

Not “disabled” but “differently abled”

Interview with Andheri-Hilfe Bonn’s long standing partner Professor Prabakar, founder of “Holy Cross Service Society, Tiruchirapalli in India” who is working in the field of Community Based Rehabilitation of disabled people in South India.

Q: Dear Prof. Prabakar, we would like to ask you first to introduce yourself in short: When did you start working with people with disabilities and why? What are the “milestones” of your work?

A: Even though I started my career as Professor of Physics, I become a worker of disabled in the year 1983. I was the Head of the first Masters course in Rehabilitation Science in India and also completed masters in Special Education in USA. The need of developing innovative programs to disabled to match the Indian condition made me to establish an NGO – Holy Cross Service Society, Tiruchirapalli in India. Today we are assisting over 3500 disabled through all models and for all categories of disabled. I planned it in such a way that every two years we add one category of disabled. Thus today we are the only organisation where a parent can walk in and get entire range of services from assessment, to equipment fitting, education, vocational training and rehabilitation. Early childhood education, Integrated Education, Prevention, cure, appliance fitment, vocational training, job placement and family support facilities are now available under one roof. Reaching large number of Rural disabled through variety of community based models, early identification at villages, support services to disabled with family support, home based services to rural autistic, spastic and multi handicapped children are the special mile stones. As recipient of the National award of the Government of India for out standing services to disabled in India, I feel we have not really done much in the field of disabled – but made honest and sincere efforts to reach the un reached and assist those who are in dire need in rural India. In addition we are assisting over 60 NGOs to spread the gospel of love for disabled through professional approach.

Q.: How many people with disabilities do you suppose to live in India today? And which kinds of disabilities are most common? And is it true that about 50 % of them are below the age of 18? If yes, what is the reason?

A.: There are no standard statistics available of the population of disabled in India. But we can state with confidence:

- Not less than 10 million children are disabled and need special care and assistance.
- If we add learning-disabled children, then the number is 40 million children.
- If we take the whole population not less than 80 million are disabled and need help.

The categories can be classified as follows

- Deaf and Mentally retarded will be the highest population. (70 % of disabled population)
- Blind falls next. (15 % of disabled population)
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- Ortho handicapped and Multi handicapped follow. .(15 % of disabled population)

I would put, including learning disabled 50% of disabled population as children. But, if we consider sensory and intellectual disability alone then the number would be around 10 million children, which is about 2.5 % of the population of the children in India. Majority of these children are in villages because 80% of Indian population live in Villages. The pathetic situation is - they have no access of services and hence even though majority can be successful in life they remain uncared for and live in miserable condition.

Q.: Can you describe in short the most common living conditions of people with disabilities in India? Which chances do they have?

A.: Whether it is Rural or Urban location, the situation of disabled in India(except for a small microscopic group living in Urban situation and using all the resources) is very pathetic. I could put three reasons for this:

- a) Parents (even highly educated) are not aware of the possibilities the child has in spite of disability. They go around for cure and do not get proper guidance or counselling (even some people who get it often search for cure so that they need not work hard for long years). So the most important period of the childhood is lost and the children remain incapable.
- b) Considering the large population and minimal resources (money, trained man power etc.) the possibility of extending assistance is very much reduced – and even the minimum resources available go to the urban elite.
- c) Not many efforts were taken to coordinate the various support programs to reach the large rural disabled.

Hence the conditions of the disabled remain static with no real effort on a large scale to reach the disabled in the professional way. Here and there, there are some sincere efforts. But these efforts are very few and do not create a total change. The net result disabled remain a “curse “ to the family.

Q.: In an article here in a German Journal called „Disability and Third World“ there was an article of Ajit K. Dalal, Professor of Psychology at the University of Allahabad. He says: “India has a rich tradition of community care of people with disabilities.” And: “These people were socially and emotionally integrated within the family-fold (of joint families)... Preparations of flower-garlands, playing vocal and instrumental music at religious places and teaching and reciting holy books were some of the jobs in which people with visual impairment could engage. The non-earning members could also find some meaningful role within the family set up...”. On the other hand we often hear that in India people with disabilities are hid by the parents in the house, that they are neglected, both by parents and community. How to understand this discrepancy? Can you also tell us little bit about the influence of the different religions on the attitude towards people with disabilities?

A.: This paper, which you refer, is the experience of few “Lucky” disabled who are getting support from committed agencies who promote community based rehabilitation work. This cannot be generalised. In a country like India with 1000 million population one paper can not generalise success stories of few of us. Yes – India has a tradition to” take care of disabled” but not give them services, so that they become contributing members. Certain States like Gujarat, Karnataka, TamilNadu and part of Maharashtra has more programs of NGOs working through CBR. But in North and many parts of India, not much has been done to the disabled. Since the community and parents have no access of support services, they do not know how to help the disabled. The ignorance of the parents, inability of the professional workers to reach rural disabled, non planning of resources utilisation to assist Rural disabled have caused the parents to ignore the disabled. The religion has its good and other influences. It helps the family to feed disabled. But they do not help the family to go beyond feeding. There are certain beliefs of cure including “chaining “ the mentally retarded in Temples etc. But these are mostly in rural community and the myths remains strongly embedded in their life.

Q.: In former times the care for people with disabilities was more “charity” like. Since the independence the Indian Government passed different acts and to launched welfare schemes for the people with disabilities. Have these efforts brought about a real change?

A.: There are definitely strong efforts from Government of India such as

- Disability act of 1996
- Scheme of Integrated Education
- Scheme of Education for all (SSA)
- Formation of Rehabilitation council of India

These are policy measures, which indicates that the Government is proactive to the disabled. But, these measures, need to be translated in to action to reach the rural disabled. For this lot of efforts need to be taken, such as allocation of funds for Rural disabled, trained man power in rural locations, involvement of families of rural disabled etc. But not much is done in this direction. So, the present condition is - even though we have made movements in policy we have not achieved much in the real life of the disabled. But one should consider the reality that we have to handle millions of disabled population.

Q.: Since the 80th the Government is more and more involving NGOs in there rehabilitation efforts, probably because they felt that Government alone would never be able to reach the WHO goal: “Health (and rehabilitation) for all by 2000”. Is there a visible advantage of this NGO involvement?

A.: We have crossed the year 2000 and we have not reached even 5 % of the disabled population. NGOs and Inter National NGOs have a big role to play in this scenario this is because NGOs generally prefer to work with un reached and Rural population helping the weaker section. Government is also aware of this. But, unfortunately in India the tie-up between the Government and NGOs is very loose and really had not taken deep roots. There are several reasons for this. Government is clear that the role of NGOs in these welfare sectors and the health sector cannot be undermined. But there is a big gap between NGOs sector and the Government. The success of support to the disabled population will be high if Government takes a active role in promoting services to the disabled through well structured programs of NGOs. Definitely there is a big advantage when NGOs and Government work together. But the ground reality is NGOs have to survive and assist the disabled in spite of several challenges.

Q.: Do you agree on reports that there have been no polio cases at all for the fast few years? If yes, how could this extraordinary result be achieved?

A.: The polio is nearly eradicated in India. We have not seen many cases. To consider India has eradicated polio, it needs to prove for several years there are no polio cases. In our location we have not identified even one polio case for the past few years. This is possible because of vaccine and it is only a prevention work to be done only two times a year with all resources. We should be proud that the Polio Plus program was sponsored and supported by International NGOs and implemented by Government through all its resources including NGO sectors. This is a great achievement and shows when united together, great results can be achieved.

But, services to the disabled require long term support, trained manpower, resources and a good plan. To achieve this we have to focus our attention to start with what we can achieve and then build it to reach large population. This fundamental difference between one time support using all resources and long term support using available resources should be kept in

mind when plans for assisting disabled are designed. The International NGOs and World Community has an important role to play to help the disabled of the developing countries.

Q.: For the past two decades the CBR-programmes have been increasingly popular. Please explain in short what is special in this kind of programmes.

A.: CBR programs have several interesting components when implemented properly . It is one model which can assure results, when the implementing NGO do it in a professional way with proper trained workers. This concept has several inherent advantages embedded in the model. But the implementing NGO should believe that CBR is not charities work or onetime help to disabled. It is a structured professional approach. In this approach

- The program is implemented in the community and family. So, the family and community take responsibility.
- The village worker hails from the community and is appropriately trained to meet the needs of the rural disabled.
- The community resources are fully utilised.
- The disabled is the part of the community and family and hence learn to live with in the community life.
- There is a support team, which ensures support to the family, community, disabled and the village worker.
- The disabled is rehabilitated with in the needs of the community and hence the cost is less and the result is better.
- Even after the withdrawal of the supportive agencies, the disabled will continue to get assistance from the worker as well as family.
- It is a low cost, high effective approach.

But the problem is many of the implementing NGOs implement CBR as a supplement to some other activity (such as rural development, health care etc.) and not as a planned program for the disabled. In such a case CBR will also may not yield good results.

Q.: You say that family and community have to be actively involved. However, very often the community – and even more the family - holds a fatalistic and negative attitude. They consider disability as “karma”. That is of course a potential barrier in planning and implementation of CBR programmes. How can such negative perceptions and attitudes be changed?

A.: Yes, It is a big challenge – but we can with our professional expertise and sincere efforts can change the situation. It may be difficult in the beginning. Once we show the results with the participating disabled and family, others will come to us for help. When I started CBR about 18 years before I have to convince the parents. But today, I do not have to do anything to convince parents as either they come because they want their children also to profit or other parents who have successful participation, counsel and guide the reluctant parents. It is only a

problem in the beginning and it is not a big barrier. In my perception this problem is never a major constraint.

Q.: The attitude of family members and community is mostly: The people with disabilities can do nothing. In a good CBR Programme the focus shifts from “disability to ability”, i.e. to make evident what people with disabilities can do. How can the family members and people with disabilities understand that in the beginning, when you try to persuade them to participate in such a programme?

A.: There are several approaches to this issue. I can share few of them here.

- a) Making successful disabled to come and talk to the community and parents.
- b) Making the parents of the successful disabled children to share their experience
- c) To conduct ability exhibition on cultural programs showing the ability of the successful children.
- d) Demonstrating with in a community with cooperative parents what the intervention can achieve to the disabled.
- e) Demonstrating how a surgery can make a disabled to walk, who was not able to walk before surgery.
- f) Involving and ensuring the community leaders understand the ability of the children, so that they communicate to others.
- g) Using local schoolteachers and inviting them to workshops, seminars etc. and showing them how disabled could be successful when trained by demonstrating abilities of disabled. They become our promoters.

There are many methods suitable to the location and community. A trained village worker knows how to handle this. Training to the village worker is the most important component of CBR. The success and failure of CBR to a grater extend depends on the village worker who needs proper training. This year for the first time in India we are offering one-year diploma course on CBR for village workers affiliated to Barathidasan University, Tiruchirapalli, India.

Q.: Still disability is often accepted as “karma. Do you agree however to the surveys, speaking of 80-85 % avoidable cases? How do you make people understand that most cases could be prevented by better hygiene, nutrition, early detection and treatment?

A.: The success stories of prevention can be understood from the fact that blindness and orthopaedic conditions, which are the large population of disabled, a decade ago, is now under control. This is because both are preventable by medicine, in case of polio the vaccine helps and in the case of Vitamin A deficiency (which is the cause of blindness in large number) a capsule can assist.

We have now completed a study with WHO on prevention of Hearing impairment. This disability can be prevented only when the parents and community are aware of the ear

problem and approach for help from ENT surgeons on a long-term basis. This means we need the CBR worker to understand concepts of prevention and continue to guide the rural children and parents to seek help. There is another problem in this – there are no ENT surgeons to assist rural population in villages. So, prevention of hearing impairment is again a planned effort requiring continuous follow up work.

Regarding mental retardation not much is known on prevention. There is no one model available, which will ensure prevention. Lot of researches are happening around the world to know the cause correctly so that it can be prevented.

In the case of learning disability, only, recently researches have identified the part of the brain, which gets disturbed; even this is not yet confirmed. And the researches have indicated another few years to know the real cause of this problem or how this problem affects the brain functioning.

So, prevention of these disabilities need sustained efforts from all concerned.

Q.: A CBR programme tries to reach different target groups:

- **the people with disabilities themselves**
- **the family members**
- **the community/the public**
- **the politicians**

Do you need highly qualified staff members for the various tasks?

A.: Definitely not. CBR is a team effort. It includes a village worker who is appropriately trained to do all the activities with in the community. There are occasions he needs help, such as for assessment, appliance fitment, meeting the community leaders, training the regular teachers etc. Hence he needs a support team. This support team is a professionally qualified group and assist the CBR worker only when he needs. In other words professional experts at the time of need, who are located in a neighbour hood city or town, constantly support the CBR workers. These professional experts can assist a large population of disabled through well-trained CBR workers. This structure has to be understood by the implementing agency.

Q.: The people with disabilities probably need support – in some way or other – their whole life long. The staff members of a CBR programme however cannot be there forever. How is the sustainability of a CBR-programme guaranteed?

A.: CBR – the term itself talks of sustainability. When the program is community based, it means it is family centred. The family is the core of the rehabilitation plan. The CBR worker also comes from the same village or community. So, the worker remains there, but not as a paid worker. The family is trained on a day-to-day basis and over a period of time understands how to assist and live with disabled. The community opens its resources for the disabled to live and also if possible to earn his living. Once the disabled is in the family and community, the support for his sustainability is ensured. This means the CBR sustainability is

ensured. It is the principle in which the “ program” may end but the “support” to the disabled remain the same. That is the greatest advantage of CBR. Again the success of this concept depends purely on CBR worker and the implementing agency.

Q.: Do you see any efforts of the people with disabilities to organise themselves in interest groups?

A: Yes. Here and there we see some results. The blind and orthopaedic handicapped have well organised groups – but mainly in big cities. The rural disabled are always left out. Now the CBR makes effort to develop village level groups of disabled so that they could demand their rights. Parents are also included in this group. But this is only in the beginning stage. This has to be done with more sincere conscious efforts.

Q.: What is your impression: Is there a change in the general attitude of the public towards people with disabilities? If you get local support today, is it still based on the attitude of “charity”?

The attitude of the public is slowly changing – but it is a very slow change. In India even those who want to help the disabled always want to give “food” to the disabled as a charity – as this charity which is called “anna dhanam” (meaning charity food) will help them to get God’s blessings. Our local support to a greater extent is based on the attitude of charity.

We have written several articles in the Newspapers of the success of disabled children. These articles are being well read and appreciated. But, when it comes to the support the charity aspect plays an important role.

Q.: You personally spend that much time and energy on working with people with disabilities. That requires a lot of understanding from your family. But it seems that they do fully support you. If that is not a too personal question: Would you like to say in which way your family just recently supported your work on a very special occasion?

A.: In 1983, when I decided to shift my career from that of Professor of Physics to a worker of disabled - it was a tough decision. both financially and professionally. But my wife Prema with two young children decided that I should go in this line in spite of several challenges. In the year 2000 when both my children completed their education, my wife Prema also left her job as coordinator of the Computer Science Department of a prestigious college and had joined me to develop computer training for disabled and to develop software for the disabled. My son who recently got married donated nearly Rs. 100,000/-, which he received as gift for his marriage to establish a trust to be run by seven women, to help the education of the poor disabled children. These are small contributions in my work life. I am so grateful to you for this question, which helped me to think thankfully the contribution of my family in this noble cause. My recently married daughter-in-law who comes from Canada brought about 100 dresses from her friends to be distributed to the Village rural children. I am happy she is now part of our commitment to the work of disabled.

Q.: Can you please be so kind to let us have two or three case studies of how children with disabilities have developed thanks to a CBR programme or also of how a community has really taken up the responsibility?

I am presenting here four case studies.

1. **Amalraj:** When I first saw Amalraj in a small village near Lalgudi I was shocked. He was tied in a cow shed along with the cow and was there for nearly 6 years. His mother a widow is so poor can accommodate the child only in the shed. Since he is a spastic child with mental retardation, and with no skills of living, the mother could not keep the child in the thatched shed of her house, which is just 100sq. Feet, she kept the child in the cowshed. To prevent him from running she has to tie him. Amalraj can make only one sound namely the sound of the cow, which he hears all the day. The mother did the best to him – as she has to work every day earn feed this child and also another girl child. When I asked the mother what she expects from me – her answer was very simple: teach my child to dress and undress, as he is now naked it hurts me. The demand is so simple. But it is a major task. I do not know what to do – as this happened in the year 1985 when I started my work. But this taught me a new concept – the concept of Community based rehabilitation. I took three experts to visit the child - and all of them said nothing could be done. In one of my visit I met the girl in the next house who was observing me with inquisitiveness. I asked her whether she would like to help Amalraj. She said yes, but also said; I do not know how to do it. I taught her how to teach living skills to a special child. This girl who was educated upto 10th grade could achieve the request of the mother of Amalraj namely teaching him toilet skills and helping him to dress, in less than 6 months. Well, I learned that to help a disabled person what we need first is willingness and mind and then to use the brain. I also learned community and resources in community can be very helpful if we look at them as assets.

The story does not end here. I left the village after training the child. Six years later the mother of the child visited me in my office. She passed the message that Amalraj passed away peacefully. She came to thank me and said I am grateful because my son lived as a human being and died as a human being and not as an animal. Even after 18 years I could recall every moment of my work with this child – especially that was the period I have no idea what spastic is and mental retardation is. I learned the basics – the needs of the individual child will decide the intervention strategy.

2. **Vincent:** Vincent is a low vision boy who was sent out of the School by the teachers when he was studying 3rd grade. When I first saw him in his house he was so angry with me because he thought I came to admit him in a school for the blind. He said I am not blind and I will not study in the school for the blind. I have to explain to him that I am

admitting him only in the general school. That is the time I was promoting Integrated Education for the blind.

Vincent till today considers himself only as sighted and not as blind. He joined third grade and studied in the village school at Vadugarpet, where I established the first program of Integrated Education. Today he is doing final year in the law school competing with sighted peers. He had scored high marks and aims to become a politician. He feels law degree will help him to establish private practice and also in his role of political activist. He wants to work for disabled by becoming a political leader as he thinks political leadership can bring quick changes in the life of disabled. We are still supporting him for education. I learned from Vincent that the individual need of the child is the most important factor in deciding the period of intervention services to the disabled. He is a good orator and a very committed individual. He is now a young man with full of hope.

3. Mani and Dhanam: These two children are brother and sister belonging to a small village – Thoppur. The parents never cared for the children, as they are deaf and mute. Their uneducated grandmother who goes to the shandy (village market place in different locations) every day and sell vegetable to earn her living is the only support to them. This place is nearly 90KM away from my office. One day the grandmother brought the two children to my room and demanded support for the children. She demonstrated that her children could speak up to 20 words. She could not accept a “no” from me, as I explained to her I have no access to that village which is far away from my place. Since she is not accepting my “no” I gave her an other option to find a girl with 10th grade in her village who could come to my place stay with us and under go training to teach deaf children. I thought this might not be possible considering the social and cultural conditions of villages. But in two days, she brought a girl “Selvamani” who becomes the first worker of a structured program of CBR for Deaf. This worker did such a good job, many parents came forward to seek services and today this location namely “Mohanur” has become a strong unit of CBR programs. Local community leaders seeing the results have formed a local society to support this work. CBR for deaf is now a reality and this experience is now spread to so many parts of India. I learned the basics – Community Resources and Family support is the core of CBR work. An appropriately trained village worker can make deep inroads in community and can change the life of disabled.

Mani and Dhanam are now vocationally trained and are working in the village. Both of them are now married and settled. The parents are now happy. The grandmother is still alive and is so proud of her grand children.

4. Akila: When we met Akila she was 17 years and was in the wheel chair , need to be carried to every place. She had a loving brother who worked as a daily wage earner and also looked after her. She studied upto 10th grade inspite of the severe orthopaedic condition.

We took her to our doctor for assessment. He said we can make efforts for cure through

surgery – but then the girl needs a minimum of three surgeries with painful follow up and such surgeries cannot guarantee results. He also said it may take several months of treatment. Both Akila and her family were prepared to under go this difficult intervention. The brother also agreed to pay up to 50% of the cost through his earning.

Akila underwent the surgeries, took the suffering with cheer and today she can walk on her own. She had taken a decision to spend her life to the cause of disabled. She joined our “Holy Cross Service Society “as worker for mentally retarded children and is now a full time worker for them.

We learned the simple fact of life – when we work for the cause of disabled, the disabled can join us to liberate them from the challenges of disability. The disabled are the partners in our work and the family is the core of CBR work.

Q.: What is most important for the future in order to change the situation of people with disabilities in India for the better?

A.: Many things should happen. But the first priority is developing quality professional workers who will work with rural disabled. This means we should develop many one year or 6 months training programs for the rural workers of the disabled. When we have sufficient trained workers they can bring a change in the life of disabled which can have a chain reaction and ensure more rural disabled get services.

In my feeling the international NGOs have a big role to play in Indian situation. This is because the rural disabled will remain isolated from many of the Government plans – as they do not have accessibility to big cities and higher officials. This is a natural condition in any country, which has millions of disabled. INGO should make policy decision that at least 80% of their grants should be used only for rural disabled. In such a case INGO and NGO network and linkages can reach un-reached population of disabled in rural parts of India and hence together become a strong pressure group to promote the needs of rural disabled in Government programs.

The training of parents and effective use of them as “teachers at home” can yield good results. The professionals should consider parent as support group and not as recipient of services alone. This concept of parent and professional working together can yield good results. One should move towards this.

The networking of NGOs for sharing of information and experiences should be strengthened. NGOs should consider their role as promoters of concept and then share their experiences to others so that the programs are replicated.

We should aim at developing at least one full pledged training institute to train grass root level workers of disabled in a highly professional way. This institute can be a model institute and can guide establishment of training programs for other regions. When we have good qualified workers to help rural disabled, we can be sure the services will be of good quality and hence will be replicated.

Finally I would like to thank you, Madam Elvira and all the friends of Andheri-Hilfe Bonn for the kind support to our cause. I am grateful, you have asked me to respond to the various questions.

In this occasion, I recall with gratitude, Madam Gollmann, who was a great source of inspiration to me. Andheri-Hilfe Bonn helped me to move to work for all categories of disabled. I am grateful to Andheri-Hilfe for the confidence they had on me. I assure you of my committed efforts to the cause of disabled.

Dear Professor Prabakar. Thank you very much for responding to our questions!

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Andheri-Hilfe Bonn e.V.
Mackestraße 53
D-53119 Bonn
Telefon 02 28 / 67 15 86
Telefax: 02 28 / 68 04 24
andheri.bonn@andheri.org
www.andheri-hilfe.de

Spendenkonto:
Sparkasse Bonn (BLZ 380 500 00) Konto 40 006
Postbank Köln (BLZ 370 100 50) Konto 155 0-505
Sonderkonto Blindenhilfe:
Postbank Köln (BLZ 370 100 50) Konto 135 00-508

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