This research study inspects the relevance and effectiveness of involving parents in the work with their mentally retarded children. It is therefore necessary that literature regarding the issue of parents of mentally retarded persons and their involvement be reviewed.

It is observed that there is no dearth of literature on feelings and reactions of parents towards retardation in their child. Literature on rationale and contents of programmes involving parents is also easily available. But on issues such as the form of intervention by parents or methods of evaluating the effectiveness and predictability of programmes involving parents, it is very difficult to find references. Therefore an issue for which literature to be reviewed is immense, the investigator has summarized and formulated all the findings. In so doing he has moved a little away from the conventional method of reviewing literature. The authors are not mentioned during the summarization but have been given credit by listing them in the References and Resource Reading at the end of the chapter.

Mental retardation could well be a disability of only the intellectual functioning but unlike the disabilities in other conditions it is the most obnoxious health and social experience. This is so because often there are
other associated disabilities e.g. motor disability or sensory dysfunctions. Most of all, this disability has the most adverse effect on learning and learning how to live in society. Therefore this condition carries with it the most stigma.

Parents are the members of society and are nearest to the retarded person. Hence their emotions have maximum relevance in the acceptance, care, education and rehabilitation of the mentally retarded persons in society.

**PART I  PARENTS AND THEIR EMOTIONS**

The emotions of the parents of mentally retarded persons and their reactions towards the child have been studied by many workers. The investigator summarizes the observations of most of these workers as follows.

**FEELINGS**. The feelings commonly observed in the parents are;

1) *Disillusionment*. All parents hope to realize their dreams through their children. Prior to the occurrence of retardation - at birth or later - the parents emotionally invest a great deal in the hope that their child will materialize their dreams. But the occurrence of retardation in the child snatches away this hope and the parents realize that the child will not fulfill their expectations.
2) Aloneness. In interacting and communicating with one's child parents generally experience a dual flow of emotions to and from the child. Owing to his inability to understand and communicate the mentally retarded child does not correspond to the emotions of their parents. This leaves parents with a feeling of aloneness.

3) Inequity. Having had an inadequate child the parents feel that justice has not been done to them. They feel cheated. But seldom can they attribute this injustice to any person or thing.

4) Loss of immortality. Along with the tendency of parents to materialize their dreams through their children, they also tend to think about the continuation of their own life-symbolically-through their children or deeds of the children. This feeling of being thus immortal is threatened by the retarded child who, they understand will not be able to continue their name, reputation, wealth or trade.

5) Frustration. Owing to child's retardation, rearing, managing and educating such a child yields rewards very slowly. The parents have to get accustomed to the reality of being satisfied with a little or no progress. This situation leads to a feeling of frustration.

It must be noted that these feelings are universal and hence occur in parents from all over. It is also observed that the same types of feelings occur in parents irrespective of the ordinal position or sex of the child.
REACTIONS / The feelings mentioned earlier give rise to reactions. The reactions and the behaviours manifesting them are:

1) Reaction of Guilt. Parents of mentally retarded persons show three types of guilt:
   a) Guilt about bringing such a child in the world.
   b) Guilt about harbouring negative thoughts for the retarded child; e.g. death-wishes.
   c) Guilt about the idea of rejecting or abandoning the child.

Most often the guilt is manifested by a compensatory behaviour of overprotection of the retarded child.

2) Reaction of Inadequacy. Becoming the parents of an inadequate child is understood by such parents as a sign of being inadequate themselves. Thus they feel inferior in the world of parents. This threatens their self-esteem.

The threat initiates them to adopt defence mechanisms like rationalization, projections, falsification of memory and, what is termed in Psychiatry as 'martyr complex' or 'martyr syndrome.'

3) Reaction of Complete Denial. This is also known as 'Ostrich' reaction. Here the parents do not accept the reality and continue living with the child as if nothing has happened.

4) Reaction of Partial Denial. Here the parents take the occurrence of retardation in their child as a temporary phenomenon i.e. some circumstance which will prevail only for a certain period of time. They believe that when circumstances change the retardation in the child will go away.
This reaction prompts the parents to go from one doctor to another or to turn to various traditional or occult forms of treatments. This is known as 'medical shopping.' Unfortunately this behaviour of parents is often reinforced not only by unqualified practitioners but also by qualified doctors.

5) Reaction of Rejection. In this parents reject the child i.e. hate it emotionally and neglect it physically. Here the functioning of hatred in parents is not only at the thought level but also at the level of action. Hence this rejection is seldom accompanied by guilt.

In this reaction the hostility towards the event of retardation in their child is directly materialized in the form of hostility towards the child. The parents may leave the child with relatives or even abandon it. In extreme situations—though very rarely—the parents may kill the child.

6) Reaction of Acceptance. Very few parents show this reaction wherein they acknowledge the occurrence of retardation as a natural event and accept to live with it.

Such parents evaluate the merits of the advice which they receive in connection with their retarded child. They are selective in implementing only that advice which is logically beneficial for their child. They seldom stop at helping only their own child and they involve themselves in some activity useful for other mentally retarded children.
The last reaction is shown to exist by nature in extremely mature parents Nevertheless, sound support from family-members, friends or professionals and proper guidance and counselling can help even other parents to reach a stage which enables them to show this reaction.

PHASES OF ADJUSTMENT IN PARENTS Conflict of parental emotions is an inevitable phase of the process of adjustment between the parents and their retarded child. This adjustment process has different phases as follows.

Phase of Shock
When the parents notice or become suspicious that their child is not 'normal' and when the doctor tells them that the child is 'mentally retarded' the parents go into a state of emotional shock. There occurs an emotional contusion. This leaves the parents defunct in terms of thought and affect towards the child.

The reaction of guilt about bringing the child in the world and the reaction of inadequacy are strongest during this phase.

Phase of Denial
The debility caused by the emotional contusion brings in a great stress on the emotions of parents. This stress calls for some defence mechanism to cope with the situation. Denial of the information received from the doctor is a common mode for doing this. Not that parents close eyes to the problem. But they wish to avoid the knowledge of the existence of the problem.
The reaction of guilt about having negative thoughts towards the child and the reaction of partial denial are strongest during this phase. In case this phase gets prolonged the reaction of complete denial may also become strong.

Phase of Sadness and Anger.

When parents do realise that the consequences of the problem cannot be denied they move in to this phase. Sadness may be caused because parents realise that they are not well equipped to meet the needs of their mentally retarded child. On the other hand there may be anger caused if the parents now see the child as an obstacle in their personal desires, ambitions, pursuits, interests and reputation.

The reaction of guilt about the idea of rejecting the child and the reaction of rejection of the child are strongest during this phase.

Phase of Equilibrium.

Support is received from near relatives and/or professionals during the phase of sadness. Similarly social restrictions operate on the parents during the phase of anger. Moreover until then parents too experience that small successes are accomplished during parenting their child. This support, restriction and success together enable parents to move to this phase.

Emotional maturity evolves and hence parents acknowledge the need to accept the child and the problems. In this period the emotional conflicts become less devastating. The emotions balance each other in effect and counter-effect. Hence this phase is so named.
The reaction of acceptance is strongest during this phase.

Phase of Reorganization.

Generally parents reach this phase if they receive conducive social environment and correct professional help. At this stage all the emotional conflicts are resolved or at least they are too weak to disturb the parents. Hence the child is emotionally accommodated in the life of the parents in all respects. They become realistic in their expectations from the child and start taking steps towards proper (special) education and rehabilitation of their son or daughter.

It is to be noted that there is no set period of time and duration for each phase. The personalities of the parents, the social climate and circumstances, and the availability and impact of professional help received, all influence the movement of parents through these phases. Similarly although conceived as progressive phases these are not necessarily so. Depending on circumstances parents belong to one or even more phases. Some may even be observed to regress to a seemingly earlier phase.
PART II  PARENTS AND PROFESSIONALS

As mentioned in the earlier chapters persons from numerous disciplines play a role in the field of mental retardation. It is inevitable that parents of mentally retarded children come in contact with several of them. The most significant professionals amongst them are the doctors, therapists (this includes psychologists and social workers) and special education teachers.

It is known that in many parts of the world there are families with mentally retarded persons which do not come in contact with any of these professionals. Yet the number of those who do is very large and therefore enough to produce literature on the relationship between the parents of mentally retarded persons and the professionals in the field.

The earliest occasion of such a contact is when the child is referred to a doctor and the condition of retardation in the child is communicated to the parents. There cannot be a particular prescribed method, style or wording which can be recommended as correct and 'shock-proof' communication. But it is observed that the WAY in which parents are told about the existence of retardation in the child has a profound effect on their emotions. Similarly WHEN (i.e., how early) the parents are told and the TRUTH in what is said by the doctor are other very significant factors which affect the parents (Cunningham, 1977).
The receipt of the communication regarding the condition of their child triggers off the feelings and reactions mentioned before. The parents, mostly the mother, are "devastated". (Lane, 1971).

The communication is only the beginning of a long association between parents and professionals. The emotionally devastated parents need help and guidance not only to help them pull themselves together but also in parenting their retarded child. It is observed that "parents who have been entirely successful in bringing up their normal children have felt hopelessly at sea with a handicapped child". (Jelfree, 1971).

In order to understand why the parents feel it difficult to bring up their retarded child, it is pertinent to learn what helps them in bringing up their normal child. The fact behind parents ability to bring up their normal child or children is their knowledge of child-rearing practices. These practices, whether right or wrong, are passed down in the family from generation to generation. (Lenore, 1981).

There is no such passing down of knowledge regarding rearing a retarded child because they do not occur in each generation of every family. Therein lies the need for such parents to take help from professionals. The professionals, on the other hand, hold information about the retardation in the child although not necessarily that about rearing such a child. Barsch called this a great
"chasm" which remains open between the extensive body of knowledge in childhood disability rehabilitation and awareness of this knowledge in the family of a disabled child, (Barsch, 1963).

What Barsch observed in 1963 is true to a great extent even at present in most parts of the world. In such parts the parents traditionally take care of their retarded child with family's support until the child becomes too large to lift or to manage easily. (Taylor, 1981).

In other parts of the world the pattern is changing. Not only that there is a formal relationship developed between parents and professionals, but the form of this relationship is changing. Three main phases are observed in the process of relationship that has been developing between the two. (Mittler, 1982).

The first phase which existed until the end of 1950s is termed (by the investigator) as 'Advice Phase'. The professionals hardly involved parents directly in the care and education of their mentally retarded children. The parents received little help from the professionals and they were largely left unsupported. The advice given rarely included practical suggestions on what the parents could do to help their child at home. Parents were frequently advised to place their mentally retarded child in residential care if one existed nearby and could be afforded.
The second phase is called the 'Transplant Phase' by Jeffree (1980). This began towards the beginning of 1960s. Professionals started regarding parents of mentally retarded persons as co-therapists or co-educators. They started training parents to use some of the management and education techniques. The parents in turn implemented these techniques at home thus actively participating in the process of rearing their retarded child. Professionals largely worked on the assumption that they knew best what the child should learn and therefore what the parents should do at home. Through research the professionals began investigating the most effective methods of training parents to carry out-like technicians- the programmes devised by professionals. (O'Dell, 1974).

From the beginning of 1980s began the phase which has been characterized as the 'Consumer Model'. Cunningham describes the logistics of this phase. In this model the main aim is to augment parenting skills. Parents are offered what is felt as the necessary information for them to live with and help their child. The parents select from this information according to their current needs and in their own time. This model takes into account the needs, resources and uniqueness of each individual family. The model rests on the assumption that services should be developed after understanding and respecting the range of different ways in which families think and live their lives. (Cunningham, 1982).
The transplant phase was the outcome of the need to understand the behaviour of mentally retarded persons in their natural environment. That need was the result of dissatisfaction with laboratory investigations. The consumer model, on the other hand, is the outcome of the realization that parents can be helped to develop effective teaching strategies and that they develop such strategies spontaneously once they have been helped to work out specific teaching objectives. (Cheseldine, 1979).

The consumer model has become most acceptable now. Many examples of good collaboration have been reported. A whole series of reports from government, professional and parent bodies endorse both its principles and its practice (Mittler, 1982).

The rationale for getting into collaborations between parents and professionals is enumerated below:

1) Growth and learning in children can only be understood in relation to the environment in which the child is living.

2) Parents need to be aware of the precise teaching methods and strategies used by teachers/professionals to achieve any particular teaching goal.

3) Knowledge and experience of normal children and ordinary parental intuition, while undoubtedly valuable, are not necessarily adequate to assist the development of a retarded child.
4) It is important for the parents to be aware of the significance of uneven development, particularly for example, in the area of speech and language development where underfunctioning is common. Parents are easily discouraged by lack of progress and hence need to appreciate the significance of even the smallest step in development and the means by which the child can be helped to attain it.

5) If parents, who seek services for their retarded child and thus become dependent on them, are trained to be problem solvers, they will be able to help their child through their ordinary day-to-day interactions with him and thus get over their feelings and reactions.

6) Parents know and are in the charge of care for the child since birth. They know intimately the child's idiosyncratic responses over a wide range of activities.

7) The parental love is such that the child is valued unconditionally and for his own sake irrespective of sex, appearance, abilities and personality. (Shearer, 1972; Kellmer, 1974; Bricker, 1980; Pugh, 1981; Mittler, 1982).

There is great variation in the levels of collaboration between the parents and the professionals. These levels can be arranged in the following order:

- Where parents are valued as consumers of the service but are not directly involved in the service (Nigeria).
Where parents recall general guidelines regarding management of the child (Jordan).

Where parents receive general guidelines and counselling at home (Sri Lanka).

Where parents receive guidance, counselling and rudimentary education about retardation and its management (Thailand).

Where parents receive guidance and training for implementing home-training (Jamaica).

Where parents are trained to work in schools and community (Argentina).

Where parents are involved in planning services for care of the retarded children (Denmark).

Where parents receive training to help at special schools and to implement home-training. They are also involved in planning services (Canada) (Stukat, 1981).

PART III PARTNERSHIP WITH PARENTS.

The focus of the study directs to concentrate on the literature on programmes which have included parents of mentally retarded persons as partners. Most of these programmes involve work with parents of babies and young children (Baker, Barrera, Bricker, Denhoff, Gordon, Hayden, Kass, Shearer all 1976; Cunningham, 1979; Fugh, 1981).
Certain characteristics are found to be common in all programmes involving parents as partners. These characteristics are:

1) The mothers are the primary object of training and bear the major responsibility for carrying out the programme.
2) Training consists primarily of operant approaches to contingency management.
3) The programmes are aimed at reduction of maladaptive behaviours.
4) The programmes help parents to provide activities to encourage perceptual-motor, physical, cognitive and self-care skills.
5) The programmes lay emphasis on interaction between parents and child as means for facilitating language stimulation.

(Berkowitz, 1972; Dunst, 1973; Hanson, 1977).

Stages of Training:

Nardine describes four stages in training and involving parents as partners in educational programmes. These stages are:

Stage 1 - Readiness on the part of the parents.
Stage 2 - Improving of observational and analytical abilities.
Stage 3 - Mastering of specialized techniques.
Stage 4 - Satisfaction of doing something.

(Nardine, 1974).
Methods and Equipment of Training

The training methods employed in such programmes include various combinations: individual and/or group training through lectures, assigned readings, programmed material, group discussion, modelling and direct coaching. The devices include telephones, video and audio tapes, films, hands, sound and light signals. (Berkowitz, 1972).

Effectiveness of Partnership with Parents

Whether the programmes which involved teachers as educationists and parents were entirely successful i.e., effective is a question which cannot be answered either affirmatively or negatively. Gordon and Dunst reviewed such Programmes and report that they were effective (Gordon, 1969; Dunst, 1973). Pryor observes the same as far as his own study is concerned (Pryor, 1974).

Gordon acknowledges that the family is the key factor in the learning and development of the child. But in the same review he confesses that the form which intervention should take is not entirely clear and mentions that there is a paucity of research data and clear theoretical positions. (Gordon, 1959).

Later Berkowitz commented that the body of literature (on the programmes) as a whole can be criticized for design limitations viz., inadequate controls and measurements, limited follow-ups, poor evaluative techniques, lack of details on training methods and parent and child behavioural changes.
He also pointed out that most parent training programmes are small-scale involving from one to five children. The exceptions to this trend was seen in programmes carried out by Walder, Hauf and Patterson who worked with 50, 19 & 20 children respectively as quoted by Berkowitz.

Commenting on the short-comings in the design Berkowitz points out that owing to high level of programme complexity, methodological sophistication and parental involvement and responsibility there appears a weakness in reporting specific data. He also states that although it is possible to obtain Pre and Post measures it is difficult to quantitatively specify the data.

Caldwell, however, makes a direct mention that early intervention programmes— and these involved parents— in general did not meet the optimistic expectations of the 1960s and that arguments about the futility or undesirability of such intervention gained favour. (Caldwell, 1974).

The effectiveness of a programme involving parents appears to be related to the socio-economic class of the parents. Luterman (1971) considered programmes more likely to be successful in the case of middle class families. In a later study it was found that it was successful with high income level parents (Sadler et al, 1976). The converse is also observed to be true i.e. programmes were less successful with parents from
the lower income groups. (Rinn et al., 1975).

As in socio-economic level a strong positive correlation is observed between educational level of parents and success (effectiveness) of programme. (Salzinger et al., 1970).

Cunningham's (1980) conclusions are different. He concludes that socio-economic level and educational level of the parents is not generally correlated with their ability to learn and apply techniques for training and stimulating their child.

If Cunningham's conclusion is accepted then the question which arises is what constitutes the success or effectiveness of a programme. Literature fails to provide the answer to this question and hence the controversy continues.

Allen and her colleagues observe that three factors are primarily responsible for the continuing controversy. The first factor is the use of varying and limited criteria for gauging programme's success. The second factor is the paucity of methodologically sound programme evaluations. The third factor is the over generality of the question of effectiveness. (Allen et al., 1984).
Although the controversy continues programmes involving parents as partners continue to be tried out. Some of them have become popular because of the content of the professional-to-parent-to-child training programme. One such programme is the Portage Project. (See Appendix 3(a) for details of the Portage Project). The model proposed and implemented in this project has been followed in several countries including India (Mittler, 1984). But the Project's method does have its own shortcomings too. Whilst it provides a life-line for some parents, its very structure may be too vigorous for others and may impose considerable strains on families whose ability to cope is already stretched to its limits (Pugh, 1981).

Literature which suggests guidelines for implementing partnership programmes have been reviewed too. All such literature is quoted at appropriate places in the following chapters.

Summary

Literature related to the parents of mentally retarded persons has been reviewed in this chapter. The chapter is divided into three parts. The first part concentrates on the feelings, reactions and phases of adjustment in parents in relation to their mentally retarded child. The second part describes the relationship between the parents and the professionals in the field of mental retardation. The third part highlights the partnership between the two and discusses the issue of effectiveness of such partnerships.
REFERENCES


Caldwell, B. A Decade of Early Intervention Programmes: What We Have Learnt. American Journal of Orthopsychiatry, 1974; 44.


Nardine, F. Parents as a Teaching Resource. The Volta Review 1974; (3).


RESOURCE READING


Latham, G. & Hofmeister, A. A Mediated Training Programme for Parents of the Pre-school Mentally Retarded. Exceptional Children, 1973; (3).


