MENTAL RETARDATION

Chapter 1

Historical Overview

Introduction

Identification of persons with mental retardation and affording them care and management for their disabilities is not a new concept in India. The concept had been translated into practice over several centuries as a community participative culture.

The status of disability in India, particularly in the provision of education and employment for persons with mental retardation, as a matter of need and above all, as a matter of right, has had its recognition only in recent times, almost after the enactment of the Persons with Disabilities Act (PWD), 1995.

Pre-Colonial India

Historically, over different periods of time and almost till the advent of the colonial rule in India, including the reigns of Muslim kings, the rulers exemplified as protectors, establishing charity homes to feed, clothe and care for the destitute persons with disabilities. The community with its governance through local elected bodies, the Panchayati system of those times, collected sufficient data on persons with disabilities for provision of services, though based on the philosophy of charity. With the establishment of the colonial rule in India, changes became noticeable on the type of care and management received by the persons with the influence from the West.

Pre-Independence–Changing Life Styles in India

Changes in attitudes towards persons with disabilities also came to about with city life. The administrative authorities began showing interest in providing a formal education system for persons with disabilities, particularly for families which had taken up residences in the cities.

Changes in the lifestyle of the persons with mental retardation were also noticed with their shifting from 'community inclusive settings' in which families rendered services to that of services provided in 'asylums', run by governmental or non-governmental agencies (Chennai, then Madras, Lunatic Asylum, 1841).

It was at the Madras Lunatic Asylum, renamed the Institute of Mental Health, that persons with mental illness and those with mental retardation were segregated and given appropriate treatment.

Special schools were started for those who could not meet the demands of the mainstream schools (Kurseong, 1918; Travancore, 1931; Chennai, 1938). The first residential home for persons with mental retardation was established in Mumbai, then Bombay (Children Aid Society, Mankhurd, 1941) followed by the establishment of a special school in 1944. Subsequently, 11 more centres were established in other parts of India.

Post-Independent India–Current Scenario

Establishment of Special Schools

Article 41of the Constitution of India (1950) embodied in its clause the "Right to Free and Compulsory Education for All Children up to Age 14 years".

Many more schools for persons with mental retardation were established including an integrated school in Mumbai (Sushila Ben, 1955).

Notwithstanding this obligatory clause on children's mainstream education, more and more special schools were also being set up by non-governmental organizations (NGOs) in an attempt to meet the parents' demands.

Special Schools

Establishment of special schools in the country since independence is shown below:

Year	*Number of Special Schools for Children with Mental Retardation*
1950	10
1960	39
1970	120
1980	290
1990	1100
2007	More than 3000

Indian Education Commission, 1964-66

The Indian Education Commission, 1964-66 made a clear mention of the presence of only 27 schools for persons with mental retardation in the entire country at that time.

In 1953, training teachers to teach persons with mental retardation was initiated in Mumbai by Mrs. Vakil.

In 1971, special education to train persons with mental retardation was introduced in Chennai at the Bala Vihar Training School by Mrs. M. Clubwala Jadhav.

In the same year, the Dilkush Special School was established in Mumbai initiating special teachers' training programs.

The various Acts passed and the policies touching the lives of the disabled are dealt with in Chapter 11, Policies and Programmes.

Conclusion

This introductory chapter is intended to dispel the myth that very few services were available in India until the period of the Colonial rule.

With the rights approach established through several legislations, the quality, accessibility, affordability and availability of an array of services have been strengthened.

Chapter 2

Definition, Incidence and Magnitude– Mental Retardation in India

Introduction

Internationally, the definition of mental retardation has moved away from a medical model to that of an educational model which is functional and support based and emphasizes the rights of the individual.

According to *the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995,* enacted in India, mental retardation means a "condition of arrested or incomplete development of mind of a person which is specially characterized by sub-normality of intelligence".

Field workers, parents and professionals in India opine that this definition has scope for improvement.

To this date, a systematic enumeration of the number of persons with disabilities in the country has not been made, the reason being the large geographical area. Data on educational and other needs of pre-school, school going children, youth, adults and senior citizens is not available.

Mental Retardation: Changing Concepts

The American Association on Mental Deficiency (AAMD)

The American Association on Mental Deficiency (AAMD), now the American Association on Mental Retardation (AAMR), and also known as the American Association on Intellectual Disabilities (AAID), has made a formal change between 1959 and 1983, to include both measured intelligence and adaptive behavior.

With the WHO definition, which is in use in Britain, and that of the Persons with Disabilities Act, 1995 in India, the AAMD definition (1983) is more prevalent among the service providers and the institutions, the usage being more of academic interest than for operational reasons.

The AAMD (1983) definition reads "Mental retardation refers to a significantly sub-average general intellectual functioning resulting in or associated with concurrent impairments in adaptive behavior and manifested during the developmental period" (Grossman, 1983). It is a more functional definition which stresses the interaction between the person's capabilities, the environment in which the individual functions, and the need for support systems.

The AAMR (1992) definition of mental retardation, manifesting before age 18, refers to a substantial limitations in present functioning, characterized by significantly sub-average intellectual functioning which exists concurrently with related limitations in two or more of the following adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.

In adopting this definition and the accompanying classification system, AAMR (1992) suggests the mild, moderate, severe and profound

classification in the previous definitions to be substituted with 'levels' of support needed by an individual: intermittent, limited, extensive, and pervasive.

These terms may be summarized as below:

- *Intermittent:* Support of high or low intensity is provided as and when needed. Characterized as episodic or short-term during life-span transitions.
- *Limited:* Supports are provided consistently over time, but may not be extensive at any one time. Supports may require fewer staff members and lower expense than more intense levels of support.
- *Extensive:* Supports characterized by regular involvement (daily) in at least some environments (work or home) and not limited (example: long term support and long term home living support).
- *Pervasive:* High intensity supports are provided constantly, across environments, and may be of life sustaining and intrusive nature. Pervasive supports typically involve a variety of staff members.

This definition essentially restates the 1983 AAMD definition except that it raises the developmental period to age 22, consistent with the federal definitions of developmental disabilities.

The Diagnostic and Statistical Manual-IV (DSM-IV) - 1994; International Classification of Diseases (ICD-10)

The American Psychiatric Association in its fourth edition of *the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV);* 1994, also retains the essence of the 1983 AAMD definition of mental retardation as well as the levels of severity of mental retardation.

Further, DSM-IV and *the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)* have coordinated sections on mental and behavioral disorders concurring with a common definition and classification system for mental retardation.

This coordination specifies four degrees of severity reflecting the level of intellectual impairment.

The AAMR 2002 definition reads "Mental retardation is a disability characterized by significant limitations, both in intellectual functioning and in adaptive behaviour, as expressed in conceptual, social, and practical adaptive skills, the disability originating before the age of 18.

A complete and accurate understanding of mental retardation implies that mental retardation refers to a particular state of functioning, which begins in childhood, having many dimensions, and affected positively by individualized supports.

As a model of functioning, it includes the contexts and environment within which the person functions and interacts, requiring a multidimensional and ecological approach that reflects the interaction of the individual with the environment.

The outcomes of that interaction are with regard to independence, relationships, societal contributions, participation in school and community and to personal well being.

Classification of Persons with Mental Retardation

Based on the 1983 AAMR definition, the operational classification for persons with mental retardation is as follows:

Level of Retardation	*IQ Range*		*Approximate percentage of persons with mental retardation*
	Stanford-Binet and Cattell Tests	*Wechsler Scales*	
Mild	52 – 67	55 – 69	89
Moderate	36 – 51	40 – 54	7
Severe	20 – 35	25 – 39	3
Profound	0 – 19	0 – 24	1

Educational Classification

In the special education centres in India, the classroom classification in operation is as shown below:

I.	Pre-Primary (A) level	
	- Chronological ages	3 – 6 years
	- Mental ages	Upto 5 years
II.	Pre-Primary (B) level	
	- Chronological ages	Over 6 years
	- Mental ages	Around 4½ years
III.	Primary level	
	- Chronological ages	7 – 10 years
	- Mental ages	5 – 7 years
IV.	Secondary level	
	- Chronological ages	10 – 13 years
	- Mental ages	7 – 9 years
V.	Pre-Vocational level	
	- Chronological ages	14 – 16 years
	- Mental ages	8 + years

Most of the classification systems define mental retardation with emphasis on significantly sub-average intellectual functioning of the individual (assessed by the standardized intelligence tests).

In India, where a majority live in rural areas, engaged mostly with traditional, semi-skilled vocations, the adapted Indian intelligence tests have limitations in assessing the exact levels of intelligence due to lack of standardization on such population.

No standard test has been so far developed suited to the Indian cultural milieu.

Certification

A disability certificate is issued by a Medical Board duly constituted by the Central and the State Governments.

The State Government will constitute a Medical Board consisting of at least three members out of which at least one may be a specialist in the concerned field.

In need of correction in the certification process are: limited availability of the specialists in respective areas of disability, distance from the residence to the assessment and certification place, lack of guidelines on the standard test and the person to be used for assessment.

No indigenously established behavior norms are available.

Table 1: Characteristics of Persons with Mental Retardation

Severity	*Mild*	*Moderate*	*Severe*	*Profound*
Pre-school	Can develop social and communicative skills, minimal retardation in sensory- motor areas, often not distinguished from those normal until late age.	Can talk or learn to communicate, poor social awareness, fine motor development. Profits from training, self help can be managed.	Poor motor development, speech minimal, generally unable to profit from training, self help little, no communicative skills.	Gross retardation, minimal capacity for functioning in sensory motor areas needs running care.
School age 6–20 years	Can learn academic skills up to approximately 6th grade level by late teens. Can be guided on social skills.	Can profit from training in social and occupational skills to progress beyond 2nd grade level in academic subjects, may learn to travel alone in familiar places.	Can talk or learn to communicate, can be trained in elementary skills and can profit from systematic training.	Some motor development present. Many respond to minimal to limited training in self help.
Adult 21 & over.	Can usually achieve social and vocational skills adequate to minimum, self support but may need guidance and assistance when under social or economic stress.	May achieve self maintenance in unskilled, under sheltered conditions, needs supervision and guidance when under mild social or economic stress.	May contribute partially to self maintenance under complete supervision, can develop self protection skills to a minimal useful levels in controlled environment.	Some motor and speech development may be achieved, but very limited self care needs are achieved.

Incidence and Magnitude of Mental Retardation in India

Estimates in India

Most available data on the prevalence of mental retardation in the country is derived from the psychiatric morbidity surveys conducted by the mental health professionals in specific or circumscribed geographical areas or on target populations, such as rural-urban, industrial population and educational institutions.

The prevalence rates of mental retardation, some from the school population, some from the general population, is reported from 1951 to 1994, in the range of 0.07 to 40 per 1000. The prevalence rates for mental retardation in the school population and the general population, rural and urban, based on psychiatric morbidity survey ranges from 0.1 to 140. The sample selected has been a skewed one.

The variation in these figures does not give a clear picture of the situation.

The National Sample Survey Organisation (NSSO)

The National Sample Survey Organisation (NSSO) under the Department of Statistics, Government of India conducts large scale survey for socio-economic planning and policy formulation. The first large scale attempt to collect information on the prevalence of developmental delays was made in the 47th round of survey by NSSO.

Data obtained from various sources indicate that the prevalence rate of mental retardation is about 20 per 1000 general population while the prevalence of developmental delays is about 30 per 1000 in the 14 year-old population.

In rural areas, the incidence of mental retardation is 3.1% and in urban, it is 0.9%. The NIMH mentions that 2% of the general population is MR. Three quarters of them are with mild retardation and one-fourth are with severe retardation (Panda, 1999).

A door-to-door survey conducted in Tamil Nadu in the districts of Kancheepuram (Rajaram-Dist. Collector), Ramanathapuram (Vijay Kumar-Dist. Collector), in 2001 and earlier in 1984 in Tiruchirapalli in a population of 50,000, (Jeyachandran) indicates a prevalence of 1 per 1000.

Difficulties in Collecting Accurate Prevalence Rates

A large, population which is diverse in psychosocial, educational, economical and cultural background, limited number of specialists and lack of standard tools for assessment are the main difficulties.

Those with mild mental retardation remain unidentified as they could be involved in a semi-skilled vocation and in a structured and restricted environment.

Government of Tamil Nadu Initiative

The Government of Tamil Nadu has initiated creation of a data base on disabilities (2007) on the population with a door-to-door survey in all its districts.

Standard formats have been developed to identify disabilities as listed in Persons with Disabilities Act and the National Trust Act.

The survey is based on the etiology of each of the listed disabilities. All the District Disability Rehabilitation Officers, village health workers, Anganwadi workers, the CBR workers, NGOs, working in the field of disability, members of the National Cadet Corps and retired veterans from the armed forces received the required training for the survey.

Estimates in India

In India, the incidence and magnitude of mental retardation needs to be looked into.

Theoretically, the horizon of special education is often restricted only up to the age of 18 years for persons with disabilities. "Schooling" or attendance in a class room alone is often considered 'education' even among the literate population of the nation.

NSSO Survey, 1991

The National Sample Survey Organisation (NSSO) under the Department of Statistics, Government of India conducts large scale studies and surveys for socio-economic planning and policy formulation. The first large scale attempt to collect such information on the prevalence of developmental delays was made in the 47th round of survey by NSSO carried out between July-December, 1991, on children age group 0-14 years, coming from 4,373 villages and 2,503 urban blocks.

Table 2: Prevalence Studies Based on National Sample Survey Organisation

Sl. No.	*Investigator/s*	*Year*	*Target Population*	*Place of Study*	*Prevalence Rate/1000*
1.	NSSO	1991	Stratified rural sample	All India	31.0
2.	NSSO	1991	Stratified urban sample	All India	9.0

Data obtained from various sources indicate that the prevalence rate of mental retardation is about 20 per 1000 general population, while the prevalence of developmental delays is about 30 per 1000 in the population of children up to the age of 14 years.

Conclusion

It is difficult to collect the accurate prevalence rate of mental retardation in a country like India reasons for which have been given above.

In the Census of India, 2001, an attempt has been made to assess the disability population in the country belonging to different categories. Unfortunately, no reliable information could be obtained from such data as regards mental retardation since it has been clubbed with mental illness, a term alien to mental retardation in its current conceptualization.

Chapter 3

Early Identification and Prevention of Mental Retardation

Introduction

With the implementation of the Persons with Disabilities Act (PWD), 1995 mental retardation has been recognized as a disability with an identity of its own. Earlier, data on mental retardation had been clubbed with data on mental illness.

It is only in the recent years that early identification of persons with mental retardation has become possible.

Systematic thinking on screening and identification emerged consequent to the National Policy on Education (NPE), 1986, even though working groups had been set up even as early as 1981 during the International Year of the Disabled Persons (IYDP) by the then Ministry of Welfare. Early identification includes screening, early diagnosis and parent counseling.

Information on early identification and prevention is also presented in Chapter 6 on 'Array of Services' and other chapters.

Screening

Screening is a procedure for an initial identification of persons with mental retardation and for a follow up with assessment.

Screening Procedure

Many of the screening techniques collated by National Institute for the Mentally Handicapped (NIMH), Secunderabad, appeared in RCI: *Status of Disability in India,* 2000.

A more systematic process and procedure has been the pooling of a battery of tests on *clinical investigations* by the *NIMH,* for identification and screening of persons with mental retardation. They include pre-natal, neonatal and post-natal diagnostic procedures:

(i) Pre-natal Procedures

- Blood tests for the pregnant mothers for any anemic condition, diabetes, syphilis, Rh incompatibility and neural tube defects in the foetal stage.
- *Ultrasonography* (during pregnancy)is carried out in the second trimester of pregnancy to detect such disorders as - neural tube defects, hydrocephaly, microcephaly, hydrencephaly, holoprosencephaly, prosencephaly and some cerebellar lesions. Intra-uterine growth retardation can also be detected through such measurements as foetal biparietal diameter, crown rump length and transverse abdominal diameter.
- *Aminocentesis* is indicated in cases of foetal chromosomal aberration, congenital metabolic errors and open, neural tube defects, severe Rh incompatibility and also in cases of advanced maternal age with previous birth history of an

abnormal child. Aminocentesis is a procedure for purposes of early identification and primary prevention for many genetic abnormalities.

- *Foetoscopy* is done during second trimester of pregnancy in diagnosing certain physical anomalies, metabolic disorders or biochemical abnormalities.
- *Chorionic Villous Sampling* where a biopsy of the chorionic villi is performed either transabdominally or vaginally. The sample is then subjected to karyotyping and enzyme determination.

(ii) Neonatal and Post-natal Screening and Diagnostic Procedure

Blood and urine examinations are conducted in the neonatal period in all suspected cases and with a previous history of mental retardation in the family.

Cretinism is another condition which can be diagnosed in the neonatal period and necessary treatment given.

- Apgar Score at one minute after delivery is an index of asphyxia and the need for assisted ventilation.
- Urine screening for metabolic errors - PKU (Phenyle Ketoneuria).
- Blood biochemistry tests for cretinism, rickets, jaundice.
- Blood antibody titres to detect infections.
- Chromosomal analysis for Down Syndrome, deletion of syndromes.
- Neonatal neuro behavioural assessments.
- EEG electroencephalogram for seizure disorder.
- Screening for visual impairments (visual acuity, fundus examination, retinoscopy).
- Screening for hearing impairments (Tympanogram, BERA.)
- Ultra sonogram.
- CT scan (computerized tomography).
- MRI (Magnetic Resonance Imaging) for intra-cranial pathology and structural abnormalities.
- *Ultra Sound Examination:* The technique can be used to detect displacement of brain midline structures, thickness of brain substance, pathological cavities in the brain. Real-time ultrasound examination of the head can reveal intracranial haemorohage in the newborn.
- Biochemical Tests in neonatal screening for identifying metabolic disorders.
- *Electro Encephalography (EEG):* EEG is useful not only in epilepsy, but in many other cases of mental retardation and organic brain lesions. In certain cases it also helps in localization of lesions and the severity of a cerebral damage. Incidence of abnormal EEGs is higher in cases of mental retardation associated with epilepsy, encephalitis, severe degree of mental retardation and brain damage sustained before birth or during birth or in the early period of infancy.
- *Computerised Tomography (CT):* There are many abnormalities which can be detected by CT scan of the CNS, such as, anoxia of tissue, intracranial haemorhage, hydrocephalous and congenital anomalies like holoprosencephaly, a-genesis of

corpus callosum, Arnold chiari malformations, congenital cysts, calcifications, etc.

- *Magnetic Resonance Imaging (MRI):* This screening helps in identifying a large number of persons with suspected disability in a limited time period.

Screening Tools

The NIMH has developed quick Screening Schedule I (Below 3 years) and Screening Schedule II (3 to 6 years) shown in Table 1.

Table 1: Screening Schedule I

Stage No.	*Child's Progress*	*Normal Development*	*Delayed Development: If not achieved by the period*
1.	Responds to name / voice	1-3 months	4th month
2.	Smiles at others	1-4 months	6th month
3.	Holds head steady	2-6 months	6th month
4.	Sits without support	5-10 months	12th month
5.	Stands without support	9-14 months	18th month
6.	Walks well	10-20 months	20th month
7.	Talks in 2-3 word sentences	16-30 months	3rd year
8.	Eats/drinks by self	2-3 years	4th year
9.	Tells his name	2-3 years	4th year
10.	Has toilet control	3-4 years	4th year
11.	Avoids simple hazards	3-4 years	4th year
		Other factors	
12.	Has fits	Yes	No
13.	Has physical disability–what?	Yes	No

- Compared with other children, did the child have any serious delay in sitting, standing or walking?
- Does the child appear to have difficulty in hearing?
- Does the child have difficulty in seeing?
- When you tell the child to do something, does he seem to have problems in understanding what you are saying?
- Does the child sometime have weakness and/or stiffness in the limbs and/or difficulty in walking or moving his arms?
- Does the child sometimes have fits, becomes rigid, or lose consciousness?
- Does the child have difficulty in learning to do things like other children of his age?
- Is the child not able to speak at all? (cannot make himself understood in words/say any recognizable words).
- Is the child's speech in any way different from normal? (not clear enough to be understood by people other than his immediate family).
- Compared to other children of the same age, does the child appear in any way backward, dull or slow?

If an answer to any of the above items is 'yes', then suspect mental retardation.

Other Screening Tools

Some of the other popularly used tools in India include

- Cooperative preschool inventory-Caldwell.
- Croydon Scales (Screening Checklist) (Wolfendale & Bryans).
- Denver Developmental Screening Test (Frankensberg, Dodds and Fandal).
- Early Childhood Assessment: A criterion referenced screening device (Schmaltz, Schramn and Wendt).
- AGS Early Screening Profiles (Harrison, et al.).
- Developmental Indicators for the Assessment of Learning-R (Mardell, et al.).
- Early Screening Inventory (Merisels, et al.).
- Brigance 'K' and 'T' Screen for Kindergarten and First Grade (Brigance).

Indian Screening Tools

- Developmental Screening Test (DST) by Bharat Raj is a widely used screening tool by professionals. The NIMH schedules noted earlier are used for further referral.
- Upanayan Early Intervention Programming System (1987).
- Functional Assessment Check List for Programming (FACP) 1991.
- The *revised* Madras Developmental Programme System Behavioural Scale MDPS-A curriculum based assessment checklist (1975) is suitable for identification purposes.

Screening of Childhood Disabilities

A multi-centered study carried out in 1994 at NIMH revealed that about 50% of parents recognize the delayed development or mental retardation of their children below the age of 2 years while 35% of the parents recognized only after the age of 2 years.

Screening Approach in the Community

The screening approach in the community involves sorting out children who are at risk and the diagnostic evaluation of those identified in screening. Bio-chemical/Metabolic Screening in Persons with Mental Retardation is in use, but not available freely to the public.

Selecting Appropriate Screening Measures

For screening or an early detection program, appropriate screening measures must be selected.

- A screening device should meet the technical criteria of standardization, reliability, validity, and normative data.
- The screening instrument should also be culturally appropriate, acceptable to the participants and cost effective.
- Screening tests must have established sensitivity and specificity to be valid.

Commonly Used Screening Instruments

Some commonly used screening instruments standardized/developed in India are shown in Table 2.

Table 2: Screening Instrument

Sl. No.	*Name of Instrument, Age Range, Administration Time*	*Author (s) Year*
1.	Developmental Screening Test 1-15 years; 10 min.	Bharat Raj 1977, 1978, 1983
2.	Gesell Drawing Tests 1 -8 year; 15 min.	Verma, Dwarka & Kaushal 1972
3.	Infant Intelligence (Development) Scale 0-3 years; 30 min.	Kulshreshta 1975
4.	Mental and Motor Growth of Indian Babies 1-2 years; 15-20 min.	Pramila Phatak 1976, 1977
5.	Vineland Social Maturity Scale 0-15 years; 15-20 min.	Malin 1970

The developmental approach is generally used for developmental assessment and for planning early intervention programs.

Developmental Schedules

The most commonly used developmental schedules are:

- Gesell Developmental Schedules.
- Baroda - Bayley Scales of Infant Development.
- Motor and Mental Development of Indian Babies (Pramila Phatak).
- Kulshrestha Infant Intelligence Scale. A focus in India in recent year is the importance of assessment for planning the teaching schedule by the teacher.

An informal functional assessment guide for all disabilities has been developed (NCERT, 1990) for use by teachers.

Assessment Tools

In addition, educational assessment tools for children with mental retardation used are:

- Madras Scale (1968).
- Madras Developmental Programming System (MDPS, 1975).
- Upanayan Early Intervention Programme (1987).
- Functional Assessment Checklists (1994) by National Institute for the Mentally Handicapped.
- Behavioural Assessment Scale for Indian Children with M.R. (BASIC-MR) – NIMH.
- ARAM- NIMH

Primary Health Centres (PHCs)

Primary Health Centres as well as the District and Municipal/Government hospitals are equipped with maternal and child health services.

Documentaries on prevention, early identification, and the support systems in the care and management are available for screening in many hospitals in the metropolitan cities. Research laboratories in the country are equipped for genetic testing and counseling.

Prevention

Prevention refers to the measures taken to prevent the disability from occurring.

The World Health Organisation (WHO), American Association for Mental Retardation (AAMR), American Association on Mental Deficiency (AAMD), International Classificatioon on Deficiency (ICD), Diagnostic and Statistical Manual (DSM-IV) definitions of mental retardation relate to three levels of prevention:

(i) *Primary level* of prevention is carried out by doctors and health professionals to prevent manifestation of the disability.

(ii) *Secondary level* prevents the manifestations of additional disabilities and regression.

(iii) *Tertiary level* mitigates the impact of disability on social isolation, stigmatization of the handicap.

Based on the principles of early identification and intervention, prevention of mental retardation is taken as early as possible.

Prenatal Prevention relates to

- Dealing with causal factors such as Rh incompatibility; maternal illness, infections and other high risk conditions, such as malnutrition in mother and child during the first trimester of pregnancy, environmental and occupational hazards and consanguinity.
- Prenatal diagnosis where preliminary investigations are carried out, blood and urine tests investigations to assess the foetal abnormalities through ultra sonography, radiography, and aminocentesis.
- Immunization to the mother for preventing illnesses and infections leading to disability in the foetus.

Follow up action is provided through periodic checkups, prompt treatment and effective management plan with a balanced diet and periodic health checkups.

Natal Prevention relates to

- Delivery conducted under hygienic conditions by a trained person and/or in a hospital, to prevent breech delivery, asphyxia, prematurity with low birth weight, occurrence of jaundice, and other post-illnesses in the child.
- Care of new borns at high risk for mental retardation in well equipped neonatal intensive care units; a close follow up to identify delays and abnormalities in development; facilitating interventions and corrections at the earliest thereby reducing the severity of handicap.

Postnatal Prevention relates to

Neonatal screening with simple blood and urine tests for metabolic abnormalities and hypothyrodisim, associated conditions that lead to mental retardation.

National Health Policy, 1983—Optimal Prenatal Care

Under the maternal and child health programs, 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 which is one of the major health problems affecting intrauterine growth of the foetus.
- *National AIDs Control Program:* The Government has set up five regional STD-cum-HIV-detection-cum prevention centers and STD reference laboratories at Kolkata, Hyderabad, Chennai, Nagpur and Delhi to deal with infection, leading to disability.
- *National Iodine Deficiency Disorders Control Program:* The iodine deficient women frequently suffer abortions and even still births. Their children may be born mentally retarded or as cretins. In India alone, 167 million people are at risk of Iodine Deficiency Disorder (IDD). The program aims at iodizing all marketed salt in the country in a phased manner. After launching the 100% Centrally Sponsored National Goitre Control Program in 1962, it has now been rechristened in April 1992 as the National Iodine Deficiency Disorder Control Program.

Role of Non-Govt. Organizations in Early Detection/Prevention

The NGOs have demonstrated their leadership in services from prevention to rehabilitation, and especially in early intervention. They have also coordinated with the government in carrying out awareness program by taking out rallies and demonstrations through street plays with primary school children, their teachers, and head masters. Information on early identification and prevention is also presented in a tabular form in Chapter 6 on 'Array of Services'.

Conclusion

In India, like in other developing countries, early detection of mental retardation has been achieved at the national level. In recent times, creation of awareness and education has facilitated the development of positive attitudes in the family and in the community. Learning environments and experiences that promote independence and inclusion in the community have now become mandatory.

The Rehabilitation Council of India (RCI) has initiated early childhood special education towards the provision of comprehensive services in the prevention, intervention, care and management of children with mental retardation.

Chapter 4

Early Childhood Care and Intervention

Introduction

The right development of the child must be ensured during the early years when great changes of long-lasting influence take place. This must be noted by the governments while making policy decisions.

Information on early childhood care and prevention is also presented in a tabular form in Chapter 6 on 'Array of Services'.

The Rationale for Early Intervention Programs–0-3 Years

Several studies conducted overseas and in India, between 1939 and 1968 and those in the recent decades, i.e., between 1986 and 1998 have shown the importance of early intervention and its effects on the developing child. The French psychologist, Robert Lafon's statement, "If you are slow, you simply have to start earlier", is relevant to early intervention programs.

Importance of Early Identification Studies Conducted in India

Jeychandran (1968) conducted The Madras Project, the first in India, concluded as follows:

- It is feasible to train mothers in day care centres; the longer the training the more positive and lasting the effect on the children. The trained mother gains a caring position as a carry-over agent.
- Greater the parental participation, faster is the impact on the child. Positive attitudinal changes in parents may be seen within six months' of commencement of training.

On the importance of early intervention, Madhuram Narayan Centre for Exceptional Children (Jeyachandran, Jaya Krishnaswamy) observed that:

- Earlier the intervention, better are the results; it limits disabilities; it helps in mainstreaming and in appropriate placement in special schools; fosters the emergence of parents' networks and the provision of special schools in the community.
- Individualized Family Services Program can be effective.
- An initial total involvement, from birth to two years, with gradual weaning, helps the parents become effective carry over agents at home.

Early Childhood Care and Education (ECCE)

Early Brain Development

At birth, a baby has about 100 trillion brain cells which must be organized into networks that require trillions of connections and synapses between them. Stimulation given to the foetus as well as to the new born baby speeds up myelination and networking in the brain.

National Policy on Education, 1964

The National Policy on Education, 1964 has given much importance to Early Childhood Care and Education (ECCE), viewing ECCE as a crucial input in the strategy of human resource development (HRD). It is a feeder and support program for primary education and a support service for working women of the disadvantaged sections of the society.

Emphasis has been given to:

- establishing linkages between the Integrated Child Development Services (ICDS) and other ECCE programs,
- the scheme of assistance to voluntary organizations, for conducting ECCE centres,
- activities of the Balwadis and Daycare centers run by voluntary agencies with government assistance, and
- the pre-primary schools/anganwadis and the maternal and child health services through PHC/sub-centers.

ECCE – A Total Development

The ECCE involves the total development, i.e., physical, motor, cognitive, language, emotional, social and moral of the child from conception to about six years.

The development process during this period includes:

- mother's care during pregnancy (ante-natal health check-up; nutritional care of mother during lactation; nutritional support and control of anaemia),
- hygienic and skilled birth attendance, immunization for prevention of tetanus following delivery,
- correct infant feeding practices, immunization of infant from communicable diseases,
- mother's education in the child care,
- early childhood stimulation, and
- health and nutritional support throughout.

Since it has a complex integral function, workers with ECCE training are required in integrated work sites or ECCE centers where the essential service flow to the young children through the period of their growth and preparation for formal education takes place.

To tap the full advantage of well integrated ECCE activities and associated programs, efforts are being directed at coordinating the functioning of various agencies which are striving to meet different needs of young children.

The Department of Women and Child Development which works in collaboration with the Labour, Education, Rural Development Departments, is the nodal agency for ECCE programs.

Community as well as parental participation is enlisted wherever possible, in resource mobilization, planning, and implementation. Adequate representation of mothers is organized.

The role of capable voluntary agencies is emphasized to create a wide and rich network of resources of ECCE.

Ongoing programs/schemes, such as, ICDS, ECCE centers, Balwadis run by voluntary agencies, Pre-Primary Schools and Day-care Centers that reflect a concern for the holistic development of young children are being improved.

Early Intervention for Children with Mental Retardation

Of all the disabilities, mental retardation is the one neglected the most. Those with mental retardation and in the age group six years and under, constitute a significant percentage of children which is substantial in view of the large population in the country.

Awareness among the public in India, about the need to provide services to infants and children with mental retardation has come only in the last decade.

With this awareness, at present, service centres are available, some providing exceptionally good services. But there are only 198 centres offering early intervention programs for the entire country, leaving the demand largely unmet.

Need for a Comprehensive Early Intervention Program

A child with developmental delays needs an individualized program taking into account the family needs, preferences and supports.

Family priorities are best satisfied with every member of the intervention team, the special educator, the parent or care-giver and the members of the interdisciplinary team of experts knowing what the priorities are and working in co-ordination and collaboration.

Early intervention is not just programming on detection of delay or disability, but it lies in the prevention of developmental delays - primary, secondary and tertiary prevention.

Primary prevention calls for systemic and societal changes in nurturing children during their development, elimination of specific conditions that lead to a later disability, counseling and guidance services to adolescents and adults in planning for parenthood and increasing availability of parental care.

Secondary prevention seeks assessment of the magnitude of the disability or delay, reducing or eliminating its future impact on both the individual and the society.

In tertiary prevention, the effects can be lessened and the development of the individual fostered.

Challenges of early intervention are:

- Infant tests not highly predictive of later functioning though they indicate a trend.
- Individual variations in the influence of environmental conditions and early intervention on the long term effects of illness and other disabling conditions.
- Difficulties in the assessment of disability in infants and toddlers.
- Absence of data on the number of children with special needs and register of services.

Parental-Child Development/Emotional Support/Respite Care/Parent Organisations/Social Services

How well the child has adapted himself/herself in performing his/her daily living activities and how he has been helped to be "included" in normal settings by the other members of the community with cultural pluralism speak for the success of an early intervention program.

Need for Social Audit on Program Implementation Services

In addition to the challenges cited above, the absence of a clear-cut social audit on program implementation that directly benefit

the child receiving the services has been felt in the country.

Several services are available each with a different type of program. There are those

- that are highly structured, and offer intensive individualized teaching directed at specific goals for each child,
- that enhance development by counteracting delay or impairment,
- that are "catch all" ranging from group play, movements, music, dance, art, and any other,
- that are operating in a vacuum with no certainty that the children in need are actually benefiting.

A social audit will give certainty and directions to the service providers enabling them to meet the needs of the child with disability. Of late, there has been a move in this direction by the Government of India.

India has a vast resource in human potential and numbers. Many of the challenges can be met by involving this rich resource.

Family Involvement and Community Participation—A Basis for Developing Intervention and Providing Services

In a family-oriented approach, every member of a family is actively involved in the management of a child with disability and towards this goal, effort- "prayaas" and, practice -"sadhana", the family members are educated, directed, facilitated and empowered by the professionals who cooperate with them in providing services. Families and professionals are then collaborators in the human enterprise – the provision of services to persons with disabilities.

Early Intervention Programs

Mathuram Narayan Centre for Exceptional Children (MNC), Chennai

Training at the Centre, which was established in 1989, is based on the Upanayan Early Intervention Program developed indigenously by Indchem Research and Development Laboratory to fulfill the need for a structured program, culturally appropriate, suitable to the Indian socio-economic needs.

The program is the first systematic one developed in the country which has since been translated and in use in many centres in the country.

The Centre is the first of its kind in the country, providing services to over 4,000 children at present. Accompanied by their mothers, about 150 children attend the Centre everyday.

Parental involvement is the foundation of the program at the Centre where the children are trained by their mothers (or close relations in a few cases), turned into carryover agents by the special educators. Parents practice yoga and pranic healing regularly with their children.

National Institute for Mentally Handicapped (NIMH), Secunderabad

The department of special education and medical rehabilitation division under the NIMH takes up early intervention program for children with mental retardation.

Infants and toddlers suspected or at risk for delayed development in the age group of 0-3 years are given early intervention services once a week by a multi-disciplinary team of experts. The parents are given guidance regarding immunization,

nutrition, feeding, motor development, speech and language development and psycho-social interventions.

A set of brochures has been developed as a part of the Indo-US project on early intervention to intra-uterine growth retardation (IUGR) children at risk for developmental delays.

A book in simple language and illustrations for children with special needs (Narayan, 1999) has been developed. It is very useful to parents and teachers in readying children with mental retardation for regular schools.

Also used by the DPEP scheme of the Govt. of India, the activities cover conversation, and creative activities for different levels of retardation.

NIMH has also brought out video films on "Step by Step We Learn Give them a chance", "Sahanuhbhuti Nahi Sahyog" for awareness building from the point of view of early intervention services, schooling and vocational training. The films bring a spirit of optimism.

Thakur Hari Prasad Institute for Research & Rehabilitation of the Mentally Handicapped (THPI), Hyderabad

The THPI, Hyderabad undertakes early interventions and early stimulations involving parents. It has adopted the Portage program and Head Start program of the West with the feeling that most of the early stimulations programs especially Portage relies heavily on home based training.

But experience has shown that at that time it becomes difficult for a poor illiterate mother in a poverty stricken, nuclear family to carry home based training and stimulation programs as both parents have to struggle for their survival all day long with very little time or energy to attempt home based training.

There is a need, therefore, for a peripatetic trainer and/or a neighborhood center for day care needs to be looked into realistically. There is a further need to have separate personnel at grass root level to attend to early stimulation programs for persons with mental retardation for sustainable intervention.

Others that could also be directed for effective interventions are: The Public Health Centre (PHC)-based or hospital-based program, District Rehabilitation Centre (DRC) rehabilitation programs, early intervention with infants at risk, Andhra Pradesh Association for the Welfare of the Mentally Retarded (APACWMR), parents self help groups; National Institute for the Mentally Retarded (NIMH Model), institution-based extension services, ACTIONAID community-based program worked in rural areas.

Deepshikha, Ranchi

Deepshikha, Ranchi through its outdoor services and extension clinics at Kanke and Hulhundu is working in the field of early intervention and child care and training.

Vijay Human Services, Chennai

Vijay Human Services, Chennai has developed a 24-hour time table for every child which is being implemented as Individualised Programme Plan (IEP) at the Centre and as Individualised Family Services Programme(IFSP) at home.

Manovikas Kendra Rehabilitation and Research Institute for the Handicapped (MRIH), Kolkata

Working since 1974, it has created public awareness on children with mental retardation, their needs and capabilities among pediatricians, neurologists, psychiatrists, and doctors in addition

to the special educators.

Services are provided for families and their children with disabilities from birth to six years. Services are provided for 9 infants in the daily sessions and for 10 children in weekly sessions.

The children undergo an early assessment followed immediately after by Individual Learning Plan. Emphasis is laid on training in the developmental areas of cognitive, social, language, motor and self-help skills. Care and counselling is given to reduce the emotional stress which parents undergo.

Sweekaar Rehabilitation Institute for the Handicapped, Secunderabad

Sweekaar Rehabilitation Institute for the Handicapped, Secunderabad, has a comprehensive and pervasive early child care and intervention unit assisted by the multi-disciplinary team.

The Center follows an individualized early intervention program. A few other well equipped centres with teaching learning materials, aids and appliances, have been established by Sweekaar at several places in the state of Andhra Pradesh.

The Centre at Secunderabad with its well provided infrastructure, offer programs for over 400 children for early intervention in a day.

Conclusion

Well developed early intervention programs are available.

Some service models with a CBR approach have been introduced to disseminate information on early intervention programs through village level workers. This effort has also helped in narrowing the lapse of time between detection and intervention.

Indigenously developed home-bound intervention programmes for young children with visiting trainees are in use in local village or urban pre-schools.

A comprehensive Early Childhood Care and Education (ECCE) includes the following services in centers for effective functioning:

- Family counselling.
- Health/Nursing/Nutrition care.
- Occupational/physical therapy.
- Psychological, Audiological, Speech/ Language Services.
- Special Education.
- Social work.
- Transportation

Chapter 5

Assessment in the Field of Mental Retardation: Current Practices

Introduction

Assessment for persons with mental retardation and associated conditions needs a multidimensional approach in terms of methodology, sensitivity and capacity building of testers with inputs from an interdisciplinary team of experts. This is necessary for a society which is culturally diverse.

Assessment of adaptive behavior, which distinguishes a person with mental retardation from others, has become an important component.

Heber (1961) has described adaptive behavior as, "the effectiveness with which the individual copes with the nature and social demands of his environment".

Prior to the development of adaptive behavior scales and intelligence tests, "social incompetence" was the main characteristic which was used to determine whether a person was mentally retarded or not (Nihira, 1969).

Assessment

For an appropriate Individualized Program Planning, accurate and comprehensive information of the individual is essential.

For this purpose a standard assessment tool is necessary. Systematic observations and analysis of an individual's skills and deficits identifies the individual's present developmental level and provides information about his strengths, abilities and developmental needs. This forms the basis for educational programming.

Overall Purpose of Assessment

The assessment tool should

- be developmental, indicative of both the strengths and the needs of the assessed individuals,
- be easy, and simple to administer and to record even by a non-professional; versatile enough to be administered individually and also in groups; economical—time-wise and cost-wise, using materials available in homes or in classrooms,
- yield results, a profile of the individual that can be easily used for program planning, interpreted to parents; useful for on going assessments; a communication tool for future use in placement and which is comprehensive about the individual's development and needs.

Specific Purpose of Assessment

- Initial identification or screening.
- Determination of current performance levels, educational needs, evaluation of teaching programs and strategies (pre-referral intervention).
- For decision-making, regarding classification and program placement.
- Development of Individual Education Program including goals, objectives and evaluation procedures.

Requirements in Programming

An assessment provides answers to the following requirements in programming:

Step 1: Behavioral assessment is a complete statement of the behavioral level or performance level of the person. A person's past behavior and present level of functioning is looked at to determine what he needs to work on now

Based on the assessment, a decision on the future program of action is taken on how far the person needs to advance in behavior and in acquiring daily living skills.

Assessment leads to an individualized program plan.

Step 2: It states in general terms a *Goal statement* arising directly from the assessment and states the *behavioral objective* which is a statement of the expected behavior in specific terms. The objectives stated, which should be *observable* and *measurable,* is followed by the method of teaching this targeted (new) behavior.

Step 3: Evaluation of the individualized program plan: It is the looking back on the behavioral objective and asking if the behavior change observed as stated in the objective was timely. If not, why not? This step evaluates the individualized program plan and not the person's entire behavior.

Note: Evaluation is done to determine the effectiveness of the program. But assessment is for creating a baseline for further programming and intervention.

Tools Available in India

Persons with mental retardation are assessed for intelligence, personality, education, social achievement, special abilities, and aptitudes.

Primary assessment includes recording of case history, physical examination of the child, pre-school assessment, school learning and post-school adjustment.

The approach, so far, has been psychometric even though adaptive behavior assessment has formed the basic component in testing for screening, placement and programming for intervention.

The Tests

Adaptive Behavior Scale (AAMD-Lambert et al., 1981), Vineland Social Maturity Scale (Doll, 1953) and a few others have been adapted for use with Indians, but there has been a wide difference in the application of each.

In this direction, the Madras Scale (Jeyachandran P., 1968), Madras Development Programming System (Jeyachandran P. and Vimala V., 1975; revised 1983) was the first adaptive behavior scale to be developed in the country for implementation of the Individualized Educational Plan (IEP). The reprinted edition (2002) is being used throughout the country.

Following this pioneering development of the Madras Scale (1968), the following were evolved at the NIMH, Secunderabad:

- Behavioral Assessment Scale for Indian Children with Mental Retardation (Peshwaria and Venkatesan, 1992, Basic-MR).
- Functional Assessment Tools (NASEOM).
- Assessment of the Mentally Retarded Individuals of Grouping and Teaching (NIMH, 1991).
- Problem Behavior Checklist (Peshwaria, 1989).
- Maladaptive Behavior Checklist (Peshwaria & Naidu, 1991a).

- Problem Behavior Checklist (Arya, Peshwaria, Naidu & Venkatesan, 1990).
- The Assessment Scale-Speech and Language (Subba Rao, 1998).
- Behavior Disorder Checklist (Mishra, 1990).
- Adaptive Behavior Scale (Indian Revision) (Gunthey & Upadhyaya, 1982).
- Educational Assessment of the Persons with Mental Retardation, based on functional performance rather on verbal performance (Jangira, Ahuja, Kaur, & Sefia, 1990).
- School readiness measure development (Muralidharan, 1975).

The Illinois Test of Psycho-Linguistic Abilities in its adapted form, available in our country (Sahoo, 1988), is used for diagnostic and related language processes.

The ERIC (NCERT) has initiated determinants to assess the psychometric validity of Indian tests in various areas which need wider dissemination

Madras Developmental Programming System (MDPS), 1975

- The scale consists of 360 observable and measurable items. Grouped under 18 functional domains, such as gross motor, fine motor, eating, dressing, grooming, toileting, receptive and expressive language, social interaction, reading, writing, numbers, time, money, domestic behavior, community orientation, recreation and leisure time activities, vocational activities.
- Each domain lists twenty items in the developmental order, along the dependence-independence continuum.
- The MDPS also provides an Adaptive Behavioral Assessment of each child with mental retardation.
- The MDPS system helps to record challenging behaviors (problem behavior) which can be taken care of through the IEP. A schedule for the management of challenging behaviors is also included.
- The administration procedure involves getting information regarding the skills and behaviors that the child can or cannot do currently.
- Information is derived through direct observation of the child, through parent/ caretakers' observations and by means of testing in simulated situations or through interviews.
- The child's performance on each item is rated from two directions, A or B, depending on whether the child does not or does perform the target behavior listed as an item on the scale.
- The data recorded/presented, graphically and/or numerically, at weekly, quarterly, and annual intervals, helps the teacher to set goals and draw behavior profiles of the assessed individual; it helps in the evaluation of a child's progress over a period of time.
- Once the assessment is completed, persons with mental retardation, as per the design, will naturally fall into the educational classifications: pre-primary, primary, secondary, pre-vocational and vocational.
- The reliability and validity of this scale has been established.

Upanayan Developmental Programming System (UDPS) for Children with Mental Retardation (Madhuram Narayan Centre for Exceptional Children, Madras), 1987

It is comprehensive, covering the management of children with mental retardation in the age group of 0-2 years and 2-6 years to meet a 'felt need' for systematic training. Appropriate to Indian conditions and suited to the cultural milieu, the printed program comes equipped with a user manual and a set of activity cards.

Upanayan Early Intervention Developmental Programming System: This System consists of background information form (Case history), the Upanayan checklist, profiles, evaluation formats – Graphical and Numerical, an assessment kit, activity cards, training materials and a user manual.

The check list, covering the five areas of development from birth to 2 years, is arranged in the normal developmental sequence, comprising a total of 250 skills, 50 from each domain, such as, motor, self-help, language, cognition and socialization.

The *activity cards* are colored differently for easy identification. The *manual* gives instructions on the use of the checklist and the activity cards and a list of materials to be used during assessment.

In the Upanayan program, age 2 + to 6 years, the check list includes 50 skills in each of the selected 12 domains, a total of 600 skills.

The domains are: communication, self-care-meal time activities, personal daily activities, social activities, community use, self direction, health and safety, functional academics–writing, reading, arithmetic, leisure time and work.

The manual includes instructions for use.

The checklist and the activity cards containing suggested activities have been field tested extensively with parents, special educators and other professionals in different parts of the country.

Behavioral Assessment Scale for Indian Children with Mental Retardation (BASIC-MR)– Peshwaria and Venkatesan, 1992, (NIMH)

- Though designed to elicit systematic information on the current level of behavior in school going children with mental retardation, in age group 3 to 16 (or 18) years, the teacher may find the scale useful even for older individuals with severe retardation.
- Relevant for behavioral assessment, the scale, field tested on a select sample, can also be used as a curriculum guide for program planning and training based on the individual needs.

BASIC MR

The scale has been developed in two parts, BASIC MR, Part–A and BASIC MR, Part-B.

- PART-A consists of 280 items grouped under seven domains— motor, activities of daily living (ADL), in motor, language, reading–writing, number, time, domestic, social and pre-vocational.
- PART-B consisting of 75 items grouped under 10 domains, that is, violent and destructive behaviors, temper tantrums, misbehavior with others, self-injurious behavior, repetitive behavior, odd behavior, hyperactive behavior, rebellious behavior, anti-social behavior, and fears, helps to assess the current level of problem behavior in the child, along a descriptive scale, namely, independent, cueing, verbal prompting, physical

prompting, totally dependent and not applicable, each scale awarded a score of 5 to 0 in that order.

- Test administration of any item within any domain can be stopped after five consecutive failures by the child. The rest of the items should be scored '0'. In such cases, maximum scores possible for the child in each of domain is 200.
- The child is rated on each item of Part-B along a descriptive scale, namely, 0 for 'Never', 1 for 'Occasionally' and 2 for 'Frequently' based on three levels of severity and frequency.

Functional Assessment Checklist for Programming–NIMH (Narayan, Myredi, Rao & Rajgopal, 1994)

- Each of the seven checklists is addressed to different levels of the child's functioning, namely, pre-primary, primary-I, primary-II, secondary pre-vocational-I, pre-vocational-II and care group.
- At each level, selected carefully and written objectively, excepting care group, the checklists cover a broad domain of skills, such as, personal, social, academic, occupational and recreational.
- When a child achieves 80% success at a given level, promotion to the next higher level considered.

Each item on the checklist is rated along a descriptive scale namely, yes (+) means the child performs the item with no help, occasionally cueing (OC), verbal prompting (VP), physical prompting (PP), no (-) meaning one has to completely support the child in the performance of the task.

- Teaching goals and objectives set quarterly (once in three months) and the progress evaluated at the end of each quarter, the checklist provides for periodic evaluation.
- This checklist has a high correlation with the Madras Developmental Programming System.

The Portage Guide to Early Education

Designed in 1975, as a home based intervention program for pre-school children aged 0-6 years with developmental disabilities, it provides a flexible model for early intervention by involving parents and families in the education of their child.

Dissemination in India –The Jamaica Adaptation

The Jamaica adapted Portage Guide disseminated in 1986, at NIMH, Secunderabad (M.Thorburn), was found culturally loaded. Hence, a programming system, suited to the Indian cultural milieu, was developed by an interdisciplinary team of experts.

Curriculum Based Assessment Checklist (MRIH), Kolkata, 2000

It was developed to help parents and professionals make curricular decisions for those learners for whom a portion of their program must be devoted to direct instruction in the community living areas.

The checklist contains 17 domains for different levels of mental retardation. These are, Motor, Self-help Skill (ADL), Language, Cognition, Safety, Health, Physical Fitness, Pre-Vocational, Vocational, Reading, Writing, Arithmetic, Money, Time, Social play, Recreation.

The full scale of the checklist consists of nine domains which contain core skills. Eight other skill areas are grouped into five performance levels (Pre-Primary, Primary, Secondary, Pre-Vocational and Vocational).

Thakhur Hariprasad Institute (THPI), Hyderabad, Diagnostic Record for Persons with Mental Retardation

This comprises the following:

- Social work related information, medical history which includes pre-natal, peri-natal, post-natal information.
- Special Education Assessment is conducted using the list of activities as in 1983.
- AAMR definition from gross motor functions to vocational skills.
- Psychological Assessment, Cognitive Vocational Abilities, Behavior Problems, Speech and Language Assessment, Speech Communication-verbal and non-verbal, Gessel Drawing Test, Seguin Form Board, Colored Progressive Matrices, Standard Progressive Matrices, Binet-Kamath Scale, Vineland Social Maturity Scale, Malin's Intelligence Scale for Indian Children, Bhatia IQ Test, Koh's Block Design, Denver Developmental Screening Test.

An interdisciplinary team of experts give their inputs using their own assessment system.

Individualized Educational Plan (IEP)

- The main purpose of IEP, evolved and implemented in the Madras Project (1968, Balavihar), is to provide age appropriate and need-based education and training to every child with mental retardation.
- IEP is developed by a team of experts and parents to provide persons with mental retardation appropriate intervention.
- The components of IEP are an assessment profile, target behavior to be achieved every quarter and the evaluation records maintained.
- This was the precursor to the IEP which emerged in the current format in 1975 and a revised version in 1977.
- The IEP format, gazetted in the Government of Tamil Nadu Special Educators' curriculum, was put to use.

Rehabilitation Council of India Recommended Tools

The Rehabilitation Council of India (RCI) recommended tools for IEP and IFSP.

The popular and most used programming systems in the country are:

- The Madras Developmental Programming System (Vijay Human Services).
- Upanayan Early Intervention Developmental Programming System (Madhuram Narayan Centre for Exceptional Children).
- Functional check list (National Institute for the Mentally Handicapped).

These tools are adequate, complete, individualistic, and inter-disciplinary in their approach.

Individualized Education Plan (IEP)–Flow Chart

The IEP a sequential process for making decisions regarding the program of management of persons with mental retardation, is essentially an assessment process for teaching, popularly

known as criterion referenced scale. With an in-built system for periodic assessments and evaluations, it helps the planners to arrive at a comprehensive picture of an individual's performance level in adaptive behavior, an area often neglected in the traditional method of "treatment planning".

The entire process of program planning can be visualized in the flow chart (Bock and Jeyachandran, 1975) shown in Graphs 1 & 2.

Assessment, the first and a necessary step in the entire system, is followed by designing the individualized program plan which includes setting goals and objectives.

After quarterly evaluation, new goals and objectives are set as needed, the entire process to be repeated annually.

The Interdisciplinary Team

Since many persons with mental retardation also have associated problems, the expertise of several professionals is necessary to provide effective programs using the skills of the interdisciplinary team. The special educator plays a pivotal role.

The most commonly involved members being the special educator, psychologist, physiotherapist, occupational therapist, speech therapist, social worker and paediatrician. The team also includes the trainee, his parents and the referral agency, all participating in the program planning activities.

Though each member of the team has a clearly defined function, all of them work together.

Program planning is a good practice, irrespective of the "tools" or "instruments" employed.

MDPS Behavioral Scale

In the MDPS Behavioral Scale, the behavioral assessment instrument is designed to provide objective and sound information about the functional skills of the assessee for purposes of program planning.

Assessment data are presented in a graphic form on the Behavioral Profile for use by the interdisciplinary team.

Formats: The priority goals and objectives set by the team based on individualized assessment are recorded on the Individualized Program Plan forms, that is, the Priority Goal Statement Form and the Quarterly Program Plan Forms.

Record of Progress: The quarterly progress can be recorded, both numerically and graphically, in the profile format in which the individual's achievement is shown for each quarter with distinct markings on the selected objectives. This facilitates a comparison between the initial assessment and the quarterly evaluations.

In the Individualized Program Plan form (Quarterly Program Plan Form) weekly progress may be recorded.

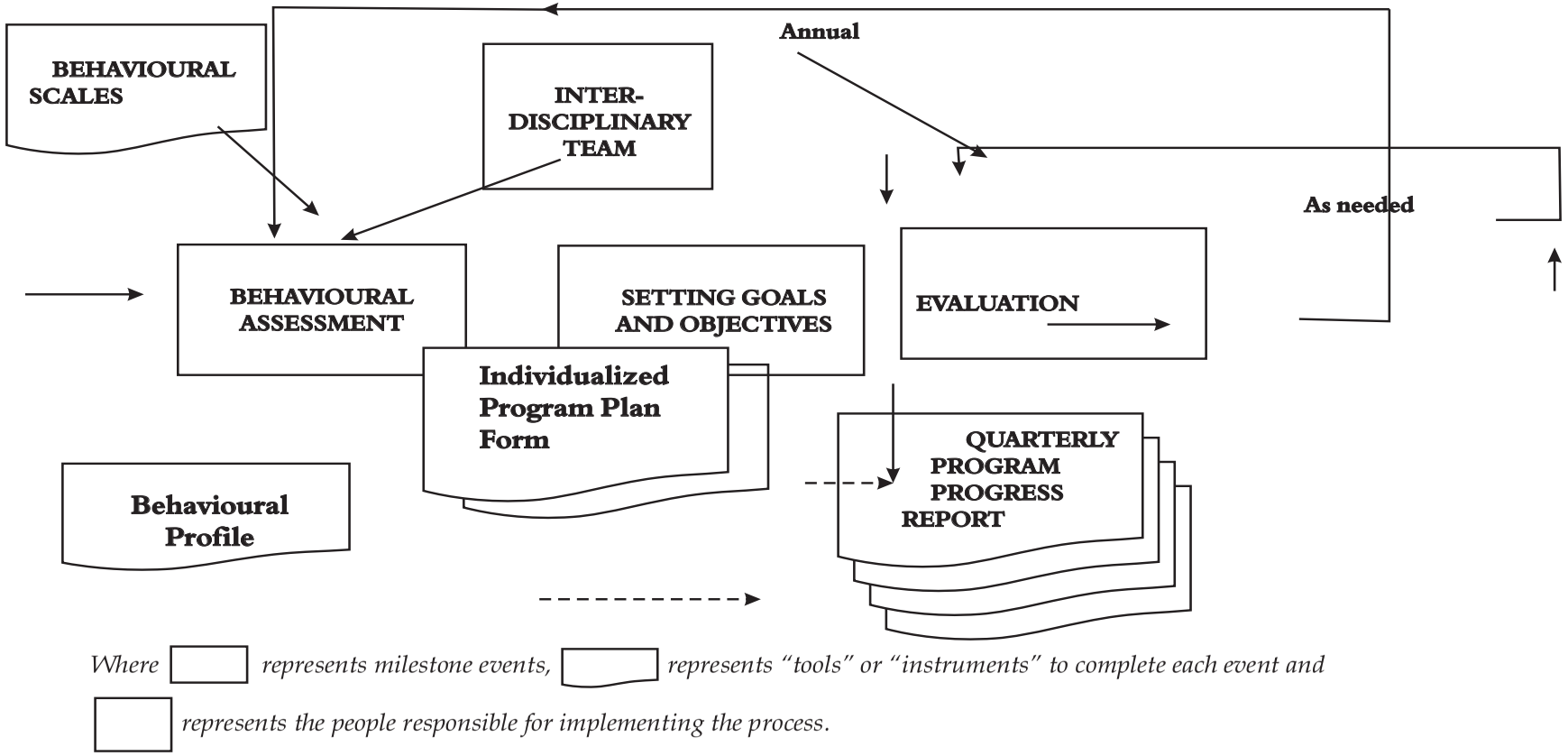
When completed, the tabular form will give a clear, consolidated picture of the progress made by the individual in regard to the objectives selected for the quarter.

On the *Problem Behavior Assessment Form,* a description of the problem behavior can be recorded. A few of the frequently observed problem behaviors is also given.

In summary, the component parts of the IEP include:

- The *Behavioral Scale –an assessment tool.*
- The *Behavioral Profile* with space to record the quarterly progress and the identifying information.

Graph 1: Individualised Education Program (IEP)



Where ▭ *represents milestone events,* ▭ *represents "tools" or "instruments" to complete each event and* ▭ *represents the people responsible for implementing the process.*

- The Individualized Program Plan Forms include the Priority Goal Statement Form, the Quarterly Program Form and the Problem Behavior Assessment Form.

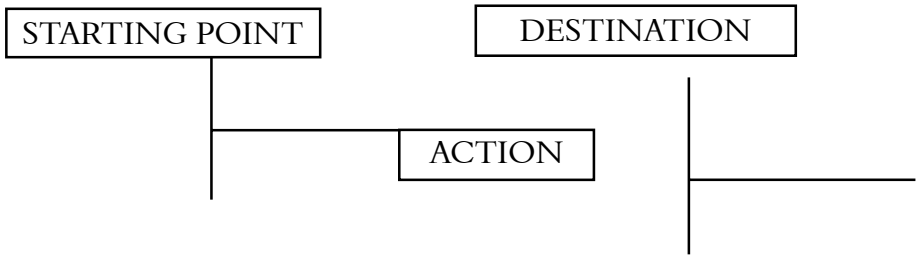
Adaptive Behavior Assessment Kit (ABAK)

Adaptive Behavior Assessment Kit (ABAK) which uses the materials available in the classroom and at home, can be used wherever simulation is necessary for assessing an individual.

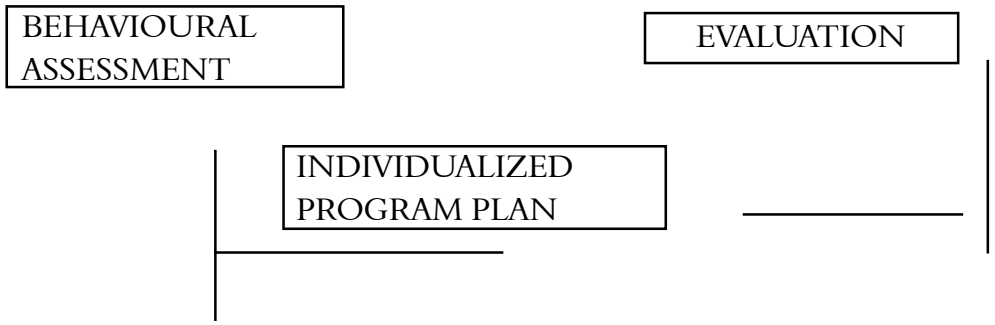
The material in the kit is established to get a valid and reliable profile of the individual (Vimala, Kumar, Jeyachandran, 1983).

Graph 2: Program Planning

Road map for program planning



The diagram below illustrates the steps involved in program planning



Steps in Individualized Program Planning

Step I Assessment		*Step II Individualized Program*		*Step III Evaluation*	
IA	*IB*	*IIA*	*IIB*	*IIIA*	*IIIB*
What are the skills that are already learnt	What is the present level of functioning in adaptive behavior?	What are the goals you would like the child to reach?	What are the specific behavioral objectives that the child must achieve in order to reach the overall goals set for him?	What are the specific methods to be followed to help the child?	Has the child achieved the activities set for him?

Individualized Program Planning (Overall Process)

Behavioral Assessment of the Domain, Dressing	*Goal*	*Behavioral Objective*	*Evaluation*
Puts on and removes clothes, does not button or unbutton, does not hold button with thumb and index finger.	To dress himself independently	When required to undress, the child will unbutton his shirt 8/10 times within a period of three months	After three months, teacher and parents will observe the child's dressing to determine the degree to which this objective has been achieved.

As seen above, the goals and behavioral objectives are set, based on the assessment. Every skill is task-analyzed into small sequential steps. All these steps in 'Task Analysis' are translated into concrete lesson plans.

Problem Behavior Assessment

Persons with mental retardation show deficits in adaptive behavior. Hence, training them to overcome the limitations in adaptive behavior is the primary aim of any individual working with persons with mental retardation. A few of them also have problem behavioral posing challenges to the educator.

Problem Behavior – Its Identification

A problem or a challenging behavior in the individual interferes with his acquiring new skills, or strengthening old skills or it interferes in someone else's activities. The behavior may be harmful to himself or may causes harm or disrespect to others.

Behavior Modification

Once the problem behavior is identified, steps should be taken for its elimination/ modification. However, the educators should remember that in a developing person, their primary aim is to develop his activities of daily living wherein inappropriate behavior modification becomes simple.

Individualized Program Planning in a Classroom Setting (Group Teaching)

The individualized program plan can be effectively carried out in a classroom set-up for five or six persons as a group in a class room set up by a special teacher.

Grouping

Grouping the persons with mental retardation homogenously for purposes of education/training could be based on the assessment made on the standard scale.

The groups are as follows:

Pre-Primary, Primary, Secondary and Pre-Vocational

- The grouping need not necessarily be a heterogenous one either. The educator needs to work on the selected skills relevant to the group in which the individual is placed.
- The grouping can be shown in the Behavioral Scale and in the Behavioral Profile Form. When the assessed individual achieves independent

performance (80% level) level, he is ready to be moved to the next higher level for training.

- However, there cannot be rigidity in grouping. Allowances must be made for minor variations. For example, an individual may not progress in functional academics, such as, reading, writing despite training for more than two years, but learns other skills. In such instances, he can still be moved to the next level by making allowances to his non-achievement in functional academics.

This will help the teacher to give age-appropriate training.

Similar situations may also occur where the individual may have motor or other associated disabilities.

Economy

It takes an average of 55 minutes only to complete an assessment on the individual if both the parent and the teacher are knowledgeable of the items in the scale and also have clear information on the child's behavior (activities).

A well planned time table is essential for the success of the individualized program plan in a group set up.

Time Table

After assessment, depending on the child's age, level and associated conditions, the goals (5-10 in number), are set for each child in the class. The activities in the first three goals to be achieved should be repeated twice a day, in a special education set up and the others, once a day.

Provision should be made in the day's time table for music, games and craft work.

Children of the same age group, but with different performance levels within the same goal areas, may be grouped together for a learning activity. They will learn the different selected skills in the respective domains, based on the current levels of performance of each individual.

However, the goal areas may also be different, especially after the first quarter; the priorities may vary depending on individual achievements and requirements.

Grouping children based on the range of activities in which they need to be trained will enhance effective implementation of the Individualized Educational Program System in a classroom.

The time allotted for the goal areas selected for each individual, the objectives selected for each of the goal areas based on the Individualized Program Plan and the intervention strategies decided upon are displayed in the time table.

Assessment in Special Education

In an All India Seminar on Assessment in Special Education - MR (MRIH - USEFI, 2001) recommendation for a Multidimensional Model of Assessment was made with a series of operational recommendations. This has been implemented.

Multidimensional assessment refers to a comprehensive and integrated evaluative approach that employs multiple measures, deriving data from multiple sources, surveying multiple domains and fulfilling multiple purposes.

Use of *multi-measures* provides a broader base and a more valid method for assessing children with developmental disabilities.

Diagnostic batteries that combine norm based, curriculum based and clinical judgment

based scales, help achieve the greatest probability of accurately describing and prescribing the complex needs of children with multiple disabilities.

Information from *Multi source,* i.e., from several contexts (home, school, clinic) and sources (parents, teachers, therapists) is gathered. This requires interdisciplinary, ecological, interactional and environmental assessment.

Multi domain assessment refers to the use of instruments that examine the child's capabilities and deficiencies within and across several developmental and behavioral areas or processes.

In *multi purpose assessment,* besides cognition, domains like social competence, communication, self-care, play, temperament, self-regulation, attention, emotional expression and coping behavior, are included.

Suggestions Made by USEFI Seminar for Development of Assessment Tool for Identifying, Classifying Persons with Mental Retardation

- Using a process oriented assessment tool (planning, attention, simultaneous, successive processing) Das et. al. (2000) instead of IQ Test (MR, L.D., Reading Disability).
- Clinical psychologists working in organizations of disability training research/NTs to take up adaptive behavior scales suitable to our culture and life (translate to regional language) and validate the schedule.
- Adoption of completely uniform procedure of testing, laying down tester characteristics for all institutions, including ethical considerations.
- Learning potential assessment device (LPAD) in content areas, in the pattern of achievement tests for different levels/ classes, is to be developed.
- Development of clinical diagnosis schedule and procedure involving National Institutes and other leading Non-Governmental Organizations.
- Adoption of information schedule for family data and ecological conditions.
- Evolving guidelines for drawing profiles in terms of developmental milestones and points of intervention.
- Evolving an outline of an assessment report–what and how it can be meaningful to parents/special educators.

Conclusion

Many persons with mental retardation also have associated problems. The services to these individuals must be rendered using the professional skills of the interdisciplinary team whose members may also be made available on a consultative basis.

The team should be involved in identifying the individual's needs and in designing programs to meet them. The individual, his family and the referral agency also form part of the interdisciplinary team. Each member of the team should utilize the skills, competencies and insights that his/her training and experience provides, but they should work together as a team without imposing constraints. The special educator plays a pivotal role in the interdisciplinary team.

The members of the team should always work together with the child as the main focus.

Chapter 6

Array of Services for Persons with Mental Retardation - Quality Services

Introduction

With the implementation of Persons with Disabilities Act, 1995, an array of services for persons with mental retardation is now available in the country.

Efforts towards a process of normalization, integration, and inclusion have already shown results in the right direction.

However, there is a need for rules and regulations in the provision of standardized services and accountability.

An outline on the available of services is given below.

Array of Services–Prenatal Care

Array of Services	*Organizations*	*Service Providers*	*Remarks*
PRENATAL			• **Genetic**
1. Prevention			**Observations:**
• **Genetic Counseling**	District Rehabilitation Centres, Hospitals, Primary Health Centres, Voluntary Care Services.	Medical Professionals Researchers, Village Level Rehabilitation Workers, Nurses, Dayis, Genetic Counsellors, Volunteers.	i. Facility available only in the metropolitan cities. ii. Not easily affordable iii. Need for improved awareness on its importance in prevention. **Action Plan:** i. Concerted effort in creating awareness on the need for genetic counseling and on how to seek the services for counseling and diagnosis. ii. Services at the district level to be set up, for basic needs with a tie up with hospitals where diagnostic services are available.

Array of Services	*Organizations*	*Service Providers*	*Remarks*
Prenatal care including Nutrition and Early Detection			• **Prenatal Care Malnutrition – in pregnant mothers/ weaning child** Of the possible 100 million pre-school children, 3 to 4 million suffer from severe forms of malnutrition. Nearly 1 million die of starvation every year. *(The Feeding and Care of Infants and Young Children,* Dr. Shanthi Ghosh, VHAI, 1992). Early detection and correction of malnutrition not available for all.
INFANCY AND PRE-SCHOOL			
Medical			**Observations**:
1 (a). Prevention (Medical) • Health check ups, investigations; Genetic Disorders, Chromosomal Anomalies, Metabolic Disorders; Screening- Nutritional deficiencies in diet	District Hospitals, Government Hospitals, Research Institutes, Primary Health Centres, Well Baby Clinics.	Pediatricians, Physicians, Gynaecologists/Obstetricians Nutritionists, Pathologists, Other Medical Professionals (relating to mother-child health), Researchers – Scientists; Health Care workers, Nurses, Lab technicians, Counsellors.	Inaccessibility / unaffordability to avail facilities in ante-natal clinics. i. Lackadaisical attitudes of some medical personnel. ii. Improved awareness on the need for periodic checkups.
Timely immunization Counseling on avoiding toxic substances. Follow up on " high risk" neonates. Tracking "high risk" mothers. Routine medical care.			**Action Plan:** i. Sensitising medical/ para medical professionals on the nature, causes and management of disabilities through periodic workshops

Array of Services	*Organizations*	*Service Providers*	*Remarks*
			updating them with scientific information. ii. APGAR Score to be taken for every new born and reported to parent; awareness on the need for corrective/ preventive action. Early detection facilities to be made available with a tie up with genetic research labs and networking with them - genetic metabolic disorders/ chromosomal anomalies. **Media** dissemination of information on types and causes of disabilities. Message on: iii. Prevention, every day at prime time. All hospitals to compulsorily introduce a screening system for 'high risk" mothers and children.
1 (b). Prevention (Psychological) • Early detection for defects, impairments, disabilities. • Early Intervention (Infant Stimulation) for developmental delays and pre-vention of secondary disabilities.	Early Intervention Centres, Child Care Agencies/Creches, Social Service Units; Child Care Centres in Hospitals; Balwadis, Primary Health Care Centres; Homes.	Parents/foster/adoptive/ surrogate Special Educators Teachers/Aids Social Workers, Anganwadi Workers, Volunteers.	**Observations:** Improved awareness in parents and the general public that disabilities detected early can become manageable with surgery/ medical treatment/ and with timely intervention.

Array of Services	*Organizations*	*Service Providers*	*Remarks*
			Action Plan: i. Dissemination of information through posters pamphlets/ workshops at all centers/ PHCs/ Agencies. ii. Establish early intervention units at all the locations mentioned above, for training. iii. More awareness needed. iv. Rural –ignorance: urban- societal/ professional unsupportive attitudes
2. Early Identification (i) Screening (ii) Early Diagnosis (iii) Parent counseling (iv) Intervention, Training / Treatment	Health Centres, Creches, Well-baby Clinics, Child Couselling Units, Health Departments, District Hospitals, Service Providing Centres.	Public Health Workers, Nurses, Pediatricians, Psychologists, Social Workers, Physicians, Therapists (Physio, Occupational, Speech), Anganwadi Workers, Creche, Care Workers.	**Observations**: i. Inter disciplinary team approach available. ii. Each department works independently, in isolation, not holistically. **Action plan:** i. Need for an inter / multi disciplinary team approach/action. ii. Field workers to undergo periodic refresher courses to update on relevant, scientific information iii. Awareness on and need for timely and corrective surgery to be created.
• **Medical-Medication Surgery**	Hospitals, Special Diagnostic Clinics, Early Intervention Centres, Child Guidance Clinics	Medical Specialists, Practitioners - Pediatricians, Neurologist, Psychiatrists, Surgeons and other specialists	Facilities to be made available. Funding for those who cannot afford.

Array of Services	*Organizations*	*Service Providers*	*Remarks*
• Therapies-Physio, Occupational, Speech: where needed. • Sensory Stimulation, Training and Special Education in Motor (Gross and Fine), Language and Cognitive Development, Self-Help (feeding, dressing, toileting, grooming) and Social Interaction. • Corrective: Aids and Appliances, as and when needed	Public Health Centres, Infant Stimulation/Early Intervention Centres/Homes, Child Development Centres	Therapists: Psychologists, Physio, Occupational, Speech, Special Educators, Teacher Aides, Social Workers, Parents, Creche Care Givers, Nursery School Teachers, Psychologist Physiotherapist Occupational Therapist, Speech Therapist, Social Workers.	**Observations:** Therapists working at tandem with special educators. **Action Plan:** i. Need for coordination in services. ii. Need for introducing mainstream teachers to the area of disability and the services needed in them.
Residential	NGOs Care Givers Homes, Community Homes, Small Group Homes, Respite Care/Medical Support Clinics; Primary Health Centres	Parent, Foster Parent Group, Home Parent	**Observations:** Need for homes for the orphans and destitutes, multiple handicapped children. **Action Plan:** Need for accreditation for such homes and a need for follow up for improvements and maintenance of the required standards with sufficient funds.
• Parental-Child Development Emotional support/respite care/parent organisations, social services.	Village Health Workers, District Rehabilitation Centres, Social Service Agencies, Parent Associations	Parent Trainers, Social Workers	**Observations:** Awareness present. **Action Plan:** Networking of Services and formation of Federation of service providers.
• Coordination and advocacy • Coordination of inter-disciplinary services as needed. Helping parents to become "advocates" for their children	Psychologist, Special Educators, Advocates, Parents Associations, Voluntary Agencies, Social Service Organisations.	Legal Aids, Social Workers, Volunteers, Lawyers.	**Observations:** Inaccessibility to professional services due to lack of awareness on the need and availability/ financial affordability.

The above mentioned Array of Services is preparatory to the school stage entry and beyond.

Array of Services	*Organizations*	*Service Providers*	*Remarks*
School Age			
SCHOOL AGE Training and Education **as in pre-school, plus** • academics. • prevocational and vocational training. • sex and family life education. • acquisition of skills in activities of daily living. • yoga. • music. • dance/movements. • art crafts. • other therapies.	Schools, Specials, Inclusive Education Schools, Vocational Rehabilitation Centres, Special Therapies Centres, Home bound programmes, Health Depts, Yoga/Music/Dance Centres, Resource rooms in schools.	Special Educators, Special teacher helpers, psychologists, counselors, rehabilitation counselors, sex educators, physio, occupation and speech therapists, yoga therapist, dance and music teachers. Resource teachers and Itinerant teachers.	**Observations:** i. Insufficient availability of number of trained professionals. ii. Need for standardization in quality. iii. Lack of "sufficient" awareness on "inclusion". iv. Poor infrastructural resources. **Action Plan:** Coordination in pooling/sharing resources with Ministries of HRD, Social Justice and Empowerment, & Health.
• **Residential** As in pre-school and in addition programs for persons of different categories and age levels.	As in pre-school years plus facilities for those with behavioural problems.	As in pre-school years plus behaviour management specialists.	**Observations:** Non-availability of sufficient number of trained /committed professionals ready to work in the field. **Action Plan:** i. Forming a resource pool of available personnel, registered with RCI. ii. Introducing training courses in management of residential homes. iii. Standardisation and accreditation.
• Recreational	Community Parks/ Centres, Recreational Programmes, Special Recreation Centres and Special Olympics.	Recreation Planner Groups, Social Workers and Volunteers	**Observations:** i. More need for barrier free, safe environment

Array of Services	*Organizations*	*Service Providers*	*Remarks*
			ii. Volunteers available only in few places. **Action Plan:** i. Awareness campaigns that persons with disabilities also need recreational facilities. ii. Providing more recreational facilities
Coordination and advocacy • As in pre-school years but with special emphasis on the assurance of education as a fundamental right be provided by the schools.	As in pre-school years	As in pre-school year.	**Observations:** The PWD Act yet to be implemented in its reality. **Action Plan:** Implementation of the PWD Act, RCI Act and the National Trust Act in letter and spirit.
ADULTHOOD **Vocational Pre-vocational** • Vocational on the job training, competitive employment, sheltered employment.	Skilled, Semi-skilled and unskilled on the job training units, workshops, factories, industry locations, offices, sheltered workshops, vocational rehabilitation centres, farms, animal husbandary units, cottage industrial units	Employers, Personnel Manager, Rehabilitation Counsellor, Supervisors in sheltered workshops (Administrators/Work evaluators, supervisors and instructors).	**Observations:** i. Very few training courses and facilities for employment. ii. Public awareness and the confidence at a low level in the employer to recruit persons with disability even with training. **Action Plan:** i. Awareness program on the need for acceptance of persons with disabilities at the workplace. ii. Implementation of the reservation policy to include jobs/identify suitable jobs for persons with mental retardation.

Array of Services	*Organizations*	*Service Providers*	*Remarks*
Day "activity" program • Primarily for severely and profoundly adults with mental retardation and providing continued training in basic self care skills and activities of daily living, recreation pre-vocational activities.	Day "Activity" Centre	Special Educator, Teacher Aides, Nurses.	**Observations:** Very few facilities available. **Action Plan:** Need for community participative projects.
Educational	Schools of Social Work	Special Educators, Social Workers, Parents, Volunteers.	
• Courses on money management. • Human Relations • Music • Appreciations • Health Care • Sexuality • Cooking • Outdoor recreation • Residential • From semi-independent living to specialized residential facility for profoundly retarded	Care givers, counselors, Supervised and supported board & lodging placements, Apartments, Subsidized family living placement, Minimum supervision group homes, Intensive training group homes, Health care facilities, facilities for persons with chronic medical problems	As in earlier years: plus health workers.	
"Support" Service Home	Respite Resources, Personal care and chore services.	"Respite" care givers, personal care attendants, village level workers, health workers, noon meal servers, school teachers.	
Health	Medical and Dental	Medical Professional	
Transportation	Subsidised Public transport system.		
Social and Recreational	Organisations and Community Recreation Resources	As in early years	
Advocacy	Advocacy Agency	As in earlier years, plus, parent groups.	
Coordination	RRTC, DRC, DRD, Case Management agencies-Voluntary	As in earlier years.	

Note: Research should be conducted at all stages of education and effective dissemination done.

Number of Special Schools Working in the Country for Persons with Mental Retardation (State-wise) as on 30th April 2007(NIMH)

Name of the State	*No. of Schools*	*Name of the State*	*No. of Schools*
Andaman & Nicobar Islands	18	Manipur	4
Andhra Pradesh	248	Meghalaya	4
Assam	12	Mizoram	3
Bihar	33	New Delhi	61
Chandigarh	6	Orissa	56
Goa	12	Pondicherry	24
Gujarat	112	Punjab	12
Haryana	24	Rajasthan	27
Himachal Pradesh	10	Tamilnadu	258
Karnataka	110	Tripura	4
Kerala	162	Uttar Pradesh	54
Madhya Pradesh	48	West Bengal	69
Maharashtra	178	**TOTAL**	**1579**

Note: Includes Special Schools run by Parents' Associations and Integrated Education for the Disabled Children (IEDC) Programs in some states.

The figures given above indicate only those schools which responded to the National Institute for the Mentally Handicapped (NIMH) Survey. Schools under the **Sarva Siksha Abhiyan** (**SSA**) inclusive program are not included.

Conclusion

Over the past two decades, the parents and caregivers have become more and more aware of the need for services for their wards with mental retardation. Trained professionals have also become more available now.

Chapter 7

Manpower Development and Special Teachers Training

Introduction

Manpower Development Programs

Programs in manpower development which are being implemented are: long duration courses, short term programs, and workshop/orientation programs, orienting to professionals in awareness of the needs of persons with disabilities of different personnel.

In 1992, the manpower development and training programs were brought under the purview of the Rehabilitation Council of India, a statutory body.

As per the RCI Act, Section 11, it is a mandatory requirement for all universities and institutions intending to offer training courses in the field of disability rehabilitation to seek RCI recognition before the commencement of the course.

So far, 125 institutions have been granted recognition by RCI to run courses in special education for the persons with mental retardation.

The Manpower Report (1996) prepared by RCI had projected that about 0.36 million persons would have to be trained during the Ninth Plan period.

A Comparison in the Status of Disability in the Years 1947 and 2007

S. No.	*Status Disability*	*1947*	*2007*
1.	Number of service providing organizations for the intellectually disabled	3	2010
2.	Early Intervention Programs–Centers	None	198
3.	Special Educators' Training Programs : • Early Childhood Special Education • School Education • Adult Programs • CBR Programs	None	70 (Including University Programs)
4.	Therapists' Training Programs		
	• Speech Therapy	None	25
	• Occupational Therapy	None	30
	• Physiotherapy	Only in the city hospitals for post surgery therapy	400 (including rehabilitation)

(Continued)

S. No.	Status Disability	1947	2007
5.	Services Available Early Intervention		
	• Home Based • Centre Based	None	Available all over the country
	• School Education Special Schools Integrated Schools Inclusive Schools Transition Vocational • Day Activity Centers • Residential Homes	None 4 (Juvenile Detention Homes)	Well structured need based residential homes
6.	Legislation	Governed by British Lunacy Act, 1910	Mental Health Act, 1987; Rehabilitation Council of India Act, 1992; Persons with Disabilities Act, 1995; National Trust Act, 1999

Training Programs

In 1993, when RCI Act came into effect, the number of training courses and institutes stood at 22 and 25 respectively. RCI recognized institutions, 17 years later, for offering courses at Certificate, Diploma, Bachelor, Masters, M.Phil, etc., number 350.

Out of 120 short and long term courses developed so far, 56 courses of 1 year duration or more, are operational in the country, turning out, annually, more than 5,000 rehabilitation professionals in conventional classroom setting and B.Ed. in special education in the distance mode. Some of these trained professionals are in demand in the developed world also.

Training institutions for the special educators rose from nil to 70. Training has made possible the inclusion of trained experts in speech, vocational training and physiotherapists as members of the interdisciplinary team in drawing up individualized program plans. The modes of training are structured, systematic and simple in application for home based, centre based early intervention, for programs in special schools, integrated, inclusive settings, transit schools, vocational activity centres, community based programs and residential programs.

Rehabilitation Council of India

RCI—Categories of Professionals

Under the Act, sixteen categories of professionals dealing with various disability areas come under the purview of the RCI for development and standardization of their training curricula, development of training norms and guidelines, regulation and monitoring of training institutions conducting these training programs. Also coming under the purview of RCI is registration of trained professionals and promotion of research in related fields.

In the area of mental retardation, training programs for teachers rehabilitation professionals

recognized by the RCI and conducted by the national institutions, universities, NGOs, etc. are: Diploma Courses in Special Education (Mental Retardation) and D.S.E. (M.R.), B.Ed., and M.Ed. in Special Education, and Bachelor's degree in Mental Retardation, Bachelor's degree in Rehabilitation services.

Courses/Programs Developed by RCI

Forty Five Days Foundation Course on Disability

RCI has developed a 45-day training program, a foundation course, which includes five areas of disability: mental retardation, hearing impairment, visual impairment, learning disabilities and locomotor impairment, with the intention of giving knowledge, skills, attitudes and instructional teaching techniques to the teachers of primary schools in the *District Primary Education Program (DPEP)* to handle the disabled children in the regular schools.

The Bridge Course

The RCI Act stipulates that all those delivering services to persons with disability must possess RCI recognized qualification and also be registered with it. Failure would result in prosecution. The scheme (covering the five areas of disability and mental retardation, cerebral palsy, learning disability, autism and attention disorders) for offering a Bridge Course was devised as a means to overcome this problem, a one-time measure designed to assist the professionals working prior to 1993 in the field of rehabilitation, but did not have qualification recognized by RCI nor registered with it earlier.

The Bridge Course launched by RCI throughout the country, 21 centers were recognized to run the program for persons with mental retardation.

National Programs on Orientation

RCI also launched a National Program on Orientation of Medical Officers working in Primary Health Centres to Disability Management. Fully funded by RCI, it was planned to train about 18,000 Medical Officers through selected agencies located all over the country.

Continuing Rehabilitation Education Program

RCI requires that the registered professionals undergo CRE programs, for a total period of 16 days within a span of five years from the time of registration.

Manpower Required

RCI has developed a schedule for manpower development for the type of professionals who would work in the field of disability and in particular in the area of mental retardation with an estimate (projected) which has been presented in Table 7.1 in the previous volume, *Disability Status India, 2003.*

In view of the fact that the estimates prepared earlier for the five-year plan periods was not based on any empirical study, RCI has hired the services of the Institute of Applied Manpower Research, New Delhi, a professional institute under the Planning Commission specialized in undertaking such studies to develop a methodology to arrive at more realistic estimates based on scientific principles.

Manpower in the Field of Mental Retardation

There is a wide gap between the need and the supply of professionals, between the projected figures (2003) and the number of professionals actually working in the field of mental retardation.

Number of Professionals Actually Working in the Field of Mental Retardation

The information is provided in a tabular form in the section on Mental Retardation in the previous volume, *Disability Status India, 2003.*

Other Efforts in Promoting HRD Programs in the Country

NCERT–Initiative in Special Education Teacher Preparation

In 1983, the National Council of Educational Research & Training (NCERT) included education of children with special needs as an area of service under its teacher education program. The first National Workshop on Special Education was organized by NCERT in March 1983.

UGC–Scheme for Special Education Teacher Preparation

In 1985, the UGC encouraged university departments and colleges of education in the country to start teacher preparation programs to educate children with special needs for which 100 per cent financial assistance was provided. The UGC has introduced TEPSE (Teacher Preparation in Special Education) scheme wherein assistance is given to Universities and Colleges of Education to start B.Ed. or M.Ed. Special Education programs to prepare special teachers.

Present Status of HRD in the field of Mental Retardation RCI Recognized Training Institutes / Universities & Training Programs Courses Specific to the Area of Mental Retardation.

Course	*Duration (years)*
Diploma in Special Education (Mental Retardation) [DSE (MR)]	2
Diploma in Vocational Rehabilitation (Mental Retardation) [DVR (MR)]	1
Diploma in Early Childhood Special Education (MR) [DECSE (MR)]	1
P.G. Diploma in Special Education (MR) [PGDSE (MR)]	1
B.Ed. (Special Education) – Mental Retardation	1
M.Ed. (Special Education) MR –	1

Though there are six types of courses operational at 79 institutions in the field of Mental Retardation, other courses like M.Phil & Certificate courses in Clinical Psychology, M.Phil & PG Diploma courses in Rehabilitation Psychology, Diploma courses in CBR & MRW, Bachelor & Diploma courses in Rehabilitation Therapy, PGDDRM, and PG Diploma in Early Intervention give sufficient coverage to mental retardation in addition to other disabilities.

Non-Governmental Organizations

Non-Governmental Organizations contribute significantly to human resource development without any substantial funding from the Government. An outstanding example is the Thakur Hari Prasad Institute of Research & Rehabilitation for the Mentally Handicapped established in 1968.

Manpower Development in Teacher-Training Programs in Mental Retardation

NIMH and its Regional Centres

The NIMH and its regional centres conduct refresher courses, training workshops and continuing education programs for the professionals apart from full time courses at various levels.

Parent Training Programs

NIMH had initiated and conducted training programs for groups of parents. The intention in this model is to empower the parents and family members to look after their children with mental retardation as against providing expensive institutional support or residential programs.

This unique program initiated by NIMH is being followed by many NGOs.

Distance Education

B.Ed. (SE-DE) Special Education Distance Mode Programme

Madhya Pradesh Bhoj (Open) University, Bhopal

Under an agreement with the RCI, the Madhya Pradesh Bhoj (Open) University has launched B.Ed. (Special Education) through distance mode for training special teachers.

Those candidates with a Bachelor's degree from any recognized university having two years' experience in any disability area in a standard institution are eligible to apply, preference being given to persons with any disability.

Indira Gandhi National Open University (IGNOU)

As per MoU signed by RCI with the Indira Gandhi National Open University (IGNOU), a number of courses have been launched through distance mode.

The Distance Education Course have been taken up by the States of West Bengal, Gujarat, Maharashtra, U.P. and Tamil Nadu.

The Ministry of HRD, Government of India

The Ministry of HRD, Government of India in its efforts to incorporate special education in the curriculum of regular school teacher training program, is modifying both pre-service and in-service training programs to incorporate special education component into the curriculum. Many pre-school teacher-training programs have also included "Education of exceptional children" in their curriculum.

Extension Programs for Professionals and Growth of Functionaries Including Parents

Both the government and the voluntary organisations are involved in the extension services of training the trainers of children with severe disabilities. Crash orientation seminars and workshops are organized for teachers of general schools on different aspects of special education.

The NIMH, Secunderabad and its regional centres, the SNDT Women's University, and MIND'S College of Education, leading NGOs such as THPI, Amarjyoti, MRIH, CHETNA, Deepshika, are running a number of programs.

These demonstrate the coverage, and continuous awareness and professional development through exchange, participation, deliberation contributing to the holistic development and rehabilitation of persons with mental retardation. These programs planned year-wise, are of very short duration.

Conclusion

Future perspectives in the HRD programs in the rehabilitation of persons with mental retardation.

In a span of sixty years, India has increased its manpower resource by more than 100 times.

Apart from teacher training, parents' training program, sensitization programs for Panchayat, Block and District level functionaries need to be taken on mass scale with the support of different Ministries.

To enhance human resource development studies on need assessment for identifying number and types of rehabilitation personnel required, their placement, role, job analysis, determination of minimum salary, etc., must precede the launching

of new training courses. Information elicited would determine the curriculum, its duration, course content, etc., to prevent wastage of time and effort.

Impact and research studies need to be conducted to gauge the usefulness of ongoing programs by involving stake holders such as clients, family members, employers, professionals, and faculty members.

Studies conducted on comparative analysis of training programs available in India and developed countries will help adoption of relevant content areas suitable to local needs.

To improve the training programs qualitatively, infrastructure in the training institutions must be augmented.

Refresher and orientation programs need to be made compulsory for the in-service and practicing rehabilitation professionals.

Chapter 8

Teaching Process and Materials for Children with Mental Retardation

Introduction

Over the past two to three decades in India and overseas, there has been a shift in the teaching process. With the individualized program plans tailor-made, the child with mental retardation has become an active learner.

This programming system fixes the onus on the teacher: "If the child did not learn, where has my lesson plan failed?"

Effective Methods

A few effective teaching methods are described briefly.

The Montessori Method

Maria Montessori's multisensory approach came to stay, initially in Chennai and later, all over India. The scope of teaching children with mental retardation was later enlarged to include normal children.

In following the multisensory approach, besides hearing and vision, other sensory modalities are also utilized, the tactile sense being depended on much, with focus on children in the pre-school and school stages.

Discrimination among weights, colours, sounds, and so on was reinforced to aid in exercising the children's judgment and reasoning.

The Project Method–John Dewey

John Dewey's 'Project Method' envisages a wholehearted and purposeful activity, carried on in a social environment. A significant landmark in the history of methodology of education, Dewey's method implies the principles and fulfills the conditions of a good learning process. Kil Patrick has enunciated this method.

Play-way–Active Participation Method–Caldwell–Cook

Cook, the first person to advocate "way of play" for educating the child. Regarded play as a means of training individuals as individuals, a wonderful technique of making school education interesting and practical.

Teaching Persons with Mental Retardation Using Behavioral Approach

Teacher-centered process giving way to a child-centred one, has influenced the area of special education with emphasis on the Individualized Education Program (IEP) planning for children with mental retardation. Along with individualized instruction, the teaching strategies introduced are cooperative learning, peer tutoring, computer-aided learning (CAL), multi-sensory teaching and clinical-diagnostic teaching.

Procedures–IPP

The individualized program plan (IPP) is based on assessing a person and evolving a baseline at the point of entry into the program, setting goals and objectives in the order of priority and converting the goals and objectives into concrete

lesson plans which include the teaching steps, the planning strategies for use, the material selection and finally, evaluation.

Behavioral Technology

Although behavioral technology principles in all cases not only ticked to certain model of teaching, but also incorporated the principle of task analysis, condition of promoting learning in special integrated setting.

At the National Institute of Mentally Handicapped (NIMH), Peshwaria and Venkatesan (1992) developed the "Behavioural Approach in Teaching Mentally Retarded Children" which has been tested in class rooms and at homes. Parents and teachers can develop programs suited to the specific needs of an individual child.

The teacher is also acquainted first with the behavioral assessment of the person with reference to the current level of functioning, and the current problem behavior/s.

The teacher must then assess each child's performance rather than its deficiency, that is, what he can do rather than what he cannot do.

The behavioral assessment tools available in India are: MDPS, NIMH assessment schedule, Functional assessment tools, and problem behavior management system (NIMH).

While teaching, the teacher has to identify and analyze problem behavior and use behavioral techniques to manage the same. The details are given in the manual and the teacher has to go through the orientation. Studies done by Narayan, Peshwaria, and Myeredi support its effectiveness.

Even though research studies prove the effectiveness of the Behavioral Approach, evaluating on that basis is not yet practiced at every teaching institution.

Curriculum–Diploma in Special Education Curriculum and Teaching Manual

Teaching strategies and programming consideration given below are being followed sporadically in some special schools.

Teaching Strategies and Programming Considerations

Success in educating profoundly and severely handicapped persons require extensive knowledge, a broad range of professional skills, and a positive attitude. Required also is individualization. A sense of humor always helps.

Since a successful approach on a day might be the antecedent for a behavioral problem on another, it is important to have a variety of teaching strategies in one's instructional repertoire.

Instructional Programming and Organizational Strategies

Normalization Considerations

Age appropriateness: Selected instructional materials and activities must be suitable for non-handicapped individuals of the same age and those reflecting the student's cultural and ethnic background as well as the cultural diversity of his society. Age-appropriate reinforcement must be used.

Help the student to look and behave as appropriately as possible as those deviant get stigmatized. Involvement in activities with non-handicapped peers and interest in their welfare must be encouraged.

Teacher Behavior

Respect the student's privacy. Use your voice to communicate, supplemented by gestures whenever possible. Remain calm and poised no

matter what. Be familiar with handling assistive devices used by the handicapped.

Avoid stereotyped judgments. Do not assume that on account of his handicap, a person is unable to acquire some skills and/or not participate in some activities and events. Assign the student a classroom responsibility no matter how severe his handicap and no matter how small the task.

Show appreciation when there is progress or compliance with your request which may be a giant step for the student. A show of warmth, interest, and love will elicit positive response. Flexibility is desirable in carrying out lesson plans, especially, if unexpected negative behavior occurs which requires immediate action.

Human Resources

Seek the co-operation of other teachers, professionals and support staff. Community helpers can assist in normalizing the lives of your students. Train teacher aides, parents, grandparents, and house parents, as agents of carry-over and practice.

Materials

Use exciting materials and activities from other disciplines. Use of current materials, toys, games, television shows, and music to motivate the student contribute to success. An element of surprise, suspense and novelty goes a long way.

Goals

Be realistic in planning goals to avoid frustration. In selecting instructional targets, future functioning of the child must be kept in mind.

Be sure the student knows exactly what is expected. Be consistent.

Progress

Provide the student with immediate feedback of results, i.e., reward him as soon as possible after he has attempted, approximated, or achieved a task. Inappropriate or incorrect performance at a task, should be stopped promptly.

Construct charts to demonstrate progress and monitor required behavior, encouraging those who want to be a party to the process.

Demonstrate the finished product whenever possible. Display the student's work at school exhibits, on bulletin boards, etc.

Instructional Considerations

Change of activities, such as alternating quiet ones with those involving gross motor actions, will maintain the students' interest. If an activity has several steps, practice them in sequence. Physically guide the student through an activity whenever he is unable to do it by himself, providing only enough assistance required to participate in or complete a task. Use pantomime, which helps to isolate the required movements, to demonstrate a skill.

Tell the student to observe and imitate your actions. Use peer models whenever practical. Use role playing, puppet play and creative dramatics to stimulate real experiences and to practice skills.

Skill Demonstration

Teach a skill at the time of its functional use, i.e., when it occurs naturally.

Due to wide diversity among the handicapped, personalising instruction is essential. Programming in small steps helps the student to be successful.

Instructional Grouping

One-to-one instruction is often not practical in classrooms. Organize your lessons in such a way as to take advantage of the benefits of peer tutoring and buddy systems.

Reverse Programming

When working on some motor skills consisting of a series of separate motor events, program in reverse. For example, the backward chaining approach is helpful in teaching the tying of shoelaces. Starting in the middle of a sequence may also be appropriate for some students.

Task Analysis

Use a task analysis approach whenever possible.

Teaching Environment

Consider the environment, i.e., the home, the school, in which the teaching activities are to be presented.

Use mirrors for visual monitoring, especially in observing the movements required to make speech sounds so that the student can see himself as he is performing a task.

Disturbing Behavior/s

Substitute a constructive activity whenever a maladaptive behavior, such as a destructive or self-stimulatory activity erupts.

Deviant behavior should be corrected in a positive manner. Say 'This is the way to play the game' simultaneously demonstrating the desired behaviour.

Use of reprimands when necessary, can be effective in structuring behavior.

Remove the disruptive student from the learning area and place him in social isolation for a short period of time, explaining the reason for his removal. Placing him near other students, right next to you, or involving him in a new activity when he returns is advisable.

Evaluation

1. Evaluation should be a continuous process. Develop criteria to assess how effective a particular technique or activity has been in achieving a desired goal.
2. Whenever possible, and when appropriate, self-monitoring should be encouraged.

Teaching-Learning Materials(TLM) for Persons with Mental Retardation

It is found in literature that we learn 1.0 percent through taste, 1.5 percent through touch, 3.5 percent through smell, 11.0 percent through hearing, 83.0 percent through sight and we remember 20 percent of what we hear, 30 percent of what we see, 50 percent of what we see and hear, 80 percent of what we see, hear and do.

Therefore, the teaching learning process should facilitate active participation of the students.

Since students with mental retardation have less ability to grasp, maintain and generalize the learned concepts, extensive use of appropriate learning material is very much warranted.

For learning to be more meaningful, students must be provided with experiences of manipulating the material themselves.

Learning Aids and Functional Aids

Special teachers use both learning aids and functional aids. Once the student learns a concept, the utility of a specific learning aid ceases whereas the same may continue to be used as a functional aid.

Teaching Learning Material for Persons with Mental Retardation

The Department of Special Education, NIMH, had undertaken a project on the development of learning materials, specifically to teach persons with mental retardation. Twelve units of hardware material, four work books and four flip books were developed, designed in a way that the same unit could be used with pre-primary to pre-vocational level students to teach a specific core area and across different core areas depending on the intention of the user. The prototypes were field tested and modified.

The same Department also developed software packages on literacy and numeracy under the project on Computer Assisted Instruction. In continuation, development of software packages on Literacy, Numeracy, My Country, Living and Non-living, Health and Hygiene, Sports and Games, Community Utilization is in progress.

TLM should be age appropriate, readily available, prepared from local material, inexpensive, attractive and colorful.

The following points must be borne in mind:

- Teacher should be aware of the hierarchy of concept development, e.g., the concept of color is taught in the stages of matching, identification and naming. Similarly, the concept of counting meaningfully cannot be taught without teaching one-to-one correspondence.
- Concept teaching should be transformed into a series of joyful, games, e.g., Ludo, Bingo, Treasure Hunt, etc.

Much repetition with variations is required. Different ways to use the same teaching-learning material, in the form of activities and games must be thought of.

Conclusion

As per the AAMR definition, persons with mental retardation require individualized program plan in adaptive behavior. Teaching learning materials have to be procured/ prepared for training of the target behavior selected.

Individualized program plan, a complete plan, has been introduced in all teaching and training programs all over the country. However, its implementation falls short of the thoroughness and the accountability desired. Social accounting and social audit systems have to be put in place.

Chapter 9

Parents' Movement–Involvement

Introduction

In the last few decades, an upsurge in the parent-support groups has been seen so as to initiate, promote or support rehabilitation services for persons with mental retardation and their families.

The parents' movement provides direction to the mechanism of service provisions, bringing transparency of the available services to persons with mental retardation and their families.

The First All India Conference on Mental Retardation, New Delhi, 1966

The then Prime Minister of India, Smt. Indira Gandhi, said in her inaugural address delivered at the First All India Conference on Mental Retardation, held in New Delhi on November 26, 1966, where many professionals, but a few parents were present: "Without the dedication, understanding and cooperation of the parents not much progress could be made. Parents should realize that by helping other children they will be helping their own children."

A Forum for Expression of Needs of Parents for their Children

At the conference, professionals and parents of persons with mental retardation and associated disabilities expressed their difficulties. Inadequacies in the infrastructural facilities from early intervention to independent living, medical care, special education, counseling for parents and social security for their wards were some of the issues brought out. Parents felt an urgent need to come together to have a clear understanding of the challenges, to plan strategies to meet them and to share concerns and experiences, etc.

The realization, in the sixties, on the part of the parents to come together has come to be known as the National Parents Association–Parivaar.

Historical Background – Parents' Associations

For the formation of the first few parents' associations in India in the sixties and seventies, the initiative was taken by a few dedicated parents in Bombay, Ahmedabad and Bangalore. During the seventies and early eighties, there was a steady growth in the number of parents' associations all over the country, all functioning independently of each other even though they were working for the same objective, viz., for the welfare of persons with mental retardation and providing them with many facilities for their education, training them to be as independent as possible and including them in the mainstream society.

The Role of the National Institute for the Mentally Handicapped (NIMH)

Development of parents' associations got a further boost because parent empowerment was one of the objectives of the NIMH established by the Government of India in the early eighties.

In the nineties, the NIMH promoted the parents' movement by organizing two National

Parents' Meet in 1993 and 1994 at its campus in Secunderabad, subsequently playing a crucial role in the formation of Parivaar to consolidate the parents' movement in India.

Formation of Self-help Groups and Parents' Associations

Consequently, during the late eighties and nineties, parents of persons with mental retardation and of persons with other developmental disabilities came together to form self-help parent groups and parents' associations, an important development in the rehabilitation process of these persons.

Another milestone reached in November, 1994, was the initiation of the National Parent Body with the technical support from the NIMH. An ad-hoc working committee was formed and the "National Federation of Parents Associations" was established.

The first one formed in 1968 in Ahmedabad, was followed by 15 States and Union Territories in India. Presently 43 registered parent organizations are working for the welfare of the persons with mental handicap in the country.

Till 1980, there were only two registered parent organizations in the country. Later, in Andhra Pradesh alone 13 parent organizations were established and in Maharashtra, there were 6 (Peshawaria, et al., 1994).

Parivaar – Its Genesis

In 1995, a few parents' groups came together to form the National Federation for Parents Association for Persons with Mental Handicap, now known as Parivaar. There were only 22 parents' associations in its Parivaar. Today there are 170.

Parivaar amended its constitution to include services to persons with Autism, Cerebral Palsy and Multiple Disabilities, in its sphere of activities in concurrence with the objectives of the National Trust Act, 1999.

Recognition of Parivaar - At National and International Levels

Over the past decade, Parivaar, has been recognized at the national level, as an apex body of parents' associations. Some of its significant achievements are:

- Playing a significant role in the enactment of the National Trust Act for the welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities, in December, 1999. Gaining a consultative status with the Ministry of Social Justice and Empowerment, Government of India, with the inclusion of the Parivaar representatives in the various core groups, the Central Coordination Committee and Central Executive Committee at the Central and the State levels.
- Conducting workshops and National Parents' Meets to bring awareness among the parents about the current issues pertaining to the problems of mental retardation and its associated conditions.
- Organizing continuing education program on 'Capacity Building' and 'Leadership Development'.
- Organizing Round Table Conferences at New Delhi, Kolkata, Chennai, etc. during the last six years to bring parents, professionals, Government and business

representatives to accelerate the implementation of various legislations pertaining to disability.

- Initiating pilot projects as follow-up action, in inclusive education, rural health, employment generation and independent living in West Bengal and Tamilnadu.
- Forming state-level coordination committees to follow-up the decisions of the Round Table Conference.
- Having a joint venture with Inclusion International, the international apex body of parents associations, to promote, support and strengthen the vital programs of Parivaar.
- Execution jointly with Inclusion International, of a research project, a first in India, a study on the Methods and Procedures Used to Improve the Quality of Life of Persons with Intellectual and Developmental Disabilities.
- The Parivaar members, in the know of the provisions in the epoch-making UN Convention on the Rights of Persons with Disabilities and demanded the ratification of the Convention by India.

Parents' Movement – Its Support Systems

The UN Convention helpng in a big way, the parents' associations have been addressing advocacy issues, such as public perception of mental retardation, protection of their legal, civil and human rights.

The Parents' Associations have taken up the task of bringing the families of persons with mental retardation and associated conditions to speak about their needs— in taking care of their academic and vocational training, their independent living needs, in helping them find/keep a job and to participate in leisure time, social and creative activities in the community. Bringing about changes through the existing social institutions and legislative channels is also being pursued.

Formation of Other Associated Groups

Sibling Groups

Involvement of sibling groups, sponsored by parents' associations, helps in promoting a healthy integration and interaction of the persons with mental retardation in mainstream community. The siblings are encouraged to participate in the training, habilitation and awareness building programs and in conducting various leisure-time activities.

Family Cottages

Children with mental retardation, their parents and family members, can utilize the Family Cottage Services on the NIMH campus for 1-3 weeks depending on their needs, to promote the dual needs of the child's training and to meet the individual needs of parents and other family members to promote healthy functioning.

Such residential programs of short duration are also being provided at Vellore (1986) and Bangalore (1993).

Other Service Models – With Parental Involvement

Home Based Models

Itinerant workers making periodical home visits to guide the parents have not been feasible, on account of the heavy finances involved.

Centre Based Models

The Centre Based models provided the base for the formation of parents' associations.

Models which can be handled by groups of parents as carryover agents at home are becoming more feasible in the Indian context.

One such model, the Madhuram Narayan Centre for Exceptional Children, Chennai provides for the total involvement of parent groups at the Centre in the initial period between birth and two years, after which the parents are weaned away when their children become more and more self-sufficient. The parents continue as carry over agents at home. The Center provides services from five different centres in Chennai.

Empowered by the compounded strength of the many parents involved at the Center, the mothers in particular felt the time was appropriate for them to take up "serious issues jointly with their spouses". Thus Maithree Parents' Association was formed.

NIMH–Centre Based Model

Centre Based Individual Model is used in the Child Guidance Clinics and in institutions providing individual-based interventions by a multi-disciplinary team of experts.

At NIMH, Secunderabad, a management program is designed by various professionals for parents as per the needs of the child to carry out the program at home. Each family along with the affected child has the opportunity to work out their individual concerns on a one-to-one basis.

Centre Based Group Activities

Due to paucity of facilities in the twin cities of Hyderabad and Secunderabad, the model was adopted at NIMH to reach out to large number of children with mental retardation.The focus is more on the child's learning.

Parents are encouraged to attend group activities along with their children and serve as mediators in training their children.

Early Intervention Programs Initiated by Parents' Groups

After the research study in Chennai, in 1968, early intervention programs were initiated by

- The Andhra Pradesh Association (Gool Plumber, 1980).
- The Karnataka Parents Association (Mathias, 1981).

Other early intervention programs were in

- Chandigarh (Tehal Kohli , 1986).
- Karnataka (Indumathi Rao, 1980).
- Tamil Nadu a research study taken up in 1986 (Jeya Chandran, Jaya Krishnaswamy), to develop training modules in early intervention.

The workability and suitability of the program was established and the modules were published. A Research-cum-Demonstration Centre was also established at Chennai–Madhuram Narayan Centre for Exceptional Children.

Research with Families

Epidemiological studies in the understanding of families as support groups is still in a nascent stage in India.

The major focus has been on studying the feasibility of training mothers (Boaz, Jeychandran, 1968) and on the positive attitudinal change in the parents towards their children with mental retardation.

Studies on the needs of parents in terms of reasons for institutional placement were conducted (Rastogi, 1981; Bhatti, et al., 1985; Channabasavanna, et al., 1985; Devi, 1976; Hariassara, 1981; Srivastava, 1978; Mazumdar & Prabhu, 1972; Chaturvedi, S.K. & Malhotra, S., 1983; Chaturvedi, S.K., & Malhotra, S., 1984; Prabhu, 1970).

Impact on the parents was studied by Seshadri, et al., 1983; Sequiera, et al., 1990; Sethi & Sitholey 1986, Tangri & Verma, 1992; Wig, et al., 1985.

Investigations into social-emotional support for parents was presented by Moudgil, et al., 1985; and the treatment seeking behaviour of parents was taken up by Chaturvedi and Malhotra, 1982.

Consumer deemed services by parents (Peshawaria, Venkatesan and Menon, 1988); and parent needs was presented from a conceptual framework (Peshawaria and Menon, 1991).

Family Intervention Services Program Plan is developed, implemented and evaluated to encourage and initiate such systematic services in the country and to promote scientific research in the area of understanding and working with Indian families.

The NIMH-Family Needs Schedule (NIMH-FAMNS) has been developed to assess the individual needs of the family including needs of each of the family members, i.e., parents, siblings and grandparents.

A study on Need-based Family Intervention model is presented to make family intervention a reality in the field of rehabilitation of persons with mental retardation in India.

Challenges

Parents' movement in India has faced challenges. They are:

- The services still continue to be basically child oriented; the emphasis is still largely on child skill training rather than on helping build strengths in the parents.
- Facilities for counseling parents and family members to cope with the emotional needs and responsibilities of handling a child with mental retardation is still not within the reach of all.
- The focus currently is on extending parents' services, and on encouraging parents' involvement in programs for training and habilitation and training different levels of workers, parents have the strongest voice. Being a constant factor in a child's life, the family teaches the child ethical values and behavior. Since they sacrifice the most, parents' self-support groups need to be strengthened.

On the positive side:

- Sarva Siksha Abhiyan, the comprehensive action plan for inclusive education for persons with disabilities, will immensely help the parents' movement.
- The National Policy for Persons with Disabilities will determine the course of action the parents' associations will have to take in the coming years.
- Parivaar and its various affiliates have given the required inputs on the inadequacies in the policy document and have urged upon the Government to revise it in the light of the U.N. Convention.

Conclusion

The parents' associations have the ombudsman's role to oversee that the system fulfills the needs of the persons with mental retardation. The last few decades have been a time of rapid change, in ideologies, legal systems, technological advancements and in the provision of services, which has been beneficial to persons with mental retardation.

As a consequence, complex ethical and legal issues have been raised and many remain unresolved. There are also adjustment problems among the various professional bodies. Even advocates dedicated to improving the lives of persons with mental retardation are often divided on some of the most critical issues. These are necessary corollaries of progress of the persons with mental retardation in making the transition from being the discarded, deviants to fully participating members of society.

Chapter 10

Innovative Practices in the Field of Mental Retardation

Introduction

A disability is due to the inter play of several genetic and ecological factors. No single method or technique can deal effectively with the various aspects of a disability such as mental retardation and its associated conditions.

Important and Innovative Programs

"Innovation" refers to something new or different in approaches – techniques, methods which are introduced to deal with the situation or condition which is to be managed so as to bring about required changes.

Some of the important innovative programs in the field of mental retardation are:

- Yoga and its effects on the child with mental retardation.
- Community Based Rehabilitation in the community.
- Augmentative Intervention, the catalysts.

Yoga–The Tradition

Yoga is known for its time tested legacy in health care which includes prevention and treatment of ailments.

Definitions

Yoga is bringing two things together to unite (V. S. Apte, 1979). It causes the movements in the mind to come together and helps one achieve the fullest of his capabilities (Desikachar, 1982).

Yoga, practised regularly and systematically, helps in focusing attention on the activity that is being performed, in achieving higher levels of performance by exploiting one's potential fully and in relying on one's abilities, making one healthy, and having better relationship with others.

The Yoga Mandiram (1977) has introduced yoga in a joint research project with Vijay Human Services, Chennai, a service organization, for persons with mental retardation.

Yoga for Persons with Mental Retardation

- The person should maintain a certain amount of steadiness in the posture without much effort or tension, "sthira" (Desikachar, 1982).
- Comfort and steadiness in a posture is attained through undistracted concentration of the mind on posture.
- The practice of asana is coordinated through regulated breathing, that is, through pranayama.

Yogasanas–Selection and Introduction in the Curriculum for Training Persons with Mental Retardation

Fifteen asanas suitable and not contra-indicative of its effects at any stage during training were introduced into the curriculum for their training. They were: Adhomukha, Savasana, Apanasana, Bhujangasana, Cakravakasana, Dvipadapitham, Tadasana, Janusirsasana,

Paschimataasana, Parsava Uttanasana, Salabhasana, Trikonasana, Utkatasana, Uttanasana, and Vajrasna.

Since 1977, four workshops at the national level, have been conducted for special educators who have had at least three years experience of practicing yoga with persons with mental retardation.

Aim of the Study

The study explored the feasibility and suitability of practicing yogasana as a therapeutic co-curricular activity by the special educators, for the total development of persons with mental retardation.

- *Yoga, as therapy,* has the following advantages: A time-evaluated system that brings about the body-mind coordination in a natural way permitting appropriate choice of asanas; it is economical, simple, easy to understand, practice and adapt through either individual or group instruction.

Results of the controlled study:

- Those with mental retardation trained in yogasanas reported significant gains compared to a group without such input.
- The trained special educators realize are best suited to teach yoga in a systematic way for the development of persons with mental retardation.

Overall Benefits

Yoga helped improve the general functioning level of persons, maintained in some and preventing deterioration in others.

It helped them in correcting postures, reducing obesity, controlling dribbling, bringing down hyperactivity, improving appetite, sleep and general health. It also alleviated some of the conditions associated with mental retardation.

Breathing exercises and chanting have augmented the effectiveness of speech therapy. Improving bilateral activities, relaxation exercises, bending exercises, promoting attention, and concentration span could also be facilitated with the support of yoga.

Absenteeism had come down, thereby time available for learning has increased and the improved general health facilitated the persons to learn more effectively without disruption and disturbance in their training schedule.

Rehabilitation Council of India (1986) has introduced yoga as part of the curriculum of the special educators' training program. All the service-providing organizations have included it in their daily schedule of Individualized Training Programs.

Reports on Studies

"Teaching Yogasanas to the Mentally Retarded" first published in 1980 was revised in 1983 and 1988 (Vijay Human Services and Krishnamacharya Yoga Mandiram).

In 1985, results of the study was presented at the 7th World Congress of the International Association for the Scientific Study of Mental Deficiency and at the American Psychology Convention.

Simplified "Teaching of Yogasanas to the Mentally Retarded" is accessible, free of cost, to a larger population in India and abroad, with translations available in Japanese, Korean, German, French and Belgian.

Yogasanas have been incorporated in manpower development and training curriculum

dealing with mental retardation and including it in the school curriculum is on its way.

Community Based Rehabilitation Program (CBR)

CBR is a solution to the available inadequate services to fulfill the needs of persons with mental retardation, especially in the rural areas.

Definition–CBR (World Health Organisation)

As defined by the WHO, CBR 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.

Facilitating Community Participation

Community may participate (through providing manpower, facilities, logistics support and funds) and may involve itself actively in understanding the problems, feasibility of the proposal for implementation and using primary care services for prevention and protection.

Community Based Rehabilitation (CBR) Program for Young Adults with Moderate and Severe Mental Retardation

Pilot Study–Alwaye

The first systematic CBR Project in India was conceived and initiated at CSI Karunalayam, Alwaye, Kerala, in 1983. The same was implemented in Chennai by Michael Gnana Durai of the Christophel Blinden Mission and Prof. P. Jeyachandran, Vijay Human Services.

Material and Manpower Resources from the Community

At Alwaye, where the residential CBR program was planned to be set up, 6 girls, aged 18 to 20 years with hands-on experience in training children with mental retardation, volunteered to help the professionals in training the wards in self-help skills, cooking meals for them, taking them out on field trips and in other tasks. With their experience, they were able to identify persons with mental retardation in their own villages, all located within a radius of 15 km.

Implementation of the Project

The volunteers attended a crash course on the basics, such as assessment, setting goals and objectives for each individual and on the implementation of the individualized program plan for those identified.

The Centre was located at a cost-free, residential facility in the village.

The helper resided in the premises. Ten children from in and around the area were brought daily by the parents for training. Initial programming was done by the special educator from Alwaye.

Visiting staff from Alwaye initially gave assistance daily tapering off to twice or thrice a week and later, once a month.

The Arivalayam Community Rehabilitation Program

A CBR program was initiated at Arivalayam, Tiruchirapalli, Tamil Nadu, in 1985.

The resource centre (instituted as a social responsibility measure by the Officers' Wives Association of the Bharat Heavy Electricals Ltd., a public sector undertaking) was a school serving 220 persons with mental retardation, where 20 trained special educators were assisted by an interdisciplinary team of experts.

Arivalayam, and three other centres which came up later, jointly serve about 300 persons in all, in Tiruchirapalli district.

Rationale for Selecting Arivalayam

Factors favoring Arivalayam were, adequate infrastructure, technical know-how, willing administration and teaching staff, which were readily available for CBR manpower development, and financial support from the Christophel Blinden Mission, India

Survey Techniques

Identification of persons with mental retardation to be served: Two blocks, with the combined population of around 50,000 people in the proximity of Arivalayam, were selected. About 12 hours, the time allotted in the school curriculum for community service, was utilized to give the orientation lecture-demonstrations to the girls-volunteers at the end of which they were evaluated on their skill in identifying at least one person with mental retardation from their respective villages. Post-training, accompanied by a special educator from Arivalayam, the girls, in groups of 10, screened persons with mental retardation, in door-to-door visits. The successful survey was due in a large measure to the sensitization received by the village health workers, panchayat officers, school teachers, political party representatives and village elders, who extended maximum cooperation. An interdisciplinary team of experts confirmed mental retardation in the 50 children thus identified, except for 3, the slow learners, who were advised to attend regular schools.

Awareness Generated by the Survey

The awareness generated in the villages through the survey was a great achievement because these future mothers would be well qualified to take care not only of themselves but also be vigilant to help other mothers in the neighborhood.

Selection of Personnel

Public notification and individual letters addressed to those involved in carrying out the survey were the means used for selecting 20 candidates, 6 for the Arivalayam sponsored CBR project, the rest to be allocated to the collaborators who were willing to run CBR programs.

For 45 days' intensive training, 80% earmarked for practical training and the rest for academics, the expert committee at Arivalayam drew up a curriculum based on the experience of the pilot project and the community needs. The trainees lived in Arivalayam along with the residents, the persons with mental retardation. A special educator with over 10 years' experience, evaluated them periodically.

The base centre from where the majority of the children were identified was selected in which children living within a radius of 2 km. were brought using local transport. The special educators from Arivalayam served as resource persons who were available full time for a week only and withdrawn when self sufficiency was achieved.

Infrastructure

Infrastructure from the noon meal centres, public health and community recreation centres was made use of. One shed was rented. Periodic evaluation was done by the interdisciplinary team of experts.

At each centre, one trained CBR worker and one untrained aid or helper were paid monthly at the prevalent rates.

Parental Involvement

Parents were trained in a trade or a craft specific to the village to generate income. Another strategy was to have them interact with similar parents from Arivalayam in one-to-one dialogues and later in group discussions.

Involving the Panchayati Raj System–For Effective Implementation and Sustenance of Community Based Rehabilitation Programmes

Though the entire project has been funded by the CBM, still talks were in progress to involve the Panchayat in each village to assist the CBR programs and to share in generation of funds to make them self-sustaining. A nominal, monthly contribution from each household could pay for the services of CBR workers/special teachers and assistants.

Arivalayam Community Rehabilitation Project

It presently creates awareness with the cooperation of the members of the community, conducts follow up programs on high risk parents for prevention of disabilities, implements centre and home-based early intervention programs, teaches functional skills required at the community level, gives vocational training (in the locally available trades either in the family or in the community) to help augment family income and arranges referrals.

Arivalayam – A Parent Body

Arivalayam – A Parent Body is a resource centre for manpower and material development, which initiates, coordinates and monitors CBR programs, interfacing with two other collaborators.

Supported by various international agencies and government organizations, several CBR Programs were initiated by organizations such as

- Action Aid, Bangalore.
- Anand Niketan, Dist Burdwan, W. Bengal
- Arivalayam, BHEL, Tiruchirapalli, Tamil Nadu
- Blind Men's Association, Ahmedabad, Gujarat
- CBR Forum India, Bangalore, Karnataka
- Central Institute on Mental Retardation, Thiruvanthapuram, Kerala.
- Chetana, Bhubaneshwar, Orissa.
- Mano Vikas Kendra, Kolkata
- National Programme for the Rehabilitation of Persons with Disabilities (NPRPD), Govt. of India
- National Institute for the Mentally Handicapped (NIMH), Secunderabad, Andhra Pradesh
- National Institute for Mental Health and Neuro Sciences (NIMHANS), Bangalore, Karnataka
- Samadhan, New Delhi
- Sewa in Action, Bangalore, Karnataka
- Thakur Hariprasad Institute, Rajahmundry, Andhra Pradesh
- Verar Program, Mumbai

There are about 100 voluntary organizations, which provide the CBR services with government support up to 95% of the expenditure.

National Open School (NOS)

Many service organizations and some mainstream schools have affiliated themselves with the NOS system of education up to the secondary level and technical instruction level, mainly to the hearing impaired, slow learners, learning disabled, those with autism, and cerebral palsy.

They appear for examinations at their own pace and the certificates received enable them for higher levels of education and placements.

Integrated Child Development Scheme (ICDS)

Health workers, urban and rural, who are given periodical inputs in health care, in early detection and identification and referrals to the health workers, nutrition, growth monitoring, and child guidance, visit the ICDS Centres regularly to implement the scheme developed by the Government of India with funding from international organizations.

Adult Leisure and Learning Program (ALLP)

An earlier survey conducted in Delhi in 1980 by the Federation for the Welfare of the Mentally Retarded, observed that persons who had received systematic schooling up to adult years were not directed to engage themselves in any productive or meaningful occupations.

With their active participation, an improvement in the quality of life, particularly in the years after completion of school life was noticed. The young adults participate in very structured and activity-oriented recreational and learning activities, such as, story telling, playing games, learning simple cooking, visiting post offices, banks, etc., which leads to greater participation in community and family life.

Foster Care Home

Foster Care Home is a special home for children with mental retardation who require accommodation and special care. Almost all the States have initiated establishment of foster homes for their practicality and traditional approach.

Augmentative Interventions

Apart from special education, other a**ugmentative interventions,** given to persons with mental retardation, are mentioned below.

Chanting

Vedic chanting practiced by persons with mental retardation has shown positive effects in articulatory movements of the lips, the tongue, and in matching the pitch in sound production (Sriram, Germany).

Dance Therapy

Rhythm, facial expressions, body language, are the different facets of dance in which training can be given. Music as an accompaniment adds to the therapeutic effects.

Dance promotes the spacio-motor perception and bilateral movements; it provides follow up to balancing skills, posture corrections and other fine and gross motor skills required in performing daily living activities. As a medium of expression through facial expressions, symbols (mudras) and body language, dance has facilitated acquisition of effective communication skills and social interaction (Jyotsna Buch, Chennai and Tripura Kashyap, Bangalore).

Percussion

Percussion facilitates in the areas of number learning, promotion of bilateral activities, sensory-motor coordination, posture, finger dexterity, fine motor skills, and multi sensory stimulation.

The Central Institute, Tiruvananthapuram, Kerala; Thakur Hariprasad Institute, Hyderabad, Andhra Pradesh; Mano Vikas Kendra, Kolkata, West Bengal; Sashi Mangalyam and Mrs. Vakil's School, Mumbai, Maharashtra have introduced this in their curricular training.

Instrumental Music

Many music band teams have been formed by children with mental retardation all over the country.

Instruments, both string and wind, and the modern day keyboard have also been introduced in special schools. Training to play on these instruments facilitates sensory motor stimulation, finger dexterity, fine motor skills, and breathing.

Hydrotherapy

Hydrotherapy facilitates observable increase in mobility, and improved balance and postures, gait improvement, treatment of hyperactivity in those with associated motor problems. Cost factor has restricted its introduction in more centers.

Other Therapies in Practice, yet to be empirically documented

Acupressure, acupuncture, ayurvedic massage, aroma therapy, brain gym, flower remedies, horse therapy, pranic healing, reikhi, tai chi, varma kalai.

Conclusion

Yoga for persons with mental retardation is now an integral part of any training program for persons with mental retardation.

Community Based Program, a traditional practice in India is now an accepted practice in its new form, to reach the services at the community level and serve the large population in need. The efficacy of the various other systems need to be yet studied.

Chapter 11

Policies and Programmes

Introduction

The Constitution of India (1950), Article 41, states the 'Right to Education and Work' and Article 45 on 'Free Compulsory Education for All Children up to the Age of 14 Years', both Articles are inclusive of children with mental retardation.

The Education Commission, 1964-66 directed to move education for persons with disabilities from that of the charity mode to one of the rights mode, hoping that at least 5 per cent of the persons with mental retardation should have received education by 1986. It lay emphasis on making persons with disabilities as useful citizens in their adult lives.

The Commission further recommended that both special schools and schools in the integrated school system should include persons with disabilities.

The National Policy for Children, 1974

The National Policy for Children, 1974 included children from the weaker sections of society and disabled.

Integrated Education of Disabled Children (IEDC), 1974

Supported through research conducted by the UNESCO, the program for Integrated Education of Disabled Children (IEDC) implemented by the Ministry of Human Resource Development in 1974, aimed at promoting access to education for all children with disabilities. The trained resource teachers support the mainstream school teachers in providing appropriate education to children with disabilities.

The move for education of persons with disabilities is its inclusion in the National Policy on Education, 1986. Project Integrated Education of the Disabled Persons (PIED) is an outcome of this policy.

The National Policy on Education (NPE)

The National Policy on Education (NPE) formulated earlier was acted upon in May 1986.

- Specific recommendations made in the policy document (NPE, 1986, 1992) were in the areas of integrated education for persons with mild disability in the mainstream schools, special schools for persons with severe disabilities with hostel facilities at district headquarters, vocational training, reorientation of teacher training program to include persons with disabilities and services provided by voluntary organizations.

The State governments are now opening facilities for at least one school in each district, either day care or residential to provide educational facilities to children of that particular district. At the district headquarters, service centres also provide for diagnosis, referrals, and interventions. Parents work as carry over agents at home for their children.

The International Year for the Disabled Persons (IYDP), 1981

India was one of the signatories to the resolution IYDP, 1981 endorsing the objectives set forth in the resolution of the General Assembly.

It was visualized to:

- form a National Policy for the disabled.
- to provide a network of services with focus on the rural handicapped,
- to set up National Institutes, and
- to establish special education cells in the State Councils of Educational Research and Training (SCERTs), State Institutes of Education (SIEs), etc.

The then Ministry of Welfare and the Ministry of Education and Culture appointed an Advisory Committee to make salient recommendations to the Government to initiate action regarding early detection, prevention, medical and physical rehabilitation, education and training of handicapped including teachers training, employment and the role of NGOs and creation of public awareness.

Project Integrated Education for Disabled (PIED), 1987

In support of the IEDC program and to provide further impetus, the Project Integrated Education for the Disabled (PIED) in 1987 was piloted by the NCERT and supported by the United Nations Children's Education Fund (UNICEF) in remote villages which were divided into blocks of 80-100 schools for program implementation. Through the project, cooperation of local officials, NGOs, community members, and parents was solicited. A three-phase training program targeted all teachers initially and culminated with introducing Teacher Education program at the community level.

Integrated Education

The term "integration" is based on the "principle of normalisation" 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".

The ideology on which integrated education is based is reflected in a unitary system of education and the approach rests on the fundamental principle of education, "all children are special" (Billimoria, 1999, p. 2.).

The Kothari Commisision, 1964-66 and UNESCO in the 1970s recommended that those children who are capable of being educated in the mainstream schools should be given equal opportunity through integrated education.

UNESCO advised the developing nations to direct their national policies towards equal access to education (1973, 1977).

Many voluntary agencies and private schools have also implemented different models of integration with special educational support in urban settings.

The major functional approaches of Integrated Education are:

- Assimilation of children with mental retardation.
- Removing the feeling of inadequacy and insecurity among the children with mental retardation.
- Promoting professionalism among teachers.
- Creating new skills and attitudes among the teachers.

The most effective means of combating discriminatory attitudes is by creating supportive communities, building an inclusive society and achieving education for all.

In India, the National Policy on Education (NPE) in 1986 stated, "the objective should be to integrate the physically and mentally challenged with the general community as equal partners, to prepare them for normal growth and to enable them to face life with courage and confidence".

The Government has established several institutions across the country for improving the education processes. They are:

- The State Council of Educational Research & Training (SCERT).
- Institutions for Developing Activities in Planning and Management.
- The National University of Educational Planning & Administration (NUEPA).
- District Institution of Education and Training (DIET).
- The State Institute of Education Management and Training.

The National Policy on Education, 1986, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) 1995, The Rehabilitation Council of India (RCI) Act, 1992, have given the needed impetus to the establishment of

- an International Centre for Special Needs Education, by the National Council of Educational Research & Training (NCERT) in collaboration with UNESCO,
- the District Primary Education Program (DPEP).

Although the DPEP was initiated in 1994 as a Government program, Integrated Education for the Disabled was added as a program component in 1997.

To begin with, states were provided with assistance to prepare action plans. By 1998, many states had initiated surveys and formal assessment camps and evolved strategies to provide resource support to children with special needs.

Residential Program

Residential centres have been established for the persons who have transport difficulties to reach special schools, those who require constant medical and custodial care, which parents and care givers are not in a position to give.

Special Schools

Special schools, the largest in number for persons with mental retardation in the country, provide for individualized attention not available in mainstream schools, though they have led to their social segregation with non-retarded peers.

One way of introducing integration in special schools is by encouraging non-disabled children to come into special schools under the National Social Service Corps (NSSC) or Socially Useful and Productive Work (SUPW) schemes. As innovative teachers build in to their curriculum, activities that take the children out into the community, shops, post offices, restaurants, involving bus travel and so on, they create opportunities for integrated septum.

Special Class

Special Class in a regular school is mainly for children with moderate and severe mental retardation, whose educational needs are more specific in nature, who can be integrated for non-

academic activities such as games, physical education, music, art and crafts.

The Community Based Rehabilitation (CBR)

The Community Based Rehabilitation (CBR) programs, yet another governmental initiative to promote integration was launched in 1985.

Though not a new concept in India, the CBR program is made more structured with funds allocated and local village leaders empowered.

The CBR was not very beneficial for those with mental retardation. However, they gained some amount of skills needed for social acceptance.

Ministry of Social Justice and Empowerment

The Ministry of Social Justice and Empowerment is responsible for the rehabilitation efforts, including administration of special schools, with supporting assistance from the Departments of Health, Labor, and Employment. Existing schools serve about 2 to 4 percent of all individuals with disabilities.

The vast majority of schools located in urban areas and the others unevenly distributed across the country, approximately one-fifth of these schools offer secondary level education.

Even though non-governmental organizations surpass government run special schools, in both quantity and quality of services, not all of them have 'inclusive' settings, some not admitting non-ambulatory students.

Non-Governmental Organizations (NGOs)

The NGOs receive 85 percent of all government sanctioned funds for persons with disabilities. Most special schools are residential so they may serve populations from remote rural areas and from States which have limited services.

Mental Health Act, 1987

As the Mental Health Act was not applicable for persons with mental retardation, a legal vacuum prevailed in the areas of protection of the persons with mental retardation, till the Persons with Disabilities Act, 1995 came into being.

The THPI, Hyderabad organized an All India Seminar to frame a National Policy for the Mentally Handicapped in February, 1987. A major outcome of the event was the appointment of the Behrul Islam Committee, which was a prelude to the subsequent Acts of Parliament in the area.

The Program of Action, 1992

This was formulated after a debate on the NPE (1986, 1992) by the Ministry of Human Resource Development (MHRD), Government of India, for implementation of the plan for the persons with mental retardation.

By the end of 1991-92, Integrated Education for the Disabled (IED) plan had been implemented and the Project for the Integrated Education of the Disabled (PIED) in 1992 included mental retardation within its Plan of Action for education in integrated settings, a status denied till then.

The faculty of 102 District Institutes of Education and Training (DIETs) in the country received training in special education program in the NCERT.

Multi-category Teacher Training (MCT) courses (through NCERT, RCEs and with UNICEF collaboration) and the National Institutes ensured availability of trained manpower to the special schools.

The programs are being monitored by the Ministry of Social Justice and Empowerment, Government of India.

At present, all SCERTs in the country have special education units and all the DIETs have trained special educators, and the NGOs have been assisted in meeting the challenges.

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

All in-service teachers, Heads of institutions and administrators have been receiving inputs in the education of the persons with disabilities, through the DIETs established during the Eighth Plan.

The ECCE scheme through the ICDS, pre-school programs, and the DPEP have included disability education, inclusive of those with mental retardation, since 1999.

The RCI, through its linkages with the National Council of Teacher Education (NCTE), universities, international agencies, the National Institutes and the NGOs have been responsible for:

- standardization of curriculum,
- monitoring and evaluation,
- assessment of teacher training,
- research and development in the field of disability including that of mental retardation and its associated conditions.

Since 1993, massive in-service programs and preparation of different categories of manpower development, nation-wide have augmented the services and the rehabilitation programs.

The Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act, 1995

The Persons with Disabilities Act, 1995 has come into enforcement on February 7, 1996 to ensure the full participation of persons with disabilities in nation building activities.

The Act provides preventive and promotional aspects of rehabilitation. This includes education, employment, vocational training, reservation, research and manpower development, creation of barrier-free environment, unemployment allowance, special insurance scheme for the disabled employees and establishment of homes for persons with severe disabilities.

The Economic and Social Commission for Asia and Pacific (ESCAP)

The Economic and Social Commission for Asia 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.

The agenda for Action for Asia and Pacific Decade of the Disabled Persons laid emphasis on enactment of legislation aimed at equal opportunities for people with disabilities, protection of their rights and prohibition of their abuse, neglect and discrimination.

The National Trust for Welfare for Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

With the current trend towards a shift from joint family to nuclear families, the care and management of the dependent children with disabilities, after the life time of their parents has become a great challenge.

The National Trust Act has made provisions for the appointment of guardians for those who have sought assistance and provided them with residential facilities through organizations where the prescribed standards of space, staff, furniture, rehabilitation and medical facilities are maintained.

- This Act provides for the constitution of a body at the National Level for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and for matters connected therewith or incidental thereto. Autism, Cerebral Palsy and Multiple Disabilities had not been covered under the Persons with Disabilities Act. Mental Retardation has been included under this Act to emphasize the guardianship requirement for persons with mental retardation. The Act also envisages extending support to registered organizations to provide need based services during the period of crisis in the family of persons with disability.

National Handicapped Finance and Development Corporation (NHFDC)

Any Indian with 40% or more disability, in the age range of 18-55 years, is eligible for the scheme introduced by Government of India for enhancing employment of persons with disabilities.

Specific jobs have been identified for persons with intellectual impairment for availing the facility of loan through the scheme.

Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP)

Persons with mental retardation may receive free of cost, assistive devices (if there is an associated locomotor disability), educational kits and supplies for daily living skills.

National Program for Rehabilitation of Persons with Disabilities (NPRPD)

The NPRPD provides the required infrastructure to provide rehabilitation facilities at state, district, block and gram panchayat (village) level. Centre-based as well as community-based programs and schemes for implementation of the programs at the state level, with financial assistance from the Centre.

It is envisaged that the unreached villagers with disabilities will have services, and the community will be empowered.

Science and Technology Project in Mission Mode

The Science and Technology Mission Mode of Government of India supports projects in Science and Technology in providing equal opportunities and access to persons with disability.

The purpose was to reach out to persons with disabilities in rural areas, with indigenous and effective methods on the one hand and for keeping pace with the technological advances for ensuring access and quality in their life, on the other.

The NIMH undertook a project funded by the S&T on computer assisted instruction for persons with mental retardation.

A total of six software programs for functional academics and independent living in community is being used.

Children with mental retardation are also trained in using these programs which helps in raising their self-esteem. *Universalisation of Education.*

Special Education for Children with Mental Retardation

The UN Declaration, 'Education For All', particularly for children with mental retardation is a big challenge which is being met by the Government of India through various schemes having different dimensions.

- Children with mild mental retardation are educated in mainstream schools (with the required curriculum modifications) and in special schools with functional academics in the curriculum if they cannot cope with the former.
- Children with severe intellectual disabilities or those who live in places which have no access to school education are on home bound programs.
- The scheme for Integrated Education for Disabled Children (IEDC) being implemented by the Ministry of Human Resource Development is implemented in the mainstream school, but as a separate unit.
- The trained resource teachers support the mainstream school teachers so as to provide appropriate education to children with disabilities in the Sarva Shiksha Abhiyan inclusive programs of education.
- The National Institute of Open Schooling (NIOS) is a program of open education, which includes children with mental retardation also.
- Those with borderline intelligence study at their own pace with a reduced curriculum content.
- Vocation-oriented education.

Sarva Shiksha Abhiyan–Education for All

The Ministry of Human Resource Development, Government of India, implemented the program in 2001 all over the country for children in the age group 6 to 14 years, following the policy of 'Education for All' in an inclusive set up.

Special educators are appointed as resource teachers for the special children, but the ratio of special educators to the number of children 'included' is not uniform for every block or in every district.

Prior to the introduction of the program, children with mild/moderate level of retardation had already been included in the normal course in mainstream schools.

The program is run by the non-governmental organizations in Tamil Nadu and run by the government in other States.

This program has served its purpose in those areas where special schools have not been established at all.

The District Primary Education Program (DPEP)

The District Primary Education Program (DPEP) towards universalization of primary education including children with special needs has been implemented in a number of districts.

- The DPEP includes children at the primary level (up to Class V) with suitable teacher preparation, infrastructural facilities and aids and appliances.
- Children who cannot cope with the regular curriculum, attend special schools. There are over 2,100 special schools run by NGOs with and without government support.

- Empowering parents by training them to teach their children in early intervention programs, serving as the carry over agents in training at home is a major mode of reaching out to children where there is no access to school.
- The Tamil Nadu Government has set up, through the non-governmental organizations, 36 early intervention centres, one for each of the districts.
- By training the caregiver or the parent, precious time in the child's developmental period when maximum learning occurs, is not wasted.
- Parents also develop a positive attitude and confidence in training their children with mental retardation.
- Such training is also center-based where parents accompany the child, learn the skills demonstrated, impart them to the children at the centre.
- Another method is to have itinerant teachers periodically to train the parents at home using locally available material, which is viable and cost effective.

With the above program in place, no child with special needs will remain unattended.

Vocational Training and Employment of Persons with Mental Retardation

In the past, vocational training was an extension of the school program where traditional routine skills such as weaving and crafts were taught. Today, with activity centres established, training involves matching the levels, ranging from mild to severe levels of retardation, with open employment, sheltered employment, family supported employment.

The Government has introduced 3% job reservation in the government sector for persons with physical disabilities, but there is no quota yet for persons with mental retardation. However, positive support is received through technical assistance and finances from the NHFDC.

Schemes of the Ministry of Health & Family Welfare

Prevention, Early Detection and Intervention

Efforts of the Ministry of Health and Family Welfare, Government of India are directed at prevention of disabilities through increasing public awareness, immunization, pulse polio immunization and sensitization of grass root level workers and PHC doctors.

Appropriate treatment and management of epilepsy and related medical problems in children with intellectual impairment is taken up.

Training is imparted to professionals and parents on simple early intervention techniques to reduce and/or arrest the severity of the condition in their wards.

Conclusion

Quality of life of persons with mental retardation has been significantly enhanced.

Families of the affected are being empowered. Self-advocacy measures are being taken and independent living skills are imparted to the persons with mental retardation.

Reaching the persons in remote, rural, tribal and hilly areas is a priority for the Government of India.

Educational and training programs suitable to the social cultural milieu of each region are being developed, so that persons with mental retardation

develop competencies to live independently in their own environments.

Translating the policies and training materials in Indian languages in print and non-print media to reach out to every person with disabilities in his community is of prime importance. This task has been undertaken effectively.

Continuous research and development in all dimensions of mental retardation is of utmost importance for future development.

Chapter 12

Vocational Training and Employment

Introduction

Persons with mental retardation are employable both in public and private sectors, in regular competitive work settings as well as in 'sheltered' ones. Attention to their vocational preparation has gained importance since the enactment of the *Persons with Disabilities Act, 1995.*

Overview

Training of persons with retardation and with associated conditions to their optimum potential has been possible through technological advancements. With greater attention being paid to school programs and very little on vocational training, progress has been slow.

Special schools in India provide education up to 18+ years, the curriculum including pre-vocational and vocational training. Yet, concern for transition from school to vocational training centres has not been serious.

There are over 60 sheltered workshops where training is given on the traditional trades, such as carpentry, candle making, caning chairs, tailoring. The Departments of Welfare in the states do not provide sufficient grants to such sheltered workshops as much as they do to the mainstream educational institutions, though sheltered workshops have to pay wages to the trainees and do not charge fees (Divatia, 1979).

Though there are over 10 centres running Diploma Course in Vocational Training, only a few provide suitable vocational training due to shortage of trained manpower. Those available are also not gainfully employed.

Vocational training is related to the needs for marketable products identified through a survey. Market survey is an area which requires attention.

Vocational Training and Rehabilitation

Vocational Training, pivotal to the rehabilitation of persons with mental retardation can be given to the person who is independent in personal, social, emotional, life, independent in survival, safety as well as work related skills.

- About 400 institutions in this country provide vocational training. So do some special schools.
- Special vocational centers have also been established.
- Still, many persons with retardation fail to be employed due to lack of training in social and work adjustment skills. Some special schools help by providing insitu training.
- *Various stages* followed in the area of *vocational rehabilitation* are
    - systematic school instruction,
    - planning for transition,
    - placement for meaningful employment, and
    - follow-up services.

Pre-reading, pre-writing, etc., the basic skills that permits an adequate development of psychomotor co-ordination constitute the systematic school instruction at the pre-primary education level. Socialization and living together also begin at this stage.

During the secondary level, job oriented functional academics are reinforced and enlarged. Simple activities are initiated — a basis for the pre-vocational stage. More attention is given to developing general work habits, well groomed appearance, communication skills and appropriate social behavior.

At the *pre-vocational period,* development of functional skills and appropriate social behavior preparatory for transition are attended to. They are necessary qualifications for any vocation.

The objectives of pre-vocational training are: imparting training and creating opportunities for development of functional academics, personal social skills, survival and safety skills and work readiness skills; developing adjustment skills by providing experiences in various life situations; and normalizing work related behavior.

The activities involved at pre-vocational stage for transition are: survey of the employment potentials in the community and desired entry level skills; the student's interest and aptitude assessment; individualized transition plan prepared in co-operation with parents and employees towards the end of school years; prior training of the students for a short period in the simulated set up in the school.

Vocational Training is also meant for adults with mental retardation who complete their special schooling with intermittent, limited, extensive and pervasive support. This support continues into their vocational training, placement and thereafter.

In the developed countries, a minimum IQ of 20 is a requirement for productive work. In India training is offered only for those with IQs of 40 or above.

Vocational Rehabilitation

The first step, assessment has to be in two areas: for the amount of support he/she may need and assessment of the job opportunities available in the community.

The five areas of assessment are: medical (for functional/organic limitations), physical (for physical performance—effort and working capacity), psychological (for intelligence, mechanical and constructional aptitudes, interest, etc.), educational (for personal, social, academic and safety skills), vocational **(**for skill level, aptitude and occupational abilities).

The purpose of community assessment is to identify potential employment opportunities in the trade in which training is given. Through assessment, specific skills (which should be the same skills on which the trainees are assessed) required for performance on a job on site is identified.

Surveys conducted on available jobs, employer contacts and job analysis should provide the information which forms the basis for the vocational training programs.

Work skills include specific skills—job task / social, and related behavior that are necessary for performing any given job.

After the selection of job site, specific skills are identified and targeted to provide systematic and appropriate training.

Placement Area

The trained person moves towards one of the three possible employments:

(i) Vocational Potential of Young Adults and Adults with Mild Mental Retardation

Persons with mild mental retardation function in regular (competitive) employment. Their performance depends on their training and the support they receive from the agencies which have placed them. They may get placed in 'sheltered' workshops where they may be under-employed or isolated from the mainstream.

Individuals with severe levels of retardation, usually work in sheltered workshops or in adult day-activity centers. The latter may not necessarily be remunerative.

(ii) 'Sheltered' Employment

The term, sheltered workshop is popularly understood in India to mean safety and protection.

A person with mental retardation may be trained in a sheltered workshop and employed there itself. Since their training in specific tasks matches their ability and working under supervision, those with mild and moderate retardation also benefit from sheltered employment where developing the required social competence is found relatively easy. Examples are, assembling and packing units in workshops, carpentry units and in spray painting.

(iii) Open Employment

The routine, repetitive jobs in the market can be successfully performed by the individuals with mental retardation with initial support from the trainer and with the necessary social competence. Careful selection is required to avoid exploitation.

Open–Supported Employment

The proven efficacy of the program in the USA, leads to a possibility of introducing the same in India, This by itself is 'inclusion' even at the vocational levels.

Individuals with mild retardation are relatively more suitable for open employment.

The following posts are suitable for open employment: office boys, helpers in canteens, in shops—stationery and grocery. Operators of photocopying, cyclostyling and washing machines. Vehicle workshops, printing press are other possible venues.

Self-employment

Those families with resources can ensure self-employment. If the person with mental retardation has been given appropriate training in the particular job/task that the family has identified or has it in its own family trade, then they are ready to provide supervision and support.

Self-employment can be counted as a good prospect for individuals with mental retardation in India. Dairy/poultry farms and agriculture are good examples.

In urban areas, there is documentation of some families employing persons with retardation using their own resources in enterprises such as envelope making, agarbathi and candle making and running a small pan shop.

Self-employment can be very successful in a supportive environment.

Mobile Work Crew

In USA, a person with mental retardation

functions as a member of a small group of workers who perform custodial tasks guided by on-the job supervisor. The mobile crew moves from site to site.

In India, building construction work, maintenance of gardens/public places/places of worship/parks/hospitals and restaurants may provide opportunities for the mobile work crew which should be organized to include persons with mental retardation also.

Enclave

Enclave, also in practice in USA, is a group oriented work setting, referring to a physical area within a business area, where a small group of persons with disability and a full time supervisor are employed.

In India, 'enclaves', exist conceptually, but persons with mental retardation are not usually employed.

List of Jobs

The following jobs suitable for persons with mental retardation at different levels, arrived at after research:

Services (domestic)

Childcare
Cleaning and room preparation: Home
Tourists' Homes, Hotel, Hospital, Rest House

Services (food)

Bus/train ticket vendor
Dishwasher: hand and machine
Helper (in cafeteria, restaurant and hospital):
cook, baker, general kitchen, service table.

Services (building)

Helper: general maintenance, porter at airport, porter, only at a barrier free railway station, watchman, lift operator.

Services (personal)

Hospital, nursing, and rest house aide and orderly, nurse's aide, companion.
Helper: barber and beauty shop.
Washroom attendant

Industry (Textiles)

Helper yard goods clothing manufacturing
Sewing machine operator

Industry (lumber and lumber products)

Helper: furniture factory, upholstery, toy factory, framing shop, box factory

Industry (general)

Small parts assembly
Soldering
Construction Labourer: highway, dam, and bridge work; building construction

Sales

Helper: retail stores, shop. Stock clerk. Packer, wrapper.

Public Service

Helper: road maintenance, garbage and trash collection, park and grounds maintenance, painting, maintenance.

Trades and Services

Helper: auto body repair, bricklayer, carpenter, concrete finisher, electrician, mechanic, painter, pipe fitter, plumber, roofer, sheet metal solderer, steam fitter, stone mason, tile setter, upholsterer, wiper (machine), welder and helper in all the construction work.

Helper: cleaning establishment, laundries, rug cleaning, diaper service, service station, car wash, parking garage

Machine operator: punch press, drill press, trimmer, buffer, grinder, sprayer, gluing, leather cutting, foot-power printing press, toner, straightener, wire bending, gear cutting

Industry (paper and paper products)
Helper: pulp mill, newsprint factory, stationery manufacturing

Industry (printing)
Helper: newspaper, greeting card, printing, book binding

Industry (leather and leather goods)
Helper: leather manufacturing, leather accessories manufacturing, shoes and boot manufacturing

Industry (stone, glass, and clay products)
Helper: glass production, brick yard, drain-tile-pile, pottery, cement block, quarry

Industry (food products)
Helper: poultry, slaughter house, frozen foods, cannery, bake shop, sweets factory, dairy products

Office Work
Clerk: general, filing, mail handler, mail/messenger
Office machine operator: copier, mimeograph

Farmwork
Hand: general farming, ranch, poultry, lumbering, forestry.
Helper: nursery, gardener, green house

Fishery
Hand: fishing, hatchery Helper: fishing boats

Miscellaneous
Delivery man
Helper: All vehicles, warehouse

Persons with mental retardation have been trained and employed as listed above, by many non-governmental organizations.

Non-Governmental Organizations –Job Training and Placements

The valuable experience gained by organizations such as those mentioned below can be of value for the new entrants:

Thakur Hari Prasad Institute of Rehabilitation & Research for the Mentally Retarded, Hyderabad; Sweekar Rehabilitation Institute for Handicapped, Secunderabad; Swyam Krushi, Hyderabad; Amar Jyothi Institute of Delhi; Vivekananda Udyogalaya; Mrs. Vakil's Sewri School, Children's Aid Society, Dilkhush Home, Malad Special School all in Mumbai; Prabhodini Trust School at Nashik; Pope Paul Mercy Home, Trissur; Blind People's Association, Ahmedabad; Navjyothi Trust Chennai; PNR Society, Bhavnagar; RAAS, Tirupathi. These organisations provide the *centre-based training* in the following vocations:

- Carpentry
- Horticulture (Nursery Maintenance, Kitchen Garden, Potted Plants).
- Offset Press, Letter Press, Book-Binding, Xerox, Cyclostyling.
- Tailoring, Needle Work, Jute Bag Making, Knitting.
- Fabric Hand Painting, Tie and Dye, Block Printing, Candle Making, Bangle Making.
- Brick Making, Weaving, Screen Printing.
- Christmas and New Year Cards.
- Bakery, Catering, Commercial-Cooking, 'Masala' (Spices) processing.
- Home Management.
- Consumer Stores.
- Assembly Line Production.
- Sub-contract jobs for Airlines.

Aims of Vocational Rehabilitation

Professionals have a major role to play in achieving vocational rehabilitation, in suitably integrating persons with disabilities in jobs and in fostering their potential in independent living, in economic, personal, social and occupational spheres.

It should also be possible to network with existing polytechnic institutes so that they 'include' persons with mental retardation in a special category for training purposes with the curriculum including courses so that they fit into jobs having the required skills.

Recognizing the importance of systematic, structured and need based training programs suitable for employment, the Rehabilitation Council of India has revised appropriately and put into use its staff training program at all training centres.

Initiatives of the Ministry of Labour, Govt. of India

Under the Ministry of Labour, in the 17 VRCs, the Special Vocational Training and Rehabilitation Centers, apart from training, based on capability, with an IQ of 50 and above, in specific trades, the VRCs helps in job search and job placement of young through their placement wing.

The Ministry of Labour also supports job-seekers with disabilities by identifying jobs for them through enrolment in the 47 Special Employment Exchanges.

In addition, the 914 regular employment exchanges also cater to the employment needs of job-seekers with disabilities.

Around 70,000 job seekers have availed the services of Special Employment Exchange for their job placement.

The Ninth Five Year Plan period had witnessed the establishment of new VRCs and a network of three Rural Rehabilitation Centres for each VRC.

The Government envisages for a linkage between the Government and the Voluntary Agencies involved in tertiary education and transition to work of youth with disabilities.

Pattern of Job Distribution

There is a large concentration of services in the urban areas. Because of the types of jobs available in the communities where they live and are well absorbed, persons with mental retardation in the rural areas are not under severe stress to perform beyond their capabilities, and their expectations are realistic in the natural environment.

Since the schemes reach out to a very small proportion of young persons with mental retardation, most of them depend on their families financially. Some are helpful in sharing the household chores or work in small measures contributing indirectly to the efficiency, productivity and economic status of the families.

Large number of young persons with severe disabling conditions resort to charity or idle existence.

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995

The Act does not provide any mandatory provision of job reservations for persons with mental retardation.

There is no evidence to say that the persons with mild mental retardation have been provided with the jobs identified by the Government of India for them.

The Government has set up Core Committees for framing guidelines for inter-agency and inter-Ministerial collaboration for effective implementation of the comprehensive legislation.

Legal Rights and Other Provisions

- The State legislatures are empowered to pass legislation regarding relief for the persons with disabilities and those unemployable as per Entry 9 of the State List of the Constitution.
- Special provisions such as job quota and reservation of particular jobs for the persons with disabilities exist.

Concessions and Benefits for Persons with Mental Retardation

- Seventy five percent concession in the basic train fare in the first and second class is allowed to persons with mental retardation accompanied by an escort and to persons in groups.
- Most of the State Governments having their own operated transport undertakings or corporations allow subsidized/free bus travel in the city and rural routes including an escort.
- Preferential allotment of telephone booths.
- A scheme of scholarships by the erstwhile Union Ministry of Welfare since 1955 awarded to persons with disability for pursuing education in special schools being run by non-government organizations operated through the State Governments and Union Territories.
- Persons with mental retardation can receive education in the mainstream school system. Various allowances and annual cost of the equipments 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 child with mental retardation to a school away from the station of his/her posting.
- Assistance is given to persons with disability for purchase and fitting of aids and appliances by the Government of India.
- 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-1401/ 4190-Estt (R) dated 15th February, 1991, makes provision for a choice in the place of posting of parents in government service having a child with mental retardation.

Assistance to Voluntary Organizations for the Persons with Disabilities

- Assistance of upto 90 percent in urban and rural areas is given to NGOs for education, training and rehabilitation of persons with disabilities.
- Emphasis is laid on Vocational Guidance and Training.

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

- In the case of cerebral palsy and mental

retardation, 100% assistance is provided to voluntary organizations for training professionals and for developing organizational infrastructure such as class room, library/hostel, etc.

Employment in Private Sector

Private sector organizations have to reserve jobs for persons with disabilities as per the state government orders and provisions in the PWD Act.

Violation of Employment Provisions

As per section 63 of the PWD Act, the Chief Commissioner for the Disabled or the State Commissioner for the Disabled has the same powers as are vested in a court under the Criminal Procedure Code, 1908.

Economic Rehabilitation

Many persons with disabilities have benefited under this scheme wherein Rs. 3,000 is given as subsidy linked with bank loan to start petty business.

Each State has its own economic rehabilitation program such as setting up telephone booths, awarding unemployment allowance, providing employment in the unorganized sector and in networking with NGOs. These programs are typical for each State according to the needs and priorities.

Conclusion

- In India, no unemployment allowance/ social security or any other security benefits are available to persons with disabilities/caregivers, youngsters with disabilities may take up any job offered.
- With greater awareness young people with disabilities can take the available semi-skilled and unskilled jobs.
- Results of the initial experiments pertaining to on-the-job training and supported integrated employment have been encouraging. Cost-effectiveness, promotion of dignity and improvement in quality of life through integrated work, have brought in greater advocacy for this approach.
- Special Employment Exchanges and Special Employment Cells have been established by the Ministry of Labour to support persons with disabilities in job-search and placement.
- National Awards instituted recognize contribution to the rehabilitation processes of employees with disabilities, placement officers and successful employers of persons with disabilities.

Chapter 13

Research and Development in the Field of Mental Retardation in India

Introduction

The first review of research in mental retardation in India appeared only in 1968 (Das, 1968).

Review of Literature

- The Study on the 'Feasibility of Training Mothers at Day Care Centres for Children with Mental Retardation-Age Group 3 to 6 years (1968 to 1971), a controlled study.
- Between 1968 and 1976, there were fifty experimental research publications by Indian psychologists in the field of mental retardation, with the maximum number (about 25%) in the year 1968.
- The first Indian Journal in the field of Mental Retardation. *The Occupational Therapy Journal,* now called *The Journal of Rehabilitation in Asia* appeared in 1960 from Mumbai.
- Another research Journal, *The Indian Journal on Mental Retardation,* published by the All India Association on Mental Retardation, Chandigarh, appeared in 1968.
- A popular Journal *Mental Retardation Digest* is being published by the Federation for the Welfare of the Mentally Retarded, New Delhi since 1970.

Research in India

The present section on Research and Development in India is discussed below under different categories.

Curriculum and Instruction

Curriculum and instructional procedure for persons with mental retardation has received little attention except in the

- Preparation of skill development material at NIMH, Secunderabad.
- Diagnostic curriculum at Amar Jyoti Trust, New Delhi (Malhotra, 2001).
- Yogasanas for Persons with Mental Retardation, Madras (Jeychandran, 1983).
- Upanayan Early Intervention Programme System (1987).

The NCERT has not developed source books for mental retardation.

The serial learning procedure followed by Goel (1980) was not clear on the concept of serial learning.

The effect of isolation on learning and memory was undertaken by Goel and Panda (1998); it led to conflicting findings.

There is need for curriculum research in arithmetic, reading, language, social skills and determination of efficiency of instructional techniques.

Research literature is conspicuously absent in this regard.

Learning and Memory

Long-term retention correlates with learning and memory in persons with retardation. The more intense and longer the learning, the better is the long-term retention and also easier the transfer of training. Mainstream children did better than those with mental retardation of the same age in all situations. Distractibility and attention deficits are pronounced in persons with mental retardation, but the isolation effect depends on the nature of the isolated items.

Behavior Modification Approach in Learning

Jeyachandran, et al. (1968) developed the Madras Scale and used the behavior modification approach to train children under 6 years with mental retardation. Also using behavior modification approach, Lidhoo, M.L., and Dhar, L. (1989) designed teaching and learning methodologies for educable children. They reported improved achievement in adaptive behaviours.

Jeyachandran and Vimala (1970) developed the Adaptive Behavior Assessment Kit (ABAK) for assessment and training of persons with mental retardation.

Peer Modeling

Comparing effectiveness of adult and peer models on learning and retention of performance skills in children with mental retardation, using a learning kit for teaching the skills developed for educable mentally retarded (EMR) and trainable mentally retarded (TMR) children, Narayan (1990) found peer modeling to be the most effective technique for learning performance skills in motor, perceptual and communication areas as compared with adult and no-model conditions for both groups of children.

- In demonstrating home based training in learning, Narayan and Ajit (1991) and Kohli (1988) found that parental involvement and support reinforced school effort.

Assessment and Needs to be Met

Assessment of mental retardation in India poses serious problems because of lack of unified procedure, culture appropriateness, and comprehensiveness.

Need

The dual purpose of assessment refer to knowing where the child is and identifying where he should be taken.

The norm referenced test, such as the intelligence test, is not suitable for instruction purposes.

Research in the field of mental retardation with developmental approach will not provide significant conclusions.

In the absence of growth studies, there is a need for behavioral assessment in the field of applied behavior analysis, behavior modification and behavior therapy.

Research should be change-oriented and criterion referenced.

There is need for research on precision teaching and formative assessment which should predict future learning and growth.

Assessment Scale

Development of assessment instrument already developed by NIMH (1991) needs to be translated for different regions for identification, placement and intervention (Panda, 1994).

Language Development

Nizamie (2001) stated that some children may have severe retardation in their language development, but may have only mild or moderate retardation in the area of self-care or visio-spatial skills.

It is important to know, on a scale which is yet to be devised, the pattern of strengths, weaknesses and performances of such children corresponding to their treatment and growth. Certain patterns of performance have been associated more with a particular type of mental retardation.

Inferior visio-constructive performance in comparison to verbal abilities in Turners Syndrome, a comparatively poor visual motor integration than simple motor skills and general language skills in William Syndrome, and right hemisphere dominance for language in Down's syndrome have been reported.

These results suggest the importance of evaluation and treatment by a multidisciplinary team.

Limitations to Intelligence Tests

Available intelligences tests are not applicable to a large section of children with mental retardation for reasons that they are devised without including such children in their normative samples; they are constructed only to recognize differences within the normal intelligence range and their insensitivity to variations at low extremes. Hence, if a child's score is below the expected range, his IQ has to be calculated by extrapolation. Any qualified psychologist will give an authentic report on the psychological tests administered.

A Meaningful Assessment

It is important in such cases to rely upon other inputs for making a meaningful assessment of the person's social behavior, development and performance ratings, etc.

In this direction, some useful work has already been done by eminent personalities such as Bondy in Germany, Schopier, Reichler and Demeyer in USA and more recently by Luria and Nebraska of Europe. Yet, there is lack of standardization.

Research aimed at developing a battery of tests which suits Indian conditions needs to be undertaken.

Available Tests in India

Panda (2001) critically analyzing the content and psychometric properties of available tests on mental retardation emphasized the need for diagnostic and predictive aspects of assessment of intellectually challenged learners in India.

The analysis addressed available:

Norm-referenced assessment techniques (intelligence, developmental schedules).

Criterion referenced assessment.

Curriculum-based assessment which traces the child's assessment, the Early Learning Accomplishment Profile (ELAP).

Upanayan Early Intervention Programming System.

Portage Guide to Early Education.

Individualised Education Plan (IEP).

Integrating and Interdisciplinary Team assessment, training objectives, monitoring and program impact; adaptive to challenged assessment (social competence); behavioral assessment tests (Basic - MR and Functional assessment); Developmental Indices (MDPS).

Tests in India in identifying, screening, assessing, capabilities and evaluating intellectually challenged learners include process-oriented measures, neuropsychological assessment and Malhotra's Curriculum Based Assessment.

However, the test - Planning, Attention, Simultaneous and Successive Processing (PASS) though very useful has not been popularized in India for its usage.

While analyzing the reliance and validity of such measures used, the shortcomings, inadequacies, built-in constraints which reduce the usefulness of the tests for use in culturally diverse Indian context have been stated.

Emerging issues and developments in diagnosis, assessment, and evaluation of persons with mental retardation and programming for them has been viewed in the background of equal opportunity, inclusion, and remediation.

These requirements are found satisfied by the indigenously developed test protocols –The Madras Development Programming System, the Upanayan Early Intervention Programming System and the Functional Assessment Check List.

Panda (2001) suggested developing a child-centered curriculum guide and a Learning Assessment Potential Device (LPAD):

- to provide continuity and a comprehensive approach for functional and behavioral assessment;
- for giving remedial inputs based on clinical diagnosis in the areas of socialization, language, cognition, motor, interpersonal relationship, all of which are directed towards independent functioning by persons with mental retardation throughout the country.

This guide encompasses assessment for the capability, pace, limits, and the inputs of learners.

A mechanism for development of such a device is now available and in use.

Ecology: School and Family

Research on disability and particularly on persons with mental retardation on acceptability in rural versus urban community have not been undertaken so far.

Socio-psychological survey to determine the rural versus urban attitudes towards acceptance of individuals with mental retardation in the community is an indicator for the directions in rehabilitation.

Most of the research on socially deprived children with low intelligence is attributed to poor social class and poverty. Area specific prevalence is yet to be undertaken.

A gross limitation of these studies is in its methodology, but the ideas are pragmatic for other researchers to undertake further studies.

Management and Family Studies

A pioneering study on the feasibility of training mothers of children with mental retardation, age group, 3 to 6 years, in day care settings was done in 1968 by Bala Vihar Residential School, Chennai funded by PL480-US Grant.

Five Groups were taken for the study were:

Group A – parent participation-6 months

Group B – parent participation- 12 months

Group C - without parent participation -18 months

Group D - children in institutions

Group E - children with no training, no parent participation

The findings were:

- Given the training the parents become the carryover agents of their children at home;
- positive attitudinal change was observed towards their children with mental retardation within a period of 6 months, and
- the longer the training, the more sustained is the learning in the children.

In recent years an increasing magnitude of research in social sciences has focused on issues relating to mental retardation.

The rationale is, mental retardation is not only a product of physiological or pathological causes, but is also the result of familial, socio-economic, environmental, and many other factors.

Hence, family ecological investigation in mental retardation has become necessity.

Self Injurious Behavior (SIB)

Self injurious behavior requires immediate and intensive intervention for persons with mental retardation and related developmental disorders.

Correlation of SIB with the degree of mental retardation shows a prevalence of 10-15 per cent among persons with severe mental retardation.

Associated with aggressive and abusive behavior towards family members and caregivers, this condition leads to infliction of significant harm to oneself the physical, emotional, and financial impact being considerable.

Children with mental retardation have more adjustment problems with their peers than the mainstream adolescent children.

Social feedback reduces the adjustment problems for them and teaches a variety of appropriate social behaviors (Sen, 1976).

Service Delivery System

Different service delivery systems are in use for the education and rehabilitation of the children with mental retardation.

Research on the beneficial effects of integrated and inclusive education systems showed significant interaction between children with and without mental retardation (Mani 1994; Jeyachandran, 1999).

The Integrated Child Development Scheme (ICDS) workers facilitated the service delivery system. NGOs involvement was inadequate.

All project officers and teachers recommended the composite area approach for integrated education.

Sociological labeling was observed in the attitudes of teachers, community members and parents, towards children with mental retardation.

In the Indian context, now children with mental retardation learn in integrated and inclusive settings with normal peers helping, parental attitudes change favorably; partnership between government and voluntary organization work (RCI, 2005).

Bio-Technology/Bio-Medical Research

In mental retardation, genetic factor is the cause in nearly 10% of the cases. Another important etiological factor is chromosomal abnormality.

Visible progress has been made in understanding the genetic basis for the occurrence of severe to profound mental retardation.

The National Centre for Biological Sciences, Bangalore; All India Institute of Medical Sciences, Delhi; University of Delhi; National Institute of

Mental Health and Neurological Sciences, Banagalore; University of Madras, Chennai; Sri Ramachandra Medical College and Research, Chennai; Tata Institute for Fundamental Research, Mumbai; Madurai Kamaraj University, Madurai; Manovikas Kendra Rehabilitation and Research Institute of the Handicapped, Kolkata are some of the leading institutes involved in genetic research on the various aspects of mental retardation.

It was reported at the Second International Conference on Early Intervention for Mental Retardation at Chennai in 2007 that a breakthrough has been made in the laboratories engaged in studies in biological sciences— the National Centre for Biological Sciences, Bangalore, and the Mind Institute, California, USA.

Mental retardation with associated physical and behavioral conditions occurs due to both genetic and environmental causes (Singh, 2001). However the genetic changes which occur in a large number of specific disorders have not yet been identified.

Multifactorial inheritance reflects the additive effects of several minor genetic abnormalities and minor environmental factors.

With the availability of the complete DNA sequence of the human genetic material, it will be possible to identify deviant genes in affected individuals in the near future.

Mind's College of Special Education, Mumbai

Chromosomal analysis was carried out in 2,002 subjects over a period of 13 years. Parents and siblings of positive cases were also included.

Various epidemiological factors such as parental ages, consanguinity, level of intellectual functioning, family history, dysmorphic features have been analyzed under various groups, e.g., Down Syndrome, Fragile X Syndrome and other chromosomal and 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.

There are a few biotechnological and biomedical research studies in addition to what has been done in cases with phenylketenuria (PKU) by Krupanidhi and Punekar (1963, 1966) and in those with nutritional deficiency and cognitive development (Dutta, T.).

Bio-chemical screening of children after birth and special diet schedules would go a long way in reducing the occurrence of mental retardation in India.

Intervention Research

Anita Ghai and Anima Sen (1992) studied the choice behavior of persons with high and low mental retardation using different games and different forms of recreational acts as means of educating the children with retardation.

The results are analysed in terms of cooperative and competitive stance utilized by the children with mental retardation and are discussed in relation to their implications for training and educating the persons with mental retardation.

The Madras Project (1968), an experimental study on the feasibility of involving parents in training their children with mental retardation indicated an attitudinal change in a shorter time and the parents as being effective as carryover agents.

The Upanayan Early Intervention (1987), after elaborate field tests, its modules were found workable and suitable in its applications.

Parikh (1992) reported on Infant Stimulation Programs for children with mental retardation and with parental involvement for those unable to benefit from mainstream education. Activities and content material beyond the range of the regular curriculum offered in the schools to encompass life skills and functional skills have to be provided.

Pati, Kumar, and Mohanty (1997) explored the effectiveness of a package program consisting of sitting at the left hand side of the subject, verbal instruction (attend your task), and secondary reward, on the task attention of the persons with severe mental retardation, in a class room setting. Significant improvement was seen in the behavior of all subjects with a relapse after withdrawal of the intervention package.

Other Recent Empirical Studies

A significant improvement in self help skills in the children, an increased awareness among the community and school teachers on the importance of training and a positive attitude were the outcomes of a CBR program on children with mental retardation, their families and community (R. Madhumathi, 2005).

Sharma (2007) showed improvement in the frequency of attacks and in general health, following augmentative therapies—pranic healing.

Subhodh Kumar (2007) found that using appropriate behavior modification techniques, problem behaviors can be changed/eliminated and those in inclusive settings are less problematic.

Intervention research studies are, however, limited.

The Group Home Experiment

In group homes, there are living arrangements where a small number of mentally handicapped persons live together in a community under supervision and get trained effectively.

The initial supervision provided by an in-house parent gradually fades into a manager system wherein one person co-ordinates the Care Staff personnel in shifts. A feeling of participation is encouraged while managing all the household chores. Thus, social and educational training, and learning to use money through actual transactions has fostered a high degree of independence successfully.

Krupa, a residential home for adult persons with mental retardation and associated disabilities was established in 1999 at Sriperumbudur under the auspices of the Dayananda- B.D.Goenka Trust.

A community based small group home, the curriculum at Krupa follows a Gurukulam pattern with less stress, yet following, an individualized program in the care and management of the residents.

Swayamkrushi

The main aim was to provide training through actual experiences of operating in a social zone, in commercial centres, at social functions and in other group activities like self-organized picnics and other leisure time activities.

Along with hygiene, training on household chores has confirmed success of this program (Kalyan, 1992).

This system is one of the pioneering efforts in India.

There are eight girls between the age group of 16 to 21 years who have been integrated into society successfully.

A powerful review mechanism has been in-built into the program. The methodology adopted is as follows:

- The house teachers meet once in three days with the ongoing evaluations.
- These progress reports are reviewed by the director in a combined performance review meeting with all the staff.
- Necessary amendments/changes in the training program are made and executed with advice from other specialists when needed.
- Most important is sending the individual back to his/her residential environment for a short period during which the parent is guided and counseled about home training and on the points on which he should report back.
- On account of reports of enormous improvements, parents of individuals with mental retardation approached the organizers to start more such group homes in different locations in the cities.
- The complex of ten units are located in residential colonies, near shopping units or small commercial centres where 'small' employment opportunities and "on the job" training are conveniently available, areas which are well connected by bus routes.

It can be concluded that such programs are most essential in the rehabilitation of the adults with mental retardation.

A few outstanding examples of Group Homes run in the above manner are: Thakur Hari Prasad Institute, Hyderabad; Sweekar, Hyderabad; Central Institue for the Mentally Handicapped, Tiruvananthapuram; Mrs J.Vakil School, Sewri, Mumbai; Hari Mohan Singh Home in Dist. Burdwan, West Bengal; Amar Seva Sangham, Ayyakudi, Tamil Nadu; CSI Home for the Mentally Retarded, Sakshiyapuram, Siva Kasi, Tamil Nadu; Asha, Bangalore, Karnataka.

Development of Instructional Materials

- A Guide Book for Teaching Yoga for Persons with Mental Retardation (1983) developed for the use of special educators, can be used by any one interested in teaching yoga for persons with mental retardation.
- Research and development activities have taken rapid strides after the NPE 1986 came into force and the establishment of the National Institute for the Mentally Handicapped at Secunderabad.

Similarly, non-governmental organizations (NGOs) like Thakur Hari Prasad Institute (THPI) Hyderabad; Amarjyoti, Delhi; Vijay Human Services, Chennai; Mano Vikas Research Institute for Handicapped (MRIH), Kolkata have also brought out innovative booklets for the benefit of persons with mental retardation.

These documents taken together represent significant contribution as well as wide range of activities relating to early intervention, skill development, instruction, employment and mainstreaming.

Chapter 14

Current and Emerging Issues

Introduction

With more awareness on the need for efficient care and management systems in early intervention, school education, vocational training, employability and independent living, parents have been demanding for more satisfactory need-based services in their areas.

With legislation in place, it has now become mandatory to provide an array of appropriate services as a matter of right, to persons with mental retardation.

Empowerment

The Rights Based Approach with Result Oriented Support Systems

A rights based approach is based on empowerment, equality of entitlement, dignity, justice, and respect by all people.

It encourages persons with disabilities, their parents/caregivers to demand quality service, according to their priorities, thereby raising their self-esteem and promoting autonomy. It implies that society becomes obligated to enable people to enjoy their rights, but with mechanisms which would redress any grievance when quality services are not given.

Legislation

The Persons with Disabilities Act, 1995

India was the first country to be a signatory to the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Decade of Disabled Persons, 1993 -2002.

In January 1996 an Act of Parliament enabling implementation of this Proclamation was passed –The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

Two other legislations, the Rehabilitation Council of India Act, 1992 and the National Trust Act, 1999 have included training and guardianship respectively in their clauses.

Looking Ahead

In the provision of services to persons with mental retardation, the main concern is, *where we have been, where we are today, and where we will be in the future.*

According to Cain and Taber (1987) three elements are of importance in defining the relationship with the past and that of the present and the future. They are:

- Continuity where the future is always influenced by the past and the present.
- Change where the future is always influenced by the unexpected events that break the continuity of history.
- Choice where the future is always influenced by the choices that people

make when confronted with a new development.

Changes and influences of the society also affect the relationship between the present and the future.

Pressures on persons with mental retardation vary significantly according to the demands of the society. The future trend, therefore, projects an everyday life which will become more demanding and technologically more sophisticated.

The impact of this trend will be felt on the nature of work which will become more technological, more automated, with more jobs being made available in the service industry.

Persons with mental retardation may live longer consequently requiring a continuum of health services.

In planning from their childhood to adulthood, there is a need for the provision of a result-oriented array of services ranging from early intervention to life as an adult.

The Array of Services

A convergence of the interdisciplinary team of experts in assisting the parent and the family members of the child with disability for inclusion in the mainstream to ensure quality life to persons with disability has been brought about.

A Holistic Approach

The array of services available in the country is exhaustive, encompassing all facets of education, medical, and social needs, required for a *holistic approach* to the habilitation and rehabilitation of persons with mental retardation, keeping in mind the person as a whole.

Much thought has to be given to human services departments in selecting, screening, training, directing, motivating and supervising the right personnel to be part of organizations.

Academia are doubly responsible in this task of considering every aspect of the services, not only in the framing the policy for the welfare of the persons with mental retardation, but also in its implementation that it blends well with the national ethos.

Networking with the departments of health, education, human resource development and employment, interacting with the players in the field towards a smooth spread of services as well as in the continued quality maintenance will have to be the vision of the service providers.

Current and Emerging Issues

Application of technology in the array of services provided to the persons with disabilities has to suit the persons in the settings they live in, whether rural or urban making their lives more comfortable, more productive and more self enhancing.

Technology in the Digital Age

The benefits of technology-based socio-economic progress had invariably got unevenly distributed in society, resulting in widening the divide between the haves and the have-nots.

In the digital age, the key to the information society is universal access, with all having equal opportunities to participate and no one being denied of any benefit from the available technology, particularly the persons with disability.

The Conference on 'Information Technology Enablers for Persons with Disability'(INTEND-2001)

The Conference on 'Information Technology Enablers for Persons with Disability'

(Intend-2001) conducted at national level, at Chennai, by IT Technologists, was an effort to 'have a fresh look at new possibilities and promises of Science and Technology, more specially, the dominant Information Technology of today. Since then, there has been a sea change in the development of technology for enabling persons with disabilities, but it is yet to reach the masses in ways, affordable and accessible.

The basic question asked at the Conference 'How can technology be made more human and humane?' still remains to be answered more expansively.

The focus of the World Telecommunication and Information Society Day (May 17) is therefore on 'Equal Opportunities and Participation in the Digital Age for Persons with Disabilities.

Developments–2001 to 2008

The developments that have taken place in the past decade in the area of Information Communication Technology have enabled a section of the population of persons with disabilities to lead a more enriched life than before.

Today, electronic banking, online shopping, e-mailing, electronic document processing, and other computer-related resources and communication products are available for persons with disabilities, again only to a section of the population. Soon, technological facilities should reach out to persons with mental retardation as well.

Technology for People with Mental Retardation and Associated Disabilities

Assistive Technology (AT) can be a device or a service. An assistive technology device is any item, piece of equipment, or product system, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. An assistive technology service means any service that helps an individual with a disability select, acquire, or use an assistive technology device (Assistive Technology Act of 2004).

Technology for the Benefit of People with Mental Retardation and Associated Disabilities

Kelker (1997) developed the following list indicating that assistive technology may be considered appropriate when it does any or all of the following things:

- Enables an individual to perform functions that can be achieved by no other means.
- Enables an individual to approximate normal fluency, rate, or standards – a level of accomplishment that could not be achieved by any other means.
- Provides access for participation in programs or activities which otherwise would be closed to the individual.
- Increases endurance or ability to persevere and complete tasks that otherwise are too laborious to be attempted on a routine basis.
- Enables an individual to concentrate on tasks—learning/employment, rather than mechanical tasks.
- Provides greater access to information.
- Supports normal social interactions with peers and adults.
- Supports participation in the least restrictive educational environment.

Use of Technology for Persons with Mental Retardation

- *Communication*

Augmentative and Alternative Communication (AAC) ranges from low-tech

message boards to computerized voice output communication aids and synthesized speech for those who cannot use vocal communication.

- *Mobility*

  Simple to sophisticated computer controlled wheelchairs and mobility aids help in direction-finding and guiding users to destinations. Computer cueing systems and robots have also been used to guide users with intellectual disabilities.

- *Environmental control*

  Assistive technology can help people to control electrical appliances, audio/video equipment such as home entertainment systems or to do something as basic as lock and unlock doors.

- *Activities of daily living*

  Technology is assisting people with disabilities to successfully complete everyday tasks of self-care. Examples: automated and computerized dining devices allow an individual to eat more independently.

- Audio prompting devices may be used to assist a person with memory difficulties to complete a task or to follow a certain sequence of steps from start to finish.

- Video-based instructional materials can help people learn functional life skills such as grocery shopping, writing a cheque, paying the bills or using the ATM machine.

Enabler and Communications Technology–Technology in Extending the Reach of Education

Technology for Education

Today methodologies, specific to each type and degree of disability have been developed/made available as part and parcel of an integrated educational system to aid communication, support activities of daily living and to enhance learning. Computer-assisted instruction can help in many areas, including word recognition, mathematics, spelling and even social skills. Computers have also been found to promote interaction with non-disabled peers.

Staff training and service providing organizations are enabled, both in government or non-government sectors, to develop programs beginning from early detection/intervention to adult independent living by means of audio-visual presentations, education satellite communication network, available freely and in local languages. Distance mode education programs have also been made accessible through this communication system.

The distance mode of education provided by Indira Gandhi National Open University (IGNOU), the Rehabilitation Council of India with M.P. Bhoj Open University, Centre for Advanced Computing (C-DAC) provide quality educational material in all the local languages, a commendable national initiative.

Technology is available in local languages, though not yet, at low cost or no cost. Based on the socio-economic need and the affordability of the persons with disability, many more products of utility in the public domain need to be made available on large scale.

The Education Satellite: EDUSAT

The Education Satellite: EDUSAT, organized and implemented by the RCI has been funded by *Media Lab Asia* which is under the Ministry of Information and Technology.

The IGNOU, the RCI and the Sarva Sishka Abhyan established satellite education programs which have imparted training to the professionals,

persons with mental retardation and their parents. The non-availability of master trainers has been solved to some extent with introduction of this mode of special education.

Computers with web cameras, computers on networks have given easy access to tele-consultation services for intervention programs, though it is yet to become more popular all over the country.

Technology for Employment

Video-assisted training is being used for job training and job skill development and to teach complex skills for appropriate job behavior and social interaction. Prompting systems using audio cassette recorders and computer-based prompting devices have been used to help workers stay on task, the latter, computerized prompting systems, helping people manage their time in scheduling job activities.

Innovations in designs and manufacturing processes are under the constraints of copyright and patent law in respect of products for the persons with disabilities and they are not therefore easily available or affordable.

These innovations will enhance the quality of life of the person with disability both at home and place of work in the type of job to be performed at every 'reserved' employment facility for the persons with disabilities. Greater efficiency will be ensured in the performance of the job and therefore there will be increased productivity.

Technology for Sports and Recreation

Toys can be adapted with switches and other technologies to facilitate play for children. Computer or video games provide age-appropriate social opportunities and help children learn cognitive and eye-hand coordination skills. Specially designed software can help people with intellectual disabilities access the World Wide Web. Exercise and physical fitness can be supported by video-based technology.

Technology and Medical Services

Advances in biomedical technology are already revolutionizing services to persons with mental retardation.

The Human Genome Project is a concentrated, multinational effort to identify the location and function of all parts of the human genetic code.

Of the approximately 4,434 genetic disorders that affect people, mental retardation is believed to be a prominent feature in 448(10%) (Moser, 1992).

Medical research in brain functions, including neural network simulations, genetics and genetic engineering are being carried out at national research institutions.

Suited to the Indian context, research, design and development of affordable assistive and augmentative devices need to be undertaken such as the Hawking Communicator or the Computer.

Barriers to Technology Used by Persons with Mental Retardation

The ARC in a survey (Wehmeyer, 1998) found that the main barriers regarding the devices were lack of information on the availability and assessment, cost, complexity of the devices, and limited training in their use.

Even though it is the goal of most technology development efforts to incorporate the principles of universal design, cognitive access is not carefully considered.

Universal design ensures that the technology may be used by all people without the need for adaptation or specialized design.

An example of cognitive access would be if someone with disabilities is using a computer program, on-screen messages should last long enough or provide wait time to consider whether to press a computer key.

The time between dialing and pressing the numerals should be sufficient to complete a phone call using a rechargeable phone card as payment. However, individuals with intellectual disabilities having a range of learning and processing abilities, it is difficult to develop assistive technology solutions that are universal.

Coordinated Efforts–Governmental and Non-Governmental Organizations

In view of the vast multiplicity of agencies that would inevitably be involved in the implementation of the technology benefits to the persons with mental retardation, a coordinated and sustained effort is needed by both the governmental and non-governmental organizations.

A barrier-free environment is yet to be made available at all public places for persons with mental retardation and associated disabilities and locomotor disabilities.

- Facilities for comfortable travel even for short distances and for transporting the wheel chair are also not commonly available.
- Wheelchair usage, relating to postural stresses, call for sustained research, development and design activities.
- Demand for walkers, motorized or self-propelled, may increase for use by persons with disabilities and the aged.
- Kerb-cuts and wheel chair usable roads and pavements are yet to be facilitated.
- Not all public buildings are disabled-friendly.

Provision of ramps, wide doorways, avoidance of split levels, provision of Braille signboards, toilet facilities, special locking and unlocking systems, are not prioritized or made mandatory.

Only in specific situations and only as a result of litigations the transportation and conveyance—bus, rail and air has been made accessible to persons with disabilities.

Possibilities of building wireless signals into lamp posts, signal posts which could provide positional, locational and directional information to road and pavement users through personal devices that incorporate navigational facilities are yet to make a beginning.

Providing Needed Assistive Technology to Persons with Mental Retardation

With legislation in place, it is recognized that persons with mental retardation need technology to be able to learn. Therefore, the school authorities, should, in the near future

- Evaluate, acquire and coordinate the necessary technology with other therapies and interventions.
- Provide training for the individual, his family, and the school staff in the effective use of the technology.

In addition, if the person's individualized education program specifies that Assistive Technology is needed for home use, the school must own and provide the device until he moves to another school.

Research on Computers in Special Education Needed

Some areas identified

- The effect of the level of cognitive development in children on the understanding of working with the computers.
- The most appropriate age, and the best way to introduce computers into the educational process and the programming languages to be taught.
- The preference of one particular subject over the other for integrating computer based learning into the curriculum.
- The most appropriate uses for computer graphics in the educational process.
- Developing new and better computer enriched instruction materials.
- The impact of computer interactions on student's learning skills (i.e., effect on the learners attention span, his/her ability to learn independently, etc.), its impact on a child's natural language development and socialization.
- Computers as a means of instruction (an electronic tutor), and end of instruction (as in computer literacy), and, as a personal productivity tool to help students produce traditional written materials more efficiently.

Challenges

Research on computer based education may also differ from the traditional research in education or in computer science which needs to be considered in evaluating research in a new area.

Currently, the use of technology is associated with therapy and in education as aids for persons with mental retardation which will become wider in scope and more encompassing in its dimensions.

Technology will be increasingly applied in the manufacture and use of assistive devices in enhancing the person's cognitive skills, and in facilitating independent living through the management of adaptive behavior.

Conclusion

Technological advances in general education and more so in special education is of recent occurrence.

The Department of Education launched a pilot project on computer literacy in 1985 in a number of regular schools. Presently in a number of States, regular school education includes computer literacy as part of curriculum (Dutta, 1986).

Word processor programs in Indian languages have been developed for wider reach.

Production of adapted peripherals and add-on devices with indigenously developed software are rapidly increasing to suit the need of the persons with disabilities.

Experts who contributed to the section on Mental Retardation

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