

Community Health Fellowship Scheme

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# **Field Mentors**

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I dedicate this entire project to my **Parents**, Family members and Friends for their encouragement and support to complete this project.

And in the last I will close this chapter by the words that "if the necessity is the mother of Invention", then "the experience is the mother of memories". And I extremely thankful to all the persons who have directly and indirectly contributed in these experiences, that will be with me in my memory lifelong.

**Juned Kamal** 

# **Executive summery**`

I am quite happy to present this report as a community health fellow of Community Health Cell Bangalore. This report is about my field experience of six months which I spent in different development organizations and groups it is contain my reflection, based on the experience which I got through the field visits and grass root level work experiences in different places.

The contents of the report are Community Based Rehabilitation of Persons with Disability, field experiences in Jan Swasthya Sahyog (JSS), Indian Social Forum, JSA NCC, state level meetings, and AIDAN / MFC meetings. These visits helped me to explore at, different levels and to understand the different dimensions of community, community health and public health. During these six months I got a chance to get exposure in the selection and training of Community Health Volunteers, in JSS. (Chhattisgarh).

Beside these activities my other learning objectives were study of PWD Act 1995, in CBR Forum, and the study on prevalence of scabies in rural Bilaspur District (Chhattisgarh). The study is still in on going and the second part of my study, which is the treatment of scabies in rural areas, will be done by the end of this month (February 2007).

These six months period helped me to learn or thing about national and international issues like globalization, privatization, and market economy, that is directly or indirectly affecting health of the communities and public health services along with the primary care. Essential public health is being privatized. The main objective of these services were to serve the community, but the anti people policy are changing the irrational drug policy, lack of budget for the health and education, corporate led globalization and industrialization, are decreasing the Govt. control over health.

I didn't do many things which I thought I would do, as I got exposure in new areas.

And now at the end of this fellow ship programme, I am confident and have learnt a lot. Every thing that I experienced here brought new learning's for me, perhaps I have gone through was new for me.

# ORENTATION AT THE BEGINNING OF



# First month orientation

First Week :-Form 6<sup>th</sup> to 11 August 2006.

- 1 First learning
- 2 Health
- 3 Community health
- 4 Public health
- 5 Primary health care
- 6 Health situation of India.
- 6 Struggle for Rs. 100/-

Report for the month of August 2006, CHFS orientation.

From 7 Aug. 2006 to 8 sep. 2006

After being selected for the Community Health Internship programme in Community Health Cell Banglore, our first session started at 9:30 am on 7 August 2006. This was the first month, of the six months fellowship programme. During this month we went through the various aspects of Health, Public Health, community health, Primary health care services, the people health movement, and we also went to the field to visit various programmes.

I am starting the very first day of the orientation class. I am including only the important points that I noted during the orientation.

# From 07 to 12 Aug.2006.

The very first day we introduced over selves with each other, and with other CHC team members, with their work responsibilities. The first thing that is used in the social or community work is a team spirit, and to know about others; Sincerity towards learning's it is a process to enhance individual skill, it is a participatory learning method through we share the information. and learn together by discussion in light of own experience. The next day 8 Aug. 2006 after looking back we got introduced to the concept of health. In this session Health, Public health, Community Health, Primary Health Care were discussed with its broader view.

# We learnt that ;

**Health** - is not only the absence of the disease, but well being of social, economical, cultural, political, spiritual, and mental conditions.

**Public Health** – is whatever the services are providing by the govt. like – sanitation, water for daily use, light, housing, safe drinking water, employment, primary health care, etc. are concerned with the public health. This is the prime responsibility of Govt. to assure all of these services for community. It is the organized of a society for health through government, voluntary organiations and civil societies etc.

**Community Health** – is a process to involve the community to take up responsibility in providing services for their own health, and demand health as their fundamental human right.

In this process of Community Health, communities come together, set their priorities, demand for services according priorities, and after getting it, they take the responsibilities to monitoring it. These services could be education, primary health care, agriculture, sanitation, safe drinking water, etc.

**Primary Health Care** – is many peoples, organizations, and institutions were working for primary health care (basic health care) by 1970's, besides the definition of WHO on health after the Alma – Ata the idea of Primary Health Care came as a revolution.

In the Alma - Ata (1978), primary health care defined. It recognized the limitations of medical science and emphasized on the need to address the determinants of health. It emphasized the need for equity and social justice in health and health care services. It emphasized the greater decentralization and involvement of local habitants in decision making, planning, implementation, and monitoring of health care system and services, according to the social economical, political and cultural conditions.

It gave the four key principals

1 Equity – this could be gained through the equal distribution of health resources and services.

- 2 Community participation through community will be responsible for their health, whether it is Public Health or Community Health.
- 3 Intersectoral coordination the different department of govt. that are working in the field of public heath like, NGOs of the developmental field, and other civil societies workers and corporate, will ensure the development through their mutual cooperation and coordination, and these development will be responsible for good health of the community.
- 4 Appropriate technology should be used for the primary health care in place of high and more advanced technology. It should not depend on what we want to provide, but it depends on according to peoples need and priorities, what they want and what will be applicable their.

It was just like a movement to turn medical care into primary health care.

Here are various components of primary health care that try to ensure health for all, by these components up to some extent primary targets could be achieved.

- Education, concerning health problem and about methods of identifying, preventing and controlling them.
- Promotion of food supply and proper nutrition.
- Adequate safe drinking water supply and sanitation.
- Mother and child services.
- Prevention and control over locally epidemic diseases.
- Provision of essential drugs.
- Availability of local health workers.
- Identifications of local health traditions, and locally available herbs and their proper use.

Beside all of these services we should know to whom , we are going to provide these services, so that history of the community and society must be understood, Bharat Darshan by slide show help to understand the various communities of India.

Followings are the learning's

- Bangladesh refugee's camp shows the lack of primary health care services and horrible picture of war and conflicts and its bad effects on human health.

- Gandhi ji's charkha shows that we are all from working class, we have hard work and labor and keep away all the disease away from us.
- Our tribes who are living in the out reach areas are quite near with the nature happy, and healthy them self, they have their own treatment systems with the herbs, but the migration and development are effecting their health and life as well.
- It focuses on primary health care services that should be reach to community according to them. Health for all not only concentrates on primary health care but also consider that social economical, political, and cultural factors in the community are the determinants of health. These factors make us enable to understand the root causes of ill or bad health. It makes us enable to understand medical aspects, under the light of SPEC aspects.

i.e. for the like malaria and other vector borne disease not only mosquitoes are responsible, but our living conditions, sanitation, water, unhygienic food, traditional system, lack of awareness, education migration, etc. all factors are together responsible. So in addition to treat the disease, the treatment of all of above factors is also importent.

These factors were looked in the case of Mahila Jagruth Sangathana, (JMS) Raichure district.

The title of story was **The struggle for Rs.100/-**, this is a responsibility of the govt. by the law and as public health provider to ensure the pension for elder persons of the society. But only to get this help they being exploited automatically, as economically – by traveling many times to complete formalities, and wage loss, politically- by beaurocracy, bribe, by Gender – women are not allowed to go out side alone, giving preference to men, in housing, cant raise voice for their rights, and by culturally – social systems, customs traditions & beliefs etc.

# Health situations in India -

As primary health mentioned before, that it is a fundamental human right and health and Education are the subjects of the state, so that following two things are important –

1\_ Awareness in the community about public health community health and primary health care services

2\_Equity in health

- Health care services should be accessible to all especially to the disadvantaged and marginalized groups of the community
- Applications of resources based on peoples need.
- Reduce the disparity in health and health care services.

- Health care utilization and resource allocation.

Our health care services are getting commercialized and more and more corporate sectors are being involve in health system and making profit, and planning to increase it.

In India	more then 75 % - private health care
	25 % - Govt. Health care

There are only 270 essential drugs declared by WHO, but more then 80,000 brands are available in the market. Too costly, inappropriate, delayed, treatment, essential drugs are not available, if available due to cost not affordable. All these factors are keeping away to health care from the approach of a common man. Health and education budget is continuously being deducted; corporate sectors are looking here the opportunities for the investment. In every time Govt. set the goals

	Programme	Goal
1	Eradication, Polio	2005
2	Eradication – Leprosy	2005
3	Zero level growth of HIV/AIDS	2007
4	TB, Malaria, and other vector born diseases	2010

But since 1982 only some health goals was achieved but a long list of targets are still not achieved. At the time of independence India and China has same economic conditions but after 53 years of independence we find a huge gape in both of the economies, health and development indicators.

In Indian population -

elite	-	65 million
Rich	-	185 million
Climbers	-	250 million
Poor	-	150 million
Destitute	-	200 million

In the morning session of 11 Aug. 2006, that What and Why we are doing? It came out in the discussion that what ever we are doing it has certain values. We brought up and born in the community today what ever we are, it is because everybody is giving his direct or indirect contribution; what ever we get comes from the community. So it is the prime responsibility of every human being to do some constructive work for the community.

In case of the community building community workers should have some skills, such as :

1) Analytical skills

- 2) Listening skills,
- 3) Communication skills
- 4) Facilitating, discussion skills
- 5) Self learning skills
- 6) Organizing and management skills
- 7) Work implementation skills

In the end of the report of this first week following session were very important.

1) Chikanahalli (Game)

2) Ralegan sidhi (case study)

These two taught us about the SPEC determinants, and improved our thinking, about community building, and working in the community with their priorities.

It change the perspective of community workers, it help to make a positive attitude towered the community, and to make ensure their participation to solve their problem according to their priorities.

The five stories of Ralegan sidhi have different perspective of the community it told us about SPEC determinants, women empowerment and some power relationship in the community. Some time when we try to facilitate (training) some of the community member, it could just like giving them some power; at this stage they can use their power for their personal benefits, so that the decentralization of the power is necessary, beside one person many persons in the community should be trained, and their monitoring should must the responsibility of community after. These ensure the community participation, and help to utilize decentralized power, in the context of community health and public health.

**Report for the second week** - (from 14 to 19 Aug. 2006.)

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  - **1.2 Social Exclusion**
  - 1.3 **Rights, Movements and Campaign**
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  - 1.5 Non communicable Diseases
  - 1.6 Peoples Health Movemetn

2 Field Visits

- 1.1 Milana
- 1.2 Mahila Samakhya
- 1.3 Life skills Orientation

# **Orientation :-**

Globalization : - With the start of the week, we went through the 1.1 broader concept of globalization especially corporate led which is increasing the poverty, malnutrition, environmental degradation. pollution, health crisis, and leading to unemployment globally. The wealth of the world population is going in the hand of corporate minorities in the name of so-called development. Community and Public is continue being violated, more and more hospitals are being opened, with expensive medicines and diagnostics systems, high frequency of checkups are putting unnecessary burden on the pocket of a person. Whereas WHO recommended only 270 medicines for saving life. But there are more then 80'000 brands in the market. In the name of Globalization the rich countries of Europe, N. America and Japan and the international financial institutions (IFis) like world Bank and International Monitory Fund (IMF) demand that govt. should cut the expenditure on health care, education, and even food subsidies, along with them Indian multinationals are fielding in India. and demographically being strong,

like –	Reliance Sahara Tata Infosys	-	Bombay, U.P. Buy real state, and finance in various state capitals of India. Orisa, Bhilai - Banglore
	Wipro	-	- Banglore Hyderabad etc.

**1.2** Social exclusion :- several social groups excluded based on cast class, gender, lesbian, gay, Homosexual. They have their own health problems but feared by disclosed identification, keeping them on lagging behind health. Busy social life due to both working partners in the nuclear families in urban areas, have bad effect on mental health of the child.

These challenges can be over come by only community building, and through community building various activities can be carrying out to get the solution of health problems. It must be clear in mind that we are not against the development, but it must not be on the cost of poor people, we can't think tof development with any part of the community. Only together we can realize development.

**1.3.1 Rights** it is defined as certain ideologies and as a institutional mechanism provided by the govt. to protect the freedom of a human being.

Like - human rights, right to health, right to freedom, right to life . Etc.

**1.3.2 Movements** – it is a voice against, and a process of collective work for the rights, it is against injustice, inequality, and could question and protest against whatever is not being good, legal and against the freedom of the community. It not funded, based on local resources, legal, and has a certain ideology. Like Peoples Health Movement, NBA (Narmada Bachao Andolan) etc.

Movement has two methods.

- 1 Direct Dharna, strikes, Media. Etc.
- 2 Indirect Press conferences, distribution of leaflets, opinion generation, research and survey

**1.3.3 Campaign** – it mobilizes to people or community on any certain issue through networking and common interests, it might be funded, or based on local resources. It try to get the attention of the state on behalf of community on certain issues.

Like child rights campaign, reservation issue, etc.

When we talk about health we always think about the treatment of diseases through medicines by doctors. Now what is the present scenario of medicines in the market most of the medicines that are being sold are unnecessary, Before 1975 in India only few medicines were manufactured. But only in 1977 1980 flood of medicine companies became appear. And continue it is growing, as a result of it more then 80,000 branded medicines are in the market.

In the first five years plane India was spending 5.00 % on the health but then 1.8% of total GDP and continue decreasing to 0.9 %. Even primary health centers are not working properly and very essential drugs are not available there. Privatization of public sectors and patent in the health is increasing the cost of very essential medicines. The cost of AIDS (ART) medicine in India is Rs. 8000/- per month, but the same medicine in America is more then \$100000/- per year.

# 1.4 Tuberculosis -

It is the king of diseases and a big and serious matter of public health. During the industrialization of the Europe especially in England peoples became migrate towered cities to work in the industries. They worked there at very low wages in unhygienic living conditions, lack of sanitation, unventilated houses, had made worse to the life of the labor class. Concerning these condition 25 % of the people died when **TB** Begun to go an epidemic, and those man made conditions were responsible for this epidemic

In India 5-7 lakh people are dying due to TB in every year. In the presence of various state and national level **TB** programme. The prevalence of TB is high in young man/ women.the national TB programme (NTP)was introduced in 1962. Because if touch of support to strengthen of primary health care services, the programme implementation hhas no then good. DOTS is the short term six month course for TB treatment, it stand for Directly Observed, Treatment Short Course.

Various programmes have been carried out at national level by the govt. of India. But RNTCP (Revised National TB control Programme) is a revised programme of govt.of India for the **Tuberculosis**.

Diseases are closely linked with the social conditions and to reduce the suffering level is a prime responsibility is the public health system, or with community health workers. The case of AIDS it is going to be an epidemic, and gender is looking a major factor in the prevalence of HIV/AIDS. Women cant negotiate for sex form Husband, Hiv positive person almost neglect by the community assume as a bad character and always abuse by the community, and in the case of women it is worsen. If HIV person died nobody comes to claim his body. Most of the NGOs working in the field of HIV/AIDS are treating only with the biological aspect or only creating awareness but the challenging work is rehabilitation of HIV/AIDS positive person in the community. Public health, NGOs, community health workers, should be responsible for this and on the other side govt.

# 1.5 Non-communicable diseases: -

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In the case of non-communicable disease, heart disease, high blood pressure, cancer, diabetes our so-called development playing a major role in the prevalence of these diseases. Poverty is in the root of all diseases, because due to it they cant fulfills their basic needs like food, water and sanitation, they are help less to live in unhealthy environment and all these together effect to health. So that Health is not related only with the medicines, but, poverty, Gender, communalism, Migration, unemployment, health policies of the State, National, and International are increasing severity of the diseases.

Environment around getting polluted, basic safe and clean drinking water, inequality in the primary health care services, Contaminated food, are the issue of public health, and continue being neglected or hitting by inadequate attention of the State.

Migration is the cause of bad and ill health, western unhealthy, busy life style, inappropriate practices of food habits or lack of nutrition in food system are the issue of community health, and on behalf of public health, Lack of proper planning, and strategy making, do strengthen to the causes of diseases, Like malaria diarrhea, diabetes, and other noncommunicable diseases and disability. Due to development of unsafe industrial practices, and mechanization, is the cause of physical impairment, in the urban and use of machines in agriculture in the rural areas.

### 1.6 PEOPLES HEALTH MOVEMENT

As it mentioned before that movement is based on certain issues and followed by its certain own ideologies, it is same with the *Peoples Health Movement*. It is a result of long struggle of various organization after Alma-Ata in 1978, in Which "*Health For All by 2000 A.D.*" declared.

It is just looks like a second freedom in India as freedom from poverty, diseases hunger unemployment bad living condition, side effects of privatized healthcare which is not affordable by the people. in the long term struggle of various peoples organization various programmes carried out by the **Peoples Heath Movement** and end result of these programmes was the first **Peoples Health Assembly** held in **Kolkatta** form 31<sup>st</sup> November to 1<sup>st</sup> December. Perhaps it was the first peoples health Assembly like its own. In which thousands of peoples got participate and put their problems, experience before the nation. Popularity can be seen that govt. runs the special peoples health trains for this assembly called **Peoples Health Trains**.

To conduct this assembly various programmes conducted during the year by hundreds of national, state regional and local level NGOs, are as follows

- Block level Seminar
- Kala Jathas
- Policy dialogs
- Public hearings
- State level Assemblies
- People's health trainings etc.

### **Objectives** :

- Hear to unheard
- To reinforced the principals of heath as a broad cross cutting issues.
- To develop coopration between concerned Actors or health workers in the field.
- To formulate peoples health charters

In the kolkatta assembly 200 issues, 100 workshops, by different 25 groups in just three days carried out.

PHM gave a new sprite all over the world to the organizations who are working or dedicated towered Peoples Health. It gave strength to slogan health is a human right and we from all over the world are committed to achieve it. PHM changed the biomedical perspective of health into social and said that not only Doctors, Medicines and loose Health Care system, but Social, Economical, Political, Environmental, Cultural War, and Violence conflicts and natural disasters also effecting to the Health of the people. It Demand

- To the community to participate in decision making planning implementation and the monitoring of community health and public health and primary health care services.
- To the Govt. to make the policies and programmes according to need of the community and try to make sure the community participation to strengthen the primary health care system with equity and appropriate technology.

# 2 Field Visits :

**2.1** Milana :- Our field visit in Milana was a new experience for my fellows and me. It was a first time when I was directly interacting with the HIV positive women's. It was a learning for me that women's who are suffering form a disease (HIV/AIDS) fighting against it and not only against disease but also against the social stigma, customs, Traditions and issues like gender, Equity, empowerment, etc. their initiative to work as a peer worker is really a brave step and a example for others who are suffering from such types of diseases.

Milana is working with more then 290 families for the Community Based Rehabilitation of HIV/AIDS patients. This organization is working

As a social support group.

As a Self-Employment training center.

As a Medical care and nutrition center.

Milana is not working only for HIV/AIDS, for the community health it is working as a social support group and conducting various activities for the families of HIV positive peoples and children's for the community based rehabilitation. And in the context of public health they are enforcing to govt. to provide ARV medicines for the HIV/AIDS patients, and provide them nutrition. Some time these ARV medicines given by the hospitals became ineffective and cause of various side effects and disabilities. Like low vision and blindness.

# 2.2 MAHILA SAMAKHYA

It is a govt. supported organization working in the KARNATAKA state. At state level it comes under the department of education; it is funded by the govt. and other funding organizations. It has different programmes for the women empowerment and development, are as follows;

### Economic Development programme :-

Under this programme Sanghas has formed it include 80-90 women's in each and through these sanghas some small savings done, and try to strengthen the sanghas, time to time these sanghas catalyzed by the organization to take up issues concerned with their problems. It at least providing them some space or platform to express them self and to rats some issues related to women empowerment, gender, development, violence, women and child health etc. **Work Area:** - Four districts of **Karnataka**, **RAICHURE,BELGAM**, **KOLAR**, and **GADAR** 

**Core Issues:** -being addressed by the sanghas –Health, Economic Development Programme (EDP),Sanghas sustainability, Justice, Legal Literacy, Panchayatiraj Participation, Reservation etc.

Nari Adalat :- this is a new programme of its kind, this NARI ADALAT conducts on block and district level. The case of NARI ADALAT become done with the consent and discussion of relatives, neighbors and villagers and local leaders of the concerned person

OTHER FEATURES :- MAHILA SAMAKHYA is running Kasturba Gandhi Kanya Balika Vidhyalay. 5000 kishories (girls) has been participated in the various activities of Mahila Samakhya.

# 2.3 LIFE SKILLS ORIENTATION :-

Life skill is a skill to adaptive and positive behaviour, that enables individuals to deal with effectively with the demand and challenges of every day life.

Life skills use as a teaching method in which by the use of the skills various work can be or carried out together and done successfully.

It involves -

- 1 Decision Making
- 2 Problem Solving
- 3 Critical Thinking
- 4 Creative thinking
- 5 And Effective communication
- 6 Problem solving skills
- 7 Self awareness
- 8 Empathy.
- 9 Coping with emotions
- 10 Coping with stress.etc

By the various of life skills like roll play, listening, creative Writing etc. programme can be made according to need.

1 Learning's :- world is progressing continuously, many technologies are being introduced in the continuously and globalization is the mean to spread them. As both side of the coin globalization has the same quality, now its up to us that how we can utilize it maximum for the community building and for health development, as a appropriate technology.

### Third week: - from 22 to 26 AUG. 2006.

# 1 Orientation

- 1.1 Tobacco
- 1.2 Social understandings equations and Health
- 1.3 CHW
- 1.4 Role of the community health
- 2 Field Visits
  - 2.1 Foundation for Revitalization of local Health Traditions (FRLHT)
  - 2.2 Padmasini Asuri

### **Orientation:-**

**1.1 Tobacco:** -Many of the diseases are the cause of the social problems, and same the social, political, environmental, economical, and cultural, problems, produce or cause many diseases. Tobacco is one of them, it could be said that due to fashion in teenagers and younger, in most of urban areas, and culture, and unemployment, in rural areas tobacco habits or practices are increasing.

When we say word tobacco, various ideas comes in mind like- injurious for health, it kills, addictive and expensive, it bad for environment, big challenge for health, it has big industrial production, cause of 0various disease, etc.

Tobacco session was figure oriented the policies of tobacco companies are shocking that their targets groups are 13 - 19 year children, as a life long user. In the context of SPEC determinants, politically strong intervention should be toward stopping the prevalence of tobacco use and its various kind. Life skills orientation can be used to prevent tobacco, and community building, advertisement of using must be band and required initiative must be take place. A strong intervention of NGO's towered community building by concentrating on individual counseling is desired one.

I would like to say that development is the cause of tobacco problem. It introduced in India by the Portuguese during 19th century. It was the period

of industrial revolution (development) in Europe. I am putting here some facts regarding tobacco. More then 25 diseases are directly linked with tobacco.

Andhra pradesh and Karnataka are the highest tobacco producer states.

70000 million worth of paper used to wrap cigarettes 40 lakh children blow 15 years are using tobacco. 60% of people start smoking by below 13 year, 90% below 20 year.

1.2 Social understandings inequalities and Health :- In the process of social exclusion and castism, it emerges in the community; and community is nothing a group or groups of people, who lives together on a place or certain area, exchange their thoughts, culture, costumes, traditions, respect and maintain the relation. It accumulates various persons related to various caste, ideologies, and many other things.

So that community is like a body, it has certain systems, it functioning independent and it is the organization of various parts. In a community various castes who think that they are better or ruler, started a system to be a ruler or dominant always to suppress or under pressure of all the other societies. World wide on some places it was based on color and language, but some places like India it was and still based on religion. This system is called **varn veywastha** (system), which contain four layers, first- **Brahman**- as a priestly caste, **Kshatriya** – for security, **Vaishya** – Business and other work, **Shudra** – worked as a servant class.

Beside all of them another people who identified later as tribe and dalits were called as **untouchable** person. In the ancient period this system was very strong and deep rooted in the society. The condition of People like **Shudra & Untouchable** was worse, no body gave them respect, people like, **Brahman Kshtriya**, **vaishya** abuse them and keep them away from their higher society. Touching to these persons was sin. Continuous struggle against these systems took a long time to eradicate from the society, but its effects still can be seen.

The condition of the **BHANGI** cast peoples in Ahemdabad (Gujrat). This society in the main urban area of Ahemdabad, and in other parts if India, is still not looking respectful eyes. They are facing many problems because of their work like gutter and drainage cleaner, road sweeper as a municipal corporation's worker. They are facing social exclusion, they are not getting safe drinking water, lack of proper sanitation, and the power has cut down by

some people living in the Next colony. Nobody talk to them, upper cast persons cant sit with them, their children facing discrimination in schools, and neglected by the teachers and other **colleagues**. A municipal employee got dismissed from his job, by asking about their rights.

On the other hand if we look at the society, we found power structure, where some so called educated, political, and corporate societies who has the power want to be dominant and to keep suppress to all other societies, and don't want them to be part of political or power structure. Politically on the name of empowerment, they makes some policies, programmes it may be gives them some economic profit but it is not realized the mean of empowerment. These policies and programmes use as a mean of temptation. In this sense poverty is a myth and a sort of socio – economic , political, and ideological exploitation on man.

**1.3** CHW :-The concept of CHV is carried out by Bhore Committee in 1946 before the Independence, after this in every panchayat of village health committees formed and late 1960 and early 1970 a lot of voluntary organizations started to work towered training and promotion of health and health workers.

Rural health scheme in 1977 gave the philosophy –

# "The community health worker will be from the community and will be accountable to the community and community will be supervise his work"

With community health workers we cant imagine and work toward community health. They are the asset of the village. so the selection should be in the hand of the local community, like panchayat, local habitant or villagers. To utilize the services of the community health workers community should know the health status of the village, and how it is effecting to the health of local community. CHW's should not treat only with the biomedical aspect but must be work with SPEC or determinants of health. CHW's should work like

- Activities providers, awareness creator,
- Motivate demanding for the services
- Service provider what ever are the primary health care services should be provide with responsibility by the CHW's.
- Help in the govt. programmes.

- As a comprehensive health worker.

**1.4** Role of the community health worker :- In the present scenario community health worker is and will play a key roll in the providing primary health care for the community health. I think the responsibilities of the CHW's as a social worker should be decided by the community, according to their needs, and the major role of CHW's could be to help the community to set their priorities as per their need. Like Education with job security, awareness about health, their health problems, drinking water, and sanitation. Here I would like to mention of the chinese poem-

"Go to people, live with them,

Love to them, save them

Learn from them; build on what they know,

Start from where they are."

This poem is guides us and gives us the basic directions to work with in the community. We should always learn from them, community workers should change the paradigms by teaching of participatory learning.

In a community based approaches we have to facilitate them help them, and have to find out the ways of community building. As a social worker it is a opportunity for us that how we can make them aware, and get them together, to help to realize and find out the problem and to motivate them towered solution, and demand for need. This a kind of empowerment of community as a whole, but it should be in mind that social, political, cultural, economical discrimination should not take place.

Community workers should facilitate to the community to set out their priorities, help them on decision making, action, demanding from govt. for public health, and after the implementation monitoring must be by the community. To work in the community CHW need following skills;

- 1 Analytical skills
- 2 Facilitation and discussion skills
- 3 Communication skills
- 4 Negotiation / conflict resolution
- 5 Self learning
- 6 Listening
- 7 Organizing / management skills. Etc.

# 2 Field Visits

<u>2.1</u> FRLHT – Foundation for Revitalization of Local Health Traditions.

FRLHT is working as :-

A traditional medicine department.

To strengthening traditional medicine system like family tradition of healing, local healers, bon setters etc.

Education of AYUSH system. (Ayurvedas, Yoga, Unani, siddhas, homeopathy.)

Make balance between modern science traditional science.

Conservation of traditional medicinal plants in forest areas.

In India 7 lakh are licensed medical practitioners and continue growing. Our medical colleges are producing thousands of doctors, but tragedy is no one is agree to work for out reach on remote villages.

In this scenario FRLHT started work towered the identification and strengthening of local healers and local health traditions by giving them some training, for primary health care. They use food recipes, hears, primary home remedies, bone setters, education of jadi booti, siddha, yoga, are other allied systems use to trained local healers.

To promote Local health Tradition -

FRLHT award to right local healers

Conservation and training about medicinal plants.

Amruth home garden – a practical way to meet primary health care .

A package of 7 to 21 medicinal plants species grown 'in home premises.

Quality of this garden is, the garden plants use for the medicine, identified in the surround area where garden has to establish. This reduces the chances of biodiversity, and help to the peoples to know about the plants are found around them (us).

Medicinal plant used for care of home remedies to meet primary health care with local importance.

**2.2 Mrs. Padmasini Asuri -** We had a session with Mrs. Pdamasini Asuri a nutritiense . She told us about our food and nutrition, our ancient food system was very rich. It cooked according to the need of the body. Every human being needs energy to perform the daily activities and we get it from our food with the presence on protein and vitamin. A balance of various nutrients required by the body for the growth or development. Nutrition is the

fundamental of health and with out health can't sustain. For a healthy diet it is not required to eat artificial or fast food fruits and others heavy diets but some concentration of our daily diets give us the nutrition.

In the Bhagwat Geeta food has classified in to three form -

1 -Sativik food -Balanced food - according to the requirement of the body.

2 – Tamas - high formatted - highly salt

3- Rjas - highly spicy - temporary energy.

She told about various types of food, balanced diet, energy food, need of body, etc. and we also have a very testy and nutritious lunch with balance diet.

Absence of hard work in human life is a cause of diseases and specially now a days by the development of various means of traveling man has dependent, busy and fast running life is pushing to human being in the sink of diseases, but the most harmful thing is that we are getting the solution of our problems (diseases) only in the biomedical model. But not looking toward our social and cultural model or system, which gives us the complete solution of every problem.

# Fifth week : 4-8 September 2006.

# 1 Orientation

- **1** Health Structure
- 2 National Rural Health Mission (NRHM)
- **3** Transaction Analysis.
- 4 Confronting commercialization on Health.

# 2 Field Visits

1 L. C. Jain

# **1.1 Health Structure**

Before the independence two committees were established for the health survey.

- 1 Sakhey committee (1939)
- 2 Bhore committee (1946)

It was the first time in India, when govt. took serious initiative to know the health status, to find out the solution of the health problems. Bhore committee gave the idea of health structure with the planning and framework.

In the ancient health system was very strong Ayurveda, siddha, yoga unani healing methods used to solve the health problems. but after arrival of britishers allopathic healing system introduced and became more and more stronger by the time and still continue. Now most of the amount spent for the health structure goes to make stronger allopathic system. System doesn't good or bad, but it depends on its functioning and how it is beneficial to community health.

India has three-tier health system at state, district and local level.

In the village, - sub centers, local health workers (CHW.ANM.AND MPW's) daie's, anganwaries traditional healers, bonesetters, jadi- booti herbalists are working.

At block level - primary health centers,

at district level - community health centers.

In the big cities big hospitals both govt. and private are working for the community health. Most of the private hospitals owned by corporates are so expensive some specialized hospitals are also for special diseases. But are away from the reach of a local people.

Some old healing system are also running by the govt. but lack of proper attention, staff and medicines they are taking an ending breath.

In India 25 national programmes are going on and all are based on the allopathic treatment, mean bio medical models are being adopt by the govt. in the every programme.

# 1.2 NATIONAL RURAL HALTH MISSION (NRHM)

It is the programme of govt. of India at the national level. Govt. first time spending its proper attention towered AYUSH system, this is the first programme, which is conducting by the direct intervention of the **Prime ministers** office. But the lacuna is that govt. is not increasing the budget of health according to the population increased.

In India per capita health expenditure by the government is

Rs. 80-120/per person/ per year Rural share is Rs. 30/per person /per year

But the nation wide it should be \$ 40/per person / per year

In NRHM at state level Integrated State Health Society formed and all vertical health programme made integrated under this society at district and state level. Three top-level secretaries are involved to execute this programme.

Main features of NRHM are

- Decentralization
- Link with AYUSH system
- Civil societies participation
- Priorities focus on 18 states, which have bad health indicators.
- Focus on health determinants by many programmes.
- Interdependent linkages with panchayati raj institutions, ICDS, family welfare dep. Women and child welfare schemes. Etc.
- Increasing number of CHC's according to the Indian public health standard system. (IPHS)

- Provision of ASHA workers, to ensure the adolescents, women and child health.

### 1.3 Transactional analysis

Human being has three types of psychologies or behaviors

- 1) Parent
- 2) Adult
- 3) Child

Parent psychology is always creates conflicts, if two person will behave like parents can't be agree on one thing.

Adult psychology has learning system or behavior. With this two-person listen to each other, respect to each other, and try to be agree on one thing, and get positive result.

Child psychology keeps person always in a learning or taking position; when a person want to get teach by some one or want to get solution of their problem.

# 1.4 Confronting commercialization on health

In present so called development age, we have the biomedical concept of the health, and it is promoted by the private doctors involved in the clinical treatment, so expensive and harmful for health and wealth of a common person by private hospitals having expansive diagnosis and unnecessary tests or specially by the drug companies both national and international marketing there are more then 80,000 brands in the market. Where as most essential life saving drugs list by WHO are 270.

More then 80 % of drugs in the market are not useful. We should use generic in place of branded. In one 75 % health care is private and only 25 % is govt, and on the other hand govt. is spending very less per capita income on health. Corporate sectors are involved in health care and health sectors are way of investment and making money. They are overcome on the govt. sectors, more and more govt. companies are being privatized or getting off.

Now the patent is emerging as an epidemic and spreading all over the world.

It is nothing but a marketing monopoly, by which maximum exploitation of man is become possible. Ones a medicine got patent the owner will decide the cost of it, no matter whether a man can purchase it or not for i.e. in USA, ARV (drug use by HIV/AIDS patient) medicine is patent and cost is 2,50,000/per month, it is a product patent. Where as India its cost is 8000/-per moth, it is a process. So that many of African countries are purchasing it from India.

More then 6000 crores per year is spending by the MNC's on drug promotion. Irrational medical care is supporting and promoting to these drug companies. Indian spent about 15000 crores every year, and 50% of the money they gives for unnecessary diagnosis and treatments.

# What to do

- Demand to the strengthening public health systems.
- Ban all the irrational drugs, and introduce the list of essential medicines.
- Patient education on the rational medical care, and demystifying doctor's patient relations.
- Public health policies should be according to the prioritized need of the community, and n during the policy-making involvement of the civil societies and NGO's should be ensuring.
- Dialogue with professional bodies to catalyze strengthen and support professions internal initiatives for the reforms.

# 2 Field Visit

# 2.1 Mr. L.C. Jain

This was a short visit was the part of our field visit orientation at different places and Mr. L.C. Jain was a last person to whom we visited. We got a lot of things or thoughts of history in the reflection of his good or bad experience in the past. Some of the things about him or we gained from discussion with him are as follows;

He is a physically not very strong but energetic, enthusiastic happier person; identify peoples very easily and build very quick relations. He met us as a friend and took introduction from all of us, like what we did and will be done, and why we opt this field as a profession.

He told us about the challenges of the social work field have faced and facing by the social activists, like Medha Patkar, Arundhati roy, and about Sanjay Ghosh who was murdered by other antisocial elements during the struggle in the community health field

He suggested us to read his following books :

1 – Dam and conflicts.

2 – Dam v/s Drinking Water.

# Learning :-

Major learning during this period are as follows,

- 1 Health structure should be more and more decentralized.
- 2 More health workers should be trained at the village level, and selection process should be in the hand of the local community
- 3 Community has to play a very important role to the development of health.
- 4 All the programmes should be prioritized according to the need of the community
- 5 Local health traditions can play a major role toward the improvement of health of the community.
- 6 Privatization of health and health care system and involvement of the corporate in this field is making the situation quit dangerous.
- 7 Relations among Doctor and patient should be demystified.
- 8 Patent is nothing but a form of earning money and exploit to the community, for their own sake.
- 9 Product patent is much more harm full then process patent.
- 10 Involvement of civil societies and NGOs working toward the health is important in policy making process.

# **CBR REPORT** INTRODUCTION • AN UNDERSTANDING OF COMMUNITY **BASED REHABILITATION** • INTRODUCTION OF /CBR FORUM. • CBR EXPERIENCES IN THE FIELD: PLANNING, MONITORING, CAPACITY BUILDING, AND EVALUATION OF CBR PROGRAMMES IN THE FIELD. • ADVOCACY • PERSONS WITH DISABILITY ACT 1995. LEARNING'S AND SUGGESTIONS

# **CHAPTER FOUR**

# Introduction

# 4.1 Placement at CBR Forum

This study is conducted as a part of block placement to fulfill the partial requirement of Community Heath Fellowship scheme (CHFS) of the Community Health Cell, Bangalore.

The overall objective of my block placement was to built my personal capacity in the field of Disability and Community Based Rehabilitation.

My other general objectives were:

- 1 To learn about planning, monitoring, evaluation of a field level CBR programme.
- 2 To gain an understanding about CBR Forum and it's functioning.
- 3 To understand the manner in which the capacities of PWDs are built up through a CBR programme.
- 4 To learn how advocacy is done through a CBR programme.
- 5 To carry out some research activities in relation to PWDs.

To achieve these overall and general objectives the study has been well designed and planned including both the theoretical and practical approach, which includes the study of both primary and secondary data and exposure through field visits.

(see planned schedule annexure 1.1)

In the following chapters I have tried to give a clear picture of my CBR experiences in the field: on planning, monitoring and evaluation of CBR programmes; of the manner in which the capacities of PWDs have been built through a CBR programme and of the way in which advocacy is promoted through CBR. I have also reported on a study done by me on the UN Convention of 8<sup>th</sup> Ad hock committee on the rights of persons with disabilities and have suggested the manner in which the PWD Act 1995 needs to be amended in keeping with the afore mentioned document. I have ended by listing my learning's in this process.

# 4.2 Community Based Rehabilitation Approach.

The end of this millennium and up to now we have seen some sweeping changes both positive and negative in the world, including changes in economic trends toward globalization the tremendous advancement in the information technology, the increasing rate of world population, and so called development. GDP growth of the countries, which Is definitely increasing the standard of individuals life up to some extent on one hand, but on the other hand income gapes between rich and poor in the world, especially in the developing countries. Increasing rated of poorest people in the world and so on. Health crisis, prevalence rate of diseases, natural disaster, conflicts and war, are these things together are contributing greater in the problem of common man. It becomes more dangerous when we talk about Persons with Disability. These changes have influenced the life of Persons with Disability (PWDs), and thinking of all those peoples who are working or involved in disability issue in various ways. The rights and entitlement are continuously being denied or violated at individual and community level. Community health and Public health services are not providing very well as it should b.

In many developing countries "individual's rights as expressed in industrialized countries do not exist". Traditionally in these countries individuals is born in a kinship group with a network of relationship that involve the mutual obligation with regards to religious and economic factor. People look towards their immediate kin for welfare and help, rather then at the traditional western types of formal services. Because of this kind of relationship, the process of empowerment of an individual in the society is more complex, irrespective of whether he is a person with disability of otherwise.

In the past two decades, WHO, ILO, DFID and UNDP, have made greater efforts to promote a most cost effective home based rehabilitation services delivery system , which is designed as a community therapy programme called CBR in the developing countries. In the beginning this model practiced located intervention, nearly identical to that of the clinical setting in the institutions, dealing primarily with the impairment. Gradually it was recognized that these programmes did not produced the desired impact unless the extrinsic cultural factors were recognized and goals modified accordingly. In 1944 the UN organization in their joint paper, reviewed CBR in a different perspective and emphasized the contribution from the external

contextual factors. The goal of CBR programme was redefine as integration of PWDs with in his community, rather then relief of impairment of disability in the PWDs. This broader view of CBR in developmental perspective, reduce the importance of medical rehabilitation in to a less significant peripheral activities.

### **Determinants of Disability:**

Poverty is the major determinant of disability.360 million people who are living below poverty line are the most vulnerable for disability, and by this they are suffering from malnutrition. Living in unsanitary and crowded conditions, have no or limited access to medical care. Social phenomenon, with different cultural and traditional believes, traffic accident, war and conflicts, poor education, lack of confidence, lack of proper health care system especially during pregnancy (could be due to poverty / customs / traditions / lack of access of services), poor industrial practices, and chemical and fluoride poisoning, and in the last finally age is the major determinant of disability. It is contributing 36% of disabled population.

# **CHAPTER FOUR**

# 4.2 An understanding of Community Based Rehabilitation

# 4.2.1 Community Based Rehabilitation

Generally people define "Disability" as physical or intellectual impairment, which has long-term consequences. Because of this understanding, the majority of disability-related programmes are aimed at maximizing disabled people's physical and mental abilities - meaning that the main focus is on medical/technical interventions.

Disability is a developmental / social issue rather than a medical / technical one, because disability is just not a medical condition. The lives of disabled people are made difficult not so much by their specific impairments, as by the way society interprets and reacts to disability. Disability segregates / isolates the person and often the family, in their own community. They are not considered as a part of mainstream life. It is not generally recognized or accepted that disabled people have equal rights as citizens of our country and should have access to equal opportunities like the rest of us.

"Can't do this" and "Won't be able to do that" are phrases we all hear frequently about people with disabilities. Such negative attitudes – their own, as well as others' - have resulted in pushing people with disabilities onto the margins of society and have denied them their human rights.

People with disabilities have some problems, but they are certainly not devoid of abilities. They are just like the rest of us. Like all of us, they have some abilities and some disabilities. They are not strangers – they are members of our families, our neighbors, our friends and colleagues.

(Notes of Mr Goutam Choudhri report on CBR)

We believe that all of us are entitled to all the same human rights, regardless of the way we look or behave, regardless of our specific abilities and disabilities.

The need is therefore for a process of social change that is sensitive to and incorporates the needs, experiences and priorities of people with disabilities. An approach not with a medical bias but with a social bias - a recognition that society needs to adapt and create space for the requirements of disabled people amongst others, so that they also become a part of mainstream life. Such a process cannot come about if people with disabilities are excluded from society – they must become a part of society, meet and relate with others, work and struggle together, respect them selves and gain respect from others.

The history of rehabilitation shows that it all began with parental concern for the disabled child. The concern of the parents and the immediate family members led to their involvement in rehabilitation of the affected child. Later, institutions were set up by the state or by non-governmental organizations.

In our country, the sorts of services the people with disabilities (schools, clinics, hospitals, etc.) receive are mostly city based. Institutional Based Rehabilitation (IBR) has a general acceptance especially among able-bodied persons because of institutional care for the disabled persons. It is based on a high degree of professionalism and is expected to bring in quick and desirable results. It is mostly confined to towns and cities, inaccessible and unsuitable to people with disability in the rural area though about 80% of people with disabilities in India are living in the rural areas. The rural poor are particularly at risk of those disabilities, which are associated with malnutrition, poor conditions of environmental sanitation and communicable diseases. Accidents arising from negligence, ignorance and lack of safety measures at work and in

the community are also major causes of disabilities. Residential institution develops negative attitudes among persons with disabilities as regards the desire to return to their homes, this leads to segregation of peoples with disability from the community. It is not affordable to the Governments in developing countries that have limited resources.

Gradually it was felt that the coverage of persons with disability needs to be increased and rehabilitation services should be universalized. Some of the international agencies like WHO, ILO, UNICEF has promoted an alternative approach.

The label of Community Based Rehabilitation (CBR) was one that has taken up and promoted by the WHO. In 1981, WHO defined **CBR** as an approach, which "*involves, utilizes and builds on existing resources in disabled persons themselves, their families and communities*".

Several factors were being cited in favor of adopting such an approach. These included:

\* Lower costs

\* Wider accessibility and coverage

\* Community involvement leading to permanent change.

#### 4.2.2 Definition of CBR

The joint ILO, UNESCO, WHO statement on CBR defines CBR as "a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities."

According to the Einer Hilander; "CBR is a strategy to improving the services delivery, for providing more equitable opportunities and for promoting and protecting the Human Rights of the disabled peoples".

UNO in 1976 defined CBR as "a serious effort towered deinstitutionalizing, derpofessionizing, and demystifying services for the person with disability".

The concept of CBR is multifaceted and each face can be looked as a separate entity altogether. It can be understood from different dimensions and perspectives in accordance with its activities.

Today the main goal of the rehabilitation has become broader then earlier, and focus beyond the individual, to his community where he is being integrated, thus the universal mission of the CBR may be expressed as:

To enhance activities in daily life of person with disabilities.

To create the awareness of persons with disabilities environment to achieve

barrier free situations around him and help him attain equal human rights.

To create the situation in which the communities of persons with disabilities participate

fully and assimilate owner ship of their integration into his society.

From one dimension, CBR can be understood as a **medical rehabilitation approach**, which concentrates on the community health, prevention of disability and early medical intervention, which aims at physical development aspect of PWDs and other in the society.

Among the weaker sections PWDs are people who are more vulnerable to exploitation and injustice because of their disabilities. Many children and women are subjected to harassment by others, or their own near and dear ones, in many ways. CBR take into account the efforts of education and imparting knowledge and skills for positive attitudinal change regarding the PWDs, so that they live in a much safer, equitable, productive and barrier free environment. CBR involves advocacy for the rights of PWDs and related issues and it is therefore also considered as an **educational approach** to the development of PWDs.

CBR is also imparted as a **participatory approach** to the development of PWDs. In order to reach out to a number of peoples and attain and retain sustainability, people's involvement is needed. Moreover people's involvement in the CBR process ensures fairness and accountability in the programmes. The long-term target of CBR is that people should be empowered in order to make them able enough to handle their own

developmental affairs. CBR is achieving this goal by **decentralizing the responsibilities** and the resources, both human and financial, to the community or grass root level organizations, so that maximum number of needs of PWDs and others are planned out and addressed bearing in mind the decision of people. CBR breaks the **donor beneficiary approach**, which is a top down relationship.

All these aspects or faces of CBR act as a catalyst to each other in maintaining the momentum toward the overall and all round development of PWDs. All these aspects contribute to the development of the PWDs along with other non-disabled people in the society. All these come together and ensure the holistic and all round development of the persons with disability in every sense, like physical, psychosexual, intellectual, socio-cultural, economical and spiritual.

We can conclude that CBR in its holistic and truest sense, in this present context, can be understood as a community development strategy which takes into account the development of its parts out of which one is PWDs.

Therefore, CBR involves more than rehabilitation efforts carried at the community level. As a social policy, CBR promotes the right of people with disability to live with their communities, to enjoy **health** and **well being** and to participate in educational, social, cultural, religious, economic and political activities. Through this process people with disability become empowered to take control of their own lives and situation.

CBR is a combined effort of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services.

#### 4.2.3 Why CBR?

The basic question that arises is why CBR and not rehabilitation clinics or institutions?

Rehabilitation began with:

- > The concern of the parents and the immediate family members and
- > Institutions set up by the state or by non-governmental organizations:
  - $\checkmark$  catering to a small number of persons with disability;
  - $\checkmark$  offering costly services;

- √ largely based in urban areas and cities which are not accessible to the common man in rural areas;
- $\checkmark$  requiring professionals whose training is time consuming and retaining them is not easily affordable.

If the coverage of persons with disabilities needs to be increased and rehabilitation services universalized, they have to be community based.

Notes of Mr Goutam Choudhri

Community Based Rehabilitation (CBR) brings rehabilitation know-how to villages and urban slums in India, and CBR personnel teach or help people to take responsibility for their own lives!

The process of CBR as the name implies, has to have its roots in the community and has to derive sustenance and support from the community.

#### 4.2.4 Basic Principal of CBR Programme

Enabling services at the home setting of the Persons With Disabilities.

- 1 Capacity building of the local human resources, especially PWDs to provided the services.
- 2 Delivery of the optimum quality of the services, which will build on the traditional good practices of rehabilitation.
- 3 Ensure the community who benefits from the services gradually takes over the responsibilities of managing the rehabilitation programme.
- 4 Ensure participation and involvement of the persons with disabilities in the Planning, Monitoring, and managing the programme.
- 5 CBR workers must be flexible so that they can operate at the local level and with in the context of the local conditions.
- 6 Local resource should be tapped to the maximum.
- 7 Ensure that the rights of persons with disabilities are not denied.

1.Annual report of the CBR Forum 2005 -2006

#### 4.2.5 Essential components of a CBR Programme

Community Based rehabilitation of persons with disabilities should be part of the entire community programme for the integration and inclusion of all the persons with disabilities, beside this the community participation in every programme, ensure the success of the programme. It must be in mind that the entire scheme and programme are according to the need of PWDs, and following essential component should be included in the schemes.

- 1. Creating a positive attitude towards people with disabilities.
- 2. **Provision of functional rehabilitation services.**
- 3. Provision of education and training opportunities.
- 4. Creation of micro and macro income generation opportunities.
- 5. Provision of care facilities.
- 6. Prevention of the causes of disabilities.
- 7. Management, monitoring and evaluation

4.2.6 Major players in the implementation of a CBR Programme

When we talk about the major players and their role in CBR programme, community always will be on the priority, without it the concept of CBR can't be imagine. Some of the major player at the community level are as follows.

- 1. People with disabilities
- 2. Families of people with disabilities
- 3. Communities
- 4. Governments (local, regional, national)
- 5. Non-governmental organizations, local, regional, national
- 6. Professionals.

4.2.7 Challenges in CBR

The process of the CBR is not quit easy to implement it in the community, a lot of challenges are lying before the NGOs and community health workers or CBR workers in the effective implementation of CBR programme, various determinants like, socio cultural, economical, political, and attitudinal factors

work together as challenges, beside these following also consider major Challenges.

- Care of severely and profoundly disabled in the homes and by the community.
- Sustainability of CBR programmes by the community to what extent is it possible? What are the prerequisites for ensuring sustainability?
- Rehabilitation of the disabled through CBR in very remote, poor and backward villages where resources for rehabilitation are nearly absent.
- Attitudes and Acceptance
- Community Priorities
- Trained manpower
- Lack of research, appropriate technology and advancement of rehabilitation science
- High and unrealistic expectation from the community
- Group dynamics, community dynamics and community composition
- Non-acceptance of rehabilitation services and measures
- Indifferent attitude of the Government, NGOs and other key players in rehabilitation
- Creating a barrier free environment for all persons with disability
- Implementation of the Persons with Disability Act of 1995.

There is a well-known saying that " if you give a person a fish, he'll eat for a day; if you teach him to fish, and he'll eat for a lifetime". Community Based Rehabilitation (CBR) brings rehabilitation known-how to villages and urban slums in India, and CBR personnel teach people to take responsibility for their own lives.

We believe that if we all work together, in a spirit of loving and caring, people with disabilities can overcome their difficulties and get back their sense of self-confidence, competence and independence.

People with disabilities have the capacities and potential to manage their lives on their own. With this faith, people like us can also help them in their struggle for gaining their rights – which is our common struggle for a just society.

#### 4.2.8 Requirements to start a CBR programme

If an organization wants to start a CBR programme, they can consider the following points:

- Find out whether the disability situation in the area justifies the commencement of a CBR programme: is there a need to work with the aim of facilitating social inclusion of people with disability?
- Do a general analysis of the community including resources available in the area.
- Help the people with disability to articulate their need.
- Help them to get a response from within the community.
- Plan to involve children, their families and the community in all the activities from the very beginning and at every stage, to build a genuine partnership rather than a relationship of dependency.
- If needed ensure the availability of support of professionals from outside the community.
- Use local resources available in the community to provide necessary services. As far as possible, utilize existing services and facilities.
- Gradually transfer the skills of rehabilitation to the parents of children with disability, adult PWDs and also to the first contact people such as anganwadi workers and village health workers.
- Disseminate information on disability and the rights of persons with disabilities.
- Create a positive attitudinal change about the abilities of persons with disabilities.

On the whole they should try their best to help people with disabilities and their families acquire the confidence to make necessary decisions for their future and help them to become confident, self-reliant persons, respected and active members of the society.

#### **CHAPTER THREE**

# 4.3 An understanding of Community Based Rehabilitation Forum (CBRF)

#### 4.3.1 Genesis of CBR Forum

For many years, Misereor Germany has been assisting the projects involved in the rehabilitation of person with disabilities. In the last few years there has been a steady and steep increase in the number of such projects and the quantum of financial assistance as to merit their special attention. After articulating the need of clarity in decision-making, Misereor decided on a focused policy, relating to disability rehabilitation projects in India.

in formulating the policy of disability rehabilitation in India, Misereor take into account three main fectors, namely magnitude of the problems of disability in India and consequent need for the wider coverage, the need to have a specialized "think – tank", and conscious decision making within the country.

Misereor then prepared a approach paper "toward defining the Misereor role with regards to support of people with disability in India" in early 1994, which was circulated to people involved in the field of disability rehabilitation in India. Subsequently a work shop was held in Madanapalle Andhra Pradesh India march 1994 with about 35 invited participants from all over the country discuss the modify and approach paper and to develop some guidelines for the taking the process forward.

The workshop of Madanapalle resulted in three clear out comes regarding the future policy of Misoreor in the field of disability rehabilitation in India.

The first was that the community Based Rehabilitation (CBR) approach would be given priority for support.

Secondly, it was agreed that the advocacy and awareness raising were important issue and need to be supported.

Finally, the workshop recommended that a Forum should be set up in India as an independent entity to play a proactive and pro-active role to implement the policies.

The CBR Forum was subsequently formed in 1996. It has three institutional members; **Misereor** based in Germany, **Caritas India** and **CBCI** both based in Delhi. The Forum can have a maximum of nine others members. Presently CBR forum is located in St. Thomas Town Post, Bangalore, and Karnataka.

(Mr C. Oddessy singh" block placement report) (Report by Misoreor on CBR)

# 4.3.2Vision of CBR forum:

"The vision of CBR forum is that people with disabilities have equal opportunities leading to improve quality of life and fully participate in a society that respects their rights and dignity".

# 4.3.3 Mission of CBR forum: -

"The mission of CBR forum is to play a proactive and promotional role in community based rehabilitation of person with disabilities in India, ensuring wide coverage with focus on the disadvantaged groups such as the poor, women, and people living in the rural areas and urban slums."

# 4.3.4 Objectives of CBR forum: -

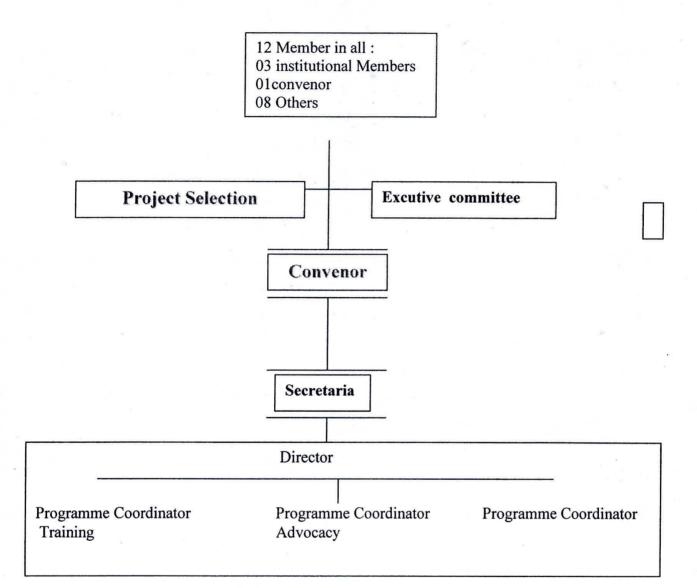
**4.3.4.1 General objectives:** CBR forum Promotes, supports and empowers organizations and people and movements for CBR by creating Equal opportunity for social integration of PWD's specially among the disadvantaged.

#### 4.3.4.2 Specific objectives:

- 1) Create awareness and sensitivity for attitudinal and behavioral changes among PWD's and the general about issue in disability, prevention and management.
- 2) Enable and enhance the capacities of PWD's, their families, communities and organizations for the development of sustainable approach for integration.
- 3) Network with organizations and govt. at all levels for influencing policy, action, and legislation, for integration.
- 4) Promote and support of peoples with disabilities.
- 5) Develop and promote a body of knowledge and skills in the area of CBR.
- 6) Mobilize resources for CBR activities.

Annual report of CBR Forum 2005-2006







# 4.3.6 CBR Forum as a developmental Organisation

Today, CBR Forum plays a vital roll in implementation and spreading CBR programmes in every nook and corner of India forming a strong networking system with many partner organizations who are working at grass root level in rural areas and urban slums, especially the downtrodden section of the society. Acting as a catalyst to these organizations in the implementation of the CBR programme, CBR Forum also acts as the monitory backbone of these partners' organizations. They assist these partners not only with requires finance but also with relevant inputs to take forward CBR programme. So from an angle the Forum can be considered as a funding agency though the funding activity is of secondary priority to the forum. It is also to be noted that the forum does not implement the programme directly but only through its partner organizations. The main source of funding of CBR Forum is the MISEREOR, Germany.

Every year the secretariat prepares the project proposal to send to Misereor Germany for the funding this proposal before sending to Misereor goes to CBR Forum board where it is through discussed / assessed.

After this, the proposal returns to the secretariat with or without suggestion, modification/ alteration. Then the proposal is forwarded to Misereor by the secretariat.

Misereor Germany assesses the proposal. If they find it all right they straight away send the MOU and a copy about it is sent to the secretariat, with the agreement, fund is released to Caritas India, which is the legal fund holder. At the same time, a copy of the details of this transaction goes to the secretariat. In case, they have some alteration to be made in the proposal, then they send it back to the secretariat with desired suggestions/conditions for the alterations.

After assessing the /suggestions and conditions the secretariat present it in front of the board. Then the board studies the proposal and the suggestion/condition. Then they take a necessary stand (with or with out the acceptance of the suggestion/condition laid down by Misereor Germany) and the proposal is sent back to the secretariat. If they are not satisfied, they can again send to the secretariat. And the same procedure repeats.

#### 4.3.7 Functioning of the CBR Forum

#### 4.3.7.1 Regarding to the partners organizations

The secretariat assesses the proposal. if it is not with in the norms of the forum it foes not study the proposal further. On the other hand if the proposal with in the norms, the secretariat appoints a resource person for the assessment of the organization, with the field reality and its needs. The resource person is also requested to present specific suggestion and clarifications or make the project more realistic and need based. After the assessment, the resource person can either recommended and support of the proposal with or without suggestions or reject it.

If the secretariat finds the support with out any suggestion from the resource person, then the project or proposal goes to the project selection committee.

In the case where the support is with suggestions, the secretariat informs the organization of the suggested conditions, if there are any from the resource person. The organization either can agree to include these suggestions or can opt to withdraw its proposal. The secretariat is informed accordingly. If they agree then the secretariat, forward the proposal to the project selection committee.

The project selection committee studied the consolidated reports presented, by the secretariat and submits their decision for support / rejection to the board of the Forum. If the proposal is supported then it goes back to the secretariat. The secretariat finalizes the proposal of those whose proposal have been accepted and forward the same to Caritas India, Delhi for the release of fund and at the same time, this approval is informed to the implementing agency or applicant.

Caritas India sends the memorandum of understanding with its term and conditions to the applying organizations ending a copy to the secretariat at the same time. Even at this stage, the organization is free to back out by refusing to sign the MOU. If it does sign the MOU, it becomes a partner of Caritas India and gets funding from the forum through Caritas India for their CBR project. Every time the Caritas India releases the fund, a copy of details of the fund released is sent to the secretariat.

The secretariat also has the responsibility to inform the implementing agency whose proposal has been turn down at any stage, of the inability of the forum to work with them as a partner.

This is how the organizations, who apply for the CBR project, can become the partner of the CBR Forum.

Just after the linking up, the new partner organizations have to undergo a sensitization workshop, where the coordinators and CBR workers are given training for 40 Days. The coordinators have training for another 12 days in addition for the 40 days training. Directors and applicants of new partner organizations also have training for 2 days.

The forum look at the possibility of partnership of maximum of 8 years and another one year in a specific project area which spread over five phases;

Phase	Period
1	9 Month
2	2 Year
3	2 Year
4	2 Year
5	2 Year

Today, CBR Forum covers 18 states having 88 partners organizations in India which are located in the following broadly categorized regions namely,

Southern Region	
Karnataka Region	11 organizations
Kerala Region	14 organizations

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Andhara Pradesh Region	12 organizations	
Tamilnadu Region	10 organizations	

(for the list of partners organisations refers Annexure 3.7.1 )

Northern and Western Region	
Madhya Pradesh	1 organization
Maharashtra	03 organizations
Delhi	02 organizations
Rajasthan	01 organization
Utter Pradesh	03 organizations
Jammu Kashmire	01 organization

Nort	hern Eastern Region
Manipur	05 organisations
Assam	02 organizations
Meghalaya	01 organization

E	Eastern Region
West Bangal	04 organisations
Orrisa	06 organizations
Jharkhand	07 organization
Bihar	04 organisations

Out of these partners 04 organizations from Manipur, and 01 organisation from Meghalaya are being funded by Light For World (LFW) Foundation, Australia, and rest are being funded by the Misereor Germany.

#### 4.3.7.2 Training of partners

Partners are given systematic inputs on various occasions.

- a) During project management Workshop, the focus of the inputs is on;
  - > Introduction of the concept of CBR and CBR Forum.
  - Expectations of the Forum / Funding agency as regard to programme and financial management.
  - The mode of drawing up a realistic rehabilitation plan for Each individual PWD, keeping in the mind the need of PWD to plan intervention at the individual and social level.
  - Inputs on activities and financial planning.
- b) During reflection workshop, the focus of the training inputs is on :

Ensuring that the provision have been built in to the plan to care for: Prevention of disabilities Networking with other partners and NGO's Formation of Self-Help Groups, and their eventual Federation.

Identification of Human and Material resources in the project area.

Meeting the provisions of the disability Act.

c) During the field level facilitation visits the focus of the training inputs is on :

The mode of drawing up of realistic rehabilitation plan for each individual PWD, keeping in mind the need of plan for intervention at the individual and social level.

Upgrading home management skills

Upgrading financial management skills.

Upgrading activity and financial reporting skills.

Facilitating and capacity building of the PWDs, their family and community members in view of enabling them to take over the programme.

d) During the regional level meeting of the partners, the focus of training inputs is on :

Functioning of SHGs

Advocacy and lobbying

Mainstreaming of disabilities.

Feedback from partners on training imparted by training centers.

Working with Govt.

Millennium development goal.

Future role of CBR Forum in India.

Sharing the stories of rehabilitation through CBR; both success and failures. Indicators of achievement for each phase of the programme.

e) In addition to the above through approved training centers of CBR forum,

all partners organizations receive training inputs from one of the training

centers of the Forum;

- **SANCHA**R in Kolkata, West Bangal.
- BLIND PEROSN ASSOCIATION (BPA) Barodara, Gujrat.
- ADD India, in Bangalore.

The focus of the training inputs through a 40 days training programme and sensitization workshop during phase one is on;

Imparting know – how to CBR workers and coordinators on CBR and skills required to care for various types of disabilities.

Imparting additional skills to co-coordinators on management of a CBR programme.

Know –how the directors /applicants on the demand of the CBR programme.

In addition to this on going training programme of 7-10 days given every year (from phase II onward) at field level to all the partners based on their specific needs.

### 4.3.7.3 Advocacy

Besides working with the partners organizations CBR Forum has its direct intervention by his own staff in the field. The secretariat has started working with the former assistant commissioner of disabilities of the Karnataka State Govt. to sensitize officers of 10 district of Karnataka states on their role in insuring that the provisions of disability Act met. This is done through taluka level disability management programme. The forum works with the officials of the districts where partners of CBR Forum are already present. the forum has successfully organized a 1 day sensitization programme after which the commissioner has ask to the district officer to report on quarterly basis to the commissioner office as regards follow up action taken to take the provisions of the Act forward.

## 4.3.7.4 Networking With the Funding Agencies:

CBRF took the initiative to bring together funding agencies that funded programme for the rehabilitation of PWDs ; Abilies, AIFO, CBM, ACTION AID, SLF, and TDH (G). Basic need an organization that gives minimal funding and technical support to partners in the field of the mentally ill was also present for these deliberations. All those present opted to work together for the promotion of CBR of PWDs. Good practices of CBR are reflected upon. Information of prospective partners is also exchanged.

#### 4.3.7.5 Monitoring of the projects:

Monitoring of the selected projects is done every six months. This is done in view of making these model projects. The staff of CBR Forum secretariat visits to the partner's organizations and monitor the CBR work. In this visit they analyze the progress of the organization in the implementation of CBR through a detailed examination of documentation maintained by the partners organizations. Through field visits and through the interaction with the CBR workers, PWDs, their families and the community, in this process checking of accounts is also done. Based on the needs at field level, the team of CBRF conducts sessions to provide necessary inputs to the staff of the partner organization. Along with the partner, they also check out a plan of action for the following six month which the partner has to take forward.

#### 4.3.7.6

#### **Partners meetings:**

Partners meet twice in a year to update knowledge and skills. They share their experiences and achievements and learn from each other. The partners meetings are conducted region wise. Earlier CBR Forum used to host the partners meetings but today the local partner hosts the same. At each meeting the host and the location of the next meeting is decided with the consent of the CBR Forum. The staffs of CBR Forum and a Board member are present in the meeting.

#### 4.3.7.7 Research and documentation:

In the future is planning to have a research and documentation wing to conduct research studies on disabilities.

#### 4.3.7.8 Field Placement:

Another feature of the CBR Forum secretariat is that, the student and other fellows from the organizations/institutions are being invited for a short term period to conduct their study or create an understanding on disability and Community Based Rehabilitation. In this process Mr.Chongtham Odessey singh as a student of Social Work from the School of Social Work Manglore, Karnataka has been completed his fellowship as a first fellow in the CBR Forum Secretariat.

### CHAPTER FOUR

# **4.4 CBR experiences in the field: Planning, Monitoring Evaluation and Capacity building in the CBR programmes in the field.**

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# 4.4.1 Experience regarding the planning, monitoring, evaluation and capacity building, in the field of C B R.

This is my personal field level experience in the field of the partner's organization, where I learnt about the planning and monitoring through field exposure.

# 4.4.1.1 The Process of planning, Monitoring, and Evaluation been divided in to following two parts.

1 One is at the CBR secretariats level. In this process CBR Forum plans for the entire year with its staff members. The important feature of the CBR Forum, both at the secretariat level and the implementing level, participatory approach has been adopted.

At the secretariat level CBR Forum does the planning for its activities for the whole year according to the Objectives. Every six months, CBR Forum organizes a reflection meeting for the evaluation of the programmes, and see that what is done and what is to be done in the next six months, and plan of some new activities for the next year t, with he staff of the organization

(The reflection meeting has done in the month of September 2006.)

(Refer annexure 4.1.1)

2 Another one is at the implementing agency level in coordination with PWDs, families, and communities along with other staff members of the organization. This is a very important feature of CBR Forum. In this process the partners organizations does the holistic rehabilitation under the guide lines (preparation of individual rehabilitation plan (IRP) social and individual dimension) provided by the CBR forum. Through this rehabilitation plans, CBR Forum ensure the holistic rehabilitation of persons with disabilities in the community. This rehabilitation plan includes both Social Rehabilitation Model and Plan and IRP Which focuses on the six areas of growth of persons with disabilities at social and individual level.

#### 4.4.1.2 Social Model of the Rehabilitation;

- I **Physical model** ensure the health care services, their accessibility, affordability, and quality for the persons With Disabilities.
- II Psychosexual Personal Growth opportunities and clarify myth and misconceptions regarding marriage and sex marital costumes in the family, society, and the internal relationship with the family, peers, and the community.
- III Intellectual level educational opportunities for the persons with disabilities, in both places family and the society, with barrier free and nondiscrimination.
- IV Socio-cultural level eradication of the negative attitudinal behavior of social and family expectations, prejudice and beliefs, and good cultural practices in the family and society.
- V Economical level to provide opportunities for the economic gain, made available by the family and the society.
- VI **Spiritual** to promote the spiritual practices in the family and society.

#### Individual Rehabilitation Plan or Individual Rehabilitation Plan.

Individual rehabilitation Plan focus on the individual needs and prepares the module under the six, **Physical, Spiritual, Economical level, Sociocultural level, Intellectual level, Psycho-sexual,** areas of growth, according to the need of the Persons with disabilities.

#### 4.4.2 At the secretariat level:

1 The CBR forum has designed long term monitoring tools for the purpose of the monitoring the model projects (Refer annexure 4.1.1)

- 2 programme officers pay fields visits ones in the six months to perform the activities of monitoring and evaluation. (Refer annexure 4.1.2)
- 3 Face wise indicators are developed by the CBR Forum for the each face, are the key tools for the evaluation of partners organization.
- 4 The external evaluators suggestions are shared with the implementing agencies by the secretariat.
- 5 The secretariat studies the report produced by the implementing agency in the recommended of the CBR Forum during the field visits feed back will be given to the partners organization.

#### 4.4.3 At organizational Level:

- 1 The organization implements the project as per the approved project planner, and discusses the planner with the organization staff, community, and families of the PWDs. Some of the monitoring and planning tools are incorporated.
- 2 Key leaders are trained and sensitized to the issues of promotion , protection of disabilities and the rehabilitation in the neighborhood.
- 3 The organization staff members have trained the key leaders according the approved planner.
- 4 The monthly targets have been fixed by the organization for the CBR workers and the coordinators
- 5 The CBR workers are expected to drive information from the field by their first hand interaction with the PWDs, their families and communities. They have to collected these information's by observation and formal interactive meetings.
- 6 The indicators made by the implementing agency, will be the key factor determines the directions of the projects, evaluate the expected outputs of the projects and facilitate the organization to monitor the same.

# 4.4.4 Field exposure

Name of the organization:Center for Overall DevelopmentAddress:Thamrassery Panchayat of Kazokode distt.Persons contacted:

#### 4.4.1 Back Ground of the organisation

C.O.D. (center for Overall Development) is working in three panchayats of Kozhikode District, Kerela. The organization is implementing various development programmes in Calicut District. The organiasation is implementing the CBR project supported by CBR Forum in 03 panchaytas namely Thamarasserry Panchyat, Marunkara Panchayat and .....

At field :-Through their survey, they have identified 444 persons with different disabilities in the target area. COD follows the philosophy integrated approach in implementation They have formed 175 (SHGs0, 350 persons with disability have been integrated with the local SHGs. Out of 175 SHGs, four (04) SHGs are formed exclusively for PWDs who are made as pressure group in the future course of time. Now the organization has already entered in the third phase of the project. During the third phase the team is going to concentrate to build the capacity of the PWDs, their families and other community members to take over possible responsibilities in the IV phase onwards. It is expected that the dependency on the organization will be reduced step by step in a steady and slow process. One of the concrete strategies the organization has taken is identification, training and induction of key leaders in the community. They are expected to carry forward the programme with the facilitation of CBR team.

For this purpose

# Planning for the next six months.

In the next session a regional meeting has to be conducted in the COD center of Thamrassery Panchayat. In which all the regional members will come in the C.O.D (Center for Overall Development) and will visit their field area learn about the CBR programme, and share their experience and their learning.

They will learn here the following things;

- Duties and responsibilities of the CBR workers.
- Duties and responsibilities of the coordinators.
- Documentation of the organization.

How the organization is working for the Individual Rehabilitation Plan (IRP). Here the CBR workers will play the role as a

- Facilitator
- Organizer and
- Catalyst

#### 4.4.4.2 **CBR Team**

There is a CBR team including five (5) members two (2) CBR coordinators and three (3) CBR workers. There I with programme officer Mr. Moses Herick set with them for monitoring of their projects then I talked to them, on the various issues and I felt that programme coordinator is new and he needs for training, their field area is quite big and they have to cover a long distance to meet the PWDs, so that they are including CBR in all of their activities and other programmes. Like HIV/AIDS, awareness, water sanitation, and training for key leaders so that they may able to take over the programme after some time and will be able to work for the PWDs.

#### 4.4.4.3 Capacity Building

The organization is working with its full strength for the rehabilitation of persons with disabilities. And including the CBR in their various others projects. It is helping PWDs to build their capacities to cope up with the community and be able to manage their life with out any dependency. In this context the organization is running a fan manufacturing unit for a sealing Fan Company. This programme is giving the economical assistance and empowering to the PWDs, and helping them.

Besides this programme, the organization is also giving the training to the key leaders from the community and from the SHGs and builds their capacities to take over the CBR programme at the end of this project. Their involvement in the SHGs and other activities conducted by the organization shows the level of their self-dependency and the empowerment increase.

Actually all the activities that are being conducted by the partners of the CBR Forum, are a form of capacity building. Through these programmes the organization is serving and building the capacities of the most poor, deprived, and marginalized sections of the community in the rural areas. These programmes are build the physical capacity, helps in the physical movements, Intellectual capacity to educate them about their right and gather them to demand from the society and govt. to include them in the main streaming society, which helps for the behavioral change of the community and shows their ability rather then disability.

# 4.4.5 Name of the organization : SANCHAR

Address:Diamond Park, Joka, Kolkatta.(West Bengal)Persons contactedMrs. Tulika Das, and Goutam Choudhri.

# 4.4.5.1 Back Ground of the organisation

Sanchar is an organization or can be called a group of "Disability workers" started working in the field of disability since 1988, with the poor people with disability in the villages of South 24 Parganas with administrative and field support from CINI (as a project of CINI – Child In Need Institute). They carried out a survey of existing services for people with disabilities in the three districts of West Bengal namely, North 24 Parganas, South 24 Parganas, and Kolkata.

In 1989, the group started working primarily with the children with all types of disabilities through community/home based programme in the village of South 24 Parganas of West Bengal.

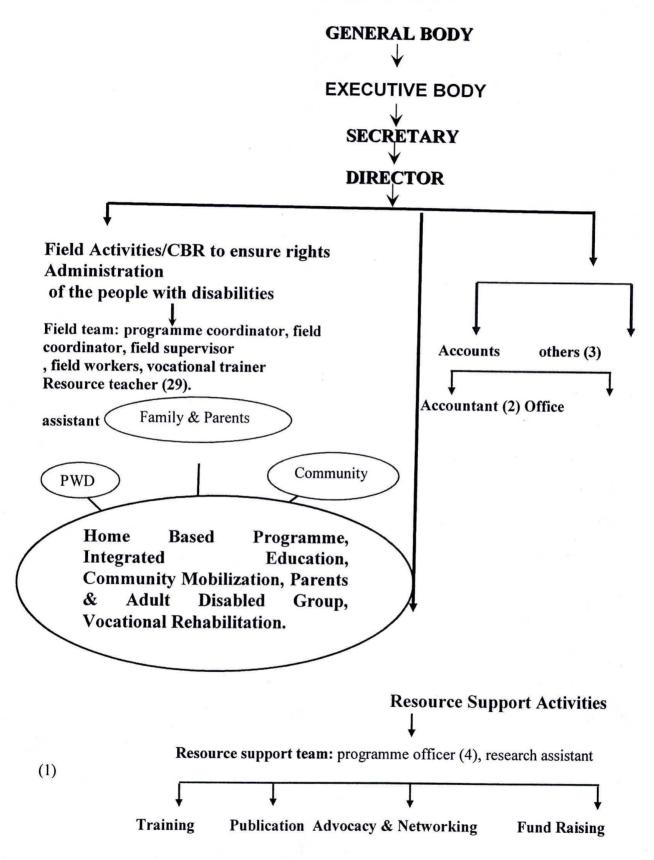
In 1990 the group registered as a society – SANCHAR A.R.O.D.(A Society for Appropriate Rehabilitation Of the Disability)

With every passing year SANCHAR expanded its field to more and more villages across the district and supported more and more people with disabilities to be integrated in the main stream of the society. SANCHAR is also working as a Resource support and training organization to promote Community Based Rehabilitation approaches for mainstreaming people with disabilities.

# Other Features of SANCHAR are;

- Working as a District Level Resource Organisation (West Bengal District Primary Education Programme)(WBDPEP)
- Joined Disability Activists forum for amendments and speedy implementation of PWD Act. 1995.

As a part of the resource support activity SANCHAR act as a facilitation center to provide the technical support to as many as 35 NGOs all over the country through the CBR Forum.(Specially for the NGOs of the Eastern Region).



#### 4.5.3 Activities for CBR programme :-

SANCHAR is carrying out various activities in the field for the communitybased rehabilitation of person with disabilities. This is a type of community health and community organization. That not only the family members, relatives, and neighbors are realizing the problem of PWDs and their families, but the whole community is being sensitized by the various activities of the organization. These activities not only help to the PWD individually to spend their daily life in a barrier free environment but change the attitudinal behavior of the community towered the PWD in the process of social inclusion.

Some of the programmes which are being carried by SANCHAR CBR workers in the field are as follows;

# 4.5.3.1 Individual home / family based Management:-

As I mentioned earlier that SANCHAR is working for the peoples (children and adult) with all types of disabilities. For each types of disability organization takes up different approach in working with the concerned person according to his/her needs. Individual Home based Programme (IHP) depends on the level of impairment of the child / adult, his/her needs abilities and limitations.

In this process the organization works in partnership with the parents and families of Persons With Disabilities. CBR workers visit ones or twice a week, does home based programme and follow up programmes to help the parents and family members to learn the activities, by these visits one of the primary intention of the organization is to build the capacity of the family so that they can be an active part of the process. They are therefore expected to continue the programme at home.

The **IHP** process starts with the support for the physical and mental/ social development, if the child is delayed in his/her development. CBR workers help the child being acquainted with the activities of daily living and household. The children who have very low impairment and can be sent to school helped by the pre- schooling activities and also help to develop their communication.

4.5.3.1	Case study		
Name -	Sunny Mondal s/o Chandan M	londal	
Villagae -	Kolar Dhari		
Intervention -	from April 2006.	Age	- 05
years			
Impairment -	Mental Retardation	Visited	
10/10/06			
Targets -	Concentration Development,	Feeding,	Bathing and
Dressing etc.			3

Status before intervention	Status After intervention		
Before the intervention he was not	After a continuous intervention of the		
able to speak any thing even his	CBR workers Sunny Mondal is		
name. He could not identify letters	learning the Activities of daily living		
and numbers, lack of concentration to	to like, Bathing, Eating; he has the		
perform the daily living activities. His	movement problem in his hand so he		
parents were unable to understand	was not able before to eat rice it self,		
about his behavior, then he heard	CBR Worker gave some exercise tips		

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about SNCHAR came into contact of	to his parents, and advice a regular	
the CBR worker.	practice during the period of absence	
	of CBR worker. Now he is learning	
	bathing him self, movements is being	
	seen in his hand and he can eat and	
	can wear his half - pant him self in	
	sitting position.	
Please see the Anneyure 4.5.3.1 and for photo and Individual Penhabilitation Plan		

Please see the Annexure ... 4.5.3.1... and for ... photo and Individual Rehabilitation Plan

# 4.5.3.1 Case study

Name of the child – ASHIQUE GAZI,

Age  $- 6\frac{1}{2}$  year,

Parents – Jameela Bibi w/o late Mr. Kalo Gazi (father has died before 2 month)

Village name - KALAGACHIA

Impairment - MR + CP

Type of intervention - Individual Home Based Rehabilitation.

Duration of intervention - form last two year

#### Targets

(From July to September 2006)

Help the child to stand up

To make learn, or Help in the bathing activities.

To make learn dressing (wearing pant in sitting position)

To help the child in hand functioning.

Feeding, especially in chewing food or meal.

Status before	Individual Target
Before the intervention he was not able to do any thing. He used to lying all the time was not able to move due to his spinal cat	After a long and continuous two years
problem.	intervention of the CBR worker he is
	able to sit, on the special chair
	provided by the organization.
	Improvement in his condition is
	taking place very slowly, but regular
	intervention of the CBR worker
	through different activities is a hope
	for his mother that after some time he
	will be self dependent, manage his
	daily life activities. Because the
	economic condition of his family is
	not good, the chair is made by the
	local resources available around
	them it is very useful to teach him
	various daily life activities,
Please see the Annexu	re4.5.3.1and forphoto and Individual Rehabilitation Plan

# 4.5.3.2 Inclusive Education

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One of the primary goals should be of every CBR organization to work for the social inclusion, and integrated/inclusive education. The process of inclusion of all children with whom organization is working is showing very encouraging results.

The first step of successful inclusion is sensitizing and creating awareness among the school authorities, teachers, and others students so that they genuinely support the process and understand the necessity and use of it. Organization feels it is as much as necessary for the schools and others children to be sensitize and prepare for integration of the children with disabilities. inclusive insure the over all development of the CWds.

As a resource organization SANCHAR tries to provide necessary teaching learning material support.

#### 4.5.3.2

# Case study

Name Of the Person	Mafizul Mollah:
Village –	Amgachia
Disability –	Visual Impairment

Seventeen years old **Mafizul** is studying in class seven in the local secondary school. His parents first identified his disability, at his age of one. Stricken by poverty, his parents left no stone unturned to carry out all possible treatments, for their child. However their efforts went all in vain. Out of sheer helplessness and of course severe money crisis eventually they had to pull out from their hard work At this critical juncture of his life, SANCHAR came to know about Mafizul. He was then six years old. First, Mafizul was made acquainted to his household items; mobility orientation was being also carried out. Mafizul made their effort fruitful by learning all these within a year.

His training continued, and the subsequent division of training included counting, recognizing money, learning multiplication table and verbal solving of sums. Other domestic activities like learning to wash his own clothes, washing the utensil after having food etc. were also covered in his training catalog. Mafizul successfully learned them within two years.

Sujit, a staff of SANCHAR, who himself is visually impaired, started teaching Braille to Mafizul. In the year 1998, the effort started to admit

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Mafizul to the primary school. It was an actual hard time for the parents and the team of SANCHAR to convince the teachers. However, after a painstaking phase of agreement and disagreement, the teachers were finally won over. Mafi was admitted to the school. SANCHAR here took initiative to organize and start teaching lessons from books of class I from **Narendrapur Blind Boys Academy**, in the form of Braille.

Currently Mafizul is studying in Avoycharan local secondary school. Organization certainly cannot foresee someone's future, but till date his steady progress, determination along with the support provided by SANCHAR to overcome the hurdles of life, truly encouraged making this integration a genuine achievement.

(Refer annexure 4.5.3.2 for the photo and his poem written in brail language)

# 4.5.3.3 Pre- vocational / vocational training and support for the economic development.

After a certain age SANCHAR provide the training support to interested individuals with disability. Organization is providing the help in terms of loan or Seed money; contacts and support as and when required, so that the individual or the group can gain confidence and start something on their own. Organization primarily encourages inclusion of boys and girls with disability in to some family trades that is convenient for the person to learn and also helpful for the family.

This year the organization has arranged the vocational trainings for the peoples with disabilities in tailoring, needle work, soft toys making, packet and envelop making, and have ensured the conditions for the practice of these vocations in their village community. Most of the PWDs are tries to involve

in their traditional, through which they can contribute much for the economic development of their and their self.

#### 4.5.3.4 Aids and appliances

Appropriate aids and appliances are one of the most important feature of the organisation for mainstreaming of people with disability. Appropriate Aids and appliances help in the general developmental of persons with disabilities, with their, family and communities. These aids and appliances help in the self dependency and mobility in the community, and built self confidence. They under take one hand material in the surrounding area and when suitable, modify the environment. In case of mobility aids like calipers, etc. organization has been facilitating the procedure of helping those persons with disabilities who are in need of avail services, which are accessible and available around our base.

Types and aids provided to the PWDs.

KAFO	05	
Extension Prosthesis	02	
Crutch (Auxiliary modified at elbe	ow)	02
Wheel Chairs	12	
Special toilet Sitter	01	
Special foot rest	01	
Special Table and Chair	07	
AFO	01	
Sack foot	01	
Tri-cycle	02	
Special chair	03	

Special Tables	02
Hearing Aids	14

4.5.3.4 Case study

Name	-	Anup Das s/o A	mul Das, Roop	a Das			
Occupation	-	Rikshaw					
Villagae	-	kamagachi					
Intervention	-	from July 2006.		Age	_	4	1/5
year							
Impairment	-Hea	ring Impairment	<b>by birth</b> Visite	ed –	10/1	0/06	
Targets	-	Concentration	Development,	Feeding,	Bath	ing	and

Dressing etc.

#### Types of intervention

The Educational activities are being carries out for Anup das. He is being helped to make straight lines, to identify the words, number name (his own and Father/Mother), dot inclusion, drawing through matching dots

Just before one week he got his hearing aids there for hearing intervention in the form of identification of different sounds and speaking practices are being carried out.

#### After intervention

Now he can identify his name or parent name. He can fill the colour in the picture drawn by him through the matching of Dots, identify the 1, 2, 3, numbers. CBR worker is advising to his parents to admit him in the school form the next year.

**Problems** – he is not interested to use hearing aids, he doesn't listen to his parent, and always roams and don't care him self. Because both his parent

work, they are not giving proper attention towards home based practices therefore he is learning very slow. (refer annexure 4.5.3.4)

4.5.3.5 Thursday - Open Day programme

On every thursday SANCHAR conducts the open day in its own premises. This open day is a source to reach those unreached peoples with disability who do not come in the field area of SANCHAR or still not being benefited from the services of the organization. Through this open day clinic the organization tries to help more and more PWDs, and their families to teach them different life skills in order to help them in their home premises for sustainability, and making their life easy and comfortable.

In spite of this intervention CBR workers visit their home for follow up process and rapport building.

# 4.5.3.5 Case study

Name - Hrit Rupam Shah, Age - 5 ½ year Father - Narendre Nath Shah Mother Barnali Nath Shah

Occupation-Police constable

Disability - Autism (Highper Active)

Since one year Hrti is getting regular intervention by the CBR workers of SANCHAR. Always his mother comes with him. He is a very active boy even one minute he can't sit in a single place.

Objective: -

To reduce the level of highper activism and to develop the concentration, through different activities, and try to teach about the things around them. *Intervention*: -

Practicing of matching different kind of toys, putting beeds into the pot, coloring in the picture and different circles. Mother is being taught through the CBR worker that in the home daily living activities should be in the regular practice. She can comes every week and consult their problem which she face during the week.

### **Previous condition:-**

Due to his high per activism he was not able to sit, he jumps and moves, he can nto remove his trouser himself before toilet activities and not put on him self often.

#### After intervention: -

After the intervention of CBR worker through **Open Day** programme he is able to do his saily living activities like toilet, bathroom, dressing, eating, but progressing very slow, so the CBR worker is doing regular counseling of her mother to give proper attention, and trying to play some teaching Games suggested by the CBR woker.

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See.	<b>1</b>		C.	<b>.</b>

## Status of the organization working with PWDs

NO. Of PWDs getting benefited by the Community Based Rehabilitation Programme. Now the organization is working in more then 100 villages of South 24 Parganas, district, with 760 persons with disabilities, for the community based rehabilitation programme.

Status or Work

No. of Villages – 100 No. of PWDs - 760

No. of families - 735

Persons with disabilities, age wise distribution, in the field area of SANCHAR.

Age group	0-5	o yrs	. 5	-10	71	0-	15	18	18-4	10 yrs	4	0+.	T	otal	Grand
			, )	TS .	15	yrs	yrs				÷γ	rs			Total
Natureof Disability	E	M	F	M	F	M	F	M	E	M	F	M	E	M	
Locomotor Disability	3	4	6	10	17	24	09	29	43	99	12	30	90	196	286
Visual Impairment	0	1	02	00	03	02	01	01	05	14	02	03	13	21	34
Hearing Impairment	00	01	12	10	14	16	07	11	32	28	01	03	66	69	135
Mentally Challenged	04	00	10	14	08	16	07	10	17	33	00	02	46	75	121
Multiple Disability	04	03	07	17	10	19	03	05	08	26	00	00	32	70	102
Epilepsy	01	00	00	01	04	02	07	05	29	31	00	02	41	41	82
Total	12	09	37	52	56	79	34	61	134	231	15	40	288	472	760
Grand Total	2	1	8	9	13	85	9	5	36	55	5	5	7(	50	

1 Sanchar annual report 2005-2006

Gender Distribution of person with disability in the field area.

Natureof Disability	Male	Female	Total
Locomotor Disability	196	90	286
Visual Impairment	21	13	34
Hearing Impairment	59	66	135
Mentally Challenged	75	46	121
Multiple Disability	70	32	102
Epilepsy	41	41	80
Total	462	288	760

### 4.06 Resource support activities

Like a resource group every year SANCHAR conducts various activities in the field of CBR at individual level and organizational level. Mainly the organization is supporting or carrying out four types of activities like, training, Publication, Networking & Advocacy, and fund raising.

#### 4.07 Training: -

SANCHAR is a training center for the partner organizations of the CBR Forum, and for CAPART (Council for Advancement of Peoples Action and Rural Technology) to train the programme coordinators and field workers who are will or who are working in their respective field areas. This is goes for 40 days through out the year divided in three phases.

First phase of training consist in 15 days training, the main focus of this training is the identification of the of person with disability, it involves:

- 1 Introduction of disability with the Identification.
- 2 Concept of Community Based Rehabilitation.
- 3 Causes and Prevention of disability
- 4 Locomot disability

This training is done through field visits and class orientation.

After this training the organization conducts two days orientation programme for the Board of members of the partner organizations, to sensitized them toward CBR and its importance.

After this programme the second phase of training for 12 days comes for only the coordinators of the partner's organizations, to make them understand their rolls and responsibilities, towered CBR, PWD Act 1995, and various schemes of Govt. and other organizations. Third phase of training comes for 18 days, after finishing the second phase. In this phase organization Again they calls all the coordinators and CBR workers, with their all the documents, to review and reflection of their experience regarding CBR.

The Training staff of **Sanchar** visits in the field of the partner organizations for 7 days, between 15 and 18 days training of the partners organizations, to help and look for their activities, and gives necessary inputs. These 7 days training is the part of 42 days training programme through out the year.

### 4.08 Publications

SANCHAR also work on publication. There are numbers of Magazines and Books in English and other languages on the disability published by the various publications, but very few efforts have been made in Bengali Language. So the Publication of Aanya Bhovan (Another World) is a great effort develops the understanding of Bangali reader's toward disability. This is a Quarterly issue, contain various topics regarding disability. In every quarter one issue is raised through the magazine and different articles are being written down through the experts. This magazine includes Life cases histories, books for the readers who want to know more regarding a given topic. Brail version of this magazine is also available in Bengla language, by the effort of **Sujit Karmakar** a visually challenged person in SANCHAR staff.

Besides this the annual report is also being published by the SANCHAR contain different activities case histories, support, and financial statements for the year. In spite of all these things different leaflets and written material got published from time to time.

(Refer the annexure 4.08, for the magazine)

## 4.4.09 Advocacy & Networking

- In the field of advocacy and networking SANCHAR is involved on various level with govt. and other developmental organizations, and working more then 40 ODOs (other Developmental Organisations) on the developmental and disability issue. Like SANCHAR is the member of State Resource group (SRG) for the integrated education for disabled.
- Sanchar is working as a district level resource group
- SANCHAR is one of the active members of the Disability Activists Forum.
- State and district level member of Sarva Shiksha Abhiyan.
- Member of SWASTHA a West Bangal network & initiative on women's heath.
- Member of network and campaign to Stop Violence Against Women and Girls.

Beside this a continuous network groups SANCHAR is involved to enforce the implementation of PWD Act 1995, on the respective govt. authorities.

## 4.4.10 Funding

There is a long list of the funding organizations that are supporting to the activities of SANCHAR in the respective field. Donation from MIBLOU, Switzerland for administration expenses, vocational training programmes.

Donation from Doundation Lord Michelham for hearing aids.

Donation from Mrs.Baldwin, London for visual disability project, donation from local resources, district primary education programme, research/projects, fund raising, consultancy etc.

### **CHAPTER FOUR**

## 4.5 Advocacy and CBR

## 4.5.1 MY UNDERSTANDING ABOUT ADVOCACY:

ADVOCACY as I understood from my field experience, is a process that ensures that the **rights** of vulnerable people are **protected**, that their **selfdefined needs are met**, and that **they are supported to make decisions** that affect their lives. It is also a vital component of patient protection, assuring that the vulnerable person's legal and human rights are respected, and that their self-determination, independence and autonomy are maintained.

"Advocacy" is a positive approach; it emphasizes a person's capacity for autonomy and ability. Particularly it offers assistance in understanding the options available, and in communicating personal preferences to others. In cases where a vulnerable person cannot instruct an advocate and is at risk of abuse or neglect, an advocate's intervention may be seen as "protection." Hence, this dimension of "protection" is included within the concept of "advocacy." It is a wining people's heart, by their favoring and doing some thing through a legal way it a fight for the rights of the most vulnerable peoples in the community. It is a process to gather people and make people aware of their rights duties and responsibilities.

It could be defined by many ways but it could be briefly defined as an action in the community through its legal roots.

# 4.5.2 HISTORICAL CONCEPT OF ADVOCACY

Most of the people think that Advocacy is a new thing, but in my opinion it is not right. We can accept it as an emerging concept but not new one. We could see its existence right from the beginning - Whether it could be the age of the emperors or earlier period of industrial revolution in the Europe or later one. In every time advocacy existed in different forms.

In the ancient period or time the king were listen to the voice of their citizens about their rights and duties what had to provided by the king in their kingdom. Their common citizens could bring their problems and complaints if some one violated their rights. It was a kind of individual advocacy.

After this from time to time the concept has been converted in various ways or forms and took different shapes. Advocacy can be done individually or together against their violation of rights or illegal custom and traditions to protect human being and promote self-confidence in participation in the society the kind of advocacy since the early period. For instance, **Raja Ram Mohun Roy** movement against the wrong customs and traditions and especially against **Satipradha**, Mahatma Gandhi's movement against **untouchabilty** and , **Bharat Chodo Andolan** and breaking Salt Law in India and non discrimination movement in South Africa are a successful type of advocacy which is being conducted since earlier periods of this millennium. It's has been proved that the process or concept of advocacy is not new but it is changing from time to time and now its in pure form.

## 4.5.3 CBR AND ADVOCACY

As it had mentioned before that the CBR is a holistic rehabilitation process done by the combined efforts and involvement of PWDs, family and the community members. It existed and practiced by the community and the family members in an informal way for centuries. Community based rehabilitation gained formal recognition and worldwide acceptance after only with its promotion by the World Health Organisation and other UN Agencies in early 80's. It was since promoted in a suitable method of rehabilitation of PWD's with and within the community level. The term of CBR has assigned to numerous concepts yet one way to understand CBRs as a group process and in this group process we are looking after the goals that are expected to achieve and these goals are also the part of advocacy like :-

- 1. How much we can create awareness or through the person with disabilities on the issued on their rights, responsibilities, their full participation in the community through the barrier free environment, change the attitudinal awareness about their ability, capacity and creativity?
- 2. How much we can enhance the capacity or activity of daily life of PWDs?
- 3. How much we can make them motivate and educate towards their rights and entitlement given by the legislation?
- 4. How we can make cohesion of PWDs with the mainstreaming society, to demand for their rights, Public Health Services and other services not completely met by the Government or the local authority?

If we look at all the above questions, we will find that advocacy is the appropriate tool by which we can achieve the desired goals, objectives or priorities decided by the community or person with disability for their full inclusion and participation with their abilities in the main streaming society. As Science has its laboratory for experiment to get the desired results, the CBR is the laboratory for advocacy science.

### 4.5.4 NEED OF ADVOCACY IN CBR.

In the course of the time welfare services were provided by the organizations in the sense of the charity and pity for their state of isolation, or segregation. But by the time and especially since the 80's the concept of

Rehabilitation is becoming much stronger and gradually shifting its paradigm from institutions to the community. As CBR expands from the small to the large icon, new researches and the advocacy issues raising and demanding for their rights will be the driven force to take the new initiatives. Now gradually more and more paradigm are shifting and the greater importance is being given to the Policy Development, Programme Planning, Monitoring, demand of the good and efficient structure, result oriented and right based public policies. These are opening the ways for the Advocacy for the community and especially in the field of CBR.

The issues demanding advocacy are the attitudinal and the behavior of the community, inaccessibility and environment with a lot of barriers for the persons with disability and the society, their discrimination and isolation within the community, Economical backwardness or poverty, lack of accessibility of the public health services and expensive private health care systems, Exclusion from the mainstream society. These issues have lead the organizations and the individuals to take of activities of advocacy in a vigorous manner. This is aiming at protecting and demanding for their fundamental human rights and entitlements given by the legislation, which is giving the greater, emphasize to the need for Advocacy

## 4.5.5 Steps in Advocacy:

Before analyzing the steps involved in the 'advocacy', it is worth understanding the concept of Advocacy. AS it is mentioned before that advocacy is the a kind of favour or to work for some one through legal action, it could be individually or together. It dose not define or favour for the particular things but it takes into account all the persons together and work for them. In the community Based Rehabilitation we demand for the inclusion of persons with disability, so when we talk about advocacy in the CBR programme, we talk about issues of common interest or problems faced by the local, poor and marginalized persons of the community. It calls mainstreaming advocacy concerned not only with the Persons with Disabilities but the whole community.

# 4.5.5.1. Location and Identification of issues

This is the first step of the Advocacy. In this step the problem identification is a major task, these problems should be concerned to the community, but it should be looked that how much the persons with disabilities are affected from the problem.

The easiest way to find out and frame an issue is in the form of a question. Try to create public opinion about the problem.

For instance :-

1) Problem- for Persons with disabilities to get medical certificate.

It is not easy Issue – Is it not a duty of the State/ District administration to ensure persons with disabilities get their medical certificate?

2) Problem- Public toilets are not accessible to disabled people

(cross disability) Issue - Is access to public facilities a violation of disabled peoples' rights?

3) Problem- In school, the teachers did not allow a child who has physical impairment to take part in sports. Issue- is there not a duty for the teacher to treat children equally and with respect and dignity? 4) Problem – persons With Disabilities are not getting the power connection they have to pay more for the electric line from the pole to their house. This is a common problem in the rural areas. Often electric polls dose not situated near the every ones house.

Issue – it is the duty of the govt. to provide single free connection

## 4.5.5.2 Establish Goals

Next step after the identification of the issue is to establish the goal, that what we want to do by this problem; what is our objective to achieve by the advocacy of the problem.

What do we want? Or what could be achievable easily goal.

- 1. What are our achievable goals?
- 2. Identify short-term goals
- 3. Identify long-term goals, if necessary

Prioritize the goals. Deal with the urgent ones immediately. Then deal with and plan strategies for the rest. The goals have to be simply stated, list just those that can be handled and most importantly they have to be feasible.

# 4.5.5.3 Framing The Problem

The framing of the problem teach about the causes of the problem, that what is the real cause of the problem. This section asks about the following question.

- What is the problem?
- Where did it occur?
- When did it happen? Is it a one time thing or a recurring problem?
- Who were the violators or people who can help, do something about it?
- How did this all come about
- 1. Identify your stand and position on it.

 Say your short term and long -term goals. Short term and long goals should well define and listed. It helps to set the priorities and to take action according it.

### 4.5.5.4 Social Mobilization

Social mobilization is the most important tool of the Advocacy. This is the only way that full fill the concept of CBR and ensures the community participation and the maximum use or utilization of the available resources. The value of this step of "social mobilization" is to show that people need to work together. This is the feature of the CBR that it involve the community in every work of common goal and motivate to take necessary steps whether it , Advocacy or other mobilization toward the community welfare.

### **Coalitions, Networking and Mobilization of people**

- 1. Organize on the basis of issues or disability.
- 2. Connect with people from cross disabilities.
- 3. Make up for each other's limitations and supplement each other's work.
- 4. Meet regularly and have a good reporting system between groups.
- 5. Network with other social organizations and grassroots groups.
- Be involved with other issues; women's rights, children's rights, tribal/adivasi movements.
- 7. Speak and communicate with Government officials, media people, teachers, professionals, corporate sector, etc.
- 8. Assess who are friends, fence-sitters, opponents.

### 4.5.5.5 Different tactics for different target groups

Speak about the different groups and the skills required from each. **Legislative** – lobbying, questions in parliament.

Courts – Public Interest litigation, criminal complaints, civil remedies

**Police** – Sensitize police persons

**Bureaucracy** – Meet the good guys, keep a list of people in various **departments** and **ministries** – **central and state** – names and numbers.

### Some of the Key strategies and action

Advocacy is a pro-active, planned and co-coordinated action. With practices, one should be able to anticipate events/ problems before they actually occur.

- Spreading awareness in public and among leaders, and create public opinion
- We should be aware about, Acts, Rights and Duties, given in the legislation or providing by the appropriate govt. understanding the real situation of person with disability or understanding their feeling is more important task while working toward Advocacy.
- Media action give information to public media
- Submit petitions, letters and memorandums to officials
- Lobbying with legislators and others, to raise the issue at a suitable forum
- Network and coalition with a wide variety of groups, organizations with whom a common working understanding can be reached. With this coalition we try to ensure that the group who are working in different fields can come together for the common causes, like
- Demonstrations, protests, dharnas, etc. are the main and important practical action shows or shore that people against the violation of their rights cant take any kind of action, and have a common plateform.
- Filing Public Interest Litigation (PIL)

(Steps of Advocacy are Mr. C. Mahesh and Mr. Chandru's notes of Advocacy and CBR)

## 5.6 Conclusion

In the developmental field every task consist in process, and process takes a long time to be completed, and some time it completed very fast. The success of the advocacy process is depends on the strategies, and the programme is prepared by the group. The identification of the problem is a very important task and with out that it is difficult to take any step forward for anything. Advocacy is a down to top process like a small plant grows up to tree. Every problem in the community creates scope for the advocacy, need is to identifies the problem, measure that how much a persons or the communities are suffering from that. It becomes more helpful for the integration of the persons with disabilities in their families and community. If the person with disabilities comes together and raise their voices for the common issues, it will show their ability activity and mobility, rather then disability.

### **CHAPTER FOUR**

## 4.6.1 Back ground of the PWD Act.1995

The persons with disability (equal opportunity and protection of rights and full participation) Act 1995.is a milestone in the field of disability. I think this is the first Act, talks about the rights and entitlements of persons with disabilities and provides the opportunity to them to participate in the community with their full potential and abilities.

I think that the Act is works on following three levels -

- 1 Governmental level (official)
- 2 Public level, and
- 3 Non governmental
- 1 Governmental level (official) At this level the role and responsibilities of the govt. toward the rights of persons with disabilities, formation of central level and State level coordination committees, district level rehabilitation centers and involvement of the Govt. and the civil societies at various level with and with out the govt. has defined. This Act takes into account implementation of the Act, and takes legal action against the violation of the rights of Persons with disabilities.
- 2 Public level the Act provides the rights and opportunities to the persons with disabilities for their equal participation with full potential and abilities, stop non discrimination in the community and public health services, departments, and structure, provides barrier free environment, reservation in employment, and relaxations in the various schemes and programme.
- 3 Non governmental level at this level Act provides the assistance, both financial and official and recognition to the institutions and the organizations working in the field of disabilities, mean while this Act has the provision of research and the manpower development for the persons with disabilities and establishment of new institutions to enhance capacity, mobility and participation of persons with disabilities.

But beside all of these features still this Act is unable to full fill the requirements of the persons with disabilities. Actually the problem starts with the certain kind of attitudinal behavior of Non disabled persons toward, the personas with disabilities. This attitude makes to the PWDs more disabled than they are. Up to some extent the word disability also creates a kind of stigma that the persons who are being addressed by this word has certain kind of disability, rather then abilities, so the need is to call them persons with different abilities.

Other reasons of failure, what I think, is that, lack of the monitoring of schemes providing by the government. Lack of responsibilities of the governmental officers, lack of awareness regarding the rights provided in the persons with disability Act 1995, to PWDs, lack of information regarding the implementation of the Act, are some causes contributing in the failure of the Act, and stopping us to get desired results.

# 4.6.2 Back ground of the UN convention on Disability

In the late 60s and 70s, people with disabilities started demanding rights, inspired by the civil rights and women's rights movements. The declaration of a UN international year of disabled people in 1981 was the beginning of a new international era in the disability movement, as it sent a strong and important message to the world. In 1982, the UN World Program of Action, a resolution aiming to improve the living condition of people with disabilities, was a milestone in raising international awareness.

UN International Decade of People with Disabilities 1983 - 1992 challenged the world's nations to implement plans to improve the living conditions for people with disabilities

In 1999, RI proclaimed the Charter for the New Millennium where it "calls on member states to support the promulgation of a United Nations Convention on the Rights of People with Disabilities." The Charter also says that "**Community Based Rehabilitation should be widely promoted nationally and internationally, as an affordable and sustainable approach to services.** 

(article

bv Tomas

Lagerwall

### Tokyo, June 8, 2005)

Seven UN Ad Hoc Committee meetings have been held since **July 2002**, and a majority of the world's nations and several international NGOs are now working together for a UN disability convention. I think that within few more years, countries will have introduced necessary amendments in their legislation and will make the policies to ensure the development, and equal participation of the persons with disabilities . It will then be up to all of us to make sure that governments ratify and implement the convention and ensure that the convention is well-known and used all over the country and the world.

And finally the 8<sup>th</sup> Ad Hoc Committee meeting complete from 14 to 24 august 2006 in NewYork. The objective of this meeting is that to prepare the final draft on the rights of persons with disability. 8<sup>th</sup> Ad Hoc committee has suggest many thing and rights based approaches for the persons with disabilities, and the all signatories bodies to implement it as soon as possible.

Health is a fundamental Human Right. As a community health worker I would try to suggest here some right-based approaches in the **Persons with Disabilities** (equal opportunity and protection of rights and full participation) Act 1995, in the light of 8<sup>th</sup> Ad Hoc committee draft in the UN convention on the rights of persons with disabilities. These suggestions are also based on what I felt during my field visits in different CBR programmes and discussions with my mentors.

<ul> <li>PREVENTATION AND EARLY DETECTION OF EARLY DETECTION OF DISABILITIES</li> <li>AWARENESS-RAISING</li> <li>25. Within the limits of their conomic capacity and development, the appropriate of adopt immediate, effective and appropriate measures to identifying and preventing the ocal authorities, with a view to greventing the ocare of or solution of preventing the ocare of occurrence of disabilities; shall-</li> <li>(a) Undertake or cause to be undertaken surveys, investigations and research rights and dignity; concerning the cause of occurrence of disabilities;</li> <li>(b) Promote various methods of preventing disabilities;</li> <li>(c) Screen all the children at least once in a year for the purpose of identifying "at-risk" cases;</li> <li>(c) Sponsor or cause to be sponsored awareness campaigns and is disseminated on cause to be disseminated on cause to be disseminated on cause to be sponsored awareness campaigns and is disseminated on cause to be sponsored awareness campaigns and is disseminated on cause to be disseminated on formation for general hygiene. Health and is distering and in disseminated on cause to be disseminated information for general hygiene. Health and is distering and in disseminated on cause to the disseminated on cause to be disseminated on cause to be disseminated on cause to be disseminated on cause to the disseminate on cause to be disseminated information for general hygiene. Health and is distering and in disseminated for preventing disabilities;</li> <li>(f) Take measures for pre-natal, parental and post-natal care of other and child;</li> <li>(g) Educate the public through the pre-schools, schools, schools</li></ul>	PWD ACT, 1995 THE PERSONS WITH DISABILITIES		Suggestion and amendments / read it as
EARLY DETECTION OF DISABILITIESAWARENESS-RAISING DEtection of Disability in child Women and Girls.25. Within the limits of their conomic capacity and development, the appropriate investigations and research 			Preventation and early
<ul> <li><b>bisinities</b></li> <li><b>c</b>. Sponsor or cause to be sponsored awareness campaigns and is disseminated information for general hygiene. Health and sanitation,</li> <li>(e) Sponsor or cause to be sponsored awareness campaigns and is disseminated or cause to be dissibilities;</li> <li>(f) Take measures for pre-natal, parental and post-natal care of general hygiene. Health and sanitation,</li> <li>(g) Educate the public through (g) Educate the public through</li></ul>		AWARENESS-RAISING	
<ul> <li>25. Within the limits of their conomic capacity and development, the appropriate conomic capacity and development, the appropriate measures:</li> <li>(a) Undertake or cause to be undertaken surveys, investigations and research including at the family level, regarding persons with disabilities;</li> <li>(b) Promote various methods of preventing disabilities;</li> <li>(b) Promote various methods of preventing disabilities;</li> <li>(c) Screen all the children at least one in a year for the purpose of identifying "at-risk" cases;</li> <li>(c) Provide facilities for training to the staff at the primary health centers;</li> <li>(c) Sponsor or cause to be sponsored awareness for pre-natal, not the idisseminated on formation for general hygiene. Health and sanitation,</li> <li>(g) Educate the public through (g) Educate through (g) Educate the public through (g) Educate through (g) Educate the public through (g) Educate the public through (g) Educate the public through (g) Edu</li></ul>	DISABILITIES		
<ul> <li>about miniteduate, economic capacity and development, the appropriate Governments and the local authorities, with a view to preventing the occurrence of disabilities, shall-</li> <li>(a) Undertake or cause to be undertaken surveys, investigations and research concerning the cause of occurrence of disabilities;</li> <li>(b) Promote various methods of occurrence of disabilities;</li> <li>(b) Promote various methods of occurrence of disabilities;</li> <li>(c) Screen all the children at least on a year for the purpose of identifying "at-risk" cases;</li> <li>(d) Provide facilities for training to the staff at the primary health concerns;</li> <li>(e) Sponsor or cause to be sponsored awareness campaigns and is disseminated information for general hygiene. Health and sanitation,</li> <li>(f) Take measures for pre-natal, and to the measures for pre-schools. schools.</li> <li>(g) Educate the public through (g) Educa</li></ul>		A REAL PROPERTY AND A REAL	
<ul> <li>development, the appropriate Governments and the local authorities, with a view to glashilities, shall-</li> <li>(a) Undertake or cause to be undertaken surveys, investigations and research concerning the cause of disabilities, and to foster respect for their rights and dignity; concerning the cause of concerning the cause of occurrence of disabilities;</li> <li>(b) Promote various methods of preventing disabilities;</li> <li>(b) Promote various methods of identifying "at-risk" cases;</li> <li>(c) Provide facilities for training to the staff at the primary health conter and sequences of adisabilities.</li> <li>(c) Sponsor or cause to be sponsored awareness campaigns and is disseminated information for general hygiene. Health and sanitation,</li> <li>(g) Educate the public through</li> <li>(a) Educate the public through</li> <li>(b) To promote positive</li> <li>(c) Screen all due child;</li> <li>(c) To promote awareness of the capabilities.</li> <li>(c) Sponsor or cause to be sponsored awareness for pre-natal, garental and post-natal care of the sonsored awareness for pre-natal, parental and post-natal care of consortious and promote positive</li> <li>(d) Educate the public through</li> <li>(ii) To promote positive</li> <li>(iii) To promote positive</li> </ul>			
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<ul> <li>and is disseminated or cause to be disseminated information for general hygiene. Health and sanitation,</li> <li>(a) Initiating and maintaining effective public awareness campaigns designed:</li> <li>(b) Take measures for pre-natal, parental and post-natal care of mother and child;</li> <li>(c) Educate the public through the pre-schools, schools, schoo</li></ul>	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	include:	
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<ul> <li>(f) Take measures for pre-natal, parental and post-natal care of mother and child;</li> <li>(g) Educate the public through the pre-schools, schools, schools</li></ul>		1 8	
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E) state parties shell take	the pre-schools, schools,	perceptions and greater	E) state parties shell take

<ul> <li>level workers and anganwadi workers;</li> <li>(ii) To promote recognition of the skills, merits, abilities and contributions of the skills, merits, abilities and contributions of persons with disabilities;</li> <li>(b) Fostering at all levels of the education system, including in all children form an early age, attitude of respect for the rights of persons with disabilities;</li> <li>(c) Encouraging all organs of the media to portray for the media to portray for the quart disabilities;</li> <li>(d) Promoting awareness training programmer Convention;</li> <li>(d) Promoting awareness training programmer consistent with disabilities and their rights.</li> <li>For the garticla, econom and other fundamental H Rights.</li> <li>For the girls with disability to part in the community disabilities and their rights.</li> <li>For the garting persons with disability of the case of denial of their sc convention;</li> <li>(d) Promoting awareness training programmer egarding persons with disabilities and their rights.</li> <li>For the gart disability to part in the community at an deter fundamental H Rights.</li> <li>The State parties protect any kind of denial human and Fundamental rid discrimination in educe employment and rehability volence at work place and kind of Physical, mental, sc harassement, against Girls disabilities.</li> </ul>			
Mission. - The State parties protect any kind of denial human and Fundamental ri discrimination in educa employment and rehabilita violence at work place and kind of Physical, mental, se harassment, against Girls disabilities.	<ul><li>level workers and anganwadi workers;</li><li>(h) Create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to be</li></ul>	<ul> <li>persons with disabilities;</li> <li>(iii) To promote recognition of the skills, merits, abilities and contributions of persons with disabilities to the workplace and the labour market;</li> <li>(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;</li> <li>(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;</li> <li>(d) Promoting awareness training programmes regarding persons with</li> </ul>	<ul> <li>enjoyment of Human rights and fundamental freedom.</li> <li>for the enjoyment and exercise and enjoyment of fundamental freedom</li> <li>For the participation protection and promotion of Political freedom state parties should reserve the seats for the women with disability in Gram Panchayat, Nagar Panchayat and Ward Member Election.</li> <li>Govt. will promote SHGs of PWDs (especially women's) at every level and will take appropriate to come together in the case of denial of their social, cultural, political, economical, and other fundamental Human Rights.</li> <li>For the girls with disability to take part in the community as a "ASHA" workers under the</li> </ul>
the state parties shell appropriate measure to			govt. should make provision to select girls with disability to take part in the community as a "ASHA" workers under the NASHA" National Rural Health Mission. - The State parties will protect any kind of denial like, human and Fundamental rights, discrimination in education, employment and rehabilitation, violence at work place and any kind of Physical, mental, sexual harassment, against Girls with disabilities. - Children with disability, the state parties shell take

	- State parties shell make policies and take legislative measures to stop of child labour for child with disability. (Article 7) - State shell be responsible for the appropriate habilitation and rehabilitation of CWDs with the parents and within the community.
	(Article - 15) – no one will be subject to inhuman or cruel torture or degrading treatment and punishment especially persons with disability.

CHAPTER V	ARTICLE 24 –	
EDUCATION	EDUCATION	
		Suggestion or
26. The appropriate	1. States Parties recognize	Amendments
Governments and the local	the right of persons with	
authorities shall-	disabilities to education.	Education is a
	With a view to realizing this	fundamental Human
(a) Ensure that every child	right without discrimination	Right.
with a disability has access	and on the basis of equal	1. Appropriate govt. at the
to free education in an	opportunity, States Parties	central and state levels
appropriate environment till	shall ensure an inclusive,	should ensure equity, non
he attains the age of	education system at all	discrimination and barrier
eighteen years;	levels, and life-long	free environment and
	learning, directed to:	recognize the rights of
(b) Endeavor to promote the		PWDs with inclusive
integration of students with	(a) The full development of	education system at all level
disabilities in the normal	the human potential and	with life long learnings
schools;	sense of dignity and self	directed to –
	worth, and the strengthening	a) The full development of
© Promote setting up of		,
special schools in	fundamental freedoms and	Human potential and
Government and private	human diversity;	the sense of dignity self
sector for those in need of		worth, strengthening
special education, in such a	(b) The development by	the respect of Human
manner that children with	persons with disabilities of	rights fundamental freedoms and Human
disabilities living in any part	their personality, talents and	
of the country have access	creativity, as well as their	dignity. b) The development of
to such schools;	mental and physical	1
	abilities, to their fullest	personality talent and
		creativity as well as

(d) Endeavor to equip the special schools for children with disabilities with vocational training facilities.	(c) Enabling persons with	c)	physical and mental ability to their full potential. The purpose of the education should be
<b>27.</b> The appropriate Governments and the local authorities shall by potification make schemet			Enabling to the PWDs to participate in decision-making planning
notification make schemes for- (a) Conducting part-time	2. In realizing this right,	1	implementation and monitoring fully and effectively in a free
classes in respect of children with disabilities who having completed education up to	States Parties shall ensure:	1	society. The appropriate govt. ensure the necessary changes in
class fifth and could not continue their studies on a whole-time basis;	a) That persons with disabilities are not excluded from the general education	t 1 2.	he syllabus of persons with disability Govt. and local rities : -
(b) Conducting special part- time classes for providing functional literacy for children in the age group of sixteen and above;	system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary and secondary education on the	a) H c a p e	Ensure every child with lisability have equal access to inclusive, free primary and secondary education on the equal
© Imparting non-formal education by utilizing the available manpower in rural areas after giving them appropriate orientation;	<ul> <li>basis of disability;</li> <li>(b) That persons with disabilities can access an inclusive, quality, free primary and secondary</li> </ul>	a fi n ii	pasis with others in an ppropriate and barrier ree environment in the mainstreaming schools in the community in which they are living
(d) Imparting education through open schools or open universities;	education on an equal basis with others in the communities in which they live;	d b) E sl	vithout any iscrimination. Insure that PWDs hould not be excluded rom generale
(e) Conducting class and discussions through interactive electronic or other media;	© Reasonable accommodation of the individual's requirements; (d) That persons with	e o re	ducation on the basis f their cast, class, eligion, race, and specially on the basis
(f) Providing every child with disability free of cost special books and equipments needed for his education.	disabilities receive the support required, within the general education system, to facilitate their effective education;	c) E th re ac	f disability. ndeavor to promote ae integration and casonable ccommodation on the dividual's
<b>28.</b> The appropriate Governments shall initiate	(d) bis That effective individualized support measures are provided in	Pe	equirements of the erson With Disability. Insure that the PWDs

or cause to be initiated		the opportunity our
research by official and non-		(children with
governmental agencies for	1 ,	disabilities) will receive
the purpose of designing	with the goal of full	the required support
and developing new	inclusion.	and assistance with and
assistive devices, teaching		within the general and
aids, special teaching		special education
materials or such other	3. States Parties shall enable	
items as are necessary to	persons with disabilities to	their effective
give a child with disability	learn life and social	education and
equal opportunities in	development skills to	vocational trainings.
education.	facilitate their full and equal	e) The state govt. make
	participation in education	
	and as members of the	
29. The appropriate	And a second state of the	effective policies and
Governments shall set up		programmes at every
•		level for the special
	appropriate measures,	education and
8	including:	schooling for the
institutions and assist the		children with disability
national institutes and other		with appropriate pre-
voluntary organizations to	(a) Facilitating the learning	vocational training and
develop teachers' training	of Braille, alternative script,	will include pre
programmes specializing in	augmentative and	vocational training as
disabilities so that requisite	alternative modes, means	an integrated
trained manpower is	and formats of	component of the
available for special schools	communication, orientation	special education
and integrated schools for	and mobility skills, and	syllabus.
children with disabilities.	facilitating peer support and	3. State govt. enable PWDs
	mentoring;	to learn life and social
	8,	development skills to
9		facilitate their full and equal
30. Without prejudice to the	(b) Facilitating the learning	
	of sign language and the	participation in the education as a effective and
appropriate Governments	000	
shall by notification prepare	promotion of the linguistic	respected members of the
	identity of the deaf	community. To this end
a comprehensive education	community;	state parties take appropriate
scheme which shall make		measure including:
Provision for-	© Ensuring that the	a) Facilitating the learning
	education of persons, and in	of Braille, alternative
(a) Transport facilities to the	particular children, who are	script, augmentative
children with disabilities or	blind, deaf and deaf-blind, is	and alternative modes,
in the alternative financial	delivered in the most	means and formats of
incentives to parents or	appropriate languages and	communication,
guardians to enable their	modes and means of	orientation and mobility
children with disabilities to	communication for the	skills, and facilitating
attend schools.	individual, and in	peer support and
	environments which	mentoring;
(b) The removal of	maximize academic and	b) Facilitating the learning
	uoudennie and	of a contacting the reatining

	1	T
architectural barriers from schools. Colleges or other	social development.	of sign language and the promotion of
institution, imparting		the linguistic identity of
vocational and professional	4. In order to help ensure the	the deaf community.
training;	realization of this right, States Parties shall take	4. In order to ensure the
© The supply of books,	appropriate measures to	protection and realization of
uniforms and other materials	employ teachers, including	rights state parties -
to children with disabilities	those with disabilities, who	a) Take appropriate measure to employ teachers including those with
attending school.	are qualified in sign	disability who are qualified in Braille and other sign languages, and to train
	language and Braille, and to	professionals and the staff who are
(d) The grant of scholarship	train professionals and staff	working in the field of education.
to students with disabilities	who work at all levels of	b) Setup adequate numbers
	education. Such training	
(e) Setting up of appropriate	shall incorporate disability	of teachers training
fora for the redressal of	awareness and the use of	
grievances of parent,	appropriate augmentative	institutions and assist
regarding	and alternative modes,	the national institutions
the placement of their children with disabilities;	means and formats of	the national institutions
cindren with disabilities,	communication, educational	and others voluntary
(f) Suitable modification in	techniques and materials to support persons with	and others voluntary
the examination system to	support persons with disabilities.	organizations or
eliminate purely	uisaonnies.	organizations of
mathematical questions for		develop teachers
the benefit of blind students	5. States Parties shall ensure	
and students with low	that persons with disabilities	training programmes,
vision;	are able to access general	
	tertiary education,	specializing in different
(g) Restructuring of	vocational training, adult	
curriculum for the benefit of	education and lifelong	types of disabilities
children with disabilities;	learning without	~
	discrimination and on an	fields so that requisite
- <sup>-</sup>	equal basis with others. To	4
	this end, States Parties shall	trained human resource
	ensure that reasonable	including PWDs could
	accommodation is provided	including I wDs could
	to persons with disabilities.	be available for the
		be available for the
		special schools,
		integrated mainstream
о 		schools with inclusive
		Seneois with metusive
		education and barrier

	free and non-
	discriminated
	environment, for the
	children with disability.
	d) Reasonable accessible and barrier free accommodation and reservation in the accommodation must be provided by the govt. as per need of the person with disability.
	e) Govt. by notification do necessary adjustment according to the Need of Persons With Disability, in the
	structure of all their departments or public places, like health institutions, education institutions, and in all
	others governmental and non governmental institutions funded fully or partially and to be
	funded by the govt. for the maximum accessibility, and enjoyment of Human
	rights. Intervention of the PWDs in bodies to implement these measures.
	f) To monitor the implementation state govt. with the help of
	the district and block panchyats, form the local bodies of PWDs including their family members or others members in the
	community, at the gram

		panchayat level.
CHAPTER VI		EMPLOYMENT
EMPLOYMENT	AND EMPLOYMENT	
	1. States Parties recognize	Article 27
<b>32.</b> Appropriate	the right of persons with	(Following are the sdditional inclusion from the UN Adhoc Suggestions)
Governments shall—	disabilities to work, on an	nom the Ort Autoe Suggestions)
(a) Identify posts, in the	equal basis with others; this	
establishments, which can	includes the right to the	31. State parties will
be reserved for the persons	opportunity to gain a living	recognized the right of
with disability;	by work freely chosen or	persons with disabilities to
(b) At periodical intervals	accepted in a labour market	work on equal basis with
not exceeding three years,	and work environment that	others; this include the rights
review the list of posts	is open, inclusive and	of the opportunity to gain a
identified and up-date the	accessible to persons with	living by work freely chosen
list taking into consideration	disabilities. States Parties	or accepted in a labour
the developments in	shall safeguard and promote	market and work
technology.	the realization of the right to	environment that should be
<b>33.</b> Every appropriate	work, including for those	open inclusive and
Government shall appoint in	who acquire a disability	accessible to the PWDs.
every establishment such	during the course of	State shell recognized the
percentage of vacancies not	employment, by taking	right to work including for
less than three per cent. for	appropriate steps, including	those who acquired the
persons or class of persons	through legislation, to, inter	disability during the course
with disability of which one	alia:	of employment by taking
per cent. each shall be		appropriate steps including
reserved for persons	(a) Prohibit discrimination	through legislation to inter
suffering from-	on the basis of disability	alia;
(i) Blindness or low vision;	with regard to all matters	54°
(ii) Bearing impairment;	concerning all forms of	(a) Prohibit discrimination
(iii) Loco motor disability or	employment, including	on the basis of disability
cerebral palsy, in the posts	conditions of recruitment,	with regard to all matters
identified for each	hiring and employment,	concerning all forms of
disability:	continuance of employment,	employment, including
Provided that the	career advancement, and	conditions of recruitment,
appropriate Government	safe and healthy working	hiring and employment,
may, having regard to the	conditions;	continuance of employment,
type of work carried on in		career advancement, and
any department or	(b) Protect the rights of	safe and healthy working
establishment, by	persons with disabilities, on	conditions;
notification subject to such	an equal basis with others,	
conditions, if any, as may be	to just and favorable	(b) Protect the rights of
specified in such	conditions of work,	persons with disabilities, on
notification, exempt any	including equal	an equal basis with others, to
establishment from the	opportunities and equal	just and favorable conditions
provisions of this section.	remuneration for work of	of work, including equal
	equal value, safe and	opportunities and equal
34. (1) The appropriate	healthy working conditions,	remuneration for work of

Governmentmay,byincluding protectionfromnotification.redressing of grievances;specified.By notification.The employer in everyEnsure that persons withas may be prescribed inin trade union rights on anabsability that have occurred(d) Enable persons withdisability that have occurred(d) Enable persons withdisability that have occurred(d) Enable persons withdisability that have occurred(d) Enable persons withor are about to occur in thataccess to general technicalspecialEmploymentprescribedandthe intervals of time for(e) Promote employmentwhich information or returnsestabilishment shallcontains shall be such as may(e) Promote employmentshall be furnished and(f) Promote opportunitiesand ereurningtoshall be furnished and(f) Promote opportunitieshave access to any relevant(f) Promote opportunitiesrecord or document in the(g) Employment,possession ofanyestabilishment, and may(g) Employ persons withdocument to be, and inspect(g) Employ persons withdocument to be, and inspect(g) Employ persons withand y question necessary for(h) Promote the employment,or take copies of relevant(f) Promote the employment,records or document to year any(g) Employ persons withand y question necessary(h) Promote the employment,otatimity any question			
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<ul> <li>particulars, they shall contain shall be such as may be prescribed.</li> <li><b>32.</b> Appropriate Governments shall— <ul> <li>(a) Identify posts, and the employment shall multiply posts, and the employment;</li> <li>(b) At periodical intervals for self-employment, entrepreneurship, the possession of any elevant record or document in the possession of any establishment, and may enter at any reasonable time and premises where he believes such record or document to be, and inspect or take copies of relevant records or documents or ask any question necessary for obtaining any information.</li> <li><b>36.</b> Where in any rearrector or any the fulled up due to non-availability of a suitable person with disability or, for any other sufficient reason.</li> </ul> <ul> <li>(b) Promote opportunities in the public or take copies of relevant records or documents or ask any question necessary for obtaining any information.</li> <li><b>36.</b> Where in any reasonable time on-availability of a suitable person with disability or, for any other sufficient reason.</li> </ul></li></ul>			as lolows)
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non-availability of a suitable person with disability or, for any other sufficient reason.			1 - 5,
person with disability or, for any other sufficient reason. other measures; and starting one's own business;	-	include affirmative action	-
any other sufficient reason. business;		programmes, incentives and	
any other sufficient reason.	-	other measures;	
(d) Promote employment	any other sufficient reason,		
			(u) Promote employment

such shall be vacancy carried forward in the succeeding recruitment year and if ;r the succeeding recruitment year also suitable person with disability is not available, it may first be filled by interchange among the three categories and only when there is no parson with disability available for the post in that Year. the employer shall fill up the vacancy by appointment of a person, other than a person with disability: Provided that if the nature of vacancies in an

establishment is such that a given category of person can not be employed, the vacancies may be interchanged among the three categories with the prior approval of the appropriate Government.

**37. (1)** Every employer shall maintain such record in relation to the person. With disability employed in his establishment in such form and in such manner as may be prescribed by the appropriate Government.

(2) The records maintained under sub-section (1) shall be open to inspection at all reasonable hours by such persons as may be authorized in this behalf by general or special order by the appropriate Government. 38. (1) The appropriate Governments and local authorities shall by notification formulate schemes for ensuring

(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

(k) Promote vocational and professional rehabilitation, job retention and return-towork programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding. obtaining and maintaining and returning to employment;

(e) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

(f) Employ persons with disabilities in the public sector;

(g) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

38. (1) The appropriate Governments and local authorities shall by notification formulate schemes for ensuring employment of persons with disabilities, and such schemes may provide for-(Additional inclusion in 38 (1) article) (g) Ensure that reasonable accommodation is provided in the workplace; and Promote vocational and professional rehabilitation. job retention and return-towork programmes for persons with disabilities.

39. All governmental educational institutions and the local authorities and

other educational institutions employment of persons with getting aid from the govt. such disabilities. and shell not only reserve, not schemes may provide forless then three present seats (a) The training and welfare for the PWDs, but also will of persons with disabilities; be responsible for full participation with out any (b) The relaxation of upper discrimination and fully age limit; the enjoyment of employment as a right, by Regulating the C their full participation and employment; barrier free environment. (d)Health and safety measures and creation of a non-handicapping environment in places where persons with disabilities are employed; (e) The manner in which and the person by whom the of operating cost the schemes is to be defrayed; and (f) Constituting the authority responsible for the administration of the scheme. 39. All Government educational institutions and educational other institutions receiving aid from the Government, shall reserve not less than three per cent seat for persons with disabilities. 40. The appropriate Governments and local authorities shall reserve not less than three per cent. in alleviation all poverty schemes for the benefit of persons with disabilities. 41. The appropriate Governments and the local authorities shall, within the limits of their economic capacity and development, provide incentives to

employers both in public		
and private sectors to ensure		
that at least five per cent of		
their work force is		
composed of persons with		
disabilities.		
CHAPTER VII	ARTICLE 28 –	AFFIRMATIVE ACTION
AFFIRMATIVE	ADEQUATE STANDARD	ATTRONATIVE ACTION
ACTION	OF LIVING AND	
	SOCIAL PROTECTION	
		42-a- To provide aids and
<b>42.</b> The appropriate governments shall by	1. States Parties recognize	appliances and to create
notification make schemes to	the right of persons with	awareness about disability,
provide aids and appliances to	disabilities to an adequate	and schemes and
persons with disabilities.	standard of living for	programmes, and rights
<b>43.</b> The appropriate Governments and local	themselves and their	provided by the legislations,
authorities shall by	families, including adequate	among the general public,
notification frame schemes in	food, clothing and housing	and especially among the
favor of persons with	and to the continuous	Persons With Disabilities.
disabilities, for the preferential allotment of land	improvement of living	rensents with Disubilities.
at concession] rates for-	conditions and shall take	b) Government will take all
(a) House;	appropriate steps to	the necessary action and all
(b) Setting up business;	safeguard and promote the	the possible means like
© Setting up of special	realization of this right	media both electronic and
recreation centers;	without discrimination on	Print, Radio or the means
(d) Establishment of special	the basis of disability.	available in the and has the
schools;		approach in the rural areas
(e) Establishment of	2. States Parties recognize	and through public
research centers;	the right of persons with	institutions & networks like
(f) Establishment of	disabilities to social	Panchayat, youth group,
factories by entrepreneurs	protection, and to the	yuva kendra, Nav yuvak
with disabilitiesriate Go	enjoyment of that right	Mandals, and various
	without discrimination on	committees, nari samuha,
	the basis of disability, and	Self Help groups,
	shall take appropriate steps	Anganwadies, ANMs, and
	to safeguard and promote	other govt. Bodies, for
	the realization of this right,	accessing and these
	including measures:	schemes.
	5	
	(a) To ensure equal access	Artcle 28 – State parties and
	by persons with disabilities	local authorities, will ensure
	to clean water services, and	by the notification to equal
	to ensure access to	access to appropriate and
	appropriate and affordable	affordable primary health
	services, devices and other	care, and Public health
	assistance for disability	services, devices, (Aids and
	related needs;	appliances) and other health

<ul> <li>(b) To ensure access by persons with disabilities, in particular women and girls with disabilities and the aged with disabilities and the aged with disabilities, to social protection programmes and poverty reduction programmes;</li> <li>(c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses (including adequate training, counseling, financial assistance and respite care);</li> <li>(d) To ensure access by persons with disabilities to public housing programmes;</li> </ul>	care according to the needs, especially for the women, girls, and old age persons with disabilities, like – clean and safe drinking water, proper immunization, Mid day meal availability and accessibility to the maximum number of children with disabilities, free or subsidies Power Supply, sanitation, Public Housing, Rehabilitation and prevocational training centers etc. <b>28-2-c-</b> equal access by PWDs to the retirement benefits and programmes, and increment in the amount of old age pension scheme then a non-disabled person.
(e) To ensure equal access by persons with disabilities to retirement benefits and programs.	

CHAPTER VIII NON- DISCRIMINATION 44. Establishments in the transport sector shall, within the limits of their economic capacity and development for the benefit of persons with disabilities, take special measures to- (a) Adapt rail compartments, buses. Vessels and aircrafts in such a way as to permit easy access to such persons; (b) Adapt toilets in rail compartments, vessels,	ARTICLE 5 - EQUALITYANDNON-DISCRIMINATION1. States Parties recognizethat all persons are equalbefore and under the lawand are entitled without anydiscrimination to the equalprotection and equal benefitof the law.2. States Parties shall	EQUALITY AND NON- DISCRIMINATION AND EQUAL RECOGNISATION BEFORE THE LAW. Article 5-(this will be add in Act article 44) 1. State parties shell recognize by the notification that all the persons with disabilities are equal before the law and are entitled with out any discrimination to the
	allag Gebere scene 1004	the law and are entitled with

<b>45.</b> The appropriate	disabilities equal and	Is	hell-
Governments and the local	effective legal protection		
authorities shall, within the			1
limits of their economic	against discrimination on all		discrimination in any
capacity and development.	grounds.		Public place, Public
Provide for-			services, Public
(a) Installation of auditory	3. In order to promote		Buildings, and Public
signals at red lights in the	equality and eliminate		
public roads for the benefit of			facilities, Public policies,
persons with visually	discrimination States Parties		Programmes, and
handicap; (b) Causing curb cuts and	shall take all appropriate		systems, on the basis of
slopes to be made in	steps to ensure that		any kind of disability or
pavements for the easy	reasonable accommodation	1	impairment. And will
access of wheel chair users;	is provided.	•	
© Engraving on the surface of	is provided.		ensure by notification the
the zebra crossing for the	Man services the effect		accessibility availability,
blind or for persons with low	4. Specific measures, which	1	affordability, and
vision;	are necessary to accelerate		comfort, for the persons
(d) Engraving on the edges of	or achieve de facto equality		with disabilities.
railway platforms for the blind		1	
or for persons with low vision;	of persons with disabilities,	(D)	Not any delay and any
(e) Devising appropriate	shall not be considered		kind of discrimination in
symbols of disability;	discrimination under the		the public and
(f) Warning signals at	terms of the present		1
appropriate places.	Convention.	1	
<b>46.</b> The appropriate	Convention.		supported services and
Governments and the local			schemes will be accepted
authorities shall, within the	ARTICLE 12 – EQUAL		and consider by the state
limits of their economic	~		and local authorities.
capacity and development,	<b>RECOGNITION BEFORE</b>		
provide for-	RECOGNITION BEFORE	c)	If any discrimination and
(a) Ramps in public buildings;			negative attitudinal
(b) Braille symbols and	THE LAW		behavior and delay will
auditory signals in elevators			be prove against the any
or lifts;			public servant or
© Braille symbols and			
auditory signals in elevators	1. States Parties reaffirm		department, any
or lifts;	that persons with disabilities		responsible authorities, or
(d) Ramps in hospitals,			against a common man,
primary health centers and	have the right to recognition		then the appropriate govt.
other medical care and	everywhere as persons		will take appropriate
rehabilitation institutions.	before the law.		
			against person and the
47. (1) No establishment	2. States Parties shall		respective authorities.
shall dispense with or reduce		d)	To ensure the
in rank, an employee who	recognize that persons with	)	discrimination in each
acquires a disability during his	disabilities enjoy legal		
service.	capacity' on an equal basis		and every public sector
Provided that, if an employee,	with others in all aspects of		and services like – health
after acquiring disability is not	· · · · · · · · · · · · · · · · · · ·		education insurance
suitable for the post he was	life.		
holding, could be shifted to	a		agriculture employment
some other post with the	3. States Parties shall take		and social justice, Law,
same pay scale and service	appropriate measures to		Human rights, and in the
benefits.			fundamental freedom,
Provided further that if it is	provide access by persons		and their enjoyment, will
not possible to adjust the	with disabilities to the		
employee against any post,	support they may require in		not be consider at any
ne may be kept on a supernumerary post until a	exercising their legal		cost with the person with
	then legal		

suitable post is available or he attains the age of superannuation, whichever is	capacity. 4. States Parties shall ensure	disabilities, and the state parties will take
earlier.	that all measures that relate	appropriate legislative action action against the
(2) No promotion shall be denied to a person merely on the ground of his disability:	to the exercise of legal	responsible persons and law. 2. State parties shell reaffirm
Provided that the appropriate Government may, having regard to the type of work	capacity provide for	that PWDs has the right to recognition as person before
carried on in any establishment, by notification	appropriate and effective	the Law and govt. will give necessary support desired by
conditions, if any, as may be specified in such notification,	safeguards to prevent abuse	the PWDs for the full and equal participation,
exempt any establishment from the provisions of this section.	in accordance with	enjoyment, and exercise for the Human Rights through
Section.	international human rights	the Law.
		3. State parties shell take
	law. Such safeguards shall	appropriate and effective measure to ensure that the
	ensure that measures	equal rights of persons with disabilities to own and inherit
	relating to the exercise of	property, to control their financial affairs, and to have
	legal capacity respect the	equal access and barrier free environment to get the bank
	rights, will and preferences	loans, mortgages and other forms of financial credit, and
	of the person, are free of	shall ensure that persons with disabilities are not arbitrarily
	conflict of interest and	deprived of their property.
	undue influence, are	4 State mention will take
	proportional and tailored to	4. State parties will take effective legislative and judicial or others measures to
	the person's circumstances,	prevent the rights of persona with disabilities. on an equal
	apply for the shortest time	basis and protection from non exploitation and violence
,	possible and are subject to	illegal human behavior including their gender based
	regular review by a	aspect, and will provide
	competent, independent and	necessary financial and legislative, moral mental, and other required supports in
	impartial authority or	this regards. (article 16 (4-5))
		a) States Parties shall put in place effective legislation
	1	DIALE ELECTIVE LEUISIANON

judicial body. The	and policies, including
safeguards shall be	women and child focused legislation and policies to promote the physical
proportional to the degree to	cognitive and psychological
which such measures affect	social reintegration in the society of persons with
the person's rights and	disabilities, who become victims of any form of
interests.	exploitation, violence or abuse, including through the
5 California da ser	provision of protection
5. Subject to the provisions of this article States Parties	b) Such recovery
shall take all appropriate and	rehabilitation and
effective measures to ensure	reintegration shall take place
the equal right of persons	in an environment that fosters the health, welfare,
with disabilities to own or inherit property, to control	self-respect, dignity and
their own financial affairs	autonomy of the person and
and to have equal access to	takes into account gender and
bank loans, mortgages and	age specific needs.
other forms of financial	c) Ensure by notification the
credit, and shall ensure that	c) Ensure by notification the provision of identification,
persons with disabilities are not arbitrarily deprived of	investigation, and
their property.	prosecution the cases of
men property.	PWDs who became the
	victims, of violence,
	exploitation harassment
	(mental sexual and physical)
ARTICLE 16 –	and abuse.
FREEDOM FROM	d) States Parties shall ensure
EXPLOITATION, VIOLENCE AND ABUSE	that, gender and age
VIOLENCE AND ABUSE	sensitive assistance and
1. States Parties shall take	support for persons with
 all appropriate legislative,	disabilities and their
administrative, social,	families and caregivers,
educational and other	including through the
measures to protect persons	provision of information or awareness and education on
with disabilities, both within	how to avoid, recognize and
and outside the home, from	report instances of
all forms of exploitation, violence and abuse,	exploitation, violence and
including their gender based	abuse protection services are
Bender bused	age, gender and disability

aspects.

2. States Parties shall also e) Appropriate govt. will take take all measures to prevent all or forms of exploitation, assistance violence and abuse ensuring, inter appropriate forms of gender disabilities fields, to handle and age sensitive assistance these cases and their desired and support for persons with help and assistance. disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age, gender disability and sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall that independent ensure authorities effectively monitor all facilities and programmes designed to persons serve with disabilities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration sensitive.

appropriate in to account necessary help give and provide to the Non by governmental Organizations alias, working in the respective

CHAPTER	IX	ARTICLE 31 -	RESEARCH AND
5		appropriate, prosecuted.	
		investigated and, where	
		disabilities are identified,	
		abuse against persons with	
		exploitation, violence and	
		ensure that instances of	
		legislation and policies, to	
		women and child focused	
		place effective legislation and policies, including	
		5. States Parties shall put in	
		5 Cut D ( 111 )	
		specific needs.	
		account gender and age	
		person and takes into	
		dignity and autonomy of the	
		health, welfare, self-respect,	
		environment that fosters the	
		shall take place in an	

	Dille a	
research for special education. rehabilitation and manpower development.	rights and fundamental freedoms and ethical principles of statistics.	
	2. The information collected in accordance with this article shall be disaggregated as appropriate and used to help assess the implementation of States Parties obligations under the present Convention, and to identify and address the barriers faced by persons with disabilities in exercising their rights.	
	3. States Parties shall assume the responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.	

UN convention of Eighth ad hock committee	Suggestions to add In the Persons With Disabilities
ARTICLE 2	5 – HEALTH
States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health- related rehabilitation. In particular, States Parties shall:	Health is a basic Human right, and it should be born in the mind that health is state of well being of all the section of human life. Like social, Economical, political, cultural, political, spiritual mental, behavioral and communal, and not merely the absence of diseases. To save this Human right various has been made at the govt. and private level.
(a) Provide persons with disabilities with	(article 25 should be include in the peoples with disability Act.1995, with the following

the same range, quality and standard of free or affordable health care and programmes as provided other persons, including in the area of sexual and reproductive health and population-based public health programmes; (b) Provide those health services needed by persons with disabilities, specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and the elderly; (c) Provide these health services as close as possible to people's own communities, including in rural areas; (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care; (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner; (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.	<ul> <li>suggestions)</li> <li>1. State parties shell recognized that persons with disabilities has the right to the enjoyment of highest attainable standard of the health with out and discrimination and equal basis.</li> <li>2. State parties shell take appropriate measures to ensure the access of health and health care services, that are gander sensitive including health related rehabilitation for the Persons With Disabilities. To fulfill these objectives state parties shell -</li> <li>g) Provide same range of quality of services and standard of health on free or nominal cost, with accessible and affordable health care services and programme provided by other persons and organizations, including the area of sexual and reproductive health, need and priority based public health services or programme.</li> <li>h) Take into account by the notification to the millennium Development goals, especially poverty elevation programme, which is the biggest root cause of the disability. The provision to the promotion of local health traditions and the training of persons with disabilities and community. Responsibilities and accountability of the gram Panchayat and village health committees of the Gram Panchayat to ensure the monitoring of the health services as close as possible to the persons with disabilities and community. Responsibilities and accountability of the gram Panchayat and village health committees of the Gram Panchayat to ensure the monitoring of the health services and need based programme. And the promotion and strengthen to the concept of the community health, through the community building, and through the community building, and through the community building, is the big to the provision for the gram Panchayat provision for the gram Panchayat provimes provision for the gram Panchayat provimes provimate provimes provime</li></ul>
	through the community building, and through the Community Based

<ul> <li>participating in the decentralized system and using the power of democracy.</li> <li>I) Ensure that the primary health services should be more rural based and the primary health care system or the services are accessible and affordable to Persons with Disability and the accessibilities of these services in the remote out reach rural areas to serve maximum number of PWDs</li> </ul>
maximum number of PWDs Appropriate govt. should take all the necessary actions and to prevent from the causes of the disability in the rural areas and trained more and more community workers to build the capacity and self – confidence of persons with disabilities

#### **ARTICLE 25 – HEALTH**

Health is a basic Human right, and it should be born in the mind that health is state of well being of all the section of human life. Like social, Economical, political, cultural, political, spiritual mental, behavioral and communal, and not merely the absence of diseases.

To save this Human right various has been made at the govt. and private level.

(article 25 should be include in the peoples with disability Act.1995, with the following suggestions)

1. State parties shell recognized that persons with disabilities has the right to the enjoyment of highest attainable standard of the health with out and discrimination and equal basis.

2. State parties shell take appropriate measures to ensure the access of health and health care services, that are gander sensitive including health related rehabilitation for the Persons With Disabilities.

To fulfill these objectives state parties' shell –

- f) Provide same range of quality of services and standard of health on free or nominal cost, with accessible and affordable health care services and programme provided by other persons and organizations, including the area of sexual and reproductive health, need and priority based public health services or programme.
- g) Take into account by the notification to the millennium Development goals, especially poverty elevation programme, which is the biggest root cause of the disability. The provision to the promotion of local health traditions and the training of persons with disability, regarding these traditions
- h) Provide these health care services as close as possible to the persons with disabilities and community. Responsibilities and accountability of the gram Panchayat and village health committees of the Gram Panchayat to ensure the monitoring of the health services and need based programme. And the promotion and strengthen to the concept of the community health, through the community building, and through the Community Based Rehabilitation.
- i) Ensure or will make provision for the community participation of the each public and community health programme to ensure the full and equal participation of the Persons With Disability, with their full potential and creativity in Decision making Planning, Implementation, and the Monitoring of the programme.
- j) Ensure the prioritization and recognition of their needs, and coalition and gathering for the demanding of their needs through legal action by participating in the decentralized system and using the power of democracy.
- k) Ensure that the primary health services should be more rural based and the primary health care system or the services are accessible and affordable to Persons with Disability and the accessibilities of these services in the remote out reach rural areas to serve maximum number of PWDs
- Appropriate govt. should take all the necessary actions and to prevent from the causes of the disability in the rural areas and trained more and more community workers to build the capacity and self – confidence of persons with disabilities

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. In particular, States Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided other persons, including in the area of sexual and reproductive health and population-based public health programmes;

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and the elderly;

(c) Provide these health services as close as possible to people's own communities, including in rural areas;

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

# ARTICLE 21 - FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise their right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice, including by:

(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;

(d) Encouraging the mass media, including providers of information through

the Internet, to make their services accessible to persons with disabilities;

(e) Recognizing and promoting the use of sign language.

# **ARTICLE 13 - ACCESS TO JUSTICE**

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

#### **ARTICLE 9 - ACCESSIBILITY**

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:

(a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;

(b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;

(c) Provide training for stakeholders on accessibility issues facing persons with disabilities;

(d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

(e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

(f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

(g) Promote access for persons with disabilities to new information and communication technologies and systems, including the Internet;

(h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

## **CHAPTER FOUR**

# 4.7 Learning's Suggestions for CBR

## 4.7.1 Learning's:

My major learning during the entire period was the concept of rehabilitation, and the concept of the disability. Problems are everywhere, it arises in the society or in the community, so for the solution of the problems should be in the society. We can't solve the problem of the persons with disabilities to segregate them from the community. To solve the problem of PWDs we have to change the attitude of the community toward them and integrate them in the community.

- I Concept of the Community Based Rehabilitation, determinants of disability and the situation of the persons with disabilities in India.
- II Nature of the organization (CBR Forum, Sanchar, COD, APD).
- III. Concept of the Advocacy, its importance, especially in the field of Community Based Rehabilitation.
- IV. Role of the CBR Forum in the promotion of the concept of CBR through the planning, monitoring, evaluation, and assistance through funding.
- V. Capacity building of the PWDs through the different activities. Like income generation, and key leaders trainings, etc.
- VI. Understanding about the Persons With Disability Act 1995, and UN Draft convention of 8<sup>th</sup> Ad Hoc Committee on the protection and rights of persons with disabilities
- VII. It helped me it understand the need of person with disabilities. What we can do to fulfill their basic requirements, and how maximum we can utilize available resources toward it.
- VIII. Individual and social rehabilitation plan to build the capacity of persons with disability at individual and social level to ensure their maximum participation and involvement in the community or social activities.

# 4.7.2 Suggestions;

Following are some of my suggestions what I experienced during the field visits and through the reading of various articles, and books in this period.

I CBR is the concept of the community participation but most of the places I felt that it is not being implemented. So the organization should ensure to the proper implementation and community participation in the project.

- II. The integration of the CBR in the various other programmes of the organization should be must.
- **III.** Organizations should be more emphasize to the trainings of the field workers. Especially the training of public relation and management.
- IV. The aim of SHGs formation not only to promote small savings, but also it should be seen as a platform which gathers peoples to demand their rights, and the participation in the mainstreaming society. It could be the best tool of advocacy.
- V. The migration from one to another job, of the CBR workers has seen as a problem and lacuna in the CBR programme, so the organization should ensure two things, first to increase the incentives of the CBR workers, and second one is the maximum involvement of the community members to ensure the success and take over the programme in the future.
- **VI.** The awareness in the community regarding the problems of persons with disabilities, disability, its prevention, attitudinal, and behavioral change should be must.
- **VII.** The employment of the persons with disabilities in the CBR programme could give them a great sense of ownership, and they can contribute with new creative ideas for the success of CBR programme.

- VIII. CBR forum should promote the organizations to conduct research at the local level to get more concrete information regarding real conditions of persons with disabilities.
- IX. CBR Forum should promote to the partner organizations to conduct the research, regarding status or real situation, about the implementation of PWD Act 1995. this data should be compile at the secretariat level for the assistance of advocacy and campaigning.

# 4.7.3 Conclusion

India is a developing country. It has a democratic governance system. The means of governance is to **government of the people**, to the people, and by the people. The aim of this system is to make empower to the every citizen of the country. And the power should be in the hand of the local citizens. This concept introduced the concept the decentralized Panchayat or local self-governance system. All these things show that the aim of every activity is to ensure the participation of the local community.

CBR is one of the kinds of democratic process; it is a developmental concept and work for the betterment of the community. It is empowering the people through the training, education, awareness, and involvement in the income generation activities. CBR shows that every person is the part of the community. Community is just like a body, and community members are parts of the body. If any part of body does not work well or properly or have any problem then whole body suffers. If one hand has injuries, then other hand comes for their help. Other part of the body doesn't discriminate, or injured hand doesn't feel the discrimination from the other parts, they come together, live together and proper coordination uphold the dignity of the body. Same as the Community Based Rehabilitation want to develop the concept and feelings in the society and community, that the persons with disability are the part of the body they should not feel or face any discrimination in the community and especially in their families, and they should be included with their full capacity and creativity, this concept empower to the PWDs in their communities and families

It can be seen that the PWDs and their families are a great asset of any CBR programme. They really know the environmental condition around them and understand the effects of their life. They have batter knowledge that what is the meaning of the disability, and how stigma is affecting their life, socially, economically, politically culturally, and spiritually.

In the end of the conclusion I would like to say that the analysis of the community structure is important with in which CBR is embedded. The existence of the power structure ; the difference between PWDs and non disabled man and women, disabled man and women, are glaring realities. The recognition of these differences is crucial for the CBR as for many community-oriented programmes

The data of census 2001 says persons with disability consist 2% population of India, and out of this two percent population, hardly 2% children with disabilities are receiving any kind of education and rehabilitation services. Most of the rehabilitation and institutional services are urban based and quite expensive, that a common man can't afford.

In this condition **CBR Forum** shifted their paradigm from urban to rural and takes into account to promote the concept of Community Based Rehabilitation in the rural areas, rather then institutional based rehabilitation, and serving to the poor & most marginalized society of the community in the rural areas. With its more then 85 partners organizations allover India. The implementations of CBR programme through the partner organizations in the field want to develop or create a barrier free environment and an atmosphere where the persons with disabilities should be accepted with their abilities, seen without any discrimination in society, and contribute in the development of community with their full potential and skills.

# JAN SWASTHYA SAHYOG GANIYARI, BILASPUR CHHATISGARH.

Learning objectives
 Health workers training
 Scabies survey

 Introduction of the study
 Village information
 Why study done
 Information about scabies
 Findings

# Placement :- JAN SWASTHYA SAHYOG (JSS), Ganiyari, Bilaspur, Chhattisgarh.

# Learning objectives:-

Following are my learning objectives for the second field placemetn in JSS.

- **O** To know about the organization (JAN SWASTHYA SAHYOG).
- To do a community based survey on the prevalence of the scabies.
- O Involvement in the Selection process of community health workers.
- Training of community health workers.

In the way to fulfill the learning objectives, and due to short placement of a month, I was not able to work on some of the following objectives;

• Planning and monitoring of different health programmes.

• To understand the involvement of JSS in the NRHM process.

But I came to know more about

• The appropriate technology for health.

Programme of the Jan Swasthya Sahyog.

My schedule during working days were as follows;

- A) On 28 of November 2006 I attended a meeting at JSS with the HIV/AIDS patient. The Chattisgarh Aids control Society wanted to start a programme with HIV positive people, with this initiative a group is formed of HIV+ people called Chattisgarh Network for Positive People.
- b) From 05/12/06 to 08/12/06 I did a pilot survey in the field are of JSS, to know the condition of scabies disease.
- c) From 09/12/06 to 14/12/06 I did asurvey on the scabies in two villages called Damanpur and Bandipara of Kota block.
- d) From 15/12/06 to 16/12/06 I attended health workers training in Shivtarai Village. This training programe was attended by the 13 new village health workers, who were selected by the JSS. In this training programme specially training given on the two issues or problem seen as a prevalence in the villages. First training on malaria and second on scabies. In the third Day the programme of slide

preparation or taking of blood smears was the most interesting work done by the health workers.

#### New health worker training

Shivtrai village. (15 to 17 December 2006).

To spread the work in the new villages after a long process JSS started a training programme for the new selected health worker in a programme village Shivtarai.

13 female health workers, out of total 17 village health workers from different villages attended this programme for two days. The process of the selection of the health workers was on the voluntary basis. Selection process done with the consent of gram sabha and family members of the selected person. Village team of JSS asked the name of either one or two health workers and then they got these few voluntary activists. Most of them are either illiterate of had left their education up to second standard.

Most of the health workers had came there with their children, they were on their respected cast in the village. This was probably the first time in their life where they are out of their village alone, and committed to the health. This training programme had an informal way to interact with each other. In this training the challenge before the trainer to was to motivate them for the discussion, to eradicate the hesitation, they were feeling and to provide and free environment to create their understanding regarding health and sanitation and make them understand about the health conditions and the realities.

Primary objectives of the training were to train them for the recognition of the common disease have prevalence around them; like Malaria, fever, pneumonia, and main objective was to train them to preparer thick blood smears at village level. These thick smears are helpful to at least diagnosis of malaria. These blood smears slides comes to the village center Ganiyari by public transport system, an innovative mechanism developed by the JSS for the early diagnosis of malaria.

**My learning's** :- to attend and look after a health workers programme was involved in my learning objectives, and this is one of my interested area in health. But it is not easy that I had been feeling earlier. Through this training programe I have following learnings :

- During the training I felt that now a days these health workers are the only hope to provide good and quality services to the un reached or out reached area where to get the public health services still is a like a dream.
- Selection of the health worker is a quite lengthy time consuming and hectic process. It is not easy to find out or make agree voluntary and women health worker. Due to gender sensitivity, and traditional culture, customs and beliefs, it is quite for the women to break them and come from the village for the social benefits.
  - Due to culture or local beliefs and family structure girls drop out rate is higher in the tribal area, so it is too difficult to find out at least primary level educated women for the programme.
  - Due to shy nature of women they often feel hesitation and don't talk frequently, this is the main problem during training to provide them free environment and motivate them to speak frequently. To solve this problem the trainer or facilitator has to have and know about them complete information, facilitation of the facilitator is a skill to make effective to the training.
- Command over the issue and information about the local belief culture, customs and traditions is also an important factor for the success of the training

#### **Appropriate technology**

Technology is and essential component of health care at all levels, which works for the detection, diagnosis, treatment, prevention, availability, accessibility, and maximum utilization in the positive sense. There for the availability of appropriate health related technologies in the field of health care is an essential tool in providing health care in the rural or out reach areas. Technologies have developed rapidly in field of health care, in the last several years, and peoples are getting benefited continuously as a life saving form. Now the several severe diseases when doctors were not able to even diagnosis, now being treated successfully. Some times it is looks like a boon given by the god, to save life. But these life saving technologies are only available to a particular section, not for every one, due to high cost in the urban areas, which is not possible to use by the poor. However the availability of the health related technologies at the primary health care level in the rural are extremely limited. In the case of many diseases and conditions of public health system

To meet the requirements or health needs in the rural areas of JSS is working and serving with the appropriate technology, and this process is still continue: Following are the man concern developed as appropriate technology;

- Measurement of anemia using copersulfate
- Diagnosis of sickle cell anemia
- O Breath counter
- Measurement of hight
- O Reproductive health kit
- Easy to read thermometer.
- o Ors
- Tablet breaker
- O Safe delivery kit
- First aid kit
- O Water disinfection system.

# Scabies prevalence study

## **Objective of the survey**

Following are the main objectives of my study on scabies.

- 1 To see the prevalence of scabies in the rural areas.
- 2 To see the economical conditions in the rural area.
- 3 To see the indebtedness in the rural areas, due to scabies and other illness.
- 4 To look at the socio-economical conditions in the rural area.
- 5 To know the awareness level the scabies in the rural areas.
- 6 To know perception regarding scabies.
- 7 To see the health conditions in the rural areas.
- 8 To see the family status of the families in the village.

#### **Back ground of the Villages**

Universe of the study

In the social research, society is the laboratory, for the social researchers. In my study I did my survey in the two villages of Bilaspur districts Kota and Lormi block one village each.

Following is the information for these two villages:-

1 Davanpur this is the village comes under the KOTA block, of Bilaspur district. 56 km away from Bilaspur, and 26 km from the KOTA block, no bus facility available or public transport available to reach this village. Peoples use two sides to reach this village one from kota and second from Shivtarai, but peoples have to cross small rivers from both sides to reach the village, and often in the rainy season these small rivers got over flooded, which cause to cut all the connections from the others. Most of the population is depend on the agriculture work and something they suppose to get from the forest. Most of the people work for the livelihood in others fields also it means they can be called agricultural labors. Agriculture production in their own field is not sufficient to fulfill their food requirements for the whole year. They want or get rice as their wage. Crops dependents on the rain and they don't have means to do irrigation for their lands. Most of the land is has taken over by them illegally, they called it "Beja kabja".

**2** Jakad bandha is more then 80 km away from the main district bilaspur and 40 km away from LORMI block of Bilaspur district. This is the highly forested area and Achahanakmar is the main village govt. of CHATTISGARH has been declared a sanctuary to this pure tribal area. This village is consisting here in three parts, URAO PARA, BAIGA PARA, and last one is jakadbandha. Three tribes are living here, in ORAO PARA most of the population is URAO tribals, and rest of the village is consists of GONDs and URAOs. This tribal village has 96 pure kachcha but clean house hold. Most of the peoples are land less labor, but for the livelihood they have captured some land in their words it is called "Beja Kabja" and doing farming activities which depends on the rain, like others tribals areas here also the lack of basic services can be seen. Basic primary public health services are disappeared. Peoples have to migrate for the search of the livelihood, to the far most area, like Bilaspur, Delhi, Bombay, Hydrabad, Bhopal, Kolkata, etc. in the absence of main persons of the family only women has to look after for their families. Education services and even Aanganwadies are not working and even being trained properly. One private mission school is here with more then 50 student from different near and far villages. Rice is the only crop being received by the village peoples, and up to some extent they use some forest seasonable crop which contributes something for their economical condition. Use of local home made liquor is very common in these areas and also the part of culture.

Three lakes are around the village. But in the summer seasons only one lake has the water to full fill the requirement of daily use of the village. To fulfill the requirement of the drinking water of the village there are only four hand pumps are serving to the whole village. Wells are also in the village but it is rarely used by the villagers.

#### Why the study

In the recent years this had been felt that peoples of the rural area suffering very much form the problem of scabies, and during the village intervention it found that the prevalence is higher and peoples are complaining regarding the problem of scabies. If the peoples have the personal hygiene and sanitation, and if they are taking the regular bath, then the mite that is the cause of scabies will disappear. But the condition in the rural areas is just different. Peoples are spending un necessary money the treatment on the scabies. Jhola chap Doctors are treating this problem through the saline bottle and injection and charging 20 to 50 Rs. For the treatment, that could be cure in just Rs 5 to 6. this un necessary treatment becomes the cause of rural indebtedness. Most of the time peoples goes to the local healers or tend to Jhad-phook due to cultural beliefs and blind faith. That also pushes them to the indebtedness. Most of the affected from the scabies are children and women, which becomes ignore or separated in the community and even in the family and doesn't come to show them self if they are suffering from the problem. Children are ignored due to lack of attention of the parents or lack of money, they does their local treatment. Their one visit from the village to health centre becomes cause of lose of their one days wage, and it becomes more severe when irrational treatment done by the doctors.

#### In this Proforma following were the information to be collected.

Respondent, caste, class, gender, family, Family members, economical condition, land food, prevalence of scabies, house hold information, and in the last their perception about the problem.

#### Something about scabies

Scabies is caused by the mite Sarcoptes scabiei, variety hominis, as shown by the Italian biologists Diacinto Cestoni in the 18th century. It produces intense, itchy skin rashes when the impregnated female tunnels into the stratum corneum of the skin and deposits eggs in the burrow. The larvae, which hatch in 3-10 days, move about on the skin, molt into a "nymphal" stage, and then mature into adult mites. The adult mites live 3-4 weeks in the host's skin.

The motion of the mite in and on the skin produces an intense itch which may resemble an allergic reaction in appearance. The presence of the eggs produces a massive allergic response which, in turn, produces more itching.

Scabies is transmitted readily, often throughout an entire household, by skinto-skin contact with an infected person (e.g. bed partners, schoolmates, daycare), and thus is sometimes, although inaccurately, classed as a sexually transmitted disease. Spread by clothing, bedding, or towels is a less significant risk, though possible.

#### Onset

It takes approximately 4-6 weeks to develop symptoms after initial infestation. Therefore, a person may have been contagious for at least a month before being diagnosed. This means that person might have passed scabies to anyone at that time with whom they had close contact. Someone who sleeps in the same room with a person with scabies has a high possibility of having scabies as well, although they may not show symptoms.

The symptoms are caused by an allergic reaction that the body develops over time to the mites and their by-products under the skin, thus the 4-6 week "incubation" period. There are usually relatively few mites on a normal, healthy person--about 11 females in burrows. Scabies are microscopic although sometimes they are visible as a pinpoint of white. The females burrow into the skin and lay eggs there. Males roam on top of the skin, however, they can and do occasionally burrow. Both males and females surface at times, especially at night. They can be washed or scratched off (however scratching should be done with a washcloth to avoid cutting the skin as this can lead to infection), which, although not a cure, helps to keep the total population low. Also, humans create antibodies to the scabies mites which do kill some of them.

#### Signs, symptoms, and diagnosis

A scabies burrow can be seen under magnification. The scaly patch is due to scratching of the original papule. The mite travels from there, where it can be seen as a dark spot at the end of the burrow.

A delayed hypersensitivity (allergic) response resulting in a papular eruption (red, elevated area on skin) often occurs 30-40 days after infestation. While there may be hundreds of papules, fewer than 10 burrows are typically found. The burrow appears as a fine, wavy and slightly scaly line a few millimeters to one centimeter long. A tiny mite (0.3 to 0.4 mm) may sometimes be seen at the end of the burrow. Most burrows occur in the webs of <u>fingers</u>, flexing surfaces of the <u>wrists</u>, around <u>elbows</u> and <u>armpits</u>, the <u>areolae</u> of the breasts in females and on <u>genitals</u> of males, along the belt line, and on the lower buttocks. The face usually does not become involved in adults.

The rash may become secondarily infected; scratching the rash may break the skin and make secondary infection more likely. In persons with severely reduced <u>immunity</u>, such as those with <u>HIV</u> infection, or people being treated with <u>immunosuppressive</u> drugs like <u>steroids</u>, a widespread rash with thick scaling may result. This variety of scabies is called **Norwegian scabies**.

Scabies is frequently misdiagnosed as intense <u>pruritus</u> (itching of healthy skin) before popular eruptions form. Upon initial pruritus the burrows appear as small, barely noticeable bumps on the hands and may be slightly shiny and dark in color rather than red. Initially the itching may not exactly correlate to the location of these bumps. As the infestation progresses, these bumps become more red in color.

Generally diagnosis is made by finding burrows, which often may be difficult because they are scarce, because they are obscured by scratch marks, or by secondary <u>dermatitis</u> (unrelated skin irritation). If burrows are not found in the primary areas known to be affected, the entire skin surface of the body should be examined.

The suspicious area can be rubbed with ink from a fountain pen or alternately a topical tetracycline solution which will glow under a special light. The surface is then wiped off with an alcohol pad; if the person is infected with scabies, the characteristic zigzag or S pattern of the burrow across the skin will appear.

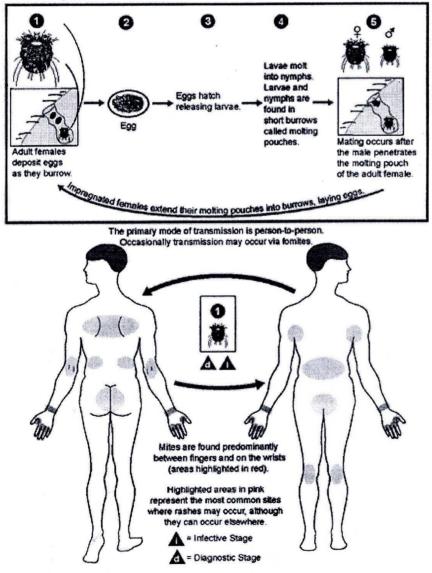
When a suspected burrow is found, diagnosis may be confirmed by <u>microscopy</u> of surface scrapings, which are placed on a slide in <u>glycerol</u>,

<u>mineral oil</u> or immersion in oil and covered with a coverslip. Avoiding <u>potassium hydroxide</u> is necessary because it may dissolve fecal pellets. Positive diagnosis is made when the mite, <u>ova</u>, or fecal pellets are found.

#### **Causal Agent:**

*Sarcoptes scabei*, human itch or mange mites, are in the arthropod class Arachnida, subclass Acari, family Sarcoptidae. The mites burrow into the skin but never below the stratum corneum. The burrows appear as raised serpentine lines up to several centimeters long. Other races of scabies may cause infestations in other mammals such as domestic cats, dogs, pigs, and horses. It should be noted that races of mites found on other animals may establish infestations in humans. They may cause temporary itching due to dermatitis but they do not multiply on the human host.

#### Life Cycle:



Sarcoptes scabei undergoes four stages in its life cycle; egg, larva, nymph and adult. Females deposit eggs at 2 to 3 day intervals as they burrow through the skin **①**. Eggs are oval and 0.1 to 0.15 mm in length **2** and incubation time is 3 to 8

days. After the hatch. eggs the larvae migrate to the skin surface and burrow into the intact stratum to corneum almost construct invisible, short burrows called molting pouches. The larval stage,

which emerges from the eggs, has only 3 pairs of legs **③**, and this form lasts 2 to 3 days. After larvae molt, the resulting nymphs have 4 pairs of legs **④**. This form molts into slightly larger nymphs before molting into adults. Larvae and nymphs may often be found in molting pouches or in hair follicles and look similar to adults, only smaller. Adults are round, sac-like eyeless mites. Females are 0.3 to 0.4 mm long and 0.25 to 0.35 mm wide, and males are slightly more than half that size. Mating occurs after the nomadic male penetrates the molting pouches into the characteristic serpentine burrows, laying eggs in the process. The impregnated females burrow into the skin and spend the remaining 2 months of their lives in tunnels under the surface of the skin. Males are rarely seen. They make a temporary gallery in the skin before

Transmission occurs by the transfer of ovigerous females during personal contact. Mode of transmission is primarily person to person contact, but transmission may also occur via fomites (e.g., bedding or clothing). Mites are found predominantly between the fingers and on the wrists. The mites hold onto the skin using suckers attached to the two most anterior pairs of legs.

#### **Geographic Distribution:**

Scabies mites are distributed worldwide, affecting all races and socioeconomic classes in all climates.

#### study of books and others

These were the main reasons to conduct the study of rural area to know the perception and to know the socio-economical, which is being affected by the disease. In this study we also tried to see the social causes and the prevalence of scabies in the rural area. In this process I started my study with the following steps

In the process of starting my study I first here study about the scabies, I read various books to create my understanding regarding the scabies like;

- Preventive and social medicine Parks text book.
- Where there is no doctor.
- Notes of doctor Ravi D'souza on scabies.
- wikipedia
- NDTV.com. etc

Doctors of the JSS helped me to diagnose the scabies patients, in the OPD I sit with them and asked my doubt regarding the scabies. In the field the health workers and village health team of Jan Swasthya Sahyog helped me to identify the scabies. I also discussed about the treatment of scabies.

Then I discussed the about the questionnaire with Dr. Yogesh jain, but before finalize the Performa I did a informal pilot survey. I did some informal visits and talk with the affected and non affected peoples, to find out the perception of the peoples about the scabies. Then after having some grass root level information I discussed with my mentors finalized my questionnaire for the survey for the study.

#### **Findings of study**

Survey has been completed in both Davanpur and Jakadbandha Villages. But the date remain to be analyzed. It is still in the process, so that I am not able to present my find on the basis of the data. I have to go back to JSS Ganiyari and have to plan for treatment of scabies, and health education on scabies in the hostels of villages. In the absence of the analyzed data, I am presenting what ever I observed during the survey ;

#### **Davanpur village**

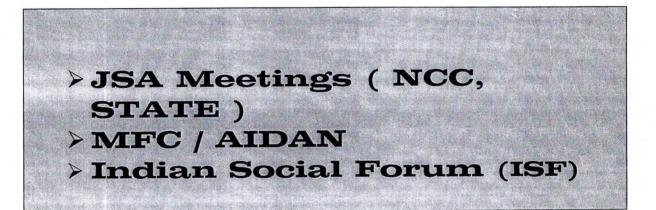
Majority of Davanpur village consist from the Gond's and rest belongs to OBC's. Majority of the peoples have Kacha houses, there are 136 household and more then 1000 population. Education system of has the same condition like other parts of the country. There is a primary school and with more then 100 children. I found that teachers which were recruited by the govt. on contract basis for the school of villages called Shiksha karmi were on the strike against their demands, only one teacher was there to interact with the children in a single room. There is a Adivasi Ashram up to 5<sup>th</sup> standard, where 85 children are studying from different villages around them, here also the prevelance of the scabies can be seen, and only one teacher is appoint for these student. This village in two parts one art called Davanpur and second part called Bandi para. Nearest health center is 26 km away from here. Here are four hand pumps and four lakes, mainly hand pumps are being used for people. Prevalence of the scabies the drinking water is used by the approximately will be 25 to 30 %, first children and second women were the most affected from the scabies . I found five to seven members in a family. Many families living together in a big house but small rooms.

#### Jakadbandha Village

This village is 80 km away from the main district bilaspur and 40 km away from LORMI block of Bilaspur district. This is the highly forested area and Achahanakmar is the main village govt. of CHATTISGARH has been declared a century to this pure tribal area. This village is consisting here in three parts, URAO PARA, BAIGA PARA, and last one is jakadbandha. Prevalence of scabies in this village is not common. Very few cases I found which were effected by the scabies. All 96 kach houses were in sequence their was the proper ventilation in the houses due to small houses people often expose their personal things like bed and bad sheets in the sun it could be the main reason of the absence of scabies. Peoples often Migrate for the search of livelihood on different places. Peoples. Villages get only one crop during the rainy season. Most of the people are land less labors and depends on the forest work, which is often has a very low wage.

In both of these villages health conditions are not differ from the others parts of the area. There no health facilities are available. Peoples are dying from the curable diseases, like malaria. To cope up with the health problems of the this tribal and semi tribal area one organisations called Jan Swasthya sahyog is working since last more then 10 years, a team of like minded Doctors trained from the one of the pioneer institution of India, had a same desire to serve the most vulnerable section of the society. After long journey of two in the different parts of the country finally their journey stopped on the little place Ganiyari a small village 18 km away form the Bilaspur, the main fast growing commercial area of Chattisgarh state. Just 100 km away from this so called fast growing developing area public health needs are not meeting to the peoples.

# **OTHER ACTIVITIES**



# Jan Swasthya Abhiyan Meet Preparatory Workshop for National Health Assembly II 4-6<sup>th</sup> January, 2007

The Jan Swasthya Abhiyan coalition consists of over 22 networks and 1000 organisations as well as a large number of individuals that endorse the <u>Indian</u> <u>People's Health Charter</u> a consensus document that arose out of the <u>Jan</u> <u>Swasthya Sabha</u> held in December 2000 when concerned networks, organisations and individuals met to discuss the Health for All Challenge.

JSA Is the result the of a conference organized by WHO and UNICEF at Alma Ata in 1978, where all the developing countries including India were the signatory of the conference. In this conference all the developing countries signed that they will provide health for all up to 2000 AD. After the 22 years later, it realized by the health professionals and developmental activists that promise made by the govt. in 1978 Is not going to be fulfilled. So that al the activists at international and national level came together on Savar Bangladesh in December 2000, in Peoples Health Assembly, where concerned networks, organizations and individuals met to discuss the Health for All Challenge, and formed a *Peoples Health Movement* at international level and *Jan Swasthya Abhiyan* which is the part the of Peoples Health Movement International.

This was the national preparatory meeting for the second national peoples health assembly, which is going to be organized in Bhopal on 23 to 25 march 2007 in Bhopal. Dr. Amit Sen Gupta gave the introduction of the national peoples health assembly and following were the main objectives of organizing this preparatory meeting.

- State wise reporting for the rural health watch.
- Opening of the dialog books in the assembly.
- Group discussion of national books.
- State level programme talk
- Discussion on the people's health workshop.

Many organizations from the different states presented their programmes taking place in their state for the preparation of JSA assembly. They mainly reported about following

- Participants of state workshop ; many organizations attended the workshop and what are the activities in process.
- Rural health watch survey of the state : the state JSA where they have done their survey presented about it that how the issues they are picking up like some organizations were interested to take up the issue of malnutrition, availability of drugs, in the state peoples health workshop.
- Local health assembly :- some states were doing activities at local level and like public hearings at local level with the help of BMO's or CMO's. sensitizations of local and panchayat leaders in different villages.
- District health assembly and state health assembly.
- Issues, which will be taken through the state workshop :- main feature of the state assembly will be the public hearings and data of peoples rural health watch will be presented by the state JSA.

On six of January 2007 JSA announced and launches officially Peoples Health Assembly (JAN SWASTYA SABHA) in the presence of many health and developmental organisation's, NGO's followed by the press conference in which different. Mr. Amit sen gupta, Dr. Ajay khare, (JSA joint convenor) Dr. Mire Shiva organize this meet.

#### JSA state workshop (Chattisgarh)

From 1/12/06 to 02/12/06

This was the first state level workshop which I attended the meeting of the **Jan Swasthya Abhiyan** (JSA) in Dallirajhara Durg distt. Programme started with the consolidation to the founder of Shaheed Hospital, and then various topics were discussed in the meeting regarding health 20 to 30 were present in this workshop and issues that were facing by the orgnisations were discussed such as human right issue, displacement migration, occupational health, function of PHCs role of local politics in the management of PHCs and availability of doctors, medicines blood, Govt. norms and regulation to manage the blod bank, Janni Suraksha yogna, lack of information of govt.

discussed by among the organizations. Each organization expressed the health scenario and the problems they are facing in regarding field where these organizations are working. Dr. Anurag Bhargav discussed on the drug policy of the Govt. and told about how the health of the poor patient are being exploited, essentials drugs are not available in the market on the name of branded drugs how the big medicines companies are robbing on the pocket of the poor people, life saving medicines are continue are coming out form the criteria of price controlling. Human right issues were discussed in this meeting. In this concern the Salva-Judum problem and exploitation, displacement of adivasies from the forest is on the name of development and interesting is that all these things being done by the govt. is another question that what the role should be played by the govt. and what the role is govt. playing, which totally against the democracy and humanity. Condition of women and girls is being worsen sexual exploitation and gunda gardi of police persons has no limits on the people and specially of the women who are help less to live in the camps. Through the JSA people could create the pressure on the govt. to make more responsible toward their duties and responsibilities. These conditions is showing that the coalition of health movements and social movements for the sake of peoples and the nation is the priority and demand of Humanity.

# MFC/AIDAN 27 to 29 dec. 2006

this was the first meeting of its kind in which 40 to 50 professional in the community health background came together for two and three days from different parts of the country, sit together and discussed on the public health education. Before this mfc meet one more meeting called AIDAN (All India Drug Action Network) took place.

I am not able to give here my reflection regarding the meeting, because CHC were organizing this meeting and we were busy in the arrangements of the participants.

On the second day mfc meeting happened. I have to present my reflection also for this meeting, but again I am really sorry that I didn't participate fully in this meeting also, due to management of the whole progamme. But what ever I attended is not sufficient for my reflection on those rich discussions

# **India Social forum**

#### Duration: - 09 to13th November 2006

**Few words** – The first WSF was held from <u>25 January</u> to <u>30 January</u> <u>2001</u> in <u>Porto Alegre</u>, Brazil, organized by many groups involved in the alternative globalization movement. The WSF was sponsored, in part, by the Porto Alegre government, led by <u>Brazilian Worker's Party</u> (PT). The town was experimenting with an innovative model for the local government which combined the traditional representative institutions with the participation of open assemblies of the people. 12,000 people attended from around the world. At the time, Brasil was also in a moment of transformation that later would lead to the electoral victory of the PT candidate <u>Luiz Inácio Lula da</u> <u>Silva</u>.

World Social Forum came in: ATTAC saw the conference as an opportunity to bring together the best minds working on alternatives to neo-liberal economic policies-not just new systems of taxation but everything from sustainable farming to participatory democracy to cooperative production to independent media. From this process of information swapping ATTAC believed its "common agenda" would emerge.

A community health fellow I have spent three months and going through the fourth month in this India social Forum. This is my first experience in this kind of convention where a lot of groups come on a common platform, and put their experiences on various issues, which they are facing in their respective field areas. Many issues discusses such as - development, displacement & migration of Dalits and indigenous peoples, Discrimination, Child issues, Women issues, health Issues, Land, Education, Food Security, Etc. All of these problems have their root in so called Development.

Further I am presenting my reflection on the issues, which I attended during my stay in convention.

**09-11-06**: - this was the first day of the convention. In the morning we completed the process of the registration then visited to the convention ground. There were many organizations from all over India putting their stalls and showing their issues, demand charters, books, and signatures campaign.

In the evening the plenary has started and continue till the midnight. Different social activists express their view on the aims and objectives of the India Social Forum. Such as our aim is that the present world could be change where the equity will be every where and no discrimination will be seen on the name of cast class and gender. The aim of our gathering is that such a huge amount of the people suffering by the same problem and their root are in present system. This system should be pro-people.

**10-11-06** :- in the morning of the 10 of November we had to attend the pre decided session but we were getting difficulty to find out the places, and due to first day session started some time letter. In the first session I listened to MEDHA PATKER on the issue of displacement and development. Like jungle is the property of Acivaises, govt. is responsible for rehabilitation and it should be the priority of the govt. to look after the displaced majority of the community who are their own people. Dames the sign of development of capitalistic society, cement and iron lobby is taking over the govt. machinery. I went to the 3 screening session where they were showing the movies on the different issues like Iraq war and protest against COCA COLA, and PEPSI in the middle East and African countries, Women empowerment, and working man in the home.

The third session which I attended was on land and livelihood organizing by **Ekta Parishad.** 

Different Peoples from the different parts of India were putting their views on problems they are facing due to developmental policies. They were against the unbalanced development policies of the govt. which is the cause of migration and poverty of Dalits, Tribels and other backward classes of the community in different places of India.and put following data of these vulnerable classes of the community.

Among the population of India, 16 crores are Dalits, and 08 crores are Adivasi. Over the last 50 years various policies and programmes were made for their development but still the conditions are not satisfactory, 45% Adivasi, and 36 % Dalits, communities are facing extreme poverty. On the name of the development more then 50 million peoples has been displaced out which 40% are Dalits. Rehabilitation process is still unseen. Govt. of the states is not paying serious attention; most of the agriculture land has been captured legally or illegally through the govt. or others land lords. Agriculture labor is Dalits community but they don't have their own land, in all of these processes the conditions of women and children is most vulnerable they are facing more socio-economical, and cultural problems.

The land reforms and proper decentralized Panchayat system could only the mean to solve the problems. Only through the community participation in the governance and community control and monitoring over the public health services can improve the status of Human life and we can achieve the development goals.

#### After Noon session (12:03)

In the afternoon session I attended the Jan Swasthya Abhiyan session on "child health".

Only good health leads to the development and empowerment. But the govt. doesn't have effective policies to improve the health conditions of all the classes of the community at all levels. in the context of the child health only internationally funded programmes like Pulse Polio, and HIV/AIDS are being focused polio vaccine is include in primary vaccination given right from the birth of the child, But because of UNICEF is funding for this programme, it has became a separate national programme. Primary data of NFHS - 3 shows that routine vaccination is falling, Govt. bodies concerned are not conformed about how many dose are required for the child. After the vaccination polio has seen in some cases. Human Rights organisation considering that it is an issue for of Human rights violation. A lot of lacunas are in the pulse polio campaign like polio is a disease concerned with the water, infection happens due to lack of sanitation and open sewage system, but in this campaign water issues are not being address. There is not any provision in the campaign to solve Nutrition and other health aspect properly. Besides all of these programmes regarding Child Health, Malnutrition, Infant Mortality Rates, Safe Drinking Water and Sanitation, issues are interlinked and concerned with the Child Health, and by the time becoming more severe only through strengthening of public health system, maximum people of the community who are marginalized, most vulnerable and prone to the diseases could be served. Other important thing is to understand the nature of programme, creating awareness in the community and realization of importance of the programme are the factors effecting to the programme.

After Noon (4-7) (11-11-06)

#### Urban Health in the context of Globalization.

Due to Globalization and Development health is affecting very much in both urban and rural areas. Same the conditions of the slum peoples are getting verse, they not very good. Now the urban renewal mission is contributing more and creating problems more severe, slums are being displaced and govt. and corporations are escaping to take the responsibility of rehabilitation and is not providing basic public health services, like water supply, power supply, sanitation, and health care services etc. These problems are together effecting on health and the living conditions of the peoples of slum community. On the name of urban renewal mission Rs. 5000 crore are allocated for the master plan of 60 cities of India. It is estimated that there are 40 lakh labors are in Delhi and due to high migration rate in next 20 it will reach up to 40 lakh, but according master plan Delhi govt. will not establish or will not invest in any which could be helpful to provide the employment to the labor class.

On the name of development in lucknow a slum has been displaced by the order of high court. Due to high cost of medicines lay mans are not able to afford health treatment, free of cost treatment is not available in govt. hospitals, medicines are not available their. 354 medicines falls in price control in 1977, but in 1995 only 74 remains under it. Now the public private partnership is a biggest source of earning money, live example is Appolo hospital. Delhi Govt. has 23 crores yearly income, by the investment of 47 crores. But the treatment of the common man is still a dream to avail the facilities or treatment, due to expensive treatment.

Diseases are becoming more then earlier days, now due to these peoples are dying, water level is getting down and due to development earth is getting recharge, rain water is not being stopped, with the concept of water harvesting peoples are still not familiar and facing the problem of water scarcity. Drinking water is not available; public health services are poor, privatized water supply contributing in the problem to be more serious. Ground water is getting contaminated continuously due to industrialization and Slums people are helpless to use this water. Not any international agencies are taking these problems seriously and coming together to raise the voice against the govt. policies, corporate, and industrialists.

#### Saving India's Public Health

Public health system is the only system by which we can reach or serve to the maximum number of peoples with appropriate and affordable cost. Now the public health policies of India's is not in the hand of our policy makers or has been hijacked though the structural adjustment programmes (SAP) of US agencies like World Bank and IMF. Now the community is the only hope to save the public health system. The democratic and decentralized system of the country provides the opportunity to the peoples to strengthen to the system whether it could be health, Education and others. Community involvement in the health programme, through prioritizing needs, decision-making, planning, implementation and monitoring could play the major role to save the public health system of the country.

In this process National Rural Health Mission (NRHM) could be mile stone. The concept of the ASHA, community health workers, and public private partnership, is trying to ensure the community participation in the public health system.

But the lacunas are still being seen, state govt. is not looking interested to implement the process of the NRHM selection of the ASHA health workers is not properly taking place. Surpanch and other panchayt members is demanding money up 3000 to 5000 for the selection of ASHA workers. Where the ASHA workers have been selected, still not getting proper trainings, and assuming like the assistant of Anganwadies or ANM's. Unless the community will take part honestly, we can't expect success of any public health programme. A lot of problems are in the community, and resources are limited. Therefore maximum utilization of resources is possible only through the community participation for the development.

# **Conference on Right to Education (Morning) (11-11-06) Modern right to education bill 2006**

Education is one of the most important fundamental right of the people, and subject of the state to provide free and compulsory education to 6-14 years children.

but with the development it is looking like a dream to have free and compulsory education. in the present era privatization is breaking the back bone of the education system. Modern right to education bill 2006 is working as a strong Jake for the irresponsibility's of the govt. and has washed all the dreams of good and quality education. 11<sup>th</sup> five year plan says "that we have a lot of opportunities in the Information Technology sector, because we working 24\* 7 for the Americans professionals, so that education should be technology based that will help to the capitalist to invest in the education sector and it will becomes more privatized on the name of providing good and quality education.

Due to facilitation of the private market govt. is keeping down their hands to ensure the privatization. At one hand this Act has provisions to take and action against parents who are not sending their children to school, on the other hand govt. is not doing any provisions and don't have any policy or programme to reduce poverty for the families where their children are the only source of income. Bill is saying children of the families who don't have residential proof will not be able to get admission in the schools, then what about thousands of labor families who are migrating every to search of food and livelihood. Govt. will not open any school where private schools are existing. This is the policy to promote the privatization of the education.

**Girl child labor** :- in the so called developing nations, the conditions of the girl child labor is getting worse, especially in the backward areas where they are working as a bounded labor. there are a lot issues regarding girl child labor like- advance credit, lack of food accessibility, customs and traditions, and dowry, are the biggest cause of the girl child labor, early marriage, heavy house hold work, early pregnancy, long working working hours, agriculture activities, are keeping them away from the education. some data says that women in the villages takes 4 to 5 hour sleep, during night, and it is more harmful during the pregnancy.

#### **Dalit Education.:-**

Education is one of the best tools of the development. Education teaches men about the life and help men to accumulate in the society so that education is for every one and it is a fundamental human right.

But right from the beginning a particular section of the society is keeping away from education, and they had not any right to have education in ancient period, only good education was available only for the rich and economically sound section of the society. A particular section of the society who had power were dominated over all the resources and utilizing it. After the independence a lot of efforts were carried out for upliftment and the development for poor, backward and vulnerable sections of the society like Dalits minorities, and tribals. Under the section 14 govt. is responsible to provide free and compulsory education upto 14 years children. But now it is a dream to get quality education in govt. schools, in rural and out reach areas. govt. is coming out from the responsibilities to provide education, and handing over it to the private sectors, which is being used as a money making machine. Education field is developing like a business sector, business men are investing on it, good and quality education is available only in big schools who r charging high fee to its students. In this scenario good and quality education is a big dream to the peoples who are living in the out reach and rural areas. They can't even think for this type of education, beside all of these problems the cast system is making worse difficult for Dalits and Adivasi students. where the these problems like Dalits and untouchables are exist, teachers don't behave properly with dalit students, almost all the bed work like sanitation, sweeping, fetching water, falls into account of dalit students. In the rural areas of Rajasthan and Gujrat, teachers don't like to teach dalit students.

I think the main problem is existing in power relations. In the rural areas if power will be in the hand of the locally dominant or a particular group they will think for development for their own class or section to eradicate the problems democratic approach could be one of the solution, but where we want to development of particular marginalized and vulnerable group power structure should be according to need of the community for their empowerment their own involvement in decision making and planning are must and they have to be understand or realized that this is their own programe.

For the development of the vulnerable and marginalized sections it is must to develop the structure according to their need. Resources must be hand over to them and govt. should monitor and assist only in the planning and monitoring. In case of the education of the dalit section, the dalit majority will be responsible for the education of the dalit section, or at least monitoring should be done through the dalists peoples.

# National Alliance for Right to Education and Equity.

#### **By Professor – YASHPAL**

Education is one of the most beautiful concepts of the world. Man should always think positive because positive thinking infinite possibilities for instance globalization is creating disparities around the globe between rich and poor man and Human societies. But with the positive thinking one can beautiful and best possible use of this globalization. like we can connect our villages through the internet. It will helpful to disseminate information regarding health, education, employment, agriculture, etc. govt. should work toward it if we want to development.

there is infinite possibilities, because Universe is infinite. Hope comes from the possibilities, so that the death of hope is a unscientific thinking. Hope keeps you alive and motivate for the invention.

National Coordination Committee (NCC) meeting of Jan Swasthya Abhiyan (JSS).

#### Place :- Indian Social Forum

on 13 of November 2006, evening NCC meeting of Jan Swasthya Abhiyan conducted during the ISF convention. Attendant of the meeting were the

social health activists from various organizations working in the field of health in the different parts of the country.

Dr. T. Sundar Raman, Dr. Abhay shukla, Dr. Dhananjay, Dr. Joe Varghees, Mrs. Indira, Dr. Vandana Prasad, Dr. Ajay Khare, mr. Sant, Mr. Naveen Thomas, Mr. Rakesh Chandore, Mr. Juned Kamal Etc.

Main Issues discussed in the meeting;

Peoples Rural Health watch survey : most of the organizations are still working at their own level and it almost has competed. This survey has been completed in Madhya Pradesh and Rajasthan. under the rural health watch states who didn't complete the will complete it a soon as possible, or up to the End of December 2006. So that it will be helpful to prepare the report for NHA - 2.

Circulation of Action Alert : this magazine was started to up date and strive the health information and health activities among the partners and other organizations directly or indirectly concerned with Jan Swasthya Abhiyan. Earlier it was continue, but interrupted in between due to problem to access of the internet or mail services. but now it will be continue from the JSA secretariat.

National security registration Act.

Public Private Partnership task group. Alternative action plan has to frame for this task group. Community monitoring is also one of the tool to look after PPP implementation. Many programme national wide are running without knowing its effects on health of the community, like Pulse Polio campaign, National malaria programme, T.B. programme, etc.

#### Preparation of National Health Assembly (NHA) – 2.

Place - Ravindra Bhavan, Bhopal, Madhya Pradesh.

Dates -  $23^{rd}$  to  $25^{th}$  March 2007.

Funding - finance is a back bone of every programme. there is approximate estimate for NHA -2 is about 25 lakh. this is quite a big amount, so that different organizations by representing their states will contribute for NHA -2. others suggestions that are comings, that many organizations could do funding for this programme, but the problem is that all the organization who are capable for the funding, are being criticized for their role in the health field. so that the funding of the programme is a big challenge before JSA.

some suggestions that will be implement during and before NHA-2 are follows,

registration fee will be charged on the participants, some funding organization will be contact like TATA Trust, CRY, and ICICI bank, for funding under the supervision of a task group formed at secretariat level.

**Translation of NHA-2 books** :- for new books written for the NHA 2 will be translated in to Hindi and local languages. book no. one Globalization and health came into account of BGVS M.P. for the Hindi translation.

State Health Assemblies :- organization in their each respective states will conduct public hearings up to the January 2007. organizations will plan according to that, and will send programme to the JSA sec.

National Secretariat :- A national secretariat will be formed for the National Health Assembly -2.

Following members will look after the work of National Secretariat.

Dr. Ekbal, Mr. Naveen Thomas, Dr. Ajay Khare, Dr. Vandana, and Mrs. Deepa, Dr. Dhananjay, Dr. Joe Verghees, and Mr. Tejram.

Another important section of Indian Social Forum that was organized by the JSA simulteneously was organized by the people

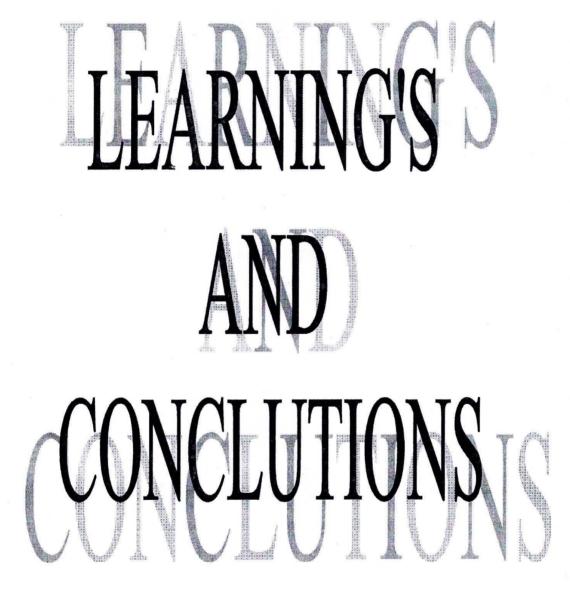
# **Conclusion:-**

In the end of this report I would like to say that India Social Forum is a social congregation and provide a plat form where various groups working in the country on the different issues came together to see a dream of another world where equity, respect, equality, equal distribution of resources, equal opportunity, or in a one word equal world without discrimination will be a reality.

It is good to come together and to make realize or aware to others regarding the actual problems of the society or community, but if we will critically examine to this problem, then we will realize that this was congregation of cattle's, where lots of cattle's in small crowd were roaming and enjoying only. In the program halls there own peoples were listening to them, most of the people don't know what is going in the next programme hall. Some popular social activists had covered all the crowd. Various programme which I wanted to go could not start due to lack of peoples. in the last which I felt that lack of togetherness in all the groups. we are living in the society, directly or indirectly we are fighting from the globalize forces, our enemy is same then why we are fighting separately. We should have to be together; our linkages will provide us support and will be helpful to be strengthening our movement. There was not any agenda came into existence on behalf of India social forum, that what will be the future strategy of the movement and how we have to fight in the future.

Presence of media without any coverage even in local news paper is another question in India social forum that why it did not happen. Why the media was not giving coverage, media is a strong source of democracy then why media is not being allowed to expose the social problems. This had done by media with consciousness or without consciousness?

I have to know the answer of all above questions. In a movement each and every step must be discussed for the success. Especially to the organizations who are working on the health field.



### Learning's and Conclusion

During this fellowship programme I interacted with various people's organizations, and various programmes which contributed in my experience a lot, other wise I may not be able to get all these things in a very short time. This all took place through my fellowship programme. For this I am very much indebted to Dr. Thelma Narayam, Dr.Ravi Narayan and all CHC team.

Followings are my learning during my six month's period.

Each of these have its very vast range of the topics:

- Understanding regarding community: community it self is very complex thing. In this Fellowship programme I went through various experiences, which helped me to learn about the community. Community is not only the group of peoples which live together, interact with each other share their experiences and have some kind of relations. They live in different places, some peoples migrate like Banjara community and some prefer to be together. For the control over the society they have some rules and regulations. If these rules and regulations come in to hand of people who are not community oriented then this is the starting point of the problems from where the clashes and issues get started. Therefore as a community health activist our role is to always try to build community. Use of life skills will be helpful for problem solving and conflict resolution. We live and believe in democratic system, because it gives the freedom to put own view and critical thinking for the betterment and development of the community.
- Community health is a process to involve the community to take up the responsibility to providing the services for their own health. This is a pure community owned action which helps people to mobilize the community towards common action. This is the involvement of all the community members together in decision making, planning, monitoring, implementation and evaluation, without any discrimination of caste, class and gender. This is community effort to make the community take responsibility for it self.
- **Public Health** :- it is an organized community effort which not only demand for the services form the system, but also responsible for the health of community. What ever the requirements of a large

community required to live the satisfactory and standard, life with dignity comes under the public health. Therefore fulfillment of these requirement not only public health services are responsibility but also community itself to provide and to demand for over all development of the community. This is the primary responsibility of the govt. to ensure all these services to the community.

• Community Based Rehabilitation (CBR):- during my first placement in the community based rehabilitation forum (CBRF) I got an opportunity to learn about the community Based Rehabilitation. It is the process to sensitize community for the persons with disabilities their requirements, needs, to stop discrimination, to spread solidarity and the integration of persons with disabilities in the community and the family itself. As a health point of view we can say that for the development of the society and community health it much more necessary the involvement of every person of community in each and every process of community initiation. It the process of maximum utilization of available resources. Which help to plan every thing in a holistic manner for the development of the community.

The Persons with Disability (equal opportunity and protection of rights and full participation) Act 1995 is a milestone in the field of disability. This is the first Act, talks about the rights and entitlements of persons with disabilities and provides the opportunity to them to participate in the community with their full potential and abilities. Persons With Disability Act 1995, was one of my area of interest in the Community Based Rehabilitation Forum, which helped me to learn about the rights based approach of persons with disabilities. Through the study on the disability I came to know the reality of PWDs all over India. For the development of persons with disabilities CBR Forum is a platform to provide financial and technical assistance to the organizations who are working for the development, upliftment, and integration of PWDs in rural areas, such as Centre for Overall Development (C.O.D.) a NGO in Thamrassery panchayat Kozikod Distt. Kerala. Providing financial assistance to PWDs to perform this activity organization is running a fan manufacturing unit. In this unit 12 workers out of 30 are PWDs. This organization is going to integrate the rights of PWDs in their other projects.

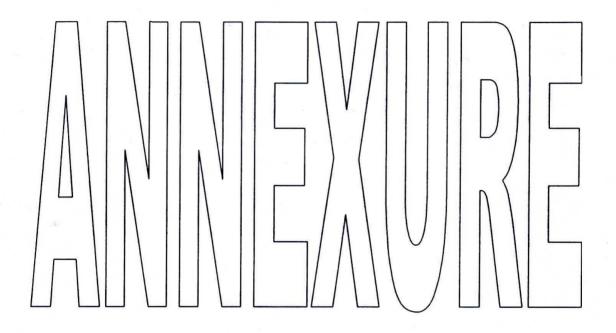
Understanding about the rural community and village health workers training have taught me various lessons, that how members of the community could be dedicated toward their work. In consequence I want to share one of my experiences; During my field placement in the JSS, one day on field visit 80 km away from the main centre Ganiyari and 100 km away from Bilaspur, a woman was suffering from severe anemia. She was living in a small hut of 10 ft\*10ft. Her blood test showed only three gm hemoglobin was in blood. Earlier two children have died and this time too her child has died during the birth. When health worker went her home and requested her to come with us for the treatment, she did not agree, as she cant go out with out any known person and permission of her husband. Then the team member of JSS requested other women to come with her. Then she agreed and came to Ganiyari main hospital. In Ganiyari another trouble was that we were not getting anyone to donate her blood. The same blood group was also not available in the hospital. Then two persons including me donated blood to save her life.

That she was not agreeing to come from the village has many reasons like her family was very poor, a women cant go out with out the permission of her husband, distance of health centre from the village, public transport is not available up to 25 km from the village. And after 25 km only few transports are available. Beside this cultural and traditional factors also effect on the health of people. Lack of food is also one of the major reasons for malnourishment of the woman. People have to migrate for their livelihood. All these factors are the determinants of health that worsen the life of the community.

If our village health team did not reach the woman, she could have died.

## Other learning's were about the importance of the following:

- Understanding about Social and Health Movement.
- Rural health conditions in the villages.
- Execution of the village health programmes.
- Health training of the health workers.
- Local customs and traditions.
- Community health system.
- Public health services.
- Appropriate technologies.
- Food habits of the in the rural areas.
- House hold information of the villages.
- Economical conditions of the villages, especially about the tribal areas.
- Education level in the rural areas.
- Concept of phulwari.
- Malnutrition and public health.



### JUNED KAMAL Community Health Fellow, Community Health Cell, (CHC) Bangalore.

Agency - Duration -	<b>Jan Swasthya Sahyog</b> (JSS) November, 2006 to February, 2007.
Week 1& 2 -	Orientation of the Jan Swasthya Sahyog, and its activities
	Observation of different aspect of JSS work. Patient careOut Patient Out Patient In Patient - Laboratory - Appropriate Technology
	- Out Reach Work — Village Clinic - Out Reach Work — Health Work
Week 3 & 6 <sup>th</sup> -	Project on epidemiology and control of Scabies Objectives Methodology Primary Steps Health Education Treatment / Management Follow up Documentation

## Week 7<sup>th</sup> - Presentation of findings of the project.

#### **EPIDEMIOLOGY & CONTROL OF SCABIES**

#### Objectives:-

- 1 To study the epidemiology of scabies in a community, related specially to the following
  - Age Educational level
  - Sex Family Size
  - Occupation Community Group
  - Income Level
  - Awareness / level of Hygiene and sanitation.
- 2 To plan, design, and conduct a health education campaign on scabies, cause, spread, treatment, and prevention.
- 3 To control scabies in the community.

#### Methodology

- 1 Identify one or two villages with a high prevalence of scabies. (Total population approximately 1000 - 1500)
- 2 Design a proforma for a house to house survey of the disease.
- 3 Read available literature on the Scabies and be well acquainted with facts of the disease.
- 4 Conduct a survey for the disease to determine the above epidemiological features incidence and prevalence.
- 5 Plan design and conduct a health education campaign on the scabies:-
  - Preparation of health education material in the local language.
  - Health education sessions at individual, family, and community level, on cause treatment and prevention of the disease.
  - Awareness level before and after health education.
- 6 Control of scabies in the community mass treatment campaign followed by a rapid assessment of control methods.
- 7 Prepare a report on the survey and the control measures.
- 8 Presentation of the report.

#### Preliminary Steps :

- 1 Procure medicines to treat scabies GBH lotion, gentian violet solution, cotrimoxazole tablets.
- 2 Read available literature on Scabies.
  - Notes on Hindi and English,
  - Text book of preventive and social medicine (PSM) Park.
  - Where there is a No-Doctor.
- 3 Design a proforma for use in survey.
- 4 Design health education material on scabies.

# CBR Forum's view of CBR

### Basic Principles of a CBR Programme

- 1. Enabling services at the home settings of Persons with Disabilities (see Annexure A for details).
- 2. Capacity building of local human resources, especially PWDs to provide services.
- 3. Delivery of optimum quality of services which will build on the traditional good practices of rehabilitation.
- 4. Ensure that the community who benefits from such services gradually takes over the responsibility of managing rehabilitation programmes.
- 5. Ensure participation and involvement of Persons with Disabilities in Planning, Monitoring and Managing the programmes.
- 6. CBR programmes must be flexible so that they can operate at the local level and within the context of local conditions.
- Local resources should be tapped to the maximum.
- 8. Ensure that the rights of PWDs are not denied.

CBR Forum's view of CBR : Mr. Nicholas Guia Rebelo

#### Essential Components of a CBR Programme

- 1. The programme should **cover all types of Persons with Disabilities of age groups** who need rehabilitation services (see Annexure 2 for details).
- 2. The programme should have a **multi-sectoral approach** having health, education, economic programmes and social integration interventions.
- 3. The programme should have access to or generate a good and effective referral system.
- 4. The programmes should aim at **full integration of the Person with Disabilities** into his / her community.
- 5. The programme needs to have **committed and well trained community members as service providers**.
- 6. The programme should have **gender and disability focus and balance**. (Special attention to care for needs of women and girls.)
- 7. The programme should strike a balance between provision of service delivery and empowering the person with disability, family and community through regular transfer of skills.
- 8. The programme should **ensure that the rights of the Persons with Disabilities are not denied** through advocacy at local, state and national level.

CBR Forum's view of CBR : Mr. Nicholas Guia Rebelo

### **Rehabilitating a PWD in a holistic manner**

#### Two dimensions: society and the individual:

When planning out the rehabilitation of a PWD in the above context it is important to look at the situation in a holistic manner.

- In drawing up an Individual Rehabilitation Plan, it is important to ensure that:
- (a) the social dimension is looked into to enable the PWD to function effectively in society and
- (b) all the areas of growth of the individual PWD (and all his / her needs) are attended to.

It is with the above in mind that adequate interventions have to be planned both at the societal and individual level. For instance, while the community is made aware of the need for prevention through inoculation, the staff of the local PHC have to be available to ensure that the inoculations can be administered. Again, while the individual PWDs need for mobility through provision of aids and appliances (crutches, calipers, walkers, wheel chairs) has to be cared for, the need for society to ensure that there is accessibility through provision of good roads, ramps, railings etc. has to be looked into.

#### Holistic rehabilitation through all six areas of growth :

When planning interventions we also have to bear in mind that we have to give attention to the needs in the following six areas of growth:

(1) Physical

- (2) Psycho-sexual
- (3) Intellectual
- (4) Socio-cultural
- (5) Economic
- (6) Spiritual

It is to be noted that holistic rehabilitation will be a reality only when needs in all these areas of growth are cared for.

#### Listing of needs under all six areas of growth :

Against each of these areas of growth, the societal needs that have to be cared for have been highlighted and individual needs have been listed. It is to be noted that this listing of societal needs / individual needs is not an exhaustive one but a pointer of the methodology to be followed. The individual's need will be realized fully only if the societal dimension is fulfilled. They are two sides of the same coin.

For instance under the area of *Physical Growth*, the *societal needs* to be cared for are:

(I) Appropriate Health services and Accessibility in family and society.

while the *individual needs* listed are:

(1.1) Prevention of disabilities and secondary complications and

(1.2) Physical assessment, intervention and mobility.

#### Listing of CBR interventions under all six areas of growth :

Specific interventions have then been suggested to realize each need at both the individual and societal levels. For instance the interventions listed under the societal dimension:

- (I) Health services and Accessibility in family and society are:
  - Awareness to the community
  - Family counseling
  - ∽ Working with PHCs
  - ∽ Training of Dhais
  - ✓ Medical camps with Govt. machinery / local resources
  - Ramps in public buildings / other modifications to make society accessible (visuals)

while those listed under the individual need:

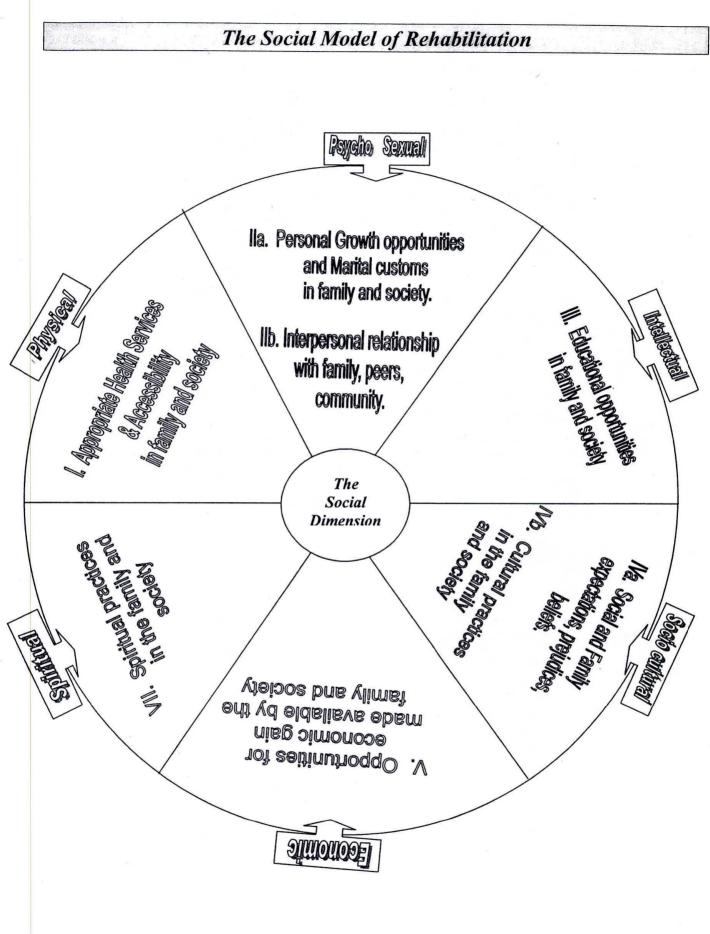
(1.1) Prevention of disabilities and secondary complications are:

- ✓ Immunization
- C Early Identification, Intervention and Infantile stimulation
- Antenatal / Postnatal care
- Genetic Counseling
- Nutrition

It will have to be borne in mind that the above interventions will have to be CBR in nature. This would imply an implicit planning as to how the PWDs, their family members and the community could be involved in each of the above interventions.

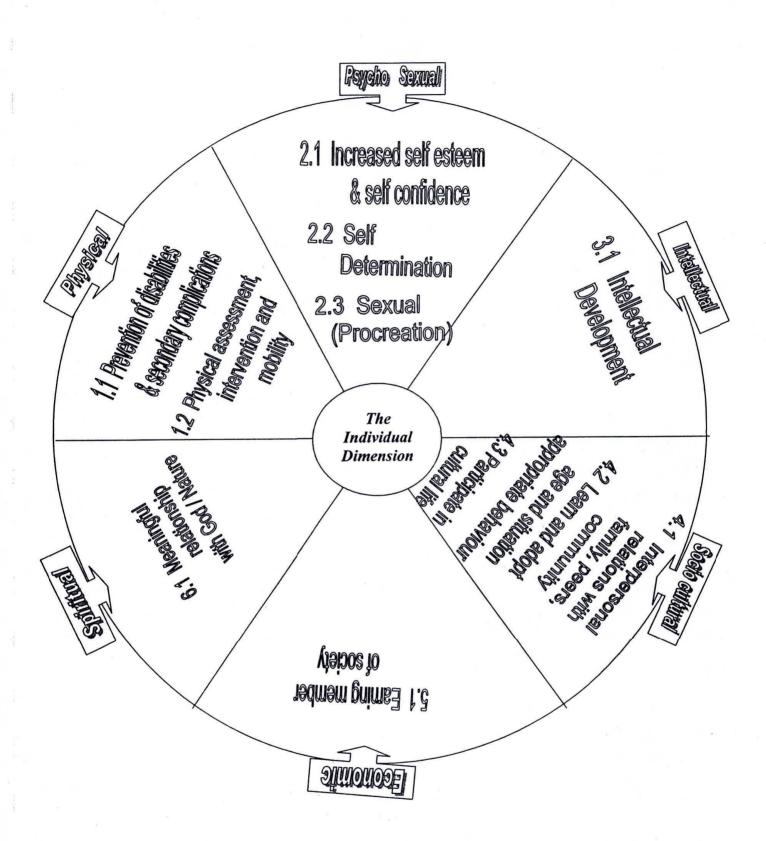
CBR Forum's view of CBR : Mr. Nicholas Guia Rebelo

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CBR Forum's view of CBR : Mr. Nicholas Guia Rebelo

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	Areas of growth, needs and interventions
	Area of Growth: Physical
- Contractor	
	Societal level:
	Need : Appropriate Health services and accessibility in family and society
•	
a anna anna anna anna anna anna anna a	Interventions:
	Awareness to the community
	Family counseling     Working with PHCs
	<ul> <li>✓ Working with PHCs</li> <li>✓ Training of Dhais</li> </ul>
	<ul> <li>Medical camps with Govt. machinery / local resources</li> </ul>
	<ul> <li>Ramps in public buildings / other modifications to make society accessible (visuals)</li> </ul>
	Individual level:
.1	Need: Prevention of disabilities and secondary complications
• 4	Need. Prevention of disabilities and secondary complications
	Interventions:
	Immunization
	Early Identification, Intervention and Infantile stimulation
	C Antenatal / Postnatal care
	C Genetic Counseling
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	<ul> <li>Nutrition</li> <li>Need: Physical assessment, intervention and mobility</li> <li>Interventions:</li> <li>Medical assessment</li> <li>Activities of daily living skills</li> <li>Therapeutic interventions:         <ul> <li>Physiotherapy</li> <li>Speech and language</li> <li>Occupational therapy</li> <li>Occupational therapy</li> <li>Aids and appliances</li> <li>Surgery</li> </ul> </li> <li>Area of Growth: Psycho Sexual</li> <li>Societal level:         <ul> <li>Need : Personal growth opportunities and marital customs in family and society</li> <li>Interventions:</li> <li>Aids and appliances</li> </ul> </li> </ul>
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#### 2.1 Need: Increased self esteem and self confidence

#### Interventions:

- ∽ Counseling (to accept disability / understand limitation / realize ability)
- Personality development training
- Leadership training

#### 2.2 Need: Self determination

#### Interventions:

- ∽ Knowledge of rights, privileges and responsibilities
- ∽ Organization of movements of PWDs / Community Groups
- Advocacy and empowerment
- Federation of PWDs

#### 2.3 Need: Sexual (Procreation)

Interventions:

Genetic counseling

Marriage counseling

#### C. Area of Growth: Intellectual

Societal level:

#### III. Need : Educational opportunities in family and society

Interventions:

Provision of formal / non formal inclusive education opportunities

Provision of special education opportunities

- Provision of skill / vocational training opportunities
- ∽ Awareness to Principals, Teachers, Peers and Parents

Individual level:

#### 3.1 Need: Intellectual development

Interventions:
 ∽ Infantile stimulation
 ∽ Early intervention
C Admission into educational / skill training / vocational setups as per need / functional level

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	Societal level:
IVa.	Need : Social and family expectations, prejudices, beliefs
	Interventions:
	Awareness to community / family on superstitious beliefs / myths.
	Awareness to community on disabilities, modes of communication with PWDs etc.
	Attitudinal change of the family / community
IVb.	Need : Cultural practices in the family and society
	Interventions:
	∽ Provision of opportunities for PWDs to take an active part in cultural events
	Sensitize local cultural troupes to train and include PWDs in cultural performances
	Individual level:
4.1	Need: Interpersonal relationship with family, peers, community.
	Interventions:
	Develop communication skills
	<ul> <li>Promote play activity</li> </ul>
	Creation of recreation clubs
4.2	Need: Learn and adopt age and situation appropriate behaviour
	Interventions:
	∽ Counseling and guidance
	C Behaviour modification
4.3	Need: Participate in the cultural life of the community
	Interventions:
	∽ PWDs attend and take an active part in cultural functions
Ε.	Area of Growth: Economic
	Societal level:
v.	Need : Opportunities for economic gain made available by family and community
	Interventions:
	Opportunities for vocational training / skill training
	Income Generation Programmes
	Availability of local resources / Government schemes
	Disability friendly policies of financial institutions / Government

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	Individual level:
5.1	Need: Earning member of society
	Interventions:
	Pre vocational training
	✓ Vocational / skill training
	∽ Habit of savings
	Mobilize local resources / Government schemes
	∽ Networking with financial institutions
	Income Generation Programmes
	Placement / Self Employment
F.	Area of Growth: Spiritual
	Societal level:
VI.	Need : Spiritual practices in the family and society
	Interventions:
	∽ Opportunities for religious education
	Accessibility to places of worship
_	Create opportunity to participate in religious rites / practices
	∽ Counseling, if needed (not to blame God for disability / not a punishment of previous life)
	Individual level:
7.1	Need: Meaningful relationship with God / Nature
a Mpaga	Interventions:
	∽ Take steps to obtain religious education
and a sport	C Join family / community in places of worship
	Participate in religious rites / practices
	∽ Conseling, if needed.

## Drawing up a Rehabilitation Plan

Partner's have been invited to use the above input on holistic rehabilitation to draw up plans for the rehabilitation of PWDs.

#### (A) Status before intervention:

Status: Needs before intervention	Interventions	Process	Linkages
	made	followed	established
1.1	1.1	1.1	1.1
1.2	1.2	1.2	1.2

The partner organization needs to begin by determining the status of the individual PWD and the milieu in which he / she lives before intervention. In order to do this effectively the partner has to determine:

- (a) the interventions made by the PWD to realize his / her needs,
- (b) the interventions made by the family and the community to enable the PWD to realize his / her needs,
- (c) the process in which these interventions were made and
- (d) the type of linkages that were established in the process.

In order to do the above the partner will have to dialogue with the PWD, his / her family and community members.

#### (B) Plan for intervention:

Plan: Needs at time of intervention	Planned interventions	Foreseen process	Desirable Linkages
1.1	1.1	1.1	1.1
1.2	1.2	1.2	1.2
		1	

After obtaining a clear picture of the status of the family, the society and the individual PWD before intervention, the partner organization has to take steps to draw up an effective intervention plan. This plan necessarily has to build up on what has already been done earlier. Here too the PWD, his / her family and community members have necessarily to be involved if we speak of a true CBR intervention.

Here the partner needs to determine:

- (a) the needs of the PWD at the time of intervention,
- (b) the needs to be cared for by the community to enable the PWD to realize his / her needs
- (c) the type of intervention required to answer these needs,
- (d) the process to be used for each specific intervention so as to ensure that the intervention is CBR in nature and
- (e) the linkages that need to be established to ensure greater efficacy and sustainability.

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#### (C) Actual intervention, Impact and Future plan:

Foreseen Needs at time of intervention	Actual Interventions made	Process followed	Linkages established	Impact	Future course of action
1.1	1.1	1.1	1.1	1.1	1.1
1.2	1.2	1.2	1.2	1.2	1.2
Other Needs perceived at time of monitoring	Planned interventions	Foreseen process	Desirable Linkages		
1.3	1.3	1.3	1.3		
1.4	1.4	1.4	1.4		

Having drawn up the rehabilitation plan the partner organization will have to ensure that the plan is monitored at least every six months. The PWD, his / her family and the community will have to be involved in the monitoring process.

The monitoring groups will have to determine:

- (a) which of the needs of the PWD the partner organization has attempted to answer,
- (b) the type of intervention made to answer these needs,
- (c) if the process used for each specific intervention was CBR in nature,
- (d) what linkages were established to ensure greater efficacy and sustainability,
- (e) the impact of each and every intervention in the life of the PWD (Eg.: if aids and appliances were give, how has this brought about a change in his / her way of life?) and
- (f) the future course of action to be taken, if any.

Understandably, the PWD may have become aware of other needs along the way. Hence, here the monitoring team has to determine:

Here the partner needs to determine:

- (a) the new needs of the PWD at the time of monitoring,
- (b) the new needs to be cared for by the community to enable the PWD to realize his / her needs
- (c) the type of intervention required to answer these needs,
- (d) the process to be used for each specific intervention so as to ensure that the intervention is CBR in nature and
- (e) the linkages that need to be established to ensure greater efficacy and sustainability.

#### (D) Learning:

Having gone through the above process the partner organization, PWDs, their family members and the community will have to document the lessons they have learnt. This process of documentation will help the PWDs, families and community become aware of their own potentials and capacity to take forward the programme. It will also be a learning tool for others to emulate.

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#### Basic Principles of a CBR Programme

#### 1. Enabling services at the home settings of Persons with Disabilities

IBR has its limitations in terms of coverage, high costs and location mostly in urban areas to meet the need of Persons with Disabilities who mostly live in rural areas. Enabling services at the home settings of Persons with Disabilities would have the following **advantages**:

- a. Services can reach a maximum number of Persons with Disabilities of all ages, all types of disabilities (physical, sensory and mental) and both sexes. The Persons with Disabilities are taken care of in their own community and familiar surroundings without being segregated in an institution where their interactions are mainly limited with others having the same disability.
- b. Interventions are provided by family members and the community with external professional guidance. Family integration and integration with a non-disabled peer group and community will enhance a smooth social integration without many of the emotional or behavioural problems.
- c. It provides a wide range of opportunities for the Persons with Disabilities for full participation and equalization of opportunity.
- d. The Persons with Disabilities are also exposed to the day-to-day risks. This **equips them with confidence and teaches them skills to overcome problems** and achieve their rehabilitation with maximum self help.
- e. The integration process right from the early stages helps to achieve the rehabilitation of Persons with Disabilities.
- f. **It gives an opportunity to the community to develop awareness** about (a) the developmental needs of Persons with Disabilities, (b) the skills they need to acquire, and (c) knowledge about integration itself.
- 2. Capacity building of local human resources, especially PWDs to provide services.

One of the principles of CBR is to **demystify the technical skills of professionals and train community members** so that the needs of persons with disability can be met in their own communities to a great extent. Moreover, the **chances that the programmes will sustain are greater**, since the trained community members are more often than not likely to live there without migrating.

The need to train community members to provide interventions to Persons with Disabilities from the community arose due to the following **reasons**:

- a. The dearth of qualified rehabilitation professionals in our country.
- b. The few who are trained are mostly urban based or go overseas for better career prospects and **more** often than not would not like to live and work in rural areas.
- c. Most Persons with Disabilities **cannot afford** to meet the cost of professional interventions due to their economic conditions.

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# 3. Delivery of optimum quality of services which will build on the traditional good practices of rehabilitation.

One of the principles of CBR is to **make the interventions cost-effective without compromising on quality**. Care should be taken to **build on the traditional good practices of rehabilitation keeping in mind the customs and beliefs of the target community**. Bear in mind that only those customs and beliefs that are good for rehabilitation have to be picked up and applied to make rehabilitation effective and acceptable:

- a. In the area of pre, post and ante-natal care the traditional birth attendants could be trained which would help in prevention of disabilities.
- b. The traditional diet of the target community can be studied and built upon to make the diet more nutritious in order to prevent disabilities caused due to malnutrition.
- c. Some herbal medicines and other forms of treatment that are practiced in the community can be studied and if proved to be effective in improving the physical condition or in the prevention of disabilities can be promoted.
- d. Aids and appliances can be used making use of locally available material, which would perhaps be more suitable for the conditions in the community.
- e. Tri-wheelers, trolleys and other play material that are made for children who are not disabled can also be used effectively for children with disabilities. This not only helps in early stimulation and play therapy but also helps in social integration with peers.

# 4. Ensure that the community who benefits from such services gradually takes over the responsibility of managing rehabilitation programmes.

- 4.1 In order to achieve this, the local community should, from the beginning be involved in planning and service delivery to Persons with Disabilities. The community should recognize the needs of the Persons with Disabilities and appreciate their potential for becoming contributing members if the required opportunities are extended to them.
- 4.2 **Mainstreaming of all activities** should occur so that the responsibility for Persons with Disabilities becomes a part of the community's responsibility for its members regardless of disability.
- 4.3 Stress should be laid on **equal opportunities** for Persons with Disabilities and non-disabled persons, **depending on their aptitude**, merit and training.
- 4.4 When the community learns to take care of its Persons with Disabilities, it **enhances its own potential for being a better community**.
- 5. Ensure participation and involvement of Persons with Disabilities in Planning, Monitoring and Managing the programmes.
- 5.1. It should be made clear to **Persons with Disabilities** that they are being regarded both as **recipients** of service as well as **contributors** to community welfare.
- 5.2. In order to give significance to the involvement of Persons with Disabilities, they must have **distinct decision making roles**.
- 5.3. Persons with Disabilities must be **encouraged to do maximum** for themselves as well as other Persons with Disabilities and their families. In fact, where disability is concerned they should play a **leadership role**.

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- 6. CBR programmes must be flexible so that they can operate at the local level and within the context of local conditions.
- 6.1. There **should not be only one model of CBR** because different social and economic contexts and different needs of individual communities will require different solutions.
- 6.2. **Flexible local programmes** will ensure community involvement and result in a variety of programme models, which are **appropriate for different places**.

#### 7. Local resources should be tapped to the maximum.

- 7.1 There should be integration, coordination and convergence of all locally available resources.
- 7.2 **Specialized services** or agencies extending services should play only a **supplementary role** in the service delivery mechanism and **only when such services are not available locally**.

#### 8. Ensure that the rights of PWDs are not denied.

8.1 Various groups of PWDs should join together as a network so as to ensure that they have a common voice to demand for the rights due to them through advocacy at the local, state and national level.

#### Essential Components of a CBR Programme

- 1. The programme should cover all types of Persons with Disabilities of age groups who need rehabilitation services.
- Providing assistance for people with all types of disabilities (physical, sensory, and mental), for people of all ages, including older people and for people affected by Leprosy should be the focus of the CBR programmes.
- 2. The programme should have a multi-sectoral approach having health, education, economic programmes and social integration interventions.
- Creation of a positive attitude towards people with disabilities: this component of a CBR programme is essential to ensure equalization of opportunities for people with disabilities within their own community. Positive attitudes among community members can be created by involving them in the process of programme design and implementation, and by transferring knowledge about disability issues to community members.
- Provision of functional rehabilitation services: often people with disabilities require assistance to overcome or minimize the effects of their functional limitations (disabilities). In communities where professional services are not accessible or available, CBR workers should be trained to provide primary rehabilitation therapy in the areas of rehabilitation such as Medical services, Eye care services, Hearing services, Physiotherapy, Occupational therapy, Orientation and mobility training, Speech therapy, Psychological counseling, Orthotics and prosthetics, Other devices.
- Provision of education and training opportunities: people with disabilities must have equal access to educational opportunities and to training that will enable them to make the best use of the opportunities that occur in their lives. In communities where professional services are not accessible or available, CBR workers should be trained to provide basic levels of service in the following areas:
  - (a) Early childhood intervention and referral, especially to medical rehabilitation services.
  - (b) Education in regular schools.
  - (c) Non-formal education where regular schooling is not available.
  - (d) Special education in regular or special schools.
  - (e) Sign language training.
  - (f) Braille training.
  - (g) Training in daily living skills.
- Creation of micro and macro income-generation opportunities: people with disabilities need access to micro and macro income-generation activities, including obtaining financial credit through existing systems, wherever possible. In slums and rural areas, income-generation activities should focus on locally appropriate vocational skills. Training in these skills is best conducted by community members who, with minimal assistance can easily transfer their skills and knowledge to people with disabilities.
- Provision of care facilities: often, people with severe and profound disabilities are in need of assistance. When they have no families or their families are incapable of caring for them, in order for them to survive, long-term care facilities must be provided in the community where they can get the assistance that they need. Moreover, day-care facilities may be needed to provide respite for families who either work or need time off for other activities.

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- Prevention of the causes of disabilities: many types of disability can be prevented by relatively simple measures. Proper nutrition is one of the more significant ways of preventing disabilities. Another important area of disability prevention is the detection of disability in young children and intervention early in their development, to minimize the effect of impairment. There are many other areas of disability prevention that are also important. These include activities to decrease the number of accidents in the home, on the road and at work, as well as other initiatives to encourage people to pursue healthy lifestyles over the course of their lives. The emphasis on prevention of disability will not only reduce the incidence of disability, but will also reduce the intensity of the handicapping effect of disability. This will ensure that available resources can be better utilized for providing services to the existing population with disabilities.
- Management, monitoring and evaluation: the effectiveness and efficiency of all CBR programme components, both in the community and in the area of service delivery outside the community, depend on effective management practices. The impact of programme activities must be measured on a regular basis. People must be trained in effective management practices. Data must be collected, reviewed and evaluated to ensure that programme objectives are met. In this way, the success or failure of a CBR programme can be honestly measured.

#### 3. The programme should have access to or generate a good and effective referral system.

The community will have to identify and establish linkages with the existing systems like:

- ✓ Health System
- ✓ Education System
- ✓ Local Government
- ✓ Financial Institutions
- ✓ Training Centres
- Business Houses and Industries
- ✓ Service Clubs and Organizations
- ✓ Local Markets
- ✓ Skilled Workers etc.

This would enable them to access their services to improve the quality of life of persons with disability.

## 4. The programmes should aim at full integration of the Person with Disabilities into his / her community.

The CBR programme should aim at identifying the potentials and needs of Person with Disabilities and providin0g appropriate interventions to optimize these, so that the Person with Disabilities can **live a life of dignity and respect to the fullest of his / her abilities**, integrated into all spheres of life within the limitations of his / her disability.

## 5. The programme needs to have committed and well trained community members as service providers.

Working with parents and families in CBR is a must. To a large extent, parents / families can make our efforts successful. It is not realistic to say that we will train the entire community. All community members are not likely to be willing. Therefore it is essential to **identify those members of the community who are committed and willing to give time for the programme on a regular basis and train them systematically over a year or two, so that they can at least carry out the role of a CBR worker. If an external organisation is implementing CBR programmes in a particular target area, it is always advisable to employ as staff people from the same target area. <b>This would not only make the programme more effective and acceptable but would also in the long-term help in sustaining the programmes.** 

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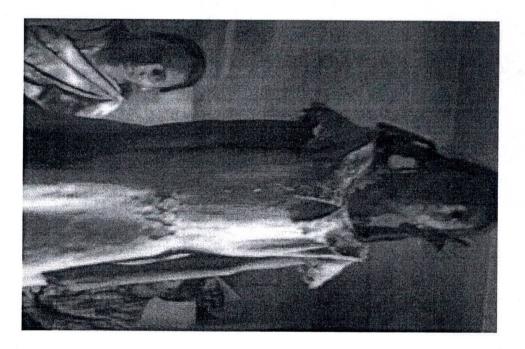


CBR intervention with a Hearing Impairment Child Annexure .....

1



CBR intervention with a Hearing Impairment Child. Annexure .....



CBR intervention with a Cebral Palsy Girl Annexure.....



Open Day Activity In the Sanchar Annexure no.....



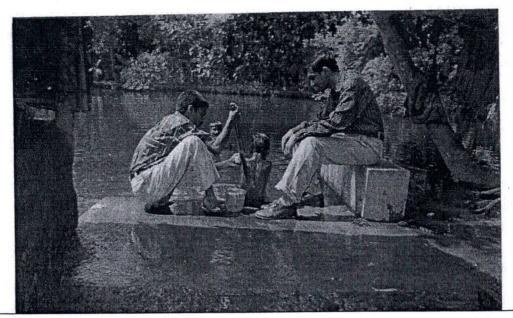
Self Help Group Of Persons With Disabilities Activity In the Sanchar Annexure no.....

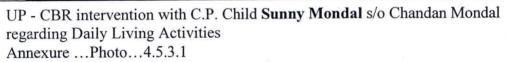


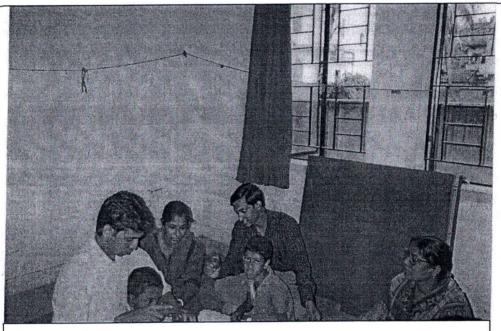
Voice identification activity under the CBR programme, with the hearing Impaired Child Anoop Das with his mother Annexure Photo - 4.5.3.4



CBR Worker MR. Sujit Da (Blind impairment) during the field visit







Annexure 4.5.3.5 **Harit Rupam Shah**, Autistic child with the mail CBR worker and his parents. LIST OF ACTIVE PARTNERS OF CBR FORUM

and a

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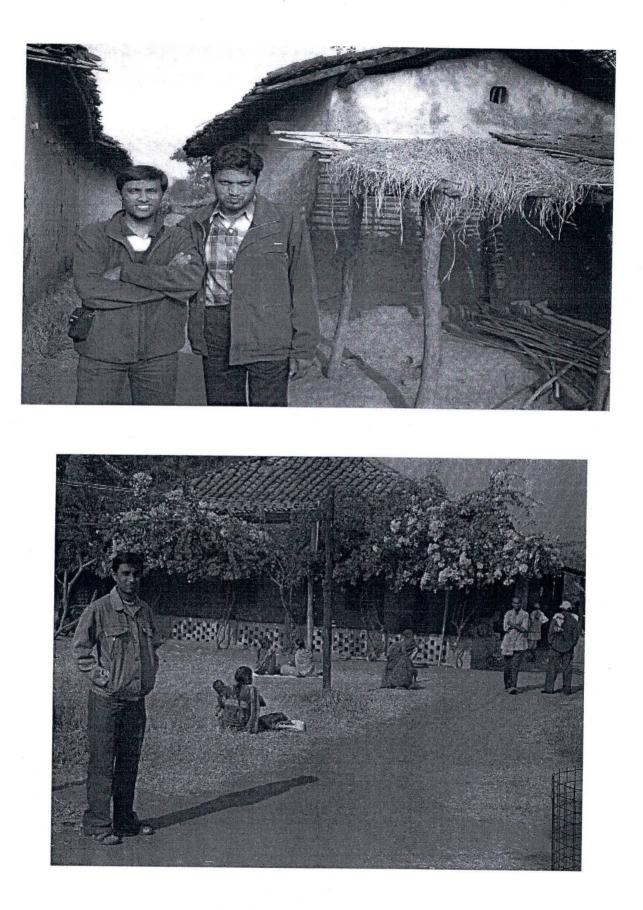
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#### Advocacy in CBR of Persons with Disabilities

This paper has three sections. The first section is on 'advocacy', second on CBR of persons with disabilities and the third is on portions of the Persons with Disabilities Act and ways to advocate for the rights of persons with disabilities.

#### Section 1 – What is advocacy?

Advocacy is finding of public, legal space in which to systematically organize an action, spread awareness on public policy, lobby with and influence leaders and opinion makers. The actions could be an attempt to

- a) Shape public policy to advance social justice and human rights
- b) Focus on inadequacy or discrimination in public policy or legislations
- c) Enforce implementation of rights given by a policy or legislation

The public policies taken up for advocacy are often a specific issue, as for example, women's issue, rights of children, education and rights of persons with disabilities.

#### Advocacy involves

- Resisting discrimination against a disadvantage group
- Supporting and empowering the disadvantaged groups to ensure that larger leel policies percolate to reality at the local and individual level
- Accessing information and networking with other groups and individuals forming coalitions to maximize the influence
- Adopting a non-violent approach, within the public and legal framework, to achieve the objective

#### Advocacy is not

- A mere combination of various tactics and strategies; and
- It is not a substitute for mobilization of the disadvantaged people and their involvement or participation

#### Key elements in Advocacy

- There should be a social cause, pertaining to a class of persons, a disadvantaged or marginalized group
- It requires the affected people to come together and work in cooperation. This effort should be continuous and systematic
- It is directed towards the establishment, for example, the government, the government, the police, an authority practicing discrimination
- It is aimed to bring about changes change in public policy, change in people's attitudes, institutional structures, in laws, rules etc.

#### **Benefits of Advocacy**

- It builds confidence in the people engaged in action, in their ability to bring about changes that matters to them
- It educates people on issues that affect their lives
- It takes the issues to a wider audience and helps change public policies, rules etc.
- It demands and enforces action on important issues

# Advocacy involves gathering information and key actions

- Collect data from the field to base the arguments on facts and figures
- Get statistical information, such as the census, to know the population figures, literacy rates, male/ female ration, education, family income and so on to project a proper picture
- Scientific information, if available, from field and research reports, can be very useful to argue the case
- Personal stories can be used effectively to demonstrate what happens in practice. It can be effective as it touches people's emotions/ feelings
- The relevant laws, rules, policies and
- Reports from government and other authentic sources

#### Key strategies and action

- Spreading awareness in public and among leaders
- Media action give information to public media
- Submit petitions, letters and memorandums to officials
- Lobbying with legislators and others, to raise the issue at a suitable forum
- Network and coalition with a wide variety of groups, organizations with whom a common working understanding can be reached
- Demonstrations, protests, dharnas, etc.
- Filing Public Interest Litigation (PIL)

Advocacy is a pro-active, planned and co-ordinated action. With practices, one should be able to anticipate events/ problems before they actually occur.

Contact and get as much support as possible from all sections for your cause. Wider, grass root support can strengthen the argument. Put forward the case in a rational manner. Do your homework. Develop credibility. Know your rights and laws.

Advocacy requires THINKING, but most of all ACTION.

## Section - 2 - CBR - Definition by WHO, UNESCO and ILO is:

"Community based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities".

CBR is implemented through the combined efforts of disabled people, their families and communities, and the appropriate health, education, vocational and social services.

Through creating awareness, organizing and training in the community, CBR programmes seek to empower the disabled and enhance their potential. It offers them the same opportunities to attend school, receive vocational training and develop incomegenerating activities, across the available social and health services, to participate and be an equal citizen in the community.

Section -3 - CBR, Advocacy and the legislation for rights and protection on persons with disabilities.

The Persons with Disabilities (Equal Opportunities, Protection of rights and Full Participation) Act focuses on three aspects:

- 1. <u>Rights of disabled persons</u>, such as the right to education, rehabilitation measures, concessions and benefits, training in vocational skills, employment, social acceptance and equal opportunities.
- 2. <u>Responsibilities of the government and the family towards the disabled</u> <u>persons</u>, such as providing opportunities to disabled persons to reach his/ her full potential, through making use of opportunities provided.
- 3. Non-discrimination of persons with disabilities

In terms of rights of persons with disabilities, the PD Act specifies that

- <u>Scholarships and travel concessions:</u> The government shall provide schemes for benefits like maintenance allowance, scholarships, travel concessions etc.
- <u>Special schools and rehabilitation services</u>: The availability of special schools, rehabilitation and intervention services will be made available in all districts
- <u>Support to students</u>: Books, learning aids etc., must be supplied in order to make integrated education meaningful to the disabled child.
- <u>Right to education</u>: The Act lays down that "The appropriate government and local authorities shall ensure that every child with a disability has access to free education in an appropriate environment till he (or she) attains the age of eighteen years."
- The Act further provides that the government must provide schemes for part-time classes for those who could not pursue education on a whole time basis, and education through open schools etc.
- <u>Disabled persons' right to access</u>: The appropriate government shall prepare schemes for accessible transport facilities and removal of architectural barriers in schools, colleges and in other public places.
- <u>Disabled people have the rights to lead an independent life</u>: Disabled children have the right to vocational training to be able to learn a skill
- Workshop for producing and repair and maintenance of aids and appliances have to be set up, especially in rural areas.

- <u>Survey and collecting information</u>: The Act provides that the government and local authorities shall take measures like undertaking surveys on the causes of disability, screening children for identifying 'at-risk' cases, sponsoring and promoting awareness programmes, promoting health care through training staff at primary health care units etc.
- The Act provides for the <u>prevention of disabilities</u>, making the government responsible to ensure that such schemes are implemented.
- <u>Disabled children have a right to be an active part of their community</u>: In furtherance of this, the Act provides that the government shall endeavour to promote the integration of students with disabilities in regular schools. It also states that necessary concessions must be made in school curriculums for disabled children.

## Responsibilities of the governments towards disabled person

- The Act specifies that the government should make plans, programmes and schemes for the welfare and betterment of life of PWDs. State level committees have been constituted to plan such programmes and schemes. Five members from NGO sector are represented in these committees
- One could ask if these committees meet regularly and ask the government to make public the decisions of these meetings, as part of right to information. One can also question when such decisions are not implemented.
- Commissioners have been appointed in all the states, whose responsibility is to ensure that plans are implemented. Their job is to ensure that violation of the rights of persons with disabilities and discriminations against them are prevented.
- NGOs can meet with the Commissioner and offer support to him/ her to ensure the above.

#### Non-discrimination in the PD Act:

- Provisions are made in the Act that no child or a person with disability is discriminated only because of his or her disability. The affected person or the NGO working in that area can bring such incidence to the notice of the State Commissioner, who should look into the complaints and take remedial action.
- The affected person, family or NGO working in that area should bring such matters to the notice of the Commissioner/ concerned authority to take action and to rectify the situation.

# The National Trust for Welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 provides for the setting up of a Trust:

- To strengthen facilities for the care and protection of persons with the four specified disabilities
- To evolve procedure for the appointment of guardians and trustees for persons with disabilities requiring such protection.

(Please read the full Act for more details)

## Action on these accordingly, should be taken at three levels -

- Individual and family
- Community/ society
- Governmental/ Political level
- At Individual level, and through NGOs, we can create awareness on the provisions and rights under the Act. We cannot remain passive and expect the government to take responsibility and act in favour of disabled people
- At family level. The responsibility of the parents to ensure that their child with disability is given proper care and trained in activities of daily living, so that he/ she can grow up to live an independent life
- Each one of us can put in some effort at home, school, in public and at work place in small but significant ways to help in this. For example, a school teacher can ensure that children with disability are enabled to attend class, and included in regular activities of the school and games etc.
- In rural areas where disabled persons have no special facility, where resources are limited, admitting disabled children into school itself is a big thing. By being with other children, he/she will feel encouraged and accepted. Children who are not so severely disabled should be integrated in to regular schools.
- In our work place, office, factory or institution, we can ensure that disabled people are given jobs. We can persuade our friends to do so as well.
- At community/ society level, creating awareness on disability is important. Giving positive image of persons with disabilities through writing slogans on walls, street plays, songs and other visual aids are also helpful.
- The PWD Act has been summarized in an easily understandable language and been translated into regional languages. NGOs can publish this widely.
- At the government/ political level, influencing and advocating with the planners to include project and schemes for disabled persons is an important step. At present this is not being done by many organizations. Unless there is pressure on the government, it will not act. Individuals and organizations in all the states can come together to gain enough political strength.

### Need to communicate and network

Raising awareness is only the first step to bring about a change. However, just raising awareness will not bring about a change. The system should also be made to provide opportunities for disabled people to benefit from them. For this, we need to work at different levels. Networking among NGOs is a positive way to do this.

In Bangalore, four years ago, several NGOs working with disabled people, parents of children with disabilities, their advocates and other concerned citizens formed a coalition called 'Disability Network'. It works to raise awareness among NGOs and general public on disability issues, acts as a forum for discussion and takes up issues with the concerned authorities regarding the provisions of the Act. Matters concerning issue of ID Cards, travel concession, school examination system, access in public places, benefits and facilities and other issues have been taken up successfully with the government through this Network.

In Andhra, Tamil Nadu and other states too similar networks have been formed. It is important that disabled people and NGOs come together to build a strong movement. There is an urgent need for advocacy and lobbying with the concerned authorities for the protection of rights, providing equal opportunities and enable full participation as provided in the two Acts. This can happen only when all concerned join together and act.

#### **SCABIES**

Scabies is a common, highly infectious disease of the skin, caused by the scabies mite. It is mainly seen in children, but can also affect adults.

#### Cause :

A small insect called the scabies mite, which can just be seen by the naked eye. Scabies is <u>not</u> spread by dirty water.

#### Symptoms and signs :

- 1. Small swellings all over the body, but more common
  - between the fingers,
  - on the wrists,
  - around the waist,
  - in the groin,
  - on the buttocks (especially in children),
  - below the breasts.

2. <u>Itching</u> which is worse at night.

3. Sores with pus - due to scratching and through infected clothing.

#### How is it spread ?

It is spread through close body contact and through infected clothing.

#### Treatment :

- (a) <u>Important points to remember</u> :
  - Treat all members of the family or household at the same time.
  - Ointment or lotion to be applied correctly over the whole body below the chin.
- (b) <u>Medicines for scabies</u> :
- 1. **Gamma benzene hexachloride (GBH)** 1% cream, ointment or lotion. Most effective, needs one application only. <u>Do not use</u> in children below one year of age and in pregnant and breast-feeding women.
- 2. **Benzyl benzoate** 25% lotion effective, but needs two applications. To be used diluted 1:3 in children below one year, and 1:1 in older children.
- 3. **Neem and haldi paste** Grind neem leaves with turmeric and apply to the whole body after a bath. Repeat the applications for another two days, without bathing. A bath may be taken on the fourth day.

#### (c) <u>Application of cream or lotion</u>:

1. GBH 1% cream or lotion – After a bath in the evening, applies to the whole body below the chin, applying more on the affected areas, eg. between the fingers. Let it remain overnight for 12 to 24 hours, and then a bath may be taken.

2. Benzyl benzoate 25% lotion -

1 <sup>st</sup> day evening	-	Bath. Apply lotion to whole body below chin.
2 <sup>nd</sup> day	-	No bath. Apply lotion again as above.
3 <sup>rd</sup> day	-	Bathe and wear fresh clothes.

- (d) <u>In case of infected scabies</u> (with sores and pus), the infection should be treated first before treating the scabies.
- Give co trimoxazole to the patient for at least five days.
- Gentian violet 0.5% solution may be applied once daily on sores.
- After sores heal, use one of the above lotions or creams.

Itching may continue for 2-3 weeks after treatment. Explain this to the patient, and give chlorpheniramine maleate tablets twice a day.

#### (e) <u>Other measures</u>:

Keep all clothes (including bedding) out in the sun for 4 to 6 hours to kill the scabies mites living in them.

#### Prevention of scabies :

Good personal hygiene

- bathing daily.
- Changing clothes daily.
- Washing clothes regularly.

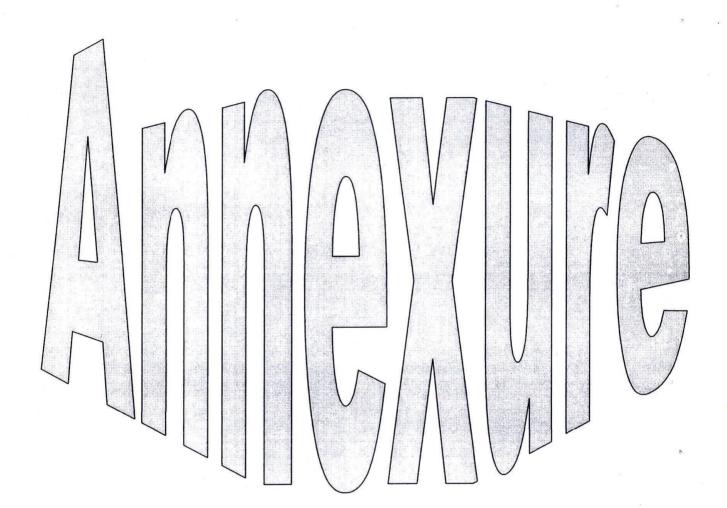
April 2005.

**Dr. Ravi D'Souza,** M.D. (Community Medicine)









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## XXXIII MFC ANNUAL MEET

Public Health Education in India: Lacunae, Challenges & the Way Ahead

#### Programme

DAY 1 (28<sup>th</sup> Dec.) Session 1 9.30-1.30 10.30-11.00 Tea Break History of Public Health Education (PHE) (prefacing the discussion with paper highlights)

- a. Public Health Education in India: A Historical Review
- b. Development of PHE in Other Countries: A Comparison
- c. Public Health and the NGO Sector
- d. A Counter-Culture View of PH in India

Chair: Anant Phadke Summarising the issues: Ritu Priya

1.30-2.30 LUNCH

#### Session 2

2.30-5.30

3.30-4.00 Tea Break

Public Health Education – Institutional Experiences

- Ja. SIHFW
- . A. Primary and Paramedic Worker Training
- . Community Health Cell

d. CEHAT

- f. CHAD, Vellore
- g. Achyuta Menon Centre,
- h. CSMCH, JNU

Chair: Veena Shatrugana Summarising the issues: Renu Khanna

DAY 2 (29th Dec.)

Session 3 9.00-1.30 10.30-11.00 Tea Break Towards an MFC Perspective on PHE: Democratisation & Public Health

a. Cross-cutting Issues of Structure, Content & Learning Methods

b. Multiple Frameworks

- PHE Needs as Seen From the Grass-roots
- Public Health Foundation India
- **Reforming Medical Education & Health Service Systems**
- Public Health Movement

Chair: Chinu Srinivasan Summarizing the issues: Alpana Sagar

# 12.30-1.30 Group Discussion (4 groups)

- a. Integrating the PH perspective in various disciplines
- b. Content of PHE
- c. Teaching/Learning Methods
- d. Regulation & Monitoring of PHE

1.30-2.30 LUNCH

2.30-3.00 Group discussion contd.

#### Session 4

The Way Ahead

Strategies, Commitments

3.00-4.00

Group Reporting in Plenary Summary of issues: Rakhal Gaitonde

4.00-5.30

- a. Gathering the Threads, and Outline of What We Feel Should be Done
- b. Towards Actualising the Plan, Specifying Commitments

Facilitators: Thelma Narayan & Ritu Priya

## Please Note:

Sharing sessions of personal reflections, dilemmas and work experience will be held post-dinner. Annual General Body Meeting of the MFC on the 30<sup>th</sup> December, 8.30-1.00.

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	b) He can derke water in a mig, but put it in- foront of the body/fourehead	b) He will learn to give water on the head with a mug
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- A START OF T	IRP OF SUNNY MONDAL.	
	Rez. No ->.	

Ashique Gazi Status Target (July 10 Sept' 2006 1. Physical =>" 1. He is suggived full physical Support to maintain oraiding He will move Position, and also to come in this with bottom suffling and Position. He can Just-mainten m. also E hand Support (in both side). 4/5 seconds, otherwise he toy to storaight g this body. ~ Ma. He is orequired sell 2. A. D. L=> to do by his & mother, alone. @ Bathing > He would be sit with full support he will lear Therefore we have made a Special batting chain. on (i) put 2 migs water on his head (ii) to give full concentration o this coal his eye-hand co-gradin 22-06-06. tion. 216. He needs a complete help to wear a half pant in ( Dorossing -> He will learn laying position (a pillow order to proof a wear a pant for this head). He can put of the this knee First in Laying pos tion (A pillow will be given Pant m laying position. He is not interestic to use his hand Under his head). Ve. If mother gives rice @ Feeding -> when he wails in his left hand, Sometimes he give release his muscle be hungry and mother give rice in to his left hand the . tone to bring side in to his month. I would brought his left hand & ruice towards this mouth. To times. TRP of ASHIMIE GINTI - Bez. No-7.

## Hope

When the Darkness of the light will recede When the morning glow will flow When the dream will come true When the heart will beat with joy That day shell

When no one will weep helpless When no one will sleep hungry When all will have roof above When al will have content heart When people will not die On foot path of the cities When the alms will not be kept On the palm of the workers When every laboring hand Will enjoy right full share That will come

When operation will not be tolerated When the home will not be burnt down When the blood will not be flow on the street. When the eyes Will not be filled with pan That day shell come

When in the name of religion People will not be taught hatred When this earth will be Sprinkled with colorful petals of love When the rays of peace will Light the world

That day shell come That day shell come

Javed Akhtar