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Disability and the role of NGOs

Is disability an individual or a social issue? Should decisions on disability be made on the basis of individual need or universal right? The answer to these crucial questions rests in policy planning for disability, the training of professionals, the provision of services and the quality of life for millions of disabled people and of able-bodied people who may acquire disability (due to accidents /natural calamities). At the individual level there is the question of how the disabled person relates to his or her impairment and that is conditioned, by the attitudes of society towards disability generally. Disability, then lies in the eye of the beholder, not in the person with impairment.

Let us illustrate with a simple example. Mr. X becomes physically impaired owing to an unfortunate accident on his way to work. His whole life changes in an instant. Mr. X who was the sole bread winner of the family. He no longer has a job because his employer feels he cannot be productive anymore. His aged parents and wife start resenting what they now perceive as an extra burden. Is this the bleak future that Mr. X can expect?

The NGOs working closely with persons with disabilities know it need not be so. It is accepted that a social infrastructure is needed to complement the inputs to ensure greater efficiency and sustainability. The NGOs strength lies in building these social infrastructures and incorporating community voices. This can happen through awareness programmes that a society can also and should play an important supporting role in his life, in acting as a bridge between the persons with disability and the information framed by policy making bodies regarding the disability and assisting such people to exercise their right through such information. NGOs can make the society understand that physical disability need not in any way impact the performance of the person in any field.

However, as society is composed of people, we also need to understand that society cannot change unless individuals change. A change in consciousness should happen at the individual level, in both disabled people and non-disabled people. This change consists in understanding that the disability is a social/community issue.

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Children Project in Lucknow



The project is being conducted in the State of Uttar Pradesh in India. Most people are poor and illiterate and are unable to send their children to school. This is where AIFO's contribution has brought about a big transformation, especially in the lives of the little ones. With the support of AIFO, at present the project runs 20 Balwadis ("a centre for children") in the villages, with an average attendance of 50 children in each Centre. In reality it serves as a nursery, Kindergarten and pre-primary school. The children's age varies from 3.5 years to 6 years.

There is an animator in-charge of each Balwadi. In the beginning the animator had to go to houses asking the parents to send their children to the centre. Now, most of the parents have seen the improvement the children make and so they willingly send them. The Balwadis takes care of the cleanliness and hygiene of the children, are taught basics of reading, writing and arithmetic according to their age. For the last two years, the report says that the

children excel in the schools in which they join after they leave the Balwadis. The schools are happy to admit children from the centres. Apart from the training, the project also provides nutritional supplement, collaborates with the government staff in facilitating vaccination against measles and chickenpox and administering polio-drops in the surrounding villages.

The balwadis not only serve as an education centre but also play an equally important role as agents of social change. They are successfully able to convince the villagers that a better life is possible inspite of their limitations. The programme also helps in creating awareness about the dangers caused by the social evils like alcoholism, drug addiction etc., in the villages. The project is able to reach out to the community successfully through children and improve the physical, social and intellectual situation with the result that the patents have become more conscious about their duties and responsibilities towards their children as well as to the society.



*From the intelligence that betrays; from the machines that enclaves,
From the money that corrupts; O Lord, deliver LOVE! - Raoul Follereau*

People behind the scene... Mrs Nighat Jabeen

It was always patients, community, MDT, drug logistics, rates, ratio, proportions, reports work, work and only work. For a change this time an interesting feature – an experience of Mrs Nighat Jabeen, wife of Dr. Syed Abid, District Technical Support Team Medical Officer, Bareilly District-UP.

The following excerpts were shared by Mrs. Nighat Jabeen of what she felt to be a DTST doctor's wife. Indeed, for those who work under similar conditions, Dr. Manimozhi says, this is an eye opener!

Mrs. Nighat Jabeen – When I first came across leprosy patients for the first time I was a small kid. It was during a visit to my aunt's place near the Leprosy hospital in Kashmir. The majority of the leprosy patients in the hospital belonged to Leh and Kargil area of Ladakh. They were shifted from Ladakh to Kashmir to prevent them from suffocation due to high altitude and also from unhygienic conditions. Their conditions changed for better and they were permitted to return home. But their relatives turned them back. Their own families refused to accept them. My knowledge of leprosy at that time was limited to patches on the skin and loss of sensitivity. Vivid pictures of patients without fingers or nose painted by my cousin about PALs (people affected with leprosy) ensured that I avoid seeing the patients as far as possible. For me they were what I would have then termed akin to 'Ghosts'.

But all this changed with my marriage to Dr. Syed Abid a doctor with DTST. My experience with PALs began again but this time, on a different light, as I watched my husband work closely with them. Once I was accompanying him in the field when he was on training with Dr. S.N. Khan in Bareilly. It was totally a new experience. That day I saw more of the patients closely. I realized they were not ghosts. In fact they are as human as you and me. They are our own people suffering from a disease compounded by the fact that they had to face the additional burden of rejection from their own society.

That is not all. There is much more being to apart from gaining more understanding of the world and humanity, there is a very personal side of being a DTST doctor's wife. I was brought up in a nuclear family. My father, after returning from his job had time to spend with his family and was very caring towards my mother. An individual's thoughts, attitudes and perception, all are influenced by the atmosphere in which one lives. So I as an individual expected the same from my marriage. Things are always different for different people. I have never been alone for a single night before my marriage. I never imagined being alone for a week. But some things are always beyond imagination. He was always on his tour. Even if he is at home, he is never empty-handed. He never spares even a holiday. He spreads all his papers in the room. To answer the question mark, felt in my expressions, he would say, "Sweetheart tomorrow is the deadline and it is very urgent."

Days of loneliness when your husband is on tour is one thing. But when the romantic gaze of your husband follows with an exclamation – "I forget to highlight holidays in my Tour Programme", you are brought back to earth with a thud! I can't blame him. He is a kind hearted and supportive person. He is caring but he doesn't have time to care. He is a good professional, dedicated to his work. For a wife can take only second place to **service** and I am proud of it!!

***Kabi Kisi Ko Mukamal Jahan Nahi Milta Kahin Zamin To Kahin Aasmaan Nahi Milta
(It's Difficult to have the Whole World; one should miss either the Earth or the Sky)***

Self Help Groups in Assam



Organising people into Self Help Groups is one of the strategies of this project. The whole process of this project is to involve people for their development, so that people acquire self respect and dignity. There are 10 animators working for formation and monitoring of Self Help Groups. Through out the year, seminars and trainings programmes were conducted at the centre and villages. Cluster meetings were organised in order to make common decision among the Self Help Groups. The project started with 10 Self Help Groups among tribes. But now there are 178 Self Help Groups consisting of 2193 members belonging to the different tribes, castes and religion. As the group is becoming economically strong and organised, the members have started to think about the social evils and threat in their development. For instance, the group members of Self Help Groups have taken many steps to control drinking of alcohol, participated in community decision making, community health, tapping government resources,

making roads and wells, helping in emergency etc. Earlier there was very less communication between different tribes and religion. But now a great understanding and change is seen especially in social occasions and meetings. The majority of Self Help Groups took challenge to redeem the mortgaged land in order to rehabilitate the poor farmers whose land is mortgaged to money lenders or rich people.

As a result, around 100 hectares of land have been redeemed since 1998. An additional impressive note is that the savings made by the groups which are used to give loan amongst the group members who are in need on small interest, the farmers have stopped mortgaging their land for the sake of money. This is the greatest achievement from SHGs as mortgaging of lands has almost come to a nil. The most important factor to note is most loans have been already repaid as the members have grown self-sufficient. Another uniqueness of the SHGs in Assam is 90% of the mortgaged land has been redeemed by the women's group. Now, as the awareness about the benefit of forming the Self Help Groups is spreading across neighbouring villages, people are coming forward to know more about the functioning of SHG and seek help from the existing ones. Now they understand that coming together to form such groups will be the stepping stone for the overall development of the community.

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