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ABSTRACT

Major components of care for mentally retarded persons are discussed from an international perspective. The use of community resources to provide comprehensive services is emphasized, including teaching and rehabilitation techniques. Topics addressed include identification and assessment; etiological factors (prevalence and causative factors); national policy formation; services (community programs, prevention and treatment, training and rehabilitation, manpower development); and the role of voluntary and international organizations. Forty-three references are appended. (JW)

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Mental Retardation: Meeting the Challenge

Prepared in collaboration
with the Joint Commission on International
Aspects of Mental Retardation

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PREFACE

This publication is the result of close collaboration between the Joint Commission on International Aspects of Mental Retardation and the World Health Organization in an area of great significance for public health and for social development.

Tens of millions of people have some degree of intellectual impairment that results in disability and severe suffering, much of which can be alleviated if appropriate measures are taken. Today many such measures are possible and have been shown to be effective. Some of them are expensive but many others are not and can be applied even in countries that have only limited resources. In this book some of these measures are discussed and it is the hope of the Joint Commission and of WHO that its publication will support the efforts of nations and individuals to improve the plight of the mentally impaired and their families.

This book could not have been produced without the contributions of many individuals, not all of whom are mentioned here. Their reward, as well as the reward of those listed below, will lie in the application of suggestions made in this publication.

The first draft of the text was produced by the Joint Commission in accordance with a collaborative agreement with WHO. It was then circulated widely and comments have been received from many people. The drafts were reviewed in detail and numerous contributions made by Dr Annalise Dupont of the Institute of Psychiatric Demography, Aarhus Psychiatric Hospital, Risskov, Denmark; Dr Srinivasa Murthy of the Department of Psychiatry, National Institute of Mental Health and Neurosciences, Bangalore, India; and Professor Zena Stein of the Sergievsky Center, Columbia University, New York, USA. Ms K. Canavan of the Division of Mental Health, World Health Organization, Geneva, also made a valuable contribution.

All the comments were subsequently included in another, pre-final draft by Dr Philip Graham and Mrs Denise McKnight. The Joint Commission, and, in particular, Professor Alan Clarke, Department of Psychology, University of Hull, England, Dr Annalise Dupont, and Professor P. Mittler, Department of Education, University of Manchester, England, have reviewed the draft and incorporated their comments into the final version.

A publication of this type can serve a variety of purposes: to inform, to stimulate discussion, and to incite action. We hope that this book will serve all of those functions and that the mentally retarded, their families, their communities and countries all over the world will benefit from its publication.

1. INTRODUCTION

The aim of this booklet is to discuss some of the main components of care for persons with mental retardation. It is based on a reaffirmation of their rights promulgated by the United Nations General Assembly in 1971, and on the principle that they are full citizens of their local communities, entitled to the same dignity and rights as any other citizen. It recognizes, however, that persons with mental retardation have special needs and that these can be met by a combination of general and specialist services.

During the last twenty years there have been striking advances in our knowledge of how the mentally retarded can be helped to learn and to develop their skills and abilities to the full. There have also been advances in the medical sciences which can prevent or lessen the effects of mental retardation.

Fortunately, most of the recent advances in education and training and in helping mentally retarded persons to develop their skills are comparatively simple and these techniques can be acquired after only a short period of training by most people irrespective of their previous experience. They can therefore be adapted for use by primary health care and community workers, parents, and volunteers. An urgent task facing all societies as well as the international organizations is to devise a strategy for disseminating existing knowledge and skills to the hundreds of thousands of people who come into daily contact with mentally retarded people.

Because the potentialities of persons with mental retardation have been seriously underestimated in the past, the more developed countries are now faced with a legacy of services that are no longer considered appropriate in the light of current knowledge. However, developing countries have the opportunity to build new services from first principles.

Until quite recently, profoundly retarded children did not usually live very long, but improved health care in developed countries has meant that more are surviving into adulthood and their life expectancy is increasing as medical care improves. This will mean that as health care improves in developing countries, the profoundly retarded as a group will make increasing demands for services. However, experience has shown that this group, while remaining severely retarded, can respond to carefully thought out step-by-step programmes that involve the setting of very small targets and are designed to help them have increased contact with their environment. Such techniques can be easily taught to non-professionals and will be described in more detail later in this book. Therefore, it is important that the severely retarded should not be excluded from programmes for somewhat abler children and adults who can act as models for more mature behaviour. Under such conditions, some persons are shown to be less profoundly retarded than seemed apparent at first.

The emphasis is now on the full use of community resources to provide a comprehensive service that aims to help all mentally retarded people to remain in the local community, and to contribute to it as fully as they are able (16,23). Teaching and rehabilitation techniques provide the means to help them to learn and to use the necessary skills.

An understanding of the nature of the problem of mental retardation is needed in order to improve the services available at present. Consideration needs to be given to the wide range of handicaps involved, their diagnosis and assessment, and the potential areas of intervention best suited to the problems in a given area. An understanding of the etiology of mental retardation is also needed in order to intervene effectively, together with an understanding of the range of services, both medical and psychosocial, that would offer practical opportunities for amelioration and rehabilitation. Finally, national policy decisions should be formulated and enacted in order to make the best use of the accumulated information and harness potential for change.

2. NATURE OF THE PROBLEM

Mental retardation includes a wide range of conditions that may be determined by many factors of a biological, psychological, or social nature. This view of mental retardation as resulting from a wide range of causes is of particular importance in considering what services should be made available.

Terminology, definition, classification, etc. for this subject are very confusing, not only in English but also in other languages. The two international organizations in this field use different terms; mental deficiency (IASSMD)[1] and mental handicap (ILSMH)[2]. The World Health Organization and some other agencies prefer to use the term mental retardation.

In the WHO publication The international classification of impairment, disabilities and handicaps, (42) the sequence of illness-related phenomena is described as: disease - impairment - disability - handicap. In this document, for the sake of consistency, the term mental "retardation" is used throughout, although there are occasions when it would have been more precise to use the terms "impairment", "disability", or "handicap".

As the term is used today, mental retardation involves two essential components: (a) intellectual functioning that is significantly below average, and (b) marked impairment in the ability of the individual to adapt to the daily demands of the social environment. There is now widespread agreement that both intellectual functioning and adaptive behaviour must be impaired before a person can be considered to be mentally retarded. Neither low intelligence nor impaired adaptive behaviour alone is sufficient.

2.1 Identification and assessment

The identification and assessment of mental retardation needs careful consideration. The severely mentally retarded can be more easily identified since their disabilities are more obvious. Those with a milder degree of disability are less easy to recognize and, therefore, to help. Primary health care workers should be trained to recognize the signs of developmental retardation in the children they see during the normal course of their work.

Once mental retardation is suspected, it is important to apply appropriate objective tests of intellectual functioning and adaptive behaviour. The best test of a person's ability to respond to teaching is to provide him with skilled teachers and to experiment continuously with different methods of helping him to learn. However, such approaches are often not available.

Assessment need not be particularly time-consuming or require a skilled professional approach. Recently developed assessment measures take into account the importance of determining a persons's actual functional abilities in key areas of day to day living and learning by systematic observation of that individual in ordinary settings, and the use of information from those who know the person well such as parents, health care workers, teachers.

Development assessment scales such as the PIP (parental involvement project) charts (20), and the Portage system (29) are simple to administer and relatively unskilled people can be easily trained to use them. Some items in the tests would, of course, have to be adapted to the culture where they are to be applied, but this should be easy to do.

The advantages of the above measures and others based on social competence, e.g., AAMD adaptive behaviour scales (1), and Gunzberg's progress assessment charts (11), over standardized intelligence tests are not only that they are easy to use but also that they are valuable in formulating teaching and rehabilitation programmes. A recent study in India (33) has indicated the advantages of changing from standardized intelligence tests to the use of measures of adaptive behaviour as the basis for rehabilitation. This is among

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[1] IASSMD - International Association for the Scientific Study of Mental Deficiency.

[2] ILSMH - International League of Societies for Persons with Mental Handicap.

the reasons for the requirement of the WHO glossary (41) which states: "The assessment of intellectual level should be based on whatever information is available, including clinical evidence, adaptive behaviour and psychometric findings".

Intelligence testing has a very long history and an enormous amount of information has been collected on the performance of children and adults, male and female, of all ages using a variety of different tests. However, most of the standardization of these tests has been carried out in developed countries and cannot easily be applied in other countries. Ideally, each test should be restandardized for a particular country, which, however, would be very expensive and time-consuming. But if IQ tests are used, it is essential that they are appropriate to the area where they are performed (the local culture), administered by persons specifically trained in their use, and regularly repeated, since experience has shown that increased opportunities and higher levels of demand and stimulation can change the IQ score. Too much reliance on a single, low value might lead to less enthusiasm in attemtps to improve the individual's performance.

Despite the reservations given above, IQ scores are still widely quoted in discussions about the classification, epidemiology, and etiology of mental retardation and they are used in that context in this book.

One of the most confusing aspects of accounts of mental retardation is the variety of terms used to describe the different degrees of handicap. The WHO Expert Committee on Mental Health (38) suggested a sub-classification based on IQ, assuming a population mean IQ of 100 and a standard deviation of 15 points (see Table 1).

Table 1. Classification and distribution of mental retardation proposed by the WHO Expert Committee on Mental Health in 1968[a]

Groups	IQ	Proportion of all mentally retarded (%)
Profound	0-20	5
Severe	20-35)	20
Moderate	35-50)	
Mild	50-70 (or 75)	75

[a] WHO Technical Report Series, No. 392, 1968.

The report stressed that the IQ is not an exact measurement and that in practice the categories would tend to overlap. However, from the point of view of etiology, it is usual to divide mental retardation into two large groups: severe mental retardation (which includes profound, severe and moderate disability) and mild mental retardation. Not only do these groups differ in incidence and prevalence, but also in the degree of handicap and ultimate prognosis. Although it is not appropriate to think in terms of a sharp dividing line, persons with an IQ below 50 (representing an intellectual level of about 7 years in an adult) are generally characterized by some form of biological impairment involving the central nervous system (CNS) while the mildly mentally retarded are much less often affected in this way. The more extensive the involvement of the CNS, the more often the person has additional impairments, e.g., problems of language or vision, epilepsy and/or cerebral palsy. As a result there are multiple handicaps in more than 50% of the severely mentally retarded.

2.1.1 The profoundly retarded. A very small minority of the mentally retarded are profoundly retarded. Their intellectual handicap is reflected in IQ scores of less than 20-25 and in developmental levels in adults corresponding to a development age of less than two years; they are also often severely physically handicapped, non-ambulant, and incontinent.

2.1.2 The severely and moderately retarded. About 0.3% of all children are considered to be severely or moderately retarded. Although many will remain to some degree dependent during childhood and adolescence, their eventual level of functioning in day-to-day life depends to some extent on the quality of the teaching or training they receive and the level of demand that is placed upon them. In developing countries, about one-third of this group will be children with Down's syndrome, while for many others who are biologically affected, the precise cause can still not always be established. Whatever the cause of their retardation, it is now thought that all children and young people are capable of responding to teaching to some extent. Accordingly, an increasing number of countries are now placing the responsibility for the education of all mentally retarded children on the education authorities and on trained teachers, working alongside other professionals wherever possible. Such provision often also caters for those who are profoundly retarded.

2.1.3 The mildly retarded. This group is much larger than the the others. At school age about 2-3% of children in developed countries have an IQ of 50-70; the frequency of this category, however, changes markedly with age and many mildly mentally retarded children are later able to function more or less inconspicuously in the adult community. Mild mental retardation can be caused by, among other things, the same etiological factors as severe mental retardation when they are present to a lesser degree. Social adaptation of mildly retarded people is largely influenced by historical, social, and economic factors, such as tradition, family structure, attitudes towards the less able, manpower balance, and provision or lack of universal schooling, as well as by the rate of maturation of the individual, and the presence of additional chronic handicaps.

Many people with mild mental retardation will not be identified, particularly in developing countries, until changes in general education and in the demands of employment and life style, which usually increase the demands placed upon them, reveal their difficulties in adapting to such changes. Just as the IQ is not necessarily constant during an individual's life-time, social adaptation may also change; a poorly adapted adolescent may become a normal citizen a decade later. His condition in adolescence was a form of temporary retardation. It is because such cases exist that the utmost care should be taken to help individuals through a difficult time (for example, with the transitory demands of school) while not artificially labelling and categorizing them.

Until recently, studies in developed countries and supporting evidence from developing countries suggested that there was a striking difference between mild mental retardation and severe mental retardation regarding social class distribution and the incidence of associated chronic handicaps. However, detailed research has shown that the distribution pattern of social classes and of mental retardation is not as closely correlated as had been assumed. While an excess of both mildly and severely mentally retarded children have been found in the lower social classes, it should be remembered that the lower social classes in all cultures tend to be those least likely to benefit from advances in health care, education, and training opportunities. As measures to prevent severe mental retardation become more readily available, middle-class families are likely to be the first to take advantage of them.

3. ETIOLOGICAL FACTORS

3.1 Prevalence and causative factors

The best estimates of the prevalence of severe mental retardation (roughly equivalent to an IQ of less than 50) in developed countries suggest that the rate is between 3 and 4 per 1000 persons. Mild mental retardation (roughly equivalent to an IQ of 50-70) is usually estimated to occur in 2-3 per 100 persons, but there is some evidence that in countries with a particularly high standard of living and quality of health, social and educational services, the rate may be considerably lower than this (13).

The prevalence of severe and mild mental retardation in developing countries is much less accurately known for a variety of reasons. Firstly, very few relevant surveys have been carried out so far. Secondly, there is often a lack of standardized measures of intellectual function and disability adapted to the needs of developing countries. Thirdly, professional workers (pediatricians, primary health care workers, etc.) are often not trained to recognize mental retardation. It has been demonstrated (10), for example, that primary health care workers often do not notice mental retardation when children are brought to them with other complaints. Nevertheless, some surveys have been carried out in developing countri , (14, 25) and, from the results obtained as well as from anecdotal evidence, it seems likely that the rate of mental retardation at all levels of severity is at least as great in developing as it is in developed countries. Certain causative factors, especially malnutrition, infection, and inadequate perinatal care (to be discussed in more detail below) are, of course, more frequent in developing countries than in developed countries. In addition the lower level of the health care in many developing countries almost certainly results in a higher mortality rate among the severely and moderately mentally retarded especially in the first few years of life. As health care in general improves, the survival rate of the retarded will also increase, resulting in a higher prevalence of the condition.

Mild mental retardation as a "condition" in an individual is very difficult to establish. Intelligence and intellectual function vary from person to person. Inevitably some will be duller than others, but this may not entitle us to suggest that the dull are suffering from a pathological condition. Further, while those suffering from severe mental retardation are likely to be handicapped to a marked degree, whatever ordinary demands society makes of them, this is not the case for the mildly mentally retarded. In developed countries, many so-called mildly mentally retarded individuals, are recognized only during their school years because of their shortcomings in academic work. Before they go to school they may have had no problems and once they leave school they may be able to cope well with an unskilled job, marriage, and child-rearing. Labelling such people as different at school may result only in lowering the self-esteem of the individual concerned and in discrimination against him or her in later life. Thus, it should be clear that the label of mild mental retardation may be a result of the complexity of demands that society places on an individual rather than of any deficit in the individual himself or herself.

Nevertheless, in societies where complex demands are made on the great majority of individuals, (and, of course, this is much more likely to occur in developed than in developing countries) treating the less intellectually able as having a "condition" may be beneficial to them. They may, for example, be provided with special educational help and given more sensitive vocational guidance when they enter employment. It is therefore reasonable, especially in developed countries (and indeed perhaps at this stage only in developed countries), to devote resources to the identification of the causes of mild mental retardation, to attempt preventive steps, and to undertake remedial measures.

3.2 Causative factors of severe mental retardation (IQ 0-50)

3.2.1 Malnutrition. Many studies have examined the effects of an inadequate diet in pregnancy and in the early years of childhood (28, 31). The main problem in interpreting the results is that poor nutrition is almost always associated with inadequate social stimulation, which also retards intellectual development. It is, therefore, usually impossible to make an accurate estimate of the independent effect of malnutrition on mental development. Nevertheless, careful studies in Colombia (34) and Guatemala (9) suggest that the intellectual development of young, malnourished children whose diet is appropriately supplemented does improve, at least for some years subsequently. Further, there is probably some interaction between social environment and nutrition, such that inadequately socially stimulated children are particularly vulnerable to an inadequate diet.

A malnourished pregnant woman is likely to produce a low birth-weight baby. Such babies can be grouped into two main categories:

(a) the true premature baby who is the right size for his fetal age, but is born too early and

(b) the "small for dates" infant who is born at term, but has not grown properly in utero.

"Small for dates" babies have often suffered from placental insufficiency resulting in an inadequate transfer of nutrients from mother to fetus. There is firm evidence for the important role of maternal nutrition in fetal growth. Birth-weight, for example, correlates with the increase in maternal weight (a correlation particularly marked in developing countries) and it is known that supplementation of the diet of malnourished women during pregnancy results in an increase in the birth-weight of their babies by an average of 300 grams. According to the Sixth report of the world health situation (43), approximately two-thirds of all low birth-weight babies born in developed countries are estimated to be pre-term. In contrast, in developing countries, three-quarters of all low birth-weight babies are undernourished and small for their gestational age, a condition with a potentially more serious outcome. Certain specific dietary deficiencies that occur in developing countries are particularly important because they may be easily and cheaply prevented. Iodine deficiency, particularly prevalent in New Guinea and Nepal, is a good example. A study in New Guinea (6) showed that untreated children born to iodine-deficient mothers showed neurological defects. It is possible, but not proven, that direct and indirect effects of malnutrition are among the most important causative factors in the production of severe mental retardation on a global basis.

3.2.2 Infection. Damage to the brain as a result of infection is an important cause of mental retardation in developing countries, although the the incidence and prevalence of such conditions is unknown for most parts of the developing world. Meningitis and meningo-encephalitis occur as a result of common bacterial, viral, and protozoal infections, all of which are especially likely to affect the malnourished child living in a poor social environment. Tuberculous meningitis is common in some developing countries. Measles, usually a relatively benign disease in developed countries, is quite frequently complicated by meningo-encephalitis in developing countries. Some cases of progressive central nervous system symptoms with mental retardation have been caused by virus infection, for example measles in children with abnormal immunological systems. Maternal rubella (german measles) infection occurring during the first three months of pregnancy sometimes results in mental retardation and/or sensory impairment in the affected child with or without other congenital malformations. Gastroenteritis, especially in the malnourished child, may be accompanied by such severe electrolyte imbalance and dehydration that irreversible brain damage may occur. Again, the importance of these infections is that they can all be easily prevented using existing knowledge.

In both developing and developed countries, brain complications associated with whooping cough are a cause of mental retardation. Immunization against whooping cough has recently been the subject of some controversy in developed countries, but it is now generally agreed that a policy of selective immunization is highly desirable.

Recent studies have also raised the possibility that other uterine infections, especially by cytomegalovirus, are of significance in the later development of mental retardation. On very rare occasions mental retardation can also be caused by toxoplasmosis and congenital syphilis.

3.2.3 Perinatal factors. The lack of adequate survey evidence for the prevalence of severe mental retardation in developing countries means that, in addition, the contribution of perinatal factors, especially injury to the brain resulting from traumatic birth, is also unknown. It is likely, however, that birth trauma ranks high among the causes of severe mental retardation in developing countries. As already discussed, premature birth is common and the brain of the premature baby is more likely to be damaged at birth. The lack of skilled professional assistance at many births in developing countries means that many complications - prolonged labour, precipitate delivery, perinatal anoxia, etc., - are unlikely to be dealt with appropriately. Consequently brain damage due to anoxia and/or haemorrhage commonly occur.

In contrast, improvements in antenatal and perinatal care mean that in developed countries, perinatal brain trauma is a relatively minor cause of severe mental retardation, accounting, in the most highly developed countries such as Sweden, for only about 10% of all cases (12).

3.2.4 *Genetic causes*. These are now the most common causes of severe mental retardation in developed countries, but their importance in developing countries is unknown. In developed countries the major genetic causes and their approximate contributions are as follows:

(a) *Chromosomal anomalies*. At present, these probably account for approximately 35% of all cases of severe mental retardation in developed countries. The majority of these chromosomal abnormalities are cases of Down's syndrome (or chromosome 21 trisomy). There is a well-established relationship between the occurrence of Down's syndrome and maternal age. The estimated risk of giving birth to a Down's syndrome baby for women aged 20-25 is about 1 in 2000, whereas in women aged 45 or over the risk is 1 in 50. In addition, it has been shown that there is a higher than normal risk of such a birth if the mother is very young or if the father is aged 50 or over.

In recent years another fairly common chromosomal anomaly has been defined - the so-called fragile-X syndrome. In affected males there is a constriction near the end of the long arm of the X chromosome in many cells. The condition is also transmitted by females, but does not usually affect them severely, although it may occasionally produce mild mental retardation. The relative contribution of this condition to the total number of severely mentally retarded males is not known, but may be in the region of 5%. A number of affected males show only mild mental retardation.

A large number of other chromosomal anomalies also exist which may be identified by special techniques. All are very rare in children above one year of age, though they are more commonly present in the neonate.

(b) *Single gene disorders*. Many single-gene diseases are known in man, (over 2000 different types have been described) and a large number of these result in mental retardation. Many of these conditions are recessive. Although each single condition is rare, (e.g., classical phenylketonuria occurs with an overall frequency of 1 in 10 000 live births in Caucasians, but varies considerably) these disorders taken together probably account for 8-15% of cases of severe mental retardation in developed countries.

In some cases the mechanism by which single-gene disorders produce mental retardation has been well documented; for others it is unknown. For example, in phenylketonuria the brain is damaged by an excess of phenylalanine in the blood. Phenylketonuria is also an example of a condition in which appropriate dietary treatment can prevent the adverse effects from occurring, although such treatment is expensive and requires a high level of health care.

Congenital hypothyroidism (as distinct from hypothyroidism produced by the dietary deficiency of iodine described above) is also a significant cause of mental retardation in developed countries and probably also in developing countries. However, it can be treated relatively cheaply if diagnosed at birth or in the first few months of life. The early identification of both phenylketonuria and congenital hypothyroidism depends on the existence of a comprehensive screening programme.

(c) *Polygenic disorders*. These occur as a result of the interaction, through natural variation, of two or more genetic factors. This interaction may not produce a harmful effect unless certain environmental conditions also occur.

Neural tube defect, perhaps the most common example of a polygenic disorder, may vary in severity from anencephaly that is incompatible with life, to spina bifida occulta - a condition producing little or no disability. Mental retardation occurs when the brain is damaged, usually by chronic infection or pressure. Neural tube defects occur world wide, but their prevalence varies greatly from country to country (e.g., 5-6 per 1000 in Dublin, Ireland, to 0.1 per 1000 in Bogota, Columbia). Retardation may occur at any level, but the contribution of such cases to the total number of severely retarded even in developed countries is relatively small. There is now some evidence (30) that vitamin supplements given to the mother at about the time of conception may reduce the chance of abnormality in the fetus.

(d) Mother-child genotype incompatibility. The only disorder of this type that is of any practical importance is rhesus (Rh) iso-immunization which can occur when an Rh-negative mother is carrying an Rh-positive fetus. Mental retardation may occur as a result of damage to brain tissue. The incidence of rhesus disease varies in different racial groups and is, for example, rare in Africans but much more common in Caucasians. In developed countries, successful treatment of the pregnant mother, requiring sophisticated techniques, is now widespread so that the contribution of this disorder to the total number of mentally retarded is small.

3.2.5 Physical and chemical agents. A variety of such agents may, in special circumstances, play an important part in the development of mental retardation. It has been claimed, although not everyone agrees, that X-ray irradiation of the pelvis increases the risk of bearing children with chromosomal anomalies in subsequent pregnancies. Certainly, powerful irradiation of the abdomen during the first trimester of pregnancy caused mental retardation with microcephaly in the offspring of atom bomb victims. Contamination of food with mercury has caused severe cerebral dysfunction in infants in an epidemic outbreak in Japan. Undue exposure to high concentrations of lead (for example, from lead batteries), and ingestion of lead paint or certain cosmetics may cause encephalopathy with subsequent severe mental retardation. Mental retardation has also been reported in cases following poisoning with other heavy metals, and with organochlorine compounds after occupational, environmetal, or nutritional exposure. In addition it has also been suggested recently that atmospheric lead pollution may be responsible for low levels of intelligence, although not to an extent likely to cause severe mental retardation.

3.2.6 Gross social deprivation. Absence of social stimulation is associated with mild degrees of mental retardation (IQ 50-75). Gross social deprivation, especially if this involves prolonged social isolation, can result in the development of severe mental retardation. However, it has been demonstrated that the resultant mental retardation is often reversible (5). The relative contribution of gross social deprivation to the total number of cases of severe mental retardation is probably low in both developing and developed countries.

3.2.7 Unknown causes. It is important to emphasize that even in developed countries, the cause of severe mental retardation may remain unknown even after intensive investigation in an advanced centre. In developed countries the cause remains unknown in approximately 15% of cases - a much smaller proportion than a generation ago.

3.3 Causative factors of mild mental retardation (IQ 50-75)

In individuals with severe mental retardation it is usually possible to identify the problem with some degree of certainty and to confirm or at least infer a single definite cause. The cause will usually be an organic defect affecting the brain. This is less often the case with moderate or mild mental retardation (Fig. 1A, and 1B).

3.3.1 Organic factors. A variety of organic factors - malnutrition, infection, genetic factors, etc., have been recognized as causing severe mental retardation. Each of these, if reduced in intensity, or if the individual concerned is less vulnerable, may produce mild mental retardation. In most surveys, less than one-third of mildly mentally retarded individuals show evidence of organic impairment, most are found to be suffering exclusively from impoverishment of their social environment (to be discussed in more detail below). However, recent evidence (13) suggests that as the social conditions of developed countries improve, so organic causative factors may increase in relative importance. In Sweden, for example, organic factors account for about 50% of cases of mild mental retardation. In these circumstances successful measures taken to prevent severe mental retardation may also produce a significant improvement in the incidence of mild retardation. Preventive measures may be possible, for example, to prevent damage to the fetus by avoiding alcohol during pregnancy. Recently it has been shown that alcohol consumed by a pregnant woman may be a cause of the "fetal alcohol syndrome" in which children with a characteristic facial appearance also frequently show some degree of mental retardation. The interaction of social and biological factors is thought to be responsible for many cases of both severe (SMR) and moderate (MMR) mental retardation classified with an "uncertain" or "untraceable" etiology.

3.3.2 Impoverishment of the social environment. Intellectual development in young children depends on the presence of stimulating adults and other children. The stimulation will be more effective if the child develops trusting relationships with those around him, with people who are sensitive to his needs. Lack of such stimulation is likely to produce mild mental retardation especially if the child is genetically poorly endowed. This situation is likely to occur when a number of adverse factors are combined in the environment of a child. These factors include:

(a) Poverty. Parents who are struggling to subsist materially will not have enough time to devote to the needs of their children.

(b) Large families. The presence of many children carries a risk that one or more may not receive adequate attention. This is less likely to be true in extended families where child care is shared among adults.

(c) Short spacing between births.

(d) Physical overcrowding.

(e) Physical or mental illness in one or both parents.

(f) Mild mental retardation in parents and/or other children.

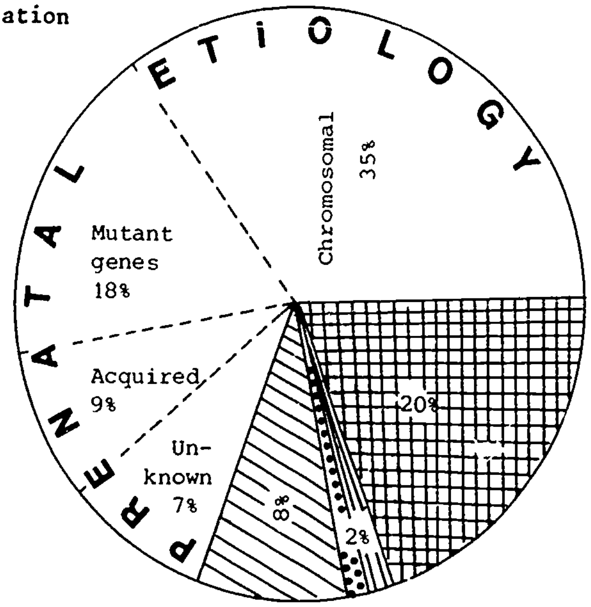
(g) Poor educational level of parents.

(h) Growing up in very poorly run orphanages or other child-care institutions.

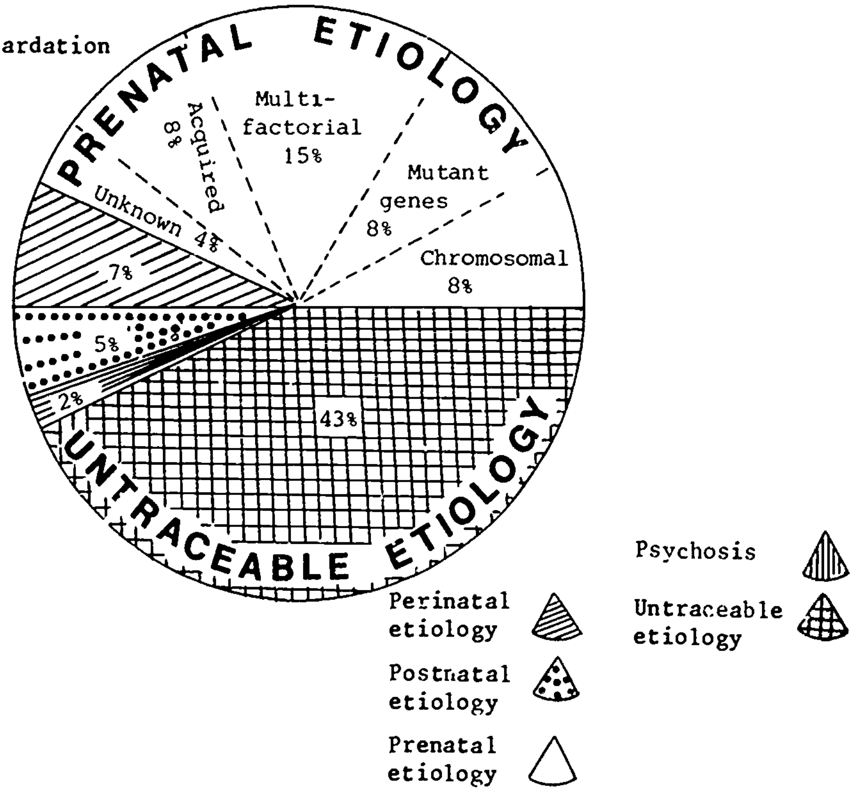
Several of these factors are likely to occur together in families living in poor social conditions, e.g., in the slums of large cities. As might be expected there is a negative correlation between social class and the occurrence of mild mental retardation. The condition occurs less frequently in middle class children, whereas in areas in which virtually all the families are living in overcrowded conditions close to subsistence level, it will often be endemic in the population.

Fig. 1a. Etiological factors of severe and moderate mental retardation in developed countries [a]

Severe Mental Retardation (SMR)



Moderate Mental Retardation (MMR)



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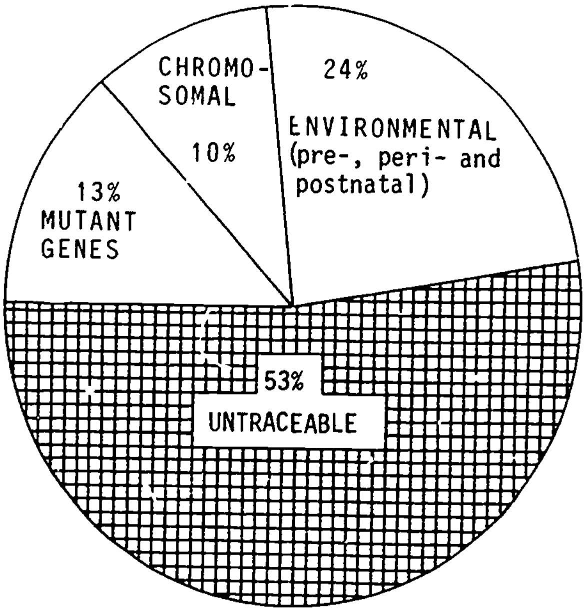
[a] Reproduced from BLOMQUIST, H.K. Mental retardation in children. Umea University Medical Dissertations, Sweden, 1982, by permission of the publishers.

Fig. 1b. Etiological factors of mental retardation in India (all degrees of mental retardation - more than 50% with IQ less than 50) [a]



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[a] Reproduced from NARAYANAN, H.S. A study of the prevalence of mental retardation in Southern India. International journal of mental health, 10: 28-36 (1981), by permission of the publisher.

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4. NATIONAL POLICY FORMULATION

As a result of many years of basic and applied research, mainly in developed countries, information is now available on ways to prevent many of the causes of mental retardation or to ameliorate the deficits (39, 40)[1,2]. Not all of these measures can be provided immediately by any one country since costs and manpower expenditure are likely to be prohibitive, particularly where existing services are minimal. Therefore, a national policy to coordinate development of services and to ensure their effective implementation is needed. This policy should avoid unnecessary duplication of effort, uneven development over the country, or too much emphasis on one speciality (e.g., education) at the expense of, or without the support of, others (e.g., basic health care). It should correspond to the needs of the society and should be realized in a given period of time rather than "in the indefinite future". The necessary resources in terms of money, mechanisms, materials, and manpower will have to be assessed and reserved for that purpose.

The process of policy development will need to incorporate a clearly defined implementation strategy, incorporating the principles of goal planning and the setting of specific planning objectives (17). Any plan, whether it is to be implemented at national or local level, must specify who is to do what, under what circumstances, and when and how the results are to be evaluated. In other words, plans must not remain at the level of global aims (e.g. "our aim is to help mentally retarded people to achieve their potential, adjust to society, develop community services"); instead they will need to be specified as a series of specific and measurable short-term goals (e.g., to train 10 health care workers in the use of the WHO rehabilitation manual and to supervise their initial contact with 10 children and their families).

A system of regular progress reviews and achievement of targets encourages accountability to the mentally retarded and to their families, who should be represented during the process of consultation and decision making.

4.1 Major steps in the formulation of policy

The following are proposed as the major steps in the efficient and effective formulation of a national policy.

(1) Establishment of a consultative body that can help in the formulation of recommendations to the government on a policy for the mentally retarded.

(2) Review of all general policies related to social and economic development, education, health, employment etc. All relevant legislation and international agreements from the United Nations and other specialized agencies should be reviewed.

(3) Assessment of the extent of the problem of mental retardation in the country. In addition to estimating how many people are affected, an attempt should be made to determine the extent of their disabilities and the likely contribution of preventable causes.

(4) Assessment of the cost and efficiency of present services including an estimate of the existing gap between service provision and need.

(5) Application of a cost/benefit approach in determining the best means for filling this gap.

(6) Development of a strategy to describe the broad lines of action required in various sectors to put the national policy into effect.

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[1] HELANDER, E. et al. Training disabled people in the community. A manual on community-based rehabilitation for developing countries. WHO unpublished document RHB/83.1, 1983.

[2] A manual on child mental health and psychosocial development. Part II: For the primary health worker. WHO Regional Office for South-East Asia unpublished document WHO SEA/Ment/66, 1982.

4.2 Consultative body - national standing committee

Where a national coordination group for the mental health programme exists, the consultative body (mentioned above) can be part of it, enlarged as needed by:

- representatives from the principal central government agencies (ministries and departments) involved - health and welfare, education, social security, housing, employment, justice, or their equivalent;
- principal professionals involved (e.g., education, medicine, psychology, social work, rehabilitation, speech pathology, physiotherapy); and
- voluntary organizations, and parents' associations where they exist.

The main functions of such a committee would be to give the following advice:

- how to develop general policies;
- how to review services;
- how to encourage the development and involvement of voluntary organizations;
- how to stimulate good practice;
- how to promote research and the application of its results;
- how to assist coordination between central agencies and local services;
- how to develop guidelines on the quality of services; and
- how to monitor services and standards.

4.3 Review of general policies

These general policies provide the framework into which strategies and programmes on mental retardation must fit. For example, the government could examine the five-year plans of various ministries, giving a description of responsibilities of various government bodies and agencies and of legislation affecting mentally retarded people.

4.4 Assessment of the problem

Some of the questions that should be considered in assessing the extent of the problem of mental retardation are listed below. This is not an exhaustive list.

(1) Can any estimate be made of the number of mentally retarded persons in the country? If this is not known, is it possible to make an estimate, based on epidemiological studies in comparable neighbouring countries? Are there likely to be changes in the incidence (number of new cases of mental retardation) or prevalence (number of people affected by mental retardation) e.g., through demographic changes in the general population, such as a falling birth rate, or by improved antenatal and obstetric services?

(2) How many mentally retarded people are served by existing services (e.g., schools, hospitals, and sheltered workshops)?

(3) Is there any information on the demand for services from people not being served at present (e.g., on the basis of small local surveys, response to a new service being created)?

(4) How many mentally retarded people are currently being served by ordinary services available to others in the community (e.g., how many are in ordinary schools, general hospitals, and sheltered accommodation)? To what extent are their needs being met in these facilities and what resources would be needed to help staff in these services to make better provision (e.g., would the advice of visiting specialists be useful)?

(5) How many mentally retarded people are being cared for by their families at home? What help is available to these families (e.g., financial assistance, and relief care)? What is known about the social functioning of mentally retarded persons in their families and about the attitude of the families towards them?

(6) To what extent are local health and other community workers aware of the needs of the mentally retarded and their families, and are they familiar with the basic and simple methods of assistance? Are there any special training courses or materials available to such workers?

(7) Have the families and the mentally retarded themselves been asked about their needs and the kind of services that would help to meet these needs? Do they have an organization to voice their needs?

(8) To what extent is it possible for the mentally retarded to be helped to secure and keep employment at a suitable level with appropriate training and assistance?

(9) What is known about community attitudes to mentally retarded people? To what extent do local and national mass media promote a positive image of the mentally retarded, their needs, abilities, and rights?

(10) What contact has been made with voluntary and private organizations providing, or wishing to provide, services for mentally retarded people, with a view to assessing ways in which their work can be assisted and use made of their experience, motivation, and manpower?

4.4.1 Sample surveys. There are many information sources that can be used in assessing the existing health status and the major health problems of a population. Sample surveys and existing health service statistics are especially useful for determining both disability in general and mental retardation in particular. The type of survey carried out must be related to its purpose and take account of existing information. The purpose, geographical area covered, sample size and available manpower will all influence the eventual costs and usefulness of the survey.

A simple house-to-house survey is a good method of estimating the number of mentally retarded where little information is available. In the WHO publication Development of indicators for monitoring progress towards health for all by the year 2000, it is recommended that for surveys covering all disabilities, a sample size of 1000 will suffice (39). If the survey is aimed at assessing specific disorders such as mental retardation, a sample size of 5000 is suggested. To achieve the most accurate estimate, it is advisable to conduct a house-to-house survey in three areas: one urban (including urban slum areas around the capital or other major city) and two rural areas, one that is relatively economically prosperous, and one that is poor.

An international study involving ten developing countries is currently in progress and should produce useful information on the number of children with significant disabilities located by means of house-to-house surveys by locally trained health care workers. This study is being supported by a UNICEF technical support programme (2).

Simple, but well designed, house-to-house and "key informant" surveys can give valuable indications of the number of people who need to be provided for; the current UNICEF studies, combined with information from other sources already available, may obviate the need for more sophisticated scientific studies unless these are required for very precise planning, or provide in-depth information for a particular purpose. It should be borne in mind that a comprehensive survey must also include those people who are at present in various forms of institutional or private care, as well as those in the community.

Information from any or all of the above sources on the distribution of etiological factors (where these are known) will be useful in determining the specific areas for attention in order to prevent initial disability. For example, at a national level, high perinatal mortality rates might indicate the need for improved midwifery services. At a more local level, a high incidence of hypothyroidism in a particular area might suggest a nutritional imbalance which could be resolved by providing dietary supplements.

4.4.2 Other sources of information. If it is not possible to conduct any survey, estimates can be based on existing health statistics. Although these statistics are often unreliable and underestimate the extent of the problem, they provide, at little cost, a way of obtaining at least enough information to begin a programme. The development of pilot projects for the mentally retarded will allow more accurate estimates to be made in the future.

4.5 Review of existing services

In order to plan an effective approach to the problem of mental retardation, an assessment and as wide a review as possible should be made of the existing services. This process should begin with the naming of facilities that provide services for the mentally retarded. If there are too many, a representative sample can be listed, for example, according to the range of care suggested - total care, partial care, and brief care - as shown below:

Total care (for totally dependent persons)

General hospitals
Psychiatric hospitals/institutions
Nursing homes
Residential centres

Partial care (for partially dependent persons)

Day care centres
Special and ordinary schools
Short-term and phased care
Sheltered workshops
Rehabilitation centres

Brief care (for persons only slightly dependent)

Hospital out-patient departments
Home-visit care
Other community programmes
Leisure programmes
Relief care

While listing these facilities, an indication of their location, (e.g., capital city, Area A, Area B, Area C), their status (governmental or private), and the number of places in each should be noted. Any rules for admission to a service should be examined and any restrictions on the admission of individuals should be recorded. Certain individuals or groups in the community may be ostracized for religious or other reasons and may receive significantly fewer services than the general population. The costs of each service should be noted as well as the number of persons using that service.

There will be an enormous variation between countries in the feasibility of preparing an analysis of services for the mentally retarded; some countries or regions may have information readily available, others may have little or no data from which to begin. Whatever the degree of accuracy that can be obtained, the main objective is to estimate the size of the gap between the needs of the mentally retarded and their satisfaction. This information will be of considerable assistance to the consultative body whose task is to bring the problem to national attention, and to ensure that the care of the mentally retarded is suitably placed in the country's priorities.

4.6 Meeting the needs of the mentally retarded: filling the gap

It is often helpful to draw up a table summarizing the services that are needed by the mentally retarded and the extent to which they are provided. Again, the amount of help which the mentally retarded are already receiving as well as the efficiency of present services will vary both between and within countries. However, a general conclusion probably applicable to most developing countries is that the number of people who both need help and receive it is very small; those who do have access to services are likely to live in a major urban centre, or come from families with above average economic and educational status. This is also true in many developed countries. Another likely conclusion will be that if custodial, institutional, and highly technological approaches are used, their prohibitive costs will probably mean that it will be impossible to reach the target of full coverage with basic services in the foreseeable future In developing countries, the vast majority of mentally retarded persons live in rural areas and will be largely unreached.

Consequently, it will be necessary to identify those approaches that are cost-effective and will have the greatest impact on the prevalence of mental retardation and the degree of handicap resulting from an intellectual impairment. All possible measures for the prevention, treatment, and rehabilitation of the mentally retarded should be considered. If there are no low-cost, community-based programmes already under way, then a pilot project might be implemented and evaluated. The establishment of a "model" local service has a number of advantages. It could demonstrate ways in which services should be provided and also form a base for training staff to develop additional skills to meet special needs. It should serve a defined catchment area. However, in order to make such models replicable, great care must be taken to ensure that they are realistic and using the possibilities and resources available on a wide scale, and that existing infrastructures are optimally used.

In addition to a review of existing services, an assessment should be made of current preventive programmes that will have an effect on the incidence of mental retardation, and the probable long-term impact of such programmes in, for example, 10-20 years should be estimated. These programmes will include those to immunize children, to manage high-risk pregnancies, to improve midwifery skills, or to train primary health care workers in the identification and management of mental health problems in children.

4.7 Developing a strategy

When the preceding questions have been considered and answered as far as is possible, the general conclusions and supporting data should be assembled into a coherent policy statement, which should contain a review of the extent of the problems, a recapitulation of policies related to mental retardation, a summary of existing services and their cost, an estimate of the real needs as compared to those currently being met, and recommended strategies for filling this gap.

5. SERVICES

5.1 Introduction

This section is divided into four major parts: a basic community-based rehabilitation programme; medical aspects of treatment of underlying conditions associated with mental retardation; measures that can be taken to habilitate and rehabilitate those already affected; and the training of staff. In each case the various courses of action are grouped into basic and more specialized measures; the steps that should receive priority are indicated (see Tables 2 and 3). Generally, the higher up each table, the less expensive the services are to provide. Expense should not be confused with cost-effectiveness; amniocentesis for women aged more than 35 years is cost-effective but very expensive and should not have priority over more basic perinatal care.

The suggested grouping of priorities is based on the assumption that, as in the case of primary health care, the ultimate aim is to provide basic care for as many people as possible. In some countries, resources may be so limited that the development of specialized services for the mentally retarded does not seem feasible in the foreseeable future. For such countries, a WHO community based rehabilitation programme is described as one promising way to approach the problem of disability. This approach should also be considered in countries with more abundant resources; it is a way of meeting the needs of a large proportion of the disabled at a relatively low cost.

The vertical arrangement of services as shown in Tables 2 and 3 is not intended to suggest that these measures should only be carried out sequentially. Most developing countries have some specialized agencies forming an essential network of referral and support services for basic care. A presentation of the possibilities for service development is given with the expectation that each country will choose the most appropriate interventions based on its own financial and human resources, patterns of services, and priorities.

Whether a country chooses to create a special agency for the mentally retarded or to provide all services through existing agencies (or a combination) will depend on its unique circumstances. Whichever system is chosen, the four important objectives will be:

(1) to provide a clear policy with a well defined scope of activities;

(2) to ensure continuity of care;

(3) to minimize the administrative obstacles for the mentally retarded and their families; and

(4) to minimize the duplication of services.

5.2 Community programmes for the disabled

WHO is involved in the design and field testing of a manual[1] on rehabilitation and disability prevention for developing countries. The need for the community based interventions proposed in the manual is based on the following facts:

(1) That, of the estimated tens of millions of mentally retarded people in the world, mostly living in rural areas, perhaps only about 2% are at present receiving any help at all.

(2) That the number of mentally retarded persons will increase, and that to provide assistance based on Western models is absolutely impossible and in many ways undesirable in most developing countries. Alternative methods of dealing with the problems of the mentally retarded must be developed.

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[1] Training disabled people in the community. A manual on community-based rehabilitation for developing countries. WHO unpublished document RHB/83.1, 1983.

Table 2. Priority health services in relation to mental retardation

Antenatal measures	Perinatal measures	Postnatal measures
Family planning	Delivery (skilled attendant present at birth)	Child health services (Basic care, nutrition check, immunization, early treatment of infections, treatment for epilepsy, cerebral palsy etc. by local means)
General public health measures (adequate nutrition, hygiene, sanitation, basic health care, public education)		
Genetic counselling		Child health services (checks of selected groups of "at risk" children
	Hospital delivery for "at-risk" birth (presence of more skilled attendants, transfusion, equipment, etc.)	
Regular antenatal supervision (anaemia, hypertension, detection of "at-risk" births, etc.)		Provision of aids to reduce disability (spectacles, hearing-aids, etc.)
Antenatal diagnosis (amniocentesis, ultrasound, serum alpha-feto protein etc.)	Hospital delivery (provision of fetal monitoring and baby units with "high technology" equipment and staff for special care)	Regular total child population surveillance Biomedical treatment of metabolic disorders replacement or dietary treatment)
	Neonatal screening (for phenylketonuria, and hypothyroidism)	Medical and surgical treatment (e.g.treatment for epilepsy, cerebral palsy, congenital malformations, psychiatric disorders, spina bifida in selected cases)

(3) That a community based approach will have a greater long-term impact in reducing the disabilities if it is based on the development of techniques which all governments who assign some priority to these problems can afford.

The WHO manual introduces a number of approaches, describing the provision of essential rehabilitation training in the community. The approach to rehabilitation has been simplified by dividing the manual into several parts. Each of these training packages has been prepared in such a way that a lay person or the disabled themselves can undertake the training. In addition to 32 such training packages, the manual also describes the implementation of rehabilitation programmes in three guides: Guide for local supervisors, Guide for community leaders, and Guide for schoolteachers.

The Guide for local supervisors contains information and material to be used by persons selected for this job in the village.

The Guide for community leaders describes the aims of community rehabilitation training and the role of various community members. The most important general community services that should be provided for all, and in particular for the disabled, are reviewed, these include health care, safe water supply, safe disposal of excreta and wastes, improved nutrition and hygiene and schooling.

The Guide for schoolteachers is aimed at local primary school teachers. It describes how schooling can be given to disabled children in the ordinary community school.

The training packages can be combined to form separate booklets. These cover the following topics: "Persons who have fits" "Persons who have difficulty with learning", "Persons who have difficulty with hearing and/or speech", "Persons who have difficulty with seeing", "Persons who show strange behaviour", "Persons with no feeling in the hands and/or feet", and "Persons who have difficulty with moving".

Each of the individual packages provides a description of the training procedure for whoever undertakes the training. Each package is divided into small sections, none of which require professional knowledge or skills except under very special circumstances, when referral services should be used. Finally, as the manual is an experimental edition aimed at field testing in developing countries, there are questions related to the evaluation of the various booklets and training packages.

Included in the Guide for policymakers and planners in an earlier edition of the WHO manual,[1] is an example of a developing country of 3.3 million people with 51 450 disabled persons. On the basis of an analysis of existing services, it was determined that the country was providing institutional services for 563 disabled people, i.e., 1.1% of the total. An analysis of the cost of alternative ways of filling the gap is given, and although these are only rough estimates, the message is clear: community-based rehabilitation efforts are far more cost-effective and more likely to achieve their objective in the foreseeable future than is the provision of institutional services.

It was estimated that an annual cost increase of US$34.00 per capita would be needed to fill the gap by the provision of institutional services (including outpatient facilities); the total manpower needed would exceed 120 000 people (of whom 20% would be professionals) and it would take 125 years to complete. Conversely, the provision of community rehabilitation services as proposed in the manual would cost US$11.78 annually per capita, require an increase in manpower of 2000 (including an increase in staff for the referral services) and could be accomplished in 11 years.

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[1] Training the disabled in the community. An experimental manual on rehabilitation and disability prevention for developing countries. WHO unpublished document DPR/80.1 Version 2) 1980.

5.3 Prevention and treatment: medical aspects

Table 2 provides a list of health service activities that can contribute to the resolution of the problem of mental retardation. Some of these are basic and highly desirable and should be available everywhere. Others, although desirable, should await the establishment of basic measures. This "range" is indicated in Table 2 where the basic measures are shown at the top of the table while other measures costing more are given in the lower part of the table.

5.3.1 Basic health measures. The improvement of the health of the general population by the improvement of sanitation and hygiene, provision of adequate nutrition, immunization programmes, and public education in, for example, child-care, nutrition, and self-care, will lead to a reduction in the number of mentally retarded people.

It is at the basic level of health care that the most important steps can be taken to improve health practices in pregnancy and child-rearing, particularly if special attention is paid to "high-risk" mothers and children. This was one of the reasons why WHO recommended that the availability of trained personnel for attending pregnancy and childbirth, and caring for children up to at least one year of age should be one of the indicators used to assess the adequate provision of basic health care (43). Another fundamental task of the primary health care worker is to teach the principles of proper nutrition. Additional projects, such as classes in nutrition for mothers, will also improve the situation (40). Immunization must also be provided at the primary level and can prevent the mental retardation that sometimes occurs as a sequel to an infection. Family planning can also help to reduce the incidence of mental retardation in the population. The significant correlation between maternal age and the birth of a child with the most common chromosomal disorder, Down's syndrome, indicates the benefits to be obtained by reducing the number of pregnancies in older women. This method of primary prevention could reduce the number of children born with Down's syndrome by up to 50%. Pre-conception iodine supplements can prevent cases of cretinism associated with iodine deficiency, although supplements given during pregnancy or after birth are ineffective.

The provision of trained personnel during pregnancy and childbirth is a necessary basic step. There are, however, many other occasions when more specialized help is desirable, e.g., when mothers are found to be "at risk" of having a complicated delivery or when problems with the newborn child are anticipated. The provision of hospital maternity services with facilities for specialized care of the newborn would prevent some mental retardation that results from perinatal complications. Facilities for prompt resuscitation at birth, subsequent monitoring of respiration, and transfusions to prevent kernicterus are examples of measures that have been shown to reduce the incidence of mental retardation in "at risk" infants in developed countries.

Much can be done at a fairly basic level to alleviate the problems caused by associated chronic disabilities. Spectacles for people with sight deficiencies, walking aids for those with movement disabilities, and hearing aids for the hard of hearing can all improve the development of mentally retarded people as well as those with such disabilities uncomplicated by mental retardation.

Basic genetic counselling could also be offered in conjunction with family planning for those with a family history of mental retardation. Health education in schools and the provision of antenatal counselling for parents, especially those "at risk", should also result in a reduction in the incidence of mental retardation.

5.3.2 Desirable health measures

(1) Prenatal diagnosis. Where professional expertise exists and finances are available, more specialized intervention is possible. Techniques of antenatal diagnosis can not only prevent the birth of a severely retarded child, but also offer the hope of healthy offspring to many parents who might not otherwise have had more children. Amniocentesis, a process that obtains fetal cells from the amniotic fluid for culture and subsequent examination, can provide a highly accurate diagnosis of many conditions with genetic etiology. In experienced hands, this technique involves little risk for the mother and child; it is mainly used to detect chromosomal abnormalities, neural tube defects, and metabolic disorders.

As many of the conditions that can be detected by amniocentesis are very rare, the technique is usually used only when the mother is at risk of producing an affected child, for example, where there has been a previously affected offspring, where there is a family history of a detectable condition, and in women over 35 years of age - a group that is particularly at risk of having a child with a chromosomal disorder. Also, techniques have recently been developed to detect abnormal levels of alpha-feto protein in maternal serum since this may indicate the possibility of a neural tube defect, which may then be confirmed by amniocentesis.

Amniocentesis and the associated techniques of prenatal diagnosis are expensive and require advanced technology, but they can be used very effectively for appropriate screening and referral where resources permit.

(2) Neonatal screening. Many of the metabolic disorders leading to mental retardation can now be detected either prenatally or early in life. They are, however, very rare. The discovery early in this century that hypothyroidism resulted from the absence of thyroid hormone suggested the idea of replacement therapy. If started early enough, thyroxine treatment (which can be taken orally) can considerably improve the child's development. The main problem has been that, previously, evidence of developmental delays had to appear before the diagnosis could be made, so that some brain damage had often already occurred. Now, however, earlier detection is possible by neonatal screening; this is already routine practice in Denmark, Switzerland, the United Kingdom, and other countries. The blood sample which is taken (on paper) for the Guthrie test for phenylketonuria can also be used to screen for hypothyroidism so that no extra work is involved for the health care staff. The therapeutic effect of treatment on cerebral development is directly related to the age at which it is started. However, the numerically most important cause of hypothyroidism, iodine deficiency, does not respond to postnatal oral iodine supplements. Only the use of pre-conceptual iodine to prospective mothers in areas at risk can prevent the condition.

The discovery of phenylketonuria (PKU) in the 1930s, another rare condition, increased further the possibilities for effective intervention. However, it was not until after the Second World War that the necessary and delicate dietary restrictions were worked out and applied. There is evidence that early and prolonged treatment can greatly diminish the extent of handicap and many children who would otherwise have been retarded achieve normal or near normal development. Women suffering from phenylketonuria who plan to have children can probably prevent mental retardation in their off-spring by following a suitable pre-conceptual diet (21).

(3) Health surveillance. Surveillance begins at birth and involves the systematic detection of a variety of conditions, some that can be easily seen on examination of the child (such as spina bifida) and others that require more expensive laboratory investigation such as biochemical testing. Subsequently, the child population at risk can be checked at regular intervals so that conditions such as global developmental retardation, specific language delays, and deafness are identified as early as possible. Surveillance can be directed towards the total population or specifically aimed at an "at risk" group, for example, all babies with very low birth weight, and those suffering prolonged anoxia at birth. It should be remembered that it is pointless to screen for a particular condition unless adequate treatment or care is available once that condition has been identified. Many useful screening procedures such as the identification of deafness and speech retardation can be carried out by primary health workers with little additional training.

(4) Medical and surgical treatment. The treatment of the many additional diseases and impairments associated with retardation (epilepsy, cerebral palsy, congenital malformations, psychiatric disorders, sensory disturbances, etc.) is very important, as their number and severity are closely related to the degree of mental retardation.

Most genetically determined conditions cannot be reversed by treatment once the child is born. Sometimes, so-called miracle drugs continue to be offered with the implication that mental retardation can be "cured". Parents and others should be warned against remedies that have not been properly evaluated. Furthermore, parents should be warned that traditional healers cannot cure mental retardation and that the treatment they provide, while sometimes providing moral support, may also be harmful in that it delays appropriate treatment for an associated disease such as epilepsy.

The child with severely impaired intellectual functioning often has additional physical problems. These should be alleviated whenever possible. For example, 30-40% of newborns with Down's syndrome have cardiac anomalies, some of which can be treated with surgery, and the respiratory problems that are common in those with Down's syndrome can be relieved with antibiotic treatment. Similarly, there is a high incidence of undetected hearing loss, with obvious implications for subsequent language and intellectual development.

5.4 Training and rehabilitation: social aspects

5.4.1 Introduction. Discussion so far has centred mostly on the medical measures that can be taken to prevent and treat the disorders leading to mental retardation. However, even if all the measures possible were taken to prevent the more common forms of retardation and to manage the conditions that can be treated, there would still be a large number of severely mentally retarded people in need of help. This is because even in developed countries the cause of severe retardation is unknown in approximately 15% of affected individuals; also many conditions of known etiology cannot be treated. Other cases result from spontaneous genetic and environmental aberrations which would not generally be detected. However, much can be done to reduce the degree of retardation that results from such impairments.

The WHO Expert Committee on Medical Rehabilitation (38a) defined rehabilitation as applied to disability as follows:

"... the combined and co-ordinated use of medical, social, educational, and vocational measures for training or re-training the individual to the highest possible level of functional ability."

At first sight, discussions about early identification and pre-school services, special schools, post-school training, and residential services may seem inappropriate or too specialized for developing countries with only the beginnings of a service for the mentally retarded. However, in spite of financial problems, lack of professional expertise and trained manpower, many of the proposals could be put into operation because they involve basic but effective measures[1] and only a few experts, and because local workers can be trained to do the intensive work at the community level. This section describes the services that could be provided to support the disabled person, from birth to old age. The selection of priorities among the proposals will have to be made at the national level.

Table 3 gives some suggestions for basic and desirable training and rehabilitation services. Policy-makers are advised to try to provide a balanced pattern of services, catering for all age groups, while taking into account the particular circumstances in their own country. The discussion of manpower development below suggests ways of dealing with an immediate lack of skilled manpower at the local level while information and resources are built up for future developments.

In the early 1950s it became clear from laboratory and field experiments that the initial ability of the severely mentally retarded to perform a task often gave a poor indication of their potential responsiveness to new learning opportunities. Although they remained impaired, the severely mentally retarded could, under certain specific circumstances, learn well, adequately retain their learning and, in different degrees transfer their new skills to different situations. The findings suggested that the main general deficit in such persons is a relative inability to profit from ordinary unstructured life experiences so that their their potential for improvement under structured, motivating conditions is obscured. The main conclusion of this early work was that there has been a considerable underestimation of what the majority of the severely mentally retarded can achieve. This conclusion suggests that the traditional modes of help are largely inappropriate (3). The improvements in shape perception and manual dexterity were found to be particularly important and these in turn led to investigation of the possibilities of industrial training and the gradual realization that for simple but important tasks a near-normal competence could be achieved. The intensive training required to achieve these goals does not need advanced professional expertise and the techniques involved can be taught to non-skilled trainers.

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[1] The information contained in the WHO manual Training disabled people in the community (unpublished WHO document RHB/83.1) describes such basic measures.

Table 3. Priority rehabiliation services for the mentally retarded

Special education (preschool and school-age provision, special units, teacher support, specialist resources)	Specialist assessment and consultation	Residential care (specialist hospital care, group homes, hostels etc.,
Preschool playgroups	Home visitor schemes (Portage, parent involvement project, etc)	Residential care (Short term relief care, fostering schemes)
Job training and placement (adaptation of existing agencies, and training units)		
Special education (integration of the mentally retarded wherever possible)	Parent information (parent groups, access to services, access to trained workers)	Professional education (alerting all professionals in contact with children to look for developmental delay
WHO manual on rehabilitation [a] (use of guides at relevant levels, application of training packages)		

[a] *Training disabled people in the community. A manual on community-based rehabilitation for developing countries.* WHO unpublished document RHB/83.1, 1983.

By the use of intensive training it was realized that the mentally retarded can be helped to lead more normal and more useful lives. Behaviour modification techniques have even been attempted with the profoundly mentally retarded, using an analytical, structured form of training involving the use of small steps and easily attainable improvements, with feedback both to the learner and the trainer. Some successful programmes of this kind have included tackling various problems, such as self-help with dressing, washing and toileting, the elimination of self-destructive behaviour, and language training. A combination of these and other learning methods can greatly enhance social adaptation, which, with language acquisition, is perhaps the key area for training. Again, these methods can be taught to parents and other non-professionals as well as to basic health care workers, who can all apply them successfully.

Mild mental retardation poses certain other challenges to rehabilitation. As noted earlier, the modification of parental attitudes and behaviour, supplemented by child development activities, has resulted in marked intellectual gains for disadvantaged children. The techniques for achieving these goals have not yet been extensively applied to mentally impaired persons in disadvantaged families. Further research in this area might result in more meaningful intervention strategies, but it seems likely that some parents may not be willing to change. If the child of such parents suffers from extreme neglect or abuse, substitute parental care may effectively prevent possible mental retardation.

For those families where there is no evidence of serious neglect or abuse and the child appears to be mentally retarded as a result of under-stimulation, parental education on child development and child stimulation, in very simple terms, can be applied at the primary level. The psychological needs of children are an integral part of health development and should be a fundamental component of maternal and child-care services.

Two important considerations should be stressed when dealing with the problems of mild mental retardation in a community:

(a) The performance of many mildly mentally retarded persons may improve with time: a process of self-improvement may diminish the degree of handicap by early adult life.

(b) Most mildly mentally retarded individuals go unnoticed except in countries where universal schooling has been introduced or the demands of a changing society on its members have increased.

5.4.2 Early identification and intervention. Early identification of mentally retarded children is important not only to begin medical treatment where this is possible, but also to begin suitable training.

The key aspects of this period in the child's development are problem identification (including developmental screening), parental involvement, and pre-school services.

(1) Identification of mental retardation. Some handicaps (such as Down's syndrome) can be identified at birth by experienced workers but many other conditions will only become apparent months or even years later.

Developmental screening of all children, even at a very basic level, could help identify mentally retarded children so that intervention programmes can be started. The WHO manual for primary health workers[1] includes suggestions such as noticing children who have fits, gross developmental delay or unusual appearance. Information about the growth of young children regarding the main stages of physical, mental, social, language and emotional development should be incorporated into all primary services. If developmental delay is suspected a more specialized assessment could be carried out either locally (if the expertise is available) or by referral.

Whenever mental retardation is suspected, it should be remembered that not all developmental delays are significant or permanent; only in severe cases should a firm prognosis be given before the diagnosis is validated. Although it is impossible to provide strict guidelines that are applicable in every case, the way in which the diagnosis of mental retardation is first communicated to parents is of such vital importance for the development of the parent-child relationship that it deserves serious consideration at the local level. When the retardation is first identified in hospital, there should be clear a procedure setting out the way in which parents are told about their child. In addition the training of local primary health workers should include some ways of communicating probable or possible mental retardation to parents, and clear follow-up procedures should be made available.

Current evidence suggests that this matter is still all too often handled without due consideration of the parents' feelings. It is essential to provide opportunities for parents to discuss their reactions and to ask questions at leisure. At this stage, parents should be offered the opportunity of meeting other parents or of being put in touch with local parent organizations or voluntary societies if they exist. Wherever appropriate they should be given a short and simply written leaflet containing the names and addresses of the main agencies who may be able to offer help, as well as any other available information (i.e., a manual or guide for parents about teaching their children). Parents may not necessarily wish to take up immediately these offers of help, but the opportunity to do so at a later stage should be made possible by providing the necessary information in written form. If the parents agree, the birth or early identification of a mentally retarded infant should be communicated to the agencies responsible for providing services, e.g., education and social welfare agencies. The procedures for maintaining confidentiality should be agreed upon and both professionals and parents informed about them.

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[1] A manual on child mental health and psychosocial development. Part II. For the primary health worker. New Delhi, World Health Organization Regional Office for South-East Asia, 1982 (unpublished document WHO SEA/Ment/66).

(2) Parental involvement. One of the most important developments during the 1970s in the care of mentally retarded children in developed countries was the demonstration of what can be achieved for such children if a working relationship can be created between their parents and professional workers. Many parents welcome opportunities to discuss their feelings and problems freely, in addition to participating in structured programmes of teaching. To this end, many mutual support groups have been established on the initiative of parents and parent organizations or by professionals with skills in individual case work and group counselling.

Parents have been encouraged to carry out a detailed developmental assessment of their own child, and in turn, they have helped to draw up and implement specific programmes of teaching and training. This has been done by means of local teams of professionals working with parents in their own homes, using the resources of specialist centres where appropriate, as well as via workshops where groups of parents and professionals meet regularly to plan developmental goals related to the assessed needs of each child (23).

This work does not need highly specialized professional workers. A similar approach has been used in some developing countries where there are few professionals. For example, in St. Lucia a group of women who displayed "natural child-rearing skills, great fortitude and resourcefulness", but who had little formal education, were trained for two months (followed by some in-service training) as community development aides. They made daily home visits to work with mothers and their children, with the particular aim of educating mothers on how to help their children. An interesting finding of this study was that during evaluation carried out some 6 months later, the majority of mothers wanted to keep their child at home, whereas before the study most mothers had wanted to put their child into government care.

(3) Pre-school services. It should be recognized that intervention starting in the first few years of life is particularly valuable for mentally retarded children who have difficulty learning from unstructured experience in the way that non-retarded children learn. Pre-school programmes for children from socially disadvantaged families that aim to improve social and intellectual functioning do exist not only in developed but also in several developing countries.

An infant stimulation programme should be started as soon as a child's handicap becomes apparent. The techniques involved need not be complicated: a training package of play activities for the disabled child and some simple stories are included in the WHO unpublished manual Training disabled people in the community. There are considerable advantages in making this package available to families as early as possible, not only because of the ultimate benefit to the child but also because of the benefits to the family. The techniques involved can help the family to see what can be done with the child; they also show practical ways of improving the condition of the retarded child (if only slightly), and help to focus on the child's abilities rather than its disabilities.

Home visitors can be trained to develop individual programmes that are designed to help the infant reach the next stage of his development from the first days of life . They help parents to set and reach short term goals that can be attained by the infant in a matter of days rather than months. At the same time, they provide emotional and social support for the family (26).

For infants whose handicap becomes apparent only after some months, similar programmes of infant stimulation in the home should be available, so that the infant's development can be actively fostered and special measures taken to compensate for specific deficits. Home visitors should be supervised by specialists. In some developed countries, specialist teams have been established, including appropriate consultants in fields such as physiotherapy, speech therapy, paediatrics, and education. The primary task of such a team is to help the family to assist the child's development in a systematic manner. Even when more specialist services are not available, home visitors are essential. Personnel for home visiting can be drawn from a range of disciplines (e.g., education, nursing, social work). Short periods of training are required in the methods used to assess the current levels of functioning, in devising an appropriate programme of home teaching, and in working with parents.

The preliminary evaluation of the early stimulation/parent teaching project for handicapped children in St Lucia shows the enormous improvements that can be made (M. J. Thorburn & J. Brown, unpublished data, 1976). This study was one of many undertaken in developing and developed countries that have adapted the Portage materials; these were originally developed in a rural area of North America as part of a home visiting service for pre-school children with delayed development, and have since been extensively used in many countries (G. Jesien, unpublished report, 1982). The system is relatively inexpensive, particularly since training can be completed in a short time, but it does involve regular control meetings for home workers, which means an on-going commitment to the scheme.

In many developed countries pre-school services for the older child (2-5 years) have also been found to be particularly valuable for mentally retarded children and ideally they should have the opportunity of attending all forms of pre-school activity available to other children in the area. Where there are no pre-school groups that the child can join, the possibilities of establishing one should be explored. For example, if parents or other volunteers are willing, they could supervise such a group in rotation. Local community workers could help, perhaps also arranging for short on-site training workshops by specialists from support services.

In developed countries, some mentally retarded children attend special schools or classes from the age of three years or even younger and appear to benefit greatly from doing so. Others attend play groups or nursery classes with normal children; it is desirable ultimately that all children, no matter how severely retarded, should have opportunities to mix with other children, and that they should come into contact with skilled teachers and other staff familiar with a wide range of methods of assessing and meeting the needs of retarded children. Parents should not have to accept the sole burden of caring for a severely mentally retarded child. Even if the child cannot attend school, the parents should be helped by regular visits from mobile teams to foster the child's development.

5.4.3 Family support services. Parents need support services to enable them not only to look after their mentally retarded child and help in its development, but also to be able to lead a life of their own both as individuals and as family members. A range of different services is needed, and families should be informed of these and told how to contact the services when they need them. In the past, families in developed countries have often been faced with a bewildering array of uncoordinated services with little information on what is available and how to benefit. Recent studies have shown the value of certain services in helping families in the relief of stress so that the need for expensive residential care is reduced.

(1) Short-term care. In many developed countries it has been found possible to provide some short-term care for a mentally retarded member of a family, whether child or adult. If possible, respite care should be available to every family; it may take the form of several short periods during the year or a continuous longer period perhaps when other family members have to make a journey, go on a pilgrimage or a holiday, or just in order to provide temporary relief. Sometimes, a form of phased care is available, i.e., one week in four. In some areas, informal and rapid access to foster families has been made possible. The parents can leave the child with a known and trusted family for a few days or perhaps only for a few hours. Temporary care at home while the parents go out in the evening or at other times can also relieve the family situation. Where the mentally retarded person has additional handicaps (e.g., epilepsy) the temporary minder would need to know how to cope with any possible problems. Some voluntary or parent organizations arrange such temporary care among their members.

A range of flexible short-term care options has been found helpful so that families can use those that are most effective and appropriate at the time. For example, one family may be able to cope during the week but need respite at weekends to give their attention to siblings, while another family may find they cannot cope during the week but can manage at weekends when both parents are available. In neither case would full-time residential care be appropriate. Contingency plans for temporary residential care should be made for every family even though there may not be an immediate need. The availability of such a contingency plan will prevent admission to an inappropriate form of residential care in the event of an unforeseen family crisis.

In addition to relief for the family, respite care can also be used to achieve positive goals. For example, a stay in a home or hostel can be used to carry out assessment or to train the person in specific skills, especially those that can be most conveniently taught in a residential setting, e.g., domestic or self-care tasks.

(2) Day care. In many societies it is normal for people to leave their home during the day - to work, go to school, or partake in leisure activities. The mentally retarded should also have this option, and regular day care has proved to be of great assistance to the family. Young mentally retarded children in developed countries may also attend play-groups,

day nurseries or other day units, not necessarily specifically for the mentally retarded, although the opportunity for early special training should not be overlooked where appropriate. Older children should attend school, and adults attend work-training units, employment, or special day centres. Leisure activities appropriate to the local culture should be encouraged.

(3) Counselling and advice Counselling services in developed countries have proved useful in connection with day care facilities or in the form of domiciliary visits from persons offering various types of help. Such family help can be very useful if it is coordinated, and especially if the domiciliary visitor is working with a team of specialists. Parents with a mentally retarded child can offer support and basic advice to other "new" families in the same position. A social worker with specialist knowledge and access to a team of other professionals can do much to relieve family stress and encourage a positive approach to the problems of the mentally retarded member of the family. In this way the family is kept intact, this being of benefit to the mentally retarded person and avoiding the need for expensive full-time residential care.

Advice on technical aid is often needed by families, since many mentally retarded people have additional physical disabilities (cerebral palsy, speech disorders, incontinence, hearing difficulties) that require aids and appliances. Many problems may have an inexpensive or practical solution (e.g., a thicker wooden handle on a spoon) which a specialist visit could easily provide but which the family may not have thought of unaided.

(4) Financial support. It has been shown that families with a mentally retarded member are a disadvantaged group. The income of these families, their chances of attending education courses, or moving to more attractive jobs, are limited. Moreover their opportunities to obtain gainful employment, are affected (8).

Many developed and some developing countries provide special allowances for families looking after a disabled member, as well as direct financial benefits for the individual involved. Families of the mentally retarded often need financial help to cope with the additional tasks involved in looking after a handicapped person, including laundry, home-making assistance, special diet, or daily medicines. Such assistance is also needed by the mentally retarded themselves if they are being trained for a more independent life. Since the provision of such services is beyond the reach of most people, alternative ways of meeting such needs should be explored. For example, one person could be employed to serve a number of families.

5.4.4 Special education. The education of all mentally retarded children (including the most severely mentally retarded) is now increasingly the responsibility of the educational authorities rather than health or social welfare agencies. The children are, therefore, included in the mainstream of educational services (32).

Recent research findings suggest that mentally retarded children can benefit from education but that they require systematic and structured teaching in skills that develop in other children without any special instruction. For example, specific methods are needed to teach children their own language; they do not learn well merely by listening to others.

Educational methods based on these findings are being developed in a number of special schools, where specifically trained teachers working with mentally retarded and other handicapped children follow a variety of systematic approaches. In this way they help children achieve carefully set objectives that arise from the process of assessment and identification of the learning and developmental needs of each child. These processes generally involve forms of goal setting or precision teaching characterized by a clear specification of the objectives to be reached by the child in a given time, the criteria for determining the extent to which this has been done, as well as a detailed analysis of the number and type of the learning steps to be used in teaching.

The dissemination of these useful methods to teachers in ordinary schools is one of the biggest challenges facing special education (24). The methods themselves can be learned very quickly, provided that the training is organized by staff experienced in this approach, that the training is practical rather than based exclusively on lectures or reading, and that it incorporates periods of supervised practice to ensure that the methods are being appropriately used.

Current thinking emphasizes the vital importance of working for both the social and educational integration of all handicapped children. This implies the education of all handicapped children, including ultimately even the most severely handicapped, in ordinary schools, and the allocation of the necessary resources (money, materials, and skilled manpower) to support the teachers in these schools. The ways in which a school system meets a child's special needs should depend on the assessed needs of that child. Education authorities in various countries have been developing a very wide range of schemes to ensure that appropriate help can be given. Some mentally retarded children attend units attached to ordinary schools and thus they can easily join ordinary classes for part of the school day or week. Some spend most of their time in the ordinary class but the regular class teacher is strongly supported by a visiting specialist who helps to assess the child's progress and needs and to develop a week-to-week programme. In other cases, a special unit catering for handicapped children is built on the same campus as the ordinary school.

Countries without a well developed system of special schools have the opportunity to plan an integrated system of special education from the outset (24). Some of the key elements of such an integrated system were discussed in the report of a UNESCO Expert Committee in 1979 (32). They include:

(a) the provision of basic information concerning handicapped children in the initial training of all teachers, including awareness training and short periods spent in the schools and other facilities for handicapped children and adults;

(b) more advanced, short, awareness courses as part of in-service training for all teachers in ordinary schools indicating the range of provision available, but also showing the basic approaches available to assess and meet the needs of handicapped children;

(c) the designation in each ordinary school of at least one staff member with specific responsibilities for developing suitable educational programmes for handicapped children in that school;

(d) the availability of a support system for teachers in ordinary schools who work with handicapped children. As a minimum requirement, each teacher should be able to call on the advice of a teacher more experienced in the education of handicapped children; support services in many developed countries also include other specialists such as school psychologists, medical staff, speech therapists, physiotherapists, and specialists in the education of children with sensory impairments;

(e) access for teachers in ordinary schools to a specialized resource centre in the locality or region, staffed by specialists in the education of handicapped children but also providing relevant assessment and curriculum materials, films and tapes illustrating specific programmes and methods of teaching;

(f) close partnership between families and school staff, which is the hallmark of a good special education service in any school. The last decade has provided many examples of such a partnership beginning when a child is first recognized as being handicapped, the laying of foundations during the pre-school period which are consolidated during the child's school years. Such a partnership not only provides parents with support, but helps them to develop skills in teaching and management that can be used to advantage when the child has left school, and during adult life. This provides a good basis for the development of independence in a mentally retarded adult, thus reducing both their dependency on specialized services and the pressures on the family (23).

5.4.5 Post-school provision. Most adolescents and adults with severe mental retardation will continue to need services to help them acquire the range of skills needed to live, work and learn successfully in the local community. Experience has shown that some adults can achieve a measure of independence and skill that might not have been expected during childhood and they respond well to programmes that provide them with challenges and a high level of demand. Others will need further training to help them become more proficient in everyday self-care skills, in the use of money and budgeting, in cooking and domestic tasks, and in the use of community facilities. Most will benefit from help in their social and personal development including aspects of personal and sexual relationships.

Training in all of these areas can begin during the school years but must continue after school if the young person is to achieve the maximum level of independence and autonomy, thereby reducing his need for support from his family and from community resources.

Development programmes in different parts of the developed world have shown that mentally retarded and disadvantaged young people can continue to learn and develop in adolescence and adulthood if appropriate learning opportunities are provided; this is in contrast to earlier views that stressed that early childhood is the only "critical learning period" and that later intervention was of very limited value. This latter view should be revised in the light of more recent evidence and the services available modified accordingly (4,15).

The design of help for school leavers and young adults will vary widely because of local circumstances but there is little doubt that some form of structured and systematic help for community living is desirable for mentally retarded young people if they are to become more independent. Some developed countries have established specialized day services, such as vocational training or social education centres. They provide intensive training in community living and pre-vocational skills with places for some 80-100 people. In many countries the aim to train young people to enter either open or sheltered employment is nowadays frustrated by a general shortage of employment opportunities in the community. As a result, such day centres are often overcrowded because very few people are discharged into employment, and new people cannot be taken in for training.

An alternative strategy is to adapt existing agencies for non-handicapped young people in order to meet the specialized needs of young mentally retarded people. Examples of this in developed countries include vocational training programmes, further education and community colleges, and other schemes providing training for young people. In view of the needs of mentally retarded young people for continued education and training in community living skills, the contribution of colleges of further education seems particularly important. Such colleges are accepting an increasing number of physically handicapped students and some are now considering how they can also meet the needs of mentally retarded students for continued education. If they are to do so effectively, they will need specialist support from experienced staff.

Training for work. In rural communities, many young people are gradually involved in the working life of the community and find a job that is suitable for their particular abilities and interests. In urban areas, however, high rates of youth and adult unemployment and the more competitive and demanding nature of many jobs severely restrict the chances of a person with limited abilities securing employment. Therefore, it is all the more important that young people with mental retardation should receive careful training and preparation to help them not only find, but also keep, a job.

A conference sponsored by the International Labour Office held in Kingston, Jamaica in 1978 concluded that:

"The mentally retarded, even the most severe cases, are capable, with proper preparation and training, of undertaking a wide range of unskilled and semi-skilled work both in urban and rural areas" (17).

A number of jobs that can be successfully carried out by the mentally retarded were listed in the report, e.g., packaging, delivery of newspapers, car washing, and clothes making.

In the WHO unpublished manual Training disabled people in the community, there is a common component in all the guides, giving advice to the teacher, community leader, and others on simple measures that can be taken to help the handicapped find and succeed in work. Those who are considered able to find work on the open market but need more extensive preparation should be considered for government training/rehabilitation schemes. For others, work in sheltered workshops may have to be organized.

It is well worth considering the appointment of a small mobile team specifically to help the mentally retarded find and keep a job. In the United Kingdom, the relevant voluntary organization (the Royal Society for Mentally Handicapped Children and Adults) has developed a scheme whereby a placement officer fulfills such a role in association with the staff of the main day and hospital services, and in collaboration with the ordinary employment services available to the rest of the community. Employers are given both financial and staff support when they accept a mentally retarded employee and a fellow worker is asked to act as "foster worker" (in return for a nominal fee) to help in the process of adjustment to the social as well as work demands of the new job. This scheme has proved highly successful even in times of high unemployment. Useful guidance manuals are available on methods of helping young mentally retarded people to be trained for employment (35,36).

5.4.6 Residential services. Research, mainly in developed countries, had led to the current opinion that mentally retarded children and adolescents should have the possibility of living with or near their own families. Adults should be able to live in homes of their own if they choose, assuming this is in their interests and those of their families. For those families who look after their son or daughter at home, as much support as possible should be provided: day services, temporary respite care, financial assistance when possible, and domiciliary support.

(1) Community residential care. For those who cannot live at home, or when such an arrangement no longer meets the needs either of the mentally retarded person or his family, residential accommodation should be provided in the local community so that family links as well as the continuity of day programmes can be maintained. Developed countries are now turning away from large, often remote, institutions to alternative systems because of financial and other advantages to both the mentally retarded and the staff.

It has been found in developed countries that the majority of mentally retarded people can live in ordinary or specially adapted housing; residential care need not necessarily be provided in special purpose-built accommodation. The emphasis should be on the creation of a domestic environment, housing only a few residents, with a minimum of restrictions. Residents should have privacy, and freedom to make important decisions about their day to day lives. Each community should have a wide range of residential accommodation for the mentally retarded; the degree of support and supervision provided should depend on their needs.

Residential accommodation may be provided by a social, health and voluntary agency, or privately. It should be home-like in character and preferably located within easy travelling distance of the resident's family. The number of residents living together should be small. Space standards and facilities in residential accommodation should be equal to good local domestic standards.

Separate provision should be made for children and adults and there should be educational and training facilities which residents can attend during the day. Where attempts are being made to provide residential accommodation in the community for all those who require it, including persons with profound handicaps and behaviour disturbances, special training programmes are needed for the most severely retarded to enable them to take advantage of the facilities and to ensure that the quality of life of other residents is not seriously impaired. Such provision is now available, though admittedly on a limited scale, in many developed countries.

For children in particular, the small group home, because of its community-based locale, poses fewer adjustment problems than distantly placed and environmentally strange institutions. The stigma of admission to an institution is avoided, the child maintains an integral role in the community, and learns new skills in the natural setting in which he must eventually apply them. Furthermore, family contacts can be preserved.

In some areas in developed countries, the small group home is also used as a temporary facility for children who are living with their families but who can benefit from a short term stay for the purposes of learning certain skills, including self-care and daily activities.

It has been found helpful for the staff of residential units to have maximum autonomy to make decisions about the day-to-day needs of the residents but within the framework of an agreed local policy for residential care. Procedures for the admission and discharge of residents should be clearly laid down; each residential unit should have written aims both for the facility as a whole and for each individual resident. In the absence of such individual programme plans, residents are likely to remain in the same sheltered environment even when they are ready to move to more independent living arrangements.

Residential services need to be strategically planned to meet a range of needs and should take a variety of forms. For example, some residents will need relatively high staff ratios and intensive levels of training in self-care and domestic skills; others may be able to live in small group homes with only occasional visits from professionals or volunteers. Similarly, some will need intensive training programmes to increase their social independence, while others may not be able to live in anything other than a sheltered environment that is for all practical purposes their home. This wide range of needs will require a variety of residential services.

(2) Substitute families. In general, programmes for finding foster homes aim to recruit parents who have successfully raised their own families and have demonstrated qualities of warmth, understanding, consideration for others, emotional stability, and security. While these personality traits are fundamental, they are not always enough for the care of children with mental limitations and disturbed behaviour. In addition, foster parents need some professional support in adjusting to a slow rate of maturation and learning, and help in recognizing the child's need for intellectual stimulation and verbal interaction. They must also be able to withstand the pressures that may arise from neighbours, because of the behavioural problems sometimes seen in such children. Supportive resources in the community taken for granted with normal children must be available to supplement the foster parents' capabilities. With these selective safeguards and special considerations, foster home care can provide a key component of community services and prevent a deterioration in the child's behaviour and the consequent demand for less appropriate and more expensive services.

(3) Institutional residential services. Most mentally retarded people in hospitals receive little more than residential care, together with some education and training. Only a minority receive medical or nursing treatment that could not be provided by community health or residential services. Therefore, the number of people admitted for long-term hospital care should be reduced to the absolute minimum, particularly in the case of children for whom hospital surroundings are generally quite inappropriate.

A small number of retarded people do require specialist resources that only a hospital can provide, for example, facilities for intensive assessment and programmes for people with multiple handicaps, including those with visual and auditory impairments, or for those with severe behaviour disturbance. Even so, it is doubtful whether more than a very small minority would require long-term hospital care if appropriate residential and educational facilities were available in the community. When hospital care is necessary, the period of confinement should be short and as comfortable as possible, so that people enjoy as high a quality of life as possible. One study in India concluded that only 25 hospital places per 1 000 000 population were absolutely necessary (R.S. Murphy et al., unpublished data, 1979).

In future, therefore, the emphasis should be on the provision of local residential services, so that those who require residential care can continue to live in their own community. At the same time, existing hospitals and institutions should be helped to develop active treatment and rehabilitation programmes in order to prepare as many people as possible to live in the community.

(4) Elderly mentally retarded people. Little attention has so far been given to the needs of the aging and elderly mentally retarded. The mentally retarded in developed countries now live longer than previously mainly as a result of improvements in both general health care and specific medical care. This has resulted in there being many more elderly mentally retarded people than was expected by earlier service planners. This pattern is also likely to emerge in less developed countries as health care improves, and this trend should be considered when planning services. Very little research has been carried out in this area even in developed countries so that no clear guidelines about the kind of provision needed can be offered, but the problems are now being recognized.

One group of the elderly mentally retarded are those who were admitted to institutions many years ago, largely on social criteria (e.g., women giving birth to an illegitimate child) that would not be acceptable today as evidence of mental handicap or of the need for institutional care. Many of this group have lived in hospital for so long that they may not wish to leave, but an increasing number have expressed the wish to live outside hospital and have been helped to live in hostels or in ordinary housing. Others have been transferred to accommodation for other non-retarded elderly persons or to geriatric hospitals. However, such provision is often unsatisfactory and decisions should always be made on the basis of personal needs and taking into account the wishes of the individual concerned.

Another group of elderly mentally retarded people who may suddenly need services are those who have been living in the community being cared for by their family. When family members die or themselves need care, the mentally retarded person may need residential care and social training at short notice.

Little is known about the process of aging in the mentally retarded but it is likely that the range of individual variation is even greater than among the non-retarded population. For example, many younger adults with Down's syndrome have been reported to show symptoms of pre-senile deterioration compatible with a diagnosis of Alzheimer's disease.

5.5 Manpower development

Lack of skilled manpower is a problem that concerns most developing countries and in the area of mental retardation there is an even more critical shortage of trained personnel. Planning for the recruitment and training of workers must be an essential component of any effort to develop services for the mentally retarded. Training should be envisaged for the following categories:

Specialists

Doctors (psychiatrists, paediatricians etc.)
Psychologists
Rehabilitation specialists (speech therapists, occupational therapists, physiotherapists etc.)

Intermediate Workers

Teachers
Nurses
Social workers

Primary Workers

Parents and volunteers
Primary health care workers
Home visit aides
Community rehabilitation workers
Students
Other mentally retarded people
The community

In general, the same principles that are applied to the development of services for the mentally retarded should be applied to the training of the staff for those services; the main objective is to provide basic care for all. This suggests that most people who work with the mentally retarded need not be highly trained but rather that they should be community members who have received some specialized, practical training aimed at solving the everyday problems of the handicapped and their families.

For primary care workers, i.e., people in day-to-day contact with children, (e.g., nurses, general practitioners, social workers, teachers) an effort must be made to include a course on mental retardation in their usual curricula.

The middle-level workers specifically dealing with the mentally retarded should be given a longer, certified course (e.g. 6 months) and will generally have a more advanced educational background than the primary worker. This middle level worker should be assigned supervisory and training responsibilities in support of the primary worker. He should be mobile, visiting the primary workers to help with practical problems. Opportunities should be given to all who work with the mentally retarded to update their knowledge and skills. This is particularly important in the area of rehabilitation and training techniques where progress has been very rapid (27).

Finally, a few highly trained specialists are needed in areas specifically related to mental retardation, e.g., psychiatrists, psychologists, learning specialists, vocational rehabilitation experts, speech pathologists, as well as for additional training for other professionals such as doctors. These experts must work closely together and should devote a substantial proportion of their time to training and supervision. The number of specialists need not be large to be effective. Short, practical workshops in skill development should take place in the settings in which people work and should be based on the real, day-to-day problems encountered. This involves a radically different approach to the traditional system of training staff members by listening passively to lectures given by specialists but without any chance to try out new methods under supervision, or the opportunity to put new ideas into practice in their own work setting.

Public awareness is an important aspect of the programmes designed to deal with mental retardation. On the one hand, an indifferent or hostile community can greatly exacerbate the handicap. On the other hand, a positive, caring community will produce a multitude of good ideas and voluntary activities. For example, there are many cases of day-care services being provided by the community. Support may be given in various ways (e.g., fathers making toys, a building donated, volunteer helpers). These services were often created to help working mothers while at the same time providing stimulating activities for the children and an opportunity to educate mothers in nutrition and child development. Similar programmes, in an infinite variety of forms, can be developed in response to the needs of the mentally retarded - once the community is aware of their problems.

Volunteers, whether themselves parents of a mentally retarded child or not, are an invaluable source of manpower. In addition to these volunteers there may be a variety of voluntary organizations in the community that can make an important contribution to the wellbeing of the mentally retarded. For example, there may be organizations concerned with sports, leisure, and recreation, and those concerned with specific hobbies or interests.

Much has been done in recent years to increase the contact between mentally retarded people, including those in hospital, and other members of the public, particularly youth and other voluntary groups.

For example, a Caribbean country has initiated a programme requiring all students who have completed a certain level of education (i.e., university) to work in the service of their country for a certain period after qualifying. This programme has allowed many young people to work with the handicapped after a short training period.

In other countries, young people from all backgrounds have made contact with the mentally retarded and regularly visit schools, day centres, and residential establishments. They help in a variety of ways, but perhaps their main contribution is that of friendship and support.

Finally, many of the mentally retarded can themselves, with proper preparation, teach other mentally retarded the tasks they have learned.

As mentioned earlier, the majority of people working with the mentally retarded do not have to be highly educated or specially trained. It is their personal qualities, together with some training, that are important. Therefore, the recruitment of workers who will make day-to-day contact with the mentally retarded and their families should begin in the community, with those who are perhaps uneducated, but are otherwise suitably qualified individuals. Additionally, supplementary training for primary health care workers, bare-foot doctors, nurses, social workers, teachers, and others in contact with the mentally retarded should be encouraged.

In providing care for the mentally retarded, the key aspects are the provision of information and education for those who will listen; this can be done through the health services, schools, community leaders. Most of the mentally retarded can learn to work and to take care of themselves, and can benefit greatly from social integration into the community - with a little help from others.

6. THE ROLE OF VOLUNTARY ORGANIZATIONS

Partnership with voluntary associations is the hallmark of a good care service for the mentally retarded, and can take a wide variety of forms. In some countries, governments delegate the running of some or all services to the voluntary societies for the mentally retarded, and provide the necessary finance; in other countries volunteer and government services run side by side. The interdependence of state and volunteer efforts is now well recognized; neither can work effectively without the other. It is significant that in most countries where the government has made a public commitment to the cause of mental retardation, the impetus came from voluntary groups.

The functions of voluntary organizations generally include:

(a) raising funds,

(b) starting, administering, and managing projects,

(c) promoting the welfare of the mentally retardated (including pressure to have mental retardation recognized and given a proper place in government policies and priorities),

(d) encouraging and facilitating the exchange of information.

Often, these organizations are created as a result of the efforts of the parents of severely mentally retarded children who try to establish a place for their own child and for other children in society. All the training and financial resources in the world cannot guarantee the qualities so often displayed by these parents and other volunteers; enthusiasm, motivation, and willingness to work diligently and ceaselessly for the people they seek to serve. Their dedication and work efforts should be acknowledged, supported, and encouraged at every level.

7. THE ROLE OF INTERNATIONAL ORGANIZATIONS

7.1 The International Association for the Scientific Study of Mental Deficiency (IASSMD) and the International League of Societies for Persons with Mental Handicap (ILSMH)

The complex problem of preventing mental retardation and improving available services requires international cooperation at many levels, as well as the help of regional, national, international, governmental, and non-governmental organizations. Research on biological, epidemiological, medical, psychological, educational, and social aspects of mental retardation often requires international cooperation and international programmes. Services need to be developed using international experience and resources. Special roles in this respect belong to the IASSMD and the ILSMH for the dissemination of scientific results and information on programmes.

IASSMD is an international organization primarily concerned with the dissemination of research findings. It holds an international conference every three years which provides a forum for reports on both research and service developments of national member societies. ILSMH is a federation of parents and professionals from some 70 countries in five continents. In addition to international conferences, it organizes a series of working groups and task forces on specific topics concerned with the development of services e.g., implementation of the United Nations Declaration on the Rights of the Mentally Retarded Persons (19), manpower needs (27), differentiation between the mentally retarded and the mentally ill, the needs of the profoundly retarded, and elderly sufferers. It has consultative status as a nongovernmental organization with several United Nations organizations, including the United Nations Children's Fund (UNICEF), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), and the World Health Organization, and has been involved in joint conferences and seminars with some of these organizations in developing countries. Its members are ready to assist in programmes of development in all parts of the world. ILSMH and IASSMD cooperate in the development of regional conferences and form the Joint Commission on International Aspects of Mental Retardation, one of the partners responsible for the preparation of this booklet.

7.2 The World Health Organization and other United Nations agencies

WHO has been involved in work on mental retardation, in collaboration with the United Nations, its specialized agencies, and nongovernmental organizations for many years. Through both the Joint Expert Committee (1953) convened by WHO with the participation of the United Nations, ILO and UNESCO, and the WHO Expert Committee on Mental Health (1968), principles relating to the development of services for the prevention and management of mental retardation have been formulated (37,38). In 1975 and 1977, the World Health Assembly passed resolutions calling upon the Director-General of WHO to collaborate with the United Nations and its specialized agencies to assist in the development of programmes of community care for the mentally retarded and particularly to focus on the provision of training in this respect. The United Nations has recognized that mentally retarded people constitute a sizeable minority in all communities, and in many instances, they remain under-priviledged, deprived of their full rights, and unable to develop their potential for productive and enjoyable lives. For this reason the United Nations General Assembly voiced their concern in their Declaration on the Rights of Mentally Retarded Persons[1] in 1971 and Declaration on the Rights of Disabled Persons[2] in 1975.

WHO has given priority to action within existing services and to interventions concerned with children. Simple methods of detection and care which can be used by public health nurses, auxilliary health workers and parents have been developed within the WHO Community Based Rehabilitation Programme which is now being taken up in numerous countries. Improved antenatal and perinatal care, the control of infectious diseases and adequate nutrition for women of child-bearing age and infants, combined with health education for parents are seen as the most effective preventive measures. WHO and UNICEF are working with countries to help eradicate iodine-deficiency disorders, which in the form of endemic cretinism is an important, and possibly the most easily prevented, cause of mental retardation.

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[1] United Nations General Assembly resolution 2856 (XXVI).

[2] United Nations General Assembly resolution 3447 (XXX).

Few countries have taken up the opportunity of fellowships for training in the field of mental retardation, but steps are being taken to strengthen training institutions within developing countries. Legislation is an important factor in the planning and delivery of care for the mentally retarded. In 1976 an international survey of mental health legislation was carried out by WHO, and it was found that in the 42 countries surveyed, only six had separate legislation covering the needs and rights of mentally retarded people, while in a further 26 there was specific reference to the mentally retarded either in mental health legislation or in public health legislation. In 10 of the countries surveyed there was no legal provision of either kind. The results of this survey have been published together with guidelines that will help countries to assess their legislation and enact new laws where necessary (7). Further work on the subject of legislation relating to the mentally retarded is being carried out or planned by WHO in collaboration with nongovernmental organizations.

Although WHO has put effort into programmes concerned with the identification, prevention, and management of mental retardation, it is recognized that significant progress will be achieved only when governments themselves decide to accord this work adequate priority in their health policy and development plans.

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This book deals with the problem facing all societies of reducing the disabilities and suffering of the tens of millions of people who have some degree of intellectual impairment. It discusses national policy formulation and the services that are required to cater for the needs of the mentally retarded. The emphasis is on the full use of community resources to provide a comprehensive service that aims to help all mentally retarded people to remain in the local community and to contribute to it as fully as they are able.

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