# The Walls of Freedom

# Therapeutic Interventions, Care and Social Skills Development in Visakhapatnam - M.V.R Raju & Georgitta J.Valiyamattam

Mental retardation is largely understood to be the single largest neuropsychiatric disorder in every civilized society affecting 2.5-3.0% of the total population (Kaur & Singh, 2010). Data obtained from various sources and statistics provided by the National Institute for Mentally Handicapped (NIMH) indicate that the prevalence rate of mental retardation in India is about 20 per 1000 in the general population i.e., around 2%, and of this one fourth suffer from severe retardation. According to the National Sample Survey Organization (NSSO), among the general population, the incidence of mental retardation is 3.1% in rural areas and 0.9% in urban areas. In India an average of 2.5% children are mild or moderately retarded and 0.5% are severely retarded. Under the age of 14 there are about 7.5 million retarded children in India and the prevalence of developmental disabilities and delays is about 30 per 1000 (Panda, 1999). Another significant mental disorder occurring in childhood is Attention Deficit Hyperactivity Disorder (ADHD). Current estimates suggest that ADHD is present throughout the world in about 1-5% of the population. It is a chronic disorder with 30 to 50 percent of those individuals diagnosed in childhood continuing to have symptoms into adulthood (Silver, 1992). In India, prevalence of ADHD is 0.02% (Aravind Pillai et al, 2008). However higher rates are estimated, as 64.9% of the referrals are from pediatricians.

The high incidence of mental retardation, developmental disabilities and attention deficit hyperactivity disorder make it imperative that a substantial emphasis be placed on both preventive and rehabilitative mechanisms for dealing with these conditions. Three vital and overlapping areas towards the management of MR and developmental disabilities include *early identification, assessment* and *early intervention*. A brief overview of the mechanisms that are currently in place in these areas in the Indian context, based on the data provided by the Rehabilitation Council of India (RCI) and the National Institute of Mental Health (NIMH) would be useful.

**Early Identification:** One of the crucial areas of current focus in the field of intellectual disability and mental retardation in India involves early identification. Even though a systematic thinking and emphasis on the screening and identification of individuals with mental retardation had started subsequent to the National Policy on Education (NPE), 1986, it is only during the recent years that an early identification of persons with mental retardation has become possible. A factor that has provided impetus to this process of identification has been the implementation of the Persons with Disabilities Act (PWD) (1995), which recognized mental retardation as a disability with an identity of its own.

Early identification includes screening, early diagnosis and parental counseling. As put forward by the National Institute for the Mentally Handicapped (NIMH), Secunderabad, the current practices for screening and identification of persons with mental retardation include pre-natal, neonatal and post-natal diagnostic procedures:

**Pre-natal diagnosis or screening:** A number of advanced pre-natal diagnostic and screening mechanisms for mental retardation and intellectual disabilities are now widely available in India. These techniques make it possible to detect the presence of structural and functional abnormalities in the growing embryo in early pregnancy. Some of the major techniques include–

- 1) Blood tests for pregnant mothers for anaemic conditions, diabetes, syphilis, Rh incompatibility and neural tube defects in the foetal stage.
- 2) Ultra-sonography carried out in the second trimester of pregnancy to detect disorders such as neural tube defects, hydroencephaly, microencephaly and intrauterine growth retardation and malformations of the brain and organs among others.
- 3) Amniocentesis (removing some fluid from the uterus of the mother) which is another early identification as also prevention technique available in India, and can be used for detecting many genetic abnormalities, foetal chromosomal aberrations and congenital metabolic errors.
- Foetoscopy which is a procedure done during the second trimester of pregnancy and is used for diagnosing certain physical anomalies, metabolic disorders and bio-chemical abnormalities.

5) Another very effective technique for screening mental retardation and other genetic abnormalities is chorionic villus sampling where the biopsy of a small piece from the placenta of the mother is performed.

Although many of these techniques are relatively safe, inexpensive and widely available in the Indian context, there are a number of unresolved ethical issues involved in applying these techniques.

**Neo-natal and Post-natal screening and diagnosis-** Neonatal and postnatal diagnostic and screening procedures currently in use in India include blood and urine examinations conducted in the neonatal period in all suspected cases which have a previous history of mental retardation in the family, blood biochemistry tests for cretinism, rickets, jaundice and other infections, and urine screening for other metabolic errors such as PKU are included. Other techniques include the APGAR score at one minute after delivery which is an index of asphyxia, chromosomal analysis for Down's syndrome, neonatal neurobehavioural assessments, screening for visual and hearing impairments, ultra sonogram for detecting structural abnormalities in brain structure and intracranial hemorrhage in the newborn, MRI scanning for structural abnormalities in the brain, electroencephalography (EEG) for cases of epilepsy, mental retardation, localization of organic brain lesions and assessing severity of cerebral damage, and computerized tomography (CT scan) for detecting a number of congenital, structural and functional malfunctions in the brain.

Assessment: Assessment is an important element of any form of developmental screening. All attempts are made to ensure that the assessment instruments and measures meet the technical criteria of standardization, are culturally appropriate and acceptable to the participants and are cost effective.

Some of the other popularly used developmental screening tools in India include the Cooperative preschool inventory developed by Caldwell, Croydon Scales (Screening Checklist) developed by Wolfendale & Bryans, Denver Developmental Screening Test developed by Frankensberg, Dodds and Fandal, Early Childhood Assessment-A criterion referenced screening device developed by Schmaltz, Schramn and Wendt, AGS Early Screening Profiles developed by Harrison, et al., Developmental Indicators for the Assessment of Learning-R developed by

Mardell, et al., Early Screening Inventory developed by Merisels, et al. and the Brigance 'K' and 'T' Screen for Kindergarten and First Grade developed by Brigance, Koh's Block Design test, Draw-A-Man test, Seguin form board test, Alexander Pass-along test and Raven's Progressive matrices.

Commonly used Screening and assessment Tools that have been either developed or standardized in India include Screening Schedule I (Below 3 years) and Screening Schedule II (3 to 6 years) developed by the NIMH, Developmental Screening Test (DST) by Bharat Raj, Upanayan Early Intervention Programming System (1987), Functional Assessment Check List for Programming (FACP) 1991,The revised Madras Developmental Programme System Behavioral Scale MDPS- (1975), Gesell Drawing Tests adapted by Verma, Dwarka & Kaushal (1972), Kulshrestha Infant Intelligence Scale, Mental and Motor Growth of Indian Babies by Pramila Phatak, Vineland Social Maturity Scale adapted by Malin, Malin's Intelligence Scale for Indian Children and the Baroda - Bayley Scales of Infant Development.

Commonly used educational assessment tools for children with mental retardation include the 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 and Behavioural Assessment Scale for Indian Children with M.R. (BASIC-MR) developed by the NIMH.

**Prevention:** Another area of focus within the Indian setting involves prevention techniques for mental retardation and intellectual disabilities. All stages of prevention including primary, secondary and tertiary prevention are focused upon. While primary prevention focuses on preventing the manifestation of the disability, secondary prevention aims to restrict the development of additional disabilities and regression, and tertiary prevention tries to control and reduce the impact of the disability on the social adjustment and rehabilitation of the person.

**Primary level prevention** techniques include dealing with preventing maternal illnesses and infections and other high risk conditions such as malnutrition in the mother and child, and environmental and occupational hazards. Additional techniques in use, include immunization to

the mother for preventing illnesses in the newborn, periodic checkups to assess foetal abnormalities, a balanced diet, preventing lead poisoning and infections such as rubella during pregnancy, awareness against the use of alcohol and drugs by the pregnant mother, delivery under hygienic conditions (preferably in a hospital and by a trained person to prevent breach delivery, asphyxia, premature delivery with low birth weight and occurrence of jaundice and other illnesses in the child, as also awareness regarding. Care of newborns who are at a high risk for developing mental retardation and related disabilities (for instance a sick newborn or cases of premature birth) in highly specialized intensive care units with close follow-up to identify developmental abnormalities also form a part of primary prevention techniques.

The government of India has put forward a number of preventive measures and schemes at the national level for dealing with mental retardation and intellectual disabilities. These include –

- National Health Policy (1983) for providing optimal prenatal care and nutrition under the maternal and child health programmes
- National Aids Control Programme with STD and HIV reference laboratories at Calcutta, Chennai, Nagpur, Hyderabad and Delhi to deal with transmission of infection from the mother to the newborn leading to disability
- 3) National Iodine Deficiency Disorders Control Programme for preventing mental retardation and cretinism in children of iodine deficient women
- 4) The Centre for Health Education, Training and Nutritional Awareness (CHETNA) organizes training for various grass root level health workers for appropriate care during pregnancy and childbirth
- 5) In 1999 the Rehabilitation Council of India took up the massive programme of orienting all primary health centre doctors in the following measures for the early identification and prevention of mental retardation i) not to expose the pregnant mother to x-rays in the first trimester of pregnancy, ii)restriction of maternal age from 18 to 35, iii) control of Rh factors through blood transfusion, iv) compulsory testing of blood and urine after birth so as to take care of recessive gene disorder through appropriate dietary control, v) Avoidance of consanguineous marriages, vi) Avoidance of exposure to lead paints, intoxicating drugs, malnutrition and high temperature, vii) immunization of the mother against infections during pregnancy,

viii) immunization of the child against diphtheria, whooping cough, tetanus, polio, measles and T.B. during the first year of birth, ix) genetic screening and counseling to parents having or in the risk of having an MR child.

Genetic research centres such as those in Mumbai, the BJ Medical College Pune, and the St. John's Medical College in Bangalore have made efforts to provide these facilities at district level hospitals.

Secondary prevention involves the early identification and assessment of the magnitude of the intellectual retardation or developmental delay and interventions for minimizing its future impact on both the individual and the society. Apart from the early identification and assessment techniques already discussed, secondary prevention in India also encompasses early intervention services such as weekly multidisciplinary assistance for newborns and toddlers in the age group of 0-3 years, guidance to parents regarding immunization, nutrition, feeding, motor development, speech and language development and psycho-social interventions including guidance for parents and teachers in preparing and dealing with the mentally retarded or ADHD child in a regular school. Awareness among the public in India, about the need to provide services to infants and children with mental retardation, ADHD and other developmental disabilities is very recent and has come only in the last decade. Currently some service centres are available that use this awareness to provide extremely competent interventional services such as ACTIONAID community-based program working in rural areas, Andhra Pradesh Association for the Welfare of the Mentally Retarded (APACWMR), National Institute for the Mentally Retarded(NIMH), Deepshikha, Ranchi and its outdoor services and extension clinics at Kanke and Hulhundu, Vijay Human Services, Chennai, Manovikas Kendra Rehabilitation and Research Institute for the Handicapped (MRIH), Kolkata, The Public Health Centre (PHC)based or hospital-based program and District Rehabilitation Centre (DRC) rehabilitation programs among others. Services provided by these and other centres include early interventions with infants at risk, early child care and training for developmentally disabled children and their parents (such as the use of yoga and pranic healing techniques), Individualized Educational Programme (IEP) and Individualized Family Services Programme(IFSP) for the developmentally disabled children and their families and a creation of public awareness on children with mental retardation, ADHD and related conditions and their needs and capabilities among various stakeholders such as pediatricians, neurologists, psychiatrists, doctors, social workers, administrative authorities and the general public. The National Policy for Persons with Disabilities ensures the development of a range of interventional programmes the utilization of latest research findings in the field of genetics so as to minimize congenital disability including mental illness, development of an appropriate plan of action for limiting effects of disability and prevention of secondary disabilities within the existing health delivery system, development and provision of specific free of cost manuals for families having persons with disabilities, human resource development institutions for developing adequate personnel needed to provide support services such as special education, clinical psychology, physiotherapy, occupational therapy, audiology, speech pathology, vocational counseling and training and social work and development and inclusion of training modules and facilities in disability prevention and interventions for medical and paramedical health functionaries, Anganwadi workers and those pursuing postgraduate, undergraduate degree and diploma in medical education

Although the scope of the proposed services is impressive, the number of governmental and nongovernmental centres engaged in the honest provision of these early intervention services, are extremely few, when compared to the need for such programmes, and hence the demand for such services remains largely unmet. The Rehabilitation Council of India emphasizes on the need for separate personnel at grass root levels to attend to early stimulation programs for persons with mental retardation for sustainable intervention. There is a need for a greater number of both general and individualized programmes for the developmentally disabled children and their families and collaboration between all stakeholders including governmental and nongovernmental agencies, as also family, community, medical experts, educators and other social support networks to work together as a multidisciplinary team. Reviews of the functioning of existing services also call for the need for a social audit to ensure that the many existing sources of services are properly co-ordinated and directed towards meeting the needs of the child with disabilities and the Government if India is currently taking steps in this direction.

**Tertiary prevention** programmes currently being practiced in the Indian setting include provision of special education, vocational training programmes for open employment, self-employment and supported self-employment, sheltered workshops, placement services for mild and moderately retarded (for e.g., candle making, xerox-copy centres), provision of continuing

medical facilities, provision of sports and recreational facilities, guidance and counseling services and awareness programmes for the general public so as to reduce the stigma associated with mental disabilities that can hamper the social development and adjustment of the intellectually disabled person and children with childhood mental disorders. Although the range of these services is fairly substantive, yet the extent and distribution of these services is not enough to meet the growing demands and a mechanism for ensuring that the services are properly utilized and reach the deserving population is also needed.

**Policies and Programmes Launched by the Government of India:** The Government of India has over the years launched a number of policies and programmes for the development of the intellectually disabled. A brief overview of some of the major policies and programmes would include-

- The National Policy on Education (NPE) (1968)- which emphasizes on the integration of the handicapped with the general community. It also places a high importance on Early Childhood Care and Education (ECCE) which focuses on the total development, i.e., physical, motor, cognitive, language, emotional, social and moral of the child from conception to about six years. It also enables the integration of ECCE programmes with Integrated Child Development Services (ICDS) as also provides a scheme of assistance to voluntary organizations, for conducting ECCE centres.
- National Institute for the Mentally Handicapped (NIMH) (1984) which serves as an apex body in the area of mental retardation. It has, as its objectives, human resource development, research and development, service delivery models, documentation and dissemination, extension and outreach programmes.
- Mental Health Act (1987) which focuses on regulating standards in mental health institutions
- Rehabilitation Council of India Act (1992) which deals with the development of manpower and systems for providing rehabilitation services.
- **Persons with Disabilities Act (1995)** which provides for education, employment, creation of a barrier-free society and social security for persons with intellectual disabilities.

- National Trust for the Welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act (1999)-has provisions for legal guardianship and the provision an enabling environment that will allow as much independent living as possible.
- National policy for persons with disabilities (2006) which ensures a rage of programmes for Prevention, Early Detection and Intervention for disabilities including developmental disabilities and MR)
- Welfare programmes for the disabled (including the intellectually disabled) such as assistance for purchasing and fitting of aids and appliances (ADIP Scheme), Revised Deendayal Disabled Rehabilitation Scheme to promote Voluntary Action for persons with disabilities, Scheme of National Awards for the Empowerment of Persons with Disabilities, Scheme of National Scholarships for Persons with Disabilities, Schemes arising out of the Implementation of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, Incentive to Employers in the Private sector for providing regular employment to persons with disabilities and Models to promote awareness about accessibility features in buildings.
- Development of Composite Regional Centres for Persons with Disabilities (CRCs), District Disability Rehabilitation Centres (DDRCs), Awareness Generation Programmes, Technology Development Programmes in Mission Mode, Project Integrated Education for the disabled (PIED) instituted with the assistance if NCERT and UNICEF.
- Educational facilities for the intellectually disabled in India consist of special schools as also opportunities for inclusive education in regular schools. The number of special schools grew rapidly in the 90s and in the 2000s the number of special schools in India were about 1200, most of which were run by NGOs, private trusts and parental organizations and (Narayan, 2005) and focused on functional skills and independent living skills with no centralized curriculum and certifying board of education.

The Integrated education of disabled children (IEDC) has been now implemented by the Department of education, Ministry of Human Resource Development (MHRD), and aims to educate children with disabilities in mainstream schools. This scheme has been implemented in more than 20,000 schools in various parts of India, covering 1,20,000 children with disabilities. (India Educational report, 2002; Narayan, 2005). However, the downside is that many children with mild or moderate mental retardation, tend to drop out in senior grades of primary education (class 4 or 5) or in secondary schooling and parents seek special education facilities for their children. Also, the curriculum and evaluation system are not designed to meet the unique needs of children with intellectual disabilities. The trend towards inclusive education has been strengthened through efforts such as the establishment of the National institute of open schooling (NIOS) where children facing difficulties in academics can engage in self-paced learning with flexibility in the curriculum and examination system. Another related development promoting inclusive education involves teacher training programmes which have inclusive education and establishment of resource rooms in regular schools as one of the focus areas (Narayan, 2005).

*The 86<sup>th</sup> Constitutional amendment (2002)* included a new article (21A) which notes education as a fundamental right: "The state shall provide free and compulsory education to all children of the age of 6 to 14 years in such a manner as the state may, by law, determine". To ensure this right, Article 51A adds a clause which states that "who is a parent or guardian to provide opportunities for education to his child or, as the case may be ward, between the ages of 6 and 14 years. In addition, early childhood care and education for children up to the age of 6 years was included in the amendment (Art.45). These amendments have direct impact on children with disabilities in the area of early intervention, education and parental involvement (Constitution of India, 86<sup>th</sup> Amendment; Narayan, 2005).

## <u>A special focus on Andhra Pradesh :</u>

As per census 2010 statistics, the total number of disabled persons in the state of Andhra Pradesh is 1,364,981 which constitutes around 6% of the total population of the state. Of them, 1,050,400 (76.95%) live in rural areas whereas 314,581(23.05%) live in urban areas. According to the 2008-09 annual report of the NIMH the number of persons with mental retardation and developmental disabilities is 90 per one lakh persons. The implementation of programmes for the

welfare for the intellectually and developmentally disabled (including prevention, early identification and intervention) is in accordance with national and regional schemes.

Among Governmental agencies engaged in the welfare of the mentally disabled in Andhra Pradesh, the National Institute for the Mentally Handicapped (NIMH), an autonomous body under the Ministry of Social Justice and Empowerment, Government of India, was established in the year 1984 with its headquarters in Secunderabad, Andhra Pradesh. NIMH has its regional centers in Delhi, Mumbai and Kolkata. Its explicit objectives include the development of appropriate models of care and rehabilitation for the mentally retarded persons appropriate to Indian conditions, development of manpower for delivery of services to the mentally handicapped, identifying, conducting and coordinating research in the area of mentally handicapped and to assist them wherever necessary, serving as a documentation and information center in the area of mental retardation, acquiring relevant data to assess the magnitude/causes, rural-urban composition, socio-economic factors, etc. of mental retardation in the country and promoting and stimulating growth of various kinds of quality sources in the country for persons with mental retardation throughout the country.

Establishment of NIMH has resulted in strengthening the HRD programmes in the country and has brought out a number of publications in the area of mental retardation as an outcome of research projects. It has also resulted in creating awareness about mental retardation, education and training facilities, vocational training and placement, parent support programmes and schemes and benefits for persons with mental retardation in the country.

In the year 1987 the NIMH launched two programmes. The first is the Early Intervention Programme launched with support and financial assistance from the UNICEF and is a pioneering programme with respect to infants-at-risk. This programme has been designed with the home of the infant as the base and is aimed at training mothers in all round care and management of infants facing the risk of mental retardation. The second programme launched by the NIMH involved training of mentally retarded children and adults and their sponsorship for participation in Special Olympics at the state, national and international levels. A number of Nongovernmental agencies are also actively involved in welfare activities directed towards persons with developmental disabilities in Andhra Pradesh. The Andhra Pradesh Association for the Welfare of Mentally Retarded (APAWMR), Hyderabad which is a voluntary organization established in 1976 and has devoted considerable efforts and resources for bringing out literature in Telugu, Hindi and English in the form of booklets, pamphlets and reports on the management and training of mentally retarded children for the benefit of parents, teachers and paramedics. The Thakur Hari Prasad Institute for Research and Rehabilitation of the Mentally Handicapped (THPI), Hyderabad undertakes early interventions and early stimulations involving parents including an adoption of the Portage program and Head Start program of the West which relies heavily on home based training. A few of the other pioneering non-governmental organizations include The Chaitanya Institue for Learning Disabled, Vizianagram, Sri Dakshinaya Bahava Samithi, Guntur, Swayamkrushi, a voluntary organization located in Secunderabad, Rayalseema Seva Samithi, Tirupathi and the Yamini Foundation, Hyderabad.

<u>Visakhapatnam district</u>: The number of disabled persons in Visakhapatnam district is 13.65 lakh and of them 1.55 lakh suffer from mental retardation and intellectual and developmental disabilities. Apart from the implementation of national and state level programmes for the prevention and rehabilitation of persons with developmental disabilities and NGO activities, educational institutions in Visakhapatnam catering to disabled individuals and in particular the Department of Psychology within Andhra University are actively engaged in a number of intervention mechanisms for enhancing the quality of life of persons suffering from developmental disabilities. A brief overview of these intervention mechanisms is provided below:

# **Play Therapy:**

Play Therapy can be seen as a specific approach towards counseling and therapy where mediums such as games, toys, drawing, painting or clay moulding are used to help children become aware of their feelings as also to regulate their emotions and express them in more constructive ways. Play therapy as is used here focuses particularly on children with mental retardation and developmental disabilities as also those with childhood disorders such as ADHD and the development of sensory-motor and social skills in these children. Two particular types of play therapy in use are ball therapy and role playing/dramatic play.

Ball Therapy involves the use of multi-colored and multi-textured balls of various sizes appropriate to the needs of the child that are used in ways that allow for a multi-sensory experience, improve sensory and motor co-ordination and balance, enhancing feelings of self-esteem and confidence through simple 'ball-tasks' and also assist in the development of basic social activities and skills (for e.g., passing a ball on request or requesting for a ball). Ball therapy when used in a group setting also focuses on inculcating basic values such as sharing and sportsmanship.

Role playing or Creative dramatic play is another play therapy technique used where children are encouraged to role play, imitate various people, including family, friends, pets and other sin their lives as also dramatically re enact and recreate various daily life situations that have occurred or that which they wish to happen. Different varieties of role play are used such as those involving the therapist as one of the participant, ones involving role reversal where the child is encouraged to enact different roles in turn, as also those involving the use of toy animation. Role playing has been found to be extremely effective with children especially those with mild retardation, ADHD and related problems in understanding their unexpressed feelings, aiding an expression of feelings and enabling working through difficult familial and personal situations, as also communicating to them various perspectives of situations.

## Neurobiofeedback:

Neurofeedback is a sophisticated form of EEG biofeedback and is a modality that can facilitate changes in brain wave patterns and regional cerebral blood flow (rCBF) activation. Trainees receive feedback or output signals that relate to their own sub consciousness neuronal activities. Thus neurofeedback is a self regulation skill that inspires growth through self awareness. Trainees are informed auditory or graphic signals each time the brain is operating more efficiently. It has been demonstrated to be highly effective in treating dozens of physical and psychological disorders. We are currently using neurobiofeedback mainly as an intervention for ADHD and are seeking an expanded use of this modality in the near future.

There are five major types of brain wave patterns namely- **Delta waves (0 to 4 hz) which is** the slowest brain wave seen in the deep sleep state, **Theta waves (4 to 8hz)** which is characterized by drowsiness, daydreaming, inattention and an absence of directed thought, **Alpha waves (8 to 12 hz)** characterized by relax focused awareness, somewhat like in meditation or yoga, **Beta Waves (13 to 40hz)** consisting of **Low beta or SMR waves** between 12 to 15 cycles per second which have ability to organize the brain in terms of biofeedback, **Beta waves (15 to 20 hz)** associated with more focused, thinking and sustained attention, processing information and **High beta waves (20 to 32 hz)** which are related to too much electrical noise in the brain and a deterioration of functioning, organizational and concentration abilities, and **GAMA waves (40 or 38-42 Hz)** which have been associated with sharp focus, language comprehension, feeling of enhanced personal insight, memory retention, and learning.

Normally, Children with ADHD show a dominance of theta waves and a deficit of faster frequency waves. People with ADHD have high theta / beta ratio. In normal adults theta to beta ratio ranges from 1 to1 or 1.5 to 1. With younger children the ratio is somewhat higher; still a ratio near that range is desirable. Other inefficiencies include excessive alpha amplitude in the front areas of the brain, excessive beta amplitude over much of the brain, inequality of brain activity between the lobes and deficiency of theta amplitude in the back of the brain. Once the brain becomes deregulated, it can have a global effect on the body after all, the rhythmic activity of the brain affects all functional systems of the body. When people with ADHD get treated with neurofeedback, other systems begin to improve because brainwaves become regulated. Not only does attention improve, but oppositional behaviour, sleep, irritability, depression, anxiety, antisocial behavior, tics and many other problems also improve. Neurofeedback treats the problem at the core.

Over a series of 40 or more neurofeedback sessions, children are gradually taught to inhibit the brains production of theta waves and increase the brain use of beta waves. Each time trainees improve their brainwave, he gets reward with points or a tone. Even obstinate children also eventually become involved the "game of controlling brain waves". As the child learns to adjust their brain wave pattern, they show an improvement in cognition, and a reduction in ADHD symptoms and behavior. When children learn to control their brain waves using neurofeedback,

the improvement in ADHD does not disappear, as it happens in case of using stimulants. The child is better and when a child completes his neurofeedback training and treatment is successful, he now has a normal beta/theta ratio and many or all of his ADHD symptoms disappear.

The basic form of brain inefficiencies found in ADHD include excesses of slow wave-frequency (theta) amplitude over much of the brain, The neurobiofeedback training provided for different forms of ADHD are briefly overviewed below-

<u>Common attention deficit disorder (CADD)</u>: The distinguishing feature of CADD is excessive theta activity over sensory motor cortex on the top of the brain. Person is easily distracted, day dreaming, and having problems in retaining information. At higher theta amplitudes child becomes hyperkinetic because of need for stimulation to reduce the discomfort of under activity of the brain. Treatment is placing the electrode at the top of the head and set the protocol to suppress theta and enhance beta amplitude.

<u>High frontal alpha attention deficit order</u>: This form of ADHD is marked by heightened alpha activity over the frontal cortex; typical symptoms are poor organizational, sequencing and planning skills and being easily distracted. Unable to complete the task, appears flighty although not having reading problems, has a problem remembering what has been read, talk too much, have impulse control problem often engaging and sociable just can't wait to say what is on their mind. The treatment is alpha suppress. Electrodes are placed over the frontal cortex and child is taught to suppress alpha waves. A variation is to increase alpha waves over the parietal area or side of the brain, increases alpha amplitude there reduces the alpha waves over the frontal cortex. This protocol is used when person also shows a deficit of slow wave in the back of the brain.

Other forms of brain inefficiencies found in AHDD include-

<u>Occipital theta deficiency</u>: The relationship between ADHD and substance abuse is striking. In neurotherapy, the link between ADHD and substance abuse disorders is found in a deficiency of slow waves amplitudes or an excess of beta amplitude in the back of the brain. The key measure is theta / beta ratio. When the ratio is low(well below a value of two), the brain lacks the ability to quiet itself but alcohol or other drugs does temporarily quiet the brain and offers the person some relief. But it further depletes the theta wave and thus increases alcohol dependences. In children, this deficiency is characterized by edginess, poor stress tolerance, marked fidgetiness,

racing thoughts, squirming while seated and often sleep disturbances. These children seem to be moving, scratching, fidgeting, sniffing, blinking and are difficult to put to bed.

<u>Hypoactive left frontal cortex</u>: With adults, an inequality in frontal lobes, with the left being less active than the right may be found in association with frequent episodes of depression. This condition can be related to their problems as children with attention and focus, such problems result from the lack of interest and motivation associated early predisposition of depression. The left frontal cortex is an important executive site in the brain. Inhibition, rational thinking, and management of communication with other brain location are all directed by left frontal cortex. They may have impulse control problems, may act without thinking and anger control problem, and may have problems with writing down or reciting previously learned information.

<u>*High right frontal alpha :*</u> When alpha waves are stronger on the right relative to the left frontal cortex, confrontational and defiant behaviour often results. When difference is greater than 20 percent, the child has difficulties in appropriate aggression, defiance and negativity.

<u>Frontal lobe imbalances and learning disorders</u>: Disparities in frontal- cortex arousal are also found in children with learning disabilities. Common form with various form of dyslexia, disorders in writing and problems in processing information. The imbalances are associated with the way various brain sites interact. In this case usual rapid and efficient transfer of information from site to site does not occur. Children frequently facing learning challenges may become disinterested in or actively avoid difficult school activities. This avoidance may look like ADHD because the child is inattentive, easily distracted and disruptive of class room activities.

<u>Anterior cingulate gyrus</u>: The cingulated gyrus lies beneath the upper layers of cerebral cortex and runs from front to back of the brain. The anterior portion of cingulated gyrus is associated with obsessive compulsive behaviour, intellectual openness and cognitive flexibility. When this section of the brain is hyperactive, the sufferer can show cognitive and behavioural rigidity. Fixed attitudes, obsessive compulsiveness, stubbornness and inability to accept another point of view of others usually found with other brain irregularities, a hyperactive anterior cingulated gyrus causes attention problems resulting from stubbornness, cognitive inflexibility, and repetitive thoughts. Hyperactiveness is indicated by an elevated ratio of amplitudes of 28 to 40 Hz/16 to25 Hz. At the other end, children with slow ratios, indicating low arousal of this gyrus, tend to exhibit excessive passivity. Depending on EEG patterns, protocols are set and subjects are trained accordingly. EEG evaluations assists in understanding if there are abnormalities in brain function that EEG neurofeedback helps in treating as it allows us to individualize neurofeedback to the unique problems of each client. The downsides of the treatment include the long time period required, i.e., at least 40 sessions. Also, each session is fairly expensive.

In India this is a relatively new treatment and there is a dearth of research in this area. Present study is an attempt to see the efficacy of neurofeedback along with counselling and behaviour therapies in the treatment of ADHD so that an effective intervention programme can be developed for ADHD children.

## **Animal Assisted Therapy:**

Animal-assisted Interventions (AAI) involves the use of animals as a form of treatment with a focus on the enhancement of human physical, social, emotional and cognitive functioning. The three terms - animal assisted therapy (AAT), animal assisted activities (AAA) and animal assisted interventions (AAI) are often interchangeably used, along with other terms and with different connotations. In an attempt to promote the standardization of terminology, the Delta Society, one of the largest and leading organizations in animal assisted therapy, distinguishes between animal assisted activities (AAA) and animal assisted therapy(AAT) as two closely related yet fairly distinct branches within the ambit of animal assisted interventions (AAI). According to the Delta Society, Animal-assisted activities (AAA) provide opportunities for motivational, educational, and/or recreational benefits in order to enhance quality of life of humans and are delivered in a variety of environments by specially trained professionals, and/or volunteers in association with animals that meet specific criteria of safety. Animal-assisted therapy (AAT) involves the use of animals as a form of treatment with a focus on the enhancement of human physical, social, emotional and cognitive functioning. Further it occurs within a structured and formal framework, with trained animals and professionals with specialized expertise, specified goals and objectives for planned sessions with individuals, and measured progress in terms of a continuous documentation and evaluation of the treatment process. (Kruger, Tratchenber & Serpell, 2004; Jackson, 2012).

We are in the early stages of using both animal assisted activities and animal assisted therapy as a non-conventional treatment modality for children with developmental disabilities including Down's syndrome and Autism. The animal assisted therapy used comprises of canine therapy (breed used-golden retriever) and seeks to provide a multisensory system for enhancing cognitive, behavioral and emotional responsiveness and controlling the behavioral and psychological symptoms of developmental disability and delay. We are currently in the process of training a four month old *female golden retriever* named *Diana*, for providing animal assisted therapy to an identified group of developmentally disabled children and are also seeking an assessment of the individual efficacy of AAT as also its efficacy in combination and in comparison with other therapeutic modalities such as counseling, CBT and snoezelen.

We plan to analyze the possibilities for a large scale use of AAT in the Indian context, with a systematic understanding of the possible culture and situation specific challenges that may arise. We are also looking at the possibility of training Indian dogs (mongrels) as therapy dogs, a success in which would make AAI an extremely cost effective therapy as Indian dogs are available in plenty, are extremely loyal, affectionate and fairly trainable, have a longer lifespan, are more suited to the climatic conditions and are easier to care for. Success in our current endeavors would definitely lead to a greater awareness regarding this nonconventional therapeutic system in the Indian setting and permit and expansion of the use of AAT to other populations such as the geriatric populace suffering from senile dementia and Alzheimer, children with ADHD as also within the regular counseling set-up.

#### Yoga:

Yoga is an alternative mode of therapy native to India that shows promise as an intervention for a variety of social, emotional, behavioural and academic difficulties (Nardo and Reynolds, 2002). Breathing is deeply connected to emotions and yogic breathing is one of the best ways working with children with ADHD. Currently we are using the Yogic Technique of Anuloma Viloma or Alternate Nostril Breathing Technique as an intervention technique for children with ADHD with extremely encouraging results. In this technique, the person inhales through one nostril, retain the breath, and exhales through the other nostril usually in the ratio of 2:8:4. A practice of Anuloma Viloma is directed towards restoring the disturbed natural rhythm of breathing in the person and equalizing and balancing the flow of Prana in the body. The practice of Anuloma Viloma is based in the principle of the nasal cycle or the fact that we do not breathe equally through both our nostrils and at any particular time it is easier to breathe through one nostril rather than through the other. It has now been widely accepted and ratified that brain functioning also corresponds with the nasal cycle and activity in the side of the brain opposite to the congested nostril is comparatively less.

The regular practice of the Anuloma Viloma produces optimal functioning in both sides of the brain resulting in higher levels of creativity, logical thinking and verbal activity. Anuloma Viloma is of particular benefit to children with ADHD because it helps to calm the mind, results in the development of greater body awareness, increases emotional balance and concentration and thereby also increases the child's capacity to engage in academic activities, school work, and other extra-curricular activities and games.

## **Behavior Modification:**

Behavior therapy work with its singular focus on external observable behavior is based on the assumption that behavior can be modified as desired (adaptive behaviors taught and maladaptive behaviors eliminated) through a system of reinforcements and punishments. Behavior modification techniques are extensively used as part of the counseling and therapeutic procedures for clients with MR (particularly mild to moderate MR) and other developmental disabilities. The techniques used by us mainly focus on operant conditioning principles and can be basically classified into token economy, contingency management and modeling and are mostly directed towards the development of basic self-care (brushing, bed-making, bathing and toilet training, basic vocational skills etc. ) and social skills (conversational skills, assertiveness training etc.) and the elimination of maladaptive behavior patterns.

The system of therapy used involves a behavioral assessment of the clients through observations, role playing, the use of structured questionnaires when required and self-monitoring when possible. The therapeutic process further involves identifying valued reinforcers and applying them systematically in the token economy or contingency systems for gaining desired behavioral outcomes, helping clients to obtain and increase the scale of reinforcement, use of time outs and response costs as outcomes of undesirable behavior and teaching behavioral self-regulation through self-reinforcement and self-punishment to an extent possible depending upon the level of

developmental disability. We also extensively behavior modeling for teaching various daily life and social skills wherein the therapist or family members of the client act as models for the behavior to be learnt. An important challenge in the use of all the above behavioral therapies involves enlisting the active and diligent support of family members through the course of the therapy for ensuring a proper supervision and regulation of the client's behavior in the familial setting.

## **Cognitive Behavior therapy:**

Another therapeutic technique that is frequently used is the Cognitive behavior therapy and has been extremely useful in dealing with clients with mild MR and less severe developmental disabilities and particularly with parents, caregivers and significant others of children and adults with mild to severe MR and developmental disabilities. CBT is especially helpful in dealing with feelings of depression, anxiety and hopelessness in the clients due to the failures that they experience in adjusting with normal life settings and challenges. It is also particularly useful in dealing with depressed and anxious caregivers and family members who find it difficult to accept the reality of a family member with MR or developmental disability or are stressed out in the process of care giving. It is often used alone or in combination with other therapeutic modalities such as yoga, meditation or animal assisted interventions.

Particular CBT techniques that are frequently used as part of the counseling and therapeutic process include talking therapy (with cognitive interventions such as disputing and humor), cognitive self-instruction, REBT techniques such as cognitive homework (use of self-help books, reminder cards, referenting, insight and visualizing), problem solving, forceful disputing (both therapist on clients and clients on themselves), role playing and role reversals. We also try to organize group sessions for caregivers and families of children with MR and developmental disabilities to meet each other and they are encouraged to perform REBT techniques on each other, as also on other family members, relatives or friends whom they feel are suffering from emotional difficulties so as to give them a greater sense of personal control and efficacy.

# **Family Therapy:**

Family therapy is another therapeutic mechanism that is provided for parents, caregivers and other family members of clients with MR and other developmental disabilities. The therapy

provided aims at understanding the specific frictions, strains and stresses in familial relationships that are caused by the presence of a member with disability and which in turn also affect the latter. Issues dealt with in family therapy include among others improving the quality of marital relationships and reducing marital conflicts, sibling rivalry and animosity, feelings of neglect among other family members especially siblings due to the extra attention devoted to the MR child, physical, emotional and financial stress, strain and burnout experienced by caregivers and family. Efforts are made to help families view themselves as an interdependent and resilient unit which can navigate successfully through chronic stress by sticking together and seeking help from extended family and friends, which in a view involves a revival of the values of the joint family set-up that has existed in India since centuries. The need for providing continuous and quality support to the developmentally disabled member is another area of emphasis in family counseling.

Therapeutic formats include couple therapy, therapy involving immediate family members, therapy involving extended family and close friends, which are used in different combinations and for durations that are most suited for the type of problems manifested. Efforts are also made to attach families to support groups (a very few are available) and to provide regular follow-up and assistance whenever required even after the formal course of counseling and therapy has ended.

Another facet of the family therapy provided involves marital and family therapy to clients with mild and moderate MR and developmental disabilities who seek to get married and also to their parents. Counseling and therapy in this context involves clarifying myths and erroneous notions regarding the concept of marriage among people with intellectual disabilities, counseling the couple and their family regarding various aspects of marital relationships, possible personal and social problems that may emerge, and the ways to tackle the same, the need for continued therapeutic guidance and assistance, genetic counseling and other aspects in case the couple intend to have children and other related issues. Although awareness regarding marital problems among the mentally disabled was very limited, there has been a lot of interest in this and related issues in recent times and many couples and families are seeking information and counseling in these areas which is extremely encouraging.

## **Social Skills Training:**

Another area of therapy engaged in, is the provision of training in social and communication skills. Social skills training is provided in the broad areas of basic survival skills such as social interaction and appropriate work habits, problem solving skills including thinking strategies to prevent social problems or escape social discomfort, conflict resolution skills for dealing with highly emotional situations, and resolving existing intrapersonal and interpersonal conflicts and communication skills.

The teaching of basic survival includes among others, training in acknowledging other persons, listening attentively and responding appropriately, identification of feelings and interpersonal perspective taking, accurate and continuous self-evaluation of behavior, maintain attention to tasks, seeking assistance when needed, complying with directions, understanding social conventions, engaging in self-reinforcement when successful and accepting and learning from consequences related to actions.

Interpersonal skills' training involves a focus on activities that are essential for initiating and sustaining social relationships. Training in interpersonal and communication skills focuses on teaching and modeling simple tasks and principles such as sharing, asking for permission, joining in an activity, understanding the basics of non-verbal communication, contributing to discussions, methods of requesting, rejecting, ordering and protesting, answering questions, interrupting a busy person or conversation, waiting for one's turn or authority figure's attention, beginning/ending a conversation and giving/accepting compliments. Training for conflict resolution and problem solving includes social skills for dealing with frustrations, threats and negative peer pressure, feelings of fear and anger, skills for negotiating, assertiveness and apologizing, managing one's own emotions and understanding the emotions of others and understanding and accepting consequences for actions.

The social skills training provided firstly focuses on a baseline assessment of the social maturity and intellectual capacities of the person. A number of training approaches including modeling, role play with practice and feedback, role reversal, relaxation with deep breathing and guided imagery, assertiveness training through instruction, modeling, practice, anger management and problem solving techniques are used in different combination depending upon the necessities and capacities of the clients. Follow-up evaluations and counseling sessions are also undertaken.

## **Functional Academic and School Skills:**

Training for the development of functional academic and school skills for developmentally disabled children is provided to both children attending regular schools as also children attending special schools (where caregivers and teachers feel the need for additional specialized training). The content of the training modules is varied according to the needs and capacities of the individual child. General training for functional academic and school skills includes training for basic skills of reading/writing, money handling, time management, discipline and participation in extracurricular activities. Also focused upon are basic communication skills such as greeting and bidding farewell to teachers and friends, asking for attention/information, seeking help, requesting, sharing, co-operation and essentials of developing and sustaining friendships, assertiveness training, understanding concepts of non-verbal communication and various aspects of communication such as sarcasm and ridicule. Techniques used for imparting these skills include role playing, practice, instruction, behavior modification techniques, modeling and homework with an active collaboration of parents and teachers. Workshops, seminars and individual and group training programmes for teachers handling children with mental disabilities are also organized and participated in.

## Self-sufficiency skills:

Training for self-sufficiency skills is also provided and basically constitutes self-management and home living skills. These most commonly include training for activities such as the basics of preparing and eating food, dressing and grooming, basics of hygiene and toileting, safety and health, assisting and taking care of others managing money and the planning/scheduling and management of time. Techniques used for developing these skills include instruction and modeling, role playing, practice, behavior modification techniques such as token economy and contingency management which are frequently used and an active collaboration of parents and teachers through supervision and management of home and classroom behavior. Training in selfsufficiency skills may also involve individualized and group counseling and training sessions with parents, caregivers, teachers and significant others.

## **Multimodal Therapy:**

Many of the intervention mechanisms that we use often take the form of multimodal therapy as proposed by Arnold A. Lazarus. The intervention and therapeutic systems focus on identifying, assessing and targeting the BASIC ID modalities of behavior, affect, sensation, imagery, cognition, interpersonal and drugs/biology. This form of therapy has been extremely useful in dealing with clients with mild to moderate retardation as also with parents and caregivers.

## **Awareness Programmes:**

The single major problem in dealing with intellectual disabilities in the Indian context is the lack of popular awareness regarding what intellectual disabilities constitute, and the mechanisms for identifying, preventing and managing intellectual disabilities and the resultant stigmatization and marginalization. Hence, a major area of intervention that is engaged in involves the development and implementation as also participation in awareness programmes in rural and urban areas. Awareness programmes in rural areas constitute community meetings and programmes, rallies, dramatization, use of pamphlets, booklets and other literature and door to door campaigning especially among high risk populations. Awareness programmes in urban areas constitute conduction and participation in awareness meets, workshops, seminars, use of awareness literature, use of mass media and targeting of avenues such as hospitals, educational institutions and other public and private sector institutions as platforms for dissemination of information related to intellectual disabilities, childhood disorders and other mental health conditions.

The major challenge that we face with regard to therapeutic interventions for dealing with mental retardation and intellectual disabilities is the need for operating at various levels in terms of conducting primary level awareness programmes, engaging in established therapeutic practices and developing, testing and implementing new therapeutic domains. Although this is a challenging task we have achieved a fair degree of success in the process and are looking forward towards adapting newer therapeutic and counseling mechanisms into the Indian context and testing their individual and comparative efficacy with other existing therapeutic modalities.

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