COUNSELLORS MANUAL FOR FAMILY INTERVENTION IN MENTAL RETARDATION

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Counsellors Manual for Family Intervention in Mental Retardation

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PREFACE

In the recent years, it is being increasingly realized that appropriate care for persons with mental retardation can be organised only by active involvement of families and parents in the care process. Consequently, newer innovative models of family-focused interventions are evolving.

A 2-week family intervention programme was initiated at NIMHANS in 1985 by Dr. H.S. Narayanan and his colleagues. Subsequently, it was decided to evaluate this model of intervention in a systematic, prospective manner. Indian Council of Medical Research came forward to fund this project, titled "A study of evaluation of effectiveness of brief inpatient family intervention vs outpatient intervention for children with mental retardation" in 1991. In the process of training the research staff, I found that there is no single book which could satisfactorily address all the issues involved in this area, though there are excellent manuals and books devoted to parent training (such as the ones published by National Institute for the Mentally Handicapped, Secunderabad). This propelled me to prepare this manual which hopefully will fill this lacuna.

This Manual, therefore, has a distinct practical orientation, and covers all the relevant broad areas. Even though it has been written with in a particular population of persons with mental retardation in a particular setting in mind - children with severe mental retardation attending a hospital, it is hoped that it would be of use to care-givers in other settings working with different types of populations with mental retardation.

ACKNOWLEDGEMENTS

This Manual is essentially an attempt to document the ideas, philosophies, practices and discussions which have arisen in the zeitgeist of NIMHANS. I have merely listened and tried to give it a shape and put it down in black and white. Innumerable number of people at NIMHANS - teachers, colleagues, friends and co-workers - have been the source of support, inspiration and guidance. I mention only a few below.

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1. INTRODUCTION

Social and cultural milieu in India as represented by the family, by its inherent nature, provides ample scope for optimum care of persons with mental retardation (M.R.) within the family itself. Perhaps for this reason, we have never had to repeat the costly error made by the West of institutionalising and segregating these individuals.

However, the fact that these children are reared at home (with rare exceptions) doesn't automatically mean that the families can always cope with the added stress of having a retarded child without any care inputs, modifications, alterations, and outside support and help. Very often, families need help in diverse aspects of child development, health, medical needs, information, and social support / welfare.

The overall aim of family intervention in M.R. is to provide this kind of help and assistance to the family members in need, to successfully adapt the circumstance of having a handicapped child in their midst. Thus, the aims and objectives of family intervention are two-fold –

(i) To ensure optimal care for the child with mental retardation in terms of the needs for his/ her development, health and wellbeing, and to become a respectful citizen of society (normalisation) and

(ii) To ensure a successful family adaptation

Any model of family intervention in mental retardation has to incorporate these two aims.

In the ensuing sections, the model development at NIMHANS to fulfil the above two aims is discussed in terms of (a) the theoretical basis for the model and (b) the model description.

2. THEORETICAL ORIENTATION

As stated earlier, the interventions are directed towards the optimal development and wellbeing of the child as well as optimal adaptation of the family. Towards this end, the model makes use of several conceptually diverse treatment orientations in an eclectic manner.

The model draws upon different theoretical considerations to intervention as follows:

i) Family Adaptation : This emphasises on assessing nature and severity of stress experienced by families; family coping, resources and support systems; beliefs, attributions, attitudes, expectations and similar mediators of stress. The interventions in this area are largely handled through counselling, and are directed towards successful family adaptation. The ecological and culture-sensitive nature of such intervention needs to be emphasised.

ii) Developmental perspective : The developmental level and stage and the needs/ priorities which go along with are taken into consideration while planning for intervention.

iii) Transactional / interactional processes : The optimal development of the child - (both cognitive and psychosocial) - is considerably influenced by parent - child interactions and relationships. The fact that developmental delay often has deleterious effect on parent -infant interaction is recognised. Optimisation of these processes is included in the intervention, specifically applicable to infant stimulation, speech/ language therapy, and behaviour problem management.

iv) Environmental stimulation / enrichment: Optimum stimulation has been repeatedly demonstrated to be crucial for even normal development and more so in those who have developmental delay. Hence, sensory enrichment in the form of visual, tactile, auditory kinaesthetic stimulation as well as creating opportunities for motor (gross and fine) development are the usual components of intervention. It is important to note that these procedures overlap considerably with transactional interventions; in other words, meaningful environmental stimulation has to happen in the context of a mutually enjoyable reciprocal interaction between care giver and infant. In practice, this model is most operative during infancy.

v) Physical care : Occasional children with mental retardation have underlying medical disorders which are treatable (such as hypothyroidism and phenylketonuria. In addition, physical ill-health (eg. undernutrition, epilepsy, vitamin / mineral deficiency) or disability (visual impairment, hearing impairment, cerebral palsy) are often present along with mental retardation. Proper and adequate attention is necessary for these aspects of physical care. Examples of such interventions are recognition and treatment of feeding skills disorders, refractive errors, worm infestations, iron deficiency anaemia and epilepsy. Cerebral palsy,

when associated with mental retardation would need additional occupational / physiotherapy inputs.

vi) Behaviour modification : The approach and techniques of behaviour modification have been extensively studied for building up new behaviours and elimination of inappropriate and odd behaviours in both children and adults. Behavioural technology has also been widely applied for training the parents in the behaviour modification of their child. This approach finds an indispensable place in the model of family intervention. The major applications are training parents in (i) teaching new skills by modelling, shaping, prompting, cueing, chaining, rewards /re-inforcements for teaching self-help skills, and (ii) elimination of behaviour problems by activity scheduling, time-structuring, ignoring, disregarding, substitution, over correction, time-out and differential reinforcement.

3. DESCRIPTION OF MODEL

The salient features of the model of Brief In-patient Family Intervention (BIFI) are as follows:

Clientele : Children under **12** years with moderate or more severe mental retardation. Model is especially designed for those with multiple handicap/problems, and families with high degree of distress/poor coping.

Duration : Model entails 2 weeks of stay of the child with family or key family members in the centre or 3-4 visits to the centre over 2 weeks.

Professional inputs : The multidisciplinary team works with family intensively during this period. Generally, a case worker accomplishes much of the intervention work under guidance, with extra inputs from other members of the team. The case worker is often a trainee in the discipline of psychiatry, clinical psychology or psychiatric social work. It should be possible for this role to be played even lay volunteers who are suitably trained.

STAGES : The intervention can be broadly divided into two phases - stage of evaluation followed by intervention.

Evaluation : This is done to build up a comprehensive data-base about the child, family and environment, on the basis of which intervention would be planned.

Such an evaluation usually covers the following areas:

1. Detailed history and examination.
2. Norm referenced psychometric assessment of child for intellectual functioning (simple ones are Vineland Social Maturity Scale, Binet-Kmat Test, Seguin Form Board; other

tests include Gessels Developmental Schedule, and Bailey Scale of Infant Development).

3. Criterion referenced development assessment for programming. Parent Involvement Programme (PIP) development chart developed by Jeffree, D.M. and McConky R., Hester Adrian Research Centre, Manchester, U.K. and Portage checklist are useful tools for this purpose.

4. Assessment of behaviour disorder using a rating scale (such as part II of Adaptive Behaviour Scale of A.A.M.R., U.S.A.).

5. Assessment of Family stress, coping resources, attitudes, expectations, child rearing practices, social support (FAS) (Please see appendix II).

6. Medical investigations (relevant)

7. Systematic assessment in specific areas such as speech/language and motor function may be needed in some children.

A comprehensive diagnosis, and an individualised intervention plan for the child and family is formulated from the information collected. The following system of diagnosis evolved at NIMHANS has been found useful in this regard-

Level I : Presence and degree of retardation
Level II : Aetiological factors/syndromal diagnosis
Level III : Associated medical disorders/disabilities
Level IV : Associated psychiatric disorders/disabilities
Level V : Parental/family factors such as perception, awareness, expectations, stress, etc

Components of individualised intervention plan (Details of some of these are laid out in ensuing chapters)

I. Medical measures : Treatment of underlying disorder
Treatment of associated medical / Psychiatric disorders/disabilities.
Genetic counseling

II. Family orientation/ priming
Communication of diagnosis
Communication of prognosis
Responding to reactions
Improving cognitive mastery
Improving coping / resources
Decreasing stress
Motivating for training

III. General parenting measures: :

a) General health measures
   Health education, immunization
   Feeding
   Hygiene, Nutrition
b) Recognition and fulfilment of Psycho-social needs
   Warmth
   Disciplining
   Stimulation
   Social skills
c) Elimination of faulty parenting
   Overprotection
   Over involvement
   Inconsistent disciplining
   Unfavourable attitudes
   Neglect, abuse, rejection.

IV. Parent training:
   Programming
   Target selection
   Technique selection
   Parent training strategies.

In a given child/family, discrete activities under each of the broad component is selected and the flow/sequencing of these interventions are determined.

CHAPTER II

COUNSELLING INTERVENTION

SCHEME:

1. INTRODUCTION

The involvement of mental health workers in the care of children with mental retardation may take many forms. But the most important type of involvement, perhaps. is counselling the parents and family. Counselling assumes tremendous importance especially with the home-based family care approach. Parent and family counselling is the foundation on which all other interventions are built upon. There is considerable research evidence to show that the successful coping and adaptation of families with handicapped individuals greatly depend on their experiences of initial contact with care givers.

In this context, parent/family counselling can be broadly defined as a series of interactions between a trained counsellor and family with the aim of (i) imparting factual information. (ii) reducing stress/distress and enhancing coping/adaptation and (iii) imparting training skills.

In the following section, some guidelines for effective and efficient counselling are offered.

2. COUNSELLOR CHARACTERISTICS

A 'good counsellor' is the single most important component of successful counselling. Some characteristics of a good counsellor are as follows:

COUNSELLOR CHARACTERISTICS

i) A genuine concern for the welfare of the children with mental retardation and their families.

ii) Being sensitive/empathic towards parents' predicament.

iii) Sufficient basic knowledge about various aspects of mental retardation.

iv) Possession of appropriate counselling skills such as listening, interviewing, exploring, guiding and supporting skills.

v) Ability to remain impartial, i,e., avoiding taking sides, with either the child or family, or among family members.

vi) Action orientation, meaning the readiness to model for parents, rather than just verbal explanations and exhortations.

vii) A keen eye to recognise minor/subtle shifts and changes in the parental feelings, attitudes, expectations and coping skills and respond appropriately to even minor positive changes.

viii) Ability to establish and maintain good working relationship with other professionals and social service networks.

ix) Ability to recognise ones own limitations and thereby being honest in interactions with families.

3. COUNSELLING SITUATIONS

Families need counselling support in a variety of situations. The requirements, approaches, and tasks for the counsellor varies in these different circumstances.

What follows now is a sketch of some of these common situations and how the counsellor can respond to them. Specifically, rest of this chapter covers the following:-

1. Initial counselling
2. Group counselling
3. Handling of family maladaptations
   - Overprotection
   - Understimulation
   - Hostility / rejection

3.1 INITIAL COUNSELLING

3.1.1 Background

This refers to a set of counselling interventions, which are made soon after the evaluation is complete. For many reasons, this is the most vital period of counselling and the way it is done is very likely to influence the future adjustment of the family.

Parents often vividly remember the circumstances and the way in which they are initially told about the diagnosis and prognosis. There is research evidence to believe that the way parents construe this situation, affects their orientation towards the child and future help seeking for their child. Therefore, the therapist has to exercise care in what she/he is saying, and communicating to the family.

Aims and objectives of preliminary counselling are as follows:

i) Communications of diagnosis and prognosis in a psychologically proper fashion.
ii) Clearing up misconceptions and building on parents awareness about mental retardation.
iii) Recognising and handling the immediate parental reactions to the disclosure of diagnosis and prognosis.
iv) Orienting the families towards successful adaptation to the difficult and distressing situation of having a handicapped child in the family.
v) Making the parents aware of appropriate treatment options and helping them to make right choices, and
vi) Imparting other factual information such as available social agencies/services, social welfare benefits (railway concession, Income-tax exemption, pension, etc).
vii) Motivating the parents for training the child and to acquire the techniques of training (priming the parents to acquire the training skills).

3.1.2 Initial counselling - Communication of diagnosis and prognosis

Background

Informing the family about the nature of the disability is a rather painful task. The minimum things to be told are that the child has mental retardation; this is a disability which is not curable by medical or any other kind of treatment, that the child will continue to have difficulties in future in terms of development, attainment, learning and social adjustment.

Many parents become very upset at this time. Best thing for the counsellor to do, when this happens, is to be silent and supportive. Parents often resume speaking after a few minutes Counsellor, then has to listen, allow parents to talk, and allow parents to lead the interview. In other words, a good way of ensuring that parents are informed of the diagnosis is a proper fashion is to allow them to "discover" the diagnosis in the course of interview.

Other things which you want to tell parents can wait till parents recover composure.

Guidelines for Communication of Diagnosis and Prognosis

Remember the following points during the initial counselling session

i) Ensure that the data-base (detailed evaluation, tests, investigations, and comprehensive diagnosis) is complete, as far as possible. Comprehensive diagnosis means level of mental retardation, possible aetiological factors, associated medical problems/disabilities, associated psychiatric problems / disabilities, and lastly but not the least, assessment of the family in terms of stress experienced and mediators of stress, such as knowledge, attitude, expectations, practices, social support (FAS data).

ii) Have the data at hand for reference.

iii) Ensure that you have enough time and sufficient privacy devoid of frequent interference.

iv) Have both parents, other key family members, and the child.

v) Adjust your language and style of communication to the socio-cultural/educational background of the family.

vi) Many parents have difficulty in grasping/understanding the irreversible nature of disability is mental retardation. The 'five-finger example' often is handy in this context (i.e. God has given five fingers to us; if one is cut, it is not possible to make it grow again by any means). Use the same example to communicate the concept of habilitation - (i.e., if one finger is lost, it does not mean everything is gone; it is possible to train the remaining fingers to do many things).

vii) At this stage family members often ask questions about future, like will he able to walk, speak, take care of self, go to school etc. Counsellor has to be honest and address these questions appropriately. It is important to avoid the extremes of either pessimism or saying that the child will completely 'grow out' of this at a later time. While sharing the prognosis, one has to make two things clear- (a) That the child will continue to develop and this can be fostered by appropriate environment, and (b) the child will continue to be disabled in terms of age-appropriateness of development. Based on the information available, 'project' the child's condition at different ages, so that parents can grasp the prognosis better and thereby can develop proper expectations from the child. Inform them about what problems will improve to what extent, and by what means.

viii) Provide pauses while talking, so that parents can collect their thoughts and ask questions. Be ready to answer, queries to the extent that you manage, with honesty. Be ready to say 'I don't know' when the answers are beyond you - you can respond to these questions at a later session, if it is possible to do so.

ix) Make sure that parents have understood what you have told; if necessary, repeat.

x) Check about misconception and provide the necessary information.

Common misconceptions about mental retardation

1. Mental retardation is always a hereditary problem.
2. Past bad deeds of father/mother/both cause mental retardation
3. Unusual/untimely sexual activity leads to mental retardation
4. Pregnant women or lactating woman not following food and other restrictions led to mental retardation
5. Tonics/vitamins cure the child with mental retardation.
6. Child with mental retardation becomes normal as he or she grows.
7. Brain operation can make child with mental retardation normal.
8. It is better to place these children in institutions meant for them.
9. Parents alone will not be able to manage the child with mental retardation.
10. Marriage improves/cures mental retardation.
11. Individuals with mental retardation are sexually hyperactive and are dangerous.
12. Persons with mental retardation are dangerous to others.
13. As these children cannot protect themselves they should not be allowed to do any activity or go out with others.

xi) Be sensitive to the immediate parental reactions and allow them to ventilate; don't suppress parental reactions. Allow them to cry if they feel so; be supportive, gentle and empathic at this stage

3.1.3 Initial Counselling - Handling Reactions

When the diagnosis is told to parents they are likely to react in many different ways. It may come as a shock to parents and they may go through many different emotions such as sadness, helplessness, disappointment, misery, and hopelessness. Some parents may deny the problem and search for some hope of cure by one way or another. Often parents tend to seek reassurance that child will be alright in future. They may request for further investigations and procedures which they have heard about, such as C.T. Scan or brain surgery, in the hope that the brain may be 'set right' and the child thereby cured. More uncommonly, parents may develop guilt and self blame, or get angry or blame themselves or their stars for this predicament. These initial reactions can sometimes lead later to chronic feelings of sadness, and other

forms of personal distress, and even to adverse family repercussions such as marital and other interpersonal conflicts.

The counsellor has to understand that these are quite natural reactions. However, this a crucial stage in counselling because how the family adapts to this situation in terms of their attitudes, expectations and copying skills depends a lot on what kind of guidance they receive during this stage. In other words, development of healthy and protective practices with regards to the child depends on what they are told. At this stage, parents generally develop a dependent relationship and eagerly look forward to advice and guidance from the counsellor.

Guidelines for handling reactions

The tasks for the counsellor during this phase of counselling are as follows:

— Allow and encourage the parents to express what they have so far understood, their feelings and what they expect about the child.

— Be ready to offer information and correct the misconceptions, if and when they become apparent. Clarify doubts and offer help in practical matters. (For eg. fixing up appointments for consultation, investigations, referrals etc.) . For this purpose, it may be necessary to ensure that the parents are not overloaded with too much corrective information at one go or in one session. They may become more confused, not being able to handle a large number of facts contrary to their initial expectations. What is essential is to ensure that they assimilate (incorporate) each bit of information well. This frequently requires 2-3 sessions.

— Make it clear that a child with mental retardation is a developing person and therefore subject to both good and bad environmental influences.

— Help them to shift their attention from the disability to the assets or abilities the child has, i.e., make them look at the things the child can do rather than what things he cannot do. (favourable attitude).

— Help them to re-orient their expectations with regard to the child.

— Emphasise on the need for training the child and motivate them to learn training skills; praise them for the efforts which they may have already made.

— Tell them about social welfare benefits, organisations which work in this area, special schools etc.

3. 1. 4 Initial Counselling - Reorientation

Background :

Parents, having noticed that something is wrong with their child, bring the child with their own notions about the nature of the problem and treatment. They generally bring the child hopeful of a cure. But having gone through the phase 1 and 2 of initial counselling (i.e., communication of diagnosis, prognosis and the ensuing reactions), the frame of mind is such that they are at the threshold of a reappraisal of the situation of having a handicapped child. They are generally in a receptive frame of mind for further activities such as learning of training skills. This stage of counselling can be referred to as that of **reorientation.** At this stage parents are generally in a twilight zone between one of painful realities of failed expectations, dashed hopes and sorrow on the one hand, a new expectations, attitudes, hunger for knowledge and an eagerness/keenness to learn new things, and to do the best possible for their child, on the other.

They are generally in a heightened emotional stage and by this time relationship with the counsellor is quite strong.

With a good counselling during this phase, the following changes can often be expected).

i) Some kind of re-organisation of thoughts, in terms of looking at the childs' and their own predicament with new awareness and a determination to help the child. This is seen as looking at the future with some degree of confidence and expectations of help.

ii) An improved observational capacity of the childs' behaviour such as noting the responses and reactions.

iii) An eagerness to learn more, cognitively as well as in terms of practices.

Guidelines for reorientation phase of initial counselling

Following is set of guidelines for counselling during this phase.

i) Look for signs of reorientation as mentioned, if they are not there, go over the earlier phase of counselling and complete the unfinished task.

ii) Appreciate the parents whenever desirable changes are noticed, comment positively on their new discoveries.

iii) Discuss the role of training/targeted intervention in greater detail. (Note: By this time, it is possible to draw up an individualize intervention programme for the child and family. Discuss aspects of this with family so that they become clear about what to expect).

iv) Give examples of how to educate/train the child (more details in section of parent training).

3.2 GROUP PARENTAL COUNSELLING

Often a counsellor has to handle several families with retarded children at any given time. Group parental counselling in such a situation offers clear advantages to the parents and the counsellor. Parents benefit by having an opportunity for interacting, learning, and sharing with each other and often overcome feelings of isolation.

There are several approaches to group counselling. The model described here is the one developed and practised at NIMHANS as a regular weekly out-patients activity since 1978. The group is primary composed of parents whose children have been recently evaluated; however, about 20-30% are 'old parents' i.e., those who have already attended the group a few times and have come again for follow-up counselling.

These sessions are basically meant for providing an appropriate orientation/priming for parents. Therefore the counselling is built around the theme of imparting factual information about nature, causes and treatment options regarding mental retardation. In addition, these sections are meant to instill a sense of confidence in parents by the virtue of group processes and motivate them for acquiring training skills. Immediately following the group sections, the parents are seen individually for further work. Though this model is evolved for a specific context, it can be suitably adapted in different situations.

Structural aspects

The group is generally composed of 8-15 families, and lasts 60-90 minutes. A large secluded room with circular seating arrangement and audio-visual facilities (black-board and projectors) is required for the purpose.

Process and Content of Group Counselling

After the group has assembled, counselling process goes through the following sequential steps:

Mutual Introduction: Have every parent/ guardian and speak for 2-3 minutes to the group about their child's problems. After all participants have spoken, bring forth the commonalities and differences in the parental reports and focus on developmental delay. Name it, define it, and emphasize differences from mental illness. Then, focus on the organ affected (you may elicit this from group easily), the importance of brain, and how brain development is the basis for cognitive development.

Normal child development: Next, relate the issue of mental retardation to normal child development - prenatal, birth (mention about onset of spontaneous respiration and refer to asphyxia), and post-natal cognitive development. Give examples of milestones/abilities of children at various ages (3.6.12.24and 36months) to clarify the point. Then bring in the role of environment in the form of stimulation, etc. in development. Give the example of speech development (Viz., child may be inherently bright, but if nobody speaks to him, he won't learn language).

Nature of mental retardation: Come back to the issue of mental retardation , by focusing on developmental delay as the salient feature of mental retardation. Talk about associated disturbances which often accompany mental retardation (fits, cerebral palsy, behaviour problem visual/hearing impairment). Introduce the concept of degrees of mental retardation and follow-it up by briefly describing common causes of mental retardation (use only simple causes, such as pre-natal infections and drugs, chromosome problems, peri-natal aspyxia, post-natal encephalitis). The next step is crucial - tell them about the continuing nature of disability and the need for life long care and supervision; irreversible nature (use 5-finger example); futility of drugs, x-rays, tests and operations. Be clear, slow and repeat once more. "Project" the prognosis for different degrees in adulthood. Also, refer here for the need for medication for associated conditions such as epilepsy.

Parental reactions: As a next step, focus on common parental reactions — that they are likely to feel disappointment, disillusionment, sadness, helplessness, disbelief and so on. Say that these are natural and perhaps, inevitable reactions and that these feelings can be gradually overcome by good coping and adjustment.

Treatment options: Focus on the question of cure - if it can't be cured, then what can be done? Use the 5-finger example again and introduce the concept of habilitation ("providing opportunity for best possible development") and training.

At this point, it is often useful to encourage 'trained parents' to share their experiences of training. While they do so, get them to talk about their efforts, difficulties they faced, successes as well as failures, frustrations and joyful moments. You may also get the other 'new' parents talking on similar lines. Intervene only when the discussion tends to lose focus. Round it off by summarising about these children's learning characteristics and common problems in teaching.

Individualised training : Once the concept of training is introduced, address the group in general about the range of training activity (sensory-motor stimulation, self-help skills training, speech and language training motor training and so on), and the need for individualisation of these activities to a given child (A one year old infant vs 6 year old boy with moderate mental retardation). Specially mention the behaviour modifications techniques to build new skills such as rewards, praise, modelling and prompting. Mention use of play as a medium of learning and necessity for toys.

Demonstration: A skilful counsellor can always manage to demonstrate some of the training techniques (such as modelling and praise) in the group itself. Parents are highly appreciative of such a demonstration and it helps a great deal to build up parental motivation to learn training techniques.

Conclusion End the session by summarising. Give enough time in the eijd for parents to ask questions and clarify their doubts once more. Conclude on an optimistic note about the possibilities for the children and their families.

What has been outlined so far as process is a general format. It can be suitably modified according to the situation.

Some do's and don't's about group counselling :

1. Include all persons who have accompanied the child into the group.
2. You must have the affected children also in the group, unless they are too troublesome and impede communication.
3. Have the case-notes of all children and go through them before starting.
4. Initially, parents tend to address the counsellor when they speak. But as the group warms up, get them to talk to the group, rather than to you.
5. Use of display cards, black-board, overhead projectors etc. will help in better communication.
6. Simple language, practical examples and encouragement for active participation will help the counselling to be effective.

3.3 HANDLING FAMILY MALADAPTATIONS

Parent's realisation that the child is handicapped may set in motion many different parenting, or child-rearing practices. Some of these, such as recognition of need for training and stimulation are very favourable and desirable/adaptive, whereas others may not be so. The common examples of maladaptive parenting include overprotection, understimulation, hostility, rejection and neglect.

These and similar, inappropriate parental/family environmental influences may lead to several problems in the child which are definitely preventable and also reversible. Such handicaps the child has are called "secondary handicaps". An important aim of family intervention is the prevention of the development of secondary handicaps and correction or reversal of these, if they have already developed. Some of these secondary handicaps are:

i) Lack of motivation to learn, lethargy.
ii) Behaviour problems such as temper tantrums, excessive clinging and demands.
iii) Self-stimulatory behaviours.
iv) Social withdrawal and autistic kind of picture.
v) Irritability, excessive crying, fussiness.
vi) Undernutrition or obesity.

Overprotection

Some parents may view their child as being very vulnerable, weak and totally incapable of learning. As a result, they may tend to always 'protect' the child and do everything for the child. This may be bad for the child because the environment becomes too restrictive and lacking in opportunities for learning. This child may develop lack of interest in learning and expects everything to be done to him. As a consequence (i) he/she may not learn the skills which is very much in his capacity and (ii) develop behavioural problems such as excessive demanding, temper tantrums and stubbornness.

Counsellor has to be alert to the possibility of overprotection and identify when it is present. Parental statements such as "I just cannot see him crying, I get too upset". "He is so weak and helpless; how can he do anything", "I constantly keep worrying that she may fall sick" indicate parental anxieties which can lead to overprotection. Direct observation of parent child interactions is often helpful to understand the patterns and degree of overprotection.

On observation, carrying/lifting the child all the time, overindulgence with child's wishes, too much apprehension when the child is out of sight, too frequent interference with child's activities, getting too anxious when she starts crying and rushing to console her, over concern about minor ailments in the child, weak attempts to discipline unwanted behaviours all these may indicate the presence of overprotection. These can be easily seen in this clinic.

Management of over protection

i) Identify overprotection and clear examples of its manifestations.
ii) Explain the deleterious effects of overprotection. Here are 2 examples.

- Now she is small and you can manage to do everything for her. But when she grows up, without learning how to do things by herself, how will you manage? Now is the time to teach and make her learn')
- 'It is such easier to do things for him now, but when he grows up and becomes big, it will be very tough for you to care for him by yourself doing everything for him. If you take some trouble to make him gradually independent, he will be able to do things by himself as he grows up'.

iii) Explain that these children need opportunities for learning/stimulation as well as disciplining just like a normal child.

iv) Explain and demonstrate methods such as rewards and reinforcements to make the child interested/motivated in learning. Ask parents to practice in front of you and give feedback.

Understimulation

As will be described in section sensory-motor stimulation (SMS), a child with mental retardation is at a great risk for understimulation. The reasons are (i) Parents' disappointment with child's lack of responsiveness and consequent reduction in stimulating parent - child interaction. (ii) Parent's sadness and depression (iii) Presence of other parental factors such as over-protection and rejection. Methods to correct understimulation is described in the section on SMS

Hostility/Rejection

Parents may feel resentful toward the child for many reasons-for having failed to come up to their expectations, need for extra care which many of these children require, being a cause for their personal distress, helplessness to deal with situations which demand internal/ external resources which may not be forthcoming in a family which is already in a difficult situation for some other reasons such as a poor social support. These feelings of resentment sometimes may become very strong and lead to hostility towards the child, rejection, neglect, and parental burn-out.

Hostility and rejection may manifest in many ways such as negative attitude towards the child, neglect of the child's basic needs, a lack of involvement/distancing from the child, lack of warmth towards the child, excessive and indiscriminate punishment, physical abuse and so on.

It is quite difficult to work with such parents and calls for a lot of patience and perseverance on the part of counsellor. He/she may develop feelings of 'Counter-transference', such as anger towards parents, and frustration. The counsellor has to acknowledge the feelings when they arise and should see that they don't interfere with the task at hand. It is very important to realise that no parent is totally rejecting towards her/his child. In other words, parents may fluctuate/alternate between feelings of care/affection and feelings of rejection towards their child,

(ambivalence). Following are a few guidelines to manage rejection/hostility.

Management of hostility/rejection

Avoid value judgement of parents - it will vitiate the relationship between the counsellor and family; parents may get the message that they are rejected in turn by professionals.

Working backwards: Try to understand the reasons and connections which brought the family to the current point of rejection/hostility.

Allow the parents to ventilate: This is specially relevant in the areas of their feelings, frustrations, stresses and difficulties.

Identify and appreciate the parental efforts to attend to needs, however small,

Demonstrate the ill-effects of hostility on the child and family: Parents need to see the vicious cycle of stress-hostility - worsening of child's problems-increased stress. Such an understanding can bring down their hostility.

Teach parents methods of emotional self-control: Examples are, disengaging from the child when they get very angry and upset and allow themselves to be calm before engaging with the child again.

Teach better methods of handling the child: These can be in terms of rewards, reinforcements, time-out procedure and training skills.

Improve the quality of relationship between the child and family members: These can be in terms of shared activities, enjoyable games, outings (quality time).

Attend to the other stresses which the family is facing such parental discord, parental mental disorder, financial difficulties and so on.

HANDLING ADVERSE SOCIAL CONSEQUENCES

Having a disabled child in the family have far reaching consequences to the family. These need not always be adverse or disadvantageous. The child can bring about strengthening of social bonds. However, negative social consequences are more often seen. The following part looks at some of the important negative social consequences and the family counselling to alleviate the same.

Altered social life

Families may respond to the presence of a member with mental retardation by a decrease in social life in terms of visits to social places, outings and social events (such as marriage and other ceremonies). In addition, there can be a decrease in the number of visits to relatives and friends and visits by the relatives and friends to the family. The relationship with neighbours may also be affected similarly. In general, the number of social contacts may decrease. The family may not send its handicapped child to play outside and conversely, the neighbours may discourage their children from playing with the handicapped child.

There are many reasons why this happens:

i) The need for extra care and attention for the affected child may cut down available time and energy for these activities.

ii) It may simply be an outcome of parental reactions, such as depression.

iii) More importantly, it may be as a result of a feeling of shame, social embarrassment, and fear of stigma, or actual experiences of stigmatisation.

Social embarrassment and stigma: As a handicapped child grows up and disability becomes quite noticeable by others, parents face a very distressing predicament of social embarrassment and stigma. The stares, hurting comments and indiscreet enquiries by others may upset the parents and compel them to avoid social situations and outings. Parents may develop marked feelings of shame, apprehensions, and social embarrassment. This may led to isolation of the child even within the family - the child may be restricted from coming out when relatives and friends visit the house, or may be left back at home when parents go out.

There are two aspects of stigma - (i) Actual instances of stigmatisation such as ridicule, comments etc. and (ii) the fear of stigmatisation. It is the latter which is more often prevalent and thereby contributes more to impaired social life of the family.

Management of adverse social consequences

i) Determine the presence and extent of adverse social consequences as described, both in terms of altered social life and social embarrassment/stigma.

ii) Determine the effects of these on the family life and relationship.

iii) Try to formulate hypothesis in terms of available data from all sources of how this family, with this child, in this particular environment came to develop these responses.

iv) Identify aspects of social functioning of the family which are clearly amenable for

change (targeting the intervention). For eg., some amount of decrease in social life may be inevitable, given the nature of child's problem. However, much of the decrease in social interactions, which is secondary to subjective fears of stigmatisation, can be effectively reversed.

v) Have a free-flowing discussion with the family about your impressions, conjectures and hypotheses and agree on common goal.

vi) There are general techniques which can be employed to reverse adverse consequences and build on healthy social responses-choose the technique depending on appropriateness.

Following is a list of such techniques

- Supportive techniques such as suggestions, exploration and ventilation.
- Reassurance about subjective fears of stigmatisation.
- Building contacts with families who share a similar predicament (self-help groups).
- Specific strategies to respond adaptively to indiscrete comments and enquiries (see box for example).

SOCIAL COPING OF FAMILIES — SOME EXAMPLES

1. Sister of a woman with mental retardation

An important daily routine for the woman as well as the family was sitting with her in front of the house in the evenings. But a batch of boys who used pass at the same time would throw funny comments and glances at her, which would upset everyone. To overcome this, the sister called one of the boys in and gently explored what they thought was the problem. The boy replied that she had a peculiar smile, way of looking, etc. Then the sister explained in simple terms what was the problem and how she was upset by their behaviours. This action on the part of the sister, surprisingly, brought about a sea change in the attitude of the boys; so much so that they became playmates for this woman!

2. **Mother of a grown up girl with mental retardation, in public transport**

The conductor grumbled. 'Why do you bring such children and add to my problem'. Mother was hurt, but replied — 'the same situation does not obtain for all; please adjust and God will bless you', conductor's attitude changed and he cooperated.

3. **Similar situation as in above, but a Father**

He said "what to do? it is our Karma. We have to do our duty as parents. Please help". Conductor fell silent and cooperated.

4. **Young parents of a 5 year old girl with Downs Syndrome**

"When our relatives see this child, they say things which imply that either we have not made enough efforts, or we were too stingy to get the proper kind of treatment which would have cured the girl of her problem, or some such statement of finding fault with us or blaming us for the girl's problem. Hearing this would make us feel very bad. But now we have learnt to handle such talk. We reply back, by either saying that I will give you Rs. 10,000/- and challenge to take her wherever you want and get her cured, or by informing them about the places where we have shown her.

- Encourage visits to such places which have a high degree of social approval and therefore least threatening — for eg. Temples.

- Graded return to social activities. (Temples-walks-parks-religious ceremonies-marriages-visits to close friends and relatives-invitation to visit house-supervised interaction with neighbourhood children - visit to neighbours and so on).

- Teaching social skills to the child.

- Sometimes just a discussion about this issue and pointing out the negative consequences of social isolation is enough to bring about change in this sphere.

- Factual information about special schools, parent organisation, training centres, other service facilities, social agencies in the neighbourhood will provide opportunities for family to become socially active.

CHAPTER III

PARENT TRAINING - A PRIMER

SCHEME:

1. INTRODUCTION
2. PRE-REQUISITES FOR SUCCESSFUL PARENT TRAINING
    a. Good database
    b. Preliminary counselling
    c. Parental motivation
    d. Working relationship
    e. Parent-child relationship
3. PROCESS OF PARENT TRAINING
    a. Choose areas
    b. Choose targets
    c. Choose techniques
    d. Impart training skills to parents
4. SOME USEFUL HINTS

1. INTRODUCTION

A great deal of time in family intervention in mental retardation is devoted to training parents. This reflects the importance and crucial nature of parent training in home-based family care. Parent training can be defined as the process of making parents or family members learn a range of skills to appropriately train their affected child in different areas of functioning. There are already, excellent User's Manuals (For instance manuals published by National Institute of Mental Handicap, Manovikas Nagar, P.O. Bowenpally, Secunderabad) for parent training. This section is meant to give a general orientation to parent training before one can start using the manuals.

The place of parent training in the overall perspective of family intervention has to be understood clearly by caseworkers; what we aim at is not the actual acquisition of skills by the child, but rather the acquisition of training skills by the parents/family members. However, during intervention, if parents do learn and practice training skills, one can expect 'small gains' in the child's functioning. Our expectation is that once the parents learn the skills under supervision and see the resultant change in the child in terms of small gains, they become confident and convinced and will continue to carry out training at home also.

2. PRE-REQUISITES FOR SUCCESSFUL PARENT TRAINING

The Counsellor has to make sure that certain steps are gone through before attempting to initiate parent training. These are as follows:

a) Good database: A good knowledge of **child variables** (such as abilities, assets, deficits, liabilities, learning styles, amenability for rewards), family variables (background, parenting styles, child rearing practices, parental 'personality', family relationships) and environmental variables (neighbourhood, opportunities for work, play and leisure) is essential for parent training to be meaningful.

b) Preliminary counseling : Communication of diagnosis/prognosis, handling parental distress, clearing misconceptions, adjusting expectations and attitudes should be complete or nearing completion before parent training can start, as described in the chapter on counseling.

c) Parental motivation: Before embarking on actual work, ensure that parents are sufficiently interested; in other words ensure that degree of readiness to understand and practice training skills is not grossly inappropriate. If lacking, build up motivation before training. Helping parents to achieve success in bringing about even small changes in child's behaviour is enough to get the parents interested. Sometimes discussing parents' own childhood experiences of up-bringing (positive or negative) and the role played by their parents in their development is useful.

d) Working relationship: Strike a good empathic relationship with parents. Once parents realise that your concern towards them and their child is genuine, they are more ready to listen to what you tell them.

e) Ensure that parent - child relationship is not grossly disturbed. This is important because, if parents are markedly hostile, rejecting, indifferent/neglectful, or overprotective/ over involved, then the chances of learning training skills are slim. In such circumstances, it is wiser to improve the relationship first. In other words, a good relationship with child leads to greater understanding of the child's needs, and his/her abilities and limitations. This, in turn leads to a realisation of need for rearing the child more appropriately, which obviously includes teaching/training. Such a stage of realisation/conceptual readiness is most optimal for imparting training skills.

3. PROCESS OF PARENT TRAINING

The actual process of training parents involves a series of steps (and this is where the manuals are handy) as follows:

a) Choose areas : You may choose either building up new behaviours or eliminate certain odd/excessive behaviours (when present). It is preferable to identify several areas (such as motor, language, social, self-help skills, conceptual skills) simultaneously.

b) Choose targets: In each given area, choose targets which is/are likely to be attained in two weeks. Fixing target in a given area is best done by a formal assessment of child's current level of development and functioning in a given area, using instruments such as PIP Developmental; Chart, Portage Check - list or VSMS. The next items, which the child is yet to master, are chosen as targets. Once the child has learnt to master these, one moves on to subsequent items, as targets.

c) Choose techniques: How is this child to be trained to achieve these targets? Behaviour modification techniques provide the answer here. The most widely used techniques are modelling, cueing, prompting, chaining, shaping and rewards/reinforcements (please see chapter on behaviour modification).

Mentioned below are two examples of choosing areas, targets and techniques

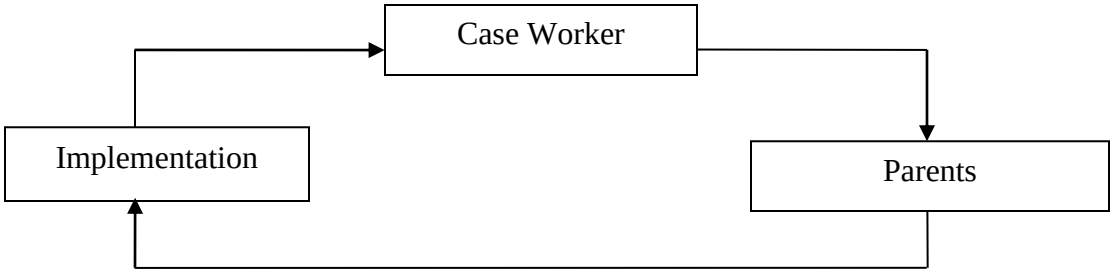
AREAS	TARGETS		TECHNIQUES
Self-help skills	(i)	Holds cup and drinks	Modelling, Prompting (physical)
	(ii)	Unbuttons worn shirt	Modelling, prompting/cueing shaping Rewards
Behaviour problem	(i)	Stops tantrum behaviours	Time-out Differential reinforcement

d) Impart training to parents: The case worker has to adopt many strategies to impart training skills to the family members. These are, explanations, instructions, discussion, modelling (demonstration), in viva rehearsal with feedback, video viewing, video recording and replay, and use of manuals/handouts.

In other words, explain the techniques, discuss with them, instruct what and how, demonstrate the techniques in front of parents, make them practice in front of you and give a feedback, and monitor on daily basis.

From this account, it is clear that actual training of parents is a very active and dynamic process and calls for considerable technical and communicative skills on the part of the counsellor, which comes with learning and experience.

Remember that parent training is a continuous, on-going process during the period of intervention. In other words, parents training proceeds as a series of interactions between parents and case worker as follows.



4. SOME USEFUL HINTS

Following are a few hints to carry out parental training in an efficient and effective manner:

- Make parents shift their emphasis from noticing failures to noticing successes, however small they are.

- Take the parents' complaints about difficulties in training seriously and discuss: Do not brush it aside saying 'that is how it is; you try for some more time'; etc.

- Be quick to observe and recognise parental efforts and praise them.

- Be quick to recognise 'small gains' which the child usually makes in the first 3-4 days and draw parents' attention to them.

- Pay special attention to the way the parents are rewarding/reinforcing the desirable behaviours, because it is a key variable in bringing about change. Ensure that what you are telling parents to do is contextually meaningful.

- Encourage parents to interact with other families; it helps them to draw strength and learn from each other.

- Structure the daily routine and incorporate, as far as possible, training activities into daily routine.

CHAPTER IV

SENSORY - MOTOR STIMULATION

SCHEME:

1. INTRODUCTION
2. DEFINITION
3. RATIONALE
4. GENERAL GUIDELINES
5. TECHNIQUES
6. TEACHING PARENTS SKILLS OF SENSORY - MOTOR STIMULATION

1. INTRODUCTION

Sensory-motor stimulation (SMS) is one of the most important techniques of intervention in infants who have developmental delay. This section provides theoretical basis as well as some guidelines for the practice of SMS in very young children.

2. DEFINITION

Very young children, who are in Piaget's sensory-motor stage of cognitive development, are dominated by their perceptual world and interact with their environment through motor manipulation. These activities are the basis on which further skills such as self identity, causality, speech and language, and socialisations evolve. In simpler terms infants learn and develop through what they perceive (see, hear, touch, smell, and taste) and handle. Sensory motor stimulation refers to a group of techniques and activities by which one can create an environment and facilitates development of these sensory-motor skills.

3. RATIONALE FOR SMS

Sensory/cognitive deprivation and understimulation have been repeatedly demonstrated to have harmful effects on normal development in studies involving experimental animals and 'wild boys'. In other words, certain amount of stimulation is essential for normal development. Experimental evidence has also demonstrated neurophysiologic changes such as dendritic branching and increased interneuronal connections following appropriate stimulation.

Children with developmental delay are at a great risk for understimulation for the following reasons:-

a) Much of the meaningful stimulation occurs through close, dyadic relationship and mutually enjoyable interactions between the mother and child. With a retarded child, the mother might feel disappointed and stop engaging the child as the child's responses are feeble and inconsistent.
b) The retarded children often have feeding problems and develop under-nutrition; this may make them lethargic and irritable and thereby elicit certain care-giving responses which may not be conducive to optimal stimulation.
c) Mother may feel depressed as a reaction to child's retardation and this will make her emotionally less available to the child.

In view of this, sensory-motor stimulation becomes an important strategy of intervention in very young children who have developmental delay.

4. GENERAL GUIDELINES FOR SENSORY-MOTOR STIMULATION

For SMS to be effective as an intervention one has to keep certain guidelines in mind. Following are a list of such guidelines.

a) Mother-child interaction

As stated earlier, much of the meaningful, enriching stimulation for the child occurs in the matrix of close, intimate, and mutually rewarding relationship between the mother and the child. A normal child tends to induce the mother into interacting by the way of his or her early attempts at socialisation, to which the mother responds by engaging and interacting with child. This affords enough stimulation for the child to develop. With a retarded child, this process may not occur and therefore, mother has to make repeated, and varying attempts to engage the child and elicit responses. Also, mother has to remember that these responses and reactions from the child initially are likely to be feeble or subtle and therefore she has to become adept at recognising them and adjust her expectations accordingly. When this happens, mother is likely to become spontaneous and devise her own techniques to engage the child and elicit responses. This mother-child interactional cycle can be broken down into following components –

i. Drawing the child's attention to her through eye to eye contact, touch, vocalisations, movements, etc.
ii. Introducing the activity and varying it till the child starts responding by smiling, motor activity, arrest of ongoing activity, excitement, etc.

iii. Noting of these responses by mother and repeating the activity to elicit further responses.

iv. Continuation of this cycle of interaction to higher and higher pitch/intensity till it reaches a zenith.

v. Moving on to another activity and repeating the cycle.

b) Activities chosen have to be developmentally appropriate

In other words, choosing an activity which is just within or outside the child's cognitive domain will more readily elicit responses from the child. e.g., a 7 month old child with a developmental level of 3-4 months will readily respond by smile to sudden facial movements.

c) Timing and setting: Choose a time when the child is well awake and is in a 'mood' to play. It is no use stimulates the child when he/she is hungry and irritable. Look for opportunities to engage the child during daily care activities such as feeding, dressing and bathing.

d) Stimulation should basically be a playful interaction with the child. Use of appropriate toys and other play materials will greatly enhance the quality of interaction.

e) Experimenting with different and innovative methods of stimulation will make the activity more mutually enjoyable.

f) Stimulation should cover all the different sensory modalities, i.e., vision, hearing, touch and other tactile sensations (pressure, temperature, vibration), kinaesthetic sensation (movement), smell and taste. Intersensory connections (for e.g., vision and hearing) can be fostered through affording sensations through different modalities simultaneously. Also, varying the stimulus characteristics (such as type, intensity, frequency, duration, distance) within each modality will expose the child to the whole range of sensory experiences.

5. TECHNIQUES OF SENSORY-MOTOR STIMULATION

Some examples of techniques of SMS are mentioned below. These are samples to convey the concept and not an exhaustive list.

- Place the child in a sitting position in the mother's lap, the child's face turned towards the mother. Hug the child, rock to & fro, making crooning noise or talking softly to the child.

- Tickle the child under the feet, arms and abdomen and elicit laughter from the child.

- Place the child sideways in a half reclined position on the mother's lap with legs dangling on side, with one hand supporting the child's head, and the other, his abdomen; then rock the child to & fro, the rocking movements have to be accompanied by one particular song or tune so that the child can associate the particular song/tune with the action.

- When the mother is engaged in household activity too, the stimulation of the child can be taken care of by hanging balls and other toys that make sound, hanging colourful cloth pieces of ribbons, balloons, dolls etc.

- Learn to stimulate the child by tickling, stroking, knocking, vocalising, simple repetitive games, so as to elicit laughter/smile from the child.

- Find out several ways of making the child smile like throwing the child up in air and holding it.

- Sit on a chair, keep your legs together and extend your legs forward. Now, raise your foot in such a way that the child can he placed at the foot, with his back resting or your legs. Now raise your legs up and down so that the child is also raised up and down.

- Make use of available household articles for play such as bangles, key chain, small containers, bells, rubber rings, glasses, spoons, plates, colourful ribbons or cloth pieces, anklets, match boxes, cigarette packs, etc.

- Make use of torch or a lighted candle light in a slightly dark room and move it from one end to another; this will help in development of eye movements.

- For the child to get various types of experiences the mother or any elder can be made to sit on a swing, placing the child on the lap and playing on the swing. Or swing the child sideways holding him/her in your arms.

- Cover the child's face with a cloth or hand and remove suddenly saying 'a-ha' or something similar.

- Give your hands, rattles or other suitable toys to child's hands; let her learn to grasp.

- Massage the body with ground-nut or coconut oil; play with her limbs and talk while doing so.

- The concept of self and others can be made clear with the help of a mirror. Having the child in front of the mirror and moving away from it, done many times making the child

look at herself and the mother, when it is crying/laughing, in the form of a play, will help the child to identify a baby and an elder in the mirror and later she will identify the reflection as her own.

6. TEACHING PARENTS SKILLS OF SENSORY-MOTOR STIMULATION

Parents, especially the young ones and those with a retarded child as the first issue, are often at a loss and confused about how to play and interact with a developmentally delayed child. But most of them can be taught the techniques of stimulation by an experienced counsellor. The following points, when remembered, will help the counsellor to successfully teach the skills to the parents.

1. Check with parents about the attempts which they have already made to interact with the child; ask them to demonstrate and praise them for appropriate efforts.
2. Discuss with them the importance of S.M.S. and make them understand the necessity of doing it.
3. Tell the parents that the brain will become more alert and active by stimulation and therapy will help the child to learn faster and develop control over his sense-organs.
4. Give examples which illustrate this point for e.g., in our culture, women in postpartum period are required wear lot of bangles, anklets and flowers; this will stimulate and help the infant to recognise the mother through sight, sound and smell.
5. Another way of instructing the parents is to tell them to learn as many different ways as possible to make the child smile and laugh. This concept is readily understood by the parents.
6. Demonstrate the techniques in the parents presence; this will help them to learn the techniques through modelling.
7. Make them practice/rehearse the activities in front of you and give them a feedback immediately about the appropriateness of their technique.
8. In short, make the session into a discussion cum demonstration cum practice session so that the parents can clearly comprehend and learn the practice of sensory-motor stimulation.

CHAPTER V

FACILITATING LANGUAGE DEVELOPMENT IN YOUNG CHILDREN

SCHEME :
1. INTRODUCTION
2. TECHNIQUES

1. INTRODUCTION

Babies can hear at birth and show a marked interest in the sound of a human voice from very early days. They enjoy being talked to, though they are unable to understand the words they are hearing. Some mothers may feel foolish talking to their babies, knowing that they can't understand. However, the input the child receives in these ways will foster the later development of speech and language skills in the child.

Frequently, in infants with developmental delay in both motor milestone and speech-language acquisition, parents do not realise the need for early speech-language stimulation as their prime concern then is the motor delay - the child's immediate inability to sit, stand or walk. Only as these skills are acquired, does their attention shift towards the speech development. But, this is not correct. Long before, the child needs to understand 'language' and feel the need to communicate. Unless parents are aware of this fact, they may miss a large part of the vital period in speech and language stimulation, in spite of early identification of the delay in development.

A responsive and rich verbal environment from the very start is essential to encourage language in young children. Whenever together with the infant, opportunity should be taken for gentle unhurried talk and verbal play.

2. TECHNIQUES

Here are some tips for parents to encourage their child to interact.

- Use normal routine activities when child gets individual attention, to talk maximally. For instance, talk and play with him every day while you feed, bathe and dress him up.

- Give a running commentary on whatever you are doing with the child at that time. React verbally to child's needs. Eg. Feeding time "I know you are hungry. Mummy will give you milk. Look, here it is, have it."

- Hold your child's attention while you talk to him. Face him and the get the child to look at you. As he listens he can watch the way you use our mouth to form sounds.

- Don't make it a one sided monologue. Listen to his noises too and respond to them. Talk to him in his ‘Language’ too. Imitate the sounds he makes and take turns making babbling noises. Provide him with new sounds to imitate.

- Pronounce words clearly and precisely. Use short words and simple sentences and stick to the present tense.

- Speak slowly and repeat important words and phrases to make a stronger impression. Vary your voice patterns.

- Use gesture and facial expressions to help clarify meaning (Eg. when you say ‘this tastes so good’ while feeding the child, smile broadly and lick your lips with pleasure as you raise the spoon.

- Name objects and activities that the child takes a special interest in and repeat the words whenever he experiences those things. Eg. ‘Water’, 'bottle', 'milk', 'wash',' etc.

- Recite nursery rhymes, sing lullabies to the child repeatedly so that the child learns to anticipate familiar sounds and rhymes. Get him to mimic related actions.

- Share a book with pictures of familiar objects/animals and point out each one as you name them - dog, chair, ball and so on. Then you can get your child to point out the same way as you repeat the words slowly.

- Play in front of the mirror with the child. lmitate his actions and also make him/her imitate your actions (actions of face, mouth, tongue, etc)

- Don't let the child feel pressured. Stop when the child is disinterested or is hungry or feeling sleepy. Resist impulses to correct too often.

- Finally give the child plenty of love and encouragement. Let him know how interested you are in his vocal play and provide him with reinforcement consistently for his efforts to communicate.

CHAPTER VI

BEHAVIOUR PROBLEMS IN CHILDREN WITH MENTAL RETARDATION: ASSESSMENT AND MANAGEMENT

SCHEME :

1. INTRODUCTION
2. CAUSES OF BEHAVIOUR DISORDER
   IN CHILDREN WITH MENTAL RETARDATION C
3. COMMON TYPES OF BEHAVIOUR PROBLEMS
4. ASSESSMENT OF BEHAVIOUR PROBLEMS
5. MANAGEMENT OF BEHAVIOUR PROBLEMS

1. INTRODUCTION

Children with mental retardation (MR) are often found to have associated behaviour disorders (B.D). Several studies have found the prevalence of B.D a in M.R. to be high - upto 40% of M.R. children may have one or other behaviour problems. Not only because of this fact of high prevalence, but also for the following other reasons, professionals working with children/families of M.R. have a sound understanding of the nature, causes and methods of evaluation and management of B.D, associated with M.R.

(i) B.D. often means added stress in the care of these children within the family. In fact, many studies have found a high correlation between severity of B.D and felt stress among family members, especially mothers.

(ii) Presence of B.D. often comes in the way of skills training.

(iii) A child with certain types of B.D. (such as overactivity, impulsivity and aggression) may prove to be dangerous to self or to others.

(iv) Some B.D's are highly 'visible' and may be perpetually embarrassing for the parents and makes the child vulnerable to social rejection.

In view of these potentially serious consequences for the family, B.D. management needs to be given high priority in the family intervention for M.R.

2. CAUSES OF B.D. IN M.R.

There are many reasons why a child with M.R. is more prone to develop B.D. — both biological and socio-environmental. These are as follows:

(i) Brain damage: B.D. is much more common in children with severe M.R than in those with mild M.R.

(ii) Syndrome specific causes: Certain pathologic disorders give rise to both M.R. and specific behaviour disturbance. For eg. Lesch-Nyhan syndrome is associated with M.R. and compulsive self -injurious behaviour.

(iii) Uncontrolled epilepsy is sometimes associated with irritability, poor concentration and overactivity.

(iv) Anti-epileptic drugs some drugs used to control epilepsy such as phenobarbitone may cause overactivity, decreased frustration tolerance and inattentiveness as a side effect in some children.

(v) Adverse conditions of upbringing: Certain maladaptive practices of child-rearing, such as overprotection, overinvolvement, rejection, hostility, inadequate/ inconsistent disciplining and lack of warmth may induce behavioural problems (dealt in detail in counselling intervention section).

(vi) Adverse family environment: Overcrowding, lack of basic amenities, family discord, poor social support and adverse neighbourhood may also significantly contribute to the development of B .D. Disturbance in parent child relationships often lead to B.D.

(vii) Low self esteem : Older children with M.R. who have a poor self image and feelings of inferiority may manifest B .D.

(viii) Understimulation: Children with M.R. are at a considerable risk for understimulation for a variety of reasons. As a consequence, these children may develop many self-stimulating patterns of behaviour such as stereotypes or attention seeking behaviours such as temper tantrums.

(ix) Speech handicap:Communicative ability of a retarded child may further be hampered by the presence of additional speech handicap. This can lead to diffuse overactivity, poor social responsiveness, withdrawal, indifference to social cues and odd behaviours.

(x) Faulty Learning: Inappropriate models in the environment induce an M.R. child to pick up faulty habits and behaviour patterns.

(xi) Nutritional deficiencies: A malnourished child may manifest problem behaviours such as irritability, excessive crying and apathy.

3. COMMON TYPES OF BEHAVIOUR PROBLEMS

All types of B.D which occur in normal children can also be present in children with M.R.The common symptoms are as follows:

1. Hyperactive behaviours : Restlessness, excessive pacing, running, excessive talking and inability to sit in a place.

2. Inattentiveness: Lack of concentration, destructibility, rapid shifts of attention, leaving tasks unfinished.

3. Conduct symptoms: Disobedience, non-compliance, stubbornness, temper tantrums,poor frustration tolerance, excessive demanding.

4. Violent, destructive and disruptive behaviours: Pushing, pinching, beating, biting, Damaging /destroying/ throwing articles, excessive noisiness, shouting, soiling, snatching, oppositional behaviours, impulsivity.

5. Self-injurious behaviour; Headbanging, beating self, self-biting, and other self mutilatory behaviours.

6. Stereotyped behaviours : Rocking, head-nodding, repetitive meaningless vocalisations, hand movements, tapping fists against head, waving hands in front of eyes, tooth grinding, thumb sucking, rotatory movements.

7. Autistic behaviours : Social withdrawal and unresponsiveness, indifference to people, self-isolating patterns of behaviour, poor eye-to-eye contact, motor and verbal stereotypes, gaze aversion, peculiar, unproductive and idiosyncratic activities, meaningless utterances.

8. Antisocial behaviours : Lying, stealing, obscene behaviours, vulgar/abusive language,bad company.

9. Dangerous behaviours: Fiddling with electric appliances, knives, fire, ignoring traffic while on road.

10. Sleep related problems : Inversion of sleep rhythm, decreased sleep, night terrors and nightmares, repeated wakening, enuresis.

11. Eating/feeding problems ; Regurgitation, messy eating habits, indiscriminate eating, poor appetite, pica, food fads, pickiness.

12. Affective disturbances : Emotional lability, excessive crying, irritability, apathy, anger outbursts.

13. Sexually inappropriate behaviours : Sexual disinhibitions, excessive and /or open masturbation, disrobing in public, socially embarrassing behaviours towards opposite sex.

14. Other odd behaviours : Socially embarrassing behaviours such as touching others unnecessarily, sitting on others, standing too close to others, playing with and smearing faces on self, hugging, kissing, spitting, indiscriminately.

A given child may have any combination of these symptoms in varying frequency, severity and duration. However, some symptoms may cluster together when a syndromal diagnosis (such as hyperinetic syndrome, infantile autism, and conduct disorder) is possible.

4. ASSESSMENT OF BEHAVIOUR PROBLEMS

A detailed assessment of B.D. is necessary to understand its origins, extent, impact on family,and most importantly, to plan for management.

The following points have to be kept in mind during assessment.

1) Screen the child for the presence of all possible behaviour problems by administering Behaviour Rating Scale (B .R.S.). The common error which is often committed is ‘diagnostic overshadowing‘, i.e., attributing disturbed behaviours to M.R. itself rather than recognising them as a separate problem.

2) Ascertain the severity (Intensity, duration, and frequency) and the context during which they are manifest (for each symptom).

3) Attempt a behavioural analysis of symptoms in terms Antecedents, Behaviours and Consequences (ABC analysis)

4) It is also important to note the concurrent deficits in behaviour. For eg. Excessive messiness during meals may be accompanied by concurrent deficits in self-eating skills.

5) Assess for the presence of underlying causes as already mentioned (biological factors such as uncontrolled epilepsy and psycho-social factors such as inadequate stimulation or disciplining). The causes of onset and/or maintenance of disturbed behaviours often can be traced to disturbed parent child interactional patterns (in terms of attitudes, predispositions, child rearing practises, disciplining methods, expectations, etc). An

assessment of these factors is a critical step because they can be effectively handledby counseling.

6) Evaluate the family members in terms of their perceptions, awareness level, attributions, and impact of B.D. on family.

7) First-hand observation of the B.D. is cmcial to understand it and formulate management. Child may have to be observed in different situations, for instance, with and without parents, indoor and out door settings. If necessary, precipitate the behaviour (for e. g. tantrum) to get to know more about it. Also note how do parents handle these problems and their stated reasons for doing so

8) Collect information from all possible sources (parents, significant others, sibs, teachers, nursing staff) to get a full picture of the problems.

5. MANAGEMENT OF BEHAVIOUR PROBLEMS

(i) Medical Measures: These include:

a) Treatment of uncontrolled seizures.

b) Replacement of anti-epileptic drug, if it is implicated as a cause of B.D.,

c) Use of medication for symptoms such as severe forms of overactivity/hyperkinesis, impulsivity, aggression and stereotypes (in only selected cases)

d) Management of undernutrition or deficiencies which may be accompanied by irritability, apathy and withdrawal, and,

e) Management of underlying disorder (such as hypothyroidism).

(ii) Optimisation of parent-child interactions

Disturbed parent-child interactions (P C I) may be a cause or consequence of B.D. In any case, an optimisation of parent child interaction often has a striking beneficial effect on B.D. The common disturbances in P.C.I are lack of warmth, overprotection, inadequate and inconsistent disciplining, and more rarely, hostility, rejection, abuse and neglect. During assessment, the case worker has to recognise if these patterns are present and carry out parent and family counselling accordingly. Lack of adequate stimulation needs a special mention here, because of its direct relevance in the causation of B.D. in M.R.

(iii) Use of behaviour modification techniques and training parents as behaviour modifier

This is the most widely used strategy for the control of B.D. The application of these techniques has been dealt with in the chapter on behaviour modification.

(iv) Attention to concurrent deficits in behaviour

This is an important step. This may involve self-help skills, speech/language, social-skills training, or methods to improve attention span.

(v) Other measures

Activity scheduling, time structuring pre vocational and vocational habilitation, and methods to improve self esteem of the child are some of the other techniques which may have to be considered to control B D.

CHAPTER VII

BEHAVIOUR MODIFICATION GUIDELINES

SCHEME: 1. INTRODUCTION
2. SOME BASIC CONCEPTS
3. TECHNIQUES FOR TEACHING NEW SKILLS
4. TECHNIQUES FOR MODIFYING PROBLEM BEHAVIOURS

1. INTRODUCTION

Behaviour modification is a system of treatment for changing behaviours. These techniques are based on learning theories and involve direct teaching and learning. In this system, there is a lot of emphasis on direct observation, measurement and recording of behaviours.

Experience with persons having mental retardation has shown that they are very effective, both for acquisition of new skills and for elimination of odd, excessive and problematic behaviours.

2. SOME BASIC CONCEPTS

It is important to be familiar with certain basic concepts of behaviour modification before one attempts to use them. They concern assessment, intervention and recording procedure. Some key concepts are as follows:

a) Goal specification: This means a very specific and detailed description of the desired changes in behaviour. Such goals have to be decided based the evaluation of assets and liabilities in the child and should be linked to the needs.

b) Task analysis: This means breaking the activity to be learned into several sequential steps to make it convenient for the person to learn. The number of steps in a given task is largely determined by the skills level and the capacity of the child. One child who is very slow to learn may require ten steps whereas another child who is faster may need only three steps.

The process of doing task analysis involves the following steps:

- Decide on you target goal

- write it in terms of measurable behaviours. Eg. Rama will sit at the table for meals and not throw his spoon on the floor (not "Rama will behave at dinner"). Eg. When asked to make her bed, Latha will go to her bed independently, pull up and tuck in the sheets and blanket, put the pillow on the bed, and cover the bed with a spread within a period of 10 minutes.

- consider your expectations carefully (including : are they high enough ? are they too high ?)

- level of independence-think about the long range goals-do you want the child to wait for a reminder or would you like him to do the task spontaneously ?

- How quickly does the child learn? Will she need assistance for a short period of time or for several months?

- Break down the task into steps appropriate for the child. As noted already, some children need to learn many steps in order to do a task successfully. Others need only a few.

- Each step should be written in terms of specific, measurable behaviours.

c) ABC Analysis

This analysis is frequently required for drawing a management plan for problem behaviours and involves and analysis of Antecedents, Behaviours, and their Consequences. Such an analysis leads to a thorough understanding of problem behaviours and helps in choosing proper techniques.

d) Rewards and reinforcers

The term 'Rewards' means pleasant events following a given behaviour and which increases the frequency of occurrence of that behaviour. Such rewards could be in the form of Materials such as food, eatables, toys, and money or privileges such as taking out for a ride or social consequences such as praise, attention, appreciation and approval.

Rewards are extremely useful to develop and strengthen new skills in children.

To be of good use, the rewards should be given (i) immediately (ii) consistently (iii) appropriately and (iv) Contingently (meaning that the rewards should be given only after a particular desired behaviour and not freely otherwise.

e) Recording system: As already noted, meticulous recording, monitoring and documentation is an essential part of behaviour modification.

3. TECHNIQUES FOR TEACHING NEW SKILLS

There are several methods for teaching a new skill; which you choose depends on the complexity of the task and the skills of the child. Here are some such techniques**.**

i) Backchaining

This method is used for teaching behaviours that have easily predictable series of steps. It is also useful with children who frustrate easily, are distractible or learn very slowly. It is possible to backchain almost any task and it is particularly successful because it is the most error-free teaching procedure.

— break the task down into several small steps (how many depends on the child).

— Teach the last step first. To do this you complete all of the steps leading up to the last one, perhaps giving a verbal play - by - play of the steps as you complete them. When you have arrived at the last step, make the child do it, assisting her verbally or physically (if necessary) to complete it. As soon as she does, lavish her with praise and give her a tangible or general reward.

— Example: Locking a door involves, for this child, six steps:

1. Taking the key out of her pockets
2. Putting the key into the lock
3. Turning the key 1/2 way towards locking the door.
4. Turning the key all the way
5. Taking the key out of the lock.
6. Putting the key in her pocket.

You do steps 1-5, telling her what you are doing as you do it. Have her put the key into her pocket say 'GOOD WORK'. Once the child has learnt step 6, you go through 1-4, assist her in step 5 and let her do step 6.

ii) **Frontchaining**

This method is the reverse of backchaining. It has a greater possibility of error and can be frustrating for children to perceive the final objective but cannot achieve it immediately. It is particularly useful for tasks where the easiest step comes first or for those that might be aversive to the child (toothbrushing, for example, to a tactile-defensive child).

— Break the task down into several small steps (how many depends on the child).
— Teach the first step first.

Example: climbing the stairs involves, for this child, several steps.

1. Standing in front of the stairs
2. Moving a foot towards the first stair
3. Resting that foot on the first stair
4. Putting weight on that foot.
5. Lifting the other foot up
6. Putting the second foot on the first stair
7. Putting weight on both feet.

Having the child stand in front of the stairs is the first thing you require. When he has done it he receives praise and a tangible or general reward.

With both backchaining and frontchaining you will gradually require the child to do more and more steps in order to be reinforced. Be very consistent about the steps and be sure that each is secure before moving on to the next.

You may find, after you have embarked on a teaching method, that you have an insufficient number of steps or too many. Revise as necessary. If you are too rigid the child will only be frustrated and the program will be unsuccessful.

iii) Shaping (successive approximation): Shaping is a useful technique when skill cannot easily be broken down into discrete steps (e.g. Vocal imitations) or is extremely aversive to the child (eg. sitting on a chair). Following steps are involved in shaping procedure:

— determine your target goal
— analyse the variable involved - in vocal imitation, for example, be aware of the child's body placement, lip formation, tongue placement, as well as the physical cues you are using.
— Begin by requiring only the behaviour that the child already has: Increase your expectations as the child make closer and closer approximations of the desired behaviour.

Example: Sitting in a chair for a child who refuses to do so involves:

1. Coming within **10** feet of the chair
2. Coming within 8 feet
3. Coming within 6 feet
4. Coming within 4 feet

5. Coming within 2 feet
6. Touching the chair
7. Sitting on the chair for **1** second
8. Sitting for 3 seconds ... and so on ...

Reinforce the child for each closer approximation, that is, reinforcement for 10 feet and then not another until she gets closer.

iv) Imitation (Modelling)

Use this only for children who have already demonstrated that they can imitate easily and well. You can use it either with backchaining or front-chaining depending on the complexity of the task and the skill of the child. You might be might able to demonstrate the entire task and have the child imitate what you do.

— break down the task into several steps, depending on the complexity of the task; either demonstrate the entire behaviour or break it down into a step-by-step demonstration.

Example: To teach bedmaking, using two side-by-side bed (one for each of you) and practice imitation as follows:

1. Pull the sheet up and cue (ask) the child to do the same.
2. Pull the blanket up and cue the child to do the same.
3. Turn down the top of the sheet and cue the child to do the same.
4. Tuck in one side (be sure the child can see what you are doing) and cue her to do the same.
5. Tuck in the other side and cue her.
6. Put pillow on the bed and cue her.

Reinforce any approximation at each stage. Neatness, at this stage, is NOT critical. If you choose to combine this task with backchaining, you do steps 1-5 and together do step six. Reinforce.

v) Total task: (Physical prompting)

Use this method when the task cannot be broken down into clear, separate steps, or when each individual step depends on previous and successive steps to make sense. Feeding oneself for example, requires that the spoon stay in the hand. It is too confusing and disjointed to fill the spoon with food and bring it to the child's mouth yourself and then transfer the spoon to her hand and guide her in placing it in her mouth. Total task requires constant guidance and lots of practice before the child can accomplish the task independently. It is difficult to fade that much guidance, but with careful thought and planning it can be done.

— break down the task into several steps. Even if the steps may not be all that distinct from one another, it is important to have a consistent pattern to follow.

— Determine what type of assistance will be most effective. Usually that such assistance will be physical. The idea is to foster independence while making it possible for the child to be successful as she learns,

Example: To teach a child to eat with a spoon, start with hand-over-hand guidance for all steps

1. Assist the child in picking up the spoon and keep your hand over hers.
2. Direct her hand to the food and scoop some into the spoon.
3. Bring her hand towards her mouth
4. Put spoon with food into her mouth
5. Remove spoon from mouth and replace in the bowl.

Praise her constantly as this is going on as if she were doing it all alone. As she gets more proficient, fade your physical guidance in the following order (but keep up the verbal cues) firm hand-over-hand (h-o-h); light h-o-h'; only your fingertips touching (in same position as h-o-h); two fingertips only; one finger tip; shadowing the child's hand with your hand. Gradually increase the distance between her hand and yours.

vi) Providing and fading assistance (Prompting)

The kind of assistance you will provide for the child depends on many factors that include both the skills the child already has and the nature of the task you wish him to perform. It ought to go without saying that verbal cues and repeated praise will be used even with other assistance. Be consistent with both cueing and praise since that will help the child to know both what is expected of him and whether he is achieving the objective.

A word about when the child is to be praised. If you usually say, 'Good Work' to a child and suddenly switch to 'Nice going' you may find that you have confused him. You can tag after the critical phrase whatever extras you wish (which will also serve to accustom him to them), but you must be completely consistent about the critical phase itself.

Other types of assistance include guiding a child through a task physically, either hand-over-hand or orienting her in the direction of the task; using gestures such as pointing; blocking her physical options in some way to help her make the correct decision (holding your hand over the hot water tap so that she can only turn on the cold); and modelling the task keeping up a verbal explanation as you do so.

You can provide some direct assistance by adapting materials in order to make the task easier, such as making the handle of spoon thicker and therefore easier to grasp. You can keep charts with gold stars for completing tasks; colour cues, such as different coloured labels on dresser drawers can be a real help. It is frequently helpful to have the assisted task come just before or just after some other event, such as washing hands before meals or brushing teeth just after a favourite story. In the first instance, the meal itself is part of the reward (though the child will learn it even if she is not successful at hand washing) and in the second, the story helps to put the child in a relaxed mood and a happy frame of mind.

Once you have provided assistance in teaching a task initially, you will need to work out a system for eliminating the assistance so that he can become independent.

Fading is a method of gradually eliminating assistance in a systemic manner.

— Fading physical assistance: start with hand-over-hand assistance (guiding the child by placing your hand over his). As he becomes more proficient, move your hand to his wrist, then the arm, then the elbow, etc. until physical assistance is not longer needed.

How do you know when to fade physical assistance?

Fading assistance is much like teaching a child to ride a bike. As you feel her start to balance herself, you let go for a moment. Gradually, you let go for longer and longer periods as she learns to ride on her own.

- Fading gestures: gradually make your gestures less obvious; when using a blocking technique, gradually uncover the blocked object.

- Fading modelling: gradually make your modelling less obvious and/or stop at the last step and let the child finish without assistance.

- Fading verbal cues: gradually reduce the verbal directions until nothing is said except for praise. Then reduce the amount of praise until it is reserved for the completed task. Verbal cues are the most difficult to fade and sometimes must be replaced by other cues which are easier to eliminate.

- Fading other types of assistance: Keeping in mind the level of independence you want the child to achieve, over the course of several weeks or months make the spoon handle thinner and thinner. With star on a chart, give them for tasks completed twice in a row moving to three times, etc.

vii) Negative reinforcement

This means to removal of unpleasant stimulus or state contingent on an adaptive or desirable response. This technique can be effectively used to build the motivation to make an appropriate response when the motivation is low. For example, withholding food when the child is hungry (an unpleasant state), till the child attempts to verbalise the need. This is especially useful in children who are cognitively capable, but poorly motivated to use language for communication. It goes without saying that this technique should be combined with modelling and positive reinforcement.

4. TECHNIQUES FOR MODIFYING PROBLEM BEHAVIOURS

These are many techniques to decrease or eliminate problem behaviours. These involve changing antecedents and / or consequences of behaviour. Some of these techniques are simple whereas others are more elaborate. The case worker has to learn the art of matching the technique to a given problem behaviour. As a general rule, it is preferable to try out the simpler ones first. However, severe behaviour problems often need several advanced techniques for effective control.

Simple techniques

i) Disregard

Ignore the behaviour but continue paying attention to the child. Basically, you are acting as if the behaviour was not occurring at all.

ii) Ignore

Ignore the child and the behaviour. You are acting as if the child doesn't exist for the period of time she's engaged in the behaviour.

iii) Redirect.

Catch the behaviour just as it is beginning (less than half-way complete) and guide the child to complete an appropriate behaviour.

iv) Blocking

Prevent a behaviour from reaching completion. This is primarily useful if children who are destructive or aggressive.

v) Gradual guidance

This means giving the child physical assistance to complete the task you have started together. Use as little guidance as possible and never use force. When you are using this technique you may spend a lot of time waiting for the child to stop resisting you. Don't use any verbal prompts after your first one.

With all these techniques it is important to reinforce appropriate behaviour when they occur so that your non-verbal approach makes an impact. If a problem behaviour does occur be sure to pause 5 to 30 seconds before you start reinforcing the child again.

It frequently happens that a child simultaneously completes a task or behaviour for which you would reinforce her and flows right into an unacceptable behaviour for which you would not. It is essential that you are alert to this possibility and refrain from giving the child reinforcement that she might interpret as reward for the unexpectable behaviour. You are teaching Radha to use spoon, for example. She has successfully gotten the food on the spoon, the spoon into her mouth, and has removed the spoon. Just as you are about to praise her 'oh, good work, Radha' — she spits the food onto the table. You can guess how she would interpret any reinforcement you might give her!

Advanced Techniques

i) Time-out

Time-out is an abbreviation for Time-out from Positive Reinforcement or attention. It is a punishment or extinction procedure for reducing maladaptive / undesirable behaviours such as temper-tantrums.

It means removal of positive reinforcement or attention for a specified time period contingent upon occurrence of a maladaptive or undesirable behaviour.

Example:

a) Isolation/seclusion in a room for a pre-decided specified period of time, contingent upon throwing a tantrum.
b) Taking away the plate of food when the child engages in undesirable eating behaviour.

Points to remember:

i) Offer verbal reason to the procedure if the child can cognitively understand it.

ii) One or two warnings can be given before carrying out time-out.

iii) Be firm and business-like while carrying it out, and avoid showing anger in any form.

iv) Location to which the child is removed may be corner of the room, or another room.

v) Time-out should be for a brief period: 3 to 10 minutes should be sufficient for most problems or release may be contingent upon a desirable change in behaviour.

vi) If undesirable behaviour occurs again on release from time-out, it is better to repeat the procedure again.

vii) Time-out should always be combined with differential reinforcement of other behaviour (DRO) meaning, make it a point to specially notice absence of undesirable behaviours or presence of desirable behaviours and reward immediately (social and /or material).

viii) Careful planning is necessary before time-out is to used, in terms of immediacy, consistency, intensity and administration.

ix) Time-out is a powerful technique and should only be tried after simpler methods such as disregarding, ignoring and distraction have failed.

ii) Overcorrection

Overcorrection means restoration of environment disturbed by the child after an episode of undesirable behaviour. For e.g. a child who throws water on floor during a fit of anger is made to clean the floor afterwards. In addition, the child may be made to clear the rest of the floor also.

iii) Response cost

This refers to withholding a privilege which the child usually enjoys, contingent upon the occurrence of an undesirable behaviour.

iv) Response prevention

Immediate physical restraint contingent on undesirable behaviour so as to reproduce mild discomfort is the simplest form of response prevention. It is always preferable to make substitutive behaviour available after the release from response prevention. Also, this techniques always has to combined with D.R.O.

v) Aversive conditioning

Even though this technique is controversial, it can still be used in certain situations. This technique refers to delivery of an unpleasant stimulus such as a painful tap delivered to hands contingent on an undesirable behaviour. Care should be taken that stimulus is intense enough, but not physically harmful and delivered immediately following (within seconds) the inappropriate behaviour. Rewarding appropriate responses (D.R.O.) is again an essential strategy to ensure efficacy of this technique. In other words, aversive conditioning will help only when it is a part of broader behaviour modification programme.

Examples:

a) Painful tap on the lips immediately on noticing open mouth (often leading to drooling).
b) A sharp painful tap on the hand for impulsive hand movements such as pulling others' hair, pinching, snatching articles, etc.

Remember

Always make it clear to the child that you are punishing the behaviour, but not the child.

APPENDIX 1

AN OVERVIEW OF MENTAL RETARDATION

This chapter is meant for refreshing the essential background information about mental retardation. The counsellor should of course, have more knowledge than written here through other sources (one excellent book for such purpose is Tredgold's Mental Retardation edited by Craft).

DEFINITION

Mental Retardation is a type of disability marked by impairment or deficiency in general intellectual functioning with onset during developmental years (0-1 8 years). Most children with M.R. have the following characteristics:

1. Delayed milestones of development from birth (motor, adaptive, social and language)

2. A slow rate of development compared to normal children leading to a limited intellectual capacity in adulthood.

3. Limited capacity for learning.

The degree to which these disabilities are present may vary from person to person, from very mild to profound. Persons with severe forms of M.R. need life-long care and supervision.

CAUSES

M.R. most often results from an impediment to normal brain development. Such an impediment can occur because of a variety of reasons. The common ones are as follows:

a) Genetic disorders: these generally are of two types - single gene disorders or chromosomal disorders. Heredity plays a role in some of these disorders.

b) Pregnancy related (maternal/environmental) : Certain types of infections in early pregnancy, use of harmful drugs in early pregnancy, severe malnutrition in the mother,alcohol intake in pregnancy, abortifacient use, iodine deficiency in the mother, excessive exposure to irradiation are one set of causes. Also, presence of certain other diseases in the mother related or unrelated to pregnancy - severe pre-eccalmpsia, Rh incompatibility - can result in M.R.

c) Complications of labour : abnormal presentations, prolonged labour, severe prematurity, low birthweight, cord round the neck, obstructed labour, cephalopelvic disproportion and other less common complications of labour can cause diminished blood and oxygen supply to foetal brain and thereby lead to asphyxial brain damage.

d) Neonatal problems : Septicaemia, severe jaundice of any cause and hypoglycaemia may also cause irreversible brain damage,

e) Other post-natal causes : Certain problems later in infancy or childhood such as brain fever (tuberculous or bacterial meningitis, viral encephalitis such as Japanese encephalitis), severe head injury, lead poisoning, severe protracted malnutrition, and severe psycho-social disadvantage can impair intellectual development sufficiently to cause M.R.

f) Cause is not known or not detectable in around 30-40% of subjects.

IDENTIFICATION

Children with severe forms of M.R. are easily identifiable because of gross, unmistakable deficits in global development. Mild M.R., however, needs careful collection of information, observations and sometimes psychological testing.

Disorders which can be confused with M.R. include cerebral palsy without M.R., specific speech delay, specific learning disabilities, infantile autism without M.R,, severely withdrawn child (emotional disorder) and sensory handicaps (deaf-mutism, visual impairment).

ASSOCIATED PROBLEMS

Other disorders and disabilities frequently accompany M,R. These include :

- Other disabilities: hearing impairment, visual impairment, cerebral palsy and orthopaedic disabilities such as dislocations and contractures.

- Medical disorders Epilepsy, undernutrition, vitamin/mineral deficiencies, feeding skill disorder, movement disorders, congenital heart diseases.

- Psychiatric disorders: Overactivity, hyperkinesis, aggressive behaviours, autistic features, temper tantrums, conduct symptoms (stubbornness, disobedience, being adamant, poor frustration tolerance and so on), self-injurious behaviour, socially inappropriate behaviours are some of the common behavioural/ emotional disturbances seen along with M.R.

CLINICAL EVALUATION

The purpose of evaluating a person with M.R. is two-fold.

- To arrive at a comprehensive understanding or diagnosis which includes presence and severity of M.R., probable cause, identification of associated medical/ psychiatric disorders and disabilities and lastly, family perceptions, reactions, expectations, attitudes and stress.

- To collect systematic information about client, family and environment to plan for an individualised intervention program.

Physical investigations are sometimes required to supplement the clinical evaluation; these may include biochemical, cytogenetic, radiological, electrophysiologic, immunologic and other rarer tests.

Psychometric tests such as developmental schedules or measures of intellectual, adaptive and social behaviour help in planning for intervention.

MANAGEMENT

Following principles guide the management -

1. Home-based family care approach with parents and other family members as partners in care.
2. Early detection and intervention.
3. Normalisation and integration.
4. Individualisation of intervention.
5. Medical measures to treat underlying or associated problems.
6. Optimum habilitation appropriate to a given child and family in a given environment.
7. Family empowerment.

These aspects have been discussed in greater detail in the chapter on model overview.

APPENDIX -2

FAMILY ASSESSMENT SCHEDULE (F A S)

(For use in assessment of stress and coping in families with children having mental retardation)

Developed by Dr. Satish Girimaji, Department of Psychiatry, NIMHANS, Bangalore for the project. A study of the Evaluation of the effectiveness of brief in-patient family intervention vs outpatient intervention for mentally retarded children funded by Indian Council of Medical Research, New Delhi.

INTRODUCTION

Description of FAS

This is a semi structured interview schedule to systematically elicit and quantify

i) The stress experienced (perceived) by families caring for child with mental retardation, and

ii) Certain key coping resources available for the family which are likely to modify the perceived stress (mediators).

The theoretical basis on which the instrument is designed largely corresponds to stress and coping theory put forward by Folkman and Lazarus. This instrument has been developed not only for recording the stress and its mediators in the family, but also to help in the formulation of family based intervention.

It has 2 major sections: Section I for elicitation of perceived stress in different areas and Section II for exploration of mediating factors.

The structure of these two sections are given below.

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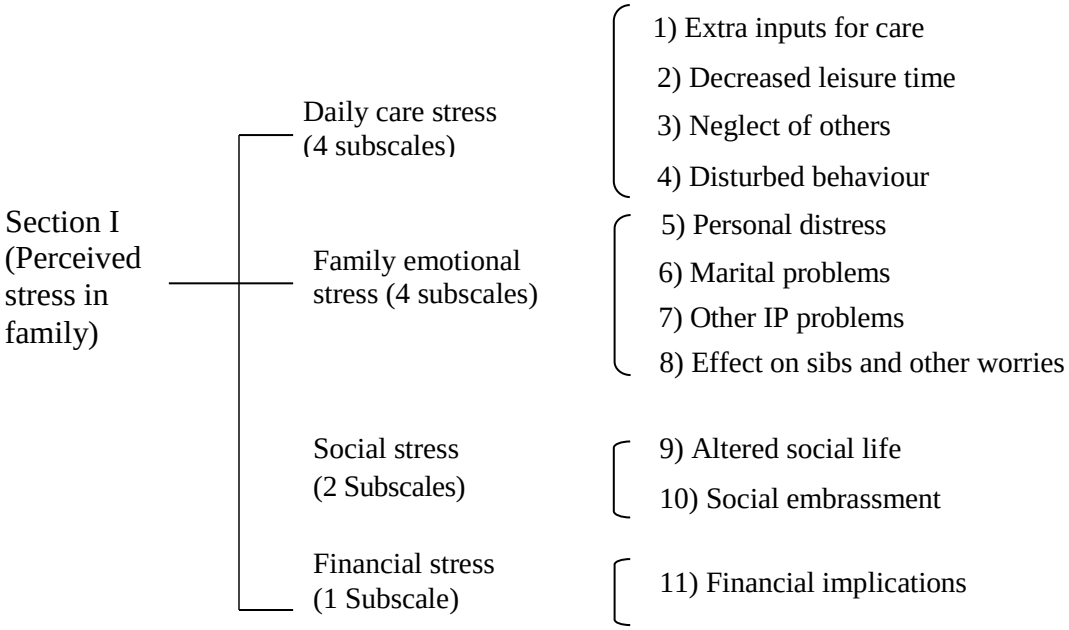

Section II
(Mediators)

1) Awareness about the child's problem
   a) General awareness (subscale No.1)
   b) Misconceptions (SS No.2)
2) Expectation and attitudes
   a) Expectation from the child (SS No.3)
   b) General attitude towards child (SS No.4)
   c) Attitude towards management (SS No,5)
3) Child rearing practices
   a) General child rearing practices (SS No.6)
   b) Rearing practices specific to training (SS No.7)
4) Social support (SS No.8)
5) Global family adaptation (SS No.9)

In short, section 1 has 4 areas and a total of 11 subscales. Whereas section II has 5 areas and a total of 9 subscales. A 4 or 5 point rating scale with scoring instructions in provided for each subscale.

In conclusion, this instrument provides for

(i) Quantification of perceived stress in the family as a whole under different areas and subscales and

(ii) Quantification of different mediating influences which are likely to alter the perceived stress.

Training Requirements for administration of FAS

1. A good working knowledge and some first hand experience of nature of mental retardation and its care from of family perspective is essential. More specifically, the rates should be conversant with family consequences, perceptions, reactions, attitudes, resources etc.

2. Rates should have a thorough understanding of the theoretical basis on which the instrument is built, so as to grasp its rationale and structure.

3. Several readings of the instrument and a few pilot administrations under supervision will ensure reliability of rating.

Guidelines for the conduct of interview

- Background information on child and family, such as generated by a detailed evaluation, has to be completed first and kept ready at hand for reference before administering FAS. Keep in mind the clues you may have already got about the family before you start.

- Have all key family members, as far as possible, during administration.

- Orient the family to the task before you begin : take consent and explain the procedure.

- Start off by exploring the stress. There is no need to strictly adhere to the sequence as per the schedule; but see that all sub-scales are covered. Be guided by the family's responses for ordering the coverage of sub-scales.

- Each sib-scale has a set of questions which have to be compulsorily asked before rating it. You may ask more questions for clarification.

- Use the anchor points to decide rating. While rating stress, rate maximum stress felt by any family member.

- Ratings have to be made immediately after all the questions in a particular sub-scale is asked.

- Use the separate sheet provided to enter rating.

- Thank the family after completion and add a word about how you are going to utilise the data for further management.

FAS SECTION I : PERCEIVED STRESS

AREA : DAILY CARE

Having this child, you may be feeling that you have to spend more time with him, give more care and attention and also feel that you have very little time for housework. I would like to ask you a few questions regarding this.

Sub-scale I Extra inputs for care

Do you think your child needs extra care compared to other children? Do you spend a lot of time in caring for your child? Do you sometimes feel that you cannot complete your housework because of your child's needs? Do you get tired?

Do you sometimes have to ask others for help to look after your child?

Scoring key for sub-scale-1

0	-	Nil
1	-	Low
2	-	Moderate - significant time or energy.
3	-	High - Significant time and energy
4	-	Very high - care felt to be highly demanding throughout the day

Sub scale -2, Decreased leisure time

Have you put off/reduced any activity or leisure because you have to devote time for your child? Do you feel that you do not have enough free time for yourself? Has any other family member's leisure time being affected because he/she has to take care of this child? (Leisure meaning free time to do what you want to do; pursuing family activities such as holidays, visits, watching movies, television and family trips etc).

Scoring key for sub-scale-2

0	-	Nil	- Not affected at all
1	-	Minimal	- Minimally affected
2	-	Somewhat	- Somewhat affected
3	-	Definitely	- Definitely affected
4	-	Totally	- All leisure time totally affected.

Sub-scale - 3 ; Neglect of others

Do you feel that you are not able to give proper amount of time to other family members now a days? Do your other children have to wait for your attention / help in school work, meals, bath etc., because of the time you spend with this child?

Do you other children/spouse complain and say that their needs are not fulfilled

Scoring key for sub-scale-3

0	-	Nil	- Not at all
1	-	Minimal	- Minimally affected
2	-	Somewhat	- One or more family member marginally affected
3	-	Definitely	- At least care of one family member definitely affected
4	-	Totally	- Several family members definitely affected in terms of amount of care provided.

Sub scale 4 : Disturbed behaviour

Do you have to be constantly by your child's side and keep him away from dangers like water, fire, knives, electrical gadgets etc.? How much does it interfere with your other activities.

Does the child exhibit behaviour like crying, shouting running around, throwing tantrums etc. which you cannot control and which needs a lot of a attention? How bothersome is it?

Scoring key for sub-scale-4

0	-	Nil	- Not at all
1	-	Mild	- Minimal disturbed behaviour
2	-	Moderate	- Occasional disturbance and needs some extra input
3	-	Severe	- Frequent disturbances and severity is marked
4	-	Very high	- Very severely disturbed behaviour, persistent almost throughout day needing extra Care/attention/vigilance; constant interference with family routines.

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AREA: FAMILY EMOTIONAL STRESS

Having children with this kind of problem may cause suffering to parents in many ways - for eg. internal suffering, worries and disappointments. It is also possible that it might affect family relationships. I would like to ask you a few questions regarding this.

Sub scale -5, Personal Distress

Do you feel sad when you think of your child?

Do you feel sad when you think of your child's future?

Do you worry a lot about her/him?

Do you sometimes lose sleep over child's future?

Do you feel the need to seek medical help?

Do you sometimes compare your child's progress with your relatives/neighbour's children and feel disappointed?

Do you feel like giving up looking after your child when he is too troublesome?

Do you feel that you would have been better off without a child like this?

Do you repeatedly feel bad and curse/blame yourself that it is all my karma/ grahachara and so on?

Do you often feel angry/resentful that God/destiny has inflicted this trouble on you for no fault of yours?

Do you sometimes blame yourself for having given birth to a child like this, i.e., feel that you are somehow responsible for the child's problem (guilt)?

Scoring key for sub-scale-5

0	-	Nil	- No personal distress
1	-	Mild	- Occassional, or transient periods of distress
2	-	Moderate	- Significant personal distress but lasting for short duration.
3	-	Severe	- Persistent dysphoria for long periods of significant intensity.
4	-	Very severe	- Very severe personal distress (depression, hopelessness, shamefulness, anger, guilt, present almost everyday)

Sub scale-6, Marital problem

Does your spouse help you in looking after the child?

Do you sometimes disagree on what is good for the child?

Has there been misunderstanding between you two because of the child? If so, in what way?

Do you disagree on major issues regarding child's welfare?

Do you fight over even trivial things regarding child's welfare? How often and how seriously?

Does your spouse complain that you are spending less time with him/her? Does your spouse blame you for the child's birth?

Has your spouse mentioned that he would like to break away or separate?

Scoring key for sub-scale-6

0	-	Nil	- No marital difficulties attributable to child's condition
1	-	Mild	- Slight differences of opinion
2		Moderate	- Difference of opinion with tiffs between couple at times, concerning/arising out of child's condition.
3	-	Severe	- Frequent fights between couples directly /indirectly attributable to child's condition.
4	-	Very high	- Threat to the marital relationship; impending divorce/separation.

Sub scale-7, Other interpersonal problems :

Has anybody blamed you for your child's problem?

Have misunderstandings occurred in the family with regard to the child's care?

Have you been visiting doctors one after another which has affected your work and other family members?

Scoring key for sub-scale-7

0	-	Nil	- No interpersonal problems
1	-	Mild	- Difference of opinion/slight non cooperation
2	-	Moderate	- Non-co operativeness and quarrels between family members at times
3	-	Severe	- Disagreement in and fights over more than two areas
4	-	Very high	- Severe disagreement in all aspects with threat to its unity.

Sub scale-8, Effect on sibs and other family worries

Do your other children repeatedly nag/make fun of this child?

Do they take care of him/her, or do they behave rudely with the child by pulling/ pushing him/her?

Because of this child, do other children avoid social activities like playing with other children, calling friends home, visiting neighbours etc.?

Does the behaviour of the child scare other children at home ?

Do you worry about the future of your other children and their marriage, career etc.?

Do you repeatedly worry about the future of this child? That this will be a big continuing problem? or do you feel that by your efforts or God's grace things will somehow work out in future.

Scoring key for sub-scale-8

0	-	Nil	- No demonstrable effect
1	-	Mild	- Slight apprehension regarding other's future/welfare
2	-	Moderate	- Apprehension and worry regarding other's future/welfare
3	-	Severe	- Faced difficulty regarding other's future, at least on two occasions
4		Very high	- Experienced more than two instances of threats regarding other member's future (marriage, education, job etc.)

SOCIAL LIFE

Relations with friends, neighbours and relative could be affected as a consequence of having a child with this kind of problem. Also, one may have disturbing feelings in taking out these children. I would like to question you regarding these aspects now.

Subscale-9, Altered social life

Do you find yourself at home more often, looking after the child than before?

Do you find less time to go outing, movies, temples, social visits? family functions like marriage etc?

Do your neighbours allow their children to play with your child?

Do your neighbours say that it is not good for their children to play with their child?

Have you stopped your leisure time activities now?

Have your relatives stopped inviting you to their house/functions, after the birth of this child?

Do you find less inclination to invite people home?

Scoring key for sub-scale-7

0	-	Nil	-	Social life not altered at all
1	-	Mild	-	Slightly altered in terms of going out
2	-	Moderate	-	Social contacts cut in l or 2 areas
3	-	Severe	-	All social contacts cut down except those of importance
4	-	Very high	-	All social contacts cut down.

Sub Scale - 10, Social embarrassment :

Do you feel apprehensive about others' comments, stares etc.? Is it only occasional? Is it frequent? When it does occur, how do you feel? Do you feel bad? Do you feel upset that you have had to face such comments? How much do you get upset? Do you think lot whenever you have to take your child out or when others are expected to visit home because of this?

Do you feel bad to take your child out?

Do you face situations where other stare and pass comments on your child? How do you react to these situations? Do you get angry, insulted, frustrated?

Do you restrict the child from coming outside when relatives/friends visit your house?

Scoring key for sub-scale-10

0	-	Nil	- No social embarrassment
1	-	Mild	- Anticipated apprehension regarding stigma
2	-	Moderate	- Apprehensive about others' comments, stares, queries etc; prevents the child being taken out
3	-	Severe	- Persistent, significant apprehensions leading to child being frequently kept away from social situations
4	-	Very high	- Active efforts/strives to keep the child constantly away from public eye in all instances.

Sub scale-11, Financial implications

In the interest of your child's welfare you may have sought treatment for him from the time you came to know that the child needs help. You might have had to spend money on the child in this regard. I will be asking you a few questions regarding your expenses and financial difficulties.

What is the expenditure incurred for the child's treatment?

How much money have you spent on special foods/appliances/special education for the child?

Have you spent money on other treatment methods like traditional healing etc.

Have you taken loans in order to help you out in financial difficulties-how much?

If loans are taken, how do you expect to repay these loans?

Have you used up the savings for the child's treatment?

Have you been put to financial trouble because of this?

Do you feel that because of this child's condition, there has been a significant drain on family financial resources? How much so?

Scoring key for subscale 11

0	-	Nil
1	-	Mild
2	-	Moderate
3	-	Severe
4	-	Very high

F. A. S. SECTION II: MEDIATORS

AREA : AWARENESS

Sub scale 12, General awareness about MR

I would like to ask you a few questions as to what is your understanding about your child's problem.

When did you first notice that the child has some problem?

What according to you, is responsible for the child's problem?

Which part of the body according to you is responsible for the child's problem?

At present, what is your child's level of intellectual functioning?

To what extent do you think, your child can become alright?

Do you think he can be completely cured, that is to say, can be normal as other children of his age?

What treatment according to you, will help the boy?

In what way do you think he can be improved?

What methods have you tried to treat the child?

Scoring key for sub scale - 12

1	-	Largely Adequate	-	Highly knowledgeable or reasonable ideas about nature, cause prognosis and treatment.
2	-	Adequate	-	Know enough in two areas
3	-	Slightly inadequate	-	Aware of only one aspect of the problem, but not clearly
4	-	Highly Inadequate	-	Very poor knowledge in all areas

Sub scale 13, Misconceptions

Do you think tablets/injections/operation will make the boy alright?

Do you feel that investigations like blood check-up, X-ray will help the child to become normal?

Do you think methods like branding, magic of religious methods (Mantravadi) will cure the child?

Do you think that there was something you did or did not do before or after the child's birth which has led to this problem? what is it?

Scoring key for sub scale - 13

1	-	No misconceptions
2	-	Misconception almost absent
3	-	Misconceptions present
4	-	Present to a large extent

AREA : EXPECTATIONS AND ATTITUDES

Now I would like to ask you a few questions regarding your feelings and thoughts about your expectations about the child.

Sub scale - 14, Expectations from child

Do you think your child can learn as well as others?

Do you feel your child can become like other normal children?

Would he do well in schooling, if he were sent to school?

Would he able to ask for his needs?

Would be able to talk/walk/socialisation as well as other children?

Do you think he can be a productive member of the family with training?

Do you think he can get married and take up responsibilities like others?

Do you think your child would be able to take up some job and earn an independent livelihood?

Would he/she be able to communicate as fluently as others?

Do you think in future he will learn at least some self help skills?

Scoring key for sub scale - 14

1	-	Largely appropriate
2	-	Mildly appropriate
3	-	Moderately inappropriate
4	-	Highly inappropriate

Sub scale - 15, Attitude towards child as a person and family member

Do you think that this child is able to communicate at least at times?

Do you think this child is able to mix with other children and play? Do you feel like playing with the child?

Is the child able to mix with sibling and family members?

Does the child enjoy playing with family members?

Does the child do something that make the family members get irritated?

Does the child get scolded for trivial matters?

Does the child respond to family members by way of play, smile, cry, anger, laugh etc.?

Do family members take pleasure at times in caring for this child?

Does the child bring joy to family members at least at times?

Do family members feel that it is enough if they fulfil/take care of his physical needs?

Do sibling keep on complaining about this child?

Does the child get appreciated for small deeds?

Do you sometimes feel that this is a God given opportunity to help your child?

At times of anger or disappointment or otherwise is the child blamed and considered misfortune?

Do you sometimes wish the child were dead?

Scoring key for sub scale - 15

1	-	Most favourable
2	-	Favourable
3	-	Unfavourable
4	-	Most unfavourable.

Sub-scale 16, Attitudes towards child management

What are the things that your child can do?

What are the things that you feel your child can learn?

Do you think it is easy for him to learn?

Do you think, with your training the child will be able to learn better?

Do you feel that it is so difficult to look after the child as that he/she is better off in an institution?

What treatment according to you will help the boy?

What treatment do you feel will help the child in learning walking, talking, toilet habits, and socialisation?

How do you think that the boy has learnt these things?

Do you feel that your attempts are important to train the child?

Do you think that the child can be an asset if trained?

Has this child learnt something new recently?

Do you think he has any assets?

Do you feel confident that he would pick up at least a few skills?

Is teaching him always frustrating, or are there moments of joy?

Has others commented on any improvement in him?

Can he be made to show/has down interest?

Do you feel that since he has this condition everything has to be done to him?

Scoring key for sub scale – 16

1	-	Most favourable
2	-	Favourable
3	-	Moderately unfavourable
4	-	Most unfavourable.

AREA : CHILD REARING PRACTICES

Parents differ in their way of handling the child/caring for the child-for e.g. in terms of amount of time spent with the child, disciplining, handling good/bad behaviours etc., I would like to know a few things about your family's methods of handling this child in general as well as with regards to his/her handicap.

Sub - scale -17 : General Rearing Practices

Is this child receiving care which is different from other children? In what ways?

How do you express your love towards him/her? How often do you do things like hugging, caressing, tickling, praising and so on? Are there some things or activities of the child which is liked by family members? How does he/she respond to your expression of love? have good time/fun with him/her?

How much attention does he/she get? How about when you are otherwise busy/working?

Do you play with him/her? What kind? how often? Do you and he/she enjoy them?

What does he play with? Odds and ends?, household articles? bought any toys? does she/he like playing with them? do you sit with his with toys?

Do you engage him by talking? what kind of talk? how often? play vocal/verbal games? (like making funny sounds) point out, name, explain things? how does she/he respond? Do you take him out?

What do you feed him? does he enjoy meals or fussy? does he refuse? what do you do then?

Is her behaviour troubling? does he sometime not listen to what you say? do you get upset about this? does he get beaten/scolded? how often?

Does he demand a lot of things? what do you do then? Are you too soft about discipline because he is disabled? do you easily given in to prevent him from crying?

Is there someone in family how is too indulgent and allows her to have her say even when she is very unreasonable? Are there differences amongst family members in disciplining? Is there a regular time schedule for various activities?

Do you worry too much that something bad might happen to her if left alone? do you always keep her in your eyesight?

Do you allow him to do things on his own? How much? what about when he makes mistakes?

Do you feel like doing it yourself?

Scoring key for sub scale - 17

1	-	Most favourable
2	-	Somewhat favourable
3	-	Somewhat unfavourable
4	-	Most unfavourable

Sub.Scale No. 18 : Rearing Practice Specific to Training

Have you recently attempted to teach/train this child in something? (like using hands, sitting/ standing/walking, increasing vocalisation, imitation, point to body parts and objects, use of different articles, new words and phrases, feeding/dressing/washing/bathing self or toilet training, awareness of time and space and so on; (NOTE TO THE INTERVIEWER- use examples appropriate to the child) How did you attempt? How often? Have you had time for doing this? What about other family members?

Has she/he learnt something new because of these attempts? Is it encouraging?

How much interest/co-operation has he/she shown in this? What did you do when he/ she did not show interest? How did you try to make him/she interested and co-operative?

Have you experimented with new ways to teach her/him something new? To what effect?

Have your sought help of any other agencies for this purpose (like a special school)?

Have you taken this child elsewhere for consultations (other hospitals, traditional healers, etc.)

Do you allow him to do things on his own? How much and how often? What do you do when he makes mistakes?

What do you do when he/she has learnt something new? Do you reward him by praise, appreciation, etc.

Scoring key for sub scale – 18

1	-	Most favourable
2	-	Somewhat favourable
3	-	Somewhat unfavourable
4	-	Most unfavourable.

Sub scale-19, Social support (also area)

In times of trouble, we all seek help from others. It may be in the form of advice, finance, enquiring about things, or even emotional support. I would like to know little more about this with respect to this child and related problems.

Ever since you discovered the problem with this child, who were the persons you sought help from? Who helped you? Immediate family extended family or relatives, friends/work colleagues. Neighbours, religious organisation, professional persons, school and Government agencies.

In times of financial difficulty was there anybody who provided help? If yes - who? When you felt sad & unhappy about this child's problem, was there anybody with whom you could share your problems and get comfort and reassurance? If yes-who? Was there anybody who guided/advised you on matters regarding the child's medication and welfare? If yes who? Was there anybody who provided you with practical help - like looking after the house and other children, when you took the child for treatment accompanied you to the hospital etc.?

Are you satisfied with the amount of help you have received/ are receiving?

Scoring key for sub scale - 19

1	-	Best social support (excellent) high level of social support available and utilized maximally
2	-	Adequate (several instances of actual support)
3	-	Somewhat inadequately available support/inadequate use of available supports.
4	-	No/very little supports available/utilized.

Sub scale - 20 : GLOBAL RATING OF FAMILY ADAPTATION (ALSO AREA)

Instruction to interviewer

This last item for rating is meant for overall, global understanding of the degree to which the family has adapted to the predicament of having a child with mental retardation. Use your judgement based on all the information available so far.

Scoring key for sub scale - 20

l	-	Extremely well adapted : Highly satisfactory coping
2	-	Adequately adapted
3	-	Inadequately adapted
4	-	Very poor coping/adaptation.

A STUDY OF THE EVALUATION OF THE EFFECTIVENESS OF BRIEF IN-PATIENT FAMILY INTERVENTION VERSUS OUT-PATIENT INVERVENTION FOR MENTALLY RETARDED CHILDREN

(Project funded by ICMR; NIMHANS, Bangalore)

Name of the child : : P/No:

Date : C.I No:

Administered to (mention relation to child) 1.
2.
3.
4.

Section-I : Stress				Section II : Mediators			
Areas	S.S No.	Name of subscale	SCORE	Area	S.S No.	Name of sub-scale	SCORE
1 Daily care	1	Extra inputs for care	-	1 Awareness	12	General awareness	-
	2	Decreased leisure time	-		13	Misconconceptions	-
	3	Neglect of others	-	2 Attitudes	14	Expectations from child	-
	4	Disturbed behaviour	-	and expectations	15	Attitude general	-
					16	Attitude Management	-
2 Family	5	Personal distress	-	3 Rearing Practices	17	Rearing practices general	-
emotional	6	Marital problems	-		18	Rearing practices specific	-
stress	7	Other I.P. problems	-	4 Social support	19	Social support	-
	8	Effect on sibs and others	-	5 Global adaptation	20	Global adaptation	-
3 Social stress	9	Altered social life	-				
	10	Social embarassement	-				
4 Financial stress	11	Financial implications	-				

SECTION -1 : STRESS

Stress total ☐

Area sub-totals

1. Day Care ☐
2. Family emotional& stress ☐
3. Social stress ☐
4. Financial stress ☐

SECTION-II : MEDIATORS

Mediator total ☐

Area sub-totals

1. Awareness ☐
2. Attitudes & expectations ☐
3. Rearing practices ☐
4. Social support ☐
5. Global adaptation ☐