



### **When patients play the role of Health Educators**

The process of drastic change in the values and beliefs commences with helping the individual in questioning his/her views on others reflected in their own behaviour.

The basic task of re-education can be viewed as one which brings about change in the individual's or the group's social perception. Only by such change in social perception, can any change in the individual's or the group's action be realised. How does one bring about change in social perception? Has the patient have any role to play in the change process?

A process of development of a positive self-image for the patient has to be initiated. Cleanliness, personal hygiene and respect-evoking social conduct of the patient will be the major plank for evoking responsive, dignified treatment from the non-patient/general community. Selected patients can play the role of "Health Educators" amongst the small neighbourhood groups through narrating their own experiences. They can even play the 'Physiotherapy-practical-demonstrator' role. On the strength of their own experiences, they can address patients far more effectively than even the field workers. This will be possible because of the lesser gap between them and their patient community. As they are amongst the patients and the local communities, a sense of self-awareness can be brought in the overall patient community. They can bring about a conviction that disabilities caused by anaesthesia can be controlled through self-care and that rooting of disability cure methods in 'self-care' lessens the anxieties of the system about the patients.

Community's active support, and patients' convictions about the scope for control of disabilities, would bring a new assurance of fear-free social existence. The new awareness about dissociation of infectivity risk from the patient coupled with his 'clean' image and self-assurance filled social behaviour, further reinforces the responsive social environment. It's like a therapy practised on the local communities by the changed social perception of the disease, devoid of its traditionally associated dread. In the process, the patient in his 'new garb' almost plays the 'Social Therapist'.

This process of 'reinforced assurance', even when leprosy is yet to be eradicated, perhaps, underlines the presence of a new sense of 'belongingness' in the community. This process of belongingness is related to the principle of in-grouping. The principle of in-grouping makes understandable why complete acceptance of previously rejected facts can be achieved best through the discovery of these facts by the group members themselves. Then and only then, do the facts become really their facts. The importance of this fact finding process for the group by the group itself, has been recently emphasised with reference to re-education in several fields.

***The Union Cabinet has approved a National Policy for Disabled People at a meeting presided over by Prime Minister Manmohan Singh.***

Sharing this information with the media, Information and Broadcasting Minister Priya Ranjan Dasmunsi told reporters on 23 December that: "The National Policy for Disabled People aims to set up mechanisms for promotion and protection of rights of persons with disabilities and provide them equal opportunity to participate fully in the society. This will also enhance their dignity and self-respect."

It will provide guidance to central government ministries, state governments, NGOs and other stakeholders for taking up programmes for persons with disabilities," the Minister was quoted as saying.

The announcement came as a surprise to the disability leaders and representatives who were expecting the final draft of the National Policy to be shared with them as per the promise made by the then Joint Secretary, Jayati Chandra, at the culmination of the National Consultation in New Delhi.

We spoke to Director, Ministry of Social Justice and Empowerment (M.S.J.E.), Asish Kumar, and quizzed him about the said promise and when would the National Policy be made public.

"The feedback that was received from all quarters, individuals and organisations, was placed before the committee and as much as was possible was incorporated in the National Policy before finalising it. The Minister, Miera Kumar, will make a formal announcement soon," he said.

The disability sector is now anxious to study the contents of this National Policy that will not only have a direct bearing on the lives of approximately 70 million disabled people but will also fundamentally determine the course of future interventions.

It needs to be mentioned here that it was only after an intense media campaign and outcry by Disabled Rights Group (D.R.G.) and others in the disability sector on the lack of participation by persons with disabilities and Disabled Peoples' Organisations that M.S.J.E. had held a daylong National Consultation on the Draft National Policy for Persons with Disabilities. At the National Consultation meeting D.R.G. had expressed strong objection to the top-down approach taken in formulating the Draft which is a violation of the mandate of Biwako Millennium Framework.

● ————— ●

***What lies behind us and what lies before us are  
Tiny matters compared to what lies within us.***  
**Ralph Waldo Emerson**

● ————— ●

## DTST West Bengal - A Summary Report

*Dr. P. K. Mitra, DTST co-ordinator, West Bengal*

- Ø In the month of November & December, 05 Intensified Supervision was taken up in all districts. This actually started along with BLAC II.
- Ø DNT & DTST of one district was moved to another district for the Supervision.
- Ø Supervision was done on training status, record keeping & reporting, Validation of cases, IEC activities & MDT Management.
- Ø Supervision pointed out irregularities in records in some places and was corrected.
- Ø Validation cleared nearly 4,000 cases.
- Ø State level Officers visited 3 (three) division of the State. Dr. Diresh Chakraborty, DDHS for Presidency Division, Dr. Mitra for Burdwan Division & Dr. Thakor for Jalpaiguri Division. SLO Supervised all over the State.
- Ø Special IEC Campaign for 3 days was done in Jalpaiguri, Malda & North Dinajpur by GLRA & District Health Infrastructure.
- Ø Orientation Training for BPHN/PHN was organized in the districts for fixation of the responsibilities to look after registers, records, MDT stock, absentee tracing.
- Ø One day Workshop is planned in January, 06 for DNT & DTST to review the performances and to prepare Action Plan for 2006-2007.

### Daily wage earner develops special cane for visually impaired users

A daily wage earner in a confectionery-making unit in Tuticorin district of Tamil Nadu has developed a special cane for visually handicapped users. It has two battery cells and makes different sounds.

Anandan, a 'mithai master' in Kulasekharapatnam, who displayed the special cane fitted with a wheel at the bottom, at a seminar on 'Innovations for human development,' told PTI that a specially fitted three-foot aerial in the cane vibrates whenever the user comes across any obstacle. Anandan said he became upset when he saw a blind man falling into a pit and struggling to regain control. From then on, he started work on developing a stick which would be useful for visually impaired users. He had first made a cane with seven wheels, making different sounds when it dashed against stones or other obstacles. However, weighing in at about 24 kg, that was a very heavy cane to carry around. Then he developed the new 1.3 kg stick, fitted with an earphone, toy car motor and a bell, by which the user can identify pits and other obstacles, he said.

*-Jayanth Kumar, CBR Coordinator*

#### Information helpline and Legal cell for people with disabilities

VOICES information centre **25213903** will offer free legal advice on every Thursday between 4:00 pm and 6:00 pm at its office. And A Daily Helpline for People with Disabilities from Monday to Friday (10 am – 5 pm) at No 165, 9th Cross, Indiranagar First Stage, Bangalore - 560038. For details, please dial **25213903**.

**Children play an important role in inclusion!!** - Extract from the online Newsletter from *eyeway.org* authored by Priti Monga, P.R. Officer at Shroff Charity Eye Hospital in Delhi. (In Direct speech)

Dear Readers,

This is a very practical article I was browsing through the online magazine *eyeway.org* Sep-Oct 2005 issue. Briefly it gives the very important message; **"only children can demonstrate inclusive love, unfettered as they are from the conditioning of society, they play a very important role in inclusion"**.

A group of 10 visually impaired children was brought to Shroff Charity Eye Hospital (S.C.E.H.) in Daryaganj, Delhi, for eye check-ups from a school for blind children unescorted. As it was going to take sometime before everyone got their turn, the waiting young patients naturally started to explore their environment.

Soon I heard little gruff sounds, shuffling feet and unsure rattling of the washroom door. As I am blind too, I could understand



the plight of the children groping around. Deciding to help them, I stepped out of my office and put my hand out to push open the bathroom door when a small boy stopped me and told me *'there was someone inside'*. I asked him, "Are you with the group which has come in from the school for the blind? How did you know I was going to push the washroom door open? Can you see a little?" **"Yes, I have come with them. I am sighted and am not a student there,"** he said. **"My friend is one of the students and so I volunteered to come with all of them, to look after them."** Amar, around 10 years of age surprised me as it did not seem that this little fellow could take care of himself, let alone of 10 blind children ranging from 11 to 15 years in age. Our conversation was interrupted by two blind boys wanting to drink water and one more wishing to go to the bathroom. Amar left me rooted to the spot with amazement, and rushed off to execute his duties.

The group stayed at the hospital till 5 in the evening and Amar rushed around busily all day; getting water for some children, taking other to the bathroom, instructing another on how to operate the complicated lock of the bathroom door. He even made sure the gang went to the canteen for lunch. Between his tasks he would chatter and giggle happily with all the waiting blind boys. Amar did not realise he was demonstrating a very important but often forgotten fact. We blind people need help in many of our day-to-day activities but I have seen very few occasions when this assistance is rendered without a fuss. It can only come from children, as they have not yet been conditioned to treat disabled people as objects of pity and dejection. I wish to emphasise the point that inclusion is something we are born with, while exclusion is something that society has developed and nurtured. The day all of us can see this as a fact, we would be living in a completely inclusive society.

TO,



January 2006 / Vol 5.1

## From differentness to Integration

Leprosy as an issue of disease control should not necessarily be handled in an isolated manner but rather should be of fully integrated into the general health services. It is also to be understood that the socio-economic integration of people affected by leprosy be seen in the broader context of community development. We must focus on those characteristics of leprosy affected persons similar to those of others in the community if we are to help reduce the isolation and the differences. Provisions for accessibility to infrastructures like buildings etc, providing loans and the like are indeed necessary but *what is more important is to empower them to better direct their on lives and futures.*



Deformities may occur even after the disease is arrested. Therefore, the strategy against leprosy must include a broad range of activities to promote community education and awareness. Offering a job to a person who has/had leprosy may provide a salary and help to achieve some sense of dignity and worth. But while workmates, family members and the wider society retain their prejudice and aversion to people affected by leprosy the task of eliminating the differentness cannot be achieved and the socio-economic integration remains still farther to achieve. Unlike the treatment of leprosy as a disease which is a medical issue, socio-economic integration of people affected by leprosy into their society is a social issue which requires to form coalitions of different specialists working together to help them to achieve their own goals. Since those goals will vary from individual to individual and from community to community no single strategy can be determined to meet those different needs. Rather we need to focus on ways of empowering people to achieve their own goals.

In the field of socio-economic rehabilitation one needs to be a facilitator rather than a doer and need to acquire skills in listening to and learning from others, to encourage and to counsel rather than just providing services. Apart from being a social issue, socio-economic integration is also a highly political issue. In any country or society when you wish to help a disempowered and dispossessed underclass to achieve its liberation, independence and dignity you may be perceived as a revolutionary and even subversive. You challenge the very assumptions of the entire society with its intolerance of persons with disabilities and its comfortable amnesia about the unseen poverty that is consigned to hidden districts of its cities and rural areas.

Working on behalf of people affected by leprosy should be undertaken with a broad alliance of partners whose goal is to help them acquire a meaningful power to change the socio-economic circumstances of their lives, to dream of a better future and work towards the realisation of that dream.

AMICI DI RAOUL FOLLEREAU

58, 4<sup>th</sup> cross, Kavery Layout, Dharmaram PO, Bangalore-560 029

Tel: 91-80-2553 1264/ 51106294, Tel-fax: 91-80-2552 0630

Email: [aifo@aifoindia.org](mailto:aifo@aifoindia.org)/[aifo@touchtelindia.net](mailto:aifo@touchtelindia.net)

Website: [www.aifoindia.org](http://www.aifoindia.org)

### **Inclusive Education Plan set for launch next year: Arjun Singh**

*News extracts from disability News and Information Service, NCPEDP*

*A National Action Plan for Inclusive Education of Children and Youth with Disability is in its finalisation stage and would be made operational by the next academic year, Human Resource Development Minister Arjun Singh said on the eve of World Disability Day at an award ceremony in the National Capital.*

The minister said the process of consultations with experts, N.G.O.s, disability rights groups and other stakeholders on the action plan was nearing completion. It would be introduced "most likely from the next academic year", he later informed. Currently, the educational needs of children with disabilities are covered either in special schools or integrated mainstream schools.



A cultural presentation underway at WDD celebrations.

While presenting the 'Plan of Action for Inclusive Education of Children and Youth with Disabilities' in the Rajya Sabha on 21 March last, the minister had pointed out that non-specialist schools could be adapted to work with children with disabilities as per the trend worldwide. With the action plan, the Centre expects greater progress in its 'Sarva Shiksha Abhiyan'. It could also help prioritise implementation of three per cent reservation in all institutions receiving funds from the Government for persons with disabilities as provided for by the Persons with Disabilities Act 1995, the minister said.

According to disability rights activists, literacy level among the disabled population is only 49 per cent as against 65 per cent for others. An estimated six to seven per cent of India's population has one or the other form of disability, they say. Singh gave away the seventh N.C.P.E.D.P.-Shell Helen Keller awards to six individuals and four organisations which have contributed positively to the cause of employment for disabled people.

=====



NCPEDP-Shell Helen Keller awardees with HRD Minister Arjun Singh.

The prestigious **Shell Helen Keller Awards** were given away. Arjun Singh, Human Resource Development Minister of India, was the Chief Guest at the awards ceremony held at the Federation House. The winners of this year's Awards include six individuals and four organisations.

*AIFO staff heartily Congratulates Sree Ramanamaharshi Academy for the Blind for bagging this award*

**AIFO International Biannual Meeting and IEC Workshop**  
*(Held at Rome Italy from 22nd to 28th Oct 2005) - By Jayanth Y.B., CBR coordinator*

A week long programme was divided in to 2 parts; first was the AIFO international congress for 2 days and second was the IEC workshop for 4 days. Both the events focused on the important issues of volunteerism, civilisation, IEC and community sensitive issues. Many individuals and organisational representatives across the world have exchanged their views on the given subjects. Mr. Jose AIFO India representative, Dr. Daisy, Dr. Manimozhi and a group of experts also shared their experiences in both the events.

Evolution of volunteerism, philosophical values and civilization of man-kind are some of the areas focused during the first meeting. Mr. Jose also shared his experiences of serving the poor as a volunteer for nearly 2 decades. He highlighted the joy of the poor with an example of a CP child provided with a special chair and when ever he does something for the needy people. The second meeting was the IEC workshop where several sensitive issues have been presented and discussed with IEC has a main focus at work. Dr. Manimozhi facilitated different sessions on IEC by introducing the subject. CBR-sexuality, advocacy, domestic violence are some of the areas covered during the workshop. Mr. Jose and Mr. Jayanth presented a paper on CBR and sexuality. On the last day, Participants from respective countries prepared an outline of the action plan focusing on the needs of their particular region.

It was an interesting experience to learn more about sensitive issues of community and volunteerism at work. This opportunity has increased my knowledge about the subjects which we discussed in the workshop. Being a developmental professional in the field, I have broadened my developmental concept, philosophical values, principles and its essence in the third world countries. It was a good exposure for me where the international organisations focused their attention on the issues concerning national developmental programmes in the developing countries. Especially, when the resources are minimum and are not fully utilised in such countries for the development of the poor and people with marginalisation. In the process of 6 days, several concerned issues were presented by various experienced facilitators from different parts of the world and deliberated in depth. This kind of exposures will become adding strength to my profession and will improve my capacity at work. Thanks to AIFO for giving me such an opportunity, support and encouragement which has increased my confidence.

===== :



*AIFO family congratulates our chairperson, Dr. Daisy for being facilitated Follereau-Damien Award by Circle of solidarity Folereau-Damien during the AIFO-ITALY workshop and Intenaltional conference held at Pescara, Italy in October 2005 . She is the first recipient to be given this award for her outstanding work in the field of leprosy.*

===== :

## **ADOR - Making its presence felt**

*Brief report of Assisi Deepti Organization for Rehabilitation, Raichur*

ADOR, started in 2002 has so far surveyed 160 villages, has identified nearly 2449 PWD's and PAL's. The project is also taking care of the medications of PALs in a Leprosy colony in the target area. Through these three years, project has conducted various activities to uplift the rights of the PWD's and PAL's. The project conducts awareness programmes in the Schools, Community meeting, Parents meetings and regularly counsels PWD's and PAL's and helps them through various means to get integrated into the mainstream society.



The project has formed 12 SHGs of persons with disability and 14 women SHG in various villages and has given them training and helping them to get benefits from other NGO's and through government schemes. Now the SHG members themselves come forward to conduct the awareness programme like Aids day, Womens day, Wall posting etc., The project has conducted different kinds of camps, sports meet, vocational training, motivating the parents of the

children with disability to enrol them to the school, conducting the national celebrations, participating in the taluk and district level meetings and sports programme to provide, motivate and encourage persons with disabilities to have aids and appliances to avoid the secondary deformities. Around 500 people got benefited from the Nutrition and health camps conducted during 2005.

The project has also conducted many integrated programmes for the welfare of PAL'S and PWD'S. Training programmes were organized in order to strengthen the women SHG and PWDs groups. Regular meetings were conducted; issues were discussed and facilitated the groups to solve their problems. Six Health camps were organized with the support of village leaders in which around 300 people got benefited. The project has



significantly noticed an attitudinal change in the people. This is strongly felt with mutual understanding and help improving among the persons with disabilities. They are also coming forward to form SHG by themselves, showing keen interest to participate in social activities like competition, celebrations etc., Resources now can be easily mobilized for CBR activities as the Community participation has increased remarkably.

TO,