

Institution Builders in the Disability Sector

Vedabhyas Kundu



**Rehabilitation Council of India
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Foreword

Keeping in mind the endeavor of the Rehabilitation Council of India to promote standardized training and services for the persons with disability, it was felt that a book profiling individuals who have been working for decades to provide quality services was the need of the hour.

In this backdrop, this book, “Institution Builders in the Disability Sector” is an attempt to take forward the Council’s objectives and I hope many of these initiatives could be replicated in different parts of the country so as to reach the unreached. It is not possible to feature all the institution builders in one volume and the Council hopes to shortly start the process of bringing out the next volume which would feature more institution builders in the disability sector in India.

It gives me immense pleasure in writing the foreword of this book, which has been written by a young writer, Vedabhyas Kundu, who has special interests in the disability sector and has been writing on it for the last several years. I hope the book will be useful for not only those involved in the disability sector, but also journalists, researchers and in general

those who are interested to know about the innovative work being done in the sector.

Major H P S Ahluwalia
Chairman,
Rehabilitation Council of India



Preface

The Rehabilitation Council of India through its focussed approach to improving the quality of life of the persons with disability has been evolving programs and schemes in this direction. It is making an intensive and concerted effort to promote a holistic approach to the rehabilitation of all people regardless of the nature and extent of their disability.

While systematically reinforcing the Council's objectives of regulation and standardization of training programs in disability, it is conscious of the need to highlight commendable work being done in the disability sector. For reaching the unreached with standardized training programs it is important that successful training models are replicated. Various channels of communication will have to be used to make people aware of these successful models. In fact it goes with the emerging need of putting in place an effective information dissemination process so that a large number of people are sensitized and educated on the work being done for the persons with disability in the country.

It is in this backdrop that the Council decided to bring out this book on *Institution Builders in the Disability Sector* which specifically focuses on people who have been assiduously working to evolve institutions in the field of disability. It highlights the work of those pioneers who have inspired institutions that are

imparting commendable service to the persons with disability in the country. All these institutions have been promoting training and have a major role in standardization of services in the rehabilitation of the persons with disability. They are the harbingers of transforming the lives of persons with disability.

The Council felt that compiling the work of the stalwarts in the field of disability would give an opportunity not only to those in the sector, but also many others like journalists, researchers and other professionals on the magnitude of the work being done. This is just the first volume of the book. It is not possible to include all the stalwarts in one volume and there may be quite a few whom we may have missed out. It would be the endeavor of the Council to include their work in the next volume.

The book is a special tribute to Mr Lal Advani, one of the pioneering figures in the disability sector in India. Mr Advani has been responsible for initiating a large number of institutions, schemes and policies related to disability in the country. It is in this context, we are devoting the first chapter to the commendable work done by Mr Advani for more than six decades.

The book has been written by Vedabhyas Kundu, a journalist and activist who has been writing on the issue of disability for the last several years. He travelled around the institutions and interviewed the pioneers in the field. His previous book, *India's Living Legends: Savants of Voluntary Action* was an attempt to profile the leading voluntary activists of the country and this is a continuation to it though focussing on those working

for the persons with disability. I hope he continues in his endeavor to write on the work being done by volunteers in the country.

We hope the book would serve the purpose with which it has been brought out.

Lastly, I would like to quote Gurudev Rabindranath Tagore:

*Where mind is without fear
and the head is held high;
Where knowledge is free;
Where the world has not been broken up into
fragments by narrow domestic walls;
Where words come out from the depth of truth;
Where tireless striving stretches its arms towards
perfection;
Where the clear stream of reason has not lost its way into
the dreary desert sand of dead habit;
Where the mind is led forward by THEE into ever-
widening thoughts and action;
Into that heaven of freedom,
My father, let my country awake.*

**Dr J P Singh,
Member Secretary,
Rehabilitation Council of India**

Introduction

*“Go ye forth,
O Bhikkhus, on your journey,
for the welfare of the many,
for the happiness of the many,
out of compassion of the many, for the good,
the benefit,
the bliss of Gods and men.”*

This is what Buddha said at the time of sending his first group of disciples to propagate the Doctrine in the second year of his preaching. It is in fact the compassion and the desire from the heart to do *seva* (work for welfare of others) that forms the guiding principles of many who dedicate themselves to volunteer efforts.

For those whom I interviewed for this book, service for the persons with disability has been the mission. As Albert Schweitzer had said, *“there is no higher religion than human service”*, these *karmayogis* have been working for decades with sheer dedication. They have been able to inspire institutions of excellence providing standardized services to the persons with disability. Over the decades these institutions have become important centers for the total development of the persons with disability, a section of the population that has always been excluded from the mainstream.

The models that I came across during the visits to the institutions gave an insight into the efforts of those interviewed to empower the persons with disability and facilitate mainstreaming. Many of these endeavors need to be replicated in other parts of the country especially in rural areas where services for the persons with disability are abysmal. One important lesson has been that issues related to disability need to be looked at holistically and not in piecemeal manner.

Also it is important that in order to provide standardized services to the persons with disability, training plays an important role. This aspect has been an important component of the work of all those whom I interviewed.

I thank the Rehabilitation Council of India for giving me this opportunity to write this book on the institution builders in the disability sector. Especially, I would like to thank the Member Secretary, Dr J P Singh for giving constant guidance and inputs while writing the book. Also I would like to thank Dr S K Mishra, Assistant Director in the Council who facilitated the interviews in different parts of the country. Besides I would like to thank Mr S P Parasher who facilitated the printing of the book.

I am grateful to all the institutions where I visited and all those whom I interviewed during the course of writing the book for not only giving their precious time in helping me to understand the work they are doing but also the hospitality they offered.

And of course there was active help from my friend,

K Kannan, Principal Correspondent, The Hindu, who did the editing of the book and Mr. S K Ghuna, who did the proof reading.

Finally, as I try to assimilate and understand the work done by the institution builders who feature in this book; their struggle and perseverance, I am reminded of a famous quote of Swami Vivekananda who aptly said, *“Great work requires great and persistent effort for a long time. Neither need we trouble ourselves, if a few fail. It is in the nature of things that many should fall, that troubles should come, that tremendous difficulties should arise, that selfishness and all the other devils in the human heart should struggle hard, when they are about to be driven out by the fire of spirituality.”*

Vedabhyas Kundu

About the Book

The Rehabilitation Council of India has been ever since its inception systematically reinforcing its objectives of regulation and standardization of training programs in the disability sector in the country. The Council is conscious of the fact that for reaching the unreached with standardized training programs it is important that successful training models are replicated. Various channels of communication will have to be used to make people aware of these successful models. It is in this backdrop that the Council decided to bring out this book on *Institution Builders in the Disability Sector* which focuses on people who have been assiduously working to evolve institutions in the field of disability. It highlights the work of pioneers who have inspired institutions that are imparting commendable service to the persons with disability in the country. All these institutions have been promoting training and have important role in standardization of services for rehabilitation of persons with disability.

About the Author



The author, Vedabhyas Kundu, is currently working as Programme Officer, Gandhi Smriti and Darshan

Samiti, the national memorial of Mahatma Gandhi. A journalist by profession, he has been writing on disability issues for several years. As a volunteer with Samatvam—the development communication group (an initiative of the International Year of Volunteers Team, United Nations Volunteers), he is part of a media volunteers team working on media and disability. One of his previous book, *India's Living Legends : Savants of Voluntary Action* was an attempt to profile the leading voluntary activists of the country and this book, for him as a writer, is a continuation though focuses specifically on those working for the persons with disability.



Lal Advani

Lal Advani

When at a time a person of his age would prefer to sit back and relax, he continues in his mission to work for the persons with disability. A pioneering figure in the disability sector in India, Mr Lal Advani has been an inspiration and force behind many a program or institutions for the persons with disability.

Having started his work at a time when there were hardly any services available for the persons with disability, Mr Advani's efforts have not been without any challenges. Truly his endeavor for the last six decades can be described as what Swami Vivekananda had said, "*Great work requires great and persistent effort for a long time. Neither need we trouble ourselves, if a few fail.*"

Born on April 26, 1923 in Hyderabad, Sindh (now in Pakistan) an unfortunate incident happened during his birth. The doctor reached late and had no time to sterilize the instruments used during child-birth. Though there was no brain damage, his eyes became red. As a child, he did not have any problem with his vision.

However, by the time Mr Advani was in Class II, he started having problems seeing the black board and used to stumble around desks. He was taken to a local doctor and was told that he had developed glaucoma. To ensure better treatment, he was taken to Quetta to a British eye-surgeon, Sir Henry Holland. He was operated upon for the first time when he was about 10 years of age. The operation was successful and he could

see well for a while. But unfortunately glaucoma that is intractable returned. Over the period of next two years, Mr Advani underwent 12 operations. His eyesight began diminishing after every operation.

In his final attempt to ensure that Mr Advani did not completely lose his sight, his father took him to a British Faith-Heeler who had come to Karachi. "Father had read in newspapers that this Faith-Heeler could cure incurable diseases," he reminisces, "Hoping that she could do something, I was taken to her." But when she looked at Mr Advani, she said nothing could be done. It was a traumatic blow to the young Advani, his world seemed falling apart. He lost his vision completely by the age of 12. Following this, Mr Advani went to a local blind school to get training in Braille. The first story he read in Braille was Romeo and Juliet, he recollects.

"In those days loss of vision was considered a total disaster", says Mr Advani, "A person with visual impairment had no other option but to either beg, become a religious preacher, music teacher or do chair canning." 'Denouncement from society' was the destiny of a person with visual impairment. Even for Mr Advani, his mother would say that she had only one son and refused to consider him as one.

Recollecting his school days before he lost his vision, Mr Advani says he was mischievous. Sharing an anecdote he says, "Once in the class, a girl did not respond to my 'namaste'. So when a friend told me that she was wearing a new sari, I squeezed an orange and spread it on her chair. Her sari got spoiled and she

complained to the teacher. No one came forward to name me. From next day onward she always said 'namaste' to me first."

By the time he was 15 years of age his father took him to a saint who suggested that he be sent to Kashi or Benaras so that he could master the Vedas. But young Advani revolted against this. He then decided to do a course in music following which he started teaching music.

In 1942, Mr Advani was nominated to do a course in Physiotherapy in Karachi. There was an agreement that he would be sent to the Middle-East at the war front after he completed the course. "As part of my practical, I was given a boy with quadriplegia to attend to. The boy was considered lazy and British officials told me to put iron rods in his legs if he did not respond. I had been interested in child psychology and was opposed to such a treatment." he says.

"The doctor was agitated and complained to Major Maxell, the head of the British Military Hospital," he continues, "The Major threatened to put me in jail and asked for my resignation. I resigned. Besides I did not want to go to the Middle East."

Mr Advani then decided to pursue his studies and went on to do General Certificate of Education. "The London University then used to conduct exams in different centers where students with visual impairment were allowed to appear. I took the exams in 1943 in Karachi," he says, "In those days all Braille books, Braille watches and other materials for the

visually impaired used to come from England.”

The turning point in Mr Advani’s career came in 1944 when he got an offer to join as an Instructor in a new Institution in Dehradun to train people who lost their sight in World War II. “At the St. Dunstan’s Hostel for the Indian War Blinded, many of the inmates had lost their self-confidence. They said they no longer were capable of doing anything after they lost their sight. So it was a challenge of not only training them but also boosting their self-confidence.”

During this time, the Viceroy Lord Webel appointed a Committee to investigate into the causes of visual impairment in India and also recommend measures for the welfare of the visually impaired. Mr Advani’s boss Mr Clutha Mackenzie, was the Secretary of the Committee. He was put to a grinding schedule – right from assisting Mr Mackenzie to taking classes. He used to work from 7 a.m. to 9 p.m.

“The Committee made two major recommendations. It said that the Ministry of Education should set up a separate unit on blindness to deal with education for the visually impaired and similarly the Health Ministry should set up a separate unit.” Mr Advani says. Besides the report talked in details about pre-nursery education, school education and training of adult visually impaired. It also noted on the need of library services for the visually impaired, prevention of blindness, enactment for the visually impaired, production of Braille literature and rehabilitation programs of disabled other than that of the visually impaired.

Mr Advani became the first person with visual impairment to be selected to the Union Public Service Commission in April 1947. He joined as the head of the unit for the visually impaired in the Ministry of Education. "Initially my immediate boss told me that there was no work for a visually impaired person. He told me to come to the office, wish him good morning, sit the whole day and then in the evening bid him good-bye." he reminisces.

But Mr Advani was not one to be cowed down. Shortly, he put up a note that blindness was not the only form of disability. "I wrote that the unit should not just deal with education of the visually impaired but with the education in other areas of disability like hearing impairment, mental retardation, orthopedic disability." he says. This was Mr Advani's first major intervention in the disability sector in India.

"The then Union Education Minister Maulana Azad agreed to my proposal and the unit was transformed to deal with education for all areas of disability." he continues.

In 1951, Mr Advani along with Prof Suniti Kumar Chatterjee, a distinguished linguist, went on to develop the India Braille Code, Bharati Braille. "In 1949, UNESCO felt there was need to develop an uniform Braille Code. In this regard, a conference was organized in 1950 in Paris. Prof Chatterjee and I attended the conference which laid down principles for devising uniform Braille Code for Indian languages." he says.

"After coming back, we worked to develop an uniform Braille Code and finally in February 1951, the

Bharati Braille was formally accepted as the code of the country," he continues, "All Indian languages can be read by the code." The country celebrated the Golden Jubilee of Bharti Braille in 2001.

Again in 1951 itself, when the First Plan was being formulated, Mr Advani requested the Planning Commission to allocate some budget for education of the disabled. "They were reluctant and it needed lot of persuasion to get Rs 11 lakh sanctioned," he says.

Meanwhile, in December 31, 1947, the then Education Minister Maulana Azad called an important meeting and decided that the Ministry would take over the St. Dunstan's Hostel. It was renamed as the Training Centre for the Adult Blind (TCAB) on January 1, 1950. From an institution catering only to military personnel, the Centre was now opened for rehabilitation of all. In 1951, it was decided to set up the country's first Braille Printing Press in Dehradun. The Press was independent from TCAB.

Mr Advani was instrumental in developing various programs and schemes for the visually impaired. In 1954, a workshop was set-up as part of TCAB to produce Braille slates and Arithmetic frames. Again in 1957, he pushed the Finance Ministry to approve a scheme for women with visual impairment. Through this scheme, a separate training section for women was started at Dehradun. On January 4, 1959, a model school for children with visual impairment was started at Dehradun to cater to the educational needs of children with visual impairment while in 1962 a National Library for the Blind was set up. All activities of TCAB

including the model school and women's training program were integrated in 1967 and was renamed as the National Centre for the Blind.

Meanwhile Mr Advani who firmly believes education is the only panacea for empowering the persons with disability was instrumental in starting a Central Scholarship Scheme for the disabled in 1952. In 1974 this scheme was transferred to the states.

Again in 1957, Mr Advani mooted efforts to initiate a Special Employment Exchange. The higher authorities initially rejected the idea. Then the International Labour Organisation was approached and an expert came who recommended the need to set up Special Employment Exchanges. On March 6, 1959 the first Special Employment Exchange was set up in Delhi.

According to Dr S R Mittal, a close associate of Mr Advani, in 1961, representatives from the International Labour Organization(ILO) came to India to explore possibilities for starting various vocational training courses for the visually impaired. Mr Advani was actively involved in this process to explore new avenues and with the help of the ILO representatives light engineering courses were started in Dehradun and Delhi.

In 1973 it was felt that services at the National Centre for the Blind needed to be expanded and made quality based. The then Education Minister Mr Nurul Hassan constituted a committee under the chairmanship of the Education Secretary to review the functioning of the National Centre for the Blind and in general to

explore the ways and means to improve the services for persons with disability. Mr Advani was the member secretary of this committee.

Mr Mittal points out that this committee made far-reaching recommendations for initiating services for the persons with disability in the country. The committee suggested the setting up of national institutes to cover all disabilities. The objectives of the national institutes were outlined as follows : to develop model educational and training services which could be given for replication to voluntary organizations later on; thrust on humanpower training; and to undertake meaningful and practical research related to various aspects related to disability.

On July 2, 1979, the National Centre for the Blind was renamed as National Institute for the Visually Handicapped. Mr Advani was appointed the first Director of the Institute. Mr Advani was also instrumental in initiating the National Institute for the Mentally Handicapped, the National Institute for the Hearing Handicapped and the National Institute for the Orthopaedically Handicapped.

While Mr Advani was working to initiate programs and policies for the persons with disability in the country, he completed his post-graduation in Philosophy from Punjab University in 1951. Then in 1952, due to the support of the then Education Secretary Humayun Kabir, Mr Advani went on to do post-graduation in special education from the London Institute of Education. Taking study leave in 1964, he did post-graduation in special education with a

specialization in mental retardation from Boston University, USA. Later on he took a diploma in special education for visually impaired students from the Perkins School for the Blind, USA.

Even after retirement in 1982, Mr Advani has been active in working for the persons with disability and furthering their cause. On April 1, 1985, he took over as the Director (Research), the National Society for Equal Opportunity for the Handicapped. He continued to work till December 31, 1996, and was responsible for initiating various research projects and studies. Since 1996, he has been working as an honorary consultant to the Rehabilitation Council of India.

Besides Mr Advani was the President of the Asian Chapter of the World Blind Union from 1984-1992. He has also been the editor and publisher of the journal, "Braille International" from 1972-1992. He was also instrumental in facilitating merger of two International bodies – the International Federation of the Blind and the World Council for the Welfare of Blind.

Mr Advani's contribution to the disability sector in India was recognized when he won the 1997 President's Award for the Best Disabled Individual. Still working assiduously, Mr Advani recollects his marriage. He shares some interesting anecdotes: In late 1950s, one of Mr Advani's friends advertised in the matrimonial column of a newspaper. The fact that he was visually impaired had been inadvertently left out. In response, he got 93 applications. He then wrote back about his impairment. None responded back.

While concluding, Mr Advani talks at length of the contribution of his wife in his remarkable efforts for the persons with disabilities. She has been the pillar of strength behind all his endeavor. He reminisces, “In 1962, two ladies came to me for help as they wanted to publish a brochure. One was a lawyer and the other a librarian. After some interactions, both wanted to marry me. Finally I got married to Nalini in January 1964. She was librarian at the Maulana Azad Medical College library.”



Beroz Vacha

Beroz Vacha

Zameer Dhale, 24, has a dream – to have his own independent business someday. The vocational training he has received has bolstered his self-confidence. His determination can be described by what Swami Vivekananda had said, “We are responsible for what we are, and whatever we wish ourselves to be, we have the power to make ourselves.”

Zameer is also enthusiastic and is good in making friends. He is not the only one whose life has been transformed after he came to the Helen Keller Institute for Deaf and Deaf-blind, Mumbai.

The Institute has brought hope to the lives of many deaf-blind children. They have now become useful members of the society and are a living proof of what Helen Keller had said, “A person who is severely handicapped never knows his own hidden source of strength until he is treated like a normal human being and allowed to shape his own life – or life is either a challenge or an adventure or nothing at all.”

One of the pioneering Institutes in the country, the Helen Keller Institute for Deaf and Deaf-blind has been working for more than two decades in the field of rehabilitation of the deaf-blind. The pillar behind this endeavor is Mrs Beroz Vacha who inherited the value of service to others by reading Florence Nightingale, Tagore, Helen Keller, Albert Schweitzer and Madam Curie.

Born on December 8, 1928, Ms Vacha went to a Municipal School in Valshad, Gujarat. "During my student days, I was moved by the plight of a hearing impaired child in our school. Students and people used to make fun of him."

Years later, when she went back to Valshad, she saw a grave in front of the school. It was that of the same boy with hearing impairment. "To me this grave was a symbol of muted spirit that was denied the right to education for no fault of his own." Ms Vacha says.

After passing out from college, Ms Vacha got married and for the next few years, she concentrated on her family life. For sometime, however, she worked as a volunteer at the Oral School for the Deaf in Kolkata. When she came back to Mumbai, she made up her mind to work for the hearing impaired.

In 1965, Ms Beroz Vacha met 17-year old Shyama Mehta. She was born deaf and had progressively lost her eyesight. By the age of 16, she lost her sight completely. Shyama's father, Shantilal Mehta, requested Ms Vacha to be with her for an hour everyday as a tutor companion. "My interaction with Shyama propelled me to work for the deaf-blind," Ms Vacha recollects, "Shyama's courage, her sense of humor and her sharp memory amazed me. She personified the true spirit of courage."

In 1970, Ms Vacha got an opportunity to receive overseas training in educating the hearing impaired from the University of Manchester and later from the International Center on Deafness at Gallaudet College, Washington DC. In 1974, she took training at the Perkins

School for the Blind and Deafblind in Boston, Massachusetts.

Between 1970 and 1977, Ms Vacha prepared herself for life-long service to the cause of the deaf-blind. Finally in July 1977, she started the Helen Keller Institute for Deaf and Deafblind with just two deaf-blind children and one deaf aphasic child. There were just three teachers including Ms Vacha. The Institute started from the residence of one teacher. "We started with a meager Rs 150, but I was confident that I would get help. I always believe that people have a lot of goodness in them and it was important for us to tap it."

"Right from day one, we worked on the premise that no one was incapable of being taught. We believed that none could develop his/her personality without education. It was the fundamental birthright of a child to be educated and loved." she adds.

"The Total Communications approach is being followed from the beginning," Ms Vacha points out. The philosophy of Total Communications encompasses oral/aural, manual, print (reading, writing, drawing). Mime, dance drama and spontaneous body language help to quickly develop cognitive levels.

"Total Communications is important in the early years of a child's development," Ms Vacha says, "It is in fact a communications philosophy and not a teaching method."

According to Ms Vacha, the Total Communications program hinges on two factors:

- a) Faith in the ability of teachers and children: Teachers needed to believe in the Total Communications approach and be willing to practice it in the classroom setting.
- b) To bring out a manual of finger spelling and sign language suitable for local languages.

Quoting Helen Keller, Ms Vacha says, "Effective Communication is the gateway to knowledge. Knowledge is power. Rather, knowledge is happiness because to have knowledge is to know the truth from the false and the lofty things from the low. To know the thoughts and deeds that have marked a man's progress is to feel the great heart – throb of humanity through the centuries; and if one does not feel inside the pulsation of a heavenward striving, one must indeed be deaf to the harmony of life."

To meet the needs of the increasing number of children, the Helen Keller Institute moved to a Municipal School in Byculla in 1979 and was housed in two rooms. At that time, there were six deaf-blind and 15 children with hearing impairment.

In tandem with its approach to its Total Communications philosophy, the Institute published the first dictionary on manual communication, 'Talking Hands' in 1979-80. It comprised 3000 signs.

A deaf-blind child is bereft of any language, communication, speech, and awareness of his family or the world outside. According to Ms Vacha, to bring such a child out from his shell, the education and

rehabilitation program needs to be tailor-made to suit him. “All teachings should be rooted in a child’s individual experience,” she emphasizes, “And this should be done right from an early stage.”

To develop personalized programs of a deaf-blind child, several factors need to be considered including the child’s current abilities and strengths and also the severity of disability, Ms Vacha points out. In the initial years, the child-teacher ratio should be 1:1 to achieve desired results, she adds.

“We have to look at the child holistically. Detailed observations, documentation and a knowledge of how our sensory processes function within the nervous system at an unconscious level are required,” she continues.

At the Institute, intervention begins as soon as the child’s disability is diagnosed. “A major constraint, however, is the lack of adequate services available in India. So most deaf-blind children do not have access to specialized rehabilitation. Early intervention programs fail due to lack of information, dearth of professional expertise, woefully inadequate services and absence of referrals,” Ms Vacha avers.



Children at the Helen Keller Institute

According to Ms Rina Bhandari, Principal of the deaf-blind section, the early intervention program has to be dovetailed to parental guidance and parent counseling. “We give a lot of thrust to interactions with parents,” she continues, “The mother is usually the focal point who understands the child best. Her observations and inputs are critical for developing an individualized program.”

The Institute has initiated a Parents Association where such interactions are encouraged. “We organize family weekends and also camps once in a year. This enables parents to come together and share their experiences,” Ms Bhandari says.

The systematic involvement of parents has ensured that many of them are actually volunteering for the Institute from time to time. “When there is a meeting or

shortage of staff, many of them come to help teachers to look after the children. They also encourage and render emotional support to a new parent," Ms Vacha points out.

The Institute addresses various areas of students' health care too. Due to inability of the deaf-blind to access information, all areas of their development are affected. "Our goal is to make the children as much independent as possible so that their self esteem develops," Ms Vacha says.

"With appropriate diagnostic procedures and a good educational curriculum, a deaf-blind child can sit, concentrate and perform useful tasks. They can be trained in different productive work and in daily life skills like dressing, toilet, mobility, etc." she adds.

Since its inception, the Institute has grown from strength to strength. By 1982, there were 50 children, 10 deaf-blind and 40 deaf. Around this time, the Institute received its first adhoc grant from the Social Welfare Department, Government of Maharashtra. Besides, Mr Shantilal Mehta, the father of Ms Vacha's first student, sponsored two teachers, one-maid attendant and transport facilities for seven years.

The Institute was able to put in place the first residential facilities in India for deaf-blind children in April 1985. The facilities were meant for children coming from outside Mumbai. The very same year, the Singapore Association for the Blind invited the Institute to start a program for deaf-blind children in their country.

“Our emphasis has been on curriculum development for the deaf blind child,” says Ms Vacha, “It is a guideline in developing skills, involving senses, motor functions and coaxing the child.” Communication skills, cognitive development skills, sensory development, motor and self-care skills, and social and emotional development skills are all in focus.

The Helen Keller Institute has pioneered a graded functional and academic curriculum leading to pre-vocational training and vocational rehabilitation. A series of co-curricular activities like swimming, camping, mobility, domestic science, mime dance and fine arts has also been instituted. Besides providing regular counseling services for parents, children and staff, the Institute has also started a short-term in-service teacher training for the deaf-blind.

In pursuit of its goal to make the deaf-blind independent, the Institute started the Vocational and Rehabilitation Unit in 1998. Here the main thrust is on imparting training in production of jewelry from semi-precious stones and making decorative candles.

On July 1, 2000, the Institute started a teachers’ training diploma course for the deaf-blind for the whole of South Asia and the same is recognized by the Rehabilitation Council of India. According to Ms Sampada Sherwade, Coordinator, Teacher Training Program, the emphasis of the 10-month diploma course is to give lots of hands-on experience including a three-month internship period. “We encourage the teachers to develop a relationship with the child. The aim is to make a child learn what we want them to learn.” she

says.

Ms Beroz Vacha has won several national and international awards including the prestigious An Sullivan Medal in 1991, the National Presidential Award for the Welfare of People with Disabilities in 1997 and the Deaf-blind International Distinguished Service Award in February 2000. Taking a leaf from Helen Keller, her contribution and achievements can be summed up as: "We can do anything we want as long as we stick to it long enough."

However, she feels education and rehabilitation therapy need to be developed alongside existing services for the deaf-blind in different parts of the country. "As the incidence of deaf-blindness is lower than other disabilities, in-service or on-the-job training should be given to staff as and when such children are identified. Schools and professionals having professional expertise must be prepared to assist in providing services and making staff available for training. The training provided must be practically oriented with theoretical knowledge so that professionals, parents and clients can understand and use the knowledge imparted to them."



Bhadraben

Bhadraben & late Jagdishbhai Patel

The devastating killer earthquake that hit Gujarat on January 26, 2001 rendered many people disabled. It was a personal setback to Mr Laljibhai Prajapati as his Navchetan Blind Men Association in Bachau, Kutch was razed to the ground and 16 inmates lost their lives. However, the incident has only redoubled his resolve to ensure facilities for all affected.

Working in Kutch since 1978, Mr Prajapati was a student of the Blind People's Association (BPA), Ahmedabad. "Many of us were inspired by our alma mater to go out to areas where there are no facilities," he says, "BPA is still a constant source of encouragement and support."

"BPA's name is a misnomer," points out Mrs Bhadraben Satia, the moving spirit behind the organization, "Though we started it, focussing to work for the visually impaired, we now work for all categories of persons with disability. But since we are already known as the Blind People's Association, we have not effected any change in its name."

Going down memory lane, Mrs Bhadraben Satia traces the growth and contribution of BPA, which is now one of the leading organization for persons with disability in the country. Albert Schweitzer had rightly said, "There is no higher religion than human service. To work for the common good is the greatest creed." It

was with this ingenuity and dedication that she and her late husband Jagdishbhai Patel worked to provide a wide gamut of services to all categories of the disabled.

Giving an account of Jagdishbhai's early life, Mrs Bhadraben Satia says he was born on September 5, 1928. At the age of eight he suffered from meningitis and lost his vision. He was sent to the Calcutta Blind School at Behala, one of the oldest school for the visually impaired in India in 1938. He went on to join the Victoria Memorial School for the Blind, Mumbai, in 1941. After passing his vernacular final examination in 1944, he took admission for a three-year course in physiotherapy at the same school. At that time, it was the only school in the country offering a course in physiotherapy to the persons with visual impairment.

Immediately after acquiring diploma, Jagdishbhai started working in the Massage Clinic of the School. Soon family pressures forced him to return to Ahmedabad where he was without work for six months. Finally on January 1, 1948, Jagdishbhai set up his own Physiotherapy Clinic with support from his father.

"I met Jagdishbhai at his Physiotherapy Clinic in 1950," Mrs Bhadraben recalls, "My younger sister had hurt herself so I had to go to the Clinic. One day he asked me if I would work for a blind association he was in the process of setting up. I agreed to volunteer everyday after 4 p.m. as I was then teaching at the Ahmedabad Women's College." That was the beginning of a life long partnership – not only as life partners but also as joint partners in their endeavor to develop a pioneering institution.

“There was lot of opposition when we decided to get married,” Mrs Bhadraben says, “My family members were shocked when I told them about my decision to marry a man with visual impairment and that too from a different caste.” The two got married in 1958.

The Blind Men’s Association (prior to 1998 the Blind People’s Association was called so) which was established in 1947 at a meeting of few leading blind persons in Surat, has a long history. In 1950, Blind Men’s Association got fragmented into three independent organizations at Ahmedabad, Pune and Mumbai. Jagdishbhai started the Ahmedabad Blind Men’s Association.

“A few blind boys used to come to Jagdishbhai’s Clinic in the initial stages and we used to teach them,” Mrs Bhadraben continues, “Later, a house was donated by Mr Ambalal Sarabhai for use as office by the Blind Men’s Association.”

“We then started a hostel with just three boys,” she continues, “Within two years there were 30 boys.” Meanwhile in 1954, a center exclusively for girls with visual impairment was started at Memnagar village near Ahmedabad.

Jagdishbhai has been the force behind important endeavors initiated for the visually impaired in the country. He was one of the prime movers behind the meeting held in 1952 in Mumbai where the National Association for the Blind was established. Over the years, the National Association for the Blind has

emerged as a leading organization for the visually impaired having branches in other parts of the country.

Braille books were in short supply in those days. To meet this shortfall, Jagdishbhai approached the Superintendent of the Sabarmati Central Jail at Ahmedabad in 1958 for involving prisoners in the embossing of Braille books. The Superintendent was excited about this unique idea. Initially 10 prisoners were taught Braille. Within a few weeks, some Braille books were brought out. Soon jail authorities allotted a room and the Blind Men's Association deputed a staff member for teaching Braille and coordinate Braille book production. This room is known as 'Braille Barrack'.

Dwelling further on the expanding work of the Association, Mrs Bhadraben talks about the Adult Training Centre for the Blind established in 1960. "Jagdishbhai had come in touch with Kanubhai Thakar in 1958. After losing his vision in 1952, while preparing for his MSc, Kanubhai had gone into a state of depression. However, after a series of discussions and meetings, he regained self-confidence and became determined to render service for persons with disability."

"Jagdishbhai encouraged Kanubhai to establish the Adult Training Centre and a sheltered workshop," she continues, "I was actively involved in the setting up of this Center. Handloom weaving and Braille writing were introduced as the first activities of the Center."

A circulating Braille Library was started in the same year. At that time not many books were available. With the setting up of the library, a large number of visually

impaired people benefited. Textbooks, novels, periodicals and often reading materials that those with visual impairment did not have access to earlier were made available.

“1962 was a landmark year for us as we were allotted land by the Gujarat Government for constructing our own building. This now serves as our headquarters,” Mrs Bhadraben says.

“During those days, it was a desolate place. There was no proper approach road to the campus. We had to pass through muddy roads and shrubs to reach there,” she adds.

The first building of the Blind Men’s Association came up in 1963. Jagdishbhai had by then initiated efforts for promoting education of the persons with visual impairment in a big way. “There was no provision for secondary or higher education for children with visual impairment in Gujarat in those days,” Mrs Bhadraben points out, “So Jagdishbhai took up the issue of recognition of a School up to class XI to be run by the Association with the Education Department. It was the first such school to be recognized in Gujarat. The first final exam for the secondary level was held during 1967 and we achieved cent per cent result in that year itself.”

In 1976, the School managed to get recognition as a Higher Secondary School. A science stream for the

visually impaired students was also started. This served as a catalyst and several other schools followed suit. With a firm belief that visually impaired persons can be trained in almost all trades with some modifications, a Vocational Stream at the higher secondary level was started in 1989. By then the organization had standardized the Gujarati Braille Shorthand system with the collaboration of the National Institute for the Visually Handicapped.

“Simultaneously, we established a Music School for the visually impaired in 1967. There were 66 blind students in the first batch,” Mrs Bhadraben says. The Music School got affiliation to the Gandharva Mahavidhayalaya Mandal in 1971.

To meet the objective of holistic rehabilitation of the visually impaired, the Technical School for the Blind was also set up. The Technical School has been imparting one-year training in various trades, viz., general mechanics, electric motor rewinding, carpentry practices, hand and powerloom weaving, cane-work, coir-work and card-board work.

According to Mr Harish M Panchal, Director, Training of the Blind People’s Association, it was realized in early 1970s that just giving technical education was not enough. “So we decided to initiate an on-the-job training program,” he says, “With hands on experience, it was easier to facilitate jobs for students once they passed out. The primary objective has been to expedite economic rehabilitation of the disabled. The Adult Training Centre (workshop) for the Blind has been an important component of the on-the-job training

program.”



The skillsets they have acquired at BPA have helped
in their rehabilitation process

“This effort at providing on-the-job training enabled us to start production of different products.

But this meant we now needed sighted people too," Mr Panchal continues, "So in 1976 we initiated a multi-category training program for the disabled. We introduced several new trades like light engineering, printing press, commercial design, tailoring, composing and printing."

To start with, the BPA approached the Government for work and was given repair work of some of its department's furniture. "When I joined BPA in 1975, I was given a turnover target of Rs 10 lakh per month," he adds, "I could achieve the target in 1977-78." In 1979, the workshop went semi-automatic and so the turnover rate increased.

"Previously most aids and appliances used by the visually impaired like the Braille Slate, Pocket Taylor's Frame etc. had to be imported," says Mrs Bhadraben, "But with new facilities at the BPA we decided to start production of these aids and appliances."

To further this aim, Jagdishbhai established the Braille Aids Workshop in 1980. In 1981, the organization started manufacturing and distribution of various ortho-prosthetic aids and appliances for the orthopaedically handicapped. The Workshop was renamed in 1982 as National Rehabilitation Engineering Institute (NREI).

"Innovation has been the hallmark of our Institute," says Dr Bhushan Punani, Executive Director, BPA, "Ranging from tricycles for those with paraplegia, low cost nylotic calipers, new prosthetic aids, battery operated tricycle, Braille micrometer to low vision device, we are constantly working on new aids and appliances. In fact, BPA encourages innovation in

various devices used by persons with disability.”

For instance, BPA has supported innovation made by Mr Bhaghirath Mankad, a father of a low vision child, who has made a device, which is benefiting many with low vision. In fact, BPA is now producing this device in a big way. The most significant aspect of the Dhairyra Low Vision Device (Mr Mankad has named the device after his daughter) is its simplicity. A small simple wooden box is fitted with an ordinary tube-light with white acrylic sheet on the top. When the board is illuminated, a person with low vision can read and even write with a marker or a sketch pen due to a contrast that is created.

Meanwhile as the sales turnover of the Workshops grew and the number of products also registered an increase, a marketing outlet, Handika, was set up in 1983. “Sustainability has been the philosophy behind these efforts,” Dr Punani says.

“In order to provide quality services and rehabilitation, we strongly felt the need for professionalism,” Mrs Bhadraben says, “This is the reason we encouraged professionals like Dr Punani, Mrs Nandini Rawal, Mr Harish Panchal and others. Besides we were always conscious of the need to develop a second line of leadership at BPA.”

“Jagdishbhai had always emphasized on the need to promote integrated education for comprehensive rehabilitation of the visually impaired,” she points out, “We launched the first project under integrated education in 1981. In fact the Mehsana District branch

of the National Association of the Blind took up a pilot experiment. Several projects on integrated education are now going on in other districts like Valsad, Banaskantha, Junagadh, Kaira, Rajkot, etc. This scheme has also been adopted by the Department of Primary Education, Gujarat Government.”

The NAB Gujarat State Branch started a Community Based Rehabilitation project at Dholka in 1983. Jagdishbhai was directly monitoring this project. In fact, it has been his staunch belief that the only way to reach millions of unreached visually impaired persons in rural areas is by initiating Community Based Rehabilitation (CBR) programs. “If we are to liberate visually impaired persons, we must go to them in their villages, convince the community and enlist the support of the families,” he had said.

The CBR Program has been successfully implemented in various parts of Gujarat. In a similar way, in 1989, an Urban Community Based Rehabilitation Project for aged and disabled was initiated.

Convinced that only education and technology can facilitate the visually impaired to go ahead in the competitive market, the Blind People’s Association started the Cama Computer Training Center for the Blind in 1984. Besides providing computer training to visually impaired students, the Center also helps in providing placement services as computer operators and computer programmers. The very next year, BPA started an electronics training center project in partnership with the Industrial Development Bank of

India. Presently, the Center is imparting training to the visually impaired and other differently abled in the assembly of antennae, production of communication components and other electronic items.



The computer center for the visually impaired at
BPA

In an endeavor to provide services to the deaf-blind and others, a Centre for Multihandicapped has started functioning from 1993. BPA also started a Diploma Course for the Secondary School teachers of the visually impaired in 1994. Besides it has been organizing training program for parents of visually impaired children.

On 31 March, 1999, Jagdishbhai died. But BPA continues its journey in its endeavor to reach out to more and more persons with disability. "We are trying to ensure that the growth and sustainability of our efforts increase simultaneously," says Dr Punani, "Besides we

are also increasingly focussing on the family instead of only the individual."



Dr Bimalendu Narayan Roy

Dr Bimalendu Narayan Roy

Sukanto Banerjee has an astonishing ability to remember dates as far as 10 years back. While not many have such a unique talent, he carries a stigma with him as a person with mental retardation. Tapas Chatterjee despite being a singer is also labeled as such by the society.

“If nurtured properly, there is nothing that persons with mental retardation can’t do,” says Ms Chinmayee Manna, music therapist at the Alokendu Bodh Niketan, Jemo unit, Murshidabad. Echoing, Francis Bacon, she says “Natural abilities are like natural plants that need pruning by study.”

Making persons with mental retardation self-sufficient has been the avowed motto of Dr Bimalendu Narayan Roy who had been working for them since the sixties. His institution, Alokendu Bodh Niketan, has been endeavoring to transform the lives of persons with mental retardation in West Bengal.

Hailing from a royal family in Murshidabad, Dr Roy, born in 1920, moved to Kolkata after passing out from school in 1938 and started a small business to sustain himself. Simultaneously, he did a LMF to become a medical practitioner, besides involving himself in social work and theatre.

Inclined to study further, Dr Roy enrolled himself in MBBS which he completed in 1951. However, by then he had already made a name for himself as a doctor and social worker. On August 15, 1947, he set up a Jemo Medical Hall to serve the poor.

“One fine day in 1951, a man came to me and suggested I should go in for a higher degree to help and serve people,” Dr Roy reminisces.

“This served as a catalyst for me to go to London and take a diploma in tropical medicine,” he says. He also briefly joined the Middlesex Hospital in 1954. After coming back to Kolkata in 1955, Dr Roy started thinking on the need for proper care and treatment of children with mental retardation. He again went to London in 1959 to do specialization in this subject.

After coming back to India in 1960, Dr Roy established a ‘Society for Child and Community Welfare’. He also ran a polyclinic for sustenance. “In those days, I used to charge Re one from my patients,” he says.

“In recognition of his efforts, the then chief minister of West Bengal, Dr B C Roy gifted me an X-ray machine. I decided to charge Rs three for an X-ray as no one gives value to altruism,” he adds.

With the help of volunteers Dr Roy started a medicine bank for the poor. “At the same time, I was moved by the plight of children and persons with mental retardation and so I decided to start a center for them.”

“Lack of trained professionals in the area of mental retardation was a major hiccup,” Dr Roy continues, “It was a challenge to provide services to persons with mental retardation. I felt there was need to start a course for those working for persons with mental retardation.”

In 1965, Dr Roy went back to London and a few other cities of Europe to get further training in rehabilitation of persons with mental retardation. Besides he started working on a module for a professional training course and with the help of professionals he formulated the 'Professional Diploma in Mental Retardation.' Initially, it had no takers and the Government too did not recognize it.

To get Government recognition for the course, Dr Roy sought an appointment with the then Prime Minister, Mrs Indira Gandhi. "I took seven boys with mental retardation along with me and told Mrs Gandhi that rehabilitation of children like these can happen only if a cadre of professionally trained care-givers was created," he says.

Dr Roy followed up the meeting with Mrs Gandhi by organizing a seminar on mental retardation on December 30, 1966. "Besides proposing a separate department for persons with disability, I pleaded for more facilities for children with mental retardation," he recalls.

The meeting with Mrs Gandhi and the subsequent seminar yielded immediate results. "When I came back to Kolkata and met the Governor, he not only extended recognition to the course but also sanctioned Rs 5,000," Dr Roy says. In the first year itself, there were 12 students. The Professional Diploma in Mental Retardation was one of the first such courses to be started in India.

1978 was another landmark year for Dr Roy. During this year, the Alokendu Bodh Niketan Residential was formally established with the aim of rehabilitating those with mental retardation and cerebral palsy through curative teaching, training and other processes. Since it was started with residential facilities, many children from far off places started staying in the complex. "Lack of trained teachers was not a problem any more as we already had some who had taken our teacher training course."

With the aim of reaching out to a larger public, Dr Roy decided to start branches in Sanada, Darjeeling in 1982 and at Jemo-Kandi, Murshidabad in 1987.



Inmates at the Murshidabad Branch

In 1993, the Alokendu Bodh Niketan started yet another branch, 'Anuradha' in Kolkata exclusively for women with mental retardation. "Slowly as these units grew, we realized that many with profound mental

retardation were generally confined to the four walls of their house," Dr Roy continues, "We decided to start a home-based training program."



Inmates at Anuradha, Kolkata

"Our special educators go to homes of children with severe mental retardation and chalk-out an Individual Training Program for them," he says, "The whole focus is on developing the potential of these children to their optimum capacity."

Vocational training has been an integral part of Alokendu Bodh Niketan's rehabilitation program. Bakery, tailoring, weaving, printing press, bookbinding, leather, woodwork, picture painting, screen printing are some of the vocations taught at the Institute. "Many of our students have been gainfully employed and no longer are a burden on their parents," Dr Roy says.

Besides, the Institute has been making efforts to

promote integration and mainstreaming of persons with mental retardation. According to Dr Subrata Ganguly, doctor-in-charge at the Anuradha unit, "After a proper rehabilitation program, those who are borderline cases are rehabilitated within their family environment and are sent to general schools. Also within the residential complex, those with mild, moderate and severe retardation stay together."

Postscript

Walter Scott had said:

Like the dew on the mountains,

Like the foam on the river,

Like the bubble on the fountain,

Thou art gone, and forever!

Dr B N Roy is no more. But his contribution to the cause of persons with mental retardation shall definitely remain engraved in the history of disability movement in the country.

A visionary, he was always worried that persons with mental retardation will be left in the lurch after their parents pass away. "We need to create facilities that shall take care of our elderly mental retarded populace," he used to say. His dream was to start an old age home for those with mental retardation in his ancestral home at Jemo, Murshidabad. A dream which is now in the hands of his successors.....

Dhun Adenwalla

I am deaf
Sometimes I am happy,
And sometimes I am sad;
I know
I am like other people
Because I can do everything like them
But I am sure
People don't get this feeling
Because I am deaf so people think
That I am different.

Bubla Ganguly, 14 years
- Courtesy, brochure of The Oral School
for Deaf Children, Kolkata

This is the story of a School that sprang out of a desire of a mother to provide the best education to her daughter. One of the earliest schools for the hearing impaired in the country to impart education up to secondary level, the Oral School for Deaf Children, Kolkata, has been following the academic-centered curriculum of general schools since 1964.

Tracing the history of the school, Mrs Dhun Adenwalla, its founder says, "It all began when I wanted to give my eldest daughter, Dinaz, quality education that was the privilege of any other child in a general school."

“There was only one school for the hearing impaired in Kolkata at that time and it would not admit children until they were eight years old. Besides the thrust was on vocational training,” she says.

Born on November 6, 1927, Mrs Adenwalla did her schooling and college from Mumbai. “I never had the inclination to work in the field of education for the hearing impaired,” she recollects. After her marriage to Dorab Adenwalla in 1958, she settled in Kolkata.

“Dinaz was born in 1959,” Mrs Adenwalla continues, “Soon after, we realized that she was not responding to my voice or any other sound. We suspected she was deaf.”

“It was shocking and we were confused,” she says, “We knew nothing about deafness nor anyone who had a child with hearing impairment. This compounded our problem. We had no idea where to go for guidance. We were, however, determined to make Dinaz a happy and well-adjusted child.”

In those days there was not a single teacher, doctor or parent either in Kolkata or Mumbai who could demonstrate a feasible way of training a child with hearing impairment. By then, she and her husband had accepted Dinaz’s handicap and the need for giving her specialized instruction and training. They were also convinced that this could happen only if they themselves got some exposure in the field.

“We taught Dinaz survival skills by being her ears,

telling her what we heard and overheard and by patterning our language,” Mrs Adenwalla says, “Through play, Dinaz acquired stimulating and relevant learning experiences.”

In 1963, the Manchester University announced the first course for training teachers of the hearing impaired at the EAR Center in Mumbai. “My husband encouraged me to take up the course,” she says, “I wanted to get trained as a teacher in order to overcome the feeling of inadequacy in dealing with a growing child who was hearing impaired.”

“After qualifying and returning home to Kolkata, I encountered a frustrating problem.” she continues, “To get Dinaz admitted in a general school was a tough task. We were left with only one option – to start a school for children with hearing impairment ourselves,” she says.

Thus started the Oral School with just two children, Dinaz being one of them. “I knew very little about running such a school,” Ms Adenwalla says, “Initially our enthusiasm was the only guiding factor.” Dunlop, where her husband was the Aviation Manager, made available their premises for running the School. Within four months, the number of children went up to 20. All were aged between three and nine years.

“It was indeed quite a challenge,” says Ms Adenwalla, “We had to produce material for teaching language to the children since it was not readily available.”

“Soon Ms Adenwalla realized that it was pure fun teaching children through play, dramatization and

language. Although I was anxious to see the children speak, I did not insist on it, nor did I disallow gestures," Ms Adenwalla informs, "Teachers always talked to children using finger-spelling and gestures to help sustain more fluent comprehension patterns whenever considered necessary."

In just five years, students of the Oral School attempted to take the Indian Certificate of Secondary Education examination. In fact it was one of the first schools in the country to do so. "Dinaz secured 88 per cent marks while another student got 72 per cent aggregate," says Mrs Adenwalla.

Being a mother as well as a teacher to Dinaz was not easy for her. "By about the age of 10, Dinaz too began to find the two roles difficult to accept. She began referring to me as 'Mrs A'. On one occasion, when her class and mine were going on a visit to a tea garden, she objected to my coming because I was 'mummy'. When I told her that I would have to go as I was also the class teacher, she first decided to opt out, but eventually agreed to come. Nevertheless, she insisted she would refer to me as Mrs Adenwalla throughout the trip. "

"From the very beginning, our school was involved in a mainstreaming program and started taking children to a regular school," Mrs Adenwalla says, "However, students did not derive much benefit from the program, so we discontinued these efforts except for science practicals."

The Oral School has always laid stress on the Total

Communications approach. "This is the best way of teaching the child with hearing impairment," Mrs Adenwala says.

The student-teacher ratio at the Oral School is 5:1 and the stress is on development of communication skills through play and other focussed activities at the pre-school and nursery level.

"Children learn new concepts at the primary, junior and secondary levels. There is greater stress on reading for meaning and writing for self expression," Mrs Adenwala adds.

"Most students have become independent and this is the barometer of our success," says Mrs Adenwala, "They are in varied professions. Some have become commercial artists, information technologists, fashion designers, prosthetic makers, etc. The School has even introduced a computer course now."

The School has also set-up a well-equipped audiology center and has trained personnel for prescribing and fitting hearing aids and ear-moulds. It is also running a clinic to counsel and guide children and adult hearing impaired persons. Besides, it conducts regular testing of hearing aids and has initiated an outreach program to provide audiological support to patients from outside Kolkata.

Underlying the importance of basic education, Mrs Amrita Banerjee, Vice-Principal of the School says, "The Oral School is one of the few schools for the children with hearing impairment in the country which lays major stress on academics. Besides, ICSE students can also take the Open School and Central Board of

Secondary Examinations.”

Now settled in Pune, Mrs Adenwalla has started a “Family Learning Center” to involve parents and siblings in teaching persons with hearing impairment. To cite an example, Mrs Armin Ghyara, a mother of two-hearing impaired children, feels the Center has helped in integrating children right from the beginning.

“It is difficult to get trained teachers. Therefore there is need for a new holistic approach in training teachers of the hearing impaired,” says Mrs Adenwalla.

“Teachers who are most effective are the ones who learn new methods of reaching the child, who can sketch or provide the right visual stimulation, and make teaching as lively and dramatic as possible.” she adds.

Referring to the role of mothers in managing their child with hearing impairment, Mrs Adenwalla says each mother’s experience is unique and the support given to the child depends largely on the attitudes and priorities within the family.

“Early management and training of a hearing impaired child is dependent on the mother. However, in India, a majority of them are not able to extend the support that is actually required due to factors beyond their control,” concludes Mrs Adenwalla.



Dr Edward Martin Johnson

Dr Edward Martin Johnson

It all started as a program for the war disabled in 1964 in Ludhiana, Punjab. Now after almost four decades, the Vocational Training and Rehabilitation Centre (VRTC) has grown into a pioneering scientific rehabilitation institution for persons with disability in Punjab. The brainchild behind VRTC is Dr Edward Martin Johnson.

It has indeed been an eventful journey for this man who lost his eyesight when young but who has been gifted with tremendous vision. Born sighted, Dr Johnson did his Masters in Social Work from the Madras Christian College after which he joined the Government-approved school and the Seva Samajam Home for the destitute and delinquents as the Superintendent.

“I was inspired to do service for others right from childhood,” Dr Johnson recalls, “I was initially associated with Mr John Mathai, the first Finance Minister of India and Mrs Clubwala Jadhav, the first President of Indian Council of Child Welfare who fuelled my passion for social work.”

Dr Johnson’s work for the destitute and the delinquents took a turn when the then Information and Broadcasting Minister Mrs Indira Gandhi was invited to inaugurate the building for children in 1962. But as they say, ways of Providence are strange and destiny played a cruel joke on him.

“The day Mrs Gandhi was scheduled to arrive, I

developed a severe flu. Even in such a condition, I worked to make the program a success. I continued to have high fever and headache even after the program," Dr Johnson recalls that fateful day of 1962, "I asked one of the inmates to apply Eucalyptus Oil on my head. Unfortunately, when he picked up the bottle, it slipped from his hand and fell on my eyes. Instantly my eyes became red like tomatoes and bulged. Though the pain subsided after nine days of medication, I lost my eyesight."

It was indeed a severe blow to the young Johnson who had nurtured an ambition to become a social scientist. "I was shocked beyond words as I was in the prime of my age. I had already become a Superintendent at the age of 23, but life seemed to come to a stop in just one single blow," Dr Johnson recalls.

"When they came to know about the situation, my parents were shocked and my mother suffered a heart attack. While she was taken to a hospital, I was taken to the Madurai Eye Hospital where the eminent eye surgeon, Dr Venkataswamy, tried his best to help me. But nothing much could be done as the optic nerve had already been damaged."

He would remain visually impaired throughout his life, he realized. This changed Dr Johnson's life completely. Reconciling with his condition, he took training in the field of rehabilitation under an American Project Grant. Later he organized the pilot demonstration of the rehabilitation project for the blind

at Madurai Medical College.

As part of the Project, he got a fellowship to go to Boston University, USA, where he studied rehabilitation counseling, management and administration for the next two-and-a-half years.

After returning back to India, Dr Johnson wanted to join the Madurai Medical Centre. However, he was posted to the Christian Medical College, Ludhiana as head of a two-year research and rehabilitation project under the PL-480 grant. "I landed in Punjab in 1964. The project was aimed at rehabilitating the war-disabled people and I had to look after both the ophthalmic and orthopedic side," he recalls.

The American grant stopped in 1974. "However, by then, I had started exploring avenues for continuing the program I was involved in," he says, "I went to Germany and established contact with the Christoffel Blinden Mission. Their officials came to Ludhiana, examined the work of the project and decided to support it."

Determined not to let down the persons with disability with whom he was working, Dr Johnson started the Vocational Rehabilitation Training Centre in 1974. There were initial hiccups due to paucity of funds despite support from the German organization.

After two years of struggle during which besides concentrating on providing rehabilitation services, Dr Johnson had to raise funds, a full-fledged rehabilitation center came up. Both the Christoffel Blinden Mission and the Union Welfare Ministry supported his project.

The Centre was established in the land given by the Punjab Government in 1976.

The main aim of the Centre was to continue the program of rehabilitation and resettlement started at the Christian Medical College besides providing vocational guidance and training to those who had lost vision suddenly. It decided to work in close co-operation with all hospitals in and around Ludhiana and offer training in mobility and travelling tactics including cane techniques to the visually impaired.

By establishing training-cum-production centers and sheltered workshops, the Center sought to instill in the disabled a sense of achievement. It also aimed at providing employment to the visually impaired and other disabled in the remote villages under the home-teaching and rehabilitation program.

Dr Johnson's effort in involving the local people, lions club and other organizations also proved to be quite successful. In the very first decade of its existence, the VRTC was able to meet immediate needs of the persons with disability including vocational training, special education, medical and relief services resettlement and placement services.

In 1976, VRTC conducted a survey to identify jobs that were available for the disabled. It has been conducting similar surveys from time to time so as to ensure employment opportunities for the persons with disability.

"The factories were very reluctant to hire our students initially," says Dr Johnson, "We had to visit

them personally and try to persuade them. Now there are about 40-50 factories that employ our students. A number of them have been employed in banks, stock exchanges and the Kapurthala Coach Factory.”

For quite a large number of students, life has changed after they joined the VRTC. For instance, Ms. Nimita Sharma is a lecturer in vocal music at the Government College, Ludhiana. She is of the firm opinion that persons with visual impairment should be given training in courses like information technology and beauticians course so that they can find meaningful jobs.

Emphasizing the role of the Vocational Rehabilitation Training Centre (VRTC) in shaping her career, Ms Sharma adds that there should be more confidence building courses for the visually impaired. “Such persons lack self confidence, so there is need to encourage mainstreaming so as to develop their confidence levels.”

Similar views are expressed by Ms Sandipika Malhotra, who was Ms Sharma’s classmate, at VRTC. She is a music teacher at the Government Girls’ Senior Secondary School, Kapurthala. She points out that the services available to the visually impaired are inadequate. Besides she feels there is need to concentrate a lot in the rural areas.

Both Ms Sharma and Ms Malhotra have been students of the first batch of the education department of VRTC which started functioning in 1975. “What we are today is because of uncle and aunty,” they say referring to Dr Johnson and his wife.



A student at VRTC who has got an University Degree is working on the computer with the help of talking software system

“We were one of the earliest Institute in the country to start computer training for the visually impaired,” Dr Johnson points out, underscoring the importance of exposing persons with disability to the Information Technology revolution.

The systematic growth of VRTC has led to the evolution of 18 full-fledged departments. These include: departments of social service counseling; medical and relief services; guidance and counseling; special education; mobility and orientation; low vision aid for the partially sighted; vocational training; transcription unit-cum-mini Braille press-cum-recording library; community-based rehabilitation; resettlement-cum-placement; sheltered workshop for visually impaired/differently abled women; integrated

workshop for the visually impaired; modern equipment bank for the visually impaired; multi-purpose mini workshops for the visually impaired and differently abled in the rural areas; public relations and fund raising; consultative services and religious and cultural activities.

“All these departments have been playing an important role,” says Dr Johnson. For instance, the Department of Special Education has been providing education up to the plus Two level and is approved by the Punjab School Education Board. Presently about 160 visually impaired and differently abled children are provided education. Similarly, the Social Service department functions as a bridge between the VRTC and patients both in rural areas and in remote villages. Counseling services are also provided to parents and members of families of patients.

The VRTC has also adopted about 50 villages in Ludhiana-Pakhawal area. As many as 250 physically and visually impaired persons have been identified and rehabilitated under the Community based Rehabilitation program. For instance the Multipurpose Mini Workshop in Bhanohar village imparts training in weaving, knitting, chair caning, candle making, tailoring, dairy farming and poultry to persons with disability in as many as 10 villages. Around 25 people are trained annually according to their aptitude and capacity. There are 15 such multipurpose workshops working in the area.



A view of one of the six Multi Purpose
Rehabilitation
Units established in the rural areas each covering
10 villages.

The results of these concentrated efforts are there for all to see. Harpreet Kaur of Chaminda village is severely polio-afflicted. She underwent a six-month training feeding cattle, taking buffaloes to grazing fields and milking them. Then she was given Rs 6000 as financial assistance to buy buffaloes. "I sell milk at Rs 10 per kg and am able to earn about Rs 60 everyday. I feel good as I am no longer a burden on others," she says.

Prof Arin Chatterjee, Chairman, VRTC says the Centre, with the advancements in technology, would have to keep pace. "New training methods would have to be devised so that our students can compete with others," he says.

“The quality of eye sight is directly related to the quality of life,” continues Prof Chatterjee, “It is important that we take all steps to prevent blindness. This is the reason VRTC’s Mobile Eye Service goes door to door creating awareness about eye care.”



A view of the Transcription Unit-cum-Braille Press
where
the visually impaired transcribe books and
biographies.

“The days of visually impaired persons not having enough opportunities are over,” Prof Chatterjee says, “VRTC strives to upgrade the technology available and impart latest training to ensure that our students compete with the rest.”

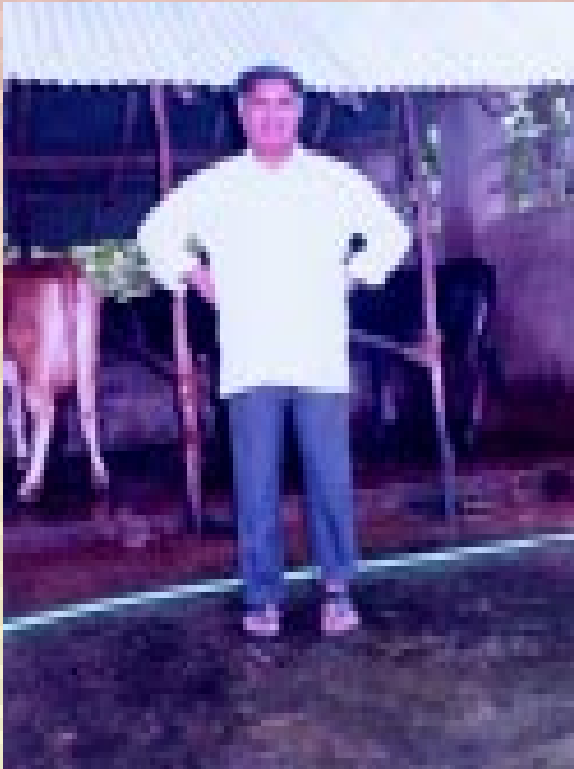
Going down memory lane, Dr Johnson acknowledges his gratitude to his wife who has been his constant support and has been the force behind his

efforts to transform the lives of persons with disability.

“I had hardly met any visually impaired person before my marriage in 1967 and was of the view that such persons were totally dependent. I was simply amazed to see how independent Dr Johnson was,” Mrs Sara Johnson says.

However, Dr Johnson feels it was impossible to overcome one’s disability completely. “I do not know how my wife or daughter looks like,” he rues.

“Probably I lost my sight only to work for the visually impaired and render services to them,” he concludes.



Father Thomas Felix

Father Thomas Felix

Trained in agriculture, they can be described as being truly 'differently abled'. Yes, Milton, Clinto, Aji and Omar not only look after cows and the rubber plantation, but they also adroitly lend their hands in cultivation too.

They are the products of probably one of the few agricultural universities for the mentally retarded. Set up by the Central Institute on Mental Retardation (CIMR) at Kuttichal, about 30 km away from Thiruvananthapuram, Kerala, the Agricultural-Horticultural Rehabilitation-cum-Training Center aims to develop living skills in them and make them self-sufficient through total development.

This agricultural university for the persons with mental retardation takes up a wide range of activities to give maximum exposure to the differently abled students. The 8.75 acres of land has an animal husbandry unit and produces spice, tubers, fodder grass, vegetables and coconut. It also has a greenhouse.

"We are now planning to set up a plant museum," says Mitilda, who is in charge of the Center, "We are also planning to go in for mass production of medicinal plants. Besides a Thrift Society would be launched soon."



CIMR's Agricultural-Horticultural Rehabilitation-cum-Training Centre

“Transforming the lives of the persons with mental retardation and their families is our endeavor,” avers Father Felix, a pioneering worker in the field of mental retardation. The agricultural university for the persons with mental retardation is his brainchild and he firmly believes that training in agriculture is important as a large number of them live in rural areas.

Born on August 31, 1936 at Kaduthuruthy, near Kottayam, Kerala, Father Thomas Felix was the fourth son of his parents. “My mother had a strong influence on me to accept the disabled as complete human beings,” Father Felix, who has been championing this cause for the last 30 years, reminisces, “She set an example by treating a child with mental retardation who lived next door with love and affection.”

After completing high school Father Felix renounced family life and joined the Carmelites of Mary

Immaculate congregation. For most part of the next decade, he prepared for priesthood, learning languages such as Latin and Syriac as also subjects as varied as Philosophy, Theology, Logic, Literature and Educational Psychology. He was a student of the Dharmaram College, Bangalore for seven years.

In 1964, he was ordained as Father Thomas Felix Kurichiaparambil. Devoting himself to social work at Changanassery in Kottayam district, he organized many constructive activities for the poor in the area like building houses for the homeless.

“My visits to the poor households brought me in direct contact with many children whose development was delayed,” recalls Father Felix, “These children were condemned to dark corners of their homes and were given no opportunity to develop into full human beings. Seeing their condition, I was reminded of the care and affection my mother used to give to the retarded child next door.”

“At that time, no religious priest was working solely for the persons with mental retardation,” he continues, “I went to the Diocesan Committee and asked whether I could start working for the mentally retarded. The Committee agreed.”

In order to have the right understanding of the problems of persons with mental retardation, Father Felix undertook three months extensive training in Gujarat besides travelling to different institutions across the country.

Finally in 1971, he started work for the mentally

retarded by setting up a center - Asha Bhavan - at Changanasserry with just five children. Funds were a major problem in the early days and Father Felix approached many religious bodies for support. However, he always believed that where there is will, lack of money cannot be a hurdle. Undeterred he continued his work.

In 1975, a new building for boarding and lodging inmates of Asha Bhavan was constructed. In order to expand his work, Father Felix enlisted the services of nine nuns and trained them in special education.

In the same year, Father Felix attended the World Congress on Mental Retardation held in Dublin. This gave him the opportunity to visit several other European countries including Spain, Belgium, Germany, Holland, Sweden, France, Denmark, Switzerland, England and Italy. He did a comparative study of centers working on mental retardation. In St. Vincenzstift, Germany, he took a course on special education.

Realizing that he should equip himself academically if he were to render better services for the mentally retarded, Father Felix enrolled himself for graduation and then post graduation in social sciences with special reference to the plight of the mentally retarded at the Duquene University in Pittsburg, Pennsylvania, USA. Subsequently he took three months training at the Birmingham Alabama Centre for Management of the Mentally Retarded.

“It was there that I realized that the existing three R’s (reading, writing and arithmetic) was not suitable for training the mentally retarded,” Father Felix says, “Instead I felt that the three C’s concept based on basic shapes and colors was more suitable.”

According to him, the three C’s are aimed at kindling creativity. They stand for Comprehension, Competence and Creativity, the three stages of development. “The premise underlying this concept is that the world around us can be reduced to basic shapes and everything else can be built up from these shapes – square, circle, rectangle and triangle,” he says.

He emphasizes that a person with mental retardation can be developed into a productive, versatile, creative and socially acceptable normal human being by training her/him to know the basic shapes. “Under the three C’s curriculum there are four stages of development namely knowing shapes, making shapes, selecting shapes and combining shapes,” he says.

“Through these classes a student is able to come to terms with the basic concept about the different shapes, how to give form to the different shapes using different materials, how to select shapes from a group and finally, how to combine shapes to produce new objects.”

“Thus, it is possible to develop four functions namely motor, psycho-social, language and cognitive,” Father Felix points out, “This leads to development of mind and body and provides the requisite skills for an

independent living.” More than 90 special schools in Kerala are now following the three C’s concept.

After returning to India in 1980, Father Felix set up the All Kerala Association for the Mentally Retarded. It is an association of parents, relatives and well wishers of persons with mental retardation. Through this association, he conducted a series of seminars throughout the state to create awareness on mental retardation. Subsequently he also set up Asha Kendram at Karikkamuri, Cochin.

In the same year, Father Felix started the Central Institute on Mental Retardation in Thiruvananthapuram for training teachers in Special Education. “The aim was to produce competent teachers for total development of a special person,” Father Felix points out, “Nothing much can be achieved without trained teachers.”

In this backdrop, Father Felix prepared a comprehensive syllabus for training competent teachers for the differently abled. “The focus is again on the three C’s concept and the curriculum is in four phases: global understanding, structured understanding, non-structured understanding and integrated total understanding.”

In 1983, he started another school for those with mental retardation, the Development Centre for the Mentally Retarded (DCMR), which trains about 200 students every year. “With the belief that those whose development is delayed need ample opportunities to interact so as to make them confident, DCMR has been initiating a large number of programs for its students,”

says Sister Elise Mary, who was one of the earliest to join Father Felix in his mission.

An Academy of Performing Arts has also been established to nurture the potential of students in various art forms. "Performing arts like dance drama serve as an effective therapy," says Father Felix.



Students performing at the Academy of Performing Arts

For instance, Kiran, a student at DCMR, has evolved into a brilliant sitar player. He can play the violin, tabla, guitar and mridangam with equal ease. Students like him are also able to perform dance dramas and have given performances in many parts of the country.

Sister Elise Mary informs that in 1989, some students of DCMR started managing a MILMA milk booth, probably the first ever booth managed completely by persons with mental retardation. Some

students have also been running a stationary shop and cycle workshop.

As part of his effort to make those with mental retardation independent, an Independent Living Group home at Kovalam was set up in 1987. Groups of youths with mental retardation trained by DCMR make use of the Independent Living facility at this Center. It forms part of their training to lead an independent life.

Since early diagnosis plays a vital role in preventing life long disability in children, Father Felix initiated the Jeevan Prakash Child Center in 1990 as a wing of the Central Institute on Mental Retardation. The Center takes up Early Diagnosis, Early Therapy and Early Intervention of abnormal motor function development in newborn babies and children through Vojta's Neukinesiologi cal Examination and Physiotherapy, Montessori therapy and Orofacial therapy.

"The Center demonstrates Vojta Physiotherapy to parents," says Sister Lucy, also working with Father Felix since long, "It enables parents to make their child do daily exercise at home, without using any equipment." For the benefit of rural people, anganwadi workers are also being given training in identifying motor function retardation in newborn babies and children. Since 1995, the Center has extended its services to hospitals of Thiruvananthapuram so that maximum number of children could benefit.

In order to provide vocational training to the mentally retarded, a program under the auspices of

CIMR and Kerala State Nirmithi Kendra was initiated in 1999. According to Sister Lucy, the major aim of the project, conceived as part of the community-based rehabilitation program, was to provide vocational training to the mentally retarded persons above the age of 17.

“From every Panchayat, a group of eight persons is selected for training. The group consists of three mentally retarded persons above the age of 17 who can undergo the training, their mothers, a volunteer who is related to the families of the mentally retarded and another person with a minimum of senior secondary education,” she says.

“After completing the training, the group goes back to the Panchayat,” she continues, “They then search other children with mental retardation in the Panchayat and integrate them and their mothers to the group with the help of Nirmithi’s centres.”

1998 was a landmark year for the Central Institute on Mental Retardation. During this year, a National Pilot Project to integrate the mentally retarded with family and community was initiated. According to Father Felix, though the original target of the Pilot Project was to reach only 7,500 families in six states including Delhi, CIMR could reach as many as 10,000 families. About 10,369 mentally retarded were identified and exercises initiated to integrate them with family and community.

“The Pilot Project provided many a valuable insight into the mainstreaming of the mentally retarded

in the Indian context. It also brought to the fore the long-standing need to start development centers for the mentally retarded at the community level," he adds.

After the successful coverage of the Pilot Project, CIMR implemented the Project in 23 states and union territories with special emphasis on the North Eastern States and Jammu and Kashmir. More than 30,000 persons with mental retardation were covered and 54 voluntary organizations were involved. Essentially the Project consisted of (a) identification; (b) assessment of the child along with the parents, and making them work independently as well as jointly in drawing books with a view to evaluate their levels of retardation; (c) distribution of teaching materials and training mothers to get them involved in the developmental and learning process; and (d) equipping the mothers and the families with instruction materials like 'Home a School' to make the home and the surroundings provide a natural learning environment.

Father Felix continues his mission to transform the lives of the persons with mental retardation despite many challenges. His perseverance can be summed up by what Joaquin Miller had written in 'Columbus':

"Brave admiral, say but one good word:

What shall we do when hope is gone?"

The words leapt like a leaping sword:

"Sail on! Sail on! Sail on! And on!"



Dr Leelavathy Patrick

Dr Leelavathy Patrick

Dr Vijaylaxmi, Vanaja , Kavita and Rosalyn are not just parents of special children. They are volunteer teachers as well. It all began when the desire to ensure better services for their children brought them regularly to the Clarke School for the Deaf and its Director, Dr Leelavathy Patrick motivated them to volunteer. Now instead of just coming to the School regularly, they volunteer their time helping other children too.

“Here at the Clarke School, I try to motivate parents to volunteer and teach children,” says Dr Patrick. “Training of parents is very important. Only then can they handle their children and families better. Education, rehabilitation and closer co-ordination between parent and child are like three sides of a triangle,” she continues, “We encourage parents of children to attend school along with them to learn methods followed here and to implement them at home. For those parents who come from far away places we impart distance education once they go back.”

Born on May 25, 1939 in Kotagiri, Nilgiris, Tamil Nadu, Dr Leelavathy Patrick’s early inspiration was her mother who used to serve street children. This induced her to volunteer from a very early age. Right from the age of 10, she used to work in the village dispensary from 7 a.m. to 9 a.m.

Soon after passing out from college, Dr Patrick took

up a job as a social worker in the rural development wing of the Tamil Nadu Government. She worked in Nilgiris, Trichy and Coimbatore.

The urge to do something different made her quit the Government job. Opting for further education, she went on to do her Masters in Education. While pursuing her studies, she came across an advertisement on behalf of the Little Flowers Convent, Chennai. The challenge was to upgrade the School. She took it up.

While working at the Convent, Dr Patrick realized that total rehabilitation was an essential component of education of persons with disability. "There was a girl with hearing impairment at the Convent who was slowly losing her sight as well," she reminisces, "She was upset and one day asked me what she could do after education. I had no answer. However, this changed my whole perception towards such children."

"To initiate the process of total rehabilitation, I decided to introduce vocational training at the Little Flower Convent," she continues, "But then Mother Superior did not give much support."

Not one to be cowed down, she initiated a Society for Aiding the Handicapped at her own residence with support of friends like Dr S K Nagarajan. "The sheltered workshop had people with all disabilities – visually impaired, physically handicapped and hearing impaired," she informs, "Within a short time, there were about 60 people. We started teaching cane work, needlework and tailoring. There was a blind boy, Ganesh, who would cook and also do shopping. Then

there was a naughty boy with hearing impairment who was trained to become a carpenter. It was all like a family.”

In 1967, Dr Patrick got a Fullbright Scholarship to the USA on a Cleveland International Program for youth leaders and social workers. From there she opted to study Masters in Special Education (for hearing impaired) at Smith’s College, Massachuchetts. “Simultaneously I got the opportunity to work in the Clarke School for the Deaf,” she says, “However I did not want to stay back in the US. I was keen to come back.”

Back in Chennai, she was raring to implement her new ideas at the Little Flower Convent. But to become its Principal, it was mandatory to be a nun. She was not and so she quit. Meanwhile, she took up a job at the American Consulate.

“The turning point came in 1970,” Dr Patrick recalls, “A couple came from Madurai with their only child, a girl with hearing impairment. She was only one-and-a-half-years old. They had come to know about me from a newspaper article and wanted my help in dealing with the child’s disability.”

“Apita’s disability had shaken her parents,” she continues, “I realized that there were many like her who needed help and guidance. I made up my mind to start a school for the hearing impaired.”

Thus with three children – one hearing impaired and two with multiple disabilities – the Clarke School for the Deaf came into existence. “Apita, Kapali and

Kamala were the actual founders of the School," she informs.

Started as a speech and hearing center, the initial phase was full of challenges. "We had only one hearing aid appliance which I had brought from the USA," Dr Patrick reminisces, "The plywood boxes in which I had brought my things from USA were converted into desks. The school was started at my residence and I took permission from the Clarke School, Massachusetts to use its name for my school. In fact, I still get technical inputs from there."

Within a year, the number of students rose to 30. In order to provide a special thrust to the involvement of parents for educating and rehabilitating the students, an Association of Parents of the Deaf was initiated in 1972.

According to Dr S K Nagarajan, the School's co-founder, most teachers those days were not interested in educating the hearing impaired. There was no proper diagnosis and even doctors did not have much idea about the importance of early identification and early intervention. "It was through several Parents' Associations meetings that we convinced people about the need for early intervention. We told them that with proper rehabilitation, children with hearing impairment could lead a normal life."

Right from its inception, the objective of the Clarke School has been to identify the disability as early as possible and provide necessary corrective and rehabilitative training and aids. Developing the

potential skills and abilities to the fullest possible extent and preparing them for integration into the mainstream provided an added thrust.

As the number of children grew steadily, the School shifted from Dr Patrick's residence and moved to its present building in 1976. Initially, it was on rent.

"Fund raising was a challenging task," Dr Patrick says sharing an interesting anecdote, "In 1982 while returning from Hamburg to Frankfurt after attending a conference, a brochure of the School accidentally fell down in the train. A lady sitting besides me picked it up and asked me how I was running the School. I replied in a humorous tone, 'by begging, borrowing and stealing.' Imagine my surprise when she gave me a booklet of the Christoffel Blinden Mission and asked me to contact them. "

"The Christoffel Blinden Mission gave us timely support to put up a new block," she says, "Unfortunately I did not note down the lady's number, so I could not thank her."

The Clarke School gives a lot of emphasis to overall development of a child's personality. Children are given extensive training in dance and drama. According to Dr Patrick, rhythm and body-posture needs to be taught to a child with hearing impairment so that their language and cognition develops. Keeping this in mind, the Sadhna Troupe for deaf artists was initiated in 1976.



Students at Clarke School

Ms Dipti Karnad, Principal, Clarke School, informs that students have been giving dance performances in different parts of the country. "Our children have won awards in many competitions," she points out.

Another thrust area of the School has been to reach out to areas where there are less or no rehabilitation services. "We have been conducting surveys and organizing camps in remote villages and slums," says Dr Nagarajan.

In 1988, the Clarke School's first rural extension project was started in Kelambakkam's Senganmmal village. "When we went to the Senganmmal village to organize a camp, we found that a lot of children were suffering from osteosclerosis and so, we decided to initiate a project there," Dr Patrick says.

"It was a dry summer and there was no drinking

water facility. Realizing the need to do something, we started our rural extension program,” she continues. Presently about 50 children are being trained here in agriculture and sericulture work. Right from a Special School to providing community-based rehabilitation, the rural extension project caters to 15 surrounding villages. Majority of the students comes from economically backward areas.

“Our holistic education and rehabilitation program has ensured that a large number of students not only go for higher education but at least 10 of them are integrated in general schools every year,” Dr Patrick informs.

The School has two separate sections with English and Tamil as the medium of instruction. The classes for the hearing impaired are grouped into Pre-primary, Pre-school, Lower School, Middle School, High School and Higher Secondary School. The teacher student ratio is about 1:12.

There is a separate section for the children with mental retardation, that is divided into Custodial, Trainable, Educable and Vocational Groups. These children are placed in respective grades according to their mental and physical abilities. A curriculum, which prepares the child for an independent life, is followed here.

In order to cater to the special needs of the deaf-blind children, a separate section was started in 1998. “Though we had deaf-blind children right from the

beginning, they were receiving education along with other children with hearing impairment," Dr Patrick says, "In order to provide more specialized services, we started Sadhana, the Centre for the deaf-blind."

The aim of Sadhana is to help the deaf-blind meet the challenges at all levels including understanding, communication skills and self-care.

"Every deaf-blind child who comes here is first examined by specialists for the nature, type and degree of sensory impairment," informs Ms Karnad. "Besides testing their residual level of hearing and vision, they are also subject to various psycho-diagnostic tests," she adds.

Sadhana, which has a model school and therapy and training center, trains deaf-blind children with the co-operation and involvement of parents. Presently there are about 22 deaf-blind children. "Here, the children are trained according to their special needs and parents also learn the special methods and techniques," Ms Patrick says.

The school has been trying to address the problem of shortage of trained manpower for persons with disability in the country. "Ever since we started the school, we have been focussing on the need to have trained teachers," points out Dr Patrick, "We have now started a one-year diploma course in education for hearing impaired. Besides another one-year teacher training program in educating the mentally challenged has also been initiated."

"We are now in the process of starting a teachers'

training program for the deaf-blind," she continues.

Age has not caught up with Dr Patrick as she continues to pursue her mission of transforming the lives of the differently abled children. Going by the number of children coming from all parts of the country and even from abroad the Clarke School has emerged as an important institution for hearing impaired in the country.

To conclude, Dr Leelavathy Patrick has a mantra for development of personality of a child with hearing impairment. "Parents should treat their child as any other child. Only then can they help the child become as independent as possible," she avers, "However, over the years, experience has shown that most parents are over-dependent on institutions. This is not a healthy trend."

Major H P S Ahluwalia

“Each man carries within himself his own mountain, which he must climb to attain a fuller knowledge of himself. The mind has its mountains and cliffs, fearful, sheer, unfathomed. The physical act of climbing a mountain has a kinship with the ascent of that inward, spiritual mountain which every man has to climb sometime or the other. The kinship is shown most clearly from the effects. Whether the mountain you climb is physical or spiritual, the climb will change you. It will teach you much about yourself and about the world.”



It has been a dream come true : The Indian Spinal Injuries Centre has emerged into a super speciality hospital for spinal injuries.

This is the philosophy of the man who has inspired South Asia’s most advanced speciality hospital for spinal injuries. The Indian Spinal Injuries Centre has

been able to bring cheers to the life of hundreds of people who have been living like vegetables. The Centre which is the only one of its kind in India has not evolved in a day. It is the fulfillment of a vow of the same person, Major H P S Ahluwalia, who when admitted at Stoke Mandeville Hospital, England decided to start a similar centre in India.

“It was while at the Stoke Mandeville Hospital, I realized that when a person with disability has to be rehabilitated physically by means of exercise, his mental rehabilitation is even more important,” says Major H P S Ahluwalia, “There for the first time I understood what my disability was and how did one make the best use of what is left.”

“The restoration of my self-confidence was the most important element in the rehabilitation process,” he continues, “There was no such facilities available in India. Then and there I decided to work towards starting a Centre having world class facilities for treating spinal injuries.”

Major Ahluwalia had his early childhood in Shimla and Lahore. During partition in 1947, he was in Lahore. He and his sister had a tough time leaving Lahore. He recalls the efforts of their tonga driver, a Muslim, who risked to take him to his sister’s school. And then their journey from Lahore to Amritsar, a journey of about 35 miles, was a nightmare. “The train halted frequently and at each halt we heard blood-curdling cries,” he reminisces the tragedy of partition.

After having passed the exams of the Indian

Military Academy, he took two years' training for permanent commission in the Army. Later he took a one-year course on basic automobile engineering. In the beginning of 1961, he did a basic course on mountaineering, later he went on to do an advance course. In 1962, he was part of the all-army team to scale the 20,000 feet high Mount Kokthang. Later he was part of the successful Indian expedition to Mount Everest in 1965.

It was during the Indo-Pak war of 1965 that Major Ahluwalia sustained bullet injuries. He recalls that fateful evening of September 30, 1965 which changed the course of life. "The war had just ended and a cease-fire had been declared. We were returning to our base when suddenly there was a crack of a bullet and I fell. The bullet had hit me in the neck." For more than one year he struggled, his condition remaining unchanged, he underwent treatment without much success. Coupled with this condition was his low self-confidence; of his not able to do anything. This all changed in Stoke Mandeville, England.

"Following the injury sustained in the war, I had to make an unusual effort at adjusting myself to the new condition of life. I think that my experience as an Everester has provided much of the inspiration to face life's ordeals resolutely. If climbing the mountain was a worthwhile achievement, would it be an exaggeration to describe the conquest of the 'internal summit' as something higher than Everest?" Major Ahluwalia quips.

“Initially, I approached the Ministry of Health for support to start a spinal injuries centre,” Major Ahluwalia says, “However, I could not get any help from them.”

Major Ahluwalia then mobilized a few friends to initiate the Indian Spinal Injuries Centre in the early 1980s. He recollects the day when he went for registration of the Centre. “When I reached the office of the registrar, I was told the registration fee was Rs 250. I didn’t have the money. I borrowed the money from my driver and deposited it for registration.

In the initial stages, fund raising was not easy. So much so, Major Ahluwalia started a lottery scheme to attract funds for the spinal injury centre. Friends and well-wishers from all over the world came in support for his project. For instance, Sir Edmund Hillary, the first person to climb the Everest was constantly trying to help Major Ahluwalia in his endeavor.

“While I was contemplating as to how to raise funds for setting up the Centre, I met a person in Italy who was willing to help. I met him while giving lectures on mountaineering in Rome,” he continues, “He informed that the Department of Cooperation in the Italian Government’s Foreign Office could support the Centre.”

After a series of follow-ups, a memorandum of understanding worth \$ six million was signed with the Italian Government to set-up the Centre in the late 1980s. Support for the construction of civil work of the Centre came from the Ministry of Social Justice and

Empowerment, Government of India.

“However soon we realized that we needed more funds in order to have the latest equipment,” Major Ahluwalia says, “Friends suggested that I meet the visiting Italian Prime Minister Mr Androtti during that time to take up this issue.”

“After great difficulty, I was given just three minutes to meet Mr Androtti during breakfast time,” he continues, “However, within three minutes I could convey to him the entire project.” Impressed, Mr Androtti asked Major Ahluwalia to reach Rome within 15 days and get all the papers ready. He did meet him at the appointed time and \$10 million were granted instead of \$ six million which was agreed previously.

Mr Harbans Lal Tandon, a close associate of Major Ahluwalia, who has been with him all through, describes the struggle involved in the evolution of the Centre in its present state. “We had to run from pillar to post to get the required support and facilities. But the struggle was worth as now the Centre is able to reach out to thousand of people with spinal injuries.”

The Centre was inaugurated in 1997. Over the years, the Centre has emerged as a comprehensive, specialized, general healthcare hospital. In fact it has now emerged as a pioneering institute of its kind in Asia. The Centre is now also advising and guiding other centres in the country. Infact it has helped in the setting up of four more centres in the country. In order to provide better services to the patients, the Centre has now started training programme for care givers.



The Centre has emerged as a comprehensive, specialised, general healthcare hospital



Madhukar Vishwanath Shirdhonkar

Madhukar Vishwanath Shirdhonkar

“The onslaught of blindness is a tragedy as it has multiplier effects on the person blinded, on his family and on his whole circle of friends and neighbors, life holds worse tragedies than this. And the first thing that needs to be done is to admit the reality and meet it face to face,” philosophizes Mr Madhukar Vishwanath Shirdhonkar quoting from a book by Reverend Thomas J Caroll.

Working for the persons with visual impairment for over four decades, Mr Shirdhonkar opines that rehabilitation of a visually impaired person has four phases: training the other senses to take over the role of sight; training in skills and use of devices; restoring psychological security; and changing attitudes of society to the visually impaired and assisting them to meet the prevailing attitude.

Born on October 10, 1932 in Jalon Urae, Uttar Pradesh, Mr Shirdhonkar had congenital blindness in left eye ever since birth. Recollecting his early childhood, he says he went to a regular school in Ujjain securing top positions.

“By the age of 14, I realized I was losing sight,” he reminisces, “It was Shivaratri and I had gone to a temple. During prayers, a jar full of water accidentally fell on my eyes. This started the process of detachment of the

eyes. I was taken to Gwalior for treatment. However, unfortunately, during this period, father got hernia and subsequently died. This delayed my treatment and within four months time, I lost the vision of my right eye."

In those days there was no ophthalmologist in Ujjain and awareness regarding facilities for the visually impaired was also not much. As if the loss of his eyesight was not enough, five relatives died during the period 1946-49.

Not knowing what to do, Mr Shirdhonkar took to studying Sanskrit. "One of our tenants suggested that I go to Mumbai as there was a school for the visually impaired," he recollects. There was life beyond visual impairment, he was told. On July 7, 1949, Mr Shirdhonkar joined the Victoria Memorial School for the Blind, Tardeo, Mumbai.

"The Principal, Mr KNK Jessawalla played a major role in shaping my career. There were very few educationists for the visually impaired in those days and Mr Jessawalla was one of them," he says. A two-year advanced training in physiotherapy followed three-year Physiotherapy training at the school. The young Shirdhonkar also took active part in group leadership, drama and sports.

The passion to do something different for persons with visual impairment took shape in 1955. "I had an opportunity to meet Helen Keller when she had come to India," he reminisces, "I experienced a strange energy passing over to me as I shook hands with her. There

and then I took a decision to devote my life for the welfare of the visually impaired.”

Another event, which served as a catalyst for future activities, was his participation in a textile exhibition in Mumbai. “It was a month-long affair and a few of us, all visually impaired, were involved in the sales. During this period we realized that no one cheated us. This gave me a lot of confidence,” he says.

Mr Shirdhonkar came back to Indore and started a physiotherapy clinic on August 15, 1955. “In the beginning, there was a poor response. I thought I would be forced to leave Indore. After more than 25 days of struggle, I was fortunate to treat a man with polio – my first patient,” he recalls.

While practicing physiotherapy, Mr Shirdhonkar was simultaneously on the look out for a Government job for which he met the Governor, Chief Minister, and others. Finally in November 1957, he got a job at Maharaja Yeshwant Rao Hospital, Indore. Incidentally, he was the first physiotherapist with visual impairment in Madhya Pradesh.

Mr Shirdhonkar cleared his class Xth in 1959. By this time he had motivated some people with visual impairment, businessmen and others to start work for the visually impaired. “There was hardly any awareness in those days and so motivating people was a challenge. After one year of talks and discussions we formed the MP Welfare Association for Blind,” he says.

In those days facilities of education for the visually impaired were far and few. Further there was no scope

for vocational training or other employment opportunities as well. It was a challenge to change all that, he says.

One of the earliest rehabilitation services initiated by the Welfare Association was training on chair canning. The rehabilitation center was started in 1961 in one room with four visually impaired persons.

Tracing the growth of the MP Welfare Association, Mr Shirdhonkar says, "It was tough to get work in the initial stages. We ran from pillar to post. Government and private offices were approached for procuring chair canning work."

In less than a year, however, the Welfare Association started a hostel for those with visual impairment. "Laxman Singh Pawar, a person with paraplegia whose house and properties had been taken away by relatives needed shelter and became our first inmate. Soon we had about eight inmates. The hostel started in November, 1961."

New vocations were introduced as the number of inmates increased. The focus was on need-based training. "We could initiate non-formal education, besides training in handloom and weaving. However, in the first 7-8 years, we confined our activities to adults," he says.

In order to bring organizations working for the visually impaired in Madhya Pradesh together, Mr Shirdhonkar organized a state-level conference in 1965. The aim was to consolidate the activities of different organizations and to develop a common line of thinking

for the cause. To commemorate one decade of service for the visually impaired, the MP Welfare Association organized an all-India Chess and Swimming tournament in 1971. There were 24 entries in chess and 45 in swimming. During this year, the Association got its new building.

Mr Ishwari Prasad Patidar, Principal of the Dr Helen Keller Dhrishtihin High School, and a close associate of Mr Shirdhonkar traces the growth of the school. He himself lost his vision in class 8th due to detachment of the retina. "I firmly believe that the persons with visual impairment be exposed to the best of education. So when Mr Shirdhonkar wanted me to take up teaching in the school, I took it up without giving a second thought."

Mr Patidar got associated with the MP Welfare Association in 1964. He learnt Braille and with the assistance of a peon in the Association, Shiv Kumar, completed his class XII. He started teaching at the School in 1974. At that time there were just two students. Presently there are about 100 students.

Mr Patidar, who has won the President's national award for best employee, emphasizes that the school keeps a balance between spiritual development and physical development. "We give 60 per cent time to education and 40 per cent to training and extra-curricular classes. Our philosophy is to provide a strong foundation to children," he says.

In 1972, the MP Welfare Association initiated a placement service with support from Oxfam and Royal

Commonwealth Society for Blind. Initially the trained boys found placement in small-scale industries. Over the years, a large number of boys got employment in BHEL, Itarsi Ordinance Factory, Bharat Aluminium, banks and in various departments of the state government.

“Initially, our boys were not treated at par with others,” Mr Shirdhonkar points out, “We established a blind labor association in 1980. The Association went to court on the issue and finally won. The labor with visual impairment then started getting equal and regular pay as the others.”

A number of students of the Association are now well settled. For instance, Sanjay Kumar Parasher took training in special employment and started his own glow sign business in 1995. His ‘Action Advertising’ is doing well. “The M P Welfare Association for the Blind showed me the path. Initially I had to struggle a lot but now I get orders from companies like Daewoo and Videocon.” Children from the Association, he adds, now come to his place for internship.

Similarly Surinder Singh Chauhan is having a plastic molding business for the past one decade. He has two units and has eight employees on his roll. He earns about Rs. 10,000 a month. He had approached the Welfare Association after his retina got detached. The Association trained him in plastic molding. He worked in a private concern for sometime before starting his own venture. “I started with a manual machine, and now have a fully automatic plant. While I handle one unit, my wife handles the other,” he says

beaming with confidence. He wants to expand his business and avers that through sheer determination and hard work, a person with visual impairment can achieve anything.



They are now self employed after getting training from the MP Welfare Association for Blind

Mr Ramesh Tomar, one of the first visually impaired to start a STD booth in Indore has initiated 'Swapnadeep Dhristiheen Sahkari Samiti', a co-operative society for persons with visual impairment. "As the financial position of the persons with visual impairment is generally weak, we aim to ensure financial self-dependence," he says, "We have already made a collection of Rs one lakh and we intend to do something really big."

The Rehabilitation Counseling Camp set up by the Association in 1974 soon became very active in the state. The idea was to generate the idea of self-employment amongst the persons with visual impairment. "We insisted right from the beginning that there should be no categorization of jobs which a person with visual impairment could do and those who cannot do," Mr Shirdhonkar asserts.

A school for girls with visual impairment was started in Dewas in 1973 by the Association. Incidentally, it was the first such school in Madhya Pradesh. Mr Shirdhonkar established the MP State branch of the National Association of the Blind in 1979 and became its founder secretary. In 1981, the Association started a Braille Press with support from UNICEF. Till then there was no Braille Press in the state

Meanwhile in 1986-87, the Association established a school for tribals with visual impairment in Jhabua district. Presently, more than 50 boys and girls are receiving education there. "We are trying to expand the

school and include more facilities,” Mr Shirdhonkar says.

Mr Shirdhonkar firmly believes that inclusive education was the only panacea for the education of children with disabilities. He avers that all vocational training should be integrated in nature as a person with disability can do anything with proper support services.



Dr P Hanumantha Rao

Dr P Hanumantha Rao

This is the story of an institution in Hyderabad which attracts people from various parts of the country. For example, Samta has come from as far as Muzzafarnagar, Uttar Pradesh to ensure that her child improve and becomes as normal as possible. She has rented a house and has been staying for the past three months with her three-year old child whose development has been delayed.

Hoping that Raghav would someday go to a normal school, Samta is determined to make him independent. Though she misses her family - Raghav's twin brother and her husband, she is prepared to make this small sacrifice.

"Never in these three months did I feel that I am alone here as the Sweekaar team has been very caring," she says, "Raghav has now started crawling and can stand on his own legs. This provides me motivation to stay here."

"I went to Delhi, Chandigarh and Hissar," she continues, "But could not get suitable rehabilitation services. I had lost all hope when a doctor in Delhi told me not to give up. He asked me if we - my husband and I - were to die what would happen to Raghav. This made us all the more determined to ensure that Raghav should be independent."

Her search ended when she came to Sweekaar-Upkaar. Another parent Mr Chawla comes from Delhi every three months for treatment and rehabilitation of

his child. He too is a case of development delay. “In Delhi, one has to approach different institutions for treatment,” he says, “There are no proper guidelines.”

The man behind Sweekaar-Upkaar, Dr P Hanumantha Rao was born on September 16, 1945 in Hyderabad. He comes from a family of doctors, which used to run a 40-bedded nursing home.

In his school days, he led an aristocratic life. But when he was doing his MBBS, the joint family broke down. “Father’s practice dwindled,” he recalls, “So much so, I was chucked out of the medical college for non-payment of fees. I implored the Principal to take me back and with great difficulty, I finished my course.”

“I am a contributory product of friends and well-wishers. While doing MBBS, I decided to work for the society, to give back whatever I had taken,” he further recalls.

After completing MD in medicine, Dr Rao went on to take training in rehabilitation medicine at the All India Institute for Physical Medicine and Rehabilitation, Mumbai. “I wanted to take up the challenging task of working with specially challenged children and reach out to the unreached,” he says, recalling those early days.

With zeal to work for the specially challenged, he started the Hyderabad Special School for Children in Need of Special Care in 1977 with just six children and two teachers.

“The School was started as part of my clinic in a

garage," Dr Hanumantha Rao recalls, "There was immediate criticism from the inmates of the complex who were opposed to housing the children with mental retardation." Undeterred, he set-up the Sweekaar Rehabilitation Institute for Handicapped to provide complete rehabilitation services to the mentally retarded. The Hyderabad Special School became a unit of Sweekaar.

"In those days, there was a lot of stigma attached to mental retardation. They were looked down upon and treated with utter contempt," says Dr Rao, "In fact one professor even asked me why I was wasting time and resources on children with mental retardation."

"I replied that there were so many people to help the abled but none to help the disabled," he continues, "I pointed out to him that all of us have one unseen disability or the other whether it was an emotional problem, short-temperedness, social maladjustment or intolerance. I told him that the disabled were actually differently abled."

Within no time, the number of children increased and the School was shifted to a new place taken on rent. There was a realization that rehabilitation was not possible till efforts were made to make them as independent as possible. To make this a reality, Sweekaar launched a Vocational Training Center in September, 1978. The Center was registered as a small-scale industry with the Department of Industry, Government of Andhra Pradesh. Initially, candle making, bookbinding, chalk piece, plastic doll making, envelope making etc were the trades that were

introduced. Later embroidery, preparation of cloth bags and wire bags and tailoring were introduced for girl students.

“As a result of our perseverance, many students have become productive members of the society. In fact, Mr Kishan Singh, one of our student was given the National Award for the best Mentally Disabled Trainee and Employee,” says Dr Rao.

According to him, the first nine years was a period of consolidation. A child specialist, he coupled his professional work with the voluntary work at Sweekaar managing to ride two horses at the same time. “I worked almost 18 hours a day,” he recalls, “By 1980, the number of students increased to 41. The services of psychiatrist, psychologist, speech pathologist and other specialists were enlisted.”

Finance was a problem in the beginning but this did not deter Dr Rao. “Never fear shadows, they simply mean there is light shining nearby. Only when patterns are broken, new worlds emerge” – this has been his strong belief.

The swelling number of students compelled Dr Hanumantha Rao to look out for new premises. After persistent efforts, he managed to secure land for construction of a permanent building. The Institute shifted to its own premises under tin roofed rooms in 1981.



Physical Medicine & Rehabilitation Centre

For the benefit of children with multiple disabilities and adults with physical disabilities, Dr Rao started a department of Physical Medicine and Rehabilitation in 1986. This department mainly caters to the needs of people from lower income groups. Besides a 24-hour Oxygen Bank was also started by him to supply oxygen cylinders to nursing homes in case of emergencies.

It was a time when not much facilities and services for all categories of the disabled were available. “Just facilitating services to one category of the disabled was not going to help the entire disabled population,” he says, “So I decided to intervene in various other categories of disability.”

Sweekaar started a Special School for the Deaf in 1986. “A need-based approach was followed whenever we started something new,” he informs.

Of the view that when an organization becomes too big, it becomes unmanageable, Dr Rao started Upkaar, a sister organization of Sweekaar, in 1987, to help the poor and needy children with their education.

“Since I had to suffer a lot during student days I thought I should do something for needy students,” he says, “Upkaar gives interest-free repayable loans for education besides awards and scholarships.”

While persons with disability in urban areas may have access to some services, those in rural areas do not have any. To bridge this gap, Dr Rao always nurtured the ambition to start a rural project. Finally, to commemorate 10 years of Sweekaar in 1988, a rural project was started in Upkaarpuram (Achaipally), Medak district, about 33 km from Hyderabad.

According to Ms Sunitha Shesadri, head of the department, Early Intervention Center, Mental Retardation, the rural project is now providing wage-based employment training and rehabilitation in agriculture, horticulture and allied farm trade like dairy, nursery, bee keeping, poultry, pottery and carpenters for adults with mental retardation hailing from rural areas.

Called Prakruti, Integrated Rural Rehabilitation Project and Research Academy, it presently houses about 60 inmates. “Our aim is to integrate them back with their families,” Ms Shesadri says.



Early Intervention Centre for Development Delay

According to Dr Hanumantha Rao if children at risk and those with developmental delays are identified early and services provided to them, the severe repercussions of the uncared or unattended problems can be nipped in the bud. With this focus the Early Intervention Services Unit was established in 1990. The Unit has Centers for both the mentally retarded and deaf.

“It is important to provide stimulation during the first six years of child development. Self-help, language, cognitive development, motor sensory developments are critical,” Dr Rao continues, “Any delay in these areas will have an adverse effect in other areas as well.”

“The services in these Early Intervention Centers are extended through home-based training programs, center-based programs and out-patient management programs,” adds Ms Shesadri, “Through early identification we help the child to become as

independent as possible.”

For instance, Anil is suffering from Cruznos Syndrome, a rare genetic disorder. When he first came to Sweekaar, he could not speak a single word. Now after two years, he can speak a few words besides writing a few alphabets. “This is the difference that early identification and intervention can make,” Ms Shesadri says.

In order to promote mainstreaming, public awareness on various issues and problems of the persons with disability is critical, says Dr Rao. “With this goal in mind, we have all along been conducting awareness drives by organizing rallies, essay writing competitions and debate competition.” For instance, in 1991, Sweekaar organized an ‘Open House Week’. During the week, over 10,000 students from normal schools visited Institutions and attended orientation programs focussing on the issues of disability.

In a similar way, a teachers’ conference was held where teachers from normal schools were given orientation on detecting the disabled children in their own school settings. A Parents’ Association was formed in the same year to involve parents actively in the efforts of training and rehabilitation of their disabled children.

Awareness generation in slums is yet another component of the sensitization program. Publicity is being done through leaflets, banners, posters etc besides conducting disability detection camps.

As a continuation of rural intervention project, an Integrated Rural Rehabilitation Program was initiated

in 1992. The Project involved screening and identification of individuals with mental retardation in rural areas besides their integration and rehabilitation within rural settings. The project is still continuing.



Integrated Rural Rehabilitation Centre

“We give a lot of emphasis to research and documentation,” points out Ms Shesadri, “There is an acute shortage of documented data on various aspects of disability.”

Started in 1992, the Research and Documentation Wing of Sweekaar has been able to initiate a lot of research activities. “For instance we are doing research on Early Intervention Services for the Mentally Retarded (0-5 years of age) - hope of the millenium,” she adds.

Dr Rao’s interventions are not just confined to the area of disability. In 1993, he initiated a clean water project in the rural area where Sweekaar is working.

The project involves sinking bore wells in the target villages.

During the same year, he also started a drug de-addiction center to screen, diagnose and detoxify identified persons on drug abuse and make attempts to reform and rehabilitate them.

The year 1993 saw several other initiatives. A half way home for mentally ill persons was started under the aegis of the rural project, Prakruti. The home admits chronic mentally ill patients for a short stay. Also during the year, an Ideal Home for Senior Citizens was started. The program accommodates 100 senior citizens above 65 years of age.

For scholastically backward children in general schools, a special centre for slow learners was started in 1994. Such children are identified and put under a personalized intensive academic training program to compete with the rest.

“Since 1998 Sweekaar-Upkaar has a Comprehensive School Health Services program,” informs Dr Rao. The objective is to identify children in normal schools who have problems relating to scholastic backwardness, learning disability, behavior disorders, problems related to physical health and malnutrition, identify speech and hearing problems.

“Once the problem is identified, it is tackled by a team of experts comprising special educators, psychologists, developmental disability specialists,

dental surgeon, medical officers, speech pathologists and audiologists,” he adds.

“We have evolved two ways of helping these children in normal schools,” adds Ms Sunitha Shesadri, “Our resource persons guide the normal school teachers on how to modify his/her teaching strategies for such students. The children too come to our Institute to attend special classes.”

“Our target group for the Comprehensive School Health Services Program is Government schools as 90 per cent of children in these schools belong to the low socio-economic strata and hence need special attention.”

In 1995 Dr Hanumantha Rao started the Upkaar Computer Training Centre for the Deaf, an exclusive training center for the adult deaf. “Since there is lack of adequate trained humanpower in the country I started a one-year diploma course in Special Education for Deaf along with a diploma in concurrent course.”

Not content with just a diploma course, Dr Rao started Shruti Institute for Research and Training in Hearing and Language, a degree college offering BSc (Hearing, Language and Speech) in 1999. The College is affiliated to Osmania University.

His passion to build institutions made Dr Rao start Ashray. With the philosophy of ‘picking up from Peter and passing it on to Paul’, Ashray aims at collecting old articles and distributing them to the needy.

“An article can be junk in some house but can bring glow in someone else’s house,” he points out.

“I want to create something like the Salvation

Army abroad," he says, "For instance books, once read, can be recycled and given to others. If we can have points in large supermarkets or public places where people can deposit articles they no longer want to use, these can be given to the needy."

A firm believer in networking, Dr Rao has collaborated with the Government-run Nilofer Hospital and revived the Physiotherapy department at the hospital. The department was not functioning for 15 years. Besides the Speech and Audiology department at the Gandhi Hospital, which had been closed for the last 10 years, has also been revived.

As part of the Early Identification drive, Dr Rao has started a separate Early Identification Centre for the persons with hearing impairment this year.

"There is need for a close partnership between Government and voluntary organizations for improving services for the disabled in the country," asserts Dr Rao.

Organizations providing rehabilitation services, he feels, need to constantly upgrade their services and training facilities. "Here at Sweekaar-Upkaar, we are trying to strengthen our services constantly," he says, "We want to set new standards in rehabilitation services."



Prof P Jeyachandran

Prof P Jeyachandran

A staunch believer in the powerful impact of yoga therapy in the lives of persons with mental retardation, Prof P Jeyachandran is an advocate of systematic yoga practice which, he says, helps prevent or arrest deterioration and also brings about cures of many debilitating conditions.

Studies indicate that yoga practice amongst persons with mental retardation leads to improvement in motor skills, in posture, control in dribbling, reduced hyperactivity, improved appetite, sleep and thus facilitates significant improvement in both physical and mental well being, Prof P Jeyachandran says.

Over the years, this genial professor has made pioneering efforts to standardize the right kind of yoga therapy and 'asanas' for persons with mental retardation. His guidebook on teaching yogasana to those with mental retardation has been translated in Korean, Japanese, French, Belgian and German.

It has been an eventful journey for Prof Jeyachandran who has been working assiduously in the field of mental retardation since 1966. He says he has handled about 21,000 cases ever since and has developed a repository of these. Many of these cases have left a deep impact on him and he hopes to write on these someday.

There was, however, one particular case in the initial stages of his work, which acted as a catalyst to propel him to work for the cause of the persons with

mental retardation. It was way back in 1966, when he was an honorary testing officer in the Juvenile Guidance Bureau.

“A girl, barely nine-years old, was brought to me for tests,” Prof Jeyachandran reminisces. “She was affable and greeted me. She could recollect only the Charminar in Hyderabad and said her name was Anandabai,” he says.

The girl used to get violent epileptic attacks and had to be admitted in the neurology department of the Government Hospital. “When she was discharged after six months, she had forgotten whatever she had told me,” Prof Jeyachandran continues, “She had now started talking about hospital routines like morning bread, tea, etc.”

“I wanted to try and trace her family down. So I sought permission from the Magistrate for the girl to be taken to Charminar in Hyderabad with an escort,” he says.

“The escort took the girl to Hyderabad. The Police Station in Charminar did not have any record of such a missing girl. However, destiny intervened. One Police constable recollected that three years back when he was posted in another Police Station, a parent had lodged a complaint that their daughter, who was mentally challenged, was missing. The respective Police Station was contacted and within 30 minutes, the girl’s parents and brothers came.”

“I was in tears when the escort came and told me about the reunion,” Prof Jeyachandran recalls, “I was elated that I had become instrumental in the reunification of a girl with mental retardation with her family.”

Born on April 24, 1946 in a small village in Madurai district of Tamil Nadu, Prof Jeyachandran had a brilliant academic record. At the age of three and half years, he was in class one. Within six months he was in class two and while in class three, he again got a double promotion.

In 1966-68, he was doing Masters in Letters in Psychology and was placed in the Juvenile Guidance Bureau for his fieldwork. “Here I found that both juveniles and mentally challenged were being treated in the same manner,” he says, “I thought it was improper. I devised a case history format for both juveniles and those with mental retardation.”

In 1968, he did a study for Bala Vihar, home for orphans with mental retardation, on ‘Feasibility of Training Mothers of Mentally Challenged Children in a Day Care Center’.

“There was no indigenous behavioral assessment scale for persons with mental retardation in those days,” Prof Jeyachandran points out, “Only the western scale was being used at that time. I took up the challenge of devising an indigenous one. This Project was funded by the US Health, Education and Welfare Department.”

The scale was christened as the Madras Developmental Programming System and is still popular among those working for persons with mental retardation. It was the only indigenous scale available till 1991 when the National Institute for Mental Handicapped developed two more scales. "Prof Cruickshank, a leading US psychologist, guided the project from the US side. After I developed the Scale and sent it to him, he commended my efforts."

In 1969, when Prof Cruickshank came to India for a national conference, it was decided that the Bala Vihar Home would start a teachers' training center.

On Prof Cruickshank's suggestion, Prof Jeyachandran developed the country's first curriculum for special educators in mental retardation in 1971. He did this with the help of students of the first batch at the Bala Vihar Training Center, Chennai. "The present day curriculum of the National Institute of the Mentally Handicapped is based on that curriculum," he says, "We have trained more than 1000 special educators working in different parts of the country." During 1971 he also did a feasibility study of training mothers of children with mental retardation in a day care center.

In 1972, Prof Jeyachandran decided to go to the United States of America for further studies. There he was asked to work in the licensing department in the state of Minnesota. "In 1974, the Federal Government sent a note to all state departments to evolve a scale which could certify institutions working for the persons with mental retardation in terms of fire safety," he says.

“My Director asked me to develop the Scale,” he continues, “I developed the first draft in 15 days. The Director was elated. He quipped that ‘I had actually wasted a fortnight’ for preparing the Scale.”

Soon he was going all around Minnesota visiting various institutions working for persons with mental retardation. In fact, Prof Jeyachandran became popular as the man who developed the Fire Safety Code. “I was taken into a five-member team to develop a scale of assessment and programming for children with mental retardation.”

Another breakthrough came when Prof Jeyachandran shared his research findings at the World Congress organized by the American Association for Mental Deficiency. “This paper took me to Central and Southern American countries and even Japan. Consequently, I was given a state dinner and was asked to stay back in the United States,” he says.

In fact, two US Senators, Hubert Humphrey and Walter Mondale took a keen interest in processing my immigration. “The department of immigration wanted to know the uniqueness of my work,” he says. The senators wrote back to the department, “If a man develops a bomb which kills thousand of people, you consider it to be unique. If a man develops a system, which would improve the quality of life of persons with mental retardation, that too should be seen as a unique contribution.”

“Within no time I was called by the immigration department and offered immigration. However, I thanked them saying I was going back to India,” he

adds.

After coming back to India, Prof Jeyachandran rejoined the Bala Vihar Training School. He has been the Principal of the School since then. In 1976, the Tamil Nadu Government insisted on standardizing the teachers' training curriculum on mental retardation. To carry its endeavor forward, the state government formed a high-level committee with Prof Jeyachandran as a member.

In 1983, UNICEF requested the Federation for the Welfare of the Mentally Retarded to prepare a standardized curriculum for Special Educators in India. The Federation nominated Prof Jeyachandran to be its Chairperson. In 1985, the National Institute for Mental Handicapped revised the curriculum.

As a member of the drafting committee of the State Policy on Disability, Tamil Nadu Government, in 1994, Prof Jeyachandran was instrumental in preparing rules and regulations to run residential homes for persons with mental retardation in the state. He has also been a pillar behind the activities of various institutions and organizations not only in Tamil Nadu but in other parts of the country as well. For instance one of the institutions that Prof. Jeyachandran is spearheading is Vijay Human Services. Besides initiating a large number of activities for the persons with mental retardation, Vijay Human Services is playing a very important role in evolving a systematic yoga therapy for persons with mental retardation.

Emphasizing the need to streamline services for

persons with mental retardation right from prevention to development of vocational programs, Prof Jeyachandran points out that though services have improved considerably, it probably reaches to only about two per cent of the population with mental retardation.

“Though right knowledge and skills are now available, they have not permeated to service providers in all parts of the country,” Prof Jeyachandran concludes, “There is need to evolve a proper system so that the latest technology reaches the children.”



Dr Pramod Karan Sethi

Dr Pramod Karan Sethi

Technology offers a real solution to the problems of the persons with disability, feels Dr Pramod Karan Sethi, the creator of Jaipur Foot. Equitable generation of technology, he adds, involves a learning curve that should be followed immaculately.

During the initial part of this learning process, there should be intense back and forth interactions between the laboratory and the field, he says. The feedback from users in the field then leads to modifications and improvements in the product processes.

“The relationship between technology generation and dissemination, and between technologists and potential consumers results in market penetration. It was this philosophy of intense back-and-forth interaction that has led to the success of Jaipur Foot,” Dr Sethi says.

Born on November 28, 1927 in Benaras, Dr Sethi had his initial schooling in Agra. “My father had a great influence on my life. Mahatma Gandhi was a major influence in our family,” he recalls.

“My father was very particular about my intellectual achievement and also that of my six sisters. My eldest sister was probably one of the first Jain girls to pass the matriculation examination, while the sister just junior to me went on to become a doctor,” Dr Sethi says.

Dr Sethi completed his MBBS from Sarojini Naidu

Medical College in Agra in 1949 and went on to do Masters in Surgery. Since the British Medical Council did not recognize this degree he became a Fellow of the Royal College of Surgeon in Edinburgh, Scotland in order to pursue a career in England. After this he applied for FRCS at the Royal College of Surgeons.

“My outstanding record ensured that I did not have to repeat my undergraduate examinations as was customary,” Dr Sethi said. He received his FRCS from Edinburgh in 1954. When he came back to India, he took up a job as a lecturer at the Sawai Man Singh Hospital and Medical College in Jaipur.

“In 1958, the Medical Council of India decided to have specialized departments of Orthopedic and Pediatrics,” recalls Dr Sethi, “In order to comply with these regulations, our Hospital had to institute an orthopedic department which I was asked to start and head.”

It turned out to be a blessing in disguise though he did not have any training in orthopedics, he recalls. He had to learn a lot to start the department from scratch. “In any other established department, I would have followed the existing pattern but here I was required to set the trend,” he says, “I also embarked upon a learning process visiting centers at Delhi, Lucknow, Kanpur and Patna.”

In those days, there were no rehabilitation services available at the Hospital. “There was an immediate need for a physiotherapy service. The only therapist, Mr C P Nair, was available only for supporting

surgeons and that too for massaging purposes. Mr Nair's equipment consisted of one case of talcum powder that was issued monthly."

"We did not have any equipment for Physiotherapy and the Hospital authorities were more interested in procuring life saving equipment. The administration was also not interested in procuring simple Physiotherapy equipment. So the only option was to get these made in the department itself."

Determined to reverse the situation, Dr Sethi asked his patients to get equipment for the Physiotherapy section. What he received was raw material components like wood and pipes. One patient donated the wages of a carpenter while Dr Sethi himself went in search of craftsmen who could build parallel bars.

"Within no time we raised the physiotherapy department in the hospital. The massage room could no longer hold it and we started using the open courtyard as an exercise area," he recalls. That was in the early 1960s. During that time, he felt the need to set up a workshop in which patients could use materials that were designed to improve motor and coordination skills while doing meaningful work.

"There was absolutely no space available to start the workshop," Dr Sethi says, "However, destiny intervened. The lease of a teashop in the hospital ground expired. The authorities were not interested in renewing the lease as shady characters frequented the shop. Instead we were offered the space. Without wasting any time we set up a workshop there and the

staff moved in.”

During this time, Dr Sethi started carrying out corrective surgery on polio patients. “I would conduct surgical operations to straighten their legs and limbs,” he points out, “A lot of appliances were needed to achieve results. At that time appliances for polio-affected patients were being made only at the All India Institute of Physical Medicine and Rehabilitation Workshop, Mumbai.”

“However, only the well-off could afford to make trips to Mumbai to get the appliances,” he says, “The poor, after surgery, would generally go back to the villages and the deformities would recur.” All his efforts were in vain, he felt, and this was the beginning of the efforts to have a local workshop in the hospital itself.

Dr Sethi had an eye for spotting talents. Mohammed Khan, a male nurse, who showed lot of interest in mechanical and technical matters, was asked by Dr Sethi to make splints and other simple aids. He also facilitated Khan’s deputation to the Mumbai Rehabilitation Workshop for a two-year training program in making appliances for persons with disability.

Mohammed Khan came back within six months, fully trained. “It took me hardly six months to master the processes involved. There was no point in hanging around, so I came back,” he recalls. Shortly after his arrival, Dr Sethi expanded his workshop. An affluent patient helped in adding two extra rooms to accommodate the workshop and also added an

occupational therapy department. Mohammed Khan's workshop was called the Fabrication Unit and its first products were calipers and clubfoot for polio patients and those with deformities.

"By 1963, I started toying with the idea of making artificial limbs. We had some prototypes made at the Pune Workshop and planned to make the same here," Dr Sethi informs. The Fabrication Unit was finally started in 1965 and limbs were made based on Western models using the "Solid Ankle Cushioned Heel (SACH)" footpiece.

Designed to be worn with a shoe that disguises its artificiality and protects it, the SACH foot has a rigid keel that does not allow freedom of movement. This led to a lot of problems in the Indian condition as many tend to squat.

"We took regular feedback on the SACH foot," Dr Sethi avers, "Most users said SACH foot required shoes to be worn with it and was uncomfortable during summers. One could not move barefoot and this posed problems for those who went to the fields. Besides being expensive, it deteriorated rapidly when exposed to water and mud."

To overcome these problems, Dr Sethi started work on an ideal footpiece. First, he developed the criteria for such a piece. "The footpiece should not require a shoe to hide it and protect it. It should look like a normal foot and be made of material, which is flexible, tough, abrasion-resistant and waterproof. The internal design should provide adequate mobility to enable sitting on

floor and walk on uneven ground where the foot is required to adapt to the rugged terrain of the countryside. Yet the foot should offer a stable support while walking.”

Dr Sethi then shared his idea with the workshop technicians. As the technicians grappled to make the ideal footpiece, another master craftsperson joined the endeavor. Ram Chandra, affectionately called, “Masterji”, had been hired by the hospital to teach vocational skills to persons with paraplegia. Masterji was initially observing the experiments which Mohammed Khan and his helpers were conducting to evolve the ideal footpiece. Skilled at metalwork and die making, he came up with suggestions and went on to make the prosthesis which later became the world famous Jaipur Foot.

Dr Sethi recollects the evolution of the Jaipur Foot. “We decided to use a solid rubber elastomer, due to its unique properties combining flexibility, toughness, abrasion and tear resistance as the outer casing for our footpiece. Automobile tyre material was used for our footpiece as it was readily available. Then to reproduce the shape of the foot, a four-piece aluminium die was prepared locally using the age-old sand casting methods. By packing rubber into the die and vulcanizing it in the hospital autoclave, a footpiece resembling a natural foot was obtained.”

Mohammed Khan recounts how the foot was vulcanized. “We had no knowledge about vulcanizing it. So, we approached Chuga Bhai, owner of a tyre retreading shop near the hospital. Excited, Chuga Bhai

characterizing its behavior under different loading conditions. Field trials on amputees revealed we could meet all design criteria. The foot seemed quite strong, breaking up only under a vertical loading strain of two tons," Dr Sethi says.

Two other problems encountered were fatigue and disaster failure. "Quite a number of amputees started returning with the external shell of rubber cracking open and the internal components virtually spilling out."

In order to prevent these, use of reinforcement with rubberized tyres cord was suggested. After repeated experiments, a product, which had durability span of 3-5 years under tough trials in rural areas, was evolved.

"But then amputees would still come back to us with cracks in their footpiece. We started plotting the cracks in the damaged footpieces which were always around the ankle region."

"The reason was encapsulation around the wooden blocks was immobile. The entire mobility resided in the junction area which was in the hindfoot region and this was the place where all stress was concentrated," Dr Sethi recalls.

What resulted was a new design revision, says Dr Sethi. The forefoot wooden block was replaced with a design which ensured uniform distribution of stress spread over the entire hindfoot and forefoot.

The first scholarly paper on the Jaipur Foot was presented by Dr Sethi at the Association of Surgeons of India's annual conference held in Bangalore in 1970. The

following year he presented a paper on modification for amputees whose feet had been taken off at the ankle (symes amputation), an adaptation made possible by constructing the foot with a boot top. The same year, Dr Sethi shared his work at a meeting of the British Orthopedic Association at Oxford, England. Again in 1974, his work attracted international attention when Dr Sethi gave the lead talk at the First World Congress on Prosthetics and Orthotics held in Montreux, Switzerland.

All this led to the setting up of a Rehabilitation Center at the Hospital Grounds. "A patient from Bihar, Arjun Aggarwal, donated money for construction of the five-storey rehabilitation department," Dr Sethi says, "The Rajasthan Government provided us matching grant."

The setting up of the new Rehabilitation Center coincided with the 2500th anniversary of the attainment of nirvana by Lord Mahavir. To commemorate the occasion, a group of Jains formed the Bhagwan Mahaveer Viklang Sahayata Samiti and raised a large sum of money to establish another rehabilitation center.

Dr Sethi felt that instead of creating another institution, more services could be provided in the rehabilitation center that was already constructed in the hospital premises. In March 1975, a Rehabilitation Center was formalized which is now focussing on providing free lower limbs and other rehabilitative aids and services. More artisans were hired for Ram Chander's workshop to meet the increased demand for limbs. The Mahaveer Society's money was used for

purchase of raw materials.

Dr Sethi recalls a study conducted at the University of Strathclyde, Glasgow, England, where in a sophisticated gait analysis laboratory, a comparative evaluation of the western foot and Jaipur Foot was carried out. "A Scottish amputee was asked to return the Jaipur Foot after completion of the study. The amputee refused to part with the foot on grounds that it enabled him to climb the mountains much more easily."

Constant upgradation and research to make the Jaipur Foot better and lighter continues. Different materials are being used now like polyurethane, polypropene and high density polyethylene.

As a major initiative, an artificial limb-fitting unit has been started at Kasturba Hospital, Gandhigram, Tamil Nadu with the support of a private company TVS Rubbers Factory. According to Mr M R Rajagopalan, Secretary, Gandhigram, the program was started in 1988 with the help and guidance of Dr Sethi.



Measurement for Jaipur Foot being taken from a patient

“We have committed workers on our rolls,” says Mr Rajagopalan, “So far we have been able to fit about 1,500 artificial limbs. Presently we are trying a new ankle joint with aluminium spring. Dr Sethi is helping us in this new endeavor.”

For his path breaking work, Dr Sethi won the prestigious Magasaysay Award in 1981. In the same year, he also won the Padmashri. Presently a consultant with the Santokhben Durlabji Memorial Hospital, he emphasizes on the need for quality training so that trainees can set-up workshops in their respective communities. “Only then we can spread the use of the Jaipur Foot to every nook and corner of the country and elsewhere.”



Dr Rajendra T Vyas

Dr Rajendra T Vyas

Time: Circa, October 1947. Place: banks of river Tapti in Surat, Gujarat. The event: a meeting of persons with visual impairment. The aim: to initiate a movement for providing services to the visually impaired. The outcome was of historical significance: The Blind Men's Association was formed.

“Indeed, it was a meeting of great historical significance to the persons with visual impairment,” says Dr Rajendra T Vyas recalling that eventful day, “It was from here that new programs for the visually impaired evolved in the country.” Dr Vyas was one of those present at the meeting in Surat who went on to become one of the fulcrum behind the National Association of the Blind (NAB) which after 50 years has emerged as a leading organization for the visually impaired in the country.

“NAB India is definitely one of the largest voluntary organization in the disability sector in the country,” he says, “We have got branches in 18 states and over 250 institutions and associations for the visually impaired are associated with us.”

Dr Rajendra Tansukhram Vyas was born on December 27, 1930 in village Bhandaria in the Saurashtra region of Gujarat. While studying in class VIIIth in a general school, he lost his eyesight completely due to bilateral iritis.

“My father was a well known doctor in Mumbai and he made all efforts to ensure that I regained my eyesight,” he recalls, “However, two years of concentrated efforts failed to restore his eyesight.” It was a disaster and young Vyas was then forced to join the Dadar School for the Blind. He studied Braille for two months and later rejoined his old school.

“Initially I would just go and sit in the class,” he says, “I used to feel bad. Only after six months, I was formally admitted.” In those days the second world war was on and the Braille writing and Arithmetic apparatus which used to come from the National Institute for the Blind in London stopped coming. In order to ensure that his studies were not hampered, his father got the special apparatus manufactured locally. However, no textbooks were available in Braille and he had to depend upon his younger siblings and a teacher to read out the textbooks to him.

Following his graduation from the Ismail Yusuf College, he went on to do Masters in Economics while simultaneously pursuing a Bachelor Degree in Law. “My day started at 6.30 in the morning when I took a local train to reach the Law College for the morning classes,” he recalls, “After that I would go to attend the School of Economics.”

After completing his LLB, he started practicing in the Mumbai High Court. In fact, he was the first lawyer with visual impairment in Mumbai. Simultaneously he joined the K C Law College as a lecturer and took evening classes. He also completed his Ph.D., his thesis being “Visually Handicapped in Bombay State, Their

Social Background and Present Status.”

While pursuing studies, he was actively involved in working for the visually impaired. “After the Blind Men’s Association was formed, we started organizing picnics and other recreation activities for the visually impaired besides helping individuals with visual impairment,” he says.

“We organized the first Provincial Conference in Mumbai in 1948 which was a resounding success,” he continues, “We then organized the first All India Conference on Work for the Visually Impaired in Mumbai in 1952. A series of brainstorming sessions resulted in a resolution to establish the National Association for the Blind (NAB) on January 19, 1952.”

In the initial stages, the NAB decided to concentrate only on policies and programs related to the visually impaired in India. Barrister Rustomji Alpaiwala, who had lost his sight at the age of 35, became its first President.

“Sir Dorabji Tata Trust gave a grant of Rs 12,000 to NAB in 1958 and we for the first time rented an office and appointed an Executive Officer to consolidate our work,” Dr Vyas says.

“NAB was able to set up employment and placement bureaus for the visually impaired way back in 1954,” he says, “Till date, we have been able to provide employment to more than 10,000 people.”

Meanwhile in 1958, the NAB started the Col Sir Jamshedji Duggan Braille Press in Jogeshwari, Mumbai.

According to Mr Ketan Kothari, the Press has grown into the largest Braille Press in the country and publishes over 11 journals in English, Marathi and Hindi. This includes 'Varthaman', the only fortnightly magazine in Braille published in India.

In 1959, the Sir Dorabji Tata Trust gave a grant worth Rs two lakhs to NAB for purchasing an estate of 200 acres at Phandsa in Gujarat. The NAB established the Tata Agricultural and Rural Training Centre for the Blind. Persons with visual impairment from rural areas are given training in agriculture, horticulture, animal husbandry, dairy farming. The trainees are then rehabilitated in villages.

"We believe that working for the prevention of visual impairment is as important as working for the visually impaired," Dr Vyas says, "In this backdrop, the NAB established the National Society for Prevention and Cure of Blindness in 1959." A NAB Prevention of Blindness Committee has also been launched and has been instrumental in setting up the All India Eye Bank Association. The Association brings together about 125 Eye Banks in India.

In 1964, NAB set up the MP Shah All India Talking Book Centre. According to Dr Vyas, the Centre produces hundreds of talking books each year and is equipped with three Talking Book Studios.

Aware of the fact that there are not enough schools and institutions for the visually impaired, NAB started an Integrated Education Program. "Integrating children with visual impairment with sighted children in their

own village and community schools helps them overcome any feeling of inadequacy or inferiority that they may have otherwise experienced,” Dr Vyas says.

In 1967, NAB started the PNM Rehabilitation Centre for the Blind in Mount Abu. It was the first full-fledged rehabilitation centre to come up in the country for those who had just lost eyesight. The Centre aims at adjusting and orienting newly visually impaired. It imparts training in orientation and adjustment, personal management, personal grooming, orientation and mobility, various handicrafts and vocations. Similarly to make the visually impaired more active and mobile, the NAB conducts physical training courses at its Mobility Training Centre for the Blind, Bangalore.

“As a very large percentage of visually impaired live in small towns and remote villages, NAB felt it was very important to reach to the unreached,” says Dr Vyas, “In this backdrop, the NAB Rural Activities Committee was constituted in 1982. The Central Coordinating Office of the Committee was set up in Ahmedabad.” The community-based rehabilitation projects undertaken by the Committee tried to address problems of the visually impaired like education, social and economic rehabilitation and prevention of blindness.

According to him, opportunities available to women with visual impairment are much less and a lot needs to be done in this regard. In order to promote initiatives for women with visual impairment, NAB started a Committee for the Advancement of the Status of Blind Women. It promotes the education and training

of women with visual impairment in urban and rural areas. It has also set up a training center for employment of visually impaired women.



NAB's Job Development Centre for Blind Women

The NAB has played a major role in transforming the lives of many persons with visual impairment. Ms Nafiza Shikhari, for instance, attributes her confidence and learning to the role played by NAB. Disillusioned when she was losing her sight, she came to NAB for guidance. After doing a course in telephone operation she got a job at the Central Bank of India.

However, it was just a beginning. She wanted to rise high in her career and so she started appearing for exams. She passed the All India Officers Examination in 1986. Now she is a manager at the Corporate Finance Branch of the Central Bank of India, Mumbai. She won the President's award for the most efficient disabled employee on December 3, 1999.

Similarly, Dr Vishakha Mehta who has been one of the Executive Committee member of the NAB was the first woman with visual impairment to do B.Ed. from Mumbai University. When she came to Mumbai from Gujarat in 1960, she was confused as what to do. After she came in touch with NAB, she was motivated to take up higher studies. Ever since she has been working to make a difference to the lives of persons with disability. While she worked in Raigarh district for 15 years to bring visually impaired women to the forefront, she also set-up a co-operative housing society for persons with disability.

“We have to go a long way in meeting standardized service requirements of the visually impaired in the country,” avers Dr Vyas, “We need more people to come and work in this area, especially in rural and far-flung places. NAB has been able to reach to a lot of areas but we need to go further. All of us have to work together and not in isolation.”



Rekha Roy

Rekha Roy

Madhumita Haksar never imagined that she would be teaching one day. She is elated and feels that her alma mater, the Speech and Hearing Institute and Research Centre (SHIRC), has been responsible for transforming her life. After having passed class VIII a year back, she took to teaching sewing in the SHIRC itself. She now wants to continue her studies further and is all set to appear for the State Open School examinations.

Similarly, Sushmita Das is no more a burden on her parents. She earns her living by knitting. It is not sympathy, which brings her respect, but the adroitness with which she knits sweaters. She had taken training in knitting at the Dhani Rural Center, Agarpara, run by SHIRC. Covering 34 villages, the Center not only imparts training in both knitting and embroidery to the children with hearing impairment of the area but also facilitates the marketing of the products made by them.

“The students themselves market the items they produce. We have initiated self-help groups which has boosted their confidence and taught them to work together in a group,” says Mrs Rekha Roy, Director, SHIRC, “Being able to earn acts as a catalyst to their overall personality development.”

This is my first introduction to SHIRC, which is trying to bring cheer to the lives of the hearing impaired not just in Kolkata and Agarpara but in three other rural centers of West Bengal. It is now working to expand to

other parts of the state as well.

Since its inception, SHIRC has come a long way in providing services to the hearing impaired and has now emerged as one of the premier Institutes in West Bengal. "The Institute was not set up by accident," she says, "I belong to a family of educators and audiologists for the hearing impaired. My father was a pioneer in the field of education of the persons with hearing impairment while mother was a headmistress of a deaf school. My uncle was a principal of a school for those with hearing impairment. As for my brother, he is also engaged in teaching the hearing impaired."

Born on July 1, 1940, Mrs Roy had a different, liberal and flexible upbringing unlike girls of those days. After completing her graduation in psychology from Delhi University, she took training as a teacher for the hearing impaired and then briefly taught children from rural areas at Suri Deaf School, Kolkata. "Since I wanted to pursue higher studies, I went to Manchester University for taking training in education for the hearing impaired in 1964-66," she informs.

"After coming back, I took up lecturership in deaf education and aural rehabilitation in the All India Institute of Speech and Hearing, Mysore," she says, "I taught and organized clinical work at the Institute besides conducting practicals for the under-graduate and post-graduate classes."

While teaching in Mysore, Mrs Roy realized that a post graduation in deaf education was not enough. She

needed further training and education to facilitate better services for the persons with hearing impairment. She then applied for Fullbright Scholarship and went on to do her MS in Speech and Hearing from Central Institute for the Deaf, Washington University.

Her marriage in 1968 did not come in the way of her pursuit of academic excellence. "My husband and in-laws were very supportive and motivated me to take up the Fullbright Scholarship," she says.

After Mrs Roy came back in 1971, she joined the All Indian Institute of Medical Sciences, New Delhi as an audiologist. But her stint in AIIMS was cut short by a heart problem. She quit her job and went back to Kolkata. After the birth of her child in 1973, she took to private practice. Later she took up a job as a part time consultant at the Institute of Post Graduate Medical Education and Research, Kolkata.

"During this period, I realized that the socio-economic status of persons with disability was lower than the others," she says, "Even parents were hesitant to spend time with their differently abled child and hence they were generally neglected. It was an eye-opener for me."

In 1978, Mrs Roy went to Vellore for treatment of her heart ailment and the doctor there encouraged her to start work for the hearing impaired. This acted as a catalyst. In the same year, Mrs Roy started the Speech and Hearing Institute and Research Centre (SHIRC) with support from her parents.

Over the years, SHIRC has been steered into areas

of early assessment, creating awareness in the whole of eastern and north-eastern region on issues relating to the hearing impaired, multi-disciplinary investigations, diagnosis, differential diagnosis, therapy education, counseling, pre-vocational training, applied research, orientation and refresher training of teachers and parents.

Like many other organizations, SHIRC too had a humble beginning. It started from Mrs Roy's residence. In the beginning, there were just two children – one was the son of a rickshaw puller and the other, a sweeper's child. There was one volunteer, Deepak D' Costa to help her.

“ Within two years, the number of children grew to 50,” Mrs Roy recalls, “We were now functioning from the garage downstairs. Simultaneously, we started the process of integrating these children with those of the adjacent nursery school.”

“Soon we felt the need for setting up a regional diagnostic center,” she continues, “We were now getting people from different parts of West Bengal and even from neighboring states. In order to provide services to the ever-increasing number of people, we took up a place in Kakoli Road in 1980.”

Thus started the outreach and extension programs of SHIRC. “Through this program, we expanded to the rural areas. The Mohispata center was started in 1987, the Agarpata center in 1988 followed by Birbhum and Bargachia. At all these centers, we trained parents for better home stimulation.”

“Over the years we have been able to reach out to a wide range of population,” Mrs Roy informs, “The effort has been to reach the unreached especially in the rural areas.”

Mrs Roy feels the provision of rehabilitation of those with hearing impairment is patchy throughout the country. The speech and hearing services are yet to reach atleast 80 per cent of the population, she says. The only way out is to establish district-wise rural service centers, she feels.

“At SHIRC, we have tried to work out new concepts, field test them, develop them into a module and then replicate them in larger groups,” Mrs Roy points out, “The community-based rehabilitation project, Shruti, started in collaboration with the local clubs. This ensures the active involvement of the local community especially the youth.”

“To ensure the right to education of the child with hearing impairment, we must lay a solid foundation in the pre-school education stage. This age is critical in the overall development of a child,” Mrs Roy emphasizes. It is with this philosophy SHIRC tries to ensure a solid foundation at the pre-school stage. Besides SHIRC’s emphasis has been on providing higher education including technical education to the hearing impaired. “Career development of students with hearing impairment is treated as a priority in our educational programs,” she informs.



Students at SHIRC, Kolkata

Besides being the pillar behind the growth of SHIRC, Mrs Rekha Roy took up other work assignments from time to time in order to expand her efforts for improving services for the persons with hearing impairment. From 1985 to 1988, Mrs Roy was Principal of Deaf School and Teachers Training College, Kolkata. This helped SHIRC get more trained teachers. "During this period, SHIRC could expand its pre-school programs in a big way," she points out, "Availability of properly trained teachers is of paramount importance in the education of the hearing impaired."

However, she was not able to effect changes in the working of the Calcutta Deaf School the way she wanted. The desire to do something more concrete acted as a catalyst and she accepted the Directorship of the Ali Yavar Jung National Institute of Hearing Handicapped (AYJNIHH), Mumbai, an autonomous Institute under

the Ministry of Social Justice and Empowerment in 1988.

At AYJNIHH, Mrs Roy tried to make pre-school education of the hearing impaired a nationwide movement. More than 25 pre-school programs were initiated during her tenure. She was also able to initiate the outreach and extension program of NIHH in a big way.

Efforts were also made to use the media in creating awareness on the hearing impaired. "The mass media has a major role in changing the attitude of the common masses towards not only the hearing impaired but also other disabled," she says.

After retirement from NIHH in 1999, Mrs Roy came back to Kolkata and now once again devotes full time to SHIRC. Inspired by Rabindranath Tagore, Mrs Roy now has dreams of starting a Vishwa Bharti University for the hearing impaired. "To work for the rural hearing impaired girl child is also my top priority," she says, "One has to work with new vigor strengthening self-employment of the hearing impaired in today's changing circumstances."



Dr Sharda Fatehpuria

Dr Sharda Fatehpuria

Swami Vivekananda had aptly said, “ Never say no; never say I cannot; for you are infinite. Even time and space are as nothing compared with your nature. You can do anything and everything, you are almighty.” Those who are fighting all odds to overcome their disability and are making determined efforts to make their lives meaningful are certainly following this great seer’s footsteps.

Rupa Ghosh, a student of Manovikas Kendra Rehabilitation and Research Institute for the Handicapped, Kolkata, is one such fighter. She is like any other child except for her low Intelligence Quotient (IQ). She has been taught Bengali alphabets and knows how to count. As part of her vocational training, she has been working on the loom for the past three years. She earns Rs 250 per month and dreams to be independent. With tears in her eyes, her mother, Mrs Archana Ghosh says, “I never thought my daughter could work at the loom. She is now earning too.”

Hailing from a poor family, Jayashree Ghosh has been trying hard to put her disability behind. She is a good singer and has won prizes in a number of competitions. Besides she has passed class Xth from the National Open School and is now learning stitching. Aiming to do Diploma in Tailoring, Jayashree also wants to learn computers.

Rupa and Jayashree are not the only ones to have benefited from the rehabilitation services rendered by Manovikas Kendra. Ever since its inception in 1974, hundreds of children have been given training and education here.

Starting as a small institute, with just one classroom and two students, the Manovikas Kendra Rehabilitation and Research Institute for the Handicapped has grown into a premier institution for training, research, prevention and rehabilitation for the persons with mental retardation.

A brainchild of Dr Sharda Fatehpuria, a simple down-to-earth lady, now in her mid-60s, the Institute is a result of her vision. It was created out of the need for providing specialized training that according to her can make a world of difference to the lives of people with mental retardation. "Through educational training designed to meet their special needs, we can try and help these children become economically independent and self-reliant," she recalls how she plunged into the field of mental retardation.

Born on July 1, 1936, Dr Fatehpuria hails from an orthodox Marwari family. Her father was a Gandhian and social worker. "Since I grew up in an environment of social service, I always had the urge to do something for society," she recalls. Sitaram Saksaria and Ram Manohar Lohia also influenced her. Dr Fatehpuria was inspired when Mr Sitaram Saksaria for the first time opened the huge iron gate of Shikshyatan College, a premier institution for girls in Calcutta in 1951. She vowed, then and there, to create an institution.

At the age of 18, when she was doing her graduation, Dr Fatehpuria got married. For any other girl, this would have meant the end of her career. But Dr Fatehpuria was different. When her in-laws came to see her, she laid down three conditions: that she must be allowed to continue her studies; no dowry would be given; and she would be free to work after marriage. "Such conditions were unconceivable from a 18-year old Marwari girl in the 1950's," she says.

After doing her graduation in Philosophy she decided to pursue her Masters in Psychology. While working on her dissertation, Dr Fatehpuria had first hand experience of the plight of the persons with mental retardation. The subject of her dissertation was probing the difference in 'interest patterns' between Bengali and Marwari children in Kolkata schools. She chose three types of schools and in all 30 of them. "As I began probing the interest patterns in C-grade schools, I found that many 14-15 years old boys were still studying in class 1 or 2. These boys were slow learners and the teachers called them 'pagla' (mad in Bengali)."

Dr Fatehpuria wanted to go deeper into this aspect of her research. She requested the University to write a letter to Corporation School Principals to lend support to her survey. "I went to the homes of about 200 boys and girls of different age groups to test their IQ level, behavioral pattern etc." she says.

"During the survey, I found that many children were having low IQ level. Then and there I decided to work for them," she recollects, "My heart and soul was

now desperately seeking out solutions to bring about a change in the lives of these children.”

Following her post-graduation, Dr Fatehpuria took to teaching in Abhinav Bharti School for six months before registering herself for Ph.D. Her research theme was scholastic backwardness in Calcutta High Schools. She took students of class VIIIth as her subjects. At that time, children with low IQ and behavioral problems were clubbed along with slow learners.

While doing Ph.D., the social spirits within her evolved to the fullest. As part of her research, she went to rural areas and slums where she noticed the complete lack of awareness on health aspects. “The five years of work for the Ph.D. taught me a lot not only about mental retardation but also about life. Earlier I didn’t have much idea about the problems of the poor and that of children with disability.”

After completing her Ph.D., Dr Fatehpuria went back to Abhinav Bharti School, Pretoria Street and requested them to give space. In 1966, she started counseling. “The initial years were quite challenging,” she recollects, “I would visit dirty slums and poor localities to make people in these areas aware of the problems of mental retardation. Then in the chamber, I would test IQs of specially challenged children and counseled parents on the need for right kind of training for these children.”

At that time the conditions in most homes of the mentally retarded were worse than prisons. “A lot of

parents didn't know where to send their children," she continues, "I realized that simply categorizing the children according to their IQ level and giving counseling was not enough. Much more needed to be done."

This realization became the genesis of the Manovikas Kendra. "I approached the President of Abhinav Bharti, Mr Sitaram Saksaria for a bigger room to open the school," she says, "He promptly agreed and in 1974 I started Manovikas Kendra in a single room with just two students."

Talking about the early challenges, Dr Fatehpuria says: "Convincing parents to send their children to school was a challenging task in the initial stages. Most parents felt I was just fooling around."

Getting trained teachers was another problem. "I could get only those teachers who could not get any other job. Moreover, there were no training institutes then," recalls Dr Fatehpuria.

Within one year, however, the situation changed. By now the Manovikas Kendra had 50 students. It was a struggle every day. She hired a mini bus and picked up children herself from their homes from 7 a.m. onwards. Later in the afternoon, she dropped the children, back at their homes.

Within a few years, Dr Fatehpuria realized that limiting the work to Kolkata was just not enough and there was need to branch out to the rural areas. So in 1986, Dr Fatehpuria started a school in Rajpur-

Dhankhet, 24 Parganas. Since then the Dhankhet Manovikas Kendra has become a major extension project of the Institute. At present there are 65 students between the age group of 5 and 18 years at this center where along with functional academics, social and self-help skills, the children are also trained in pre-vocational skills. They learn to make paper bags, jute mats, sewing and embroidery.

Since then, Manovikas Kendra has started extension projects in other rural areas including Purulia (1988), Burtalla Slum Project (1990) and Balrampur (1993).

As the school began to grow and had several units, there was need for an independent building to house the various departments. Hence, the school shifted to 6, Short Street in 1991. It was here that Manovikas Kendra was registered as Manovikas Kendra Rehabilitation and Research Institute for the Handicapped. Almost six years later, Manovikas Kendra reached a very important milestone as it moved into its own premises at Eastern Metropolitan Bypass.

"We have clear aims and objectives for each of the units at Manovikas Kendra like the pre-school, school, pre-vocational and vocational areas," Dr Fatehpuria says.

According to Ms Anamika Sinha, incharge of the School, the pre-school unit aptly called the "Earth" is the junior most unit. "Here, children come from different socio-economic backgrounds," she says. The

next higher unit, “Water” or school unit has children who are more than 10 years of age. Here, they are taught basic functional skills.



Children of Manovikas Kendra

Children aged 13 or above go to pre-vocational unit called “Wind”. The Vocational unit or “Space” is for children above 16 years of age. Four major vocations are taught at the Kendra, viz., weaving, tailoring and embroidery, baking and confectionery, cookery and canteen management. The minor vocations include dye and block printing, jute bag making, card making, toy making, envelope and letter-pad making.



Children of Manovikas Kendra

The children are imparted vocations according to their abilities. For instance, Ramanuj Chowdhury has become an expert in baking. He loves cooking as well and hopes to start a baking unit at his home someday.



Bakery Unit at Manovikas Kendra

Priti Shah, an assistant at the Kendra has been working for the last seven years. Before that, she was a student at the Kendra. She teaches simple English, Hindi, Mathematics and drawing to pre-vocational students. She earns Rs 1100 per month.

The Kendra has also started a unit for providing education and training to children with hearing impairment. This unit comprises of more than 55 children with mild to profound speech and hearing problems. Emphasis is mainly given on language development through total communication procedure here.

Recently, the Manovikas Kendra has initiated Computer-aided learning program. As part of this program, it provides a general working knowledge of computers, word processing, data entry, simple designing, and calculation besides fun-learning games. According to Ms Sinha, the program has proved beneficial to students of the hearing impaired section and to those appearing for National Open School exams.

Ms Saptaparna Choudhury, Special Educator at the Kendra talks of the therapeutic program. According to her, children and young adults with physical deformities are provided therapeutic treatment through structured activities and repetitive exercises. "The entire program is designed to improve the child's physical and mental activities and agility," she says. Hydrotherapy, multisensory unit, yoga therapy, music therapy, dance and drama therapy, play therapy, psychotherapy and speech therapy are some of the

therapeutic programs currently being undertaken.

Ms Anindita Chatterjee, Psychologist informs that the out-patient department of the Kendra has grown over the years and now patients not only come from all over West Bengal but even from Bangladesh. She points out that the objectives of counseling and training parents are to provide home-based management program; to boost parent's confidence levels as primary facilitators of their child's development; and to provide a platform for interactions between family members to encourage mutual feelings of competence and enjoyment.

Inspite of these achievements, Dr Fatehpuria feels a lot remains to be done especially in rural areas and slums. More organizations, she feels, need to come forward and provide services to the mentally retarded with focus on integration. "We shall be happy to guide these new units," she says, "Voluntary organizations need to come under one platform and facilitate networking for creating an impact."

Following Elbert Hubbard who said 'the ability to discover ability in others is the true test', Dr Fatehpuria and Manovikas Kendra have taken up the challenge to make the lives of the persons with mental retardation meaningful. "They should get the same opportunities like any other child," concludes Dr Fatehpuria, "We should fight for the rights of these children."



Sudha Kaul

Sudha Kaul

Jeeja Ghosh, a social worker, is an epitome of courage and determination. Despite her disability, she not only completed her higher education but also went on to train in self-advocacy and disability rights in England. She represents what Swami Vivekananda said, "To succeed, you must have tremendous will. I will drink ocean says the persevering soul, at my will, mountains will crumble up. Have that sort of energy, that sort of will; work hard, and you will reach the goal."

She asserts that empowerment bolsters the pride of people with disability. They and other powerless groups of society organize themselves into groups where they can validate their shared experiences, build up skills, offer support to one another and synergise their efforts to get individual and collective messages heard, she feels.

This 'voice' to fight for her rights is a gift of her alma mater, the Indian Institute of Cerebral Palsy, Kolkata.

Sumita Sahu, another ex-student of the Institute now works as kitchen assistant in the Institute's Catering Unit. Like Jeeja, she too feels that governmental facilities for the differently abled are inadequate. Trained in various fields of catering, Sumita has even bagged orders for the catering unit.

Jeeja and Sumita are not the only ones whose lives have changed after coming to this Institute that started in 1974. There are many more like them whose lives

have been transformed through the training they have received here.

“We had a humble beginning,” says Mrs Sudha Kaul, the pillar behind the Institute and its founder. Her perseverance has transformed it into one of the leading Centers for cerebral palsy in the country. The Institute started with just two children and two teachers. “Both of us were untrained,” continues Mrs Kaul, “Janie was an actress working as an insurance agent and I was an unemployed librarian. But both of us were determined to learn and make the center work.”

“It all evolved out of a need to give education to my son, Arjun,” Mrs Kaul narrates, “There was hardly any facility for those with cerebral palsy in the country at that time. Since we knew very little, I started burning the midnight oil reading books on special education and psychology.”

The Army at Ballygunge Military camp made two rooms available and the Center was started under the banner of West Bengal Spastic Society in November 1974. Despite initial challenges, the offer of help was readily forthcoming. “Mithu Alur, who has pioneered the cerebral palsy movement in India, gave me a one week crash course on special education in her center in Mumbai. Motivated by our efforts the tea industry promised support. Within a few months, we had our first trained staff.”

“Right from the beginning, we were very clear in our approach. Since there were problems involved in teaching children with cerebral palsy, it was essential to have well qualified staff,” she continues, “With this

in mind, we held our first in-service teachers training course way back in 1976." The British Council then invited two specialists to organize the first professional training course for the Spastic Society.

Training for management of a child with cerebral palsy is very important, says Mrs Ranu Bannerjee, Principal, Center for Special Education. A lot of time is otherwise wasted in managing the child. Besides, one must know the child's potential, she adds.

Going down memory lane, Mrs Kaul recalls an interesting anecdote. "We had organized a workshop in 1975 and invited a senior official from the state government as chief guest. Despite having received a brief on our activities, he in his inaugural address referred to our organization as one working on Plastic!"

By 1976-77, the Center had organized two seminars at which specialists from different parts of the country participated. "We sought help from England and a trained physiotherapist, Tessa Hamblin came over and established our physiotherapy department. The social work department was also set up a little later."

Fund-raising receives a lot of attention at the Institute. As early as 1978, the Calcutta Tea Traders Association held a special tea auction to raise funds for the Center. Also, a special fund-raising event was organized and the first fund-raising brochure was also brought out. All these helped the Institute expand its services.

There was a major expansion of service programs by 1980. There were already more than 60 children at

the Center for Special Education by this time. Also a diagnostic assessment and an outstation advisory service was formally established. After a survey was carried out in Chetla in collaboration with All India Institute of Hygiene and Public Health, the Institute stepped into community work in the same year. During this time the first publication, "What is a Spastic?" was brought out.

In 1981, the name of the society was changed from West Bengal Spastic Society to Spastic Society of Eastern India. "The change of name signified not only expansion of services in the eastern region, but also meant more facilities for people with cerebral palsy," says Mrs Kaul, "We were now increasingly trying to help local organizations in various districts of the eastern region to start units for treatment and education of children with cerebral palsy."

Training maximum people so that they could start their own organization in their locality soon became a mission. "We were able to start services in more or less in all districts of West Bengal and also to branch out to other places in the North-East and elsewhere," Mrs Kaul continues.

Finding regular funds and committed personnel became a major challenge for many of these programs. "We took it up as a challenge. By 1997-98, there were 14-affiliated groups in the country and 15 district partners in West Bengal," she adds.

"In 1982-83, the support of the Army and the Calcutta Port Trust, secured for the society an acre of

land. Here we raised our present premises," Mrs Kaul says. The teacher-training program was extended by four months, assessment facilities were offered and a comprehensive system of referrals was also developed.

1984 was another landmark year as the Jadavpur University entered into collaboration with the Spastic Society of Eastern India for its training courses. "Probably we were the first voluntary organization to be recognized by an University," says Mrs Kaul. During this time, the outpatient department expanded its services to meet the needs of parents coming from outside Kolkata.

"Today we meet the needs of about 800 families," says Mrs Reena Sen, Deputy Director, Indian Institute of Cerebral Palsy, "Our endeavor has been to empower the community to help persons with cerebral palsy. We always prioritize the needs of families and emphasize working with them."

An exhibition on "A Decade of Service" was organized at Birla Industrial and Technological Museum in 1984-85. "During this time, the publications division became more active and the Vocational Training Unit expanded to include more vocational skills," informs Mrs Kaul, "The Research Division also expanded and an audio-visual training kit for parents and professionals was developed."

The vocational training unit now offers training courses in catering, silk screen-printing, computer data entry and programming. The training programs vary from three-months to two-years and are open to adults

over the age of 18. The objectives of these programs are focussed to help trainees to get absorbed in the open market or go for self-employment.

Meanwhile the Department of Science and Technology recognized the Spastic Society as a research organization in 1986. During this time, an organizational structure of the society was also evolved and a new department, Institute of Cerebral Palsy was started.

The Institute building came up in 1987-88. Within the next few years, district services were started in Coochbehar, Nadia, Malda, West Dinajpur and Batanagar. "By the 1990s, we realised that on the threshold of adulthood, our young adults needed a brighter future," Mrs Kaul says, "The Indian Market Research Bureau was asked to conduct a market research to identify potential areas for contract jobs."

On the basis of the study, the Adult Training Center was established in 1992 with the objective of rehabilitating young adults with multiple disability. Its aim is total rehabilitation whereby the trainee can become a useful and contributory member of the society. Vocational Training and Placement Service are major components of the adult training program. Four independent units were created in the Center: computer unit, catering unit, leather and printing unit, and the adult leisure and learning unit.

According to Mrs Kaul, the aim is to bring rehabilitation to the doorstep of local communities. In this regard, an Integrated Education Department was

set-up where students with specific learning problems in mainstream schools are assessed for specific learning difficulties. Both students and teachers in the mainstream schools are given advice to cope up with the problem.

Presently the Institute provides services under several divisions. Under Human Resource Development, it provides manpower training; research; information, education and communication; therapy and rehabilitation services; social services guidance and counseling; P R advocacy information cell. Amongst the courses run by the Institute are the post-graduate diploma in special education, basic management of cerebral palsy for medical practitioners, basic management of multiple disabilities in the community; basic management of multiple disabilities in community-advanced; computer training courses for adults with physical and multiple disabilities.

Besides the Institute also provides a wide range of services including family services, school services, adult services, community services and residential services. The family service include a diagnostic clinic, neurology clinic, the out-patient department, infant screening clinic, baby clinic and outstation service. The school service includes the Center for Special Education. The Center is a day care center for education and treatment for children with cerebral palsy. There is even a pre-school playgroup for children aged 2-5 years. The Special Learning Unit caters to the educational needs of students with profound and severe learning difficulties.

“In 2000, we decided to change our name from Spastic Society of Eastern India to Indian Institute of Cerebral Palsy as we have now evolved into an institution of national importance and are serving over 2000 families directly,” says Mrs Kaul.

“There is now a greater focus on a time-tested way of reaching out to the children and persons with disability who are deprived of services,” avers Mrs Kaul, “Our growth has been due to the collective sharing of knowledge and networking.”

“We shall continue to give greater emphasis to training, information dissemination and standardization of services,” avers Mrs Kaul. She concludes with a feeling of elation, “A little more than 25 years ago, as Junie, Om (my husband) and I sat and planned Arjun’s future, we did not even, in our wildest dreams, imagine an organization of this stature, magnitude and appeal.”



Sister Rita Mary

Sister Rita Mary

OS Marden had rightly said, “There is no medicine like hope, no incentive so great, and no tonic so powerful as expectation of something tomorrow.” It is with this hope, a dream that her son would become a computer engineer that Dr Mini Shibu quit her job.

It was not an easy decision for her to take as she was working as an assistant professor at a medical college in Gujarat. “Initially I was a bit sad to leave the job and come to Chennai for Ashish’s education,” she says, “But now I find the task of bringing up a child with hearing impairment more satisfying and challenging.”

She exudes confidence that some extra effort, a little extra love, a little more training can really transform the life of a child with disability. This is the duty of the child’s parents, she feels.

In her bid to bring up her child, she gets support and strength from the Little Flower Convent School, which caters to the educational requirement of children with both hearing impairment and visual impairment.

Started in 1926 by Belgian sisters, the driving force behind the Little Flower Convent has been Sister Rita Mary, formerly its Principal.

Born in 1937 in Uttamapalayam, Madurai, Sister Rita Mary initially did not have any exposure to the problems of the differently abled in her life. “I took up training to teach general children after I came in touch

with the Belgian sisters who were running a school in Sirivenliputhy near Madurai," she recollects.

"In 1964, the Belgian sisters said I would be more suitable to work for the differently abled and placed me here at the Little Convent," she says, "At that time, it was called the School for the Blind and Deaf."

Two years later, she resolved to dedicate her life completely for the persons with disability. She decided to become a nun. After completing her training in 1968-69, she came back and rejoined the School. "Soon the Principal, Sister Andreas fell ill. At that time, I was asked to go to Mumbai to take training for the deaf," she reminisces, "Immediately after coming back I was asked to take over as Principal of the deaf school."

Sister Rita Mary shares an interesting anecdote from the early days of her becoming the Principal. "A senior teacher at the school was my teacher in school days. So other teachers used to inquire about me - like whether I was regular at school. She used to wonder how a person like me who loved materialistic things could give up everything to become a sister."

After taking over as Principal, Sister Rita Mary decided to reorganize the school. Changes were imperative to make the school an institution of excellence, she felt. She went to England to do a Diploma in Advanced Education for the Deaf to enhance her knowledge base. "I went to Germany, Denmark and France to get acquainted with the scenario there," she continues, "One of the first things I did after coming back was to re-christen the School."

The vagueness in the name of the school – ‘School of the Deaf and Blind’ was actually pointed out by a small girl. “We changed the name to Little Flower Convent for the Deaf and Blind. Now the two schools are separately called Little Flower Convent for the Hearing Impaired and Little Flower Convent for the Visually Impaired.”

Another major initiative that Sister Rita Mary took immediately after coming back was to start the process of involving parents. “Parents have to be made equal partners in the development of a child. In this regard, a large number of children at school were made day scholars,” she says.

“Earlier all children were staying in the hostel. We explained to parents that home was the best place for the development of a child and that their role was critical,” she adds.

Besides, efforts were initiated to reach out to different sectors of the society. “As part of this networking process, we started inviting people from various sectors of the society to preside over different school programs. The tradition of having only priests presiding over functions was thus broken.”

“In one such program, the chief of the Chennai’s Pallavam Transport was invited. I requested him to provide buses for the students. He agreed immediately,” she recalls.

To further involve the parents in children’s education, Sister Rita Mary initiated a process where

parents could come, sit and observe on what was being taught in the class. "This innovative method where parents can keep track of their child's progress has contributed in a big way to their education. A large number of our students have done really well and are now well settled."



Students of the Little Flower Convent for the Hearing Impaired

Chitra, a former student, now works with the Income Tax department. A President's award winner for best employee (deaf category), Chitra says all she has achieved in life is due to the Little Flower Convent School. Now she comes to her alma mater everyday as her daughter is also studying in the same school. She is confident that her daughter would also be able to make her career studying in the School.

The School's Jubilee year in 1976 saw several new initiatives. Conscious of the need to impart quality education and services a teachers training program was

started. "In the same year we sent our students to appear for class Xth exams. We were one of the first schools in India to send students with hearing impairment both for class Xth and class XIIth exams," Sister Rita Mary says.

Besides, a Guidance Home for Adult Deaf Girls was started. "Probably it is the only disabled girls hostel in the country. The Guidance Home aims at installing confidence, preparing the girls for integration, identifying and imparting training for jobs," she adds.

In 1983, Sister Rita Mary went to Holland for a three-month training on ways of conversing with speechless children in the classroom. Later more teachers were sent for the same training. The objective was to understand and put into practice the maternal reflective method.

"We now use this method to teach pre-school going deaf children," she informs, "The method involves heart to heart conversation among the children and between children and teachers in the classroom. This helps in making the classroom livelier. Besides, the method helps children to understand grammar rules by themselves. It also helps in developing the reading skills of the students"

Presently, Principal of the St. Louis College of the Deaf, Sister Rita Mary retired from the Little Flowers Convent in 1994. "Hearing impairment is an invisible handicap. People with such an impairment are thought of as normal," she says, "That is why they are not given proper concessions. Besides there are none to voice their rights."

Sister Rita Mary feels that for total rehabilitation, early intervention should be made a priority. Besides, she strongly advocates the need for inclusive education. "Implementation of various schemes of the hearing impaired are very tardy and this needs to be reversed," she concludes.



T D Shroff

T D Shroff

Tanaaz slowly reads the headlines of the morning's newspaper. Her classmates excitedly listen as she reads to them a news item pertaining to their favorite actor Hrithik Roshan getting married to his sweetheart Suzanne Khan. What is in progress is the news communication session in the Jai Vakeel School for Children in need of Special Care. The aim of the session is personality development.

Samir, Tanaaz's classmate, loves to play the Solitaire, a game of cards while Clyde has learnt to make bills and use calculators. They are no longer withdrawn and are now able to relate to happenings around them.

A former student at the School, Dharmender Kelkar, profoundly retarded, is now earning Rs 500 every month. He is now employed in the School as a helper and teaches how to make folders and envelopes.

Barry Mohammed, 26, in the vocational group, has learnt to make agarbatis and gets a stipend of Rs 30. Another student, Rafiq Kanchwalla came to the school at the age of six. Partially hearing impaired with low intelligence quotient, Rafiq is now a brilliant painter and visualizer. He has even represented India in the International Special Olympics in football.

One of the oldest Institution of children with special needs in the country, the emphasis at the Jai Vakeel School has been on holistic development of the child. The aim is to make them as much self-dependent

as possible besides enhancing their personality.

“The main reason for our success over the years is our emphasis on identifying the aptitude of our children and developing them accordingly,” says Mrs Tehmi D Shroff, Secretary of the Research Society for the Care, Treatment and Training of Children in Need of Special Care. The Society runs the School.

“The Research Society has evolved into one of the pioneering institution in the country engaged in total rehabilitation of children with mental retardation, many of whom are also afflicted by cerebral palsy, visual and auditory impairment and are physically challenged,” Mrs Shroff says. The Society has been able to spearhead the setting up of several institutions including the School, a Vocational Training and Rehabilitation Center, a Research Center, Rural Outreach Programs, Residential Complexes for boys and girls and a College of Special Education.

The Research Society or the School for the Children in Need of Special Care did not come out of the blue. “My sister, Dina was born in 1936,” recalls Mrs Shroff, “By the time she was two months old, my parents realized that her development was not quite normal. When she was six months, a family doctor diagnosed that Dina was a victim of Down’s Syndrome.”

“My parents took the news with stoic resignation. They allowed Dina to grow at her own pace, facilitated her participation in all family activities,” she continues.

“When she was four years old, we asked mother when Dina would go to school,” Mrs Shroff recalls,

“Mother said Dina was a very special child and needs a special school. She said we would start a school for Dina.”

On October 10, 1944 Mrs Shroff’s mother, Mrs Jai Vakeel started the ‘School for Children in Need of Special Care’. It was started in her drawing room with just two students, Dina and Nargis Daruwala. The main objective was to offer children with mental retardation special understanding and individual attention.

“Being one of the first school of its kind in the country, there were no guidelines that mother could refer to,” Mrs Shroff says, “She had to do a great deal of research on mental retardation. She corresponded regularly with Dr Johnstone and Ms Helen Hills of Vineland School besides several other doctors abroad.”

Mrs Vakeel had to innovatively construct all items from scratch, right from the equipment used to the syllabus. Within a few months, there were 25 children in the school.

According to Mrs Shroff, the ultimate aim of the School is total rehabilitation and making a child with mental retardation into a productive member of the society. To achieve this a Vocational Training Section was started in 1948 with the help of the Salvation Army in the garage of Mrs Jai Vakeel with one handloom and two desk looms. The Section aimed at helping the students achieve as much independence as possible besides keeping them meaningfully occupied.

The local Government recognized the School in

1949. By now it was imparting training in home science, embroidery, knitting, string work, weaving and basket making. Carpentry was introduced as a new activity in 1951 and in the same year, the School got recognition from the Government of India. In the same year, the Research Society for the Care, Treatment and Training of Children in Need of Special Care was formally registered to provide a wide range of facilities for the treatment and development of children with mental retardation.

“Right from the beginning, mother concentrated on upgradation of the activities of the School and introduction of trained teachers,” Mrs Shroff recollects, “As early as 1946, she started organizing lectures by renowned doctors and professors. By 1952, we were ready to start a Special Education course, the first of its kind in India, to meet the shortfall of trained teachers. The course was recognized by the Maharashtra Government.”

From the two-storied bungalow of the Vakeel’s, the School moved to its present premises in Sewri Hills in 1957. Here, the Vocational Training School was started in a more organized way. The residential blocks were completed in 1959.

As part of its efforts to provide comprehensive services, the Research Society has been giving lot of emphasis to research. The first research work undertaken by the Society was as early as 1948. The Parsi Panchayat and the Bombay Head Masters’ Association wanted information on the number of

children with mental retardation among the school going population of the city of Mumbai. The Society was entrusted with the job of collecting data in this regard.

By 1964, the Society had formed a proper research panel within the school itself and started investigating the root-causes of retardation and to suggest ways of preventing or alleviating them. For seven years, the laboratory conducted tests in the school premises itself. In 1971, through a donation of Rs six lakh, a separate building for research activities was constructed and was named as Shrimati Motibai Thackersey Institute for Research in the Field of Mental Retardation.

According to Dr Aparna Parikh of the Institute, there is a multi-disciplinary team comprising of pediatricians, psychiatrists, clinical psychologists, speech therapists and audiologists, occupational therapists, cytogeneticists, biochemists, physiotherapists and social workers at the Research Center. The Center has a cytogenetic laboratory, biochemical laboratory, audiometry and EDP Department. Over the past 25 years, more than 6000 cases have been assessed at the center and suitable training and rehabilitation programs planned for them.

“The research team has developed programs for early detection and intervention of developmental delay, developed therapy facilities for maladjusted children, parental counseling, genetic counseling, etc,” says Dr Parikh. The Center is also involved in research work including study of etiological factors in mental retardation, detection of fragile X mental deficiency

syndrome, study of chromosomal anomalies in mental retardation and study of inherited metabolic disorders in mental retardation.

“Today there are more than 400 students at the School. In academics, there are pre-nursery, nursery, pre-primary and primary and higher education sections. The school provides pre-vocational training and personality development, arts and crafts, sports. The psychosocial activities include parent counseling, home visits and gardening,” says Mrs Shroff.



Children of Jai Vakeel School performing dance drama

“We lay special emphasis on dance dramas as they help in cognitive development of a child and have a greater effect on a child than therapies,” says Ms Manisha Shastri, Project Coordinator.

“Since 1940 our students have been taking part in

dance drama,” recalls Mrs Shroff, “My sister, Dina performed Cinderella with her teacher in 1949.”

Referring to the Vocational Training and Rehabilitation Center, Mrs Shroff says there are approximately 250 boys and girls for ‘open’, ‘sheltered’ and ‘home’ employment. “When choosing an occupation for students, care is taken to identify a suitable field in which the student is comfortable,” she says, “Since 1992, pre-vocational training and personality development program have been implemented in a big way.”



Vocational Training being imparted at Jai Vakeel School

As a continuation of the Special Education course started in 1952, a Minds College of Special Education B.Ed Special (MR) started with a B.Ed. course in 1991. The course is affiliated to the University of Mumbai

and is also recognized by the Rehabilitation Council of India. The College also runs a Diploma in Special Education course which is affiliated to the National Institute for the Mentally Handicapped.

As part of its expansion program, a rural branch of Jai Vakeel School was started on January 21, 1998 at Sai Baba Seva Dham, Kanhephatta Village, Mawal Taluka. A survey of 64 surrounding villages with a population of approximately 1,00,000 persons was carried out before starting the school.

The Research Society has also set up a special center – Sairam Autism Center for Children with Autism and Related Disorders. In this Center, comprehensive assessment, therapeutic, dietary and other intervention services are being provided for autistic children with the help of a multi-disciplinary team of medical and para-medical professionals.

In recognition to its commendable contribution in the field of Mental Health, the Research Society has won several awards. Its founder Mrs Jai Vakeel got the Padmashri in 1977. In 1990, the Research Society got a national award for its outstanding performance in the field of Handicapped Welfare. Again in 1991, two members of the Vocational Training Center, A K Roy and D P Nemane won the National Technology Award for the Welfare of the Mentally Handicapped for inventing 'Jai Loom', a one-hand operated weaving loom. This invention has helped students with severe disability to earn according to their capacity.

For more than 50 years the comprehensive center



Dr Thakur Hari Prasad

Dr Thakur Hari Prasad

For Ms Govindamma, it is not just the education or vocational training that the children are exposed to at the foster care homes but equal emphasis is given on basics like bedmaking, toiletries and changing dress. "This is almost a 24-hour job as we have to be always conscious of the special needs of the children," she says. She is the warden of the foster care homes.

Probably one of the few institutions in the country to develop foster care homes for children with mental retardation, the Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped (THPI) has come a long way since 1967 in providing comprehensive services for the persons with mental retardation.

"The children are in constant supervision of foster care mothers," Ms Govindamma continues, "Here we have four children and one trained foster care mother in one cottage."

"At THPI, we conceive empowerment as the total development of persons with mental retardation. It means not just the development of work skills, but also the development of the person on the whole," points out Ms Anuradha Jegannathan, additional director adding that child from different parts of the country come to the foster care homes.

The force behind the evolution of THPI as a leading organization for those with mental retardation has been Dr Thakur Hari Prasad. Born on July 1, 1935, Dr Prasad

hailed from a family having a background in philanthropy and social service. Even as a student his hobby was to collect funds for social causes as he had an innate passion for child development activities.

To take forward his passion, he worked on a pilot project on child development in 1959-60 that was incidentally his first intervention on policy issues at the national level.

He succinctly recalls how he made the intervention. "I was the Secretary of the Andhra Pradesh unit of the Indian Council of Child Welfare in 1959-60. During this time we had an Executive Committee meeting in New Delhi. Mrs Indira Gandhi was the President of the Organization at that time. At the end of the second day of the meeting, Prime Minister Nehru had invited us at tea in Teen Murti Bhawan."

On meeting Pandit Nehru, Thakur Hari Prasad said, "Sir, I am honored at having tea with the architect of modern India. I think you alone can understand our concern. We are working on child development, but unfortunately child development is not a priority in the National Perspective Plan even though the second five-year plan is almost through."

Pandit Nehru immediately called his secretary, Mr Iyengar who informed that Rs 64 lakh had already been allocated for a pilot project on planning for child development. "Pandit Nehru said he would give us Rs 64 lakh for 64 villages in Andhra Pradesh for five years to work on pre-natal, ante-natal and post-natal care."

"We took this up as a challenge and the Pilot Project

was a 100 per cent success," Dr Prasad recalls, "We followed it up with the first All India Seminar to frame a national policy for child welfare. During this seminar, we evolved a framework and then presented it to Pandit Nehru. It was accepted in toto and Rs three crore was allocated in the Third Plan Period."

While working for the Pilot Project, there were developments in the personal front, which actually propelled Dr Prasad to work for the persons with disability. "In 1960, I had my first son who was born normal. He got a severe diarrhea attack when he was just four years old. The doctors suspected he was losing his eyesight. So they put clippings on his head. This injured his head and he developed mental retardation. Then and there I dedicated myself to the service of persons with mental retardation."

Destiny took Dr Hari Prasad to Stockholm for the first World Children's Congress in 1967. "Sweden is the Mecca of services for the persons with mental retardation and I got a good exposure to the facilities there. The Government there takes care of those with mental retardation with a philosophy of 'womb to tomb'," he says.

After coming back from Sweden, Dr Hari Prasad met the Andhra Pradesh Chief Minister and told him that he wanted to start a rehabilitation institute for the persons with mental retardation. He immediately helped him in getting a palace called Sagar Nooma just next to Raj Bhawan.

Thus was started the Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally

Handicapped in September 1968 with 30 staff members. "The only major qualification I had was that I was the father of a child with mental retardation. This was responsible for my total commitment at the personal level," Dr Hari Prasad says.

"We were the first Institute in the country to evolve a multi-disciplinary approach towards rehabilitation of the persons with mental retardation," he says, "Mental retardation is a condition that causes heterogeneity in special needs of individuals affected. Hence intervention has to be need-based and should be made by professionals and para-professionals from different disciplines."

Right from the inception, THPI has had full time faculty in neuro-paediatrics, psychiatry, clinical psychology, special education, speech pathology and audiology, physiotherapy and occupational therapy. Besides the Institute also offers augmentative interventions to supplement clinical therapies through dance therapy, music therapy, yoga, hydrotherapy, art therapy, horticulture, etc.

According to Dr Thakur Hari Prasad, a multi-disciplinary approach ensures a holistic and integrated service delivery resulting in optimum benefit of persons with mental retardation. Besides providing intra, inter and multi-disciplinary interactions and collectivity in management decisions, the approach enables clinical intervention to become part and parcel of daily life as mid-level para-professionals are empowered to train grassroot workers and families.



Vocational Training for Students at THPI

At THPI, the multi-disciplinary team meets every week to review the weekly programs and to plan for the forthcoming week. An open forum of all the clinical, teaching and training team is held on the first Saturday of every month to review the multi-disciplinary co-ordination of the previous month and formulate plans for the ongoing month.

“The institution became popular within a year of its existence,” reminisces Dr Thakur Hari Prasad, “Our

philosophy has been 'let us rewrite new standards in rehabilitation services and establish monitoring system for compliance'." He constantly urges his team to introspect, evaluate, consolidate, streamline and upgrade the standard in every avenue of operation of the organization through interactive and participatory modalities.

"Till 1985 nothing substantial was taken up in the country as part of the International Decade of the Disabled," Dr Prasad, underlying the contribution of THPI at national level says, "One fine day I was surprised to see disability as the eighth point of Rajiv Gandhi's 20-point program for the nation."

"Enthused, I sought an appointment with the Prime Minister," he continues, "I told him I would volunteer to prepare a national policy for the persons with mental retardation. Without a moment's hesitation he lent his support for the policy."

"I went around the country and met almost all chief ministers and chief secretaries requesting them to send representatives for formulating a national policy on mental retardation," he adds.

The THPI organized an all-India seminar for policy formulation for the mentally retarded in February 1987 in Hyderabad. A document was prepared after the seminar and in January 1988, a 45-member delegate presented it to Prime Minister Rajiv Gandhi. Within seven days, the Government appointed the Behrul Islam Committee as a follow-up to the presentation. An exclusive working group was also constituted under

the Eighth Plan for disability.

“Till the Seventh Plan, there was no mention of disability management in any Plan Period. Within 60 days, the Behrul Islam Committee was asked to give its report,” Dr Hari Prasad says, “We could push the issue of disability in the Eighth Plan Period. Besides the Committee recommended the enactment of a Disability Act.”

“The Act was not immediately passed,” he continues, “It needed a sustained campaign on the part of the entire disability sector to force the enactment of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. It infact coincided with the Asia-Pacific Decade of the Disabled Persons, 1991-2002. ”

The Policy Seminar of 1987 had recommended the setting up of a National Trust for those with mental retardation. The aim was to ensure security of the persons with mental retardation after the death of their parents. Extensive lobbying since then has ensured the setting up of a National Trust for the Welfare of the Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.

“I also initiated the campaign to convert the Rehabilitation Council of India from being a society to a statutory body by an Act of Parliament,” Dr Hari Prasad points out, “To improve the quality of services, we should have regulation. Besides we have to ensure equalization of services and opportunities for the disabled.”

The intervention of the THPI include rehabilitation of children and young persons with mental retardation under judicial custody. Since 1985, THPI conducts annual screening of children at the Government Juvenile Home for Boys. Those identified as mentally retarded are brought to the Institute daily and put through individualized interventions apart from systematically planned educational and training programs.

Meanwhile in 1987, the Institute initiated an early detection and intervention project, 'Surya Jyothi' in collaboration with German experts. Its main focus was on early detection, early intervention and early social integration of infants and children afflicted with or threatened by mental, physical or multiple handicaps. Subsequent integration is done in the Montessori environment.

Another major project was 'Anvenshana'. According to Dr Jegannathan, early detection and integration was carried out in the neighboring rural areas. The basic aim of the project is prevention, early detection and management of disability among 0-5 years children within the existing infrastructure of the community.



Children learning skillsets at THPI

“Though 80 per cent of the persons with disability lives in rural areas, rehabilitation services for them are almost non-existent,” rues Dr Hari Prasad. There is need for humanpower development, devising local training

methods and integration in the rural areas, he adds. According to him, community participative rehabilitation centers are the panacea for such needs in rural settings.

In this backdrop, the THPI initiated a rural program in Lalacheruvu, near Rajahmundry, East Godavari District of Andhra Pradesh in 1990. The main focus of this program is on convergence of services, local participation, local suitability, and available and affordable rehabilitation measures. The Rural Center has developed viable and sustainable strategies to reach out to the whole of East Godavari District. "The objective of the project has been to evolve a replicable comprehensive and integrated community approach to the rehabilitation of the mentally retarded in the country," he says.

A rural camp program involving detection, intervention and follow-up of services for persons with mental retardation is the highlight of the program. Individuals with other disabilities are also supported and referred to appropriate agencies.

The Thakur Hari Prasad Institute had the distinction of hosting the XI World Congress on Mental Retardation in 1994. It was the first time that the World Congress was organized in the country.

In 1998, Dr Thakur Hari Prasad assumed office as the Chairman of the Rehabilitation Council of India. During his tenure, two important national programs were initiated – a Bridge Course of one-month duration, in each major area of disability, for those who

have been working in the field prior to 1993 and a training program for doctors of Public Health Centers throughout the country.

Dr Thakur Hari Prasad has often emphasized on the need to enrich the creative life of a community. “Creativity is a part and parcel of life itself, giving life long learning opportunities to many people. Our role is to reach out to people, raise awareness of what is around us as a community, present opportunities for growth and involve disabled people in creative activity that would influence all aspects of their lives,” he concludes.



Dr Uma Tuli

Dr Uma Tuli

*God, give me strength
To instill life in flowers
To show the right path to the world.
Give me strength
To spread the sweet fragrance all around
To welcome and bid adieu to the Sun.
Give me strength
To light the eternal flame of knowledge
To dispel darkness
And spread light everywhere!*

It is a prayer that is being recited every morning at the Amar Jyoti School for the past 17 years. A pioneering institution promoting integration right from day one of its inception, its major thrust has been economic independence. This has been a vital component of its rehabilitation program that makes mainstreaming students with disability more dynamic.

Probably that is one reason why Amar Jyoti has a unique ratio of 50:50 when it comes to children with disability and general students in a class. Also its aim has been to inculcate a better understanding of disability among the general students while instilling confidence among children with disability.

“Here at Amar Jyoti, both disabled and non-disabled students compete on equal terms whether it is academics, sports, dance, music or vocational skills,”

says Dr Uma Tuli, its progenitor.

Born on March 3, 1943, Dr Tuli had her education in Gwalior, Madhya Pradesh. Both she and her brother, Mr Arun Kapoor were active in school in various fields including sports and cultural events.

A student of English, Dr Tuli had no prior exposure to persons with disability till a tragedy struck her family. Recalling that eventful day in 1965 that sowed the seed for a life long commitment to work for the persons with disability, she says, "I was at the college mela having fun at the merry-go-round when I received a message that my brother had met with an accident. I rushed to the hospital and saw my brother, being brought inside the hospital in a car with his leg hanging out. Amputation was inevitable. It was the time of the Indo-Pak war and the hospital had received many young men with their upper or lower limbs amputated. With one blow many of these active young men including my brother had been rendered handicapped."

People with disability were a secluded lot those days, says Dr Uma Tuli. There was absence of an earnest desire to look into the problem of persons with disability, though there was no dearth of sympathy. "The orthopedic wards which I visited during that period were full of people in deep despair. They knew they faced a bleak future with meager treatment facilities and almost non-existent rehabilitative services," she recalls.

"From these experiences I realized that the only way to tackle disability was to introduce integrated

education, vocational training for self-employment and necessary medical assistance for mobility and meaningful existence. So, I decided to do something constructive in the field of disability,” she continues.

At that time, Dr Uma Tuli was working as a lecturer. In fact, she was one of the youngest lecturers to be appointed by the Union Public Service Commission, and taught at both Gwalior and Delhi University. Her dream of setting up a rehabilitation center with a difference received overwhelming support from her parents, relatives and friends. She was depositing her entire salary in the post office. After marriage, she and her husband went around the country and abroad to have an overview of the rehabilitation services so that the best could be assimilated into the proposed center.

Finally in 1981, during the International Year of the Disabled, Dr Uma Tuli started the Amar Jyoti Charitable Trust. “Initially we decided to focus on the Orthopaedically disabled though with a goal to eventually offer cross-disability services,” she says. The aim was to integrate people with disabilities in society, increase awareness about the holistic approach to rehabilitation and provide an opportunity for integrated sports and cultural activities.

As most Institutions like this have a humble beginning, so did Amar Jyoti. “In July 1981 we started Amar Jyoti from the terrace of our house at Greater Kailash in New Delhi. We also started a workshop for manufacturing calipers and artificial limbs,” Dr Tuli recalls.

“Initially we raised money through small donations from friends and well-wishers,” she continues, “Besides we had a lot of volunteers who were enthusiastic and dedicated. They helped to conduct surveys in the under-privileged colonies and also hold camps after identifying the cases. Measurements were taken at these camps and calipers, artificial limbs, wheelchairs and tricycles were provided free.”

Dr Tuli’s determination to effect a change in the life of persons with disability can be gauged from a poem she wrote in the first publication of Amar Jyoti:

“Who listens to my cry,
It has a feeling but no poetry,
There is agony,
But no tears.
Give hearing aids,
To those who have ears,
But cannot hear.....”

“To identify people with disabilities and to meet their immediate need for artificial limbs was among the first programs we took up after starting Amar Jyoti,” Dr Uma Tuli says.

To evolve an integrated approach to rehabilitation, Dr Tuli planned to start a school. Since it could not be started at her residence, she began the search for a good location. As luck would have it, Air Chief Marshall (retd.) P C Lal, a trustee of the Raja Ram Mohan Roy Trust offered a space under the shade of trees in the Trust premises at Rouse Avenue.

“We started the school under the shade of trees in July 1982,” recalls Dr Tuli, “There were 30 students in all – 15 disabled and 15 non-disabled students. Integration was the mantra right from day one.”

A major objective of the school has been to ensure that students gain admission to mainstream schools when they leave Amar Jyoti and become confident in undertaking further studies.

Says Ms Mini Bhandari, now vice-principal of the Amar Jyoti School: “I was doing my graduation when Dr Tuli, who was my lecturer in college, told me about the school she had started. Initially, I used to go and teach students in my free period.” She formally joined the school in 1986 after completing her masters and B.Ed.

According to Dr Tuli, the Amar Jyoti School has been able to strike a balance between the integrated and inclusive education systems. While ensuring equal numbers of non-disabled and students with disability in the school, it also lays a major emphasis on co-curricular activities and sports. The school is till class VIII after which students are encouraged to join regular schools. Those with severe disability are motivated to join the National Open School to complete their class X and XII. Besides, the school has also evolved an Individual Education Program.

“The growth of the services using Individual Education Program made us realize that we needed some facilities for those with mental retardation,” Dr Tuli says, “There were children who were unable to

pass for two consecutive years and would generally end-up as drop-outs. This could solve the problem of the school, but not resolve the child's problem." In this backdrop, a special section was started for them. Students in this section are integrated into mainstream classes wherever possible. They also participate in all co-curricular activities along with other school students.



Students of Amar Jyoti taking part in a march past

Help came from unexpected quarters in small but meaningful ways. "There were some who donated file covers and papers for office use, College students volunteered to take classes. Kausalya, a volunteer from the community, with her team of supporters conducted a survey for identification and initially worked as a peripatetic teacher also. The most touching contribution came from a 12-year boy living next door, who donated

his pocket money of Rs 10 every month for several years.”

Fund raising has received a major thrust at the Amar Jyoti Charitable Trust. The first major campaign was undertaken during the Asian Games in 1982. And as early as 1983, the foundation stone of the Amar Jyoti Rehabilitation and Research Centre was laid at Karkadooma. Vocational training courses and medical services were started during the same year.



Students of Amar Jyoti at an Archery Contest

“At Amar Jyoti, students are provided vocational training alongside academic studies. Those who show an inclination for higher studies are encouraged to do so. Others are trained in various vocations as per their proficiency,” says Dr Tuli

The vocational training at the Centre include computers, watch repairing, crafts, tailoring, textile

designing, weaving, secretarial work, electrical repairs, beauty culture, screen printing, candle making and carpentry. According to Dr Tuli, holistic rehabilitation is the first major step towards empowerment. "It comes only from increased mobility and augmented ability to control body movements, but also most importantly through equipping a person with disability with life skills necessary to make integration into the mainstream a viable proposition," she adds.

Another critical and vital component of the holistic rehabilitation process is taking services to the doorstep of those who require them. Towards this end, Amar Jyoti has been following the Camp Approach. Presently rehabilitation services are being provided in 30 urban slums through the Amar Jyoti Community Based Rehabilitation Project centres. The community workers and volunteers in these slums conduct door-to-door surveys and identify persons who require various specialized services. A team of doctors, therapists, paramedical staff, orthotists and prosthetists, psychologists and counselors offer on-the-spot comprehensive services. Professionals do follow-up through visits. Many a time, the beneficiaries are themselves brought to Amar Jyoti.

Innovation and ability to respond to new challenges over the years has resulted in evolution of new programs at Amar Jyoti. One such innovation has been the Child Guidance Centre started in 1990 as a response to parents' need to solve their children's problems. The Centre has developed a home training

program that has contributed to a greater understanding of the child within the home environment.

“To provide adequate services for persons with disability, there is an important need to meet the increasing demand for humanpower,” says Dr Tuli, “Accordingly, we started a multi-category teacher training course in 1992, besides a diploma course in special education in mental retardation.” Another landmark achievement was the starting of BSc Physiotherapy course recognized by Delhi University.

Comprehensive Medical Services has been developed at Amar Jyoti. Over 30 leading doctors volunteer their time to augment the permanent medical and para-medical team. Services include day hospital, operation theatre, radiology, pathology and therapeutic services including physio, occupational and speech therapy, audiology, prosthetic and orthotics engineering.

Dr Tuli always had a dream to start rehabilitation services at Gwalior, her place of birth. This dream became a reality in 1990 and the center there has been running a holistic rehabilitation program. Her two-decade long contribution to the cause of persons with disability got due recognition when she was appointed the Chief Commissioner of Persons with Disability in April, 2001.