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#### *Edited Books:*

Sarkar, S. (2005), Natural Resource Environment, Pollution and Women Health. In T. Sabanna (ed.). *WTO and the Agriculture*. Serials Publications, New Delhi.

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Head, School of Applied Economics Kannur University, Thalassery Campus  
Playad Post 670 661 (Keral), India, E-mail: drkgangadharan@gmail.com

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# Health Transition and Enhancement of Health Among Children with Mental Retardation

R. MADHUMATHI\* & K. ANURADHA\*\*

Health transition refers to the broad study of mortality transition involving interaction of cultural, social and behavioral factors with economic and medical factors to produce declines in morbidity and mortality. Health transition is the result of efforts to improve maternal and child health via primary care and outreach services and such efforts have been responsible for a decrease in the birth rate; reduced maternal mortality, improved preventive services; reduced infant mortality, and the increased life expectancy that define the transition.

The purpose of this article is to review the health transition taking place in the lives of children with Mental Retardation. This paper confines to various health problems of children with Mental Retardation who have Down's syndrome and Cerebral palsy, and how advancement of Medicines and other therapies including Early Intervention Programme help them to extend their lives and make them lead independent life. And it also dwells on the role of social worker in creating health awareness among parents of mentally challenged children.

Mental retardation is a term that was once commonly used to describe someone who learns and develops more slowly than other children. According to Persons with Disabilities Act (1995), Mental retardation means condition of arrested or incomplete development of mind of a person which is specially characterized by sub-normality of intelligence". Mental retardation in other words is also called as "intellectual disability" or "developmental delay." Such children have

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\* Principal, RASS College of Special Education, Rashtriya Seva Samithi. (RASS) Tirupati.  
([redim.madhumathi@gmail.com](mailto:redim.madhumathi@gmail.com))

\*\* Professor & Head, Department of Social work, SPMVV, Tirupati. ([komanduriradha@gmail.com](mailto:komanduriradha@gmail.com))

problems in learning and functioning in everyday life (adaptive functioning). Due to low intelligence level, a child with mental retardation has limited capacity to understand, learn, think, reason, judge and discriminate.

Mental retardation affects about 1-3% of the population. There are many causes of mental retardation, but doctors find a specific reason in only 25% of cases. Children with mental retardation are usually classified as profound, severe, moderate and mild, as assessed by the individual's need for supports, which may be lifelong. (Subodh Kumar 2007).

Literature also points out that (Barrof, G.S. 1986, Fraser, W. I., 1991 and Narayan Chandra pati 2006) Mental Retardation is caused due to brain injury or infections during prenatal, natal, neonatal and postnatal stages, Abnormalities of chromosomes and genes, growth and nutrition problems, poor diet and health care, drugs during pregnancy (alcohol and smoking), exposure to radiation during pregnancy, severe jaundice in early childhood, lack oxygen to the brain etc. are also the possible etiological factors .

### HEALTH TRANSITION IN DOWN SYNDROME CHILDREN

Down's syndrome, described by Dr. John Langdon Down (1866), is a genetic disorder that causes lifelong mental retardation, developmental delays and other problems, occurring in 1.3 out of every thousand live births. (Sunder, S. 2010, Verma, C. 2000). The cause for Down syndrome is a chromosomal abnormality called Trisomy 21. Increased understanding of Down syndrome and early interventions make a big difference in the lives of both children and adults with Down syndrome.

Some of the clinical features of Down Syndrome are skull is small and round with small ears, flattened facial features, protruding tongue, upward slanting eyes. Children with Down syndrome also have poor muscle tone, broad, short hands with a single crease in the palm, relatively short fingers, and excessive flexibility.

### LIFE EXPECTANCY

Life spans have increased dramatically for people with Down syndrome. In 1929, a baby born with Down syndrome often didn't live to age 10. Today, someone with Down syndrome can expect to live to 50 and beyond, depending on the severity of his or her health problems. Life span continues to increase because of early interventions and better care.

Children with Down Syndrome have variety of complications, including Heart defects, Leukemia, Infectious diseases like pneumonia,

Dementia, sleep apnea, Obesity, gastrointestinal blockage, thyroid problems, hearing loss, skeletal problems and poor vision and type 1 diabetes. (Pirgon, O. *et al.* 2009) and adults with Down Syndrome may displays maladaptive behaviors due to dementia ( Huxley, A. *et al.* 2005; Uru, T. K. *et al.* 2008).

There are various lines of treatment based on the severity of the condition. They are as follows:

### TREATMENT FOR HEART DEFECTS-VENTRICULAR SEPTAL DEFECT (VSD)

A ventricular septal defect (VSD), also called a hole in the heart, is a common heart defect that's present at birth (congenital).

A baby with a small ventricular septal defect may have no problems. A baby with a larger ventricular septal defect or associated heart defects may have a telltale bluish tint to the skin — due to oxygen-poor blood — often most visible in the lips and fingernails. Fortunately, ventricular septal defect is readily treatable. Many people with ventricular septal defects have normal, productive lives with few related problems.

Other common congenital heart problems include:

- Tetralogy of Fallot,
- Persistent ductus arteriosus,
- Atrial septal defect V.

If the heart defects have been identified before the onset of pulmonary hypertension, surgery has provided favorable results.

### DRUGS FOR LEUKEMIA

Leukemia is one of the malignant diseases. Generally medicines like:

- Prednisolone,
- Vincristine,
- Daunorubicin,
- Cytosine arabinoside and
- L-asparaginase are used. (Ghai O. P. *et al.* 2009)

### DRUGS FOR PNEUMONIA

Due lack of resistance power, Down syndrome children are more susceptible to pneumonia, it can be treated by

- pencillin G,
- chloramphenicol

- cefotaxime,
- III generation cephalosporin.

### DRUGS FOR THYROID PROBLEMS

There are two types of thyroid problems which occur. They are Hypothyroidism and Hyperthyroidism.

For Hypothyroidism, the used drug is

- thyroxine

For hyperthyroidism

- propylthiouracil,
- Beta-blockers,
- lugol's iodine.

### SURGERY FOR SKELETAL PROBLEMS

Depending on the severity of the problem, orthopedic doctors can take decision on skeletal problems of Down syndrome children and can be corrected by surgery.

### TREATMENT FOR POOR VISION

Due to cataracts approximately 3 per cent of children with Down syndrome are suffering with poor vision.. Cataracts can generally be removed surgically.

### TREATMENT FOR OBESITY

- *Dietary measures:* Mild caloric restriction and alteration in dietary habits. Intake of 1200-1800 calories depending upon age of the individual with 30-40% Restriction is recommended.
- Reduction in consumption of junk foods, carbonated drinks and saturated fat along with an increase in fiber, fruits and vegetables intake are helpful.
- Increase physical activity like swimming, running, playing outdoor games should be encouraged.
- *Drugs*
- Anti obesity drugs like orlistat (gastric lipase inhibitor) in severe obesity cases.
- Sibutramine (neurotransmitter modulator).
- Metformin (Children with insulin resistance).

- Surgery last resort for morbid obesity. Laparoscopic gastric banding is directed at reducing gastric capacity, which results in reduced appetite and weight loss, if sustained for a period of 1 year. Experience with obesity surgery in children is limited.

### TREATMENT FOR RESPIRATORY INFECTIONS

Children who have cough due to occult asthma because of retained tracheobronchial secretions. Mucociliary transport of secretions is helped by the beta-adrenergic agonists and the xanthine group of drugs both in the asthmatic as well as non-asthmatic children with chronic bronchitis.

Physio therapy treatments like chest clapping, vibrations and postural drainage are useful in facilitating removal of bronchial secretions. (Anthony S. Fauci, 2008).

### REMEDIES FOR HEARING LOSS

Hearing loss can be assessed by Audiologist. Depending on the severity level, appropriate hearing aid will be used and it follows auditory training and speech therapy.

### THERAPIES TO IMPROVE MUSCLE STRENGTHENING

Physiotherapy for strengthening of muscles and increased muscular activities. Studies reveal that some exercises like tread mill training Intervention improves physical activity in infants with Down syndrome (Angulo-Barroso, R. *et al.*, 2008).

Apart with these, there is need to prevent or correct the condition of Down syndrome at prenatal period. The several screening tests to diagnosis Down syndrome at prenatal period are

- First trimester-Ultra sound test and blood test to measure PAPP-A (Pregnancy Associated Plasma Protein-A).
- Second trimester-done 15 to 20 weeks of pregnancy. Measure blood level of alpha, fetoprotein, estriol, Hormone Chorionic Gonadotroin (HCG).
- Amniocentesis.
- Chorionic Villus Sampling (CVS).
- Percutaneous Umbilical Blood Sampling (PUBS).

Each of these three tests is 98 to 99 per cent accurate in diagnosing Down syndrome before birth. (Siegfried M. Pueschel *et. al.*, 1995).



## DIAGNOSTIC TESTS FOR NEWBORNS

The initial diagnosis of Down syndrome, after birth is often based on the baby's appearance. If the child displays some or all of the characteristics of Down syndrome, doctor may order a test called a chromosomal karyotype. This test is an analysis of child's chromosomes. If there is an extra chromosome 21 present in all or some of the cells, the diagnosis is Down syndrome. Genetic counseling to the parents gives information about disorders with a genetic component and explain the risk estimation and follow up. This will help the parents to understand the situation and regain their strengths. (Sunder, S. 2010). In few cases, Down Syndrome children may display more autistic tendencies like stereotyped patterns of behaviors, interests and activities. It is important for professionals to consider the dual diagnosis which will entitle the child to a more specialized and effective educational and intervention services. (Ghosh, M. *et al.* 2008). Team of professionals including pediatric cardiologist, gastroenterologist, Endocrinologist, pediatrician, audiologist, physical therapist, speech pathologist, Special educator, and occupational therapist must involve in diagnosis process. They help in providing appropriate medical care and help the child to develop skills as fully as possible.

New technologies like Magnetic Resonance imaging (M.R.I) and Computed Tomographic Imaging (C.T.) scanning helps to identify congenital heart diseases. These two are modalities of choice for the evaluation of disease. (Anthony S. Fauci, *et al.*, 2008). Strategies to reduce inequalities in people with Intellectual disabilities (I.D) need to focus on decreasing mortality from potentially preventable causes, such as respiratory infections, circulatory system diseases and accidental deaths. In the study of Tyrer, F. & McGrother, C (2009). On cause-specific mortality and death certificate reporting in adults with moderate to profound Intellectual Disability (ID) in England reveals the importance of effective record linkage and ID reporting in health and social care setting to facilitate the government's confidential inquiry into causes of death in this population. In India also there is a need to maintain a record for cause of death of mentally challenged people. So that the Scientists and Medical practitioners can have a look to prevent the causes.

## HEALTH TRANSITION IN CHILDREN WITH CEREBRAL PALSY

Cerebral palsy (C.P) is the commonly used term for a group of conditions characterized by motor dysfunction due to non-progressive brain damage to the developing brain. (Sundar, S. 2010).

Cerebral = "of the brain", palsy = "Lack of muscle control".

Symptoms of Cerebral palsy are lethargy, or lack of alertness, irritability or fussiness, abnormal, high – pitched cry, trembling of the arms and leg, poor feeding abilities secondary to problems of sucking and swallowing, low muscle tone, abnormal posture, such as the child favoring one side of their body, seizures, starting spells, eye fluttering, body twitching, abnormal reflexes etc.

*There are different types of cerebral palsy:* Spastic, athetoid or hypotonic, Ataxic and mixed type. The most common type of CP is spastic.

A child with spastic CP hyper tonicity the muscles may be stiff and exaggerated reflexes (spasticity); walking with one foot or leg dragging; walking on the toes, "scissored" gait; and muscle tone that is either too stiff or too floppy.

Athetoid CP affects the child's ability to control the muscles of the body. They have uncontrolled involuntary movements.

A child with ataxic CP has problems with balance and coordination. Stability of the head on the trunk and the body on the pelvis is poor.

Based on number of limbs affected C.P. can be classified as monoplegia (one limb affected), diplegia (two upper limbs affected), Paraplegia (two lower limbs affected) Triplegia (three limbs affected) Quadriplegia (four limbs affected), Hemiplegia (one side of the body affected) (Narayana Chandra pati, 2006).

- Cerebral palsy can be caused due to various reasons. There may be various reasons that lead to C.P. Some of the causes are maternal viral infections such as TORCH infections (Toxoplasmosis, Rubella, Cytomegalovirus varicella, or Herpes simplex), Metabolic disorders, RH incompatibility, (prenatal causes), Asphyxia, anoxia, trauma to head during labour, Uterine hemorrhage, Forceps application, prematurity, Eclampsia etc. (natal causes), trauma to head, meningitis, encephalitis, tuberculosis, malignancy and Hydrocephalus (postnatal causes).

Some of the complications of children with C.P .are limited communication skills (few cases), limited intelligence (few cases), drooling, poor nutrition, osteoporosis, joint contractures, hip dislocation and arthritis in the hip joint, accidents (falls), pneumonia and scoliosis. Literature reveals few children with C.P. have epilepsy. In the study of Carlson, M. *et. al.* (2003), it was found that the frequency

of epilepsy was found to be 38% (55 out of 146 children). All children with tetraplegic CP and about one-third of the children with other CP types developed epilepsy. Age at onset of epilepsy varies with type of CP; children with tetraplegic CP tended to have an earlier onset of epilepsy than children with other types. Partial seizures were the most common seizure type; all children with hemiplegic CP had partial seizures. Children with cognitive or intellectual impairment had a higher frequency of epilepsy than those without cognitive impairment. CP aetiology may predict the development and outcome of epilepsy, as children with CP caused by CNS malformation, CNS infection and grey matter damage all showed a higher frequency of epilepsy than children becoming seizure-free. Similar results were found in the study of *Anejas et. al.* (2001). Blood tests, CT scan of the head, Electroencephalogram (EEG), Hearing screen will help in diagnosis of CP child.

#### TREATMENT

There is no cure for cerebral palsy. The goal of treatment is to help the person be as independent as possible.

*Treatment requires a team approach, including:* Primary care doctor, Dentist (dental check-ups are recommended around every 6 months), social worker, Nurses, Occupational, physical, and speech therapists, neurologist, rehabilitation physician, pulmonologist and gastroenterologist.

Treatment is based on the person's symptoms and the need to prevent complications.

#### TREATMENT FOR BONE THINNING OR OSTEOPOROSIS

Doctors suggested taking supplements like calcium tablets, Vitamin D, Phosphorus, magnesium, vitamin K, Zinc etc.

#### TREATMENT FOR BOWEL OBSTRUCTION

Doctors suggested to take good diet, drink enough water, and do not postpone eliminating bowl.

*Hip dislocation and Arthritis and accidents and falls:* Surgery is recommended, and suggested to control weight.

#### POOR NUTRITION

Depending on the cause of malnutrition, treatment is given by doctors. Some general symptoms are fatigue, dizziness and weight loss.

The treatment usually consists of replacing missing nutrients, treating symptoms as needed and treating any underlying medical

condition. Suggested for liquid vitamins, Mineral supplements, omega 3 fatty acids and vitamin supplements.

## SCOLIOSIS

Treatment depends on the cause of the scoliosis, the size and location of the curve, and how much more growing the patient is expected to do. Bracing is usually recommended to help slow the progression of the curve. There are many different kinds of braces used.

## TREATMENT FOR EPILEPSY/CONVULSIONS

Medications may include Anticonvulsion drugs to prevent or reduce the frequency of seizures. They are

- Diazepam, Lorazepam, Midazolam, Valproic acid, Paraldehyde, Phenytoin, Fosphenytoin, Phenobarbitone, Pentobarbital, Propofol, and Lignocaine.

Prompt administration of drugs helps to prevent or reduce and cure convulsions. Depending on the type, cause and frequency of seizure, doctors prescribe medicines. It is recommended to use drugs with the advice of efficient medical practitioners.

- Scopolamine and botulinum toxin reduce drooling (Salivary flow) (Vanderburg, J.J.W. *et al.* 2006; Yam, W.K.L. *et al.* 2006).
- Muscle relaxants (baclofen) are used to reduce tremors and spasticity.

*Surgery* may be needed in some cases to:

Control gastroesophageal reflux

- Cut certain nerves from the spinal cord to help with pain and spasticity
- Place feeding tubes
- Release joint contractures
- Along with the Medication, Parents have to play very important role in taking care of the needs of children with intellectual impairment. Studies reveal that individuals with Intellectual Disability (ID) perceive themselves as less central in their own family. (Widmer, E. D. *et al.* 2008). It is the responsibility of the family members to ensure that child is getting enough food and nutrition, keeping the home safe, performing exercise recommended by the health care providers, practicing proper bowel care (stool softeners, fluids, fiber, and regular bowel habits), protecting the joints from injury. Otherwise health affected, it plays

an impact on functional ability of the child. In the study of Henderson, C. M. *et. al.*, (2009) it was found that functional impairment severity is associated with health status among older persons with intellectual disability and cerebral palsy.

Parents must cooperate with the Interdisciplinary team which makes the child to improve in speech, language and communication and motor functioning.

Along with the above recommendations *Therapies* help children with C.P. to become independent in their lives. They are,

### **Speech Therapy**

Speech and language therapist helps to develop better control of the jaw and mouth muscles, which can improve speech and language skills and eating abilities and for those who cannot speak, for them create communication methods like sign language or using a communication board or how to use special equipment such as computer that talks to the children. Children who are able to talk may work with a speech therapist on making their speech clearer, or on building their language skills by learning new words, learning to speak in sentences, or improving their listening skills.

### **Physical Therapy**

Physical therapist specializes in improving the development of the large muscles of the body (gross motor skills), such as those in the legs, arms and abdomen. They may help children with C. P. learn to walk, use a wheelchair, stand by themselves, or go up and down stairs safely. Physical therapy will help avoid contractures, prevent musculoskeletal problems as well as helping the child to perform everyday activities.

### **Occupational Therapy**

Occupational therapist assists children with the skills needed for day-to-day life in school and at home, including eating, writing, and work skills. He is specialized in improving the development of small muscles of the body, such as the hands, feet, face, fingers and toes. He also helps in finding appropriate special equipment to make everyday jobs a little easier.

### **Sensory Integration Therapy**

This therapy helps to overcome problems in absorbing and processing sensory information. Therapies include stimulating touch sensations and pressures on different parts of the body. With the use of water,

Styrofoam chips, or textured toys. This therapy will also motivate children to learn sequences of movements.

### **Aquatic Physical Therapy**

When the child is in the water, he benefits from its buoyancy, support and gentle resistance. The therapist will work on individualized, measurable goals designed to improve flexibility, gait, relaxation, balance, coordination and other physical abilities.

### **Stem Cell Treatment for Cerebral Palsy**

Recently there has developed a comprehensive program for Cerebral Palsy patients combining both nerve stem cell activation and stimulation treatment, and stem cells injections. This combined treatment has so far proven itself to be the most effective means to achieving a high level of recovery.

### **Hyperbaric Oxygen Therapy**

Hyperbaric oxygen therapy is recently developed therapy, where the patient receives 60 to 90 minute long exposure to 100% oxygen at controlled pressure, which increases oxygen in blood and also in brain cells. HBOT is a way to maximize the recovery from the brain damage. It helps to recover brain cells.

Literature quoted that there are other therapies like Dolphin Therapy, Botox Injection – which increase range of motion, in children with Cerebral palsy, which are not much prominent use in India.

### **USING AN EXERCISE BALL**

- Use an exercise ball to increase flexibility, stretch and tone different muscles, as well as improve balance and posture.

### **USING A BALANCE BOARD**

According to a study published in the Developmental Medicine & Child Neurology (2003), balance training in children with cerebral palsy demonstrated an overall improvement in their ability to recover stability, indicating that balance board training may be an effective tool to use in treating patients with cerebral palsy.

### **YOGA**

Practicing yoga poses will not only help to loosen and stretch tight muscles, which is so often characteristic of children with cerebral palsy, but will also help to balance both sides of the body and improve core strength, which is necessary for good balance and posture.

## ORTHOTICS, CASTS AND SPLINTS

Most of children with CP will be prescribed orthotics, casts or splints to supplement their therapy programmes. These include mobility devices like with or without motorized wheel chair, walker, joystick; communication devices like book or poster with pictures that show things the child might want, or an alphabet board that the person can use to spell out their message. There are computers that are used as communication aids that actually talk for the child. Daily living aids like special grips and handles are used for eating (holding cups, bent spoons), and for writing (Insert pencil in the rubber ball, taping cloth/tape around the pen or pencil for grip).

By employing all of the above methods we can maximally improve functions such as sensibility, mobility, and language. Putting the child in regular schools is recommended, unless physical disabilities or mental development makes this impossible. Special education or schooling may help.

Hopefully, the family of the affected child will be able to approach their physician regarding these alternative treatments.

## CONCLUSIONS

With advancement of science and technology there is a tremendous change in the treatment procedures of children with mental retardation including children with Down syndrome and cerebral palsy. (Soot, A. *et. al.* 2008) All the treatment procedures and medicines and other intervention programme make children with mental retardation to be independent in their life skills and include them in mainstream society with quality of life. It is the responsibility of social worker to create awareness about various treatments like drugs and other therapies available. Encourage parents to involve in early intervention programme. Studies reveal that home-based rehearsal training improves memory span of the children with Down syndrome. (Conners, F.A. *et. al.* 2008). Most of the parents are unaware of curative treatment, chromosomal nature of the disorder and prenatal screening and testing options, (Girish, K. M. *et. al.* 2007). Social worker should have sound knowledge about preventive measures and various treatment procedures relating to Mental Retardation especially about Down Syndrome and Cerebral palsy and should be able to coordinate special care services, (Therapeutic services and genetic counseling), educational services (Inclusive as well as Special education), in and out of home care, family support and other public and private community services (Clinics/parent associations) that are important

to the overall health of the child/youth and family. Also help the parents to reveal their pent up emotions and feelings and make them think realistically, accept the condition of the child, and make them fulfill their role in and out of home and with therapeutic team. Prepare parents to celebrate for a small achievement of their child. With all these strategies social worker makes the parents lead satisfactory life along with their special kid.

(The authors consulted concerned specialists before preparing this article).

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