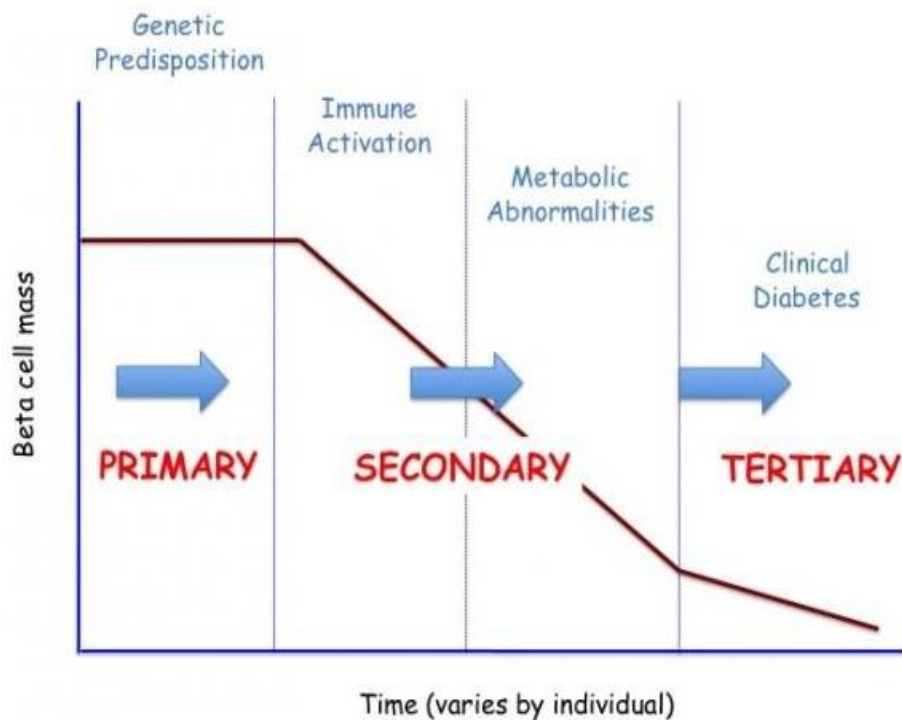


# Mental Retardation- Intervention and Educational Programmes Part 1

## Introduction



The importance of early intervention is acknowledged by professional's non-professionals alike. It advocates promotion of positive assets and development of the child and the family. Hence, the effort is to provide comprehensive, services to respond to the needs of the children and their families. The major purpose of early intervention is prevention of disability developmental delays. Prevention could be at primary level, when we seek to prevent the occurrence or development of the condition or it could be secondary prevention wherein we aim at reducing the impact and magnitude of disability or delay development.



Early intervention is both primary and secondary prevention. Designed to be cost effective and independent functioning of the child intervention may focus on the child, parents; the ultimate goal in intervention is to enhance normal development family or community. Since the child's development is dependent on endowment and its interaction with the environment, it is imperative to focus on child and the environment in early intervention. Since genetic characteristics are predetermined and fixed it is only the environment which can be manipulated to in the child. The child after birth is nurtured and cared for by the parents and the immediate family bring out the best with regard to development and learning environments of their dwelling. Therefore, intervention programs are either focused or psycho social in nature, where the focus is family and environment best outcome however, is expected when both of them are implemented. and coordinated and in It is the genetic the in the child The combined and early intervention is defined as the introduction of planned programming deliberately timed and arranged in order to alter the anticipated or projected course of development.



#### The Rationale for Early Intervention Programs–0-3 Year

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

## Human Resource Development



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 day care centers run by voluntary agencies with government assistance
- 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 (antenatal health check-up; nutritional care of mother during lactation; nutritional support and control of anaemia),
- Hygienic and skilled birth delivery
- Correct infant feeding practices, immunization of infant from communicable diseases
- Mother's education in the child care
- Early childhood stimulation
- 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. On-going 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, counselling 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 benefits the child receiving the services has been felt in the country. Several services are available each with a different type of program.

- That are highly structured, and offer intensive individualized teaching directed at specific goals for each child
- That enhances 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 fulfil the need for a structured program, culturally appropriate, suitable to the Indian socioeconomic 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 every day. 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 poverty stricken, nuclear family to carry home based training and stimulation programs as both parents have to struggle for their survival all daylong with very little time or energy to attempt home based training. There is a need, therefore, for a peripatetic trainer and/or a neighbourhood 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 paediatricians, 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.

### Assessment Tools



In context of functional deficits resulting from condition of Mental Retardation require COMMUNITY BASED ASSESSMENT tools for comparing effects of given training program with reference to functional status of adaptive skills that are exclusive for given individual. Indigenous COMMUNITY BASED ASSESSMENT tools have been developed for wide range of age group, severity and level of Mental Retardation. Efforts have also been initiated to address assessment of educational needs across Special School, Resource Room in Regular School, Home Based and Community Based settings. In current scenario existing tools can meet assessment needs at comprehensive nature. A brief description of Indian based assessment tools using COMMUNITY BASED ASSESSMENT approach will enable selecting a suitable tool for any age level, severity and level of MR person for planning educational program.

#### Madras Developmental Programming System:

This is the oldest assessment tool in India for use in special education for Persons with Mental Retardation. Madras Developmental Programming System was developed in 1967, by Prof. Jeychandran in BalaVihar – Chennai, who was responsible for adapting Minnessotta Development Programming System to Indian cultural and functional context.



This tool covers assessment needs of persons with mental retardation of all age groups and severity level in mental retardation. It contains checklist of functional statements covering 20 domains (each domain listing 18 items arranged hierarchically from early years competency to adult stages of functioning) cover

functional adaptive behaviours suitable in Indian culture and conditions. This tool is applicable for all age groups ranging from Early Intervention, Special School, Home Based and Community Based settings. This has an assessment matrix which uses color and symbol code to record level of achievement. Color Blue denotes formative stages of achievement and Color Red denotes independent levels of achievement.

Spread  
THROUGH



Striped codes refer to time covered for training, referring to term levels 1st to 3<sup>rd</sup> quarter of academic term. Demographic profile of child is stated in the above mentioned matrix, for purpose of tracking and general background of the indexed child. This tool has a manual that provides instructional guidelines to administer the tool. This tool is widely used across the country by Special Educators and is approved by RCI for training Special Educators in working with Persons with Mental Retardation. This tool is applicable for all age groups ranging from Early Intervention, Special School, Home Based and Community Based settings.

a) This has an assessment matrix which uses color and symbol code to record level of achievement. Color blue denotes formative stages of achievement and Color red denotes independent levels of achievement. Striped codes refer to time covered for training, to term levels 1st to 3rd quarter of academic term. Demographic profile of child is stated in the above mentioned matrix, for purpose of tracking and general background of the indexed child.

b) This tool has a manual that provides instructional guidelines to administer the tool. This tool is widely used across the country by Special Educators and is approved by RCI for training Special Educators in working with Persons with Mental Retardation.

c) This is the oldest assessment tool in India for use in special education for Persons with Mental Retardation. Madras Developmental Programming System was developed in 1967, by Prof. Jeychandran in BalaVihar – Chennai, who was responsible for adapting Minnessotta Development Programming System to Indian cultural and functional context. This tool covers assessment needs of persons with Mental Retardation of all age groups and severity level in Mental Retardation. It contains checklist of functional statements covering 20 domains (each domain listing 18 items arranged hierarchically from early years competency to adult stages of functioning) cover functional adaptive behaviours suitable in Indian culture and conditions. This tool is applicable for all age groups ranging from Early Intervention, Special School, Home Based and Community Based settings.

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## Conclusion

Well-developed early intervention programs are available in our country. 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) include the following services in centers for effective functioning:

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