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The
Spastics
Society
of India

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My involvement with handicap over twenty-two years has been both professional as well as personal.

Personally, I am proud to be the mother of a twenty-two year old spastic daughter, called Malini, who has just passed her Bachelor of Arts Degree; I have learnt a great deal from her; she is a person full of the joie-de-vivre and has faced her severe disabilities with a smile. Her attitudes have affected me and many others deeply.

Professionally, I am an educationist - and this helped me in pioneering a new model of education and treatment for the handicapped, under the roof of a special school setting, in India, starting in 1972. This comcept later spread to different parts of our country.

It has been both an enlightening and enriching experience, where I have gained more than I have given.

As you well know, 'spastic' is a jargon term used to describe the medical condition known as cerebral palsy.

A neuromuscular disorder, as a result of brain damage, cerebral palsy is a condition which is chronic and lifelong. It is non-progressive, usually present at birth involving an insult to the brain and leading to impairment of motor control.

There are three major types of cerebral palsy; damage to the cortex which leads to the 'spastic' condition; to the basal ganglia leading to athetosis and to the cerebellum leading to ataxia. There are no drugs, unfortunately, which can suddenly and miraculously cure the condition; nor can quick surgery help. There's no cure or panacea.

Turning to the country in which I work, India, - we all know that it is a vast subcontinent, mammoth in its complexity, size and diversity. It is beyond easy description or analysis. Two-thirds the size of Europe, its population is greater than the masses of Africa, New Zealand and Great Britain combined. An African found India just too overwhelming, "Too many people, too many customs, too many gods - too much of everything". British historian, Arnold Toynbee called India " a land of some magnitude, as our western civilisation... a whole world in herself"....and according to Mark Twain, "India is a land of fabulous wealth and fabulous poverty, of splendour and rags : contradictory, confusing, elusive beyond explanation and formula."

The handicapped in this complex set-up tend to be neglected, as in most developing countries. Factors dominating are religion, illiteracy, joint family systems, casteism, rampant poverty and inadequate funding. The social and economic milieu compound to make the problem, an acutely difficult one. Added to this is a certain lack of awareness and a lack of political will. The handicapped are last on the list of priorities for the Government. The Government still relies rather heavily on non-governmental agencies to provide schools and services. However, in the last decade,there has been a change in the attitude of the Government. They now provide more funds and have set up half a dozen National Institutes all over the country. But neglect of the handicapped and lack of political support still is a very tangible reality.

Numbers and statistics about the handicapped vary: our own and U.N. surveys show ten percent of the population disabled, that is nearly eighty million people; the world's largest democracy has the world's largest population of handicapped people!

The Spastics Society has been a scientific and technical organisation. Friends and well-wishers from all over the world have come forward to help us in this pioneering effort. ODA (British Government), Church of Sweden Aid, and Spastics Society of U.K. with CEC, Brussels are some of the international affiliates of the Society who have helped us, not only through financial aid but also through technical collaboration.

Our new centre, the National Centre for Training and Research into Cerebral Palsy and Other Physical Disabilities is a culmination of twenty years of work. The Society runs early infant clinics, child development centres in slums, special schools, employment units and training courses for teachers, therapists and community workers. It also has departments handling research, publications, press, community awareness, liaising with Government and the corporate sector and taking care of the administrative needs of what is today, one of India's largest charities functioning for the disabled.

Since each child or individual with cerebral palsy varies, with many areas getting affected, the person must be considered in his or her totality with an holistic approach being worked out. A large team of specialists work together with doctors and, of course, parents who are now widely recognised as being important members of the team.

PARENT SERVICES.

Early detection and a link-up with the family is most important in the first two years. Sometimes, parents 'shop around' endlessly for a 'cure'. They believe in faith healing, advice from gurus or strong medication as a quick panacea. All this plays a very powerful part, delaying the start of proper management.

COUNSELLING

This is a crucial area of our work. During the assessment period, we spend a long time with parents, getting to know about family dynamics - the socio-economic level of the household, the number of family members living together. Many of you will know that, in India, we have large joint families. Parents-in-law, uncles, aunts, grandparents, all live together. It is a tradition we love. In a typical home, the mother-in-law dominates. The son would have to have complete obeisance to his mother - her word is law! **We can never change age-old traditions that have existed in India for centuries. Rehabilitation can only be considered within this set-up and worked out within the system.**

While observing and assessing the needs of the family, we must never forget that parents are in a state of rude shock about their child; it is a time of acute crisis when they learn that their child is handicapped for life. As a well-known paediatrician has said, they are our "primary patients". They need immediate care and attention.
Sensitivity, understanding and kindness are vital ingredients to be added to specialisation. The aura of professionalism must be discarded when one is face to face with suffering. I am sorry to say that, in the early seventies, this attitude to parents was completely new.

After battling for over a decade, we have managed to get our children very young. Pam Stretch, my deputy from U.K., who has pioneered services in India for eighteen years, is able to evaluate children from as early as two months. Dr. Vojta and his team have come from Germany and have helped train our therapists to diagnose developmental delays at a very early and difficult stage. Infants are referred to me for educational evaluation from around one - two years. They then go through an intensive home management programme and, later, through a pre-school programme after which they are admitted to a regular nursery class by the age of one and a half years.

CENTRE FOR TREATMENT AND SPECIAL EDUCATION

For treatment and education, an eclectic approach is used. Bobath, Vojta, modified Peto, all have their place in our treatment plans, plus modified Vojta which Pam Stretch and her team are researching. This they call Intrinsic Development or I.D.

Research shows that it is children with neurological disorders who tend to suffer more from perceptual motor/visual-spacial problems which affect academic performance in later years.
Perceptuo-motor remediation, based on various exponents like Brereton, Frostig, Kephart et al, is done by the teacher and therapist together in the early years (0 to 5) as a preventive method.

We know that many spastic children may not be able to hold a pencil and write, so the educational technology used to break communication barriers in the classroom is cost effective, such as rubber stamps, BLISS charts, magnetic boards and flash cards, or more expensive, like electronic pointers, manual, electric and electronic typewriters. The curricula and syllabi are geared to Indian needs. The Centre is officially recognised under the Board of Education, Maharashtra. Recently, ten of our students have obtained their Bachelor of Arts degrees, showing that the system has worked.

POST-GRADUATE TRAINING

Post-graduate courses for teachers and therapists from all over India were set up soon after the schools. Consultants from U.K. Leslie Gardner, Klaus Wedell, Sophie Levitt and many others lectured and helped to make it on par with western models, again geared to Indian needs. The main idea behind the training was to decentralise services and professionalise special education and I think we've achieved this. To date, more than three hundred specialists have been trained all over the country, helping considerably in the spread of knowledge and services.

VOCATIONAL REHABILITATION

Vocational rehabilitation begins from the age of 13-15 for children from the non-academic streams. They move into a pre-vocational programme and, later, into the Work Training Units. We have been functioning from sheds and porta-cabins, but now our employment centre - a joint

venture between us, the Spastics Society U.K. and C.E.C., Brussels, is ready.
This project is called the National Job Development Centre, and the main thrust is to set up a model of employment in the rural and district areas which can be replicated on a national level.

The National Job Development Centre has been a collaborative effort between the Spastics Society of India, the National Institute for Disability, Research and Rehabilitation, U.S.A. and the Government of India. It was initiated as a research project to provide professional back-up services to people with disabilities, to their potential employers and for an efficient follow-up system to mainstream them into the society.

After three years, we have now moved away from this tripartite arrangement and are now totally autonomous, being maintained by the Spastics Society of India.

RESEARCH

Research into low-cost aids goes on, as we work closely with young brains from technical institutes, devising appropriate technology and inventing indigenous aids. The Research Department also indicates to us where new services are needed. A survey of 10,000 families gave us stunning results, that sixty-three percent of handicapped children come from very poor families and that the family's net income is less than one thousand rupees.

REHABILITATION IN THE SLUMS

Research also showed that the largest concentration of handicap is in the slums. Therefore we moved our work into Asia's largest slum, a place called Dharavi, made up of a migrant population, diverse backgrounds, religions and caste, all crammed together in sub-human conditions - no hygiene, no sanitation, and rampant with disease and sickness.

In this slum background of thieving, fighting, gambling, and stark cruelty, lies our handicapped child. We had to establish a rapport with the slum lords or dadas to reach the families. It's a very difficult scene to work with, the slum culture. Its rules had to be understood before we could begin our work or before we were accepted.

Most crucial of all, our studies have shown that poverty is closely related to disability; the majority of the people we serve are the poorest of the poor.

RURAL REHABILITATION.

Our studies show that services for the multiply handicapped get even more complicated in the rural set up. In the rural areas, casteism still rears its ugly head. For instance, leather cannot be touched by the Brahmin or the higher castes, but only the lowest caste or the chandals could work on it.

We have learnt that the person's entire world cannot be changed just because he is handicapped, rather that the attitude to his handicap may urgently need a change. Acceptance and tolerance are essential keynote qualities we have to develop towards a community's attitudes, if we wish to serve the disabled in the remote corners of India.

An important lesson,in our philosophy of service and professionalism, that I have learnt from my involvement is that it is crucial to make the handicapped, however rich or poor, feel emotionally and socially strong. They will always need determination, grit and moral stamina, to face up to the lifelong battle of not only a chronic handicap, but the social handicaps of poverty, illiteracy and the stigma attached by the community.

A famous spastic who became a doctor - Earl Carlson - said, "Success depends not on what you lack, but what best use you make of what you have." Religious and moral studies and extra-curricular activities are an essential part of our curriculum. Children excel in painting, drama, music, singing, arts and crafts, swimming, etc. All this helps to build up their self-esteem, courage and confidence.
Leo Tolstoy once said, "The most important thing in life is to love life, to love it even if one suffers, because life is ALL, Life is God and to love life means to love God".

This element of love is what I find runs through India, rich or poor, high or low. This makes our services different.

I have travelled extensively and seen some of the best centres in the world, with specialists and hi-technology aids, but often what is lacking is not money, but emotion.

Human suffering needs a large dose of nurturing through love and affection, to build up self-confidence and to rise up to the struggle for better understanding. Emotion, is essential in the rehabilitation process and, most important, is the grass-root contact between patient and specialist.

"To love means to serve and sacrifice" said one of our sages. Another strong element that runs through the services is a spiritual feeling.

Specialists work for a pittance. They feel strongly about the spirit of service, as if service is their religion.

Hundreds have come forward to serve and sacrifice for the cause of the handicapped, hundreds more will, I am sure. Services such as the one I have described are now available in all major cities.

It may be years before India's disabled are accepted as citizens with their own rights and needs. However, we have brought the handicapped out of institutions, hospitals, bedrooms and slums and humanised them, shown them as people.... people who can think, laugh, cry who feel sorrow, pain and, above all, joy - just like you and me.

The road ahead may be stormy, tempestuous and we have miles to go, but as Confucius said...."a journey of a thousand miles begins with one single step...".

I think we've taken that important step, in India.

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