	1 0
4iv	1 0
4v	1 0
4vi	1 0
4vii	1 0
4viii	1 0
5	1 0
6	1 0

Total

ASAT Scoring and Rating Sheet Continued

Schedule VI

Item	Score
1i	1 0
1ii	1 0
1iii	1 0
2i	1 0
2ii	1 0
2iii	1 0
3	1 0
4i	1 0
4ii	1 0
4iii	1 0
4iv	1 0
4v	1 0
4vi	1 0
5i	1 0
5ii	1 0
5iii	1 0
5iv	1 0
5v	1 0
5vi	1 0
6i	1 0
6ii	1 0
6iii	1 0
7i	1 0
7ii	1 0
7iii	1 0
8i	1 0
8ii	1 0
8iii	1 0
9i	1 0
9ii	1 0
9iii	1 0
9iv	1 0
10	1 0
11i	1 0
11ii	1 0
Total	

Schedule VII

Item	Score
1i	1 0
1ii	1 0
1iii	1 0
1iv	1 0
1v	1 0
1vi	1 0
1vii	1 0
2i	1 0
2ii	1 0
2iii	1 0
2iv	1 0
2v	1 0
3	1 0
4	1 0
5	1 0
6	1 0
7	1 0
Total	

Schedule VIII

Item	Score
1	1 0
2	1 0
3	1 0
4	1 0
5	1 0
6	1 0
7	1 0
8	1 0
9	1 0
10	1 0
11	1 0
12	1 0
Total	

Schedule IX

Item	Score
1i	1 0
1ii	1 0
1iii	1 0
2i	1 0
2ii	1 0
2iii	1 0
2iv	1 0
2v	1 0
3	1 0
4	1 0
5	1 0
6	1 0
7	1 0
Total	

Schedule X

Item	Score
1i	2 1 0
1ii	2 1 0
2	2 1 0
3	1 0
4i	1 0
4ii	1 0
4iii	1 0
5i	1 0
5ii	1 0
6i	2 1 0
6ii	2 1 0
6iii	2 1 0
6iv	2 1 0
6v	2 1 0
7	2 1 0
Total	

	I	II	III	IV	V	VI	VII	VIII	IX	X
Score:										
Level:										

APPENDIX C

Questionnaire for Landladies

QUESTIONNAIRE FOR LANDLADY

Name of lodger......................... Date....................

Address..

....

Name of landlady...

1) How long have you known the lodger?.......................

2) How long has s/he stayed with you?........................

3) How is his/her appearance?...............................

....

....

Dirty & slovenly Untidy Tidy Appropriately dressed Well groomed

4) How does s/he keep his/her room?..........................

....

....

Very dirty Dirty Adequately clean Clean Extremely clean

Very untidy Untidy Occasionally untidy Lived in Very tidy

5) Could you comment on his/her behaviour at your house?

Are there any aspects which concern you?

(e.g. well behaved, polite, punctual, etc.)..................

....

....

....

6) How does s/he get along with the people in your house/

(e.g. causes trouble, picks fights, causes complaints etc.)

....

....

....

7) How does s/he manage in the kitchen?........................

....

....

....

a) Unable to manage any tasks

b) Is capable of simple tasks, e.g. tea, washing-up

c) Can do simple meals with supervision

d) Can do simple meals WITHOUT supervision

e) Fully competent to manage alone

8) How does s/he manage money?.................................

....

....

....

a) Totally dependent upon someone else

b) Requires supervision in almost all areas

c) Supervision in certain areas only

d) Minimum of supervision required

e) Fully independent

9) What does s/he do in his/her spare time?...................

....

....

10) Does s/he have any friends? If so, of what sex?...........

....

....

11) Are there any other comments you would like to make?........

....

....

....

APPENDIX D

Questionnaire for Employer

QUESTIONNAIRE FOR EMPLOYER

Name of employee..........................Date.................

Name of employer..

Address...

....

1) How long has s/he worked for you?.........................

2) What kind of work does s/he do?...........................

....

3) How is his/her performance of this work?...................

....

Poor Fair Quite good Excellent

4) Is s/he able to understand instructions and carry them out?

....

5) How does s/he get along with fellow workers?

(e.g. a trouble maker, undergoes ridicule)..................

....

....

6) Does s/he have any friends at work?.........................

7) Does s/he show problems in any of the following?

Attendance..

Punctuality...

Reliability...

Persistence...

Conformity to rules.......................................

8) Do you think that s/he has the potential to improve with further training?...

....

....

9) Are there any other comments you would like to make?

....

....

....

APPENDIX E

Community Evaluation Form (revised)

COMMUNITY EVALUATION FORM

Date of interview: ....

SECTION I: PERSONAL DATA

1. Name: ....
2. Address: ....
3. Sex: M. F.
4. Marital status: Single: ... Married: ... Other (specify).............
5. Date of institutionalisation: ....
6. Date of discharge: ....
7. Number of years institutionalised: ....
8. Number of years in community: ....
9. IQ: Test: .... Score: ....

SECTION II: LIVING ACCOMODATION

10. Boarding house .... Rented room .... Flat .... Private home .... YWCA-YMCA .... Live-in .... Group home .... Other (specify) ....
11. How long has S lived at this residence: ....
12. Number of residence changes since discharge: .... Reason ....

.... Reason ....

.... Reason ....

.... Reason ....

3. How do you like where you are living now:

ery satisfied .... Moderately satisfied .... Dissatisfied ....

4. What do you like (or dislike) about where you are living ....

....

5. Do you live alone or with someone else (other than your spouse): ......

If someone else) Who: .... For how long: ....

no pays the rent: ....

no pays for the food: ....

ow do you feel about these arrangements: ....

....

6. Does your landlord treat you fairly: Yes .... No .... N/A ....

no, explain: ....

....

7. Has S ever been robbed: ..... If yes, explain: ....

....

DDITIONAL COMMENTS:

CTION III: PERSONAL FINANCES

. Salary/wages per month (net): ....

. If S is unemployed, how long: ....

20. Do you have a savings account: ..... Amount: YES........NO.....

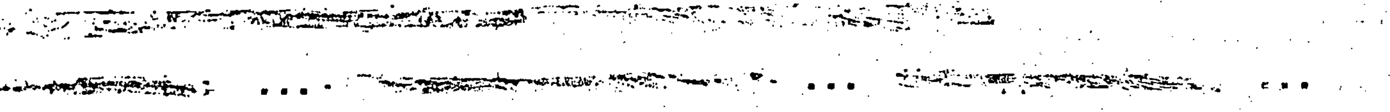
21. Do you have a cheque account: ..... Amount: YES........NO....

If no, how do you pay your bills: ....

22. Do you owe money on anything: YES...., NO ...

On what: .... Monthly payments: ....

On what: .... Monthly payments: ....



23. What major items have you bought recently: ....

....

Why did you buy them: ....

24. Did you ever buy anything that didn't work well, didn't fit,

or wasn't what you asked for: Yes: ... No: ...

If yes, explain: ....

....

....

What did you do about it: ....

....

....

25. Have you ever loaned anyone money, clothing, or personal posessions:

Yes: ... No: ... If yes, explain: ....

....

26. Did you get it back. Explain: ....

....

27. Have you ever done any betting or gambling: Yes: ... No: ...

If yes, explain: ....

o you often win or lose: ....

8. Do you spend all your money, or do you save some: ....

hat are you saving for: ....

9. Do you wish you had more money: Yes: ... No: ...

hat would you like to buy:........ ....

[illegible]

[illegible] ... [illegible] ... [illegible] ...

0. What do you consider your most valuable posessions: ....

....

1. Do you think of yourself as: Rich: ... Poor: ...

2. How satisfied are you with the amount of money and personal posessions

ou have now: Very: ... Moderately: ... Dissatisfied: ...

DDITIONAL COMMENTS

ECTION IV: VOCATIONAL

3. Type of job: .... Employer: ....

4. Skill level: Unskilled: ... Semiskilled: ...

5. Length of time S has held present job: ....

6. Manner in which job was obtained: ....

....

7. Number of jobs since discharge and reason for leaving:

.... Reason: ....

.... Reason: ....

.... Reason: ....

38. Total time unemployed since discharge: ....

Interviewer's rating of employment history:

Always unemployed: ... Mostly unemployed: ... About equally employed/unemployed: ... Mostly employed: ... Always employed: ...

(Judge part-time work into the middle three categories.)

39. Upward mobility: Have most jobs represented increased salary and/or status: Yes: ... No: ... Specify: ....

....

40. Have you ever been asked to work longer than your usual hours:

Yes: ... No: ... N/A: ... If yes, was overtime paid: Yes: ... No:

41. Job benefits: Holidays (how many): ....

Sick leave (how much): .... Pension plan (type): ....

Meals provided (how many; for how much): ....

42. Have you had any raises or promotions: Yes: ... No: ... N/A: ...

Specify: ....

43. Do you have any friends at work: Yes: ... No: ... N/A: ...

Are there people you eat lunch or take breaks with: Yes ... No ... N/A ...

Do you see these friends outside of work: Yes: ... NO: ... N/A: ...

44. How do you get to and from work: ....

45. How well do you like your job:

Very satisfying: ... Moderately satisfying: ... Dissatisfied: ...

ADDITIONAL COMMENTS

SECTION V: LEISURE TIME

46. What do you like to do in free time, after work, on weekends or holidays:

....

....

47. Does S belong to any clubs or organisations: Yes: ... No: ...

If yes, specify: ....

48. How often does S go to a film: ....

49. How often does S go to a sporting event: ....

50. Do you ever go to the library: Yes: ... No: ...

51. Do you ever go to church: Yes ... No ... How often ....

52. Are church groups/activities an important part of S's life:

Yes: ... No: ... Specify: ....

53. Where have you gone on holidays: ....

....

....

How did you get there: ....

54. Are there places you'd like to Go where you've never been:

Yes ... No ... If yes, where: ....

What prevents you from going there: ....

55. Do you ever read books: Yes: ... No: ... If yes, give examples:

....

56. Do you ever read magazines: Yes: ... No: ... Give examples:

....

57. Do you read a newspaper: Yes: ... No: ... Which one:

....

8. How often do you watch TV: ....

hat are some of the programs that you watch: ....

....

9. Do you listen to the radio: Yes: ... No: ... What programs do you

isten to: ....

0. Do you have a hobby: Yes: ... NO: ... Specify:

....

....

1. How satisfied are you with the way you use your leisure time:

ery satisfied: ... Moderately satisfied: ... Dissatisfied: ...

2. Interviewer's rating of S's use of leisure time:

ery effective: ... Moderately effective: ... Ineffective: ...

DDITIONAL COMMENTS

ECTION VI: SOCIAL AND EMOTIONAL ADJUSTMENT

3. Have you made new friends since you left Alex: Yes: ... No: ...

4. Are most of your friends former Alex residents or are they new friends:

....

o you have contact with your neighbours: Yes: ... No: ...

pecify: ....

5. What do you do when you and your friends get together: ....

....

66. Do you ever visit friends: Yes: ... No: ...

If yes, about how often: ....

67. Do your friends ever visit you: Yes: ... No: ...

If yes, about how often: ....

How long do they stay: ....

68. Would you like to have more friends: Yes: ... No: ...

If yes, what keeps you from making new friends: ....

....

69. Do you have friends who are the opposite sex: Yes: ... No: ...

70. Do you have trouble meeting people of the opposite sex: Yes ... No ...

If yes, why: ....

71. Do you have any problems with people of the opposite sex:

Yes: ... No: ...

If yes, specify: ....

72. (If S is unmarried): Do you date: Yes: ... No: ...

If no, Would you like to: Yes: ... No: ...

If yes, What do you like to do on a date: ....

....

Would you like to get married someday: Yes: ... No: ...

If not, why not: ....

73. (If S is unmarried): Do you have a boyfriend (girlfriend): Yes ... No .

74. (If S is married): What do you and your spouse like to do when you go out

together: ....

....

75. Do you have any contact with your family: Yes: ... No: ...

If yes, when and on what occasions do you see your family: ....

....

76. Do you help them, give them presents, or lend them money (specify):

....

77. Do they help you, give you presents, or lend you money (specify):

....

78. Would you like to see your family more often: Yes: ... No: ...

If yes, what prevents you from seeing them: ....

....

79. How do you feel about living on your own: ....

....

80. Do you ever feel you would rather be back at Alex: Yes: ... No: ..

81. When you were at Alex, did you learn what you needed to know about how to live on your own: Yes: ... No: ...

If no, what do you wish you had learned at Alex: ....

....

82. How do you feel about being from Alex: ....

....

83. Does it bother you that you used to live at Alex: ....

84. Do you know why you were at Alex: ....

85. Do most of your friends know that you used to live at Alex: ....

86. Do you think that it matters to them: ....

87. Do most of the people at work know that you used to live at Alex: ...

88. Do you think that it matters to them: ....

89. Do you think that they treat you differently: ....

90. Are there certain people you tell that you have lived at Alex, and certain people you do not: ....

Who: ....

Why: ....

91. If you were to give advice to an Alex resident who wants to leave, what would you say: ....

....

92. Do you go to meetings and social events at Alex: ....

93. Do you call people at Alex when you are in trouble: ....

94. Have you had any problems that you feel you couldn't handle:

Yes: ... No: ... If yes, what happened:

....

....

95. Are there certain things or situations that you are afraid of:

Yes: ... No: ... If yes, what are they:

....

....

96. Are you nervous often: Yes: ... No: ...

97. Do you bite your nails: Yes: ... No: ...

98. Do you have trouble sleeping: Yes: ... No: ...

99. Do you often have headaches: Yes: ... No: ...

100. Do you often feel lonely: Yes: ... No: ...

101. When you are upset about something, do you have someone in your family or a friend with whom you can talk things over:

If yes, who: ....

If no, why not: ....

102. Have you had any health problems: Yes: ... No: ...

Specify: ....

What do you do when you get sick: ....

Do you have a doctor: Yes: ... No: ...

103. Have you had any accidents (home/work/car): Yes: ... No: ...

If yes, specify: ....

104. Do you manage by yourself, or do you depend on your family or other people for help (specify type and amount of aid): ....

....

105. Have you ever been arrested: Yes: ... No: ... If yes, specify circumstances

and outcome: ....

106. How do you feel about your life in general:

Very satisfied: ... Moderately satisfied: ... Dissatisfied: ...

[illegible]

[illegible]

[illegible]

[illegible]

ADDITIONAL COMMENTS

SECTION VII: MARRIAGE (if S is married)

107. Is spouse employed: Yes: ... No: ...

Type of job: ....

Spouse's income: Monthly: ......

Educational level: ....

108. Children: Age: ....

Children: Health: ....

Children: School level: ....

Are children living at home: Yes: ... No: ...

If not, where are they: ....

109. Are birth control methods used: Yes: ... No: ...

If yes, specify: ....

110. What does S consider as problems in the marriage situation (specify):

....

....

[illegible] age/family [illegible]

[illegible] ctory: ... [illegible] tely [illegible] ctory: ... [illegible]

ADDITIONAL COMMENTS

APPENDIX F

Correlation Matrix

APPENDIX F

Correlation matrix of "improvement scores" with age, IQ and length of institutionalization for experimental group

	A	IQ	Inst.	I	II	III	IV	V	VI	VII	VIII	IX	X
A	1,00												
IQ	0,00	1,00											
Inst.	0,64	-0,22	1,00										
I	0,13	-0,02	0,14	1,00									
II	-0,17	0,39	0,28	0,33	1,00								
III	-0,03	0,51	-0,20	0,09	0,21	1,00							
IV	-0,21	-0,05	0,09	0,25	0,12	0,34	1,00						
V	-0,05	0,08	0,15	-0,15	0,29	-0,28	-0,37	1,00					
VI	-0,56	-0,05	-0,49	-0,05	0,10	0,29	-0,03	0,20	1,00				
VII	-0,07	-0,67	-0,10	-0,11	-0,52	-0,56	-0,11	0,42	0,22	1,00			
VIII	0,00	0,13	0,02	-0,14	0,25	-0,12	-0,07	0,67	0,07	0,33	1,00		
IX	-0,45	0,26	-0,16	-0,51	0,26	0,01	-0,15	0,50	0,16	-0,06	0,26	1,00	
X	-0,25	0,04	0,24	-0,28	0,60	-0,12	-0,18	0,35	0,00	-0,28	0,25	0,57	1,00

APPENDIX G

Evaluation of the ASAT Schedules

APPENDIX G

EVALUATION OF THE ASAT SCHEDULES

As mentioned previously, the present study was the first to utilize the ASAT schedules for research purposes, and, in closely supervising and organising the assessments, several problems in their administration and scoring became apparent which were not obvious in the initial reading. Because it is thought that the content of the schedules is extremely relevant and that they fill an existing gap in the assessment of retarded persons, it was decided to outline the major difficulties encountered with each schedule, in the hope that they may be revised in the future. It is felt that such revision would be extremely valuable, both for increased ease of admininstration and for the use of the schedules in future research. It must be stressed that this evaluation is based solely on the experience gained in this study (personally and from discussions with nursing assistants) and that other users of the schedules may have a different perspective.

The problems encountered fall into a number of general categories, some of which appear in more than one schedule. To avoid unnecessary repetition, the various problem areas will be discussed first, then related to each schedule in turn.

Personal judgment. In a number of instances personal judgments are required for the scoring of items and, considering that those administering the schedules have had no training in attempting to be objective, scoring could be unreliable. Staff in a large centre become accustomed to residents with various degrees of retardation so their (the staff) assessment of "normality" might be more generous than that of an "outside" person.

Sources of information. Although it is stressed that information should be obtained through observation over a period of time, it is not clear how this is to be done. The person completing the schedules is not able to observe the resident in all areas of his/her daily living, and so obtaining information from a secondary source would appear to be unavoidable. In some instances information could be obtained from the resident directly but this might be unreliable. No guidelines are given which would help the person completing the assessment to decide which source of information would be most valid or how the information should be obtained in lieu of actual observation.

Difficulties in scoring. A number of questions are phrased as single questions but include a number of items. This creates uncertainty in scoring when a resident knows part of what is required but not all. A rating scale or a number of separate questions would eliminate this problem.

Ambiguous phrasing. The intended meaning of a number of words and phrases is ambiguous. It is not clear what is meant by "understands", "is capable of", "knows", "recognises" and "avoids". These are common every day words but in the context of assessment can cause considerable confusion. Sometimes a resident is "capable of" something but only with supervision and no reference is made to this very crucial factor. It is not clear how one would score "avoids frequenting unsafe places" when the resident simply has no opportunity for contact with the outside world. No guidelines are given as to how to score an item which the resident may very well be able to do but for which he has not had the opportunity.

Assessment of behaviours in the community. Assessment of behaviours in the community is extremely difficult because as soon as one "observes" one tacitly "supervises". Thus an element of prediction is implied in the scoring as to how the resident would manage when alone.

Analysis of Problem Areas of Each Schedule

Schedule I

Question 1,7 -- Personal judgment required.

8, 10 -- Source of information not indicated.

Schedule II

1, 3, 4, 5, 8 -- Difficulty in scoring, one part may be applicable but not all.

6 -- Personal judgment required.

Schedule III

The grading of some questions makes scoring much easier.

1, 2, 3, 4 -- Personal judgment required.

Schedule IV

1, 2, 3(v), 6(i) -- Source of information not indicated.

3(i) -- Ambiguous phrasing: "understands". How information is to be obtained is not indicated.

3(ii) -- Ambiguous phrasing and difficulty in scoring. Source of information is not indicated.

3(iii) -- Ambiguous phrasing: "is capable of".

Schedule V

1(i) -- Difficulty in scoring.

2 -- Difficulty in scoring. Ambiguous phrasing: "understands".

3 -- Ambiguous phrasing: "understands", "recognises". How information is to be obtained is not indicated.

5 -- How information is to be obtained is not indicated.

Schedule VI

2(i), 2(iii), 4(iii), 5(ii)(iii)(iv)(v), 6(i)(iii), 7(i)(ii), 8, 9, 10 -- Source and method of obtaining information is not indicated.

Schedule VII

The information required is more clearly presented but there are no guidelines on how to obtain it. "Understands" and "Knows" are ambiguous.

3, 4, 7 -- Difficulty in scoring as resident may know one part but not all. Present scoring cannot be used to indicate what must be learnt next.

Schedule VIII

The information required is more clearly presented but there are no guidelines on how to obtain it. "Understands" is ambiguous.

6, 7, 8, 9, 10, 11, 12 -- No opportunities when living in a large centre.

Schedule IX

It is extremely difficult to assess whether a resident would be able to use community facilities unsupervised.

Schedule X

The information required is much clearer and less ambiguous than the other schedules but, although it is obvious that this information can only be obtained from the resident's work supervisor, there is no indication of this.

Recommendations

The previous section outlined the main categories in which problems were encountered. It is not possible to indicate in detail how particular questions could be altered but some general comments can be made. It is felt that reliance on the subjective judgment of the person completing the schedules should be avoided whenever possible. If this is considered absolutely necessary then specific studies of inter-scorer reliability need to be undertaken. (Studies of inter-scorer reliability need to be undertaken for the schedules as a whole but it is anticipated that areas requiring the demonstration of practical skills would be less problematic.)

It is recommended that as many questions as possible be couched in specific operational terms so that ambiguity is reduced to a minimum. Instead of such terms as "understands", "recognises" and "knows", specific instructions could be given to the person completing the assessment. For example, instead of "understands that switch should be off before inserting/removing appliance" (Schedule VI, 6(ii)), the instruction could be "ask the resident to plug in and then unplug an appliance". It is felt that although the instructions for the schedules would necessarily be much longer than at present this would be preferable to the present ambiguity, particularly if the schedules are to be used by untrained persons.

Clear instructions also need to be given as to the particular sources and methods of obtaining information. Ideally alternatives could be suggested to allow for retarded persons living in different types of settings. In addition, specific mention needs to be made of whether a skill is performed with or without supervision.

This evaluation of the ASAT schedules is necessarily brief as it was not the main focus of this research. The face validity of the schedules is extremely high but if they are to be used with confidence, both as a guide to training at Alexandra and for future research, it is

essential that, in addition to giving attention to the points mentioned above, standardization and reliability studies are carried out. In spite of the time, personnel and finance needed it is hoped that systematic revision of the schedules will take place in the near future because a reliable procedure for assessing the living skills of retarded persons is simply not available at the present time.

24 JUN 1982