CHAPTER V

ASSESSING THE RELEVANCE AND EFFECTIVENESS OF TRAINING RURAL-BASED PARENTS TO MANAGE AND EDUCATE THEIR MENTALLY RETARDED CHILDREN.

THE NEED

Mental retardation is a condition which is prevalent in the entire world. It cuts across the barriers of Nation, Religion, Culture, Race, Caste, Sex and Socio-economic status. Although mental retardation is primarily a medical condition, because of the inherent deviation in the learning pattern and social behaviour, the person with retardation faces a handicap in the society. The degree of handicap is directly proportionate to the complexity of the social environment in which such a person lives.

In India's rural community too, mental retardation is prevalent. In fact in India, the prevalence rate of mental retardation is higher in rural areas than in urban areas. Yet the issue of services for the mentally retarded persons in rural areas is practically totally neglected in India.

It is true that deviant behaviour and learning pattern of the mentally retarded person is not a major handicap in rural community. This is so because the social environment in a rural community is simple and restricted in terms of group contacts, social differentiation,
social stratification and social mobility. This makes it all the more necessary to provide a service of systematic education and training for the retarded person in rural areas. The structure of the society into which the retarded person is to be integrated being simple, the education and training which will make the retarded person ready and suitable for meaningful integration, can be argued to be simple in goals and methods. Besides, it should not be forgotten that even the retarded persons from rural communities have their rights to education, training and rehabilitation as given to them by the United Nations Declaration on the Rights of Mentally Retarded Persons.

Since 1975 some work in the direction of providing services to the rural-based mentally retarded persons in India has begun. It has been undertaken by organizations from Bangalore, Chandigarh, Hyderabad, Jaipur, Lucknow, Madras, New Delhi and Vellore. The programmes implemented by these organizations vary in their methods. Most of them train and involve the parents as co-educators of their retarded children. The remaining train and involve the local Primary Health Centre Workers or Anganwadi workers in the care, management and education of the retarded children. But while reviewing the works of these organizations Shrinivas Murthy does point out that, "the need for evaluation of the effectiveness of the above intervention is imperative lest it remains a 'goody-goody' programme." (Shrinivas Murthy, 1985).
The Experts Group on National Planning for the Mentally Handicapped in India have made some suggestions regarding services for rural mentally retarded persons. They suggest some models of services to be implemented by Community Health workers, Balsevikas and Multipurpose Workers. (Sinclair, 1979). These models have neither been implemented nor tested.

Thus it can be concluded that there is a strong need to organize a programme and evolve a service model which should be implemented, tested and verified for its suitability in view of providing services for the mentally retarded persons in the rural community of India. It will be impractical to organize a single programme in which all the suggested models of service can be tested. Of all the models suggested and implemented, the one involving parents as co-educators is the most common. Hence the need to test and verify this model for its suitability is foremost.

THE PROBLEM

In other countries—mostly the developed countries—the issue of providing care and educational service to the rural mentally retarded persons has been studied at various levels. Some related works have been referred to in Chapter III. Some of them raise questions regarding the effectiveness of programmes involving parents. Owing to the shortcomings in the methodology of
programme evaluations, the queries have not been satisfactorily responded to, and the approach of involving parents has been practised unabatedly. Some models and methods of involving parents have got established e.g. Portage Project, the Read Project. It is hence possible to look at these models as prescriptive solutions for evolving educational and training programmes for mentally retarded persons in rural India.

The fact, however, is that these models need to be tried on an experimental basis in rural parts of India. The villages and villagers in India differ a great deal in terms of education, social, cultural and economical aspects from those with whom projects like the Portage Project was implemented. Each of these four aspects present major issues which need to be examined so as to establish whether villagers from India will accommodate some newer viewpoint regarding their mentally retarded child. The issues are as briefed further.

In rural India education, for a very long period, was the privilege of a few, and of those belonging to specific castes. Even as it is at present, education of ordinary children too is neither compulsory by law nor a necessity in many families in the rural community. Under such conditions the issue is to find out if there is any chance of education being made a desired
aspect in the lives of rural mentally retarded children. The rural people in India are socially a little more conservative and traditional. In most rural families, which are usually joint families, the general practice is to leave the children, even the ordinary or normal ones, in the care of some elderly member of the family. The parents are thus free to pursue their vocations, household chores, and even leisure-time activities. These people take a rather stoical view of life and are less enthusiastic to change. With this background it is necessary to examine the possibility of the rural parents changing their life-style for the sake of education of their retarded child.

Culturally the rural persons in India are simple. Their need to accomplish skills is mostly limited to those related to their own vocation which is mainly agriculture or otherwise household chores. How far they will make an effort to learn new skills that of educating their retarded child is a matter of investigation.

Lastly, in terms of economic status, most of the rural persons in India are in an impoverished condition. Their main source of income is agriculture and allied work, and this is dependent on the capriciousness of nature. Hence the schedule of work and spare-time of the rural persons is controlled by factors like weather. It may therefore be difficult or impossible for the parents to accommodate in their schedule an additional
The task of teaching their retarded child.

The issues mentioned here seemingly indicate that the matter of managing and educating their retarded child does not relate to the matter on the hands of the rural parents. Therefore there is a possibility that an attempt to so train these parents has no relevance in the lives of these parents. In other words the matter on hand could function as constraints on the actual urge for doing something for their retarded child other than attending to the child's acute medical needs.

A part of the problem to be studied is the relationship between the constraints and the actual urge referred to in the previous paragraph. This will explain the aspect of relevance of training rural-based parents in managing and educating their retarded children.

The other part of the problem to be studied is whether or not, and to what extent or how well do the rural-based parents materialize this actual urge for doing something, if the means and skills for managing and educating their retarded child is provided to them. The means provided stand here for the training which will be given. This aspect i.e., the effectiveness will depend upon the variables like parents' level of education, training, level of relating with the child, and the child's characteristics, condition and age.
The method of training to be provided will also influence the effectiveness aspect but it will be seen independently.

THE OBJECTIVES

This study intends to examine the problems mentioned earlier. This exercise will find out the relevance and effectiveness of training rural-based parents in managing and educating their mentally retarded children.

In view of realizing the intention the study is aimed at the following objectives.

1) To establish a service for training the parents of mentally retarded children in rural area.

Two main weaknesses which affect Community Development Projects have been pointed out by those who studied earlier Community Development Projects in rural India. These weaknesses are:

a) The projects were not self-initiated or locally initiated.

b) The projects were implemented with an interest of the political machinery in the area.

While establishing the parents-training service the following constraints will be laid down in view of avoiding the above mentioned weaknesses.
1) The service will be conceptualized, initiated, planned and implemented with the help and under the auspices of a non-government, voluntary service organization based in the rural area.

2) This organization should be engaged in activities which address the issues relating to health and/or education and/or welfare of the underprivileged sections of the society.

3) This organization is free of any political clout lest the name of the organization itself puts an undue pressure on the target population of the area.

4) The philosophy of working of the organization should be democratic and one which facilitates maximum participation and dialogue from and with the users of the service.

5) In the event of not finding such an organization it is deemed as necessary to establish one such organization which will befit the above description.

II) To observe how the parents respond to the availability of such a service and whether they participate in the programme of the service.

III) To observe how the parents receive the training given to them and how and to what extent they apply the knowledge obtained through the training.

IV) To observe how the child responds to the work done by the parents.
V) To observe whether and how the changes in the child, if any, affect the behaviour of parents.

VI) To observe if this service has any effect on the other members of the primary group of social contact.

VII) To evaluate the scope for continuing such a service.

SELECTION OF THE ORGANIZATION

The investigator explored the possibility of finding organizations which would fit in with the description of the desired organization as given in objective No.1. It was certainly difficult to identify them. A couple of organizations which were suitable for the purpose expressed inability to get into a project concerning the field of mental retardation. Their rejections were valid.

During this exploration the investigator experienced the importance which communication in regional language carries in the functioning of community Development Programme. Hence it was decided that organizations active in Western Maharashtra alone should be contacted. This was because the investigator himself hails from this area and thus there was little possibility of facing any problem with the language and dialect spoken in the area.
This further restricted the probability of finding a suitable organization. Therefore the investigator had to contemplate on initiating the formation of a suitable organization. The investigator's attempt in this direction met with success. The investigator met the parents of mentally retarded persons from Wai, District Satara, Maharashtra and this marked the beginning of the process of forming an organization.

THE ORGANIZATION

In 1981 a camp for 'Detection of Mental Retardation' was organized at Wai by the local parents of such children with the help of the local Lions Club and an Institute for mentally retarded persons from Pune. It was then realized that there are many children within Wai taluka who are mentally retarded and that there is no service for them or those with any other disability in the vicinity of over a hundred kilometres. As a result the local parents became eager to start some service at Wai. These parents and the investigator met and thus the collaborative work of forming an organization started in 1982. Initially the nature of service was in the form of planning home-based programmes for mentally retarded children in Wai. In May 1982 the parents and some considerate members in the community came together and formed a Registered Society with the name Wai Akshar Institute. In due time the Smt. P.C. Alwani School for the Mentally Retarded was started at Wai by the Wai Akshar Institute.
This Special School received its recognition from the Directorate of Social Welfare, Government of Maharashtra in 1984. For some time thereafter the Institute concentrated its attention only on developing the Special School under the supervision and guidance of the investigator and his colleagues from Ahmedabad, Gujarat.

By 1985 the Institute had become stabilized and was ready to address any additional issue in relation to the mentally retarded children in Wai taluka. It was realized that there were some obvious limitations of any Special School. The school could not accommodate more than a certain number of children. It could not cater to the needs of certain types of children and it was too out of the way for those living away from Wai city.

This period was then considered as the most opportune time to give priority to a service such as the one desired in the objectives of this study. Hence in 1985 the investigator started the actual work of this study as an activity of Wai Akshar Institute in Wai Taluka.

REFERENCES

Shrinivas Murthy, R. Community Care of the Mentally Handicapped Persons Living in Rural Areas of India. New Delhi: Souvenir of 7th World Congress of International Association for the Scientific Study of Mental Deficiency, 1985.