SUMMARY AND CONCLUSIONS
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Mental retardation is a complex problem and is not a disease or an illness which can be treated with medicines. It is a human condition resulting from organic or developmental deficits which manifests itself in below average intellectual functioning and difficulty in learning social behaviour.

The prevalence of mental retardation is estimated to be three percent in the general population; in 100 cases, 5 are likely to be severely retarded 20 moderately retarded and 75 mildly retarded (Khaprade, 1987). Studies have revealed that about 2 percent of the population in India are mentally retarded (Reddy, 1988).

The problems caused by mental retardation are well known. Apart from learning disability it leads to psychological problems such as behavioural, emotional, personality growth and related problems; and social problems such as social maladjustment, prejudice, discrimination, segregation and stigmatisation. The presence of a mentally retarded person in the family also leads to several psychological problems among the family members. The causes of mental retardation including its etiology have been well researched and several factors other than medical have been identified.
The present focus of research is therefore centred around the development of support services and habilitation of these individuals with community support. There is a need to remove stigma attached to mental retardation and change the attitude of society favourably so that community based programmes for training, education and welfare of the mentally retarded can be effectively implemented. With the National Policy of Education (1986), a lot of emphasis has been given in India for the education of the mentally handicapped. Presently, most of the retarded children undergo some kind of training or education and increased special educational facilities are being set up.

There are various helping strategies to promote education and rehabilitation among the mentally handicapped, such as, special education, integrated education, and community based rehabilitation programmes which include home-based early intervention programme such as Portage, rural-based District Rehabilitation Centre Scheme, vocational training and self-help groups.

The community based programmes directly involve parents as partners in training and educating their mentally retarded wards with the help of professionals, para-professionals and non-professionals in their homes or in the centres. Mentally retarded adults after their schooling can be placed in jobs or trained vocationally.
Community plays a very important role in the training and education of the retarded individuals who belong to the categories of educable and trainable mentally retarded. For the success of a programme, community participation is very essential. Community based programmes are frequently adopted to suit the needs of the urban and rural mentally retarded individuals. Such community based programmes are cost-effective with maximum output.

Special curriculum planning is very essential for educating the mentally handicapped individuals, according to their individual needs which involves specially trained teachers. Special education as a process has the responsibility of helping the mentally retarded person to improve his level of functioning in each area of human ability and help him to cope up with daily chores of life.

Integration transfers the best elements of special education from special to ordinary school so that both are enhanced and the children benefit socially and academically (Mittler, 1986).

Early intervention programmes are more readily adopted for pre-schoolers. Studies have revealed that such a programme encourages effective parent involvement as partners in the education and management of their children with special needs in their homes. This intervention can also be offered through hospitals, clinics, child guidance clinics and institutions for the mentally handicapped. Portage
service is a home based intervention for the pre-schoolers, from which the pre-school mentally retarded children gained developmentally (Cataldo, 1977; Baig, 1979; Kohli and Dutta, 1982; Ross, 1984; Kohli and Saggar, 1985; Kohli and Azad, 1986 and Kohli, 1989).

District Rehabilitation Centre (DRC) Scheme is a rural-based programme for the disabled living in rural areas. More than 80 percent of the population still live in rural areas in India, and considering the magnitude of their problem, the Government of India launched a Pilot Programme in 1985 in collaboration with the National Institute of Disability & Rehabilitation Research in the USA for providing a package of model, comprehensive rehabilitation services to people with disabilities in the rural areas. The scheme provides all the inputs required to maximize the disabled person’s potential capability so that he too can live as equal partner in the society with dignity (Dhar, 1990).

Intervention through self-group programme, cares and provides training and education to all levels of mentally handicapped persons, according to their individual rehabilitation plans. Services are delivered to urban and rural population. Parents involve directly in the training and education of their mentally handicapped children.

National Policy on Mental Handicap (1987) reported that the self-help group movement is an expression of the potentials for helping each other among families
with a mentally handicapped individual. This movement allows for services to develop within homes and in small communities without excessive amounts of professional inputs; self-help group has become an increasingly important vehicle for providing educational and mental health services for the population and is highly cost effective.

India, a developing country with meagre resources, massive population and geographic immensity, is faced with an estimated population of 18 million mentally retarded, who require services in various areas. There is a need for cost-effective delivery system to reach this population. Besides the financial crunch, the lack of trained personnel and professionals compounds the problem. The self-help group intervention requires little infrastructure to conduct a suitable programme and appears to be within the reach of the community. Also, the professional help is sought to the minimal. The self-help groups programme can easily find a suitable place within the locality, convenient to all.

There appears to be little or no specific area of research to compare community based programmes in India on the basis of cost. Self-help group intervention holds the hope of reaching out to the millions of urban and rural, silently suffering mentally retarded and their parents in India. This has enthused the investigator to take up the present study.

The exact statement of the problem is as follows:
STATEMENT OF THE PROBLEM

The problem under study reads as follows:

"Psycho-Social Problems of Mental Retardates and the Role of Self-Help Groups".

OBJECTIVES

The main objectives of the present study would be to:

1. Survey the psycho-social problems of mentally retarded individuals.
2. Measure the knowledge, orientation and attitudes of parents of mentally retarded children, towards mental retardation and its management.
3. Study the differentials in knowledge, orientation and attitudes of parents of mentally retarded children and its management between various groups such as institutionalised and noninstitutionalised, mild and moderate.
4. Ascertain the effectiveness of self-help groups in improvement of social skills and adaptive behaviour in mentally retarded individuals and the favourable changes in attitudes it would bring about in their parents.

DELIMITATIONS OF THE STUDY

1. Mentally retarded subjects with chronological age between 6 to 18 years with IQ ranging from 35 to 70 only were selected for the purpose of this study.
2. For phase-II of this study 15 mentally retarded subjects and their parents belonging only to the noninstitutionalised group were selected as experimental group.

3. For phase-II of this study a matched controlled group could not be established, as influence of professionals and community on the mentally retarded subjects and their parents which would directly affect the area of research could not be ensured by the investigator.

DESIGN OF THE STUDY

The study was conducted in two phases. Phase I consisted of surveying the psycho-social problems of institutionalised and noninstitutionalised mild as well as moderately retarded individuals; phase II of the study aimed to assess the effectiveness of self-help group programme on a sample of mild and moderately retarded individuals who participated in self-help group programme and attended all its meetings. They formed the experimental group. The parents of the children were assessed for changes in attitude towards mental retardation. Pre-test and three post-tests were administered. Since it was not possible to establish a matched control group, (as the investigator could not control all those influences of professionals and community on the subjects and their parents which would influence the subject area of research), a time series quasi-experimental design was used in the present study.
Sample for phase I of the study constituted 150 cases of institutionalised and 150 non-institutionalised mentally retarded individuals selected on the basis of IQ and chronological age; and the parents of these 300 selected children also formed part of the sample for phase I. 164 institutionalised subjects were screened to select 150 cases. IQ tests were administered on 242 noninstitutionalised subjects to select a final sample of 150. For phase II of the study, 15 mentally retarded individuals within the sample of 150 noninstitutionalised cases living in and around Bangalore and attending the self-help group programme were selected as the experimental group.

HYPOTHESES

The following hypotheses were formulated for the present study:

1. There would be significant differentials with regard to psycho-social dimensions of mildly and moderately retarded individuals of institutionalised and noninstitutionalised groups.

2. There would be significant differentials in knowledge, orientation and attitude towards mental retardation and its management between parents of institutionalised and non-institutionalised mentally retarded individuals.
3. Self-Help group programmes would have positive impact on mental maturity, social maturity and adaptive behaviour of mental retardates under study; and also would have positive impact on the orientation, knowledge and attitude towards mental retardation and its management, of parents of mental retardates under study.

4. Parents participating in self-help group programme would express their satisfaction with this intervention programme.

TOOLS USED

The tools employed in the present study are as follows:

1. Binet Kamath’s Intelligence testing of Indian Children by Kamath, (1934).
5. Parental Attitude Scale (P A S) by Bhatti, (1975).
9. Parental Opinionnaire (tool constructed by the investigator).
10. Interview with parents (audio recording by the investigator).

PROCEDURE FOR DATA COLLECTION

In phase I, the investigator carried out a survey on 150 mentally retarded institutionalized subjects and their parent/parents from two institutions at Pune. The investigator assessed each subject’s performance independently, so that clear idea about the subjects’ intellectual functioning and adaptive behaviour in addition to their detailed case history could be obtained.

A total of 150 noninstitutionalised subjects who met the criteria of age and IQ were selected together with their parents to form the noninstitutionalised group for phase I of the study. Data was collected from Jammu region of J&K state and Bangalore region.

A total of 300 subjects, 150 institutionalised and 150 noninstitutionalised, of both sexes and belonging to mild and moderate degrees of mental retardation together with their parents were selected for the purpose of phase I of this study. Five psychological tests were administered on the subjects of Phase I with their parents’/teachers’ co-operation. All the subjects of Phase I were administered Binet-Kamat’s test of Intelligence, Developmental Screening Test and Vineland Social Maturity Scale. Parents were
administered Socio-Economic Status Scale, Parental Attitude Scale and Psycho-Social Checklist.

For phase II of this study, 15 subjects from the non institutionalised group of Phase I, living in and around Bangalore and attending the self-help group programme comprised the experimental group. As in phase I, subjects for phase II of this study met the criteria of selection. 15 subjects along with their parents comprised the experimental group.

Before the commencement of the daily self-help group and weekly self-help group programmes, the psychological tests were administered on the subjects of phase II as done in phase I.

In phase II, two additional tests were administered on the subject of experimental group; viz, Madras Developmental Programming System (MDPS) and Raven’s Coloured Progressive Matrices (RCPM). The parents in addition to tests of Phase I, responded to Parental Opinionnaire and Interview (Audio Recording).

STATISTICAL ANALYSIS

Various statistical techniques were employed for testing the research hypotheses. A brief description of these techniques is being made here as follows:

- Raw scores of DST and VSMS were converted into IQ 2 and SQ respectively.
- Combined IQ was obtained by averaging IQ Binet-Kamath, IQ DST and Social Quotient VSMS.
- Chi-square test of significance is used to compare institutionalised and noninstitutionalised
subjects for various psycho-social dimensions. The t-test was applied to different groups to test the difference in means of the variables measuring mental and social maturity of mentally retarded subjects and parental attitudes.

Paired t-test was applied between pre-test and three post-tests on the experimental group to ascertain if the impact of self-help group training was significant in measures of mental and social maturity, and also in parental attitudes towards mental retardation.

Graphic representation was done wherever necessary.

RESULTS

The results obtained in the present study are given below.

Prevalence of Mental Retardation

Out of the total sample of 300 subjects, 98 (32.7 percent) were mildly retarded and 202 (67.3 percent) were moderately retarded.

Out of the total sample of 300 subjects, 114 (38 percent) were female and 186 (62 percent) were male.

Among the 150 institutionalised subjects, 33 (22 percent) were mildly retarded and 117 (78 percent) were moderately retarded; 55 (36.6 percent) were female and 95 (63.3 percent) were male.

Among the 150 noninstitutionalised subjects, 65 (43.3 percent) were mildly retarded and 85 (56.7 percent) were moderately retarded.
percent) were moderately retarded; 58 (38.6 percent) were female and 92 (61.3 percent) were male.

Out of the total sample of 300 surveyed, 16 (5.3 percent) belonged to socio-economic class I, 58 (19.3 percent) belonged to class II, 139 (46.3 percent) belonged to class III, 58 (19.3 percent) belonged to class IV and 29 (9.7 percent) belonged to class V.

**Psycho-Social Dimensions**

The 150 institutionalised subjects were compared with 150 noninstitutionalised subjects for various psycho-social dimensions. The results obtained are given here:

Out of the 17 dimensions, the two groups differed significantly at .01 level in (1) Presenting problems, (2) First noticed problems, (3) History of organcy, (4) Inconvenience in house-hold affairs, (5) Effect of behavioural problems on the family, (6) Financial stress, (7) Overall stress, (8) Parents' attitudes, (9) Family's expectations of the child and (10) Support systems.

The two groups differed significantly at the .05 level in (1) Family history and (2) Decrease in interaction with neighbours.

The two groups did not differ significantly in (1) Behavioural problems, (2) Consanguinity, (3) Disturbance in the inter-personal relationships in the family (4) Presence of marital disharmony and (5) Psychological
problems caused in the family.

Comparison of Institutionalised and Noninstitutionalised Subjects for Socio-Economic Status and Parental Attitudes

The two groups institutionalised (N=150) and noninstitutionalised (N=150) were compared for socio-economic status and parental attitudes. The following are the results:

- The mean value of scores for variables SES, ORN, KGE, ATMR, ATMG and PAS were found higher for parents of institutionalised subjects compared with scores of parents of noninstitutionalised subjects.
- The two groups differed significantly at .01 level for the variables SES, ORN, KGE and PAS.

The two groups, institutionalised mildly retarded (N=33) and noninstitutionalised mildly retarded (N=65) were compared for socio-economic status and parental attitudes. The following results were obtained:

- The mean scores of variables SES, ORN, KGE, ATMR, ATMG and PAS were all higher for the institutionalised group.
- The mean scores of variables SES, KGE and PAS for the two groups differed significantly.

The two groups, institutionalised moderately retarded (N=117) and noninstitutionalised moderately retarded (N=85) were compared for socio-economic status and parental attitudes. The following results were
obtained :-

- The mean scores of variables SES, ORN, KGE, ATMR and PAS were all higher for the institutionalised group.
- The mean scores of variables SES, ORN, KGE and PAS for the two groups differed significantly.

Effectiveness of Self-Help Group

The self-help group programme would have positive impact on mental and social maturity, adaptive behaviour and parental attitudes of 15 subjects and their parents has been examined. The results are :-

IQ 1 - 8 gained on scores and 7 had marginal loss.
IQ 2 - 10 gained on scores and 5 had marginal loss.
SQ - All the 15 subjects gained on scores.
IQ Comb - All the 15 subjects showed an increase.
PAS - 11 parents showed gain in scores and 4 parents lost marginal in scores.
MDPS - All 15 subjects showed increase in scores.
RCPM - 9 showed increase in scores and 5 subjects showed loss in scores.

A paired t-test was done to compare pre-test with post-test scores. Significant t values were obtained for IQ 2, SQ, IQ Comb, MDPS and RCPM.

Parental opinionnaire was administered to elicit information from parents on their satisfaction with self-help group programme. The results showed that :-

- 83.33 percent of the parents expressed satisfaction with the self-help group, with the response percentage for individual questions
varying from 16 to 90 percent.
- For 6 out of 12 questions, the parents responded negatively with percentage varying from 5 to 25 percent.
- All the 12 questions elicited response of some times/some extent, with variation in percentage from 5 to 60.

CONCLUSIONS

In the light of findings of the present study, the following major conclusions can be drawn.

The ratio of mild to moderately retarded individuals is 1:2.06 for the entire sample under survey. The ratio is 1:3.54 and 1:1.3 for institutionalised and noninstitutionalised subjects respectively.

Sex distribution gives a female to male ratio of 1:1.63 for the total sample, 1:1.72 and 1:1.58 for the institutionalised and noninstitutionalised subjects; thus there is a preponderance of males.

Socio-economic status of the sample indicates that 25.6 percent belong to higher socio-economic status and 75.4 percent belong to lower socio-economic status. Comparison of the institutionalised and noninstitutionalised subjects for the various psycho-social dimensions, show that out of a total of 17 dimensions, in 12 (70.5 percent) dimensions, the two groups differ significantly. In 5 of the dimensions they do not differ significantly. Thus we can conclude that significant differences exist in psycho-social dimensions between institutionalised and noninstitutionalised subjects.
The comparison of parents of institutionalised and noninstitutionalised, both mildly and moderately retarded subjects, for socio-economic status and parental attitudes indicate that parents of institutionalised subjects are from a higher socio-economic class and had better knowledge and orientation towards mental retardation as compared with parents of noninstitutionalised subjects. It can be concluded that significant differences exist in socio-economic status and parental attitudes between the institutionalised and noninstitutionalised subjects.

Results of the measures of mental and social maturity, as well as adaptive behaviour indicate that the self-help group programme had a positive impact on the mental retardates. The subjects attending self-help group showed gain in scores of measures of mental and social maturity. Loss in scores were insignificant. The parents participating in the self-help programme showed more favourable parental attitudes toward mental retardation and its management, though the gain in scores of measures of parental attitudes were not statistically significant. 83.3 percent of the parents attending self-help group programme expressed satisfaction with this intervention programme. Thus it can be concluded that self-help group programme has a positive impact on the mental maturity, social maturity and adaptive behaviour of mental retardates; and also leads to more favourable parental attitudes.
The following related areas are considered worth exploring and suggested for further the research work:

1. A study to compare the effectiveness of self-help group programme in similar settings, with a control group not participating in it.
2. 'Self-advocacy' by the mental retardates during self-help group meetings.
3. Research work to establish effectiveness and reach of this programme compared with other community based programmes should be carried out.
4. Involvement of governmental and voluntary social agencies for expanding and enriching such programmes.
5. Studies to compare effectiveness of self-help groups in urban and rural settings and increased age range.
6. Further research work should be undertaken to replicate the present study in other regions of India and abroad.