

MOVING FORWARD

An Information Guide for Parents
of Children with Mental Retardation.



AUTHORS

Reeta Peshawaria

D.K. Menon

Rahul Ganguly

Sumit Roy

Rajam P.R.S. Pillay

Asha Gupta

R.K. Hora



National Institute for the Mentally Handicapped

(Ministry of Welfare, Govt. of India)

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N. Karunakar**

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Authors of this book**

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STRENGTHENING FAMILIES PROJECT TEAM

Dr. Reeta Peshawaria	:	Principal Investigator
Dr. D.K. Menon	:	Consultant
Dr. Rajam P.R.S. Pillay	:	Co-Investigator
Mrs. Asha Gupta	:	Co-Investigator
Mr. Sumit Roy	:	Co-Investigator
Mr. Rahul Ganguly	:	Research Officer
Mr. Vinod Kumar	:	Research Assistant (from 21.11.93 to 30.5.94)
Mr. Radhey Shyam Giri	:	Research Assistant (from 23.11.93 to 10.1.94)
Ms. Lamat Ayub	:	Research Assistant (from 21.1.94 to 31.3.94)

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FOREWORD

A democratic welfare society which we advocate is where people live unprejudiced, equal and free lives, the Society gives, when democratic values are settled as leading ideologies in particular, where humanism and rationalism are interwoven in the fabric of our lives.

We need easy, renewed and advanced knowledge, ideas and strategies that would enhance the quality of our services for the people with mental handicap and help them for better lives by exchanging the results of our research practices and experiences in areas of special education, vocational education, medicine, social movement, public awareness and family involvement. The mentally handicapped people with special needs have had less attention from the community than those with other disabilities due to the idea of inefficiency preference in this highly technological world. Persons with Mental Handicap in this connection are people essential for our society although they tend to be limited in their intellectual ability and social life. For the cause of human equality, they too should be given enough opportunities; an opportunity to be educated, an opportunity to access to medical services, an opportunity to enjoy family life and an opportunity to participate in community activities.

In implementing the individually based education, it is crucial to establish the education policy, goals, programmes and methods that will develop each individuals abilities to its fullest. The maximised learning is based on psychology as it provides the principles of education. How much child learns depend on his/her intellectual ability, learning style, learning speed and learning circumstances. It is urgently required to perform resources to make all these as effective as possible.

A remarkable social, economic and medical advances have brought much progress in the field of mental retardation. However, we see many problems still remain from us to work on including the public insensitivity to the needs of those people with mental retardation.

The Parents of persons with mental handicap in general keep worrying with various doubts and queries and hunt for information that can enable them to understand the needs of their child with mental handicap better "How" to help them out. They have numerous concerns and worries as to "Will they become normal", if not, "What can be done to facilitate a less dependant living"; "Who will take care of them" and "What will happen to them after us"? "Can they work"? "Will they ever get married"? "Will they be exploited at work situation" etc.

These concerns need to be addressed as they remain chronic stress factors, otherwise, blocking their constructive contribution towards less dependant living. Moreover parents are emerging as an indomitable force taking increased concern in the quality and efficiency of the training programmes offered to their son or daughter with mental handicap and those forces need to be contained in a most empathetic and reciprocative manner. The "Deaf ear syndrome" of professionals and "I know it all" attitude needs to be totally extinguished to accommodate this trend and work with it in a positive manner.

Knowledge is power and we ought to empower parents with adequate information which they deserve. Empowerment should be our focus in order to overcome the insurmountable blocks in the rehabilitation process i.e., ignorance, misconceptions and apathy.

The inadequately informed parent can be more dangerous to his son or daughter than others. No amount of work is sufficient to respond to the growing worries and issues of parents of today. We need to come out with awareness building materials that suit the needs of parents of different strata - literate, illiterate, those residing in remote rural and tribal areas and those residing in urban areas, their doubts are same, worries and concerns are also same, though the form in which it is manifested are different, and they need to be talked and empowered accordingly.

With the advent of the proclamation of the "Decade of the Disabled" by the United Nations from 1982-1992, tremendous benefits have been accrued world over in creating larger awareness around the globe. In India, though a late starter, the initiative taken by Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped by conducting an All India Seminar to frame National Policy for Mentally Handicapped during February 2-5, 1987 was indeed a historical event, in the sense that the Seminar was participated by Sufferers i.e., parents of persons with mental handicap, scientists, professionals, NGOs working in the area and Policy Planners including the Planning Commission and alongside the Ministry of Welfare, a Nodal Ministry and other important connected Representatives of the Ministries and State Governments.

The National Policy Report presented by me alongwith my Core Committee Members to the then Prime Minister of India Shri Rajiv Gandhi on 14th January, 1988 became indeed a historical event in the lives of persons with mental handicap. Within few days the Prime Minister of India appointed Justice Behrul Islam Committee with a direction to bringout comprehensive study of the document, recommendations for legislation, constitution of an exclusive Working Group for the Disabled for the first time in the 8th Five Year Plan, constitution of Inter-ministerial committee to monitor various problems of the Disabled at given periodical time frame. This again resulted in the statutorisation of Rehabilitation Council of India on the lines of Medical Council to monitor universalisation and standardisation of curriculum development in the preparation of manpower development which indeed is a happy augury. Further the move for constituting National Trust for welfare of the Mentally Handicapped as an answer to the anguished parents of persons with mental handicap that "what would happen to our Mentally Retarded Children after their demise", and the comprehensive Disabled Act are indeed in the right direction which are likely to be cleared before this monsoon session which will be a historical land-mark in the history of Disability in India.

We have developed and implemented various welfare policies for the handicapped people for the past 10 years since the welfare of the disabled has increasingly become the concern of everybody. We will have to focus our efforts to substantiating the existing law and systems and carry out the measures that can directly touch the lives of the Handicapped.

Mental Retardation is not an issue that concerns the Nation or a people, but an issue that concerns the whole mankind. I therefore think that continuing cooperation among organisations concerned and among nations in terms of education, medicine, welfare and so on is more needed than any other areas.

A Society we consider to have and hopeful is where mentally handicapped people live in harmony with their human colleagues fully understood and fully supported.

I am glad the Authors of the Book "Moving Forward" Dr. Reeta Peshawaria and her colleagues have taken right initiative in providing as an Information Guide for parents of mentally retarded children. I am sure this will go a long way in filling-up the gap and responding to the needs of the parents and will also clear many misconceptions, myths and information on certain areas of ignorance.

I once again convey my best wishes to the Authors in meeting the purpose for which this Book is being brought out.

I hope this Book will bridge the gap between the Parents and professionals in rehabilitation process promoting the partnership.



(Dr. THAKUR V. HARI PRASAD)

PREFACE

This book **"Moving Forward : An Information Guide for Parents of Children with Mental Retardation"** is an outcome of the multi-centered project **"Strengthening Families"** taken up by the National Institute for the Mentally Handicapped, Secunderabad in 1993-94 in collaboration with three other non-governmental organisations working in the country. The other contributions brought out separately under the project include (a) book for professionals on **"Needs of Indian families having children with" mental retardation** and (b) 30 minute video film in Hindi with sub-titles in English **"Manzil Ke Oar"** for parents of mentally retarded children.

Having worked in the area of mental disability for nearly twenty years, I still come across comments such as **"non-cooperative parents"**, **"parents have a habit of shop hunting"**, **"parents are over anxious and over concerned"**, **"they just want drugs for cure"**, **"they think going to that temple will help"**, **"parents just want to dump their child"**. All this sound very pathetic. This is a strong indication of how little we as professionals would have used our learnt skills with these parents to help them understand, realise and accept the situation they have been accidentally forced into because of having a mentally retarded child.

After looking at the analysis of interviews conducted with 140 families having mentally retarded children under the project including mothers, fathers, sisters, brothers, grandparents at Secunderabad, Bhopal, Thiruvananthapuram, and Delhi and also out of our professional experience, we strongly feel that one of the greatest needs of parents of mentally retarded children is to get **right information** about their child's condition at the **right time** in the **right way**. That is, to provide accurate information early, at appropriate time and conveyed in an empathetic and sensitive way. The first contact that parents have with the professionals, may it be with a medical doctor, a psychologist,

a teacher or a social worker is very crucial. How they are handled at this stage goes a long way in determining their quality of the adaptation to the loss of having a normal child and also in determining their attitudes towards their mentally retarded child and the situation in general. It has been observed that once a rapport is built with the professionals, parents have so much to ask, so much to clarify and these parental needs definitely require to be met.

Needs of each child are unique so are that of the family yet amongst this uniqueness there are common concerns which all parents having mentally retarded children may share at different stages of theirs and their child's life span. Such common concerns, queries/questions which parents frequently ask were compiled into a question bank. Conduct of group parent training programmes over the last ten years at the National Institute for the mentally handicapped and across in the country provided an opportunity to establish a reliable "pool of questions". Also, the authors of the book added from their wide professional experience and helped further delineate the most common questions frequently asked by parents. Following this, these questions were sorted under various sections such as, General information about mental retardation, Impact on families, Early intervention, School, Academics, Activities of daily living, Communication, Behaviour, Employment, Leisure, Sexuality, Marriage, Parental support, Community support, Financial planning, Legal, Social security, Hostel, Government benefits and concessions.

These questions were then answered, and clarified keeping particularly the Indian context in mind. It has not been an easy task answering these questions as for certain areas we in India are still struggling to "move forward" especially when we consider issues such as integrated schooling, employment opportunities, legal social security for mentally retarded children. Anyhow, we have come a long way and we still have a long way to go. An honest attempt has been made by the authors to place the available information explicitly before the parents.

To be able to express one's own thoughts could be easier for an artist, but to express someone else's thoughts in an art form could be more challenging. This however, has been achieved by Mr. Karunakar, with great finesse. His art work and illustrations contained in the book is found to be profoundly appealing.

Mr. V. Shankar Kumar, Stenographer, NIMH provided good support in typing the script as and when required. We thank him for his contributions.

The project team would like to thank Mr. L.Govinda Rao, Deputy Director (Admn.), NIMH and his dedicated team of workers in Administration and Accounts Section for their ever helping and positive attitude during the project.



Dr. REETA PESHAWARIA
Principal Investigator

GENERAL INFORMATION

On hearing that their child has 'mental retardation' parents tend to get utterly confused. This technical jargon probably makes no sense to them as to what mental retardation is, why it has been caused, whether there is any cure for it, what is the prognosis, that is, whether he will be able to become normal or not. Along with mental retardation if the child also has associated problems such as epilepsy/fits, sensory problems, autism, etc. the situation gets even more complicated for parents to comprehend. This leaves the parents desperately wanting to gather accurate and right information about their child's condition. It has been seen that one of the foremost needs of parents is, getting the right and honest information about their child's disability. The reactions of the parents, their adjustments, attitudes and involvement in the training of their child depends on how effectively and sensitively this information is communicated. This section includes answers to questions which parents generally ask related to the condition of mental retardation its causes, associated conditions and management.

Oh my God! Seeta has again got a fit.



Put a spoon in her mouth

Make her smell a shoe

Sprinkle water on her



Seeta is having an epileptic fit. You should consult a doctor immediately.



Why don't you take her to the doctor?

Are you coming with me to the doctor?



You know, I've got to go for work.

I think it would be good if both of you go together to see the doctor.



Yes, fits can be controlled with medicines. Don't stop or change the medicines without medical advice.



This book which is written for parents in English is also translated in Hindi. The language has been kept intentionally very simple and as far as possible jargon free. However, few common technical terms have been retained to enable parents familiarise with them and help them build better communication with the professionals.

For the benefit of parents, additional information has been appended on selected reading list, addresses of various registered parent associations working for the welfare of the mentally retarded individuals in the country and list of vocational rehabilitation centres.

We strongly believe that a well informed parent is better equipped to make wiser and better decisions that would help his/her child and the family. This book essentially aims at this and does hope that parents consider this book as a good "starter" to "move forward" and acquire further information from various sources to meet their unique individual needs.

Parents having children with mental retardation are requested to send us their honest feedback using the feedback form appended at the end of the book and list of additional questions that parents would like us to answer, may be in our next addition of this book.



Dr. REETA PESHAWARIA
Principal Investigator

ACKNOWLEDGEMENTS

It is with utmost humility and gratitude that we would like to thank parents and families having mentally retarded children who helped us in understanding their concerns. But for their trust and sharing with us we would have not known what to focus on, in this book.

National Institute for the Mentally Handicapped, ventured for the first time in funding multi-centered projects as the present one, in collaboration with the non-government organisations. I express my deep appreciation and grateful thanks to Dr. D.K. Menon, Director, NIMH for encouraging initiation of research projects such as this, which aims at "Strengthening families having children with mental retardation". Also, the expert guidance and continued support provided by him throughout the project has been most encouraging.

It has been an enriching experience sharing and working together as a team with the coordinators of the project Dr. Rajam P.R.S. Pillay, Director, Bala Vikas Institute, Thiruvananthapuram; Mrs. Asha Gupta, Director Navjyoti Centre, Delhi and Mr. Sumit Roy, Executive Director, Digdarshika Institute of Rehabilitation and Research, Bhopal.

Mr. Rahul Ganguly, Research Officer, deserves a special mention. He has been a great asset to the project. It was a real feeling of pride to see him growing from my student to my colleague. His true and total involvement and significant contributions to the project, deserves special credit.

We would like to express our special thanks to the parent members of "Parent Association for the Welfare of Mentally Handicapped Persons", Hyderabad (PAWMENCAP) for promptly responding to our request for reviewing the book and providing us with useful and very encouraging comments.

1. Are there any specific signs by which we can know that the child is mentally retarded?

Children with mental retardation do not form a uniform group. The nature of mental retardation, its severity, and the child's ability to cope with the problem all influence how this disability is visible to an observer. However there are some specific signs and symptoms which can help in early identification of delayed development in a child (WHO, 1989):

- the person does not learn new activities as easily as other people,
- the child may have difficulty sitting up, using his or her hands, or moving from place to place,
- the person may be slow to respond to what others say and to what happens around him or her,
- the person may not understand as well as other people what he or she sees, hears, touches, smells, and tastes,
- the person may not be able to express his or her needs or feelings in a way that other people understand,
- the person may not be able to think clearly. For example, the person may not be able to compare people or things. The person may not be able to understand the difference between here or there, now or later, or more or less. The person may not know the meaning of where, when, what, how much, and why,
- the person may remember only for a short time what he or she has been told or what has happened in

the past. Or the person may not remember these things at all,

- the person may or may not be able to pay attention to one person or to one activity for long,
- the person may have difficulty controlling his or her feelings,
- the person may have difficulty making decisions. He or she may not know what to do, to say, to wear, and so on.

2. How early can one definitely tell that the child is mentally retarded ?

Early detection depends upon the severity and the nature of mental retardation :

- many genetic abnormalities can be identified before birth. Some of the methods of identifying include: amniocentesis, fetoscopy, chorionic villus sampling, sonography, and blood screening tests,
- some conditions like Down's syndrome, microcephaly (small head circumference) can be identified at birth,
- after birth if the growth and developmental milestones are delayed and there is presence of neurological signs and symptoms, identification of mental retardation can be made with fair degree of certainty within one year,
- in cases having mild delays of development, assessment of intellectual functioning becomes crucial tool for diagnosis which can be performed with reliability by the age of 3 to 5 years.

3. What is the prevalence of the condition of mental retardation in our country?

Nearly 2% of the general population in our country is affected with mental retardation. There are presently about 168 lakhs of mentally retarded people in our country. Mental retardation can affect people from all walks of life.

4. Do all mentally retarded children have same problems?

All children with mental retardation are not alike. Each individual with mental retardation has unique problems based on the severity of condition and the ability to cope up with the problem. However, children with mental retardation generally have problems in:

- motor coordination,
- carrying out day to day activities like toileting, bathing etc.,
- reading, writing and arithmetic,
- communication,
- behavior, and
- socialization.

Some mentally retarded individuals may also have sensory defects such as visual impairments, hearing loss or other problems like epilepsy/fits, etc.

5. Does brain development have any links with mental retardation?

The brain coordinates and directs various bodily functions.

Each component of the brain controls some aspect of an individual's behavior and affects the understanding of the world around him or her. The brain not only controls involuntary movements of organs like heart, kidney but also initiate voluntary movements like walking, running and also higher order functions like thinking, reasoning, memory, etc. The abnormal developmental functioning of any part of brain thus makes an individual less able to adjust to the environment and give rise to various disorders, one of which is mental retardation.

6. Are there any drugs that can cure brain damage ?

Mental retardation is an irreversible condition. The damage caused to the brain is permanent. With available knowledge and techniques for management and treatment of mental retardation, no drugs have been found to repair the damage occurred to the brain.

7. What are the chances of producing a mentally retarded baby if one marries within close relations ?

Data reported from various clinics in the country show that in 60% of the cases identified as mentally retarded, causes can be attributed to genetic disorders. Consanguinous marriages i.e. marriage between uncle-niece, nephew-aunt, first cousins or related cousins have greater chances of producing a child with genetic disorders including mental retardation. In case there is already a child with mental retardation, the parents should seek genetic counselling before planning to have another child.

8. Is It true that the age of mother/father/or both at the time of conception is crucial for producing a normal or a retarded baby ?

Age of the mother is very important for producing a normal baby. Mothers over the age of 35 face higher risks for :

- chromosomal abnormalities,
- prematurity,
- complication during pregnancy, and
- congenital abnormalities in the offspring.

Very young mothers below 15 years of age, whose reproductive systems are still immature and whose bodies are still growing, also face greater risks of producing an abnormal baby. Highest risks for mental retardation are reported among children from mothers who have borne three children before the age of 20, and children from mothers having first pregnancy over the age of 35.

Genetic defects also increase significantly with maternal age. For example, incidence figures on Down Syndrome are 1 in every 2,000 births for 20 year old mothers, and 1 in every 50 births for mothers over 45.

As far as father's age is concerned, the chances of having a mentally retarded baby are higher when the age of the father is over 50 years.

9. What are the factors that contribute to mental retardation before the birth of a child ?

Some of the important factors are as follows:

- chromosomal abnormality,
- genetic disorders,
- infections in mother during the first three months of

pregnancy. Some common infections that affect the developing brain of the foetus are rubella, herpes, syphilis, CMV, toxoplasmosis,

- maternal diseases like diabetes mellitus, high blood pressure, hypothyroidism and hyperthyroidism,
- malnutrition,
- exposure to X-rays in the early months of pregnancy, using harmful drugs,
- maternal-fetal blood incompatibility: Rh factor,
- maternal use of alcohol, drugs and smoking.

10. Can we detect during pregnancy if there is something wrong with the baby?

Several methods are now in use with pregnant mothers to obtain information about the presence or absence of abnormality in their unborn baby. These include:

Name	Description	Diagnosis of	Safety
1. Amniocentesis	Drawing of amniotic fluid under local anaesthesia and ultra-sonography which is subject to analysis Ideal Time : 12-16 weeks of pregnancy	* foetal sex * trisomic child * inborn errors of metabolism * X-linked disorders	Abortion 1 - 1.5% risk. Repeat amniocentesis is 9% risk of abortion
2. Ultrasonography	Echoes generated by ultrasound waves Ideal Time : 8-15 weeks of pregnancy	* anencephaly * microcephaly * congenital heart disease * intra uterine growth retardation * spina bifida	Nil Contd...

Name	Description	Diagnosis of	Safety
Contd...			
3. Chorion villus sampling	A small amount of chorionic tissue is suctioned by a hollow instrument and analyzed Ideal Time : 8-10 weeks of pregnancy	<ul style="list-style-type: none"> * trisomic child * X-linked disorders 	Miscarriage 10/1000
4. Fetoscopy	Insertion of fetoscope in the amniotic cavity Ideal time : 18-22 weeks of pregnancy	<ul style="list-style-type: none"> * malformation of limbs, face, genitalia and spine 	5 to 10% risk of abortion
5. Fetal blood sampling	Blood drawn from the root of umbilical cord Ideal time: 18 weeks	<ul style="list-style-type: none"> * thalasaemia * Sickle cell disease 	Risk of inducing abortion is upto 10%

11. If a woman during pregnancy suffers from frustration, failures or disappointments, what are the chances that such situation will make her more vulnerable to produce a baby with mental retardation?

Failures, frustrations and disappointments directly are not linked with producing a baby with mental retardation. However, these factors can affect indirectly. For example a pregnant mother who remains sad may not eat properly which may then effect the growth of the baby.

12. If there were no problems during pregnancy Is there still any chance that a baby will develop mental retardation at birth?

Mental retardation can also be caused due to the following factors :

- premature birth,
- prolonged state of hypoxia,
- low birth weight,
- trauma to the head of the new born baby,
- prolonged labor,
- excessive coiling of the umbilical cord around the neck of the foetus,
- abnormal position of the foetus,
- severe jaundice in the new born due to various causes.

13. Can a baby who is born normal, become mentally retarded after birth ?

All the characteristics of mental retardation can appear long after birth because of injury to the brain anytime during the period of development upto 18 years of age. Injury to the brain can be caused by the following factors:

- severe malnutrition in the child especially during birth to 2 years of life,
- infection to the child such as meningitis or encephalitis (brain fever),
- repeated episodes of epileptic fits,
- injury to brain from accidents or falls,
- strangulation, smoke inhalation, or near drowning,
- accidental poisoning.

14. Can vaccination to the child lead to mental retardation ?

This particular problem is very rare following triple vaccine where the pertussis (P) component of the vaccine can cause encephalopathy. This should not deter parents from giving vaccines to the child as they protect the baby from a variety of deadly diseases.

15. If mental retardation basically means below average intellectual functioning, are there any drugs to increase the individual's intelligence ?

There are no proved drugs so far which have stood the scientific scrutiny and claim producing increase in intelligence. If it was so, mentally retarded individuals would cease to exist in the world which is not presently so. If there were drugs available to increase intelligence the world that we live in would be quite different, filled in only by super intellectual human beings.

16. Would a special diet consisting of almonds, milk, pure ghee, butter improve the mental abilities of the child ?

Feeding a child especially in the first two years of life on a balanced and nutritious diet which includes proteins, carbohydrates, fats, mineral salts, vitamins etc. is essential and can influence the mental as well as physical growth of the child. However, over emphasis on feeding a child only with almonds, pure ghee, butter or milk could rather prove harmful to the child.

17. Can mentally retarded individuals be cured completely ?

Mental retardation as a condition is not curable. It is also considered permanent in the sense that once the damage to the brain has occurred, the condition is established and it is irreversible. There are, however, few conditions where prevention is possible. In case of mental retardation caused due to Phenylketonuria (PKU), special diet low in phenylalanine is required to be taken. Mental retardation caused due to thyroid deficiency can be prevented by medical treatment, while in case of hydrocephalus, surgical intervention can reduce the pressure in the brain by using a shunt.

18. If there is no cure for mental retardation what should be done with this child ?

Within the limitations of the disability, the child will adapt and accomplish whatever is possible, provided the opportunities for learning should be made available to the child at the earliest. The efforts of professionals working cooperatively with parents are directed at functional independence to achieve realistic goals in persons with mental retardation. So it is very essential that parents seek out services at the earliest.

19. How long do mentally retarded individuals live ?

Life span of individuals with mental retardation vary depending upon the cause and nature of his/her mental retardation. If a child with mental retardation has associated medical problems which are life threatening in nature, such

children don't live long. However with improved medical care the life span of persons with mental retardation has increased to correspond with that of a normal human being.

20. Are mentally retarded individuals mad ?

Individuals with mental retardation are not mad. Mental retardation is a condition which generally leads to a handicap whereas madness or mental illness is a disease. Mentally retarded children are slow in learning and development. Their mental age is below their actual age. For example, a seven year old mentally handicapped child may act, talk and behave at the level of a 3 year old normal child. Thus, he may show a developmental delay of 4 years. On the other hand, mentally ill or mad persons don't show any developmental delay. They may show disturbances in behavior, such as being extremely moody, withdrawn, seeing or hearing things which are not there, reduced sleep, etc. However, mentally retarded children can suffer from mental illness for which psychiatric treatment should be sought.

21. A deaf child and a mentally retarded child both have difficulty in talking. Are these two conditions similar ?

Although, both the deaf child and a mentally retarded child will have difficulty in talking, the conditions are not similar. A deaf child will show a delay in the area of language and communication only, whereas a child with mental retardation will have a generalized delay in all the areas of development like motor, cognitive, social, language etc.

22. Can a mentally retarded child also have physical disability, visual or hearing problems ?

A child with mental retardation can also have associated physical, visual or hearing problems. The more severe is the brain damage, the more chances are there for multiple impairments associated with mental retardation.

23. What is cerebral palsy ?

Cerebral palsy (CP) refers to a complex non progressive condition caused by damage to brain within first 3 years of life that produces a disability because of muscular incoordination and weakness. The word "cerebral" refers to brain and "palsy" to a disorder of movement or posture.

Cerebral palsy involves various types of impairments in gross and fine motor coordination. Most common types of cerebral palsy are:

- spastic (most prevalent, present in 50 % of CP cases): It is characterized by loss of voluntary muscle control. Spasticity results from the damage to the part of the brain known as cerebrum,
- choreo-athetoid: It involves the presence of abrupt, involuntary movements of the body. In this type of cerebral palsy, the difficulty is of controlling movement and maintaining one's posture. This results from damage to basal ganglia,
- mixed: As the name implies, the mixed type cerebral palsy includes both spastic and athetoid forms. For example, in a child with mixed type of cerebral palsy, arms may be rigid while legs may be spastic or the same



CHILDREN WITH MENTAL RETARDATION CAN ALSO HAVE
ASSOCIATED CONDITIONS

child may become suddenly rigid or floppy at different times.

24. Can a child with cerebral palsy also have mental retardation ?

The brain damage that causes cerebral palsy may also produce a number of other disorders including mental retardation, seizures, visual and auditory deficits. The more extensive the brain damage, more chances that the child will have mental retardation. It is however very important to realize that all children with cerebral palsy are not mentally retarded. There are many persons with cerebral palsy who have normal intelligence. Mental retardation occurs only whenever there is extensive damage to the brain.

25. Does a mentally retarded child with cerebral palsy require special training ?

The child with mental retardation and associated cerebral palsy will have dual set of problems. Such children will require training in activities of daily living, language and communication, socialization, functional academics and cognitive areas like other children with mental retardation. In addition, services of professionals like physiotherapist and occupational therapist will also be required for development of coordinated voluntary movements and postural training.

26. What is Down Syndrome ?

Down syndrome is a chromosomal disorder that is caused by the presence of an extra chromosome at pair no 21.

The incidence in the general population is 1 in 800 live births but the incidence increases as the age of the mother increases (1 in 50 for mothers over 45 years of age). Affected children have slanting eyes, flat noses and large tongues. Congenital heart defects and gastrointestinal malformations are common. Most of the children with Down Syndrome have mild to moderate mental retardation.

27. What is autism ?

Autism is a rare disorder that occurs in about 4 in 10,000 children. In a child with autism, thinking, language, and behavior are all affected. The disorder is about two to four times more common in males than females. In general, autistic children have the following characteristics:

- language disorder: language is both delayed and deviant,
- strange behaviors like ritualistic hand movements or repetitive behaviors,
- social isolation: They don't enjoy being held or cuddled, and may neither respond nor appreciate feelings of others.

Some of the children have isolated skills e.g. they may be able to assemble complex puzzles , multiply as quickly as pocket calculators, and read the newspaper with expression but not understanding.

28. Can children with mental retardation have autistic features ?

Autistic features characterized by socially withdrawn behavior, ritualistic behaviors and delayed and deviant language can be seen in some children with mental

retardation. Change of behavior may range from extreme social withdrawal to mild form. In extreme cases, it is categorized as socially inappropriate syndrome.

29. What is epilepsy/fits ?

Epilepsy is not an illness. Epileptic fits are caused due to abnormal electrical discharge in the brain which gets generalized. Epilepsy or fits is a condition characterized by jerky movements which last usually for about 2 to 3 minutes. During this the person may remain unconscious for about 20 to 30 minutes. This type of epilepsy is called grandmal. Following the epileptic seizure, the person does not remember anything which happened during the seizure. If seizure occurs when the person is walking, driving, or cooking, the fit may begin by a fall. Due to this fall, a person may sustain injury depending upon place and type of activity.

Another type of epilepsy is called petit mal which is characterized by short absence of consciousness lasting few seconds upto a maximum of 20 seconds. Following the petitmal seizure, the person resumes the original activity.

30. Do all mentally retarded persons have fits ?

About 10% of children with mental retardation have seizures. More severe is the degree of retardation, more are the chances of having epilepsy. The convulsions may start right at birth or develop later. If not managed, seizures can cause harm to the individual with mental retardation like:

- repeated fits can damage the brain and lead to further retardation,

- it results in the impairment of memory which interferes with learning process.

31. Can fits be controlled ?

Medical treatment must be taken for controlling seizures. Other treatment approaches include special diets, called ketogenic diet and surgery. Some commonly used drugs are as follows:

- phenytion sodium/eptoin,
- phenobarbital,
- primidone,
- carbamazepine (tegretol),
- sodium valproate (valparin),
- clonazepam.

Parents should seek advice of medical doctors for seizure control. The exact dosage of drugs and combination of drugs must be taken regularly as prescribed by the doctor. Treatment is generally long term and continues for 3 - 4 years even after the seizures have stopped.

32. Why is that even when the child is having medicines for a long time, yet fits are continuing ?

Possible reasons that fits are persisting inspite of medications are as follows :

- severity of mental retardation is such that there is an extensive brain damage and consequently, medicines are not able to control fits,
- use of less dosage of medicines,

- irregular consumption of medicines,
- sudden stopping of drugs without consulting the doctor,
- metabolic defects not controlled by drugs.

33. Is giving medicines for fits for a long period of time will harm the child ?

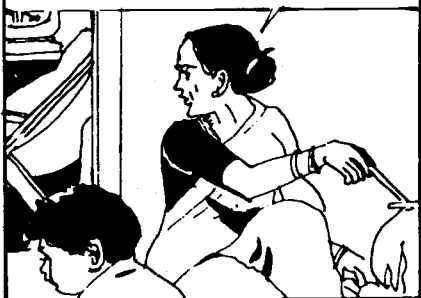
Many persons with mental retardation on long term medications for seizures face risks of side effects of the drugs used for controlling fits/seizures. Some of the side effects of the commonly used medications for controlling fits are like laziness, hyperactivity, rash and liver damage, but reversible mostly. However, regular use of antiepileptic drugs for control is a must for normal functioning in all type of situations despite side effects.

IMPACT ON FAMILY

Having a mentally retarded child causes a great amount of stress to the family and calls for life long adjustments on the part of the parents and other family members. It sometimes becomes difficult for parents to meet the needs of the mentally retarded child as also the needs related to family functioning as a whole. The entire family including parents, brothers and sisters and extended family members such as grandparents get affected in specific ways because of having a mentally retarded child in the family. This section includes information on how families generally get affected, what has been found useful and what has not been found helpful by parents in coping with such a situation and which professionals to contact in times of need. Also, answers to some of the typical questions which parents generally ask such as, whether siblings of the mentally retarded children get affected or not are also included.



Why can't you just take care of this child for a few minutes till I finish cooking. He is throwing everything around.



You manage him yourself. This is your duty. I've to watch world soccer match just now.



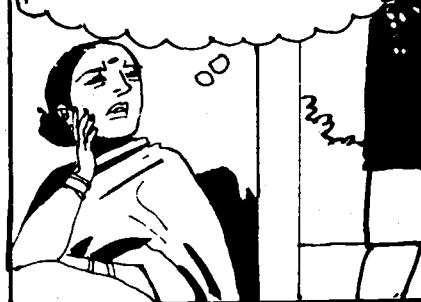
Aditya please take care of your brother. Vijay is not allowing me to cook.



Mummy I'm going to my friend's house just now. He has not given me back my notes yet.



Why God had to curse me with this child. I'm fed up. There is nobody to help me with this problem.



34. *The birth of a mentally retarded child produces immense pressures to all the family members. Do all families having such children experience the same ?*

The birth of a child whether disabled or non-disabled is known to produce pressure since it includes adjustments and extra responsibilities for various members of the family. However, birth of a mentally retarded child does produce greater pressure on the family because of extra demands of child care, greater financial burden and above all the worry and tension that the child is not normal.

35 *How does having a mentally retarded child effect the family ?*

Each child is unique in this world so is each family having its own strengths and weaknesses to face the challenges from time to time. Most of the parents and other family members naturally do start worrying about the future of the mentally retarded child, feel sad or depressed at various stages of child's life, the social life of the family gets affected, they may like to keep themselves aloof from others and indulge less in recreational or leisure activities. Some families face rejection or neglect from the family members, friends or relatives and hence the interpersonal relationships get strained leading to loss of support. Some generally the mothers may give up their jobs leading to greater financial strains, fathers may seek out jobs or transfers at places where services for such children are available. The effects however vary from family to family depending upon the quality and quantity of emotional, financial and physical support available, degree of child's handicap and his age, and whether the child has additional problems such as physical disability or behaviour problems.

36. Could a family experience any positive effects because of having a mentally retarded child ?

Families where parents prior to having a mentally retarded child had good marital relationship i.e. had a strong relationship of caring and sharing tend to come even closer to each other to face the situation of having a mentally retarded child. Some parents report becoming more patient and humanistic in their attitude.

Brothers and sisters of the mentally retarded individual may choose to take up professions which are of helping nature, develop more humility, become more considerate, concerned, cooperative and tolerant in their dealings with others.

37. On knowing that the child is mentally retarded what are some of the common emotional reactions that parents go through ?

On knowing that the child is mentally retarded and shall not be able to recover from the condition fully, the hopes of the parents do get totally shattered. It is normal for any human being to react to such a situation of loss. Different parent's may react differently. Some may initially experience shock or disbelief, that their child could be mentally retarded, some may deny and hope that everything will be all right after some time, some may get angry and blame self or others for such conditions. Some parents may get extremely upset, depressed and nothing may seem important to them anymore. These reactions may not stay permanently. It is not necessary that all parents pass through these reactions. What is important to know is that these are normal reactions to a situation of loss.

Some parents take longer than others to adjust with the situation whereby they start taking constructive steps to face the reality and do their best to help train their mentally retarded child.

38. Can parents resolve these emotional reactions on their own or do they need professional help ?

Some parents are able to understand their own feelings, analyze their own problems and adjust faster hence, may require minimal help from professionals. Some parents take much longer and require more professional help to overcome feelings of shock, guilt, anger, depression or denial that their child is mentally retarded.

39. If these emotional reactions remain unresolved what effects it can have ?

The earlier these feelings are overcome the better it is because if they continue to stay longer it can effect the healthy adjustments within the family, cause detrimental effect on the physical and mental health of the parents. This could lead to undue delay in initiating or carrying out the right training programmes for the mentally retarded child and may also interfere in healthy parent professional relationships.

40. Who are the persons who could provide help to the parents in dealing with their emotional reactions ?

Trained counsellors, psychologists or trained social workers are the professionals who could be consulted. Other professionals like doctors, teachers could also be of help if they are trained in counselling skills. Many a times talking out and sharing your concerns with people in whom you

have trust does help, especially with those who can listen to you patiently without pushing you always to accept their own ways of thinking. These may include your spouse, relatives, friends or even other parents being in a similar condition of having a mentally retarded child.

41. How does a mother get affected because of having a mentally retarded child ?

Some mothers are able to cope up better with the situation of having mentally retarded child than the others. However, mothers are generally known to face maximum stress and pressures because of owning the major responsibility of bringing up the child. Fathers generally do not make a bigger contribution than they would in ordinary families hence mothers continue to struggle between meeting the household work and mentally retarded child's extra needs. If the mother happens to be a working lady she has to put up with much greater pressures. Stress is known to be higher in mothers than in the fathers of mentally retarded children. Mothers are at a greater risk of developing stress related illness such as migraine or tension headaches, body aches and pains, hypertension, anxiety, depression, etc.

42. Do fathers get affected in any ways because of having mentally retarded child ?

Fathers are generally known to take longer to adjust with the situation of having a mentally retarded child. It could be because they tend to spend less time with the child and also their contact with the professionals may also be less which gives them less chances to sort out their problems. At times having to put up with a male front of

trying to solve all problems on one's own with less chances of sharing with others and hiding the true feelings about the mentally retarded child make it more difficult for them to adapt in a healthy way. Fathers too are known to suffer from depression, though less than the mothers and develop problems in marital relationship and personality difficulties. Their official work may get affected so also their relationship with employers or colleagues.

43. Do parents of mentally retarded children have greater marital problems ?

The parents of mentally retarded children are at greater risk of developing marital problems. Marital difficulties may arise because of the conflicts between parents on sharing the additional demands for caring of the child, they may start blaming each other for producing such a child, may disagree between themselves about the treatment of the child, sexual problems may arise due to fatigue, lack of privacy or fear of producing another such child.

44. Does having a mentally retarded child in the family affect non-disabled siblings (brothers and sisters) ?

Female siblings generally are known to get more affected as they are expected to share the burden of caring for their mentally retarded brother or sister at the cost of their free time, play recreation or study time. In the presence of their friends they may feel embarrassed especially if their brother or sister behaves in socially unacceptable ways. Parents may put more pressures on normal sibling to over achieve in order to compensate the

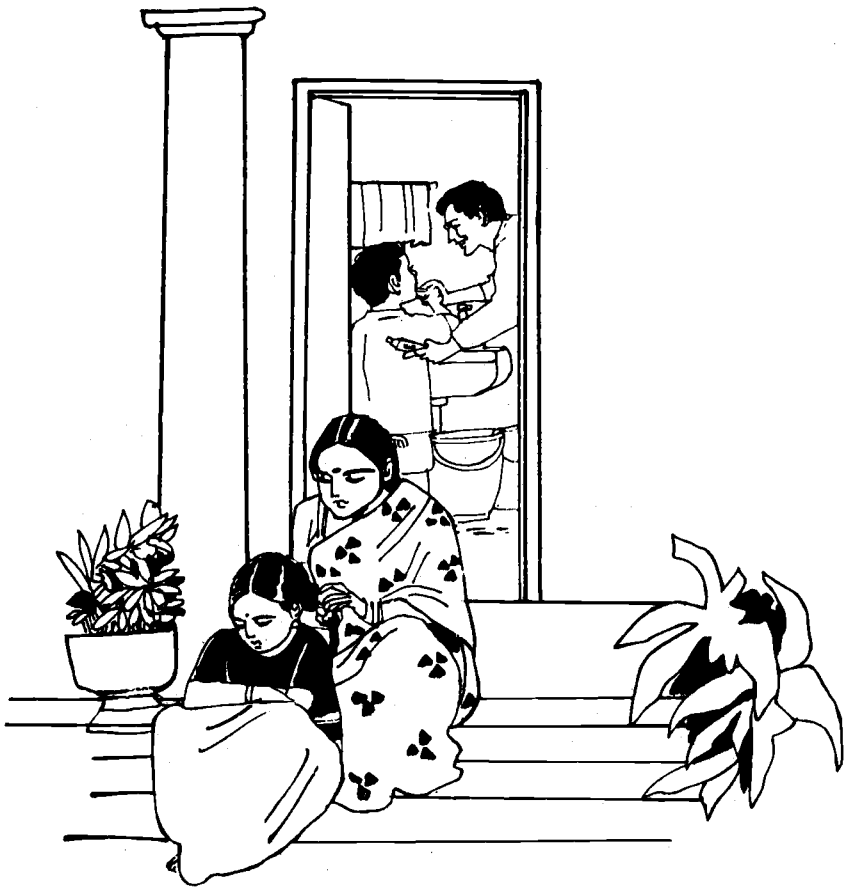
under achievement of the mentally retarded child. Parents may spend less time with the normal sibling making them feel neglected or jealous. They may miss out on sharing a relationship otherwise of having a normal sibling, worry about the future of their mentally retarded sibling, worry about finding a spouse who would be accommodating and accept the mentally retarded brother or sister and also fear themselves of producing a mentally retarded child.

45. Are grand parents affected in any way because of having a mentally retarded child in the family ?

Having a mentally retarded child affects the whole family and grand parents are no exception. They too, depending upon their concern and involvement with the family worry about the mentally retarded child and his/her future. They may worry about their own son/daughter who is undergoing pressures of bringing up a mentally retarded child. At times they may provide timely support to the parents in sharing the child care responsibilities providing financial support and even emotional support to the effected parents. Occasionally the grand parents may feel neglected by their own children, or miss out on their social life and recreational activities due to need for extra caring of their mentally retarded grand child.

46. What are some of the factors that have helped famillies having mentally retarded chlld to adjust better ?

Indian parents report that the major things found most useful in coping up with the situation of having a mentally retarded child include getting physical help for looking after the mentally retarded child especially by the spouse/ husband or grand parents. Other things found useful include



INVOLVEMENT OF BOTH PARENTS HELP

acceptance of mentally retarded child especially by the paternal grand parents, financial help, early and timely advice provided by the professionals and their empathetic attitude. Above all, parents reported that having faith in God does help to ease out tension from time to time.

47. Are there any factors which act as barriers or inhibitors in coping up with the situation of having a mentally retarded child in the family ?

Some of the major things which the Indian parents found inhibiting them in coping with the situation include lack of acceptance of the mentally retarded child within the family especially by the paternal grand parents, other relatives, in the neighbourhood and by people in the community. To manage a mentally retarded child having behaviour problems is also found to be a major block. The wrong or delayed advice given by the professionals and their insensitive handling of the whole situation has been reported to be found most upsetting and discouraging to the parents. Other inhibitors include poor physical health of the family members, lack of facilities for training their mentally retarded child and loss of support from family members and relatives.

48. Are there any extra responsibilities that father's need to take in order to help cope better with the situation of having a mentally retarded child in the family ?

Both the parents i.e. father and mother play a crucial and significant role in meeting the extra demands placed on the family because of having a mentally retarded child. It has been observed that father's who are supportive to their wives in sharing the responsibilities of looking after the mentally retarded child and other household chores, who

provide emotional support to their wives in times of distress, does help the family to become stronger to face the challenges and cope up with the situation better. Father's also need to involve themselves in the training programme for their mentally retarded children maintain professional contact as and when needed and spend time with their wife and children in caring for them and sharing concerns with them apart from only being a bread earner.

49. Do siblings have any role in helping their mentally retarded brother or sister ?

Companionship and support between brothers and sisters outlives that between parent and child. This is true of any family. Siblings are the natural support systems which can be strengthened and utilized depending upon the socio-cultural set up and needs of the given society. In India we do not have social security support systems provided by the Government which may be available in developed countries hence all the more reason to build on and strengthen the natural support resources. Siblings are considered as natural future guardians of mentally retarded individuals. The earlier the siblings are sensitized to the needs of their mentally retarded brother or sister the better it is. Parents can help build up better relationship between their mentally retarded child and siblings by informing them truly about the condition of their mentally retarded brother/sister, encouraging them to play, share and care for each other.

50. If siblings spend time in caring for their mentally retarded brother or sister will it not adversely affect their studies or careers ?

Every individual who comes to this world has to learn to

adjust to various situations in life. Siblings of mentally retarded individuals may also need to learn to adjust and adapt to the situation of having a brother or a sister who is mentally retarded. Parents need to play a very significant role in helping non-disabled siblings to cope up with this situation better. Keeping them non-involved with their mentally retarded brother or sister may not help. Parents if use right child handling techniques can help train siblings in the appropriate use of time. This will further help siblings to cope up with the responsibilities of both studies and building up their careers as also involve themselves in contributing to the caring of their mentally retarded brother or sister.

51. Are grand parents living in a family having the mentally retarded child considered a hindrance or a help ?

Grandparents can be of help if they are helpful to the family and a hindrance if they are creating problems for the family. Grandparents can be great natural supporters of the family. They can help by sharing the household responsibilities and looking after the child care needs, provide emotional support to their own children and if possible provide financial support to tide over the financial crises if the family is facing. They could be a hindrance if they are found criticizing, blaming or neglecting their own children, do not involve or care for the mentally retarded child, place extra caring demands on their children for meeting their own needs, cause financial strain if not contribute financially and lead to over crowding and loss of privacy if there are problems of space.

52. We tend to spend more time with our mentally retarded child than with our other children. Will it have any negative effects on them ?

Because of the special needs of the mentally retarded child parents do tend to consider that their mentally retarded child needs them more. However, it is important to understand that every child whether disabled or non-disabled have their individual needs which parents need to understand and meet. If these needs are not met children may start feeling neglected, left out and at times start feeling jealous of their mentally retarded brother or sister. This may interfere in the relationship between the mentally retarded child and other siblings as also between the parent and the other children and give rise to behaviour or emotional problems in them. It is not so essential how much time one spends with the mentally retarded child or other children as much as how well you spend the time with your children and make them feel needed and wanted by you.

53. Is there any professional help available to assist in managing family problems arising out of having a mentally retarded child ?

Professionals help need to be sought by parents if they tend to face family problems. Clinical Psychologists, Psychiatrists trained counsellors, or social workers are professionals to contact who can help parents resolve their problems. They are generally available in mental or general hospitals, child guidance clinics, marriage or family counselling clinics, institutions or special schools for the mentally handicapped individuals.

NOTES

EARLY INTERVENTION

Though the situation is changing in our country for the better yet a large number of parents still tend to reach out pretty late for appropriate services for their mentally retarded children. There are reportedly many reasons for it such as lack of proper guidance, non-availability of services, reluctance on part of the family members, misconceptions that child will become normal as he grows big or attitudes of stigma. This section deals with issues and parental queries especially related to what is early intervention, for whom it is applicable, how early should early intervention begin for a child with developmental delay, what services are provided under early intervention, who provides and where are these services available etc.



Sonam is now 1 year old. She is not able to sit. We should go and see a doctor.



You are always very keen about going to a doctor. I'm telling you that everything would be alright.



Ma, there is no harm in seeing a doctor. Let's see what he has to say.



Yes, your child will be able to sit and also learn to walk but, early intervention services is essential.



54. How does a parent come to know that the baby is not developing normally ?

Growth and development follows a predictable pattern as all children pass through the same stages of development. Such as holding neck by approximately 3 months, sitting by 6 months, standing by 11 months, walking and talking by 1 year etc. However the rate of development may not be the same as there are individual differences. In early years, babies often show spurts or slow rate of growth and development. As compared to children of his/her age if a child is observed to be slow and lagging behind in development, parent should suspect retardation.

55. What should a parent do if the baby is found to be slow in development ?

If the baby is found to be slow and lagging behind in development as compared to other babies of same age, medical consultation from neonatologist (pediatrician working with new born babies) should be sought at the earliest. Such specialists are available in medical colleges and large hospitals. Systematic clinical examination will provide relevant information on the deviation from normal development and helps in making choice of therapy, nursing and care of the infant with developmental delay.

56. What constitutes early intervention services ?

Early intervention procedures for the children with mental retardation below the age of 5 years give specific emphasis on sensory motor training and infant stimulation programme. Typically early intervention program is aimed at reducing the deficits by training children in activities to

promote development and learning of new skills which might not occur by itself or naturally in children with developmental delay. In case of mentally retarded children having associated condition like cerebral palsy, physical therapies and postural adaptations are used.

57. Does early Intervention help ?

Early intervention program is necessary for the healthy growth of the mental and physical abilities of the child with developmental delay. Early intervention benefits not only the child, but also the family and society at large. Significant benefits of early intervention are as follows:

Benefits to the child

- early intervention helps in developing the skills for future learning,
- reduces the occurrence of associated handicaps,
- provides opportunity to live with the family from the beginning,
- child can attain maximal potential.

Benefits to parents

- helps parents to learn effective parental skills that will help them to teach and stimulate their child,
- early counselling can help parents to accept the child better,
- early counselling can minimize disruption in the family and establish positive pattern of interaction among the family members.



EARLY IDENTIFICATION AND EARLY INTERVENTION HELPS

Benefits to siblings

- feelings of self worth are increased when siblings are helped to understand their brother/sister with mental retardation and are allowed to be a part of constructive family efforts to help the mentally retarded child develop optimally,
- future guardianship role is facilitated.

It must be stressed that early intervention will not cure the disability, but will give children a greater opportunity to realize the potential they have, build a network of support systems to strengthen the family to face the situation of having a child with mental retardation.

58. How early should a parent seek early intervention when their baby is found to be developmentally delayed ?

As soon as it is recognized that the young child is developmentally delayed, prompt treatment and intervention will help the child reach his/her optimal level of attainment. To start intervention and treatment early is important because of the great adaptability and plasticity of the infant brain. It is well known that the first 24 months of a normal child's life involve tremendous and rapid growth and development. Hence the earlier the parent seek early intervention services, better it is for the child.

59. How long the child needs to attend early intervention services ?

Early intervention services generally are given till 3-5 years of age, i.e. the time before the child enters a traditional

school programme. Programme of early intervention services is directed towards early formative years of children-at-risk upto the age of five years.

60. Who are the experts required to provide early Intervention services ?

The impact of mental retardation is likely to be seen across all aspects of the child's development. Thus, if intervention efforts are to be effective, attention must be given to a child's total well being, including physical, sensory, motor, linguistic, cognitive, and social development. Developmental progress in all these areas is interrelated. Progress in one area facilitates gains in other. Hence intervention approaches must address a child's need in every developmental domain. Early intervention is multi disciplinary, involving services that overlap several professional fields. Effective intervention requires the input and cooperative teamwork of many professionals such as paediatricians, physiotherapists, special educators, psychologists, occupational therapists, social workers and speech pathologists who serve the developmentally disabled and at risk children and their families.

61. Can medicines alone help treat a child with developmental delay ?

There are no medicines available to cure a child with developmental delay and make him normal. However, there are medicines that can be used to treat associated conditions like epileptic fits that a child with developmental delay may be suffering. Other medical conditions like deformity in limbs may require corrective surgery.

62. If there are problems in the family due to presence of mentally retarded child, who should the parents consult ?

Very often parents of children with mental retardation will find that their immediate family and friends don't fully understand the problems faced in raising their child with special needs. Parents may receive all kinds of advice from others. Parents should look for professionally trained personnel like clinical psychologist or social worker to discuss family issues arising because of having a child with mental retardation in their family. Another important source of talking about problems comes through the parents' religious affiliation. But right guidance and information is very crucial to the parents at this early stage which should be available from professionally trained people.

63. Where are early Intervention services available ?

Early intervention services are available at :

- child guidance clinics in general and mental hospitals,
- well baby clinics in pediatric centers,
- early intervention clinics in institutions working for the habilitation of mentally retarded individuals.

Information on the early intervention centers in various places around the country can be had from directory of institutions published by NIMH, Secunderabad and available in most institutions working for the welfare of mentally retarded individuals.

64. Is it that the nature of early Intervention services are same throughout the country ?

The goal of early intervention is to facilitate optimal development in the child. However, since no two children with mental retardation are alike, intervention programs are designed to suit the specific needs of the child. Training in sensory-motor, cognitive and social areas, speech therapy, parent counselling and training, medical and nutritional intervention form essential components of early intervention services.

65. If there are no early Intervention services where the family resides, what should the family do ?

At the National Institute for the Mentally Handicapped, Secunderabad, family cottage programmes are available where in a family along with the child receives programmes during their stay. The stay may range from one week to three weeks depending upon the needs of the child and the family. Follow up is provided as per requirements. For further details please write to the Coordinator of Family Cottage Programmes, NIMH, Secunderabad. Information on the early intervention services available at other centers in the country can be obtained from the directory of institutions published by NIMH and available in most institutions working for the welfare of mentally retarded individuals.

66. How can parents help in the development of the child ?

The role of parents is crucial in early intervention. Parents

act as therapists or co-therapists or teachers to their child with developmental delay. By providing opportunities, stimulation, general care and nurturance parents can help children to develop skills they need to facilitate future learning.

67. Other than the mother, is there any need to involve father in the early intervention programmes ?

The support of father can be of utmost importance during the early years when parents come to recognize, understand, and finally accept their child's disability. During this trying and often painful process, parents need to support each other. Having a child with mental retardation produces extra burden on the family which need to be shared by all the members of the family including the father. Both father and mother may need to work through their emotional reactions and concerns because of having a child with mental retardation and come to terms with it as early as possible. Intervention programmes are reportedly more successful if both the parents are involved. Hence it is very essential to involve father in early intervention programmes.

68. Can other members of the family help in the development of the child ?

The birth of a child with mental retardation is known to cause stress in the family. The degree of stress experienced and the adjustment and coping of the family to stress largely depends upon the severity of the child's condition and the family's existing support system, that is the amount and quality of emotional, physical or financial help provided

within the family and outside the family. Significant family members like siblings and grandparents play an important role in helping the family adjust better. They can also contribute by involving in the intervention program with the child under the guidance of expert or the parent who is being trained.

69. Is it true that if the parents spend more time training the child, better would be the results ?

Each child has individualized training needs which require varying degrees of training time. The activities of training the child can also be built in the living style and daily activities involving the parent child interactions. More than how much time parents spend is important how well the parents spend time with the child to produce optimal result.

70. How does a parent decide whether to continue with early intervention services or send the child to a preschool or nursery ?

Typically early intervention programmes are available upto the age of three years and can be extended upto 5 years. After that the child enters into preschool for further education. Further guidance in this area can be provided by special educators and psychologists.

71. What after early Intervention ?

Early intervention in India often continues upto 5 years of age. Once the child has reached 5 years parents should consider sending the child to normal, integrated or special school depending upon the level of severity of the child and

availability of resources. If the child with mental retardation has severe mental retardation and no school is willing to admit him, home based training programmes should be pursued. Professionals like special educators and clinical psychologists can help parents in the choice of services. But much depends upon what kind of services are available in that place for their child with mental retardation.

SCHOOLING

With emphasis on free and compulsory primary education by the Government, rapid urbanization along with growing awareness among people about their rights and benefits of being literate in the world of today, parents aspire for greater academic achievements for their children. Under this background when parents find intellectually normal children gaining admission to schools and doing well in studies in contrast to their mentally retarded child who is still lagging far behind, the worries and anxiety of parents start mounting up. Parents may find difficult to get admission for their mentally retarded child in a school. They may be unable to decide whether to send their child to a normal regular school or to a school for the mentally retarded children. Some mild mentally retarded children who do find their way to normal schools find it difficult to cope up with the curriculum of the normal schooling making their intellectual deficits obvious. At this juncture, parents are seen searching for appropriate guidance to help them to decide what to do. This section answers some of the frequently asked questions by parents regarding schooling for their child with mental retardation.

I wonder whether Ramesh will ever be able to go to school.



You were thinking of admitting Ramesh in the special school. What happened?

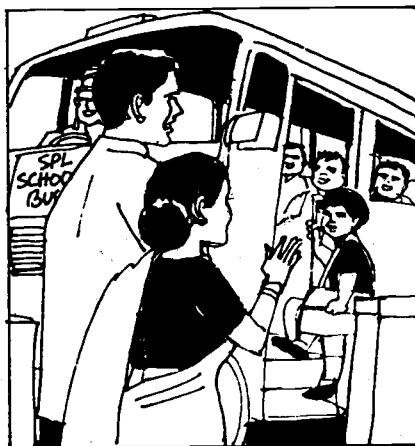
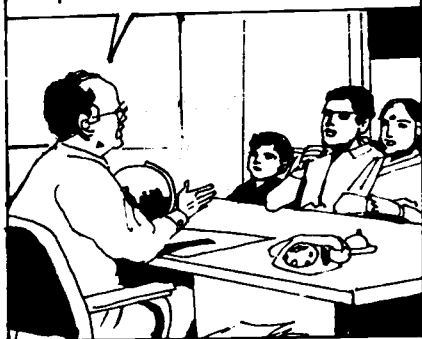
Oh! that school for the mentally retarded. He could probably become worse.



But Radha's daughter is showing a lot of improvement in that school. Why don't you go and meet the principal.



I understand your concern Mrs Rao. Each child is taught as per her/his level and needs.



72. How early should a mentally retarded child be admitted to school ?

A child with mental retardation should be admitted to school by 5 to 6 years of age. However, it is advisable that before a child is admitted to formal schooling, parents should seek out early intervention and preschool services.

73. What is the criteria followed for admission in a special school ?

Special schools in India have their own set of rules for admission. Some of the general guidelines followed for admission are as follows:

- production of certificate that the child is mentally retarded,
- child should be between 5 to 18 years of age,
- child should be toilet trained,
- child should be mobile,
- child should not be having significant associated conditions such as epilepsy, behaviour problems etc.

However, some special schools do run home based training programme for those mentally retarded children whom they may not be able to admit due to various reasons. Under such circumstances parents are trained to train their child at home till the child becomes eligible for special school admission.

74. If a mentally retarded child has behaviour problems will he/she be refused admission in a special school ?

Managing behaviour problems in mentally retarded individuals do require special knowledge, skills and time

on the part of the teachers. Depending upon the resources available in a given special school they may refuse or admit a mentally retarded child with behaviour problems.

75. Is I.Q. testing essential for admission to special school ?

As per the definition of mental retardation, assessment of intellectual functioning is essential to identify and diagnose a case of mental retardation. To ensure that special schools meant for mentally retarded students admit only mentally retarded students, I.Q. assessment reports are crucial.

Intelligence test scores are found useful for diagnostic purpose, grouping of children for teaching and procuring scholarships or other social benefits provided by central and state governments. However, for programming and teaching, assessment of the child's adaptive behaviour, language skills, academic achievement, school experiences, cultural back ground, motivation, living environment and other factors are necessary.

76. What are the various kinds of options available for educating mentally retarded individuals ?

Basically, there are three options available for teaching and training mentally retarded individuals :

- special schools meant exclusively for mentally retarded individuals,
- integrated schools wherein mentally retarded children are trained along side non-handicapped students,
- home based training programmes wherein parents are trained to train their mentally retarded children.

77. What is a special school ?

Special schools are institutions for learning that serve individuals with disability during daytime hours. Most common are schools for the blind, for the deaf and hearing impaired, mentally retarded and for orthopedically handicapped children. The prime purpose of special day schools is to provide special educational services.

Special schools may or may not offer residential services. Those offering residential services are known as special residential school, while those that don't offer residential services are known as special day schools.

78. What is Integration ? What is Integrated schooling ?

Integration refers to the concept of training the handicapped children within regular/ normal school programmes along side non-disabled students with additional support services and resource teachers to meet special needs of retarded children. An integrated set up for a student with mental retardation can be of two different types namely:

- a mentally retarded child sits along side non-disabled student in a classroom. However, depending upon his/her needs extra coaching is provided in a special class or on one to one basis with a special teacher,
- a mentally retarded child continues to be educated in a classroom along side non-disabled children and is never pulled out from the class for special teaching. However, a special teacher assists the classroom teacher from time to time in meeting the specific needs of the special child.

79. Do we have Integrated schools in India ?

There are schools in our country which offer integrated services. But the number of such schools is very few. For information where these schools are, write to the Information and Documentation Officer, National Institute for the Mentally Handicapped, Secunderabad or to the Joint Secretary (School Education), Department of Education, Ministry of Human Resource Development Shastri Bhavan, New Delhi, or to the National Council for Education, Training and Research (NCERT), New Delhi.

80. What are the benefits of sending a child to a special school ?

The child with mental retardation requires individualized assessment and specialized training. Special schools offer the following benefits to a student with mental retardation :

- smaller sized classes i.e. 6-8 students,
- specially trained teachers,
- individual or small group teaching,
- use of special learning materials and equipments,
- reduced academic pressure and competition,
- training towards social living and vocational skills,
- a warm, tolerant and accepting environment,
- intensive training and therapy directed towards meeting the unique needs of each child,
- academic expectations based on realistic assessment of student's capability,

- structured, controlled, tightly organized special school activities.

81. How should parents decide where to send their mentally retarded child for schooling ?

Each child's needs and environment is unique. Assessment by a psychologist or special teacher is essential for making placement decisions. However, following are the factors which are generally kept in mind in arriving at such decisions:

- the nature and severity of the child's handicap,
- the resources available within the local neighbourhood school to meet the child's educational needs,
- the resources available within the community for caring the child,
- the social companionship available for the child within the community and neighbourhood,
- the effect of providing the child's daily care on his/her family life and family relationships.

82. For how many hours in a day does an individual with mental retardation need to go to a special school ?

If a student is attending a special school as a regular student, the number of hours of school time is decided by the school administration which ranges from 5 hours to 6 hours daily.

83. Are all children with mental retardation taught the same things ?

All children with mental retardation cannot be taught the

same things because of the individualized needs of these students. Individuals with mental retardation will learn if provided with an appropriate teaching program and a teaching process that is oriented to their individual needs. Individualized education programme (IEP) is developed and followed for each child. Decisions on what to teach is based upon an objective assessment of each child i.e. what the child already knows or does not know. Generally in the decision making process parents, school teachers, professionals like psychologist, speech therapist, occupational therapist, medical doctor etc. and wherever possible the concerned child is included.

84. Are the same teaching methods used for all mentally retarded children ?

The teaching methods for educating and training students with mental retardation have been derived from the field of behavioural psychology. This approach emphasizes breaking learning tasks into small and obtainable steps and rewarding gradually to shape behaviours toward the desired goals.

The teaching methods are not same for all students with mental retardation. Students with severe handicaps require more systematic and precision teaching model to help them to learn skills in still smaller steps.

85. Do special schools follow a uniform syllabus throughout the country ?

The goal of education for individuals with mental retardation is to teach adaptive living skills necessary to decrease the dependence on others and to increase self dependence. Selection of a uniform syllabus throughout the country is

not possible because of the heterogenous needs of each child and different demands of the community throughout the country. Although the domains of curriculum remain constant like motor, self-care, social, communication, and functional academic skills, however, modifications could be made based upon the present and future needs of the child.

86. If the child is taught in a language, other than the language spoken at home, does it have any effect on the child with mental retardation ?

Although, language training should as far as possible more rely on the child's mother tongue to improve the opportunity for communication, our society by nature is multilingual i.e. most of us use more than one language. It has been observed that exposing a child with mental retardation to a number of languages in his natural process of learning tends to make him multilingual. However, children with mental retardation do face problems in learning more than one language. This may sometimes lead to low academic achievement resulting in frustration and loss of self esteem.

It is advisable, that some sort of workable cooperation between parents and teachers at school is met in order to make teaching of mother tongue possible in the intervention, training and education programme. Anecdotal reports and research findings do indicate that in an environment which provides positive opportunities, some mentally retarded individuals tend to acquire second language when it forms a part of a school training programme.

87. How much can a student with mental retardation learn in academics?

Most students with mental retardation will benefit from training in the basic academic subjects. With systematic teaching programme, an individual with mild mental retardation can achieve as high as fifth or sixth grade level in reading and arithmetic. Since students with mental retardation don't learn as quickly or as effectively as their non retarded age mates, the traditional approach to teaching basic academic skills as such may not be appropriate for these students. For moderately and severely retarded, academic skills such as reading, writing and arithmetic may not be a priority. For these children training may be focussed on adaptive living skills.

88. In special schools all the children are mentally retarded. Does this kind of environment have any adverse effects on the individual with mental retardation?

Special schools have a number of advantages, yet, do have some limitations. A potential negative effect of sending a child to special school is the isolation of the individual with mental retardation from their non-handicapped peers, and hence the loss of opportunities to observe peers who can model age-appropriate skills and social behaviors. Another potential disadvantage is the isolation from the real world environment in which individual with mental retardation must still learn to function and adapt. Children may tend to initiate and learn a lot of bad behaviours if teachers find it difficult to manage such behaviours. Some of the ways that one can compensate for these effects could be, by providing mentally retarded children a lot of opportunities

to interact with non-disabled people at home and in the community.

89. What helps a child with mental retardation to learn better and faster ?

A child with mental retardation learns faster if:

- the goals and objectives for teaching have been selected based on his present level of functioning,
- the goals and objectives for teaching are based upon his present and future needs,
- provides opportunities for practicing the skill very often in natural environments such as home, community etc.,
- use of systematic methods of teaching,
- high family and professional involvement.

90. Is it that the mentally retarded child is supposed to go to a special school before going to a normal school ?

It is not necessary for a child to attend a special school before moving to a normal school. However, depending upon the specific needs of the child and availability of resources a decision could be taken to place a child temporarily in a special school before transferring the child to a normal school setting.

91. Does a mentally retarded individual continue to stay in the same class ?

Special schools follow their own criteria for grouping mentally retarded children which is quite different from the

system that is generally followed in normal schools for non-disabled children. In special schools, grouping is done based upon mental ages, adaptive functioning levels and physical age of children. They could be classified as pre-nursery, nursery, primary, pre-vocational and vocational classes or it could be pre-primary, primary, secondary and pre-vocational.

Each class has a set of skills covering domains like motor, communication, social, self help etc. that need to be mastered by the student before she/he can be promoted to the next class. Generally, 80 % skills of a given class are needed to be mastered for promotion to next class.

92. How frequently is the special teaching and training programme evaluated ?

The special teaching programme for a child consists of long term goals and short term objectives. Evaluation is done after every three months for the short term objectives while the long term plan is evaluated annually. For the conduct of evaluation apart from the special teacher, it is useful to include parents, other professionals like speech therapist, psychologist, medical doctor, occupational therapist, social worker and wherever possible the concerned child.

93. How can a special teacher help a parent ?

The special teacher can help the parents in a variety of ways:

- the teacher can help parents gain understanding of their special child,

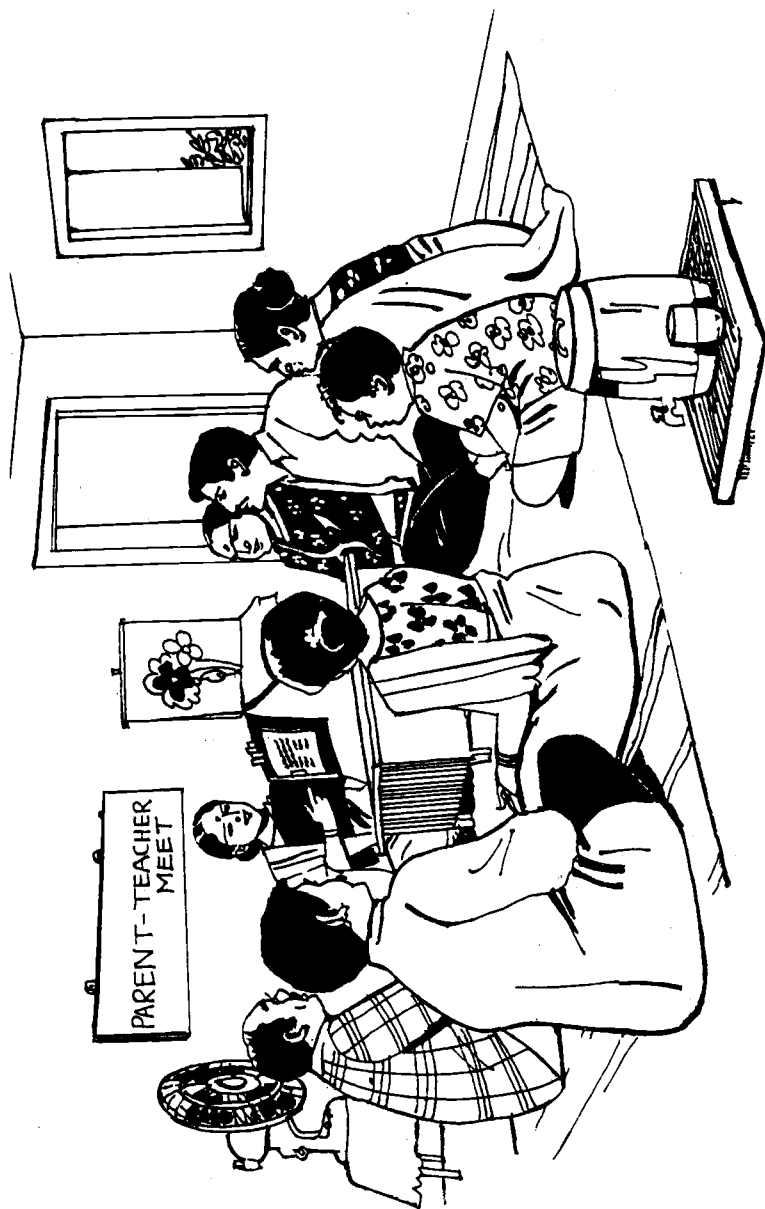
- the teacher can assist improving the quality of interaction between the parent and child so that the exchanges are more helpful to learning,
- teachers can train parents in the methods of training their child,
- teachers can help increase the involvement of parents and help them to carry out the programmes at home,
- the teacher can recommend toys, games, records, books, and other educational aids that might be useful and would supplement the school programme,
- to identify needs of families and refer promptly for other support services.

94. Do parents have a role in educating their child with mental retardation ?

Parents play a crucial role in shaping the lives and personalities of their children. The care and nurturance they provide and the quality of parent-child interactions are some of the most powerful factors that affect educational achievements of their children. Parents play an important role in planning, designing and implementation of the training programme of their child. Parents can also act as potential advocates for their child and the family.

95. How frequently should a parent visit the teacher ?

Every school has their own guidelines on parent-teacher meeting. However it is advisable that parents meet the teachers of the school personally at least on monthly basis to document the progress of their child. In addition,



POSITIVE PARENT TEACHER RELATIONSHIP IS ESSENTIAL FOR OPTIMUM GROWTH AND DEVELOPMENT OF THE CHILD

parents should communicate through the child's school diary at least once a week if not daily.

96. What could be the reason that a student can perform certain activities at home but does not perform the same activities at school or vice versa ?

This is a problem of generalization wherein the student with mental retardation has not yet learnt to perform the learnt skill in all settings and situations. Hence the training programme needs to be evaluated for which special teacher could be consulted.

97. Can a special school expel a child with mental retardation because he has behaviour problems ?

Some special schools may request parents to withdraw their child who has severe behaviour problems till the behaviour problems are managed. When such a situation arises, parents should seek consultations from a clinical psychologist/Psychiatrist.

98. For how long should the mentally retarded child go to a special school ?

Ideally, a student with mental retardation should attend special school till 18 years of age after which he should graduate to a vocational or adult day activity training center.

NOTES

BEHAVIOUR PROBLEMS

Nearly 50-60% of the mentally retarded individuals have behaviour problems. Presence of behavior problems is known to produce great amount of stress and management difficulties to parents and other family members. At times wrong advice given by well wishers to be overstrict or to tolerate bad behaviours and to fulfill all demands of mentally retarded individuals in order to keep them happy makes matters worse. Due to the presence of behaviour problems mentally retarded children may find difficult to get admission in schools, cause embarrassment to the parents, and family members due to the presence of socially unacceptable behaviours. Mentally retarded individuals may also find difficult to retain jobs or adjust to work setting if behaviour problems persist. No wonder controlling problem behaviour is a priority for many a parents. This section answers questions on behaviour problems like, when does a behaviour becomes a problem, what causes it, and where to turn for help for managing these problems.

Get down, Ramesh at once. Since you are stealing food you will not get icecream today.

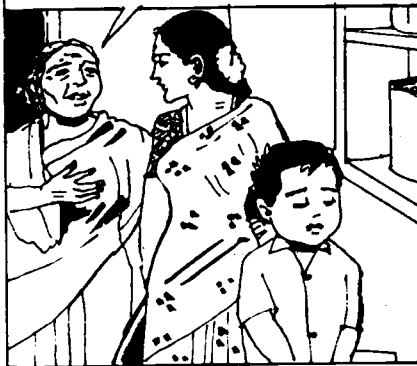


He is a young boy and then he is retarded. Why do you have to punish him?

If we don't teach him what is right and what is wrong, how will he learn.



What has giving an icecream to do with it?



If he has done something wrong, he needs to know that. When he does something right, don't you see that I hug him and praise him.



But after all he is still a child.

If we don't teach him right behaviors now, it will be a problem and your grandson will be branded as a foodstealer. Do you want that to happen?



I guess you are right.



99. Are behaviour problems found more, less or same in mentally retarded individuals in comparison to intellectually normal individuals.

Behaviour problems are found to be 4 to 5 times more in mentally retarded individuals than in intellectually normal individuals.

100. What could be the reasons for mentally retarded individuals to have greater behaviour problems ?

According to the behavioural point of view mentally retarded individuals are seen to have greater behaviour problems precisely for the following reasons :

- have difficulties coping up with different kind of situations,
- have poor cognitive ability,
- have poor social skills,
- have poor communication skills and above all,
- wrong handling by people in the environment.

101. What are the various kinds of behaviour problems seen in mentally retarded individuals ?

Mentally retarded individuals may show different kinds of behaviour problems such as :

- aggressive and destructive behaviours,
- rebellious and disobedient behaviours,
- temper tantrums i.e. crying or insisting till needs are met,

- self-injurious behaviours such as head banging, biting self etc.,
- running away from home,
- repetitive behaviours such as frequent and continuous body rocking,
- sexual problems which may include masturbation in presence of others, touching other's at odd places etc.

A given mentally retarded individual may have one or more behaviour problems which may cause immense concern to the parents.

102. Are mentally retarded individuals generally disobedient ?

One of the major complaints given by parents of mentally retarded children having behaviour problems is that their child is stubborn or disobedient, i.e. he/she does not do, what he is told to do or does the opposite of what he is told to do, or takes too long to do what he is told to do. But many mentally retarded individuals are also known to have learnt to be quite obedient and amenable.

103. At times an advice is given by elders and well-wishers that we need not worry if the child is behaving badly as he/she is small yet and will come out of this problem as he grows older. How far this is correct ?

It is well known that mentally retarded children take longer to both learn and unlearn behaviours. Mentally retarded individuals may not naturally outgrow behaviour problems on their own easily. Due to less of understanding ability, they don't realize on their own as to what they are doing

is wrong till they are made to change their behaviours. Behaviour problems in mentally retarded individuals can be managed through modifying the environment in which the problem behaviour occurs and through the use of the specific behavioural techniques of management. Behaviour problems in mentally retarded children need to be managed as early as possible or else they tend to loose out a lot on social acceptability.

104. How early should parents need to manage behaviour problems in their mentally retarded children ?

There is no age recommended for managing behaviour problems in mentally retarded individuals. As soon as the behaviour problems in the child are recognised these should be managed.

105. Are there any indications for parents to recognise when the particular behaviours in their child would require treatment or management ?

To call particular behaviour as problematic or not is generally very subjective. As some parents may tend to tolerate a lot of bad behaviours in their children which in fact is not advisable as these can be modified. The following aspects of behaviours could help parents in deciding to make decisions to change behaviours in their child :

- if the problem behaviours are occurring too frequently,
- if it occurs for a long duration,
- if it is too severe,
- if it interferes in the learning process,

- if it is socially unacceptable,
- if it is harmful to child himself,
- if it produces disturbance or harm to others.

Even if one of the above aspects is found applicable to the child's behaviour, it is indicative that the child's behaviour requires modification.

106. Some times an advice is given that since our child is mentally retarded we should try to keep him happy by fulfilling all his needs. Is this how we should handle him ?

The desire of parents to keep their children happy is a very noble one, however to achieve this through fulfilling all their needs even if they are unjustified may not be correct. Parents do own great responsibility in disciplining their children which helps children in regulating their lives as also live in socially acceptable ways. Meeting unjustified needs generally lead to behaviour problems and indiscipline which then may require behaviour management.

107. Should medicines be used to treat behaviour problems in mentally retarded individuals ?

If the cause for the behaviour problem is found to be organic or internal then use of medicines could help. There are side effects of drugs such as drowsiness, low reacting levels, reduced attention to tasks and physiological changes. How far the use of drugs will give long term benefits such as learning the right ways of behaving to replace the bad behaviours must be considered before putting

the child on medicines. If behaviour problems are not too severe it may be appropriate to first try non-drug approaches for behaviour management. Occasionally, in cases with severe behaviour problems, drugs are used along with behaviour modification techniques with gradual tapering off the drugs and behavioural management fully taking over.

108. We have been told that both the parents should not be strict with the child as that would spoil the child. Instead one parent should be strict and the other lenient so as to keep the balance. Is it correct ?

If parents desire their children to be well behaved and disciplined, then both the parents should own equal responsibility. Parents need to be good models to their children. Parents need not be either lenient or strict to the child, however, they need to be consistent in their behaviour with their children.

109. Is it true that when the mentally retarded child reaches adolescent stage he will have a lot of sexual problems ?

Mentally retarded individuals pass through the same stages of physiological growth and development which intellectually normal individuals do. Hence, mentally retarded individuals experience the same physiological and hormonal changes linked with adolescent stage of development. Mentally retarded individuals are at a greater risk to pose more problems during this stage due to their poor adaptability and their ignorance as to how to cope up with the situation. However, help from special educators/special teachers, psychologists, and counsellors in sensitizing

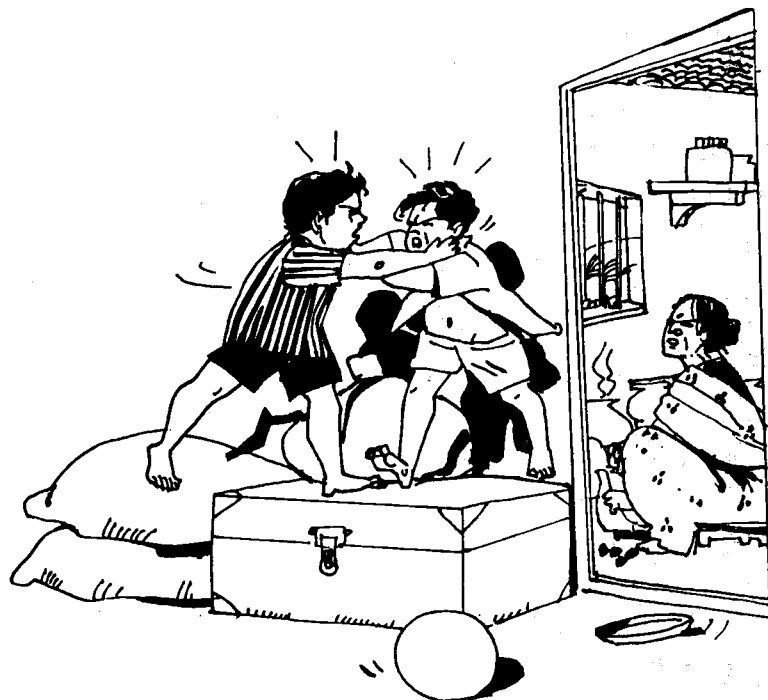
them as also in preparing and training them to meet their adolescent needs goes a long way in overcoming these problems.

110. The old proverb, "spare the rod and spoil the child", how far is it applicable to the mentally retarded individuals ?

Hitting, spanking, abusing children are not the best methods to bring changes in the behaviours. These may lead the child to suffer from frustration, disgust and anger and also foster poor self concept and damage the self-esteem and self-confidence of the child. The user of these methods may also suffer from negative emotions of extreme anger and later may be with feelings of guilt. There are healthier and more appropriate methods available to achieve the same objective that is, to discipline the child which are called as behaviour modification techniques.

111. What is the behaviour modification approach ?

Behaviour modification technology involves behavioural methods to both increase desirable behaviours and or decrease undesirable behaviours in individuals. These methods are based on learning principles from the field of psychology. This technology is based on the premise that all behaviours good or bad are learnt and hence can also be un-learned. It believes that each individual is unique and so is his behaviour. Using this technology the behaviour in question is understood in the context of the environment in which it occurs. The environmental factors and causes linked with the behaviours such as interactions of the child with the people he/she interacts with child's own characteristics,



**PROBLEM BEHAVIOURS IN CHILDREN WITH MENTAL RETARDATION
CAN BE MODIFIED**

the physical environment, etc., are scientifically and systematically studied using an approach called "functional analysis or eco-behavioural analysis" following which behavioural methods are decided upon both to increase and or decrease identified behaviours in the given individual.

112. Can this behaviour modification approach be applied to all mentally retarded individuals ?

This approach is applicable to all mentally retarded individuals irrespective of age, sex or degree of mental retardation. It is applicable in any setting i.e. home, school, work or community setting. These can be used with groups of mentally retarded individuals or on individual basis.

113. Can parents be trained in the use of behaviour modification techniques ?

Parents have been found to benefit a lot from training programmes which help them to become better behaviour modifiers of their own children. Such training programmes are being regularly conducted at the National Institute for the Mentally Handicapped, Secunderabad with groups of parents as also on individual basis. Other institutions working for the mentally handicapped individuals or professionals having training and expertise in the use of behaviour modification technology, could also be contacted.

114. Is there a need to give rewards to a mentally retarded child and bribe him to learn? Should he not understand on his own that he needs to learn ?

Mentally retarded individuals have poor ability to learn.

They may not understand on their own the need to learn certain basic skills or behaviours which would help them to survive in the world much in contrast to the intellectually normal individuals for whom learning may occur naturally during their interaction with the environment e.g. independent eating, toileting, bathing or dressing skills, etc. Hence, to get these mentally retarded individuals to learn these behaviours, rewards need to be used. Rewards make learning more pleasurable and enjoyable. Once the behaviour is learnt, the rewards are then gradually removed using specific methods. Rewards are not bribes. Bribes are used to achieve personal ends, here, rewards are used to help mentally retarded individuals learn better and faster.

115. What are the various kinds of things which mentally retarded individuals find rewarding ?

Different things are found rewarding by different mentally retarded individuals. These could include, any of the eatables or drinks, money, points, stars given by teachers or parents on the notebooks, tokens, watching T.V., going outside the house, cycling, playing cricket, playing ball, games, listening to radio, music, different objects such as pens, pencils, books, new clothes or verbal praise, hugs, kisses, making child incharge or monitor or leader etc. However, each child is unique and rewards may need to be identified for each child separately. Whether the child finds the particular things as rewarding or not depends upon your skill in identifying the potential rewards for your child and also how you deliver or give the reward to your child, which at times have to be learnt by the parents.

116. *Is it that punishment should never be used with the mentally retarded child ?*

Under behaviour technology punishment means removing something from the child what he/she likes or presenting to the child what he/she dislikes immediately following an undesirable behaviour. As likes and dislikes vary from child to child, these would need to be identified. Using hitting, spanking or abusing is to be discouraged. Punishment may be used judiciously to manage behaviour problems in mentally retarded individuals but as a last resort. However, punishment may still form only as a part of the total behavioural management programme. Other methods would include such as restructuring of the environment, differential reinforcement, etc. Depending upon the needs of the specific child, decisions about the methods to be used are made after a thorough understanding of the environmental factors causing the problem behaviour. Parents are always included in the decision making process.

117. *If the child is disobedient to parents but generally listens to others. Is it all right to place the child in residential hostel or a place away from parents ?*

The very fact that the child behaves well with other people and not with parents indicates that the problem is with the parents and in their handling. Hence, by sending him away to a residential hostel is not a permanent solution to the problem. The problem will return back when child will be required to interact with parents. Such disobedience in mentally retarded individuals can be corrected, provided the parents are ready to change their ways of handling their child.

118. If one of the parent follows the behavioural treatment programme with their child but the rest of the family members do not follow, will this have any effects on the child's behaviour?

To get optimum results it is essential that all members of the family as also those people who interact with the child follow consistently the same desired methods of behavioural management. If one parent follows the desired methods consistently the child may start behaving appropriately with that parent but may continue to misbehave with others.

119. Who are the professionals to contact for managing behaviour problems.

As per availability parents could seek guidance from clinical psychologists, educational psychologists, special educators, trained special teachers or psychiatrists. The professionals should be trained in the behavioural management of mentally retarded individuals.

NOTES

COMMUNICATION

Some of the major worries of parents begin when the child is unable to speak. Meaningful speaking is linked with comprehension which in turn is highly related to cognitive and intellectual abilities of the individual. Parents start guessing for various reasons why their child is unable to speak or unable to speak as clearly and fluently as a normal child. Tongue-tie or some defect in the structural aspects related to speaking is probably one of the first reason that strikes them necessitating to seek professional help. Parents search answers for many a questions such as: will he be able to speak, when will he speak, what is the reason why he is not able to speak, how can we train him to speak or what is needed to be done. Answers to some of these common questions asked have been included in this section.

Will my child be ever able to talk?



The assessment reports indicate that your child has severe mental retardation. Hence, she may not be able to talk like you or me.



So how will he ask for things or communicate?



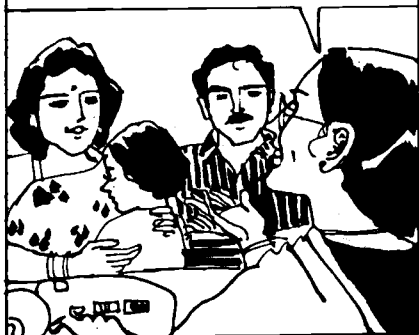
Apart from speech we will teach her alternate forms of communication like using signs, gestures or using communication boards.



Will that help her to talk?



With training, she will be able to communicate her basic needs.



120. What Is communication ?

Communication is a process by which two or more individuals exchange information, needs, feelings or desires. This message can be transmitted in a variety of ways like speaking, reading, writing, gestures, etc.

121. What Is the need for training an individual with mental retardation in communication skills ?

The need for communication is as important for individuals with mental retardation as for any other individual. One of the problems in individuals with mental retardation usually involves some degree of delayed or inappropriate communication skills. Depending on the severity of handicap there may even be a total absence of expressive communication. In order to enable the individuals with mental retardation to express their physical needs, their need for social interaction, and their need for competence in understanding and organizing their surrounding, communication training is needed.

122. What are the most common ways of communication ?

People communicate in different ways by using sensory modalities like touch, smell, hearing, and seeing. Examples of the common ways of communication include :

- hearing : speaking, morse code, telephone, alarms, etc.,
- seeing : reading, writing, gestures, facial expressions, body postures, telegrams, television, dance, etc.,
- touch and smell : shaking hands, kissing, hugging, punching, smell of rose, etc.

123. Do speech, language and communication mean the same thing ?

Although used interchangeably by many people speech, language and communication don't mean the same thing. Communication is the process by which two or more individuals exchange information, needs, feelings, or desires. Language is the information communicated via means of words and symbols related to a system by which members of a particular community interact. Speech is the frequently used way of production of the sounds of language communication. For example, if two persons are talking in Hindi, communication refers to exchange of information between the two persons through the language Hindi. Since both of them are talking, communication is occurring through speech.

124. Do Individuals with mental retardation communicate in the same way as non-disabled persons do ?

Speech is the most common way to communicate among non-disabled people. Individuals with mental retardation due to their nature of handicap may experience great difficulty in communicating by spoken language. However, in recent years, individuals with mental retardation have been taught successfully to use sign systems. Signs are used along with the spoken word so that the child continues to see and hear the words at the same time as they are seeing signs. Although these systems have their limitations, it can significantly reduce the frustrations associated with lack of communication. Other means of communication which mentally retarded individuals use include body language, gestures, written words and pictures.

125. Do all individuals with mental retardation have communication problems ?

A significant number of children with mental retardation do have difficulties in speaking or talking, which to varying degree could affect their educational progress. Communication problems may have a physiological cause, or may arise from social, emotional, cultural factors.

About 80 percent of persons with mental retardation have problems in communication. The range of communication problems include :

- complete inability to speak;
- difficulty in making ordinary word sounds, resulting, for example in "slurred" speech, poor pronunciation;
- problems in understanding other's speech;
- difficulty in putting words together.

About 40 percent of the persons with mental retardation are non verbal i.e. they have no speech at all. In addition, nearly 40 percent of individuals with mental retardation are known to have hearing problems. Parents could consult, a speech therapist/ENT specialist for their child's specific communication problems.

126. Do all children with communication problems have mental retardation ?

All children with communication problems don't have mental retardation. Communication problems occur due to multitude of reasons like problems in hearing, motor or emotional. Only those children who show slow rate in all the areas of development like cognitive development, motor development, language development, etc. have a very high risk of becoming mentally retarded.

127. How can a parent know whether a child hasn't learnt to speak because of hearing problem or of mental retardation ?

Although hearing loss interferes in the acquisition of speech and normal speech production, there are differences in the child's behavior that will indicate that the child has not learnt to speak because of hearing problem or mental retardation. If an infant is born deaf or acquires a hearing loss very early in life, few symptoms initially signal the problem, like inability to turn head towards the source of sound when clapped from behind. Early behaviour and development of a child with severe or profound hearing loss is much like that of a non impaired infant. A child with hearing loss stops babbling after the age of 6 to 8 months. However, the most obvious characteristic for an individual considered to be mentally retarded is the slow rate of development and reduced ability to learn. Early reports of individuals who are eventually diagnosed as mentally retarded indicate delays in overall development of age appropriate skills such as head control, rolling over, sitting, standing, crawling and walking or mastering toileting skills or early feeding skills. A thorough intellectual or developmental assessment as also audiological assessment can help clarify the issue.

128. My child is unable to hear properly. Could it be one of the reasons why he hasn't been able to speak so far ?

Adequate hearing is essential for speech and language acquisition. If the person with mental retardation is not able to hear words clearly, it will be difficult for him/her to learn to speak. This may often lead to frequent frustration and disappointments both for the person with mental retardation and others.

Although about 40 percent of individuals with mental retardation have hearing problems, it is also essential to note that ability to speak also depend on certain other factors like adequate motor abilities, intact sensory mechanism, adequate information processing skills and a rich and stimulating environment.

129. How early can parents detect signs of communication problems in their child with mental retardation ?

A parent can detect signs of communication problems in their child as early as within 3 weeks after the birth of the child based on physical-neurological status of the child and by the delay in acquisition of developmental milestones. In addition, detection of eventual communication problems is possible at birth if the baby is born with physical handicap like cerebral palsy, cleft palate problem.

The physical-neurological status, as assessed in a physical examination, is good indicator of potential speech/language difficulties. The normalcy of early reflex patterns is one of the means for identifying children at-risk for possible speech difficulties. Abnormal tonic reflexes usually suggest delays or abnormal development of the central nervous system. Also, abnormal neuromotor movements such as swallowing, chewing or sucking may suggest possible speech difficulties. Immature oral-motor functions if persist beyond certain age may interfere with the development of the speech.

Once the parent suspects any communication problems, there is a need to take the child immediately to an ENT specialist/Speech therapist for guidance.

130. Is it necessary to have an intact physical structure for speech to occur? Is it generally found intact in individuals with mental retardation?

Speech production is a complex process. Speech is produced with the help of speech mechanism structures like tongue, jaw, lips, etc. in coordination with the brain. Hence it is very necessary that the physical structure involved in the production of the speech be intact. The speech mechanism like lips, tongue or throat etc. could be affected in individuals with mental retardation. The extent of damage is dependent on the severity and nature of the handicapping condition.

131. What are the errors committed by some parents in communicating with their child having mental retardation?

It has been observed and reported that some parents tend to talk less with their child with mental retardation because they feel that the child may not understand. The content of the parents speech may lack variety and include monotonous instructions like come, get, give, eat, etc. In addition parents expect and insist correct production of the speech sounds from their child which could be quite frustrating for both the parent and the child.

132. What is the role of parents in promoting speech and language development in their child?

Parent involvement in communication training is very important because parents spend more time vocalizing with their children than any other adult or child during the first few years of life. Children first learn the "communication game" through interaction with parents and begin to experience the enjoyment of mutual communication. What

vocabulary or set of words parents use, how parents encourage and praise the child as he makes attempts to respond and vocalize or speak, how they correct their child or help the child to learn and provide instructions constitute a set of experiences which highly influence the child's language development.

133. Can communication training for individuals with mental retardation be taken up at any age ?

During the initial years of life, the child's mind is plastic which can be moulded. It is receptive, more amenable and flexible which help him to learn language very quickly. If the child's communication problem is not recognized early and effective help is not provided, the crucial years for learning communication skills may be lost. Speech development and language learning follows rapidly from birth to about 3 or 4 years of age. Results are best when training occurs between 0-6 years. However, it is always better to start late than never.

134. Do all individuals with mental retardation undergo the same type of communication training ?

No two individuals with mental retardation are alike, hence the training is provided to the individual, based on the abilities and needs of the child. Generally, children with severe mental retardation receive training on a variety of important behaviours like requesting, and following instructions. Children with mild mental retardation receive training to increase the rate of language development, rate of talking and the ability to carry on instructions.

135. What is cleft palate ?

A cleft palate is an opening in the roof of the mouth connecting with the canal of the nose. Usually 1 in about 800 children is born with cleft palate.

136. Are individuals unable to speak because of cleft palate problems ?

Children born with cleft palate are at a risk of developing communication problems. The child may be slow to use language or may develop abnormal patterns of language use. Research indicates that children having cleft palate use shorter and less complex sentences than normal children. In addition, the physical abnormalities of the children make it impossible for the children to produce certain sounds accurately. If the child is unable to make certain sounds easily, he/she may start to substitute them with other easier sounds or omit those sounds altogether. For example sounds made at the front of the mouth are replaced by sounds at the back like /t/ will be produced as /k/ therefore TAP will become KAP /d/ will be produced as /g/ therefore DOG will become GOG.

In addition, oral sounds involving air being passed through the mouth are replaced by nasals like /b/ will be produced as /m/ therefore BALL will become MALL /d/ will be produced as /n/ therefore DAY will become NAY.

The sound of the voice may be different from that of a normal child. Generally speech is characterized by hypernasality (too much nasal resonance). The combined effect of the above behaviour will severely limit the child's speech intelligibility and clarity.

A speech and language therapist and ENT doctor can help parents in the management of children with cleft palate problem.

137. What is cleft lip ?

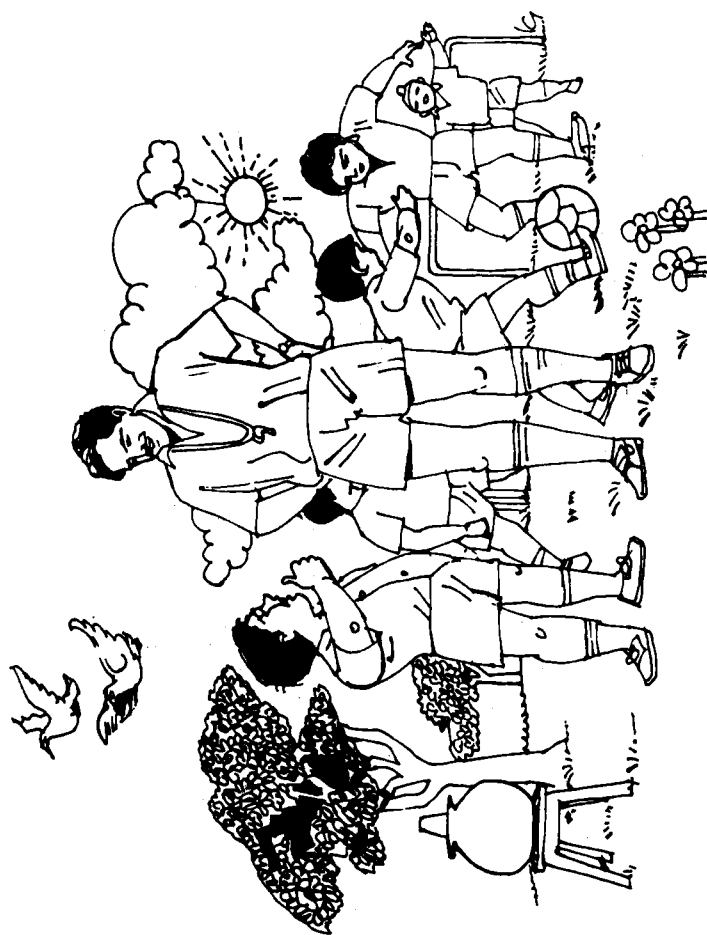
An elongated opening in the lip resulting from the failure of the parts to fuse or merge early in the prenatal development i.e. between 6th to 12th week of the mother's pregnancy is referred to as cleft lip.

138. Are Individuals with mental retardation unable to speak because of cleft lip problem ?

Certain sounds are produced by pushing air through lips. Unclear speech if present due to cleft lip can be minimized by repairing of cleft lip through plastic surgery. However, even if after the cleft lip has been successfully repaired speech problems in individuals with mental retardation can still persist. This is because the ability to speak also depend on certain other factors like adequate motor abilities, intact sensory mechanism, adequate information processing skills and a rich and stimulating environment which are generally found deficient in mentally retarded individuals in varying degrees.

139. My child with mental retardation can pronounce certain sounds like /p/ and /m/ but cannot pronounce sounds like /zh/ or /v/ What is the reason for this ?

Children acquire speech sounds production in a pattern. The production of less complex sounds appear before more complex sounds appear. Certain words are learnt earlier before others in the child's early range of vocabulary.



INDIVIDUALS WITH MENTAL RETARDATION CAN BE TRAINED TO COMMUNICATE USING SPEECH, SIGNS, GESTURES, OR COMMUNICATION BOARDS

140. Can language and communication training take place only in speech therapist's room ?

Language and communication skill training cannot occur in isolation. The speech therapist assesses the child's abilities and demonstrates few strategies in his clinic. Language and communication learning essentially need to take place in the daily activities of interaction like dressing, eating, washing etc. between parent/caregivers and the child. Hence, it is very essential that the language and communication training occur in the most natural environment of the child i.e. his/her home, school and other natural settings. Actual implementation of the program can be effectively carried out by teachers or parents in natural environments under the guidance of a speech pathologist/therapist.

141. How much time in a day should a parent/caregiver spend in training a child with mental retardation in communication skills ?

There is no specific amount of time limit laid down as a rule that should be spent on training communication skills to the child. It is suggested that language and communication training should be incorporated in the routine of daily activities of the child with mental retardation which would allow maximum opportunity to practice the skills.

142. Do all individuals with mental retardation eventually learn to speak? If not, what are the other ways by which mentally retarded individuals can learn to communicate ?

Although language and communication training would

assist individuals with mental retardation to express his/her needs and desire, yet about 40% of the mentally retarded individuals will always experience greater difficulty in communicating through spoken language.

Mentally retarded individuals who are unable to communicate through direct speech can be trained in the use of non-verbal means of communication. These include use of body language, gestures, written words and pictures. Non verbal communication systems are grouped under two main categories namely:

- unaided communication systems like use of sign language systems,
- aided communication systems like use of picture charts, electronic devices, etc.

143. What is sign language ? How far is it useful to individuals with mental retardation in India ?

Sign language is a type of non-verbal communication wherein individual communicates the message through the movement and positioning of hands. Although developed for persons with hearing handicap, sign language has been used as a communication aid for individuals with mental retardation that helps them to communicate their day to day basic needs.

Individuals with mental retardation require systems that are simple. The gestures and signs used in sign language are highly culture specific and differ from place to place.

Also, only a limited portion of the general population understands signs and gestures limiting communication to select individuals. Persons with mental retardation may also have associated physical problems which may hinder in signing. Hence the applicability of sign language is limited. However there are other systems like communication boards that may help individuals with mental retardation communicate better.

144. Is it true that if a child is taught sign language, he would stop speaking ?

Individuals with mental retardation share the universal need to communicate. Due to variety of motor, neurological or sensory deficits, some individuals with mental retardation may have greater difficulty in developing speech skills. Thus, it may be necessary for them to devise a non-speech system for helping them to communicate. Sign language is one such non-speech system.

Non-speech systems of communication are developed when the individual with mental retardation has very little chance of using speech as mode of communication. Various factors considered before deciding on non-speech communication include assessment of sensory-motor mechanism, stage of language development, situation, inter-relationship with age and acceptability of the system.

However, it must be remembered that introducing a non speech system is not a decision made once and for all. It is only a means to facilitate communication.

145. How long should parents continue to seek communication training for their child with mental retardation ?

For most individuals with mental retardation communication training is lifelong. It is advisable to see the speech therapist from time to time to note the progress of the child. At the same time support and encouragement from the home, spending time, talking and listening to one's child may be just as important as getting expert's help.

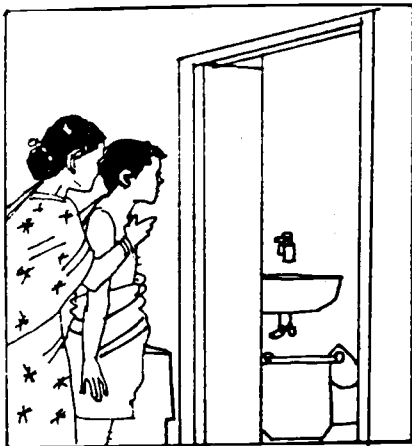
146. We live in Delhi. We speak Telugu at home. My child is taught in Hindi at school. Will it have any adverse effect on the child ?

Although, language training should as far as possible rely more on the child's mother tongue to improve the opportunity for communication, our society by nature is multilingual i.e. most of us use more than one language. It has been observed that exposing a child with mental retardation to a number of languages in his natural process of learning tends to make him multilingual. However, children with mental retardation do face problems in learning more than one language. This may sometimes lead to low academic achievement resulting in frustration and loss of self esteem.

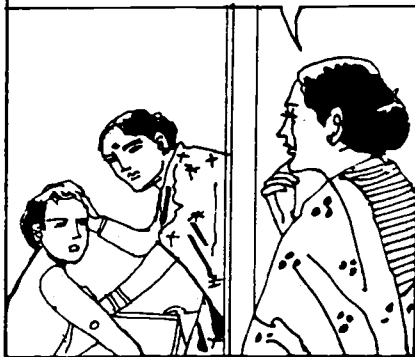
It is advisable, that some sort of workable cooperation between parents and teachers at school is met in order to make teaching of mother tongue possible in the intervention, training and education programme. Anecdotal reports and research findings do indicate that in an environment which provides positive opportunities, some mentally retarded individuals tend to acquire second language when it forms a part of the school training programme.

ACTIVITIES OF DAILY LIVING

All parents especially the mother goes through the pressures of bringing up and caring for the child. Such pressures even if the child is normal are more during the early years of child's life as the child is yet dependent on the mother for meeting some of his/her basic needs such as toileting, feeding, dressing, etc. Parents happily bear such problems knowing well that very soon the child will become independent in meeting his self care needs. However, this is not the case with a mentally retarded child as the dependence on parents is much prolonged. Each day from the morning till night it can be a tough ordeal for the parents, more so, if the child is severely retarded and having associated physical handicap. Parents like to seek answers to a number of questions such as, will my child ever be able to eat on his own, for how long does one have to continue to take care of him, clean him in the toilet, are there any ways to train him to look after his basic self care needs, can female mentally retarded individuals be trained to take care of their menstrual hygiene. Some of the pertinent questions related to these aspects are answered in this section.



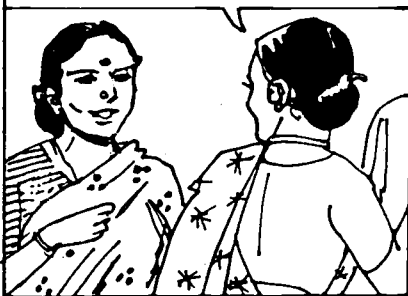
How come you are still giving bath to Ramu, he is so grown up.



I thought Ramu is going to school. Has the teacher not told you anything about it.



I never brought up this issue. Moreover they don't teach these things at the school. I'll talk to the teacher.



I think your husband or your elder son should help Ramu in taking bath. Since he is growing big, it may lead to some problems later.



147. What is meant by activities of daily living? What does training in activities of daily living for individuals with mental retardation include?

Also known as self care skills, activities of daily living (or ADL as they are commonly called) refers to practical skills needed to care for one's basic survival needs and to function in the society. Training in activities of daily living includes teaching :

- basic skills like eating, toileting, dressing and undressing,
- more advanced skills like grooming, bathing, menstrual hygiene, tooth brushing, clothing care and purchase, shopping skills, housekeeping and home safety skills, food preparation and related social skills as table manners.

148. Activities of daily living are routine activities. Won't individuals with mental retardation learn these activities naturally.

Due to their mental handicap, individuals with mental retardation often lack many thinking tools and observation skills that helps to learn even some of the basic daily routine activities. Given such a situation, it is important that individuals with mental retardation be given training in basic self care at the earliest.

149. Can all individuals with mental retardation be trained to look after their basic needs by themselves?

With appropriate intervention, most individuals with mental retardation can learn at least some basic self care skills like eating, toileting, bathing, dressing, etc. Although the extent

to which individuals with mental retardation can be trained to look after their basic needs depends on the severity of their handicap, it is still important to look for ways in which they can be encouraged to become increasingly independent. Therefore, it is very possible that with proper training, opportunities and experiences an individual with mild and moderate mental retardation with no significantly associated conditions can achieve mastery of self care skills, whereas individuals with severe and profound mental retardation may master some basic skills.

150. Our child is 4 years old. We find it is a waste of time to teach activities like eating, dressing, bathing, etc. to him as it would save a lot of time and energy if we do all these things for him. What do you suggest ?

It is never a waste of time to train individuals with mental retardation to look after their own needs. All individuals with mental retardation irrespective of their intellectual levels can be trained. By training the child in the self care areas parents can be relieved from the burden of constantly looking after the basic needs of the child. Also, the child becomes independent and gains a sense of competence which increases his self confidence.

151. How early can toilet training start ?

Toilet training can be initiated if :

- the child with mental retardation regularly urinates or defecates within certain daily time periods,
- if the child can stay dry for 1-2 hours regularly,
- if the child is minimum 2 1/2 years old.

It is recommended that for optimum benefits, training for severe mentally retarded children could be started at 5 years. However, if an individual with mental retardation who is not toilet trained meets the three criteria described, toilet training should be initiated anyway, regardless of the level of mental retardation.

152. How can one know that their child is ready for toilet training ?

Essentially there are five conditions that help determine whether the child with mental retardation is ready for toilet training :

- does the child stay dry consistently for 1-2 hours?
- does the child consistently soak as compared to dampen the diapers?
- absence of any physical problems for bladder and bowel control,
- the child with mental retardation should be able to understand what a 2 years old normal child can understand,
- do parents have the time to follow through with the training.

153. By what age can one expect an individual to be toilet trained ?

Learning toileting skills varies considerably for each child with mental retardation. All toilet training is dependent upon the child having reached a certain level of physical maturity, training opportunity and experiences

given to the child. It is very important that parents give top priority to toilet training in early life.

With appropriate training however most individuals with mental retardation can learn at least some toileting skills. Generally individuals with mild mental retardation with no significant associated conditions and optimum inputs of training attain independence in toilet training by 7-8 years. Individuals with moderate retardation can master this skill by about 10 - 11 years. Although individuals with very severe and profound mental retardation will need lifelong support, it is still important to look for ways in which they can be encouraged and trained to become increasingly independent.

154. What does toilet training for individuals with mental retardation include ?

Toilet training involves learning bowel and bladder control. Toilet training enables individuals with mental retardation use the toilet appropriately when needed. Toilet training includes :

- ability to go to toilet when required,
- undressing/dressing during toilet use,
- urination or defecation in the toilet or appropriate area,
- cleaning self after toileting,
- pouring water/flushing the toilet.

155. Is it important for individuals with mental retardation to learn to remain dry ?

The joy of being able to do things for self, along with the praise from others for their successes, increases

the confidence of the child with mental retardation and encourages to do more. The more competent the child gets, the more confident he/she feels about self and his/her abilities.

The failure of individuals with mental retardation to remain dry may lead to restrictions in schooling and recreational activities. Failure to remain dry also reduces the teaching time between parents and the individual with mental retardation who is not dry. Serious health hazards in the form of inadequate hygiene, dysentery and intestinal infection can occur. Unable to stay dry also makes the individual with mental retardation less pleasant and acceptable to others.

156. My 10 years child wets the bed at night frequently. Can he be trained to remain dry during nights ?

Bed-wetting at night, even if, toilet trained during the day is generally reported among individuals with mental retardation. Causes of night time bed-wetting alone in mentally retarded individuals is generally found to be "organic" such as delayed development or maturation, heredity or age of the child. Very occasionally in mentally retarded individuals the causes could be emotional or psychological in origin. If the child is able to remain dry during most of the day time, and no training has been provided to develop night time bladder control then a trained special teacher should be able to guide you. If the causes for night bed-wetting are emotional or psychological you may need to consult a clinical psychologist for further guidance.

157. The special school refuses to admit my 8 year old child because he's not toilet trained. What should I do ?

Trained special teachers are needed to train mentally retarded individuals who are not toilet trained and a special school may refuse to admit your child on the grounds that they have less trained manpower, though ideally all special schools need to be equipped with the required infrastructure to handle such situations. A special school may however decide to take the child on home based programme wherein the parents are trained how to train their child at home.

In case, there are no schools in your area that will admit your son the best option is to pursue a home based programme. The Child guidance clinic can also help you in this regard.

158. My child is 4 years old. Presently I feed her as she is unable to eat on her own. Will she eventually learn to eat on her own ?

Most individuals with mental retardation can learn to feed themselves, however certain factors can act as barriers and lead to delay or difficulty in the acquisition and learning of eating skills in mentally retarded individuals. These include :

- motor or neurological handicaps,
- structural abnormalities in the oral cavity and musculature,
- attention problems,

- extreme disruptive behaviours,
- special dietary needs,
- sensory deficiencies,
- inadequate learning environments such as overprotective,
- uninvolved and poor training of parents, may lead to delayed, incomplete development of eating skills.

To train mentally retarded individuals with motor and neurological handicaps, aids are used. An occupational therapist or a trained special teacher would be able to guide parents in the selection and usage of aids for independent feeding.

159. What are the problems which parents generally face with their children with mental retardation during feeding times ?

Feeding problems in children with mental retardation can be due to associated physical conditions or due to poor learning environment. Problems that parents face due to the physical condition of the child include :

- poor head and trunk control,
- poor sitting balance,
- difficulties to bring hands to mouth,
- poor eye hand coordination.

To help the child overcome these problems it is advisable to seek help from an occupational therapist or a trained special teacher.

Feeding problems that have been reported as a result of poor learning environments include :

- too much time spent while eating,
- disruptive behavior while eating,
- spilling the food,
- not indicating hunger,
- not able to discriminate between edible and non-edible things,
- stealing food.

To help the child learn self-feeding skills and right behaviours during meal time it is advisable to seek help from a clinical psychologist or a trained special teacher.

160. My 7 year old child takes a long time to eat. Is it advisable to let him eat before the rest of the family eats ?

It is very important that the child with mental retardation eats along with other family members during meal times. Meal times can be one of the best occasions for family get together wherein irrespective of the disability children generally learn good eating habits by observing elders behaviour of eating. Also, depending upon how will the parents utilize this time, a lot of positive learning and sharing can take place between the parents, children and other family members. Mentally retarded individuals benefit from such situations hence should be included during family meal time. If the mentally retarded child takes too long to eat this can be managed by studying the reasons for it.



WITH PROPER TRAINING, INDIVIDUALS WITH MENTAL RETARDATION
CAN BE TAUGHT BASIC SELF CARE SKILLS

A clinical psychologist or trained special teacher could be consulted for help.

161. What are the problems which parents generally face with their children with mental retardation while brushing their teeth ?

Common problems reported by parents of children with mental retardation during brushing teeth are :

- difficulty to spit,
- habit of swallowing paste,
- lack of coordination of fingers to hold brush,
- inability to reach the back of teeth,
- lack of initiation or refusal to brush teeth,
- insisting others should brush even if child knows how to brush.

To help the child master the tooth brushing skills and overcome problems during teeth brushing time it is advisable to seek help from a clinical psychologist or a trained special teacher.

162. How Important Is oral hygiene for individuals with mental retardation ?

Healthy teeth and gums and maintaining good oral hygiene is important for any individuals' overall health and well being irrespective of disability. They are needed to improve feeding, aid speech development and maintain an attractive appearance and increase social acceptability by preventing foul smell.

163. Are problems related to teeth and gums found more in mentally retarded individuals ?

The amount of gum disease is much greater in persons with mental retardation and is due to poor oral hygiene. Severe gum disease is a particular problem for persons' with Down syndrome, the lower front teeth can be severely affected and are frequently lost early in life, posing both eating and aesthetic problems. In addition, individuals with mental retardation may have more chances of developing gum diseases due to following reasons :

- poor mouth and tongue control resulting in sticking of the food to gum and teeth and not be able to clean away by the natural movement of the tongue,
- feeding children with disabilities soft sticky foods resulting in soft, weak and unhealthy gum,
- teeth grinding which causes excessive wear on the teeth,
- drugs for epilepsy can cause swollen or unhealthy gums,
- sometimes children with mental retardation are 'spoiled' by giving them extra sweets which causes tooth decay.

164. Can individuals with mental retardation be trained in oral hygiene ?

With proper training, given to the child with mental retardation, it is possible for him/her to become independent in oral hygiene. However, individuals with severe to profound mental retardation will require life long support and assistance from parents/caregivers. Few guidelines

to follow in this regard are :

- to brush teeth daily,
- to rinse or brush teeth after taking meals,
- to select the right tooth brush which suits child's gums and teeth,
- to use the right procedures for brushing teeth generally circular motions of brushing teeth are recommended as it looses less enamel,
- to see the dentist at the earliest on having dental problems.

165. What are generally the problems faced by parents while bathing their children with mental retardation ?

Common problems observed during bathing of the child with mental retardation are as follows :

- lack of initiation to take bath regularly on time,
- lack of coordination of hands,
- preference of the parent/caretaker to bathe the child rather than allow the child to take bath by self,
- inability to apply soap, rub and wash the entire body,
- uses more water, uses more soap, does not come out of the bathroom, takes too long to take bath.

166. Can individuals with mental retardation be trained to take bath on their own ?

With proper training, opportunity and experiences given

to the child with mental retardation, mastery of bathing skill is possible. The probability becoming independence on this skill is enhanced if the child with mental retardation :

- has the ability to follow instructions,
- has proper eye hand coordination to apply oil, soap, pour water and dry body parts.

167. By what age do girls with mental retardation attain sexual maturity ?

Girls having mental retardation are known to attain sexual maturity at the same age as the intellectually normal girls i.e. between 12 to 16 years of age.

168. Can females with mental retardation be trained in looking after their menstrual hygiene ?

It is important that when mentally retarded females achieve menarchy that they are trained to look after their menstrual hygiene. Adaptations in their underwears may be used to help them achieve independence. How far mentally retarded females achieve independence in menstrual hygiene care will depend largely upon their intellectual abilities, opportunities provided for training and presence or absence of associated conditions.

169. Who are the persons in the family who should be involved in training the individuals with mental retardation in activities of daily living ?

Caring for the child with mental retardation creates additional burden to the members of the family. If all the

family members contribute in the training and rehabilitation of the child, the burden felt will be less. It is therefore suggested that all the family members should be involved in training the individual with mental retardation in activities of daily living. It is also suggested that as far as possible when training the child with mental retardation in toileting, bathing, dressing or menstrual care, same sex family member/care giver should be involved in the training for reasons of privacy.

170. I am a mother of a 17 years old mentally retarded boy and I bathe him every day. I find it quite embarrassing. What do you think I can do ?

It is suggested that you involve a male member to help, who can assist your son in taking bath. With appropriate training programmes, individuals with mental retardation can be taught to care for themselves. A trained teacher could train you and concerned person in teaching your child with mental retardation to acquire skills in bathing.

171. My son is 40 years old and is still unable to take care of his basic needs. What do you suggest ?

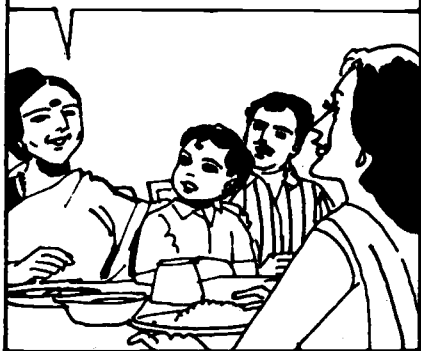
With appropriate training intervention, however, most individuals with mental retardation can learn at least some basic self care skills. It is also important that parents seek out professional help in training of their child with mental retardation at early stages in the life of the child so that he can learn and perform better.

Seek help from a trained special teacher or attend a parent training program which will help you to learn skills how to train your child in meeting his basic self care needs.

ACADEMICS

Depending upon the level of mental retardation, the curriculum for academic skill is determined. In most cases, the aim of training in academics is to train children with mental retardation in functional academics (which train them in survival skills). In most cases the aim is to train them to handle money correctly, to commute independently, and to conduct minor business transactions like shopping, transactions in banks, post offices etc. Persons with mental retardation have to be prepared for responsibilities in adult life. Therefore, it is necessary for them to not only be aware of the time but also punctuality and other work related behaviours. Parents often ask questions as to what their child with mental retardation can be trained in and what kind of skills are necessary for the child to acquire. The group of questions related to academics are dealt in this section.

Do you know that Ramesh is counting upto 50 now?



Ramesh can you get me 2 spoons for serving the curd and curry. I forgot to get 2 spoons.



Ramesh I told you to get 2 and not 6 spoons. Can't you count.



Next Day

Why is it that my son who can count upto 50 can't get 2 spoons correctly?



Two different situations i.e. rote counting and meaningful counting is involved here. Your child has yet to learn meaningful counting.



172. *What is taught to Individuals with mental retardation under academics ?*

Traditionally, education programmes for individuals with mental retardation have emphasized the learning of academic skills. Under academic skills are included reading, writing, arithmetic, time concept and money handling. For those students who may not be ready for learning in academics, prerequisites are usually taught, for example, sorting colours and shape, matching pictures etc.

173. *Who teaches academics to Individuals with mental retardation ?*

Special teachers who have been trained in special education impart training in academic skills. Depending on the needs and resources of a given institution or special school, educators and educational psychologists may also be involved.

174. *When does training in academics for Individuals with mental retardation begin ?*

Individuals with mental retardation move through the same stages of development as their non-retarded peers but at a slower rate. Generally, training in academics for mild mentally retarded individuals begin at the age of five to six years when the child is admitted to special school. However, training in pre-academics could have started earlier for them. For children with moderate to severe mental retardation, deficits in intellectual and social functioning are evident prior to school years. To clarify further, by

5-6 years severe and moderate mentally retarded individuals would have still not become independent in looking after their basic self-care needs such as toileting, eating or dressing. Hence, priority for their training would be related to self help and social skills and if needed in motor skills along with pre-academics.

175. How much can Individuals with mental retardation achieve in academics ?

Most children with mental retardation will benefit from instruction in the basic academics. Due to differences in the rate of learning, different levels of academic achievement is seen among individuals with mental retardation.

With proper and systematic training, individuals with mild mental retardation can pass upto 5th or 6th standard. However, children with mild mental retardation develop poor reading skills and comprehension. Individuals with moderate to severe retardation can be taught to read at least protective vocabulary like 'danger', 'stop', etc, their names and common words which they may encounter in the community.

176. Individuals with mental retardation do not seem to put much efforts to learn hence remain poor academic achievers. How far is this true ?

The intellectual capabilities of children with mental retardation are deficient in comparison with their non-retarded peers. The greater the severity of retardation, the greater the deficit in intelligence and hence the greater the problems

in learning. Poor learning and memory functioning in children with mental retardation has been attributed to many factors like :

- poor ability to focus on the relevant event in a learning situation,
- poor ability to transfer learning from one situation to another,
- poor ability to benefit from incidental learning,
- poorly developed central nervous system.

177. Are individuals with mental retardation taught academics the same way as normal individuals ?

Mentally retarded individuals have difficulties in learning such as poor ability to transfer learning from one situation to another or across persons and places etc. Hence, special methods of training are used to teach academics to them. Their instruction program includes an increasing number of activities that helps them to learn immediately usable skills that are crucial for day to day living and lead them to independent functioning in the natural environment as far as possible.

178. What does functional academics mean ?

Functional academics involves instruction in reading writing and arithmetic activities skills that are necessary for everyday living. These abilities are also referred to by many as 'survival skills'. The skills could be relatively simple for many people such as counting change from a basic purchase or reading the sign in a toilet in an unfamiliar situation. They could also be complicated and

involve balancing of cheque book or shopping. Since mentally retarded children are not able to generalize and transfer classroom learning situation to everyday situations, training in functional academics is a must for them. This will assist them to learn the basic skills necessary for existence within the community.

179. Can students with mental retardation be taught to read ?

Meaningful reading involves understanding or comprehending what one reads. Individuals with mental retardation can be taught how to read meaningfully depending on their severity of handicap. With systematic training, individuals with mild mental retardation may be capable of learning to read books requiring 4-6 grade skills. Individuals with moderate to severe retardation because of severe learning deficits can be taught to read at least protective words like 'danger', 'stop', etc., their names and common words which they may encounter in the community in their day to day life.

180. Do students with mental retardation need any prior training before they can be taught to read ?

A child with mental retardation may need prior training in pre-reading skills before he/she can be taught to read. Basic pre-reading skills include :

- teaching comprehension like child finds picture to match spoken word,
- teaching visual discrimination like child matches objects and pictures,

- teaching sound discrimination like child tells whether the sounds of two words is same or different,
- intact visual or sensory mechanisms.

181. What is taught under reading skills ?

The goal of reading programme as with any other academic programme for individuals with mental retardation is directly oriented to daily living activities, leisure time and vocational preparation. A functional reading program focuses on reading for protection and information. Protection reading program will allow student to read building signs, street signs, and other common environmental safety words. Information reading program would teach individuals with mental retardation functional skills related to vocational proficiency (e.g. filling up application forms, reading classified jobs etc.) use of telephone directories, maps and reading newspapers.

Since no two individuals with mental retardation are alike care is taken that the reading program is developed based on the ability and needs of each individual.

182. Do individuals with mental retardation need any prior training before starting instructions in arithmetic skills ?

An individual with the mental retardation may need prior training before he/she can be taught arithmetic. Basic pre-arithmetic skills include :

- child demonstrates understanding basic quantity concepts such as more, less, large, small etc.

- child demonstrates understanding basic labeling concepts like rote counting etc.
- child demonstrates understanding basic measuring concepts such as weight (heavy, light) etc.
- child demonstrates understanding basic symbols related to quantity like 1, 2, 3 etc.

183. What is included in arithmetic skills ?

The goal of training mentally retarded individuals in arithmetic skills involves two basic aspects. First step involves training students to perform basic arithmetic operations like addition, subtraction, division, multiplication. Secondly, training them in the application of arithmetic skills to everyday problems as a survival tool in work setting and day to day activities. Basic arithmetical operations like division, addition, subtraction, multiplication, use of money, telling time and measurement form the main contents of arithmetic training programme.

184. My child is able to count 1 to 100 but is unable to count the five people sitting in a room. Why is it so ?

This is a very common problem among children with mental retardation. Children with mental retardation are not able to effectively transfer knowledge to new tasks or situations. Thus, while the child has learnt to count 1-100 by rote, he cannot meaningfully count upto 5. Meaningful counting is what the child needs to learn. A trained special teacher could be consulted.

185. My child is able to bring items from the shop when asked to, but is unable to bring back the correct change/money. Can he be trained in the required skills ?

With appropriate training, opportunities, and experiences given to the child with mental retardation at school and at home the child will learn and perform at his best. Although some children would be restricted to some degree in money handling skills by the very degree of intellectual handicap, however, it is still important to look for ways by which mentally retarded individuals can be encouraged to become independent.

Although the extent to which an individual with mental retardation can be taught handling money depends on certain prerequisite skills like counting, indentifying coins and able to do basic addition/substraction, these skills can be taught without teaching advanced academic skills. For example, pocket calculator can substitute for computational skills while shopping or a student could learn to pay the fare of the bus learning to select the exact coins or having a monthly bus pass. A trained special teacher could be consulted for further guidance.

186. My child is not able to tell time? Can he be trained in this skill ?

The extent that the child with mental retardation will be able to tell time is dependent on his degree and nature of mental handicap, the amount and nature of training and opportunity given to him to learn. In addition, certain skills that would facilitate time telling are as follows :

- counting meaningfully from 1-60, (to include digital watch)

- reading numbers meaningfully from 1-60,
- counting meaningfully by 5's to 55.

A trained special teacher could be consulted for further guidance.

187. Do individuals with mental retardation need any prior training before they can be taught to write ?

A child with mental retardation may need prior training in pre-writing skills before he/she can be taught to write. Basic pre-writing skills include :

- adequate eye-hand coordination,
- gross motor (large muscles) and fine motor (finger, small muscles) coordination,
- knowledge of basic concepts like up-down, left-right etc.

188. What is taught under writing skills ?

Acquiring writing skills depends largely on intellectual abilities. The training in writing skills for mentally retarded individuals emphasize on acquiring such skills which help them in their day to day living and work setting. This includes writing name, address, filling up cheque, writing an application for a job, writing letter to friends and writing a leave letter etc.

189. What does training in concepts include ?

Training in concepts include teaching basic matching and sorting skills, teaching specific concepts like colour, size,



FUNCTIONAL ACADEMICS SHOULD HAVE DIRECT RELEVANCE WITH DAY TO DAY FUNCTIONING

gender and shape. The objective of training in concepts is generally functional i.e. the child with mental retardation should be able to use them in his day to day life.

190. My child is able to remember the film story seen on the T.V, but finds difficult to memorize multiplication tables! Why is it so ?

The above mentioned learning situations involves two different concepts. Watching a film on T.V is a concrete and meaningful concepts while learning tables is abstract concept. Children with mental retardation are able to grasp concrete and meaningful concepts which they can directly see and experience in a situation much better than they can grasp abstract concepts which involve imagination and higher intellectual functioning which they are deficient in.

191. Whenever we sit down to teach our child to read and write he just starts crying or tearing the books. It is difficult to get his cooperation., Can anything be done for this ?

There could be many reasons why the child starts crying or tearing books as soon as you ask him to read or write. The reasons may differ from one child to another even though the problem such as crying or tearing books may be the same for two individuals. A thorough functional or behavioural analysis is required before one can suggest any behavioural management programme. However one or more of the following possibilities may be present.

- the child is not interested in what you want your child to learn,

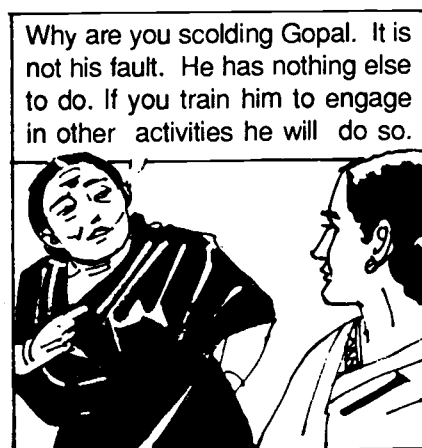
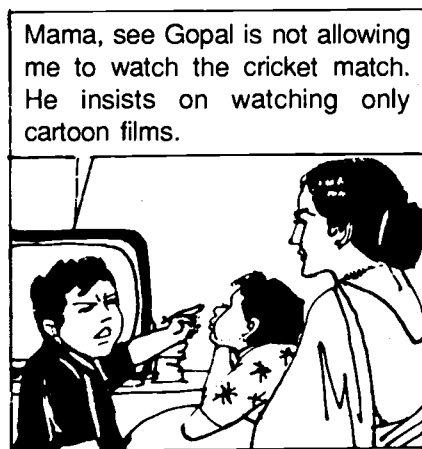
- the task may be too difficult or too easy for him to do,
- the physical setting in which you are teaching him may not be appropriate, that is, too noisy or overcrowded,
- by crying or tearing, the child may have learnt to avoid doing the task as occasionally or generally you allow him to stop doing the task following crying or tearing behaviour,
- the child is fond of playing or doing things of his choice which he occasionally or generally gets to do after he starts crying or tearing books,
- your teaching methods may not be appropriate such as putting too much pressure on the child, rebuking him or not providing him appropriate guidance or rewards while teaching him.

A clinical psychologist or a special teacher trained in behavioural technology could be consulted for further analysis and management of the problems.

NOTES

LEISURE

Too often individuals with mental retardation do not have the necessary skills to utilize their free time creatively or constructively. They participate in an educational programme for a relatively small part of the day and then have nothing to do during the rest of the day. Unoccupied time is, therefore, an important part in the life of the individual with mental disability. During this unoccupied time mentally retarded individuals tend to engage in activities which could be highly inappropriate and problematic. Mentally retarded individuals need to be trained in constructive and useful activities to help them to learn how to spend their free time. This section answers questions raised by parents regarding the leisure activities of individuals with mental retardation.



192. What is leisure? Is it necessary for individuals with mental retardation to have leisure time ?

The word "leisure" refers to an individual's "free time" when presumably, the individual can engage in activities that he/she prefers. Leisure activities can take place with other individuals or may occur in isolation.

Need for leisure and recreation for persons with mental retardation is as important as for any other individual. It has a positive and a creative function and also contributes to the emotional and psychological development of an individual. Leisure skills have been traditionally associated with free time away from school and work that can be enjoyed with friends and families.

193. Normal individuals can plan their leisure time activities. Are individuals with mental retardation also capable of the same ?

Without systematic instruction and training in leisure skills, individuals with mental retardation may not learn the skills necessary to use or plan leisure time appropriately. The extent of training will vary based on the severity of handicap i.e. more amount of training is required for an individual with severe mental retardation than an individual with mild mental retardation.

194. An idle brain is a devil's workshop. Is there a need to keep them busy in training activities ?

It is important to help individuals with mental retardation learn how to enjoy themselves during their free time. It is good that individuals with mental retardation remain busy,

but, it is not true that they should just be kept busy with any kind of available activity. The leisure activity chosen should be liked by the individual. Each and every leisure activity that is to be taught should be based on the choice and needs of the child and taught in a programmed step by step manner.

195. Can all individuals with mental retardation indulge in leisure activities ?

Most of the individuals with mental retardation can participate in leisure activities. However, the extent of their participation in the leisure activities is dependent on the severity of the handicap. With appropriate training, experiences and opportunities given to the individual at school and at home, the individual can learn to enjoy and perform activities which are satisfying and bring joy to him/her.

196. What is the purpose of teaching leisure activities to individuals with mental retardation ?

For individuals with mental retardation the need for leisure education is crucial as they have significantly large amount of free time. Individuals with mental retardation participate in an educational program for a relatively small part of their day and then have nothing to do during the remaining part of the day. Constructive activities must be offered to fill this void. The play and leisure activities must be encouraged and systematically programmed as free time programming is essential. The purpose of leisure activities is to teach the individual with mental retardation to play independently or with someone of his liking with preferred activities whenever free time occurs. Also, development of

leisure skills promotes social, cognitive, domestic, language and motor skills development.

197. What are the various kinds of activities that individuals with mental retardation generally enjoy ?

Individuals with mental retardation enjoy a wide variety of leisure activities. However, the extent of participation depends on the severity of handicap the individual has, as also the amount of training, opportunities and experiences provided to the individual.

Leisure activities could range from watching others play, dance, sing etc. to actual personal participation. It could be scanning a magazine to reading a story or gossiping. It is important to understand that how we tend to utilize our free time is also a resultant of our learning experiences. Many mentally retarded individuals have easy access to T.V. radio, so they get glued to that only. Mentally retarded individuals, if provided with right experiences can learn to swim, horse ride, play different musical instruments, paint, draw, play different outdoor and indoor games, cook, and involve in a whole range of various activities.

198. Should the leisure activities be planned in such a way that learning occurs through such activities ?

Involvement in leisure and recreation activities is one of the most effective ways for individuals with mental retardation to learn and practice new skills in areas of language, motor, social, cognitive and household skill development. However, it is very essential to note that the expectations about the performance from the individual with mental retardation has to be based upon his/her existing

strengths and achievements. Also, not to forget that leisure means free time with no pressures of learning but participating in activities by choice.

199. During free time, what are some of the negative behaviours that individuals with mental retardation may indulge in ?

Individuals with mental retardation may indulge in inappropriate and unacceptable social behavior due to lack of appropriate leisure skills. Common behavior problems reported are body rocking, hand flapping, spinning objects, self injurious behavior like biting, social withdrawal, inappropriate sexual behaviours, etc.

It has also been observed that, if individuals with mental retardation are taught appropriate leisure skills, then unacceptable behaviors also tend to decrease.

200. Do parents have any role in teaching individuals with mental retardation to enjoy various activities ?

Parent/family involvement is crucial to development and maintenance of leisure skills in individuals with mental retardation. The involvement of the parents, siblings grand parents in the child's use of leisure time seems natural in the context of home. Parents, siblings and other family members can help mentally retarded individuals engage in activities that they find enjoyable and satisfying.

201. What are the factors parents need to consider while planning for leisure activities for their children with mental retardation ?

Some parents of individuals with mental retardation tend to



IF PROPERLY TRAINED, INDIVIDUALS WITH MENTAL RETARDATION CAN INDULGE IN VARIOUS LEISURE ACTIVITIES

believe that their son/daughter would need protection from physical and social risks, would never mature and that their responsibility as parents is to "accept" the handicap and hold very reduced expectations of the child. The results of these beliefs can be that, individual with mental retardation may miss out on the opportunity of learning to engage themselves in appropriate and socially acceptable leisure time activities

Hence, it is very necessary that the parents keep an open mind and wherever possible provide opportunities for mentally retarded individuals during the developmental process to participate in normal leisure activities.

202. Should parents encourage individuals with mental retardation to make friends with non-disabled persons ?

Wherever possible, individuals with mental retardation should be encouraged to make friends with non-disabled individuals. This would facilitate overall personality development of the individual and promote acceptance in the community.

203. As parents of a child with mental retardation we find it difficult to manage our children after school hours and during vacations. What can be done ?

It is suggested to meet and discuss with the teacher of the concerned child of ways to incorporate leisure skill training as part of education plan. This will help the child to learn new leisure activities as part of his/her regular training programme at school. Also, it will help the child with mental retardation to use free time constructively.

204. Do special schools organize any leisure activities for individuals with mental retardation ?

Leisure activities training are an integral part of many special

schools. Most of the special schools in the country take part in the Special Olympics events. In addition, some special schools also offer music, dance, drama and art as leisure activity programmes.

205. What Is Special Olympics ?

Special Olympics is an international body founded by Mrs. Eunice Kennedy Shriver in 1968 under the auspices of Joseph P. Kennedy Jr. Foundation. The main task of the body is to organize international games for people with mental retardation, once in four years. Administration of athletics, sports and games for people with mental retardation in India is looked after by Special Olympics India, a trust having its head quarters in Bangalore.

206. What is the aim of Special Olympics ?

Special Olympics for individuals with mental retardation provides opportunities for individuals to meet on the common ground, interact with each other and also give them a chance to compete with each other in order to test their skill. Special Olympics was created to provide an opportunity for individuals with mental retardation to learn the value of challenge and the joy of winning. It also provides an opportunity for groups of individuals with mental retardation to meet in a situation that is both social and competitive.

207. Who all can participate In Special Olympics ?

Currently, the Special Olympics offers competition in 16 official and 6 demonstration sports. Participation is open to any athlete with mental retardation who can meet the following standards :

- adhere to rules and regulations of the particular event,

- physically demonstrate the ability to perform the movements required by a particular event,
- cognitively demonstrate an awareness of competing against other athletes.

However, for individuals with very significant disability and who cannot participate in the official Special Olympics, there is Special Olympics Motor Activities Training Program.

For further information contact the nearest Special Olympic Office in your area.

208. My child with mental retardation aged 18 years is very fond of watching Hindi movies. To keep him occupied we have been getting video cassettes regularly for him to watch. Am I doing the right thing?

Too much of every thing is bad. There can be a high probability that your son may display inappropriate behaviors that he may pick up from the videos which you may then find difficult to manage. In addition, your child's vision may get affected. It would be advisable that you start exposing your son to various other leisure activities. A trained teacher may help you in this regard.

209. Do individuals with mental retardation require extra support to participate in leisure activities alongside non-disabled individuals?

Due to their motor, neurological or sensory deficits, some individuals with mental retardation may require extra support to participate in activities alongside their

non-disabled peers. But, individuals with mental retardation utilizing the adapted equipment or facility must not at the same time be separated from interacting with the community in general.

210. How much time in a given day should be allotted for leisure activities for individuals with mental retardation ?

"All work and no play makes Rohit a dull boy". This is also true for individuals with mental retardation. Although there is no such thing that a specific amount of time should be allotted for leisure time activities, it is advisable to initially program phases of the day for leisure activities. This will help the individual with mental retardation to understand the need for leisure skills and when to use it.

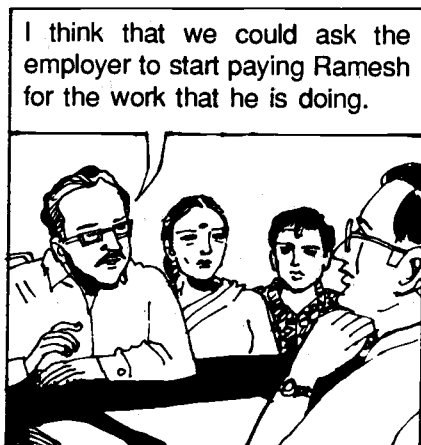
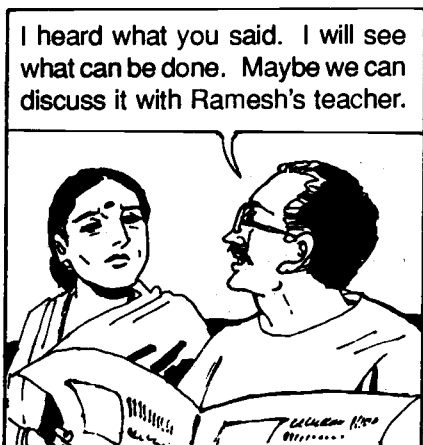
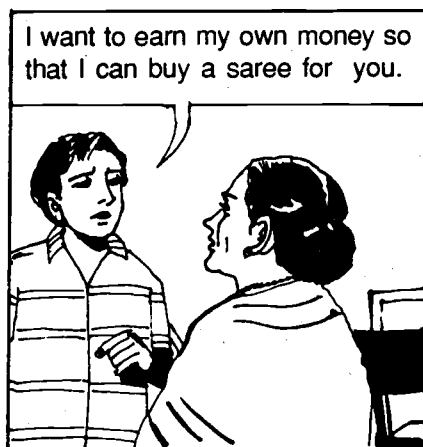
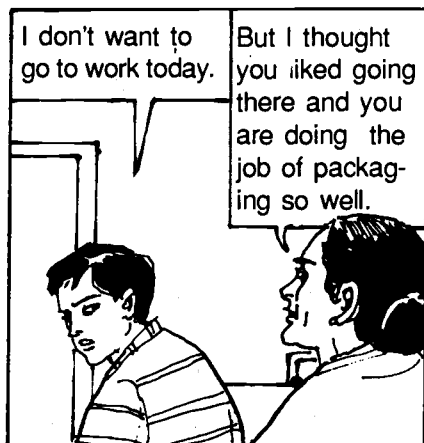
211. Are there any organizations which plan and conduct leisure activities for individuals with mental retardation ?

There are no specific organizations known which provide only leisure activities. However, a number of parent organizations, non-government organizations and government organizations organize various leisure activities specially during vacation period. They generally undertake leisure activities like painting, singing, dancing, trekking, and summer camps. These activities can be only for mentally retarded individuals or taken up as an integrated activity along with their normal peers and siblings. Such activities, however, need to be encouraged as much as possible.

NOTES

EMPLOYMENT

In a country like ours, where we do not have any social security systems to depend upon, each individual has to learn to fend for oneself by working and earning irrespective of disability. Parental concerns and worries about the child's future and employment is but natural when the child is generally seen being dependent on others. With improving training facilities for the mentally retarded individuals, growing awareness about the capabilities of mentally retarded individuals and their acceptance in the community, it is becoming more and more possible for mentally retarded individuals to work and earn a living. Though there are enough challenges yet to be met in the vocational habilitation of mentally retarded individuals, the efforts in this direction need to continue. Apart from earning a living, employment provides an opportunity for mentally retarded individuals to interact with others and socialise. It also helps in the development of sense of self worth and provides an opportunity to contribute usefully to the society. This section answers questions related to vocational training, work and employment of mentally retarded individuals.



212. Do individuals with mental retardation need to work ?

An individual's value in the society is often judged by his or her contributions to society. Work provides an individual with mental retardation a chance to contribute to the community and be accepted as a valued member. Through work, not only one develops skills and new relationships, but more importantly, develops self esteem resulting in personal satisfaction. As parents, coworkers and the general public witness the completion of the valued work, the dignity and respect for the individual increases. Hence, it is very necessary that individuals with mental retardation work. Work may also be related to employment and employment with earning which is necessary for survival.

213. Can individuals with mental retardation work ?

Adults with mental retardation have the capability to perform meaningful work. Mental retardation does not mean that such individuals are unable to learn, perform or work. In fact, with appropriate training techniques individuals with even relatively severe mental retardation can learn and produce products which can earn them remuneration and meaningful employment.

214. Can individuals with mental retardation earn a living through work ?

The ability of adults with mental retardation to work is frequently underestimated. One reason for this unfortunate phenomenon, is that the few vocational settings to which the mentally retarded individuals may have entered

promoted incompetence or exhibited poor work habits. These deficits seen could be the result of lack of adequate planning and vocational training.

As a result of this adults with mental retardation are working in jobs that don't pay very much. Adults with mental retardation have already demonstrated the capability to learn and work and also the capacity to earn a living. Parents need to consult a vocational rehabilitation counselor or employment specialist who will be able to turn this capability of mentally retarded individuals into useful long term employment.

215. Are there individuals with mental retardation for whom vocational training is not applicable ?

Ideally, all individuals with mental retardation should be given employment related training. There may be certain medical or associated conditions such as epileptic fits, associated visual or hearing impairments etc. which may prevent a mentally retarded individual from taking training in a particular type of job. A vocational rehabilitation counselor can guide parents in determining the eligibility of individuals with mental retardation to work.

216. When should a parent consider vocational planning for their child with mental retardation ?

Actual vocational planning is done when the child has reached 16 years of age. However, parents should provide opportunity at home to perform domestic tasks from an early age. This will help the parents look into the strengths and weaknesses of the child with mental retardation and help in vocational planning. Vocational

rehabilitation counsellors can help parents in vocational planning for their child.

217. What are the factors to consider while planning for vocational training for individuals with mental retardation ?

Vocational training programs prepare individuals with mental retardation for employment either by specifically designing a training program for one job or job type or by systematically presenting a range of community work experiences from which an individual placement is later selected. Age is the key factor to consider. In addition, variables that need to be considered are :

- physical abilities of the individual,
- sensory abilities of the individual,
- previous work history,
- aptitude and interest,
- family background.

218. What role does the special school play in the vocational rehabilitation ?

Children with mental retardation enter special school with a variety of strengths and needs. Through the schooling process, teachers attempt to develop existing abilities and train towards achieving the goal of producing independently functioning adults. The school provides pre-vocational training thus preparing a child for vocational training. The school thus plays an important role

in the transition process of an individual from pre-vocational to vocational levels.

219. Are there specific skills that need to be mastered by individuals with mental retardation before they can work ?

Prior skills like time management and punctuality, ability to carry out instructions, maintaining appropriate hygiene at work, getting along with co-workers are some of the specific skills or work related behaviours that need to be mastered before an individual with mental retardation join work. However, it is not a must. There are many creative ways to generate alternative solutions to presumed deficits. These deficits should not hinder giving opportunities to individuals with mental retardation to experience the world of work as soon as possible. Vocational rehabilitation workers need to be contacted for training in work related skills.

220. Do individuals with mental retardation need prior training before they join work ? Where can they get such a training ?

Prior training in the work related behaviors and job related skills definitely assists the individual with mental retardation to learn a task faster as also to retain the job. However, if the person hasn't had prior training, he can still be trained to enter work force. On the job training needs to be provided which is very crucial for success.

Such training is available at pre-vocational sections of the

special schools and at vocational training centres run by the Government and Non-Government organisations.

221. When an individual with disability goes to work/vocational training centres he has to commute. How will the transport be arranged ?

Vocational centers offering services to individuals with mental retardation may have a transport vehicle for the benefit of students/workers. Parents have to pay a monthly bus fee to the center. Since students/workers live in different parts of a locality, it may not be possible for all the vocational centers/work set-ups to provide transport to every corner. Parents may have to bring their son/daughter personally to the centre/work set-ups or bring them to a common point to be picked up by bus. Individuals with mild mental retardation can be trained to commute independently from home to vocational center/work place and back by means of public transportation.

222. How safe is it for individuals with mental retardation to commute from home to work place and back?

If an individual with mental retardation travels by a public bus, he is in full view of the general public. Hence, chances of exploitation and abuse are much less. However, chances of exploitation cannot be ruled out. While undergoing training in commuting, mentally retarded individuals need to be trained how to protect themselves from exploitation and abuse as far as possible.

223. Can parents register their child with mental retardation in Special Employment Exchange? Do individuals with mental retardation get any special preference ?

Presently, Special Employment exchanges don't serve individuals with mental retardation. They offer their services to the blind, hearing handicapped, physically handicapped and orthopedically handicapped only.

224. What are the types of employment for individuals with mental retardation ?

Individuals with mental retardation like any other individuals have vocational aspirations. However, because of their intellectual limitations, these individuals may find it more difficult to obtain vocational positions matching with their aspirations. These difficulties and limitations may be caused not only due to their own limitations but also by the lack of imagination and creativity and stereotyping tendencies of some of the professionals. Broadly, two types of work settings dominate employment service delivery. They are as follows :

- sheltered settings, wherein individuals are placed in settings where the work force is composed entirely of people with disabilities,
- open setting, where individuals with mental retardation work alongside non-retarded individuals.

225. What is sheltered employment ?

Sheltered employment is a structured program involving work evaluation, work adjustment, occupational skill

training and partial employment designed to prepare individuals either for competitive employment or for continued work in a protective environment

Sheltered employment can be of three major types :

- pre-vocational activity center: The goal of this center is to provide educational program that emphasizes the teaching of vocational skills to people who are not ready for employment. Most special schools contain a pre-vocational center where majority of the time is spent on teaching the individuals with mental retardation tasks like sorting, candle making, matching, and minor assembling tasks. There are generally no wages involved or if it is paid, it is very low,
- sheltered workshop: This is a facility that offers mentally retarded individuals who are not able to work in competitive employment. It provides them opportunity to work in a controlled environment at their level of functioning. In this model, workers are placed in settings where the work force is composed entirely of people with mental retardation. Supervision is provided by the persons without disabilities who are employed by the agency. Wages are given to mentally retarded workers in the form of stipend or based on productivity,
- work stations: Work stations are a bridge between the traditional sheltered employment and employment of people with disabilities in community business and industries. In this option, a group of individuals work in a community-based business or industry under the

supervision of a trained employee of the vocational agency.

226. *How can a sheltered workshop for individuals with mental retardation be started ?*

The process of starting a workshop starts with the formation of the planning group. The planning phase begins when an individual or a group of individuals who becomes sufficiently committed to the development of the individual with mental retardation inquires into its feasibility. Planning requires three things :

- i) forming a planning group for collecting information and making decisions,
- ii) collecting information on the service needs, marketing opportunities of the products to be assembled,
- iii) preparing the program proposal.

While preparing the program proposal, answers to the following questions are of considerable importance :

- what kind of work may be provided?
- how should the work be obtained?
- how should it be organized?
- how should teaching occur?

Individuals who plan to start a sheltered workshop should meet other organizers who have initiated workshops to be able to know day to day issues of maintaining the workshop. The planning committee should also check

with the local Dept. of Social Welfare to see if the state provides any financial assistance schemes for starting workshops.

227. What kind of work is done by individuals with mental retardation in a sheltered workshop ?

Although the nature of the tasks done by individuals with mental retardation varies greatly from place to place, they share some general characteristics. Successful running workshops tend to emphasize on packaging, assembling, and shipping of products rather than actual manufacturing.

228. How are the individuals with mental retardation paid in a sheltered workshop ?

In a sheltered workshop, individuals with mental retardation are paid a piece-rate production rate or a monthly stipend irrespective of the productivity. Although no national study in India is presently available, wages in a sheltered workshop ranges from Rs 30 to Rs 300 per month.

229. In a sheltered workshop, all the co-workers are mentally retarded. Does it have any adverse effect on the individual with mental retardation ?

A potential adverse effect of sending an individual to sheltered workshop is the isolation of the adult with mental retardation from their non-handicapped peers, and hence the loss of opportunities to observe peers who can model age-appropriate skills and social behaviors. Another potential disadvantage is that working in workshops does

not provide opportunities for handicapped worker to learn to accept criticism and ridicule to which all individuals must adjust.

230. Do individuals with mental retardation need constant supervision at work ?

One of the most frequently heard complaints from the employers about individuals with mental retardation is that they cannot work independently over sustained periods of time. However, with systematic training technique, individuals with mental retardation can be trained to perform work on their own. The degree of assistance from the trainer will depend upon the physical and mental abilities of the individual with mental retardation.

231. Can mentally handicapped individuals work in a normal setting along with normal people ? Are these type of work options available in our country ?

Individuals with mental retardation can work in a normal setting along with non-handicapped workers. Most jobs can be modified and with appropriate training and assistance, a person with mental retardation can be successful and, productive employee. This kind of work option is still at its infancy in our country. There have been very few placements in settings where individuals with mental retardation have been placed alongside normal individuals.

232. What is integrated work setup ?

In an integrated work setup, individuals with mental retardation are employed in a setting where the work force

consists mostly of people without disabilities. Individuals with mental retardation may receive varying degrees of assistance from vocational training centers but they are still considered employees of the business in which they work. Integrated work set up is of two major types :

- supported employment: This model involves working for pay in community settings with support in the form of training and assistance from the vocational centers. The concept of supported employment is based on identifying the nature of assistance required by the handicapped employee, providing the assistance as long as it is required and fading assistance in a gradual, steady manner while monitoring the worker's progress,
- competitive Employment: This means obtaining a job for pay in the general workforce by virtue of being the person most qualified for the position. Here the person holds the job without outside support.

233. What kind of work is done by individuals with mental retardation in an integrated set up ?

There have been few placements of individuals with mental retardation in integrated work setup in our country however in the west success has been reported in the manufacturing, food service, clerical, yard maintenance sales and child care fields. Further, success is limited only by the imagination of families, employers and professionals. Most of the individuals placed successfully have mild mental retardation. However, with appropriate training and long term assistance, individuals with moderate and less severe disabilities can also be put into the regular workforce.



INDIVIDUALS WITH MENTAL RETARDATION CAN WORK ALONGSIDE
NORMAL INDIVIDUALS, PROVIDED OPPORTUNITIES ARE GIVEN

234. Is it true that work in sheltered workshop prepares an individual with mental retardation to work in an integrated set up ?

There has been a long-held belief that individuals with mental retardation need time in a variety of work environments before employment in integrated work setup is possible. For example, in this approach, individuals with mental retardation would begin work in a vocational training center and when they have mastered some designated skills would then advance to sheltered work shop wherein again they have to master some skills before they can be placed into regular or integrated work setup.

Although this assumption appears to be a sound one, unfortunately, experience and research does not support this. On the contrary, there is evidence to support the concept that the vocational counsellor needs to identify the best community placement and work for the mentally retarded individual that is based on matching the employee abilities and skills versus that of work requirements. From this analysis, level and type of assistance required to be provided to the mentally retarded individual is determined that would enable successful placement of individuals with mental retardation instead of waiting endlessly for the potential mentally retarded individual to pass through several stages of employment readiness.

235. Once the individual with mental retardation is placed on a job, does he/she require any on the job assistance ? Who provides this assistance at work ?

Many individuals with moderate and severe mental

retardation would not be able to hold a job without varying degrees of assistance. Assistance required can be directly related to work or other employment related issues like getting to and from work, self care management etc. Generally, the vocational training centers, family members and the employers provide this assistance. Since each individual will have unique needs, it is advisable that parents, the vocational counselling center and employer act as a team to facilitate maximum success at work.

236. If an individual with mental retardation is working in a normal setting along normal people, will he/she be paid regular wages ?

If an individual is working in a normal setting along with normal people, he/she should be paid regular wages. However, in order to get full wages, an employee may have to work the total hours in a day stipulated by the employer. Otherwise, the employer can pay wages according to the number of hours the individual has worked or based on the productivity rate.

237. Getting along with co-workers is essential for adjustment in work setup. Do individuals with mental retardation need special inputs of training to get along with coworkers ?

Interaction between individuals with mental retardation and non-retarded employees is very important to retain a job in a regular work setup. Not only employees with mental retardation need special inputs in social skill training, building appropriate behaviour but non-disabled workers too need training about how to accept the handicapped

employee amongst them. Individuals with mental retardation must be taught how to accept criticism in work place, make friends and get along well with co-workers.

238. How safe is it for women with mental retardation to work alongside normal persons including male and females in a setup ?

If a woman with mental retardation is working in such a setup, vulnerability may be same or a little more increased as that of a normal woman. Individuals with mental retardation need to work alongside normal persons so that they can model appropriate social behaviour. The vulnerability of a woman employee in a sheltered workshop may be no less. Individuals with mental retardation, both males and females need training to protect themselves from exploitation and sexual abuse.

239. Why is it that some individuals with mental retardation are not able to retain their jobs ?

There are many factors that are responsible when the individual with mental retardation is not able to retain a job. Limited intelligence by itself may not necessarily be the cause, except in severe cases. Inappropriate social skills and inappropriate behaviours has emerged as one of the most important factors. In addition, associated physical handicaps, employer's attitude, poor communication skills, behavior problems also affect adversely.

240. Why do employers hesitate to employ individuals with mental retardation ?

The ability of adults with mental retardation to work is

frequently underestimated. One of the reasons for this is that the employers are not aware of the abilities of such mentally retarded individuals and possibly not sure of their competence in performing tasks. Also because of poor training, the mentally retarded individuals may end up being less adequate employees. The behaviour problems in mentally retarded individuals which remain untreated or the general non-acceptance of mentally retarded individuals may also prevent the employers to employ mentally retarded individuals.

241. What is meant by self employment? What kind of work is done by individuals with mental retardation in self employment?

Self employment refers to the smallest type of enterprise that employs few workers, maybe only the owner. Self employment is one of the ways in which an individual with mental retardation can attain economic independence. However, it must be understood that self employment is not for all individuals. It is generally associated with mildly mentally retarded individuals. Associated physical conditions, reactions of family members or the community to the disability may have the effect of reducing their self confidence and making them less or more able to take the initiatives.

A variety of self employment schemes have been initiated in India. In running these schemes, parents support have been quite crucial. With parental and professional support some of the following self-employment schemes can be

carried out by mentally retarded individuals.

Lottery ticket sales	Farming
Bookbinding	Poultry keeping
Umbrella repair	Screen printing
Brick Making	Picture framing
Shoe cleaning	Pan shop
Figure moulding	Scrap metal dealing
Petrol selling	Toy shop
Photocopying	Laundry worker
Telephone booth	Plant nursery
Pottery	Postage stamp selling
Garment business	

242. How can a self employment scheme for a mentally retarded individual be started ?

Adult vocational centers and Vocational Rehabilitation Centers offer training programs in a variety of trades. The individuals with mental retardation can get himself trained in the trade that he wants to pursue as means of livelihood. Once trained, the individual with mental retardation can pool his savings and start his business. It must however be seen that the trade in which the individual is trained has a market value. Currently, there is no financial assistance provided by the Government for individuals with mental retardation to start self employment. Bank loans may be available which can be drawn by

the parent or guardian of the concerned mentally retarded individual as individuals with mental retardation cannot enter a contract.

**243. What Is Vocational Rehabilitation Center (VRC)?
What are the nature of services available at VRCs ?**

Vocational Rehabilitation Centers (VRC) were created by Government of India to provide people with disabilities the opportunity to become employed and therefore to enhance their self identity and their contribution to society. Presently, there are 13 VRCs located all over the country working for the welfare of all types of disability. VRCs provide a wide array of services like :

- evaluation of every client to determine eligibility conditions,
- guidance and counselling services through personal contact with a counselor,
- vocational training and work adjustment programmes,
- procurement of telecommunication, sensory aids and other technological aids,
- placement in suitable employment,
- post employment services.

Although the goal of VRCs is to serve all types of disability, they typically serve individuals with mild mental retardation who have the highest potential for open employment. Further information on the variety of programs and eligibility criteria can be obtained from the local VRC unit. (List of VRC's is appended in this book)

244. How can parents contribute in the vocational rehabilitation of the individual with mental retardation ?

"A parent is worth 10,000 masters" (Chinese proverb). Perhaps the single most critical factor in vocational rehabilitation is the support and attitude of the family. A supportive family usually will help compensate significantly for whatever deficiencies there are in the training programme, the worker's skill repertoire, and even the local economy. Supportive family members like parents, siblings, grand parents, friends and well wishers can help in job identification, help improve work habits, and be a major source of accurate information about the person's interest's and capabilities. The family can also help arrange transportation, be flexible in work schedules and extend support to the professionals in training the individual at the job site. Lot of parent organizations in our country are creating vocational training centers for their children.

245. What happens if the individual with mental retardation falls to find a job ?

Although work is an important thing in the life of the individual with mental retardation it is not the end thing in itself. In case an individual with mental retardation is unable to find a job, the steps must be taken to enrich his life by leisure and recreational programs in integrated settings so that the individual does not feel segregated. At the same time the prospect of voluntary work should also be looked into.

NOTES

SEXUALITY

Mentally retarded individuals pass through the same sequential stages of development such as infancy, childhood, adolescence, adulthood, middle age and old age. The origin of sexual feelings and sexual behaviour in human beings is generally linked with the adolescence stage of development irrespective of disability. Intellectually normal human beings during the process of their development learn to express their sexual feelings in socially desirable ways. However, individuals with mental retardation may not learn to do so due to lack of social opportunities to learn, inadequate or no exposure to training in meeting sexual needs and due to poor intellectual abilities reflected in not understanding the consequences of their behaviours. As a result of this, some mentally retarded individuals may end up being sexually abused or exhibit inappropriate sexual behaviours which could cause great embarrassment. Some of the parental concerns related to mentally retarded individuals sexually growing up and their sexual behaviours are dealt with, in this section.

Have you read in the newspaper today That a group of girls with mental retardation are undergoing hysterectomy.



But why are they performing hysterectomy on these children.



They say that since they are unable to look after their menstrual hygiene, the uterus should be removed so as to solve the problem for ever.



My child with severe mental retardation has been trained by a special teacher to look after her menstrual hygiene....



..... She remains quite clean during her periods.



If that is so, rights of the mentally retarded women should be considered before taking decisions on such matters.



246. Do Individuals with mental retardation have sexual feelings ?

Individuals with mental retardation grow from childhood to the adult world sharing the same feelings, thoughts, and physical desires as non-handicapped persons. They also develop sexual feelings and sexual desires. However, the intensity of sexual expression may decrease as the severity of the disability increases.

247. Do Individuals with mental retardation achieve sexual maturity at the same age as normal individuals ?

Physical growth and development including sexuality of the individual with mental retardation is generally similar to that of any other child. However, development of secondary sexual characteristics such as development of pubic hair, beard etc. in boys and development of breasts etc. in girls may get delayed based on the nature of mental retardation.

248. How do Individuals with mental retardation express their sexual needs ?

Touching, talking, embracing, kissing, caressing, fondling, rubbing, masturbation, normal sexual intercourse or just holding hands are some of the ways by which individuals with mental retardation express their sexual needs.

249. Are Individuals with mental retardation more vulnerable to sexual problems ?

Mentally retarded individuals are more vulnerable to sexual

problems due to :

- limited opportunities to learn the socially acceptable ways of expressing sexual feelings and desires,
- having less reasoning ability,
- unable to understand the consequences of behaviour,
- mentally retarded individuals may be unduly rewarded for inappropriate expressions of sexual desires.

250. What are the common sexual problems reported in mentally retarded individuals ?

The common sexual problems reported in mentally retarded individuals include :

- masturbation in public places,
- undressing in public,
- over affectionate or over aggressive behaviours,
- excessive hugging or kissing,
- constantly touching or clinging to others,
- unwanted pregnancy,
- homosexual behaviour.

251. Can individuals with mental retardation be trained in meeting their sexual desires appropriately ?

By providing a formal sex education program throughout childhood and adolescence, individuals with mental retardation can be taught to meet their sexual needs appropriately. However, the degree of independence in

expressing sexual needs will vary based on the severity of mental retardation of the individual.

252. Do individuals with mental retardation have the right to have sex ?

All individuals irrespective of disability should have equal rights. However, every "right" carries with it an equally strong "responsibility". Although it is ideal that an individual with mental retardation should lead a happy and good life, but when his actions involve another person, it is not only a question of "right" but also a question of consequences and responsibilities.

253. Can individuals with mental retardation have normal heterosexual relationship ?

Individuals with mild mental retardation with no associated conditions can have a normal heterosexual relationship. However, it becomes increasingly difficult to have a normal heterosexual relationship as the severity of mental retardation increases.

254. Are individuals with mental retardation more vulnerable to sexual abuse ?

Due to poor control of sexual impulses, individuals with mental retardation are more vulnerable to sexual abuse. Studies have indicated that part of the reason for high level of abuse is the actual disability. Major factors that increase the possibilities of sexual abuse of persons who are mentally retarded include :

- lack of knowledge about sexuality and relationships,
lack of knowledge about public or private behaviour,

- Individuals with mental retardation are generally isolated and lack social opportunities to make friends which make them feel lonely, starved for affection, and thus more susceptible to abuse,
- lack of assertive skills to refuse contact and low self esteem

Research findings mainly from the west indicates that majority of the persons who inflicted sexual abuse were known to the victims who were disabled.

255. Individuals with mental retardation may not be able to communicate sexual abuses against them. Are there any behavioural indicators of sexual abuse ?

There are several behavioural and physical indicators to indicate that sexual abuse could have taken place :

- difficulty in walking or sitting,
- torn, stained, or bloody underclothing,
- pain or itching in genital area,
- bruises or bleeding in genital or anal area,
- venereal disease,
- pregnancy,
- difficulty in sleeping or sudden and frequent nightmares,
- avoidance of a previously trusted and well-liked person,
- unexplained stomach aches or change in eating habits,
- fear of being left alone,
- bed-wetting,
- change of leisure habits, or reluctance to join previously enjoyed recreational activities,

- delinquency or running away,
- refusal to undress, to bathe or to be bathed,
- sudden infantile behavior (sucking, biting rocking).

256. Should individuals with mental retardation be sterilized ?

There is no direct 'Yes' or 'No' answer to this question as the same would apply to any individual with or without disability. Decisions regarding sterilization would depend upon the specific merits of the individual case. Generally, the responsibility for such a decision would rest on the parents or guardian of the mentally retarded individual. However, in order to ensure the right decision, the parents should involve apart from the medical doctor, a rehabilitation expert and where ever possible the mentally retarded individual himself/herself in the decision making process.

257. Should attempts be made to curb sexual urges in individuals with mental retardation ?

Curbing and denying a person's right to sexuality can be one of the most dehumanizing violations of human spirit. Training in appropriate expression of sexual urges could open doors to the joys of positive adult relationships for mentally retarded individuals.

258. Does masturbation cause blindness and weakness ?

Masturbation does not cause blindness and weakness. Masturbation is a harmless source of sexual pleasure that releases tension and helps the person learn about their own bodies. Studies in the west have shown that more than 90% of males and 60% of females masturbate some time.

259. Individuals with mental retardation at times masturbate in front of others which is very embarrassing! Can this behaviour be changed ?

One of the major problems with individuals with mental retardation is their inability to express their sexual urges and desires in socially acceptable ways. Individuals with mental retardation find it difficult to understand as to when and where the behaviour needs to be carried out. Consulting a trained clinical psychologist or a special educator can guide parents to handle such issues.

260. Individuals with mental retardation at times copy/imitate sexual overtures of models on the screen ? What can parents do ?

Mentally retarded individuals do tend to learn or copy a lot of behaviours good or bad by seeing others doing. They may not understand the social appropriateness and consequences of imitating such behaviours in presence of others that it becomes a problem. If mentally retarded individuals are provided opportunities and encouraged to indulge in and learn other useful leisure activities including indoor or outdoor this may possibly give them wider range of alternative and constructive models to imitate.

261. Individuals with mental retardation insist to sleep with parents even when they have reached adolescence or adulthood. Should it be allowed ?

Mentally retarded individuals take long time to learn as also to unlearn behaviours. Understanding of the social acceptability or desirability of their behaviours is less in mentally retarded individuals. One of the behaviours which

intellectually normal children in India generally out grow with age is sleeping with the parents. Mentally retarded individuals however, may not naturally out grow this behaviour unless conscious efforts are made by the parents to teach their mentally retarded child to sleep separately. Sleeping separately could be initiated as early as from 3 - 5 years of age or even earlier. If the child shows intense fears on being separated, then, parents need to consult a clinical psychologist for behavioural treatment.

262. I as mother of a 16 years old boy find it difficult and embarrassing to bathe and wash him? How far do you think it is appropriate ?

It could be appropriate that a male member is involved who can assist your son while he is taking bath. With appropriate training programs individuals with mental retardation can be taught to care for themselves. Consult a trained teacher who can train you and concerned person in teaching your child with mental retardation to achieve mastery in bathing.

263. My daughter who is 20 years old comes out of the bathroom naked in presence of others after taking a bath? Can she be trained to overcome this habit ?

Individuals with mental retardation may not learn a sense of shame which non disabled individual acquire normally during the course of development. Hence, they may have difficulty in understanding between behaviours that need to be performed in public or private. It is also essential that parents instill a sense of privacy, early in mentally retarded individuals. However, mentally retarded children can be trained in maintaining privacy by using

right methods of training. A special teacher/educator or a psychologist could be contacted for help and advice.

264. Individuals with mental retardation sometimes have a habit of touching others at odd places on the body. Should this be allowed ?

Some mentally retarded individuals may learn to indulge in such socially inappropriate behaviors which could be quite embarrassing. Mentally retarded individuals may indulge in these behaviours due to different reasons such as : to get attention from others, to initiate or maintain social interaction with others or to express sexual feelings. As reasons for indulging in these behaviours may vary from individual to individual analyzing them becomes crucial to suggest the right strategies for management. A psychologist or trained special teacher could be contacted for help and advice.

265. What role can parents and family members play in preventing sexual problems in individuals with mental retardation ?

Parents are often the first and primary sex educators for their children. What they teach their children about sexuality, social behaviors, values and beliefs depends on their own behaviour and attitudes, which they practice and verbally express. Sometimes it is difficult and harder for parents to talk to children with mental retardation about sex. By maintaining close contact and seeking advice from professionals like clinical psychologist, trained social worker, psychiatrist or medical doctor, parents can help train mentally retarded individuals in appropriate expression of sexual desires and prevent sexual problems.

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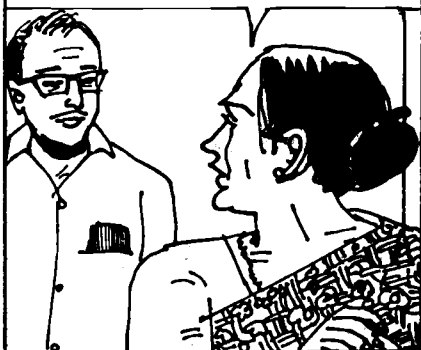
MARRIAGE

Marriage is considered as an important milestone in one's life not only for the individual getting married but also for his/her parents. Marriage is a social system which is generally linked with adulthood, independence parent hood and security. As the mentally retarded individual enters adulthood parent's worry about the future security of their mentally retarded child becomes paramount. Questions like what after parents are no more there? Can the mentally retarded individual be married in order to ensure security for him/her? Should he/she be married at all, what are the risks involved? Do mentally retarded individuals have equal rights to marry. Are mentally retarded individuals able to cope up with the responsibilities of being a wife/husband father/mother. These, and many other such issues or questions are quite complex and difficult to give generalised answers as these are linked with merits of each individual case, legal status, socio-cultural values and practices of local community and a given family. However, an attempt has been made in this section to answer some common questions asked by parents.

I was just thinking of a match for Anita.



So, what. Why are you saying all this?



I was just thinking about that owner of Kirana shop near our house. He has no parents or any liability.



Anita is mentally retarded. When she is not able to look after her own needs, how will she take up this responsibility. If she happens to give birth to a mentally retarded child?



You mean to say that Anita will never get married? why don't we both go together and discuss this issue with the psychologist so that we take the right decision.



266. Can individuals with mental retardation get married ?

Marriage is a union between two consenting adults. It involves adjustment made by partners, ability to carry on day to day responsibilities of married life, to bear and rear children, planning for future, and have sufficient financial resources to run the family. How far individuals with mental retardation can carry out the duties related to married life should be considered before marriage can be thought about.

However, by the law of the land, individuals with mental retardation are considered to be minor and hence can't enter into a contract. Therefore marriage of individuals with mental retardation will be declared null and void.

267. Can marriage cure mental retardation ?

Some parents still feel that by providing their mentally retarded adult with sexual gratification or by having him to shoulder the responsibility of marriage it would help cure their child's problem of mental retardation. This, however remains a myth as the condition of mental retardation is not curable.

268. What are the factors to be considered before deciding to marry an individual with mental retardation ?

Before deciding to marry an individual with mental retardation the factors to be considered are related to:

- level of functioning of the individual and the proposed partner,
- practical matters as financial resources, employment status and the question of child bearing,

- acceptance of both the partners to enter in wedlock knowing fully the condition of mental retardation and its implications.

269. An individual with mental retardation requires lifelong support. To cope up with this problem parents at times consider marrying their son/daughter with mental retardation to normal or even a disabled person having normal intelligence. Is this advisable ?

The essence of marriage is companionship. How long the individual with mental retardation can satisfy the companionship needs of the partner needs to be seen. It may become very easy for the intellectually normal partner to get remarried or indulge in extramarital affairs, but the emotional trauma on the individual with mental retardation can lead to serious adverse effects. There may be other useful ways to meet the life long support needs of mentally retarded individuals such as through natural family support systems etc. Before a parent takes such a decision it is advisable to seek consultations from a clinical psychologist or a trained social worker for guidance.

270. What are the chances that a normal baby would be born to a couple where mother or father is mentally retarded ?

The probability that a normal baby would be born to a couple where one of the partners is mentally retarded depends upon whether nature of the effected partner's condition is genetic or environmental. Although there are no studies to indicate prevalence, it has been reported

that many children of mentally retarded parents function within the normal range of intelligence. However the percentage of the children who are mentally retarded are substantially higher in parents where one or both are mentally retarded than in parents with normal intelligence. A genetic counselor can offer guidance in this area.

271. How far marriage involving an individual with mental retardation is successful ?

Financial resources, the ability to acquire and keep a job and compatibility between partners are considered essential ingredients of a successful marriage. Information based on anecdotal reports indicate that employment status of the mentally retarded individuals doesn't match that of non-disabled persons and financial problems are frequently reported. Reports also indicate that married individuals with mental retardation are relatively socially isolated and have few friends to rely on. They may require constant or frequent support from the families which at times is not forthcoming.

272. If a son having mental retardation is not earning and parents are willing to provide all the needed support, should the parents in that case entertain the idea of marrying their son ?

The essence of marriage is companionship. Before deciding to marry their child with mental retardation the following factors need to be considered by the parents/guardians.

- level of functioning of the individual and the acceptability of the contemplated partner in marrying a person with mental retardation.
- practical matters as constant financial support and resources, employment status and the question of child bearing and rearing.

Before a parent takes such a decision it is advisable to consult a clinical psychologist or a trained social worker for guidance.

273. To protect exploitation Is It advisable for parents to consider marrying their son/daughter with mental retardation within their family ?

Marriage is not a solution to ensure lifelong support for individuals with mental retardation. Marriage within relatives is one of the probable genetic cause of mental retardation. Marriage of a mentally retarded individual within the family increases the probability of having a child with mental retardation. Seeking consultations from a social worker, clinical psychologist or a special educator can help parents find a long term solution to care for the individual with mental retardation.

274. Are there any people who could help us in making the right decisions about various issues related to marriage of my child with mental retardation ?

A clinical psychologist, a trained social worker, a genetic counselor, a psychiatrist or any other trained

MARRIAGE CANNOT CURE MENTAL RETARDATION



rehabilitation expert can offer guidance to parents on issues related to marriage.

275. What are the common problems reported by normal marriage partner of individuals with mental retardation ?

Most of the reports have been anecdotal. Responses given have indicated :

- sexual dissatisfaction,
- problems in coping up with the demands of married life,
- problems related to child care and child rearing.

276. Can an individual with mental retardation be trained to carry on the normal family responsibilities associated with marriage ?

Depending upon the severity of handicap, individuals with mental retardation can be trained to carry out normal family responsibilities. Many mentally retarded parents require financial assistance, training in health and child care, and counselling in managing day to day problems of running a household. This can be possible with professional and parental support.

277. How stable are marriages which involve mentally retarded individuals ?

Although there is no research in our country to indicate the stability of marriages involving individuals with mental retardation, anecdotal reports suggest the importance of input of special service agency like that of a clinical psychologist or a trained social worker in terms of assisting the couples to cope with the responsibilities of everyday life.

278. What are the risks or responsibilities that parents should be prepared for, if they decide to marry their mentally retarded son/daughter.

Following are the tentative risks and responsibilities that parents should be prepared for when deciding to marry individuals with mental retardation :

- risk of producing a mentally retarded child by the mentally retarded individual,
- caring and bringing up offspring of the mentally retarded individual,
- providing financial support to the family when needed,
- protection of mentally retarded individual from abuse and exploitations,
- depending upon the severity of mental retardation providing physical help in running the home,
- spouse leaving or divorcing the mentally retarded individual.

279. My mentally retarded daughter is married to a non-disabled man. They have a 8 year old mentally retarded daughter. All of them are staying with me. Recently my daughter with mental retardation insists on staying separately with her husband and daughter. What is advisable ?

Every individual has the right to stay at a place of his/her choice. If parents feel that their daughter with mental retardation can carry out the responsibilities of a married life, they should allow and encourage the person to live independently with his/her family. However, guidance from a clinical psychologist or a trained social worker must be sought.

NOTES

PARENT SUPPORT

Parents have a significant role to play in promoting welfare activities which can meet both the needs of the mentally retarded individual as also the family. During the last decade or so parents of mentally retarded individuals are coming together and forming parent groups or parent associations. This is considered as an important milestone in the rehabilitation process of mentally handicapped individuals in our country. It has been observed that the appropriateness of services tend to increase with increased parental involvement.

Parent associations, depending upon their group needs are engaged in different kind of activities such as running service centres, special schools, training and production units for their mentally retarded children. Apart from this, they are also actively involved in providing parent to parent information and emotional support, organising awareness programmes for parents and community and acting as advocates for their mentally retarded children. Questions related to parent associations and parental involvement are dealt with in this section.

It is very difficult for us to bring the child every week to you for training.



I'm sure it is. There are no services in your town for children with mental retardation. I think some parents could come together and start services in the town itself.



But who will train the mentally retarded children?



We could help you in identifying a trained teacher and provide technical assistance from time to time.



That sounds good. I will discuss this with the parents.



280. Can parents contribute in any way in the training and rehabilitation of their child with mental retardation ?

Parents play an important role in the training and rehabilitation of their child with mental retardation. Parents are permanent teachers, socializing agents and primary caregivers for the child. Since parents know their child best, effective intervention programs can be developed involving parents, teachers and professionals.

281. What are the contributions that parents can make in promoting welfare of the mentally retarded individuals and their families ?

Family circumstances, parental attitude and other factors such as, amount of time parents have, their financial position may influence the contributions that parents can make. Parents have contributed in a wide range of possible activities and services either actively or passively which can be broadly classified under four broad areas :

- Establishing or running various services for the mentally handicapped individuals and their families such as : managing and running special schools, vocational training centres and production units, organising leisure activities and camps, sharing information with other parents, providing support to parents and families having mentally retarded children and establishing better parent professional relationship.
- Supporting professionals to further the interests of the mentally retarded individuals and their families by participating in the intervention and training programmes,

providing information about the mentally retarded child and meeting needs of other members of the family.

- Establishing links with the community by running public awareness programmes using various media and involving interested persons in the welfare and rehabilitation programmes.
- Acting as advocates and participating in the policy making at local, state, national or international levels related to welfare and rehabilitation programmes for the mentally levels retarded individuals and their families.

282. Are parents required to take over the role of teachers ?

Parents are parents and teachers are teachers. In a strict sense none can replace each other. Parents continue to be natural teachers as they knowingly or unknowingly help their children to learn. Under guidance of the trained teachers parents can supplement, support and involve themselves significantly in the training programmes of their mentally retarded children. Teaching mentally retarded individuals is a complex process. If a parent decides to take up teaching mentally retarded individuals as a profession he/she can do so by undergoing special teacher training courses which are conducted at various Institutes working for the mentally retarded individuals in the country.

283. How far a parent can help another parent having a mentally handicapped child ?

The "veteran" parent has an important role to play with the parent of a newly diagnosed child with mental

retardation. The veteran parent or a parent undergoing a similar experience of having a mentally retarded child can provide emotional support, information about the services and by his or her mere presence-testify the fact that one can survive and even meet the parenthood demands.

Parents provide valuable support to each other as they listen, share experiences, and give assistance (e.g. transportation, helpful information and advice) to each other.

Some parent associations working for the welfare of the mentally retarded children in the country have started such parent to parent support programmes which are proving very useful.

284. How can parents help the teachers in meeting the needs of the child ?

An individual with mental retardation spends the greater part of his/her day with parents. Therefore, parents are in a better position to influence and regulate the development of their child. Parents can help teachers in planning an appropriate intervention programme for their child by providing information about their child's special problems and what their children can do or cannot do.

Parents can also involve themselves to motivate and encourage their child to perform acquired skills or behaviours at school, in the home and other situations. Teachers may request support from parents to carry out programmes with their mentally retarded children which may be best suited for training only in natural environments like home and community setting.

285. Do parents need to come together to meet their needs ?

To enhance support for parents of children with mental retardation and also to help themselves organise better in order to contribute constructively towards the welfare of their children and families, parents do need to come together to form parent groups or parent associations.

286. Are there any parent associations for the welfare of the mentally retarded individuals already existing in the country ?

The first parent association for the welfare of the mentally retarded individuals was started in early 1960 at B.M. Institute Ahmedabad. After a lull, in 1970s and the early part of 1980s, parents organizations have now sprung up in the last decade in various parts of the country. Currently, there are 40 registered parent associations in our country who are engaged in various kinds of activities to promote the welfare of the mentally retarded individuals and their families.

Presently 4-5 registered parent associations are being added almost every year. Details of these parent associations and their activities are contained in a directory published by NIMH, Secunderabad.

287. How can a parent association be formed ?

Interested parents of mentally retarded children could come together and form an association by working out :

- Aims and objectives of the parent association depending upon their present needs and future plans.

- Laws and bye-laws i.e. the constitution which would govern the running of the association.
- Listing elected/nominated members of the association including president, vice-president, general secretary, treasurer, executive and general body members.
- Minimum 8 members are required to form an association (Fathers and mothers can be treated as separate members).

288. *What should be the goals which a parent association need to aspire for ?*

Parents of children with mental retardation come together to form associations for meeting various objectives. Parent associations depending upon their needs have organised and started schools or vocational training centers for the mentally retarded individuals or provide information and support to parents etc. Whatever be the nature of activities the parent associations are performing, there overall goal could be :

- to ensure that assistance is provided for persons with mental retardation, their families to discover and move towards a more desirable personal future and live with dignity and mutual respect as part of ordinary community life,
- to help support and strengthen families and friends who are well wishers and care for the person with mental retardation,
- to help make available environments at various stages during the course of the life of mentally retarded individuals

which provide experiences for promotion of optimum growth and development.

289. What is the role of professionals in facilitating parents association ?

By virtue of greater contact of professionals with the parents, professionals can help initiate interaction between interested parents by providing them initially a neutral place for contact. Depending upon the further needs of particular parent groups the professional could provide support such as, helping identify needs of the group, facilitating parent group meetings, fostering mutual concern among parents, helping develop policies and programmes to be undertaken, providing technical guidance, motivating parents to mobilise resources and any other activities which could help parents in helping themselves.

290. Should parent associations ensure that needs of all parent members are met ?

Parents come together and form association in order to meet their needs, as also strengthen and support the existing rehabilitation programmes. Parents as a group may have common needs which are experienced generally by all the members as also some specific needs which may be different for different parent members. It may not be possible for any parent association to meet each and every individual needs of every parent member, though an association should aspire towards it. Hence, it is essential to prioritise the needs to be met by the association on consensus basis. How far the needs of



PARENTAL INVOLVEMENT ENSURES MEANINGFULNESS OF SERVICES

parent members are met go a long way in keeping parents united and together.

291. What are the various activities which have been taken up by parent associations in the country ?

Parent associations currently are involving themselves in a number of activities in order to meet their family needs and to strengthen and support existing rehabilitation services. These include :

- running services and training programmes for mentally retarded individuals such as special schools, vocational training centres, production units etc.,
- information sharing with parents by arranging talks and lectures from professionals and experts or through news letters, periodicals, magazines or through informal talks and discussions,
- providing mutual help, parent to parent support and counselling services to meet needs of all family members,
- organising social get togethers, picnics, leisure recreational and sports activities for children with mental retardation and the families,
- conducting teacher/parent training programmes,
- conducting community awareness programmes by organising exhibitions etc.,
- working as a liason between professionals and parents,
- advocating the needs of mentally retarded children and

their families and also involving in policy making at various levels local, state, national or international.

292. Who should be included as members of parent association ?

Both mothers and fathers of mentally retarded children should essentially become parent members and try to equally involve in the activities of the parent association. Apart from parent members (who should actually stay in majority in order to continue to keep the focus of the association towards meeting the parent/family needs) other members could be included such as well wishers, patrons, technical experts or other active, interested and concerned individuals.

293. What is the role of siblings in parent association ?

Siblings form a significant part of the natural family support system for both the mentally retarded individual as also for the parents. Much of the siblings contributions in present or in future will largely depend upon how parents bring up and shape the siblings through early training and involvement. Parents need to involve brothers and sisters of mentally retarded individuals in the activities of the parent association. Siblings can form sub group within the association and organise programmes such as recreation, leisure or sports activities which facilitate healthy interaction between mentally retarded individuals and the non-handicapped individuals. Talks from experts could be arranged to help make them more aware of the

special needs of their brothers or sisters and how to manage them better or even share experiences of how it is to have a brother or sister who is mentally retarded leading to mutual support.

294. What is the role of community in parent association ?

Community participation is essential for the existence of parent association. The community nurtures and sustains the development of the parent association by helping the members in matters related to fund-raising, awareness programmes and rehabilitation programmes.

295. How can one facilitate linkage of parent associations with other organisations in the country ?

By participating in national meets of non-government/ government organisations, advertising in newspapers regarding goals and objectives of their programme and by doing collaborative projects with other agencies, parent association can increase their linkages. As a beginning towards this objective the first ever meeting of registered parent associations working for the welfare of mentally retarded individuals was organised by NIMH, Secunderabad on 30 November, 1990 and the second such parents national meet was conducted on 11-12 July, 1994 also by NIMH, Secunderabad.

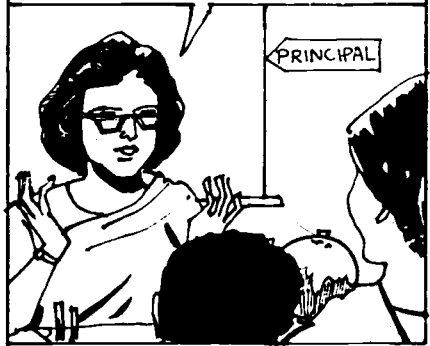
COMMUNITY SUPPORT

Acceptance of mentally retarded individuals by the community is essential to achieve total rehabilitation of the mentally retarded individuals. Mentally retarded individuals with appropriate training are gradually proving themselves as useful members and contributors to the society. It is now for the community to open doors for them and make available all possible opportunities to help them to grow and normalise rather than stigmatise them as an incapable lot. Such a positive change from the community is slowly now coming about but this change process needs to be accelerated. People in the neighbourhood, friends, relatives, employers, co-workers, playmates, co-passengers and other citizens in the community, need to be educated as to how they could usefully contribute in helping mentally retarded individuals and their families, giving them equal rights to live as a free indian citizen. Parents and other family members at times find great difficulty to cope up with the rejecting and non accepting attitude towards mentally retarded individuals from the people in the community. How to facilitate better co-operation from people in the community? Can parents having mentally retarded children and other family members themselves do something to seek out community support, how people in the community can contribute? These and a few other related questions are answered in this section.

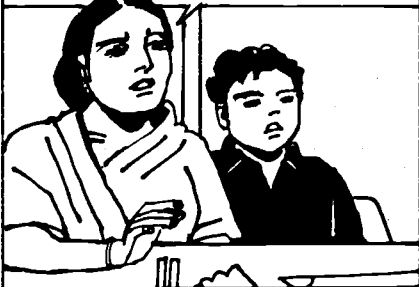
You are asking Rs 200/- per month as van charges. How can I afford that. His father is also not alive to support us.



Why don't you bring him to school and take him back on your own?



How can I do that. The child is also physically handicapped and to lift a 10 yr old boy and change 3 buses is very difficult for me.

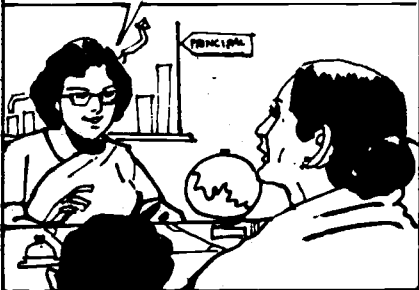


Let me see what I can do, come and see me next week.



Next week

I spoke to one of the owners of a Tac-Mac company. They've agreed to sponsor the child and pay the van charges.



May God bless him and his family for his generous act. I was so depressed. He has really solved my problem.



296. *Is mental retardation a social problem ?*

Social acceptance of persons with mental retardation depends upon how they are perceived by the community. Image of a person with mental retardation will much depend upon how useful and productive member he/she is in the society. Negative images are created where persons with mental retardation are hidden and not allowed to interact with people in the community. The main aim of training and habilitation of persons with mental retardation is to make them independent as far as possible and become integral part of the society.

297. *Families of children with mental retardation experience considerable isolation from community. Does it have any adverse effects on such families ?*

Social isolation is a two way process. It could be the result of non acceptance by the community on one hand or it could be due to apprehensions and non-participation by the family itself. Prolonged isolation can have adverse effects on the development of the mentally retarded child. This can also lead to less chances of building support systems such as material or emotional support from the neighbours, friends, co-workers, religious groups, or extended family members. Such support systems are considered crucial for better coping with a situation of having a mentally retarded child in a family.

298. *Can parents involve themselves in building up community support ?*

For meeting and promoting the needs of the mentally

retarded individuals community support is essential. People in the community need to become aware and understand as to who these mentally retarded people are, what are their special needs and how acceptance and support from the people in the community can help mentally retarded individuals develop, achieve and contribute better. To help build up community support parents need to :

- allow their mentally retarded children to interact with the people in the neighbourhood and community,
- wherever possible talk to people or group of people about the needs of mentally retarded individuals and what they are capable of,
- organise awareness programmes for general public by holding exhibitions of products produced by mentally retarded individuals,
- contribute by writing literature projecting the capabilities of mentally retarded individuals.

299. One of the greatest difficulties parents face is communicating their own child's condition to people in the community? How can we present a positive image of our child? Are there any guidelines for this.

One of the reported reasons why some parents hesitate to take their mentally retarded children along with them to public or family functions is because they find difficult and uneasy to answer queries of people related to their child's condition. To help people develop right opinions and attitudes about mentally retarded individuals it is important that parents communicate their child's condition to others

appropriately which they can do so only if they themselves are first well aware of their child's condition. Honest communication is possible only if parents would have resolved their own emotional reactions of guilt, shame etc., and have accepted their mentally retarded child as he is, rather than as he ought to be. While communicating to others about their child, parents need to be truthful, precise and open in answering questions. It could be helpful if parents emphasize more on what their child can do than one on what he/she cannot do.

300. Because of the embarrassment caused due to child's behaviour we have stopped visiting friends so also some of the friends have stopped visiting us. Do you think it will have any effect on our child with mental retardation ?

Social skills development of the individual with mental retardation can get affected significantly due to the restricted social interaction. There is also a great possibility that the child looses on social acceptability because of his unacceptable behaviours. Behaviours of mentally retarded individuals can be modified and these need to be managed as early as possible. Clinical Psychologists or special educators trained in behavioral technology can be consulted.

301. Children in the neighbourhood don't like to mix with my child. How can I build better relationship between them ?

Families of children with mental retardation often have to deal with the reactions of neighbours to their child. These

reactions may range from helpful and being kind to fearful or rejecting. There is a need that parents themselves take the initiative to build better relationships in the neighbourhood. This could be done by inviting children from the neighbourhood for small parties or get together to their house. This will give other children a chance to mix up with the mentally retarded child. Parents could also use this opportunity for explaining about child's disability to other children and how could they be of help. Some parents have found organizing group games for children in the neighbourhood quite useful. Mentally retarded children also need to be taught social and play skills which will help them to mix with others for which help could be sought from a special teacher or a psychologist.

302. Is it possible to change the negative attitude of the community towards children with mental retardation and their families ?

Ongoing awareness campaigns by private and government agencies will continue to bring about a better understanding of individuals with mental retardation. In particular, various media, especially television, have helped educate the public and enhanced their awareness of the problems related to mental retardation. Various non-governmental organizations including parent organizations and the National Institute for the Mentally Handicapped have organized special awareness programs to help the society accept the individual with mental retardation. Attitudinal changes come about slowly, but happens definitely if right methods are used. Parents, professionals and well wishers in the community

need to continue their efforts, especially in projecting what the mentally retarded individuals are capable of and what they can do.

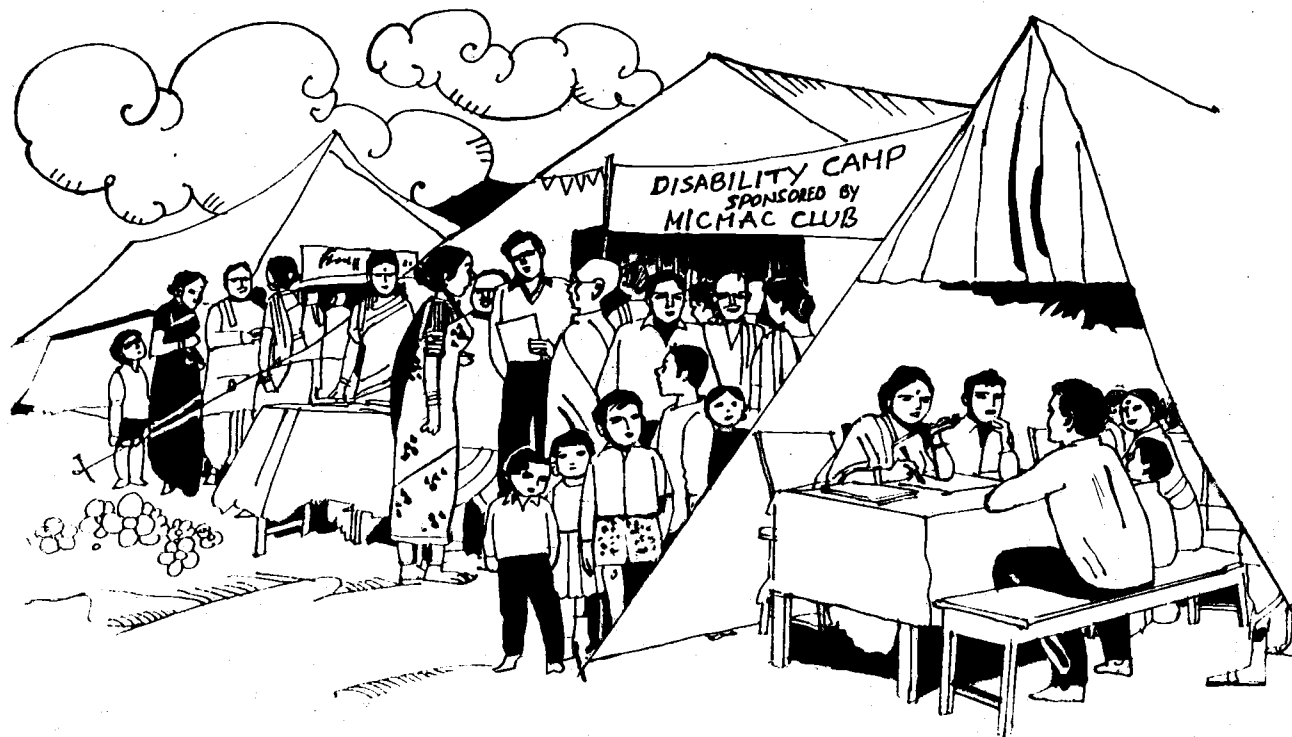
303. Some people show excessive interest in our child and give a number of suggestions to treat our child which we know is not correct. We find difficult to avoid such people. Is there any specific way to handle such people ?

It is probably out of inquisitiveness and wanting to help you that some people would give a number of suggestions which you may not find of any use. Generally such people have very limited understanding of the problem of the condition of mental retardation. It may be helpful if you educate them honestly about your child's condition and inform them that you have already sought professional advice if you have done so. At times it is difficult but not impossible to change the topic of discussion, which does help. Parents need to understand that the ultimate decision for any action still rests with them.

304. How can community provide support to families having children with mental retardation ?

The biggest support that people in the community can provide to families having mentally retarded children include :

- by accepting the mentally retarded individuals as they are and by ensuring equal opportunities for their growth and development, education, training, employment,



COMMUNITY SUPPORT IS ESSENTIAL FOR PROMOTING REHABILITATION PROGRAMMES

recreation and help leading a normal life as any other citizen of the country,

- by spending and sharing their time, money or skills whichever possible to promote welfare activities for mentally retarded individuals.

305. Can voluntary organizations like Rotary Club, Lions Club, Red Cross etc., help families having children with mental retardation in any way ?

Voluntary organizations like Rotary Club, Lions Club, Red Cross etc., have been helping families having children with mental retardation in many ways like :

- setting up special schools in the country,
- sponsoring a child coming from a poor family to special school,
- donating items like table fan, typewriters and other equipments to special schools,
- fund raising to conduct programmes for mentally retarded individuals,
- organizing picnics and festivities for mentally retarded children,
- providing scholarships to deserving students with disability,
- sponsoring and organizing screening/identification camps,
- organizing public awareness programmes etc.,

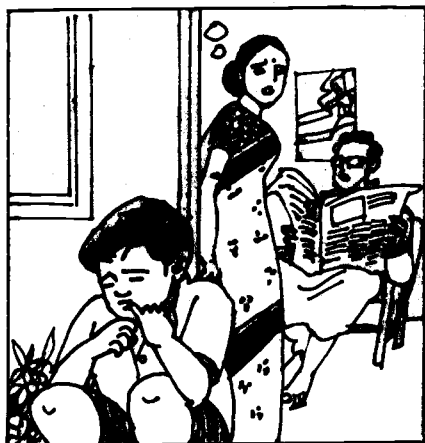
With proper understanding of the needs of mentally retarded individuals and their families and links with the professionals, such voluntary organizations can be a great resource and a useful support in fostering welfare activities and training programmes for people with disabilities.

306. Can religious organizations provide any support to the families having children with mental retardation ?

Religious organizations can provide great emotional support to parents of children with mental retardation. In addition, some religious organization provide material or financial support to families who need it. Such kind of emotional or material support is essential for many parents in coping up with the situation of having a mentally retarded child. However, it is important to note that for a mentally retarded child to become functionally independent in life, structured training is absolutely necessary, for which professional help needs to be sought.

HOSTEL

Unlike the western countries, in our country, state sponsored residential institutional facilities are very few. Historically, residential facilities were created in order to keep people with mental retardation away from the community as they were considered untrainable and a hindrance to the family and the society. Times have changed so has the definition and perception of the community about mental retardation. In the rehabilitation process sending people with mental retardation to residential institutions is presently discouraged as it does not provide normal quality of life. However, temporary or long term residential institution facility may be unavoidable and considered as a last resort, for example, when the family is under severe stress and is unable to look after the mentally retarded child appropriately. Nearly one-third of the special schools which are run by the voluntary organisations have hostel facilities. Parents often ask this question whether hostel facility will benefit their mentally retarded child. What are the kind of facilities and programmes available in the hostel. This section deals with such issues commonly raised by the parents.



What will happen to my child when we are no more?



I'm thinking to put him in a hostel, that will take care of the problem.



But do you think people in the hostel will look after him the way we care for him at home. He is definitely going to miss us all.



I know nothing can be better than being in one's own home. God knows whether his brother or sister will take care of him.



I think we should talk to our children directly and get their opinion.



307. What is the best living arrangement for individuals with mental retardation ?

Living in one's own home along with parents and siblings is the best living arrangement for individuals with mental retardation. Living at home provides a natural security as also an environment where effective training can occur. Families do undergo a lot of adjustments and stress due to having a mentally retarded child for which sometimes parents look out desperately for residential facilities. It is seen that if appropriate professional, family and community support is made available to the family at the earliest as per the individual needs of the affected child and the family during the life span it enables and strengthens the family to cope up with the exigencies and additional demands as also make appropriate decisions regarding child's training or placement.

308. Normal individuals when reach adulthood have an option to live with the family or away from the family. Can an individual with mental retardation have the same option ?

Unlike normal individuals, many persons with mental retardation are unable to take a decision whether he or she will be able to live independently because of their below average intellectual capacity. The extent to which an individual with mental retardation can be taught to live independently depends upon the severity of his/her mental handicap. Currently, there are two living options available in our country for a person with mental retardation: he or she could live with his/her family or in an institution.

309. What is a hostel ? What facilities does it provide for individuals with mental retardation ?

Hostel is a public, private or government facility or building(s) providing specified services to persons on a 24-hours residential basis. In a hostel for individuals with mental retardation, only persons with mental retardation live under 24-hours supervision. The activities of the individuals are governed by a system of explicit formal rulings and a body of officials.

Well supervised hostels offer complete rehabilitation services for individuals with mental retardation. Properly run hostels provide balanced diet, hygienic surroundings, facilities for play, leisure time activities, social interaction facilities and facilities for education and training.

310. Do all hostels for individuals with mental retardation have similar facilities ?

There is no single or common body which governs the functioning of the hostels for mentally retarded individuals. Also, there are no strict standards laid down so far by the State or Central Government for the functioning of such hostels. The programmes or the staff involved also may vary from one hostel to the other. Hence, the facilities available in a given hostel may depend upon several factors, mainly including the availability of resources such as financial, trained professional expertise or physical resources such as space and above all the commitment of organisations and staff towards quality care.

311. Is it true that individuals with mental retardation become more independent if they live in a hostel rather than live at home with the family?

The family home provides a natural setting for learning. With proper education and training, individuals with mental retardation can become independent if they live at home with their family. Independence or dependence behaviours attained are part of the training and caring which each individual goes through in a family irrespective of disability. It is the parental attitudes of over protection towards the mentally retarded individuals or less opportunities of learning experiences provided by the parents to achieve independence which generates dependence behaviour. Hence, it is not essential that only by separating the child from family that the child would learn to become independent. Instead changing the attitude of overprotection and insisting on independent functioning may help.

312. Is it advisable at all to consider placing an individual with mental retardation in a hostel? What are the factors parents should consider?

There is no set criterion for determining whether the hostel is an appropriate learning and living setting for any person with mental retardation, although it is widely viewed that hostel living causes adverse effects on intellectual, psychological and physical development due to restricted environment.

Following are the conditions presented which generally could guide parents to decide on placing a child in a hostel.

- if no day care services are available in the place that the family resides and all the efforts to initiate services for such children have failed,
- if severe pathology in the family exists e.g.. parents are mentally or physically sick, or no support whatsoever is available from the family,
- if severe behaviour problems in mentally retarded individuals are present necessitating temporary residential placement.
- In case of death of both the parents with no brother sister or relatives to take over the responsibility of the mentally retarded individuals.

For further guidance parents are advised to consult trained rehabilitation professional, clinical psychologist, trained social worker or special educator.

313. Who all in the family should be involved in the decision of placing an individual with mental retardation in a hostel ?

Ideally, the whole family i.e. parents, siblings, grandparents, and the concerned mentally retarded individual should be involved in the decision of hostel placement. In addition, talking to other parents of mentally retarded children and guidance from trained social workers, special educators and clinical psychologists would be very helpful.

314. Are there separate hostels for boys or girls ?

Since both boys and girls with retardation have unique needs, most hostels in India don't have co-educational facilities. Also difficulties of proper supervision and control

has also been reported as a reason for having separate hostels for boys and girls.

315. How much would it approximately cost to put the individual with mental retardation in a hostel ?

There is no uniform cost structure for hostel placement of an individual with mental retardation. Depending upon the services provided and cost of living index in a particular area, costs may vary from Rs 400 to Rs 1500 per month or even more. Since most of the organizations providing hostel facilities are non governmental agencies, parents may be asked to pay for equipment buying and other infrastructure expenses.

316. What sort of programs are run in a hostel ?

Hostels provide comprehensive rehabilitation services for individuals with mental retardation. Programmes offered by hostels vary from institution to institution. Generally programmes include training in self care activities, communication skills, leisure skills, domestic living skills and socialization skills.

317. Are hostel admissions restricted to certain categories of mental retardation ?

Each hostel may have their own rules and regulations governing admission. What is generally observed is that individuals having moderate or mild mental retardation are preferred over severe and profound mentally retarded individuals and also those who have associated problems such as epilepsy, physical handicap etc.



EAST OR WEST HOME IS THE BEST

318. What are the factors parents should consider before seeking living arrangements for their child with mental retardation ?

While considering hostel placement parents should consider among others the following :

- availability of trained personnel like special educators, clinical psychologists, trained social workers, medical personnel, physiotherapist, speech therapist and vocational counsellor,
- the program's reputation for training children with similar condition as their child,
- the location of the hostel,
- the cost of the program broken down by category (like tuition, room, board, equipment etc),
- admission eligibility requirements,
- how will the child benefit from the programme,
- supervisory staff versus inmates ratio.

It is advisable that parents seek guidance from other parents, trained social workers, special educators and clinical psychologists on this matter.

319. At what age should a child with mental retardation be admitted in a hostel ?

There is no such age as when a child with mental retardation needs to go for residential placement. However, most hostels in the country have admission age criteria ranging from 6 to 15 years.

320. Is it advisable to place a child with mental retardation in a hostel at an early age ?

For individuals with mental retardation, as said earlier living with the family provides the most natural setting for effective learning to occur. During the early years the child with mental retardation develops emotional relationship with parents which acts as a foundation for future learning. Also, the relationships tend to develop and strengthen between mentally retarded child and his brothers and sisters. This could be very vital as in our country the brothers and sisters become natural guardians of the mentally retarded individuals after the parents death. Hence it is not advisable to place a child with mental retardation in a hostel at an early age.

321. In a hostel, all the residents are mentally retarded. Does it have any adverse effect on the individual with mental retardation ?

A potential adverse effect of sending a child to a hostel is the isolation of the individual with mental retardation from their non-handicapped peers, and hence, the loss of opportunities to observe and learn appropriate social and other behaviours from normal peers or individuals. The quality of life gets largely affected as the mentally retarded individuals gets deprived of normal interactional patterns and normal living conditions due to restricted environment in the hostel.

322. How long does an individual have to stay in a hostel ?

A number of hostels in India have specific guidelines

regarding the length of stay in the hostel based on the age of the child with mental retardation. It generally ranges from 16 to 21 years of age. However, there are institutions which don't have any guidelines regarding the length of stay. In these hostels, the individual stays as long as his parents want to keep him away or have the money to keep him there.

323. Will an individual with mental retardation be safe from abuse in a hostel ?

Although many hostels proclaim an abuse free environment, unfortunately hostels can't guarantee an abuse free setting. Abuse in hostels can be committed by the staff, people from within the community or by the individuals with mental retardation on each other. However if the hostel has well qualified staff and effective supervision procedures the probability of abuse decreases. In addition, hostels in India hardly offer comprehensive sex education training for the residents to prevent sexual abuse.

324. Are there any hostels where parents can keep their child with mental retardation temporarily ?

There are only very few known residential set-ups in the country which encourage and insist, only on temporary placement of mentally retarded individuals. However, there is a need for such an arrangement which parents can use during emergencies such as parents falling sick etc. Parents of mentally retarded children between themselves can provide such support to each other in times of need.

325. If parents are not alive and there is nobody to look after the person with mental retardation, are there any hostels for such people ?

Under the circumstances, if a person with mental retardation is found without any caretaker or guardian and he/she is produced before the District Magistrate, he will be sent to juvenile homes or residential homes for mentally retarded individuals run by the respective State Governments. When admitted to such State Govt run residential institutions the guardianship of the person with mental retardation rests with the State.

326. Are there any alternatives other than hostels to living away from home ?

Presently, there are limited number of options available for mentally retarded individuals in India to live away from home. One of the concept that some organizations are experimenting with is called group home option. Group home is a form of alternative living arrangement away from ones own family in which individuals with mental retardation live in the community setting rather than in institutions. A maximum of three to four people with mental retardation live together in this type of arrangement under supervision. How far these options are practical, feasible, affordable and acceptable by parents/guardians of mentally retarded men and women is yet to be experimented and seen.

In our country primary residential option for a person whether retarded or not is their living with their family. Professionals like clinical psychologist, trained social worker and special educator can guide parents to make right decisions in this regard.

FINANCIAL PLANNING

As the condition of mental retardation requires life long commitment of time, energy and resources by the family it is therefore necessary to plan well ahead of time and to anticipate the needs of the child with mental retardation. Whatever may be the magnitude of savings, if invested appropriately, can be of great relief to a family in the time of need. Currently, there are hardly any schemes which cater to the needs of the family having a child with mental retardation. However, there are some several promising ideas which are being tried out by certain parents and also by various groups of parent organisations collectively. Similarly, certain groups of parents have launched advocacy campaign to motivate LIC, to come up with a policy which is helpful to the parents having a child with mental retardation. The possibilities of group insurance has also been explored. Issues related to financial planning have been discussed in this section.

Geeta, God forbid if something happens to me today and I die what will happen to you all.



You shouldn't ever speak like this.



Our children are so young. You have to settle them in life, marry them and look forward to playing with your grandchildren.



What troubles me most is Raju's security. He is 10 yrs old now. What will happen when we are no more in this world?



Could we think of some scheme.



We could start saving some money right now which could provide financial security for Raju after we are no more.



327. How early should a parent consider financial planning for a child with mental retardation ?

It is well known that the condition of mental retardation is life long and a person with mental retardation cannot achieve total financial independence. If family resources permit, parents should consider financial planning when the child with mental retardation is young so that the expenses towards living, training and rehabilitation can be met out of savings at his later life.

328. What are the factors to consider for financial planning for individuals with mental retardation ?

Family composition and family resources are perhaps the main considerations for planning financial support in the future life of the child with mental retardation. In case, the family has limited income, it is desirable to set aside even a small amount for the future needs of the child. The small savings in a span of 20-25 years can grow into a large sum enough to generate interest to meet the living expenses of the person with mental retardation even after the death of the parents.

329. Can an individual with mental retardation open an account in a bank or other financial institutions ?

A person with mental retardation irrespective of age can open a joint saving fund account in any bank. However, he/she will be treated as a minor and the account will be operated by a guardian.

330. Can an individual with mental retardation apply for a loan from a bank or other financial institutions ?

Although facilities for obtaining loan at concessional rate of

interest is available for people with physical disabilities, similar facilities are not available for individuals with mental retardation. Persons with mental retardation being legally considered minor will not be eligible to apply for this loan.

331. Can we as parents start a life insurance policy for our mentally retarded son/daughter ?

The Life Insurance Company of India, doesn't have any special provision for giving life insurance policies to persons with mental retardation. However parents can have a life insurance policy and can nominate their child with mental retardation to be the recipients of proceeds of the policy in the event of their death.

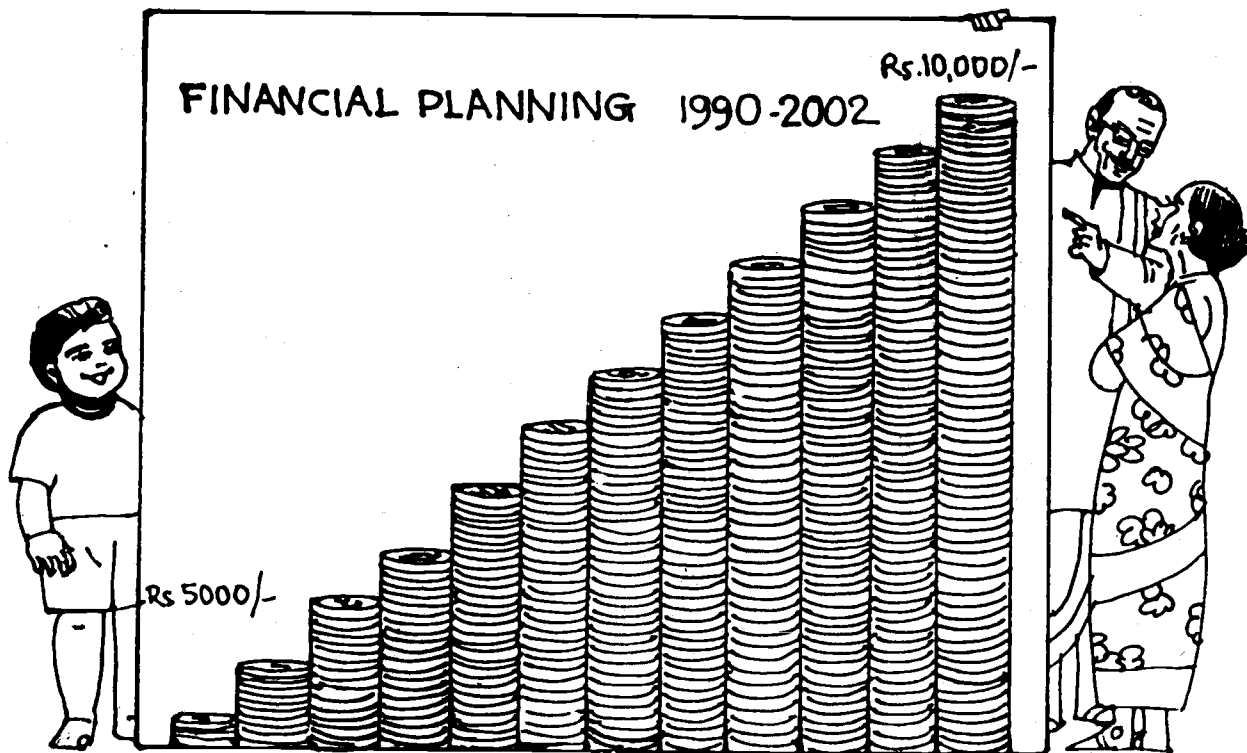
332. What are parent cooperatives/trusts ? Can parent cooperatives/trusts help in financial planning of individuals with mental retardation ?

It is desirable for a group of parents to join hands in order to take a group insurance policy and nominate their children with mental retardation to be the beneficiary in the event of death of the parent.

If a group of parents form a trust, the receipts from the life insurance policy can be credited to the trust. The income generated by the trust can meet the living expenses of the persons with mental retardation. The respective parent members of this trust can also bequeath the property to the trust and transfer the guardianship rights of the individuals with mental retardation to this trust.

333. Can a trust be created by the family to look after the person with mental retardation ?

In case the family has some property which they want to



FINANCIAL PLANNING SHOULD BEGIN EARLY

set aside so that the income generated from the property is utilized for meeting the living expenses of the person with mental retardation, a private family trust can be formed by signing an agreement.

Family members can be nominated as trustee to manage the property. One of the family members can assume the role as a manager while the other family members can supervise the work of the trust. The family trust is basically private rather than a registered charitable trust offering services for the public.

334. Are there any trusteeship schemes in our country ?

It is just the beginning. Few parent groups and few well meaning people have initiated trusteeship schemes by registering a public charitable trust under the Trust Act. Property can be bequeathed to such trust although transfer of guardianship to such trusts is not legally valid. It is necessary that the trustee are accountable for the property bequeathed plus the rights of the beneficiaries i.e. persons with mental retardation are also protected.

335. What will happen to the mentally retarded child if parents die without leaving any assets in terms of property or money ?

If parents die without leaving any assets of property or money, the guardianship of the person with mental retardation automatically passes on to the next head of the family. Only in case of destitute person with mental retardation, without any close relations, or found wandering

in the streets, custodial care will be provided by the State Government. For this purpose State Government have residential homes for persons with mental retardation who are destitute.

336. If a parent likes to leave property for their child how will it be safeguarded ?

A private family trust can be created which can be managed by one of the family members as desired by the parents. The income generated from the property can be utilized for the treatment and living expenses of the person with mental retardation.

In case, the parents don't find anybody in the family to take over the guardianship and manage the private trust, parents can move the court for appointing of trustee who can manage the property so that the income derived from the property can be utilized for treatment and living expenses of the person with mental retardation.

NOTES

LEGAL

The Indian Lunacy Act 1912 made provisions for custodial care of persons having lunacy/or idiocy. This act has now been replaced by the Mental Health Act 1987 which has excluded persons with mental retardation from its provisions. As a result, as of now, a vacuum has been created in the legal position of persons with mental retardation particularly with the laws concerning their civil liberty, guardianship, custodial care, contract and legal provisions concerning criminal procedures and punishment. With education, training and rehabilitation programs directed towards independent functioning, employment and independence, many persons with mild mental retardation are considered capable of understanding terms and conditions for employment, sale and purchase and a wide variety of transaction required for independent functioning.

The Government of India constituted Bahrul Islam Committee which has recommended several legislative measures. The Ministry of Welfare has introduced legislative bill for creation of National Trust, which is yet to be passed by both the houses of the Parliament. This section answers questions related to legal issues.

Now that we are getting old, we need to transfer our property among everybody.



How can we ensure that income for Ramesh is spent on him?



Can we entrust our children to take care of his share. What do you think?



But who knows what is going to happen after us? Let's talk with Manish and Manisha?



Father, Why don't you 'Will' the whole property to Ramesh. You, please don't worry about us.



Manish is right. Can't we create a family trust which would ensure that the income from the property is spent on Ramesh.



337. *Can Individuals with mental retardation Inherit property legally ?*

Persons with mental retardation can inherit ancestral property as well as properties of parents and relatives if indicated in the "Will". However persons with mental retardation are considered 'minor' in legal terms even through their age may be over 18 years. Therefore, persons with mental retardation are not competent to handle or manage the inherited property. Hence, the property inherited by the mentally retarded individual has to be managed by the natural guardian or court appointed guardian.

338. *Is marriage of Individuals with mental retardation legally acceptable ?*

As per the Hindu Marriage Act, marriage of a person with mental retardation is considered "null and void" as person with mental retardation is legally considered "minor" and also incapable of entering into a "contract" as per the Law of the Contract.

The Indian Divorce Act, governing the Christians, considers marriage with a person with mental retardation as a nullity. It is only under the customary Islamic Law that a person with mental retardation is treated as a minor. The guardian can validly conduct a marriage on behalf of the person with mental retardation under Islamic Law.

339. *Can an Individual with mental retardation enter Into a contract legally ?*

A person with mental retardation is legally considered incompetent to enter into any "contract" due to intellectual



DIFFERENT METHODS CAN BE ADOPTED TO PROTECT THE PROPERTY RIGHTS OF INDIVIDUALS WITH MENTAL RETARDATION.

impairment. Therefore, any contract signed by a person with mental retardation is considered "null and void" may it be, marriage, acceptance of terms of conditions of employment, deed or any other form of contract between two parties one of whom is mentally retarded.

340. If a person with mental retardation commits a crime what are the legal implications ?

It is extremely rare that a person with mental retardation is involved in a crime either as a witness or as an undertrial for allegedly committing a crime. As per the Law of the Land, a person with mental retardation is not considered competent to stand trial unless he/she is certified by the medical authority appointed by the court that the given person with mental retardation is capable of understanding the nature, responsibility and implications of committing the crime. In case of trial, if any, the person with mental retardation will be considered as "minor" and punishment given accordingly.

341. Do individuals with mental retardation have the right to vote ?

Persons with mental retardation don't have the right to vote as they are considered legally "minor".

342. Can individuals with mental retardation be legally sterilized ?

Mentally retarded individuals are considered to be 'minor'. Hence, parents/gaurdian can take decisions related to sterilization on their behalf. However, such a decision should be taken as a last step in consultation with experts like a medical doctor, psychologist and trained social worker.

Wherever possible, it is advisable to take the consent of the concerned mentally retarded individual in order to give due respect to human rights.

343. Are there any laws applicable to mentally retarded individuals regarding employment ?

Employment is considered a contract between the employer and the employee. As per the Laws of Contract, a person with mental retardation is considered to be "minor" and incapable of entering into a contract with anyone.

In order to encourage employment and economic independence of persons with mental retardation, existing laws need to be changed for those categories of persons with mental retardation who can live independently and understand broad terms and conditions of the contract.

344. Are there any laws to protect individuals with mental retardation from sexual abuse ?

There are no special laws exclusively for persons with mental retardation to protect them from sexual abuse or any other kind of abuse. Like other citizens of the country they are also protected under the Indian Penal Code and Criminal Penal Code.

345. Should there be special laws for persons with mental retardation ?

In order to give equal opportunity to persons with mental retardation and to ensure their right to education, training and employment, comprehensive legislation is necessary. Existing laws don't fulfill the basic needs of persons with mental retardation.

346. Do the current laws protect the person with mental retardation or are they designed to protect the society from persons with mental retardation ?

It is true that Indian Lunacy Act 1912 envisaged segregation of people with mental illness and mental retardation and to keep such persons in residential institutions away from the society. Such laws which promoted segregation have already been replaced in many parts of the country. However, there is an urgent need for having comprehensive legislation to protect the rights of mentally retarded individuals.

NOTES

GUARDIANSHIP

Social security is one of the major concerns of parents having a child with mental retardation. Unlike other developed countries, we do not have state residential institutions or pension scheme for persons with mental retardation. As developing countries are in the process of dismantling residential institutions and are promoting community living, such programmes are obviously not suitable for our country. Nor the central/state government can afford to give pension to the vast number of people with mental retardation. Parents of children with mental retardation have a nagging but a genuine fear as to who would look after their child after they are no more.

Traditionally, family systems are very strong in our country. In many of the recently developed Asian countries like Japan, Indonesia, Singapore and Malaysia, the family system has with stood the pressure of socio-economic changes. The family has been providing social security to all its members. It is therefore necessary to find innovative methods for streng thening families and enhance social security within the system. Commonly asked questions by the parents regarding family trust, national trust, transfer of guardianship, bequeathing property and management of property inherited by a child with mental retardations covered in this section.

I've 2 years of my service left before I retire. I'm worried as to who will take care of my son after I'm no more.



There is a hostel I know which admits mentally retarded children. Why don't you think of admitting him there.



Don't you think that we should look into our own resources in the family. If brothers and sisters can look after him.



But they also have to lead their own life. Will they be able to make such a sacrifice.



We are talking on behalf of our children. Don't you think we should talk directly to them as to how they feel about it.



I think it is very correct, if one's own family members don't come forward to help who else will.



347. What is guardianship? Who may serve as guardians ?

Guardianship refers to the functions of care, protection and custody of the child with mental retardation.

Parents are natural guardians of children with mental retardation. In absence of parents, siblings and close family members assume the role of natural guardians. In case parents become incompetent due to mental illness or become physically invalid, the next person in the family who assumes the role as head of the family becomes natural guardian. In the case of destitute, having no family members to look after, the guardianship is taken over by the state government.

348. When is guardianship needed ?

In absence of parents, siblings and close family members assume the role of natural guardians. In case if there is nobody in the family to look after the individual with mental retardation, the court can appoint a legal guardian who can manage the property or take decisions on behalf of the person with mental retardation.

349. What are the factors to be considered in deciding guardianship for mentally retarded individual ?

Parents in old age, in the absence of support from non-disabled son(s) and daughter(s) may find themselves unable to look after their child with mental retardation. Under such circumstances, parents may like to enter into contract with a relative, friend or well wisher to look after their child with mental retardation by transferring part or whole of guardianship rights. Many a time such contracts are oral

based on mutual faith and trust. While deciding transfer of guardianship, parents may consider the following :

- the availability, willingness and ability of relatives or friends to assume guardianship role,
- the life expectancy and health of the persons to be considered for guardianship,
- the financial resources of the family.

Such a transfer of guardianship may or may not involve financial considerations, like transfer of property or money or regular income, depending upon relationship between two parties. There may or may not be any written contract.

350. What is the nature of duties the guardian is required to perform for the mentally retarded ward ?

The guardian appointed by the court will look after and manage the property of the ward with mental retardation under the supervision of the court. The guardian is also responsible for providing food, clothing and shelter to the ward with mental retardation. The expenditure on treatment, care and management or living expenses in the care of ward with mental retardation will be met out of the profits or income generated by the property.

Actual living arrangements can be made by having foster parents or the child with mental retardation can be put under the care and management of an institution/school having residential/hostel facility.

351. How long does guardianship last ?

Normally, for an individual with mental retardation who

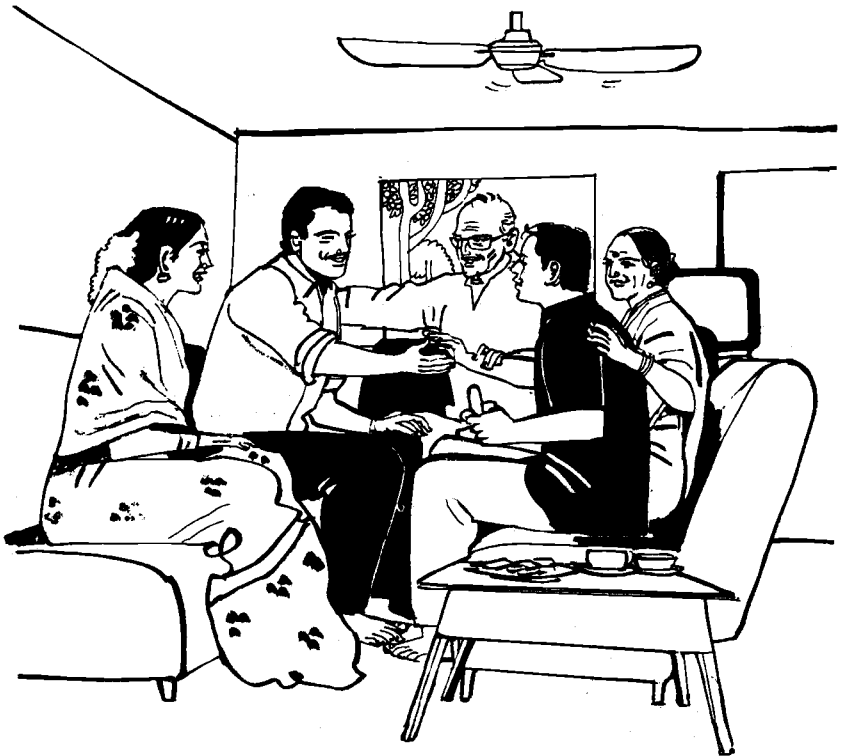
has been legally declared incompetent to handle his own affairs is subject to guardianship as long as it is found necessary by the court.

352. What happens to the mentally retarded individuals who have no one to look after them ?

In case a person with mental retardation is found wandering on the streets uncared and unattended, on production before a District Magistrate such a person will be sent to a mental hospital under the provisions of Indian Lunacy Act of 1912.

In case there is no one in the family to look after the person with mental retardation, neighbours or friends can also approach District Magistrate for custodial care in State run Homes.

In the states where the Indian Lunacy Act of 1912 has been replaced and the Mental Health Act of 1987 has come into operation, persons with mental retardation are not considered persons with mental illness and hence will not be sent to mental hospitals. Under such circumstances, if a person with mental retardation is found wandering in the street without any caretaker or guardian he/she will be produced before the District Magistrate and will be sent to juvenile homes or homes for the mentally retarded persons run by the respective State Governments. When admitted to such State Govt. run residential institutions the guardianship of the person with mental retardation rests with the State.



BROTHER(S), SISTER(S) AND CLOSE RELATIVES ARE NATURAL GUARDIANS OF INDIVIDUALS WITH MENTAL RETARDATION AFTER THEIR PARENTS

353. *Is the Government of India planning to create a Trust to look after the persons with mental retardation after their parents are no more ?*

The Govt of India had appointed Bahrul Islam Committee which recommended introduction of legislation for the welfare of persons with mental retardation and persons with cerebral palsy. The function of this "Trust" will be to provide care and rehabilitation to persons with mental retardation and persons with cerebral palsy in serving institutions set up by the "Trust" and to provide guardianship and foster care. The act will enable parents to bequeath properties to the "Trust" and transfer guardianship rights to the "Trust" after their death.

The National Trust is still under the consideration of the Government. When passed by both the houses of Parliament and ratified by the legislators of the State Governments, then only the "National Trust" can become operational.

354. *Are there any other options for guardianship of mentally retarded individuals ?*

Some parents of mentally retarded individuals have formed groups and registered themselves as parent organizations, associations or cooperatives or registered as "trust". With mutual understanding they can agree to "will" their property to the trust. As a result after their death, the guardianship as well as the responsibility of caretaking of the mentally retarded individual will be taken over by the registered trust.

Such associations or trusts are still in the initial stages of evolution. Few trusts have established hostels to provide

residential care to mentally retarded children of parent members.

355. *What are the laws regulating guardianship ?*

Under the Family Law, the Transfer of Property Act as well as Guardianship Act gives the guidelines for appointment of guardians as well as the duties of the guardians so appointed by the court of Wards.

As the needs of each family are unique, it will be necessary to seek legal advise regarding guardianship.

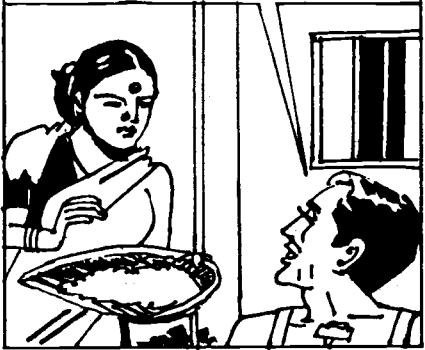
BENEFITS/CONCESSIONS

A welfare state looks after the interest of all kinds of people including destitutes and persons with disability. Eversince the formation of Ministry of Social Welfare, wide variety of concessions and benefits have been extended by various departments of the Central/State Governments. These include Income tax concession, free distribution of aids and appliances for people with disabilities who cannot afford, concessional railway fare, reservation in jobs, scholarships for school and college education, loans at concessional rate of interest for starting self-employment ventures and a host of other benefits like preferential allotment of plots for physically handicapped persons, etc. The realisation that persons with mental retardation also require concessions and benefits is of recent origin. As a result, some of the most commonly available concessions relate to free bus travel in State Roadways corporation, Income tax benefits and scholarships for training in special schools. The information given in this section primarily pertains to the needs of the family having a child with mental retardation and wherever possible comparison has been made with benefits and concessions available to other categories of people with handicap in the hope that similar concessions may be forthcoming for people with mental retardation in the future.

We need to send Raju to a school.



I would like him to go to school but the fees is too high.



Mrs Ghosh's son is attending a special school when his father is out of job. Let's find out how they are managing.



How much fees are you paying for sending Ashok to the special school?



The regular fees is Rs 60/- a month but it is totally reimbursed by the state government.



Is it so? That really solves our problem. We should admit Raju to a special school immediately.



356. What are the benefits and concessions offered by the Government of India to relieve the financial hardships of families having children with mental retardation ?

Basically two types of concessions are offered by the Central Government. The first is related to concession in Income tax while the second one is concession in the rail fare.

357. What are the Income tax benefits offered by the Central Govt to parents to compensate for expenses incurred for the medical treatment (including nursing) training and rehabilitation of one or more handicapped relation (son, brother, sister or any other blood relative) dependent on the assessee ?

Under section 80 DD of Income Tax Act (1961), a deduction of Rs. 15000 in addition to the standard deduction from the assessment year 1994-95 and account year 1993-94 is allowed in the income of parents having one or more children with mental retardation. This income tax concession can be availed only by parents whose child is having severe mental retardation with an intelligence quotient less than 50 obtained on an intelligence test.

For the purpose of availing government benefits and concessions, as per the G.O.Ms.No. 109, Women's Development Child Welfare and Labour Department dated 5-6-1992, a person with mental retardation must be certified by a clinical psychologist/psychiatrist and signed by the medical superintendent, District Medical Board.

358. What are the Income tax benefits offered by the Central Govt. to compensate directly a resident

Individual suffering from permanent physical disability or total blindness or mental retardation reducing his capacity substantially for gainful employment ?

Under section 80 U of Income Tax Act (1961), a resident individual suffering from permanent physical disability or total blindness or mental retardation reducing his capacity substantially for gainful employment is entitled to a deduction of Rs 20,000 from his/her gross annual income from the assessment year 1992-93.

359. Are there any income tax benefits offered by the Central Govt to parents in whose income, the income of the minor child is included and such minor child is suffering from physical disability /mental retardation ?

Under the section 80V of Income Tax Act (1961), concession in income tax is given to parents in whose income, the income of the minor child is included and such minor child is suffering from physical disability/mental retardation of the nature as specified in section 80 U above.

Such parents shall be allowed a deduction from his gross total income for an amount that would have been allowed to the minor child under section 80 U had the child been assessed separately i.e. to the extent of the income of the handicapped minor clubbed in the income of the parent or Rs 20,000 whichever is lower.

360. What are the railway travel concessions offered by the Central Government for people with mental retardation ?

Railway fare concessions are granted to wide variety of condition of disability such as blind, T.B and cancer

patients orthopedically handicapped, non infection leprosy patients, deaf persons, mentally retarded persons, and thalassemia major patients.

Two types of railway concessions are available to individuals with mental retardation based on the nature of journey :

- individuals with mental retardation travelling in a party,
- individuals with mental retardation travelling with an escort.

361. What kind of railway travel concessions are offered by the Central Government to individuals with mental retardation travelling in a party ?

75 percent concession in the basic fare in 1st and 2nd class is allowed to mentally retarded pupils in parties not less than 4 studying in schools or institutions recognized by state or central government. Free ticket for one escort for every 2 pupils in the same travel class is allowed whether the pupils hold adult tickets or half tickets. Travel is also permitted by 2- Tier A.C. on payment of concessional first class fare and full surcharge for 2-Tier A.C.

This railway travel concession is admissible to individuals with mental retardation when they are travelling :

- between their homes and school/institute,
- place of vocation,
- place of examination center in India.

This railway travel concession is admissible to government recognized schools and institutions. The concession can be availed if the school/institution make an application to the

Station Master of the local railway station in the prescribed application form and concession certificate.

362. What kind of railway travel concessions are offered by the Government to Individuals with mental retardation who can only travel with an escort ?

Two types of railway concessions are available to individuals with mental retardation who can only travel with an escort.

- single journey tickets,
- monthly season tickets (MSTs)/ quarterly season tickets (QSTs)

363. What are the concessions available for mentally retarded Individuals on single journey tickets.

An escort accompanying a child with mental retardation aged 5 years or below will be allowed 75 percent concession in the basic fare in 1st and 2nd class travel. Only one escort will be allowed to travel with one individual with mental retardation. An escort can be any adult accompanying the person with mental retardation. It is also not necessary for the individual with mental retardation to be present at the station at the time of purchasing the ticket. They should also be given preference in the allotment of coupe when reservation in first class is required. Facility of issue of concessional return ticket is also available. Period of availability of return journey tickets will be one month from the date of commencement of outward journey. Travel is also permitted by 2-Tier A.C. on payment of concessional first class fare and full surcharge for 2-Tier A.C.

The combined concession tickets for the individual with mental retardation and their escorts will be issued directly by the Station Master on production of the prescribed photostat certificate of mental retardation.

Twenty five percent of the basic fare is charged both for the individual with mental retardation and his/her escort.

364. What are the concessions available for mentally retarded individuals on monthly season tickets (MSTs)/ quarterly season tickets (QSTs)

50 percent concession in the 1st and 2nd class monthly season ticket fares for both the individual with mental retardation and his escort over suburban and non-suburban section of Indian Railways is allowed.

The combined concession MSTs/QSTs for the individual with mental retardation and his/her escort will be issued directly by the Station Master on production of the prescribed photostat certificate of mental retardation. In addition, other conditions regarding issue of MSTs/QSTs as applicable to general public may also apply.

365. Is there any validity period of the certificate issued for the railway concession ?

The certificate issued by the psychiatrist/clinical psychologist is valid for 3 years from the date of issue. This certificate gives particulars of the individual with mental retardation like age, sex, personal identification marks and signature or left hand thumb impression and IQ of the individual with mental retardation.

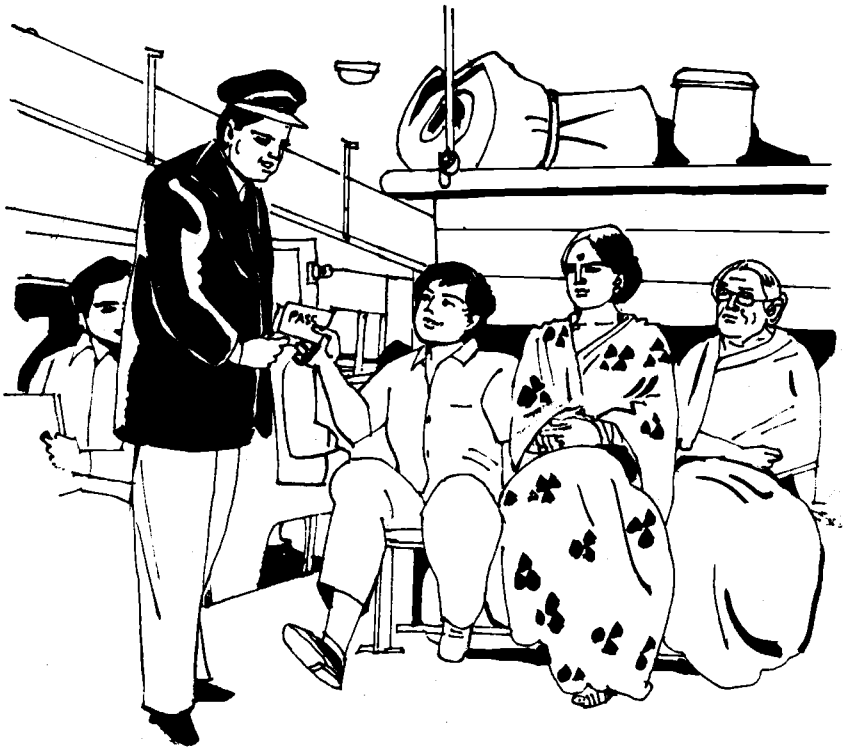
366. What are other travel benefits available to Individuals with mental retardation ?

Most State Governments having state owned and operated Regional transport corporations allow subsidized/free bus travel in the city and rural routes for persons with mental retardation along with their escort on presentation of the certificate of mental retardation. For example, in Andhra Pradesh city, bus travel for a mentally handicapped child is free while the escort pays a sum of Rs 20 for 3 months. District routes both the individual with mental retardation and escort is charged 50 percent of the fare.

367. Does the Central Government give any assistance for purchasing aids and appliances for mentally retarded Individuals ?

Aids and appliances like wheelchairs, crutches, hearing aids are required by individuals with disabilities for mobility and independent functioning. Persons with mental retardation having associated conditions like hearing impairment or physical impairment may require aids and appliances.

The Central Government Scheme open to Indian citizens of any sex and age covers only those aids and appliances which don't cost less than Rs 25 and more than Rs 3000. Where more than one aid is required, limits will be applied separately. Only persons who are employed or self employed and whose average income doesn't exceed Rs 2500 per month from all sources or if dependents, parent/guardians income doesn't exceed Rs 2500 per month are eligible for assistance.



GOVERNMENT PROVIDES VARIOUS BENEFITS AND CONCESSIONS TO
INDIVIDUALS WITH MENTAL RETARDATION AND THEIR PARENTS

The amount of assistance is as follows:

Total Income Amount of Assistance

- Upto Rs 1200 p.m. Full cost of aid
- Rs 1201- 2500 50 % of the cost of aid

For availing this benefit, the individual need to be certified by competent authority regarding his/her disability and prescription of the aid/appliance. Most rehabilitation centres operate this scheme to supply aids and appliances, cost of which is reimbursed by the Central Government.

368. Are there any other benefits offered by the Govt. available to its employees because of having a child with mental retardation ?

Broadly four types of benefits are available to Govt. employees for education, training and rehabilitation of the child with mental retardation. These benefits include :

- reimbursement of medical expenses,
- family pension,
- reimbursement of tuition fees,
- priority of transfer to places where rehabilitation services are available.

369. Can the expenses incurred on the medical treatment of persons with mental retardation be reimbursed ?

Central and State Government employees are required to seek treatment from designated medical authority.

Where the Central/State Govt dispensaries/hospital are not available expenses incurred are reimbursed by the State/Central Govt. as per the prescribed rules.

Employees working in public sector undertaking also have the benefit of medical treatment from the designated medical authority. Those employees working in industrial establishments covered under ESI scheme also have the benefit of seeking treatment in ESI hospitals/dispensaries. Reimbursement occurs only if the treatment is not available at the ESI hospital or dispensary.

369. Can a Government employee having a child with mental retardation be given a posting or be transferred at a place of his/her choice ?

The Department of Personnel and Training in its office memo No. AB-14017/41/90-Estt(RR) dated 15 February, 1991 has directed the Ministries/Departments to take sympathetic view on the merits of each case and accommodate request for posting to the extent possible. The Government employee, if parent of a child with mental retardation, can be given posting of his or her choice to places where facilities for education and training for the child with mental retardation are available.

370. Can pension benefits of a parent be passed on to his/her mentally retarded child after the parent's death?

The family pension is payable to the family of an employee on his death in service/after retirement on monthly pension. Family here means the deceased persons spouse, son(s) and unmarried daughter(s) below the age of 25 years. The family pension is payable to the surviving spouse till

his or her death or remarriage whichever ever is earlier and thereafter to eligible children one by one in order of their birth irrespective of their sex.

If the family of the deceased has a son suffering from a disability like mental retardation, pension will continue for life or till they start earning their livelihood. In case, of daughter having such disability pension will continue till she gets married in addition to the above two.

371. Is there any scheme of the Central Govt. to reimburse the school fees of mentally retarded children ?

Reimbursement of school fee is available to all Central Government employees having a child with mental retardation without any pay limit.

A maximum of Rs 50 per month is reimbursed if the institution in which the child is studying has been recognized/approved/ aided by the Central Government/ State Government/Union Territory, Administration, but the fees charged are not approved. If however, the fees charged are approved by the Central Government/State Government/ Union Territory Administration then the fees payable and the actually paid will be reimbursed.

372. Do the State Government also provide concessions/ scholarships to a school going mentally retarded individual ?

Some of the State Governments have the scheme of providing scholarship to school going children with disability including children with mental retardation. The Govt. of Andhra Pradesh gives a scholarship of Rs.100/- per month to the institution/ special school where the child with

mental retardation is studying provided the income of the parent is less than Rs.1200/- per month. Maximum amount available is Rs.1000/- per given year. Information on similar benefits extended by other State Govts. may be had by contacting the Dept. of Social Welfare of the respective State Govts.

For availing the scholarship scheme, the special school must be recognised by the State Government. A parent cannot avail double benefit of scholarship from the State Government and reimbursement of school fee as a Central Government employee.

373. Do the State Governments in the country have a common scheme/ policy of benefits for families having individuals with mental retardation ?

Each State Government has its own programs and activities for the welfare and rehabilitation of people with disabilities and their families.

The benefits and concessions vary from state to state depending upon the priority given by the state Govt. to particular program or activity. For further details contact the Dept. of Social Welfare of respective State Govt. looking after the welfare of handicapped persons.

374. Are there any concessions available for air-travel ?

Indian Airlines Corporation offers 50 % concessional fare to blind persons on single journey or a single fare for round trip journeys on all domestic flights (Circular No CIM/17). However, escorts have to pay the full fare. No concessions in air fares are given to individuals with mental retardation.

NOTES

SELECTED READING LIST

The following books are suggested for parents to refer to, if possible, for further reading. Parents, however can always expand their reading list as per their own choice, resources, contacts knowledge and availability.

GENERAL INFORMATION

1. R. Smith (1983). **Children with mental retardation: A parent's guide.** Exceptional Parent Library, 1170 Commonwealth Avenue, Boston, USA. \$14.95.
2. J. Schleichkorn (1993). **Coping with cerebral palsy: Answers to questions parents often ask.** PRO-ED, 8700 Shoal Creek Blvd, Austin, Texas (USA) 78757 \$24.00
3. H. Reisner (1987). **Children with epilepsy: A parent's guide.** Exceptional Parent Library, 1170 Commonwealth Avenue, Boston, USA. \$14.95.
4. M. Aarons & T. Gittins (1992). **The handbook of autism: A guide for parents and professionals.** Routledge, 11 New Fetter Lane, London, EC 4P EE. 14.95 British pounds.
5. K. Stray Gundersen (1988). **Babies with Down Syndrome: A new parent's guide.** Woodbine House, 5615 Fishers Lane, Rockville, MD 20852 (USA). \$19.95.

IMPACT ON FAMILY

1. K. Moses (1983). **Impact of initial diagnosis: Mobilizing family resources.** Resource Networks Inc., 1618 Orrington Ave. #210 Evanston IL (USA) 60201. \$5.
2. K. Moses (1983). **Impact of childhood disability: The parents struggle.** Resource Networks Inc. 1618 Orrington Ave. # 210 Evanston IL (USA) 60201. \$5.
3. R. Taylor (1992). **All by Self: A father's story about a differently abled child.** LIGHT ON Books and Video tapes, P.O. Box 8005, Suite 358, Boulder CO (USA) 80306. \$10.
4. D. J. Meyer & P. F. Vadasy (1985). **Living with a brother or sister with Special Needs: A book for siblings.** University of Washington Press, P.O. Box 50096, Seattle, WA 98145-5096. \$12.95
5. E. Thompson (1986). **Bringing up a mentally handicapped child :It's not all tears!** Thorson Publishing House, Dennington Estate Wellingborough Northants (U.K) N82RQ. 5.99 British pounds

EARLY INTERVENTION

1. T.B. Brazelton (1983). **Infants and mothers-Differences in development**. Delacorte Press, 1 Dag Hammarskjold Plaza, 45 east 47 street, New York, NY (USA) 10017. \$14.95
2. F. Caplan (Ed). (1978). **The first twelve months of life**. Bantam Books. 666 5th Avenue, New York, NY (USA) 10103. \$5.99.
3. M. Klein (1990). **Parent articles for early intervention**. Therapy Skill Builders, 3830 E. Bellevue/P.O.Box 42050. Tucson, AZ (USA) 85733. \$39.
4. D. Mitchell (1982). **Your child is different: A handbook for parents of young children with special needs**. Unwin Publications 40, Museum Street, London, WC1A1LU (U.K.). 2.50 British pounds.
5. M. Hanson & S. Harris (1986). **Teaching the young child with motor delays: A guide for parents and professionals**. PRO-ED, 8700 Shoal Creek Blvd, Austin, Texas (USA) 78757. \$27.00.

BEHAVIOUR

1. R. Peshawaria (1991). **Managing behaviour problems in Children: A guide for parents**. Vikas Publishing House, New Delhi. Rs 50.
2. S.S. Kaushik (1988). **Parents as teachers**: Northern Book Centre, 4221/1 Ansari Road, New Delhi 110002. Rs 145.
3. Martin Herbert (1989). **Behavioural Treatment of Problem Children: A Practical Manual**. Gausse & Stratton Inc, 111 5th Ave, New York 10003. \$16.50.
4. J.Presland (1988). **Overcoming Difficult Behaviours: A guide and Sourcebook for helping people with severe mental handicap**. BIMH Publications Sales, Foley industrial park, Stourport Road, Kidderminster, Worcs DY 11 7QG. 19.95 British pounds
5. J. Douglas (1989). **Behaviour Problems In Young Children**. Routledge, 11 New Fetter Lane, London, EC 4P EE. 9.99 British pounds.

ACADEMICS

1. D. Jeffree & M. Skeffington (1985). **Let me read**. Human Horizon Series, 43, Grand Russell St, WC1B 3 PA. 3.50 British pounds.
2. H.D. Bud Fredricks et al. (1985). **The teaching research curriculum for severely and moderately handicapped**. Charles Thomas Publication, 2600 South First Street, Springfield, I.L (USA) 62794-9265. \$19.75.
3. M. Bender, P.J. Valletutti, M.Bender (1985). **Teaching the moderately and severely handicapped Vol I, II, III**. PRO-ED, 8700 Shoal Creek Blvd. Austin, Texas (USA) 78757. \$54.00

COMMUNICATION

- 1 R. Seinkiewicz- Mercer & S. Kaplan (1989). **I raise my eyes to say yes.** Houghton Mifflin, 2 Park Street, Boston MA (USA) 02108. \$17.95
- 2 M. Schrader (Ed) (1987). **Parent articles-Enhance parent involvement in language learning for early intervention.** Therapy Skill Builders, 3830 E. Bellevue/ P.O.Box 42050. Tucson, AZ (USA) 85733. \$39.
- 3 D. Jeffree & R. McConkey (1978). **Let me speak.** Souvenir Press, 43 Great Russel Street, London, WC1B 3 PA. 6.95 British pounds.
- 4 A. Manolson (1992). **It takes two to talk : A parent's guide to helping children communicate.** Haven Center, Ontario. \$25.00.
- 5 S. Schwartz & J. Miller (1988). **The language of toys: Teaching communication skills to special needs children. A guide for parents and teachers.** Woodbine House, 5615 Fishers Lane, Rockville, MD 20852 (USA). \$12.95

ACTIVITIES OF DAILY LIVING

- 1 C. McClannahan (1987). **Feeding and caring for infants and children with special needs.** Book Order Dept, American Occupational Therapy Association, 1383 Piccard Drive, P.O. Box 50096, Rockville, MD (USA)20849. \$5.20.
- 2 **Problems with eating. Interventions for children and adults with developmental disabilities (1987). (10 papers related to eating behaviour.)** Order No. 1520, Book Order Dept, American Occupational Therapy Association, 1383 Piccard Drive, P.O. Box 50096, Rockville, MD (USA)20849. \$ 10.00
- 3 J. Carr (1985). **Helping your retarded child: A step by step guide to every day problem.** Penguin Books, Hammondsworth, Middlesex, England. 2.50 British pounds.
- 4 S. Stumpf (1988). **Pathways to success: Training for independent living.** AAMR Publications, 5101 Kalorama Road, N.W., Washington D.C. 200009-2683. (Price available on request.)
- 5 D. Werner (1987). **Disabled Village Children.** Hesperian Foundation, Palo Alto, CA (USA). (Price available on request.)

LEISURE

- 1 D. Jeffree & S. Chaseline (1986). **Let's join in.** Souvenir Press, 43 Great Russel Street, London, WC1B 3 PA. 6.95 British pounds.
- 2 R. Lear (1990). **More play helps : Play ideas for children with special needs.** Butterworth & Heinemann, Linacres House, Jordan Hill, Oxford OX28DP. 13.50 British pounds

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3. P.Weelman (1977). **Helping the mentally retarded acquire play skills.** Charles Thomas Publication, 2600 South First Street, Springfield, I.L (USA)62794-9265. (Price available on request)
 4. A.Fine & N.Fine (1988). **Therapeutic recreation for exceptional children.** Charles Thomas Publication, 2600 South First Street, Springfield, I.L (USA)62794-9265. \$49.25
 5. R.McConkey & F.Galagher (1978). **Let's play.** University of Ulster, St. Michael House (U.K). (Price available on request)

HOSTEL

1. G. O'Conner (1976). **Home is a good place.** AAMR Publication, 5101 Kalorama Road, N.W., Washington D.C. 20009-2683. (Price available on request)

COMMUNITY CARE

1. A.Naik (1984). **Public awareness and attitudes towards problems of mentally handicapped.** AWMH, Turner Morrison Bldg, Bank Street, Bombay 400023. (Price available on request)
2. P. Abbot & R. Sapsford (1988). **Community care for mentally handicapped children.** Open University Press, 12 Cotteridge Close, Stony Stratford, Milton Keynes MK11 1BY, England. 4.50 British pounds.
3. L. Gething, R. Leonard & K. O'Loughlin (1986). **Person to person : Community awareness of disability.** William & Wilkin Inc, ADIS PTY Ltd, 404 Sydney Road, Balgowlah, NSW2093, Australia. \$16.95.
4. C. Brown (1990). **My Left Foot.** Mandarin Publishers (available at most bookstores). \$6.95.
5. L.D. Park (1987). **How to be a friend to the handicapped.** Life Services for the Handicapped, Inc, 352 Park Avenue South, New York, NY10010. (Price available on request)

FINANCIAL PLANNING

1. D. Talc (1992). **Financial planning for the mentally handicapped - a guide for parents and counsellors.** TISS publication, Deonar, Bombay. Rs 25.
2. H.R. Turnbull, A.Turnbull, G.J. Bronicki, J.A. Summers & Rodder-Gordon, C.(1992). **Disability and the family - A guide to decisions for adulthood (3rd ed.).** Paul H.Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. \$29.00.
3. D.P. Holdern (1985). **Financial planning for the handicapped.** Charles Thomas Publication, 2600 South First Street, Springfield, I.L (USA)62794-9265. \$32.50.

SOCIAL SECURITY/GUARDIANSHIP

1. **After I am gone what will happen to my handicapped child.** - Gerald Sanctuary (1984). Souvenir Press, 43 Great Russel St. London WC 1 B 3 P A. 5.95 British pounds.

SEXUALITY

1. E. Dubey, G. Kothavala & M.Pillai. **Sexuality and the Mentally Handicapped: A manual for parents and teachers.** AWMH, Turner Morrison Bldg, Bank Street, Bombay 400023. (Price available on request)
2. R.K. Manat (1982). **Sexuality and the Mentally Retarded.** College Hill Press, San Diego, CA92120. \$19.95
3. D. Griffiths, V. Quinsey & D. Hingsburger (1989). **Changing Inappropriate Sexual Behaviour.** Paul Brookes Publishing, P.Box No 10624, Baltimore Md (USA). \$30.00
4. M. Craft & A. Craft (1982). **Sex and Mental Handicap: A Guide For Parents.** Routledge & Kegan Paul Ltd, 9 Park Street, Boston MA 02108. (Price available on request)
5. Green, A.M.(1986). **Sexuality In W.I. Fraser, R.C. M. Gillivray, A.M. Green (Eds) Caring for People with Mental Handicaps.** Butterworth & Heinemann, Linacres House, Jordan Hill, Oxford OX28DP 19.95 British pounds.

BENEFITS & CONCESSIONS

1. R. Peshawaria (1991). **Government of India benefits and concessions for the mentally handicapped individuals.** NIMH, Manovikas Nagar, Secunderabad 500 009. Free.
2. District Rehabilitation Centre (1992). **Programmes and concessions given for the disabled by the state government.** Ministry of Welfare, Shastri Bhavan, New Delhi. (Price available on request)
3. All India Confederation of the Blind (1990). **Programmes and concessions for the disabled.** NIVH Publications, Rajpur Road, DehraDun. (Price available on request)

PARENT INVOLVEMENT

1. C.R.Callahan (1990). **Since Owen: A parent to parent guide for the care of disabled child.** John Hopkins Press, 701 W 40 the Street, Baltimore, MD (USA)21211. \$16.95.
2. Kerth Topping (1986). **Parents as educators.** Brookline Books, P.O. Box 1046, Cambridge, M.A. (USA) 02238. \$12.95

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3. T. Shea & M. Bauer (1985). **Parents and teachers of exceptional children: A handbook for involvement**. Allyn & Bacon Inc, 7 Wells Avenue, Newton, MA (USA) 02159. \$37.00
 4. G. Patterson (1978). **Living with children**. Research Press, P.O. Box 3177, Champaign IL (USA) 61826. 5.95 British pounds.

LEGAL

1. **The Indian Lunacy Act, 1912**. Available on request from NIMH, Secunderabad.
2. J.N. Pandey (1986). **Constitutional Law of India**. Central Law Agency, 11 University Road, Allahabad-2. Rs. 55.
3. B. Islam (1988). **Report on the committee on the legislation for the handicapped**. Ministry of Welfare, Shastri Bhavan, New Delhi. (Available on request).

EMPLOYMENT

1. A. Chattopadhyay (1986). **All India Directory of educational and vocational training institutes for the handicapped**. Patriot Publishing House, Link road, Bhahadur Sha Zafar Marg, New Delhi-2. Rs 55.
2. E. Helander et al. (1988). **Training in the community for people with disabilities**. WHO, 1211 Geneva 27, Switzerland. (Price available on request).
3. M.S. Moon & A. Beale (1984). **Vocational training and employment: Guidelines for parents**. Exceptional parent, 14, 35-38. Exceptional Parent Press, 1170 Common Wealth Ave, Boston, MA (USA). \$19.95.
4. C. Scott (1982). **Work experience for mentally handicapped adults**. Mencap National Center, 123 Golden Lane, London. 1.50 British pounds.
5. M. Harper & W. Momm (1992). **Self employment for disabled people: Experiences from Africa and Asia**. ILO, CH-1211, Geneva, Switzerland. (Price available on request).

NIMH PUBLICATIONS

HANDLING
CHARGES
IN RUPEES**GENERAL INFORMATION**

- | | |
|--|-------|
| 1. MENTAL RETARDATION A MANUAL FOR VILLAGE REHABILITATION WORKERS. | 10.00 |
| 2. MENTAL RETARDATION : A MANUAL FOR MULTI REHABILITATION WORKERS. | 10.00 |
| 3. MENTAL RETARDATION : A MANUAL FOR GUIDANCE COUNSELLORS. | 10.00 |
| 4. MENTAL RETARDATION : A MANUAL FOR PSYCHOLOGISTS. | 10.00 |
| 5. ANNUAL SEMINAR ON MENTAL RETARDATION 1989. | 10.00 |
| 6. DIRECTORY OF PROFESSIONALS IN MENTAL HANDICAP IN INDIA. | 20.00 |

EARLY INTERVENTION

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| 7. HANDBOOK FOR THE TRAINERS OF MENTAL RETARDATION : PRE-PRIMARY LEVEL. | 30.00 |
| 8. PLAY ACTIVITIES FOR YOUNG CHILDREN WITH SPECIAL NEEDS. (English, Hindi) | 10.0 |

SCHOOL

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| 9. DIRECTORY OF INSTITUTIONS FOR THE MENTALLY HANDICAPPED PERSONS IN INDIA. | 25.00 |
| 10. SUPPLEMENT OF THE DIRECTORY OF INSTITUTIONS FOR THE MENTALLY HANDICAPPED PERSONS IN INDIA, 1989. | 10.00 |
| 11. SUPPLEMENT TO THE DIRECTORY OF INSTITUTIONS FOR THE MENTALLY HANDICAPPED PERSONS IN INDIA, 1992. | 10.00 |
| 12. ORGANISATION OF SPECIAL SCHOOL FOR MENTALLY RETARDED PERSONS. | 8.00 |
| 13. ORGANISATION OF SPECIAL CLASS IN REGULAR SCHOOL. | 8.00 |

BEHAVIOUR

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| 14. BEHAVIOURAL APPROACH IN TEACHING MENTALLY RETARDED CHILDREN : A MANUAL FOR TEACHERS. (English, Hindi) | 10.00 |
| 15. BEHAVIOURAL ASSESSMENT SCALES FOR INDIAN CHILDREN WITH MENTAL RETARDATION (BASIC-MR) WITH RECORD BOOKLET. (English, Hindi) | 10.00 |

COMMUNICATION

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| 16. MANUAL ON DEVELOPING COMMUNICATION SKILLS IN MENTALLY RETARDED PERSONS. (English, Hindi) | 10.00 |
|--|-------|

ACTIVITIES OF DAILY LIVING

- | | |
|---|-------|
| 17. TOWARDS INDEPENDENCE SERIES : ENHANCING GROSS MOTOR SKILLS. | 10.00 |
| 18. TOWARDS INDEPENDENCE SERIES : FINE MOTOR SKILLS. | 10.00 |
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24.	TOWARDS INDEPENDENCE SERIES : TRAIN YOUR CHILD GROOMING SKILLS.	10.00
25.	TOWARDS INDEPENDENCE SERIES : TEACHING BASIC SOCIAL SKILLS.	10.00
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27.	SKILL TRAINING IN MENTALLY RETARDED PERSONS : BATHING.	10.00
28.	SKILL TRAINING IN MENTALLY RETARDED PERSONS : GROSS MOTOR SKILLS.	10.00
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33.	SKILL TRAINING IN MENTALLY RETARDED PERSONS : DRESSING.	10.00
34.	SKILL TRAINING IN MENTALLY RETARDED PERSONS : GROOMING.	10.00
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WORK

36.	VOCATIONAL TRAINING & EMPLOYMENT OF PERSONS WITH MENTAL RETARDATION.	10.00
37.	OPEN EMPLOYMENT OPPORTUNITIES IN RAILWAYS FOR MENTALLY RETARDED PERSONS.	10.00
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40.	PREPARATION OF POLYBAG NURSERY, VEGETABLE GARDEN AND SEED PACKETS.	10.00

SERIAL PUBLICATIONS

1. MENTARD - An awareness bulletin (BI-MONTHLY).
2. KARAVALAMBAN NEWSLETTER (QUARTERLY).

EDUCATIONAL FOLDERS & POSTERS

1. MY TOOL BOX.
2. TEACHING TIME
3. SAYING SIMPLE WORDS.
4. TELL THE DATE, DAY AND MONTH
5. GREETING SKILLS.
6. TEN DIFFERENT POSTERS (in English, Hindi & Telugu languages) ON PREVENTION AND MANAGEMENT OF MENTALLY RETARDED CHILDREN.

VIDEO FILMS

- | | | |
|----|--|--------|
| 1. | STEP BY STEP WE LEARN (English, Hindi) | 150.00 |
| 2. | GIVE THEM A CHANCE (English, Hindi) | 150.00 |
| 3. | SAHANUBHUTI NAHI SAHAYOG (Hindi) | 150.00 |

Note : The payment for the above books or films should be made in the form of Demand Draft drawn in favour of Director, NIMH and the same along with the requisition may be sent to the Information & Documentation Officer, NIMH, Secunderabad 500 009.

REGISTERED PARENT ASSOCIATIONS

ANDHRA PRADESH

1. PAWMENCAP (MANOKRISHI)
Special Education Centre for
Mentally Handicapped
H.No. 10-2-289/83
(Ground Floor), Meher Mansion
Meherbaba Marg, Shantinagar
Hyderabad - 500 004.
2. D.A.E. PARENTS ASSOCIATION
FOR THE MENTALLY
HANDICAPPED
NFC, Hyderabad - 500 762.
3. PARENTS ASSOCIATION FOR THE
WELFARE OF THE MENTALLY
RETARDED CHILDREN
199-201 B, B.N.R. Nagar
Vanasthalipuram
Hyderabad - 500 661.
4. PARENTS ASSOCIATION OF A.G.'S
OFFICE EMPLOYEES FOR
THE WELFARE OF MENTALLY
HANDICAPPED
LEKHADEEP Voc. Rehab. Centre
No. C-49, A.G.'s Staff Quarters
Yousufguda, Hyderabad - 500 045.
5. PARENTS ASSOCIATION OF
PUBLIC SECTOR EMPLOYEES
BALANAGAR FOR THE WELFARE
OF THE MENTALLY RETARDED
CHILDREN
HMT Colony, Near HMT Post Office
Balangar Hyderabad - 500 037.
6. PARENTS ASSOCIATION FOR THE
WELFARE OF ADULTS WITH
MENTAL RETARDATION
VRC, ATI Campus
Vidyanagar
Hyderabad - 500 007.
7. PAMENCAP (PARENTS ASSN. FOR
THE MENTALLY HANDICAPPED
PERSONS)
Manochaitanya, Plot No. 5
Wellington Road, Picket
Secunderabad - 500 003.
8. AAKANKSHA
Parents Association of South Central
Railway Employees for the
Welfare of the Mentally
Retarded Children
Adjacent to S&T Workshop
Mettuguda
Secunderabad - 17.
9. PARENTS ASSOCIATION FOR
HUMAN SERVICES (PAHS)
201 Crown Apartments
12-8-431 &
438 Mettuguda, Secunderabad.
10. PAMENCAP
Parents Association for Mentally
Handicapped Persons
H.No. 2-8-113
Mukarampura
Karimnagar - 505 030.

-
11. PARENTS ASSOCIATION FOR
THE MENTALLY HANDICAPPED
PERSONS
(PAMENCAP)
T2 - 48 Power House Colony
P.O. Godavarikhani,
Dt. Karimnagar - 505209.

12. PARENTS ASSOCIATION FOR THE
MENTALLY HANDICAPPED
Fertilizer Corporation of India Ltd.,
Fertilizer City
Ramagundam-505 210.

13. SURYAKIRAN (PAMENCAP)
11-3-16, Opp. Thurpu Bhavi
Macherla, Guntur - 522 426. A.P.

DELHI

14. PARENTS ASSN. FOR THE
WELFARE OF CHILDREN WITH
MENTAL HANDICAP
GENETICS UNIT
Room No. 113, Dept. of Pediatrics
Old Operation Theatre Bldg.
AIIMS, New Delhi - 110 029.

15. ASSOCIATION FOR
ADVANCEMENT AND
REHABILITATION OF
HANDICAPPED
224, Vasant Enclave
New Delhi - 110 057.

GUJRAT

16. SOCIETY FOR THE WELFARE OF
THE MENTALLY RETARDED
51 Krishna Society, Nr. Law College,
Ellisbridge, Ahmedabad - 380 006.

17. PARENTS & GUARDIANS
ASSOCIATION FOR
MENTALLY HANDICAPPED
CHILDREN & ADOLESCENTS
15, Kamalnayan Society, Post
Navjivan, Ahmedabad - 380 014.

HARYANA

18. RED CROSS PARENTS
ASSOCIATION FOR
WELFARE OF MENTALLY
HANDICAPPED CHILDREN
Gandhinagar, Rohtak (Haryana)

KARNATAKA

19. KARNATAKA PARENTS
ASSOCIATION FOR MENTALLY
RETARDED CITIZENS
New No. 60 (Old No. 16)
Grant Road, Bangalore - 560 001.
20. SWA SAHAYA SAMUCHCHAYA
B-4, B.E.M.L. Flats
Jayalakshmiapuram
Mysore-570 012.

KERALA

21. CANNANORE PARENTS
ASSOCIATION FOR
THE MENTALLY RETARDED
Sree Ragam
(P.O.) West Ponniam - 670 641.

22. ALL KERALA ASSOCIATION OF THE
MENTALLY RETARDED
Nalancheru
Trivendrum.

23. STATE COUNCIL FOR
EXCEPTIONAL CHILDREN - A
FEDERATION OF PARENTS
ASSOCIATION
FOR THE MENTALLY
HANDICAPPED - KERALA
XLI/2303, Paramara Building
Kochi - 682 018.

MADHYA PRADESH

24. PARENTS ASSOCIATION FOR THE
WELFARE OF MENTALLY
HANDICAPPED CHILDREN
A-28, Padmanabha Nagar
Near Rly Crossing Govindpura
Bhopal - 23.

25. PARENTS ASSOCIATION FOR
MENTALLY RETARDED
CHILDREN
Sneha Sampada Vidyala School &
Trg. Centre for Mentally
Handicapped Children
32, Bunglow Chowk
Old Guest House , Bhilainagar
Sector - 8, Durg - 490 006.

MAHARASHTRA

26. AWMH - PODS
(ASSN. FOR THE WELFARE OF
PERSONS WITH
MENTAL HANDICAP PARENTS OF
DOWN SYNDROME)
Hill Road Clinic, 102-B
Rizvi Palace
Hill Road, Bandra
Bombay - 400 050.

27. ASSOCIATION OF PARENTS OF
MENTALLY RETARDED
CHILDREN
5A/14, Pareira Nagar
Behind S.T. Workshop, Agra Road
Thane (W) 400 601.

28. AMEYA PALAK SANGHTANA
3 Jai Anant Cooperative Hsg. Society
Near Suyog Mangal Karyalaya
Dombivili (East) 421 201.

29. THE JAI VAKEEL PARENTS
WELFARE ASSOCIATION
C/o. Indotex Export House Pvt. Ltd.
"Jasville", Opp. Liberty Cinema
9 Sir Vithaldas Thackersey Road
Bombay - 400 020.

30. SWEELAR
Association of Parents of Mentally
Retarded Children
85, RMS Colony
Nagpur - 440 013.

31. UMED PARIWAR
A/7, Advaitanand Society
1221, Sadashiv Peth
Pune - 030.

MANIPUR

32. ALL MANIPUR MENTALLY
HANDICAPPED
PERSONS ORGANISATION
Keisamthong, Top Leirak
Imphal - 795 001.

-
33. PARENTS ASSOCIATION FOR
THE MENTALLY HANDICAPPED
Manipur, Keisamthong
Top Leirak
Imphal - 795 001.

ORISSA

34. ORISSA-ASSOCIATION OF
PARENTS WITH SPECIAL
CHILDREN
Dutta Tota
Puri - 752 002.

RAJASTHAN

35. VIVEK, SOCIETY FOR THE
WELFARE OF THE
MENTALLY HANDICAPPED
5 CHA - 9, Jawahar Nagar
Jaipur - 302 004.

TAMIL NADU

36. SOCIETY FOR SOCIAL SECURITY
OF RETARDED PERSONS
8, D' Sylva Road
Madras - 600 004.
37. ARUNOTHAYAM
Society for the Welfare
of the Mentally Handicapped
Pathipanoor - 623 608
Ramand Dt.

TRIPURA

38. "SWABALAMBAN", ORGANISED BY
ALL TRIPURA SCHEDULED
CASTES, TRIBES, MINORITY
UPLIFTMENT COUNCIL
Ramnagar Road, No. 1, Agartala
P.O. Ramnagar, Tripura (W)-002.

UTTAR PRADESH

39. UTTAR PRADESH PARENTS
ASSOCIATION FOR THE
WELFARE OF THE MENTALLY
HANDICAPPED CITIZENS
B1/42, Aliganj
Sector - K, Lucknow

WEST BENGAL

40. ASSOCIATION FOR THE
INTELLECTUALLY DISABLED
98 N. Block E, New Alipore
Calcutta - 700 053.
41. BODHAYAN, AN ASSOCIATION OF
PARENTS HAVING PERSONS
WITH MENTAL RETARDATION
109 B, Block F
New Alipore - 700 053.
42. BEHALA BIKASAN
51/1, Jagat Roy Chowdhury Road
Calcutta - 700 008.

VOCATIONAL REHABILITATION CENTRES

MINISTRY OF LABOUR, GOVERNMENT OF INDIA.

ANDHRA PRADESH

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
ATI Campus, Vidya Nagar
HYDERABAD - 500 007.

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
C/o. Sub Regional Employment
Exchange
Kothi Building 1ST Floor
VADODARA - 390 001.

ASSAM

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
Rehabari
GUWAHATI - 781 008.

KARNATAKA

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
22, Hosur Road, BANGLORE -29.

BIHAR

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
GOVT. OF INDIA, MIN. OF LABOUR
A/84, Gandhi Vihar
Anisabad, PATNA - 2.

KERALA

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
Nalanchira, Thiruvananthapuram-15.

DELHI

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
ITI Hostel Building
ITI Campus, Pusa
NEW DELHI - 12.

MADHYA PRADESH

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
Napier Town, Near Bus Stand
JABALPUR - 482 001.

GUJRAT

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
ATI Campus, Kubernagar
AHMEDABAD - 382 340.

MAHARASHTRA

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
CTI Campus, Sion
BOMBAY-400 033.

ORISSA

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
SIRC Campus, Unit Eight
BHUBANESHWAR - 751 012.

UTTAR PRADESH

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
CTI Campus, Udyog Nagar
KANPUR - 308 022.

PUNJAB

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
ATI Campus, Gill Road
LUDHIANA - 141 003.

WEST BENGAL

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
38, B.R. Lane, Beliaghata
CALCUTTA - 799 005.

RAJASTHAN

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
4-SA, Jawahar Nagar
JAIPUR - 302 004.

TAMIL NADU

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
CTI Campus, Guindy
MADRAS - 600 032.

TRIPURA

VOCATIONAL REHABILITATION
CENTRE FOR HANDICAPPED
Ministry of Labour
Abhoy Nagar
AGARTHALA - 799 005.

ABOUT THE AUTHORS

REETA PESHAWARIA is presently working as a Lecturer in Clinical psychology at the National Institute for the Mentally Handicapped, Secunderabad. She is also the Director (honorary) for the mental disability wing of India Vision Foundation, New Delhi. After obtaining her post graduate degree in Psychology in the year 1972 from Punjab, she underwent intensive two years training in Clinical Psychology at the Central institute of Psychiatry, Ranchi where she passed her D.M & S.P with distinction in the year 1975. She got her further training in the application of behavioural technology with the mentally handicapped children from Maudsley Hospital, London, U.K in the year 1986-1987. She completed her Ph.D. from Utkal University in 1993. Before joining the National Institute for the Mentally Handicapped in 1985, she was incharge of the Child Guidance Clinic at the Hospital for Mental Diseases, Shahdra, Delhi.

For the last 20 years she has been actively involved in the treatment of emotional and behaviour problems in children and working with the families. So far she has conducted nearly 70 training workshops across the country for parents and professionals working in the field of mental handicap in the application of behaviourally based methods for teaching and training of children with severe learning difficulties, psychological and behavioural assessment, working with families and counseling skills.

She has contributed nearly 20 research papers in reputed national and international journals. She has written chapters for books, and also published books as first author which includes "Managing Behaviour Problems in Children: A Guide for Parents" (1990) : "Play

Activities for Young children with Special Needs" (1991); Behavioural Approach in Teaching Mentally Retarded Children: A manual for teachers (1992); Behavioural Assessment Scales for Indian Children with Mental Retardation (1992); Needs of Indian families having children with mental retardation (in press). She has also co-authored training manuals "Mental Handicap: A manual for Psychologists" (1988) and "Mental Handicap: A manual for Guidance and Counselors" (1989).

DESH KEERTI MENON is the Director of the National Institute for the Mentally Handicapped, Secunderabad since its inception in the year 1984. After his post graduate degree in Psychology from Punjab University in the year 1968, he underwent two years of training in Clinical Psychology at the Central Institute of Psychiatry, Ranchi where he passed his DM&SP with distinction in the year 1971. He obtained his Ph.D. in Clinical Psychology from Post Graduate Institute of Education and Research in the year 1980. He has worked in various capacities as a District Guidance Counselor in Chandigarh; Clinical Psychologist at Punjab Mental Hospital, Amritsar; Senior Social Scientist with World Health Organization Collaborating Center at Post Graduate Institute, Chandigarh; Senior Research Officer with Indian Council of Medical Research, New Delhi before taking up the Director's position at NIMH.

Over the last 25 years, he has contributed significantly in the field of mental retardation and mental health. He is on various national level policy planning committees which includes Advisory Committee on Mental Health, Indian Council Of Medical Research; Working Group on Handicapped, Planning Commission; National Council on Welfare of the Handicapped, Ministry of Welfare, Govt. of India; Rehabilitation Council's Committee on mental retardation; and

Coordination Committee for the education and welfare of the handicapped, Ministry of Human Resources Development.

He has nearly 60 publications to his credit which have been published in reputed national and international journals. Which includes books, chapters in books and research papers. His publications have been mainly in the areas of early intervention, families, vocational rehabilitation, community awareness and materials for rural health workers.

RAHUL GANGULY is presently working as the Research Officer in the multi centered "Strengthening Families Project" funded by National Institute for the Mentally Handicapped (NIMH) Secunderabad. He obtained his Bachelor's degree in Mental Retardation from the National Institute for the Mentally Handicapped in 1990. On receiving Graduate Teaching Fellowship award from Specialized Training Centre, University of Oregon (USA), he underwent two years of intensive training program leading to Master of Science (Special Education and Rehabilitation). Following post graduation in 1992, he has worked as a Systems Change Consultant for Washington County Mental Health, Vermont (USA). In addition, he has also worked as Employment Training Specialist with Mckenzie Personnel Systems (Oregon, USA) and has been associated with federally funded-Employment Projects, at University of Oregon for nearly two years.

Over the past 4 years, he has been actively involved in the training and rehabilitation of the individuals with severe disabilities. His work has focused on supporting families achieve desirable lifestyles for their son/daughter with mental retardation and also assisting human service agencies to be more responsive to family

and individuals needs. His areas of interest include working with families of individuals with autism and computer assisted vocational rehabilitation of individuals with mental retardation.

SUMIT ROY is the Executive Director of Digdarshika Institute of Research And Rehabilitation, Bhopal which he established in 1990 along with his wife Smt. Kakoli Roy (also a clinical psychologist). He is the Coordinator of the Diploma course in Mental Retardation at Digdarshika. After obtaining his postgraduate degree in Applied Psychology in the year 1982, he underwent two years training in Clinical Psychology at Central Institute of Psychiatry, Ranchi, where he passed his DM & SP in 1984. He has worked at Christian Missionary Hospital in Bethul district (M.P.) as a clinical psychologist. In addition, he has also worked as Research Officer at the All India Institute of Medical Sciences, New Delhi and at Indian Council of Medical Research project for Bhopal gas tragedy victims.

Over the past 10 years he has been actively involved in the assessment, diagnosis and treatment/training of individuals with psychological problems, disabilities and impairments. In addition, he has conducted workshops for families and the community as part of community mental health programs. He has published research papers in reputed journals and written articles for newspapers in the field of mental health. His areas of interest include working with families of children with mental retardation having psychological problems and awareness building in the community.

RAJAM P.R.S. PILLAY is the Director of Balavikas Training Center, Trivandrum and also the coordinator of Diploma course in mental retardation at the Balavikas Training Centre. After obtaining her

postgraduate degree in History from University of Bombay in the year 1962, she completed her Master degree in Education (Ed.M) from Boston University (USA) in the year 1970. She also completed her Ph.D. in the year 1994 from Kerala University. She has been the executive secretary of Federation for the Welfare of the Mentally Retarded in New Delhi. Presently, she is the member of the High Level Committee constituted by the Kerala Government for drafting curriculum for teaching children with mental retardation. She is also a member of the curriculum committee, NIMH and a member of the Advisory Committee on Mental Retardation, Rehabilitation Council of India.

She is keenly involved in promoting human resource development in the field of rehabilitation in the state of Kerala. For the last four years she has been conducting state level seminar annually in Kerala on mental disability. She has published over 30 articles on various aspects of mental retardation besides giving series of radio talks on mental retardation on All India Radio.

ASHA GUPTA is presently working as Principal / Director Navjoyti Centre for Children with Special Needs. After obtaining her Bachelor's degree in 1964, she underwent one year of training leading to Diploma in Child Education (University of Delhi) in 1970. She also completed a certificate course in Special Education offered by the Federation for the Welfare of the Mentally Retarded in 1982, and completed one year diploma course in Mental Retardation from Regional Training Centre of National institute for the Mentally Handicapped, Delhi in 1987. She has worked as a teacher in Balwant Rai Mehta School for Exceptional Children in New Delhi for nearly two years.

Over the last 14 years she has been involved in the training of individuals with mental retardation. She is a parent of a son with mental retardation. She has established Navjyoti Centre to provide individuals with mental retardation maximum opportunities for participating in occupations of their choice. Presently, her area of interest lies in developing strategies for the economic rehabilitation of the individuals with mental retardation. She is also a member of Samadhan Association (New Delhi) and treasurer of the Marketing Federation For the Handicapped (New Delhi).

R.K. HORA is presently working as Assistant Professor of Pediatrics at the National Institute for the Mentally Handicapped (NIMH) Secunderabad for the last four years. He passed MBBS in 1974 and then underwent one year of training and three years of post graduation (M.D.) in the field of pediatrics from Government Medical College/Rajendra Hospital under Punjabi University, Patiala. Following post graduation he has worked as Registrar in the Department of Pediatrics of Lok Nayak Jai Prakash Narayan hospital/Maulana Azad Medical College in New Delhi for a period of 3 1/2 years. He then joined defence forces and worked for 6 1/2 years in various defence hospitals.

He has conducted a number of training workshops for parents and professionals especially on the medical aspects of mental retardation. He is actively involved in the clinical teaching and research programmes at NIMH. His present interests include early detection of metabolic disorders in children, possible prevention of disability and genetic counseling.

NOTES

NATIONAL INSTITUTE FOR THE MENTALLY HANDICAPPED
Manovikas Nagar, Secunderabad - 500 009

"STRENGTHENING FAMILIES PROJECT"
IDENTIFYING AND MEETING INFORMATION NEEDS
OF PARENTS HAVING CHILDREN WITH MENTAL RETARDATION

FEEDBACK FORM

Date :

"Moving Forward" this book for the parents contains answers to commonly asked questions by parents related to their child with mental retardation and the family. This book is not written to help the parents/ family members train the child with mental retardation. This is an information giving book meant only to raise the information level of the parents which could help them to make better decisions about their child and the family both for the present and the coming future. Reviewing the book from this angle will be highly appreciated.

Dr. Reeta Peshawaria
Principal Investigator

IDENTIFICATION DATA OF THE PARENT

1. Name of Parent :
2. Age :
3. Sex :
4. Education :
5. Occupation Status :
6. Relationship to the child
with mental retardation :
Mother/Father/
Grand Father/Grand Mother
7. Address :

CHILD CHARACTERISTICS

1. Name of the child :
2. Age :
3. Sex :
4. Level of Mental Retardation
(If known) :
5. Presence of (tick applicable) :
 - a. Epilepsy :
 - b. Behaviour Problem
 - c. Hearing Impairment
 - d. Visual Impairment
 - e. Physical Impairment
 - f. Any other (please specify)
6. Education :
7. Occupation :

Kindly answer the following questions:

1. HOW FAR DO YOU THINK THAT THE QUESTIONS ANSWERED IN THE BOOK ARE RELEVANT TO MOST PARENTS IN EACH OF THE FOLLOWING SECTION?

AREAS	Rating		
	Most Relevant	Relevant	Not Relevant
1. General Information			
2. Impact			
3. Early Intervention			
4. Schooling			
5. Behaviour Problems			
6. Communication			
7. Activities of Daily Living			
8. Academics			
9. Leisure			
10. Employment			
11. Sexuality			
12. Marriage			
13. Parent Support			
14. Community Support			
15. Hostel			
16. Financial Planning			
17. Legal			
18. Guardianship			
19. Govt. Benefits and Concessions			

Any Suggestions :

2. DO THE ANSWERS TO THE QUESTIONS GIVE ENOUGH OF INFORMATION TO HELP A PARENT BEGIN TO SEEK FURTHER INFORMATION FROM OTHER SOURCES?

AREAS	Rating		
	Most Relevant	Relevant	Not Relevant
1. General Information			
2. Impact			
3. Early Intervention			
4. Schooling			
5. Behaviour Problems			
6. Communication			
7. Activities of Daily Living			
8. Academics			
9. Leisure			
10. Employment			
11. Sexuality			
12. Marriage			
13. Parent Support			
14. Community Support			
15. Hostel			
16. Financial Planning			
17. Legal			
18. Guardianship			
19. Govt. Benefits and Concessions			

Any Suggestions :

3. HOW DO YOU FIND THE LANGUAGE USED IN THE BOOK?

AREAS	Rating		
	Simple	Difficult	Very Difficult
1. General Information			
2. Impact			
3. Early Intervention			
4. Schooling			
5. Behaviour Problems			
6. Communication			
7. Activities of Daily Living			
8. Academics			
9. Leisure			
10. Employment			
11. Sexuality			
12. Marriage			
13. Parent Support			
14. Community Support			
15. Hostel			
16. Financial Planning			
17. Legal			
18. Guardianship			
19. Govt. Benefits and Concessions			

Any Suggestions :

4. HOW DO YOU FIND THE ILLUSTRATIONS IN THE BOOK?

AREAS	Rating		
	Very Appropriate	Appropriate	Not Appropriate
1. General Information			
2. Impact			
3. Early Intervention			
4. Schooling			
5. Behaviour Problems			
6. Communication			
7. Activities of Daily Living			
8. Academics			
9. Leisure			
10. Employment			
11. Sexuality			
12. Marriage			
13. Parent Support			
14. Community Support			
15. Hostel			
16. Financial Planning			
17. Legal			
18. Guardianship			
19. Govt. Benefits and Concessions			

Any Suggestions :

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5. DO YOU THINK THAT BY READING THIS BOOK YOU HAVE GAINED IN ANY WAY?

VERY MUCH / LITTLE / NO GAIN

6. IF YOU HAVE GAINED IN ANY WAY KINDLY DESCRIBE WHAT ASPECTS OF THE BOOK YOU FOUND USEFUL?

7. DO YOU THINK THAT THIS BOOK WOULD BE FOUND USEFUL BY OTHER PARENTS OF MENTALLY RETARDED CHILDREN? IF YES, IN WHAT WAY DO YOU THINK IT WILL BE HELPFUL?