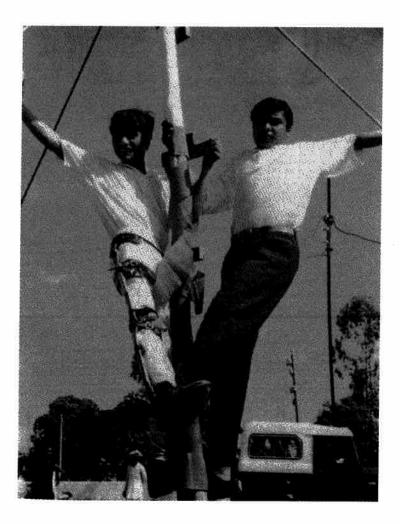
# Locomotor Impairment



# Acknowledgements

# Locomotor Impairment

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#### CHAPTER 26

# LOCOMOTOR IMPAIRMENT: PREVALENCE AND CAUSES

#### **INTRODUCTION**

Today, it is estimated, 1.6 per cent of the Indians—the figure comes to around 16 million in absolute terms—are inflicted with locomotor disabilities.

The very dawn of creation, perhaps, was accompanied by physical challanges. Advancement of human endeavour for the better only aggravated them. The first millennium bore witness to it, and all the millenniums yet to come may or may not prove any exception. And, at least in the coming millennium, physical disabilities cannot be wished away. Yet we can strive to minimise its impact through a concerted effort of us all—may we be medicos, technologists, administrators, public opinion makers, or just the commoners.

Theirs, as Konard Biesalashi stressed, is not the medical problem alone. The German orthopaedic surgeon's remark, made at the turn of the nineteenth century, held good for the next century and cannot be said will not for the next. For, the social overtones attached will remain so alive that any overlooking would be on the society's own peril. The silver lining in the cloud is the light Konard kindled. It has brought an awakening in the world to the problem. And the U N Decade of the Disabled People was a pointer.

Locomotor impairments, though need medical attention and in certain cases specialised ones, social problems that it poses need an integrated approach. For a locomotor patient, as the experience goes, the need of a medico is as much as that of a congenial surrounding, which cannot be provided in isolation. The society as a whole has to come forward to accept the challange of providing the physically challanged a wholesome ambience. No single section of the society can handle the problem on its own. It has to be an integrated approach in which the medicos, social scientists, engineers, administrators and a whole lot of others have to come together to come to grips with the challanages to the satisfaction of that section of the society which got a raw deal for far too long. They should not feel left alone.

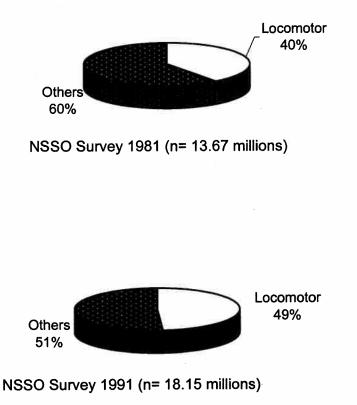
#### Impairment

An impairment is a permanent or transitory anatomical, physiological or psychological loss or abnormality. For instance, a missing limb, paralysis after polio, mental retardation and so on. Impairment may cause functional limitations which may be partial or total inabilities to perform those activities necessary for motor, sensory or mental functions within the range and manner of which a human being is normally capable of, say walking, seeing, hearing or speaking and so on.

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#### **Its Prevalence**

Something like ten per cent of the world's population is said to be suffering from one or other disability. In India the figure of people afflicted with one or more of disabilities such as locomotor, mental, visual or deafness is estimated to be around 100 million. No precise estimates are, however, available because of various definitions adopted during the different surveys. Besides, house to house survey becomes a gigantic problem in a country of India's dimensions. Even then there is an unanimity among the surveyors that the figure could run between five and ten percent. And roughly 10 percent of the disabled are the victims of one or more than one type of disability. Also, eight of every ten disabled persons live in rural India. The National Sample Survey of the Union Labour Ministry had put the percentage of disabled in 1991 at 1.9 percent and the largest number of them suffered locomotor disability. Their figure was estimated to be around nine million then compared to 5.4 million just a decade ago. It shows the number of locomotor disabled in absolute terms rose by mind-boggling figure of 3.6 million within the span of a decade. And of India's below 14 years old child population of 300 million in 1991, approximately three million were afflicted with locomotor disability-the most common cause of which, in the case of our country, is poliomyelitis. The second most common cause is Cerebal Palsy. The National Sample Survey in its 1991 report also estimated that 467 of 1000 person of 60 plus age as having locomotor dysfunction. It is anyone's guess that the number must have gone out of the roof by now.



#### Number of Physically Disabled Persons in India

# **LOCOMOTOR IMPAIRMENT - CAUSES**

A person's inability to execute distinctive activities associated with moving, both personally and objects, from place to place, and such inability resulting from afflictions of musculo-skelatol and, or nervous system, has been defined as the Locomotor Disability Locomotor disability can be classified as: congenital and acquired. The common causes of these two forms of affliction can be classified as: congenital and developmental. Common examples being : cerebral palsy, CTEV, meningocele, meningo myelocele, phocomelias, congenital dislocation of hip. Causes of the acquired disability can be put within the following jackets : Infective and Traumatic. The infective ones are: tuberculosis of spine or other joints, chronic osteomyelitis, septic arthritis, acute poliomyelitis, G.B. syndrome, leprosy, encephalitis, AIDS etc. Traumatic ones are: traffic accidents (air, water, road), domestic accidents, industrial accidents, agricultural accidents, fall from height, bullet injuries, explosions, violence, sports injuries, natural catastrophies like earthquakes, floods etc. Then there can be other causes as well, such as vascular. Common examples are: cerebro vascular disease, peripheral vascular disease, perthe's disease. Neoplastic conditions are yet another cause of locomotor disability. For example, brain tumors like astrocytoma, meningioma, spinal tumors like meningioma, astrocytoma, and osteo sarcoma etc.

Metabolism, as has been said earlier, too can be the villain. Common examples are: rickets, diabetes mellitus, gout etc. There can be degenerative causes too. Examples are: motor neuron disease, parkinson's disease, multiple sclerosis, osteo arthritis, spondylosis etc.

Among the miscellaneous causes can be muscular dystrophies, rheumatoid arthritis, systemic lupus erythematoses, lathyrism, ankylosing spondylitis, iatrogenic, and so on .

A brief numeration of common conditions causing Locomotor disability is given below:

#### **Poliomyelitis**

The number of polio disabled people in India is quite colossal. A 1994 World Health Organization (WHO) report on global situation on polio estimated that of the 10 million people affected with polio, approximately 60% live in India alone. The recent reports on India have, however, shown a decline in the number of cases, which is encouraging. Whereas over 20,000 cases of poliomyelitis were reported in 1986, the number came down to 3400 odd cases in 1995. The decline may be attributed to the National Immunisation Programme, and the recent introduction of Pulse Polio Programme, aimed at eradication of poliomyelitis. Poliomyelitis is an acute infective disease caused by the Poliovirus. There are three distinct serotypes of the virus, viz., 1, 2 and 3. Humans are the sole natural reservoir for poliovirus. Infection is transmitted by the oropharyngeal faecal circuit. Poliovirus enters the human body through the mouth and alimentary tract. The virus multiplies in the intestines. It then travels to the regional lymph nodes and reticulo endothelial structures.

Viremia may occur for a short period. As a result of this, type specific antibodies are produced in the blood and gut. If the immune response is adequate and fast, the virus

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is neutralized and illness does not occur. If conditions for spread of the virus are present, the virus involves the nervous system. Poliovirus selectively damages some special areas in the nervous system, the most commonly affected area being the anterior horn of the spinal cord. There is no sensory involvement.

Poliomyelitis occurs mostly in young children. It is uncommon in adolescents and adults. The clinical picture ranges from inapparent illness to extensive paralysis of the muscles, respiratory failure and even death. Either of the following manifestations may present :

#### **Asymptomatic Infection**

- Abortive poliomyelitis: Illness lasts for 1-4 days. Symptoms are fever, headache, sore-throat, nausea, vomiting, loss of appetite, vague abdominal pain. Neurological manifestation are absent.
- Aseptic meningitis like syndrome without paralysis: The symptoms are like those of abortive type. In addition, there is pain and stiffness of the back and legs. Neck rigidity is usually present and is necessary for diagnosis.
- **Paralytic poliomyelitis:** It is the least common of all. The manifestations are similar to non-paralytic type. In addition, there is weakness of one or more muscle groups. Distribution of paralysis is characteristically patchy. Depending on the site of involvement, it may be classified as follows :
- Spinal: There is weakness of muscles of the neck, abdomen, trunk diaphragm, thorax or extremities.
- **Bulbar:** There is weakness in the motor, distribution of one or more cranial nerves and may affect voice, breathing and swallowing.
- Bulbospinal: is combination of bulbar and spinal forms.
- **Encephalitic:** the child is irritable and may become disoriented and drowsy, tremors and convulsions may occur.

There are three stages of paralytic poliomyelitis—acute, convalescent and residual. Recovery may occur noticeably in the first six months of the illness, but after a period of two years, the paralysis does not show further recovery.

**Post polio syndrome:** Decades after recovering much of their muscle strength, survivors of paralytic polio experience unexpected fatigue, pain and weakness. The cause appear to be degeneration of motor neurons.

#### **Cerebral Palsy**

Incidence of cerebral palsy is quite alarming in India with various reports having indicated that 1.5 to 3.5 per thousand of all live births may be followed by the child developing cerebral palsy. Cerebral palsy is a "persistent disorder of movement and posture appearing early in life and due to a developmental non-progressive disorder of the brain." Cerebral palsy is not a disease, nor is it hereditary. Although the abnormality of movement and posture cannot be completely corrected, they may improve as the child's nervous system grows and matures. The causes of cerebral palsy frequently cannot be pin-pointed. They include developmental defects, hypoxia and hemorrhage, infection, toxin and poisons, trauma, isoimmunization reactions, defects of biochemical maturation and genetic defects. These factors can affect during pregnancy, during delivery or after birth. There are different types of cerebral palsy. Spastic type is most common and comprises 70% of all patients. Dyskinetic type is present in 10% of all patients, while mixed type (a combination of spastic and dyskinetic types) is present in 20% of all patients.

Based on the topographic distribution of neuromotor involvement, classification is also made as (a) quadriplegia (b) diplegia (c) paraplegia (d) hemiplegia (e) triplegia and (f) monoplegia.

Various problems frequently co-exist in cerebral palsy. Seizures occur in about half the children, more often in those with spastic hemiparesis or quadriparesis and rarely in those with pure dyskinetic form. Mental retardation is more common in children with microcephaly, seizures and spastic quadriparesis. It is rare in dyskinetic type. Mental retardation is mild in one-third of all children with cerebral palsy. Visual problems occur in about half the children with cerebral palsy. Most common problem is strabismus. Hearing problem occurs in 12% cases. Speech impairment is frequently associated with drooling and feeding problem. They are most commonly seen in children with spastic dyskinetic or dyskinetic cerebral palsy.

Attention deficits, easy distractiability, learning disabilities, emotional lability and behaviour problems are common in children with cerebral palsy. Other medical problems include failure to thrive, constipation, frequent colds, ear infection, wheezing etc. Common orthopaedic problems include joint contractures, hip dislocation and scoliosis.

# **Muscular Dystrophies**

The muscular dystrophies are a heterogeneous group of inherited disorders with gradual degeneration of the muscle fibres. There are three main types of muscular dystrophies. These are : pseudohypertrophic or duchenne type, fascio scapulo humeral type and limb girdle type.

The most common type is *Duchenne muscular dystrophy*. It occurs only in male children. Early development of the child is normal or slightly delayed. It starts with difficulty in walking, running and climbing stairs when the child is around 2 or 3 years of age. The child has difficulty in standing up from the recumbent position, and, classical "Gowers sign" may be present in moderately severe disease. Waddling gait is present. There is *hypertrophy* of calf muscles.

Weakness of shoulder girdle muscles occur subsequently. Eventually all the muscles atrophy and the child becomes severely incapacitated and bed-ridden.

Ambulation usually ceases by 12 to 14 years of age, and death occurs prior to age 20 years in 75% of cases due to intercurrent infection or associated cardiomyopathy. Intelligence is usually in the subnormal range.

*Fascio scapulohumeral* type affects both sexes. Age of onset is around puberty. There is weakness of facial and shoulder girdle muscles. Forceful eye closure and whistling are not possible. Progress of weakness is slow and is compatible with a normal life span.

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Limb-girdle muscular dystrophy may start to appear during childhood, adolescence or adulthood. Pelvic girdle muscles are most commonly affected. Course of illness is slower and moderately progressive.

#### Arthritis

The word 'arthritis' literally means joint inflammation. It is characterized by pain, swelling and limitation of joint movement. There are many types of arthritis, such as:

Osteo arthritis (OA): This is the most common type of arthritis. Osteo-arthritis is a degenerative joint disease. It is characterized by loss of joint cartilage and the formation of bony out growths at the edges of the affected joints. Usually one or two of the larger joints are affected. The joints most frequently involved are those of spine, hips and knees. The exact mechanism for loss of cartilage is not known but obesity and stress to the joint contributes to the damage. The likelihood of OA increases with advancing age.

It is estimated that nearly 75% of people over 60 years of age will experience symptoms of OA. Young people can also get osteoarthritis when the joint has been damaged by disease or injury or congenital deformity. OA may manifest as pain, stiffness, limited range of motion and swelling of the joint. Osteophyte or bone spur is the single most common feature of OA. Muscular wasting is always present to a greater or lesser extent. quality of life is affected by OA by limiting mobility and functioning.

*Rheumatoid Arthritis (RA):* It is far less common than osteo arthritis but potentially more serious. Rheumatoid Arthritis is a systemic disease. The common symptoms are joint pain, stiffness, fatigue, anorexia, weight loss and fever. Small joints in the hands and feet, wrists, ankles and knees are commonly affected, usually in a fairly symmetric pattern. Subcutaneous nodules may appear over pressure joints (for example, just distal to the elbow). Range of motion of joint is restricted and correctable in early cases. In later stages of the disease, severe restriction with contractures and fixed deformities occur. The disease may occur at all ages, but the usual onset is in the fourth decade. It affects women 3 times more than men. The exact cause is unknown, but it is thought to be the result of several factors, some of which may be genetically determined, while others may be of environmental origin that triggers an abnormal immune response. The disease may be self limiting or run a prolonged course; there are times when the disease is "quiet" and times when it flares up. During the "quiet" periods of remission, the symptoms of the disease disappear. The severity of RA varies widely, from minor pain and inflammation in the joints to life-threatening complications involving the internal organs.

#### Stroke

Stroke is characterized by sudden loss of motor control usually hemiplegia i.e. involvement of face, arm and leg of one side. It may be accompanied by unconsciousness, speech disturbance, visual and hearing loss, numbness, burning pain, sensory deficit and psychiatric disturbances. In mild cases of stroke, the manifestation is trivial and does not interfere with the activities of daily living. Stroke is the most common cause of severe disability in the aging population, only 28% of strokes occur in persons younger than 65 years of age. Precise figures on prevalence of stroke in India are not available. A 1981study by P. Dalal reported a prevalence rate of hemiplegia to be 56.9 per 100,000. Incidence of stroke is higher among men than women. Several risk factors have been identified. They include hypertension, diabetes mellitus, heart disease, smoking, excessive alcohol use, and sickle cell disease. The risk factors are found to be higher in some races (Blacks, Japanese).

The causes of stroke can be grossly classified as ischemia (deficiency of blood) or haemorrhage (due to rupture of blood vessel). Ischemic brain injury is the cause of stroke in 85% of cases and occurs due to occlusion of blood vessel from thrombosis or emboli. Thrombosis occurs most commonly in the presence of atherosclerotic cerebrovascular disease while cerebral emboli are usually of cardiac origin.

All body functions are represented in the brain, some in the left and some in the right hemisphere. Right sided functions like motor, sensory or visual fields have representation in the left hemisphere and left sided functions are represented in the right hemisphere. The nerve fibres, both motor and sensory, cross at different levels in the nervous system. The knowledge of the site where the fibres cross is important in localisation of the damaged area. The neurological deficit in stroke reaches its maximum within seconds, minutes, hours or a few days, depending on the nature of the lesion. Later in the course of the illness, if the attack is not fatal, stabilization occurs and is followed by improvement in varying degrees. This improvement gradually takes place over weeks or months.

#### Spinal Cord Injury

It is a traumatic insult to the spinal cord that can result in alteration of normal motor, sensory or autonomic functions. It can result in paraplegia i.e. involvement of lower extremities, or quadriplegia i.e. involvement of all extremities. The involvement may be complete or incomplete. The injury is termed incomplete when there is sparing of some sensation, or motor function, or both, distal to the injury. Common causes of spinal injuries are fall from height (root, tree, stairs), motor vehicle accidents, gun shot injury, stab wounds, sports injuries and iatrogenic injuries of cord following surgical procedures.

The incidence of spinal cord injury is 5-15 per million population. It is estimated that in our country there are 12000 fresh cases of paraplegia every year.

In general, spinal cord injury should be suspected in patients where there is a history of trauma, who have head injury with loss of consciousness, and in those who have multiple injuries following a motor vehicle accident. A fall from a height associated with tenderness over the spinal column or paraesthesia in the lower limbs should arouse suspicion. A gap or angular deformity may be palpated on careful examination. Gross paralysis may be present. Spinal cord injury is a devastating injury. Except in cases where substantial or complete recovery occurs, the person is confined to bed or wheelchair existence for the rest of his life. In addition, he may have inadequate or loss of control over his bowel and bladder functions adding to his incapacitation. The spinal cord injury patient is prone to develop pressure sores and urinary tract infection. At the same time, mental and emotional functions are affected. In our country, large number of spinal cord injury patients succumb to complications for want of appropriate treatment.

#### Amputation

Amputation implies the absence of all or part of the limb. Amputations are musculo skeletal problems of a special nature because the disability results not from a pathologic

condition, but from treatment that has eliminated the pathologic condition. It can also occur due to congenital skeletal deficiency and trauma. The causes of amputation may be broadly classified as congenital or acquired. Congenital skeletal deficiencies can be transverse or longitudinal. Transverse is defined as absence of all skeletal elements distal to the deficiency. It can further be described as total, upper one third, middle one third, distal one third.

Longitudinal deficiency is an absence extending parallel to the long arm of the limb. The deficiency may be partial or total. Probable causes of congenital skeletal deficiencies are hereditary abnormalities, teratogenic agents, excessive radiation etc.

The causes of acquired limb loss are : accidents, malignant tumors, death of tissue from peripheral vascular insufficiency of atherosclerosis and diabetes, death of tissue due to peripheral vasospastic diseases such as Buergers disease and Raynauds disease, thermal injuries both from heat and cold, long standing infections of bone and other tissues that leave no chance of restoration of function, uselessness of a deformed limb that is objectionable to the patient, neurogenic resorption. Global incidence of amputation is estimated at 30 per 100,000 population. Figures in India are not available. Traumatic amputation is the major cause followed by vascular diseases, infections, tumors, and congenital causes.

#### Cancer

Advances in early cancer detection and treatment are allowing more and more people to live longer. In India nearly 15 lacs cases are reported to be suffering from cancer, with 5 lacs new cases of cancer being reported every year. The National Cancer Registry Programme data shows that the most common cancers in males are those of oral cavity, lung, oesophagus and stomach; while in females, cervix, breast and oral cavity are the common sites. Cancer survivors suffer significant physical and psycho-social problems.

They suffer from a range of disabilities related to cancer and the treatment received. Neuromyopathies, pathological fracture, pain, gait problems are not uncommon resulting in significant problems in activities of daily living.

#### AIDS

The magnitude of the problem of AIDS is staggering. AIDS or Acquired Immuno-deficiency Syndrome is caused by Human Immuno-deficiency Virus or simply HIV. HIV disease is a progressive disease in which AIDS was first discovered in USA in 1981, its magnitude has increased over 100 fold. Studies in India in 1996 have reported an estimate of 1,750,000 cases with HIV infection and 2095 registered cases having AIDS. HIV infection primarily attacks the immune system, eventually rendering cell mediated immunity ineffective. This can lead to dysfunction in a number of organ systems.

The types of disability that result from HIV disease is virtually identical to that resulting from cancer. The common problems causing disability relate to immobility, central and peripheral nervous system involvement, myopathies, bony involvement, lymphoedema, pain and psycho-social illness.

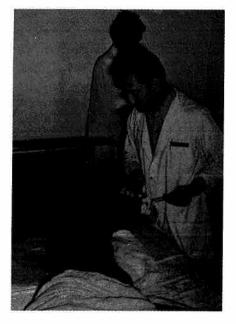
#### Hansen's Disease

Every third leprosy patient of the world is an Indian. Prevalence rate of leprosy is about 6.7 per 10,000 population in India. Hansen's disease, which is commonly known as leprosy is a chronic infectious disorder caused by Myco-bacterium eprae. It primarily affects skin, peripheral nerves and other organs e.g. eyes. The cardinal features of Hansen's disease are insensitive skin and paralysis due to involvement of peripheral nerves such as median, ulnar or lateral popliteal nerve. The above defects usually result in unsightly deformities and ulcers in the affected extremities. The common deformities seen are wrist drop, foot drop, claw hand etc. depending on the peripheral nerve involved. The number of cases of Hansen's disease with deformities is quite large in India, although there is a considerable drop in the number of active cases of Hansen's with the advent of multidrug therapy [MDT].

#### **Tuberculosis [TB] of Bones and Joints**

Tuberculous infection of bone occurs in vertebral bodies or in association with tuberculous infection of joints. It can also occur as an isolated lesion of a long bone or of a bone of the hand or foot. Tubercle bacilli reach the bone either through the blood strem or by direct extension from an adjacent focus in joint or soft tissue. The clinical picture depends on the site of the infection. There is usually evidence of constitutional ill health. Early symptoms include pain, spasm and limitation of movement. Tuberculosis of bones and joints usually results in locomotor disability because involvements of joints and causes loss of motion. In the spine, it may result in hunchback or paralysis of limbs, because of involvement of spinal cord. In India T.B. continues to rage wild. About 14 million people are estimated to be suffering from tuberculosis of which 3 to 3.5 million are highly infectious.

#### Lathyrism



Lathyrism is a crippling disease caused by consumption of the pulse lathyrus laturis [Kesari dal] is large quantities. Kesari dal is a cheap product and is used to adulterate other dals. The disease is prevalent mostly in parts of Madhya Pradesh, Uttar Pradesh, Bihar and Orissa. Lathyrism, mainly affects adult males between 15 to 45 years of age. The disease is characterised by gradually developing spastic paralysis of the lower limbs. In the early stages of the disease, the patient walks with a slight limp, but as the disease progresses, there is bending of knees with crossing of legs and tendency to walk on toes, and he requires assistance of stick for walking. In advanced cases, the patient is unable to walk and is reduced to crawling. The scourge of lathyrism can be eliminated only if cultivation of Kesari Dal that causes it is banned.

# CHAPTER 27 HISTORICAL PERSPECTIVES

#### **INTERNATIONAL PERSPECTIVE**

History records first ever attempt on prosthesis to the pre-Christianity era. It was a successful one. It was practised by a prisoner to escape death. And the death he did escape and even moved about but then, luck failed him and not the artificial limb.

Hegesistnatus, incarcerated and condemned to death in 484 BC, cut off his foot chained to a stock and vamoosed. And to be able to walk around after his wound healed, he crafted a wooden foot for himself. He put it on his footless leg and moved around. The Persian army even found him a good soothsayer. But then his luck ran out. The Spartans, from whom he had fled, spotted him. He was taken as a prisoner again and ultimately put to sword.

Herodotus has chronicled this piece of Greek tragedy as an essay in the annals of the medical history. One of the oldest prosthesis, dating back to the Sammitian war of 300 BC, still exists. It was found in Italy. The artificial limb, made of wood and reinforced with leather, iron and bronze, had been on display at the Royal College of surgeons in London.

Ironically, it took centuries for humanity to take cognizance of the disabled within itself. For the first time 'custodial care' homes for crippled children got established through a wave of humanitarinism that ripped through Europe in early 19<sup>th</sup> century. Even then the concept of 'rehabilitation' of the disabled people — to cater to the individual needs — remained conspicuous because of lack of such an awareness. It was given to a German Orthopaedic Surgeon, Dr.Konard Biesalashi, to arouse the public conscience towards the responsibility to the crippled children. It was sometime in 1906 that Konard Biesalshi spoke of the crippled children, not as a social problem alone, since, he emphasized, such children were also 'sick' and thus a 'medical' problem too. What his observation implied was that the medicos could not absolve themselves by taking care of the medical problem alone but had to play a key role in the adjustment of their such medical wards to the world around. For the German surgeon, a physician was not just to diagnose the problem and initiate subsequent medication. He or she was to act also as a guide and philosopher and not to the patient alone but to the society as a whole to make it to work for the welfare of the disabled children through legislation and otherwise.

And to give a concrete shape to his, then a revolutionary concept, Konard Biesalshi established the Oscar Helene Hein in Berlin in 1913 to reach to the problem in an integrated approach. The new institute was holistic from all aspects for the care of the crippled child. It was equipped with all the medical and surgical facilities, besides physi-

cal and occupational therapies, prosthetic and orthotic systems and educational and vocational training facilities to take care of a disabled child from infancy to adulthood. A child-patient, admitted as a disabled, came out as a skilled one to face the world at large on one's own terms instead of looking for sympathy.

An individual's effort shone like a lighthouse. It was truely an example to be followed for the care of locomotor disabled. The second world war, which left thousands of able adults disabled, came as a catastrophy which loomed large the world over. A crying demand rose for the institutes which could once again put the disabled people back on their feet. The German surgeon's institute showed the way. In Europe and North America a large number of comprehensive management centres flowered for the locomotor disabled. Thousands upon thousands of disabled military men and civilians, who would have been condemned to live on the sympathies of others were up and kicking, taking the world on their own terms.

Of course, with the passage of time and advancement of the medical sciences specialised rehabilitation centres started coming up which now cater to various, once considered impossible, problems such as spinal injury, stroke and cerebral palsy and so on. In the west, besides these specialized centres, the society as a whole has recognised the problems of its disabled section of the society to give it an effective social cover.

#### **DOMESTIC SCENE**

Mention is found in the ancient Indian literature about the treatment of disability. But the 'Atharva Veda', considered as the earliest treatise of the Indian medical system, is silent about the prosthesis. Use of cold and hot water, application of mud and various forms of poultice, sourced from various types of leaves, plants and trees, have been prescribed for the treatment. Artificial limb to substitute amputated leg or arm, or an eye to replace a blind eye, does not find any reference in the monograph of reverence.

However, the Indian history is full of anecdotes on the lives of physically disabled who were even used as court jesters, though there are two main schools of thought on such a practice. The one school of historians frown upon such a practice, taking it as a demeaning act of human dignity. The other school, however, looks at it with indulgence. They consider it as a kind of social security. In the regime of the Ashoka the Great, the state established charitable institutions to aid the disabled. Chandragupta Maurya, however, employed the physically disabled such as dwarfs and hunchbacks in his court as jesters. King Harsha too found employment for the disbled in his court. Employment of the disabled found encouragement in the days of the Mughals and the Rajput rulers. During the British regime, the christian missionaries established homes for the leprosy patients where they were treated as well as helped in rehabilitation. Sialkot, now in Pakistan, was the place where the composite India's first ever limb fitting centre got established during the Second World War. After the partition of the country, the Indian defence forces set up an artificial limb fitting centre at Pune in Maharashtra, mainly to cater to its own needs. Later on, civilian amputees too could look for prosthesis there.

In early 1950s, Professor Howard A. Rusk of New York University Medical Centre visited India on a lecture tour on the problem of disabled, and he spoke how medical profession could mitigate the sufferings of the disabled. One of his centres of focus was:

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rehabilitation. His lecturing did bring aid for the establishment of two rehabilitation centres – one in Delhi and the other in Madras, now renamed as Chennai. It was done with US aid, under PL - 480.

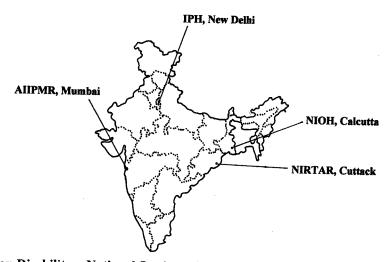
The Union Government too by then came alive to the situation. An All India Institute of Physical Medicine and Rehabilitation came up at Mumbai under the aegis of the Central Health Ministry. The Centre's main occupation is to provide rehabilitative services to the locomotor disabled. A number of non-governmental organisations too chipped in meanwhile to do something for the locomotor disabled persons who constitute a section in itself within the Indian society. Fellowship for the Handicapped, run by Ms Fatima Ismail, National Society for Education of the Handicapped, which comes readily to mind, has done pioneering work in Mumbai, where it is active. In other parts of the country too, such NGOs have come up. Ms Kamla Nimbkar's is perhaps one name that any one, even remotely connected with the problems of the disabled, cannot forget to recall. It is her yoeman's service in the training of occupational therapists in the country that will always stand her out.

#### **GLOBAL INITIATIVE**

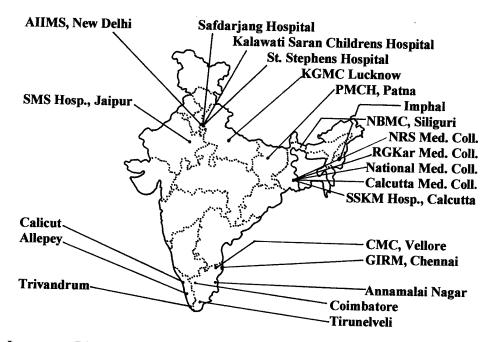
The problem of the disabled, especially the social part, no longer confines to any rigid borders. It has been acknowledged as the global problem which transcends colour, caste or any other barrier. The United Nations and its various arms have come out with fiscal and other contributions to exhort the developing countries to pay greater attention to the needs of the disabled by way of rehabilitation, besides the medical aid. The General Assembly of the world body declared the decade between 1983–1992 as the one of the disabled. Integration of the disabled with the mainsteam without any reservations, as an important need, is one of the foremost outcomes of the world body's efforts.

The Asian and Pacific Decade of Disabled Persons came at the termination of the UN Decade of Disabled Persons in 1992. 'Full participation and equality' of people with the disabled was the resolution of the Economic and Social Commission for Asia and Pacific. In India, the World Health Organisation, in association with the UNICEF and UNDP, launched "Impact – India" in 1983 to prevent disabilities in vulnerable areas. The World Health Organization (WHO) began promoting the concept now known as Community Based Rehabilitation or, simply, "CBR". The strategy is to develop awareness within the community for the rehabilitation, equalization of opportunities and social integration of the disabled. The CBR is implemented through the efforts of disabled people, their families and communities, and also through appropriate health, education, vocational and social services. The declaration of the year 1993 as the SAARC Year of the Disabled Persons at the World Summit on Social Development in Copenhagen was yet another vital global event.

In India, the Medical Council of India (MCI) sent a directive to all medical colleges to start a department of physical medicine and rehabilitation, so that the undergraduates are exposed to principles of rehabilitation medicine, besides setting up postgraduate training courses in this speciality. The teaching of rehabilitative medicine has been included in the curriculum of the undergraduate medical students too by the MCI. All India Institute of Medical Sciences, New Delhi, the Universities of Jaipur, Calcutta, Kerala have started MD course in Physical Medicine & Rehabilitation. National Board of Examination awards Diplomate in Physical Medicine and Rehabilitation. Diploma in physical medicine and rehabilitation training is being conducted at Safdarjang Hospital in New Delhi, Institute of Rehabilitation in Chennai, Christian Medical College in Vellore, Medical College in Triruvananthapuram. This has led to the training of a number of doctors in the speciality of physical medicine and rehabilitation which has led to the expansion of rehabilitation services for the locomotor disabled in India. Simultaneously, a number of institutions for physiotherapy, occupational therapy, social workers, vocational counsellors, clinical psychologists, prosthetists and orthotists came up and trained manpower in these areas increased to some extent.



Locomotor Disability - National Institutes/National Level Rehabilitation Institutes



Locomotor Disability - Rehabilitation Departments in Medical Colleges/Hospitals

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### **ROLE OF UNION MINISTRIES**

# Health and Family Welfare

The Ministry of Health and Family Welfare is responsible for the implemention of health programmes of national importance, including those for prevention and control of diseases, which form the main plank of development efforts and have an impact on the recurrence of morbidity and disability in the country. The Ministry has, through successive Five Year Plans and at the recommendations of various committees, set up a large health infrastructure at the primary, district and state/central levels, rendering preventive, promotive and curative services.

The National Health Policy approved by the Indian Parliament in 1983 commits the Union and State governments and the people to the cause of "Health For All". The policy laid stress on preventive, promotive, curative and rehabilitation aspects of health care and points to the need of establishing comprehensive primary health care services to reach the population in the remotest areas of the country.

Under the National Scheme of Medical Rehabilitation, conceived in the Sixth Five Year Plan, a pilot project of Rural Rehabilitation was undertaken by the Department of Rehabilitation, Safdarjang Hospital, New Delhi, to provide disability prevention and rehabilitation services in the rural sector. The Department of Rehabilitation of Safdarjang Hospital in New Delhi and the All India Institute of Physical Medicine and Rehabilitation in Mumbai were strengthened to meet the challenges in this field.

The National Institute of Mental Health and Neuro-Sciences of Bangalore was established in 1974 as an autonomous institution — as a joint venture of the Central Government and the Karnataka Government. It is the premier research and training centre in the field of mental health and neuro sciences. The three important activities are directed towards manpower development, patient care and research.

The National Board of Examinations, established by the Government of India in 1975, became an independent autonomous body of the Ministry of Health and Family Welfare in March, 1982. The Board holds examinations in February and August each year in 33 disciplines including physical medicine and rehabilitation. The Board's aim is to elevate the standards of postgraduate examinations in medical subjects. Candidates are awarded certificates as Diplomate of NBE in various broad and super specialities.

A pilot project on medical rehabilitation, under the auspicies of Mumbai's AIIPMR, was launched in November 1995, with an emphasis on provision of rehabilitation services through primary health care. The project was started in five districts each of Andhra Pradesh, Kerala, Madhya Pradesh, Maharashtra and Tamil Nadu. The main objective of the project was disability prevention and provision of basic rehabilitation services by training, re-orientation and equipping/strengthening Primary Health Centres.

# Social Justice and Empowerment

The Ministry of Social Welfare, rechristened as Ministry of Social Justice and Empowerment, was made the nodal ministry to provide rehabilitation services to the disabled in India. It has developed National Institutes in each area of disability, which are engaged in providing services, training of manpower, development of educational material and research activities. The institutions engaged in rehabilitation of the locomotor disabled are National Institute for Rehabilitation Training and Research (NIRTAR), Olatpur in Orissa, National Institute for Orthopaedically Handicapped (NIOH), Calcutta, Institute for the Physically Handicapped (IPH), New Delhi.

The National Institute of Rehabilitation Training and Research, originally known as NIPOT or National Institute of Prosthetics and Orthotics Training, was started in 1975. The main aims and objectives of the institute are: to promote the use of ALIMCO products; to undertake, sponsor or coordinate training for the rehabilitation personnel; to conduct, sponsor, coordinate or subsidise research on bio-medical engineering, surgical or medical procedures for orthopaedically handicapped; to promote, distribute, subsidise manufacture of prototype designed aids and appliances; to develop models of service delivery programmes for rehabilitation; to undertake vocational training, placement and rehabilitation of the physically handicapped, and to document and disseminate information on rehabilitation in India and abroad.

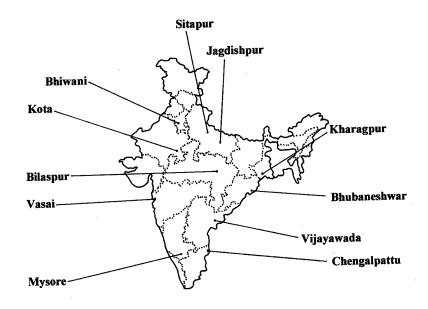
The National Institute for Orthopaedically Handicapped established in 1976 is the apex organisation in the country for the welfare of locomotor disabled. It is the premier institution for development of manpower, specialised research services, standardisation of aids and appliances, documentation and information, consultancy to the state government and non-government organisations.

The Artificial Limbs Manufacturing Corporation of India (ALIMCO), set up at Kanpur as a Government undertaking, mainly for social services and not for profits, started production in October 1976. Its objectives include: to establish facilities for manufacture of artifical limbs, accessories and constituents thereof and to promote, encourage and develop the availability, supply and distribution, at reasonable cost of artificial limbs, accessories and constituents thereof to needy persons including disabled personnel, hospitals and other welfare institutions.

The product range includes Orthotic (Calipers) and Prosthetic (Artificial Limbs), appliances for both upper and lower extremities, spinal braces, cervical collars, traction kits, rehabilitation aids like wheel chairs, crutches, three-wheelers and special tools and equipments required for fitment of prosthetic and orthotic assemblies by limb fitting centres.

The District Rehabilitation Centre (DRC) Scheme was initiated in 1985 by the Ministry of Welfare as a pilot study at 11 centres of 11 districts in 10 States in collaboration with the National Institute of Disability and Rehabilitation Research (NIDRR) and Department of Education and UNICEF. The services provided by these centres are [1] prevention and early detection, [2] Medical intervention and surgical correction, [3] Fitment of artificial aids and appliances, [4] therapeutic services such as Physiotherapy, Occupational Therapy and Speech Therapy, [5] Provision of training for acquisition of skills through vocational training and [6] Job placement in local industries.

National Information Centre on Disability and Rehabilitation came in 1987 to fill a colossal void of information on disability and related areas. The main objective was to provide comprehensive information which would be useful to a large cross-section of users, policy makers and planners for implementing programmes, researchers, practitioners working in the field of disability, govt. officials and decision makers, and above all for persons with disabilities.



**District Rehabilitation Centres** 

To sensitize intelligentsia, especially media, about various aspects of disability and for collating of various types of awareness materials produced in the country, a 'Media Cell' was set up. It is collating, screening and developing the media material, helping in production of new materials and working out modalities for its dissemination and publicity in the country.

Utilising latest technology for rehabilitation of the disabled, the Governement of India started in 1988 a S & T project in Mission Mode on Application of Technology for the welfare and rehabilitation of the handicapped with the Ministry of Welfare as a nodal agency. The aim of the project was to make available the benefits of science and technology to persons with disabilities quickly and with cost effectiveness.

The Institute for the Physically Handicapped, New Delhi conducts [1] B.Sc.(Hons) courses in Physical Therapy and Occupational Therapy, [2] Diploma in Prosthetic and Orthotic Engineering, [3] Workshop for the fabrication of Orthotic and Prosthetic appliances, [4] Physiotherapy, Occupational Therapy and Speech Therapy out-patient services, [5] Special Education School upto primary level for the orthopaedically handicapped children and [6] Vocational Rehabilitation of the Orthopedically Handicapped.

The National Handicapped Finance and Development Corporation (NHFDC) was incorporated on January 24, 1997 under section 25 of the companies Act, 1956, as a government undertaking. It functions as an apex financial institution for routing funds through the channelising agencies authorised by the State Governments/Union Territory administrations. The objective is: to promote economic developmental activities for the benefit of handicapped persons. It would provide loans to disabled persons whose annual income does not exceed Rs.60,000/- in urban areas and Rs.55,000/- in rural areas.

In the year 1995, a bill entitled "Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995" was passed by the Parliament, which came into effect from February 2, 1996. The act makes provision for: prevention and an early detection of disabilities, for free education to the disabled children; and expects appropriate governments to prepare a comprehensive education scheme providing for transport facilities, supply of books, etc. to the disabled children. It also aims at making schemes for ensuring employment of disabled persons with the stipulation of three per cent reservation of posts for them besides granting three per cent seat reservation of seats for disabled persons in all educational institutions, and provides for incentives to employers to ensure five percent of the work force is composed of disabled persons. It further stipulates affirmative action, such as provision of aids and appliances to disabled persons, framing of schemes for preferential allotment of land for certain specified purposes. Provision also exists for removal of physical barriers in the built environment and on roads. It also contains provision for promoting research in areas like prevention of disability, rehabilitation, including community based rehabilitation, development of assistive devices including their psycho-social aspects, job identification and on site modifications in offices and factories.

To meet the requirements of the disabled persons in rural areas, the Union Government has evolved a new scheme, known as Viklang Bandhu Scheme. According to this scheme, a group of disabled persons from a selected village would be imparted short term training and would then be provided an assistance of Rs.15,000/- for establishing a local unit which would be responsible for promoting services for the disabled members. The training programme has already been started by some of the National Institutes and the Regional Research Training Centres.

The Government of India have been giving Naional Awards annually in the field of welfare of the handicapped since 1969. The scope of the scheme has been expanded in recognition of the efforts made by the employers of the handicapped and the handicapped employees in their economic rehabilitation. These awards given to outstanding employers of the handicapped and most efficient handicapped employees have provided great incentives to the employers to employ more handicapped persons and stimulate better performance by the handicapped employees. The scheme is applicable to the Govt. Departments, Public and Private sectors, including self-employed handicapped persons. In order to provide incentive to the voluntary sector, engaged in the Rehabilitation Services for the disabled persons or the Govt. of India also gives National Awards to the best Institution as well as the best individual voluntary worker. From 1988, a National Technology Award for best technological invention for the welfare of the disabled has also been introduced. The award is given annually for a technological invention for an aid or appliance which would ameliorate the handicap and substantially help persons suffering from these disabilities.

#### **Human Resources Development**

With a view to integrate the disabled children with mild handicaps, with others in common schools, Ministry of Welfare initiated a centrally sponsored scheme of Integrated Education of the Disabled in 1974. The scheme is now handled by the Ministry of Human Resource Development and the latest revision was made in 1992. The scheme purports to provide educational opportunities for the disabled children in common schools, to

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facilitate their retention in the school system, and also to place in common schools such children already placed in special schools after they acquire the communication and daily living skills at the functional level. The scope of the scheme includes pre-school training for the disabled children, counselling for the parents, etc. The project of Integrated Education for the Disabled was not, however, as popular as expected. It was felt that the lack of expected result was perhaps due to inadequate awareness and lack of co-ordination the school authorities, who were generally government employees, voluntary agencies, implementing the scheme, and availability of manpower. In order to tackle the problem, Ministry of Human Resource Development, with UNICEF assistance, adopted in 1987 project called Integrated Education for the Disabled. Here a cluster, usually a block of population, instead of the individual school, is taken as the project area. Teachers are subjected to three types of training programme: [1] Level I – A general one-week training is given to all the primary teachers in the project area, [2] Level II - A more intensive training of six week duration is imparted to some teachers in each school, which is expected to equip the teachers to handle the children with disability in the school and [3] Level-III-Training is of the duration of one year and is provided in the colleges of NCERT, as a multicategory training. The project has been implemented in one administrative block each in ten States.

The Integrated Child Development Scheme (ICDS) was started in 1975 in pursuance of National Policy for Children with the aim that the beneficiaries will be children, below 6 years, pregnant and lactating women and women in the age group 15-44 years. The services included pre-school education, immunization, primary health care and referral services, supplementary nutrition and health education. Prevention and early detection of disablities is an integral part of this package of services.

#### **Rural Development**

The Integrated Rural Development Programme (IRDP) is a major instrument of overnment strategy to alleviate rural poverty. Main objectives of IRDP are to raise families of the identified target group above poverty line and create substantial additional opportunities of self-employment in rural sector. The programme is financed by means of subsidies provided by the government and loans advanced by banks. There is provision of three per cent reservation for the disabled.

Training of Rural Youth for Self-employment (TRYSEM) is an allied programme of the IRDP. It aims at development of technical skills among the rural people.

The Council for Advancement of Peoples' Action and Rural Technology, or CAPRAT, has developed a strategy to promote the participation of people with disabilities in programmes for rural development. As a part of this strategy, CAPART will extend support to voluntary organisations whose project proposals are in consonance with the overall thrust and guiding principles of this strategy, and which will further its implementation.

#### Labour

The overnment has been assisting a large number of voluntary agencies for providing vocational training facilities. Both the government industrial institutes and private indus-

trial training institutes all over the country are catering to trainees. Under the Craftsmen Training Programme, there is a provision of three per cent reservation for the handi-capped.

To facilitate employment of the disabled persons, the government has set up a number of special employment exchanges for the selective placement of the disabled persons. They attempt to secure for the disabled the most satisfying form of employment, suitable to their residual physical and mental potentialities.

In addition to the Special Employment Exchanges, special cells for the physicaly disabled have been set up. Besides, a Special Placement Officer has been attached to the normal Employment Exchanges for the handicapped. All these efforts are totally funded by the Central Governement's Ministry of Labour.

The first two Vocational Rehabilitation Centres (VRCs) were started in June, 1968 in order to assess the vocational and psychological needs of the physically disabled persons and to render them assistance in their rehabilitation. Now 17 such vocational rehabilitation centres are functioning at different places in the country.



**Vocational Rehabilitation Centres** 

The programmes of Vocational Rehabilitation Centres are extended to rural areas through Rural Rehabilitation Extension Centres.

### **Rehabilitation Council of India**

The Rehabilitation Council of India, or RCI was set up in 1986 by the Ministry of Welfare to improve the quality of trained manpower in the field of disability by bringing uniformity in the training programmes of the various courses being conducted in the country. The Council was given statutory powers by an Act of Parliament that came into force in July 1993.

The objectives of the Council are: [1] to regulate the training policies and programmes in the field of rehabilitation of disabled people, [2] to prescribe and regulate minimum standards of education and training of various catergories of professionals

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dealing with disabled people, [3] to recognise institutions/universities running degree/ diploma/certificate courses in the field of rehabilitation of the disabled, [4] to recorgnise foreign degrees/diplomas/certificates awarded by universities/institutions on reciprocal basis, [5] to maintain Central Rehabilitation Register of persons possessing the recognised rehabilitation qualifications and [6] to encourage continuing rehabilitation education in collaboration with organisations working in the field of disability.

As mentioned earlier, the prime objective of the Rehabilitation Council of India is to improve the quality of trained manpower in the field of disability by bringing uniformity in the training programme of the various courses being conducted in the country. The Council has prepared a perspective plan of manpower required for providing services to the disabled persons in the country during Ninth and Tenth Plans.

In order to impart knowledge to the existing manpower in the field of health and social welfare regarding rehabilitation of people with disabities and to sensitize them about their problems, it was felt essential to couduct short term orientation courses. The RCI, which is the regulatory authority for manpower training in the field of rehabilitation, planned to conduct the undermentioned courses.

# Bridge Course for Untrained Personnel

In an effort to train a backlog of an estimated 15,000 untrained but experienced personnel across the country and with a view to complete this task before the year 2000, the RCI devised a unique and one time opportunity by offering bridge courses for this group of workers who have served in the field of disability for several years prior to the enforcement of the RCI Act. The Bridge course was launched in the year 1998. The main aim is to provide the necessary knowledge and skills to the personnel who have been working with persons with different types of disabilities and who had no formal training.

In the year 1999, the RCI launched a national programme to orient the medical officers working in the Primary Health Centres to disability management with the main objective to disseminate knowledge about prevention, promotion, early identification, intervention and rehabilitation for the common disabilities viz. locomotor, mental retardation, hearing and speech and visual, and to make them aware of the existing institutions available for the people with disabilites [PWD], so that medical officers can refer the patients to the appropriate place for management. This training would also enable them to provide the leadership role in promoting disabled movement at grass root level by propagating the needs and right of the disability issues such as social legislation, human rights and organisation of PWD for asserting their roles and responsibilities and needs.

# Linkages with Professional Agencies

In order to share the new programme developments and latest emerging technologies, the Rehabilitation Council of India maintains linkages with various National and International agencies. It also helps in exchange of literature, updating knowledge and collaboration at various levels.

#### **Other Developments**

In the voluntary sector, a large number of organisations have come up in the recent past who are working in the field of disability. Most of them are engaged in provision of services in single disability sector. Provision of services is in the form of therapeutic interventions including aids and appliances, education, counselling, and vocational training etc. Some voluntary organisations are engaged in manpower development. There is a scheme of assistance to organisations under the Ministry of Social Justice and Empowerment for developing services for the disabled. The RCI also provides grant-in-aid to organisations for the disabled for manpower development. There are approximately over 300 such organisations working in the area of locomotor disability in the country. A number of international voluntary organisations are also funding the voluntary sectory in India.

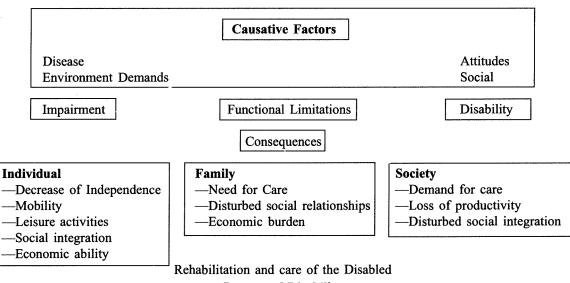
There have been attempts to develop disability specific specialized centres. Indian Spinal Injuries Centre was started recently in the non-governmental sector, with international aid, realizing the need of such centres in the country. Of late a number of self help organisations established by the persons with locomotor disabilities have come up. Their main aim is to act as pressure group to look after the interest of disabled welfare, and to provide them opportunities for interaction by organising various activities like sports, recreation, seminars etc.

# **CHAPTER 28 EARLY IDENTIFICATION** AND PREVENTION

#### **INTRODUCTION**

Rehabilitation of locomotor disabilities is demanding, and it is challanging too. It is all the more so, for the resource strapped developing economies like India. For, the battle against the infliction on medical or the social fronts consumes a lot of funds, which are in short supply. Also, it calls for high level of professionalism, costly equipment and a higher degree of social understanding. All round cooperation and coordination, thus, becomes the keyword to take on the scourage. More importantly the persons inflicted with the disability may themselves become a burden on the society if the measures to prevent it, or at least lessen its ferocity, are not taken in time. Of course, the agony the disability causes to the inflicted person cannot be set aside. In the wake of rising incidence of disability-on account of causes, most of which are preventable, what is of paramount importance is prevention of the onset of the disformation.

'Prevention is better than cure' may sound a cliche but it conveys the message in more ways than one in the prevailing domestic scene. A small chart on the disability process, given below, should bring home to the reader as to how the tormenting malady creeps in, which, naturally, calls for rehabilitation.



**DISABILITY PROCESS** 

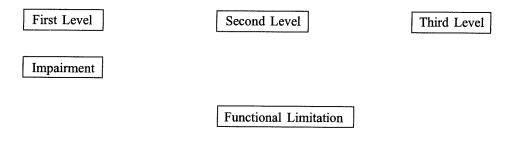
**Process of Disability** 

The above figure clearly shows that the disability process is multidimensional. Physical impairment leads to functional limitation and functional limitation leads to disability. An impairment is any loss or abnormality of psychological, physiological or anatomical function. Impairment may cause functional limitation which can be the partial or total inability to perform those activities necessary for motor, sensory or mental functions within the range and manner of which a human being is normally capable of. For instance, walking, seeing, speaking, writing etc. A functional limitation may last for a short time or long time, be permanent or reversible. Disability, in which functional limitation or impairment is a causative factor, is an existing difficulty to perform an activity in the manner or within the range considered normal for a human being. It should be recognised that difficulties related to disability are not only experienced by the individual himselfvarying degrees of dependency on others, but also by other persons close to him. The family must deal with the problems related to the disabled person i.e. need of care, economic burden and so on. For the society, there are many implications, which are increased demand for care and economic support, loss of productivity, thereby leading to decrease in the Gross National Product (GNP).

#### **DISABILITY PREVENTION**

Disability prevention includes all actions taken to reduce the occurrence of impairment (first level prevention) and its development into functional limitation (second level prevention), and to prevent the transition of functional limitation to disability (third level prevention).

It includes, intervention in the health sector plus a wide range of social interventions, acting upon the individual, his immediate surroundings and the society as a whole. This is explained in the diagramatic representation given below (Fig. 28.2):



Disability

#### **Prevention of Disability**

#### **Levels of Prevention**

As explained above prevention of locomotor disabilities can be undertaken at three levels:

- First Level
- Second Level
- Third Level

# First Level Prevention

This includes all measures directed at reducing the occurrence of impairment i.e. action taken prior to the onset of disease. First level prevention of locomotor disability may be accomplished by measures designed to promote general health and well being and quality of life of the people, or by specific protective measures. The concept is also now being applied to the prevention of chronic diseases such as coronary heart disease, hypertension and cancer, based on elimination or modification of risk factors of the disease.

Prevention measures for other levels include the following:

- Prevention of congenital diseases through prospective counselling (high risk cases) or retrospective counselling (by MTP, contraception etc.).
- Prevention of communicable diseases by immunisation, hygiene, health education
- Prevention of malnutrition and vitamin deficiency.
- Prevention of accidents by provision of safety measures at home and work place, and enforcement of legislation e.g. wearing of helmets to prevent head injury.
- Prevention of production, use and sale of anti-personnel landmines.
- Elimination of exposure to situations in which locomotor disabilities may occur, in particular, war and other forms of violence, and chemical and environmental pollution.

Reduction of incidence of locomotor disability at first level primarily calls for health education for the general public and also at the level of health personnel, especially attached to a PHC, village workers and anganwadis. Information, education and communication (IEC) activities are essential to accomplish proper health education to the masses.

# Primordial Prevention

Primordial prevention is a new concept, becoming increasingly important in the context of prevention of chronic diseases and locomotor disabilities. It is, in essence, a first level intervention measure, as it is concerned with prevention of emergence or development of risk factors in population groups in which they have not yet appeared. For example, prevention of harmful lifestyle including eating pattern, lack of physical exercise, smoking, etc. which have their origin in early childhood and later contribute to health problems like obesity, hypertension, etc., result in or contribute to locomotor disabilities .

### Second Level Prevention

When impairment occurs, it is necessary to try to prevent any long term functional limitation from occurring. To achieve it, measures are required specifically in the following three areas :

• Ability to identify the impairment that might lead to functional limitation (i.e. development of diagnostic ability) e.g. to diagnose tuberculosis, Leprosy, Polio- myelitis, fractures etc.

- Proper and prompt care of impairment in the acute stage to avoid subsequent functional limitation i.e. care of acute cases e.g. administation of first aid measures, proper nursing care etc.
- Proper care of impairment in the chronic stage to avoid functional limitation i.e. care of chronic cases. This includes provision of appropriate drugs for chronic diseases e.g. Tuberculosis, leprosy, hypertension, diabetes, mellitis etc. provision of theapeutic exercises and proper positioning to avoid deformities e.g. in polio myelitius, stroke etc.

In order to achieve it, proper diagnostic and treatment facilities should be uniformly available at all levels of health care. In the case of accidents, facilities for immediate evacuation and transfer to the proper place of treatment are essential. Adequate follow up and two way referral systems are also required to be developed in order to provide the patients continuous care and prevent complications, if any, at the earliest.

### Third Level Prevention

When long term functional limitation has developed, measures instituted should aim at prevention of disability. Such measures may be divided into medical, psycho-social, educational and vocational. Third Level Prevention of locomotor disability aims at enabling the individuals to perform the varying roles expected by the family, community and society at large to the extent possible and thereby restore the patient back to normal or near normal condition. The measures include training to increase independence in self care (ADL), educational and vocational measures aimed at achieving economic independence and psycho-social measures aimed at restoration of personal dignity and to ensure full integration and acceptance in the community.

# NATIONAL HEALTH PROGRAMME FOR PREVENTION OF LOCOMOTOR DISABILITY

The Government of India has taken several measures towards locomotor disability prevention. Research in areas of prevention of disability, screening of "at risk" cases, provision of training to medical and paramedical personnel and provision of awareness campaigns on causes and prevention of locomotor disability, are some of the important actions taken. Also, National Health Programmes which have a direct bearing on the prevention of locomotor disabilities are being implemented. They include:

- Univeral Immunisation Programme
- National Leprosy Eradication Programme
- National Tuberculoses Control programme
- National AIDS Control Programme
- National Cancer Control Programme
- Child Survival and Safe Motherhood Programme.

### **Universal Immunisation Programme**

Universal Immunisation Programme was started in India in 1985. It has two vital components: immunisation of pregnant women against tetanus, and immunisation of children in their first year of life aganist the six EPI (Expanded Programme on Immunisation) targeted diseases, which are the most common preventable childhood diseases viz. tuberculosis, diptheria, pertussis (whooping cough), tetanus, poliomyelitis and measles. The impact of the programme is seen in the declining trends of the diseases e.g. poliomyelitis which has shown a significant drop in the number of cases reported. With the aim to eradicate poliomyelitis, in addition to the regular immunisation programme, Government of India has introduced the Pulse Polio Immunisation programme since 1995. This is a mass polio vaccination programme given to all children irrespective of their immunisation status on two National Immunisation days at interval of 30 days each year. Initial target age was 0-3 year but later all children in age group 0-5 years were included. From the year 1999, the programme has been further modified by giving 4 doses in a year from November to February, with the aim to eradicate Polio by the end of 2000 AD.

# National Leprosy Eradication Programme

The National Leprosy Control Programme (NLCP) has been in operation since 1955 to achieve control of leprosy through early detection of cases and DDS ( dapsone) mono therapy on an ambulatory basis. In 1983, the control programme was redesignated National Leprosy Eradication Programme. The goal was to eradicate leprosy by the year 2000. Multi-drug chemotherapy was recommended aimed to reduce the quantum of infection in the population, reduce the sources of infection and break the chain of transmission of disease.

# National Tuberculosis Control Programme

This programme was started in 1962. The objectives included: [a] reduction of tuberculosis in the community to that level when it deceases to be a public health problem [b] detection and effective treatment of TB cases [c] vaccination of newborns and infants with BCG and [d] undertaking of the objectives in an integrated manner through all the health institutions of the country.

A revised strategy for National Tuberculosis Programme was evolved in 1982. The salient features included [a] Achievement of at least 85 per cent cure rate of infectious cases through supervised short cause Chemotherapy involving peripheral health functionaries [b] Augmentation of case finding activities through spectrum microscopy to detect at least 70 per cent of estimated cases, and; [c] involvement of NGOs, information, education and communication, and improved operational research.

# **National AIDS Control Programme**

National AIDS Control Programme was launched in 1987. In the year 1991, a strategic plan for prevention and control of AIDS was developed. The Ministry of Health and Family Welfare has set up a National AIDS Control Organisation (NACO) as a separate

wing to implement and closely monitor the various components of the programme. Important components of the national strategic plan include : establishment of surveillance centres to cover the whole country, identification of high risk groups and their screening: issuing specific guidelines for management of detected cases and their follow up, formulating guidelines for blood banks, blood product manufacturers, blood donors, and dialysis units, information, education and communication activities by involving mass media, research, reduction of personal and social impact of the disease, control of sexually transmitted diseases and condom programme.

# National Cancer Control Programme

National Cancer Control Programme was started during the year 1975-76 by providing financial assistance to institutions for purchase of Cobalt Therapy Units for treatment of cancer patients. Over the Sixth and Seventh Five Year Plan periods, the scheme continued, and at the same time, ten major institutions were recognised as Regional Cancer Centres which received central financial assistance. During the Eighth Five Year Plan emphasis was on prevention, early detection and augmentation of treatment facilities in the country. Other schemes include: scheme for District Projects; Development of Oncology Wings in medical colleges/hospitals; and scheme for financial assistance to voluntary organisations for the purpose of undertaking health education and early detection activities in cancer.

# Child Survival and Safe Motherhood Programme

This national programme launched by the Government of India assumes great importance in prevention of childhood disabilities. Care of mother during pregnancy such as protection against nutritional anaemia, infection, use of toxic drugs, exposure to radiation, prevention of complications during the delivery process which would lead to hypoxic brain injury or intracranial haemorrhage to the child, and, care of problems in the new born, for example, jaundice, septicaemia, head injury etc., are major contributory factors towards locomotor disability prevention in children. The Government of India has taken up a programme of Social Safety Net Scheme with assistance from World Bank, under which, facilities at the Primary Health Centres will be upgraded in ninety districts in the country. These facilities would include labour rooms, equipment, trained staff, regular supply of water and electricity and facilities for education and information. It is intended that mothers will be helped with institutional deliveries and safe motherhood. The scheme has been taken up from 1992-93.

# CONTRIBUTION BY PUBLIC TOWARDS PREVENTION OF LOCOMOTOR DISABILITIES

The lay man and the public at large have a vital role to play in locomotor disability prevention. Information, education and communication regarding the causes of locomotor disability and its prevention will help the public to a large extent in contributing towards prevention of locomotor disabilities. Important guidelines for the common person are :

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- Maintaining good personal hygiene and sanitation and avoidance of pollution.
- Immunisation against diseases like poliomyelitis and other communicable diseases.
- Education regarding appropriate dietary pattern and physical activity, and avoidance of smoking to prevent obesity and hypertension which can result in locomotor disabilities.
- Prevention of vitamin deficiency disorders e.g. rickets and osteomalacia by adequate exposure to sunlight and adequate intake of milk and other dairy products.
- Avoiding marriage among close relatives to prevent genetically linked locomotor disabling diseases.
- Adequate nutrition, avoidance of drugs, smoking, alcohol, irradiation during pregnancy, and care during delivery to prevent locomotor disabling disorders in children.
- Adequate safety measures at home, and work place to safeguard against accidents.
- Use of helmets while driving or riding to protect from head injuries.
- Adequate measures for prevention of road, rail, air, agricultural and industrial accidents.
- Prevention of war and other forms of violence.
- Prevention of HIV infection/AIDS by observing universal safe precautions such as use of sterilised needles, use of screened blood and safe sexual practices.

# EARLY IDENTIFICATION OF LOCOMOTOR DISABILITY

If locomotor disability has occurred inspite of preventive measures early identification becomes important.

Earlier the identification and treatment, better are the chances of postponing, or at least, reducing the occurrence or severity of locomotor disability. A regular medical check up of the child or adult will help in identifying weakness, deformities etc. at an early stage so that corrective measures could be instituted promptly to prevent further deterioration.

Early identification of the locomotor disabled person can be done at health centres, at schools and even at homes. Some important signals which will help in identification of locomotor disability in a child or an adult are :

- Any deviation or slowness in a child's developmental milestones.
- Excessive stiffness or floppiness of child.
- Use of limbs of only one side of the body.
- Difficulty or abnormality observed when the patient is asked to do the following:
  - -Lift arm overhead
  - -Pick a small object lying in front of him/her
  - -Pick a stone from the ground
  - ----Walk a few steps
  - -Run a short distance
- Difficulty in standing up from sitting position.

- Range of motion of joint decreased or excessively increased.
- Absence of limb in part or full.
- Use of appliances e.g. stick, crutches, wheelchair, tricycle.

In addition, early detection of locomotor disabling diseases based on early biochemical, morphological and functional changes that precede the occurrence of manifest signs and symptoms is of particular importance in chronic diseases.

#### CONCLUSION

Locomotor disabilities, being the largest group of disabling disorders, call for a gigantic effort to tackle. The government as well as the public need to work hand in hand. Though, all of the locomotor disabling disorders are not preventable, a significant proportion is fully preventable. Prevention can be achieved by first level, second level or third level intervention measures. In a developing country like ours where health services and infrastructure are still inadequate, and rehabilitation services are still in infancy, first level intervention would play a major role in preventing or minimising the occurrence of locomotor disabilities.

How aptly Dr. Hafden Mahler, Former Director-General of the World Health Organisation, has summed it up: "Disability is a problem of such magnitude, severity and duration that efforts to reduce it should be a matter of priority for the people and the governments. It is estimated that about half of all disability in developing countries can be prevented or postponed by action taken in the context of primary health care".

# **CHAPTER 29 REHABILITATION APPROACHES**

'Disability causes anguish to those affected and to their families. With assistance and training, the disabled can become useful citizens and lead fullfilling lives.'

–Indira Gandhi

# INTRODUCTION

Disability is an affliction which traumatizes living the disabled and those around. Thus, it turns out to be an agony which calls for medical, social and environmental corrections to tackle it. In other words, it can be said, it is the rehabilitation of the physically challanged person that is what is needed. And this is how the World Health Organisation, or simply WHO, has defined it. Rehabilitation, it says, is 'all measures aimed at reducing the impact of disabling and handicapping conditions, and enabling the disabled and handicapped to achieve social integration.' Thus, rehabilitation does not mean just the training of the disabled and handicapped to lead them to their environs. It also denotes effective intervention in their immediate environment and the society as a whole to facilitate their social integration.

Measures to reduce the impact of the disabling and handicapping conditions, as per the WHO's 1981 definition, mean medical rehabilitation/intervention, such as surgical



correction of deformities, provisions of aids, excercise therapy and so on. It is to reduce the impact of impairment as well as to improve functional status of such patients. The patients' and their families' education regarding the impairment, its potential complications alongwith early identification of the problem and its prevention go a long way in minimising the risk of developing such complications.

The patients with locomotor impairment encounter the following problems:

- The locomotor impaired patients' usual problems are: Motor weakness/Paralysis; Spasticity; Sensory loss; Pressure ulcers i.e. bed sores; Deformities and contractures; Loss of limb or its parts; Urinary and faecal incontinence; Urinary retention; Pain etc.
- Hearing, speech, visual impairments, and/or mental retardation etc, can also get associated.
- The locomotor impairments limit the function of the patient's daily activities like moving, toiletting, bathing, grooming and so on.

# PRINCIPLES OF MANAGEMENT OF LOCOMOTOR IMPAIRMENTS

# Motor Weakness/Paralysis

Common causes of motor weakness are : stroke, cerebral palsy, polio and diseases of muscles. The patterns of motor weakness commonly seen are :

Manall		seen ale .
Monoplegia		Weakness of one limb
Paraplegia		
		Weakness of both lower limbs
Hemiplegia		
		Weakness of one half of body
Quadriplegia		Weakness of all four limber 1 1
	-	Weakness of all four limbs including trunk
Weakness can	be con	inlete [naralysis] or nartial [naratia] IV

Weakness can be complete [paralysis] or partial [paresis]. Weakness of upper limb can result into decreased dexterity, inability to grasp, pinch, write etc. Weakness of lower limb can lead to difficulty in walking.

Rehabilitation interventions are aimed at :

- Maintaining the full mobility or range of movement of the joints
- Improving the muscle power in the affected limbs
- Restoring the function of the affected limb by appropriate training
- Providing splints or calipers if needed

Before we embark on the treatment, a total assessment of the affected limb has to be done in addition to muscle charting and the examination of functional status of the limb. After the assessment, the treatment starts in the form of passive full range of movement of the joints, gentle massage to improve venous and lymphatic drainage and muscle strengthening exercises. Electrical stimulation is also used to stimulate the muscles.

Appliances like calipers and splints are useful to prevent deformity due to muscles imbalance, stabilize unstable joints affected by muscle weakness, provide relief from weight bearing, facilitate walking and maintain a stable posture.

Surgical intervention is also used to correct deformities. It is done through such operations as soft tissue release. Also, to improve muscle balance tendon transfer is done. Unstable joints can be stabilized by fusion or fixing them.

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#### Spasticity

Muscle tone is a state of contraction or tension found in a normal muscle. Spasticity means increased tone in the muscles. Spinal injuries, Stroke, TB of the spine, Cerebral Palsy etc. can cause spasticity. If muscles are spastic there is loss of power and coordination. This can lead to muscle imbalance, and development of deformities.

For controlling spasticity, passive range of movement exercises are carried out. Drugs like Diazepam, Baclofen, Dantrolene etc. can be prescribed and, also procedures like nerve blocks can be contemplated. Surgical methods like release of tight tendons and selective cutting of nerve roots and nerves, are undertaken, wherever, indicated

#### Sensory Loss

Sensory loss often accompanies motor weakness. Loss of sensations leads to loss of sensory feedback i.e. awareness of what the limb or the part of the body is doing. This leads to incoordination and loss of dexterity. Loss of sensations also cause injuries, pressure sores etc. in the affected area.

Patients are educated to avoid any further injury by undertaking appropriate care and are also taught self inspection of the skin of the affected area so that they can prevent any pressure sore from developing. They are also advised protective gloves, footwear, padding, frequent change of posture in bed to avoid constant pressure on a particular part specially bony prominences. "Sensory consciousness" is to be inculcated in the mind of the patient to prevent the complications arising out of the sensory loss.

If pressure sores develop, daily dressing and removal of dead tissue should be done. If there is any infection, proper antibiotic coverage is to be instituted. After the wound is clean, skin grafting or flaps are applied.

# **Deformities and Contractures**

A deformity is defined as an abnormal position which is not passively correctible, assumed by a part of the body as a result of some disease or injury. Factors contributing to the development of deformity are habitually faulty posture, muscular weakness, muscle imbalance, gravity, faulty walking pattern, inequality in length of limbs etc. Appliances used to prevent and correct deformities and contractures are called orthoses. Surgical correction of deformities and contractures can also be done, if these are not correctible by non operative means.

# Amputations

Loss of a limb in part or whole can be due to trauma or disease. Artificial limbs or prostheses are fitted to the stump at the earliest and the patient is trained in their use. Use of artificial limb usually restores functional independence in lower limb amputation. In upper limb amputation, unilateral amputee usually manages with one limb. In bilateral amputations of upper limbs, artificial upper limb and good training in their use is needed.

# Neurogenic Bladder and Bowel

Bladder and Bowel problems are common in paraplegia and quadriplegia. These include retention of urine, loss of voluntary control over urination, overflow, recurrent infections of the urinary tract, constipation etc. Repeated infection can lead to kidney failure.

Bladder management is aimed at avoidance of overdistension, prevention of infection and restoration of continence by bladder training. For preventing infection the patient should have abundant water intake, antibiotics, if needed, and, bladder wash daily. Self intermittent catheterisation is now a commonly used method, in which patient or attendent is trained to catheterise himself at regular intervals so as to remain continent.

Bowel care includes softening of stools by laxatives, digital evacuation, use of suppositories and enemas. High roughage diet and plenty of fluids help in easy bowel evacuation.

#### Pain

Pain is nature's warning that there is some imminent damage to the system. Rheumatoid arthritis, gouty arthritis, osteoarthritis, fractures, low backache, ankylosing spondylitis, soft tissue injuries etc. produce pain.

In addition to drug treatment, various physical modalities can be used to control pain. They can be either heat in the form of hotwater bags, hot fomentation, hot packs, wax baths, electrical sources of heat like diathermy, ultrasound. It can be cold in the form of cold packs, ice massage, ice baths, ice towels etc.

Drugs used are mainly of two types. They can either be non steroidal anti inflammatory drugs or opioid analgesics. Of these non steroidal anti inflammatory drugs are commonly used either in the form of tablets or as gels combined with counter irritants for topical application [i.e. application over skin].

Local injections of steroids are a highly effective method to combat pain in conditions like plantar fascitis, tennis elbow, dequervain's disease etc.

#### **Daily Living Activities**

Activities of daily living are those tasks which a person does regularly to prepare or adjust for participating in his or her day to day work. These include toiletting, grooming and other such self care activities. Use of modifications in the instruments and implements a person uses in his day to day work also is a part of management of activities of daily living. The aim of this training is to gain maximum independence, to achieve function, to ambulate, to communicate etc. The disabled person is trained in actual performance of these activities.

#### Aids and Appliances

Aids and appliances are very important component in rehabilitation of locomotor impairments.



#### Orthotics

An orthosis is an appliance which is added to the patient to enable better use of a body part.

Purposes for which orthoses are fitted:

- Purpose of orthosis is to prevent and correct deformity,
- relief of pain by limiting motion or weight bearing,
- immobilisation and protection of weak, painful or healing musculoskeletal segments,
- reduction of weight bearing and
- improvement of function.

In the upper limb mobility and function are more important than stability. There are a variety of dynamic hand splints which help in function e.g. dynamic cock up splint for wrist drop due to radial nerve palsy, knucle bender splint and opponens splints for median nerve palsy.

Spinal orthoses are used in spinal injury and tuberculosis of the spine. A common orthosis used is the Taylor's brace which is a thoracolumbosacral orthosis or TLSO which immobilizes the thoracolumbar spine.

A cervical collar limits neck motion in cervical spondylosis, cervical injury etc. A four post brace or SOMI [sterno occipito mandibular immobilizer] can also be used to immobilise the cervical spine.

#### **Prosthetics**

Any artificial substitute for a lost body part is called prosthesis. Prosthesis can be for external or internal use. Internal prosthesis are the joint replacements, heart valves etc.

External prostheses are used for upper and lower limbs which have been amputated. The aim of prosthetic rehabilitation is to achieve maximum function out of the remaining stump. A good stump ideal for prosthetic fitting should have adequate length, good muscle power, full movement in proximal joint, healthy non adherent scar, adequate but not excessive soft tissue cover with no bony spurs and normal skin sensations.

Essentials of stump care to achieve a good prosthetic fitting are compression bandages with elastic crepe to improve its shape, stump exercises to improve motor power and movement in the proximal joint, stump hygiene to maintain the skin and scar in good condition.

In the last few decades, great advances have been made in the fitting and fabrication of prosthesis due to advances in material sciences. Modular prosthesis can be assembled quickly because except the socket which is custom made, the other parts are marketed in various sizes.

Mention must be made here of the Jaipur foot which is particularly suited for Indian conditions. If allows barefoot walking as it looks exactly like a normal foot and is cosmetically well accepted. If permits squatting, cross legged sitting and walking on uneven surfaces. The conventional SACH foot [Solid Ankle Cushion Heel] requires a shoe for its use.

In an upper limb prosthesis, there is a socket, elbow joint or arm cuff, forearm shell piece with wrist unit, terminal device, a harness and a cable system for controlling the prosthesis. Terminal devices commonly used are split hooks for heavy work, cosmetic hand with movable fingers and the recently introduced myoelectric hand.

# Walking Aids

Walking aids are used to increase the mobility of a patient as they enable some of the body weight to be supported by the upper limbs. The different types of walking aids are parallel bars, walking frames, crutches and sticks etc. Selection criteria of a walking aid suited to a patient depends on stability of the patient, strength of the upper limbs and lower limbs, degree of co-ordination of movement of upper and lower limbs, degree of relief from weight bearing that is required.

A parallel bar or walking frame is used when the patient starts gait training. This is useful in a patient who lacks confidence to walk as he can concentrate entirely on moving his lower limbs without having to bother about moving the walking aid.

Commonly used crutches are the axillary, elbow and gutter crutches. While axillary crutches make possible all degrees of weight relief, elbow crutches are for patients who can bear some weight on the feet, but need an aid for balance and confidence.

Walking sticks assist in balance, provide moderate support for a lower limb to improve gait and help in the relief of pain.

Wheel chair is used when ambulatory capacity is permanently lost due to total paraplegia. Nowadays power driven wheel chairs and even stair climbing wheel chairs are available.

Outdoor mobility aids are hand popelled three wheelers which are very useful in Indian conditions.

### **Sexual Rehabilitation**

Some spinal cord injured patients show loss of sexual function. A healthy sex life is the part of a happy and fulfilled human life. So this aspect of rehabilitation cannot be ignored.

After spinal cord injury, one of the primary problems seen is loss of erectile function. There are various techniques making use of reflexogenic action which is present to achieve erection. These include stroking, oral stimlation, vibration, pulling pubic hair or a full bladder. The patient is encouraged to experiment and find his own method of stimulation. There are also other methods like injection of papaverine into the corona of the male sexual organ to achieve an erection. Prostaglandin E, is also used for this purpose. A new device is also available which produces a vaccum when put over the organ and when operated produces an erection. This is maintained by a constriction band put around the organ. Penile prosthesis are also available.

For vaginal lubrication, different types of jellies are available. A problem encountered in female patients is pelvic floor and adductor muscle spasticity. This is managed by drug therapy.

Both male and female patients must learn to empty their bladder and bowel prior to sexual activity and must remember to void or catheterise themselves after sexual activity to avoid urinary infection.

Retrograde ejaculation or ejaculatory failure is seen in patients with paraplegia. The higher the spinal cord lesion, the more likely the patient has an erection, but is less likely to have an ejaculation. Ejaculatory failure is seldom seen in those with lower lesions or incomplete lesions. Ejaculation is promoted by various methods like vibratory stimulation of penis, stimulation by a probe in the rectum etc. and the semen is collected and then deposited in the female partners reproductive tract.

Female spinal cord injured patients can get pregnant and bear children, but UTI thrombophlebitis, edema of legs, pressure ulcers, premature labour and immobilisation induced osteoporosis complicate the pregnancy. Patient with complete lesions above T10 vertebral level will not appreciate contractions of uterus and also are not aware of foetal movement. Delivery may require assistance by forceps or vaccum.

Sexual problems can also occur in stroke, head injury, diabetic neuropathy and diseases of blood vessles. Heart attacks also predispose to decreased sexual activity.

# SPORTS AND RECREATION, A MUST

Sports is a wonderful medium for the overall development of a human being. Sports and recreational activities provide opportunities for social interaction, fun, health and fitness in addition to bringing cheer and happiness in life. For a person with locomotor impairment in addition to above mentioned aspects sports and recreational activities have therapeutic value as well. These activities act as rehabilitation interventions as they help in regaining lost muscle power, improve balance and equilibrium and develop neuromuscular coordination.

Food, they say, is the fuel for life, but do not forget to add hastily: 'recreation works as the tonic'. Could any one hold a view contrary to it?—able-bodied or disabled. It is a universal truth which does not need logic to prove. Yet, till very recently most of us mocked at such ideas which encouraged the physically challenged person to take to sports. In fact, even a casual mention of such a thing brought only a derisive laughter.

Thank heavens, such attitudes towards the disabled are turning into a passe. Awakening towards the recreational needs of the physically challenged too are getting recognition. In the developed economies, sports and recreation gets introduced in the lives of disabled right from the stage when signs of disability start showing themselves up. And it was not for nothing that Ross, considered as one of the leading lights among the psychologists, called the 'sports' as 'a nature's mode of education'. There could not, possibly, have been any better, yet so succinct an expression, to educate us on sports.

For the all round development of human personality there could not be any better means than sports which provides physical as well as mental recreation. It is the best form of social interaction as it entertains both, the participant and the spectator.

But what to most able people may come as a surprise is that sports also works as a therapeutic agent for the locomotor disabled. It helps in regaining the muscle power, body balance, equilibrium and neuromuscular coordination—loss of all these vital essentials of the human body is the bane of locomotor disability. Sports and other means of social recreation being the forms of societal contact, thus, gives a big boost to the psychosocial rehabilitation of the disabled.



Holding of Para—Olympics every fourth year has come into vogue. The very country which plays host to the Olympic games holds the Para—Olympics where the disabled display their sports skills in a fierce competition. Two more international sports events organised for the disabled are : the Commonwealth Championship Games for the Disabled—held every four years, and the Asia Pacific Games which are organised every two years.

In India, frankly enough, the effort is still a piece meal one. Some of non-Government Organisations, which have better come to be known through their acronym, NGOs, are engaged in organisation of sports for the disabled at the national and other levels too.

Some of the disabled Indian sportsmen and women have represented in competitive sports at International level too. In the present scenerio, the sports activities for the disabled are not well organized in the country because sports amongst disabled has not been recognized as a competitive sports, as is the case with the able-bodied. With the result the disabled do not feel motivated to participate in games to the extent that is needed. There is also non-availability of organised infrastructure in the form of trained manpower, special equipments and stadia which are exclusively built for the disabled.

Moreover, no apex body, that could plan, organise and implement the sports activities for the disabled, exists. From the disabled persons' point of view, he or she is unable to participate in sports, because of other priorities and also non-availability of effective transportation. Even the PWD Act, 1995 has not taken care of this aspect of the disabled.

It is quite obvious, thus, that not much headway can be made in this field unless the government takes concrete action to develop the basic infrastructure in the form of special stadia—at least one in each State, develop trained manpower by special training to the coaches and by recognizing disabled sports as competitive one. Of course, funds have to be allocated to achieve it. Such efforts will pay rich dividends, once the sports for disabled are promoted. The therapeutic advantages of sports too will, thus, get available to the persons with disabilities.

# **REHABILITATION APPROACHES**

Various approaches are being used to provide rehabilitation services to disabled persons. In the conventional approach services are basically supply generated and are planned by experts with preconceived ideas.

# **Institution Based Services**

In this system, a disabled person comes to the institute and receives training from the professional personnel there. This is the prevailing system in the developing countries. This system provides rehabilitation services using high technology inputs for only a small group of disabled persons. Patients coming from far off places are detached from their community and environment and face problems of transportation. The institution based delivery system is inappropriate when it comes to providing services to very large number of disabled persons. Most disabled people in developing countries come from poor families with little education and are unlikely to take initiative to avail these services. Further, the costs and requirements of professional personnel are constraints.

### **Reach-out Institutional Based Delivery System**

In a reach-out system the professional goes out from the institution to the home of the disabled person and deliver training or other interventions there. If necessary, disabled person is referred to an institution. This approach is likely to lead to better and more practical results. However, by this system the profession may be able to treat lesser number of disabled there at the institute. Transport poses another problem. So this type of service-delivery-system lacks efficiency. Many government and non government organisations are providing rehabilitation services at the periphery by holding camps in rural areas and providing the disabled with mobility aids. These camps are one time activity and have very poor follow up.

# **Community Based Rehabilitation**

Community Based Rehabilitation (CBR) strategy was developed by the World Health Organisation after 1978 Alma Ata Declaration, which stated that comprehensive primary health care should include promotive, preventive, curative and rehabilitative care. The major objective of CBR is to ensure that people with disabilities are able to maximise their physical and mental abilities, have access to regular services and opportunities and achieve full social integration within their communities and their societies. The objective uses the broader concept of rehabilitation that is one which includes equalisation of opportunities and community integration. As a broad concept, CBR is recognised as a comprehensive approach which encompasses disability prevention and rehabilitation in primary health care activities and integration of disabled children in ordinary schools and provision of opportunities for gainful economic activities for disabled adults.

As a component of social policy, CBR promotes the right of disabled to live within their communities, to enjoy health and well being and to fully participate in educational, social, cultural, religious, economic and political activities. CBR, thus, enjoins upon governments to transfer responsibility and necessary resources to communities so that they can provide the base for rehabilitation.

CBR is implemented through the combined effort of disabled people, education, vocational and social services. This means that community resources are mobilized to rehabilitate the people with disabilities. The community health worker or other community volunteer, who has undergone training in CBR, identifies people with disabilities and provide basic information about self care and mobility etc. The community health rehabilitation worker and all other activists in rehabilitation programme, require the assistance of referral services for vocational and social services. It implies that CBR is multi-sectoral program and involves several government departments and their services are to be co-ordinated at village, block, district, state and central level.

### **CHAPTER 30**

# **PSYCHO-SOCIAL REHABILITATION**

Rehabilitation of the locomotor disabled would not be complete unless the physical rehabilitation is accompanied by their psycho-social rehabilitation. The main difficulty faced in this regard is that a disabled person is not acceptable to the society in whatever position he or she is in. Conflicting societal attitudes ranging from pity/charity to aversion confront physically challanged persons. The attitude of the family also greatly influences the psycho-social dimensions of the problem of the disabled.

Physical impairments of a disabled person, substantially limiting his activity, place him/her under great emotional stress. The effect disabilities can have on the suffering of an individual depends on the way he/she reacts and adjusts to his/her unusual or changed life situation. The common reactions of an individual to his/her disabled condition are: feelings of inferiority, self-devaluation, fear, hostility, resignation and a tendency to accept the role of a recluse.

### SOCIETAL ATTITUDES

Members of the society show conflicting attitudes towards a disabled person. Most people exhibit pity or believe in charity for them. Many treat them with indifference, while some demonstrate a tendency of aversion. Only a small number have a positive attitude towards them. The negative attitudes shown by a large number of people leave an adverse effect, thus emotionally undermining the capacity of the disabled to cope with the disability.

Attitude of the family exerts a great influence on the disabled person. For example, some parents regard the disabled child as useless. Consequently, the child develops feelings of worthlessness. Some parents, on the other hand, pamper such a child so much that he/she becomes completely a dependent. The dependence causes frustration and hinders development. Other members of the family turn jealous of the disabled child who then faces isolation.

Even able-bodied persons, at times, experience depression, anxiety, uncertainty and pain. A disabled person has obviously more reason to face such a phenomenon. Greater effort, therefore, is needed to solve emotional problems of the disabled. Claim to love and sympathy, both from the family and society, is greater from such people.

### **Change of Attitudes**

Change in social attitudes is essential for psycho-social rehabilitation of the disabled. The public should be educated about the abilities and handicaps of the disabled with regard



to their contribution to the society. Particularly those, like doctors, nurses, social workers, employers, government officials, etc. need intimately be connected with the disabled. In our country where a vast majority of people are illiterate, audio-visual methods such as exhibition of films and documentaries would be more effective. Moreover, use of T.V. and radio, seminars and cultural programmes, holding of exhibitions depicting problems of the disabled and focusing on their achievements would create general awareness of the predicament of the disabled.

Parental attitudes too need a change. They must be advised to avoid extremes of attitudes, and accept the disabled child as it is, fully recognising his/her handicap. Proper understanding of the child by the parents would make adjustment with the family and society easier.

# **PROBLEMS OF ADJUSTMENT**

The matter of maladjustment faced by the disabled is the greatest hurdle in the process of rehabilitation. This matter has to be tackled effectively to promote fullest possible rehabilitation. In other words, it needs to be seen how and why this maladjustment occurs. The observations that come to mind:

Whereas the able-bodied enjoy independence and security and are thus able to find outlet for their tensions, the disabled are unable to satisfy their social and emotional needs, resulting in devaluation of the self. Development of frustration and a sense of inferiority is thus but natural.

The disabled also suffer the sense of lack of security. Obviously, disablement causes uncertainty and confusion in the entire gamut of the disabled's life style. The sense of security, enjoyed before the disablement, thus, vanishes which causes yet another kind of uncertainty in their minds.

Insecurities that grow in the minds of the disabled all the while, can be physical, emotional and social. Let us now examine them separately.

### Physical

Result of the physical disability is that an individual is unable to use his body like an able-bodied person. The loss of mobility, thus, cuts him off from the outside world. In some cases a disabled person is compelled to seek assistance of others in performance of his daily activities, and becomes a dependent on others. The normal reaction seen in such cases is : either ever dependence on others, or else, ignoring the others help to meet the daily needs. Both the situations have been found to militate against adjustment ultimately.

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### Emotional

Physical handicaps reduce the range of activities in which the disabled person engage and may lower the level of performance in some of the activities. Unable to achieve the goals, the disabled experiences an intense frustration.

### Social

Apart from physical and emotional insecurity, the disabled individual feels very insecure in the social life, particularly when faced with conflicting attitudes of society.

### **Unrealistic Goals**

Success depends on aspirations and the goals one sets for oneself. A disabled person, it has been observed, is tempted to accept the goals of his non-disabled associate as his own, which obviously are difficult to attain and thus experiences failure. The family and friends of the disabled person, at times, try to over-protect him and to save him from doing certain tasks. This stymies the natural confidence in him. And it leads to the worst form of defeatism.

### **Adjustment factors**

After having discussed various forms of frustrations of the disabled, we must now talk logically about adjustment of the disabled to his/her given environs. The experience so far has shown it depends on various odds, which are :

### Extent of disability

Opinion of psychologists regarding correlation between the severity of disablement and adjustment of the disabled person differs. It has, however, been seen that in many cases, the extent of severity of disability does influence adjustment of the disabled people.

### Type of disability

In some cases, there may be no correlation between the type of disability and the nature of maladjustment. Yet in case of certain disabilities like multiple sclerosis and muscular dystrophy, mental and emotional changes have been seen. In certain cases, disability results in personality changes in an indirect way.

### Cause of disability

The cause of disability also influences adjustment of the disabled individual. There is great variation in the responses of a born cripple and a soldier who receives disablement while fighting for the nation.

### Age at onset of disability

The age at onset of disability is seen to have a bearing on adjustment of an individual. For example, a disabled child will react in a different way than a disabled adult.

# Level of intelligence

Some correlation between the level of intelligence and the adjustment to be made has undoubtedly been found. While some experts on the subject hold that a less intelligent boy adjusts more quickly to new situations because of lack of sensitivity, some others are of the view that higher intelligence facilitates adjustment.

# Attitude of family

Attitudes of parents and close relatives have an impact on personality adjustment. As pointed out earlier, while some parents are over-protective, some others neglect their children.

# Mechanism of adjustment

Personality maladjustment is more common among physically disabled persons. In the face of continued demands that exceed his adjustive resources, a disabled person exhibits increasingly disorgnized and disintegrative behaviour. Responses to the physical, social and cultural environment become more exaggerative. Very common responses made by the disabled person are : depression, anxiety, escapism, identification, rationalization and sublimation. The more complex reactions are as shown under :

# Compensation

A disabled person tries to compensate for the shortcoming resulting from disability by developing a special ability, the shortcoming acting as a stimulant that draws out his latent ability. Thus, depsite their disability certain great men have shown extra-ordinarty abilities.

### Projection

Insecurity felt by a disabled person compels to resort to projection, that is, transferring the blame of shortcomings to others and attributing to them own unacceptable impulses, thoughts and desires. Though may occur that the disability is the result of others' actions.

### **Psycho-neurotic Reactions**

Here it may be a case of conversion, a hysterical response, a phobic reaction or perfectionism. Conversion is a neurotic defence in which symptoms of some physical illness appear without any under-lying organic pathology. The patient avoids the problem by falling sick. This invites extra sympathy and attention. A hysterical response is manifested in panic-reactions involving emotional outbursts and some motor activities. A phobic reaction is a persistent fear of some object or situation which presents no actual danger to the patient or in which the danger is magnified out of all proportions to its actual seriousness. For instance, a disabled person having lost a limb in an aircrash may refuse to travel by air. Perfectionism is the response where a disabled person may refuse to leave the institution where he is undergoing treatment on the plea that he is not yet cured. He may refuse to accept substitutes like a artificial limb. He may become obsessive with cleanliness or about dressing himself, though he cannot afford these.

# Hypochondriasis

This is the situation of morbid anxiety about one's health with numerous and varying symptoms that cannot be attributed to organic disease. Due to limiting of his activities, a disabled person shows this tendency in more pronounced form as his disablement attracts his attention constantly.

# ACCEPTANCE OF DISABILITY AND FACTORS CAUSING IT

For proper psycho-social rehabilitation, a disabled person must accept his disability, realize limitations resulting from it and accordingly modify his/her goals. Acceptance of disability implies that the individual does not overestimate his disability nor does he underestimate it.

It should be remembered that the tendency to deny disability may afford a temporary relief from emotional disturbance caused by disability. However, this denial will ultimately prove injurious as the reality of existence of disability will constantly be staring him in his/her face. Such an attitude rather imports distortions into his/her behaviour which will cause serious strain in the relationship of the disabled with the members of the family and strangers.

Moreover, despite his/her endeavour to hide the disability, since he/she continues to be a handicapped person in the eyes of normal people, thus will be regarded as an outsider. Also, since in his/her anxiety to identify himself/herself with the normal group, he/she avoids contact with disabled people the person will find himself/herself outside their grouping. Thus he/she will neither belong to the normal group nor to the disabled fraternity.

The severity of disability can be mitigated by replacing a missing limb with an artificial one. Yet the disability in some form will continue to be there. The physically disabled person can be made to accept his disability in the following ways:

A disabled person naturally gets a very friendly reception amongst other disabled people. Therefore, close interaction between disabled people will encourage acceptance of their disability. Self help organisations of disabled person can facilitate this process. Moreover, depicting of success stories of the handicapped or exhibiting films/documentaries relating thereto also helps in this regard.

Lack of proper knowledge of the cause of their disablement creates a sense of insecurity, anxiety and confusion amongst the disabled persons. Armed with adequate knowledge of the real cause of their disability, they will develop a realistic attitude which is conducive to acceptance of disability.

# Setting up of Realistic Goals and Feeling of Security

Like normal people, the disabled also have goals in life. But these goals should essentially be realisable, otherwise they will face frustration and disappointment. Moreover, to ensure that a disabled person achieves more success than failure, he should aim at a variety of goals in various fields. As we have seen, a disabled person suffers from [1] physical insecurity, [2] emotional insecurity and [3] social insecurity. The physical insecurity can be reduced by making a disabled person independent in regard to his/her daily activities by appropriate medical rehabilitation interventions. He/she will feel more secure psychologically, if his/ her achievements have increased. In this respect, education of the disabled person and the members of his/her family in all aspects of the disability and the role of the social worker and psychologist who helps the disabled person to give vent to his feelings will greatly promote psychological security. Regarding social security, the society must have a positive attitude towards his/her disability. The social worker's help should be enlisted in making the community at large aware of the problems of the disabled.

# **Sports and Recreation**

Cultural activities like dance, music and debates, etc., contribute towards the process of acceptance of disability. Moreover, recreation has a socializing influence making the disabled feel socially secure. Sports and recreation afford an outlet for the conserved energy and general opening up of the disabled, thereby enabling him to overcome the agony of his disabled situation and to recapture the sense of enjoying bounties of life. Similarly, camping and other outings improve their morale, heighten their spirit and promote better inter-personal relationships that widen their horizon.

# **Spiritual Outlook**

A physically handicapped person is not physically free and independent. It is therefore desirable that he/she should inculcate freedom of spirit. This is where the concept of spirituality comes in. Swami Vivekananda has expressed the view that "A spiritually strong and sound man will be strong in every other respect, if he so wishes. Until there is a spiritual strength in man even physical needs cannot be well satisfied". He further points out that there is always the necessity of spiritual religion for mankind adding that man cannot always think of matter how pleasurable it may be. According to him, the mainspring of strength of every race lies in its spirituality and the death of that race begins the day that spirituality wanes and materialism gains ground.

Stresssing the immanent nature of religious laws, which he calls the grand truths of spirituality, Swami Vivekananda says that these laws are working all the time. These laws would surely work to raise the human race, to raise the human nature. In a spirit of exhortation he states that the infinite ocean of spiritual truth lies before us to be worked on, to be discovered, to be brought into our lives.

There is no doubt that the view a disabled person takes of his/her life, and its purpose will influence in a profound manner his/her reactions to disability. Religion has been found to be one of the strongest forces in the acceptance of disability. This also leads to reconciliation of the disabled to his/her disability. Dwelling on the value of spirituality, Harold Russel says in his autobiography:

"The important thing is that this seeming disaster has brought me a priceless wealth of spirit that I am sure I could never have possessed otherwise. There is no easy formula for a happy living. It is not what you have lost, but what you have left that counts. Too many of us squander precious energy, time and courage dreaming of things that were and never can be again, instead of dedicating ourselves to realities and the heavy tasks of today. For me that was and is the all important fact that the human soul, beaten down, overwhelmed, forced by complete failure and ruin, can still rise up against unbearable odds and triumph."

### PSYCHO-SOCIAL REHABILITATION OF DISABLED AND HUMAN RIGHTS

Disabled people face direct and indirect discrimination in society. They are as human as able-bodied and must enjoy full human rights. Owing to their disability they are exposed to emotional and psychological disturbances. They have a special claim on society for sympathy and constructive help.

Recognition of fundamental rights of the disabled is implicit in Article 25 of the Universal Declaration of Human Rights, 1984, which says that everyone has the right to security in the event of disability. Section 22 of the Vienna Declaration and Programme of Action stipulates that special attention needs to be given to equal enjoyment of all human rights by disabled persons. Section 63 *ibid* lays down that human rights unreservedly include persons with disabilities. Then Section 64 *ibid* provides that persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society.

We are supposed to be a welfare state. In tune with the philosophy of a welfare state, disabled persons, who constitute a vast group, should have received special attention like the scheduled castes and scheduled tribes, etc. Unfortunately, our constitution has not made any special provision for their all-round upliftment. However, the Persons with Disabilities [Equal Opportunities, Protection of Right and Full Participation] Act was passed by our Parliament in 1995. In this Act, provisions have been made for education, employment, social security and affirmative actions like allotment of plots for house building and for recreation centres, etc. These provisions have great potentials in advancing the cause of psycho-social rehabilitation of the disabled. All efforts must be made to implement the provisions of this Act fully and in good speed. Then and then alone, the basic human rights could be made available to the disabled.

#### CONCLUSION

Human being is a complex entity consisting of the physique and psyche, that is, the body and mind. Physical disability is accompanied by some sort of psychological disturbance. A psychological upheaval affects general health. Moreover, a disability affects the personality of the suffering individual in two ways: first, by handicapping him/her in the matter of performing ordinary tasks of life, and, second, by inviting prejudicial and sometimes discriminatory societal attitudes towards him/her.

First and foremost is the attitudinal change of the family, for it can undermine the personality of a disabled. Social workers can play a vital role in easing family tensions, say, by home-visits, as some parents need counselling. Attitude of the society towards the disabled having various ramifications also needs reorientation. Effective propaganda and

education through the mass media like T.V., radio, the press could be used to arouse greater sensitivity towards the problems of the disabled.

A healthy attitude of the disabled is equally important for social and psychological adjustment. He/She must accept his/her disability, set realistic goals and interact both with the disabled and able-bodied persons. It is now recognised that rehabilitation can not be through other's help alone. They are helped 'to help themselves'. Spirituality and especially the theory of *Karma* provide succour and promote acceptance of disability.

A disabled person should not be regarded an object of pity or charity. We must realise that a disabled person has an equal right to live with the dignity and self-respect of a human being. He/she has a legitimate claim to enjoy the universally accepted human rights. The problem of psycho-social rehabilitation of the disabled is a national issue. We must square up to it not only boldy but with complete understanding of all its is implications. Urgent implementation of the PWD Act in totality will be an important step in this direction.

# CHAPTER 31 MEDICAL EMERGENCIES

Locomotor disability, although, usually arises due to chronic diseases, which at times are prone to develop certain problems, requires urgent medical intervention, otherwise an uncalled for delay can lead to death. Some of the important medical emergencies faced by the locomotor impaired are :

### Autonomic Dysreflexia

This is one of the commonest and important emergencies seen in the practice of rehabilitation medicine. Sudden onset of headache, sweating, nasal stuffiness, facial flushing, pounding pulse, goose skin and so are some of the symptoms which manifest in the patient. If not treated immediately, life threatening complications, such as brain haemorrhage, fits, heart failure, lung congestion, loss of consciousness, visual disturbances, may arise, resulting into death finally.

This complication is commonly seen in spinal cord injured patients. The autonomic nervous system is responsible for maintaining the blood pressure, heart rate, skin blood flow and breathing in a normal human being. If the spinal cord injury is at a higher level the integrity of autonomic nervous system is lost and it can act haphazardly, causing damage to the body.

The common precipitating factors are bladder and bowel distension, pressure sores, tight fitting clothes, urinary infections, ingrowing toe nails etc.

The treatment should be urgent and immediate. The first action taken is to raise the head end of bed, monitor blood pressure, remove the painful stimuli or the cause which is causing dysreflexia [most commonly evacuate the bladder or bowel]. Drugs that reduce the blood pressure like nifidipine can be used. Recurrent episodes of dysreflexia can be prevented by proper bladder and bowel management and skin care. Patient and family education is very important in the prevention and early identification of autonomic dysreflexia.

## **Blocked Catheter**

The patients with blocked catheter present themselves with pain in lower abdomen, distension of abdomen and, at times, dribbling of urine by the side of catheter. Painless enlargement of urinary bladder can also be seen in spinal cord injured patients. If untreated, it can cause autonomic dysreflexia. It may also cause acute kidney failure due to backflow of urine to the kidney. The catheters kept inside the body for longer time tend

to get blocked due to discharges, calcium deposits etc. Immediate step is evacuation of bladder by replacement of the catheter with a new one and treatment of autonomic dysreflexia, if it is present.

### Hyperpyrexia

The word hyperpyrexia denotes an increase in body temperature of more than 105 degree F. As the term itself explains, the patient presents with increased body temperature. Associated disorientation, fits, unconsciousness may be present. If left untreated, there may be prolonged coma or fits which cause permanent residual disability.

The commonest causes are : various infections, commonly of brain and spinal cord, but it can also be seen in high spinal cord injured patients and persons with sudden brain haemorrhage.

The immediate treatment is to take off the patient's tight fitting clothes, switch on the fan, cold water or ice application over forehead, chest or whole body, if needed.

The reduction of temperature should be gradual since sudden decrease is not advisable. Paracetamol injection can be given to reduce body temperature. Other treatment should be directed towards the underlying cause which is responsible for the hyper pyrexia.

### Acute Vertigo

In acute vertigo [viz. giddiness or dizziness] the patient presents with sudden rotatory sensation of the external world or head itself. Patient is unable to stand or move. If not treated immediately it may incapacitate the patient in executing his/her normal activities. It may also cause injury to the body by fall. It may be accompanied by blackouts, nausea, vomiting, tinnitus, increase of blood pressure and lack of confidence. The commonest causes are cervical spondylosis, diseases of the middle ear and hypertension. The immediate treatment is to minimise the neck movements, use of neck collars, if necessary, drugs e.g. vestibular sedatives, which suppress the symptoms. Psychological reassurance, avoidance of postures which aggravate the symptoms, and, further, the treatment of the underlying cause should be done.

### **Respiratory Failure**

In some locomotor impairments, like muscular dystrophies and spinal cord injury of higher level, there is paralysis of muscles which assist in respiration resulting in insufficient breathing capacity. These patients usually suffer from frequent chest infections, thus compromising the respiratory system. Sometimes these patients may undergo respiratory failure and present with sudden breathlessness during rest or after minimal exertion. There may be associated pain in the chest and signs of cyanosis. If not treated immediately it may lead to unconsciousness, fits, coma and ultimately death.

Immediate treatment is required by administration of oxygen, certain bronchodilator drugs and respiratory stimulants. In extreme cases patient may have to be put on artificial respiration by means of mechanical ventilator. In order to prevent recurrent episodes of chest infections in such patients, it is important to educate them to do regular breathing exercises to maintain the breathing capacity and to protect themselves from cold.

#### **Deep Vein Thrombosis and Pulmonary Embolism**

Some locomotor disabling conditions may force the patient to bed for prolonged periods, especially those suffering from paralysis of limbs and patients suffering from spinal cord injuries, and stroke. Due to prolonged immobility and paralysis of muscles the normal blood flow is affected and there is sluggish flow in the veins. It may lead to clotting of blood and formation of thrombosis in the veins. If so, the patient presents with swelling of the lower limb which is conspicous by the absence of associated pain, because of loss of sensations. The condition is managed by round the clock heparinisation in appropriate doses.

If the condition is not diagnosed, the clot may get dislodged and lead to pulmonary embolism, which if untreated leads to heart failure and death. The condition presents with breathlessness, pain in the chest, haemoptysis and sometimes heart failure.

It requires immediate medical treatment in the form of oxygen administration, heparinisation and other life saving measures as dictated by the patient's condition.

### Syncope [Sudden Collapse]

Syncope is one of the common emergencies seen in rehabilitation medicine. It may be seen when deep heat therapy [US, SWD] is given to the patient. It is also seen when the patient is made to sit up after a prolonged period of bed rest. Patient suddenly feels sinking sensation and falls down. Loss of consciousness, paleness of skin, palpitations, breathlessness heart standstill may also be seen. If not treated immediately, it can cause residual mental disability or sometimes death.

The basic cause is usually circulatory disturbances of the blood, anxiety, generalised weakness and so on.

The treatment should be urgent and immediate. Make the patient lie down, loosen all tight fitting clothes, foot end elevation of the bed, oral/IV fluid administration, oxygen therapy, and cardiac massage if necessary.

# Precipitate Labour in Spinal Cord Injured Patient

In spinal cord injured females with pregnancy there are chances of precipitate delivery due to absence of labour pains. In order to prevent it from occuring, it is essential to monitor such patients during the third trimester of pregnancy in an hospital setting.

# CHAPTER 32

# **EDUCATING LOCOMOTOR DISABLED**

Education, for G.K. Chesterton, was 'simply the soul of society', since, as he put it, 'it passes from one generation to another'.

And B.F. Skinner saw in education something that 'survives when what has been learnt has been forgotton'.

Notwithstanding the descriptions the two luminaries have given to the word 'education', the term is said to have its roots in classic Latin. The term, 'education', is said to have been derived from the Latin word of 'educare', which simply means 'to bring up'. Another possibility is that it was the similar looking Latin term, 'educare', meaning 'to draw out', which wombed the term education. Whichever of the two Latin phrases gave birth to the English word 'education', one can see both had a close link with the human activity. 'To bring up' denotes nursing or rearing. For the well being of the human child, it has to be trained and for that drawing the child out becomes imperative. It is only with such a process the child can have his innate qualities drawn out and learn to be a better human being. Even the authoritative English dictionary, Chambers, has defined 'education' as, 'bringing up or training, as of a child', among other things.

*Rig Veda*, the most ancient Indian philosphical treatise, has called the education as something which makes a man self-reliant and selfless. And for Upanishads, another treatise of the Indian hoary past, education is the end product for salvation. Kautilya, that Indian master of statecraft, whose expositions on economics, nay, *Arthshastra*, are still viewed with an awe and respect, called the education a means of training for the country and bringing out awakening for the love of the nation. Adi Shankara considered the education as the means of self realisation.

Swami Vivekananda, among the modern Indian philosophers, termed education as 'the manifestation of divine perfection already existing in man'. Nobel laureate Rabindranath Tagore viewed the education as 'means which enables the mind to find out that ultimate truth which emanicipates us from the bondage and gives the wealth, not of things but of inner light, not of power but of love, making the truth its own and giving expression to it'. The Father of the Nation, Mahatma Gandhi, said : 'By education, I mean all-round drawing out of the best in child and man, body, mind and spirit'. Dr.Zakir Husain, the academician who once adorned the office of the Indian President, opined that the 'education is the process of the individual mind getting to its full possible development', adding: 'it is a long school which lasts a life time.'

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# **DISABLED TOO NEED EDUCATION**

Considering the meaning of education and its purpose, the importance of education is no less for the disabled child than for a normal one. History has shown that a physical handicap per se is no barrier to achievement. Many great world leaders have suffered from physical handicaps. Franklin D.Roosevelt was crippled by poliomyelitis; Charles Stenmetz, the electrical genius, was born a cripple; Dr.Mary Verghese, a pioneer rehabilitation expert in India, was a paraplegic. The very fact that great achievements were made by many handicapped people raises hope that given training commensurate with their needs and abilities the handicapped can make as valuable contributions to society as the normal people.



# **EDUCATION : A BASIC HUMAN RIGHT**

Even otherwise right to education is a fundmanetal human right, recognised as such globally. Article 26 of the Universal Declaration of Human Rights stipulates that everyone has the right to education. Similarly, Article 13 of the International Covenant of Economic, Social and Cultural Rights provides that the States, parties to the present Covenant, recognize the right of everyone to education. Para 22 of Section I of the Vienna Declaration and Programme of Action, adopted on June 25,1993 by the World Conference on Human Rights, lays down that special attention needs to be paid to ensuring non-discrimination, and the equal enjoyment of all human rights and fundamental freedoms by disabled persons, including their active participation in all aspects of society. Para 63 of Section II thereof reaffirms "that all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities. Every person is born equal and has the same rights to life and welfare also to education and work. Any direct discrimination

or other negative discriminatory treatment of a disabled person is, therefore, a violation of his or her rights. The World Conference on Human Rights calls on Governments, where necessary, "to adopt or adjust legislation to ensure access to these and other rights for disabled persons". Para 64 *ibid* further stipulates that the place of disabled persons is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society.

It is unfortunate that the sacred declarations and covenants adopted by the International fora are yet to be implemented appropriately by most of the governments or societies. This is the bounden duty of all concerned to secure this fundamental human right to education to all disabled people around the world.

# THE PERSONS WITH DISABILITIES ACT— PROVISIONS FOR EDUCATION

Evidently, in the spirit of the afore-mentioned basic human rights, the meeting convened by the Economic and Social Commission for Asian and Pacific Region at Beijing, adopted in December 1992 a Proclamation on the 'full participation' and 'equality' of people with disabilities in the Asia and Pacific region. To give effect to the proclamation the Indian Parliament passed the Persons with Disabilities [Equal Opportunities, Protection of Rights and Full Participation] Act in 1995. Chapter V of the Act deals with the education of the disabled children. The salient features of this chapter are given below :

- Section 26 of the Act makes provisions of : free education to the children with disabilities till they attain the age of eighteen years; for promoting the integration of such students in the mainstream, their education will be done in normal schools; setting up of special schools in government and private sectors, and equipping the special schools with vocational training facilities.
- Section 30 of the Act makes provision for facilities, such as :
  - [a] Transport facilities to the disabled to enable them to attend schools,
  - [b] Removal of architectural barriers from schools, colleges etc.
  - [c] Supply of books, uniforms and other materials,
  - [d] Grant of scholarship and
  - [e] Restructuring of curriculum.
- Section 27 speaks of schemes of non-formal education for the disabled for which appropriate government and local authorities ill be responsible. These are:
  - [a] Conducting part-time classes for disabled children who could not continue studies beyond fifth class on a regular basis and for providing functional literacy for children in the age group of sixteen and above;
  - [b] Utilising the available manpower in rural areas after giving them appropriate orientation to impart non-formal education;
  - [c] Imparting education through open schools or open universities; and
  - [d] Providing every child with disability special books and equipment free of cost; and

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[e] Conducting class and discussions through interactive electronic or other media.

- Section 28 of the Act envisages initiation of research by official and non-governmental agencies for the purpose of developing new assistive devices, teaching aids, special teaching materials for the disabled children, so as to give them equal opportunity in education.
- Section 29 provides for setting up of adequate number of teachers' training institutions and for developing teachers' training programmes specialising in disabilities so that requisite trained manpower is available for special schools and integrated schools for the disabled.

# **EXTENT OF PROBLEM**

The problem of educating the disabled is really enormous. The extent of the challange can be gauged from the estimates made by the NSSO in 1991. According to these estimates, 70% of the physically disabled in the rural areas, and 46% in the urban areas were illiterate. Only 4% of the disabled in rural areas and 12% in urban areas were reported to have educational level of "secondary and above". Even Kerala, claiming to have achieved total literacy, has about 38% of its disabled population as illiterate. With the increase in population and for various other reasons, the number of disabled people in our country has been constantly increasing. According to one estimate, 120 million disabled people needed to be educated in 1995 and this number was likely to increase to 150 million by 2010.

The extent of the problem gets further compounded due to shyness of the parents to send locomotor disabled children to schools. It is especially so in rural areas. Since the largest number of disabled children come from lower income strata, there is greater urge within this section to deploy them in various earning jobs. There is also lack of encouraging environment as the community at large does not have a positive attitude towards the education of these children. The apathetic behaviour of teachers and normal students in the schools make adjustments of disabled children difficult. Moreover, physical barriers of other kinds in the school and the classrooms present another obstacle in promoting education of locomotor disabled children. Lack of provision of adequate financial resources is yet another stumbling block.

# **INTEGRATED EDUCATION OF DISABLED CHILDREN (IEDC)**

Attempts have been made from time to time to address to the problems of educating the children with locotomor disabilities. The Ministry of Welfare initiated a centrally sponsored scheme of Integrated Education of Disabled which is presently handled by the Ministry of Human Resource Development. The scheme was intended to provide educational opportunities for the disabled children in common schools, to facilitate their retention in the school system, and also to place them in common schools after they acquire the communication and daily living skills at the functional level in special schools. The scope of the scheme includes pre-school training for the disabled children under the scheme

will continue upto the senior secondary school level and it includes vocational courses, equivalent to the senior secondary stage.

Obviously, this was in conformity with the objectives of the National Policy of Education adopted in 1986, namely to integrate the physically and mentally handicapped with the general community as equal partners, to prepare them for normal growth and to enable them to face life with courage and confidence. The following measures were to be taken in this regard:



- Wherever it is feasible, the education of children with motor handicaps and other mild handicaps will be common with that of the others.
- Special schools with hostels will be provided as far as possible at district headquarters for the severely handicapped children.
- Adequate arrangements will be made to give vocational training to the disabled.
- Teachers' training programmes will be reoriented, in particular for teachers of primary classes, to deal with the special difficulities of the handicapped children.
- Voluntary effort for the education of the disabled will be encouraged in every possible manner.

# Facilities Under I.E.D.C.

There is provision for identification of disabled children in the blocks/districts where the scheme is yet to be implemented. The facilities that may be given to disabled children include:

- Actual expenses on books and stationery upto Rs.400 per annum.
- Actual expenses on uniform upto Rs.200 per annum.
- Transport allowance upto Rs.50 per month.
- Escort allowance for severely handicapped with lower extremity disability at the rate of Rs.75 per month.
- Actual cost of equipment subject to a maximum of Rs.2000 per student for a period of 5 years.
- One attendant for 10 children in a school in case of severely orthopaedically handicapped children.
- Boarding and lodging charges as admissible under the State Government rules to those living in hostels.
- Assistance of a helper or an ayah with a special pay of Rs.50 per month, out of employees of the hostel, to severely orthopaedically handicapped children.

# EQUIPMENT AND INSTRUCTIONAL MATERIAL

Regarding equipment, the State-level cells will make arrangement for equipment, learning materials, staff, etc. in order to provide education to the disabled children. A resource room having all the essential equipment, learning aids and materials may be provided for a cluster of schools implementing the scheme of integrated education. According to the handbook prepared by the NCERT, in case of locomotor disabled, provision is to be made for adjustable furniture, special writing thick pen and improvised prosthetics/orthotics Availability of requisite teaching/learning material for the disabled is vital for successful implementation of the scheme. Financial assistance under this scheme will be available for purchase and production of instructional materials for the disabled, as well as for the purchase of equipment required for their production.

# **ARCHITECTURAL BARRIERS**

Existence of different kinds of physical barriers is a matter of great concern for those interested in the education of the disabled children. Therefore, it would be necessary to remove all architectual barriers or to modify existing architectural facilities, so as to provide access to locomotor disabled children to the school premises. Grant shall be available for this purpose for the schools where such disabled children are enrolled.

# RELAXATIONS

It is also provided that the State Governments and other concerned agencies should frame regulations for relaxation of rules relating to admissions, promotions, examination procedures, etc. for improving access of the disabled children to education. For instance, age relaxation by 2-3 years is essential in the transitional phase.

# GRANTS TO STATES AND VOLUNTARY ORGANISATIONS

The scheme makes provision for payment of grants to State Governments/Union Territory (UT) Administrations for the purpose of education of the disabled. It lays down the procedure for processing by them of proposals for grants and the manner in which these grants should be released. Similarly, provision has also been made for financial assistance to voluntary organisations, fulfilling the prescribed conditions of eligibility. They are required to send their proposals with the recommendation of the State Government concerned to the Central Government which would release the grants in the manner laid down.

### AN OVERVIEW

A few general observations may be made in this context. First, the locomotor disabled children are capable of studying most of the same subjects as the normal children study. Second, locomotor disabled children will probably be behind in grade for their age and the grade lag could be wider depending on the nature and extent of their disability. Third, possibly because these children have been overprotected athome or in the community and have thus acquired dependency patterns, the attitude must always be to develop rather than to protect the individual. Fourth, participation in sports is as important for disabled children as it is for the normal child. Some games, e.g. wheelchair dances, basketball and table tennis could be arranged. Help of a mobile or itinerant physical education instructor could be obtainted in case some games need adaptation, to suit needs of locomotor impaired children.



# **CLASSROOM MANAGEMENT**

The majority of children with locomotor impairment do not require special education. They can participate and profit from general education given in regular schools. But the school needs to be made barrier free. Class rooms should be located on the ground floor, so that children can alight from the school bus and reach their clasrooms with minimum of difficulty. If that is not feasible, the school should have ample elevator service and/ or inclined ramps, especially for children who use wheel chairs for their mobility, built environment needs to incorporate level access, ramps, lifts/elevators, handrails and grab bars, larger toilet cubicles, adequate wide paths, doors, entrances, etc. Desks and chairs should be constructed so as to make each child as physically comfortable as possible. Composition of floors should be so designed as to minimise the effects of a possible fall. Toilet facilities should be located either immediately adjacent to the class room or very close by. Provision should also be made for easy access to the lunchrooms. In addition to a special teacher one or more attendants should be provided to help those needing additional assistance in carrying out their toilet needs.

### **TRANSPORTATION**

The disabled children require special transportation to and from the school. This facility is almost non existent in our country. It is necessary that provision should be made for specially constructed coaches for locomotor disabled children, with ramps for children in wheel chairs or hoists to lift them onto the coach. They should have seats with safety belts to prevent them from falling and special wells in the floor of the coach into which the wheels of the wheelchairs can be securely braced. Also, routes to the places of education should be prudently selected to avoid long drives especially because these would be fatiguing for the severely handicapped.

# SPECIAL FACILITIES/EQUIPMENT

In addition to specially designed classrooms, specially designed instructional equipment should be provided. An expert has suggested that large crayons or pencils may be easier to manipulate for those children who find difficulty with the standard sizes. Also a disabled child who cannot manage to write with a pencil or pen may be provided the use of electric typewriter. Another expert has suggested that the ideal arrangement would be for each classrooms to be accompanied by second room equipped with cots, where the crippled child can get the rest he generally needs.

### **TEACHER ORIENTATION**

An understanding teacher is an essential requirement for the successful implementation of the teaching programme for the locomotor disabled children. Such a teacher, it is suggested, should have certain basic qualities such as an integrated and stable personality, liking for the individual child, emotional maturity, ability to help educate the community and ability to teach a disabled child in normal classes. Both pre-service orientation and in-service orientation have been suggested for the teacher. Preservice information about locomotor disabled children needs to be given to men and women who are going to be entrusted with teaching such children. Pre-service orientation should consist of well-organized lectures on all types of locomotor disabled children, extensive readings to supplement lectures, planned and scheduled observations of children in school etc. The teacher should have observed the work of the physical therapist. Moreover, he should have knowledge of realities of the disabled children, their normative growth and development.

As regards in-service orientation, it is frequently assumed that a teacher, simply because he or she is a teacher, understands the nature and needs of all children. However, proper orientation is an absolute essential to the success of the teaching programme. Without first hand experience with disability, teachers will be subject to the stereotypes which have grown up around locomotor disabled children. Experience has shown that properly oriented teachers approach positively all types of disabled children.

In India teacher orientation programmes are provided by various institutions both at the State and Central levels, such as by District Institute of Education and Training, Central Institute of Education, and Institutes of Advanced Studies in Education.

# **PROVIDING EQUAL OPPORTUNITY**

There is no gain saying the fact that people with locomotor impairments have excelled in every branch of education like their able-bodied peers. Many such disabled people have attained high positions in all walks of life and professions, such as, administration, health, law, business administration, personnel management and even in engineering. Therefore, if proper opportunities and conducive environment are provided to them, they would make great contribution to society. If this is not done, we will be exterminating from our society by way of dereliction many potentially useful citizens and denying the right to a satisfying life for those who never will be able, because of severe disabilities to become self sufficient.

At birth all children are not equal in their mental or physical capacities. Moreover, children may develop genetically induced disabilities or may acquire disabilities after birth, either owing to accidents or as a result of diseases. Therefore, if these children are not given facilities and opportunities commensurate with their disabilities, especially in the field of education, the concept of equal opportunity would be nullified in their case. In that case, the unwholesome principle of survival of the fittest will prevail.

# **SPECIAL SCHOOLS**

No matter how well equipped the regular school may be it will not, as a rule, be able to cope with the needs of those whose handicaps are of a particularly serious nature i.e. severely handicapped children. To cater to their needs, sometimes special schools are set up where the special education facilities are made available. Special education implies tailor made programmes according to the individualised needs of each child. The class rooms may be small with teacher to student ratio 1:6 or 1:8 or sometimes 1:12. The

ultimate goal of a rehabilitation team is to eventually mainstream these children as soon as they are ready academically, physically and emotionally. While following the syllabus of a regular curriculum, they may require a 'writer' or an 'adapter', or longer examination time, while appearing for the competitive examinations.

When there is an associated learning problem alongwith physical handicap, these children may not be able to attain the high academic goals. The special schools will therefore, have to modify their syllabus, give more attention to provision of assistance in activities of daily living. The parents of such children will have to be involved in designing long term individualised planning on sustenance and income generation programmes based on family resources.

### ALTERNATIVES

It is a fact that even a large number of children of the normal category are not, for one reason or the other, able to receive education in regular schools. This applies equally, or rather with a greater degree, to the disabled children. Therefore, just as in the case of normal children, alternative ways of imparting education have been devised, there is a need for providing such facilities to the disabled children. For instance, the system of non-formal education that was launched on a massive scale to deal with the problem of illiteracy of the population should be extended to the disabled as well. For this purpose, retired teachers, ex-servicemen, postmasters, revenue officers, older students and unemployed youth could be given the necessary orientation courses and utilized for massive campaigning for the education of the disabled. National Open School System and Open Universities that have been set up for purposes of higher education can be usefully employed for the education of the disabled. In the modern technological age, with satellite and communication system having spread all over the country, the tele-school could also be easily organised to spread education among the disabled children.

# **VOCATIONAL EDUCATION**

Undoubtedly, normal academics or liberal education is essential for every individual. However, from the view point of getting suitable employment in future, vocational education of children is also very much necessary, especially in the case of the disabled children. This is so because from the sociological and psychological points of view every disabled child needs to be made economically independent. Concerted efforts are required to provide necessary teaching facilities to the disabled to receive the requisite vocational education. One view is that this can be done in a most cost effective way in integrated set up. For this purpose special resource books containing information about the types of jobs that could be performed with special equipment should be prepared. Vocational education can be profitably imparted to the disabled children in the following areas :

- Book binding
- Tailoring

- Leathergoods
- Cardboard making
- Envelop making
- Art & Design
- James & Pickles
- Woodwork/Carving
- Screen Printing
- Candle making

### **SCHOLARSHIP SCHEME**

Disabled children, especially those coming from lower income group families, need financial assistance to pursue their studies. There is a scheme of scholarships for the handicapped students under which students having a particular level of disability and studying in Class-IX and above whose parents have an income of upto Rs.200 per month are eligible for scholarships at different rates depending on the class. The scheme, which was centrally administered until 1992-93 is now a state scheme. A large number of students are benefitting from this scheme every year. The scope of this scheme should be broadened to cover students from VI class onwards and the income limit raised in view of rising prices over the years.

In spite of various attempts to universalize elementary education all these years, a great mass of the people in our country is still illiterate. According to one estimate we will have 50% of the world's illiterate people by 2000. In this scenario, the plight of the locomotor disabled children can be easily imagined. It is also observed that in planning for education, the handicapped children are generally left out and there is a general lack of awareness about their problems.

Despite adoption of the National Policy of Education and passing of the Persons with Disabilities [Equal Opportunities, Protection of Rights and Full Participation] Act, 1995, no great headway has been made in promoting education of the locomotor disabled children. With a view to implementing the various projects effectively, efforts on a war footing must be made at all levels, micro and macro, so that the national goals of universalisation of education are obtained without much loss of time. Proper monitoring of the progress on a continuous basis should also be done by preparing periodical reports at regular intervals.

Last but not the least, is the question of mobilising adequate funds for the implementation of the programmes for the education of the locomotor disabled children. No doubt provision exists for grants to the State Governments and voluntary organizations, as is the ease with the scheme of IEDC. However, keeping in view the requisite facilities and aids required for these children, enormous money would be needed to complete successfully the process of education of these children. An all out effort has to be made by all the authorities concerned to allocate adequate financial resources, treating this as a top priority area.

### CHAPTER 33

# PROGRAMMES, TRAINING AND EMPLOYMENT

'No man needs sympathy because he has to work. Far and among the best prize that life offers is the chance to work hard at work worth doing', Theodore F. Roosevelt once remarked.

How pithily one of the great US Presidents brought home the simple truth that no person is unequal to the given task, it is the societal attitude which makes it so. For Roosevelt, one can surmise, the immediate need must have been to pull his fellow Americans out of the centuries old prejudice against the disabled in the wake of thousands of American troops returning home maimed by the insane Second World War. And it is heartening that his timely message has sunk in. For, there is now a greater appreciation of the fact that disabilities, like loss of sight, hearing or a limb, do not necessarily close the doors of knowledge or work on the disabled. But it cannot be left at that. An aggressive approach has to be adopted for imparting of education, appropriate skills and finally job placement to the disabled. It is all the more so since in many countries realisation is dawning that the limitations of the disabled get aggravated due to barriers that get created by the social negative social attitudes towards the physically challanged.

A world-wide programme got initiated on December 3, 1982, when the United Nations General Assembly adopted resolution 37/52 with the aim to promote effective measures for prevention of disability, rehabilitation and the realisation of the goals of 'equality' and full participation of the disabled in the social life and developmental work. Obviously, the basic focus is to get equal opportunity to the physically challanged in the society and to allow them to breathe in an environment which upholds the human dignity for all in equal measure.

Soon after came the adoption of Convention no.159 and Recommendation no.168 by none other than the International Labour Organisation. The adoption came in June of 1983. It concerned vocational rehabilitation of the disabled. The two instruments also stress on full participation in the social, and developmental work by the disabled, without discrimination or prejudice.

In India too, public awareness and state's eagerness to respond to the needs of the physically challanged has shown remarkable increase in the post-independence era. The Union Government is fully committed to the full participation and integration of the disabled in the mainstream of the society. Even a central legislation, adopted by the two Houses of Parliament, called : 'The Persons with Disabilities [equal opportunities, protection of rights and full participation] Act of 1995, received the Presidential consent on

January 1,1996. It aims at promotion of effective measures for realisation of the goal of full participation of disabled in social life and development. And to achieve the objective, the Union Government has devised various schemes to arm the disabled with enough skills to fit in the appropriate job slots. A chart below will gives a fair idea of these schemes.

# **VOCATIONAL TRAINING**



# **Craftsmen Scheme**

The objective of the craftsmen training scheme of Director General, Employment and Training (DGE&T), Union Ministry of Labour is to ensure a steady flow of skilled workers in different trades and to reduce unemployment among the educated youth. As on today there are approximately 3,000 industrial training institutes in the country with seating capacity of about 4.25 lakhs imparting craftsmen training in 60 trades. Disabled persons who are declared medically fit for training in a trade by the medical board are admitted to the Industrial Training Institutes. The National Council of Vocational Training (NCTVT) has formulated guidelines on reserving three per cent seats for trainees with physical disability in Industrial Training Institutes in both Engineering and Non-Engineering trades.

# **Apprenticeship Scheme**

To regulate the programme of training of apprentices in industry and to utilise fully the facilities available in industries for imparting practical training with a view to meeting their requirements of skilled workers, the Apprentices Training Act, 1961 was enacted and implemented with effect from March 1, 1963 for trade apprentices. Some 1.6 lacs odd apprentices are undergoing training in 135 designated trades in 218 specified industries in some 25,000 enterprises. Physically handicapped persons, who are declared medically fit for apprenticeship training in a trade by the medical board, are admitted as apprentice. Under the Apprentices Act, three per cent of the vacancies are reserved for people with disability.

# Scheme for Women

Under the Women's Vocational Training Programme, launched in 1977 by the DGE&T, a National Training Institute for Women was set up at NOIDA, in Uttar Pradesh as an apex institute. Ten regional Vocational Training Institutes for Women have been set up at Bombay, Bangalore, Trivandrum, Hissar, Calcutta, Tura, Allahabad, Vadodra, Indore and Jaipur with the objective of providing facilities for training women in selected trades suitable with high employment potential. Disabled women who are declared medically fit for training in a trade by the Medical Board, are admitted to these institutes.

### **In-plant Training**

Disabled persons are offered stipend of Rs.250/- per month upto one year for receiving training in industrial establishments. While there is no guarantee of employment after the expiry of the period of such training, it is expected that such candidates would be offered suitable employment by the concerned establishment, having regard to the skills acquired by the disabled persons.

# **VOCATIONAL REHABILITATION CENTRES**

### For Men

In order to assess the psychological and vocational needs of the disabled persons and also to render assistance in the rehabilitation of such persons, two Vocational Rehabilitation centres (VRCs), one each at Mumbai and Hyderabad, were set up in 1968. Subsequently 15 more centres were set up—one each at Ahmedabad, Bhubaneshwar, Bangalore, Calcutta, Delhi, Jabalpure, Jaipur, Guhwati, Kanpur, Ludhiana, Chennai, Trivandrum, Agartala, Patna and Vadodra. These centres assess the residual capacities of the disabled persons taking into account the disability, aptitude and interests. Based upon the assessment of the centre, a vocational plan is prepared for each disabled person. Such a plan may direct a client to vocational training, or on the job training or work adjustment training or even immediate employment in open industry, sheltered employment or self–employment. 3.3 Lacs disabled persons were evaluated and 1.2 lacs were rehabilitated by the end of December , 1997. It is proposed to establish one VRC in each of the remaining states during the 9<sup>th</sup> Five Year Plan.

### For Women

Presently, there is one Vocational Rehabilitation Centre exclusively for women at Vadodra. Nine VRCs for women are proposed to be set up during Ninth Plan in places where Regional Vocational Training Institute for women are functioning.

### **Skill Training**

Experience of Vocational Rehabilitation Centres has shown lack of skill in 80 percent of the disabled persons who approach Vocational Rehabilitation Centres. Consequently, seven skill training workshops were established at Vocational Rehabilitation Centres in Mumbai, Ahmedabad, Bangalore, Chennai, Trivandrum, Hyderabad and Kanpur. Nonformal job oriented skill training is provided at these workshops.

# **RURAL REHABILITATION EXTENSION CENTRES**

Rehabilitation services are also extended to the disabled persons living in rural areas through mobile camps organised by the VRCs and Rural Rehabilitation Extension Centres, set up in 11 blocks under five VRCs at Mumbai, Calcutta, Kanpur, Ludhiana and Chennai.

# **EMPLOYMENT EXCHANGES FOR PHYSICALLY HANDICAPPED**

Special employmentSpecial cells in normalAssistance to disabledexchangesemployment exchangesex-servicemen

## SPECIAL EXCHANGES

Although all the employment exchanges are responsible for the placement of disabled persons, special employment exchanges have been set up for their selective placement. There are 24 special employment exchanges in the country at Ahmedabad, New Delhi, Bangalore, Mumbai, Ludhiana, Chennai, Jabalpore, Thiruvanathapuram, Calcutta, Patna, Chandigarh, Shimla, Jaipur, Bhubaneshwar, Guhwati, Agartala, Baroda, Kanpur, Surat, Rajkot, Imphal, Mysore, Kozhikode and Kollam. Nearly 9,000, including 7,500 orthopae-dically handicapped persons were registered during 1996 and over 1,000, including nearly 900 orthopaedically handicapped, found placement.

### **Cells in Normal Exchanges**

Fifty Five Special Cells were set up at normal employment exchanges manned by a Special Placement Officer to promote the placement of disabled persons. The number of disabled persons placed in employment during 1995 by the Employment Exchanges were 3.71 thousand, including 3.31 thousand orthopaedically handicapped.

### For Disabled Ex-servicemen

An ex-servicemen cell has been established in the Directorate General of Employment and Training to provide placement services to the disabled ex-servicemen and the dependents of defence service personnel killed or severely disabled in action.

# **COMMUNITY BASED REHABILITATION**

Community Based Rehabilitation Programme (CBR) is a provision of comprehensive services based on community participation with active involvement of persons with disabilities, organised and co-ordinated by governmental and non-governmental organisations. The rehabilitation services are provided to persons with disabilities in their own environment as far as possible through the utilisation of facilities and services as well as human and material resources available. CBR also includes referral services at district, state and if necessary the at, national level. Rehabilitation personnel at these levels provide skilled assessments and rehabilitation plans for disabled people with problems that cannot be solved at community level. Eighty per cent of the disabled persons in the country live in rural areas, the CBR approach for rehabilitation is a priority programme of the government. Ministry of Social Justice and Empowerment has established a National Community Based Rehabilitation (CBR) programme during the Ninth Plan. At the block level, covering about 5,000 population, two multi-purpose rehabilitation workers (MRWs) have been proposed. At the Grampanchayat level comprising a cluster of vil-

lages, two CBR workers – one male and one female from the area, would be suitably trained to cater–to about 5,000 population. One of the components of CBR programme is to provide income generation activities for the disabled, by resources available in the community itself.

### **CONCESSIONS IN GOVERNMENT JOBS**

It often happens that for lack of understanding on the part of the society, the disabled are denied even the opportunities to show their capabilities. Thus, creation of a necessary climate to enable a disabled person to compete on equal footing with others becomes a must. The Government has provided a number of facilities for the education, training and placement of disabled persons. Concessions like entry age, travel, medical fitness and preference in sponsoring by employment exchanges against vacancies are also available. The persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 provides that every appropriate government shall appoint in every establishment not less than three per cent for persons with disability—one per cent each for visually handicapped, hearing impaired and locomotor disability.

### NATIONAL HANDICAPPED FINANCE AND DEVELOPMENT CORPORATION

The National Handicapped Finance and Development Corporation was set up in January, 1997 to function as an apex financial institution for providing financial assistance to disabled persons for their economic growth and development through self-employment and education.

### INFERENCE

It is the social disadvantages and not the disability which limit an individual's initiative, may it be at social level or the place of work. Disabled persons find themselves excluded from the services and the activities which are considered normal for other people. Such exclusion gets more pronounced in the case of disabled women. The situation of disabled people will improve only, if policies concerning their training and employment, take into consideration, the concept of equality in opportunity as set forth in the UN standard rules. The Disabilities Act of 1995 marks a radical change as it talks of equality of opportunity, protection of rights and full participation of the physically challanged.

# CHAPTER 34

# **ROLE OF EMERGING TECHNOLOGY**

### **INTRODUCTION**

Locomotor impairment is a major disability problem, if quantified in sheer numbers of inflicted, or qualified in the form of difficulties it poses in the daily chores of the afflicted. What is even worse, it maintains no calender. It can creep in at any age—childhood, youth or senescence. What we know for certain is its remarkably uniform incidence. Accidents dominate the adult group. In the advanced years it is the degenerative diseases which cause it. It could be congenital, or maladies like Polio take their toll in stripling.

Muscular and skeletal system abnormalities are principal ultimates, though neural, hormonal or any other body system may fall into it. In face of causative factors being too many, the risk of an individual falling victim to such a physical challange at any time cannot be ruled out. Such being the case it becomes imperative that prevention and management of locomotor disability gets equal attention on priority. Luckily, technology has made a lot of advancement in the medical field too, and thus, it can be harnessed to the advantage of the disabled.

### **PREVENTIVE TECHNOLOGY**

In the course rehabilitation of the afflicted, a number of facets come to fore, one among which is, what has come to be known as, Preventive Technology. A very vital aspect of the technology is to advise steps to the patient which do not aggravate disability. Assessment of movement pattern has been seen to have shown considerable benefits. Determination of excessive stresses and strains can help in suggesting such movement patterns which do not worsen the disability. In muscle and joint problems the technique has definite value. Bio-feedback can be added to train muscle segments to avoid undue stresses to the joints.

Use of technology comes handy in preventive rehabilitation. For, many a disabilities have cropped up directly from the use of technological products. Vehicular accidents, to name, are one such instance. Paradoxical as it may appear but it is the same technology which can be first applied to study the human ergonomics, and then used for safer technological structures and protective devices. A shin-guard on a motorcycle, is a commonly used protective, provides a fine example.

Yet another facet is the aids for the use of the disabled whose use helps psychologically. The benefits may not be so perceptive as that of some prosthetic aids, but the benefits are of far reaching nature. Preventive measures nothwithstanding, the prevelance of locomotor impairments cannot be wished away. Technology has been developed as an aid to help the management of locomotor disability, and not as an end in itself.

### LIMB ORTHOSES AND PROSTHESES

Orthotic and prosthetic devices have been mentioned in early historical writings. The walking stick, simple leg braces and the peg leg have been in use for a long. Modern technology has radically transformed these devices, besides bringing into existence a wide range of additional aids. The four cardinal aspects of technology, which have led to the progress are : biomechanical studies; engineering design; materials technology; and manufacturing processes. In historical times it was at the best through an intutive feel of forces of motion in locomotion that worked, and the orthotic and prosthetic devices were hand made based on such a perception. The materials available for the making of such devices were only wood and leather. The range of disability that could be managed was limited. As a result, the longevity of locomotor disabled at all stages of life was very short after the onset of the handicap. Also, even in cases where help through such devices was possible, the help was quite inadequate in restoring most of lost functions. Expenditure of human energy was high and even the user felt quite stressed. The devices were cumbersome too. Very often, the aid itself caused damage to the body. Skin abrasion and muscle ligament tear could be cited as the examples. Surprisingly most aids were as rugged and environment resistant as are presently available today.

Bio-mechanical studies of locomotion were taken up to overcome such problems. Initially, only visual observation and assessment of forces by means of the investigators natural senses were the tools. Later various adaptations of the camera and the weighing machine enabled quantitation. The data could be linked to the basic Newton's Laws of Motion and anatomical knowledge to give an understanding of the dynamics of the normal locomotor process as well as in situations of disability. This understanding was further tied up with engineering designs, particularly to aspects of statics and kinematics of linkages to come up with new and improved forms of orthotics and prosthetics. Calipers for polio patients and above knee leg prostheses are some of the aids which have emerged as a sequence of the bio-mechanical knowledge. Concurrently material sciences too had advanced. A wide spectrum of metals, rubbers and plastics had become available. Devices which could not be made earlier on account of the limited strength of the traditional materials now became a routine. For example, the artificial hand and arm. Moreover, some biocompatible materials like stainless steel (SS316) and silicone rubber (Silastic brand) had been developed, and so, endoprostheses like the hip joint could be implanted for rehabilitation.

A more recent technological input to the field of limb orthoses and prostheses is microelectronics and microprocessors. These additions have opened up a new dimensionto increase functional capability and optimizing performance. Till the 1980s artificial limbs were designed and made for a particular set of functional characteristics. The functional parameters remained invariant in the use of cycle, though some minor changes were introduced in variable damping hydraulic piston-cylinder assemblies. The aids, thus, did not adjust to the changes in environmental conditions, such as terrain of walking and

user behaviour, like alteration in the speed of walking. Fixed nature of the aids was particularly a severe limitation in arriving at dextrous use of artificial hands and arms. Microelectronics and microprocessors, which may be considered to be miniature computer data processing elements, have changed the picture. Now minature sensors can be inbuilt in the artificial limbs and microelectronic circuitry, which are positioned in close proximity to the sensors generating signals that give information regarding the environment and the user. With this, characterstics like : walking terrain; shape and firmness of an object held in an artificial arm; speed of relative motion between limb segments; and instant to instant muscle activity, can be assessed and the data passed on to the microprocessor. The microprocessors are programmed to analyse the data and arrive at the optimal set of functional parameters for each phase of the use of cycle as a disability aid. Accordingly by the means of minature actuators placed inside the artificial limb parts the functional characteristics can automatically change to maintain optimal conditions. An intelligent artificial limb is thus obtained. Feedback mechanisms too can be incorporated so that a person with an anaesthetic foot, caused by leprosy, can judge the foot pressure and avoid straining. In an artificial hand feedback on grip force is now made available to user to ensure that while shaking hands exerts the right degree of grip pressure.

Furthermore, remote sensing devices are fitted now into the limb designs. An ablebodied person approaching any obstruction during walking or in arm movement through biological control, changes the tone and contraction patterns of the muscle, which are not possible for a disabled. Ultrasonic as well as infra-red laser sensors, located in the artificial limbs, sense obstructions from a distance by bouncing invisible energy and thereby provide data to the microprocessors to adjust the characteristics of the artificial limb segments. These provisions mimic the natural system to a very high level of accuracy. With the artificial limbs almost all tasks of daily life can be performed, with movements so natural that bystanders can never make out that an artificial limb is being used.

# FUNCTIONAL ELECTRICAL STIMULATION

With the advent of electronic technology in rehabilitation, yet another dimension of activating weakened or non functional organs of the body by means of electrical stimulation has been addeded. The underlying physiological phenomena is that all cells in the human body carry an electrical charge. When the cells are subjected to an external electrical field the cellcharge magnitudes change and the cell's functional status is altered. Muscle and nerve cells constitute a special subset of cells which are 'excitable'. A small electrical current can lead to a marked change in the cell transmembrane ionic transfers and consequently of the transmembrane potential. Thus, both nerve and muscle cells when excited electrically generate an electrical activity of its own and muscle cells contract. Deriving some specific function by electrical stimulation is known as Functional Electrical Stimulation (FES). Combining FES with controlled and powered electromechanical devices constitutes the field of neuromuscular robotics.

Neuromuscular robotics has wide ranging applications in rehabilitation. Partial or total paralysis of segments of the body is a problem quite frequently encountered. An accident may lead to a nerve injury and then the person is not able to move or control the limb associated with the injured nerve. A more serious situation prevails when the injury is at the spinal cord level and supply from that region is involved. In this case a large number of nerves emanating from the injured part of the spinal cord get damaged and thereby a body segment is paralysed. In modern society with stresses mounting up another type of complication is often encountered. Cerebral strokes affect the movement control centres in the brain and hemiplegia (paralysis on half side of the body) results. The disability may also occur on both sides of the body.

In both these cases the actuating force that is the muscle remains intact. It is only that the nerve control which is affected and the muscles, thus, do not receive the electrical signals necessary for initiation of the contraction. Not only a person gets paralysed, but the muscles also undergo an atrophic changes in the cause of time. Inactivity gradually causes the muscles to become flaccid that leads to the cosmetic distortions.

In clinical medicine, as it is practiced in India today, the functions of the impaired limbs are not restored. Only passive movements of the limbs, with the help of a physiotherapist or the patient's relatives, is advised to slow down the rate of atrophy and avoid contractures. Sometimes mild massage is also prescribed. Muscles with residual power are given physiotherapy by compensating for the gravitational effects. Electrical stimulations to the muscles are also given to make them contract and this too slows down the rate of atrophy. All these measures are a mere attempt to maintain the muscle in its original form in the hope that the neural functions of that part will spontaneously recover.

While the situation in the clinics in India remain as indicated, recent research and developments have shown that very active intervention is possible. Computer programmed electrical stimulation can be selectively given to different muscle groups, thereby well coordinated movements of paralysed limbs can be obtained. The basic aspects of these researches were investigated for years by a number of researchers in Yugoslavia and the U.S.A. The technique could not nevertheless be fully explored because, in use, processing of data was not practicable with the technological tools of the past. The advent of microprocessors has changed the situation now dramatically. Now complex programmed stimulations can be given. Also, with the help of miniature transducers instant to instant data regarding position velocity and acceleration of the body segment can be processed to generate control signals for natural body movements. These subsystems have some aspects in common with the sensors for artificial limbs but have major differences on account of their being employed in the present case to assess natural body segments and living tissue responses. A pocket sized computer can analyse the data and activate a set of stimulators to deliver the specific type of stimulation pulse required at that instant for the contraction of the muscle. Hence, functional electrical stimulation has now come within the realm of biomedical engineering tools with practical utility.

Additionally, FES helps in prevention of muscle atrophy; relaxation of muscle spasms; improved circulation; and in obtaining increased range of motion and function.

Besides application to limb paralysis, FES is useful in the management of urinary micturition abnormalities following spinal cord injury. By means of implanted electrodes and electronic stimulators, the sphincter muscles may be maintained in contraction to check incontinence, and deactivated to produce flow. Also spastic neurogenic bladder can be treated. These stimulators have also been found to be useful in cases of urinary incontinence arising out of complications of parturitio in female patients.

A variant of FES now coming into the field of rehabilitation is 'Orthokinetic Orthoses'. These are particularly useful for persons with upper extremity movement dysfuction following Cerebro Vascular Accident (CVA). According to Neeman and Neeman (1991) "The application of orthokinetic orthoses is based on the rationale of the neurophysiological mechanism of orthokinetic treatment of muscle imbalance in paretic limbs, which utilizes the difference of elasticity between the active (fully elastic) and inactive (relatively inelastic) fields of the orthokinetic cuff, overlying respectively muscle agonists and antagonist, with resulting activation of the agonist. This mechanism proposes selective cutaneous stimulation of low-threshold. slowly-adapting mechanoreceptors (e.g. Merkel's disks) via excitation of alpha motoneurons, and of gamma motoneurons by alpha-gamma coactivation, with reciprocal inhibition of antagonist musculaturee(s)". There are significant gains by adopting the approach as for restoration of the ability to put on and take off gloves and feed himself independently.

Spinal Cord Injury (SCI) also has adverse effects on sexual functions. In males the sperm development in the testis is affected within three days. Impotence is a common sequel of SCI and causes considerable psycho-social problems. Technology can help in a number of ways. Penile prosthesis have been deviced, which although do not alter the orgasm achievment outcome, help in vaginal intromission. Primarily there are two types of penile prosthesis : semi-rigid and inflatabl. The inflatable types can be deflatated to allow convenient relaxation to the penis after intercourse.

The ejaculation still remains a problem and becomes a cause for infertility. An electrical probe may be inserted into the rectum and electrical stimulation given to produce ejaculation. The semen so collected may be used in artificial insemination procedures.

When the SCI is higher up in the cervical region, besides the limb activities, other functions of the body are affected. For example, the cough reflex is depressed. The accumulation of secretions in the lungs makes the patient susceptible to chest infections. In such cases augmenting of the cough reflex is necessary. FES has proved to be very useful in this regard and can be a routine part of the management of high SCI patients.

## LIMB MAKING AND FITTING

Making of artificial limbs and fitting to the residual body segments has undergone a near revolution with the advent of modern technology. By means of special optical scanners coupled to computer systems, the anthropometric dimensions and contours of the body in three dimensions can be mapped out without any contact with the body. Refined measurements of tissue elasticity and deformability can be performed by safe and patient acceptable techniques based on sensitive pressure sensors and ultrasound. With the Virtual Reality Technique the interaction of different configurations of prosthetic and orthotic devices with the body can be visualized theoretically with the presentation of almost like real-life like experimentation. Using these tools the optimum configurations of the devices can be selected for each individual. The artificial limbs can then be made accordingly. The procedure cuts short trial and error, leads to optimal performance and patient comfort and reduces costs at the same time. With such Computer Aided Design (CAD)

and Computer Aided Manufacturing (CAM) perfectly matching artificial legs can be provided immdiately after an amputation. Furthermore, there can be a provision that adjustments can be made when there is shrinkage of the stump.

Alongwith making of the design and making of the aids, technology provides a very valuable input in respect of gait training in lower extremity problems. Dynamic computer graphics, prepared taking into account patient and prosthesis/orthosis data, can be utilized to present to the subject the effects of changes in gait pattern. Since the presentations are visual and dynamic in form the patient is able to appreciate the significance of the gait modification advice given and adopt them. Similar methods are also being applied to gait assessment of persons, with minimal or no disability to correct incipient gait problems which would eventually lead to disability (Johnson et al, 1996). Thus disability is prevented.

### FUNCTIONAL ASSESSMENT

Traditionally the disability is quantified by an estimation of functional loss. Modern technology is changing this approach by bringing in residual ability assessment as a major help in rehabilitation. The force and movement abilities of body parts can be quantified by sensors and the data can be assembled by special computer techniques to assist in selecting suitable activities for an individual as well as ways to perform a task by movements which differ from those used by those without that disability. In this exercise isometric, isokinetic and isoresistive modes of testing are all employed to study the velocity, torque and power capabilities of each movement sub–systems. From these data the capability available for any particular segment of an overall task can be determined in a simulation model. With such assessments and analysis, very often a disabled person gets to perform a task with no aids or with minimal aids as compared to usage of extensive aids otherwise. Furthermore, body segments which have not been directly affected can be assessed to optimize mobility. Assessments of body power for wheelchair propulsion is an example.

## **RESEARCH TOWARDS MORPHOLOGICAL AND FUNCTIONAL RESTORATION**

Although currently the major technological inputs into rehabilitation medicine is to provide aids and appliances to support some function, there are in the scientific horizon exciting possibilities of morphological and functional restoration with interventions at the cellular level. Nerve tissue regeneration is one such direction and possibilities are visible in spinal cord regeneration. Regeneration of the spinal cord using Embryonic Cell Transplant therapy, is being carried out as a patient service procedure by Drs. Fernando Ramirez del Rio and Carlos Romero Gaitan, Mexico. Injuries at the L-2 level have been seen to respond very well and those at C-2 level regenerate more slowly. Added electrical stimuli by means of special electrical pulse generators augment regrowth. Currently, the treatment is expensive, costing between \$65,000 to \$85,000, but in times to come, the cost is expected to reduce markedly.

Recently rodent cell lines have been developed that stop dividing after transplantation (so that there is no risk of tumour formation) and that mature into very specialized nerve cells. Research has now shown that these cells can restore function after SCI. Very recently scientists have learnt that some cells of the adult CNS can be stimulated to divide and develop into new nerve cells. Also neuroglial cells in CNS inhibit regeneration. Schwann cells in PNS stimulate regeneration. So genetically engineered Schwan cell implant or auto transplant of Schwan cells may be used in the program. Spinal cord may also be transplanted to promote regeneration.

### **CONCLUSION**

Technology has already had a major impact on all facets of locomotor disability. The field is progressing rapidly, and, in the near future, a number of restorative techniques are expected to become available.

### CHAPTER 35

# FACED WITH FORTITUDE AND WON-SELECTED CASE STUDIES

At 48, heading a huge engineering unit of one of India's top business houses, with a collegiate son and a daughter and an understanding wife to fend with a hefty pay packet, life for Ishwari Prasad Bhargava could not have been any better. But then it was not to be so. A morbid disabling disease struck him so stealthily that everything nice and cosy came unstuck.

He was away on an official tour, and staying in a classy hotel. And even after two decades of the event he shudders even to recall those moments of that September morning of 1979. The previous day he had a very heavy schedule, as he was keen to finish his official assignment to fly back home next morning. Despite having gone to bed very late at night, he had instructed for an early wake up call to catch the flight in time.

Misty eyed when he woke up to receive the call, his right arm would not stretch out to grab the ringing phone. Suddenly jolted out of his wits, he attempted to shriek out for help. But no he could not utter a word. Soon enough he could make out something terrible had happened to him. But before he could analyse anything everything became hazy. When he finally came around he found himself surrounded by white-coats. He tried to open his eyes wide enough to look around, it was then he caught the glimpse of a familiar face. But could not make out whose face it was. Then he heard some one saying: "It is me. Can you recognize?". Somehow he knew, he says, it was none other than his wife but, by then, as he came to know later, three months had passed by and he had remained in the hospital bed all the while.

In late 1930s, a chirpy young girl, decked in her best would trudge the dusty road of her town in Sindh—now in Pakistan, day after day for her early schooling which, recalls Nalini Advani at the age of 66, she adored. Barely had she attended the school for a month or so, the scourge of polio visited the town, and she became one of the victims—a lifelong affliction. She was barely six then.

A cousin of his, very diffidently, told his parents, "that I could not run as fast as other schoolmates of mine", confides Sumeet Arora, a bank officer, who, alongwith his elder brother, is confined to wheel chairs because of a crippling infliction.

Bhargavas, Advanis and Aroras are among the millions of Indian faces, physically challenged, because of, what medically is termed as, 'locomotor impairment'. They are mentally agile but are left behind in the mad rush to attain, because the society as a whole is yet to reconcile itself to the needs of this section. They can surmount their physical disabilities and add their mite to the society almost as the able ones. But the need of the hour is proper chanellisation of the resources and will of the society to act in unison to carry them alongwith the rest.

For Bhargava, and his family of three members, the ailment had descended as a devastating blow. Life for the family had come to a standstill, and for Bhargava it was a ploding between the hospitals. But what kept them together was determination to battle it out with the adversary in conjunction with doctors, physiotherapists and occupational therapists, besides a host of other well wishers. And today, sitting in the drawing-room of his own DLF house in the outskirts of the capital, Bhargava, though still with a disarticulated voice, presents a picture of confidence that all is not lost after all.

Nalini is a saga of courage, especially in wake of so little facilities, medical or otherwise, available then. Not to be left alone with the affliction, she made her way through all the maze. Her parents, she says, never let her down. They were always there to walk an extra mile with her. And she mastered in the Library Science. The Capital's then biggest medical library of Maulana Azad Medical College recognized her merit, and, she rose to head it as the Chief Librarian, and remained there till retirement. The sphere of her activity has not come to an end with her superannuation, however. She is the guiding force of an NGO, called Handicapped Welfare Federation, which is, as she puts it, ''by, of and for''the locomotor impaired people.

The story of the two Arora brothers does not stand out differently. The two brothers, in their 30s now, have been hit by the one and the same morbidity—known as muscular dystrophy, again a disabling disease, which was detected in them even before they had reached secondary classes of their schools.

In the case of elder brother, Sunil, parents realized that their son, then 13, had to clamber up the stairs to reach his class in school or to board the school bus. His younger brother, Sumeet, the parents had been told, could not match in races with his classmates. A family physician diagnosed the ailment as 'myopathy' in both the boys, but referred them to the Orthopaedics Department of the prestigious All India Institute of Medical Sciences. Confirmation of the diagnosis at the AIIMS came as a blow to the haggard parents. Alongwith the deterioration in the conditions of the two boys came slow, but the coming affliciton began to manifest itself. They had to be literally taken to the school by the father, and later, fetch them home. For the parents, though it was traumatising experience physically, mentally and financially, they plodded along the two boys, thus encouraging them to face the reality with fortitude.

A young businessman, Manoj Dawar, however, had a gala time till an unsavoury accident of March 1990. Managing a big stainless steel utensil shop in the posh Delhi market of Lajpat Nagar, he was going great guns giving his competitorsa a run for their money. But all this changed when a bullet pierced through his groin, leaving him a physical and mental wreck. Flabbergast, parents would do anything to get their son on his feet once again. It led them to believe in hearsay. And the result was Manoj had his agonies aggravated.

He was sent to Rishikesh in Uttar Pradesh to a 'Gurujee' on the advice of a relative or a friend as the so-called hermit was believed to be blessed with yogic powers. The experience Manoj had at the Rishikesh Ashram [hermitage] was traumatic. The wiseman, says Manoj, consulted a tome whenever 'I was summoned' for treatment and one day, to Manoj's horror, acid was poured on one of his knees. It did not help him but left an ugly scar for all time to come. As if it was not enough, the parents then packed him to Kerala for some sort of 'oil treatment' which, finally, left him with joint-stiffness and kilos of weight to carry for want of physical activity.

Experimentation had left him completely baffled. "Enough of it", he recounts, was his retort in a gruff tone, when a relative of his suggested something else. Resigned to his fate, Manoj turned up at the Rehabilitation Centre of the Delhi's well-known Safdarjang Hospital to secure a 'certificate' for his disability. With a glow of satisfaction in his eyes, he adds, "the visit proved a blessing in disguise". It was the real turning point. He found a new ray of hope in his otherwise, dreadful life. The medicos, physiotherapists and occupational therapists of the centre, he points out, "gave a new meaning to my life". They taught him how to combat with the adversity instead of brooding in melancholy. And today, he is a successful enterprenuer, with a loving wife as the life companion.

Disabled, troubled they are physically, do not seek sympathy but understanding from the society. They can add their mite without being a liability. A simple thoughtfulness from others around can mitigate their hardship without taxing any one. Sumeet brings it home poignantly when he refers to how his school principal had thoughtlessly refused to shift his classroom from the first floor to ground initially. And how another school principal made things easy when Sumeet was to take secondary examination. As the examination centre head, adds Sumeet, the principal arranged a seat at the ground floor for him even without putting a request. His aggregate pass percentage in the senior secondary examination came to 77 per cent, with a distinction in Economics.

In a country, where the population of disabled is estimated to be around 60 million, there is a crying need that the society, as a whole and not one of its wings, say official machinery, alone should recognise its responsibility towards the less privileged as the disabled are. It may come as a surprise to most that physical aids, like lifting devices, for the disabled have to be imported despite such a huge domestic market. Should it not make an economic sense to any of our industrialists' to put a plant to manufacture some of the such appliances?, wonders Sumeet. Close interaction with some of such patients gives quite an insight about the problems the disabled face. Thus, it is also seen that the family of a disabled plays a pivotal role in not only mitigating the sufferings but in moulding the outlook of the physically handicapped. In the case of Mr.Bhargava, for instance, it was the wife and two college going children who stood by him, despite the fact, as Mr.Bhargava says, he was made to resign his cushy job by the industrial house. No mercy was shown to him. No on-job infliction compensation was paid. Whatever funds he could garner by way of gratuity payment or the provident fund was just enough to cover medical and incidental expenses. The trio-wife and the two children-kept their cool, and today the family is once again on its feet.

But there is other side too attached to the coin: it is an over indulgent family. Take the case of Manoj. The crippling incident occured in his life when he had barely entered his twenties. In the parents' eagerness to see their child once again old self, heeding to indiscriminate advice became the habit. It led to mental agony more than the physical one, as Manoj says. And he would have suffered more had he not headed towards the Rehabilitation Centre which, he acknowledges, has accorded him a new lease of life. The close ones like the family have to be discerning while seeking medical or other attentions for their disabled. There is no substitute to learning, whether it is academic or otherwise, as both are aimed at making the afflicted person financially viable. The two Arora brothers would not have been gainfully employed had they not excelled in their academics. Manoj, hailing from a business family, would not have ever been materially in want as a disabled. But since he preserved his marbles he has been able to chalk out an independent path for himself, thus making himself and his wife economically viable.

In a developing economy like India, employment generation always poses a problem. And the result is that the physically impaired are always looked down as the second rate tools. The mindsets of the employers' always work as a barrier. In the state sector, legislative enactments do exist for the compulsory reservation of vacancies, it is the private sector—again a massive employer—which has to be harnessed to the cause of handicapped. If need be, as it has time and again been pleaded, suitable enactment should be brought about than leaving it to the whims and fancies of individual employers.

Physical handicap, as Manojs, Summets and others have cried themselves hoarse, does not denote lack of emotions, though, they are stressful, the society in general takes it so. For Summet it is impossible to visit a cinema show for he cannot reach the hall in the absence of ramp or a lift. Similarly, eating out is always out of question, for his wheeled situation does not permit him legway anywhere. As in the west, working places, entertainment centres and so on should be disabled friendly which could give them easy access to such places and thus make them part of the social structure and not outside it.

### CHAPTER 36

# POST-INDEPENDENCE DEVELOPMENT: A CRITIQUE

## FROM CHARITY TO PROFESSIONALISM

A locomotor disabled, to put it mildly, is doubly disadvantaged. To wit : physical challange and then societal apathy. It makes the problem of rehabilitation of persons so afflicted formidable thus. What adds severity to the situation is the grim reality of mounting figures of such disabled if they do not get the consideration it calls for. The National Sample Survey Organisation indicated in 1991 that some nine million odd people in the country were suffering from the trauma of locomotor disability. And the fears are the number might have scaled further up on account of various reasons, some of which, ironically though, may have led to such progressive steps as drastic increase in longevity of an average Indian and reduction in infant mortality rate.

A vast network of health care system developed through successive developmental Five Year Plans for the country's gargantuan population, sadly enough, lacked the medical rehabilitation component. Furthermore, the specialised institutions developed over the years to afford specialised health services are still small in number compared to the vastness of population. But what adds insult to the injury is the confinement of such specialised health service institutions to the big cities, and thus, bypassing the villages where in majority of the Indians live. No doubt there is an army of city, primary and subhealth centres, numbering something like 170,000 or near about, dotting all over the country.

The first ever endeavour towards medical rehabilitation came in 1956 with the setting up of the All-India Institute of Physical Medicine and Rehabilitation at Bombay lately christened as Mumbai. Since then, partly on account of lack of planning, and partly because of paucity of funds, it has remained the lone institution of its kind, though there is a crying need for similar institutions elsewhere because of physical vastness of the country. Obviously, it deprived majority of our denizens of the medical rehabilitation facility.

For the disabled, who deserved the medical rehabilitation most alongwith the social one, even the next two decades of sixties and seventies could not bring any cheer as no notable place for them could be located when the courses of the national level health policies were being chartered. The silver lining, however, came in the form of establishment of National Institutes by the then Union Ministry of Welfare as they were equipped to deliver complete range of medical attention to the disabled people. Preventive, promotive, curative and rehabilitative aspects, though formed the core component of the health care following the Alma Ata Declaration of 1978, it missed out on the rehabilitative feature. Thus, the health care services got further distanced from the locomotor disabled.

The observation of 1981 as the International Year of the Disabled saw the flowering of the rehabilitation services for the disabled in the country. The then Ministry of Social Welfare, now baptised as the Ministry of Social Justice and Empowerment, was declared as the 'nodal ministry' for the welfare of the handicapped. The four National Institutes for the disabled: Institute for the Orthopaedically Handicapped at Calcutta, Institute of Rehabilitation, Training and Research at Orissa, the Institute for Physically Handicapped, New Delhi, and Artificial Limb Manufacturing Corporation of India of Kanpur, were strengthened. A scheme of District Rehabilitation Centres got off the ground on a pilot basis four years later. In 1989, its evaluation was carried out but without encouraging results.

The Rehabilitation Council of India, established in 1986, developed, standardized and circulated 48 degree/diploma/certificate level training programmes, over a dozen of which are specifically meant for locomotor disabled persons. Yet, developments of eighties proved as disincentives for health planners to take initiative in the area of medical rehabilitation.

In November 1995, a Pilot Project on Medical Rehabilitation was launched under the auspices of the AIIPMR of Mumbai in five districts of five states. The objective was disability prevention and provision of basic rehabilitation services by training, re-orientation and equipping/strengthening of primary health centres. It was another right initiative, and experience gained after its completion, could be utilized for introducing systemic changes in PHCs all over the country to widen the sphere of rehabilitation services. The project is being continued as a Central Sector Health Project in the Ninth Five Year Plan. Adequate funds should be provided and effective steps taken to bring all categories of handicapped within the ambit of such services by the end of the Plan.

During 1999, the RCI launched a national programme to orient the medical officers working in the Primary Health Centres to disability management, the main objective being disseminating knowledge about prevention, promotion, early identification, intervention and rehabilitation for the common disabilities, and also to make them aware of the existing institutions available for the disabled persons, so that the medical officers could refer the patients to the appropriate place of management. It can prove as a crucial measure in promoting the cause of rehabilitation of the disabled. Unless the programme is pursued with real zeal and necessary resources, it will not succeed in providing the rehabilitation services at the grassroot level.

In spite of setting up of the National Institutes, and Institutes at other levels, and also launching of various programmes and schemes, it has not been possible to overcome the serious shortage of rehabilitation services for the disabled. The most important drawback in the delivery of medical rehabilitation services to the disabled has been that the various national programmes, which are being pursued through primary health care network, did not find any component of medical rehabilitation in their intervention package. It is because the primary health care services, which are covering 90 percent of the population of the country, are without any medical rehabilitation services. Moreover, development of these services has been very uneven and unbalanced which have left most of the rural population without such basic health care too. Regional imbalances also exist. Consequently, the disabled people have to travel long disatances to avail of whatever services are available in the country. The experience has revealed that the Community Based Rehabilitation [CBR], a strategy, promoted by the WHO since 1970, will be an effective tool of providing rehabilitative services to the disabled if the scheme is integrated into the primary health care. There is, therefore, a strong case for launching a National Programme of CBR to universalise services in rural and urban areas throughout the country. If serious efforts are made in this regard there is every likelihood of securing more assistance for the purpose from the WHO, as it has pioneered the concept of the CBR.

It is also seen that Kerala and Tamilnadu are leading in so far as the health parameters of locomotor disabled are concerned. They have a network of medical rehabilitation services through independent PMR Department at medical college and district levels while at the primary health care system and down below, it is fully integrated in the PHC by additional logistic training and funding. It is necessary to recommend that the Central Government shall adopt the Kerala and Tamil Nadu system as the role model for every state, and encourage then to emulate it.

We may now critically discuss the other aspects of rehabilitation of disabled persons who should necessarily have complete integration with the society.

India has a very rich tradition of voluntary participation. It speaks for voluntary sector participation in the rehabilitative needs of the locomotor disabled. During the past five decades the approach of the voluntary bodies has transferred from *charity to professionalism*. The Government of India and the State Governments have also encouraged the voluntary sector by providing financial support in opening centres/departments/institutes for the rehabilitation of the locomotor disabled and training the rehabilitation professionals, required for providing the services. But the net result is, there is an unbalanced mixture of governmental and non-governmental organisations providing rehabilitation services to the locomotor disabled. It has boiled down to a situation that the locomotor disabled services are hardly accessible to less them five per cent of the disabled population. The key factors responsible for this poor coverage are: un-coordinated planning, inadequate funding and ill planned services. Therefore, effetive strategies must be developed in order to rectify the shortcomings so that universal coverage of services can be provided to the locomotor disabled.

Rehabilitation of the disabled is not complete without their social integration which cannot be without education. The government introduced in 1974 the scheme of Integrated Education of Disabled Children (reference has been made earlier). According to the 1998-99 Annual Report of the Ministry of Human Resource Development, the scheme was being implemented in 26 States/Union Territories in 1500 schools, benefiting 55,000 children. The scheme, though started 25 years ago, is slow and also not very satisfactory. It can be successful only if facilities can be provided to the mass of the disabled population. There are very few schools providing integrated education in rural areas, and special schools meant for children with severe disabilities, are virually non-existent. Neither the State Governments nor the voluntary organisations have shown much concern for the disabled children in the rural areas. There is thus need for expansion of IEDC scheme to cover rural areas, where Special Schools in adequate numbers too should be set up.

There is dearth of qualified teachers for dealing with disabled children in regular schools. The National Council for Teacher Education is engaged in developing a curricu-

lum for teacher orientation training so that both 'general' and 'resource teachers' are trained to handle disabled children. These efforts have to be stepped up to meet the growing demand.

Realizing that the IEDC, in its existing form was, not producing the expected result, the Ministry of Human Resource Development adopted in 1987 the Project Integrated Education for the Disabled [PIED] (briefly discussed earlier). Apparently the PIED approach appeared to be an improved version and could be universalized in all the blocks of the country to benefit the disabled children.

Vocational training of the disabled is very necessary for their gainful employment. It has to be given top priority. Vocationalization should start early enough when it is realized that the particular child cannot benefit from any further academic education. The IITs and the various National Institutes set up by Government no doubt provide vocational training to the disabled but considering the number of disabled persons we do not have sufficient number of vocational training institutions. Moreover, the existing training programmes cater largely to the needs of the organised sector of urban areas. The training facilities should be expanded at every level to give cover to rural areas and unorganized sector. The ITIs and the National Institutes must be strengthened to meet the ever increasing demand.

To help the disabled persons in getting gainful employment, 24 Special Employment Exchanges and 37 Special Cells in normal employment echanges set up by government are functioning throughout the country. Three per cent of the vacancies in Group-C and Group-D posts under the Central Government are being reserved for the disabled persons— One per cent of them is meant for the orthopaedically disabled. But even this meagre quota of reserved vacancies does not get filled up. Urgent action should be taken to fill the vacncies reserved for the disabled and also to clear the backlog of unfilled vacancies.

The private sector has by and large neglected employment of the disabled. Measures must be initiated to effect progressive employment of these people in this sector. It can be done by implementing the stipulations of Section 41 of the PWD Act, which speak of providing incentives to ensure that at least 5 per cent of the workforce is composed of the disabled persons. If necessary, suitable legislation be enacted spelling out percentage of employment for the disabled in the private sector.

The National Handicapped Finance and Development Corporation set up in 1997, promotes inter alia self-employment of the disabled. The amount of assistance provided for example, during 1998-99 was Rs.28 crore. [Annual Report of the Ministry of Social Justice and Empowerment, 1998-99]. There is need to augment this assistance considerably to cover a wide spectrum of the disabled in urban and rural areas. Skill training suitable for self-employment particularly in rural sector, should be developed for the benefit of unemployed disabled youth.

Only seventeen vocational rehabilitation centres are at present functioning, although the scheme was started 25 years ago. The institutions are very useful in providing vocational guidance, training and counselling to the disabled after assessing their vocational and psychological needs. There is a need for setting up more such centres both by central and state governments in the years to come.

Need to increasing the mobility of the disabled is of paramount importance for their social integration. Provisions have been made in the PWD Act for removal of physical

barriers from roads and the built up environment. In most of the public buildings/places, such as, railway stations, offices, post offices, banks, etc., ramps and slopes do not exist nor are there proper facilities for movement of the disabled, especially those who have to use wheelchairs. The disabled persons are thus prevented from using the facilities offered by these places. It is incumbent on the authorities controlling/owning the public places to provide ramps, slopes, wide doors and so on in such places. Similarly, the local authorities concerned must provide curb cuts and slope in pavements for easy access of wheelchairs. The provisions of the PWD Act such as in Sections 45 and 46, regarding non-discrimination on the roads and in the built up environment, are relevant in this connection and should be scrupulously enforced.

In the residences of the disabled, the family/parents are duty bound to remove all physical barriers from homes by suitable architectural modifications, if necessary. Unfortunately, the indifferent attitude of many parents in this respect plays havoc with the lives of the disabled who have then to face physical and psychological trauma.

The disabled need different kinds of aids and appliances, including walking aids, for restoration of their mobility as far as possible. The Artificial Limbs Manufacturing Corporation of India [ALIMCO], a public sector company, which has been manufacturing such aids since 1976 is unable to meet the requirements. The private sector units producing such devices turn out products of inferior quality. So, standardization by Bureau of Indian Standards is called for. Furthermore, either the manufacturing capacity of the ALIMCO should be considerably increased or another plant of this type should be set up to cope with the rising demands. In addition, research inputs in this area are essential to develop better, light weight and cosmetically acceptable appliances suiting indian conditions.

Under the 1981 scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances, assistance is provided to needy physically disabled persons for aids/ appliances not costing less than Rs.50/- and not more than Rs.6000/- as per the schedule of incomes given in Annexure-I. The income limits need modification/revision from time to time, keeping in view the prevailing inflation. It is also observed that an amount of only Rs.25 crores was allocated for this purpose during 1998-99 and Plan outlay of Rs.26 crores has been proposed for 1999-2000. Considering the large number of persons need-ing the aids and appliances throughout the country, provision now being made is meagre, it needs to be enhanced.

Holding of exhibitions of aids and appliances, like the international exhibition that was held in Delhi in September 1998 should be a regular feature so as to make the public understand the potentiality of the disabled and generate a confidence in the common man in the abilities of physically challanged.

It will be seen that in spite of great expansion of the health care system in our country during the past fifty years, the lack of adequate manpower, especially in the areas of disability prevention and rehabilitation has been a weak link in the national health programmes because of which these programmes could not achieve their targets. In fact, the number, and pace of production of trained manpower has not been keeping pace with the needs of the country. The problem of mass emigration of trained manpower in search of greener pastures aggravates the situation.

All the National Institutes of Rehabilitation as well as Rehabilitation Institutes of National Level are actively contributing to the training of rehabilitation manpower. The key role of medical colleges is manpower training. It is felt that the government should build up the facilities at the district hospitals also. The availability position of trained manpower is really very unsatisfactory as revealed by the 1996 report on Manpower Development of the RCI. As shown therein the number of institutes offering training courses in rehabilitation was 27 for the locomotor handicapped category and the available trained manpower in this category was 1502. There is an acute shortage of trained rehabilitation personnel. (The projected number of rehabilitation professionals needed for looking after the locomotor disabled persons is reflected in earlier chapters.) To augment supply of manpower, a comprehensive plan at the national level is needed which must aim at strengthening of the existing training institutes/colleges and creating such new institutes as may be considered necessary.

The Rehabilitation Council of India, set up to improve the quality of trained manpower in the field of disability, is playing a very useful role in contributing to development of manpower in almost all disciplines connected with the rehabilitation of the disabled. In particular, the Bridge Course, a unique one-time opportunity devised by the RCI since October 1998 has been quite beneficial. It provided the necessary knowledge and skills to personnel for working with persons with different types of disabilities, who had no formal training. The National Programme for Orientation of PHC Doctors to disability management, started in 1999, would also promote the cause of rehabilitation of the disabled persons.

The Medical Council of India is also playing a good role in this regard. It has sent a directive to all Medical Colleges to start the department of physical medicine and rehabilitation in their colleges to enable the undergraduate students to get orientation to the rehabilitation medicine and also to start postgraduate training in this speciality. Inclusion of the teaching of rehabilitation medicine in curriculum of the undergraduate medical students by the MCI is also a welcome step towards acquisition of the requisite training material.

However, the MCI directive has met with difficulties. The central/state governments must ensure speedy implementations of the directive, so that in the near future all the medical colleges have a department of physical medicine and rehabilitation.

There is a great need for reliable statistics relating to disabilities in order to plan the strategies of rehabilitation of the disabled. These are, however, lacking at present.

It is observed that the then Ministry of Welfare had set up in 1987 the National Information Centre on Disability and Rehabilitation to collect and compile information on different aspects of the welfare of the disabled. The establishment of this centre was no doubt a welcome addition but a much needed step. As stated above, various schemes and programmes for the welfare of the disabled persons have been started by different agencies from time to time. Many problems and new situations may be encountered in the process of carrying out of these schemes, as otherwise, there are numerous issues connected with the rehabilitation of the disabled. Therefore, authentic statistics relating to all the aspects of rehabilitation (for instance education, employment, leisure, social security etc.) age-wise, disability-wise, region wise, strata-wise, etc. need to be prepared and made easily accessible to all agencies and individuals concerned with the rehabilitation/welfare of the disabled. It is another must in a country of multi-languages and with a culture of different nuances. Use of technology in the sphere of rehabilitation of the disabled has certainly mitigated the functional limitations caused by physical impairments. Latest technology should continue to be applied in the manufacturing and devising of aids and appliances. The Government of India started in 1988 an S&T Project in Mission Mode on application of technology for providing suitable and cost-effective aids and appliances using new technologies and improving the mobility and enhancement of employment opportunities for the disabled. If pursued effectively, this scheme will go a long way in revolutionizing manufacture of aids and appliances needed for the disabled. In the course of reasonable time, we should be able to have the use of motorized tricycles and battery operated wheel chairs and automatic guided vehicles in appreciable numbers. Also, we can have lighter prosthesis made of carbon fibre, polyurethane etc. Powered wheelchairs and computerised wheelchairs would also become available. Moreover, with a puff wheelchair, which is also on the anvil, a totally paralysed person can be made mobile. Furthermore, remote controlled machinery in the industries would facilitate increasing employment opportunities for people with locomotor problems.

These facilities can be possible only if sustained efforts are made to update the technology in this field. Need is to standardize the products, and ensure their manufacture by providing industrial incentives.

The onus of relieving the economic distress of the disabled lies on the society as a whole. Therefore, facilities like disability allowance, compensation in case disability is acquired while working, compulsory insurance, insurance against disability, etc., should be available to them. Some social security benefits are available to persons working in the organised sector of employment, but the vast majority of the working population in unorganised sector, and those employed in agriculture, are outside the ambit of social security net. Urgent attention needs to be given to provide relief to these sections of disabled persons.

The existing provision of disability pension/social security pension of rupees one hundred per month admissible to disabled persons of sixty years and above is not enough and its limit should be raised while the age limit of sixty and above should be brought down so that a substantial number of needy persons could be benefitted. Similarly, the unemployment allowance of rupees fifty per month given to disabled persons registered with employment exchanges should also be raised from the pittance of rupees fifty per month to a respectable amount, say, rupees five hundred.

The social security measures provided in the PWD Act, namely, insurance scheme for the disabled or an alternative security scheme for the disabled employees has now a legal backing and should be implemented without further delay.

Another matter that deserves serious and urgent attention is the uncertainty about the future of disabled children/persons whose earning parent or parents die leaving the young disabled behind in dire circumstances and uncared for. Some sort of rehabilitation homes must be established by the State to take care of these unfortunate individuals. This aspect was stressed by Minister of State for Social Justice and Empowerment, on the occasion of National Awards function on the International Day of the disabled, 1999 at New Delhi.

The concept of the Welfare State is reflected in our Constitution, which envisages special provisions for special groups, namely, women, children, scheduled castes and scheduled tribes. But unfortunately, no special dispensation has been made for the disabled persons. With a view to give a fillip to measures for the total upliftment and rehabilitation of disabled, it is suggested that suitable provisions in this regard may be incorporated in the Constitution, even if it calls for necessary amendments. Moreover, suitable amendments may also be made in the Constitution for reserving seats for the disabled in the Lok Sabha—proportionate to their numbers—to give them a representation in the process of law making. Also thought should be given to the feasibility of nominating disabled persons to the Rajya Sabha. The two steps together can help disabled to have their say on issues concerning them.

Apart from the guarantees that may be introduced in the Constitution for the disabled, suitable legislations may also become necessary from time to time to ensure continuing rehabilitation of the disabled in all respects. The PWD Act in this context is a welcome step. However, the provisions made in the Act for securing welfare/rehabilitation of the disabled by Government and other authorities, are hedged in with the clause "within the limits of their economic capacity and development". This stipulation would restrict the scope, in some cases reduce the impact, of the measures that may be taken for the amelioration of the lot of the disabled. Therefore, this stipulation may be done away with, and the various provisions of the Act must be implemented on the priority basis. Even otherwise, the position regarding implementation of the PWD Act, as it is, has been very unsatisfactory. This is examplified by the statement of the Chief Commissioner for Disability, appointed under the Act, who said in New Delhi on December 11, 1999 that only four states [Kerala, Gujarat, Punjab and Rajasthan] had so far taken initiative to appoint full time Commissioners for Disabilities. Lack of commitment to implement the PWD Act is obvious.

The Government of India has been giving annual National Awards in field of welfare of disabled. Separate awards are presented to outstanding employers of the disabled and the most efficient disabled employees including self employed persons from the Government, Public and Private sectors. In these three sectors, two awards each are given to locomotor disabled. In each sector one award is given to employers.

Awards are also given to the best placement officers. The best institutions working for the welfare and rehabilitation of the disabled persons and the best individual voluntary worker also get National Awards. Since 1987-88, the Government has also been giving annually National Technology Awards for the best technological invention for an aid or appliance which would ameliorate the handicap and substantially help persons suffering from the disability.

The scheme of giving National Awards is a positive step of recognizing efforts rendered in the cause of disabled persons. The National Technology Award has the added advantage of improving effectively the productivity or employment potential of the disabled. The scheme should be made more attractive by increasing the quantum of awards. Wide publicity should also be given to this dispensation to encourage people to participate in the scheme in increasing numbers. TV and radio interviews of winners of National Awards should be regularly arranged to increase awareness amongst the masses about the potentialities of the disabled. It is suggested that a scheme of giving awards to production of literature intended to promote the cause of the disabled persons in areas of education, training and employment should be started. Such a step would further increase general awareness amongst the masses about the problems faced by the disabled.

## CHAPTER 37

# LOOKING BEYOND THE MORROW

### INTRODUCTION

With his time transcending observation: 'Hope springs eternal in the human breast', the 18th century English poet and critic, Alexander Pope, gave vent to the immortal optimism that humanity personifies. For, the poet, crippled in childhood by a spinal affliction, had to face the world at a time when it was yet to awake to the needs of disabled. Yet, despite his physical disability he self-educated himself and reached the pinnacle of fame which encountered no barriers.

A disabled, faced with all sorts of physical limitations, can prove to be a worthwhile member of the society provided the physically challanged themselves in well coordinated efforts with the concerned agencies of the government or otherwise make a concerted effort to improve their seemingly hopeless situation. Of course, meticulous planning, alongwith the will of planners, administrators and the community in general, has to be made keeping in view of the extent of the problem. One should not forget, with the advancement of medical and other sciences and technologies we may be able to reduce considerably some of the present forms of disability, though there cannot be any guarantee that a few newer one will not arise. Yet, every segment of the society should be sensitized to the problems of physically challanged so that the society can reduce the impact in a concerted manner.

### POSSIBLE FUTURISTIC TRENDS OF THE CHALLENGE

India, as per the 1991 National Sample Survey, is saddled with some nine million locomotor disabled. In other words, it means roughly one per cent of the Indian population is afflicted with the problem. And there are sure signs of the problems rearing its head in future instead of lowering down. The indicative factors are :

- Burgeoning population is almost touching 1,000 million mark. The UN's Fund Population Activities has put the world's annual population growth rate at 80 million, and what is disconcerting, according to the UN estimates, one fifth of this increase comes from India. Speaking plainly, it means, we are adding some 16 million mouths, and many of them with congenital factors, each year.
- Drop in infant mortality rate—considered to be 71 per 1,000 now, a happy tidings otherwise, again adds to the problem. It means, with improved child survival rate the high risk babies are able to survive, thus contributing to the rise in childhood related disability like cerebral palsy.

- With improvement in medical and health care programmes and practices, many elderly people, who would otherwise have not survived now have a longer life but in a disabled state. A closer look will show the country may have to do with a larger segment of elderly disabled in wake of increase in average life expectancy—63 years at present, since advanced age gives rise to degenerative conditions.
- Bane of the industralization is increased urbanization. This coupled with the green revolution has given rise to urbanized problem of road, industrial and mechanized farming accidents.
- Decrease in morbidity, caused by communicable maladies like Poliomyelitis—which is virtually on its way out—signifies that locomotor disabilities caused by Polio would not be there in future. Of course, an encouraging sign.

The scenario just presented is a mixed bag. With the extinction of Polio, locomotor disability will be less. But the other four afore-mentioned causes give rise to hope and despair at the same time. For instance, longevity in life expectancy, drop in infant mortality rate, improved health care, all bring a good news. But all this leads to locomotor disability in one form or the other. Thus, it can be anyone's guess that well coordinated efforts in a concerted manner would be needed to lessen, if not ward off completely, the problem of disability and give cheer to those who, despite the best of everything, get inflicted.

### Accidents

In a large number of cases, locomotor disabilities can be prevented, if due precautions are taken in advance. While India is said to have one per cent motor vehicles in the world, its share of road accidents is nearly six per cent—isn't it mind boggling? A great number of accidents can be reduced considerably if traffic regulations are vigorously enforced, performance of vehicles and drivers is improved to create a better traffic sense. Besides, attention should be given to proper maintenance of roads.

Agricultural accidents too can be prevented largely by redesigning existing machines like threshers, chaff cutters etc. Similarly, proper vigilance and better maintenance of machines in industrial establishments would reduce accidents to a great extent. For prevention of accidents, an organised effort need be made together with optimum use of mass media and educational campaigns.

## Leprosy

As regards leprosy, the preventive measures that were already in existence, got a boost with the redesignating of the National Leprosy Eradication Programme in 1983. With the advent of MDT, the number of new leprosy cases have come down drastically, but the leprosy affected patients with deformity and ulcer, will continue to require medical rehabilitation services. The Union Government intends to eradicate leprosy by the year 2000 A.D. While efforts to eradicate Leprosy should continue, but it is doubtful if it is possible to achieve the goal by next millineium. Given the requisite zeal and the political will we may hope to eradicate leprosy during the first decade of the next millenium, at the best.

### Malnutrition

The problem of malnutrition is complex and is undoubtly related to poverty. Schemes, such as the Integrated Child Development Scheme [ICDS], Special Nutrition Programme and Mid-day meal programme have in certain States been launched to fight the problem of malnutrition amongst children. It is, however, felt that owing to small quantity of food supplied compared to actual need, interruption in supplies, culturally unacceptable food supply and soon much headway could not be made. It was quite unrealistic to expect that these schemes, not pursued with the requisite zeal and backed by inadequate resources, could solve the problem of malnutrition among children at a massive scale. The focus therefore shifts to poverty. The vast majority of India's population is poor. According to the UNICEF report of 1995, India had the largest number of malnourished children in the world. Unless poverty is removed, the problem of malnutrition cannot be solved. Even after 52 years of our independence the problem of poverty is still with us, and given the existing socio-economic scenario, the prospect of removal of poverty in the near future seems indeed bleak. Therefore, there is need for a deep introspection and radical overhaul of our socio-economic policies and programmes to solve the problem of poverty to eradicate malnutrition.

### Fluorosis

Fluorosis, caused by excessive amount of fluoride in drinking water may eventually lead to crippling. Though untreatable, it can, hower, be prevented by checking drinking of high fluoride water and eliminating consumption of food items, drugs and toothpaste which contain excess fluoride. Now that the technology of measuring fluoride content in water and to defluoride water is cheaply available, the government can make efforts to solve the problem through more concerted efforts and tackle the problem on priority basis. A variety of media means should be utilized in educating the public about the damage that is done by consumption of water and other edibles containing excessive fluoride.

### Lathyrism

The scourge of lathyrism can be eliminated only if cultivation of *Kesari Dal* that causes it, is banned. This is a cheap product and is used to adulterate other dals. All State Governments, except Bihar, Madhya Pradesh and West Bengal, have prohibited the use of this dal for human consumption. But only the State of U.P. has banned its cultivation. Half-hearted measures, like prohibition of its use for human consumption would not suffice. No risk can be taken with the human lives and a total ban on its cultivation has to be imposed to avoid adulteration now and in future too.

## Polio

Polio is another preventable condition through administration of polio vaccine. Inspite of this, it had been the most common cause of locomotor disability in India. The government is fully seized of the enormity of the problem, and of late, a massive campaign of

immunization is being conducted every year. It is hoped that given the sustained commitment and strong social mobilization, India would be able to meet the WHO target for global eradication by 2000 AD.

### Tuberculosis

In India, 14 million people are estimated to be suffering from active tuberculosis, of which 3 to 3.5 million are highly infectious. Tuberculosis causes a large number of locomotor disabled due to tuberculosis of brain, spinal cord, bone and joints. A National TB Control Programme was in operation since 1962 to contain the problem of tuberculosis. The programme was reviewed in 1992 and the Revised National TB Control Programe [RNTCP] is in operation now, and is periodically reviewed by the Ministry of Health and Family Welfare.

Concrete efforts are required to control the spread of tuberculosis by various factors contributing its spread head-on.

### Stroke

A pilot project was initiated by the Indian Government in 1995-96 to deal with the control of non-communicable diseases like cardio vascular disease, stroke and diabetes mellitus. It is envisaged that with this governmental effort, the number of cases of stroke and other noncommunicable induced locomotor disabilities will be brought under control in the near future.

### **MEDICAL INTERVENTION**

Medical intervention is an important component in the process of complete rehabilitation of person with locomotor disabilities. There are, however, some deficiencies in the existing status of medical rehabilitation services. Only two percent of the disabled people are able to receive rehabilitation facilities in urban areas, and, the rural areas where majority of our population lives, are virtually left to the divine care Also, the institutions providing the requisite facilities are very few in number in the government sector. The organizations in the voluntary sector are also not able to meet the country's requirements. Moreover, there are hardly any specialised disability specific centres.

There is, therefore, a need for more rehabilitation centres both in the government and other sectors. These centres should be spread all over the country uniformly in urban and rural areas and the services should be made available in all the three tiers, i,e., the centre/state level, district level and PHC level, with a good built-in two way referral system. These services can only be provided in future by utilizing the existing health infrastructure.

For providing the above said services, the Medical Colleges need to follow the mandatory requirement of the Medical Council of India to start the rehabilitation department at least one in each state to start with, which will act as Central/State level service providing centres in addition to being referral centres. It will also be able to generate manpower in the field of rehabilitation so as to provide medical rehabilitation services.

The rehabilitation services will have to be planned and provided at the district level because the district provides an excellent organizational framework without which no changes in the health system can be introduced.

Special mention in this connection may be made of the practice introduced in Kerala. Here the State Health Department has provided a rehabilitation unit at district level with the result that rehabilitation services are available uniformly in the State. It would be most desirable that a similar structure is created in other states in order to provide medical health services more effectively.

In the course of her speech on the occasion of the National Awards Ceremony on the International Day of the Disabled, 1999, the Union Minister of State for Social Justice and Empowerment said that the Ministry was in the process of identifying 100 districts where basic rehabilitation facilities will be established in partnership with the State Governments, their district administration and local NGOs. Each centre will meet the requirements of 5 or 6 districts so that persons in all parts of the country could be serviced added the minister.

As regards specialised service centres, it may not be possible to have such centres in the government sector in the next 10 years. Since, there is a crying need for such centres, necessary provision in this respect should be made in the future plans.

## **COMMUNITY BASED REHABILITATION**

The concept of the Community Based Rehabilitation was developed by the World Health Organisation some two decades ago. The process has its roots in the community and has to derive sustenance and support from the community. While utilising the resources of the community in the task of rehabilitation, the community itself has to be further equipped, empowered and prepared to rehabilitate the persons with disabilityies the objective of rehabilitation being integration of such persons in the community.

Given the requisite infrastructure, the strategy can provide the opportunity for people with disabilities to increase their self-care abilities, communication skills and moving freely around. It could also promote their integration in schools, work places and social activity areas. Experience confirms the importance of integrating the community based rehabilitation services into the primary health care system.

It is felt that the CBR would be appropriate for our urban and rural areas and for people all age groups. The approach democratizes the rehabilitation process, and the people, who benefit from rehabilitation, participate in the decision making process to know what rehabilitation consists of for them. It is high time we launched a national programme of Community Based Rehabilitation on the lines of similar other national health programmes. The strategy will have to be adjusted to the prevailing cultural and social conditions.

The CBR strategy is meant for mass scale transfer of knowledge and provision of services. This should be implemented unfailingly all over the country. If adequate provision for medical intervention and CBR is made in the five year plans, a good infrastructure of these services would be developed within a decade or so, and thus will be able to provide very effective services.

### **ROLE OF VOLUNTARY SECTOR**

In the matter of rehabilitation of the people with locomotor disabilities, the voluntary sector has played a prominent role and hopefully it would continue to do so. Their fields of activity include education, training, fitment of appliances and physical restorative services, placement, psycho-social rehabilitation, manpower training etc. Apart from NGOs of the country, certain foreign agencies, mainly sponsored by the United Nations Organisation, have provided assistance in this regard. In addition to rendering financial assistance and providing expertise, they have set up units, such as Cheshire Homes for the severely disabled people.

The voluntary sector has, however, a mixed record of service. Some of the organisations, which have no proper credentials have come up and a tendency has risen to be one up in the game. In many cases, they project certain personalities, most of whom are city based, as to be the head. It is done to gain respectability and to corner resources. There is, therefore, need to make a proper appraisal of the functioning of the voluntary sector. A suitable mechanism has to be there to supervise their working on a continuous basis. The NGOs are mostly urban based and need to spread out in the rural areas where a majority of the locomotor disabled people reside.

Advisably, the voluntary organisations should be multi dimensional. That is, they should perform more than one restorative function. This mitigates hardship of the disabled who would otherwise be forced to run from one place to other to avail of the different facilities needed for their rehabilitation. There is also need for proper coordination within various sectors of functioning of the NGOs, so that working of one sector is closely linked with the other, in accordance with the needs and potentialities of the disabled people.

It is also desirable that proper liaison is maintained among the voluntary organisations and the various governmental agencies and National Institutes catering to the rehabilitation of the disabled. The National Institutes should continue to organise annual seminars and also conduct periodically such seminars on professional matters where voluntary organisations working in the relevant field should be asked to participate. This will provide a forum for professional interaction and learning from each other.

There are always constraints on our financial resources. Therefore, special care should be exercised in the matter of grants and other financial assistance to the voluntary sector organisations. Often, more than one NGO are found functioning in the same area. Moreover, they may be operating in the same kind of activity connected with the field of rehabilitation. These organisations should be asked to operate in one given area instead of performing identical function. This is necessary to rule out duplication of work and the same beneficiary getting rehabilitative assistance without providing any extra rehabilitative services. Avoidable waste of resources must be halted.

### **MANPOWER DEVELOPMENT**

Manpower planning and development in the rehabilitation sector is of crucial importance. All the National Institutes of Rehabilitation as well as Rehabilitation Institutes of National Level are actively contributing to the training of rehabilitation manpower of

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Physiatrists, Therapists, Prosthetists, Orthotists, and Counsellors. The key role of Medical Colleges and Institutions of National level in rehabilitation of persons with disability is manpower training. However, out of a total of 162 medical colleges, only 25 are providing post-graduate training in physical medicine and rehabilitation. The training facilities in these institutes, etc. have to be augmented substantially to meet the growing needs of the country for the trained manpower in future.

According to the 1996 report on Manpower Development, prepared by the RCI, projected requirements of manpower for locomotor disabled persons in future would be as indicated in Table 13.1.

S.No.	Category of Personnel	Nos. to be trained In IX Plan	Nos. to be trained in X Plan
1.	Physiatrists	1000	2000
2.	Physiotherapist/	2000	4000
	Occupational Therapist		
3.	Orthotic/Prosthetic Engineers	1000	2000
4.	Rehabilitation Engineers	500	1000
5.	Clinical Psychologists	100	200
6.	MRWs	5000	10000
7.	Pre-School Teachers	1000	2000

### Table 37.1: Manpower Requirement for Locomotor Disabled

In addition to this, existing manpower has to be sensitized to the rehabilitation needs of the persons with disabilities, through continuing medical education, training programmes.

### **EDUCATION**

Education is essential for empowerment of locomotor disabled people and for their social integration. The government of India has been implementing the scheme of Integrated Education of the Disabled Children [IEDC] since 1974, which has been revised from time to time. The scheme is meant for disabled children with mild handicaps. For children with severe disabilities, Special Schools have been set up, but the number of such schools is very small. According to one estimate, only about 1% of the disabled children have access to education. In this scenario, the coverage of the IEDC and the scheme of Special Schools need to be widely expanded to attain the goal of universal education.

The National Open School and other modes of open learning should be employed for the benefit of the disabled children. In this context, distant learning mode aopted by the IGNOU by utilizing media for the purpose would be of great advantage. Full use should also be made of technology, like computers, for spread of education and for making the disabled self-reliant in getting gainful employment. Similarly, the system of non-formal education needs to be utilised to educate the disabled children. From the sociological and psychological points of view every disabled child needs to be made economically independent. Vocational education is, therefore, very necessary for the disabled children. All Junior Technical schools, Industrial Training Institutes and other such institutions should be strengthened adequately to cater to the vocational training of the disabled on a massive scale.

Physical and social barriers existing in educational institutions and among the people are a great impediment in the way of education of the disabled. All physical barriers must, therefore, be removed wherever they still exist and it must be ensured that all new buildings have a barrier free environment. Negative attitudes of parents of the disabled children towards education must also be removed. Parent enrichment and the counselling programmes are of crucial importance in this regard.

The Union Minister of Human Resource Development told on November 26,1999, at a Press Conference at New Delhi that the Government will amend the Constitution to make elementary education a fundamental right for children in the age group 6 to 14 years. This will fulfill a long-felt need and greatly promote education of the disabled.

### EMPLOYMENT

On the eve of the seminar on Developing Linkages between the RCI and the International Organisations organised by the RCI at New Delhi on 8-9 December, 1999, it was estimated that not more than one to two per cent of people with disabilities are able to secure remunerative work in the organized and unorganized sectors. This causes untold misery to the disabled people as they face lack of social security and have to depend on the mercy of the joint family system or other social institutions. Facilities for the vocational training need to be expanded and upgraded to promote the employment of the disabled.

The existing reservation of three per cent for disabled persons in public services and the public sector in respect of Group C and Group D posts need to be increased to remove the backlog of unemployed disabled youth. The reservations should also be extended to group A and Group B posts. The private sector should also be brought within the ambit of these reservations.

The provision in the PWD Act of giving incentives to employers to ensure that at least five per cent of their work force is composed of persons with disabilities is a step in the right direction.

The employment potential in the governmental sector is limited. Unless the measures as stated above are taken, no major breakthrough in solving the unemployment problem of the disabled youth can be made. The Special Employment Exchanges and Special Cells in Employment Exchanges would not serve much purpose in the face of shrinking employment opportunities, especially in the public sector.

Undoubtedly, self-employment of the disabled persons would further increase employment opportunities for the disabled. The National Handicapped Finance and Development Corporation set up by the Central Government to promote self-employment among the disabled persons should serve as an example for the State Governments to establish such corporations at the State level. The self-employed disabled person should also get priority in placement of orders for their goods to boost marketing of their products.

A debate is raging across the country amongst the political leaders and intelligentsia whether right to work may be declared a fundamental right and incorporated as such in the constitution. On merits there is a strong case for doing so. In fact, such a declaration would be in keeping with the spirit of the International Covenant on Economic Social and Cultural Rights. Article 6, of Part-III *ibid* states that the States Parties to the present covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right.

Till this is done, the unemployed disabled persons should be paid an unemployment allowance depending on their educational and/or vocational attainments, to mitigate their financial hardships.

The Chinese have a system of welfare factories where substantial number of persons with disabilities are employed. Tax concessions are given to enterprises employing more handicapped persons. The factory bus transports workers to and from the place of residence. Japan has promoted employment of the disabled through a system of fixing quota for all government and private enterprises. All firms exceeding a given strength of employees have to employ a prescribed number of disabled employees. Bigger companies set up subsidiary-type organisations which employ mostly the disabled and the parent company guarantees the buyback of the produce. These examples are worth cosidering for adoption in India.

The position of employment of locomotor disabled persons in the rural areas is very unstasfactory. Lack of awareness and fatalistic attitude of the rural fold are some of the stumbling blocks in the way of generating employment in the rural sector. The Nationalised Banks can play a vital role in promoting employment in rural areas by extending the facility of easy loans to the disabled. These people should be encouraged to engage in enterprises like poultry, dairy, fishery etc. They can open petty shops with small investment.

The existing schemes such as IRDP and its allied programme, namely "TRYSEM" may be pursued with greater vigour to generate more emloyment for the disabled persons in the rural sector. Similarly, the strategy developed by "CAPART" to promote rural development by enabling participation of the disabled persons may also be pursued more vigorously.

### RESEARCH

The need for continuing research in matters/areas connected with rehabilitation services of the disabled can hardly be overemphasized. The scenario in disability field is fast changing. New diseases and new techniques in medical treatment are giving rise to unexpected disabilities. Environmental factors are also changing the pattern of disabilities. It is, therefore, necessary to undertake research programmes in co-operation with the National Institutions, universities and other research organisations so as to improve the quality of different rehabilitative services. Similarly, it is hoped that adequate research would be undertaken to develop various materials and strategies for dealing with the diverse needs of people with different disabilities. Hopefully, the RCI will become in the near future a nodal agency for research initiatives in order to co-ordinate research programmes to achieve maximum benefit from the research projects. The areas of research would be varied. These may include the following :

- Prevention of disability;
- Medical intervention [including diagnostic and therapeutic];
- System of measuring quality of life of the disabled persons, like independence, integration income generation, improved relationships, meaningful leisure time pursuits;
- Comparative advantages of different systems of education [integrated or special schools];
- Training and employment;
- Cost beneift analysis of tertiary education;
- Attitudinal changes arising out of tertiary education;
- Identification of cost effective adaptations in jobs, worksettings, working tools, high technology etc.

Reliable statistics of disabilities are not available in India. They are needed for publicity and planning purposes. It is, therefore, hoped that data pertaining to handicapped population—disability-wise and age-group wise—would be collected in a concerted manner in the near future. This is an area calling for urgent attention, if we are to accelerate the pace of rehabilitation of the disabled.

## INTERNATIONAL COLLABORATION

Providing a complete specturm of rehabilitation services to about 100 million odd people with different disabilities and living in different socio-economic environment is a formidable task. This requires financial resources of great magnitude which can not be provided by national effort alone. Therefore, international collaboration is of vital importance. Some international aid and expertise has been forthcoming but the total assistance so far received has fallen for short of our needs. The U.N. Development Fund and several other U.N. agencies have been thinking of offering more assistance to developing countries in the field of rehabilitation and some international governmental organizations have also been contemplating more assistance. It is hoped that the International Organisations, especially, the WHO, the UNICEF, the World Bank, and the ILO would be extending abundant help to supplement national resources in providing much needed rehabilitation services to the disabled population.

### **DISABILITIES ACT**

The PWD Act, 1995 fulfills a long felt need and provides legislative support to the ongoing entire gamut of the rehabilitation processes in the country. It caters to the different aspects of rehabilitation of the disabled people. These include :

1. Prevention and early detection of disabilities;

- 2. Free education to the disabled children, with related facilities;
- 3. Provision of employment to the disabled;
- 4. Affirmative action e.g. provision of aids and appliances to disabled persons, preferential allotment of land for specified purpose;
- 5. Removal of physical barriers in the built environment and on roads;
- 6. Promotion of research in all areas related to the rehabilitation process.

High hopes of the society and the disabled people are pinned on the proper implementation of the Act. If all the provisions of the Act are fully implemented quickly the cause of rehabilitation of disabled population would be adequately served and the hardship faced by them greatly mitigated.

## SPORTS AND RECREATION

A person with locomotor disabilities needs recreation like any other normal person. The disabled person frequently suffers from frustration and sports and recreation can provide the much needed outlet. In fact, recreation can work as therapy for the disabled in as much as emotional needs of a person stimulate the use of muscles which need exercise.



Many sport events of different kinds are organized by various organisations on a global scale in which the disabled from all over the world are invited to participate. In India, a number of voluntary organisations working for the locomotor handicapped are organising sport events at state and national levels. Such events are conducive to social integration of the disabled and should be a regular event with expanded parameter. Much more, however, needs to be done in this direction. Sports should form a necessary component in the progamme of education for the disabled. Similarly, sports and recreation facilities should be provided to the disabled in their workplace.

### **INTEGRATION**

Integration of the locomotor disabled persons should have some obvious components. These are more or less rare in the lives of many disabled people and incidentally their initial letters spell the work 'rare'—a useful aid to the memory. The components are : [i] recognition, [ii] acceptance, [iii] relationship and [iv] experience.

The disabled person must be accorded his appropriate status. If he/she is an adult, he/she should not be treated as a child or as mentally sub-normal. This is first priority. Second, he/she must be accepted by others for what he/she is and he/she must feel this acceptance. Third, he/she must have the opportunity to make normal satisfying relationships in the family and outside. Forth, he/she must have the opportunity to have a normal experience, so far as is in his power.

Moreover, integration with life outside is very necessary for the disabled. It is the prime condition for the development into mature members of the community rather than of an artificial sub-group. And of course acceptance in the community with equal rights, equal status etc. is the *sine qua non* of full psychological health and a good self-image.

Too often, the disabled person is treated as though he were still a child, deprived of adult status of responsibility, choice, freedom of action, beholden to others and expected to obey. Vital decisions and choices are generally made for him, he is overprotected and is unaccustomed to hazards, responsibilities and challenges of running his own life in his own way. These tendencies must be curbed and the disabled person allowed to behave in a natural environment. Otherwise he will never become independent and develop a dependency pattern. On his part a disabled person, to be accepted, must first accept himself as he is, realistically and must achieve a measure of integration within himself.



The fact that provisions for the disabled are made out of charity or compassion fosters undesirable attitude amongst the disabled. Phrases like 'these unfortunate children' often used by the so-called charitable individuals create an additional psychological barrier, making it more difficult for the disabled persons to find the natural acceptance as a fellow human being which he has a right to expect. Such attitudes must be given up. Of course, people with locomotor disabilities do need special provision and special facilities but their purpose should always be to enable them to approximate to normality.

#### MOBILITY

Locomotor disability implies a persons's inability to execute distinctive activities associated with moving, both himself and objects, from place to place. This inability results from affliction of their bones, joints, muscles etc.

Para 64 of Section II of the Vienna Declaration and Programme of Action 1993 says that the place of disabled person is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society. As we all know, loss of mobility is the biggest hurdle in the social integration of the disabled person. As a result of his disability, the person concerned is unable to move freely and the unnatural restriction imposed upon him gravely undermines his social inter-action. He often becomes depressive. It is here that medical intervention comes. Surgical correction in many cases reduces considerably the impact of impairment suffered by him. Therapeutic interventions must be undertaken at an extensive scale to such persons for further improvement of functioning of limbs and muscles. Aids and appliances are a necessary concomitant of the process of physical rehabilitation of the disabled. The vast majority of poor people with disabilities cannot afford the costly material available in the market. Therefore, serious thought needs to be given in this regard and arrangements made to supply different aids and appliances to the poor at nominal rates.

The Government of India has a central scheme of assistance to disabled persons fulfilling the prescribed conditions of eligibility for purchase/fitting of aids and appliances under which suitable aids/appliances can be made available to them at subsidized rates or free of cost.

Many of the aids and appliances required by persons with certain locomotor disabilities are not at all available in the country. Hoists or lifters, electronic wheel chairs etc. fall in this category. Import of these is very expensive and therefore, there is an urgent need to arrange for manufacture of these appliances in India and for their supply to the needy persons at nominal cost.

## **BARRIER FREE ENVIRONMENT**

Locomotor disabilities greatly restrict mobility of the persons concerned. This adversely affects their social integration. Lack of mobility even has detrimental effects on their daily living and life style. In this scenario, barrier free environment is a necessity. However, there is lack of awareness in this respect in our country which is evidenced by the fact that most of the public buildings present physical barriers, and even our homes are not free from such barriers. Charity begins at home, is the age old experience. Therefore, first of all, we must have a barrier free home where the disabled can move freely while using aids and appliances. In many cases special toilets catering to the needs of individual disabled persons are needed.

Sections 45 and 46 of the Persons With Disabilities Act deal with the question of removal of barriers on roads and public places. In keeping with these provisions, ramps must be provided in all public buildings, such as, government offices, post offices, banks,

railway stations, airports, hospitals, municipal buildings etc. In some such places ramps are already provided. But where such ramps do not exist, necessary architectural modifications must be made to make these places accessible to the disabled people, especially using wheelchairs. Toilets in all public places must be so built that they can be utilized by persons with locomotor disabilities. It should be made mandatory for the shopping centres/complexes to have ramps. All newly planned structures in future should take care of accessibility for disabled persons.

As regards roads, to facilitate their outdoor mobility, the disabled need to be provided suitable aids and appliances to enable them to go on to the road. It is also necessary that curbs/cuts and slopes are made in the pavements for the easy access of wheel chair users. This facility is invariably provided in the developed countries and there is no reason why this provision cannot be made in our country. Similarly, separate parking places should be provided for the disabled persons for whatever vehicle they may possess.

## **AWARENESS BUILDING**

Lack of right attitude in society about the persons with disability, lack of awareness about their problems, lack of knowledge regarding their potentialities and absence of information as to what could and should be done about them have been the main obstacles in their rehabilitation process. Not only people at large but also planners, teachers and social leaders etc. need in one way or the other to be made aware of the various implications of the rehabilitation processes of the disabled.

It is suggested that like messages disseminated through the media regarding prevention of diseases etc. the media could also cover messages relating to prevention of disabilities and rehabilitation of the disabled people. Wide publicity through the media of the different centres/organisations offering different facilities of rehabilitation would go a long way in educating the people in this regard.

Media can be usefully employed for the purposes of

- moulding and changing the prevalent negative attitude and reinforcing positive attitude amongst the persons with disabilities, parents, families, and the society in general;
- creating awareness about potentialities of the disabled persons and the social and economic benefits of rehabilitation and preventive measures;
- providing right and adequate information to persons with disabilities, parents, families, society in general and the professionals about various schemes, technologies, availability of services etc.; and
- Highlighting employability of the disabled persons to foster encouragement amongst them and to prepare them to undertake jobs suited to their ability and capacity.

There is also need for creating awareness both agmonst disabled persons and their parents/families about the importance of education. Counselling of parents is particularly necessary as many people tend to think that disability of their children have made them useless and education would not benefit them. Career guidance is equally important to the disabled persons and their families to enable them to become productive members of society. Adequate information systems should also be evolved to enlighten business community, industrialists, government officials, etc. about the jobs that can be usefully undertaken by the disabled people. Jobs in which the disabled persons can be employed commensurate with the type of their disabilities need to be properly identified.

### HOUSING

Section 42 [Chapter VII] of the Persons with Disabilities Act *inter alia* lays down that schemes in favour of persons with disabilities should be framed for the preferential allotment of land at concessional rates for house building. In actual practice, negligible work has been done in this regard. The various authorities responsible for allotment of land for building purposes have not launched tangible schemes for the benefit of the disabled persons. Ad-hoc provisions made from time to time can hardly address the problem adequately. Concerted and well coordinated efforts should be made to allot house sites to the disabled at concessional rates, in every scheme of allotment of house sites sponsored by the Government or Local bodies.

But allotting house sites to the disabled would not solve the problem of their housing. In most cases, they may not be able to build houses with physical and financial constraints. Therefore, state should intervene and build houses for them and allot built accommodation to them on easy terms.

### WORKING HOSTELS

There is provision for hostels for the working women in major cities. The Central Social Welfare Board has sponsored a scheme of hostels for the blind where working adults live. Many such hostels have come up. The facility of working hostels on the lines of the afore-mentioned provision should also be provided to persons with locomotor disabilities working in different organisations. These persons should be charged rent on a nominal basis. The hostel should have the facility of food for the residents. Provision for suitable transport to take the disabled to their work place and back should also be made at concessional rates. The hostels could also provide recreational facilities.

### SOCIAL SECURITY

Chapter XIII of the Persons with Disabilities Act deals with social security. Section 67 of the Act states that an insurance scheme for the benefit of employees with disabilities shall be framed by the government. Similarly, Section 68 *ibid* provides that the appropriate governments shall, within the limits of their economic capacity and development shall frame a scheme for payment of an unemployment allowance to persons with disabilities registered with the Special Employment Exchanges for more than two years who could not be provided with gainful employment. These provisions recognise that society has the responsibility to relieve economic distress faced by the disabled people. It is, therefore, in the fitness of things that when income is interupted by unemployment, sickness, accident, etc. social security measures must be provided to alleviate the financial hardship confronting the disabled.

While providing social security to the disabled population in the organized sectors would not be difficult, those who are in agriculture and in the unorganised sectors and are more vulnerable have at present no chance of access to any social security. Therefore, serious thought should be given to provide social security to all sections of the disabled people whether in the organized or unorganised sector both in urban areas/rural areas. Adequate financial resources will have to be allocated for this purpose.

## **TRAVEL TRANSPORT**

The persons with locomotor disabilities would be in need of special transportation system. This facility is almost non-existent in our country. Necessarily, provision should be made for specially designed buses for the disabled with ramps for those using wheelchairs. Hoists to lift them onto the coach are also needed. Seats should have safety belts.

Travel is not only a luxury but a social necessity for the persons with locomotor disabilities. Travel becomes necessary also on many occasions when these people have to travel to participate in social/family functions. Therefore, travel by rail may be unavoidable in many circumstances. However, ordinary railway coaches are not suitable for the disabled to travel. These do not have adequate space for easy movement of disabled people using aids and appliances. Similarly there is no facility for entering of such people into the compartments, except by physically lifting them and putting them into the train. It is thus necessary that special coaches should be designed by the Railway Department keeping in view the requirements of people with locomotor disabilities. Until this is done, mobility of these people would again be jeopardised.

### **SELF HELP ORGANISATIONS**

Every locomotor disabled person must cultivate the spirit of self-help to achieve a dignified place in society. He must be fully conversant with the nature of his problems and should be alive to his potentialities. In the past, lack of adequate participation of the people with disabilities themselves has restricted the development of rehabilitation services in the country. There is, therefore, great need for adequate social mobilization of the disabled people alongwith the communities in which they live. A few self-help organizations consisting of the disabled people have come up in the recent past. These organizations are doing useful work in furthering the cause of the disabled people. They can better serve this cause by their own activities as shown below:

- Creating awareness and familiarising masses about the precise needs of the disabled people and their potentialities;
- Giving patient hearing to the disabled people to relieve them of their pent-up feelings, and counselling with the family members of the disabled to sort out problems faced by either of them;
- Keeping the disabled acquainted with information about various facilities and beneficial schemes of government and other agencies;
- Serving as pressure groups in drawing attention of the community to their different problems and thus prompting remedial measures to be taken;

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- Encouraging social interaction amongst the disabled persons and between the disabled persons and able-bodied persons;
- Providing economic rehabilitation to the disabled by mobilizing their own resources;
- Arranging vocational training to the disabled to enable them to become economically independent;
- Publishing and circulating literature to highlight the problems of the disabled and their potentialities to become productive citizens.

There is need for a large number of self-help organisations throughout the country, may be with one such organization having branches at more than one place. The existence of such organizations will by itself stimulate attention and concernof the society to the cause of the disabled.

## CONCESSIONS AND FACILITIES

The Government of India has given certain concessions from time to time and have also been allowing some exemptions and relaxations to persons with locomotor disabilities. Certain financial incentives are also provided to the disabled. These are summarized in Annexure–III.

The existing concessions and facilities, etc., would need to be revised from time to time, keeping in view the escalating costs owing to inflationry effects.

# PARTICIPATION OF LOCOMOTOR DISABLED IN DECISION MAKING

Experience has shown that locomotor disabled persons are not generally consulted at the time of framing of policies, programmes and schemes for their rehabilitation. Consequently, such schemes when implemented fail to achieve the desired results. It is necessary that the disabled people are adequately involved in the decision making stage whenever any policy/programme is drawn up for their upliftment. They should also be represented at committees/commissions set up in connection with rehabilitation of the disabled. This will create a conducive atmosphere for the rehabilitation process to proceed to its successful completion.

The locomotor disabled people constitute almost 2 per cent of our population. They have a legitimate claim for reservation of proportional seats in Parliament and State Legislatures so that their voice is also heard when legislation relating to their rehabilitation is being enacted.

### **OVERVIEW**

A good system of rehabilitation of locomotor disabled persons must first concentrate on effective preventive measures to eliminate causes of disablement. Early medical intervention is then of paramount importance in minimizing the impact of the impairments suffered by the disabled. For their proper integration with society, a comprehensive system of education in all its aspects, including vocational training must be made available to the disabled. More effective steps are needed to remove unemployment of the disabled population. More vigorous measures to provide them social security have also to be taken.

For their full social integration, their diminished mobility has to be increased by providing absolutely barrier-free environment, both inside home and outside. Aids and appliances required for the purpose must be produced more abundantly and supplied to them at subsidized rates. Indigenous manufacture of devices not yet available in India should be started.

It is hoped that while implementing the PWD Act, the Central and other agencies would set up more effective, comprehensive and dedicated machinery capable of giving a continuing and powerful thrust to the delivery of rehabilitation services. It is also hoped that all imbalances area-wise and region-wise, regarding availability of rehabilitative services would be removed and greater stress given to covering rural areas where the vast majority of our people live. With mobilisation of maximum national resources, coupled with the expected international assistance, resource constraints should not be allowed to stand in our way of giving the disabled a useful and quality life in the coming decade.

A positive attitude of the community towards social and psychological problems of locomotor disabled persons is a pre-requisite for the successful implementation of policies and programmes of their rehabilitation. Awareness regarding the requirements of the disabled people is growing in the country. The heightened awareness would lead to a considerable change in social attitudes. The changed social scenario would also augur well in the coming years for proper implementation of systematic and comprehensive programmes of rehabilitation of the disabled for which an adequate infrastructure is being developed.

## **CHAPTER 38**

# FACILITIES AND CONCESSIONS FOR LOCOMOTOR DISABLED

### INTRODUCTION

Whatever is the stage of economic development of a country, none of its citizens (specially, the physically handicapped) could be left out of planning to bring about an improvement in their conditions in a welfare state. With this end in view, a number of concessions for purposes of employment, training, travel, medical examination etc. have been granted to the physically handicapped persons by the Central as well as State Governments.

The persons with locomotor disability constitute a significant section of our population whose potentials should be utilised to the optimum limit. They are gradually coming to be recognised as useful citizens of society. The Central as well as the State Governments have launched several schemes to educate and train the disabled persons and to place them in useful and suitable employment in offices, commercial organizations and industrial houses. Both the Central and the State Governments have taken a number of steps in this direction by way of providing certain concessions to the handicapped.

## SCHEMES TO HELP IN ECONOMIC ASPECTS

#### **Reservations in Jobs**

Since 1977, the Central Government has reserved three per cent of the vacancies in lower level posts. This reservation is not against all vacancies, but is limited to posts which the handicapped can satisfactorily manage. Similar reservations in favour of the handicapped have been made by several State governments and union territories. This reservation policy has been genuinely welcomed by the handicapped population. The Central Government has also set up Special Employment Exchanges to exclusively register and place handicapped job-seekers.

It is generally found that orthopaedically handicapped persons can handle a wide variety of jobs in most organizations. Locomotor disabled persons do not suffer from any learning or sensory difficulty and could, therefore, handle most jobs. Field jobs, which require a high degree of mobility, would, however, present difficulties for them. Locomotor disabled persons should not generally be excluded from any job and should be considered as eligible for holding all jobs other than those types which are outside their physical capabilities. Most of the jobs, whether technical or non-technical can be handled by the locomotor handicapped persons depending upon the nature of the jobs and the degree of the disability. Most of the undertakings/banks and representatives of the various departments are of the view that persons with loss of not more than one upper limb could handle a large number of jobs both in technical and non-technical areas while persons with disabilities of lower extremities could handle jobs in which a high degree of mobility is not needed/ required.

Jobs in Finance, Accounts, Hindi (Translation), Law and Personnel Departments can be handled by the orthopaedically handicapped.

Proper placement of the handicapped persons is not possible without identifying the jobs suitable for employment of handicapped persons.

- 1 % vacancies are reserved for the orthopaedically handicapped persons in group 'C' and 'D' posts in Central Services and in comparable posts in government of the Public Sector Undertakings. Priority is accorded for submission of candidates by employment exchanges against Central Government Vacancies for Group 'C' and 'D' posts.
- Where a sufficient number of persons belonging to a given category of the physically handicapped is not available, the unfilled vacancies will be carried over for a period upto three recruitment years.

## OTHER CONCESSIONS/RELAXATIONS IN RELATION TO EMPLOYMENT OF LOCOMOTOR DISABLED PERSONS

### (a) Age

The upper age limit in the case of orthopaedically handicapped persons has been relaxed up to 10 years for the purpose of appointment of group 'C' and 'D' posts through the employment exchanges.

Physically handicapped persons belonging to the Scheduled Castes/Scheduled Tribes are allowed another 5 years over and above the age relaxation admissible to them as scheduled castes/scheduled tribes.

### (b) Physical Fitness

Physically Handicapped persons are not subjected to the usual medial examination by the appointing authorities but the report of the Medical Board attached to the Special Employment Exchanges for the Physically Handicapped is sufficient for entry into Group 'C' and 'D' of Central Governments Services except in Railways.

(c) Qualifications

Exemption is allowed from typing qualification for appointment to clerical posts if they are found otherwise qualified and certified as being unable to type by the medical board attached to Special Employment Exchange or by a Civil Surgeon where there is no such Board.

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(d) Others

Various Government of India undertakings like Air India, Indian Airlines, Public Sector Banks have also extended some concessions/relaxations in upper age limit varying from 5 to 10 years and physical fitness for recruitment to clerical and subordinate cadres.

## **Economic Assistance for Self Employment**

Under the Differential Rate of Interest Scheme, physically handicapped persons who are pursuing a gainful occupation and have income from all sources not exceeding Rs.3,000/ - per annum in urban areas or semi-urban areas or Rs.2,000/- per annum in rural areas and satisfy certain other conditions, can take loans from the Nationalized Banks.

The amount of loans depend upon the particular scheme proposed to be financed. The normal limit for such loans is Rs.1,500 for Working Capital and Rs.5,000 for term loan.

The rate of interest is 4% per annum. The payment can be made within a period of 5 years.

## Pension and Unemployment Allowance

Some of the State Governments have introduced disability pension/unemployment allowance schemes. Under these schemes assistance from Rs.30/- to Rs.100/- per month is paid to the handicapped.

### Others

Educated unemployed physically disabled persons are eligible for allottment of STD/ PCOs. The educational qualifications for the applicant is VIII/middle school pass for rural areas and at least matriculation/high school pass for urban areas.

### EDUCATIONAL ASSISTANCE SCHEMES

### **Educational Facilities/Scholarships**

### Ministry of Welfare

The scheme covers scholarships for general education from Class-IX onwards and for technical training at certificate, diploma and degree levels.

### Department of Social Welfare

State Governments also provide scholarships to pursue education from Class-I to Class-VIII.

## **Programme of Integrated Education**

The Programme of Integrated Education by placing handicapped children in ordinary schools provides for special coaching classes qualified and specially trained teachers for

every type of handicapped child. Assessment at the time of admission and later at regular intervals is a major feature of this programme.

The Central Government has taken the responsibility of meeting 100% expenditure.

### **Fellowships**

The University Grants Commission has reserved 1% of the fellowships allocated to the Universities for the handicapped.

### **Admissions into ITIs**

In Industrial Training Institutes, State Governments have reserved 3% seats for the handicapped under the Craftsmen Training Programme at the Centre/State level have been instructed to identify trades from among the existing 136 trades designated under the Apprentices Act, 1961 considered suitable for Apprentices. Training of the physically handicapped and to place the maximum number of handicapped apprentices in the establishment concerned so as to achieve the overall target of 3% taking all the establishments in the public and private sectors together.

### Others

Handicapped persons are exempted from payment of application and examination fee as prescribed by UPSC/SSC.

Hostel facilities for physically handicapped students are provided by certain States and Union Territories.

## **TRAVEL CONCESSIONS**

### **By Road**

Many of the State Governments offer either full concession or 50% concession for Travelling in state run buses.

### By Rail

The Ministry of Railways allows the disabled persons travelling with an escort, travel by rail at the concessional fare up to 75% in the first, second and sleeper classes. The concession is 50 % for the season ticket - first and second class.

### By Air

The Indian Airlines Corporation does not give concession to Orthopaedically Handicapped persons, as given to the blind persons. But, the Orthopaedically Handicapped persons are allowed to carry a pair of crutches / braces or any other prosthetic devices free of charge.

### Others

Disabled employees used to get Rs. 100 as conveyance allowance per month. The Vth Pay Commission has revised this scheme. Now persons suffering from disability affecting their lower limbs get transport allowance, that is double of the allowance normally entitled to them in accordance with their pay scale.

### TAX CONCESSIONS

### **Income Tax Concessions**

Section 80 DD of the Income Tax Act provides for a deduction in respect of the expenditure incurred by an individual on the medical treatment (including nursing), training and rehabilitation etc. of handicapped dependents. The limit of deduction is Rs.15,000/-.

Under the Section 80 V, the parent of a disabled minor is allowed to claim a deduction up to Rs. 20,000/-.

Section SS B provides for an additional rebate from net tax payable by a resident individual, who has attained the age of 65 years, to 20% in case where the gross total income does not exceed Rs. 75,000/-

A deduction of Rs. 20,000/- from the taxable income of the parents or guardians of handicapped children has been allowed provided this amount is deposited in any approved scheme of LIC, UTI etc.

Deductions from the total income of the handicapped persons under Section 80 U is Rs. 40,000/-.

### **Customs Duty Concessions**

The Central Government exempts certain pre-identified categories of goods when imported into India by a locomotor handicapped or disabled person for his personal use, from the whole of the duty of customs and the additional duty subject to the condition that the importer produces to the Assistant Collector of Customs, at the time of importation, a certificate from the Civil Surgeon of the District, Medical Officer or the Administrative Medical Officer or the Director of Health Services of the concerned State or a Specialist in the concerned speciality attached to a Government Hospital or a recognised medical college to the effect that the importer suffers from the particular handicap or disability and that the imported goods in respect of which the exemption is claimed are essential to overcome the said handicap or disability. The list includes:

- a) Orthopaedic appliances falling under heading 90.21 of the first schedule to the Customs Tariff Act.
- b) Wheel Chairs falling under heading No.87.13 of the said first schedule.

### **Other Tax Concessions**

Physically handicapped persons owning a motorised vehicle get exemption from paying road-tax.

### **OTHER BENEFITS**

## Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances

The main objective of the scheme is to assist the needy physically handicapped persons in procuring durable, sophisticated and scientifically manufactured aids and appliances that promote their physical, social and psychological rehabilitation. The scheme is implemented through centres run by institutions registered under Companies Act, registered Societies, Trusts or any other institutions recognised by the Ministry of Welfare (now Social Justice and Empowerment) for the purpose.

According to this Scheme (ADIP, 1981), aids and appliances upto the value of Rs.3,600/- are distributed to the disabled persons free of cost if their monthly income is upto Rs.5,000/- and at 50% of the cost if the same is between Rs.5,000/- and Rs.8,000/-.

## Assistance to Voluntary Organisations for the Disabled

The Scheme was started with a view to provide assistance to voluntary organisations working in the filed of handicapped welfare. It is comprehensive scheme to cover different areas of rehabilitation physical, psychological, social and economic. Financial support is given upto a maximum limit of 90% of the total project cost with built-in ceiling for certain items. Financial assistance is also given for projects such as vocational training centres special schools, counselling centres, hostels, training centres for the personnel and placement services etc.

# Assistance to Voluntary Organisations for Rehabilitation of Leprosy Cured Persons

India has a large population of leprosy affected persons, the estimated figure being 4.50 lakhs. The scheme provides financial assistance to NGOs in a phased manner for the rehabilitation of leprosy-cured persons both in rural and urban areas. Assistance is given upto 90% of the project cost. Programmes like awareness generation, early intrevention, educational and vocational training, economic rehabilitation, social integration, etc. are undertaken under the scheme.

### Allotment of Accommodation

Ad-hoc allotment of general pool residential accommodation to the physically handicapped employees is allowed on request after recommendation by the special recommendation committee and on approval of the Ministry of Urban Affairs and Employment.

### National Awards

Each year on the occasion of the World Disabled Day, National Awards are given by the President of India to the Best handicapped employee and self employed and other categories.

### Schemes Transferred to State Governments

Two central schemes namely Scheme of Scholarship to Disabled person from Class IX onwards and Scheme of subsidy on purchase of petrol/diesel to physically handicapped persons have been transferred to the State/U.T. Govt. for smother functioning of the programme where the facilities/grants are available in each State/U.T. The details of the schemes are:

Type of Course	Rate per month for Day Scholar	Rate per month for Hosteller	Reader's Allowance
Class-IX,X, Pre- University courses and I.A./ I.Sc.	Rs. 85/-	Rs.140/-	Rs. 50/-
B.A./B.Sc./B.Com. etc	Rs.125/-	Rs.180/-	Rs. 75/-
B.E. / B.Tech./ MBBS	Rs.170/-	Rs.240/-	Rs.100/-
B.Ed./L.L.B. Diploma in Professional and Engineering studies etc./ In-plant training M.Sc./M.A.//Mcom/	Rs.170/-	Rs.240/-	Rs.100/-
LLM/ Med etc.	Rs.170/-	Rs.240/-	Rs.100/-

## (i) Scheme of Scholarship to Disabled Persons (from Class IX Onwards)

The Scholarship under the scheme is limited to maximum period of 6 years after Class-XII. Under this scheme no scholarship would be admissible to post M.A./M.Sc. and M.Phil. level as there are many schemes under the Universities to provide scholarships to students at this level. Income limit of parents/guardians of the candidate should not be more than Rs.2,000/- per month.

## (ii) Scheme of Subsidy on Purchase of Petrol/Diesel to Physically Handicapped Persons

Physically handicapped owners of motorised vehicles are granted exemption from the payment of road tax by State Government/Union Territory Administration and are eligible to claim refund upto 50% of the expenditure incurred by them on purchase of petrol/diesel from recognised dealers subject to a ceiling as indicated below:

Vehicle upto 2 H.P. — 15 Liters per month

Vehicle more than 2 H.P. — 25 Liters per month

The physically handicapped persons having an income upto Rs.2,500/- from all sources would only be eligible for the grant of subsidy on purchase of petrol/diesel.

The scheme is operative through District Social Welfare Officers or Tehsildar or any other Equivalent anthority.

Besides these there are different other concessions etc. for the disabled persons, the details of which can be found in the document mentioned at the end of this chapter.

### FURTHER READING

Concessions/Facilities Available To Disabled Through State/U.T.Governments, Compiled by: National Information Centre on Disability & Rehabilitation, CACU-DRC Scheme, Ministry of Welfare, 4, Vishnu Digamber Marg, New Delhi-110 002, Government of India, Ministry of Social Justice and Empowerment, 1998.

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