Chapter One

INTRODUCTION

The problem of mental retardation is a profound one. It is not only an enormous misfortune, but it is also possibly the largest area of morbidity and one which is still largely of unknown causation. In the strict medical sense, once a child is mentally retarded, he is incurable and this is not only a personal tragedy to the afflicted individual and to his family, but also a great social burden falling on the entire community.

Mentally retarded individuals comprise a vast amount of the handicapped section of the society. This syndrome, because of its irreversible nature and the deep seated behavioural problems it generates, needs to be given a major attention by workers, educators, medical technicians and afflicted family units. The major intervention agencies which affect the development of the retarded individual are the family unit of the retardate, and the special educative school which strives to inculcate skills within the retardate and maximise his potentials.

The special school is however a rarity, in the present society and a minimal section of the retarded section can therefore benefit from it. In cases where the special school privileges are denied to the retardates (either due to the retardates inability to gain admission or due to the
retardate's level of functioning which is so low as not to benefit from school intervention strategies), it is just the family which maximises or minimises his/her potentiali- 

ties. In cases where the retarded child falls within the privileged category of receiving the special school educative influences, it is felt by educators that the two agencies should work hand in hand towards the progressive development of the retardate.

The Effects of the Two Intervention Agencies

A hostile and rejecting family atmosphere can undo the beneficial effects of the special school - where there is positive stimulation of the cognitive, social and self help skills, bestowed on the retardate. On the other hand, special schools or classes where the retardate is ridiculed, teased and not stimulated to bring forth his optimal functioning level, can have a further deteriorative or retarding effect on the development of the retardate. Under such circumstances, the retardate dreads the special school and even the positive influences of the family are not enough to maximise the retardate's development process. Bearing in mind, the powerful effects of the two intervention agencies on the retardate and the fact that each retardate has an individual potential for cognitive and social growth, it is imperative to identify variables within the family and school milieu which would be conducive for the retardates positive growth
and final rehabilitation within the community.

An analysis of literature on mental retardation reveals a gross lack of studies on the complex problem of isolating variables within the retardates environment which are conducive for the retardate's development and which are further detrimental for his already lowered levels of social psychological and cognitive functioning. This leads to a further problem which educators like, Hewett (1966), Rabinow (1964), Rothstein (1966), Maclen (1962), Dayan (1964) are increasingly bringing into focus - the concept of improvement or deterioration of the retardates level of functioning as compared to his individual growth and developmental potential. Each retardate is regarded as an unique case with his own predicted level of growth and hence education for them within the special school emphasises individualized appraisal in a collective setting, the latter, to promote social and adjustive skills.

Viewing the psychological problems surrounding the growth and rehabilitation of retarded children, the present research focuses primarily on the family of the retarded child. Families of retarded children, as displayed by studies of Adams (1960), Rothstein (1966), Srinivas (1977), Farber (1964), Chennault (1967), Ingram (1969), Ginzb erg (1969), in general tend to have more problems in individual and marital adjustment, child rearing practices, and sibling relationships. The family members are significantly
affected - socially, economically and emotionally - by mental retardation and the stressful impact of having a retarded, handicapped and partially non-productive member, is felt by all. The present focus is on the dynamisms and variables within the family environment which would facilitate and maintain the training effects of the special school under two conditions - (a) when the retardate is functioning in a minimal school and maximum home background and (b) when the retardate has left the special school influences and is solely within the charge of the family. The research aim is to call attention to a much neglected area in research, i.e., the relationship between the kind of family environment and its effects on the performance and psycho social functioning of an educably mentally retarded child within a special school, and out of the purview of the special school.

The present focus emanates from the harsh realization that the prevalence statistics of mental retardation are vast and the facilities and institutes catering to the cause of mental retardation are indeed very minimal. What emerges is an awareness that the family unit in a totality is the primary intervening agency for skill inculcation and where the school leaves off, the maintaining agency of skills inculcated in the retarded. The family unit in the midst of a tragic reality crisis of having a handicapped member has to be alerted, supported and educated with regard to the guidelines of rearing and rehabilitating the retardate.
Prevalence Statistics in the Western Countries

The magnitude of the problem can be imagined by the starting revelation of the President's Panel on Mental Retardation (U.S.A., 1968). According to this report of the panel, mental retardation affects and disables ten times more individuals than diabetes, twenty times as many as tuberculosis, twenty-five times more than muscular dystrophy, and six hundred times more than infantile paralysis. Even though it is critical to determine the number of retarded people within the population, determining, prevalence is not always easy. The usual methods are to survey clinics and agencies for lists of cases, or survey the school systems as they presumably have a relatively complete list of children of school age and have made some attempt to distinguish the retarded.

Another problem is that, depending on how mental retardation is defined, prevalence figures will be significantly different. The most recent AAMD (1963) guidelines place the cut off point at IQ 70, but many school systems have an IQ cut off at 75 or 80 for mental retardation. Goodman et al. (1956) in a survey in Onongada city, New York, with IQ 75 as a cut off point, found 3,787 cases of retardation, which yields an approximate prevalence rate of 35.2 per thousand. Dunn (1966), conducted a prevalence study in Hawaii that yielded a prevalence figure
of 23.6 cases per thousand among school age children. In this study IQ's below 65 were considered retarded. A recent prevalence study by Jane Mercer (1973) utilized IQ cut off point as 65, as well as adaptive scales, in Riverdale, California, quoted the prevalence figures to be 34.7 per thousand. Farber (1968) summarized 10 project prevalence figures and quoted that the increasing trend towards more and more retardation victims would mean a prevalence rate of 6.5 million in U.S.A. by 1970. Hence whatever be the determining cut off IQ point, the gross amount of retardation victims are indeed staggering.

A number of studies have been conducted to study the differences in sex, age and socio-economic factors with respect to prevalence figures of mentally retarded individuals. As regards the sex factor, Farber (1968), Goodman (1956), Silverstein (1964), Stang (1957), cite the predominance of male over female retarded people. Certain tentative explanations have been put forward to account for this occurrence. Medical evidence, Taylor (1962), Diggs (1964), postulate that male fetuses and neonates are more prone to birth trauma, hence giving rise to the incidence of mental retardation. An important psycho social explanation is that male retardates are prone to be aggressive and often disruptive and hence are more likely to come to the notice of school psychologists for remedial referral, rather than the backward female retardate who tends to sit quietly
in class and not engage in any problem behaviour, Mercer (1973). Emphasizing on prevalence differences at different ages, Mercer (1973), Meyerowitz (1963), Appel (1964), Wang (1965), reported that there were about half as many mentally retarded pre schoolers, and half as many adult retardates, but twice as many school going retardates as would be predicted if retardation were evenly distributed across ages. Explanations as postulated by Mercer (1973), Dunn (1964), and Appel (1964), are: (a) numerous cases of retardation among pre schoolers and adults, remain undiagnosed because there is no effective screening system for these age groups. Once the retardates attend school, they are diagnosed by psychologists and educators, but once they leave school, the institutes loose contact with them and they are no longer included in the prevalence statistics; (b) a person can often be regarded retarded in some situations but not in others, meaning, that many people who are considered retarded in school where great intellectual demands are made, are no longer categorized retarded once they leave the academic milieu.

Relating retardation prevalence rates to the socio-economic status, workers like Rothstein (1964), Verma (1974), Beck (1966), postulate that retardation is found more frequently among the poor, than the well off families. Mercer's (1973), in her survey of agencies dealing with the retarded, found that while 40 per cent of the population of
her community lived in low income housing districts, 69 per cent of the retardates reported by these agencies lived in low income housing areas. Possible reasons could be malnutrition, cultural deprivation, inadequate stimulation of faculties, deemphasis on school training etc.

**Prevalence Statistics in India**

In India, mental deficiency represents a formidable and staggering problem. It must be stressed here that there are no adequate prevalence statistics available in this regard. The statistics that are available are largely based on the information from school census figures, sample surveys, and speculations and would not adequately reflect the actual number of children who require remedial treatment and care at an early age. According to Dybwad (1961) several important considerations suggest caution in the use of above statistics. Firstly, as in the case of western prevalence statistics, the intelligence quotient arrived at, on the basis of one or more standard tests, have different ceilings in different states. The higher the ceiling is pushed, the numbers also increase, signifying that the usage of IQ 75 would include a larger group among the retardates, than the usage of a cut off point at 70. Further more, the mentally retarded group is not a static one, as retarded individuals, given improved nutrition, medication and psycho social remediation, move from one group to another as a result of improved
performance. Finally, recent medical advances also substantially affect these figures. The advent of antibiotics has markedly decreased the previously high rate of deaths from infectious disease during childhood and adolescence, and this increases the number of adult retardates. Medical skill also keeps alive an increasing number of infants who formerly would have died before or during birth.

No definite statistics are however available for the incidence of mental retardation in India. Mentally retarded are estimated to constitute 3 per cent of the population. According to the 1968 census, there are about 20 million mental defectives in the country with Uttar Pradesh alone bearing a vast amount of 2.5 million mentally retarded individuals.

Faced with the problem of a high incidence of mental retardation within the Indian setting, it is discouraging to note that the number of institutions offering diagnostic and remedial measures are grossly few.

**Facilities Available for Mentally Retarded in India**

In an analysis of institutions for mentally retarded in India, Boi (1966), it is found that there were 51 institutions in India in October 1966, catering to 1,886 retardates. Some of these institutions catered for other
types of handicapped as well. There were only 3 institutions in India prior to 1950. Of the rest, about half came into existence during fifties and remainder during the period 1961-66. Ten institutions offered clinical services. Teacher training programmes were offered by 2 institutions. Four institutions offered medical rehabilitation, 39 institutions offered educational programmes, 9 were purely educational, one offered vocational and rehabilitational programme and 16 offered educational and prevocational training. Research was done by 6 institutions. Psychotherapy was offered by one institution and two provided care and medical treatment. Sixteen were purely residential institutions, 24 were non-residential and 8 were both. Twenty institutions were provided, 15 government-aided, 7 government, 3 semi-government, and 6 were not known. Upto July 1970, there have been 80 institutions in the country, Boi (1968), FWMR (1970) catering for about 2,400 retardates and few more institutions were to open in near future. Lately the number of institutions has shot up to 91 published in the FWMR manual covering the Asian Conference on Mental Retardation, held in Bangalore (1977). However, diagnostic and guidance clinics have been negligibly few in this country.

Surveying the data on the availability of institutional facilities for the mental defectives, an important fact needs to be elaborated. The phenomenon of mental retardation, for purposes of assessing growth and developmental potentials
and the consequent license for special remedial treatment and rehabilitative measures is divided into three district categories.

The Categories of Mental Retardation

The categories are the 'EMR' or the educable mentally retarded, the 'TMR' or the trainable mentally retarded and the 'SMR' or the severely or custodial mentally retarded. The trainable are defined as a group than can have minimal social skills inculcated within them and can be minimally trained for repetitive and mechanical activities within sheltered workshops or a similar restrictive milieu. The custodial group is one which exists in a vegetative state without the development of any cognitive or adjustive skills. This group exists at the mercy of certain authority figures or within the restricted four walls of an institution.

The E.M.R. Group

The educable mentally retarded however is the only group which can benefit from educational or training intervention programmes. This group can be inculcated with oversimplified academic concepts and certain social adjustive mechanisms, which would allow them to function in a semi-independent manner within the society. Hence, where the retarded group is considered for diagnostic and consequent school placement or referral measures, educators/psychologists
have in mind the EMR group, which can benefit from intervention strategies and maximise their basic potentials. This is the only group which can be effectively stimulated by school and family units into functioning levels much higher than what they are born with and consequently it is this group that has come maximum within the benign perception of educators, social workers, psychologists and psychiatrists. But even with the E.M.R. representing a vast majority of the retarded section (as the severely/custodial retarded group are subject to high infant mortality rates) the facilities affording them treatment and training programmes to inculcate skills and maximise their growth potentials are grossly few.

Here again it is noteworthy to observe that the only constant intervention agency which the EMR group be sure of is the services offered by the family milieu. The family, by pooling its psychological and physical resources, can effectively combat the tragic reality crisis of having a handicapped member.

The Critical Role of the Family

The major emphasis on the family unit of the retardate is because it is imperative to assess the family variables operative in the handling of a retardate in cases (a) where the family is the primary and sole intervention agency, for those retardates not attending special institutions and (b) where the E.M.R. children attending a special school
complete the tenure and return with inculcated skills to the family which stands out as the sole agency in furthering growth and maintaining inculcated skills within the retardate.

The family reaction on the birth of a retarded child or discovery that a child is retarded is always of a severe emotional nature and can run the gamut of feelings of despair, guilt, ambivalence, overt hostility to a calm acceptance of the crisis at hand and a summoning of family resources in the upbringing, training and promotion of cognitive and social skills within the retarded.

Menolascino and Wolfensberger (1976) report that these parents experience three kinds of crises, a novelty crisis, which is a reaction to the sudden impact of a major change in one's life; a value crisis, brought about by the fact that it is necessary to alter one's values to accept a child with few desirable characteristics, and a reality crisis, that is a reaction to the concrete kinds of problems presented by having such a child in the family. Out of these reactions develop a family milieu which is based on an intervention model that can either help the retardate grow as an almost equal and normal member of the family, or which can retard him further by inflicting hostility, neglect or rejection on the retardate. What is aimed in the present investigation is a systematic and thorough appraisal of the family unit and the dynamic variables operative within,
which either facilitate or retard the retardate's growth and developmental potentials. An understanding of the only constant remedial and psychological referral unit afforded to the mentally retarded, would lend a direction in the development of education and counseling guidelines for the family, which in turn can enforce them to facilitate growth and rehabilitative measures for the retarded children.

The Rationale of the Research

The present investigation deals primarily with the powerful effects of the family and school milieu on the performance, perceptions, and consequent progress or deterioration patterns of functioning of E.M.R. children attending a special school. The study, hence, deals with the retardates who fall within the privileged category of the 6,000 educable retarded children, who can be absorbed in the available institutions in a country where approximately 20 million such handicapped children live.

A Preliminary Study

A similar research problem was earlier studied by the investigator, Ghatak (1978). The investigation was designed in order to evaluate the family environment in terms of the dynamic variables operating in the various retardate-family interaction facets. The nature of the family milieu was related to the retardate's improvement or deterioration
of the functioning levels on the cognitive speech, communication and social maturity dimensions. The results established a positive relationship between a congenial warm and caring family environment and the retardate's performance and psycho social improvement within the special school milieu. The retardates deterioration in performance was related to a hostile and uncaring family environment where a positive acceptance of his potential and handicaps was missing, and the retardate sensing non nurturant and non-stimulating milieu regressed into lower levels of functioning.

The research outlined emphasizes the role of the family unit alone but did not take into consideration the powerful effects of the special school milieu and the attitudes of the retarded member himself as related to his family and school milieu and his personal self. Based upon these pressing needs and stresses faced by personnel in constant interaction with retarded children, whether it be a family member or a school personnel, and a realization that there were tremendous research gaps in this particular area of investigation (which can be assessed as most critical in the (a) promotion of the retardates mental and psychological health, (b) maximum utilization of special school benefits, (c) promotion of mental health of the retardate's family), the present problem was decided upon.
The Present Research Focus

The function of an intervention training programme afforded to the E.M.R. children aims at the inculcation of cognitive and adjustive skills within the retardate, the maximization of the retardate's psycho-social growth potentials, and the induction of vocational and rehabilitational competence within the retardate. The special intervention programme induces adequate adjustive mechanisms within the retardate for him to maintain himself in a semi-independent manner within the society and attain an adequate level of vocational competence. In these aims however, the intervention programme does not function alone. The paucity of such intervention programmes and the fact that these programmes are limited in time, indicates that the E.M.R. child is once again returned to the family milieu.

The family of the retardate functions as a major intervention agency and helps augment the already present level of inculcated skills within the retardate by the special school. The family needs to provide a conducive milieu where the retardate can be stimulated, supervised and inculcated with the basic self help and adjustive skills.

However, it is not sufficient for the family to only reinforce the skills inculcated within the E.M.R. child. The family not only supplements the special school training programme but also functions as a maintenance agency of the
retardate's inculcated skills, after the retardate has left the special school milieu.

An identification of variables, operative within the family milieu in cases when the child is attending a special school and in cases when the child has left the special programme to function solely within the family milieu, would be ideally undertaken by a longitudinal study. Such a study would encompass the assessment of the family dynamisms during the E.M.R. child's school functioning time and a later assessment of the family variables when the retardate would have left the special intervention programme.

Since the above specified aim was not possible due to its long range and time consuming element a cross sectional study was undertaken. The study broadly encompasses a research programme conducted in two phases, phase I involving an identification of the family variables related to the psycho social progress/deterioration of a sample of school going E.M.R. children and phase II involving an isolation of the family dynamisms, operative in the psycho social growth of a sample of ex school E.M.R. children.

Defined in broader terms, the research aim at the initial phase was to identify the dynamisms within the family milieu and their effect on the cognitive and psycho social performance and perceptions of the retardate regarding his self, home and school milieu. In the second
phase of the investigation, a follow up programme was undertaken to determine the relative efficacy of the family variables operative in the maintenance function of the skills inculcated by the special school intervention programme.