Mental Retardation
Acknowledgements

Mental Retardation

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CHAPTER 39

HISTORICAL OVERVIEW

INTERNATIONAL SCENE

Attitude towards and treatment of persons with mental retardation can be traced back to ancient civilizations (including Egypt, Sparta, Rome, China and the early Christian world). The earliest recorded mention of mental retardation is thought to be in the "Therapeutic papyrus at Thebes" in 1552 B.C. (Doll, 1962).

People with mental retardation during middle ages were viewed as "innocents of God" and provided with humane care either at home or in monasteries. On the other hand, some cases with mental handicaps were viewed as visitations of the devil and were subjected to exorcism and torture. Beginning in the latter years of the middle ages and continuing through the 18th century, many individuals including individuals with mental retardation were persecuted and executed for practicing witchcraft.

During the 17th and 18th centuries, which encompassed the age of reason and the enlightenment in Europe and the colonial period in America, understanding of brain function and certain types of mental retardation (e.g. cretinism and hydrocephalus) increased. However, the treatment of individuals with mental retardation seemed to reach an all-time low. Individuals with mental retardation were confined to institutions (e.g. foundling homes, hospitals, prisons). The death rate of children placed in these facilities was appallingly high. People with mental retardation were incarcerated with criminals and individuals with mental illness. A few humanitarian individuals did attempt to improve the prevailing conditions. During the same period, in the U.S.A., dismal conditions prevailed for people with mental retardation.

The history of the systematic treatment of individuals with mental retardation began in the 19th Century. Mental retardation became a conspicuous social problem during this period. As industrialization expanded and grew, opportunities for a simple agrarian existence decreased. With technological advances, jobs became more complex. Mass education became more common. Inability of some children to handle school curriculum led to the identification of mild mental retardation.

The disciplines of Medicine and Psychology progressed considerably during this period. Scientific developments began to support a more clearly defined concept of mental retardation. Many of the clinical types of mental retardation were identified, and classification systems were proposed.

Reform movements began to appear in both Europe and U.S. The major aim of these reforms was to urge the states to provide humane treatment in the form of well-designed,
specialised, residential facilities for individuals with mental retardation and mental illness. Many distinct etiological categories were identified and described (e.g. Down Syndrome, cretinism, hydrocephaly, microcephaly) although the causes of many of these conditions were poorly understood (Scheerenberger, 1983).

During the last half of the 19th century, the idea that individuals with mental retardation could benefit from education and training finally came into its own. By the turn of the century, the attitudes of society towards people with mental retardation worsened as the condition was increasingly attributed to hereditary factors. Public opinion began to support the segregation of people with mental retardation.

The first public day-school classes for children with Mental Retardation in the U.S. are generally thought to have started in Providence, Rhode Island in 1894. From 1900 through the 1920s, optimism concerning the prospects of ameliorating mental retardation was replaced by profound pessimism. The first decades of the twentieth century represented the nadir of professional sensitivity towards mentally retarded persons, at least as a class or sub population. Education and training efforts in institutions were largely replaced by custodial care. The belief that mental retardation was caused by environmental factors was replaced by a belief that mental retardation was caused by hereditary factors.

The period between 1930 and 1950 has been described as the “The Great Lull”, during which little progress was made in this field, though residential and community programmes were established that determined the direction of future developments in the field.

During the 1950s, children with moderate mental retardation emerged as a focus of concern, largely through the efforts of increasingly well-organised parent advocacy groups. An important event during this time was the formation in 1950 of the National Association for Retarded Children (NARC), now known as the ARC (Association for Retarded Citizens). In North America, the emergence of civil rights movement assisted the cause of people with mental handicaps.

The 1960’s were dominated by a concern for the rights of minority individuals, including individuals with mental retardation. In US, President Kennedy appointed the President’s Panel on Mental Retardation in 1961. The panel of experts recommended an extensive eight-point programme in 1962 which covered every aspect of mental retardation from preventive to rehabilitative measures.

There is a considerable increase in the literature on the topic of mental retardation throughout the world, and in the recent years the discoveries and methodological innovations have increased. Recent times have witnessed the advent of new directions in educating and training students with mental retardation. There is a trend toward providing community based instruction and programming for these students. Great strides have been made in providing services to infants, toddlers and other young children. Transitional programming is in evidence. New models for making these individuals employable have been introduced. Competitive employment options are replacing the former sheltered employment model.

Self advocacy and consumer awareness, that have empowered people with disabilities globally, have made human services to recognise and restructure their programmes and strategies.
**HISTORICAL OVERVIEW**

Four thousand years ago, when the *Ayurveda* (book of medicine) was conceptualised, mental retardation was not left out. Charaka, the “Father of Indian Medicine”, and Susruta, the “Father of Surgery”, hypothesized that mental retardation or “manasamandyam” was a result of defective genes, poor condition at the time of pregnancy and faulty child rearing practices in much the manner it is understood even today. Charaka’s explanation of the role played by the parental seed or the “Germ Plasm” in subsequent personality development incorporates concepts now recognised as Darwin’s concepts of “gemmule” and Spencer’s “Id”. However, both the *Charaka Samhita* and the *Susruta Samhita* professed reservations about the genetic basis of mental retardation, emphasizing instead the influence of divine forces and “Grahas” (planetary influence). This line of thinking, i.e. in which the present, past and future are attributed to supernatural powers, typifies Indian philosophical thought with its belief in the “Karma” accepted in large part even today (Puri and Sen, 1989).

The ancient Indian literature reveals the existence of the rural “Pathasala” (day school) or the ‘Gurukul’ (residential learning centre) which gave due emphasis to a child-centred approach, by identifying the learning channel and pace of each learner and by individualizing both teaching and learning. The teacher in both types of education designed the curriculum to offer utility and durability to the learning on a long time perspective but dispensed it according to the functional proficiency or deficits in the learner. Thus the system of education could cater to the educational needs of a wide range of learners—the highly gifted to the sub-average. Many students with the special educational needs were effectively integrated in the group of normal students and participated meaningfully in the community in adulthood.

Several invasions, influence of colonisation and the prolonged rule of British Raj, brought about changes in Indian education. British models of education were adopted which emphasised on standard general curricula with specificity in the duration of coverage and content. This led to the alienation of the learner with special needs, when emphasis shifted from the importance of the child and its educational needs during the 24 hours of interaction with different social situations to a highly academically loaded curriculum and rigid evaluation procedures (Hari Prasad, 1999).

A review of the progress made in the area of mental retardation is quite relevant now. The country gained independence in 1947 and since then has been struggling to provide elementary education to the ever increasing school age children. The policymakers in education naturally felt that the problem of educating the retarded can be postponed. Besides, medical care was also not very popular due to underdeveloped state of paediatrics in our country. Added to this is that, people have not demanded facilities for the retardates. The disinterest in the care and education of retardates resulted partly from indifference and partly from attention paid to reconstruction which was more vital after independence than mental retardation.

To add to these, there is variety of language and culture. Neither any assessment test nor baseline information on mental retardation was available which would have paved the way to have early detection of retardation. In spite of this, some good schools for education were established in Bombay and Ahmedabad which reflect probably the unfair
attitude toward mental retardation. With rapid growth of industrialisation and urbanisation, the over anxious professional parents have become aware of the need to train and educate the backward child. Educated mothers also played a key role in this. Thus, urbanisation and its discontent stimulated public support for work in retardation. The Central Government through its various agencies have begun to take an interest in this area.

Growth of schools for the mentally retarded in the sixty years until the advent of independence was extremely slow and sporadic. By 1947, the schools for the mentally retarded were just three but rose to 20 by 1980 and at present there are over 1100 schools in the country. The first school in one of the associated disabilities, i.e. cerebral palsy, was started in 1973; and today there are more than 15 schools of CP, though without any facility for artistics.

A peep into the past would reflect that institutions for training and care of the mentally retarded have grown out of the personal efforts of dedicated individuals or of philanthropic organisations. Now, infrequently, the primary donors for a certain institution have within their family someone mentally defective. This is also true of majority of social workers who have taken interest in the growth of a retardate institution. By 1968, when the first review of the status appeared, there were only 18 institutions for mental retardates, (15 out of which were headed by women) which indicated an interest - “the labour of love”, in the words of Pt. Jawahar Lal Nehru. A majority of the institutions depend primarily on donations from the public but they also receive assistance from state and federal governments through welfare departments.

Welfare, not education was the main concern then. The institutions for the retarded in India have both residential and day schools. Many of these institutions were started as boarding houses for the retardates, but were later expanded to include scholastic and vocational education. All such institutions were established after independence. A few institutions have, included in their objectives, parent counselling for the retarded child. Staff members were essentially psychologists, physicians, teachers. Special education did not have a headway then, and some of these institutions were also attached to most of the mental hospitals in India (Das, 1968).
The development of education for the disabled and particularly for the mentally retardates took a different progressive turn after 1964-66 when the Education Commission, following the Constitutional Directives, suggested with emphasis that education for the handicapped has to be organised not merely on humanitarian grounds but on grounds of utility by making them useful citizens. The Commission emphasized that the education of handicapped children should be an inseparable part of the general education system; and suggested that initially education should be extended to four groups of disabled of which mental retardation was one.

At the time Education Commission made this recommendation, there were 27 schools for the mentally retarded in the whole country. It expressed hopes that at least 5% of the mentally retarded may receive education by 1986. This was impeded by lack of special teachers and financial constraints. And, further, the Commission recommended that both special schools and the integrated school system should take care of the handicapped, including the mentally retarded.

The *National Policy for Children* (1974) came in and the measures were intended to cover all children including those who came from weaker sections of society and those who were handicapped. Integrated Education for the Disabled commenced with central funding in 1974. There came the seminal year of International Year for the Disabled Persons (IYDP) in 1981.

India was one of the signatories to the resolution proclaiming IYDP, 1981 and it endorsed the objectives set forth in the resolutions of the General Assembly. Accordingly, it was visualised to form a National Policy for the Handicapped, provide network of services with focus on rural handicapped, and set up National Institutes and special education cells in the State Councils of Educational Research and Training (SCERTs)/State Institutes of Education (SIEs) etc.

To make the programme planning more realistic, working groups on the education of disabled child were set up in 1981 by the Ministry of Welfare and Ministry of Education and Culture, Government of India. The committee suggested nine categories of handicapped children to be taken care of through pre-school education, and school education using special and integrated schooling approaches. These included day school, special residential school, resource teacher programme, and partial integration. The programme was proposed on a 20 year time span.

The Ministry of Welfare and the Ministry of Education and Culture appointed advisory committee to make salient recommendations for the government to initiate action. These were:
Early detection, prevention, medical and physical rehabilitation
Education and training of handicapped including teacher training
Employment
Role of NGOs and creation of public awareness.

The National Institute for the Mentally Handicapped (NIMH) was established in Secunderabad in 1985.

The National Policy on Education (NPE) was formulated in 1968 and got the seal of approval in May 1986. The Policy emphasized integration of handicapped with the general community as equal partners, to prepare them for normal growth and enable them to face life with courage and confidence. Specific recommendations were made in the policy document (NPE, 1986, 1992) which were in the areas of:

- Integrated Education
- Special Schools
- Vocational Training
- Teacher Training
- Voluntary Organisations.

In the meantime National Council of Educational Research and Training (NCERT), following the guidelines of NPE 1986 and with the assistance of UNICEF, introduced in ten states the Project Integrated Education for the Disabled (PIED) programme for the disabled, but then this did not include mental retardation within its ambit. To make it workable, it also introduced the 9-month orientation course at the headquarters and the multi-category teacher training programme for the handicapped in its regional colleges for development of human resources.

Simultaneously, the Thakur Hari Prasad Institute at Hyderabad made a frantic effort to prepare a draft national policy on mental handicap by organising an All India Seminar to frame a National Policy for the Mentally Handicapped in February, 1987. The National Policy document was presented by Dr. Thakur V. Hari Prasad on 14th January, 1988 to the then Prime Minister, Mr. Rajiv Gandhi. Major outcomes of the event were appointment of Behrul Islam Committee with Dr. Thakur V. Hari Prasad himself as a member; constitution of an Exclusive Working Group on Disability in the National Planning Commission for the first time during the 8th Plan period; statutorisation of RCI Act 1993; and the Persons With Disabilities Act, 1995.

The Programme of Action (1992) which was formulated after much debate of the NPE (1986, 1992) by Ministry of Human Resources Development (MHRD), Government of India took care of all historical antecedents and focused on operational framework for implementing the plan of education of the handicapped.

At the end of 1991-92, the Integrated Education for the Disabled (IED) plan had its headway, and the PIED 1992 included mental retardation within its Plan of Action for education in integrated settings, which had been denied the status so far.

The faculty members of 102 District Institutes of Education and Training (DIETs) in the country have received training given by NCERT in special education Multi-category Teacher Training (MCT) courses (through NCERT, RCEs and with UNICEF collaboration)
and national institutes ensured supply of trained manpower to the special schools. NGOs were activised and grants were provided to activise the programme. In fact, the NGOs out numbered the government organisations in the field of MR and other disabilities as well. This was monitored by the Ministry of Social Justice and Empowerment, Government of India.

The Ministry of Labour manages 17 Vocational Rehabilitation Centres (VRCs) for the disabled for their placement. Some states are still reluctant to have IED and inputs from Community Based Rehabilitation (CBR), District Rehabilitation Centre (DRC), IED and Early Childhood Care and Education (ECCE). However, some of the NGOs were active in rural areas in this regard.

The state governments were assisted in the matter of strengthening State Councils for Educational Research and Training (SCERTs) and DIETs for augmenting the education of the handicapped. At present, all SCERTs in the country have a special education unit and all DIETs have trained special educator, and NGOs have been strengthened to undertake the challenge.

The Ministry of Labour is providing training through Craftsmen Training Scheme (CTS), Apprenticeship Training Scheme (ACT) and VRCs on a continued basis.

All the DIETs have been established during the Eighth Plan. All in-service teachers and heads of institutions and administration are receiving inputs on the education of the disabled. National Institute for the Mentally Handicapped along with its regional centres is continuously training special educators, NGOs and Universities.

The ECCE scheme through ICDS, pre-school programme, and District Primary Education Programme (DPEP) have included disability education including mental retardation since 1999.

The education of disabled and particularly mental retardation has been amply activated by the establishment of the Rehabilitation Council of India (RCI) through an Act of Parliament in September 1992, and effected in June, 1993.

The RCI through linkages with National Council of Teacher Education (NCTE), universities, international agencies has been responsible for standardisation of curriculum, design of 45 new courses, monitoring and evaluation, accommodation of teacher training, and research and development in the field of disability including MR. It is an autonomous body whose recommendations and decisions are mandatory for special education programmes. Since 1993, nation wide development, massive inservice programmes and preparation of different categories of manpower have augmented the services and rehabilitation programmes.

To add to this, the enactment of the Persons with Disability Act (PWD),1995, commensurates with the World Declaration of Human Rights and United Nations Standard Rules, in November, 1994. Two other international events led to the passing of the Disability Act in India.

- The Economic and Social Commission for Asian and Pacific (ESCAP) at its forty-eighth session held at Beijing adopted a resolution 48/3 proclaiming the period 1993-2002 as the Asian and Pacific Decade of Disabled Persons with a view to giving impetus to the implementation of World Programme of Action concerning disabled persons in the Asian and Pacific Region.
The agenda for Action for Asian and Pacific Decade of the Disabled Persons laid emphasis of enactment of legislation aimed at equal opportunities for people with disabilities, protection of their rights and prohibition of abuse and neglect of these persons and discrimination against them.

**The PWD Act, 1995 seeks to achieve the following objectives:**

- To spell out the responsibility of the State towards the prevention of disabilities, protection of rights of persons with disabilities and medical care, education, training, employment and rehabilitation of persons with disabilities.
- To create barrier free environment for persons with disabilities.
- To remove any discrimination of persons with disabilities in the sharing of development benefits, vis-a-vis, non-disabled persons.
- To counteract any situation of the abuse and the exploitation of persons with disability.
- To lay down a framework for comprehensive development of strategies, programmes and services for the equilisation of opportunities for persons with disabilities; and
- To make special provisions for the integration of persons with disabilities into the social mainstream.
- To provide for better protection of rights of persons with disabilities and to enable them to enjoy equality of opportunity and full participation in national life and to provide for their social security and matters connected therewith or incidental thereto.

The achievements to date are laudable in every field of education, training, rehabilitation, curriculum development, accreditation and country-wide programmes (regular, in-service, and short term).
Charter on Disability for Third Millennium

Dr. Thakur V. Hari Prasad, Chief of Indian Chapter of Rehabilitation International, Chief Consultative Body of WHO, UNICEF, ILO, UNDP on disability seen presenting Charter on Disability to the Prime Minister Shri Atal Behari Vajpayee on World Disabled Day. The Charter urges the comity of nations to develop a Comprehensive Plan with clearly defined targets to provide succour to Disabled Persons in the new millennium. The Prime Minister gave patient hearing and assured to follow the Social Summit Charter to provide relief to the Disabled Persons in the next millennium, treating disability management as officially accepted National Agenda of Action.
CHAPTER 41

MAGNITUDE OF THE PROBLEM

Mental retardation is observed to be prevalent in all societies and cultures. Throughout the world, the prevalence of mental retardation is estimated to be 30 per thousand. Nearly 75% of people diagnosed to have mental retardation, fall in the category of mild mental retardation, while the remaining 25% having IQ (Intelligence Quotient) 50 or below are classified as moderately, severely or profoundly retarded. Nearly 10% of people with mental retardation have associated medical conditions like Epilepsy, Hyperkinesis or mental illness. Nearly 4% of all children with mental retardation have multiple handicaps.

A highly systematised and fairly large scale study has been conducted by the Federation for the Welfare of Mentally Retarded (FWMR) (1977) on 2742 children from 12 Municipal Schools of Delhi attended by children from lower strata of the society. It has been revealed that 10.3% of the children were retarded, 9% of whom were mildly retarded mainly due to differential environmental and lower socio-economic backgrounds.

In a large scale survey (including 4373 villages and 2503 Urban blocks) conducted by the National Sample Survey Organisation (NSSO) in 1991 of children in the age group of 0-14 yrs. with developmental delays, it was found that 31 out of 1000 children in rural areas and 9 out of 1000 children in the urban areas had developmental delays, usually associated with mental retardation (Table 41.1 and 41.2)

PREVENTION

An average of 2.5% of all children are mild and moderately retarded, and 0.5% are severely retarded. There has been no systematic national survey to determine the prevalence of MR in India; the figures of prevalence vary from 0.22 to 32.8 per thousand population. Family history and retardation had high association. Those born to mothers of below 18 years of age had more chances of being retarded as are those born beyond the maternity age of 35. In rural areas, the incidence of retardation is more. The NSSO, 1991 states that within the 0-14 age group in rural areas incidence of MR is 3.1% and in urban it is 0.9%. Under age 14, there are about 7.5 million MR children in India (NSSO, 1991).

Of late, preventive activities have received priority attention. Three steps are being taken from the viewpoint of public education: (i) dissemination of available knowledge on ecology of MR through public media like newspapers, radio, television (ii) to bring together the parents and interested public to mobilise their efforts to channelise funds and family, and (iii) strengthening national level organizations to coordinate and disseminate the efforts.
Table 41.1: Prevalence Studies Based on National Sample Survey Organisation

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Investigators</th>
<th>Year</th>
<th>Target Population</th>
<th>Place of Study</th>
<th>Prevalence Rate/1000</th>
<th>Techniques used and Criteria Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>NSSO</td>
<td>1991</td>
<td>Stratified Rural Sample</td>
<td>All India</td>
<td>31.0</td>
<td>Developmental Delay</td>
</tr>
<tr>
<td>2</td>
<td>NSSO</td>
<td>1991</td>
<td>Stratified Urban Sample</td>
<td>All India</td>
<td>9.0</td>
<td>Developmental Delay</td>
</tr>
</tbody>
</table>

Source: Mental Retardation in India: Contemporary Scene, NIMH, 1994, pg. 5.
<table>
<thead>
<tr>
<th>Sl.No.</th>
<th>Investigators</th>
<th>Year</th>
<th>Target Population</th>
<th>Place of Study</th>
<th>Prevalence Rate/1000</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Kamat</td>
<td>1951</td>
<td>School population</td>
<td>Karnataka</td>
<td>40.0</td>
</tr>
<tr>
<td>2</td>
<td>Ganguly</td>
<td>1962</td>
<td>School population</td>
<td>Calcutta</td>
<td>8.0</td>
</tr>
<tr>
<td>3</td>
<td>Kuppuswamy</td>
<td>1968</td>
<td>School population</td>
<td>Mysore</td>
<td>14.0</td>
</tr>
<tr>
<td>4</td>
<td>Verma</td>
<td>1968</td>
<td>Primary School Population</td>
<td>Nagpur</td>
<td>17.0</td>
</tr>
<tr>
<td>5</td>
<td>Verma</td>
<td>1968</td>
<td>Sec. School Population</td>
<td>Nagpur</td>
<td>3.0</td>
</tr>
<tr>
<td>6</td>
<td>Verma</td>
<td>1968</td>
<td>High School Population</td>
<td>Nagpur</td>
<td>0.1</td>
</tr>
<tr>
<td>7</td>
<td>Gupta &amp; Sethi</td>
<td>1970</td>
<td>Rural Community</td>
<td>U.P.</td>
<td>25.3</td>
</tr>
<tr>
<td>8</td>
<td>Bharatraj</td>
<td>1970</td>
<td>School children</td>
<td>Mysore</td>
<td>140.0</td>
</tr>
<tr>
<td>9</td>
<td>Gupta &amp; Sethi</td>
<td>1970</td>
<td>Urban community</td>
<td>U.P.</td>
<td>18.5</td>
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<tr>
<td>10</td>
<td>FWMR, India</td>
<td>1977</td>
<td>Municipal schools</td>
<td>Delhi</td>
<td>103.0</td>
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<tr>
<td>12</td>
<td>Narayanan</td>
<td>1981</td>
<td>Rural Population of SMR</td>
<td>Bangalore</td>
<td>3.4</td>
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<td>13</td>
<td>Suramanya</td>
<td>1983</td>
<td>Rural Population</td>
<td>Bangalore</td>
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<tr>
<td>14</td>
<td>DRC Scheme</td>
<td>1988</td>
<td>Rural Population</td>
<td>Peddavutapalle</td>
<td>0.9</td>
</tr>
<tr>
<td>15</td>
<td>DRC Scheme</td>
<td>1988</td>
<td>Rural Population</td>
<td>Gampalagudem</td>
<td>1.2</td>
</tr>
<tr>
<td>16</td>
<td>Deivasigamani</td>
<td>1990</td>
<td>Urban School Children</td>
<td>Madurai</td>
<td>29.0</td>
</tr>
<tr>
<td>17</td>
<td>NIMH</td>
<td>1994</td>
<td>Rural Preschool Population</td>
<td>Narsapur</td>
<td>36.8</td>
</tr>
</tbody>
</table>

Source: Mental Retardation in India: Contemporary Scene, NIMH, 1994, pg. 4 & 5.
From the medical point of view improvement of prenatal, and postnatal care are being taken up. The maternal and child health services which are in operation have to be activised in order to take care of rural population.

In 1999, the RCI has taken up massive programme of orientating all the Primary Health Centre (PHC) doctors in the entire country to scan, identify and provide services for early identification and prevention of MR, and, in fact, all disabilities.

Some of the common preventive measures being followed include the following:

- The pregnant mother is not exposed to X ray in the first trimester of pregnancy.
- The maternal age be restricted to 18-35.
- Rh factor be controlled through blood transfusion.
- Compulsory testing of blood and urine after birth to take care of recessive gene disorder by appropriate dietary control.
- Avoidance of consanguineous marriages.
- Avoidance of lead paints, high temperature malnutrition, maternal use of intoxication, drugs, etc.
- The pregnant mother should take immunisation against infectious during pregnancy.
- The child should be immunised against diphtheria, whooping cough, tetanus, polio, measles, and TB during the first year of birth.
- Genetic counselling be provided to parents having MR.

Preconceptual Genetic Screening and Counselling

Although information about genetics has been disseminated through newspapers, magazines, television and biology courses in high schools, it may not reach young couples in need of specific facts about genetics pertaining to particular circumstances. The actual carrier status or risk of carrying particular gene can be determined for an increasing number of genetic disorders. Genetic Research Centres at Bombay, BJ Medical College (Pune), St. John’s Medical College (Bangalore) have made efforts for improving outcome through provision of genetic counselling and prenatal screening at leading district hospitals. Tests for Fragile X syndrome are carried out at leading genetic centres. The main aim is to detect women who are carriers and whose children are likely to have genetic disorders.

Prevention During Pregnancy

Optimal Prenatal Care

Under maternal and child health programme, the National Health Policy (1983) in the context of global objective of Health For All by 2000 A.D. has inter alia set the following points:

- Reduction of infant mortality to less than 60/1000 live births.
- Prophylaxis scheme against nutritional anaemia among pregnant and lactating women. Nutritional anaemia is one of the major health problems affecting mothers which determines intrauterine growth of foetus. The nutritional well being of pregnant women is the most decisive factor in preventing low birth weight.
National AIDS Control Programme

The National AIDS Control Programme (NACO) has been recently introduced by the Government of India as a centrally aided scheme, as part of the ongoing programme of Sexually Transmitted Diseases (STDs) which are also responsible for transmission of HIV infection. The Government has set up five regional STD cum HIV detection cum prevention centres and STD reference laboratories at Calcutta, Hyderabad, Madras, Nagpur and Delhi.

National Iodine Deficiency Disorders Control Programme

The iodine deficient women frequently suffer abortions and even still births. Their children may be born mentally deficient or cretins. In India alone, 167 million people are at risk of Iodine Deficiency Disorder (IDD).

The programme aims at iodising all salt in the country in phased manner. After launching 100% centrally sponsored National Goitre Control Programme in 1962 it has now been rechristened as National Iodine Deficiency Disorder Control Programme in April 1992.

Prevention during Prenatal, Neonatal Periods and Early Childhood

Care During Delivery

Centre for Health Education, Training and Nutrition Awareness (CHETNA) organises training for different target groups like grass-root health workers, trained birth attendants, balwadi and anganwadi workers from urban slums, tribal and rural areas, etc.

Expanded Immunisation Programme

It is centrally sponsored scheme being implemented since 1985-86 with the objective of reducing mortality and morbidity due to six vaccine preventable diseases namely diphtheria, pertussis, tetanus, poliomyelitis, measles and childhood tuberculosis. The target groups are infants and pregnant women.

Integrated Child Development Services

Following the adoption of National Policy in 1974, the scheme of ICDS was initiated for target group of 0-6 years of age and pregnant and lactating mothers. As on 31st December, 1992, 2571 centrally sponsored and 194 state sector projects are going on and over 182 million children were receiving nutritional supplement and 0.9 million preschool children were receiving preschool education.

EARLY IDENTIFICATION

The past two decades have witnessed exponential progress in research on mental retardation that has direct application to prenatal diagnosis and neonatal screening. Advances in mass newborn screening programme can eliminate certain forms of mental retardation that had
plagued humanity since antiquity. Advances in neonatal care permit premature infants to survive and in some instances escape damage, which otherwise would have resulted in death in the past. The future promises more effective and widely applicable metabolic screening through the application of recombinant DNA technology. The various clinical investigations required for screening and early detection of mental retardation are given below.

**Investigations for Screening and Early Detection of Mental Retardation**

- Urine tests for metabolic diseases such as metachromatic leukodystrophy, phenylketonuria, homocystinuria, galactosemia, etc.
- Chromosomal studies for confirmation of diagnosis where chromosomal anomalies are suspected.
- Dermatoglyphics.
- Biopsy of any tissue to confirm storage or other disorders, including biopsy of bone marrow, liver, retum and brain.
- Blood examination for deficient enzymes and excessive metabolites.
- Serological and viral tests for intrauterine infections.
- X-rays of the skull for evidence of calcification, craniosynostosis, basilar impression and hydrocephalus.
- Rheumoecephalograms may be helpful in cases of hydrocephalus, porencephaly.
- Angiography for vascular anomalies.
- Computerized axial tomography can show pathology, such as porencephaly, absence of the corpus callosum, tuberous sclerosis, and many other conditions.
- Amniocentesis with examination and culture of the amniotic fluid in cases where prenatal diagnosis of defect is suspected. Foetoscopy—to visualizae the foetus in uterus and to draw blood for examination.
- Electro Encephalogram (EEG) for seizure disorder. Positron Emission Tomography (PET).
- Nuclear Magnetic Resonance Imaging (NMR)

**Screening of Childhood Disabilities**

A multi-centred study carried out in 1994 at NIMH revealed that about 50% of parents are able to recognise the delayed development or mental retardation of their children as early as below the age of 2 years of the child, while 35% of the parents could recognise only after the age of 2 years.

**Screening Approach in the Community**

The screening approach in the community involves evaluating children at two stages. First, to sort out children who are at risk and second, to conduct diagnostic evaluation of those who are found positive on screening.
Table 41.3: Bio-chemical/Metabolic Screening in Persons with Mental Retardation

<table>
<thead>
<tr>
<th>Item</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>M.R. Screened (N)</td>
<td>5,479</td>
<td></td>
</tr>
<tr>
<td>Positive Cases (n)</td>
<td>266</td>
<td>(4.85 %)</td>
</tr>
<tr>
<td>Phenylketonuria</td>
<td>10</td>
<td>(3.6 %)</td>
</tr>
<tr>
<td>Male syrup urine disease/organic, asciduria, ketoaciduria</td>
<td>18</td>
<td>(6.8 %)</td>
</tr>
<tr>
<td>Galactosemia</td>
<td>5</td>
<td>(1.9 %)</td>
</tr>
<tr>
<td>Porphyria</td>
<td>1</td>
<td>(0.4 %)</td>
</tr>
<tr>
<td>Mucopolysaccharidoses</td>
<td>47</td>
<td>(17.7 %)</td>
</tr>
<tr>
<td>Tyrosinuria</td>
<td>22</td>
<td>(8.3 %)</td>
</tr>
<tr>
<td>Histidinaemia</td>
<td>7</td>
<td>(2.6 %)</td>
</tr>
<tr>
<td>Homocystinuria</td>
<td>5</td>
<td>(1.9 %)</td>
</tr>
<tr>
<td>Hartnups Disease</td>
<td>8</td>
<td>(3.0 %)</td>
</tr>
<tr>
<td>Leucodystrophy</td>
<td>5</td>
<td>(1.9 %)</td>
</tr>
<tr>
<td>Miscellaneous (Albumin, Reducing Sugars, Bilirubin, Ketone bodies, Other Disorders)</td>
<td>138</td>
<td>(51.9 %)</td>
</tr>
</tbody>
</table>

Source: Mental Retardation in India-Contemporary Scene: NIMH, 1994, pg. 8.

Methods of Screening and Early Detection

There are three important methods for obtaining screening information:

- **Parents’ Reports:** Interviews with the parents, administration of questionnaire and inventories can provide wealth of information about the development of the child.
- **Observational Methods:** Direct observation of the child’s development and behaviour is of critical importance.
- **Screening Tests:** This consists of carefully selected items, question or tasks, to obtain systematic information on a child’s abilities.

Screening Instruments

For planning a screening or early detection programme, it is necessary to select appropriate screening measures. Any screening device should meet the technical criteria of standardization, reliability, validity and norms. The screening instrument should also be culturally appropriate, acceptable to the participants and cost effective.

Screening test, in order to be valid, must have established sensitivity and specificity to minimise detection of false positive and false negative cases. Sensitivity is the proportion of true cases who would be correctly identified by a screening test. Specificity is the proportion of children who truly are not cases and who are correctly identified as non-cases by the screening instruments.

Although there are multitude of available screening devices, most of them do not meet the required technical criteria. Some commonly used screening instruments standardised/developed in India are given in Table 41.4.
Table 41.4: Multi-dimensional Screening Instruments

<table>
<thead>
<tr>
<th>Sl. No.</th>
<th>Name of Instrument</th>
<th>Age Range</th>
<th>Administration Time</th>
<th>Author(s)</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Gesell Drawing Tests</td>
<td>1-8 years</td>
<td>15 min.</td>
<td>Verma, Dwarka &amp; Kaushal</td>
<td>1972</td>
</tr>
<tr>
<td>3</td>
<td>Infant Intelligence (Development) Scale</td>
<td>0-3 years</td>
<td>30 min.</td>
<td>Kulshreshtra</td>
<td>1975</td>
</tr>
<tr>
<td>4</td>
<td>Mental and Motor Growth of Indian Babies</td>
<td>1-2 yrs.</td>
<td>15-20 min.</td>
<td>Pramila Phatak</td>
<td>1976, 1977</td>
</tr>
<tr>
<td>5</td>
<td>Vineland Social Maturity Scale</td>
<td>0-15 yrs.</td>
<td>15-20 min.</td>
<td>Malin,</td>
<td>1970</td>
</tr>
<tr>
<td>6</td>
<td>NIMH Developmental Screening Schedule</td>
<td></td>
<td></td>
<td>Saroj Arya &amp; Menon</td>
<td>1988</td>
</tr>
<tr>
<td>7</td>
<td>NIMH Developmental Assessment Schedule</td>
<td></td>
<td></td>
<td>Saroj Arya &amp; Menon</td>
<td>1988</td>
</tr>
</tbody>
</table>


NIMH Developmental Screening Schedule (DSS)

A simple screening tool comprising ten test items of key developmental milestones considered as sensitive indicators of developmental delays was developed by NIMH for screening of preschool children in rural areas. The screening results obtained on rural children showed that DSS can accurately screen 98% of children, thereby indicating the efficacy of the screening instrument for predictive purposes. This Developmental Screening Schedule was found to children with mental retardation in the rural community.

In context of early identification, it is relevant to define the role of Primary Health Centres also.

Assessment of Individuals with Mental Retardation

The psychological assessment of mentally handicapped persons is useful mainly for two reasons: (i) as a guide to diagnosis, classification, eligibility determination, i.e., for purpose of certification and social benefits; and (ii) as a guide to planning, implementation, monitoring and evaluation of intervention programmes.

The assessment of mentally retarded Children is a complex process because the test findings need to be interpreted in the light of the child’s background and opportunities available. The developmental approach is generally used for developmental assessment and for planning early intervention programmes. Various developmental scales have been used for developmental assessment of the mentally handicapped children. The most commonly used developmental scales are:

- Gesell Developmental Schedules
- Bayley Scales of Infant Development
- Motor and Mental Development of Indian Babies (Pharmila Phatak)
- Kulshrestha Infant Intelligence Scale

The traditional tests of intelligence, like Binet and Wechsler Scales, Paper and Pencil tests, Raven's Progressive Matrices, Bhatia's Performance Test of Intelligence and Maza tests have made significant contribution to assessment. There is increasing recognition that they should be only the first step in the assessment process and that there is now need to go beyond IQ.

The importance of assessment for teaching by the teacher has come to the focus in India in recent years. An informal functional assessment guide for all disabilities has been developed (NCERT, 1990) for use by teachers. In addition, educational assessment tools for mentally regarded Children such as Madras Developmental Programming System (MDPS, 1991) an adaptation of Minnesota Developmental Programming System, Indian adaptation of Portage Guide to Early Education (1987) and Functional Assessment Checklists (1994) by National Institute for the Mentally Handicapped are popularly in use in India. Another assessment scale developed by NIMH is called Behavioural Assessment Scale for Indian Children with M.R. (BASIC-MR) which is available for making objective assessment for planning training programme. The linguistic, socio-cultural practices vary from region to region in India and there is a trend in various states to develop functional assessment tools suitable to their region.

The Functional Assessment Checklists (NIMH) have the items described in terms of activities rather than skills for early monitoring. Periodic quarterly assessment provision is made and the checklists are separately developed for children from pre-primary to pre-vocational levels covering the age range of 3 to 18 years. Separate checklist for profoundly retarded children in the name of care group is provided for these children.

Role of Primary Health Centres

Role of Primary Health Centres (PHCs) in the present condition of MR is much more relevant than others because PHCs are the first interventive channel through which a rural MR passes. Their role is like a first observer of detection and intervention of MR. Recently from July 1999, the RCI started a national level programme, training programme for PHC doctors, to train them in disability management. This programme is getting success. Like the success of Pulse Polio programme, this national level programme named—"National Programme on Orientation of Medical Officers Working in Primary Health Centres to Disability Management", is basically a training programme and this proposed programme will train 30,000 Medical Officers through a three-day orientation module on different aspects of disability management. The basic objectives of this training programme are:

- To orient all Medical Officers of PHCs on various types of disabilities, such as locomotor, speech and hearing, visual and mental retardation.
- To disseminate knowledge about prevention, promotion, early identification, intervention and rehabilitation for all types of disabilities.
- To make them aware of the existing facilities available for the persons with disabilities so that Medical Officers can refer them for further management.
To enable Medical Officers to impart this knowledge to various multi-purpose workers and other functionaries working within the community.

To enable them to provide the leadership role in making the disabled movement at grassroot level by propagating the needs and rights of the disabled.

To sensitise Medical Officers about the general disability issues such as social legislation, human rights, gender issues and organisation of the persons for asserting their roles, responsibilities and needs.

The implementation of the entire programme will be done in a two pronged approach.

- **Apex level**—An apex co-ordinator committee under the chairmanship of Chairman RCI.
- **State level**—Implementation committee under the chairmanship of Secretary Heath or a designated officer. RCI will designate a co-ordinator for the training programme from among the selected agency/agencies.

Our country has 1,33,500 sub centres, each catering 5,000 population, 22,000 PHCs catering needs of 30,000 population, 1900 community Health Centres each catering 1,20,000 population and 507 district hospitals. This programme will certainly reach up to the real beneficiary. The scope of orientation Medical officers in PHCs to Disability Management are:

- National level information dissemination in rural areas
- Better prevention, early detection, early referral
- Effective networking with resources in villages
- Convergence of services
- Community and family empowerment
- Improved quality of life of persons with disabilities.

Thus PHCs are functional infrastructures available throughout the country, for providing services in rural areas. This training programme will surely increase their functional and creative capacities in early identification, detection and better prevention of MR in rural India.

**INTERVENTION**

Early intervention does not necessarily form a sequel to early detection in the Indian context. Invariably as per case records of screening, the first person to disclose the mental retardation in young children is a medical doctor. However, most of them do not refer the children to early intervention centres or professionals. Majority of the doctors inform parents that there will be delay in the developments of their child and that it will not pose a problem as and when the child grows up. The non-medical aspect of special training or therapies is not discussed with parents often. Some of them do not convince the parents that the condition is incurable. Still other practitioners prescribe treatments or medicines for improving intelligence “for enhancing memory”, etc. Some parents on their
demand are referred for CT scans and other investigations of radiological nature, thus long after realising the fact that their son/daughter has mental retardation, parents still go to different disciplines of medical investigation or other faith healing or native treatments either to disprove the diagnosis or to seek second or third opinion on the plan of action.

Therefore, there invariably is an average gap of 2-3 years between first information of mental retardation in their sons/daughters and the first meaningful intervention in the case of older children. With regard to young children below 5 years of age, the shopping around for services make children lose the critical period of development without appropriate intervention.

However, there are instances of new diagnostic methodology that detect developmental delays and many impending disabilities from postural reactions of new born and young infants in India. As the multi-disciplinary stimulations are very useful to the development of sensory, motor, communication, self-care, cognitive and pre-academic capabilities are incorporated in the early intervention programmes. The qualitative impact of early interventions on the developmental process of young children has been studied longitudinally in many centres. However, the opportunities for regular intervention with the support of families as co-therapists is accessible only to a small extent of the population.

Some service models with a CBR approach have reached rural areas of India to dispense the early interventions through village level workers. This effort has also helped in narrowing the lapse of time between detection and intervention.

Home-bound interventions of young children with visiting trainees similar to the portage programmes and early integration programmes in local village or urban pre-schools have enabled many young children to avail multi-disciplinary interventions under the monitoring support of the pre-school teachers.

Early intervention accessibility for children can be enhanced by appropriate guidance in counselling and information to the pediatricians and general practitioners. To counsel the parents appropriately for early intervention para professionals and community workers involved in early detection programmes should be oriented to motivate families to undertake measures for early interventions. Home based interventions through rural grassroots workers is gaining momentum in the country.

**Leading Early Intervention Service Facilities in India**

1. Association for the Welfare of Persons with Mental Handicap in Maharashtara, Bombay.
3. Anveshana, Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped, Hyderabad.
5. Developmental Centre for Exceptional Children, Bangalore.
7. Samadhan, Delhi.
8. Srimathi Motibai Thackersay Institute of Research in Mental Retardation, Bombay.
9. EIS Clinic, National Institute for the Mentally Handicapped, Secunderabad.
11. Dr. G. Shashikala, Consultant Developmental Neurologist, Nagpur.
12. Early Intervention Programme, Department Of Paediatrics, KEM Hospital, Pune.
13. NIMH Supported Centre at T.M.A. Pai Rotary Hospital, Mangalore.
14. NIMH supported centre at Shri Shivanand Charitable Hospital, Rohtak.
15. NIMH supported centre at Project Swarajya, Cuttack.
16. NIMH supported centre at All India Rural Women’s Upliftment, Manipur.
17. NIMH supported centre at Bal Niketan (ICDS Project), Indore.
18. S.S.Hospital, Kota, Rajasthan.
19. Paediatrica Genetics Unit, All India Institute of Medical Sciences, New Delhi.
20. Early Intervention for Down’s Syndrome, Institute of Genetics, Hyderabad.
21. Early Intervention Programme, Spastic’s Society of Tamil Nadu, Madras.
22. Spastic’s Society of India, Bangalore.
24. Spastic’s Society of Northern India, New Delhi.
25. Spastic’s Society of India, Madras.
26. Department of Psychiatry, PGIMER, Chandigarh.
27. Department of Psychiatry, AIIMS, New Delhi.
CHAPTER 42
SERVICES AVAILABLE FOR MENTALLY RETARDED

INTRODUCTION

Some education is well within the realm of possibility for a number of mentally retarded children. It is sometimes estimated that the great majority of children who are labeled as retarded have mild form of retardation. In India education is imparted to children with disabilities both in special schools and under the integrated education programme of the Ministry of Human Resource Development.

Human resource development is of crucial importance for the education of mentally retarded children. Currently about 500 teachers are being trained annually. This number will need to be greatly increased if 7.5 million children with mental retardation in India are to be given access to education.

The National Institute for the Mentally Handicapped under the Ministry of Social Justice and Empowerment runs a number of centres for the training of teachers of the mentally retarded.

SPECIAL EDUCATION

In a way of defining special education first we have to define education as “the process of learning and changing as a result of schooling and other experiences” and the special education is the “Instructions designed for students with disability or gifts and talents who also have special learning needs. Some of these students have difficulty learning in regular classrooms, they need special education to function in school, others generally do well in regular classrooms, but they need special education to help them master certain skills to reach their full potential in school.” Their disability results from a medical, social or learning difficulty that interferes significantly with the students normal growth and development such as the ability to profit from schooling experiences or the ability to participate successfully in work activities. Thus special education may also be defined as the “Specially designed instructions which enacts the unique needs of an exceptional child with material techniques, equipment and other facilities.”

The origin of special education in India can be traced to the era of “Gurukula” education, which adhered to fundamental principles of special education like:

- Determining the strength and needs of each pupil.
Individualisation of teaching targets and methods to match the skills and interests.

Preparing the pupils for meeting the societal expectations of their prospective roles (Prasad, p. 17).

However, in the modern era, the history of special education for the disabled in India begins from 1885 when first school for the Deaf was opened and in 1887, the first school for the blind was established by the missionaries. During the late 1960's and the 1970's due to the efforts from the various voluntary organisations many special schools were established, and during early 1980's recent technologies regarding therapeutic interventions were included with special education as a curricular or co-curricular programmes. Multi-disciplinary approach was adopted by many special schools. Finally, after the efforts of NGO's, the National Institute for the Mentally Handicapped was established in 1985 under the Ministry of Welfare, Government of India.

Presently through special diagnosis methods, special clinical teaching procedures, special materials, special individual and systematic instructions, and parents’ counselling, special education is engaged in close cooperation between home and school. In today’s perspective, the role of special education for the disabled is as a cost effective, productive, promotive, altruistic, corrective and more subjective method of education. Special education has a very important role in fulfilling the basic and special needs of a person with MR i.e., enabling them to move about freely, to look after one-self, to make them a part of the society, to help them in communicating with others, recreation to them, affection with them, to make them able to learn. Thus special education plays a functional role in the life of a MR person, because children with MR require functional oriented curriculum as they cannot qualify in the general and higher secondary curriculum. Thus fair education is provided primarily in special school with special curriculum. The curriculum will contain functional reading, writing, arithmetic including time, travel, money and such other skills.

Tables 42.1 and 42.2 show the distribution of institutes, and individuals with MR at various special schools and distribution of professionals working in various special schools with MR.

**Integrated Education**

The meaning of the term “integration” is based on the “principle of normalisation” which means that “you act right when making available to all persons with intellectual or other impairments of disabilities, patterns of life and conditions of every day living which are as close as possible to or indeed the same as the regular circumstances and ways of life in their communities” (Nirje, p.16). In simple terms, “integrated education is the practical
expression of an ideology that regards a child as first and foremost a child and the ability, disability or giftedness as secondary. The cornerstone of this ideology is reflected in a unitary system of education and this approach rests on a fundamental principle of education—all children are special” (Billimoria, 1999, p.2).

The history of Integrated Education in India is not very old. The Kothari Commission (1964-66) and UNESCO in 1970’s studied the possibilities of educating children with disabilities in the existing general education system and recommended that those children who are capable of being educated in the ordinary schools should be given equal opportunity through integrated education. Keeping in view the socio and economic scenario of developing countries UNESCO recommended that disabled children may be educated in the regular schools and advised the developing nations to direct their national policies towards equal access to education (1973, 1977). India launched a centrally sponsored scheme of Integrated Education for the Disabled in 1974. In 1987, the National Council for Educational Research and Training (NCERT) in collaboration with UNICEF introduced a Project Integrated Education for the Disabled (PIED) to strengthen the programme in ten states and union territories. However, many voluntary agencies and private schools have also implemented different models of integration with special educational supports

<table>
<thead>
<tr>
<th>State/UT</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andaman &amp; Nicobar Islands</td>
<td>1</td>
</tr>
<tr>
<td>Andhra Pradesh</td>
<td>41</td>
</tr>
<tr>
<td>Assam</td>
<td>4</td>
</tr>
<tr>
<td>Bihar</td>
<td>9</td>
</tr>
<tr>
<td>Chandigarh</td>
<td>3</td>
</tr>
<tr>
<td>Delhi</td>
<td>24</td>
</tr>
<tr>
<td>Goa</td>
<td>4</td>
</tr>
<tr>
<td>Gujarat</td>
<td>34</td>
</tr>
<tr>
<td>Haryana</td>
<td>1</td>
</tr>
<tr>
<td>Himachal Pradesh</td>
<td>1</td>
</tr>
<tr>
<td>Karnataka</td>
<td>73</td>
</tr>
<tr>
<td>Kerala</td>
<td>74</td>
</tr>
<tr>
<td>Madhya Pradesh</td>
<td>6</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>83</td>
</tr>
<tr>
<td>Manipur</td>
<td>1</td>
</tr>
<tr>
<td>Orissa</td>
<td>13</td>
</tr>
<tr>
<td>Pondicherry</td>
<td>2</td>
</tr>
<tr>
<td>Punjab</td>
<td>6</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>5</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>55</td>
</tr>
<tr>
<td>Tripura</td>
<td>1</td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td>15</td>
</tr>
<tr>
<td>West Bengal</td>
<td>27</td>
</tr>
</tbody>
</table>

Total 482
in urban settings. The “Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped” (THPI), Hyderabad and its Rural Project at Rajahmundry are involved in integration of children with disabilities in rural pre-schools (Balwadis) in over 400 villages in the state of A.P. The institute also provides social integration opportunities for older children with a Mental Handicap through partial integration in neighbourhood schools and Inverse Integration approaches like Summer Camps, at Local, National and International Levels.

Table 42.2: State-wise Distribution of Individuals with Mental Retardation on Rolls in Various Special Schools in India

<table>
<thead>
<tr>
<th>State</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andhra Pradesh</td>
<td>969</td>
</tr>
<tr>
<td>Assam</td>
<td>162</td>
</tr>
<tr>
<td>Bihar</td>
<td>249</td>
</tr>
<tr>
<td>Chandigarh</td>
<td>55</td>
</tr>
<tr>
<td>Delhi</td>
<td>1,305</td>
</tr>
<tr>
<td>Goa</td>
<td>141</td>
</tr>
<tr>
<td>Gujarat</td>
<td>1,361</td>
</tr>
<tr>
<td>Haryana</td>
<td>21</td>
</tr>
<tr>
<td>Himachal Pradesh</td>
<td>40</td>
</tr>
<tr>
<td>Karnataka</td>
<td>1,511</td>
</tr>
<tr>
<td>Kerala</td>
<td>2,199</td>
</tr>
<tr>
<td>Madhya Pradesh</td>
<td>235</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>4,928</td>
</tr>
<tr>
<td>Manipur</td>
<td>60</td>
</tr>
<tr>
<td>Orissa</td>
<td>344</td>
</tr>
<tr>
<td>Pondicherry</td>
<td>27</td>
</tr>
<tr>
<td>Punjab</td>
<td>42</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>257</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>2,455</td>
</tr>
<tr>
<td>Tripura</td>
<td>16</td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td>356</td>
</tr>
<tr>
<td>West Bengal</td>
<td>1,546</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>18289</strong></td>
</tr>
</tbody>
</table>

Source: Mental Retardation in India : Contemporary Scene - NIMH, 1994, pg. 17.

Thus, the major functional approaches of Integrated Education are:

- Assimilation of MR child with the normal child.
- Make a feeling of belongingness among MR child.
- Based on the principle, all children are same.
- Not limited the teachers’ potential.
- Creates new skills and attitudes among teachers also.
- Remove feeling of inadequacy and insecurity among MR child.
- Promote professionalism among teachers.
- Feeling of equalness among MR child after sharing common educational facilities with normal child.
There are also some recent policies, which are relevant also. These are:

- The first important and recently proposed 33rd Constitutional amendment making “education free and compulsory for all children” (July 28th, 1997) reflects both a radical change as well as implies a different reality. The implications of this amendment on education in general and on professional development in particular are obvious.

- The second important development has been the enactment of legislation, namely “The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995”. Chapter V, clause 26 (2) of the said act states that the government endeavours to promote the education of such students with disabilities in the normal schools. The implications of such pronouncements are evident. The days of teaching specially but separately are numbered. This however, does not mean that specialised schools will cease to exist, far from it—they will always but only be required for those children with profound disabilities. For the rest, schools in future must be integrated in order that we address their needs through one unified system of education.

- The third important policy development is the recognition by the S.S.C. Board (in Maharashtra) for children with learning difficulties. In recognition of these needs certain concessions have been made, for instance
  - Children with specific learning disorder can learn two languages instead of three and in view of this opt for a vocational course.
  - can learn lower level maths and instead take a vocational course.
  - They be allowed extra time to complete their examination.

- The fourth policy development, “The Maharashtra Pre-school Act” 1997, promoting the Neighbourhood School concept. Under this policy, all children in the neighbourhood will recourse to the same school. This will also apply to children with differing capacities.

- The fifth policy development, the introduction of scheme of “Integrated Education of the Disabled Persons” (IED), education of the disabled children in the mainstream is being experimented in one block each in ten states of the country. Children with mild disabilities and motor disabilities are admitted to general schools with the necessary adaptations in curriculum and the educational and physical environment. ‘Resource room facilities’ is an emerging concept under the IED scheme. The resource teacher who is specially trained is expected to train the disabled children systematically in co-ordination with regular class teacher in the general school. Very few schools have implemented this system and the results are yet to be seen.

Studies showed that forty per cent of India’s population constitutes children (till the age of 14) i.e, about 450-500 million. The UN estimates that around 10% of our school population suffers from some form of ‘learning disorder’ and/or ‘disability’. While 2.63% of these are estimated to be MR, only 0.5% need a specialised education as they constitute severe retardation. On the other hand, seventy per cent can very well be absorbed into regular schools, as they are capable of learning.
Thus 'The School for All' philosophy which is being propagated in recent years has existed in India. Irrespective of the intellectual or other learning deficits, children were admitted to many mainstream schools. The philosophy is to enrich studies by providing
- Special units in ordinary school.
- Provision of resource rooms.
- Inverse integration approach
- Integration in non-academic activities in neighbourhood schools.

Apart from being cost effective, integration has bridged the gap between normal child and children with MR by clearly understanding the strengths and needs of children with MR by a large group of peers, their families, the main stream school staff and the families of children with MR.

VOCATIONAL TRAINING

On occasions, a mentally retarded child has been described as a bitter blossom. This is fallacious. With modern training procedures quite a number of retarded children can engage in some occupations and achieve at least partial economic independence. Vocational training is therefore of great importance and about 200 institutions in this country do offer vocational training. NIMH has identified a number of simple occupations like making file covers etc. That can be undertaken by mentally retarded people.

People with mental retardation pose unique educational and vocational problems which call for specialised efforts. There is acute shortage of trained manpower in the field. Therefore, Ministry of Social Justice and Empowerment has a special scheme to give 100% assistance to suitable NGOs for developing trained manpower in the field of mental retardation and cerebral palsy.
SHELTERED WORKSHOP

As evident from a survey carried out by Venkatesan et al. (1992) the training strategies available in our Indian context are predominantly based on sheltered workshops. About 68% of the institutions with a vocational training facilities have adopted this sheltered workshop mode. Most of the production work carried out at majority of these institutions is based on demand and products are sold by exhibition sale.

PLACEMENT SERVICES

In concern with the placement services for the MR in India, it is observed from a survey carried out by Venkatesan et al. (1992) that 10% of the total number of institutions rendering vocational facilities to the adult handicapped persons have taken up this challenging job of placing the adult mentally retarded persons in open employment set up with little support.

There are some other examples of home based self employment in our Indian context:
Aggarbatis making; candle making; running xerox-copier centre; managing petty shop; chalk making; preparing edible goods; operating telephone booths.

MEDICAL FACILITIES

The psychological assessment of MR persons is useful mainly for two reasons: (i) as a guide to diagnosis, classification, eligibility determination, i.e., for purpose of certification and social benefits; and (ii) as a guide to planning, implementing, monitoring and evaluation of intervention programmes. Various developmental scales have been used for developmental assessment of the mentally handicapped children. The most commonly used developmental scales are:

- Gesell Developmental Schedules
- Bayley Scales of Infant Development
- Motor and Mental Development of Indian Babies (Pramila Phatak)
- Kulshrestha Infant Intelligence Scale

There is increasing recognition that they should be only the first step in the assessment process and that there is now need to go beyond IQ.

GUIDANCE AND COUNSELING

The role of parental counselling in a family of any MR child/person is very much important because the parents have to deal with MR child/person in two ways

- They have to deal with the normal developmental and inter-personal crises in the MR child.
- They have to cope with the complications introduced by the reality of child’s disability of which they have little knowledge or experience.
Because of this second reason they need counselling. Through counselling, they get proper knowledge of child care and development, specific guidance in areas, such as providing compensatory experiences, maintain and safe guarding health discipline and punishment, stimulating the child’s attempts at socialising, enabling children to develop a positive self image etc.

In addition to helping and facilitating the normal tasks of parenting counselling also help parents cope with a number of fairly predictable challenges i.e.,

- The first exposure to overt or covert rejection
- The problem of making friends
- Physical harm by MR towards others
- Damages to property by MR
- Temper tantrums
- Disobedience
- Repetitive behaviours
- Self injurious behaviours
- Restless physically overactive
- Odd behaviour of MR child/person
- Problems of puberty, adolescent awareness and consequent identity crises
- Adolescent and adult sexuality
- Problems of vocational planning and marriage

Through individual and group counselling sessions as well as family therapy, the family members are helped to understand and cope with the limitations imposed by the disability on certain aspects of the child’s development as well as on his capacities for overall growth in many cases.
Today, several voluntary organisations are engaged in parents’ counselling through their multi-disciplinary approach. This counselling is usually done by the Medico Social Worker. The counselling service is co-ordinator and mediator between parents, family doctor or specialist and the facility with which the child is catered to. Thus, adequate counselling in time can help the parents to accept the fate of their MR child/adult. On the other hand, this makes the necessary basis for all capacities to be developed.

The coming of a retarded child in the family is a highly disturbing event. Parents are shocked and benumbed. It is necessary from that stage onwards to counsel parents. Their problems must be understood and psychological support provided. Parents must be given adequate understanding of the nature of the problem of their child, and the possibilities of improvement.

A number of training procedures are now available. The parents must be taught how to train the child at home in all self care skills. The parents must also be put in touch with professionals for appropriate guidance. The National Institute for the Mentally Handicapped has developed considerable material for the guidance of parents. This would help many parents in growth and development at home and in supplementing the work done at school.

**REHABILITATION SERVICES**

**Vocational Rehabilitation**

Theoretically, vocational rehabilitation is defined as “the continuous and co-ordinated process of rehabilitation which involves the guidance, vocational training and selective placement designed to enable a disabled person to secure and fit in suitable employment”. Various stages of vocational rehabilitation are:

- Systematic school instruction
- Planning for transition
- Placement for meaningful employment
- Follow-up services

We can summarise the various stages of Vocational Rehabilitation as follows

*Pre-primary education*—Where the MR child acquires the basic skills such as pre-reading, pre-writing that will permit an adequate development of psychomotor coordination. In this stage socialisation and the act of living together must begin.

*Secondary period*—During this period, job oriented functional academics is reinforced and enlarged. Simple activities are initiated - a basis for the pre-vocational stage. More attention is given to develop general work habits such as neat appearance, communication and appropriate social behaviour.

*Pre-vocational training*—Is a systematic training by which an individual acquires functional skills and appropriate behaviour which are necessary for a particular vocation. The objectives of Pre-vocational training are:
- To prepare work oriented programmes
- To impart training and create opportunities for development of functional academics, personal social skills, survival and safety skills and work readiness skills.
- To develop adjustment skills by providing experiences in various life situations.
- To normalize work related behaviour.

The activities involved at pre-vocational stage for transition include the following:

- Survey the employment possibilities in the community and desired skills for entry level employees.
- Functionally assess the student’s interest and aptitude.
- Prepare an individualised transition plan towards the end of school years in cooperation with parents and employees.
- Train the students for a short period in the stimulated set up before learning the school.

*Vocational training*—The adult MR person entering into the employment market can be grouped into four categories on the basis of the training which they received in childhood and adolescent stages.

- The adults with MR who completed special school programmes and available prevocational training.
- The adults with border line intelligence and mild MR who are unable to complete the normal schooling due to low intelligence.
- The MR adults who have not undergone any normal or special school programmes especially in rural areas.
- The adults who are employed and lost their jobs due to lack of vocational training and professional help during job placement.
For vocational rehabilitation, the first step is the assessment. The assessment has to be done in two areas:

- Assessment of the trainee.
- Assessment of the available job opportunities in the community.

The general assessment of the trainee is done in five areas:

- **Medical:** The functional/organic limitations impaired by the disability.
- **Physical:** The actual physical performance in terms of effort and working capacity.
- **Psychological:** Level of intelligence, mechanical and constructional aptitudes and interest etc.
- **Educational:** Personal, Social, Academic and Safety Skills.
- **Vocational:** Skill level, Aptitude and Occupational abilities.

The purpose of community assessment is to identify potential employment opportunities in the community in which the trainee receives training and eventually leads to employment. A community assessment assists in identifying specific skills required for performance on real jobs in actual employment site.

The information gathered from survey of available jobs, employer contacts and job analysis should serve as the basis for the trainee skills assessment. The skills identified as required for success on jobs should be same skills on which the trainees are assessed.

The trainee’s work skills should be considered in selecting a specific job and on-the-job training. Work skills include specific job task skills, related behaviours, and social skills that are necessary for performing any given job. After the selection of job site, specific skills must be identified and targeted to receive systematic training.

On completion of the training, the adult MR person moves towards one of the four possibilities of employment.

- **Open Employment:** Is viewed as the entry of the individual into a normal work setting.
- **Supported Open Employment:** Is an employment approach for individuals with MR which enables them to be placed, trained and supported in competitive jobs in integrated environments with the assistance of professionals.
- **Sheltered Employment:** A work oriented rehabilitation facility with a controlled working environment and individuals vocational goals, which utilises work experience and related services for assisting the handicapped persons to progress towards normal living and a productive vocational status.
- **Self Employment:** Working in ones own business.

Thus, more specifically, the aims of vocational Rehabilitation can be summarised as:

- Integration of the disabled into work according to their remaining functional abilities, skills and aspirations.
- Efficient use and training of working capacities.
- Reversion instead of aggravation of disabilities through adoption.
Establishment of safe working conditions so that a disabled person will not endanger himself or others.

Prevention of occupational disability and handicap.

The recent trend in the field of MR is integration of the MR population into the mainstream of the society. This particular notion stimulates the professionals interest in exploring the employability of MR persons. Sincere pursuance in this matter by the professionals laid the conclusion that MR persons can be economically independent either partially or fully, if trained properly. MR persons can lead successful adult life by becoming independent in personal, social and occupational spheres if proper training programme can be imparted from the beginning. Professionals, no doubt, have major role to play in this respect. “The philosophical and programmatic changes in vocational services for persons with MR have created a great demand for professionals who are qualified to provide those services (Renzazlia & Bverson, 1990).” For the achievement of the goal, a carefully planned training programme has to be carried out at different levels, which would facilitate a successful adult life.

SPORTS AND RECREATION

Play is basic for all children, especially to the retarded who in addition to their intellectual deficit and impaired adaptive behaviour are likely to have a lack of co-ordination, less resistance to fatigue, lower level of strength and poor body movements. Therefore, to develop his/her physical fitness, a MR child has to play and has to learn skills of individual, parallel and group play. It is also necessary to develop his/her co-ordination. Julian Stein states in one of his articles—“Programming for the MR—Report of a National Conference” with play, physical education, recreation, outdoor education, motoric, moviegenic base or care, we can reach the retarded and they can and will progress. These activities must be deemed in their broadest sense as educational, potent, etc. learning devices. Recreation for example, is more to the retarded than preparation for leisure -time participation, recreation is education and education is recreation; play is learning and learning is play for the retarded.
The MR need help with leisure activities because leisure activities are genetically related with a social person and the MR are not exceptional. The National Policy on Education (1986) has declared that leisure and recreational activities in the form of sports and games, music, arts and craft work are integral part of the learning process. It is so with the educational programme organised for persons with MR who enjoy music, dance, drama, scouting, trekking, modeling, painting and sports and games as integral part of their school curriculum, and also the following:

- Special Olympics India was founded in 1988 to provide opportunity for persons with Mental Handicap to participate in National and International sports and games. Special Olympics India is an accredited body and has about 15 states affiliated with it. This national body conducts periodic coaching camps for coaches of the Mental Handicapped people and organises National Games to select appropriate candidates for the International Special Olympics. National Games are held once in four years. The Special Olympics National Games were held at Hyderabad in January 1995.

- To promote the talents in art, an International Committee for Arts with the Handicapped was established. This committee originated in Washington, USA, in the year 1974, and ventured a major event. Very Special Arts Festival (VSAF) which served as a forum for disabled and non-disabled children to participate in a non-competitive event, viz., ‘A Festival for Arts.’ Since then, this committee has promoted and created a platform for practising and for performing arts, for about 6,00,000 challenged children and adults, in about 40 Nations, through the organisation of 450 festivals. Each of this festivals leads to the organisation of workshops, providing training courses for the disabled, creating a platform for performances and finally disseminating information to persons who care for the challenged. In 1984, ‘Very Special Arts International’ (VSAI) was established and formalised ties with 40 Nations giving birth to National Chapters in these countries. India showed interest in this progressive direction by starting a chapter in 1984 with headquarters at New Delhi.
India undertakes the following activities:

- Organising festivals at national and regional levels in arts.
- Providing scholarships to the talented and challenged persons.
- To promote and facilitate marketing of craft items prepared by the challenged at International levels.
- To sponsor the talented persons to compete in competitions for arts.
- To organise workshops and art demonstrations for the challenged persons.
- To develop directory of talented artists with disabilities in India.
- Training the trainers of persons with disabilities.
CHAPTER 43

HUMAN RESOURCE DEVELOPMENT

For the human resource development programme, RCI is very conscious of its role in maintaining and providing well qualified professionals, and for providing high quality standards of services. For this purpose, RCI has formulated norms for recognition of institutions and programmes. These are (i) only agencies/institutions receiving grant either from the Central Govt. or the State Govt. are considered, and (ii) the required infrastructure and professional standards have been clearly prescribed for each category qualify to recognition by RCI. After fulfilling the above criteria, inspection teams of highly qualified professionals are sent to study the capabilities of institutions for giving recognition by RCI. The Council has given recognition to 19 institutions, under the Scheme of Assistance to Organisation for Manpower Development.

The Manpower Report (1996) prepared by RCI has projected that about 0.36 million persons would have to be trained during the 9th Plan period. At present, only about 3000 persons per year are being trained.

Now, various national institutions as well as the Ministry of Social Justice and Empowerment are implementing the Manpower Development Programmes. Currently 22 such centres run the Diploma in Special Education (Mental Retardation) D.S.E. (M.R.) course with recognition from the RCI producing about 400 special teachers every year. The University courses offering B.Ed., and M.Ed. in Special Education have also increased gradually and about twelve Universities offer the courses funded by University Grants Commission (UGC) currently.

Thakur Hari Prasad Institute of Research & Rehabilitation for the Mentally Handicapped (THPI) was established in the year 1968. It has made significant contribution in the field of MR in India over the last decade. More specifically, THPI has contributed as to the field of manpower development by conducting the following courses:

- PGDDR - Post Graduate Diploma in Developmental Rehabilitation
- DSE(MR) - Diploma in Special Education (Mental Retardation)
- Diploma in Medical Pedagogy.
- Diploma in Developmental Therapy.
- Course for Pediatricians and Clinical Psychologists in Neuro Kinisiological Diagnosis.
- Diploma in Vojta Therapy.
- Training for para-professionals etc.
- Need based Training Programmes.
- Certificate course in Vocational Training.
Training of school teachers.
- Resource services.
- National Bridge Course on Mental Retardation
- National Training Programme on Orientation of Primary Health Doctors to Disability Management.

**MULTI-DISCIPLINARY APPROACH**

Multi-disciplinary approach is a multi-prolonged way to solve multi-faceted problems of MR child/adult. An MR child/adult always faced their problems in multiple ways in different degrees in different areas, so to solve their this multiple structure of problems Multi-disciplinary approach is used. Multi-disciplinary team and their functions are given below:

- **Neuro Paediatrician & Psychologist**: Early detection, identification, nutrition, treatment for epilepsy, hyper activity and other psychiatric problems, counselling of parents and prevention.

- **Psychologist**: Diagnosis, classification developmental assessment, intellectual assessment, parental counselling and guidance, behaviour modification, interaction programmes and research.

- **Physio & Occupational Therapist**: Intervention programmes, vojta therapy/neuro developmental therapy improving fine motor skills, precepts motor training.

- **Speech & Language Pathologist & Audiologist**: Intervention programmes improving articulation, voice, fluency and speech.

- **Special Educator**: Intervention programmes, diagnostic assessment, post assessment counselling, home based training, remedial compensatory education for MR children attending regular schools, integrated education programme, parent and sibling training, vocational training.

- **Medico-social Worker**: Initial screening, family and medical history, restructuring the family environment, parental counselling, mobilisation of social and community resources.

Thus this multi-disciplinary approach covers all the aspects of the life of a MR and this approach also enable professionals of different areas to create new scientific and remedial techniques for the development of the MR child/adult.

The RCI approved programmes are being offered with reciprocal approval and recognition by UGC, NCTE, NCERT in different National Institutes and their regional centres, and NGOs for teacher preparation.
ROLE OF ORGANISATIONS

ROLE OF VOLUNTARY ORGANISATIONS/NGOS

In India, while the government plays an important role in making constitutional and legislative procedures, evolving schemes, national policies, providing resources ensuring co-ordination between different Ministries and ensuring implementation of executive order and other provisions, it may never be possible for it to deliver services and programme on its own. However in India, the voluntary sector continues to play a dominant and significant role in providing welfare and rehabilitation services for the disabled. Many voluntary agencies not only provide services but also act as potential pressure groups. In India, NGOs have always been in the forefront in responding to the ever challenging rehabilitation needs of persons with disabilities in myriad ways. Though voluntary service care for disabled persons had its origin decades back, NGO action in the field of Disability Prevention Rehabilitation and Inclusion has become more spectacular since a decade and a half contribution of NGOs in providing quality Rehabilitation Services and in reaching the unreached in rural and tribal areas through its various innovative strategies remained unmatched by government action. By doing so NGOs have not only played a complementary role and supplementary role but sometimes in the main role in the rehabilitation of persons with MR.

One such example of a Premier NGO in India is sufficient to show the creative and purposeful efforts of NGOs in the field of services for the MR i.e., “Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped”, Hyderabad. Some landmarks achieved by THPI in the field of rehabilitation of persons with MR are as follows:

It is an NGO which rose to the occasion—need for drafting a National Policy for the Mentally Handicapped by mobilising the participation of policy makers, government officials, reputed professionals, NGO representatives, representatives of different Ministries and parents which resulted in an All India Seminar for Policy Formulation for the Mentally Handicapped in 1986. The policy document thus evolved was presented to, the then P.M., Mr. Rajiv Gandhi and the President of India, which resulted in the constitution of Behrul Islam Committee as a follow-up to its presentation. An exclusive working group was constituted under the 8th Plan for disability. All these efforts resulted as “Persons with Disabilities (Equal opportunities, Protection of Rights and Full participation) Act -1995”, the setting up of the Rehabilitation Council of India to standardise the curriculum and to regulate the Rehabilitation courses, the increase in the allocation of Budget from rupees 4 million to 1200 million in the current plan for the rehabilitation of disabled persons and so on.
THPI by its efforts organised a XI World Congress on Mental Retardation in 1994, which brought members from 102 countries to deliberate on various issues on MR. It was a global event. This world event which was held in the Capital city of the country created sensation all around the capital and in India on the whole.

THPI was the first ever NGO, which concentrated on the condition of MR in Rural Sectors also, because 80% of the country's population resides in rural areas and the rural people are completely incapable to reach up to the professional services. THPI established a Rural Community Participative Rehabilitation Centre in Lalacheruvu, East Godavari District of Andhra Pradesh. This centre with a full time multi-disciplinary team to cater to the need of the MR persons in the rural and tribal areas remains first of its kind, with its community based training services, human resource development modules and awareness creation strategies.

Besides, through its voluntary social actions, THPI is engaged in services for the MR with full of devotion. With its various programmes, THPI is serving as a role model having a clear and single Vision and Mission.

Thus, voluntary organisations/NGOs are engaged in nation service by providing individual need based services, utilising community resources, promoting innovations, research and development and taking such measures for improving quality of life of persons with MR.

ROLE OF GOVERNMENT

In the pre-Independent India, there was practically no initiative from the Government to introduce any services for people with Mental Handicap and nor, there was any demand to initiate services for these persons since public awareness on mental disabilities was dismally low. Public attitude towards mentally disabled persons oscillated ambivalently between pity, tolerance or superstition at one end to apathy or ignorance at the other.

Disability received national attention and concern only during UN's International Year of the Disabled Persons (IYDP - 1981). Service schemes with a nationwide coverage were contemplated upon by the Government of India during the Decade of the Disabled that followed. Grant-in-aid schemes for the special schools run by NGOs to subsidise their outlay on services was introduced to meet stipulated criteria or norms set by the Government of India. The situation gained a fillip in 1984 when the then Ministry of Social Welfare, recognising the paucity of appropriate models of care and key personnel involved in education of the Mentally handicapped established National Institute for the Mentally Handicapped in 1984 with the objective of undertaking research and human resource development to meet the national needs in collaboration with the NGOs of the country.

As a follow-up action, an exclusive working group for the disabled was constituted in the 8th Five Year Plan by the Planning Commission. An Inter-Ministerial committee comprising of the representatives of all the Ministries associated with disability was formed. The Justice Behrul Islam Committee was appointed to review the recommendations of the National Policy.

The Government of India has enunciated a National Policy on Education (1968) along with a scheme for Integrated Education of the Disabled Children in 1974 under the
Ministry of Welfare. However, it became operational in the year 1986 when it was transferred to the Ministry of Human Resource Development. In 1987, the NCERT, in collaboration with UNICEF introduced a Project Integrated Education for the Disabled (PIED). The project was implemented with support of aids, appliances and resource teachers, financial assistance for teacher training, equipments, books and assessment facilities were provided. The project was implemented in Government schools.

The first University course in Special Education, B.Ed. (Special Education) was initiated in 1977. The National Institute for the Mentally Handicapped, under the Ministry of Social Justice and Empowerment introduced Diploma in Mental Retardation in 1985. The UGC, the NCERT and its four Regional Institutes, conduct teacher-preparation programmes for different disabilities.

The establishment of Rehabilitation Council in 1986 as a government registered society and its conversion in 1992 into a Statutory Body by an Act of Parliament has gone a long way for quality control in the area of personnel development to work in the field of disability. The Council has been vested with the responsibility of instituting developing and standardising, training and educative programmes.

The first community based rehabilitation programme was established at Virar by the All India Institute of Physical Medicine and Rehabilitation (AIIPMR) in 1982.

The District Rehabilitation Centre (DRC) scheme was launched in 1985 by the Government of India with an ambitious objective of providing rehabilitation services in rural areas. “The Persons with Disabilities (Equal opportunities; Protection of Rights and Full Participation) Act, 1995” was enacted by Parliament and has been enforced from February, 1996. The Act covers right to education, training, employment, prevention and health and overall rehabilitation of the disabled.

The Union Ministry of Social Justice and Empowerment is the nodal point for the welfare of people with disability. All policy initiatives in the area of welfare for handicapped are taken up by this Ministry. The welfare and rehabilitation programmes for people with disability are mainly implemented through NGOs while technical inputs are provided by the National Institutes and apex level institutions.

During the past two decades, several schemes have been launched by the Ministry of Social Justice and Empowerment to support rehabilitation services, viz. medical fitness educational, vocational and employment services for people with disabilities. The various schemes, such as, giving aids and appliances, scholarship for education of people with disability, assistance to voluntary organisations to run rehabilitation services, establishment of special schools, setting up of special employment exchanges and creation of infrastructure facilities for training and research through National Institutes in different areas of disability, establishment of the RCI for ensuring maintenance of standards in rehabilitation training, science and technology projects mission mode, National Information and Documentation Centre are some of important initiatives taken by the Central Government.
CHAPTER 45

TECHNOLOGIES IN THE SERVICES OF MENTALLY RETARDED

EMERGING TECHNOLOGIES

As we have entered the new millennium this is an excellent time to evaluate our past. When we realise that deinstitutionalization, normalization, least restrictive environments, community integration, supportive employment and social support are not terms or processes that we used before 1960, we become immediately aware of how far we have come.

Today, we can see glimmers of hope. In New York city at the Albert Einstein College of Medicine, a Paediatric Acquired Immune Deficiency Syndrome (AIDS) with family, school and staff. Also in New York, at Montefiore Medical Centre and St. Luke Roosevelt Hospital, a managed Health Care initiative is underway for persons with MR. At City University of New York, a new training programme has been designed specifically for the direct-care providers of services and programmes in the field of MR. It is a college level degree programme that offers a new curriculum and education to enhance the career opportunities for these workers and to address the serious shortage and turnover problems in this important area.

Another unique programme now operating successfully in 111 universities and colleges in USA, matching college students with a “buddy” with MR. This programme enables them to become friends, to build a relationship based on mutual needs and interests, and to participate together in social, recreational and educational activities that enhance the life experiences of both.

In Ohio, at the University of Akron, an innovative programme for elderly persons with MR was developed, which provides them with a “peer” companion—a non-disabled elderly friend. Both parties gain great benefits and enjoyment from this fine programme.

New advances in technology, such as computer-enhanced learning assistance devices, also offer great potential and an enhanced quality of life for those with disabilities.

All of these examples give hope for the future, but these examples are the western model of technological inventions in the field of MR. In India, we can summarise the emerging patterns of technologies and persons with MR into 3 major categories:

- Technologies in therapy and education
- Assistive technologies
- Standard technologies in the work place, community and home.
Advancing technologies will provide:

- Like a broader intervention programme, teacher-therapists with increasingly more powerful and easy-to-programme therapy and education aids.
- Technologies related with animation and sound.

Assistive technologies that an individual keeps and uses as a tool or an extension of his/her abilities. These also can be divided into two major parts:

- *Extending/Enhancing aids*: designed to help strengthen the skills that an individual already has i.e., a memory or reminder aid, a prompter or an assister in problem solving.
- *Companion/Tools*: that not only extend or enhance the individual's cognitive abilities but also augment the user's cognitive abilities with a second cognitive ability. Aids that incorporate artificial intelligence techniques to the point that they begin to take on the characteristics of an intelligent entity themselves could be very helpful to an individual with MR and would fall into this category.

Currently technology can address only a small portion of the problems faced by individuals with MR. In general, it is much easier to apply technology to meet individual's needs in the area of physical or sensory disability. This will probably continue well into the next century. However, advancing technologies are slowly beginning to provide us with tools that are powerful enough to better address some of the need of persons with cognitive disabilities. Currently, the use of technology in therapy and education represents the bulk of the application of technology with persons with MR. This role will continue and will expand. In addition, we should see increasing applications of technology as assistive devices to either enhance the person's cognitive skills, or to act as a "companion," which can facilitate independent living. One of the most important ways, however, that technology will affect persons with MR is through its incorporation into the community around us.
INFORMATION AND DOCUMENTATION

The literature produced by the voluntary organisations and government institutions are usually not recorded by the Registrar of Publications and therefore, not deposited at the National Depository Centre as these are basically meant for private circulation and this makes it difficult to quantify the number of documents published in the field.

Here we are including Tables 45.1, 45.2 and 45.3 which included different studies and literature related with MR.

Table 45.1: Number of Institutions Producing Different Forms of Literature on Mental Retardation

<table>
<thead>
<tr>
<th>Forms of Literature</th>
<th>No. of Institutions Producing the Literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Printed Material:</td>
<td></td>
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<tr>
<td>Brochures</td>
<td>44</td>
</tr>
<tr>
<td>Pamphlets/Handbills</td>
<td>38</td>
</tr>
<tr>
<td>Booklets on training MR children</td>
<td>22</td>
</tr>
<tr>
<td>Booklets describing services</td>
<td>37</td>
</tr>
<tr>
<td>Reports (Annual/Audit reports)</td>
<td>44</td>
</tr>
<tr>
<td>Diaries</td>
<td>15</td>
</tr>
<tr>
<td>Newsletters/Newsmagazines</td>
<td>28</td>
</tr>
<tr>
<td>Bulletins</td>
<td>3</td>
</tr>
<tr>
<td>Educational Posters</td>
<td>24</td>
</tr>
<tr>
<td>Books/Manuals</td>
<td>14</td>
</tr>
<tr>
<td>Newspaper features</td>
<td>22</td>
</tr>
<tr>
<td>Cable relays</td>
<td>5</td>
</tr>
<tr>
<td>Non-print Materials</td>
<td></td>
</tr>
<tr>
<td>Video cassettes</td>
<td>13</td>
</tr>
<tr>
<td>Audio cassetts</td>
<td>7</td>
</tr>
<tr>
<td>Slides</td>
<td>11</td>
</tr>
<tr>
<td>T.V. Spots</td>
<td>2</td>
</tr>
<tr>
<td>T.V. Shows</td>
<td>8</td>
</tr>
<tr>
<td>Films</td>
<td>7</td>
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</table>

Source: Mental Retardation in India: Contemporary Scene, NIMH, 1994, p.55.

Table 45.2: Total Number of Items in Different Forms on Mental Retardation

<table>
<thead>
<tr>
<th>Type of Material</th>
<th>Total Number of Items Produced</th>
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<tbody>
<tr>
<td>Brochures</td>
<td>62</td>
</tr>
<tr>
<td>Pamphlets/Handbills</td>
<td>79</td>
</tr>
<tr>
<td>Booklets on training MR children</td>
<td>67</td>
</tr>
<tr>
<td>Booklets describing services</td>
<td>53</td>
</tr>
</tbody>
</table>
Reports (Annual/Audit reports) 65
Diaries 17
Newsletters/Newsmagazines 34
Bulletins 3
Educational Posters 61
Books/Manuals 50
Newspaper features 40
Cable relays 6
Video cassettes 42
Audio cassettes 57
Slides 35
T.V. Spots 2
T.V. Shows 13
Films 33

Total 719


**Table 45.3: Journals/Newsletters Published in India in the Field of Disability and Rehabilitation**

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Name of the Journal</th>
<th>Periodicity</th>
<th>Since When Published</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Journal of Rehabilitation in Asia</td>
<td>Quarterly</td>
<td>1960</td>
</tr>
<tr>
<td>2</td>
<td>Indian Journal on Mental Retardation</td>
<td>Half yearly</td>
<td>1968</td>
</tr>
<tr>
<td>3</td>
<td>Indian Journal of Disability &amp; Rehabilitation</td>
<td>Half yearly</td>
<td>1987</td>
</tr>
<tr>
<td>5</td>
<td>ICCW Journal</td>
<td>Half yearly</td>
<td>1993</td>
</tr>
<tr>
<td>6</td>
<td>Action Aid Disability News</td>
<td>Half yearly</td>
<td>1990</td>
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<tr>
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CHAPTER 46

INNOVATIVE PRACTICES

COMMUNITY PARTICIPATIVE REHABILITATION

Though Community Participative Rehabilitation (CPR) is a multi-faceted phenomena, it may be defined as “Not just a way to help a person with disability, but process of empowerment in which the community members including persons with disabilities co-operatively participate in a process that leads to decisions by and for themselves critical to an understanding of ‘the real CPR (earlier CBR) is the involvement of the community in deciding what its needs are, rather than having these imposed from outside” (Brar: 1992). This definition clearly implies that basic philosophy of CPR is:

- To participate the ‘MR’ with the community
- To make the approach according to his/her understanding
- Do not make him/her outsider in the rehabilitation process of his/her own.

The concept was also defined by the WHO - “it involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled and handicapped persons themselves, their families and their community as a whole.” There are some ways through which a community can participate:

- Community can provide facilities, manpower, logistics support and possibly funds to the services.
- The community can be actively involved in studying its problems, decide upon feasible solutions and implement them.
- Joining in using primary care services (for preventive and protective measures).

The needs of CPR are:

- Communication of knowledge to the parents, village level leaders, opinion builders, religious leaders, primary doctors etc.
- Training programmes for the PHC doctors, health workers, rehabilitation professionals, NGOs and the basic components of their training are—the possible causes of MR, preventive measures, facilities available.
- Encouraging community participation.
- Effective Networking among various channels of CPR.

Certain major approaches of CPR which have been implement by both government and NGOs are:
Programmes that are promoted by co-ordinating the delivery of rehabilitation resources to rural communities (THPI model, Hyderabad).

Institution-based extension services e.g. (NIMH Model).

Entirely community-based programmes (Action Aid—THPI Model, Lalacheruvu).

PHC-based or hospital-based programmes (DRC “Early intervention with infants at risk” implemented by APACWMR).

On the basis of a detailed review, Srinivas Murthy (1989) has grouped various experiences as under:

Parents as partners in care (AIIMS, Delhi, Nambikkai Nilayan, Vellore)

Primary Health Care Personnel (Raipur Rani Experience, Sakalawara, NIMHANS)

ICDs personnel (Krishna Murthy et al, 1984).

DRC personnel.

Village level volunteers (Sever-in-action, Bangelvri).

Interacted Education for the disabled (IED scheme, GOI).

‘Camp’ approach (THPI, NIMHANS)

Few NGOs have done outstanding work in terms of running CPR programmes for the prevention of disability (a few of them are, the CPR programme run by THPI, Hyderabad, Seva-in-Actin, Bangalore, Samadhan, New Delhi, some of the UNICEF funded projects, Action Aid, Bangalore etc.). One of the pioneering institutions to go in for CPR was THPI. It may also be noted that THPI is the first and unique of its kind to open a Rural Community Based Rehabilitation centre for the MR in Lalacheruvu of Rajahmundry Distt., Andhra Pradesh.

Through various approaches and various models, CPR is involved in a real participative function. If we are realistic, we will see that the evolving ideas and practices of CPR have the potential of being not only more affordable, but more important of being more relevant to the lives and future of many handicapped people with more experiences we may well evolve what we should have had all along a people based Rehabilitation (Prasad, 102).
FOSTER CARE HOME

Foster Care Home is a home away from home, specially mentioned home for children with MR, who require accommodation and special care. Many organisations are now acquiring this method. As a special case of THPI, Hyderabad, special education unit and the Mult-disciplinary team maintain an effective link with the Foster Care Home. Around 60 children from different parts of India are beneficiaries of this programme.

Each cottage in THPI, takes care of four children with the help of trained Foster Care Mothers. Individualised follow-up programme for the foster care home is set as part of IPR (Individual Rehabilitation Programme) and is reviewed periodically. This is in addition to the daily routine of the home starting with the secular prayer in the morning concluding with the evening prayer and dinner. Here they also learn and master their activities of daily living, viz.—toiletting, behaviour, bathing, grooming, dressing, eating and brushing with the support of their foster care mothers, who impart very systematic training and guidance.

Foster Care Home is really a most traditional and realistic approach in a way of socialisation of a MR child and also plays an important role in assimilating the MR child with the normal behaviour of society.

The advent of CBR services started in our country with the introduction of Portage Programme way back in 1977. Since then, several centres initiated home training of children with mental retardation using the concept of home teachers and home visitors.

DRC SCHEME

The formal and comprehensive CBR services started with the initiation of District Rehabilitation Centre (DRC) Scheme by the Government of India in the year 1985. On a trial basis, DRC scheme was initiated at 11 districts. Four Regional Rehabilitation Training Centres (RRTC) were set up at Bhubaneswar, Lucknow, Chennai and Mumbai.

The services provided by the DRC team relate to detection of cases having mental retardation through house to house survey. Once a case is detected, comprehensive assessment is undertaken. As and when the diagnosis of mental retardation is established, group parent training programmes and consultation to the individual family are provided by the experts through multipurpose rehabilitation assistants. All along the emphasis is given on home based training of children with mental retardation.

There are about 50 voluntary organisations, who run CBR services. The Government of India has recently formulated a scheme to support CBR in the country. As rehabilitation services are proposed to be implemented through voluntary organisations financial support upto 95% extent will be given by the Ministry of Social Justice and Empowerment, Government of India. Each Non Governmental Organisation taking grant from the Government of India will be required to take up at least ten PHCs in the district so as to provide services of screening, detection, assessment, training, management and care, vocational training and job placement to people with disabilities.
CHAPTER 47
EMPLOYMENT AND RIGHTS OF MENTALLY RETARDED

LEGAL RIGHTS AND OTHER PROVISIONS

The Constitution of India as the basic law carries the guarantee of legal security for all its citizens. It mandates that the laws to be made pursuant to the authority of the constitution must conform to the principles of fairness, equal objectivity and fraternity of the people. There are for instance, fundamental rights guaranteed to the citizens who also have certain fundamental duties in relation to follow citizens and the government. These are:

- The constitution secures to the citizens including the disabled, justice, liberty of thought, expression, belief, faith and worship, equality of status and of opportunity and for the promotion of fraternity, just as it does for other citizens who are not disabled.
- Article 15(1)—not to discriminate against any citizen of India (including the disabled) on the ground of religion, race, cast, sex, place of birth or any of them.
- Article 15(2)—no citizen (including the disabled) shall be subjected to any disability, liability, restriction or condition on any of the above grounds in the matter of their access of any public place or in the use of any public commodity which is for the general public.
- Article 17—No person (including the disabled) of his belonging can be treated as an untouchable. It would be an offence punishable.
- Article 21—Each person (including the disabled) has his life and liberty guaranteed.
- Article 23—There can be no traffic in human beings (including the disabled) and beggar and other forms of forced labour is prohibited and the same is made punishable in accordance with law.
- Article 24—Prohibits employment of children (including the disabled) below the age of 14 years to work in any factory or mine or to be engaged in any other hazardous employment.
- Article 25—Guarantees to every citizen (including the disabled) the right to freedom of religion. Every disabled person (like the non disabled) has the freedom of conscience to practice and propagate his religion subject to proper order, morality and health.
- No disabled person can be compelled to pay any taxes for the promotion and maintenance of any particular religion or religious group.
- No disabled person will be deprived of the right to the language, script or culture which he has or to which he belongs.
- Article 32—Every disabled person can move to the Supreme Court of India to enforce his fundamental rights.
- No disabled person owning property (like the non-disabled) can be deprived of his property except by authority of law though right to property is not a fundamental right. Any unauthorised deprivation of property can be challenged by suit and for relief by way of damages.
- Every disabled person (like the non-disabled) on attainment of 18 years of age becomes eligible for inclusion of his name in the general electoral roll for the territorial constituency to which he belongs.
- Article 29(2)—Provides that no citizen shall be denied admission into any educational institution maintained by the State or receiving aid out of State funds on grounds only of religion, race, caste, language or any of them. This right is as much guaranteed to the disabled as to the non disabled. If the disabled belong to a minority religion or language they shall have the right to establish and administer educational institution of their choice and the State shall not discriminate in granting aid to such educational institution under the management of the minority whether based on religion or language.
- Article 45—Directs the State to provide free and compulsory education for all children (including the disabled) until they attain the age of 14 years.
- Article 47—Imposes on the Government a primary duty to raise the level of nutrition and the standard of living of its people and the improvement of the public health and in particular to bring about prohibition of the consumption of intoxicating drinks and drugs which are injurious to health except for medicinal purposes.
- Article 41—Provides that the State shall within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in case of unemployment, old age, sickness and disablement and in other cases of undeserved want.
- The Mental Health Act, 1987 (Primary Lunacy Act of 1912)—is an Act to consolidate and amend the law relating to the treatment and care of mentally ill persons, to make better provisions with respect to their property and affairs and for connected matters. Under this Act, provisions have been made for admitting persons to any psychiatric hospital or psychiatric nursing home for treatment as a voluntary patient. The medical officer in-charge after making necessary inquiry within 24 hours may admit the patient. the patient can be discharged only after the medical officer in-charge has taken the opinion of a Board consisting of two medical officers as to whether further treatment is necessary.
- Persons with Disabilities (Equal Opportunities, Protection of Rights and Full participation) Act, 1995—was enacted to give effect to the proclamation on the full participation and equality of the people with disabilities in the Asian and Pacific region
Employment and Rights of Mentally Retarded

held at Beijing from 1st to 5th December 1992. This Act spells out the responsibility of the State towards the prevention of disabilities, protection of rights, provision of medical care, education, training, employment and rehabilitation of persons with disabilities. It also provides for creating a barrier free environment for persons with disabilities to remove any discrimination against persons with disabilities in the sharing of development benefits vis-a-vis non-disabled persons, to counteract any situation of the abuse and exploitation of the disabled persons, to lay down strategies for comprehensive developments for programmes and services and for equal opportunities for disabled persons and for their integration into the social mainstream. The Act provides the constitution of Co-ordination Committees and Executive Committees at the Central and State level for carrying out the functions assigned to them under the Act.

- The Rehabilitation Council of India Act, 1992, was also enacted to provide for the constitution of the Rehabilitation Council of India for regulating the training of rehabilitation professionals and for maintenance of a central rehabilitation register and for matters connected therewith or incidental thereto.

- Under the Hindu Succession Act, 1956 (which applies to Hindus), it has been specifically provided that physical disability or physical deformity would not disentitle a person from inheriting ancestral property. Similarly, in the Indian Succession Act, 1925, which applies in the case of intestate and testamentary succession there is no provision which deprives the disabled from inheriting ancestral property. The position with regard to Parsis and the Muslims is the same.

- The State legislatures are empowered to legislate on “relief of the disabled and unemployable” by virtue of Entry 9 of the State List of the Constitution. There may be special provisions made for the benefit of disabled workmen such as job quota for the disabled, reservation of particular jobs for the disabled, concessions in the performance and output of the disabled.

- Special procedures have been laid down in sections 328 to 339 of the Criminal Procedure Code, 1973 for trial of accused persons of unsound mind who are incapable of making their defense. Sec. 84 of the IPC excepts a person who does any offense if he is in capable of knowing the nature of the act, or that he is doing what is either wrong or contrary to law.

- The Income Tax Act, 1961 recognises the plight of the disabled and allows concessions to the blind or those subject to permanent physical disability and also allows deductions incurred on the maintenance of the disabled.

**CONCESSIONS AND BENEFITS FOR THE MENTALLY RETARDED**

A number of concessions and benefits have been granted by the central government of India as well as State Governments for persons with Mentally Retarded.

- 75% concession in the basic train fare in the first and second class is allowed to a person with MR accompanied by an escort and to periods in groups or fans. These are liveable between this homes and school/institutions, place of vocation and examination centres, provided they are recognised by the government. Most State
governments having own and operated transport undertakings or corporations allow subsidised/free bus travel in the city and rural routes. Persons with MR are allowed to travel with an escort. For this purpose, a certificate must be issued by a medical practitioner in government service or an institution/school.

- Public telephone with or without STD facility are allotted by the Department of Telephones to enable the public to make telephone calls at prescribed charges. MR persons are being given preference in allotment of telephone booths as means of sustenance, vocational rehabilitation and income generation.

- The Union Ministry of Welfare since 1955 has been operating through the State Governments and Union Territories a scheme of scholarships awarded to disabled person for pursuing education in special schools being run by non-government organisations. The scholarships are awarded to MR students subject to their being certified by clinical psychologist/psychiatrist.

- The handicapped children have the benefit of receiving education in the regular school system. Various allowances and annual cost of the equipment are provided under this scheme.

- A government servant is eligible to draw Children's Educational Allowance when he/she is compelled to send his/her MR child to a school away from the station of his/her posting.

- The government of India operates a scheme under which assistance is given to disabled persons for purchase and fitting of aids and appliance.

- Most housing boards and urban development authorities have schemes of preferential allotment of plots and housing sites to individuals with disability.

- The Government of India, Department of Personnel and Training vide O.M. No. AB-14017/41/90-Estt (R) dt 15th February, 1991, makes a provision for a choice in the place of posting of parents in government service having a child with MR.

There are some assistance to voluntary organisations for the disabled also. These are:

- Assistance upto 90% in urban and 95% in rural areas is given to NGOs for education, training and rehabilitation of the disabled.

- For rehabilitation of people recovering from mental illness, a special component to assist NGOs working in this areas has been added.

- Emphasis on vocational guidance and training.

- Liaison with nearest psychiatrist centre/hospital essential.

- Provision for half-way homes.

- For manpower training of professionals and also for developing organisational infrastructure such as class room/library/hostel etc., in the field of cerebral palsy and mental retardation, 100% assistance is provided to voluntary organisations.

- For setting up special schools, voluntary organisations receive grants upto 90%.

- Preference for opening schools in new districts and upgradation of existing schools.
The Government of India has set up a National Trust for the MR and the Cerebral Palsied. The objective of the trust is to set up care services for those who cannot achieve economic independence or cannot be cared for by their own families.

**Assistance to Voluntary Organisations for the Disabled**

- Assistance upto 90% in urban and 95% in rural areas is given to NGOs for education, training and rehabilitation of the Disabled.
- For rehabilitation of people recovering from mental illness, a special component to assist NGOs working in this area has been added.
- Emphasis on Vocational Guidance and Training.
- Liaison with nearest Psychiatrist Centre/Hospital essential
- Provision for half-way homes.

**Assistance to Voluntary Organisation for Manpower Development in the Field of Cerebral Palsy and Mental Retardation**

- For manpower training of professionals and also for developing organisational infrastructure such as class room/library/hostel etc. In the field of cerebral palsy and mental retardation, 100% assistance is provided to voluntary organisations.

**Assistance to Voluntary Organisation for Establishment of Special Schools**

- For setting up special schools, voluntary organisations receive grants upto 90%.
- Preference for opening schools in new districts and upgradation of existing schools.
CHAPTER 48

COMMUNITY, PARENTAL ATTITUDE AND INVOLVEMENT

FAMILY SUPPORT AND ATTITUDE

The advent of a MR child/family in a family leads to many stresses in the family dynamics and it is necessary that the family is considered as a whole and help given to enable them to work through the many problems that will arise. The home is usually the ideal situation in which to rear a handicapped child as this can usually meet all the emotional needs and the child can be treated as an individual from the start. Initially the handicapped child is no different as regard the degree of dependence on the mother from a normal child, except those with severe associated physical abnormalities. However, as the child gets older, the level dependence does not decrease normally and this throws an increasing burden on the parents who can often see no relief and help and support will be needed to maintain the child at home. This help will usually be in a concrete form e.g. home helps, special aids etc., but this practical help for the problems must not be to the exclusion of the emotional help that will be required though often not requested openly. Thus the special needs of the MR and their family can be encountered as follows:

- Early identification.
- Complete assessment.
- Prompt treatment of anything that is treatable.
- Social setting to give love and security to allow maximum development of the personality.
- Suitable education adopted to the individual’s complex handicaps.
- Appropriate contacts and leisure time activity.
- Follow up and continuous assessment.
- Family guidance and support.

Besides family support, the attitude of the family especially of the parents is also very important factor in the development of a MR child. It was found, parental over-indulgence over solicitude and over-pampering were related to maladaptive and neurotic behaviour in the child. There are six main additional dimensions among parents of MR child and its effect on child behaviour and these are: responsibility, discipline and conformity, uncertainty, rejection, personal-social and understanding the child.

The attitudes that mentally handicapped should be cared for outside the normal society in institutions cared for outside the normal society in institutions is in general in
most countries considered past, and gives way to the knowledge that most of them can, by creating the right ambulant aids, be kept in the family and in society and may, as grown-ups, contribute themselves to a happy, useful life within society by doing productive work.

As all measures to help are linked to each other like a chain, an overall programme covering all necessary measures from birth to death has to be developed.

First of all, the problem of a handicapped child is also a far-reaching family problem as in nearly all cases the effect of the handicap is manifested, especially at the beginning, as an interference, if not a danger to the natural community of all family members.

On the other hand, however, it is just the handicapped child that depends in a special way on the personal care of his mother, who on her part is generally only reluctantly ready to let others take care of the child who is so dependent on her help and guidance.

For this reason planning of services for handicapped children and adolescents can only be successful if the family is involved in the total system of help and if parents' counselling is placed at the beginning of all actions to be taken.

Apart from the multi-dimensional examination of the child and parents' counselling, these counselling services have also to fulfil an essential co-ordinating function in the total system of help and should be placed in the centre of all services for child and family.

Although rearing an MR child on the family appear to be complex and many families are faced with problems including those of management, finance deprivation of rest and leisure to the parents, but there are so many examples which may cope very well and remain cohesive and creative units in which other children may grow up normally and happily. It all depends upon the parental attitude. Thus, family as a primary centre of socialization, centre of recreation, affection, self identity, economic vocational/educational needs of the MR child can play a positive and decisive role in the development of their MR child.

PARENTAL INVOLVEMENT

It is a well known fact that in India parents play an important role in the development of their child even their child is disabled or not. If it is disabled, then their involvement with their child is countable. In India, parents are naturally involved with their child and if they could be appropriately trained and involved in the management of their child this could help build up a natural permanent constructive resource for MR person in our country (Peshawaria, 1988) and it is widely assumed that involving parents will effect changes in the child directly (Hornby & Murray, 1983; Backer, Heifitz & Murphy, 1980) as a result of enhancing parental management skills or indirectly improving family functioning through support and counselling. It was found through the researches that:

- An educationally stimulating home environment is associated with adaptive competence of the child.
Social adjustment of the child is related to cohesiveness and harmony at home.

An educationally stimulating home environment for the trainable children depends primarily upon the quality of parenting and child rearing practices.

An educationally stimulating home environment for the Educable MR child involves psycho-social climate of home as well as culturally stimulating atmosphere and educational expectations.

Family harmony and quality of parenting are related to the family’s ability to cope with the problem of MR.

The family is likely to feel that the MR has major impact on the family, especially when there are other family conflicts.

The feeling of impacts is also related to in-adaptive behaviour of the child.

Thus, parental involvement with the MR child can play a major role; parents can play a role of educator, therapist, psychiatrist also. Through involvement in child programmes, parents organisations, opinion and public policies available extended families, community support, utilisation of professional services, promoting simplicity in administering services, promoting the family as a receiving health services, providing financial support to parents, the participation and involvement of parents can be increased.

Parents participation is expected thus to benefit the child, parent, family and society at large. The different ways of viewing parent involvement, however, is that it should have positive parent outcomes i.e., reducing stress, increasing family coping and improving relationships within the family.

Though there is no quantitative data available so far with us whereby we can list the contributions made by the people in the community. Voluntary organizations like Rotary Club, Lions Club, Red Cross, well wishers from private sectors, public undertakings have supported programmes for the welfare of the individuals with mental retardation by:

- Setting up special schools
- Sponsoring a child coming from a very poor family to a special school for some period of time
- Distribution of clothes and food to the children with mental retardation
- Organising picnics and festivities for children with mental handicap
- Providing scholarships to deserving students with disability
- Sponsoring of organising screening and identification camps
- Organising public awareness programmes
- Starting vocational training programmes and by providing employment opportunities to individuals with mental handicap.
Research relating to mental retardation in India falls into seven different categories. They are:

- Conceptual issues
- Service delivery system
- Curriculum and instruction
- Management
- Survey and Rehabilitation
- Assessment
- Bio-Medical Research
- Recent advances

CONCEPTUAL ISSUES

Not many works have been undertaken regarding specifying the characteristics and classification of MR. Often it is done by intuition, observation of morphology, use of one available test or redundant of combination of tests. This is not to say that what existing in India is not worthy of doing but there must be a systematic research to develop
learning potential assessment device (LPAD) which would take into account cognitive competence and adaptive behaviour, appropriate to the age levels based on performance and daily living skills. In the socio-cultural context in which the MR children find themselves in India this is a dire necessity. The next emphasis should have been on psycho educational characteristic of MR children quite a few studies have come up under the authorship of Sen (1983) and Sen (1988) but these studies are mostly related to attention, learning and memory. The findings reflect comparative status quo between normal retarded differences.

There is hardly any normative studies on profile of characteristics of MR on cognitive, affective or skill learning.

SERVICE DELIVERY SYSTEM

Mental retardation is socio-cultural as well as familial. Therefore sociological labelling expressed in terms of labels, stigma, negative expectancy are more prominent in our society rather than pragmatism and progressivism. This has been reflected in attitudes of teachers, community members and parents, particularly negatively for mental defects. But there is no attempt to examine its real basis. No research seems to have been conducted in Indian context to know whether an MR child can or cannot learn in an integrated setting. Can normal peers help MR child to learn? How can the parental attitude change towards the retarded? How far government and voluntary organization compare? Unfortunately till today we have no research evidences in our society probably because the MR stigma is so strong. There is one study by Kamila on “Haves and have-nots” Is special school the answer”? The answer is No. Instead it suggests a mainstreaming model. (Kamila, 1997).

CURRICULUM AND INSTRUCTIONS

Curriculum and instructional procedure for the Mental Retarded have received scant or no attention from researchers except in preparation of skill development materials at NIMH Secunderabad and THPI at Hyderabad. Diagnostic curriculum at Amar Jyoti, Jogan exercises at Madras. Although NCERT developed a source book for teachers of visual impaired, and hearing impaired it has lost eight of MR which constitutes the largest segment of the disabled population. The effect of isolation on learning and memory was undertaken by Goel and Panda (1998); it led to conflicting findings because the procedure followed by the first author was unfortunately not in line against of the concept of serial learning. However, isolation of materials does improve learning and memory of the retarded. There is a need for curriculum research in arithmetic, reading, language, social skills and determination of efficiency of an instructional techniques. The research literature is conspicuously absent in this regard.

MANAGEMENT

Socio-cultural mental retardation is by and large ecology specific. The home, the school and the society have influence on the incidence of retardation by the way of precipitation
in the contest of prevailing attitudes, stereotypes, prejudices. Hence, the best of the programme has not made any difference. The studies on attitudes on MR are negative and expectations are limited whether mainstreaming would have a long term impact what would be the role of parent and community what kinds of functional environment can promote learning adjustment are quite significant but we do not have any such systematic report excepting that of Panda (1992).

**BIOMEDICAL RESEARCH**

Hardly there is any bio-medical research excepting that of PKU by Krupanidhi and Punekar (1963, 1966) and nutritional deficiency and cognitive development (Dutta, T). Bio-chemical screening of children after birth and dietary habit would go a long way in reducing occurrence of mental retardation in India where an expectant mother in India does not smoke, dring, does not expose to radiation but there may be culture specific influence such as malnutrition ignorance about infection which create a predisposing condition for MR condition. Hardly we have any research evidence to support.

**SURVEY AND REHABILITATION**

Indian research on disability and particularly on MR on acceptability in Rural verses Urban community have not been undertaken so far. Scoio-psychological survey could determine the attitudes of rural verses urban attitude towards the acceptance of retarded individual in the community would be an indicator for their rehabilitation but again the research scene in Indian contest is dismal. Most of the research dealing with low intelligent children are in the contest of cultural depravation attributed to poor social class and poverty. Area specific prevalence is yet to be undertaken. One of the significant studies in research on rehabilitation was recently taken up by Mrs. Yasho Karan Singh, (1996), which analysed the socio-psychological adjustment of mentally retarded children, Role of intellectually disabled in the work-force, exposure of mentally handicapped children to school setting open and self employment sheltered workshop, cooperative employment and recommended a series of rehabilitation action programmes. A gross limitation of these studies are its methodology, but the ideas are quite pragmatic for other researchers to undertake.

**ASSESSMENT**

Assessment has two basic purpose one is to know what the child is and the second is to place him in a setting for restoration. The use of intelligence as a measure does not fulfill cultural mentality. Since, of late retardation is considered as a developmental delay, inferential generalisation of MR should be more comprehensive. The research position on MR has received serious criticism with development approach and will probably never provide conclusive evidences. In the absence of growth studies, there is a need for behavioural assessment in the field of applied behaviour analysis, behaviour modificaton and behaviour therapy. Research should be change oriented and criterion referenced. But Indian research on assessment of MR has been over the years piecemeal, incidental, checklist oriented and therefore, fall behind in quality and quantity. There is a need for
research on precision teaching and formative assessment which should predict future learning and growth. Development of assessment instruments already developed by NIMH needs to be translated for different regions for profitable identification, placement and intervention (Panda, 1994).

**RECENT DEVELOPMENTS IN RESEARCH**

It is true that recent years has noticed a change from medical diagnosis to multi-professional assessment, treatment to education, categorisation to individualised need programme (Evans and Verma, 1990; Pandey and Advani, 1995). Yet, research in India has not made much headway in the field of MR. Perspectives for education of the disabled has been provided by Narsimhan and Mukerjee (1986), and Panda (1974). Most of what is available in psycho–educational research on disability are quite limited. A glance at the Indian Journal of Mental Retardation, Disability and Impairment and Journal of the Institute of Speech and Hearing would substantiate such observations although except for Disability and Impairment the other two are virtually out of scene.

Quite a few significant studies have appeared under the guidance and involvement of individual researchers. Noted amongst them are the contributions of Prof. A.K. Sen and Prof. Anima Sen at Delhi University with reference to MR and specifically on learning and memory processes (Das, 1968; Goel and Sen, 1985), psych–osocial integration of the handicapped (Sen 1983, 1988), Peer Modelling in MR (Narayan, 1992), isolation effect on learning in MR (Panda, 1995) etc., are among the significant ones. NIMH has also researched into skill development in MR.

Research have concentrated more on learning, memory, attention, personality, community attitudes, efficiency of systems but hardly are oriented towards interventions but for few which are at aimed skill development, development of learning package. National Institutes, NCERT, University Departments have not catered to significant research but contributed more to education training of personnel for handling the disabled. Efficacy studies have come up recently (Mani, 1993; Rath, 1993) but researches taken as a whole in the field of special education are in an embryonic state.

There is no denying the fact that even till now the area of disability has remained as an area of welfare, rehabilitation and care, than research, development and education. Both the directions are important and research can well integrate the two to the advantage of the disabled particularly of the mentally retarded.

The cause of mental retardation is known in about in 70% cases. Of these, genetic factors play an important role in the etiology of 30 to 50% cases of mental handicap. Chromosomal abnormalities are recognised as an important etiological factor in human disease and in particular in mental retardation.

In the study conducted by Mind’s college of special Education, Mumbai, chromosomal analysis was carried out in 2002 subjects over a period of 13 years. Cases included individuals with mental handicap where the cause was not known, those with a known recognisable syndrome or with dysmorphic features, and those with a family history of mental handicap. Parents and siblings of positive cases were also included.

In all, there were 1241 males and 761 females in this study. These included 987 cases referred for detection of fragile sites on the X chromosome.
Down Syndrome

- Down Syndrome is an Important Cause of MR
- 12.3% of All Cases of MR
- 37.9% of Chromosomal Aberrations
- 67.6% Had An I.Q. < 40 Points
- 3 Cases of Mosaicism Had Mild, Moderate and Severe Mr. Each
- All cases had varying degree of MR
- Only 1 Child had Borderline Developmental Delay
- More than 80% mothers were < 35 years of age at time of Birth of Down’s Child
- Hence the role of advanced maternal age in the etiology of non-disjunctional MR is questionable
- Triple marker screening using maternalAFP, estriol and hcg should be considered as a routine in all pregnant women
- High risk or screen positive women should be taken up for pre-natal diagnosis.

Of the 2002 cases analysed, 1351 cases were found to have a normal chromosome complement. Six hundred and fifty one (30.7%) cases were found to have an abnormal chromosome complement. There were 236 (23.9%) cases positive for fragile X out of a total of 987 cases. This included 162 males and 74 females. There were 251 cases with Down Syndrome. The remaining 164 cases showed various other chromosomal aberrations in the form of deletions, translocations, additions, etc.

Various epidemiological factors such as parental ages, consanguinity, level of intellectual functioning, family history, dysmorphic features have been analysed under various groups e.g. Down Syndrome. Fragile X Syndrome and other chromosomal syndromes. The possible role of these factors, if any in the causation are known now. The rarer aberrations and their clinical correlation have implications for future research.
CHAPTER 50

SOME REFLECTIONS FROM THE FIELD

For preparing the status report on MR in India, it is also important to look at some of the institutions, their functioning and views of the beneficiaries from the programme being floated in the country. Institutions were randomly selected from the directory of the institutes of NIMH and Sankalp. Two sets of questionnaire were developed by the THPI, Hyderabad, one was for the organizations and the other for the parents. The questionnaire were sent to the selected group of organisations. Responses of only one third of the respondents were received.

On the basis of the information supplied by them, few ideas emerged. Institutions in the file of MR at the moment are largely functioning on private initiative and finance with partial support from the government. In the second line, there are few organizations which are govt. funded with private contributions. Full funded government institutions are comparatively few.

Nearly 82% of the institutions had minimum five professionals in the medical field including physiotherapist, occupational therapist and speech therapist. On an average, they have five staff members in psychological, special education and social work; five in dance, yoga, music, etc., and nearly 15% of the institutions had around 5% staff belonging to the other services. Invariably, half of the professionals working are registered with RCI.

On an average, 150 beneficiaries receive services from an organization. During the last two years, their figures represent the five categories as well as both boys and girls. By and large, they came from middle income groups followed by low income groups. Very few of them have high income background. The beneficiaries largely came out from rural areas and they were referred by parents, medical practitioners, and teachers.

Nearly 50% of the organisations have diagnostic services, early intervention, home-based and special pre-school for education, vocational training centres, placement services and CBR. However, about 30% of the institutions have provision for integrated education, single category vocational training institutions on the job training extension services.

Around 90% of the institutions conduct IRP maintain progress report largely quarterly evaluation, use standardised scales for diagnostic purpose. They have their training programmes for staff as well as for others. Less than 50% of the organisations undertake action researches and awareness building programmes in rural area.

The suggestion that they have offered assisting the MR beneficiaries after the death of their parents is putting in Foster Care Health Service, Residential Centres, Insurance Policy and provision of self-employment with community support.
The challenges before the beneficiaries in the field of MR are community awareness, setting up special government schools providing job security, increasing parental awareness, providing for future care, mainstreaming through integrated education.

These observations mainly provide some of the existing state of affairs and concern in the sample institutions which may reflect nature of such institutions of MR in the country.

The parental perceptions of education and rehabilitation services provided in the field of MR reflect lack of information and guidance. As a result, they lag behind in programme involvement excepting being caretaker of the children, even their ignorance about various legislative measures and practices of educational training of MR in the country.

While they voiced for more facility to MR, they are unable to make any candid suggestions. These observations lead us to conclude that there is a greater need of dispelling ignorance particularly among parents. This is only a cursory view on the basis of data gathered. Detailed report would further clarify and highlight their specifics even though the sample is limited.
CHAPTER 51

LOOKING AHEAD

This is a question which is difficult to answer, but professionals irrespective of speciality in the field of disability must concentrate basically on issues and problems, which are relevant to educational and rehabilitation aspects by and large.

A major focus of our research endeavours must specify comparative studies on different therapeutic interventions and practices, sensory stimulations much early in the process of development and identify efficient procedures for developmental quotient and not merely IQ changes, competence, skills and social personal adjustment would be the primary focus leading to school readiness. Such research areas are painstaking and challenging but worth undertaking.

Special education in our country is an emerging field but there are many sound research generalisations elsewhere the field that had an earlier origin. It is time for us to think and say on the basis of our own studies whether home based interventions are any way better than the institution based interventions, integrated system vs. the special system, efficacy of community based rehabilitation and family studies. Public attitudes, acceptance and awareness are to be assessed and manipulated through various awareness programme since disability seen in home is sustained because of negative attitudes and stigma by the society.

How far rights of the retarded are ensured or are they still discriminated against despite legal provisions? Disability occupation-fit studies are essential for initiating training using a global socially desirable approach to draw attention or pay a lip service to the vital areas.

Technology has come in a big way. How can it be used to the advantage of the disabled?—in terms of aids and appliances, classroom learning, teaching, self-learning, mastery learning, evaluation; diagnostic as well as normative, microprocessors and their use in case of teaching the disabled. Many such issues will appear. These are some directions only. While disability specific research is a matter of individual concern these are some of the area that come in any area of disability.

Behavioural scientists tend to be obsessed by their methods often at the expense of their results. It is not proper to enter into any philosophical debate on the process nor can any methodological formula for scientific research be formulated. The principal way of attending competence is to do it and develop insight. These methodological issues relate to design in research, sampling frame and to size, qualitative vs. quantitative research techniques. The field of special education is essentially fraught with many such issues since researchers in special education have migrated from other disciplines with their well established rigid, hard-core or soft-core training and temperament. The field of
special education even without sacrificing research ethics, propriety and rigour can still follow a clinical model, a sample size of 1, a single subject research design using withdrawal or multiple baseline data; across subjects, across situations, quasi-experimental design can take care of extreme groups in such research, as well as purposive sampling are acceptable practices in spite of procedural lapses and regression, when sample size is not large as is typical in the field of special education. What needed is that researchers in special education should take care of the methodological issues even when they use qualitative research techniques for fact finding participant observation, interviewing, documentation and review. The fact should remain that it should maintain credibility, transferability, dependability, confirmability, authenticity and fairness.

In the field of education, the year 2000 will see changes in educational index but what of disabled children? Can improved educational opportunities be extended to this group? Can inclusive education be benefiting the disabled or is medium of our self preservation exercise and instinct? If not, research in the next decade should focus on the development of functional skill training, even using computer technology and computer aided instructions. A few suggestions for the future are:

- Allow students to proceed at a more individual pace, thereby reducing stigmas.
- Enable developmentally disabled to work at home.
- Provide learning aids specifically designed for a group of disability.

In summary, research in the next decade and ahead should focus on:

- Identification of available services and resources.
- Development of learning potential assessment device test as basis of diagnosis.
- Epidemiological investigation of the retarded population.
- Research and advocacy of treatment approaches and techniques.
- Community integration with a comprehensive care system and a full operational prevention process.
- Identification of individually suitable teaching practices, peer tutoring and modelling, education and service delivery system.
- Family studies.

These are but a few reflections but there will be many more if really we are committed to the cause of helping mentally retarded children in our society.
CHAPTER 52

TRAGEDIES CONVERTED INTO CHALLENGES: A CASE STUDY OF RURAL PROJECT, LALACHERUVU, RAJAHMUNDRY (ANDHRA PRADESH)

A GLIMPSE OF CURRENT ACTIVITIES—A DECADAL PROGRESS

THPI rural project at Lalacheruvu, Rajahmundry is situated amidst rural community of East Godavari District, serving the long-felt and hitherto unmet needs of Coastal Districts. As a nodal agency this Rural Project is not simply limiting itself to render few service programmes for persons with mental handicap and their families, but also making endeavours to generate models of service care delivery systems that can be cost-effective and be easily replicable throughout the country in the rural sectors, as well can stand out as field tested models for all developing countries.

Rural areas in Andhra Pradesh have not been actively covered nor taken into serious consideration, in terms of rendering scientific services to rural based masses, facing the challenge of mental handicap from social, economic, educational, social, integrational, employment generation and integrational rehabilitational dimensions, concerning the hitherto untouched lives of neglected
persons with mental handicap. Either or branding as mentally ill are the only few alternatives left out to public in rural areas while handling issues related to mentally handicapped. Family members too have few options, either resorting to harsh punishments, isolating, imprisoning in the house, social rejection or resorting to suicidal attempts, when they are handling challenges created by persons with mental handicap. At the back drop of this pathetic condition, THPI Rural Project has set it’s foot, ahead in the course of ameliorating thousands of persons with mental handicap in the rural areas of Andhra Pradesh, by initiating preliminary actions at Rajahmundry. This rural project was initiated in 1991 at Lalacheruvu near Rajahmundry of East Godavari district, one of the most populated districts of Andhra Pradesh.

Reaching out to the unreached in rural areas for another 50 years, services for persons with mental handicap can never be provided, Unless community based rehabilitation/community level rehabilitation is adopted in developing countries like India, where there is acute scarcity of trained manpower, shortage of financial and material resources.

THPI, Rural Project is planning to concentrate more on the employment of adult persons with mental handicap in various situations and in extending services to remote villages and tribal areas in order to reach out to more persons with mental handicap and their families.

The Importance of Rural Project of Lalacheruvu can be realised only if we have a glimpse of present national scenario and rural realities.

**IMPORTANT CONTRIBUTIONS OF THE ORGANISATION SINCE 1990**

1. Pushkaram Public Exhibition in 1991
   Distributed 50,000 free pamphlets for Awareness generating on prevention, early identification, social integration of persons with Mental Retardation

2. Zonal Sports Meet-1995:
   Sports Meet on Special Olympics lines was conducted, 300 players from 5 Districts took part

3. RCI National Workshop-1997 on National Workshop “Approaches & Methodologies for Rehabilitation of Persons with Mental Handicap in Rural Communities” was held in THPI Rural Project.

4. Development of Models of Community Participation:
   Local Management Committees where programmes were conducted and executed

5. Teaching Aids:
   Development of ecologically suitable rural oriented teaching aids, learning material

6. Mini Camp Approach:
   Mass Awareness in Rural areas in fast manner with limited personnel

7. Rural Camps:
   Since 1990 Rural Camps were organised to generate mass awareness in rural areas

8. Service to Tribal Areas:
   Tribal based PHC personnel, ITDA Officers sensitisation, Tribal based camps were carried out.
9. “Sankalpam”.
   Telugu magazine was initiated for awareness among Telugu reading population
10. National Pulse Polio Programme:
    The Programme was coordinated and PHCs were supported since 1995. Around 52 to
    70 thousand below 5 years children identified and vaccinated.
11. Rural Rehabilitation Centers:
    Entire Rajanagaram Mandal was covered by establishing 16 rural rehabilitation centers.
12. Produced series of literature for parents
    Developed series of simple literature for supporting parents by supplying technical literature.
13. Video Cassette:
    Video Cassette were produced for public awareness and attitudinal change on Mental Handicap
14. Discreet Trial Teaching for Autistic Children:
    For Autistic Children Discreet Trial Teaching Models were developed.
15. Model Developments:
    Therapy models were developed for enhancing communication skills and self advocacy.
17. Training/Sensitising of PHC Doctors and Para-professionals/Parents/Professionals.
18. Open Employment Generation.

**MENSTRUAL HYGIENE**

In training persons with mental handicap the role of parents, siblings and grandparents is extremely important. Children with mental handicap learn slowly because of their poor adaptive and cognitive skills. Hence intensive training is necessary to make them as independent as possible.

While training the adult female mentally handicapped the role of mother or female sibling plays an important role in helping adult persons with mental handicap to become as independent as possible in the area of menstrual hygiene. Being an Innovative exercise, THDPI's Imaginative role in this area is laudable.

**HOW IS THIS DONE?**

Before starting the programme is observed whether the trainee can report her periods or not? If she reports her periods, by noticing a red stain of blood on the panty of her undergarments I hope she starts training in dressing from that state. If not, she is taught to report her periods where the other part can be taken care of by family members and our social workers.
PRESENT NATIONAL SCENARIO

1. Population of persons with disability (Mental, physical, visual & speech & hearing) = About 10 Crores
2. Population of persons with mental disability + About 3 Crores
3. Rural Population = About 70%
4. Inaccessibility to basic services for rural persons with disability

THE RURAL REALITIES

<table>
<thead>
<tr>
<th>Poor Awareness</th>
<th>Misconceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poverty</td>
<td>Misconceptions</td>
</tr>
<tr>
<td>Ignorance</td>
<td>Myths</td>
</tr>
<tr>
<td>Illiteracy</td>
<td>Resulting to</td>
</tr>
<tr>
<td>Inadequate Medical Facilities</td>
<td>Traditional unscientific practices</td>
</tr>
<tr>
<td>and non-availability of</td>
<td>viz., witch craft, faith healing, etc.</td>
</tr>
<tr>
<td>Basic Services for Disabled</td>
<td>Violation of Human Rights</td>
</tr>
</tbody>
</table>

Major Thrust Areas of Rural Project

- Attend to the problems of the disabled – mental handicap in particular
- Develop economically viable programmes
- Generate mass awareness creation
- Sustained development through community support/participation
- Provide basic services to the disabled
- Alter negative patterns of practice
- Provide gainful and suitable employment and income generating opportunities
- Mass transfer of knowledge and skills
- Empower the persons with mental handicap and their families

Strategies Devised

1. Convergence of services by networking with local existing governmental and non-governmental agencies
2. Optimum Utilisation and Mobilisation of available Resources
   - Health infrastructure (Directorate of health, district hospitals, P.H.C.s, sub-centre, etc.)
   - Educational institutions/training centres (local schools, universities, I.T.I.s, etc.)
   - Local community Groups (Local Panchayat, Mahila Mandals, Youth Clubs, Local voluntary organisations, religious organisations, etc.)
– Local functionaries (Government and private) (ICDS workers, balwadi teachers, health workers)
– Local persons (Local leaders, religious leaders, faith healers, etc.)

3. Mass awareness creation through rural camps, mini camps, distribution of hand-outs, etc.

4. Human resources training
   – Crash orientation programmes – for P.H.C. personnel, practitioners of alternate medicines, pre-school & primary school teachers, multi purpose health workers & volunteers.
   – Training Modules Developed in:
     a) Orientation and sensitization programmes
     b) Short training programmes
     c) Intensive skill based training programme

Management and Monitoring of Programmes

The managerial guidance, technical support and programme evaluation and training consultancy service is provided by the project’s multi disciplinary team comprising of

1. Neuro paediatrician
2. Medico social worker
3. Clinical psychologist
4. Speech pathologist & audiologist
5. occupational therapist
6. Physio therapist
7. Psychiatrist
8. Special educationist
9. Other specialists services (E.N.T., dental, etc.)

The community is empowered to monitor the programme by formation of local management committee comprising of village president, spiritual leaders, post master, school teachers and other key persons.

Constraints

– Dispersed population
– Villages situated far from each other with no proper roads
– Extremely difficult conditions, viz., food, shelter, clothing and health
– Deep rooted age old cultural beliefs in fate and karma (Cause of mental handicap)
– Strong caste feelings
– Non availability of villagers during the day time (for training and interaction as they depend on daily wages)
– Improper education system
– Inadequate health care systems and many more
Tragedies Converted into Challenges: A Case Study of Rural Project

BENEFICIARIES SINCE INCEPTION

<table>
<thead>
<tr>
<th>Total population covered</th>
<th>6,62,100</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Godawari district</td>
<td>5,34,200</td>
</tr>
<tr>
<td>West Godawari district</td>
<td>1,27,900</td>
</tr>
<tr>
<td>Direct beneficiaries</td>
<td></td>
</tr>
<tr>
<td>Males identified</td>
<td>22,847</td>
</tr>
<tr>
<td>Females identified</td>
<td>7,397</td>
</tr>
</tbody>
</table>

INDIRET BENEFICIARIES

<table>
<thead>
<tr>
<th>Partents</th>
<th>14,560</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary school teachers</td>
<td>687</td>
</tr>
<tr>
<td>Community leaders, key persons</td>
<td>5,502</td>
</tr>
<tr>
<td>Government &amp; non government officials</td>
<td>247</td>
</tr>
<tr>
<td>P.H.C. Staff</td>
<td>556</td>
</tr>
<tr>
<td>Private doctors &amp; Medical practitioners</td>
<td>196</td>
</tr>
<tr>
<td>Administrators</td>
<td>25</td>
</tr>
<tr>
<td>No. of rural camps conducted</td>
<td>9</td>
</tr>
<tr>
<td>No. of mini camps conducted</td>
<td>36</td>
</tr>
<tr>
<td>No. of adults with mental handicap employed</td>
<td>767</td>
</tr>
<tr>
<td>No. of children integrated in pre-primary school</td>
<td>103</td>
</tr>
<tr>
<td>No. of children integrated in primary school</td>
<td>910</td>
</tr>
<tr>
<td>Academicians and university student</td>
<td>720</td>
</tr>
<tr>
<td>Volunteers &amp; voluntary organisations</td>
<td>450</td>
</tr>
</tbody>
</table>

The objectives of the Rural community Centre are

1. Empowering the rural communities by enhancing scientific understanding on the aspects of prevention, early identification, cost-effective procedures of rehabilitating persons with mental handicap, social integration and normalisation aspects.

2. To initiate field based operational and audience research on rural ecological based low cost no-cost based, interventional approaches for rehabilitation.

3. To generate the community will and community’s active involvement at all levels of these rehabilitation programmes.

4. Extending service coverage to hitherto unmet rural areas with socio-culturally and economically effective methodologies.

5. To organise awareness creation-cum-service based rural camps actively in order to meet the vast number of needy at a short span of time.

6. To generate rural ecological based interventional modalities, special educational and training procedures, that is suitable for rural areas.

7. To initiate measures for producing ecologically suitable teaching aids and instructional processes, which are hitherto less prevalent.
8. To work out locally relevant models of rehabilitation and gainful employment models for persons with mental handicap in rural areas.

9. To initiate research on the key aspect of ability development of persons with mental handicap in rural areas.

10. To investigate the role of socio-cultural and other environmental factors, that seriously influence the lives of persons with M.H.

11. To design models suitable for social integration in rural areas.

12. To initiate measures for active involvement of key village persons in all the rehabilitation programmes for persons with mental handicap in rural areas.

Retrospect and Prospect

The major achievements starting from 1991, are reflected below:

1. Awareness creation regarding mental handicap and the positive abilities of persons with mental handicap.

2. Initiating community based rehabilitation programmes.

3. Developing rurally suitable training programmes.

4. Conducting rural camps for enhancing positive understanding about persons with mental handicap.

5. Initiating measures for social integration by starting 20 village based linkage centres in East Godavari District.


7. Sensitizing District Administrative Machinery.

8. Conducting Clinical based Diagnostic Evaluation, consultation and regular follow-up services through THPI Rural Project at Lalacheruvu as a Nodal Agency.

9. Initiating measures for human resource development to meet the challenge of acute scarcity of trained manpower to serve persons with mental handicap.

10. Generating community participation and involvement of key village persons through linkage centres.

11. Initiating measures to generate rural, ecological based, interventional approaches for the ability development of persons with mental handicap.

12. To conduct workshops, seminars, training campaigns to sensitize volunteers, field workers, in the rural areas.

These measures are only a cross-sectional expression of the ever increasing, ever enlarging and dynamic initiatives, generated by THPI Rural Project at Lalacheruvu. Following is the data depicting the beneficiaries and type or programmes.

Rural Camps (For prevention, awareness creation, early identification and social integration)

Rural camps have no second alternative, when the matters come to the aspect of working with widely spread misconceptions, superstitious beliefs and wrong practices towards persons with mental handicap.
The rural camp programmes are regularly reinforced with follow-up measures and ongoing consultation services of the Rural Project.

**Excursion**

The mentally retarded inmates were conducted to excursion. It is heartening that they were able to integrate Mentally Retarded with local children and participate in the integrated activities which was a grand success.

**Different Service Units and Services Offered by THPI Rural Project**

*Department of Medical & Psychiatric Social Work*

1. **Strengthening Community Programmes**

This Department is actively involved in conducting various community based services, since the inception of rural Project.

a) To being with this Department has taken active initiative to generate involvement of key district officials and key persons of the community by sensitizing them at various levels.

b) Sensitizing Medical Practitioners: This Department has taken initiative in sensitizing local Medical Practitioners and qualified Doctors who are part of the opinion builders in the community regarding mental handicap.

c) Sensitizing youth: Through various programmes such as ‘Lay Volunteers Participation’, guest lectures in colleges, youth in academic areas has been actively sensitized by this Department. Even uneducated youth in villages are also tapped for this purpose.

d) Sensitizing key village persons: Through community visits, by organising key village persons meetings, efforts have been made by this Department to sensitize the key village persons regarding the scientific aspects of the problems of mental handicap.

e) Organising and participation in Camps: This Department has been actively involved in organising awareness creating community based Rural Camps and Mini Camps, to enhance mass level of prevention, early identification, training and rehabilitating persons with mental handicap.
f) Transfer to Technology: This department is actively involved in transferring technology to grass root level workers known as ‘Linkage workers’ working in 20 villages around Rajahmundry. Social interventional approaches, evaluation and screening methodologies and social integration technology has been transferred to these linkage workers by this Department by organising workshops and short training programmes and group discussions.

II. Training and Development

a) This department is actively involved in teaching DSE (MR) Course candidates in the aspect of family and community role in rehabilitating persons with mental handicap.
b) This department has developed a model of enhancing self esteem in persons with mental handicap in rural areas.

Department of Clinical Psychology

This is crucial department of Multi-disciplinary Team working in rural areas of THPI Rural Project range. This Department specifically concentrated its energies in order to render services to effect the psychological deficits in persons with mental handicap.

Major Services:

2. Behavioural intervention programmes.
3. Transfer of Technology.
4. Teaching aids production.
5. Research and development.

Strengthening community programmes:

The Institution plays crucial role in strengthening community programmes.

a) Campaign approach: To begin with this Department has put in lot of organised efforts to sensitize rural communities about the psychological abilities of persons with mental handicap in a scientific manner by organising mini camps and rural camp programmes.
b) Sensitizing key village persons: This department actively participated in sensitising key village persons, village youth and other concerned volunteers, by enhancing their awareness regarding the scientific aspects of behavioural deficits of persons with mental handicap. This Department has also made effort to create therapeutic community environment to develop the psychological potentialities of persons with mental handicap.

Clinical Based Services

This department is keenly involved in regular diagnostic and evaluational services as well in transferring technology about behavioural management to special teachers and parents.
Transfer of Technology

This department has made key efforts in order to equip the grass root level workers and special teachers to acquire scientific skills and understanding on the aspects of various behavioural interventional programmes to be carried in rural areas.

Teaching Aids Production

One of the key contribution of this department is preparing ecologically based, low cost culturally suitable teaching aids to enhance psycho-educational potentialities of persons with mental handicap.

Department of Speech/Language Pathology and Audiology

This is another key department of THPI Rural Project in enhancing rehabilitation prospects of persons with mental handicap by improving the speech, language and communication potentialities.

Services offered

1. Regular diagnostic evaluation.
2. Follow up and consultation services.
3. Transfer of technology to special teachers and grass root level workers.
4. Research and development
5. Community based intervention.
6. Manpower development through training DSE (MR) Course candidates.

Departments of Physio Therapy and Occupational Therapy

These departments carry the crucial work of enhancing motor functioning of persons with mental handicap. Along with they are as well involved in the following regular services:

1. Diagnostic evaluation
2. Follow up services.
3. Training Special teachers and grass root level workers in Physio and Occupational Therapy programmes.
4. Camp Process: these departments enhance the community understanding on the aspects of prevention, early identification, early intervention, vocational planning aspects through camp approach.
5. Manpower development is carried through DSE (MR) Course candidates training.
6. Department of special education:
   The department is the central converging unit which implicates all the multi-disciplinary interventions in class room as well in the home environment.
Following are the regular services of the Department

1. Diagnostic evaluation.
2. Conducting parents counselling programme.
3. Carrying special educational training services in the Campus.
4. Conducting community based interventions through the linkage workers. For this purpose, this department trains linkage workers periodically in the basic essential skills of functional academics, self help skills, training and such other skills necessary for survival in day to day file.
5. Workshops for parents: This department conducts periodicial workshops for parents and remaining family members on the aspects home based follow-up, generalisation of skills learnt through training programmes. Parents are also given demonstration regarding skill training. Parents participation is elicited at all stages of rehabilitation. In this course, this department works in close co-ordination with other multi-disciplinary units such as medical and psychiatric social work, clinical psychology, speech pathology, physio and occupational therapy.
6. Involving key village persons: Plays a key role in sensitizing community leaders and key village persons in certain basic skills for enhancing functional academics and self help abilities.
7. Monitoring village level linkage centres: Involved in the key programme of monitoring village level linkage centres and their services in the community set-up. This Department reviews the performance of the village level linkage workers to ensure proper implementation of programmes.
8. Annual Parents’ Meeting: Also monitors annual parents meetings by taking very key role in organising and conducting the yearly meetings.

Psychiatry-Medical Wing

This Wing specially concentrates on neurological and medical aspects of mental handicap. The Unit also works for awareness creation and generating mass level understanding on pregnancy related care to take and adopt preventive measures of disability. In rural areas, many persons are ignorant of preventive care.

Community Based Intervention Programme

THPI Rural Project, has a special wing for operationalising the philosophy of community based rehabilitation programmes. It has 20 community level centres, which takes care of community based interventional programmes. Each centre is further organised by a linkage worker at village level. Each centre creates a local management committee consisting of key village persons of respective villages. Though 15 villages were allotted, extension services in regard to prevention, early identification, intervention services were extended to 37 villages.

Through this local management committees endeavours are made to evolve active community involvement, forming the foundation basis of community level rehabilitation.
THPI Rural Project is rendering intensive efforts to generate employment prospects for adult persons with mental handicap in rural communities.

Methodology

To begin with systematic efforts are being initiated by the village level linkage workers under the guidance of C.B.R. Team of THPI Rural Project.

Locating Jobs

As an initial step job survey was carried out, in which suitable jobs were located by extensive visits of the community. After these visits, suitable jobs were located.

Contacting

Next step the employers were contacted and they were talked about needs and abilities of these trainees. These employers were convinced after series of orientations.