

# **CEREBRAL PALSY**

## *Chapter 1*

# **Historical Perspective**

**W**illiam Little, a British surgeon, first identified Cerebral Palsy then called 'Cerebral Paralysis'. He raised the possibility of birth asphyxia as a chief cause of the disorder.

Sigmund Freud, in 1897, suggested that difficult birth was not the only cause but rather only a symptom of other effects on fetal development. Research in modern times has shown that 75% of the cases were not due to birth asphyxia. This supported Freud's view, even though through the 19th and 20th Century, Little's view was the traditional explanation.

In India, services to the Cerebral Palsy (C.P.) population, historically has depended on the initiatives of parents, mostly hospital based which were evidently at best partial fragmentary and grossly inadequate. The first special school for Cerebral Palsy (C.P.) was set up in 1973. It was followed rapidly by several schools being opened in Kolkata, Bangalore, Chennai and New Delhi. Spastics Society of Northern India in 1977, Spastics Society of Karnataka in 1980, Spastics Society of Tamil Nadu in 1980 and Spastics Society of India

(Chennai) now Vidyasagar in 1985 have been formed.

Spastics Society of India, Mumbai, as a catalyst, started training of teachers and therapists and skills development. Inclusive education has received a great deal of active propagation with the establishment of a National Resource Centre for Inclusive Education at Bandra, Mumbai. Similarly, the Spastics Societies located in the Eastern, Southern and Northern regions have been very active in training, in providing technical support and networking.

The Spastics Society of Karnataka has established facilities for early diagnosis, appropriate intervention, special education, with a National Open School facility. It also runs a vocational polytechnic and ongoing training programme in all these areas. It is a nodal Centre for National Trust. The community based programmes, both rural and urban, run by the Spastics Society of Karnataka, have a wide and effective reach. Fundamental ideology is effective inclusion in the time frame of about 2-3 decades.

## Chapter 2

# Incidence and Magnitude of the Problem

A group of disorders *caused by* injury to the developing brain in children result in what is collectively defined as “Developmental disabilities”. It affects a very large number of children in India. The condition has far reaching consequences to the individual, family, and the community in the spheres of socio-economic, emotional and quality of life to large number of the affected population is indeed serious. Included among the developmental disabilities are: Mental Retardation, Cerebral Palsy (C.P.), Communication Disorders, Learning Disability, Attention Deficit Hyperactive Disorder and Childhood Autism. These may occur singly or in combination as multiple disabilities. At a conservative estimate, these disabilities account for nearly 15% of the child population (1 in 6).

Against this background, Cerebral Palsy has to be viewed in terms of its incidence, etiology, clinical definition, diagnosis, therapeutic and associated interventions. Long term care, programmes for mainstreaming with vocational and educational inputs, and well researched and meaningful approaches to prevention also become relevant.

Cerebral Palsy includes a group of conditions that are characterized by chronic disorders of movement or posture. The site of lesion is with cortical site of lesion, its onset is early in life. It is not the outcome of a progressive disease. The condition often is accompanied by seizure disorders, sensory impairment and cognitive

limitations. Both in its causation and manifestation, cerebral palsy is a heterogeneous condition. A static encephalopathy, cerebral palsy excludes all progressive neurological disorders. Associated neurological deficits add to the disability caused by motor deficit.

Prevalence of C.P. is in the range of 1.5 to 2.5 per 1000 live births. While exact figures are unavailable in India, it can be safely estimated that the cumulative figures for living population at any given point may be staggering.

Cerebral palsy is a condition with multiple etiologies in the antenatal, natal and in the postnatal periods. Intrauterine infections, developmental malformation of brain are accountable in some of the cases. Eight to ten percent of the cases are due to perinatal damage, while genetic factors contribute to 2% of the cases. Birth asphyxia, especially a prolonged one, increases the risk for C.P., accounting for about 10% of the cases. Preterm birth and underlying pathological lesions, such as, periventricular hemorrhage, venous infarcts are also contributory. In a majority of the cases, C.P. is due to unknown etiologies. CNS infections, meningo-encephalitis, hyperbilirubinemia, CVS accidents and head trauma are among the recognized causes of C.P.

### Facts About Cerebral Palsy

1. *What is the history of Cerebral Palsy?*

William Little, a British surgeon in the 1860s

first identified Cerebral Palsy then known as 'Cerebral Paralysis'. He raised the possibility of birth asphyxia as a chief cause of the disorder.

Sigmund Freud in 1897 suggested that difficult birth was not the only cause but rather only a symptom of other factors on the fetal development. Modern research has shown that 75% of cases were not due to birth asphyxia supporting Freud's view even though through the 19th and 20th Centuries. Little's view was the accepted explanation.

2. *Give the updated version of definition.*

Cerebral Palsy is a group of conditions that are characterized by chronic disorders of movement or postures; it is cortical in origin, manifests itself early in life and is not the outcome of a progressive disease.

Cerebral Palsy is a syndrome as the following a combination of characteristics can be seen:

- (a) Motor Disorder.
- (b) Medical Conditions.
- (c) Sensory Impairments.
- (d) Hearing Disabilities.
- (e) Attention Deficits.
- (f) Language & Perceptual Deficits.
- (g) Behavioral Problems.
- (h) Mental Retardation.

3. (a) *What are the congenital causes of Cerebral Palsy ?*

- Malformation of the brain & blood vessels.
- Neurological damage as a result of
  - (1) Intrauterine viral infections (torch).

(2) Pollution (affect of environmental toxins).

(3) Poor oxygenation of brain as a result of placental factors.

(4) Vascular factors (Congenital heart disease, sepsis, etc).

(b) *What are the peri-natal causes of Cerebral Palsy ?*

(1) Birth asphyxia.

(2) Damage to the white matter of the brain.

(3) Severe untreated jaundice, hypoglycemia.

(4) Sepsis (Meningitis, encephalitis).

(5) Premature infant with complications.

(6) Intracranial bleeding.

(7) Multiple births.

(c) *What are the causes after the birth of the child (Post-natal causes) which are about 10 to 15% of Cerebral Palsy?*

(1) Infections (bacterial or viral).

(2) Post-surgical vascular complications.

(3) Asphyxia due to aspiration.

(4) Traumatic brain injury.

4. *What are the different types of Cerebral Palsy depending on the type of tone and movement?*

(1) Spastic (increased muscle tone) 60 to 70%.

(2) Ataxic (balance and coordination) 10 to 15%.

(3) Athetoid (involuntary, uncontrolled) 10 to 20%.

(4) Mixed type.

5. Name the body parts involved in different types of Cerebral Palsy.

- (1) Hemiplegia (One arm & leg of the same side).
- (2) Diplegia (both legs were involved than arms).
- (3) Quadraplegia (all form extremities involved).

The distribution of cerebral palsy when the child is of low birth weight (less than 1500 grams) is as follows:

- |                  |   |     |
|------------------|---|-----|
| (a) Diplegia     | - | 57% |
| (b) Quadriplegia | - | 22% |
| (c) Hemiplegia   | - | 11% |
| (d) Mixed        | - | 10% |

6. The athetoid form of CP is seen when the extra-pyramidal system is involved. It is more common in full term infants with severe perinatal asphyxia or secondary kernicterus. Fluctuating tone is seen when extra-pyramidal signs are present.

7. What are the causes of ataxic type of cerebral palsy?

- (1) There are congenital abnormalities in the cerebellar area.
- (2) Genetic causes.
- (3) Metabolic disorders.

8. What are the signs of Ataxia?

- (1) Child with low basic tone more in the proximal areas (shoulder, trunk and hip).
- (2) Joints are hypermobile.
- (3) Incoordination.
- (4) Dysmetria (over shooting or under shooting when reached out at objects).
- (5) Wide based or waddling gait.

9. Do all children with Cerebral Palsy unable to walk (ambulate)?

S. No.	Clinical type	Ambulatory (%)	Non-ambulatory (%)
(1)	Hemiplegia	100	0
(2)	Diplegia	85	15
(3)	Quadraplegia	68	32
(4)	Athetoid	77	23
(5)	Ataxia	100	0
(6)	Atonic	0	100

10. What does the Paediatrician do to evaluate a child with cerebral palsy?

- (1) Paediatric Neuro-development examination.
- (2) Screen for regulatory disturbances, sleep feeding and behavior.
- (3) Screen for ophthalmic problems.
- (4) Screen for auditory impairments.

Note: Paediatrician refers the child for few laboratory investigations also for a proper diagnosis.

11. What are the other professionals Paediatrician refers to and for what evaluations.

- (1) Evaluation by Speech Therapist.
- (2) Evaluation by Physical Therapist.
- (3) Evaluation by Occupational Therapist.
- (4) Evaluation by Neuro-Psychologist.
- (5) Evaluation by Psychologist.
- (6) Evaluation by Special Education Teacher.

12. What is Multi-handicapping Syndrome?

A child who has the following or combination of the conditions:

- (1) Neurological.

- (2) Sensory impairments (loss of vision/hearing, etc.).
  - (3) Growth.
  - (4) Gastro-enterological Tract problems (feeding, i.e., no closure of mouth, swallowing could be a problem).
  - (5) Respiratory problems (common in quadraplegia).
  - (6) Orthopedic problems (contractures and deformities).
  - (7) Osteoporosis due to poor nutrition, disease, no weight bearing.
13. *Are there any Neurological problems associated with Cerebral Palsy?*
- (1) Seizure Disorders (fits)      33% - 50%
  - (2) Mental Retardation            50% - 70%
  - (3) Learning Disorder            60% - 70%
  - (4) Attention Deficit Hyperactive Disorders/  
Behavioural problems
  - (5) Speech deficits/ shallow breath
  - (6) Dysarthria - 50%
  - (7) Feeding difficulties – swallowing problems, mouth closures, tongue moments.
  - (8) Sleep disturbances.
14. *Do children with Cerebral Palsy have other medical problems?*
- (1) Growth retardation occurs frequently in cerebral palsy.
  - (2) 30% due to poor nutrition.
  - (3) Gastro – Enterological – Regurgitation (GER), chronic constipation are common in quadriplegics.
15. *When there is a feeding problem, what are the areas to be evaluated?*
- (1) Complete nutritional history, intake types/textures and consistency of food.
  - (2) Oral and oral pharyngeal function.
  - (3) Involuntary movements of the tongue and chewing.
  - (4) Position of the head and neck and muscle tone.
  - (5) Gastro – Enterological – Regurgitation (GER).
16. *Do children with Cerebral Palsy need to have Dental check ups?*
- Yes, they have:
- (1) Caustics in both milk teeth & permanent teeth.
  - (2) Gingivitis
  - (3) GER causes food to remain in oral cavity causing decay.
  - (4) Difficulty in providing oral care.
  - (5) Inability to close or open mouth totally.
  - (6) Teeth grinding.
17. *What are the common associated orthopedic problems in Cerebral Palsy?*
- (1) Dislocated/Sub-located hips.
  - (2) Scoliosis.
  - (3) Contractures at joints.
  - (4) Discrepancy of Skeletal Growth.
  - (5) Deformities of hand and feet.
  - (6) Deformity of the Pelvis.
18. *What are the sensory deficits usually seen in Cerebral Palsy?*
- (1) Visual Impairments 40% to 50%
  - (2) Auditory Impairments 25% to 40%
  - (3) Sensory Motor Difficulties.
  - (4) Tactile defensiveness, hyper sensitivity to touch.
  - (5) High threshold for pain due to in Child hyposensitivity.

19. *What are the methods of managing these sensory disorders?*

- (1) Refer to an Ophthalmologist for treatment.
- (2) Refer to an ENT and audiologist for evaluating & treatment.
- (3) Early intervention to provide vision therapy & auditory language training through early intervention programmes.
- (4) Therapies for speech language disorders also should include oral mouth therapy.
- (5) Sensory Integration Therapy.

20. *What are the Psycho Social Intervention needed from the child if diagnosed with Cerebral Palsy?*

- (1) Identify strengths and need of the family and child.
- (2) Community Services available in the locality.
- (3) Recreational Services available in the locality.
- (4) Financial status of the family and if support is required.
- (5) Respite care facilities available.
- (6) Parent Support groups.
- (7) Counseling Centre in the locality.

21. *What are the needs of person with Cerebral Palsy who turn into an adult?*

- (1) Employment (for maintaining self esteem).
- (2) Maintenance Therapy (by care giver).
- (3) Receiving arrangements (disabled friendly).
- (4) Leisure (recreational facilities being disable friendly & inclusive).
- (5) Self advocacy (self help and advocacy).
- (6) Transportation group in the locality.

## **Magnitude of the Problem: Causes and Incidence**

Nearly 2.0%, i.e., around 20.0 million people with visual, communication, and loco motor disabilities are believed to be the affected segment. Out of this, C.P. may conceivably constitute a significant proportion. This may not include moderate to mildly disabled. At an approximation, it may not be out of the mark to state that at least 2.0 million children and adults may manifest one or more of the symptoms of C.P. Even in developed societies such as the USA, about 5,000 babies and infants are diagnosed with C.P. each year, in addition to 1200-1500 pre-school age children annually are recognized to have C.P. Extrapolation of these observations to the Indian scenario may be difficult; notwithstanding, given our population which is three times greater, and the socio-economic and health care system both in quality and reachability reflecting severe limitations, the number of population affected with C.P. in India would be staggering. A brief mention of the major causes would be in order to support the above, to underline the environmental factors contributory to the incidence of C.P. An important cause is an insufficient supply of oxygen reaching the fetal or new born brain. This may be caused by oxygen supplied interrupted by premature separation of placenta from uterus, awkward birth position of baby, prolonged or abrupt labor, or interference with circulation in the umbilical cord. Premature birth, low birth weight, RH or A-B-O blood type incompatibility between mother and baby, infection of mother with German measles or other viruses pregnancy and infections attacking the infants' CNS are risk factors for C.P. Thus, most causes are related to the child bearing and developmental process, and the condition is not inherited mostly (Congenital C.P.). In India, malnutrition of the mother, deficient in a number

of essential nutrients as well as macronutrients in terms of calorie and protein is a major factor, evidently these factors contributing to the fetal development and pregnancy outcomes. A less common type is acquired C.P., occurring before two years. Head injury by falls, accidents, child

abuse being some of the causes. It becomes, evidently, logical given the conditions of pregnancy, childbirth and childrearing, the problem of C.P. in India is sufficiently large to call for remedial action, preventive measures, early diagnostic and rehabilitation with long term care.

## *Chapter 3*

# **Measures Initiated for Prevention and Early Identification**

**S**ince causes of C.P. in most cases are not clearly known, it is difficult to apply preventive measures. It should be emphasized that since prematurity in at least 30% of cases has an association with C.P., there are hopes of preventable measures to address this condition. Good health practices prenatally and prior to pregnancy may prevent prematurity to an extent. Good nutrition, in childhood and adolescence, up-to-date immunization, particularly against rubella, correction of physical abnormalities and elimination of infections particularly of the genital tract, avoidance of smoking, alcohol and addictive drugs coupled with regular prenatal care supervised by a qualified person are good preventive steps.

Control of neonatal jaundice (hyperbilirabinemia) through prevention of blood

incompatibilities can eliminate choreo athetoid forms of C.P. In C.P. cases where a metabolic or inherited etiology is indicated, early diagnosis and management may prevent onset of progression of neurological deficits. Routine genetic and metabolic studies will separate a group that are not truly C.P. Overall, it should be noted, at a national level, a comprehensive and broad coverage of preventive measures has yet to emerge. Nevertheless, there is a strong case for carefully planned studies in several Indian States where the educational and nutritional status of the vulnerable mother and child populations are reasonably satisfactory, and others where they are below normal, both retrospectively and prospectively. This would substantially help in evolving preventive measures on a national level.

## Chapter 4

# Parental and Social Attitudes Towards Disability

**D**isability of the individual with C.P. in this frame of reference, has to be understood both as a family and social issue. Problems of C.P. persons has to be viewed in the context of the family, school, community, work place and also in different stages of the development of the affected subjects, viz., childhood, adolescence, adulthood and old age. The issues also include the gender perspective, whether the C.P. person is a male or a female. In terms of education, employment, reservation, concessions, government schemes, and allocation of resources, it is gratifying, thanks to various government and non-government agencies involved in the overall programmes, with a strong, focused and committed leadership provided by the Rehabilitation Council of India, encouraging steps are being taken in all these directions. What factors essentially inhibiting progress in the area partly were attitudinal problems in family (parents included) and society. Parents often experience shame, shock, guilt, sorrow and helplessness in bringing to this world of a C.P. child. These sentiments are upper most in their mind and attitudes. If they perceive an opportunity in the environment to enable the child perform like other children, they feel positive and encouraged and put in positive efforts to help the child develop. Compared to about one or two decades ago, the current situation which provides such opportunities has brought about an observable, however small change in both parental and familial attitudes. In fact, it is becoming apparent, what

disables a person with a condition like C.P. is the attitude of his or her family and friends. Poor or rich, disabled or not, children need and deserve love. The key to success in every programme is attention to attitude (positive) to see the *abilities* and not the opposite.

It is imperative that improvement of the quality of life for the C.P. population, from birth to childhood, in all interventional programmes of therapy, education, vocational training, jobs, living in adulthood and old-age has to have the underlying attitudinal foundation of “acceptance” and *ability* to see their “abilities”, and eschew disabling attitudes.

### Parent Support

Following Questions and Answers are guidelines as to how to enhance parent support:

- I. (Q) How would the parent know you are interested in their child with Cerebral Palsy?  
(A) Only by showing respect and being friendly with the child.
- II. (Q) When the parent is talking, what are you suppose to do?  
(A) Listen with full attention, listen for the causes of the problem, give enough time for the parent to talk.
- III. (Q) How should one talk to the parent?  
(A) (1) Think before you talk and learn to

wait and be silent at times use positive body language.

- (2) Encourage with a great sense of empathy by giving an opportunity for the parent to express her/his positive and negative feelings.
- (3) If you have a doubt gently request the parent to clarify. Do not put too many questions at a time.
- (4) During the course of the conversation help the parent to link the causes of the conversation, help the parent to link the causes of the probe to appropriate areas of development & interventions.

IV. (Q) How do you know what is the need for the day for this particular parent regarding her child?

- (A) When you identify and define the problem you can make the judgement when you summarise and get the confirmation from the parent that you have understood the needs of the child and the needs of the parent in terms of what are the immediate needs and the general direction one need to work teaming with parents. Be consistently empathetic.

V. (Q) What are the inputs and attributes to be avoided while establishing a supportive relationship with the parent?

- (A) Avoid advise unless asked for giving false hope interrupting the parent, dominating being overpowering during the conversation.

Avoid crying with the parent or becoming non-pulsed or fidgety when the parent remains silent.

Avoid arguments & be pleasant & relaxed.

### **Pioneering Work in the Services to Persons with Cerebral Palsy—An excellent example**

It is to the credit of Dr. Mithu Alur, who pioneered the establishment of the first Spastics Society of India in Mumbai, exclusively for C.P.

The Spastics Society of India was founded in 1972 at a time when very little was known about the complicated disorder of cerebral palsy. Initially it provided education and treatment services gradually broadening its scope to teacher training, vocational training of young adults, advocacy and awareness, support for parents and other professionals.

Today, it is one of the foremost organization in the medical and social field working for children with developmental disorders. It has facilities for identification, assessment, education and treatment. It has early infant clinics where babies at high risk are assessed; it runs schools providing a holistic program combining education and treatment under one roof.

Other Spastics Societies were set-up based on this model. Each of the Societies is today independent and well known for their innovative work for disabled people. This paradigm has now been replicated in 16 of the 31 states. However all this has been on a micro level.

The Spastics Society of India began its second journey....the journey of inclusion.

#### *The National Resource Center for Inclusion*

Following the findings of this doctoral research the Society moved away from segregated education to inclusive education. It strongly felt that education of children with disabilities must become the State responsibility. Disabled adults and families who have suffered from being marginalized for years must be brought to the

forefront and rightfully take their place in the country as citizens. The aim is to construct an inclusive community where all children who face barriers to learning due to social disadvantages, gender or disability are included.

The National Resource Centre for Inclusion (NRCI) was created at Mumbai in 1999 to address these issues on a macro-micro level. A charter was developed. The admission policy was changed to address all children with disability as well as other children facing barriers to learning.

### **Able Disabled All People Together (ADAPT)**

On the national level a disabled activist group or the Rights Group has been formed. This is called ADAPT. ADAPT stands for Able Disabled All People Together. Many barriers exist that limit people with disability from being active participants in every day life. Their basic human rights denied, invisibility in public policy, negative attitudes, inaccessible facilities and transportation systems. Through its activities ADAPT will attempt to address these barriers:

#### *Objectives of ADAPT*

- Raise awareness on disability issues.
- Advocate and lobby on issues and concerns of people with a disability.
- Provide a forum for sharing information and resources.
- Organize seminars, workshops, social events.
- Network with individuals and other similar organizations to achieve common goals.

#### *Attitudes & Awareness*

Attitudes of Society towards people with disability has its roots in religion, myths, prejudice and ignorance. ADAPT endeavors to bring about changes in attitudes through dissemination of information regarding various disabilities through print and electronic media and by organizing appropriate events.

#### *Inaccessible Facilities and Transportation Systems*

A major barrier faced by persons with disability is inaccessible transport system and public places like cinema halls, restaurants, public exhibitions, shopping centers, etc. An ongoing project of ADAPT is to survey various public places in addition, the authorities are being approached to modify them by adding ramps or elevators wherever needed. Newspaper interviews and articles are used to create awareness among people. It has recently ensured access to various public places like the Bombay High Court, IMAX Cinema Hall, Globus, Shopping Centre, etc. The main aim of ADAPT is to move the organization from a service delivery one to rights and entitlements, keeping with the new model of disability emerging around the world. The slogan of ADAPT is: *‘Nothing for the Disabled Without the Disabled’*.

## List of Institutions Dealing with Persons with Cerebral Palsy in India

<i>State</i>	<i>Spastics Societies</i>	<i>Nature of Persons Admitted</i>
Assam	Shishu Sarothi, Spastics Society of Assam, K. K. Battha Road, Chenikuthi, Guwahati - 781003	CP
Andhra Pradesh	Indian Family of Cerebral Palsy, Dept. of Neurosurgery, NIMS, Panjagutta, Hyderabad - 500082	CP
Delhi	Action for Ability Development and Inclusion (AADI), formerly The Spastics Society of Northern India, Balbir Saxena Marg, Hauz Khas, New Delhi - 110016	CP
Karnataka	Spastics Society of Karnataka, Centre for Special Education, 5th Cross, 5th Main, Indiranagar, Ist Stage, Bangalore - 560038	CP
Maharashtra	Spastics Society of India, Sion-Trombay Road, Chembur, Mumbai - 400071	CP
	The Spastics Society of India, Bandra Reclamation, K. C. Marg, Bandra (West), Mumbai - 400050	CP
Mizoram	Society for Rehabilitation of Spastic Children, Chhunga Building, Saron Veng, Aizwal - 796001	CP
Tamil Nadu	Handicaps Opportunity Project for Quality - HOPE, 285-A, Mulai Nagar, Coimbatore - 641041	CP
	Spastics Society of Tiruvannamalai, P. O. Kadaladi Village, Polur Taluk, T. S. District, Tiruvannamalai - 606908	CP
	Vidya Sagar, 1, Ranjit Road, Kotturpuram, Chennai - 600085	CP
	Spastics Society of Tamil Nadu, 16, V. P. Colony, North Street, Ayamavaram, Chennai - 600023	CP
	Spastics Society of Tiruchirapalli, D-59, 10-A Cross, Thillai Nagar, Tiruchirapali - 620018	CP
Tripura	Spastic Society of Tripura, Ramnagar Road 1, P. O. Ramnagar, 2nd Lane, Agartala - 799002	CP
West Bengal	Spastic Society of Eastern India, P-35/1, Taratolla Road, Kolkata-700088	CP

*Source:* Details as per Directory from NIMH, Secunderabad.

## Directory of Institutions for Persons with Cerebral Palsy in India

<i>State</i>	<i>Institute's address</i>	<i>Nature of persons admitted</i> <i>CP/All types children</i>
Andhra Pradesh	Akshaya Kshetram Adj. to North Post Office, R.S. Gardens, Tirupathi - 517507	All types
	Centre for Disabled Children, Lenin Nagar, Pedda Cheruvu, Narsarap Pet, Guntur - 522601.	CP
Assam	Manovikas Kendra, Vikasapur, Kahilpara, Guwahati - 781019.	CP
	Prerona Pratibandi Shishu Bikash Kendra, Spastics Society of Jorhat, Cinnamara, Jorhat	CP
Haryana	Blessings Centre for Mentally Hadicapped, Spastics & Slow Learners, H. No. 783/14, Gurgaon.	Spastics
Kerala	Adarsh Rehabilitation Institute for Spastics and Neurologically Impaired, 21/322, Chonmaya Road, Ford, Tripunithura, Cochin - 682301.	CP
	Jyothi Special School, Francis Road, Near AKG, Overbridge, Calicut - 673003.	CP
Maharashtra	Dyanganga, M.R. & C.P. Special School, Mokde Nagar, Tumsar, Dist. Bhandara - 441912.	CP
New Delhi	Krishna Bikalang Kalyan Sanstha, H. No. 6, Ranghat Colony, Wazirabad, New Delhi - 110054.	Guidance to all handicapped
Orissa	Chetana Institute for the Mentally Handicapped, At. Bahadir Bagochapada, Kalahandi, Bhawanipatna - 766001.	CP
	Jiban Jyothi Welfare Association for Mentally & Physically Handicapped, At. Rathagada, Dhenkanal - 759001.	CP
	Manpower Institute of Tact Research Action (MITRA), At. New Balabhadrapur, P. O. Korian, Dhenavanar - 759013	CP
Rajasthan	Prayas, 343, Lane No. 2, Raja Park, Jaipur - 302004	CP
Tamil Nadu	Bethshan Special School, 2/19, Koodal Nagar, Madurai-625018	CP with normal I.Q.

## Chapter 5

# Educational Services for Persons with Cerebral Palsy

Historically, children with special needs have been much restricted in terms special schools dedicated to their special needs requiring educational technology and teachers adapted and trained to meet such needs. Though a few institutions were set up for the education of the visually and hearing impaired as early as in later part of the 19th century in India (Amritsar and Mumbai – to begin with), Special schools for C.P. were very late to come – as late as 1973 and subsequent two decades – even now they are grossly inadequate both in number and the quality that can be provided, given the current state of knowledge and technology to deal with the education of the C.P. Despite the large number – more than 3,200 special schools – schools for the C.P. are insignificantly small. These special schools brought with them a certain disadvantages. Firstly their reach was largely urban and not cost effective. Even worse, they segregated the special needs children from the mainstream, fostering and perpetuating a “disability culture”.

### **Integrated Education of Disabled Children**

Integrated Education of Disabled Children as a scheme was launched in 1979 with the objective of providing educational opportunity to Special Needs Children in regular schools, to facilitate their retention in the school system and to place children from special schools in common schools. To achieve these objectives the requirements are

access, adaptation of curriculum and assistive devices for function.

### **Integrated Education for the Disabled (IED)**

Launching by the Ministry of Human Resource and Development along with UNICEF of the Project Integrated Education for the Disabled in 1987, is a significant step. A significant increase in the orthopedically and severely disabled under this scheme is a remarkable sign. These children perform on par with non-disabled children. Absenteeism is lower and retention higher. Attitudes of teachers have changed as well as the acceptance by the community and parents. Interaction between the disabled and the non-disabled is good. A major shift in the view that the school system contributed to the learning of the child and therefore required reform came out of the inclusive education programmes. This essentially emphasizes that the child is a product of his/her experiences in the school environment which has to be “engineered” to facilitate the child to learn and develop. Under the inclusive education scheme and philosophy, child-centred pedagogy, learning opportunities to their special needs, strategization of providing resource support and remedial assistance with special needs is gaining acceptance and emphasis.

Open schooling through several accredited Institutions and Open Basic Education, reaches any group of persons with circumstances appropriate

to educational needs to this kind. With such facility, learning materials, audio-video cassettes, and working kits reach at the doorstep of the disabled learners.

The steps needed for implementation of IED can be classified under the three headings:

*(a) Direct Services to Children*

The first step is identification of CWSN for micro-planning of IED in terms of Visual Impairment, Hearing Impairment, Locomotor Impairment, Mental Retardation, Learning Disabilities and others. The next step involves formal and functional assessment of each identified child to determine the nature and extent of disability. This should be followed by preparation of individualized need based profile which delineates all the needs, special services required, duration of such services and evaluation procedures. After this the most suitable learning environment is to be identified for each child. All necessary required support, aids and appliances and learning material suitable to the special need of a challenged child should be provided. Finally, all schools must not only be barrier free and provide easy access to children with special needs, but also be equipped with other facilities to take care of their special needs.

*(b) Support Services*

There is need to generate awareness and appreciation of the potential and utility of the education of CWSN, and educate and sensitise parents, teachers, community leaders and the community as a whole. Parents of CWSN also need to be trained in coping with the disabilities of these children and helping them. Teacher training should form the backbone of inclusive education. Support services in the form of physiotherapy, occupational therapy, speech therapy, counseling, etc., should be provided in the resource room. SSA missions may also plan for Vocational Education of Disabled Children at Upper Primary Level. The planning of IED may include extra curricular activities like drawing, painting, dance, music, sports, craft and indoor games. Use of technology is also advocated in the shape of special aids and appliances, computer assisted instruction and development of low cost/no cost, Teaching and Learning Aids using indigenous material. While taking care of the special educational needs of children with special needs, it is also necessary to consider adaptations in the evaluation system.

*(c) Monitoring and Evaluation*

This is an important aspect for assessing progress and providing improvement in the process. Therefore, an adequate and efficient mechanism needs to be in place for this purpose.

## Chapter 6

# The Role of the School in Preparation for Employment and Vocational Training

Vocational programmes for severely disabled start too late, say around 16 to 18 years of age. In a short period of four years, large number of both general and specific skills will have to be learned. Further, most school-based programmes do not place job placement/employment as a end point of training. Thus, many C.P. young adults graduate from school with no job training or assistance for placement. This calls for a “Value clarification” of the C.P. school-goer from the parent, educators, the community and the school.

- (i) Employment in non-sheltered integrated setting should be an important objective, example, working with a non-disabled person is normal and represents participation in a normal work force.
- (ii) Promotes interaction, friendship of the abled with the disabled, which is highly desirable for community acceptance of disability.
- (iii) The disabled performs far better in settings where competent peer models are around to observe.
- (iv) Self-perceptions of the disabled working in a normalized integrated setting is higher than the self perception of those confined to sheltered or segregated work environments.

### Vocational Education for Multihandicapped Youth

*Jobs identified for persons with Cerebral Palsy*

Computer operator  
Micrographics  
Microphics Clerk  
Mail Order Clerk  
Clerk Typist  
Inventory Information Clerk  
Junior Accounting Clerk  
Remittance Processing Technician  
Mail Rook Clerk  
File Preparation  
Quality Control Clerk  
File Clerk  
Inventory Clerk  
Accounting Clerk  
Data Entry Operator  
Accounts Payable Clerk  
Accounts Receivable Clerk  
Consolidation Account Clerk  
Tape Library Technician  
Switchboard Operator  
Lift Operator

Document Preparation Clerk

Key Punch Operator

Reproduction Clerk

Xerox Clerk

Computer Graphics

Animation

Horticulture

Sericulture

Small /Petty Shopkeeper

Canteen Management Services, Cashier,  
Supplier

*Sheltered workshop oriented production activities*

Art Craft Items

Production of Hand Made Paper items

Assembling ball pens/switch board

Bakery items–Production, packing, maintaining of  
production, cash register

Production of Tailoring items

## *Chapter 7*

# **Recent Historical Perspective in India Regarding Cerebral Palsy Movement**

**A** path breaking landmark legislation which would safeguard and provide statutory mandate in bringing about quality and effectiveness of rehabilitation programmes in India, was passed in 1992 constituting Rehabilitation Council of India (RCI). Subsequent amendment made in 2000, provides for monitoring the training of rehabilitation personnel and professionals, promoting research in rehabilitation and special education as additional objectives of the Act. RCI, the apex body has contributed immensely to the development of quality human resources. This has substantially augmented both the programmes and the quality of services across the country, in rehabilitation, education and services to the disabled in general and cerebral palsied in

particular. The RCI Act and the Council's functioning have provided a much needed supportive structure and direction in rehabilitation. RCI is the apex body for recognition of qualifications for rehabilitation professionals, which enrolls and maintains a Central Register for Rehabilitation Professionals and also for regulating their conduct. The Council's pivotal role in the rapid growth of all services needed for the disabled, C.P. in particular, conforming to very high standards is well recognized. In particular its management culture in networking across the country with the numerous agencies, professional bodies in education, vocational training, placement, etc., is indeed praiseworthy, as evidenced by the outcome in developments in the field.

## Chapter 8

# Teachers' Training

The imaginative and unrelenting commitment of the RCI in the decade has resulted in a very good number of Institutions, Universities, National Institutes imparting approved training courses around the country. As can be seen from the geographical location of these Institutions, the coverage is vast and is expanding. Over the few years to come, this can be expected to augment our trained teacher resources significantly to reach greater number of C.P. population countrywide.

### List of Training Institutions/Universities/National Institutes Imparting RCI's Approved Rehabilitation Training Courses in Cerebral Palsy

Assam	Shishu Sarothi, Centre for Rehabilitation and Training for Multiple Disability, off Ramakrishna Mission Road, Birubai, Guwahati-781016.	DSE(CP)
Delhi	Action for Ability Development and Inclusion (AADI), Formerly The Spastics Society of Northern India, Balbir Saxena Marg, Hauz Khas, New Delhi-110016	PG Dip.in Developmental Therapy (CP & Neurological Disabilities) PG Diploma in Spl. Edu. (CP & Neurological Disabilities)
Gujarat	Smt. Parsanben Narandas Ramji Shah (Talajwala) Society for Relief & Rehabilitation of the Disabled, 51, Vidyanagar, Bhavanagar-364002.	DSE(CP)
Karnataka	The Spastics Society of Karnataka, 31, 5th Cross, Off-5th Main, Indiranagar, Ist Stage, Bangalore-560038.	DSE(ASD) DSE(CP)
Kerala	Raksha Society for the Care of Children with Multiple Handicaps, "Yasmin Manzil", VII/370, Darragh-es-Salaam Road, Kochangadi, Cochin - 682002.	DSE(CP)
Madhya Pradesh	Shiv Kalyan Shikshan Samiti, LIG-26, 2nd Floor, Harshwardhan Nagar, Bhopal-462003.	DSE(CP)

Orissa	Open Learning System, Plot No. G-3/A/1, Gadakana Mouza, DSE(CP) P.O. Mancheswar Railway Colony, Near Press Chhak, Bhubaneswar-751017.	
Rajasthan	DISHA, Centre for Special Education Vocational Training & Rehabilitation, 450 AB, Nirman Nagar, King's Road, Jaipur-302019.	DSE(CP)
Tamil Nadu	Spastic Society of Tamil Nadu, Opp. T.T.T.I., Taramani Road, Chennai-600113.	B.D.T. Course for Children with CP & Neurological Handicapped. DSE(CP)
West Bengal	REACH, Institute of Special Education, 18/2/A/3, Uday Sankar Sarani, Golf Green, Kolkata-700095.	P. G.Dip. in Spl. Edu. Multiple Disabilities (Physical & Neurological)

## Chapter 9

# Emerging Technologies - Concept of Rehabilitation Engineering (RE)

1. Systematic application of technology to help individuals with disabilities (C.P. in this instance) overcome barriers in education, employment and independent living. This means the “engineer” fabricate devices, adjusts a series of tools, also evaluates the individuals’ abilities and develop, augment and enhance those abilities. Example, if a C.P. individual is capable of only the movement of his left forearm as the only outward physical to action, the rehabilitation engineer should turn this forearm into the principal conductor to activate switches and utilizing devices. This forearm becomes the porthole for the C.P. individual’s relationship with others and means to employment. The rehabilitation engineer and employment specialist together should work out functionality as well as comfort at work.
  2. The R.E. interfaces with the physical therapist, occupational therapist, speech therapist, employment specialist and the C.P. person to determine individual goals and needs. They must assess the environment the C.P. individual operates in, to ensure technology used is compatible to his/her life and style. Mobility, seating, adaptive communication should all be factored in.
  3. Experience in the West indicates that RE may not need an advanced degree. Undergraduate and graduate programmes can be organized to build a cadre of these engineers in this field which can have a profound effect on the lines of the disabled in general and C.P. in particular.
  4. Evaluation/Assessment
    - (i) Based on observation, interview and consultation with treatment team (teachers included), R.E. evaluates a C.P. person’s individual strengths and makes recommendations as to how technical intervention can enhance C.P.’s abilities.
    - (ii) *Site evaluation:* R.E. visits the work site and living areas to determine what modifications should be made to allow for independent functioning of a disabled person or a group of disabled.
    - (iii) Commercially available aids and devices are assessed for cost and functional effectiveness. After implementation, following training and adaptation a follow-up for effectiveness, comfort, productivity, success and failure should be made and course correction implemented.
- Rehabilitation Engineering services should be widely publicised, once they are tested for success and productivity, to be widely available. All concerned should be made aware of the technology and its value for the C.P. populations’ productive employment and economic security.

A Business Advisory Committee can be formed for providing a strong and ongoing relationship between business community and

Vocational Training providers. Such a committee can help with curriculum information contacts, job restructuring, equipment consulting, etc.

## *Chapter 10*

# **Conclusions**

**O**ver the last couple of decades, there is a positive change in the medical intervention programmes for the persons with C.P.

We need to go a long way in terms of Educational and Vocational Training Programmes.

We need to do more scientific studies and action based systematic documentation to provide validated relevant reference materials in India to help in planning programmes of education and rehabilitation, etc.

We need to reach the rural population with more intensive and workable programmes keeping in mind the problems of C.P and the rural environment.

Every child with C.P. should be our concern irrespective of socio-economic profile, geographic location and linguistic identity vernacular or English.

## Chapter 11

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*Eligibility:-* Registered organizations.

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