TRAINABLE MENTAL RETARDATION IN THE COLOURED AND BLACK COMMUNITIES OF CAPE TOWN: PREVALENCE AND PROVISION OF SERVICES

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Thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts in Clinical Psychology

UNIVERSITY OF CAPE TOWN

SEPTEMBER 1985

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ACKNOWLEDGEMENTS

My sincere appreciation is due to the following people:

My supervisor, Ann Levett, whose guidance and support throughout always made the completion of this thesis seem inevitable.

The workers of Cape Mental Health Society, particularly Toni Tickton and Mandy Roux, whose help I could not have done without.

Janet Hollingshead, Professor Vera Grover, Susan Lea, and many other people working in the field, too numerous to mention, who generously gave of their time and experience.

Janet Bailey, Bev Dickman, Sally Swartz, Leslie Swartz, and the Class of '84, who provided assistance when this thesis was in its formative stages and provided encouragement throughout.

Ilidia de Sousa, whose patient, efficient, and accurate typing was of great assistance.

Lisa Thorne, whose support, understanding, and encouragement sustained me at all times.

The HSRC provided financial assistance: however, the views expressed here are those of the author alone, and not those of the HSRC or any other organisation.

ABSTRACT

This thesis estimates the prevalence of trainable mental retardation in the Coloured and Black communities of Cape Town; estimates the present shortfall in facilities provided; and discusses implications of present conditions for the future provision of a comprehensive service network.

Information regarding prevalence is necessary in order to facilitate planning: however, since detailed data are not availalbe, this study estimates prevalence on the basis of data derived from previous prevalence studies, conducted both overseas and in South Africa.

Results indicate that the present provision of facilities in the study area is inadequate : however, while the shortfall is serious in the Coloured community, it is critical in the Black community.

The implications of present conditions for the future provision of services is discussed,this being informed by overseas and local experience and by contextual difficulties such as economic constraints and State policy. Proposals are made with specific reference to issues such as co-ordination, and that response be context-related and dictated by locally-identified needs.

In conclusion, the thesis outlines a number of directions for further work in this and related areas, the overriding principle being that there is a great need for research to be community-oriented.

CHAPTER ONE : INTRODUCTION

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This thesis may be broadly divided into three parts. Firstly, it estimates the size of the trainable mentally retarded population of the Coloured and Black communities of Cape Town;secondly, it relates this estimate to the present provision of services; and thirdly, it draws implications from this for the future provision of services.

This chapter provides an orientation to the study by outlining the methodology followed, and by introducing the study area.In addition, it briefly examines a number of conceptual issues with regard to mental retardation, and particularly the issue of assessment.

1.1 METHODOLOGY

In order to estimate the size of the trainable mentally retarded population, two types of data are required: overall size of the population of which those with trainable mental retardation form part; and the prevalence rate (or proportion) of cases of trainable mental retardation in that population. With regard to the overall size of the "background population", this is reasonably easy to estimate on the basis of the most recent population census(conducted in 1980), updated to the present. The specific methodology for doing so, together with factors which complicate this procedure, are dealt with in Chapter Four below. Establishing the prevalence rate of trainable mental retardation in the study area is more difficult. Although a number of studies have attempted to establish this rate, various problems with regard to finding cases have probably affected their accuracy, as will be discussed in Chapter Two. Therefore, results of similar studies conducted in other parts of the world have been used to adjust the rate established by these studies. The dangers inherent in doing so are considerable: not least of these is making the assumption that diverse contexts are equivalent. Chapter Two examines these studies in the light of these dangers, and explores a number of dimensions along which they differ . On the basis of this examination, a prevalence range is determined: the prevalence rate in the study area is expected to fall between the upper and lower limits of this range.

The second part of this thesis relates the estimated size of the trainable mentally retarded population to the present provision of services. In Chapter Three the existing services available to the population of the study area are described, and quantified where possible.This is only possible in the case of facilities which serve a specific number of people, such as training centres. On the basis of these data, it is possible to estimate the extent of need for these facilities in the study area: this is undertaken in Chapter Four. In addition to estimating the present (1985) need, the population of the Coloured community is projected to the year 2000 in order to obtain an estimate of the future size of the Coloured trainable mentally retarded population, as an aid to planning for appropriate facilities in advance.

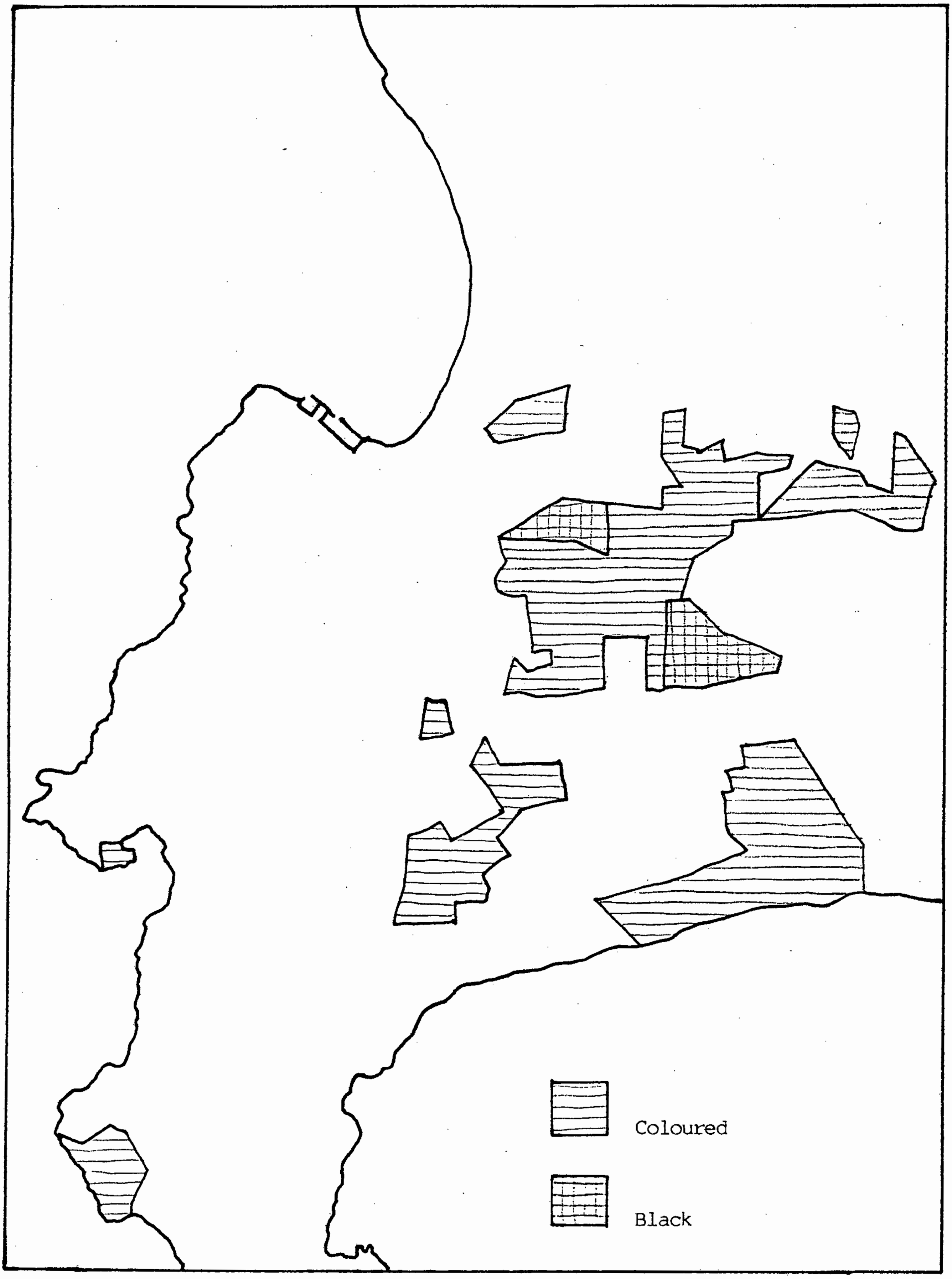
Chapter Five discusses the implications of the present shortfall in service provision for the future provision of services. This is informed by drawing from a number of sources, including overseas experience, experts presently working in this field in the study area, and from other considerations relating to local conditions such as State policy and economic constraints.

1.2 THE STUDY AREA

The study area includes all the Coloured and Black residential areas in the metropolitan area of Cape Town. These are shown in Figure 1.

FIGURE 1 : COLOURED AND BLACK GROUP AREAS OF

METROPOLITAN CAPE TOWN



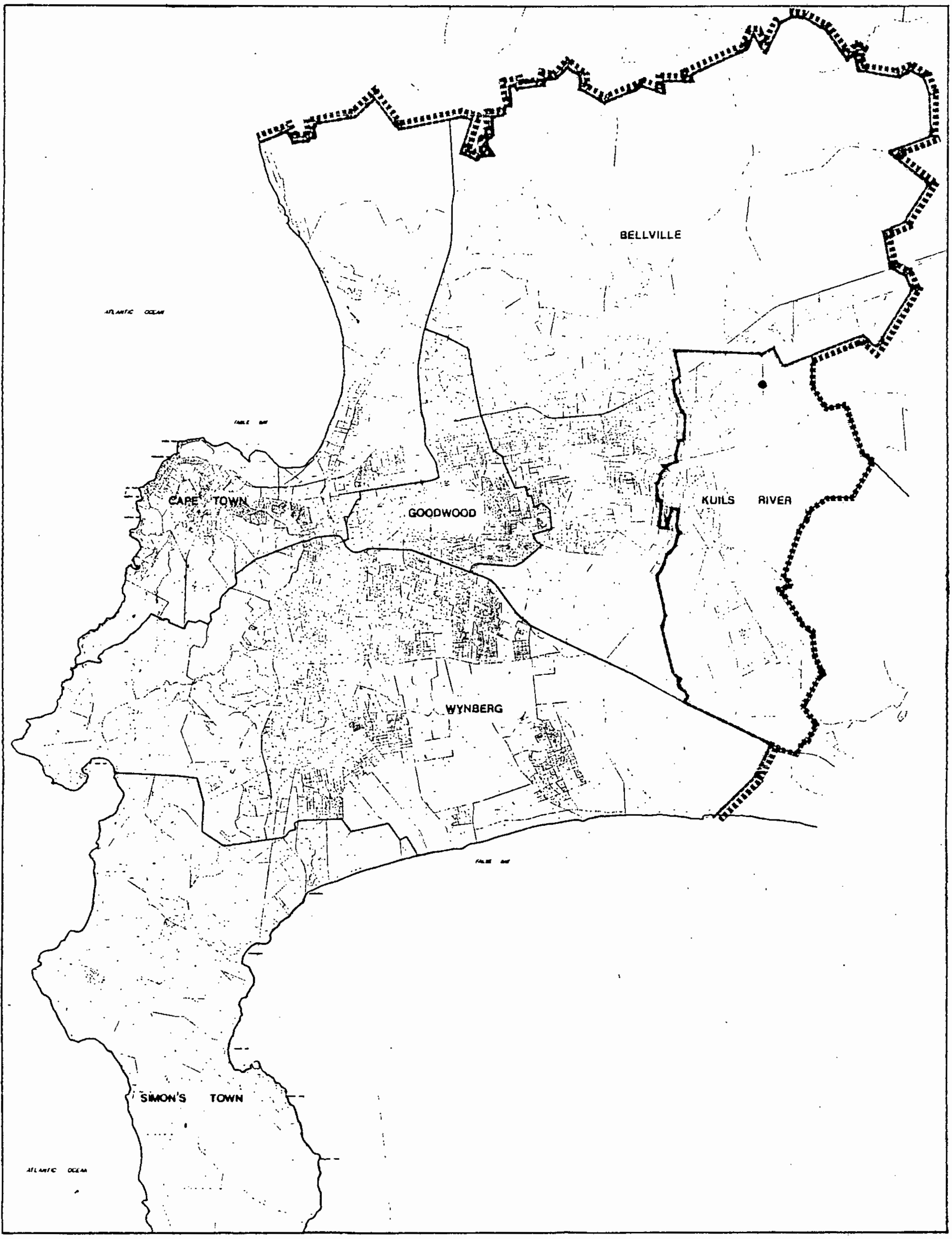
The metropolitan area of Cape Town consists of whole or part of fifteen local authority areas (see Appendix A), and includes the magisterial districts of Bellville, Cape Town, Goodwood, Kuils River, Simon's Town, and Wynberg. These are shown in Figure 2.

The many characteristics of the Coloured and Black communities which distinguish them from the White population are well known and do not need to be examined in detail here: see, for example, October and Young,(1984). In any event, this falls beyond the scope of this thesis. At the same time there is a need to briefly refer to some of these in order to contextualise the communities under consideration.

Discrepancies between the Coloured and Black community on the one hand and the White community on the other exist at two levels. Firstly, at a racial level, in the Coloured and Black areas environmental features include poor quality housing and poorly-developed recreational facilities such as parks and sportsfields; social features include high levels of residential crowding, low incomes, and low levels of car ownership. Statistical evidence for these and other discrepancies, deriving from official census data, is contained in Appendix B.The effects of these discrepancies are found in all areas of life, such as lower education levels, poor nutrition higher relative transport costs, and poor mobility. Within the Coloured and Black community, further differentiation is evident: the Coloured population is consistently better off than the Black population.

The second level of discrepancy is that of class. The Coloured and Black population is predominantly working class, the principal commodity at their disposal being that of their own labour.The White middle class, by contrast, has access to economic power far out of proportion to its size.

FIGURE 2 : MAGISTERIAL DISTRICTS OF METROPOLITAN CAPE TOWN



Taken as a whole, this evidence points to consistent underdevelopment of the Coloured and Black community relative to the White community, with very great differences in living standards. The provision of facilities for trainable mentally retarded people conforms to this overall pattern: the Western Cape Forum for the Mentally Handicapped estimates that 86% of the White need for facilities, 35% of the Coloured need, and only 5% of the Black need, is presently being met (Grover, personal communication).

Thus an overriding feature of the Coloured and Black community is that of poverty, which, according to Yosslowitz (1982), is both stable and persistent. Citing Lewis (1968), Yosslowitz (1982) speaks of four major characteristics of the "culture of poverty": these are qualitative rather than quantitative, but apply with some accuracy to the population of the study area. Firstly, there is a lack of effective participation and integration in the major institutions of the larger society due to factors such as a lack of economic resources, segregation, and discrimination. Secondly, economic traits include a struggle for survival, unemployment, low wages, and unskilled occupations. Thirdly, there are a wide range of social and psychological problems, such as crowded conditions, lack of privacy, high levels of alcoholism, use of violence in the settlement of disputes, wife battery, authoritarianism, a belief in male superiority, and a high tolerance of pathology.Fourthly,there is a present-time orientation, along with a sense of resignation and fatalism. There are a number of points of criticism with respect to this description of the "culture of poverty". A particularly serious one is its view of a poverty-stricken community as resigned to its lot and fatalistic, whereas it may in fact be highly organised. However, However, this description is included here only to illustrate a number of qualitative dimensions of poverty, and a detailed criticism falls beyond the scope of this thesis.

The above discussion highlights a number of general characteristics of the Coloured and Black community. More specific features of these communities will be outlined with respect to the present provision of services for the mentally retarded at relevant points below, particularly in Chapter Three.

1.3 CONCEPTUAL ISSUES

The principal concern of this section is with the concept of mental retardation: what it is understood to be and how it is measured. Owing to the complexity of the debate surrounding these issues, it is not possible to even approximate comprehensiveness here: rather, a number of trends of thought will be outlined, and this thesis will be placed in relation to them.

A very wide range of names has been applied to the condition, from "fool", "idiot", "imbecile"; through "subnormal", "mentally deficient", "backward"; to "mentally handicapped", "developmentally young", and even "poorly gifted" (Kanner, 1964; Lombaard, 1982; Ryan and Thomas, 1980). "Names supplant each other very fast in this field, in the illusory search for a designation that is neutral or euphemistic" (Ryan and Thomas, 1980, p.11). However, despite the recognition that this search is illusory,the illusion is maintained: "... the terminology (should give) least possible rise to stigmatization" (Lombaard, 1982, p.11). Lombaard goes on to argue for terminology to be both "scientifically" and "socio-ethically" correct (1982, p.11), and in so doing fails to recognise that difficulties in definition result from seeking to impose precise,neutral, "correct" criteria on conditions which intrinsically lack such precision. The essential problem is that mental retardation is socially-defined and relative, rather than scientifically-defined with clear-cut boundaries. Brooks and Baumeister (1977) argue that definitions of mentally retarded behaviour are inescapably social, and vary between cultures and within cultures. A fundamental difficulty is that the concept implies deviation from social norms,which are notoriously difficult to establish. This thesis uses the term "mental retardation" in preference to "mental handicap", which is in parallel use today, because the latter implies a disability in relation to expectations or requirements of the individual's environmental circumstances (Editorial, 1973). Such a disability cannot be inferred on the basis of the present study.

In the case of mental retardation, deviation typically takes place from a number of norms at once: although this serves to compound the impression of deviation in the direction of retarded rather than accelerated development, it also further adds to the complexity of deciding when to affix a label of "mentally retarded", and of what degree of mental retardation is present. This is particularly so since tremendous variation is found between mentally retarded people, who may score similarly on one dimension of deviation (eg, measured intelligence) while varying greatly with regard to another (eg, expressive language) (Hutt and Gibby, 1979; Jeffree, McConkey, and Hewson, 1977).

In this light, it becomes more meaningful to speak of mental retardation as a set of deviations from the norm rather than as a deviation from a single norm. As will be shown in Chapter Two, the more extreme the deviation from a given norm, the more likely that significant deviations will be found from others as well (Hutt and Gibby, 1979). This suggests that there are levels of correspondence in deviations from norms, and these are in fact generally found. In very broad terms, the upper 75% of the mentally retarded population, scoring between two and three standard deviations below the mean on IQ, or between 70 and 55 IQ points, can learn to do simple reading, writing, and arithmetic. They can perform a variety of simple jobs with success, but experience shortcomings in relation to tasks in which judgement, decision-making,and abstract thinking are required. The 20% of the mentally retarded population which scores between three and four and two thirds standard deviations below the mean, or between IQ 55 and IQ 30, can learn considerable self-care skills. They have major difficulties with regard to symbolic communication, including reading, writing, and arithmetic, but can learn to be productive under sheltered conditions. This thesis is primarily concerned with this group. The lowest 5%, which scores below IQ 30 or four and two thirds standard deviations below the mean, requires constant protection to survive. They are generally unable to take care of their own basic hygienic needs and cannot learn to discriminate between danger and safety. This group usually requires institutional care (Baroff, 1974; Gearheart and Litton, 1975; Hutt and Gibby, 1979; Steenkamp and Steenkamp, 1981). The three most frequently encountered criteria of mental retardation are impaired scholastic functioning, impaired social functioning, and impaired intellectual functioning (Clarke and Clarke, 1974).

Given that there are numerous criteria of mental retardation,which of these takes precedence in situations where discrepant results are found? In other words, which single criterion is taken as the most invariable indicator of mental retardation in practice? There can be little doubt that this is impaired intellectual functioning, as measured by an IQ test (Gilbert, 1981; McConkey and Walsh, 1982). On the basis of this result alone, the diagnosis of mental retardation is frequently made, specifying the degree of retardation. Although this method of diagnosis is often the most expedient, it has numerous potential dangers. Binet and Simon, who are generally credited with the development of the first systematic intelligence test, warned against using IQ as the sole criterion of mental retardation (Wortis, 1965). Furthermore, there is a high degree of measurement error, especially at the lower levels of IQ tests: this is compounded by the fact that the same IQ on different tests may not reflect identical arrays of ability. The same IQ on the same test could also mean different things because of restandardizations of the test; and a given IQ only reflects functioning at that time, since intellectual development does not necessarily proceed at a constant rate (Gilbert, 1981; McConkey and Walsh, 1982; Mittler, 1973a, 1973b). In addition, problems with regard to the testing of IQ in the Coloured and Black communities are even more pronounced on account of the lack of a suitably standardized test, which introduces the issue that tests currently used are culturally biased (Young, personal communication). Along with these problems, which relates to the reliability and validity of IQ tests in themselves, this means of diagnosis flies in the face of evidence which recognises that mental retardation is made up of a composite of features, as discussed previously.

At this point, however, two distinctions need to be made. The first is that between diagnosis of mental retardation in the individual and diagnosis required for purposes of reseach. The above dangers are invariably present to some extent when testing an individual, but only apply to research where each case included in the study is individually tested. In the case of the present study, no such testing has been undertaken since prevalence is estimated rather than definately ascertained. However, this method has its own problems, which are more appropriately discussed in Chapter Two.

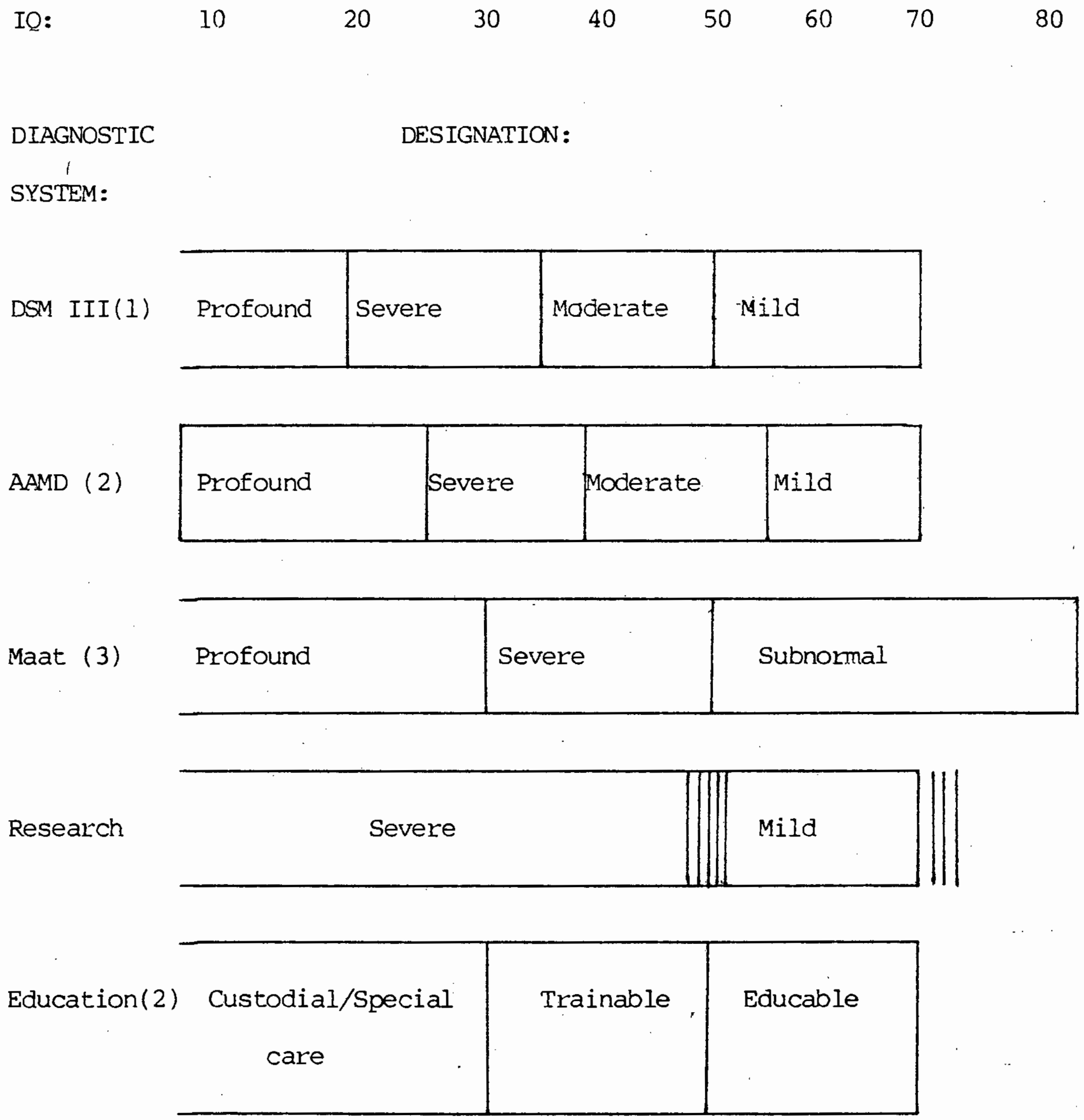
The second distinction which needs to be made is that between diagnosis and assessment, both of which necessarily take place in relation to individuals. Diagnosis is more properly limited to establishing aetiology (where possible) or to identifying the level of mental retardation, which may be done chiefly on the basis of an IQ score, although incorporation of other criteria should always be sought. Assessment, on the other hand, is more concerned with the identification of specific strengths and weaknesses with a view to remediation, and therefore carries implications for treatment. This distinction will be further discussed in Chapter Five. Of importance here is that psychologists have become far more concerned with assessment (of which diagnosis forms part) as a means for formulating a treatment plan than with diagnosis as an end in itself (Clark, 1984). Mittler (1973a) writes: ✓

> Many psychologists have expressed dissatisfaction with the routine use of assessment procedures unrelated to the needs of the handicapped person, and have pressed not only for a much more selective and discriminating use of tests but for the forging of a closer link between assessment and the design of appropriate treatment programmes (Mittler, 1973a, p.v).

However, even though assessment may be of great importance in working with the individual person, there are occasions when individual differences need to be collapsed into a single criterion to some extent. Such an occasion is when a child is assessed for placement in a training centre. At these times there may be little alternative to depending primarily on the outcome of an IQ test: under these conditions, however, the qualitative aspects of the child's performance can provide valuable additional information, particularly through procedures such as "testing the limits" or through testing the child's ability to improve her/his performance with practice. As far as possible, the primary concern of measurement should be assessment rather than diagnosis.

A final issue which needs to be discussed here is that of the varying terminology employed in describing different levels of mental retardation. With regard to diagnostic cut-off points, the American Psychiatric Association (DSM III) and the American Association on Mental Deficiency apply the same terms to slightly different IQ ranges, while in South Africa Maat (1975) has proposed a third system differing considerably from these. Researchers into the prevalence of mental retardation have generally employed a different system again, in which all cases of IQ's approximately 50 and below are considered "severe", thereby overriding finer differentiations of other systems. To further complicate matters, educationists have devised their own system, using different terminology, in order to emphasise differing educational capabilities. These five contrasting systems are shown in Table 1. In this thesis, terminological usage conforms to that used by researchers when discussing research findings; at most other times, except where DSM III terms are used, educational terminology is used, since the stress is on services and facilities required rather than on diagnostic considerations.

TABLE 1 : DIFFERENCES IN DEFINITIONAL CRITERIA



Source:

(1) American Psychiatric Association, 1980

(2) Lombaard, 1982

(3) Maat, 1985

1.4 SUMMARY

This introduction has served to introduce the methodology to be followed in subsequent chapters; to provide a broad framework to contextualise the study area and its inhabitants; and to briefly examine some of the wider conceptual issues surrounding the notion of mental retardation in general, with particular emphasis on the problems associated with its assessment.

The methodology consists of a progression through three stages. Initially, it estimates the size of the trainable mentally retarded population in the study area; subsequently, it relates this estimate to presently available facilities in guaging the current need for facilities; and finally, it draws implications from various dimensions of the present situation for the future provision of services.

The study area was shown to be one of a poverty-stricken,predominantly working-class community. Access to resources is limited, and subsequent chapters will indicate that this situation applies equally well to its mentally retarded members, with regard to their access to appropriate services.

The social origins of the concept of mental retardation were alluded to,and it was shown to embody the notion of deviation from socially-accepted norms. From this basis it was indicated that deviation from IQ norms was a predominant factor in the diagnosis of mental retardation, despite its many intrinsic shortcomings, and that such a measure should be embedded in an assessment (with implications for treatment) rather than merely serve a labelling (or diagnostic) function.

CHAPTER TWO : EVALUATION OF PREVIOUS STUDIES OF PREVALENCE.

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2.1 INTRODUCTION

This chapter evaluates a total of 56 studies into the prevalence of mental retardation around the world, using a number of dimensions in order to highlight problematic areas as well as areas of consensus. On the basis of this evaluation a research-based prevalence rate, considered an appropriate approximation of the true prevalence rate of trainable mental retardation in the population of the study area, will be derived. In Chapter Four this rate will be applied to the overall population of the study area in order to estimate the size of the affected population.

Direct comparison of the findings of prevalence studies is made difficult because of variations between the studies. These variations include: definitions of mental retardation, some studies employing IQ scores only and others including criteria of social adjustment, IQ score cut-off points and criteria themselves varying; sources of data; the time period over which data was collected; size, age, and other population characteristics; geographical factors; date of survey; and aetiological factors, some studies restricting their data to Down's Syndrome or non-specific retardation (Lindsey and Russell,1981). In addition, some studies provide insufficient information for any but the most gross comparisons (Sen, 1975).

The following sections examine the above-mentioned and other variations by exploring the factors influencing the outcome of these studies. On account of the particular importance of South African work in view of local conditions, South African studies will be considered separately in section 2.12 of this chapter.Accordingly,sections 2.4 to

2.10 refer almost exclusively to studies conducted elsewhere. Sections 2.2 and 2.3 provide an introductory framework by outlining the concept of "prevalence", and by examining theoretical estimates of prevalence.

2.2 THE CONCEPT OF PREVALENCE

The term "prevalence" refers to the number of cases (in this context, cases of trainable mental retardation) relative to the population at risk (here, population of the study area), in a given time period. It is contrasted with the concept of "incidence", which refers to the number of new cases reported during a specified period of time, relative to the population at risk. These may be expressed as a percentage, but are more usually expressed as cases per 1000 population (Pyle, 1979).

Tizard (see Brask, 1972) distinguishes between three types of prevalence: "ascertained" prevalence, or the number of cases recorded by the authorities; "administrative" prevalence, or the number of persons needing services provided by the authorities; and "true" prevalence, the total number of cases, whether identified or not. This study is primarily concerned with "true" prevalence. Most studies to be discussed below obtained their data through mental retardation registers (i.e.,"ascertained"):however, estimates of "true" prevalence are usually extrapolated.

Tarjan, Wright, Eyman, and Keeran (1973), however,caution that the limitations of the term be recognised. They identify four assumptions embedded in the concept which do not stand up to empirical evidence: firstly, that diagnosis of mental retardation is based essentially on an IQ score; secondly, that it is identified in infancy; thirdly, that the diagnosis does not change; and fourthly, that mortality rates among the the mentally retarded are similar to those of the general population. However, diagnosis usually implies a degree of impairment in adaptive behaviour in addition to low IQ, as discussed in Chapter One. Since adaptive behaviour is related to chronological age, diagnosis is age dependent, and may even disappear in adulthood if retardation is relatively mild. Furthermore, mortality is inversely related to IQ, with only the mildly retarded having life expectancies approaching those of the general population. These points will be returned to in later sections.

Three major sources of influence on the prevalence rate introduced by the researcher are the definitions of mental retardation used; the method of finding cases; and the accuracy of the denominator (the population "at risk") (Abramowicz and Richardson, 1975; Kushlick and Cox, 1973). Definitions will be discussed in section 2.4 below. The methods used have generally either been the examination of "ascertained" cases (where such records have been considered reasonably accurate) or by direct survey (where the population at risk has been small and accessible enough). In the present study neither method is suitable, since neither set of conditions is met. As regards the denominator, age-specific cohorts deriving from census data or a population projection are most frequently used.

The primary value of ascertaining the prevalance rate of mental retardation in a community is in guiding the planning of new services, and, when data from subsequent studies are available, in assessing the impact of changes in the pattern of services (Kushlick and Cox, 1973; MacKay, 1971; Wing, 1971).

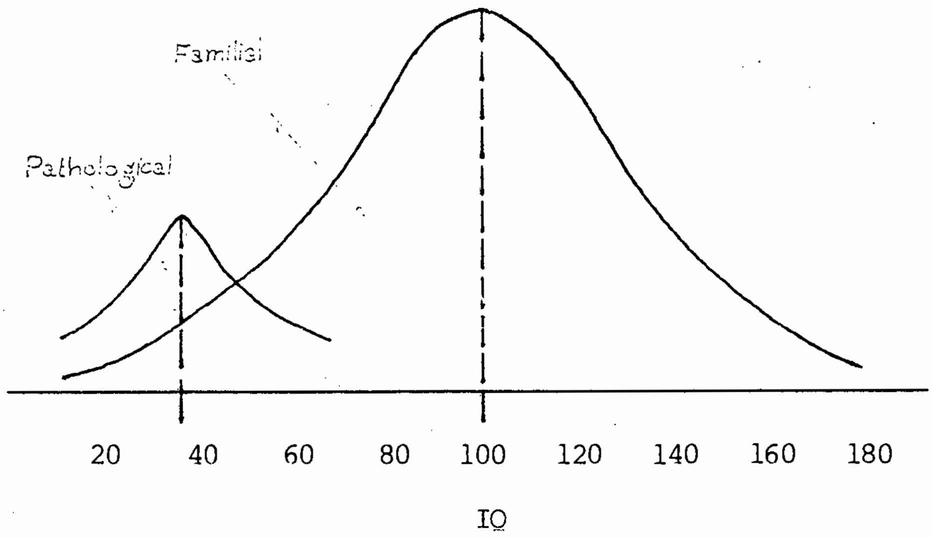
2.3 THEORETICAL EXPECTATIONS OF PREVALENCE

This section examines briefly the prevalence rate expected from the theoretical normal distribution of mental ability, and then explores the reasons given for deviations from this rate found in empirical work.

In terms of the normal distribution of IQ (with a mean of 100 and a standard deviation of 15), it is expected that mentally retarded people (with IQ's of 70 and below) make up 2,27% of the total population: this proportion falls below two standard deviations from the mean. A prevalence rate of 1,3 per thousand is expected below three standard deviations from the mean (i.e., an IQ of 55 or less): the prevalence rate for IQ's of 50 and below is 1,2/1000 (Anastasi, 1976). Even allowing for the fact that mental retardation may be diagnosed in terms of criteria additional to IQ, prevalence rates are generally found to be considerably higher below the IQ of 50, although prevalence rates above IQ 50 tend to conform to the Gaussian distribution (Richards, 1974).

In making sense of this apparent anomaly, Penrose (1963) reasoned that mental retardation was composed of two components. The familial component, the distribution of which would correspond to the normal distribution of IQ scores, would account for those cases theoretically expected. The excess of cases below the IQ of 50 was considered to be due to a pathological component: due to the additional organic impairment there would be little association with the normal distribution, and IQ scores would fall mainly below 50. In combination, these two components would yield a theoretical prevalence rate of 0,3% below IQ 50, and 2,3% between IQ 50 and 70: see Figure 3. These figures have been largely borne out by research (Solomons and Solomons, 1973).

FIGURE 3 : PENROSE'S DISTRIBUTION OF INTELLIGENCE



However, a number of recent studies have led to Penrose's theoretical distribution being questioned. Hagberg, Hagberg, Lewerth, and Lindberg (1981) found a prevalence rate of 0,4% for mild mental retardation in a Swedish county, and quote two other studies which also indicate prevalence rates below that expected in terms of Penrose's distribution. They suggest that this discrepancy could be due to a shift of the true IQ distribution to the right, with a mean of 110 or 112 ± 15, as a result of economic, social, technical, and educational progress in Sweden. Although such progress could influence the expression of Penrose's "familial" component, and accordingly mild levels of retardation in particular, it is less likely to influence the prevalence of "pathological" retardation, except through improved health and medical care.

The present study is unlikely to be affected by considerations of progress to the extent that prevalence rates in Sweden have been: firstly, the present study is concerned with prevalence below IQ 50, and would therefore theoretically include a high proportion of cases of "pathological" mental retardation; and secondly, standards of health care and nutrition are unlikely to parallel those of Sweden, which is reknowed for its high standards in these areas.

2.4 DEFINITIONS OF MENTAL RETARDATION USED

Diagnostic criteria of mental retardation were discussed in Chapter One: this section deals more specifically with criteria employed in prevalence studies, and focuses in particular on the problems which arise in this connection. Areas of coherence will be derived, and this will be used to inform the present study.

In diagnosing mental retardation in an individual, a composite clinical assessement can highlight particular features, circumstances, strengths and weaknesses. In large-scale prevalence studies this clinical richness is necessarily collapsed into a neat, operational definition, in which diagnosis is of the all-or-none variety.

A major problem in this regard is that mental retardation may or may not be a symptom of another condition, and furthermore that a large number of identifiable causative conditions can give rise to mental retardation. On the other hand, a medical diagnosis can be made in only exceptional cases (Akesson, 1974; Kushlick and Cox, 1973). The difficulty of separating what may be called primary mental retardation from secondary mental retardation has been a major problem in arriving at a unitary operational definition, and a number of studies have used aetiological features to more precisely delineate their focus of concern. Examples here are Down's Syndrome (Read, 1982; Thase, Liss, Smeltzer, and Maloon, 1982) and non-specific mental retardation (i.e., excluding cases where a causative condition is known: Herbst and Baird, 1983).

The usual approach to overcoming the problem of aetiology has been to ignore it in final derivation of the prevalence rate and to use a purely psychometric criterion instead. But this, too, is not without its problems, as there are no clear-cut boundaries between levels of intelligence, and because mental retardation by definition includes criteria other than subnormal intelligence. However, problems of this sort are largely confined to the fixing of the cut-off point at the upper end of the range (MacKay, 1971): there is general agreement that mental retardation of IQ 50 and below is far more reliably measured than is mild retardation (Lindsey and Russell, 1981). MacKay states that "social inefficiency appears to be an invariable concomitant of IQ's at this level" (1971, p.12). As this study and most of the other studies surveyed are concerned with this group it is reasonable to assume that definitional and functional variability of cases included will be fairly restricted.

A final problem to be discussed here (though not specifically addressed elsewhere) concerns the issue of importing a cut-off IQ score of 50 into the study area and simply assuming this to represent a similar level of intellectual functioning as elsewhere in the world. This is of central importance in the light of firstly, the cultural bias inherent in both the concept of intelligence and in the majority of intelligence tests available; secondly, the unreliability of measurements obtained at the lower ranges of IQ; and thirdly, the tendency of locally-standardised intelligence tests for children to produce inflated scores. This problem can be overcome, however, by assuming that the intelligence of the at-risk population follows Penrose's distribution, and that the appropriate cut-off score occurs 3,34 standard deviations below the mean, a standard deviation representing 15 points. This cut-off score is 50 if the mean is assumed to be 100. These theoretical assumptions regarding the at-risk population are made in this study.

2.5 AGE-SPECIFIC PREVALENCE

This and the following five sections examine the findings of the prevalence studies surveyed, each section dealing with an aspect of prevalence which can be more-or-less separated from the rest. It is worth noting at the outset that prevalence rates for severe mental retardation indicate an average of about 4 per thousand, with a lowest rate of 2,16/1 000 and a highest of 5,8/1 000 (Kushlick and Cox, 1973) in the 56 prevalence studies covered here. Considerably wider variation is found in the prevalence rate of mild mental retardation.

This section examines the phenomenon that prevalence rates vary considerably between age-groups. Usually the peak prevalence rate obtained (which generally reflects the ascertained prevalence) is taken as a gauge of true prevalence, and reasons for possible discrepancies between these two rates are hypothesised.

A higher prevalence rate of severe mental retardation is normally reported for older children than for young children or for adults. This is probably due to more cases becoming recognised as these children grow older rather than to new cases arising in the population, as severe mental retardation is usually present from early infancy (Abramowicz and Richardson, 1975). A number of factors are probably implicated in this, such as hesitancy to classify children as mentally retarded when young in order to "give them the benefit of the doubt" (Goodman and Tizard, 1962). In addition, children with no other handicaps (see section 2.10)may be expected to go unrecognised for a longer period than children who exhibit additional conditions such as epilepsy, behavioural difficulties, or cerebral palsy. Inadequate health and associated services, such as in the case of the study area, are also likely to result in more cases remaining unrecognised, in terms of diagnosis, registration, and provision of services. For older age-groups, prevalence declines. This may be partially due to contact being lost with such cases, older case records being less reliable than more recent ones, diagnostic services and notification procedures being more comprehensive than they were previously, and other factors related to the reliability of data rather than to the true prevalence. However, at least two processes do appear to lead to a reduction in the true prevalence: amongst the mildly retarded population a significant proportion tend to lose the diagnosis due to improvement in social functioning: Tarjan, Wright, Eyman, and Keeran (1973) estimate this figure as 66%; and amongst the more severely retarded, a higher than average mortality rate serves to reduce their numbers as well. Mortality rates will be further discussed below.

The age-groups sharing peak prevalence in the studies under examination vary to some extent, depending on factors such as the upper age level included in the study and ascertainment biases (Abramowicz and Richardson, 1975). Some studies found peak prevalence between the ages of 10 and 14 (Brask, 1972; Goodman and Tizard, 1962; Gustavson, Holmgren, Jonsell, and Blomquist, 1977; Henderson, Pate, Wegman, and Ross, 1972), while in others peak prevalence occurred between 15 and 19 (Akesson, 1974; Blomquist, Gustavson, and Holmgren, 1981; Kushlick, 1961, in Kushlick and Cox, 1973; Innes, Kidd, and Ross, 1968; MacKay, 1971). Although

Henderson et al,(1972) argue that the peak prevalence for the 10 to 14 year age group should be the closest approximation to the true prevalence, most sources agree that this approximation is most likely in the 15 to 19 age-group (Brask, 1972; Innes, Kidd, and Ross, 1968). However, as was suggested above, such discrepancies are to some extent to be expected given methodological differences between studies. Abramowicz and Richardson (1975) come to the conclusion that the highest age-specific prevalence rate in any study is most likely to be the one closest to the true prevalence. From their review of 27 community studies of the epidemiology of severe mental retardation they conclude that the best approximation of true prevalence is likely to be between 3 and 5 per thousand.

Mortality rates have been found to be higher amongst the mentally retarded than amongst the general population, with that of mild cases approaching normality. In British Columbia, Herbst and Baird (1983) calculated the mortality rates for mild and moderate levels to be twice that of the normal population; for severe mental retardation, seven times; and for profound levels, 31 times as high. However, conflicting evidence is produced by Carter and Jancar (1983) and by Tait (1983): in a 50-year survey, Carter and Jancar found that the difference in mortality rates at all levels of retardation were relatively small in relation to the general population, compared to the situation of fifty years ago. This increased life-span was attributed to improvements in drug therapy, better diet, and better care and environment. In this time, they found that that longevity amongst Down's Syndrome patients increased by forty years. Tait (1983), on the other hand, found an increase in mortality in Down's Syndrome in the middle life period: by discounting this excess mortality and that of the profoundly retarded in early life, it was found that the remainder of the mentally retarded population had a life expectation approaching that of the general population. Carter and Jancar's findings, however, may not be generally applicable as their subjects had all received good medical care at a group of British hospitals : it seems not unreasonable to expect mortality rates to increase somewhat where such facilities are not available. The issue of mental retardation in old age is relevant to the present study in that it provides important qualitative data in gauging the overall needs of the mentally retarded community of the study area. Accordingly, increased longevity may be expected along with improvements in health care in the future, and the needs of increasing numbers of aged mentally retarded people will have to be provided for.

The natural history of severe mental retardation, evident from the above discussion, suggests that the greatest need for facilities (in terms of the number of cases recognised) is amongst children aged 10 to 19. Although usually present from early infancy, severe mental retardation is most often recognised during this period, except in cases where mental retardation is accompanied by other conditions requiring particular attention, or where physical signs make the diagnosis self-evident (as in Down's Syndrome). At the same time, it is equally evident that the advantages of providing early education (i.e., at preschool level) in the individual case are considerable, as will be discussed at greater length in Chapter Five. This requires the extension of early diagnostic services, which would lead to a higher ascertained prevalence rate among the younger age-groups, and concomitantly an increased need for services for these children. The variability of age-specific prevalence rates found within studies makes it impossible to estimate a ratio of younger to older severely mentally retarded children requiring services, although such a ratio would be useful in planning for age-specific services. In addition, with the probable decline in the mortality rate with improvements in health care, it is clear that appropriate facilities for the aged will become progressively more needed.

2.6 SOCIO-ECONOMIC DIFFERENCES

Almost all of the prevalence studies surveyed derive from the First World. Sen (1975) quotes a figure of 4% for mental retardation in India based on a number of surveys conducted in major Indian cities, but gives no further details. He explains that detailed figures are not available owing to a lack of funds for undertaking a comprehensive survey. This factor, combined with a lack of appropriately-trained personnel and other characteristics of deprivation commonly associated with the Third World, is likely to explain the paucity of data from these regions.

Of the prevalence studies from the First World, a minority make reference to socio-economic differences in prevalence, and fewer still provide sufficiently-detailed information for comparitive purposes. Even in these cases, the applicability of findings to conditions in the study area needs to be evaluated with circumspection, since characteristics of deprivation (such as levels of nutrition, infection, pre- and post-natal care, and social conditions such as violence and parental drug abuse) may not be equivalent. For these reasons, some reliance must be placed on findings other than those deriving from prevalence studies. Of relevance to this study are findings of research into the association of mental retardation with poverty-related factors, on account of poverty being a major characteristic of the population of the study area (see Chapter One). Although numerous factors are associated with poverty, only the effects of poor nutrition will be discussed at any length below, as these are less easily recognised and treated than the effects of infection, overt brain injury, and other factors.

Accordingly, this section will initially discuss the findings of prevalence studies, and subsequently the findings of studies into the relationships between malnutrition and mental retardation. Thereafter, relevance for the present study will be discussed.

2.6.1 Findings of prevalence studies

A number of studies recognise mental retardation as being more common in lower socio-economic groups: Tarjan, Wright, Eyman, and Keeran (1973) state that "a child born and reared in a disadvantaged environment has 15 times the probability of being labelled as mentally retarded as does his age mate of suburbia" (p.371). Amongst the mildly retarded, Brask (1972) in Denmark found that environmental factors such as local socio-economic conditions and traditions in the education system affected prevalence. Czeizel _et al_, (1980), in Hungary, found that the rates of unskilled and semi-skilled workers among the parents of cultural-familial (or "familial") mildly retarded children were more than twice the rates found in the pathological, more severely retarded groups. Blomquist, Gustavson, and Holmgren (1981) also note that an improved environment and increased stimulation can lead to mental development among the mildly retarded.

It is generally considered that the effects of a poor socio-economic environment are greater on the prevalence of mild mental retardation than on severe levels (Lindsey and Russell, 1981; Richardson, 1968; Tarjan, Wright, Eyman, and Keeran, 1973). Brask (1972), however, suggests that environmental factors will operate in a different way on the severely retarded, through factors such as complications during pregnancy and childbirth, and higher infant mortality rates.

Abramowicz and Richardson (1975) evaluate the results of four studies, all conducted in Great Britain, which examine the effects of socio-economic differences on the severely retarded. Two of these studies found that severe mental retardation was evenly distributed across social classes, while two found that severely retarded children were over-represented in lower social classes. However, on account of serious methodological flaws in three of these studies, Abramowicz and Richardson conclude that "the best evidence suggests an absence of social-class gradient among the families of severely retarded children" (1975, pp. 29-30). In a study in Mannheim, Germany, Liepmann and Marker (1978) found a predominance of mentally retarded children from "lower socio-economic environments", but insufficient data make comparisons with other studies difficult.

In summary the above prevalence studies indicate that mild retardation is "closely associated with poverty, the lifestyle of the unskilled working class, and the social and educational services they receive" (Kushlick and Cox, 1973, p. 751). On the other hand, there is generally less variation in prevalence rates of severe mental retardation, which occurs equally in all strata of society.

A number of points need to be made with regard to these findings, however. Firstly, it is significant that these prevalence studies do not refer to the substantial body of work on the association between malnutrition and mental retardation. Although malnutrition may not have been a major variable in the populations studied, the findings of these studies need to be transported with care to populations in which malnutrition is widespread.

Secondly, it appears that they frequently equate socio-economic differences with variations in psychosocial conditions such as educational traditions (Brask, 1972), levels of stimulation (Blomquist, Gustavson, and Holmgren, 1981), and lifestyle (Kushlick and Cox, 1973). Czeizel et al, (1980) speak of variations in cultural-familial mental retardation, i.e. Penrose's "familial" component, which is vulnerable to psychosocial deprivation of these kinds. Accordingly, the finding that psychosocial deprivation and "familial" mild mental retardation are associated does not contradict theoretical expectations, and it is equally to be expected that severe mental retardation, with a large "pathological" component, is not markedly affected by psychosocial deprivation. Since organic factors are implicated in "pathological" retardation, it may be hypothesized that factors such as malnutrition, prematurity and low birthweight, and other poverty-related diseases and conditions frequently associated with lower socio-economic populations such as those resident in the study area, should be more frequently found among the severely mentally retarded of the lower socio-economic classes than amongst those of the higher socio-economic classes. However, aetiology is unknown in the majority of cases of severe mental retardation (see section 2.10), and the only study which examined cases of this sort (Herbst and Baird, 1983) did not control for social class.

At this point, then, evidence appears to be of uncertain value to the present study, and further evidence from alternative sources is required to clarify the issue of whether the prevalence of severe mental retardation is associated with socio-economic differences.

2.6.2 The relationships between malnutrition and mental retardation

It is assumed here that levels of malnutrition vary between socio-economic classes, and that evidence for an association between malnutrition and mental retardation will indicate that retardation resulting from malnutrition will be highest among the socio-economic classes which experience malnutrition worst, namely the lower classes. In addition, it is assumed that the sequelae of malnutrition are organic, therefore affecting "pathological" retardation, which is most frequently associated with severe levels of retardation.

It is extremely difficult to study the relationships between malnutrition and mental retardation, as controlled studies of nutritional deprivation are out of the question for ethical reasons. Therefore, although links can be established, these are frequently by implication.

At this point, it is worth noting that "the root causes of major causes of ill-health are socio-political" (Saunders, 1980, p.46). Thus, any suggestion that malnutrition may be a significant factor underlying the prevalence of severe mental retardation on the Cape Flats does not imply that this is the final cause. A thorough investigation should examine the socio-political conditions in society which give rise to malnutrition: however, such an analysis is beyond the scope of this study and will not be considered further, despite its central importance.

Numerous studies show a correlation between early undernutrition and subsequent development (Behar, 1968; Celedon, Csaszar, Middleton, and deAndraca, 1980; Hurley, 1968; Kaplan, 1972; Kotch, 1970; Poskitt, 1980; Scrimshaw and Gordon, 1968; Scrimshaw, Taylor, and Gordon, 1968).

Some of the effects of nutritional deficiencies are reversible if treatment begins early enough. During the last six months of pregnancy and the first six months of life cell division is producing rapid growth of brain tissue. Nutritional deprivation during this period can severely retard psychological development, and is probably irreversible unless treatment begins before cell division ends. From six months of age to approximately the first or second year of life the rate of brain growth is still very rapid, mainly by protein synthesis. Nutritional rehabilitation during this time can still be partially effective. However, after this period the brain grows significantly more slowly, and the effects of treatment on IQ are negligible after about four years (Kaplan, 1972).

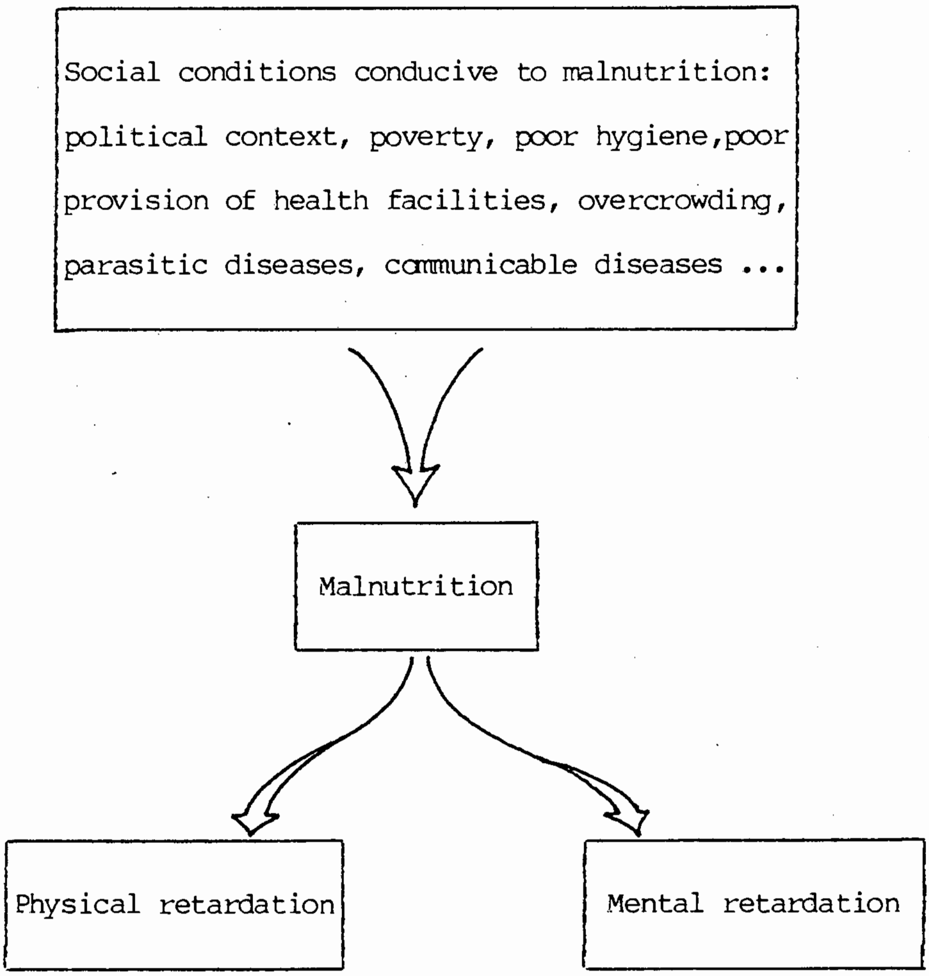
Knobloch, Rider, Harper, and Pasamanick (1956, in Kaplan, 1972) examined a variety of factors related to physical and mental development in premature babies and found that the severity of abnormalities increased as birth weight decreased. These findings have been supported by numerous subsequent studies (Kaplan, 1972).

In a well-known study in Cape Town, Stoch and Smythe (1967) conducted a study in which 20 "Cape Coloured" children who had been grossly undernourished during infancy were followed up for a period of 11 years. They were compared periodically for head circumference, height, and weight with a group of matched controls, who themselves were not optimally nourished. At the end of this period they underwent a series of intellectual, psychological, and EEG examinations, which showed that undernutrition during the period of active brain growth had resulted in reduced brain size and impaired intellectual development. The results of certain non-verbal sub-tests indicated defects in visuomotor ability and pattern perception, a finding which Stoch and Smythe suggest could be due to organic brain damage resulting from malnutrition.

Wilton and Irvine (1983) compared the nutritional intakes of socio-culturally mentally retarded children with non-retarded children of low and average socio-economic status. They found that the retarded children had significantly lower daily intakes of almost all basic nutritional substances than was the case in either of the two control groups. They conclude that although the developmental significance of their findings are not clear, it seems prudent to incorporate a focus on diet in intervention programmes. In a study in Chile, Monckenberg et al, (1972) studied two groups of preschool children from differing socio-economic backgrounds and nutritional status in order to determine effects of chronic undernutrition on behaviour and mental capacity. They noted a high incidence of psychomotor retardation in the group from the lower socio-economic level, the severity of which was directly related to the amount of animal protein consumed, and to physical and cranial growth.

In summary, it appears that strong evidence exists to suggest that mental retardation can result from malnutrition: the earlier it occurs, the greater the extent of possible damage unless treatment is initiated quickly enough. Although mild levels of retardation can result from certain types of undernutrition (such as marasmus and kwashiokor), severe mental retardation can result from gross and chronic undernutrition. Figure 4 (modified from Collis,and Janes, 1968, p.69) serves to illustrate the processes involved, and also to replace malnutrition in the social context from which it was abstracted for purposes of this discussion.

FIGURE 4 : MALNUTRITION : PRECONDITIONS AND CONSEQUENCES



(modified from Collis and Janes, 1968,p.69)

Malnutrition is not the only cause of mental retardation which may be expected to be more common in lower socio-economic groups than in higher ones. Chemogenic changes to brain tissue can occur through maternal alcohol abuse (Graham-Clay, 1983) or to the toxic effects of disease processes such as encephalitis; the foetus can become infected through maternal rubella, syphilis, or use of various drugs which can cross the placental barrier; and the newborn child can contract various infections, such as meningitis (Hutt and Gibby, 1979; McKinnon, 1980). As was the case with malnutrition, early intervention can prevent mental retardation in some cases: however, if medical care is not received in time the sequelae become progressively more severe and can end in death.

The question arises, however, of why it is that the expected higher prevalence of severe mental retardation in low socio-economic groups is not reflected in the majority of prevalence studies. Drillien, Jameson, and Wilkinson (1966), in a study in Edinburgh, found that in the IQ range 30-54 mental retardation in the absence of other overt abnormalities tends to be higher in low socio-economic groups. This suggests that these children would be more likely to go unrecognized because of the absence of overt distinguishing features. Furthermore, it is likely that access to diagnostic and treatment services would be worse for lower socio-economic groups than for high ones; and the difficulty of registration and follow-up would also be likely to be greater for this group. Finally, the supposed "greater tolerance level" of the lower socio-economic groups might lead to children repeatedly failing at school being simply considered "slow", "late developers", or "not academically-minded". This problem would be increased through poor diagnostic services, and could result in inappropriate placement of the child (for example, in special classes of ordinary schools). This "greater tolerance" would also lead to behaviour difficulties, commonly associated with mental retardation, being more easily accepted than in higher socio-economic groups. In general, these factors suggest that the absence of a socio-economic gradient in relation to severe mental retardation may partly be explained by problems of ascertainment of these cases at lower socio-economic levels, rather than as an accurate reflection of the prevalence.

However, despite the above evidence, it is clear that higher prevalence rates are to be expected only, and that these expectations are contrary to the general trend of findings. At the same time, it appears realistic to take cognisance of this expectation in the present study owing to the high rate of malnutrition and other poverty-related diseases common in the study area. Should these processes lead to one additional case of severe retardation per 1 000, as is considered reasonable, this would raise the expected prevalence from 4/1 000 to 5/1 000.

2.7 GEOGRAPHIC DIFFERENCES

Comparisons, when made, are on two levels: across countries or large regions, and on intra-regional differences. Bearing in mind that countries compared are all First World, it is evident that prevalence rates are fairly constant from country to country (Henderson, Pate, Wegman, and Ross, 1972; McDonald, 1973).

Some surveys have indicated intra-regional variations (Gustavson, Holmgren, Jonsell, and Blomquist, 1977; Innes, Kidd, and Ross, 1968; Lindsey and Russell, 1981; McDonald, 1973). Whether these variations are due to a true difference in prevalence is uncertain as different ascertainment rates and services, as well as differences in population characteristics, may influence the rates obtained. Some studies suggest that "inbreeding" of isolated communities may lead to increased prevalence (Gustavson et al, 1977; Lindsey and Russell, 1981).

A second, more specific type of intra-regional difference which has been examined is that of urban/rural variation. Abramowicz and Richardson (1975) conclude from their review of four studies which included an urban/rural breakdown that there was no consistent difference, and that only one early study (conducted in 1929) indicated that rural rates were higher than urban ones. They believe that advances in technology and communication would explain the closer agreement of urban/rural rates in more recent studies. However, Hagberg, Hagberg, Lewerth, and Lindberg (1981) in Sweden noted that urban populations have a lower prevalence of mild retardation, and Akesson (1974) in Denmark found that the prevalence rate of severe mental retardation varied inversely with population density. Thus, the conclusions reached by Abramowicz and Richardson need to be viewed as uncertain. Although this does not materially affect the present study, an implication is that prevalence rates in rural areas (and presumably smaller towns) could be higher than those of the study area.

2.8 TIME TRENDS

The question of whether prevalence rates are declining, increasing, or remaining constant has implications for the future provision of services; and if a second survey of a population is conducted after a suitable period of time, the effectiveness of preventive and other services during the interim period can be guaged. It is evident that future service needs of the study area can be informed by data obtained through surveys conducted elsewhere: however, there is no substitute for comprehensive surveys in evaluating effectiveness of present services in the study area itself.

Trends in prevalence rates over time are far from clear, however. Goodman and Tizard (1962) suggested that the prevalence of "imbecility" and "idiocy" was likely to increase, since a decline in infant mortality was likely to cause an increased number of children to be born with defects. On the other hand, Abramowicz and Richardson (1975) note that prevalence rates have remained remarkably constant over the years, at around 4 per 1 000. This is supported by Elwood and Darragh (1981), who found that prevalence of severe mental retardation in Northern Ireland established in their study was very similar to that obtained in an earlier survey. They state that "this is despite the fact that ... during the same period the infant mortality rate in Northern Ireland halved from forty per 1000 live births to around twenty per 1000 live births "(p.151). In addition, facilities such as schools, hospitals, workshops, and hostels had become increasingly available.

A number of recent studies have indicated a declining prevalence rate, particularly in Sweden. Blomquist, Gustavson, and Holmgren (1981) noted a decline in mild mental retardation in a northern Swedish county over an eleven-year period, attributing this to improved environmental conditions. Gustavson, Hagberg, Hagberg, and Sars (1977) noted a decline in incidence of severe mental retardation in central Sweden, from 5,3/1 000 in the 1959-1962 birth cohort to 3,1/1 000 in the 1967-1970 birth cohort. Gustavson, Holmgren, Jonsell, and Blomquist (1977) also found a reduced incidence of severe mental retardation in northern Sweden, and state that the decreased incidence was almost entirely due to a reduction in the incidence of Down's Syndrome to a third of its previous level. This they found was correlated with lowered maternal age. As if to deliberately complicate matters further, Read (1982) states that there has been an increase in the incidence of Down's Syndrome in recent years, mainly affecting young mothers. This he attributes to environmental factors, and he suggests an association with the contraceptive pill. Herbst and Baird (1983), in Quebec, also found a decline in incidence over a thirteen-year period, but state that this is due to a decrease in the frequency of cases at the upper levels of functioning (i.e. mild retardation, since their study included cases up to IQ 67). They believe that insufficient time has elapsed to suggest reasons for this decline.

The above data suggests little evidence of an increase in severe mental retardation over time. Evidence indicating a decrease comes predominantly from Sweden, which suggests that this phenomenon results from the comprehensive health service provided in that country. On account of the poor health services available in the study area, it is unlikely that prevalence rates will be affected in this way. Supporting this assumption is the fact that many studies indicate that prevalence rates have remained largely unchanged over time.

2.9 SEX RATIO

Evidence here is largely unequivocal: prevalence is higher in males (for example, Czeizel et al, 1980; Herbst and Baird, 1983; MacKay, 1971; Wing, 1971). Malzberg (1953: in Henderson, Pate, Wegman, and Ross, 1972) suggested two possible reasons for the male excess.

Firstly, there was a higher likelihood of males being presented for ascertainment because of differential expectations regarding the behaviour of the sexes; and secondly, there is a higher prevalence of some disorders (eg. Down's Syndrome) in males. The higher risk of pre- and perinatal damage to males is well-known: Henderson, Pate, Wegman, and Ross (1972) state that this factor is probably implicated in the higher prevalence of males among the severely retarded.

Although the general trend is clear, the extent of the male excess is not. Blomquist, Gustavson, and Holmgren (1981) record a male:female ratio of 1,8:1 in Sweden; MacKay (1971) records a ratio of 1,14:1 in Northern Ireland.

In the present study, however, no attempt will be made to estimate a sex-specific prevalence, since this will not affect the need for services.

2.10 AETIOLOGY AND ASSOCIATED HANDICAPS

The wide range of disorders known to predispose the individual to mental retardation numbers in excess of four hundred. Discussion here will be largely confined to, firstly, noting findings of prevalence studies; and secondly, drawing implications for the provision of services. Closely linked to this are the handicaps associated with mental retardation, which may have a common aetiology with the retardation itself, or may be a consequence of it.

In most cases, the cause of severe mental retardation is unknown. For example, Innes, Kidd, and Ross (1968) state that in 84% of cases the diagnosis is not known accurately. Hutt and Gibby (1979) point out that up to 94% of cases are of unknown aetiology if the definition of the American Association of Mental Deficiency is used. It is apparent that the proportion of cases with a known aetiology will be dependent on a number of factors, such as the sophistication of the diagnostic procedures used.

As was noted in section 2.6.2 above, early treatment of certain known disorders can result in prevention or amelioration of mental retardation. For this reason, adequate diagnostic and treatment services are essential.

With respect to associated handicaps, a general finding is that these increase in number and severity as IQ decreases. Abramowicz and Richardson (1975) estimate the prevalence of severe mental retardation in combination with associated handicaps at 2 per 1000: that is, approximately half of the population with severe retardation will have an associated handicap as well. The most common of these are cerebral palsy and epilepsy (Drillien, Jameson, and Wilkinson, 1966; Gustavson, Holmgren, Jonsell, and Blomquist, 1977; Herbst and Baird, 1983; McDonald, 1973; Wing, 1971), although hydrocephaly and microcephaly are also fairly common, becoming more so with increasing severity of retardation. Liepmann and Marker (1978) found that 89% of cases in Mannheim (Germany) had associated handicaps, but it is unclear whether their classification included behavioural difficulties.

Kramer (1976) comments that the level of retardation can itself increase by the presence of associated organically-induced handicaps, such as epilepsy, hypotonia, and ataxia, which make it difficult for the infant to explore the environment.

It is widely recognised that mental retardation is frequently associated with a wide range of psychiatric disorders. Slater and Roth (1977) refer to an increased incidence of manic-depressive psychosis, but not schizophrenia, in the mentally retarded; Varley (1984) describes three cases of mentally retarded girls who exhibited schizophreniform psychoses following sexual assault; Corbett (1976) discusses a number of disorders and their treatment in children. Reid (1980) examined the occurrence of psychiatric disorder among a group of 60 children over a period of "some years". He found that "the natural history of the psychiatric disorders in the children in the survey was comparable to that found in children of normal intelligence" (p.296). However, there was a tendency for certain disorders to prove unusually persistent: he related this to the familial nature of these problems, and emphasised the intense difficulties under which some families with mentally retarded children labour.

As is the case with all forms of associated handicaps, data on psychiatric difficulties are essential for planning services. The severity of stresses faced by families indicates a strong need for intervention at this level, and psychological intervention may be required in dealing with relevant problems. Behavioural techniques have proved extremely useful, particularly with regard to behaviour difficulties (Corbett, 1976; Cytrin and Lourie, 1980).

Associated handicaps specific to the elderly are also of importance in considering the planning of services. Some evidence for an increased incidence of dementia (particularly Alzheimer's Disease) compared to the non-retarded population was shown by Thase, Liss, Smeltzer, and Maloon (1982) and a number of other studies, although other studies have not supported these findings (Eisner, 1983; Tait, 1983).

2.11 SUMMARY OF OVERSEAS STUDIES

The ascertained prevalence of severe mental retardation is highest in the 10 to 19 age-group. In addition, it is higher in males than in females, and is higher in rural areas than in urban ones. In general, evidence indicates that prevalence rates have remained largely constant over time. In most cases, aetiology is unknown: however, approximately half of those affected are likely to express at least one additional physical handicap, and a considerable proportion also suffer from psychiatric difficulties.

These characteristics of the trainable retarded population may be expected to apply to the affected population of the study area. However, it was suggested in section 2.6 that the finding that prevalence does not vary across socio-economic groups needs to be considered in the light of evidence obtained from sources other than prevalence studies. Conditions of poor nutrition, and by implication poverty, may possibly play an important role in the causation of severe mental retardation. On account of the high level of poverty in the study area, it is likely that prevalence is above the world mean for this reason.

Overseas studies of prevalence indicate a world mean of approximately 4 per 1000. However, these studies invariably include all cases of retardation below IQ 30 as well. As the prevalence rate of this group is approximately 1/1 000 (Tickton, personal communication) this leaves a world mean of 3/1 000 for cases between

IQ 30 and IQ 50. For the present study, this figure is considered the lower end of the expected prevalence range: accordingly, at this point it is justifiable to use a range of 3/1 000 to 5/1 000.

2.12 SOUTH AFRICAN STUDIES

It is evident that very few studies exist in this area: in fact, most authorities in South Africa contacted in this regard did not know of such work (eg, Albert, personal communication; Wagner, personal communication). Only two studies which specifically addressed this question are known: Friedlander and Power (1982), and Power (1977), although a small number of others have examined various aspects discussed in previous sections above.

Both these studies were carried out in Coloured communities in Cape Town of mixed social classes: Friedlander and Power (1982) in Heideveld, and Power (1977) in Athlone. Both sought to identify all cases of severe mental retardation (ie, IQ's of 50 and below) in children whose parents lived in the area studied. The authors approached all hospitals, local authority clinics, state institutions, social welfare agencies, school psychology services and primary schools serving the area. Power (1977) identified 111 cases aged 6-17 years, of which 74 could be included in his study; Friedlander and Power (1982) could identify 50 cases,aged 0-18 years. "Administrative prevalence"[1] was found to be 2,5/1 000 in Heideveld, and between 2,62/1 000 and 3,36/1 000 (depending on how the figure was calculated) in Athlone. In Athlone, the maximum age-specific prevalence, 3,49/1 000, was found in the 15-17 age group, and Power considered this likely to be closest to the "true" prevalence in Athlone. Paradoxically, however, Power also states that "the true

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[1] The term used by the authors: in Tizard's terminology (see section 2.2 above) this would be termed "ascertained prevalence".

age-specific prevalence rate for Athlone must lie between 2,62 and 3,36 per thousand" (1977, p.32), here assuming a correspondence between "true" prevalence and the prevalence ascertained in his study.

In both studies, no attempt is made to explain why the prevalence rate obtained is lower than that of studies conducted elsewhere. At least two possible explanations may be proposed. Firstly, that true prevalence in both Heideveld and Athlone are considerably below the world mean. In favour of this is the argument that a larger-than-average proportion of mentally retarded children is likely to die during infancy, in view of the higher-than-average infant mortality rate of the Coloured community (Molteno, personal communication). However, as was shown in section 2.5 above, this is in keeping with overseas findings (Herbst and Baird, 1983), and is therefore not particular to the Coloured community. It would need to be demonstrated that a larger-than-expected proportion of infant deaths occurred among the mentally retarded: because of the early age of death,however,diagnosis would need to be based on physical criteria, such as found in Down's Syndrome and other abnormalities frequently associated with mental retardation. Therefore, it may be expected that a high proportion of infant mentally retarded mortalities, without overt physical signs associated with mental retardation, would be indistinguishable from other infant deaths on grounds of mental retardation. An additional problem would be the cause of death: it would need to be shown that death was inevitably a result of the child's mental retardation (and associated disorders), rather than of another condition. However, even if this argument could be tested and be supported, it was shown in section 2.5 that the excess of mentally retarded infant mortalities tended to be among the most severely retarded and those with physical abnormalities. This suggests that trainable mentally retarded children would make up a greater proportion of those with IQs of 50 and below in the communities studied than in overseas studies. This is borne out in the data of Friedlander and Power (1982), which indicate 18% of their cases to have IQs of 30 and below as opposed to the expected 25%.

A second explanation of the lower-than-expected prevalence rates found is that not all cases were identified. This is more likely, given that few (if any) overseas studies consider their case-finding methods infallible, even in countries in which sophisticated registration procedures are found, such as Sweden. Additional evidence for this is that Power (1977) could not include 37 previously-identified cases in the study because they had either moved out of the area (16), could not be traced (20), or had since died (1). This attests to the difficulties of case-finding and maintaining contact in the study area. An interesting, though spurious observation is that, since 100% of cases which could be traced were found to be eligible for inclusion, had the study been able to include all 111 previously-identified cases, the prevalence rate in the 6-17 age group would have been 4,82/1 000. This is considerably above the world mean.

In both studies, a preponderance of males was found, in keeping with overseas studies.

A number of other issues were examined in these studies. However, as these are not directly relevant to the focus of this chapter, being concerned primarily with the adequacy of service provision instead, they will be discussed in Chapter Three.

Smart (1981) investigated the incidence of Down's Syndrome children born in Cape Peninsula hospitals between 1977 and 1979. It was found that, in White children, the rate was one Down's Syndrome baby in 185 live births; in Coloured children, 1:830; and in Black children, 1:1 170. Smart indicates the world mean to be 1:600. The high incidence in Whites is attributed to the fact that Whites may be more aware of the availability of chromosome studies, and may specifically request them. In addition, many White babies are born in private clinics, for which no general birth statistics are available. The low rate in Black children may be due to the fact that the Down's Syndrome babies born outside the hospitals are not reported to relevant authorities.

With regard to factors related to poverty, Freeman (personal communication) reports that undernutrition is generally not a major contributor to the development of mental retardation in children admitted to the Livingstone Hospital in Port Elizabeth. Accurate figures are not available, since patients are normally classified under the primary diagnosis only (such as meningitis), with no reference to possible cerebral damage. As the link between meningitis and subsequent mental retardation is well-established (see, for example, Slater and Roth, 1977; Cytrin and Lourie,1980), it is possible that cases of mental retardation may escape detection in this way. Potter et al, (1984) surveyed 213 children who presented to the various teaching hospitals in Cape Town during one winter month with meningitis. They state that this is a common infection in Cape Town, accounting for 8 to 10% of all admissions to the Red Cross Hospital emergency ward. Its serious nature is shown in that it accounts for 25% of all deaths in children during winter, and its association with conditions of poverty is reflected in the ethnic distribution of cases: 94% occurred in the Coloured (69%) and Black (25%) populations. These proportions, particularly in the Black community, could conceivably be greater on account of cases remaining untreated, or treated in community clinics rather than in the teaching hospitals. Jubber (1980) in a study of 63 children institutionalized at the A J Stals institution, found that 40% of these were the result of post-natal causes, of which 29% were caused by tubercular meningitis.

Freeman (personal communication) estimates that between 7/1 000 and 10/1 000 neonates develop cerebral damage as a result of trauma or neonatal illness, and that 2% of children aged 0-12 admitted to general wards in Livingstone Hospital are left with residual brain damage. Major contributory factors are birth trauma, meningitis, gastro-enteritis with electrolyte and fluid inbalances, and head injuries. These factors are all frequently associated with conditions of povery.

Molteno (personal communication) acknowledges that the prevalence rate may be affected by poverty-related conditions, but believes that this may be offset by a higher infant-mortality rate. However, as shown above, numerous factors suggest that an increased mortality rate in mentally retarded infants is likely to have a differential effect according to levels and types of mental retardation, with those having profound mental retardation and physical abnormalities being most likely to be affected.

In summary two South African studies of ascertained prevalence, both conducted in Cape Town, reveal a prevalence rate below the world mean. This rate, however, is likely to reflect an under-enumeration of cases rather than the true prevalence. The influence of poverty-related factors on true prevalence is uncertain, owing to the necessity of using surrogate evidence: none-theless, this evidence is sufficiently strong to suggest that true prevalence may be above the world mean, and very strongly suggests that it is above the ascertained prevalence rates established in the two studies discussed.

2.13 CONCLUSION

Available evidence from all sources supports the use of a prevalence range of 3/1 000 to 5/1 000 in estimating the number of people with trainable mental retardation in the Coloured and Black communities of Cape Town. The lower end of this range, i.e. 3/1 000,is consistent with the world mean. In addition, its use is supported in that this is currently the officially-recognised prevalence rate in motivating for the establishment of new facilities. Evidence in support of the 5/1 000 upper limit of the prevalence range is less conclusive: clearly, the more it deviates from accepted rates the more tentatively it must be viewed. However this rate is used as it approximates the highest prevalence rates ascertained in empirical research elsewhere (5,8/1 000 for IQs 0-50: ie, 4,8/1 000 for IQ's 30-50: see Kushlick and Cox, 1973). It may be expected that the true prevalence in the study area will fall between these two limits of the range, and these rates are accordingly used in Chapter Four in estimating the true prevalence of trainable mental retardation.

CHAPTER THREE : PROVISION OF SERVICES IN THE STUDY AREA

CHAPTER THREE : PROVISION OF SERVICES IN THE STUDY AREA.

3.1 HISTORY OF THE CARE OF THE MENTALLY RETARDED

Although it makes interesting reading, the general history of the care of the mentally retarded is not relevant here (see Kanner, 1964; Rosen, Clark, and Kivitz, 1976; Ryan and Thomas, 1980). This section, however, briefly examines the historical development of organisations involved in the care of the mentally retarded in South Africa, and specifically the Western Cape. It does not claim to be comprehensive (see, for example, Gilbert, 1981; Herring & Jaffe, 1981; Minde, 1975), but rather is addressed chiefly at contextualizing the present.

Differences in provision along racial lines are immediately apparent. Although speaking of mental health facilities in general, Solomons (1980) notes that "Mental health facilities were always unequally distributed between the white and black race groups, favouring the whites. Although the differences in some spheres have narrowed, the overall picture in 1976 was still one of a grossly unequal service" (p.286). Solomons notes that the State planned new facilities for 1 130 "Whites", 1 000 "Coloureds", and 0 "Blacks" in 1976 (1980, p.292).

Steenkamp and Steenkamp (1981) state that since the promulgation of the Mentally Retarded Children's Training Act (No. 53 of 1974), day centres controlled by the (White) Department of National Education have received almost complete state subsidization, and add that "other population groups willl receive state aid within the near future" (p.9). The extent to which this promise has been met is discussed in the following section.

In 1920 the National Council for Mental Hygiene and for the Care of the Feebleminded was established: this became the South African National Council for Mental Health in 1946 (van der Bergh, 1983). This body made a number of representations to the Government to investigate the provisions of the Mental Disorders Act (no. 38 of 1916), according to which the mentally ill (including the mentally retarded) were seen as a homogeneous group needing custody rather than a therapeutic environment (Minde, 1975). Finally, the van Wyk Commission was appointed as a reaction to Verwoerd's assassination by Tsafendas: as a result, the Mental Health Act (no.18 of 1973) was promulgated. This Act placed emphasis on prevention, and on the promotion of mental health. Thus, from 1974 there was a shift in emphasis from mainly institutional care to care in the community (van der Bergh, 1983).

In addition, the S.A. National Council for Mental Health requested the government to investigate the care of mentally retarded children. A committee (known as the van Wyk Committee) was appointed in 1965 to examine conditions for White children (Gilbert, 1981). In 1974 the Mentally Retarded Children's Training Act (no. 63 of 1974) was passed: this transferred the responsibility of education and training from the national Department of Health to the Department of National Education. In terms of this Act, education is provided for children between the ages of 6 and 18, although children may stay at school until the age of 21 if their progress should warrant this (Lombaard, 1982).

3.2 PRESENT PROVISION OF SERVICES

This section will approach its subject matter from two perspectives. Firstly, that of the organisation of the provision of services, with emphasis on the various bodies concerned and their co-ordination; and secondly, education, training, and other facilities presently available. Finally, some attention will be focused on likely conditions for cases unknown to the responsible authorities.

Information obtained for this section derives in large measure from personal communication with numerous people presently working in this area. These include Cooke, Grover, Hollingshead, Molteno, Rosenthal, Roux, and Tickton. Other sources of general information include Vries, van den Worm, and Steenkamp (1982), and Lifeline (1985). More specific references will be identified at relevant points.

3.2.1 Present organisation of the provision of services

As will become evident, the picture is a complex one. For this reason, the following discussion can only identify the more fundamental components of the present structure. Accordingly, some attention will be directed at a number of organisational issues in order to highlight consequences for the provision of services.

The complicating dimensions include different authorities being responsible for different levels of mental retardation, races, ages, and types of services. In order to communicate some of the flavour of this complexity, it is necessary to range beyond the scope of this thesis to some extent.

Cases of mental retardation below IQ 30 are the responsibility of the various "Own Affairs" State Departments of Health. This group includes the profound and part of the severe range (see Chapter One), and are collectively known as persons in need of special care. Owing to the severity of their retardation, these people require almost constant aid and supervision throughout their lives, and in most cases institutionalization is required. The White population of Cape Town is well served, facilities including the Alexandra Institution and the Glendale Home; for the Coloured population, the A.J. Stals Care and Rehabilitation Centre and the Goodwood Oasis Special Care Centre exist in Cape Town. However, no facilities exist for the Black community in the Western Cape whatsoever.

Cases of mental retardation above the upper limit included in this study, ie from IQ 50 up to the ceiling of the mild group at IQ 70, are the responsibility of the respective "Own Affairs" Departments of Education for each race group. This category is known as "educable". White children are placed in Special Classes attached to ordinary primary schools, following a full psychometric assessment and the conset of the child's parents. After completion of their primary school education they are placed in Special Secondary Schools, of which there are three in the Cape Town metropolitan area. Here, emphasis is placed on practical training in preparation for apprenticeship to a trade (Leary and McKerrow, 1980). The responsibility of the Provincial Department of Education, under whose immediate jurisdiction these schools fall, ends when the child leaves school. Thereafter, responsibility is transferred to the "Own Affairs" Department of Health Services and Welfare of the House of Assembly. In general, facilities for the educable White group is adequate: psychological assessments are undertaken by school psychologists and at a number of school clinics, and some screening is also undertaken by the school health service provided by the Provincial Department of Education.

For Coloured and Indian Children, the organisational structure is similar, although facilities are very much less adequate than for Whites. Because of the small size of the Indian community in the Western Cape, no exclusive facilities are provided. Educable Coloured children ideally are placed in Adaptation Classes attached to ordinary primary schools although there are too few such classes to cope with the need for them. However, no Special Secondary Schools exist, and only one school clinic is run by the Department of Education of the House of Representatives. A school health service is run by the Department of Health Services and Welfare of the House of Representatives. On account of the lack of facilities, it is likely that a considerable number of children are inappropriately placed: children who should be placed in an adaptation class remain in ordinary classes owing to the lack of such classes and to inadequate assessment services; of children presently in adaptation classes, it is estimated that IQ's are as low as 40 (Rosenthal, personal communication), thereby keeping children for whom adaptation class is better suited from receiving this education; and other children who could benefit from adaptation class education are placed in training centres as such placements are not available for them. These, in turn, restrict places available for trainable mentally retarded children in these centres. This situation has parallel difficulties for those completing adaptation class primary school education, since appropriate secondary school education is non-existent. Their primary education is inadequate to permit ordinary secondary schooling, and is beyond the qualification appropriate for training centre placement (even if such places were available). Therefore, many perhaps leave school at an early age, and enter the unskilled workforce.

For Black children, the situation is very much worse again: no adaptation classes exist, and there is only one psychologist to undertake assessments in the Western Cape. No developmental screening can be undertaken by the school health service, as none exists. Such children presumably remain in ordinary classes, where repeated failure is to be expected. Upon leaving school, most perhaps undertake unskilled work.

It is therefore evident that White educable mentally retarded children are reasonably well catered for. However, for other population groups the situation is extremely inadequate, and for the Black community in particular this lack of facilities is critical. Although in the context of the inumerable other shortcomings of the Black education system the present situation is not in itself anomolous, the particular difficulties faced by teachers of ordinary classes with mentally retarded members clearly requires vast re resources of dedication. Their need for assistance, at a variety of levels, must be considerable.

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The "trainable" group of mentally retarded children, generally with IQ's ranging from 30 to 50, is the responsibility of various racially-specific state departments. For White children this is the Department of Education of the House of Assembly, formerly the

Department of National Education; for Coloured children, the Department of Education and Culture of the House of Representatives, formerly the Department of Internal Affairs, Division of Coloured Education; and for Black children the Department of Cooperation, Development and Education, a "General Affairs" State department, formerly the Department of Cooperation and Development. Asian children fall under their own "Own Affairs" department of the House of Delegates, formerly part of the Department of Internal Affairs. Upon leaving their training centres, all these children cease to be the responsibility of these various departments, and become the responsibility of the various departments concerned with Welfare instead.

And thus is exposed perhaps the greatest single obstacle faced by those responsible for providing services: the vast bureaucratic duplicating machinery so familiar (or unfamiliar) in South African life. In order to obtain funds for service provision, for example, it is necessary to approach each State department separately, each department having its own requirements for submission of requests for funds. Accordingly, it is necessary (and required) to view service provision as composed of officially mutually-exclusive parts, rather than as a comprehensive whole. Added to this are numerous other difficulties, such as differential rates of funding that are racially-determined; that funds obtained from one department cannot be used to provide facilities for other population groups, even if the service required is identical, regardless of relative need; and that funds received for a particular purpose (eg, a teacher's salary) must be used for that purpose and no other (eg, a teaching assistant's salary), regardless of between-budget, short-term priorities. An interesting observation with regard to this funding system is that funds for all departments derive from a single State source, the Central Treasury.

To further complicate the picture, organisations providing services may not approach the relevant State department directly. Two exceptions to this rule are in the case of fundraising (for which legislation exists to permit direct liaison with the Department of Health Services and Welfare of the House of Assembly) and in the establishment (ie, not continued operation) of training centres for Coloured children (for which contact may be made directly with the Department of Education and Culture of the House of Representatives). For all other social work and related matters, such as staffing needs (creation and filling of posts, salaries, etc.), transport claims, vehicle needs, and other financial and administrative matters, the South African National Council for Mental Health (SANCMH) must be approached in the first instance. This body, through its Division for the Mentally Handicapped, therefore acts as an intervening authority, and exists to provide the State with a means to co-ordinate the activity of the numerous private organisations providing services. The desirability of State control will not be considered here.

For trainable children, the role of the Central Government is primarily the subsidization of training centres, which are usually sponsored by private organisations such as the various Mental Health Societies and the Oasis Association. However, this subsidy is not given as a single grant: rather, a 100% subsidy pertains to salaries, the purchase of fixed equipment, the transport of children to and from the centre and on outings, and for the administrative costs of running the centre. Costs of building a new centre receive a 95% subsidy: however, this is only obtained after the remaining 5% has been raised. Owing to the high costs of building such a centre, together with the fact that funds are seldom available from an already-inadequate budget, raising this 5% is in itself no easy task. Other aspects of training centre funding are subsidized to the extent of 75%. The balance of funds required is raised by fundraising activities, private donations, and other similar sources. As noted above, the uniquely-South African bureaucratic system greatly complicates the position: for example, a vehicle bought for the transport of White children cannot be used to transport Coloured children, as trips of this sort are not permitted for travel subsidy purposes.

An additional level of this administrative structure is that of the Regional Welfare Board, of which there are one each for Whites and Blacks, and three for the Coloured population in the Western Cape. However, these are fortunately only of peripheral importance with regard to mental retardation, and need not be further discussed.

There are at present at least forty-five organisations providing various services for the mentally retarded in the Western Cape. In order to provide a forum for these organisations, and to enable some measure of co-ordination and the joint planning of services despite State insistence that these be viewed as racially separate, the Western Cape Forum for the Mentally Handicapped (WCFMH) was formed in 1970. This body has established a number of sub-committees to examine various problem areas in the provision of services, and a number of reports on facilities for Blacks are expected to be published shortly.

3.2.2 Services presently provided

Besides the administrative and financial role played by the Central Government, the other tiers of government (ie Provincial Administrations, and Local Authorities), also play some role in the direct provision of services for the mentally retarded. However, this is not done in a co-ordinated way.

The Provincial level of government is primarily concerned with curative services, including assessment. Such facilities are provided at the Red Cross Children's Hospital (the Developmental Assessment Clinic, DAC) and at Tygerberg Hospital. These units undertake psychometric and genetic testing of children where appropriate, and also of parents where required for purposes of genetic counselling. Referrals to the DAC come chiefly from the community health clinics run by local authorities (approximately 95% of all referrals), while almost no referrals originate from private doctors. Children identified as mentally retarded by the DAC are referred, together with their families, to agencies in a position to take further action. However, it is recognised that the prospects of training centre placement are remote, at least in the short-term or until further centres are built. Accordingly, the Child Care Information Centre (CCIC), which is connected to the DAC and is part of the Department of Paediatrics and Child Health of UCT, undertakes parental counselling and also runs a toy library. In addition, the CCIC is concerned with the dissemination of information regarding mental retardation to parents, professionals, and others. The CCIC Toy Library travels to various points in the study area, and provides parents with toys and guidance appropriate to their child's developmental needs. Owing to the great need for this service, the toy library attempts to limit itself to the pre-school age group in order to provide the early stimulation essential to foster maximum development. However, in practice this is not easily accomplished, as upon reaching the upper age limit there are no training centre placements available. Consequently, a number of cases remain long after this age, including one woman who is presently aged 21. Although some attend toy library clinic sessions regularly (such as this woman), in most cases attendance is sporadic. Various reasons for this are evident, a major one being the cost of attendance in terms of time and money. Despite reduced distances on account of the library travelling into the community, transport is still a problem for many. In addition, a severe blow to the enthusiasm of concerned parents is the fact that coming to a toy library session may require taking an entire day off work, without pay: this loss of income may be prohibitive for families already poverty-stricken. However, despite these drawbacks, and the problem that much-needed intervention can only be provided once a week, it is clear that the toy library is providing a very useful service.

Local Authorities (in the study area, the Cape Town City Council and the Cape Divisional Council) are chiefly concerned with preventive services. These include "Well Baby" Clinics and Nutrition Clinics, as well as other community health services. Referrals are made to the DAC on the basis of suspected developmental delays, although this is not automatic procedure. One doctor working in the CCC community health clinic system said that not enough was known about who to refer clearly identifiable cases to, such as Down's Syndrome, microcephalic, or fetal alcohol syndrome children.

As was mentioned previously, private organisations generally deal directly with identified cases of mental retardation, and undertake the provision and running of training centres. In the Cape Town metropolitan area, the three main organisations which provide such facilities for the Coloured and Black communities are the Cape Mental Health Society (CMHS), the Oasis Association, and the Fish Hoek, Noordhoek, and Kommetjie Welfare Association. Of these CMHS will be discussed in some detail, as it provides the majority of services available in the study area.

CMHS is one of approximately 13 Mental Health Societies which operate in South Africa. It was founded in 1913, and is the oldest community-based mental health welfare agency in the country. It is concerned both with the mentally retarded and with people suffering from a psychiatric disorder, particularly schizophrenia. For this group, it provides a variety of therapeutic activities and social skills training, and a residential after-care service. The CMHS aims, in general, to enhance the quality of life of its clients, and to provide support, counselling, and other advice to them and to their families. It also has a preventive function, and seeks to develop community-based social work services.

With regard to facilities for the mentally retarded, CMHS attempts to provide a comprehensive "life-long" service as far as possible: this includes residential facilities, training centres, protective workshops, occupational groups, and recreational facilities, for all ages from preschool through adulthood.

For children of preschool age, CMHS runs a toy library in certain areas where fixed facilities are inadequate or non-existent. A number of members of staff, including a teacher, a social worker, a psychologist, and a physiotherapist meet groups of mothers and their children at various community venues, and undertake a team assessment of the specific needs of each child. In the light of this assessment, individual programmes are devised for each child, and appropriate educational toys are provided. In addition, a home programme is worked out in conjunction with the child's mother, and other practical guidance (with respect to behaviour and discipline problems, for example) is offered when necessary. On subsequent occasions, development is monitored, and the programme is amended as required. The function of the toy library is primarily to prepare children for placement in a training centre or, where such placement is unlikely owing to a shortage of facilities (as is generally the case), as an alternative source of programmed developmental stimulation.

At present, this service caters for 35 children in Mitchell's Plain and 30 in Grassy Park (including Ottery, Retreat, Lotus River, and Parkwood Estate). A new service, to serve approximately 30 to 40 children, is to start in Bonteheuwel next year. A group for 15 special care children is run in Mitchell's Plain as well. Problems encountered are similar to those experienced by the toy library of the CCIC, mentioned previously. However, although attendance fluctuates, it is clear that this service is performing an extremely useful function under conditions in which permanent facilities would be better suited to the requirements. Of major benefit to the parents who attend is the possibility of speaking to others who experience similar circumstances: from this contact has arisen a number of informal groups, run by the parents themselves. When necessary, these groups request specific assistance from CMHS. Various collective activities are arranged informally,such as child-care groups.These include those children too old for the toy library or who cannot attend regularly, and also function on those days when the toy library is busy elsewhere.

For mentally retarded adults, i.e.those beyond training centre age, a number of employment possibilities exist in principle. A small number of people, near the upper limits of the mildly retarded range, are capable of working in the open labour market. Those capable of 50% productivity on the open labour market (as compared to the hypothetical productivity of a normal person) may be admitted to "sheltered employment". This type of work is only available to Coloured men: no places are available to Coloured women.Furthermore, no facilities whatsoever are available to Blacks. These facilities are also intended for the physically disabled. However, in practice there are long waiting lists, and few mentally retarded people are accepted by these facilities. This scheme is administrered by the State Department of Manpower.

For those capable of 30% productivity on the open market the CMHS runs a number of "protective workshops". Facilities for the Coloured community exist in Retreat and Athlone: a White workshop is run in Fish Hoek. Other facilities for the Coloured community run by organisations other than CMHS, are in Elsies River (Oasis) and Ocean View. This type of work is suitable for the majority of people who have previously attended a training centre, and the specific work done by each person depends on his/her capabilities. This is generally of a straightforward nature, ranging from the weaving of fairly complex designs to removing stamps from envelopes. The workshop management obtains contracts for this work, the contractor supplying the raw material and any equipment required, and the workshop provides the labour of its members. A per capita subsidy is paid by the State. These workshops provide a major service to the adult mentally retarded population, but once again the demand for places far exceeds those available: generally, such a centre is able to accomodate 45 to 60 people. For those fortunate person is gainfully employed, which immeasurably enhances self-esteem, and also gives a sense of reduced dependency on others. Concomitantly, for those on whom the mentally retarded person would otherwise be heavily dependent, and who accordingly would need to make major sacrifices in meeting these needs, this reduced dependency is a major asset in freeing them for other necessary activities.

Finally, for those adults whose level of productivity does not make them suitable for protective workshop placement or for whom such facilities do not exist, the CMHS runs a number of "occupational groups". These are not subsidized by the State. One of these, Mompumelelo Occupational Group is the only facility of any sort available to Black adults in the study area and caters for only fifteen people. The current register of need for this group is 21, and therefore 42% of known cases are presently accommodated. However, as will be shown in Chapter Four, only a small fraction of the estimated prevalence is known for various reasons outlined above, and this figure is therefore rather misleading. Groups for Coloured people are run in Athlone (30 members), Retreat (45), and a new group of 8 people has recently begun in Bonteheuwel. These groups are all run five days a week. A once-weekly group is run in Mitchell's Plain for 11 people. The waiting list for placement in either a protective workshop or an occupational group in each of these areas is 22 in Athlone, 72 in Retreat, 76 in Bonteheuwel, and 78 in Mitchell's Plain. The extent to which the known need is being met in each area is 58%, 38%, 10%, and 12% respectively.Again, these figures relate only to known cases awaiting placement. The extent of the potential waiting list will be estimated in Chapter Four. Occupational groups are intended to increase the level of self-sufficiency of its members,and to provide activities suited to individual capabilities.For children aged between approximately six and eighteen, ie. of schoolgoing age, CMHS operates two training centres. For Coloured children, the Mary Harding Centre in Athlone caters for about 137 children, of whom 50 girls may be accomodated in the Garden Home, and 50 boys in the Torrance Home. Such accomodation is offered in cases where home conditions are unlikely to encourage maximal development of the child's potential. The Mary Harding Centre also operates three satellite centres in Bonteheuwel, Mitchell's Plain,and Retreat. These cater for a further 18, 22, and 22 children respectively, for whom transport to the main centre may be unavailable. Waiting lists for these centres are: Athlone 131, Bonteheuwel 70, Mitchell's Plain 148, and Retreat 142: therefore, they presently serve 51%, 20%, 13%, and 13% of the known needs of their respective communities. Staff at the Mary Harding Centre include teachers, teacher aides, a nurse, a speech therapist, and two occupational therapists. The Mompumelelo Training Centre (Mompumelelo = "Success") in Nyanga has been recently expanded, and accomodates 50 Black children from Nyanga, Langa, Crossroads, and Guguletu. The waiting list for this centre is 95 children at present: accordingly, only 34% of the known need is met.

Two other training centres for Coloured children exist in the study area, one in Ocean View, and the other in Elsies River (the Goodwood Oasis). The Ocean View centre is presently functioning beyond its capacity on account of its policy to transport otherwise unserved children to the centre from areas a considerable distance away, such as Grassy Park.

In order to qualify for admission to a training centre, a child must be assessed by a psychologist as trainable (rather than educable), and must be certified as exempt from ordinary school. However, because of the shortage of facilities, actual admission to a centre is unlikely within the following four years. The numerous problems associated with this delay include that the child might move in that period and become impossible to trace, and that the leeway lost by a four-year period of intermittent educational contact (at best) makes maximal development an unlikely possibility. For those children who are fortunate enough to obtain a training centre placement, the school day consists of various periods in which emphasis is placed on developing the child's potential. Academic subjects are avoided except insofar as they provide the child with essential skills, such as being able to handle money (ie, basic arithmetic) and reading (where possible). Other practical training is provided with regard to self-care and hygiene; social behaviour; domestic tasks such as making beds, tea, and going shopping; and road safety. With increasing age and attainment of higher levels of development, the programme is adapted accordingly. Some basic sex education is undertaken, and children gradually learn new skills to be used when (and if) they enter a protective workshop.

In addition to the above facilities, which are specifically for the mentally retarded, a considerable number of mentally retarded children are provided for in other types of facility, particularly where there is an associated problem. Of particular importance here are special schools for cerebral palsied and autistic children, and also special schools for the deaf.

With respect to recreational needs, which are as important in the lives of mentally retarded people as for anyone else, a number of Gateway Clubs exist. These cater primarily (though not exclusively) for young adults, and provide recreational and social activities in an informal setting. Recreational activities for children are provided in the training centres.

The above discussion does not mention facilities available to the White population, as these fall beyong the scope of the present study. However, indications are that these are generally adequate for the needs of the population. It is also evident that a fairly well-developed support system exists, with a specialized association for Down's Syndrome children. Although in principle this organisation is non-racial, in practice all but a small fraction of its work is with the White population.

Thus, in general it can be said that the availability of services is strongly determined by race. Whereas for Whites the position is reasonably positive, for the Coloured population facilities are far from adequate, and for the Black community the position is critical. It must be noted that no mention has been made in the above discussion of Khayelitsha: although its population is presently estimated at over 90 000, no services for the mentally retarded exist whatsoever, although discussions are underway in this regard.

Numerous factors underlie the present availability of facilities. The most important constellation of these, the socio-economic policies of South African society, have already been discussed: it is clear that discrepancies cannot be overcome if these policies are not removed. In addition, it is evident that the Black community is suffering a lack of facilities so severe that attention needs to be directed at understanding this dimension of the overall shortage of facilities in particular. Firstly, it is to be expected that some relative improvement of facilities for Coloured people has followed (and is following) the reformist policies of the White government, particularly on account of some Coloured participation in the new parliamentary system. No similar avenue for improvement of facilities exists for the Black community.

Secondly, the State has sought to abrogate its responsibility to the Black community to a considerable extent by its "homeland" policy, thereby requiring the homeland governments to provide for the bulk of the needs of the Black population. As an adjunct to this policy, the Western Cape was declared a "Coloured Preference Area" in 1962, according to which only a highly restricted sector of the Black population - that group whose labour was required by the economy of the Western Cape - was permitted to reside in the region. In all cases, preference had to be given to Coloured people, and only where such labour was unavailable could Black labour be employed.Although it was announced in 1984 that this policy was to be scrapped, the institutional structures that enforce and administer influx control continue to operate as before (Johnson, 1985). This policy, together with its numerous legal supports (such as the Black (Urban Areas) Consolidation Act, no. 25 of 1945, and the Act governing the "Orderly Urbanization of Blacks") have had far-reaching effects on the Black population. These are generally well-known, and need not be discussed here: however, with respect to the Black mentally retarded population, two points are significant. Firstly, due to their low productive capacity and resultant low value to the economy, most are illegal residents in the region. To prevent their removal to homelands, they need to remain undeclared to the authorities : this results in a dual problem in that bodies providing services are unable to even identify the extent of need, while they cause additional financial difficulties for their already poverty-stricken families. Secondly is the dilemma of how to provide services for the known "illegal" mentally retarded. The consequences of the administrative gymnastics required are both tragic and ludicrous: how does one obtain a school-exemption certificate for a child who is not legally entitled to be educated in the Western Cape in the first place?

3.2.3 Conditions for unserved cases of mental retardation

As is evident from the above, facilities are inadequate. What are conditions for those presently uncatered for? Two groups may be recognised here: those identified, but for whom placements are presently unavailable, and those who remain unidentified.

Of the former group, a proportion would be partially catered for through toy libraries and the associated services offered at these sessions. However, this attention is available for only a fraction of the child's week: for the rest of the time the parents need to utilize their own resources. For those who can attend toy library sessions, these are of enormous benefit, as discussed previously. For other parents, the only services available may be infrequent contact with a social worker or some other professional, from whom some support and intervention at times of crisis may be available. For other parents, for whom contact of even this limited form may be impossible, it is possible that alternative caregivers would include relatives and friends. Of particular importance in this group are those known cases with whom contact has been lost, a considerable problem in the Black community.

For unidentified cases, conditions can of course only be guessed at. A principal issue here is why these have remained unidentified. In the Black population, it is likely that a major proportion of such cases remain unknown on account of the threat of removal to a homeland for "illegal" residence in the Western Cape. Other reasons for remaining unidentified are more generally applicable.

At preschool age, cases in which mental retardation is frequently expected through association with another condition are likely to be identified following identification of such a condition. The majority of these, it may be assumed, would be referred to appropriate agencies, although it is clear that these avenues of referral may not be known. The rest probably become absorbed into the community, as developmental delays are frequently not noticeable at preschool age, and their mental retardation may only become apparent upon entering school. For cases of mental retardation taking a more subtle form, such as following meningitis, identification is more difficult: these children are even more likely to remain undetected until some schooling has been undergone. An additional factor is that of parents unable (or unwilling) to recognise their child's developmental delay who would not bring these to the attention of health workers. Clearly, more severe degrees of mental retardation are more likely to be recognised at an early age than milder degrees because of the greater relative discrepancies from normal development.

Consequences of remaining unidentified are neglible on the family at preschool age, as these children do not impose burdens on the family markedly greater than would a normal child. However, as is the case with normal children, early stimulation is of great benefit in maximizing the child's developmental potential, and it is here that the greatest benefits of early intervention would accrue.

At school age, the chances of non-identification are reduced: however, children without overt signs and with some language may simply be viewed as "slow", particularly by teachers unskilled in recognizing a significant developmental delay. These children may be exposed to highly inappropriate normal education and be transferred to an adaptation class (if available), where they would continue to make minimal or slow progress. By the time such children are recognised as mentally retarded, they are possibly too old to benefit maximally from appropriate placement (again, if such placement is available). In other cases, mentally retarded children may be kept out of school altogether, and thus receive no attention whatsoever. In either situation, the parents need to fall back on their own resources in looking after their child at home, without assistance in dealing with their feelings about their child, behaviour and discipline problems, impact on family life, and financial implications.

It is likely that the school-age years are the most difficult for the parents of a mentally retarded child to handle without assistance, and it is during this period that the potential for complications in care-giving are greatest. Behaviour difficulties constitute a major problem area, and it is here that advice is sorely needed by parents. An additional problem area is that of their child's growing sexual awareness, coupled with the dangers of sexual abuse, which are considerable for children living in the community. A further area of difficulty is that of teaching their child basic social skills, without which both child and parents are at a distinct disadvantage with regard to their ability to participate in social activities.

3.3 SUMMARY AND CONCLUSION

The above discussion has documented the provision of facilities for the mentally retarded in the study area, and has indicated that these are severely inadequate for the Coloured population, and are critically lacking for the Black population. In addition, it has outlined a range of consequences of this shortage for the communities involved.

Despite the seemingly hopeless position, two important points need to be made. Firstly, conditions of today are vastly better than they were ten years ago; and twenty-five years ago the only facilities in existence were large residential institutions (such as Alexandra), with little else being provided. It is evident that the situation has improved immeasurably: by placing the present in its historical context, past achievements take on a new significance (Grover, personal communication). In this light, present difficulties may be seen to have their parallels in history, and as a set of challenges to be overcome through gradual attrition, rather than as a set of impenetrable barriers which must inevitably lead to defeat. Secondly, it is with this frame of reference that workers in the field are approaching the problem of fulfilling service needs. The difficulties are recognised, and ongoing efforts are being made to rectify current deficiencies. Plans are being formulated to introduce services to Khayelitsha; large extensions to the Mary Harding Centre are to be undertaken in the near future; the Nompumolelo Centre was recently extended; the Bonteheuwel occupational group has just started, and the toy library is to begin operating there next year. Planning has been facilitated by the co-ordination of activity by the Western Cape Forum, and ongoing research into service needs is undertaken constantly by CMHS. The Oasis Association, also, is seeking various ways of improving its service: for example, it is presently investigating the setting up of a new special care facility in Goodwood. Therefore, to conclude that the present shortage of facilities must inevitably reflect future conditions does not acknowledge the improvements that have already taken place, and does not acknowledge the energy with which current service difficulties are being addressed and overcome.

CHAPTER FOUR : RESULTS

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As noted in Chapter One, the calculation of the prevalence of trainable mental retardation in the study area has a number of components:

1. Present (1985) prevalence;
2. Present shortage of facilities; and
3. Expected prevalence in the year 2000.

Each of these will be examined in turn below. Owing to methodological and statistical variations, each section will contain a discussion of the specific methodology used. It will be noted that figures at times do not add up to the total indicated: this is because of inaccuracies in the base data and the calculation methods used.

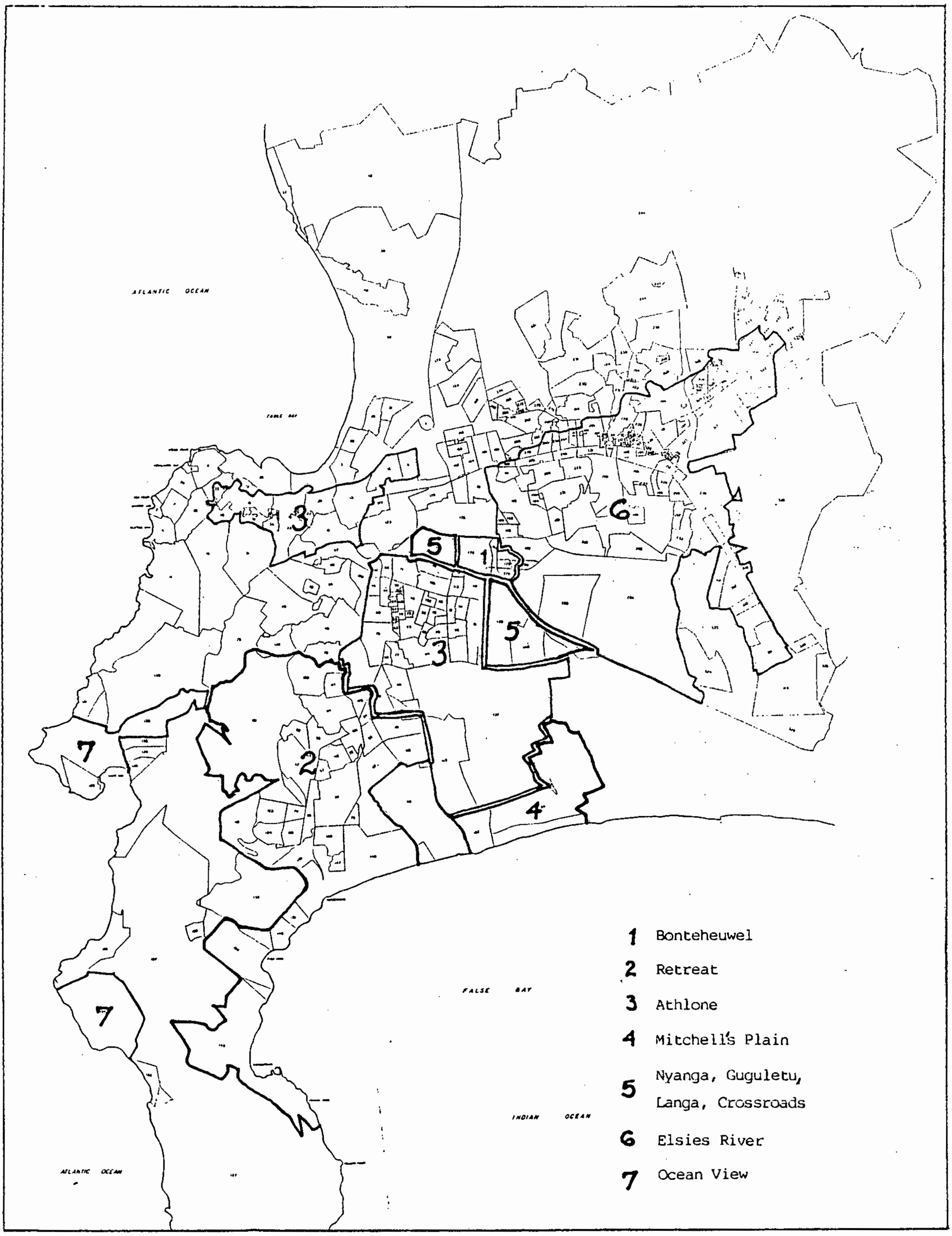
4.1 PRESENT PREVALENCE

This calculation involves two steps: firstly, estimation of the present population of the study area; and secondly, applying the prevalence range determined in Chapter Two to this population.

In estimating the present population, the data contained in the 1980 population census was used as a base where possible. To this was added annual natural increase, or excess of births over deaths, a rate of 2,5% per annum (MOH,1985). This method was considered suitable for all areas in the study area except for Mitchell's Plain, Crossroads, and Khayelitsha. With respect to both Mitchell's Plain and Khayelitsha, intensive development took place subsequent to the 1980 census. The population of Mitchell's Plain was estimated in mid-1984 by multiplying the number of dwellings constructed by a factor of 5, this being the mean dwelling occupancy of the Coloured community in Cape Town (Romanofski, personal communication). To this was added the natural increase of 2,5% in order to estimate the population in mid-1985. The population of Khayelitsha was estimated in 1985 by multiplying the number of sites occupied by the occupancy rate of thirteen people per site: this is the mean number of people per dwelling in the Black commununity as calculated by the Technical Management Services Branch of the Cape Town City Council (Roux, personal communication). With regard to Crossroads, it is generally accepted that the population was greatly underenumerated in the 1980 census, owing to the high proportion of "illegal" Blacks who refused to be included for fear of being removed to a "homeland". The official 1980 population of Crossroads totalled less than 32 000 (TMS, 1984). To rectify this inaccuracy, the number of dwellings was calculated from aerial photography, and this figure was multiplied by the mean dwelling occupancy. The population size used in this study (150 000) was estimated in 1984 (Gentle, personal communication) although it is reported that aerial photography in June 1985 revealed 14 000 dwellings, giving a population of 182 000 at 13 residents per dwelling (Roux, personal communication). However, this could not be confirmed.

The information contained in the 1980 census is provided by "local area", of which there are 325 in Greater Cape Town (TMS, 1984). Because of the large number in the study area, they have been condensed into eight "feeder areas" in order to facilitate discussion: see Figure 5. These feeder areas are population and spatial units accepted by agencies providing services in the study area, and represent the areas which "feed" the centralised facilities (whether existing or proposed) in each.

FIGURE 5 : FEEDER AREAS OF FACILITIES FOR THE TRAINABLE MENTALLY RETARDED



Their usefulness in the present study is enhanced in that waiting lists for training centres and occupational groups are divided according to feeder area: therefore, use of corresponding geographical units permits the calculation of need, undertaken in 4.2 below. Population estimates for 1980 and 1985 are shown in Tables 2 and 3.

TABLE 2 : POPULATION OF THE STUDY AREA : 1980 CENSUS

FEEDER AREA	POPULATION:1980 CENSUS, BY AGE GROUP			
	0 - 4	5 - 19	20+	TOTAL
Bonteheuwel	7 460	25 620	29 220	61 700
Retreat	16 760	57 500	67 770	152 030
Athlone	28 700	96 420	146 780	271 840
Mitchell's Plain (1)	-	-	-	-
Nyanga, Guguletu, Langa, Crossroads (2)	11 440	34 440	86 420	262 300
Khayelitsha (3)	-	-	-	-
Ocean View	2 380	5 440	7 700	15 460
Elsies River	27 920	84 330	97 300	222 880

NOTES:

(1) See Table 3.

(2) Crossroads: official figures excluded from 1980 census data above. 1984 estimate included in 1985 feeder area estimate.

(3) See Table 3.

TABLE 3 :POPULATION OF THE STUDY AREA : 1985 ESTIMATE

FEEDER AREA	POPULATION:1985 ESTIMATE, BY AGE GROUP			
	0 - 4	5 - 19	20+	TOTAL
Bonteheuwel	8 028	27 570	31 444	66 396
Retreat	18 035	61 876	72 928	163 600
Athlone	30 884	103 758	157 950	292 528
Mitchell's Plain (1)	18 453	61 842	86 784	167 079
Nyanga, Guguletu, Langa, Crossroads (2)	42 211	61 021	151 097	412 262
Khayelitsha (3)	26 686	34 834	59 874	121 394
Ocean View	2 561	5 854	8 286	16 637
Elsies River	30 045	90 748	104 705	239 842

NOTES:

(1) June 1984 estimate plus annual natural increase.

(2) Crossroads : official figures excluded from 1980 census data. 1984 estimate included in 1985 feeder area estimate.

(3) 1985 estimate.

The prevalence range determined in Chapter Two was then applied to the 1985 population estimates. Rates of 3/1 000 and 5/1 000 were used, in order to give the lower and upper limits of this range. Prevalence figures thus obtained are shown in Table 4.

TABLE 4 : ESTIMATED 1985 MENTALLY RETARDED POPULATION

FEEDER AREA	Prevalence Rate: 3/1 000 Number of Cases, By Age Group			Prevalence Rate: 5/1 000 Number of Cases, By Age Group		
	0 - 4	5 - 19	20+	0 - 4	5 - 19	20+
Bonteheuwel	24	83	94	40	138	157
Retreat	54	186	219	90	309	365
Athlone	93	311	474	154	519	790
Mitchell's Plain	55	186	260	92	310	434
Nyanga, Guguletu, Langa, Crossroads	127	183	453	211	305	755
Khayelitsha	80	105	180	133	174	299
Ocean View	8	18	16	13	29	26
Elsies River	90	272	314	150	454	524
TOTAL:						
Coloured	324	1056	1377	518	1690	2203
Black	207	288	633	331	461	1013

4.2 PRESENT SHORTAGE OF FACILITIES

This is obtained by relating the present number of places available in each facility to the prevalence in its feeder area, as determined above. This may be done in terms of training centres and protective workshops/occupational groups, for which figures are most readily available. Tables 5 to 8 indicate the position with regard to these facilities, at the prevalence rates of 3/1 000 and 5/1 000. In Tables 5 and 6, data relating to the Retreat and Ocean View areas have been combined, since a large proportion of children attending the Ocean View training centre live in the Retreat area. Owing to the great shortage of facilities in Retreat, these children are transported to Ocean View. Separately, the Retreat centre caters for 22 children, and Ocean View for 70 children. In Tables 7 and 8, Ocean View is excluded because the protective workshop presently operating caters for all types of handicap, including cerebral palsy and physical handicap, and is therefore not specifically for mentally retarded adults. It caters for a total of 35 people, of whom a minority are mentally retarded (Davis, personal communication). The "places required" apply to both protective workshops and occupational groups, and could conceivably be accommodated in either type of facility.

TABLE 5 : SHORTAGE OF FACILITIES : TRAINING CENTRE PLACES AT 3/1000 PREVALENCE RATE

FEEDER AREA	Places Available	Prevalence	Places Required	Extent of Need served (%)
Bonteheuwel	18	83	65	22
Retreat/Ocean View	92	204	112	45
Athlone	137	311	174	44
Mitchell's Plain	22	186	164	12
Nyanga, Guguletu, Langa, Crossroads	50	183	133	27
Khayelitsha	0	105	105	0
Elsies River	118	272	154	43

TABLE 6 : SHORTAGE OF FACILITIES : TRAINING CENTRE PLACES AT 5/1000 PREVALENCE RATE

FEEDER AREA	Places Available	Prevalence	Places Required	Extent of Need served(%)
Bonteheuwel	18	138	120	13
Retreat/Ocean View	92	338	246	27
Athlone	137	519	382	26
Mitchell's Plain	22	310	288	7
Nyanga, Guguletu, Langa, Crossroads	50	305	255	16
Khayelitsha	0	174	174	0
Elsies River	118	454	336	26

TABLE 7 : SHORTAGE OF FACILITIES : OCCUPATIONAL GROUP PLACES AT 3/1 000 PREVALENCE RATE

FEEDER AREA	Places Available	Prevalence	Places Required	Extent of Need served(%)
Bonteheuwel	8	94	86	8
Retreat	45	219	174	20
Athlone	30	474	444	6
Mitchell's Plain	11	260	249	4
Nyanga, Guguletu, Langa, Crossroads	15	453	438	3
Khayelitsha	0	180	180	0
Elsies River(1)	58	314	256	18

(1) Once-weekly group.

TABLE 8 : SHORTAGE OF FACILITIES : OCCUPATIONAL GROUP PLACES AT 5/1 000 PREVALENCE RATE

FEEDER AREA	Places Available	Prevalence	Places Required	Extent of Need served(%)
Bonteheuwel	8	157	149	5
Retreat	45	365	320	12
Athlone	30	790	760	4
Mitchell's Plain	11	434	423	3
Nyanga, Guguletu, Langa, Crossroads	15	755	740	2
Khayelitsha	0	299	299	0
Elsies River (1)	58	524	466	11

(1) Once-weekly group.

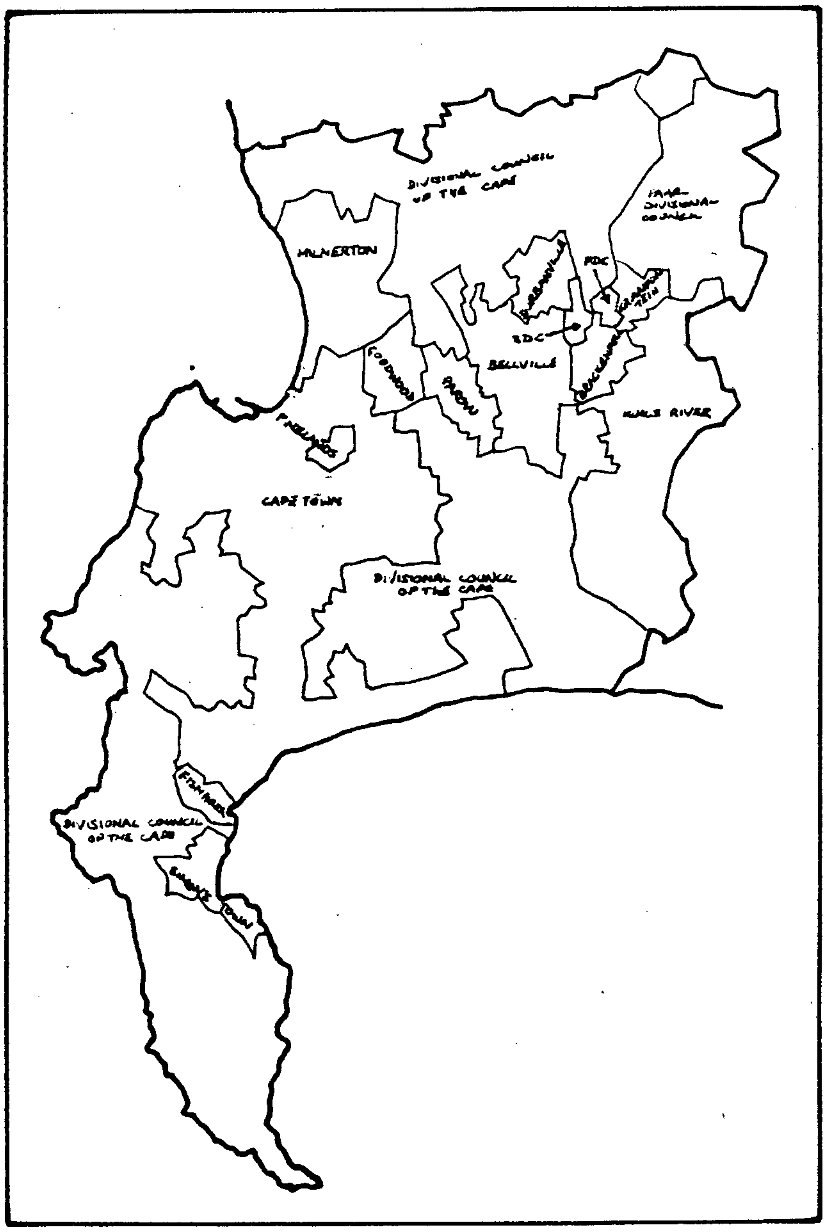
4.3 EXPECTED PREVALENCE : 2000

This calculation requires, firstly, projection of the present population to the year 2000, and secondly, application of the prevalence range to this figure to indicate the size of the mentally retarded population.

A population projection over a period of five years, as undertaken in section 4.1 above, poses relatively few problems. This is particularly so in this case since the projection is retrospective, and anomalies in the base data can be modified according to later refinements. However, projections using this data over longer periods into the future are more complex.

Two major points may be made in this regard. Firstly, owing to factors such as the maximum population which can be accommodated on a given area of land, the resultant natural migration of "overflow" population to new areas, and ideologically-based population movements, it is not meaningful to undertake a projection of relatively small areas such as the feeder areas used above. The dramatic effect of such population movement is illustrated by the growth of Khayetisha in the past few years: this State-induced movement is intended to absorb most of the Black population increase in the region in the future. An additional source of uncertainty is that of the rate of in-migration to the Western Cape from other areas. As a result of these factors, population projections to the year 2000 are undertaken for metropolitan Cape Town as a whole (TMS, 1983). Local authorities contained in this area are listed in Appendix 1, and are shown in Figure 6.

FIGURE 6 : LOCAL AUTHORITIES IN THE METROPOLITAN CAPE TOWN AREA



Secondly, the accuracy and sophistication of the projection is fundamentally affected by the quality of the base data. In the case of the White and Coloured populations this is sufficiently reliable to enable use of the Cohort-Survival method: this method is able to take account of birth, death, and migration rates. As each five-year age-group (or "cohort") is processed separately, it is possible to estimate the size of each cohort in the year 2000: this is shown in Appendix C.

As regards the Black community, sufficiently accurate data on births, deaths, and migration are not available. Projection to the year 2000 is necessarily limited to mathematical extrapolation of past trends (TMS, 1983). As this method is a relatively crude one, no estimate of the size of individual cohorts is possible. In addition, since it is entirely reliant on offical census figures, which are acknowledged to be highly inaccurate; and since the planned relaxation of the Coloured preference policy for the Western Cape in likely to encourage urbanization at a rate well beyond that found in the past, any estimate for the year 2000 must be considered highly problematic from the outset. This is borne out by the fact that the highest of three estimates of the Black population undertaken by the Cape Town City Council (TMS, 1983), using the exponential projection method, gives a total population smaller than that estimated for 1985, viz. 497 000 in 2000 as opposed to 533 656 in 1985. For these reasons, it was considered meaningless to calculate estimates of the size of the Black trainable mentally retarded population in 2000.

The results of the projection for the Coloured community is shown in Table 9, together with estimates of the size of the trainable mentally retarded population by applying the 3/1 000 and 5/1 000 prevalence rates used in section 4.1. Relevant cohorts are combined in order to estimate the size of the mentally retarded population in the Coloured community of preschool, training centre, protective workshop/occupational group, and geriatric age. Inherent in this projection is the assumption that the fertility rate of the Coloured community will not decline by the end of the century. If it is assumed that this rate will gradually decrease to that of the White population, the Coloured population will total approximately 50 000 people fewer (TMS, 1983).

TABLE 9 : POPULATION PROJECTION AND PREVALENCE OF TRAINABLE MENTAL RETARDATION IN THE COLOURED COMMUNITED : 2000

Population Projection		Prevalence of Mental Retardation		Relevant Facility Type
Cohort	Cohort Size	Rate:3/1000	Rate:5/1000	
0 - 4	124 000	372	672	Preschool
5 - 19	348 000	1 044	1 740	Training Centre
20- 54	605 000	1 815	3 025	Protective Workshop
54+	116 000	348	580	Geriatric

CHAPTER FIVE : DISCUSSION

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There can be little doubt that the present provision of services for the mentally retarded population of the study area is grossly inadequate. However, a number of sources of error exist in the calculation of the extent of need, undertaken in Chapter Four. Firstly, the prevalence range employed is an estimate, and it is possible - though improbable - that the actual prevalence rate might fall beyond this range. Secondly, population data for the study area derives mainly from the 1980 population census, which is widely held to have under-enumerated the Black population, in particular. The method used in attempting to correct for this, ie by multiplying dwellings (identified by aerial photography) by known mean dwelling occupancy, is itself open to question. Even so, it is likely that this estimate will be more accurate than the official census data. Nonetheless, even given these shortcomings, in the absence of accurate statistics estimates are essential in order to undertake planning.

The central concern of this chapter is with the improvement of present service provision. This needs to be informed by considering a number of factors, including the expressed requirements of the people being served; overseas experience; local conditions, bearing in mind that these are considerably different to those found elsewhere; and the availability of funds. These will be implicitly drawn into the following discussion: however, the need to respond to expressed requirements of the people concerned is arguably of particular importance, and will therefore be addressed as a separate issue on its own (Bailey, 1984).

A number of factors make the idea of responding to locally-identified needs rather more difficult than may at first appear. These include the problem that although one may readily be able to identify one's own current needs, it is considerably more difficult to anticpate one's future needs (Mazziotti, 1974). Nonetheless, there can be little doubt that those who receive a specific service are eminently qualified to evaluate its applicability.

Ayer (1984) undertook a 3-year study of 132 mothers caring for their severely mentally retarded children of school-going age at home in England. It was found that many mothers lacked an awareness of available services; that services were determined by professional perspectives rather than by the community; that available services tended to substitute, rather than reinforce, the parents' caring capacity; and that services were ad hoc rather than co-ordinated. As a result of these (and other) problems "increasing numbers of parents are seeking support through mutual aid and self-help groups" (Ayer, 1984, p.127).

Four studies conducted in Cape Town have some relevance here. Friedlander and Power (1982), in a study of 50 children with IQ's of 50 and below living in Heideveld; Power (1977), in a study of 74 such children living in Athlone; and Siwundla and Power (1981), in a study of 47 such children living in the Black areas of Langa, Nyanga, Guguletu, and Crossroads, all found a serious lack of day-care facilities. Friedlander and Power (1982) report that 50% of cases received no day-care at all, and of those who did, 75% received this at normal schools. Power (1977) found that 73% of cases received no day-care at all, and half of the rest were accommodated in normal schools. Siwundla and Power (1981) found that 33 children (or 70% of cases) received no day-care at all. Parents identified education for their children as their greatest need. All three studies found that additional handicaps received inadequate treatment. Of particular importance are behavioural difficulties: very few (if any) cases were receiving assistance in this area, despite being a major problem. Siwundla and Power (1981) report that 44 (or 94% of cases) exhibited troublesome behaviour, including aggressiveness, restlessness, and destructiveness. Friedlander and Power (1982) also note adolescent sexuality as a problem area.

With regard to welfare services, Friedland and Power (1982) and Siwundla and Power (1981) found these to be adequate in the communities studied. In general, those eligible for State grants were receiving these: however, Power (1977) found that this was not the case in Athlone, and recommended that this be investigated. All three studies, on the other hand, found a great need for parents groups: after educational placement for their children, this was the greatest need identified by the parents. These groups could offer support and encouragement (Siwundla and Power, 1981) and provide insight and education concerning their children's handicaps (Friedlander and Power, 1982). Power (1977) identified a need for supportive visiting of the parents. By implication, the need for parent groups suggests that parents feel inadequate, confused, and isolated. This is hardly surprising, given their de facto isolation in many cases, coupled with the considerable behavioural problems posed by their children with whom usual parenting skills are inappropriate. Support for this implication is that very few parents in the surveys could identify concrete plans for the future care of their children.

These studies indicate two distinct areas where action in improving services is needed: firstly, training and ongoing care of the children, including the treatment of additional handicaps; and secondly, work with the parents, including the organisation of parent groups and parental counselling.

All three studies refer to the need for day-care rather than institutional care for their children. However, a study by Jubber (1980) of 63 parents of mentally retarded children institutionalized in the A J Stals Care and Rehabilitation Centre indicated that 37% of these would not have been able to manage the child themselves with day-care only, and argues that a strong need for institutional care still exists in Cape Town. He reasons that community-based programmes are more suited to the middle class: families are generally small, with large amounts of leisure time, are affluent, social tolerance is high, community infrastructures are well-developed. This contrasts strongly with the poor quality of life of the working class. If conditions for the mentally retarded numbers of these communities are to be improved, broad social change is a precondition.Persuasive and justfied though this argument may be, a number of counter-arguments may be advanced. Firstly, his study is of a highly specific population: in their cases, institutionalization may have been unavoidable because of intolerable home conditions or some other factor strongly favouring institutionalization; and parents may have been strongly motivated to justify what was probably an extremely emotionally-laden issue, either to the researcher or to themselves. Secondly, Jubber himself acknowledges that the costs of running "total institutions" are approximately four times that of running community-based, home-centre care programmes. In the light of financial limitations, motivation for Jubber's option must be seen as tenuous. Thirdly, moral issues arise: the world-wide trend is towards more humane methods of service delivery, while Jubber's proposal runs counter to this trend; the other three studies quoted previously do not indicate a preference for institutionalization, thereby suggesting considerable community opposition to it; and institutionalization reduces community involvement in service delivery programmes rather than increases it, a fundamental criticism underlying a number of findings in Ayer's (1984) study.

Despite these criticisms, Jubber's findings clearly indicate that the debate surrounding the question of institutionalized versus de-institutionalized care is not of the all-or-none variety, and that for a considerably number of parents institutionalization provides the best, perhaps only, option. This important point will be returned to in section 5.2.3. below.

The following discussion focuses on avenues of improving the present system of service provision. In doing so, attention will initially be directed at organisational issues, and subsequently on specific services required.

5.1 ORGANISATIONAL ISSUES

It is clear that the primary difficulty is that of State apartheid policy. Without doubt, comprehensive changes in service provision must be predicated upon a major refashioning of these policies, including the scrapping of the Coloured Preference Area status of the Western Cape. Whether such a refashioning can occur in the absence of fundamental changes to the social superstructure is a question beyond the scope of this thesis. Attempts to improve conditions while operating within present constraints must be viewed as palliative, at best.

Within these present constraints, a number of major issues can be identified. One of these is the requirement that planning be undertaken for each race group separately. In order to promote the rationalization of planning, it is proposed that the State consider placing these services under the control of a single "General Affairs" department, instead of maintaining their present fragmentary nature, in which they are split between various "Own Affairs" and "General Affairs" departments. In the light of calls for all racially-separate education departments to be amalgamated into a single "General Affairs" department, the creation of a division for the mentally retarded would appear a natural extension of the scope of this department.

A further issue in the co-ordination of service provision (see Aiken et al, 1975) is that of liaison between bodies providing different types of service, including genetic counselling, parent counselling, assessment, education, and prevention. This is one of the central reasons for the existence of the Western Cape Forum for the Mentally Handicapped. Fruitful discussion could take place between member organisations on mutually problematic aspects of service provision, such as that of areas presently excluded from feeder areas (for example, Woodstock, Salt River, and Observatory), and transport difficulties. Subsequently, it may be necessary to lobby the State, approach other organisations, or inform the media in attempting to publicise and improve conditions. In addition, inclusion of organisations providing different types of service could facilitate research on the interface between these services: for example, investigating the effect of preventive services on the need for facilities at a later date, including areas of concern such as identifying target groups, publicity, and sensivity to cultural differences. A further example might be collaboration on staff training, such as increasing the skills of teachers and teacher aides, and devising training programmes for people running informal neighbourhood groups in the community (Bailey, 1984). Programmes such as these could be informed through contact with other bodies not specifically concerned with mental retardation, but rather with areas such as pre-school education (eg, the Grassroots Trust, Aspect, and the Early Learning Resource Centre). A general problem which arises here, however, is that many organisations who could contribute to an increased level of co-ordination are hamstrung by their governmental links, and the plethora of regulations which inhibit their activities.

A number of issues may be raised with respect to planning of physical services. Firstly, that of the reservation of land for provision of facilities for the mentally retarded in the planning of new urban development. At present, town planning authorities are obliged to consult with various bodies for the setting aside of suitable land for schools, churches, etc, and it should be requested of local authorities (such as the Cape Town City Council and Cape Divisional Council) to consult with organisations concerned with provision of services for the mentally retarded to encourage participatory, pre-emptive planning. This would facilitate the setting aside of land of the required size and appropriate zoning (together with a specific use reservation), in a suitable position. This would prevent the post-hoc acquisition and rezoning of land, perhaps at high prices dictated by the land market, of inadequate size and poorly located, subsequent to development of the planned project. A second issue is the present high cost of training centre construction: under present economic conditions and in the light of the extent of need for many additional facilities, less costly alternatives would permit available funds to be used for more projects. Such a policy would have implications such as use of cheaper building materials, and building standards attuned to local needs rather than imported from overseas contexts. Bradley (1978) emphasises that response should be dictated by context.

This need to acknowledge that local conditions require local responses in addition to imported, "First World" ones applies to other areas as well. An example here is that of the training of teachers employed in training centres. Tizard (1964), in England, deplored the lack of properly qualified teachers in England and Wales in 1959, and supported the idea that, despite staff shortages, the relevant training course be doubled in length. This proposal was rejected by the Central Health Services Council as unrealistic. In South Africa, various writers have called for a training course for teachers to be instituted (Gilbert, 1981; Herring and Jaffe, 1981; Lombaard, 1982; Steenkamp and Steenkamp, 1981). Underlying this call is a recognition that mentally retarded children have special needs and require teachers with special skills: however, the present shortage of appropriately-trained teachers requires short-term responses in addition to long-term, more sophisticated training. Such intervention could include brief training courses (such as a series of workshops) for the upgrading of qualifications of presently-employed or prospective teachers: of importance here is that such courses (or combination of courses) should be recognised for salary pruposes by the relevant Education authority. An additional level of intervention could be increased emphasis on the role of neighbourhood groups through the transmission of educative skills, thereby allowing these groups to take on an expanded educative role in addition to that of support and child-minding. A development programme and team needs to be set up in order to transfer relevant skills to these groups (Bailey, 1984).

With respect to State funding, present conditions require increased expenditure on a wide range of services. However, this is unlikely in the short term on account of economic constraints such as the recession and associated heavy demands on treasury resources. Accordingly, attention needs to be directed at ways in which funds are currently allocated in order to highlight avenues of improvement. One such avenue is the simplification of the procedure for obtaining funds: in addition to the need for a single State department for all races is the need for the role of the S A National Council for Mental Health to be evaluated. Intended to operate as a separate entity on the interface between the State and private bodies, it would be more rational to include some of its functions in the appropriate State department (such as liaison and others best suited to the national level such as co-ordination and national priority planning), while other functions would be best delegated to bodies at the regional level (such as detailed planning and service co-ordination at the regional scale). State representatives could be involved at this level to ensure that State procedural requirements are complied with.

Associated with this is a need for greater flexibility in the use of funds. This would be greatly facilitated if a single budget could be submitted to a single department. A second, arguably more profound, level of flexibility would be achieved through giving organisations providing services greater autonomy in the use of State funds (Bradley, 1978). This would enable firstly, an increased ability to respond more sensitively and appropriately to local needs, and secondly, a greater sense of independence and control for the community in that local opinion would be central to determining the nature of services rendered. The extent to which control and discretion can be devolved would need to depend on the expertise available at the local level. State concern for the suitable use of treasury funds would be respected through channels such as ordinary audit procedures and State representation on service planning bodies.

As is the case with other dimensions of the present shortage of services, the allocation of funds needs to be tailored more closely to the requirements of the local community than by norms more applicable to countries such as the United States and Sweden. Since present policies for the allocation of funds, through the application of high standards in building construction, etc., are unlikely to meet the needs, these policies themselves require attention. "Planning for reform ... entails a re-examination of the appropriateness of services currently being provided and a determination of what services in their place will more adequately meet the needs ..." (Bradley, 1978, p.63).

With respect to the provision of specific types of service, a number of organisational issues stand out. First is the need for a comprehensive register of identified cases, containing data of all cases known to all organisations involved in the provision of services (Farmer & Rohde, 1983). This would minimise the duplication of services, improve the accuracy of data, aid the tracing and follow-up of cases, and facilitate planning. This last-mentioned benefit is of particular importance: although basic data (eg, name, address, age, IQ) can be used in estimating broad service needs in a rather crude fashion, a comprehensive register would enable planning of a more sophisticated nature. Such data would include a needs assessment (Bradley, 1978) and an index of social competence (McConkey & Walsh, 1982) covering various areas of skill, such as community (or independence), self-care, and communication. On this basis a profile of abilities and deficits can be drawn up, and can be used to assess the particular needs of each individual. Bradley (1978) adds that it is important to differentiate between identified needs and speculative needs: these could be further differentiated by assigning a priority rating to each. Bradley also warns against "the collection of odds and ends of information with no cohesion" (1978, p.61), resulting in a needs assessment which is unfocused. Although the setting up of such a register is a costly undertaking, the benefits for the planning of services are considerable. Two sources of difficulty in this regard may be identified: obtaining funds and ensuring registration of all known cases. It is suggested that a study be undertaken to examine the practical issues involved (eg nature of data required, liaison between the various bodies concerned, areas of responsibility, staff and equipment requirements, methods of follow-up and planning) and to explore in more detail the benefits to be derived; and thereafter to draft a comprehensive report for submission to the State, requesting that funds be allocated for this project. With regard to ensuring that all cases are registered, the existence of such a register would need to be made known to all those who may come into contact with a mentally retarded person, such as doctors, psychologists, teachers, and social workers. This notification procedure would need to be repeated regularly (perhaps annually) as a reminder or in order to contact new members of the professions concerned.

Under present conditions, planning must be undertaken in terms of an estimated prevalence of three cases per thousand people in the general population. On the basis of data contained in Chapter Two, it may be argued that this rate is an under-estimate. It is therefore considered necessary to re-evaluate the applicability of this figure in the study area. This would permit an increased rate of provision of services.

In summary, the above discussion has outlined a number of organisational needs in the attempt to meet the challenges faced by those bodies whose task it is to provide services for the mentally retarded population. Present difficulties are numerous and complex: predominant among these are those which result from national racial policies, including inadequate funds for services for the Coloured and Black working class, fragmented funding policies, and the requirement that service planning and provision be racially-specific. These difficulties have consequences which override those of problems of other types, and major changes in service provision are extremely unlikely while these policies persist. A second group of negative consequences for service provision results from the application of inappropriate standards in areas such as building construction and in the provision of funds. This results in a relatively high quality of service for the small proportion of those needing service who receive it, while the great majority receive a very inadequate service or none at all. In seeking to provide a more equitable service for all, in the face of limited funds, it is necessary to evaluate present standards of service provision in the light of local community needs rather than in terms of idealized policies deriving primarily from overseas contexts.

5.2 THE NEED FOR SPECIFIC SERVICES

The form taken by a system of services will be largely determined by policies regarding their provision, as discussed above. However, despite this potential variability, various categories of service must be included if the system is to be comprehensive. These can be conveniently discussed in terms of Caplan's (1964) triaxial framework of prevention. Deriving from his theory of community psychiatry, it can be applied to service provision for mental handicap with only minor amendments. His "primary" axis is concerned with services which prevent disease and defect, and correspondingly promotes mental health. His "secondary" axis includes services for early diagnosis and treatment, while his "tertiary" axis is concerned with the prevention of further disorder or dysfunction. Implicit in this "tertiary" axis is the idea of "rehabilitation", which does not apply to mental retardation, since the condition is permanent. However, this can readily be replaced by "habilitation", which transforms this axis into one incorporating services for education, training, and care.

These three axes will be discussed in turn below. The primary and secondary axes will only be discussed at a conceptual level, since these services and facilities are determined less by specific numbers than are facilities on the tertiary axis, such as training centres, which are constructed with a pre-determined maximum number of places available. This is not to suggest that primary and secondary services are infinitely flexible, without a ceiling capacity beyond which efficiency declines.

5.2.1 Primary Services

These services are concerned with the prevention of mental retardation, and are essential to include in the planning and co-ordination of services. "Prevention becomes all the more important where cure is not possible in the sense of reversing a condition" (Cowie, 1981, p.36).

These can be loosely divided into "physical services" and "information services", although most services contain elements of both.

Physical services include those specifically aimed at people at high risk, such as aging mothers and parents who have previously had a mentally retarded child. A number of conditions (such as spina bifida) can be identified through various prenatal screening techniques (of which amniocentesis is probably the best known). Use of these techniques is not standard procedure, however, on account of their expense and the risk of spontaneous abortion, and so are usually restricted to mothers of forty years of age or above (Smart, 1981). Genetic counselling is particularly important on account of the high proportion of chromosomal and genetic disorders found in lower levels of mental retardation. It is especially valuable to parents who have previously had a mentally retarded child, and who can ill afford to have another. If genetic counselling and prenatal screening are used in combination, the incidence of severe mental retardation could fall by up to 16% (Bundey, 1980). On the basis of these tests, prospective parents can be counselled with regard to the advisability of having a child, or on personal and legal issues involved in obtaining a therapeutic abortion.

Other physical services which play a preventive role are the various community clinics, including nutrition and "Well Baby" clinics. The early identification and treatment of diseases and infections (such as meningitis) prevents the subsequent development of mental retardation, and the correction of poor diet in pregnant women (Cowie, 1981) prevents vitamin, iodine, and other forms of nutritional deficiency. The health of pregnant women who abuse alcohol, tobacco, and other drugs can be monitored, thereby preventing the onset of mental retardation resulting from disorders such as fetal alcohol syndrome. After birth, these clinics aid in preventing postnatal malnutrition and brain underdevelopment (Poskitt, 1980). These clinics therefore have an important preventive function, although this may easily go unrecognised because of their primary focus on treating the disorder from which mental retardation may subsequently arise. As Power points out, ideally "the 'bait' of care for current illness is used to draw children into the preventive net" (1980, p.11). In order to formalise this preventive function of community clinics along with their more traditional curative one, Power supports the idea of training paediatric health care nurses, as discussed by Wagstaff and Beukes (1977). These nurses would have wider areas of expertise than mental retardation specifically, and would be easily accessible to the community. They would be able to monitor growth and development as indices of the child's overall state of well-being, have knowledge of other relevant services, be able to refer the child to more specialised services when necessary, and be able to assist with the on-going care of people referred back from these services. Their work would therefore extend beyond the primary axis of Caplan's framework. Their ability to advise on on-going care of identified cases would be of major importance to those who cannot be accommodated in training centres or toy library groups. The proposal by Bailey (1984) that semi-skilled mental health assistants be trained can be understood as similar to that by Power (1980) and Wagstaff and Beukes (1977) with regard to paedia- tric health care workers, though with a different primary area of concern.

Information services are those concerned with the dissemination of information about mental retardation. A number of target groups can be identified. Firstly, those whose work brings them into contact with the mentally retarded, including general practitioners, social workers, psychologists, teachers, and the staff of community health clinics (Poskitt, 1980). In addition to information on prevention, these services could provide other educative material, such as what problems arise, what the prognosis is likely to be, how to identify cases, who to refer to, and how to deal with parents. To a large extent, this work is being carried out by the Child Care Information Centre at Red Cross Children's Hospital. However, to further increase the general level of awareness of those who may encounter cases of mental retardation in their work, regular updates of information may be necessary. The general public is a second target group, of which large numbers can be reached through the target group mentioned above. However, information regarding prevention of mental retardation frequently applies equally well to other disorders and conditions, and in order to minimise costs by taking advantage of economies of scale, it may be possible to combine with other health and health-related organisations in an orchestrated community awareness campaign. In this way, projects in addition to that of prevention of mental retardation could be served in a comprehensive way. Of particular importance to mental retardation would be, firstly, prenatal hazards to the developing fetus, such as maternal drug abuse, including tobacco and alcohol, and reasonable diet (Cowie, 1981); secondly, reasonable diet during the postnatal period and infancy; and thirdly, the possible consequences for mental functioning of various infections (if not treated timeously), and various forms of brain damage, such as that resulting from road accidents and accidents in the home (Klaus and Fanaroff, 1979).

The "community awareness campaign" suggested above must be paired with various public health interventions: infection and poor diet are inevitable under conditions of poor housing, sanitation, and education. Any health promotion programme aimed solely at those whose health is at risk is in danger of ignoring the environmental, economic, and other factors which contribute to poor health (Wortis, 1965). Therefore, effort needs to be directed at ameliorating these environmental conditions, which presumes that representations be made to those under whose jurisdiction these conditions fall. These bodies include local authorities in the first instance, and the

State. Such representation would add a voice to others in the communities being served, demanding improved living conditions. Clearly, a subsequent step in analysing the factors undermining efforts at preventing mental retardation is to recognise the role played by the country's racial policies.

From the above discussion of Caplan's primary axis of service provision, the role of "physical" preventive services is vital among those at high risk, particularly aging mothers, parents who have other mentally retarded children (or who are themselves retarded), and pregnant women. However, present economic constraints prevent large-scale extensions to these services. The argument here is not for a major shift in emphasis in service provision, but rather recognition that prevention is possible for certain forms of mental retardation, and that various bodies (such as community health clinics) play an easily-overlooked role in this. On this basis, it can be recommended that community health authorities be included in the process of planning for services. This would aid in greater co-ordination in undertaking preventive work and in discussion of problems encountered. The function of "information" services is very important, not only in improving skills of those encountering mentally retarded people and their families in their work and in publicising specialised services offered, but also in addressing the needs of the general public by firstly, a comprehensive health promotion campaign and secondly, hrough public health measures. Here, co-ordination with other bodies concerned with health promotion would be of major benefit in ensuring co-ordinated action.

In combination, these facets of preventive work at the primary level can only result in an improved community service.

5.2.2 Secondary services

Services included here are those required for early intervention, the benefits of which are considerable for both child and his/her family. For the mentally retarded child, training can begin at the appropriate developmental stage. As with all children, certain skills become more difficult to acquire the further the child develops beyond the stage when developmental preconditions are best suited for the acquisition of that skill. In the same way, early intervention can aid in extinguishing an inappropriate behaviour before it becomes ingrained in the child's behaviour repertoire and more resistant to change. For the parents of the child, early intervention helps in clarifying the problem, and in encouraging them to express and deal with the emotional turmoil of having produced a mentally retarded child. Unless this occurs at an early enough stage, these unresolved feelings could become submerged, only to surface later in a disguised, and possibly destructive, form. The impact on siblings is also great, and needs to be addressed.

Two essential components of early intervention are early diagnosis and early treatment. Clearly, the former must precede the latter. An intervening step, which links the two, is that of assessment. These will be discussed below.

The first opportunity for early diagnosis is through prenatal screening, discussed in section 5.2.1. above. It becomes relevant here when the possibility of a therapeutic abortion is ruled out. At birth, a number of physical signs may indicate the presence of mental retardation. These are generally well known to medical practitioners, although some subtle ones may not be. As an aid to doctors present at the birth of a baby in which mental retardation may be suspected, the making known of published tests or organic batteries may help to clarify uncertainty. Two examples here are the test described by Fried (1980) in diagnosing Down's Syndrome in the newborn, useful in that it permits the parents being informed before mother and baby leave the maternity ward, and in areas where sophisticated cytogenetic laboratories may be unavailable; and the use of the Organic Mental Syndrome Battery with older children, described by Herman, Bala, Atkin, and Rofowitz (1983). Knowledge of such tests would also be valuable to others concerned with assessment, in that they might indicate the need for organic investigation where relevant. A special group of children in whom organic pathology might be suspected are those at high risk as a result of factors such as maternal drug abuse (including alcohol and tobacco), CNS infections, prematurity, birth trauma, undernutrition, and head injury. Identification of some of these high-risk children may depend more on a comprehensive history than on physical examination, and here assistance may be offered to primary health workers, doctors, and others through suggested history-taking procedures.

In cases where evidence of organic pathology is absent or inconclusive, earliest detection would follow the identification of developmental delays, both physical and psychological. Of prime importance here are the staff of the community health clinics and other primary health workers. Their diagnostic skills might be enhanced through being provided with appropriate tests found useful in other situations. Also of fundamental importance are preschool teachers, whose in-depth knowledge of their children and developmental norms would make them extremely important links in the early-detection network.

Following early diagnosis or detection of a developmental delay, more specialised assessment is usually required. The distinction between "diagnosis" and "assessment", discussed previously in Chapter One, is crucial here. "Diagnosis" refers to the application of a specific, global term to cover the child's condition, and may imply a given aetiology (or set of aetiologies), such as "tuberous sclerosis"; or may be of a wider, generic nature, such as "severe mental retardation", in which the child's specific characteristics are submerged in a framework of commonly-found and expected handicaps. "Assessment" provides an overall picture of the child's developmental and functional strengths and weaknesses (Jeffree, McConkey, and Hewson, 1977), and provides a frame of reference for designing a treatment programme (Herring and Jaffe, 1981). For assessment services to be properly integrated into the service network, two paths of communication are essential.Firstly,diagnostic and detection services (such as cytogenetic laboratories, preschool teachers, and health care workers) need to know of the existence and role of assessment services. This implies a programme of actively disseminating infor- mation to those who may lack it. Secondly, assessment services need to have adequate knowledge of services and facilities to which mentally retarded people can be referred following assessment. Although these lines of communication do not give rise to problems where contact is well-established (for example, when diagnosis, assessment,and placement are arranged within a single organisation), problems may arise with regard to people or organisations providing a partial service with little information about other components, such as psychologists, speech therapists, occupational therapists, and remedial therapists in private practice, or child guidance clinics attached to universities.

The process of assessment has a number of aspects, not all of which may be relevant in every case. However, two broad levels are fundamental: assessment of the child and assessment of the family.

Assessment of the child has a number of dimensions, each of which may be investigated by a wide range of tests and techniques (see Gearheart and Litton, 1975; Hallas, Fraser, and MacGillivray, 1982; Mittler, 1973a, 1973b). These dimensions include intelligence, a rather crude measure of little value unless qualitative data is stressed; and many aspects of social and cognitive functioning.Tests of social functioning frequently allow the plotting of a developmental profile, highlighting both strengths and weaknesses (Bernsen, 1980). The Adaptive Behaviour Scale, for example, examines seven variables (Salagaras and Nettlebeck, 1983), and has many potential applications, including individual programme development (Spreat, 1980). An advantage over the Vineland Scale of Social Maturity, frequently used in South Africa, is that it measures maladaptive behaviour as well as adaptive behaviour (Roszkowski,1980). Other developmental scales have been developed in South Africa, of which the Grover Developmental Charts are well known. Other areas of assessment include perceptual and motor skills and their integration; and speech and language abilities. Neurological and other medical tests may be required if conditions such as epilepsy are suspected. As is evident, a wide range of assessment skills may be required: these skills may not be readily available, on account of staff or financial shortages. A possible source of these skills could be university departments, in which students of occupational therapy, speech therapy, psychology, and other such fields could undertake relevant assessments as part of their coursework. Benefits would accrue to all concerned.

As regards the family, material conditions and their general quality of life are important in evaluating their ability to absorb their mentally retarded member. Aspects of family functioning are also important in this regard. In general, the focus of family assessment in this context is to guage the impact of the child on the family, and the family's resources to cope. This has both long-term and short-term implications.

In general, assessment needs to be multi-dimensional, and hence multi-disciplinary. This reflects the multi-dimensional nature of the problem. However, the "team" approach, especially if it incorporates members of different professions, is often not as easy to accomplish as may be desirable. In practice, the mechanisms of teamwork need to be carefully considered, avenues of communications made imperative, and processes of power-sharing or power allocation discussed. These need to be made explicit, and discussed openly when problems arise. Results of this team assessment would usually yield clues as to interventions required: therefore, treatment plans are a natural extension of assessment.

Three components of early treatment of children may be isolated. Firstly, in cases where reversible organic aetiology is present, such as phenylketonuria and meningitis, early treatment may prevent the development of mental retardation. This was discussed in section 5.2.1. above. Secondly is the need to incorporate the child into appropriate training programmes at the earliest feasible time, depending on facilities available: this will be further discussed in section 5.2.3. below. Thirdly, additional handicaps need early attention in order to reduce their impact on the child's subsequent development. This treatment might include anti-epileptic and other medication, behaviour therapy, speech therapy, and physiotherapy. Where possible, the institution of home programmes could have major benefits, in that directed stimulation of the child could extend beyond the limited time spent with the relevant therapist. This is particularly important, given the need for repeated exposure in order to encourage learning. Furthermore, this would encourage greater contact between parent and child. Jubber (1980) found that the middle-class view of the family often did not hold in his study of the families of 63 children institutionalised at the A J Stals Centre. Frequently the chief caregiver was not the mother, as is usually the case in the traditional, middle-class family, but another person, usually a relative. Siblings were frequently found to be extremely important. The father frequently was absent, either being in prison, having died, or having left home, and "functions as a symbol of the negative" (1980, p.60). Where present, he was often peripheral. Beckman (1983), in a study of the stress encountered in families of handicapped infants, found that the only demographic characteristic associated with the amount of stress was in the case of single mothers, who experienced more stress than mothers in intact homes. In the light of the conditions of absent or peripheral fathers frequently found in the study area, it may be expected that similar high levels of stress are to be found. Given the great burden placed on the care-giver of a mentally retarded child, early intervention should attempt to distribute tasks of care-giving more equitably: the development of a home programme could be a vehicle for doing so. By involving more people at an early stage, greater shared responsibility could be encouraged and may serve to inhibit development of later family difficulties.

With regard to early treatment of families, two important parts of this are providing practical assistance in the form of discussing with them the diagnosis, causes, prognosis, and treatment of their child's condition; and in dealing with the emotional upheaval which this is likely to generate. Klaus and Kennel (1976) identified five stages of parental reaction to the birth of a mentally retarded child: shock; disbelief; sadness, anger, and anxiety; equilibrium; and reorganisation. The negotiation of this process, and the resolution of the many complex feelings which arise, is undoubtedly made easier by understanding and knowledgeable counselling. Each stage of the process requires different strategies of intervention, from crisis counselling and aiding the family in making decisions, to more in-depth parental counselling or family therapy, according to the need. Early intervention is benefical at each stage: if family resources are unable to cope, inadequate (or no) intervention will make progress to a subsequent stage more difficult. The counsellor needs to be alert at all times to hints that a particular area is causing unexpressed difficulties, such as one parent blaming the other for their child's mental retardation.

The impact of the diagnosis, and therefore the earliest contacts between the family and relevant authority, is emphasised by Baraitser (1980): "No period is more critical than the moment of discovery and the way this is handled influences all future experiences" (p.1025). As this is frequently undertaken by a person other than someone specialised in the field of mental retardation, ways of handling this situation could be publicised, emphasising that sensi- tive handling aids the work of those who will subsequently work with the family.

The benefits of early family treatment are many: initial confusion and distress can come to be understood and worked through; misconceptions can be corrected; familial disharmony connected with their family member's mental retardation can be explored; the need to work collectively, with shared responsibility, can be stressed.

Such treatment, however, cannot be on-going, on account of the great expense and need for large staff resources; nor is this desirable, since there is a danger of the counsellor taking on a parental role towards the family and increasing their dependency on him/her, without being aware that this process is taking place.There is therefore a need to identify crisis points, when early intervention is indicated: this will be further discussed in section 5.2.3. below.

In summary, the important role played by secondary services, including those concerned with diagnosis, assessment, and early treatment, is crucial in a comprehensive service network. They are closely linked with the provision of facilities for on-going care, since the nature of the person's needs, as determined by the secondary level of service provision, will indicate the type of facility best suited to these needs.

5.2.3 Tertiary services

These services are concerned with the on-going needs of those who are mentally retarded and their families. As may be expected, and as was shown in Chapter Three, these services can take a variety of forms. To facilitate discussion, they will be broadly grouped into those principally concerned with the needs of the mentally retarded person, and those principally concerned with the needs of their families. The needs of the mentally retarded person may be divided into training, which is to some extent age-determined, and leisure. Training needs exist at the preschool, training centre, and adult work levels.

Into this discussion will be brought the implications for service provision of the shortfall of present facilities and future needs, outlined in Chapter Four. This "short-fall" and future "needs" was calculated on the assumption that all people with trainable mental retardation will require placement (i.e., a correspondence between "true" and "administrative" prevalence): however, this is not so since a proportion of cases will be accommodated elsewhere or not require placement for other reasons (Aiken et al, 1975; Bradley, 1978). Accordingly, the actual need for facilities will be considered equal to the lower end of the prevalence range used, i.e. 3/1 000. Use of this figure is supported by the fact that it is officially accepted for purposes of subsidizing training centre provision.

A number of writers have stressed the need for individual training programmes, based on the mentally retarded child's strengths and weaknesses. These can focus on specific areas requiring more intensive attention, and can thereby help the person derive maximum benefit from training (Baumgartner, 1960). They also help to improve communication between different members of the therapeutic team, and between the team, community services, and the child's parents (Raynes, Pratt, and Roses, 1979). Furthermore, they enable the child's progress to be evaluated, and thereby provide a framework for evaluating the programme's applicability and areas for improvement (Raynes, Pratt, and Roses, 1979). These evaluations need to stress present levels of functioning in all developmental areas; expose specific problems requiring additional emphasis; and home conditions and their impact on the child (Steenkamp and Steenkamp, 1981). There is, therefore, a continuity between this on-going evaluation process and the initial assessment undertaken before placement of the child, as discussed in section 5.2.2. above.

Despite the importance of devising individual programmes for each child, it is equally necessary for the child to be placed in a class or group, in which individual differences cannot always be catered for. This is necessary on account of economies of scale, staff shortages, and the numerous advantages of group contact for the child. There are two levels at which these apparent conflicts in emphasis need to be reconciled. Firstly, in routine activities in the group context, such as creative activities, the classroom teacher needs to offer stimulation to each child according to his/her developmental level. Secondly, for purposes of receiving specialised attention, such as speech therapy or physiotherapy, the child needs to be taken out of the group and worked with individually. In this way the child receives the benefits of both group stimulation and individual attention. Of importance is that regular meetings be held between the classroom teacher and therapists working with the child individually in order to co-ordinate their efforts: therapists can act as consultants to the classroom teacher, while the teacher can assist in formulating therapeutic goals by contextualizing the child's progress in everyday activities. Remedial therapists trained in programme planning could play a valuable role on account of their knowledge of, and skills at, both group and individual levels of intervention.Through co-ordination of effort (eg, setting up weekly themes), the child will receive intensive and graded attention: without such co-ordination, the child may be unable to fully integrate the variety of disparate stimuli being directed at him/her. This co-ordination could extend into home programmes, thereby integrating parents as much as possible in their child's training, while also serving to alert staff to problems which may arise outside of the training centre environment.

A problem arises, however, where trained specialists are not available to undertake individual training programmes. A possibility here may be the training of teachers or assistants in the use of relevant techniques, this permitting a measure of specialisation. These courses could form part of an attempt to upgrade the qualifications of those presently involved in the training of mentally retarded children, as was suggested in section 5.1 above.These "intermediate" specialists could then function as advisors to other teachers,thereby partially reducing the need for professionally-qualified consultants where these are unavailable.

A considerable body of work indicates the importance of intervention at the preschool age. Benefits accrue to both child and parents (Baroff, 1974): with regard to the child, Hutt and Gibby (1979) note that intelligence tends to become stabilized by approximately four years of age, and that very intensive stimulation is required to encourage mental development thereafter. In addition, they state that significant deficits in basic sensorimotor skills, language, and other communication skills have become prominent by this time, and if remediation does not begin early enough, subsequent training is made more difficult. Gearheart and Litton (1975) add that preschool programmes offer the child opportunities to grow and develop in an appropriately structured environment, under the guidance of specialised staff. This allows the child to develop a routine of daily living, while the initial group-learning experience builds a foundation for later social relations while also developing a sense of self-awareness and early behavioural controls.With regard to the parents, early involvement with their child's training can be fostered (Gearheart and Litton, 1975), while also relieving them from some of the stress of looking after a mentally retarded child. Furthermore, parents can be brought into contact with other families of mentally retarded children (Baroff, 1974), thereby providing the support network which is so important (Siwundla and Power, 1981). The benefits of a preschool programme are particularly great for those from "psycho-socially deprived" (Kirk, 1958) or "disadvantaged" homes (Hutt and Gibby, 1979).

Hutt and Gibby (1979) warn that the value of these programmes may be diluted unless they are properly planned and implemented. This includes that personnel are adequately trained, and that objectives are carefully selected. Baroff (1974) emphasises that a wide range of skills should be included in such a programme, including self-help, language, socialization, motor, play, and cognitive skills.

In the study area, Chapter Four indicated a total of 324 Coloured and 207 Black trainable mentally retarded children of preschool age in 1985. Although some of these are being catered for, mainly through toy library services, the great majority remain unserved. By the year 2000, the Coloured total will be 372, while the Black total may be expected to be very much greater than at present on account of increased urbanization. How are these children to be provided with the early stimulation considered fundamental to their subsequent development, particularly in the light of limited funds presently available? As was shown in Chapter Two, the age range of greatest ascertainment is 10 to 19: therefore, this age group is likely to absorb a large porportion of the available funds, as will adult facilities on account of their high cost: accordingly, a greater emphasis needs to be placed on informal sources of stimulation for preschool children. In the future, hopefully increased expenditure on services for the mentally retarded will permit the construction of formal preschools, and these should be able to accommodate a proportion of these children by the turn of the century. A further proportion might find placement in normal playgroups, a policy favoured by Baroff (1974), although a study of 7 Down's Syndrome children by Sinson and Wetherick (1981) found that they tended to become excluded when placed in normal playgroups. In the light of these conditions, two interlinked avenues of providing stimulation to preschoolers are the toy libraries and neighbourhood groups, the latter being a concept which is presently comparatively unexploited, while holding considerable promise.

As was shown in Chapter Three, the toy libraries are already providing a valuable community service, although attendance fluctuates for various reasons. Through toy library (and other) contact, neighbourhood groups have formed for purposes of providing support and informal care of one another's children. It may be possible to use this community network as a means for instituting more formal preschool programmes. Members of the group could contribute towards paying an allowance to the person acting as care-worker and for food for the children, while the toy libraries could visit these groups on a regular basis, providing toys, advice, and more specialised services, and also transmitting skills to the care-worker. In this way neighbourhood groups could make a substantial contribution to the early stimulation of mentally retarded children in their neighbourhood, relieve the burden of the child on the family, and aid in preparing the child for placement in a training centre.

The benefits of training centre placement are largely self-evident, and were mentioned in Chapter Three. In a study conducted in London, Wing (1971) stated that "there can be no doubt that (improvements in day-care facility provision) helped to relieve the burdens on the families" (p.413). According to Steenkamp and Steenkamp (1981), the four main benefits are, firstly, the development of skills, with which is associated development of feelings of self-sufficiency. This is achieved through learning self-care, social adapatation skills, emotional development, motor activities, and cognitive tasks. Secondly, the development of a positive self-image and self-confidence through successful completion of appropriate tasks, graded according to her/his level of development. Thirdly, assistance to parents through teaching them ways of handling their child, providing them with relief, and bringing them into contact with other parents faced with similar difficulties. And fourthly, liaison with the community, thereby encouraging links between the ordinary child and the mentally retarded child.

Chapter Four indicated a total of 1056 Coloured children of training centre age (ie 5-19 years) and 288 Black children. These figures represent an excess of 669 Coloured and 238 Black children over the places available for them. Although some of these could be accommodated in neighbourhood groups should formal placements be unavailable, it appears that there can be little alternative other than construction of additional training centres. This is particularly important considering the need to provide suitably-graded activities for each child over a twelve-year period and perhaps longer, the need for the children to experience and accept the structure provided in preparation for subsequent placement in a protective workshop or occupational group, the need to undergo some vocational training before such placement,and the right to appropriate schooling enjoyed by the children and their parents.

For these reasons, together with the fact that during the training centre period children negotiate a number of important periods of crisis, notably adolescence, it may be argued that, with limited funds available, greater emphasis should be placed on the provision of training centres than on formal preschool facilities. Furthermore, given the present shortage of training centre facilities, an emphasis on the preschool age-group will have short-term benefits only, both for the child and the parents. Although contrary to modern approaches in First World contexts, present needs in the study area are arguably greatest at the training centre level. To some extent, this dichotomy can be overcome by considering that preschool training can best be met through informal means, such as neighbourhood groups, while the needs of older children are best met through formal training centre placement.

During their adult lives, mentally retarded people derive many benefits from being actively employed, as was discussed in Chapter Three. In Chapter Four it was estimated that 1209 Coloured and 618 Black adults aged 20 and above were not placed in protective workshops or occupational groups. By the year 2 000, it is estimated that 1815 Coloured adults between the ages of 20 and 54 with trainable mental retardation will live in the study area. Although protective workshops are preferable to occupational groups in that they receive a State subsidy, the pace of construction of such workshops is slow because of their cost. It therefore seems likely to expect occupational groups to play a major role in providing adults with work. However, their provision is limited on account of not being State subsidized, and it is important that a subsidy be received in order to meet the growing need for work opportunities. In addition to purely work-related activities, a second major function which these groups need to serve is on-going adult education. As Herring and Jaffe (1981) state, "according to formal education structures, the child must discontinue his education at the age of 18 or 21 years - at a time when the person is only beginning to understand what he needs to know in order to live a fairly independent existence" (p.96).

A further dimension of adult needs are geriatric services, for those beyond working age. It is estimated that by the year 2 000 there will be 348 people in the Coloured community who fall into this category, taken as above the age of 55. However, as was shown in Chapter Two, mortality rates in the mentally retarded tend to be above the mean for the normal population and longevity tends to be reduced. Therefore, it is possible that the actual number requiring geriatric placement will be less than this figure.

Besides the types of facility for the mentally retarded discussed thus far, which are concerned primarily with training and work, a number of other areas also need to be considered. Firstly, as Jubber (1980) pointed out, a proportion of parents will be unable to look after their child at home: it is therefore important to provide residential facilities for those parents for whom institutionalization is the best option. Secondly, short-term residential facilities are required for children of families experiencing particular difficulties at a certain time, or who wish to go away on holiday without the additional problems which their child would present. Thirdly, additional handicaps need to be attended to in people of all ages, and avenues of referral need to be established throughout the service network. And fourthly, the leisure and recreational needs of mentally retarded people also require to be met: these include not only activities which would form part of the normal day in a neighbourhood group, training centre, or adult facility, but also (for example) holiday camps during vacations.

Throughout the above discussion, the stresses faced by families of mentally retarded people have been referred to, and specific attention must be directed at meeting the needs experienced by them. This is becoming increasingly important because of the modern stress on home-based rather than institutional care. Wilkin (1979) has noted that "the success of policies designed to care for the mentally handicapped in the community depends on the families who undertake the burden of care" (p.56). There are undoubtedly periods when the burden becomes very great, and at these times the family needs to depend on others for support. "The parents are seeking help, and sometimes their distress is greater than that of the child ..." (Mannoni, 1973, pp.135-136).

Numerous studies have been conducted on the impact of a mentally retarded child on the family (for example, Beckman, 1983; Crnic, Friedrich, and Greenberg, 1983; Nihira, Meyers, and Mink, 1983; Tizard and Grad, 1961, in Wing, 1971), and questionnaires have been designed specifically to measure stress in families of mentally retarded children (Holroyd, 1974). Mannoni (1973) documents the mother-child relationship, with emphasis placed on psychodynamic features. Steenkamp and Steenkamp (1981) state that occasionally the child may be rejected and receive physical abuse, and recommend that here the child should be removed from the care of the parents; however, more often the child is pampered and overprotected, thereby remaining dependent and making subsequent social integration more difficult. Wilkin (1979) reviews much of the literature on this wide and important topic.

In the context of the present thesis, however, the major concern is with strategies of intervention. Two main components of this are the provision of practical aid and the provision of emotional (or counselling) aid. The former includes helping to arrange grants from the State, helping the family make concrete plans for the child's future, and helping in carrying out these plans. Wilkin (1979) warns against unnecessarily pathologising the family: "... a number of books and articles ... have maintained that they are essentially the same as any other family, but that they face special problems with which they require practical help" (p.56). Baraitser (1980) believes that parents benefit greatly from a prolonged discussion about diagnosis, cause, risks of recurrence, prevention, developmental expectations, and educational facilities available, approximately eighteen months after learning of their child's mental retardation. This presumes that the counsellor working with the family has a detailed knowledge of the practical issues which are likely to arise, or has access to others who may be better qualified to assist. At the same time, it is to be expected that much of the practical help needed will have emotional overtones, and these need to be respected and worked with.

With respect to the provision of counselling services, it was noted in section 5.2.2 above that it was necessary for intervention to be restricted to points or periods of crisis in the family. These may be identified by the family itself, and could include parental stress, severe behaviour difficulties, embarrassment of other children (particularly adolescents) with regard to their mentally retarded sibling, and uncertainty in knowing how to deal with relatives and neighbours (Winterbourn, 1958). These problems require that avenues of consultation be open to parents. Other points of crisis may be identified through research conducted into commonly encountered periods of special difficulty, largely related to stages of the child's development. These include birth, diagnosis, the beginning of training centre placement, adolescence, starting adult life and work, and old age. It may therefore be beneficial to schedule meetings with a counsellor at regular intervals in order to assess the problems encountered by the family and whether counselling intervention is required.

In view of the heavy demands which increased communication would place on a relatively small number of professional counsellors, it may be possible to increase community participation through the involvement of a network of "lay counsellors" to undertake some of this work. This is already done to some extent by the Down's Syndrome Association, using as counsellors parents who themselves have Down's Syndrome children. This service could be expanded through participation of parents with children in training centres and other facilities, or through other interested people who could receive some training beforehand. In this way, a community support network would be strengthened, and as a group they could fulfill other valuable functions such as organising leisure activities and lobbying the State for provision of further facilities for the mentally retarded. A system of this nature would therefore distribute the work of counselling between both formal and nonformal levels of intervention.

In conclusion, tertiary facilities are an extremely important part of the overall system of service provision: they could be seen as being in the "front line" insofar as they are faced with the task of directly providing care and support for the mentally retarded and their families. Adequate provision of facilities is imperative, and without this, services at the primary and secondary levels partially lose their efficacy. Early diagnosis and assessment may be of academic interest only, if the absence of appropriate care facilities means that the child and family must be returned to the community without treatment; formal prevention programmes may be a luxury under conditions where the great majority of cases cannot be prevented.

5.3 CONCLUSION

As is apparent from the above discussion, few services can be located comfortably on only one of Caplan's axes and no other. Most services play an educative or counselling role, even if this is not a principal function. This overlap is inevitable, indeed necessary to some extent, if the service system to be provided is to be comprehensive.

Furthermore, since the service system by its nature is community orientated, maximal success can only be achieved if it is based on the needs of those to be served. This implies a high level of community participation and a stress on research into community needs.

Owing to the wide range of services which are involved in dealing with mental retardation, a premium needs to be placed on co-ordination and integration (Tarjan, Wright, Eyman, and Keeran, 1973).

Finally, the extent of the present shortage of facilities, particularly at the tertiary level, indicates that much has still to be achieved. However, this needs to be placed in the context of what has been achieved already, and the great efforts presently being made to overcome these shortages. Therefore, although the outlook may at first appear to be dark and the problems impenetrable, it is evident that this is only true in a relative sense: accordingly, attention needs to be placed on documenting the present in order to throw light on the way forward, and not merely to become overwhelmed by the extent of the need.

CHAPTER SIX : CONCLUSION

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In summary, this thesis has estimated the present prevalence of trainable mental retardation in the Coloured and Black communities of Cape Town, and projected the prevalence in the Coloured community to the year 2000. This estimation was based on the results obtained in similar studies and other relevant studies conducted both overseas and in South Africa. By comparing the estimated prevalence with services presently provided, an evaluation of the extent of need was carried out in the context of drawing implications for the future provision of services.

Results supported the assertion made by many presently working in this field that service provision is inadequate: while service needs of the White community are reasonably well met, in the Coloured community only one in three known cases is being served, while in the Black community this ratio is one in twenty. When these results are viewed in the context of South African social conditions as a whole, it is clearly evident that they display parallel relations of power and access to resources. A natural extension of this recognition is that the provision of services for the mentally retarded has been profoundly influenced by the ideology of apartheid and the web of economic and social relations with which it is associated.When these results are viewed at the level of the mentally retarded people themselves and their families, stresses resulting from social conditions are compounded by stresses resulting from mental retardation. The difficulties experienced by those caring for mentally retarded people, without the benefits of much-needed intervention by people skilled in dealing with these problems, are enormous.

These results were then discussed with particular reference to their implications for meeting present needs and for the provision of future services. Given that the provision of services for the mentally retarded is inescapably imbedded in State apartheid policy, equitable distribution of facilities requires the prior removal of this policy. More specific service needs were discussed in terms of Caplan's triaxial framework of primary ("preventive"), secondary ("early intervention"), and tertiary ("on-going care") services. A number of themes were identified as running through this discussion, the most important of which were seen to be: the need for services to be context-bound and responsive to locally-identified requirements; the need for community participation; and the need for co-ordination and communication between all components of the service network.

The overriding conclusion of this study is that it is imperative for conditions to be improved, a conviction strongly held by those who are involved in directly providing what services they can while constantly seeking ways to improve them. However, they are constrained by limited budgets and State subsidies, together with numerous sets of regulations determining the use of these funds. It is therefore clear that local attempts to improve services need to be strongly supported with corresponding action at the State level.

As is to be expected, this study raises the need for more work to be done in this and related fields. Directions for further study include examination of the complex practical issues involved in setting up a comprehensive register of mentally retarded people; a detailed analysis of the many dimensions of mental retardation which have special significance in South Africa, such as the influence of poverty-related factors on prevalence; and an investigation into the role and training of "lay" community workers in the field of mental retardation and in the wider field of mental health.Other directions for further work include an analysis of the social and political relations of the provision of services for the mentally retarded; and an exploration of methods for assessing the severity of associated behavioural difficulties, to be used by workers not specifically qualified in this area, as a means for guiding referral decisions.

It is hoped, in conclusion, that this study will provide some suggestions and points of discussion for those striving to overcome the difficulties experienced by the mentally retarded population and their families in Cape Town.

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PERSONAL COMMUNICATIONS

Information for this study was also obtained through personal communication with the following:

Dr A.P. Albert	Director, Assessment Clinic, Eastern Province Blood Transfusion Service.
Mrs Bouwer	Oasis Association.
Mrs J. Cooke	Co-ordinator, Western Cape Forum for the Mentally Handicapped.
Mr Davis	Principal, Ocean View Training Centre.
Dr A.A. Freeman	Head, Department of Paediatrics, Livingstone Hospital, Port Elizabeth.
Mr R. Gentle	Urban Studies Officer, Technical Management Services Branch, Cape Town City Council.
Prof. V. Grover	Western Cape Forum for the Mentally Handicapped.
Ms J. Hollingshead	Head, Child Care Information Centre, Red Cross Children's Hospital.
Dr C.D.Molteno	Principal Paediatrician, Department of Paediatrics and Child Health, Red Cross Children's Hospital.
Mr P. Romanofski	Urban Studies Officer, Technical Management Services Branch, Cape Town City Council.
Mrs M. Rosenthal	Lecturer, Faculty of Education, University of Cape Town.
Ms M. Roux	Researcher, Cape Mental Health Society.
Ms T. Tickton	Director, Cape Mental Health Society.
Mrs van der Merwe	Secretary, Oasis Association.
Dr J. Wagner	Paediatrician, Transvaal Memorial Hospital Assessment Clinic, Johannesburg.
Mr G. Young	Director, East London Mental Health Society.

APPENDICES

APPENDIX A : LOCAL AUTHORITIES INCLUDED IN THE METROPOLITAN CAPE TOWN AREA

Cape Town

Fish Hoek

Simon's Town

Pinelands

Milnerton

Goodwood

Parow

Bellville

Durbanville

Kraaifontein

Brackenfell

Kuils River

Part of Divisional Council of the Cape

Part of Paarl Divisional Council

Part of Stellenbosch Divisional Council

(Source: TMS, 1984)

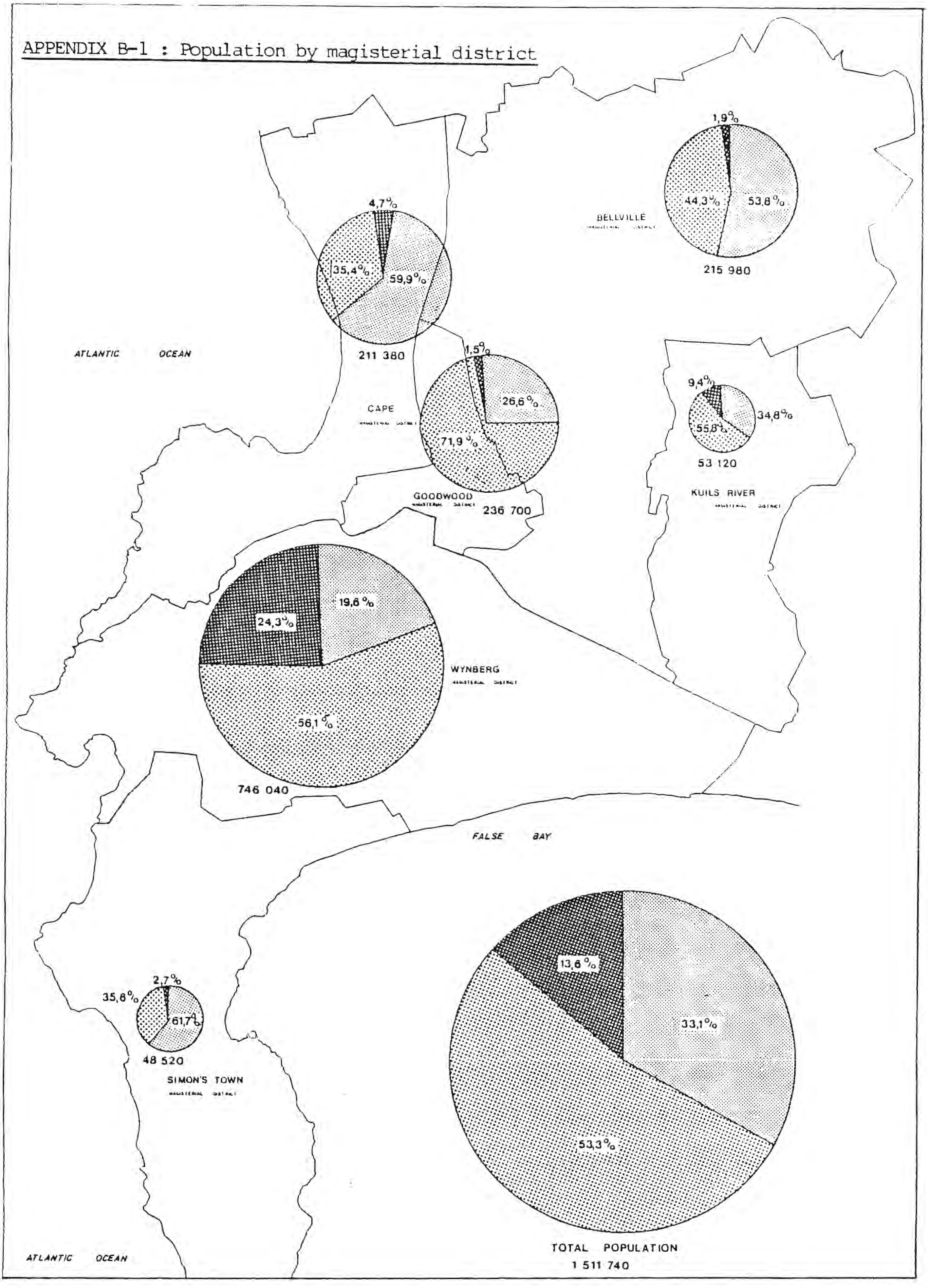
(See also Figure 6)

APPENDIX B

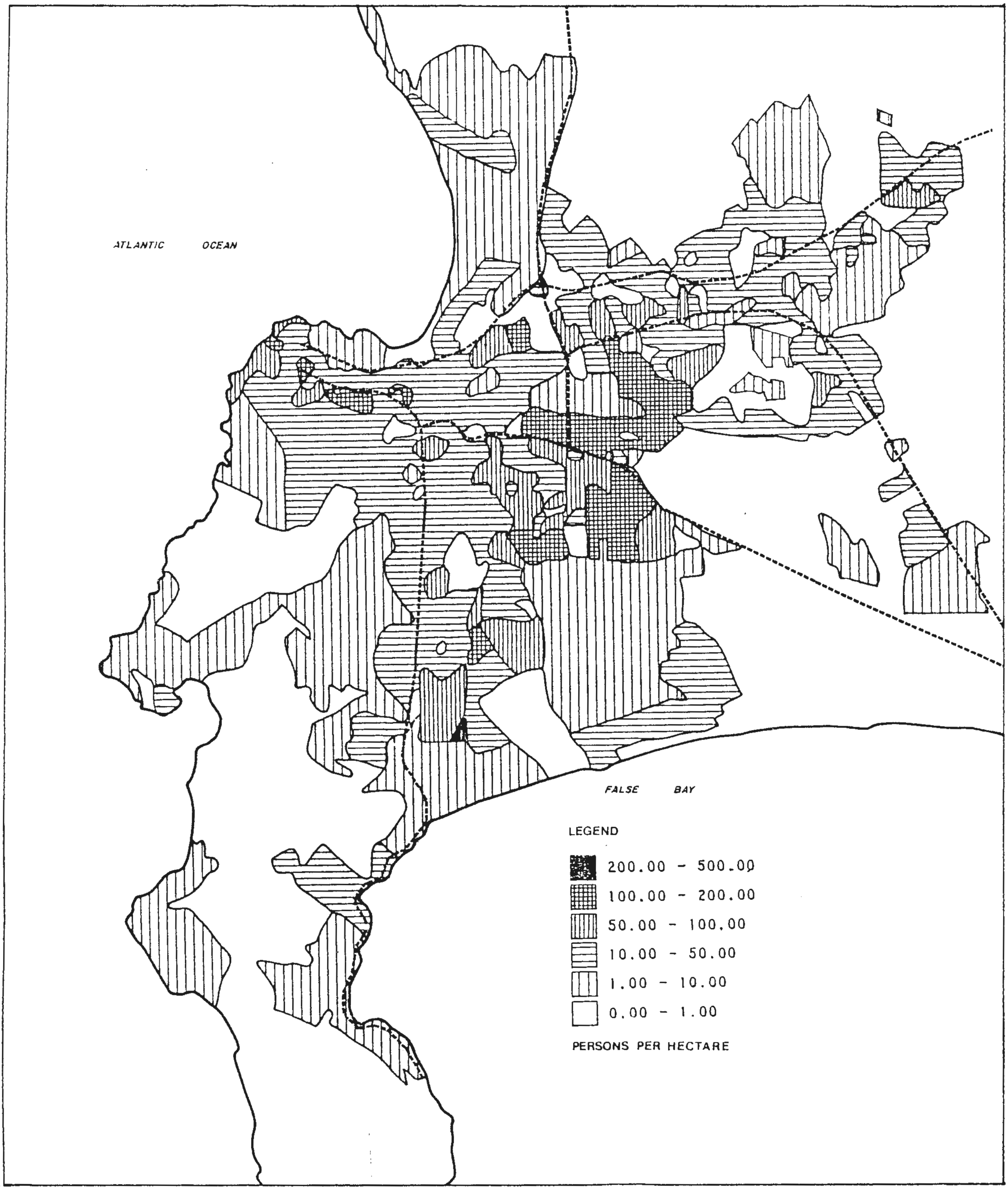
DEMOGRAPHIC CHARACTERISTICS OF THE POPULATION OF METROPOLITAN CAPE TOWN

Source: TMS (1982, 1983)

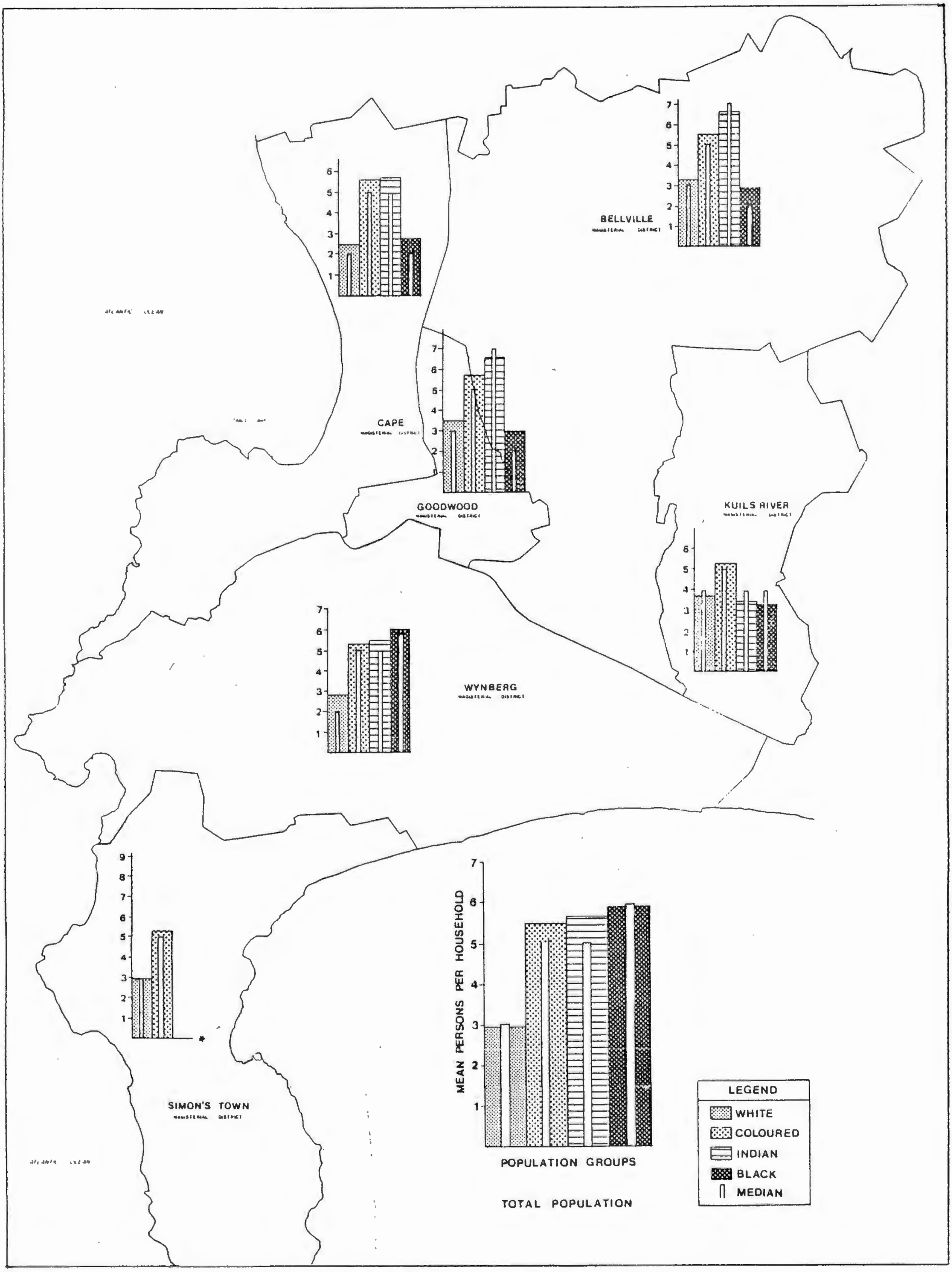
APPENDIX B-1 : Population by magisterial district



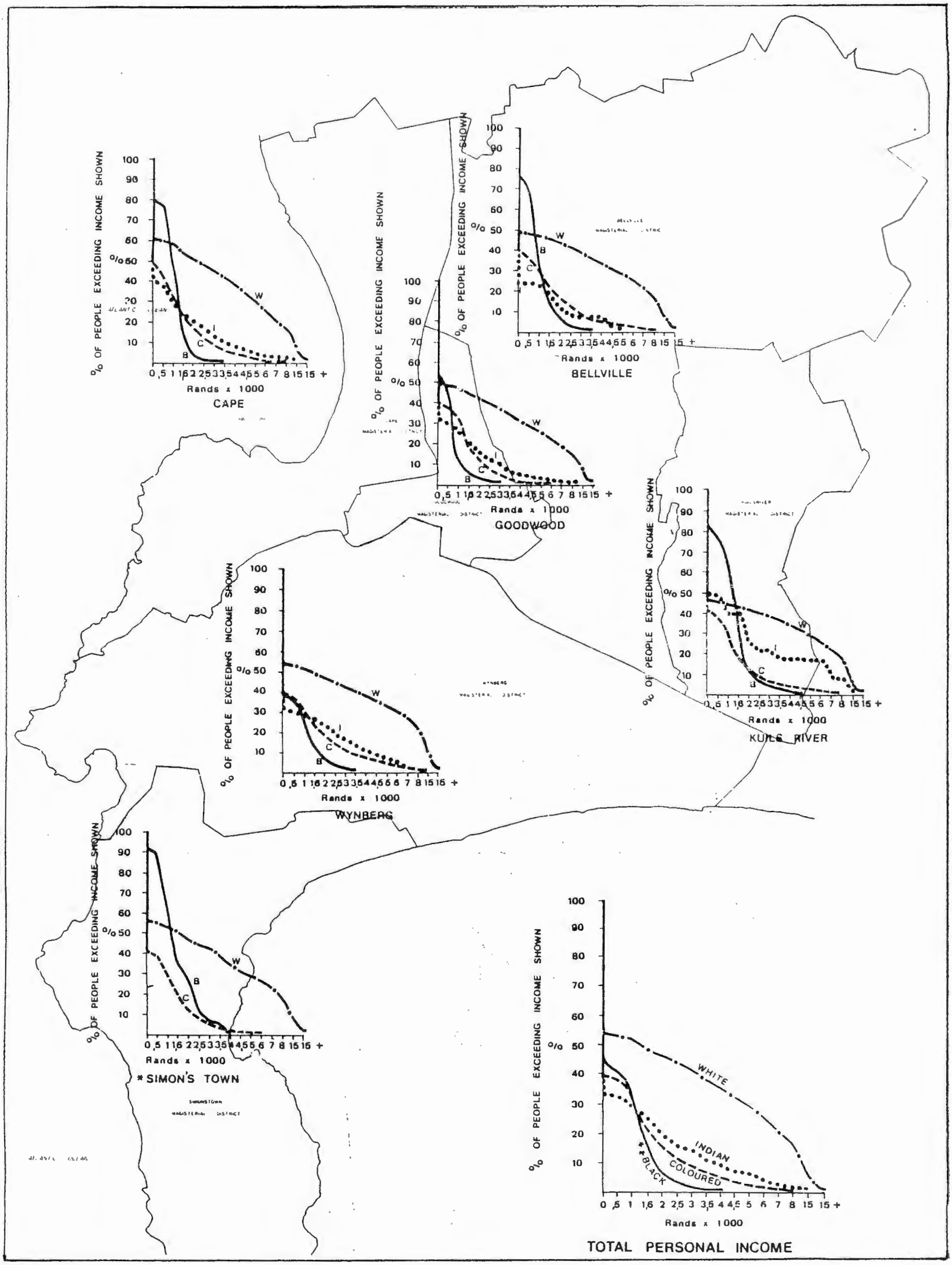
APPENDIX B-2 : Population density



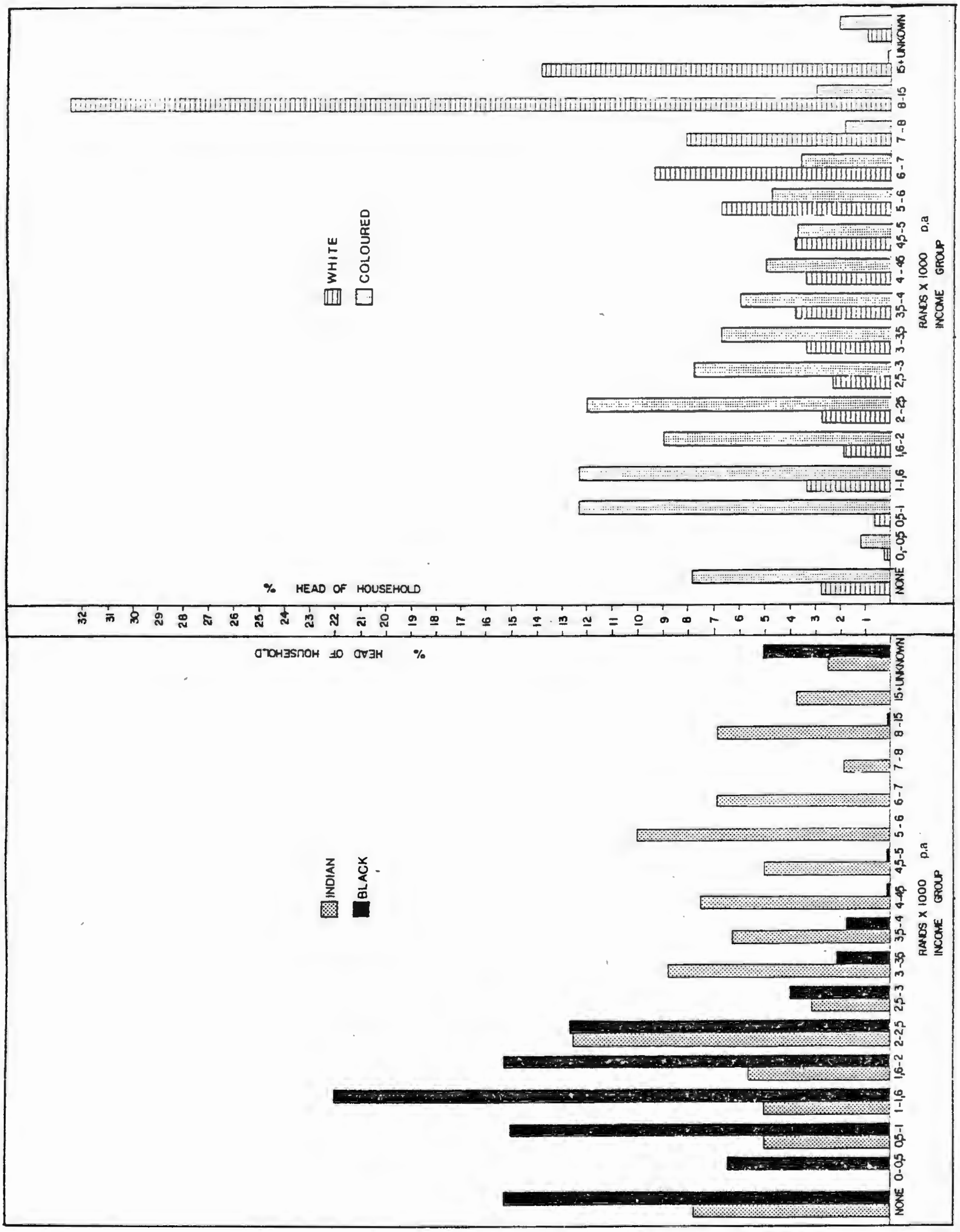
APPENDIX B-3 : Mean persons per household



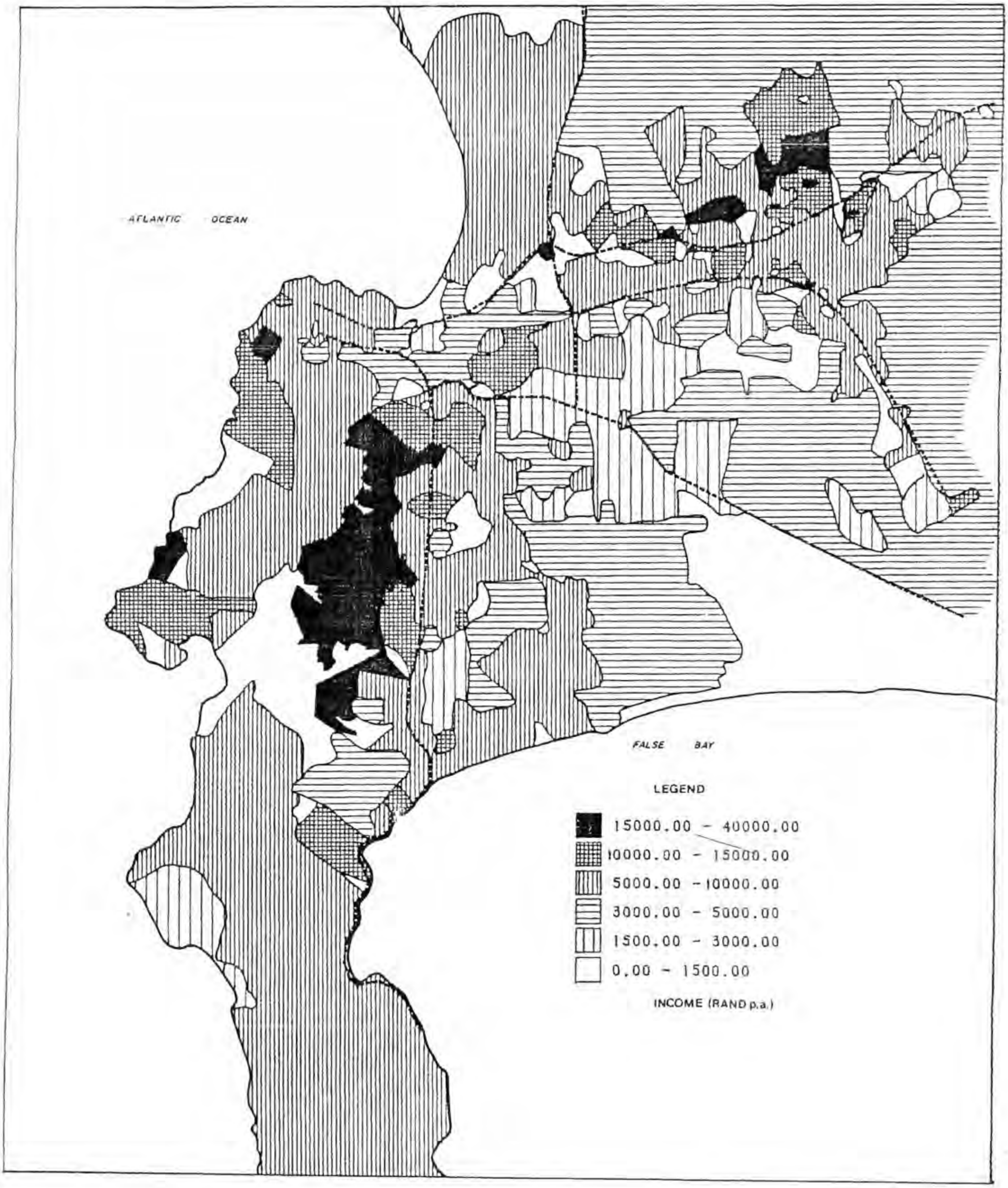
APPENDIX B-4 : Personal income



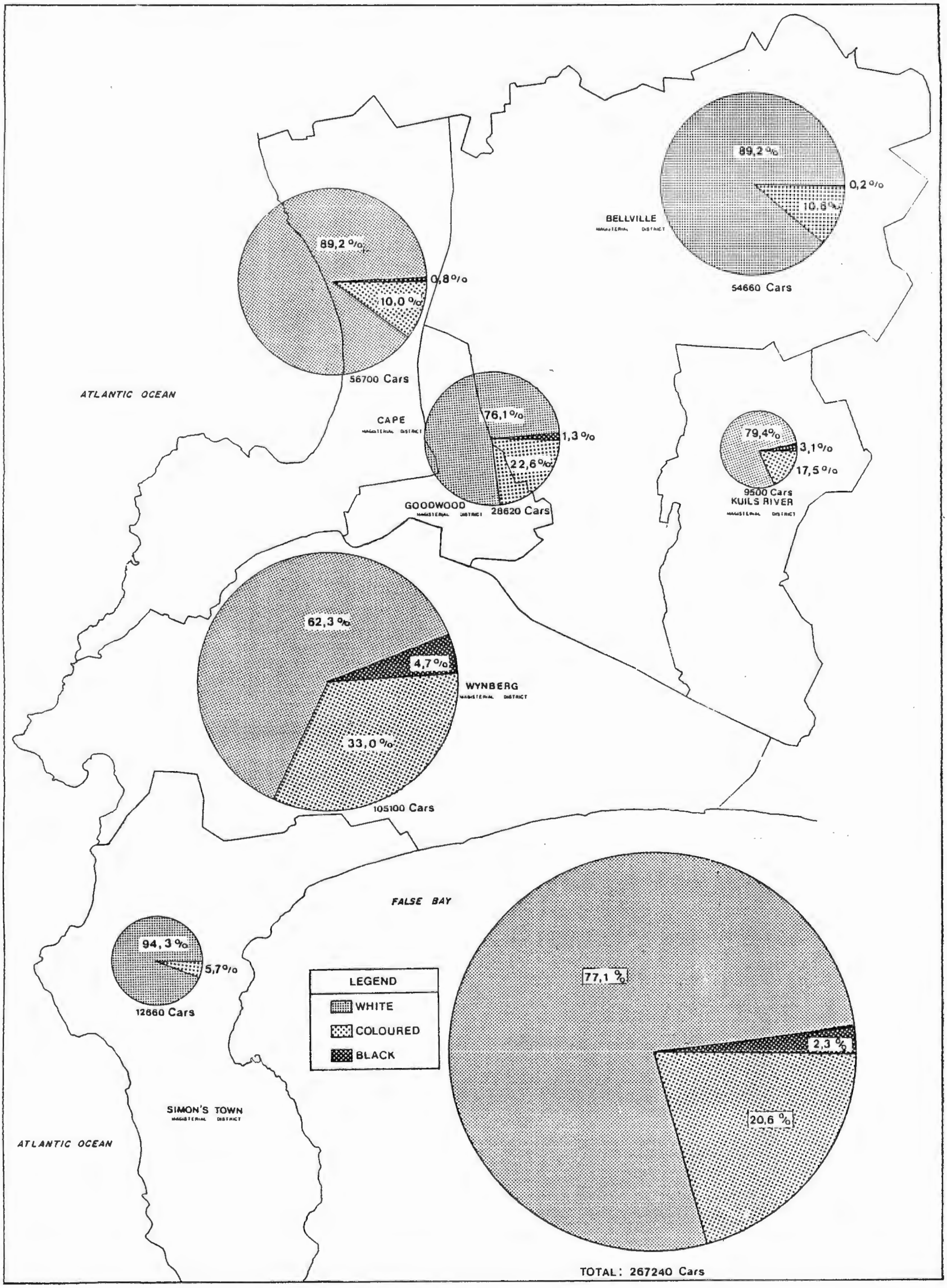
APPENDIX B-5 : Head of household income by population group



APPENDIX B-6 : Mean head of household income per annum



APPENDIX B-7 : Motor car ownership



APPENDIX C

POPULATION PROJECTION 1980-2000:
AGE-SPECIFIC POPULATION CHANGES
IN THE COLOURED COMMUNITY

Source: TMS (1983)

APPENDIX C : POPULATION PROJECTION 1980-2000 : AGE-SPECIFIC POPULATION CHANGES IN THE COLOURED COMMUNITY