FRIDAY MEETING TRANSACTIONS

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Editor's Comment

The field of disability rehabilitation has moved from a medical and impairment orientated focus, to one focusing on rights and group organisation. Of late there is increasing emphasis on issues related to rights of persons with disabilities and on organising them into self-advocacy groups so that they can demand and fight for their rights at different levels and on different platforms. Many field level programmes are also organising self-help groups of persons with disabilities and their families for different purposes. However, the process of group formation for any purpose is a challenging one. In the disability sector in particular, this process has not been studied much or documented.

Usually, groups tend to be either democratic or autocratic in nature. A democratic group is one where all members have an equal say and the leader may only play a subdued role. An autocratic group on the other hand, revolves around a single leader, who directs the goals and activities of the group. At present, many people in the disability sector are focusing on formation of groups for advocacy and self-help, which are democratic in nature. Formation of democratic groups is distinguished by certain singular characteristics. Firstly, in such groups, the members come together to fulfil a commonly perceived need. Secondly, every member in a democratic group has a role to perform, which helps in group decision-making in a participatory way, in order to achieve the shared goal. This is a very difficult aspect of the process of group formation and usually takes a long time to reach fruition. In many developing countries, people are not used to democratic styles of functioning in a group, and there may be power struggles, fragmentation into sub-groups, or exclusion of some stakeholders in an attempt to limit membership and thereby reduce perceived threats or competition from others. The third important aspect in group formation is the value addition that each member brings to the group, in order to achieve the shared goals. This can be measured by the willingness of members to contribute resources to the group, that are of high value to themselves. Through this process, others who may not be ready to contribute resources can be excluded, as their commitment to the shared goal may not match that of those who are ready to contribute.

Before any democratic group is formalised therefore, it is necessary to ensure a few basic prerequisites, such as the definition of a shared need and goal, delineation of roles and responsibilities of each member and commitment of resources of value from each member. It is important to do this before the group is formalised, in order to prevent disintegration or fading of interest at a later stage. Since group organisation for different purposes is gaining importance in the disability sector, it is time that the process of group formation is studied in detail in this sector, for more effective functioning and better outcomes.

The editorial team of the Asia Pacific Disability Rehabilitation Journal Group wishes the readers a Happy New Year!

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MENTAL HEALTH IN DEVELOPMENT AND CBR

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INTRODUCTION

In recent years, there has been a significant growth in different aspects of psychiatric care in the community, along with the increasing involvement of NGOs and other sectors such as social welfare and education, in mental health services. However, many difficulties persist, preventing mentally ill people from participating in the development process. The stigma of mental illness continues to prevent people from coming forward to seek help, or to organise themselves into self help groups. Many established development and CBR programmes do not include people with mental illness under the purview of their services because of lack of expertise to deal with this issue at the community level.

People with mental health problems tend to be very marginalised by society. Almost every society attaches stigma to mental illness. It is this social ostracism that makes it difficult for people with mental health problems to be a part of standard poverty reduction programmes.

To address this problem, Basic Needs India (BNI) was started and registered in 2001. It is a social and non profit making organisation, governed by six trustees. Staff membership comprises of a Programme Manager, Administrator and two facilitators(for Psychiatric Social Work and Income Generation Programme).

PURPOSE

Basic Needs India aims to concentrate on the social, economic and development needs of people with mental illness and their families, through new initiatives to contribute in the reduction of poverty.

PROCESS
Basic Needs India will:

- work with established development organisations particularly in the rural areas, to enable them to adapt their programmes so as to take into account the needs of people with mental health problems.

- encourage the formation of self help groups of people with mental illness and their families. They will be supported to provide for themselves through appropriately developed and managed schemes.
- train and support people with mental illness and their family members to become contributing members by developing appropriate income generation programmes.
- develop partnership with existing organisations to help them include poverty alleviation work in their own communities.

Basic Needs in participation with persons with mental illness, their carers\ families and CBO's (community based organisations) has evolved a developmental model comprising of five components.

Community Mental Health Care : The purpose of Community Mental Health Care is to assist the individual with mental illness to obtain an adequate level of functioning, to enable them to participate in a sustainable self-reliant programme, leading them to exert the human potentials within their own communities.

Income Generation: Basic Needs India firmly believes that poverty is a consequence and cause of mental illness. The mentally ill, and families will be encouraged to get involved in economically viable activities of their choice.

Capacity building and Animation: To build capacity in already existing groups within the community to address the issues of people with mental illness. This process enables Basic Needs to reach out to many people and ensures optimum utilisation of resources and community development.

Research: Action research will be developed along with people who have experience of mental illness to understand their lives in the community. It will be a kind of therapy (like psychodrama) conducted in groups, as there is a chance for ventilation, sharing and discussion. The end product of research is attaining knowledge, leading to a change in the life styles of people with mental illness. The findings of this research will be disseminated to interested individuals and organisations.

Administration: To provide a well co-ordinated programme and planned activities, to ensure timely reports and to meet statutory requirements. To promote and support partnership with community based organisations.

CURRENT WORK

 Basic Needs India has established partnerships with-ADD-India, Mitra Jyothi Bangalore, SACRED Anantpur, Narendra Foundation Tumkur district, Association of People with Disability Bangalore, Saumanasya Dharwad, Gramina Abhudaya Seva Samastha Dodballapur, Samuha Raichur and Koppal. It is also exploring the possibilities of establishing secondary partnerships in North India in Bihar, UP, MP. Through this work, Basic Needs India visualises a community where persons with mental illness and family members are accepted and fully participate in all aspects of life including social and cultural.

D.M. Naidu

MENTAL HEALTH AGENDA IN THE NEW MILLENNIUM

The tragedy at Erawadi, Tamil Nadu, in which 27 unfortunate human beings disabled by mental illness died, was a disaster waiting to happen. It is a collective failure of responsibility of different sections of society, due to indifference, lack of concern and disregard for the plight of people disabled by mental illness. The Mental Health Act 1987, the People with Disability Act 1995, and the Rehabilitation Council of India Act 1992 were all designed precisely to prevent Erawadis happening, by giving protection to all aspects of care of persons with mental illness. However, due to failure of implementation at various levels, it is questionable as to how many persons disabled by mental illness benefited even in small measure by any of these parliamentary acts.

The majority of persons in the Erawadi asylum needed rehabilitation. Rehabilitation means restoring the capacity of the disabled persons such that they reintegrate as useful, productive members of society in their own right. This is to be carried out in the community where we all live, amongst and alongside us. Rehabilitation is based on the bio-psycho-social model, designed to instil independence, humaneness, dignity, honour, hope, the work ethic, autonomy, self respect, self discipline, self regulation, and interpersonal skills. To deliver this rehabilitation package, psychiatrists, psychologists, social workers, psychiatric nurses, occupational therapists, families, self help and advocacy groups are required to act in concert, as a community mental health service care team. In most parts of the country, there are not enough psychiatrists to go around, leave alone the other members of the team. The major issue here is how to recruit, pay, maintain and retain them, especially in rural areas. In the bio-psycho-social programme, the psychiatrist is needed a few hours weekly as part of the core management team. Yet, the Mental Health Act demands a full time psychiatrist as per the medical model. Many families are struggling bravely against overwhelming odds and dire financial straits to care for their wards at home. How to look after and provide financially (long-term, lifetime) for the affected family member and what happens after the parents are no more, is a major worry for families. Disabling mental illness is a family illness. Stigma, burden, discrimination and social ostracism are worsening in a society in which family, community, cultural, traditional and national values are rapidly eroding in favour of the "I, me myself" ideal.

It is necessary to understand the larger issues and concerns in the mental health service care system that may have led to the situation in Erawadi, in order to put Erawadi into the current mental health perspective. The following section attempts to do so.

Psychiatry as a medical speciality, is towards the bottom of the heap of the career priority list of medical graduates. Psychiatric rehabilitation is at the bottom of the career priority list in the psychiatric fraternity. Doctors and many psychiatrists regard rehabilitation as a boring, thankless drudgery with no career or financial prospects in the long term. Like other medical professionals, psychiatrists do not like serving in rural areas where the main (80 percent) problem exists. India is said to have a pool of 3500 psychiatrists Perhaps 25 are in psychiatric rehabilitation. The maximum 'guesstimate' of mental health professionals including psychiatric social workers, psychiatric nurses, psychologists, psychiatrists and occupational therapists, is 10,000. India's population is 1 billion. Fifteen million need long term care in rehabilitation. Forty three asylums providing mainly medical and some rehabilitation care are the chief service providers. Public and private sectors together account for 40,000 beds. Mental illness affects 4-6 percent of the population. Major depression is in the top 5 of the World Health Organisation illness list, at the beginning of the new century. Whichever way one looks at it, the numbers just do not add up. If the numbers are to add up, a radical frame shift in the mental health mind-set of the country as a whole, has to take place. Only then, can the millennium mental health agenda be built upon a new paradigm, be put together to address the overall mental health of the nation in which mental illnesses are rapidly climbing to the

top 100 WHO illness list. Physical illness/ disability is clearly perceived and thus defined and measured by verifiable, predictable, reproducible internationally accepted norms and guidelines. Mental illness/disability presents not as an obvious physical defect, but, as changes in behaviour manifesting as dysfunctional disability. Behavioural dysfunctional disability is gauged in terms of internationally specified, minimally agreed upon, operationalised, descriptive definitions based on speech, thought, actions and corresponding changes in physical systems. However, there can be a wide variation, fluctuation, and unstable, unpredictable manifestation of illness. There are other explanations of behaviour in illness/dysfunctional disability, such as possession by devils and demons, the "evil eye" (commonly believed magico-religious origins world-wide), wilful misbehaviour (another universal belief) and deficient moral-psychological fibre (one more widely held belief). No wonder it is difficult to define and measure disabling mental illness. It is no surprise therefore, that disabling mental illness is frequently misdiagnosed, mistreated, misunderstood, mismanaged, misused and abused. The magico/religious dimension leads to the Erawadi style treatment, rehabilitation and care. Psychiatry and its allied disciplines have gained respectability in the last 40 years. The disability sector is 25 years old. The mental health disability movement is probably 15 years old. Stigma, myths, misconceptions coupled with lack of awareness of this new disability has resulted in a primitive, skeletal mental health agenda thus far. The sheer size, needs and novelty of this new disabled kid in the disability sector has not helped in integration with other disabilities or society; nor resulted in reaping the benefits of various parliamentary acts. There is talk of discrimination from other constituents in the disability sector, by virtue of stigma and fear that this new disability will bite off a large chunk of the woefully small disability benefit cake.

However, some good news is starting to flow in. There is evidence that the mainline "mad" illness schizophrenia, managed medically and properly in the initial critical 6 months of illness, can be cured with no residual psychiatric disability. New, wonderful, easily affordable, medicines taken correctly, results in sufferers leading normal/near normal quality lives as worthy members of society. An internationally accepted dysfunctional disability scale is being presently field-tested and could help channelise benefits for the needy, and add muscle to the just demands of the mental health lobby. The stigma syndrome shows signs of reducing as the number one mental illness depression, becomes common in society. It is becoming acceptable to discuss depression openly, as it is as treatable as diabetes or heart disease, which can also be controlled such, that sufferers lead normal/near normal quality lives. At least in the bigger cities and lesser metros, awareness of the cause and treatment and rehabilitation of mental illness/disability, is on the increase and individuals and groups are fighting for the rights of the mentally disabled as children of the same God. The disability sector is trying to act inclusively within the grain of the disability sector, and in tandem with the government. Many groups and organisations are at work in Bangalore and Karnataka. There is active, informal networking between government, public, private and voluntary sectors. The multidisciplinary bio-psycho-social team model is becoming a reality. The print and electronic media, realising the overwhelming importance of health care and education take an active interest in mental health issues, concerns and needs. The Karnataka government and its disability and mental health authority wings are actively interacting with mental health organisations for the betterment of the disabled mentally ill.

Having placed Erawadi in the current mental health context, I now venture to formulate the millennium mental health agenda.

1. A grand alliance of forces in mental health, needs to be formed as equal partners on a level playing field. The government, public sector, private sector, voluntary sector, families,

committed individuals and affected persons need to come together as a broad federation on a common platform, subscribing to agreed principles and objectives. Such a forum allows open, informed debate; wide discussion and honest difference. Co-operation, collaboration, consensus, co-ordination, cash and commitment are the watch words rather than conflict and competition. Inevitably, in an economy driven by market forces with huge mental health service care requirements, the mental health business (hospitals, nursing homes and carehomes) will be active. The government will look to the private/voluntary sector to take over, and run health care in the future. The four cardinal principles of the alliance should be a)Commitment, b)Cash, c)Sinking /Rising above/around differences and d) Sublimating egos.

2. Awareness is necessary through psycho-education and publicising widely that early, proper treatment and post-acute rehabilitation means good recovery, well being and normal/near normal quality of life, especially in schizophrenia.

3. We must ensure minimum standards, reasonable care and maximal utilisation of care in all service institutions.

4. Advocacy work is necessary to highlight equal rights and full participation of persons with mental illness, in all activities and walks of life as equal citizens under the law.

5. There is a need to work and network with other lobbies towards inclusion in some Acts, such as the National Trust Act, and to amend and influence implementation of other Acts benefiting persons with disability, such as the PDA act 1995 ; Mental Health Act 1987 and the RCI Act 1992.

6. It is necessary to publicise the mental health agenda in the media and work with the media to strengthen the lobby.

7. Prevention needs to be strengthened. Evidence indicates that schizophrenia is a neuro-developmental brain disorder, potentially prevented by better mother-baby care before, during and after delivery.

8. Integration of mental health into community based rehabilitation: The answer to countrywide mental health care awareness is CBR. Mental healthcare activity is almost non-existent in CBR. For mental health to be a full partner in CBR, I suggest a new approach titled Cadhambari. The Cadhambari concept stems from the WHO definition of health as a state of physical, mental and social well being. Cadhambari is a twin track (induction; focus), three pronged (physical, mental, social[spiritual]) approach to mental health service care, formatted to transform strongly held negative magico/ religious views of the causation, treatment, rehabilitation and services of mental illness/disability into positive mystical/spiritual values without hurting religious sentiment; which thus far has constituted the main stumbling block to proper medical management by reason of attached stigma. Most mental health programmes for the general public fail because of stigma. The objective of the "induction phase" is to indirectly but affirmatively combat stigma. Human kind is social by nature and in India social well being is irretrievably inter-linked with "spiritual" well being. Interpersonal and other life skills so important to social well being, are learnt through intercourse in "social" settings such as pilgrimages, satsangs, festivals and discourses with a strong religious background. Such social activities have wide-spread public appeal and encouragement. Cadhambari takes advantage of this socio-spiritual nexus, modifying the 10 WHO life management skills (problem solving, decision making, creative thinking, critical thinking, communication skills, interpersonal relations, empathy, self awareness, emotional management and stress management), essential for a wholesome and balanced (emotion-logic-spirit aligned) lifestyle. The majority of life skills have a spiritual-philosophical view point and it is at this node that practical, spiritual exercises useful

in daily life, are deployed. Spirituality has general approval as the undisputed distilled goodness of all religions and is integral to humaneness. The mental well-being segment of Cadhambari is the application of the WHO life skills programme, eschewing stigma sensitive terminology like "mental" and "psychiatric", in a therapeutic community ambience, using transaction analysis and Kohutian 'self/groupself' psychological therapy, as the bedrock of group interaction. Kohutian psychology, unlike cold, clinically detached remote, individual Freudian psychoanalysis, is ideally suited to our feudal democratic mind society/world view. Simple relaxation exercises are taught to participants of the mental well-being module. Allopathic medicine for physical well being has near universal acceptance. Simple information/advice (diet, exercise, habits, relaxation, illness) on healthy life style and having a conduit for referral/feedback of physical problems is central to physical well being. The entire programme can be carried out as a stand alone or as part of disability, or other community based services. A psychiatric social worker, psychiatric nurse or lay counsellor trained in the life skills, called a life skills manager, conducts Cadhambari. Borrowing from the AA (Alcoholics Anonymous) model, the work can be done in any available vacant space (hall, kitchen, office, sitting room, out house, shed, garage, banyan tree shade), in any town or hamlet across the length and breadth of the country. Eight to ten people form the group, meeting for 2 hours 3-5 times weekly. Materials needed are tables, chairs, pencil, paper, pen, floor mats, chalk, slate and health information pamphlets. The "induction" phase concentrates on transforming negative magico/religious beliefs to positive mystical/spiritual values and building trust and confidence in the service in the community. The induction phase terminates when the service takes root in the community and comes to be regarded as an invaluable community resource. The "focus" phase spreads awareness and knowledge of the true medical nature of mental illness/disability, certain of the goodwill reposed by a community, openly receptive to the full fledged Cadhambari programme in an atmosphere free of stigma.

The new mantra for development includes broad band (BB). I believe India is BB wired upto the village level. BB represents a golden opportunity to harness the resources of the entire subcontinent regardless of distance or terrain: facilitating free transmission of information from anywhere to anywhere; fast forwarding India into the twenty first century. The remotest hamlet or at least the nearest district headquarters can be connected via PC/Internet/e-mail to a central unit, which will mentor and monitor the Cadhambari programme with periodic central in-house continuing education pulse sessions. I believe a carefully conceptualised, crafted and controlled Cadhambari programme can make the difference in mental health care as it costs little, or nothing.

Dr. R. Lakshman

SUMMARY OF THE DISCUSSIONS AT THE FRIDAY MEETING ON 27TH JULY 2001

The participants debated on the need and strategies to include persons with mental illness in other community based programmes, and the importance of networking between organisations in such an effort. The need for awareness, education and training materials to remove stigma was emphasised. The group agreed that self-help groups of persons with mental illness would be beneficial, particularly in promoting awareness about rights.

IMPLEMENTATION OF PERSONS WITH DISABILITIES (EQUAL OPPORTUNITIES, PROTECTION OF RIGHTS AND FULL PARTICIPATION) ACT, 1995

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OFFICE OF THE CHIEF COMMISSIONER FOR PERSONS WITH DISABILITIES (CCPD)

Activities at a glance

To monitor implementation of the provisions of Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, the Office of the CCPD was established in 1998. Mr. B.L. Sharma, was the First Chief Commissioner from 30th September 1998 to October 2000. Dr. Uma Tuli joined office in April 2001, and took several new initiatives for implementation of the Act.

To motivate the Government and Non-Government organisations to work together for implementation of the PWD Act, the CCPD has visited the States of Uttaranchal, Gujarat, Maharashtra, Karnataka, Rajasthan, Chattisgarh, and Madhya Pradesh. The State Commissioners have been appointed in all those States where there was no Commissioner till now. For the first time, an approach of convergence has been introduced in every meeting where the CCPD requested the Commissioner to invite the NGOs and Government Officials together, so that joint activities can be planned. This concept of convergence also included the Heads of Rehabilitation Council of India, the National Trust, District Rehabilitation Centres, National Handicapped Financial Development Corporation, National Abilympics Association of India and so on, for dissemination of information regarding the respective schemes of the Government. The joint presentations not only resulted in useful interaction, but also made the programmes cost effective.

Access for All – A New Initiative

For effective implementation of barrier free environment, the CCPD formed a National Access Committee and a Core Committee of trained resource persons to plan workshops and Access Audits all over the country. Five workshops have been planned during 2001-2002, in which, six representatives (three from NGO and three from Government) are invited for training in Access Audit. They are supposed to train groups of people in their respective States, Districts and Panchayati levels to conduct Access Audit and submit reports for required rectification for proper access in all public and private buildings, including places for recreation. The CCPD's office follows up by getting the owner of the building involved in the required alterations or additions, either from the owner's resources or with the help of a donor.

The first workshop was held in Delhi, in July 2001. The participating States of the first workshop have already started working as per expectations. The second workshop was held in October 2001, with representatives from 7 states.

Mobile Redressal Court

During interactions with the state Commissioners, it was realised that persons with disability face many problems in getting their disability certificates, bus passes and train concessions. They also have grievances regarding employment, promotion, admission and other entitlements. To solve these problems, a multi-preview camp approach was adopted, where, with the help of the state

Government officials, concerned officers from all the departments could be invited to issue the required documents, so that persons with disability could be aware of the facilities. The first Mobile Redressal Court was held in Dehradun (Uttaranchal) in July 2001. Over 2000 persons with disability attended and availed the benefits.

Focus on women with disability

Considering that the current year is for women and the girl child, the CCPD has stressed the need to identify and rehabilitate women with disabilities in all the States. In Rajasthan, 2 special camps were organised in Udaipur and Chittorgarh where corrective surgeries were performed on 529 women with disabilities, in and around Udaipur. At the Chittorgarh Camp, special focus was on rehabilitation of women with disability. For economic independence, several sewing and knitting machines were distributed. Necessary aids and appliances were also given as per need. In Gwalior, the CCPD announced a special survey to be conducted for identification of women and girls with disability, so that a plan of action could be made for necessary rehabilitation. The work has already started with the help of NGOs and the Department of Social Welfare and Education.

Legal Aid

The regular legal aid through the court of the office has also increased considerably. The total number of cases registered till date, is 3525. Out of these, 2873 have been disposed of, while 652 are under process. The CCPD visited Tihar Jail and requested the police officers to give the list of disabled male/ female prisoners. The office has received the list and the necessary action is being taken.

Abilympics

The 6th International Abilympics are to be held in India in November 2003. In the Fifth International Abilympics held in Czechoslovakia, the Indian contestants brought back 3 gold and 3 bronze medals along with a certificate of excellence. At the same time, the bid to host the Sixth International Abilympics was also accepted unanimously by the International Abilympics Federation. The CCPD has helped the National Abilympics Association of India in promoting the concept. As part of awareness raising, the different functionaries involved in organising the event are motivated to discover talents in vocational skills, so that persons with disability can have better opportunities for employment and also learn the latest technology through the mega international event.

Education and employment

To promote employment avenues in the private sector for persons with disabilities, the Office in collaboration with Ministry of Social Justice and Empowerment, has interacted with different business houses. A comprehensive detailed employment policy is being drawn up shortly, to facilitate private sector employment of persons with disabilities.

Through the use of conciliatory measures in accordance with the quasi-judicial powers vested in the CCPD's office, an increasing number of universities, educational institutes and Government and Public Sector undertakings like Medical Council of India, Indian Institutes of Technology and Pharmacy Council of India are reserving 3 per cent of seats for persons with disabilities, for higher education. The office is also providing speedy resolution to the grievances of people with disabilities in their work environment. Till date, 1400 cases have been received in this office, out of which 72% have been disposed of.

Awareness about the Act

Posters and Publications of the Disability Act have been designed and distributed at meetings and conferences. A Manual on Barrier Free Environment has been developed by this office for training

of Access Auditors. The office has also reprinted lists of schemes under Swarna-Rozgar Yogna, barrier free designs and jobs identified in the private sector, for circulation.

Future Plans

A website will be developed for collection of data and statistical information available on inclusion/integrated education, disability friendly access, learning and teaching materials. On line facility will be developed to register grievances of persons with disabilities.

A model resource room will be created in the new office, with the collection of latest technological devices.

Additional activities are planned for attainment of the vision of having 'India which places its citizens with disabilities on the same platform as non-disabled citizens'.

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Dr. Uma Tuli

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SOME SUGGESTIONS FOR THE OFFICE OF THE CHIEF COMMISSIONER FOR PERSONS WITH DISABILITIES

1. Strategies for Implementing the Act

While there is much talk about the implementation or lack of implementation of the Act, there is little understanding about the indicators to measure the level of implementation. At present, conducting a session on the Act or putting up posters on the Act, are referred to as 'advocacy'. A clearly defined set of indicators for the implementation, needs to be worked out.

Sharing the responsibilities of implementation:

1. Is it the job of only the Commissioner's office to implement the Act?
2. For instance, what are the steps taken by the Ministry of Rural Development to make sure that 3% of the beneficiaries are persons with disabilities?
3. How many cases have been referred by the District Rehabilitation Officers?
4. What are the systems by which different departments report to the Commissioner's office?
5. Do we make good use of the Commissioner's office – at least by writing a letter?
6. Do we highlight in the media, when we see injustice happening in the name of providing services to persons with disabilities?
7. How many of us have complained when people have to pay or get unnecessarily harassed to get the income certificate/ medical certificate, without which we are not eligible to access any Government Scheme?
8. Why should it be only the Commissioner's office's responsibility to bring the people together to meet and advocate with different Government and other departments?
9. Have we trained and created an environment for persons with disabilities to speak up for their rights?
10. How many persons with disabilities are in groups discussing disability issues?

Information, success stories and problem areas at the Commissioner's office need to be made known to people so that we are in a better position to interact.

People in the Office of the Commissioner must be well versed in disability issues.

This is critical for the success of implementation. One person in the office must also know sign language to communicate with hearing impaired persons. This is happening in Karnataka. Preference should be given to employ persons with disability, in the office.

There is also a great need to come up with strategies to decentralise the implementation of the Act at the District/ Taluk and village level.

There is also a need to depend less on a fast-track system and focus on long-term change. For example, when the offices of the district commissioner or tahsildar are not accessible, an announcement is made, which says that the concerned person will be available on a particular day in the ground floor. How practical is this solution?

Review the performance of the State co-ordination committee:

1. How effectively has this committee been functioning?
2. Has its performance been reviewed?

When State level advisory committees are formed, members do not attend the meetings, meetings are held without preparation or follow-up, thus losing their value. There is a requirement for the committee to meet regularly, be accountable and keep all the information available on the Internet, or at least post this information to the organisations working closely with the Commissioner's office, so that the concerned people are able to interact and speed up the process of implementation.

Creating awareness and reaching out to people by Lok Adalat:

For getting a first-hand information, the office needs to conduct regular lok-adalat, or include representations from persons with disability in regular lok-adalats, as the Commissioner cannot be present at every adalat at the district and taluk levels. This way, the number of people benefiting from the Commissioner's office can increase. It will also lead to more awareness among people, and different departments about the Act, and everyone's roles and responsibilities.

All this underscores the need for a full time Commissioner at the State level.

Review the existing Social-Security programme of the Government.

The process of accessing Government assistance for corrective surgery, aids and appliances needs to be simplified and accessible. For example, for a corrective surgery in Bangalore, a person has to visit 5 different departments located in different places for various procedures, before the surgery takes place.

1. How many people will benefit with such a cumbersome process? Even if some people are able to access such a service, it is only with the help of NGOs.
2. When there is a Referral centre in Bangalore, which provides free services, why duplicate this corrective surgery scheme to be done at private hospitals?
3. Can the State Referral Centre be a single point from where everything can be processed and surgery completed?
4. When people in Bangalore are finding it difficult to access the scheme, what about people coming from outside Bangalore?
5. How will people benefit when the above-mentioned 5 departments are not in the same district? This is the case in a majority of places.
6. It is mainly the poor, who access the Government schemes for corrective surgeries and aids and appliances. So is there need to produce income certificates for accessing government resources, or can alternatives be worked out so that poor people can access corrective surgeries, aids and appliances.

Quality of services

What do people do when they get poor service and are harassed by people from centres that are set up exclusively for the rehabilitation of persons with disabilities? The feeling that "nothing can be done for this child" gets reinforced, and the parents and the child get more depressed. Many centres have limited experience to deal with person with disabilities. Surgeries are prescribed to people who do not require them, or contradicting opinions of intervention are suggested. The situation is pathetic. The situation regarding aids and appliances is even worse, for which people are yet to find an answer. The public's level of faith and confidence in the Government set-up and its effectiveness is low. NGOs might be working in different villages and remote places, but their intervention is very limited and also, many times, limited to only their self-help group members. The Government is the only resource for the poor, and this needs to be strengthened. The people need to work with them and the Commissioner's office for it to happen.

Free bus passes for persons with severe disabilities (who do not have both legs or both hands) have been announced in Karnataka. Persons with disabilities have been protesting against the way the free bus pass scheme has been announced. Can persons with such severe disabilities climb buses? How many will use this pass? Some persons with less degree of disabilities have managed to get the pass through their contacts. A lot of confusion has been deliberately created, so that people with disabilities do not get the bus pass. A revised order should be issued so that all people having above 40% disability, as specified by the Act, get a free bus-pass. If this is not possible, let the pass be given on a priority basis to students and trainees.

Employment
Unemployment is one of the major issues. There is a need to focus on enhancing the quality of the vocational training, so that disabled people are able to compete with the rest. There is a need to review/ create more opportunities for self-employment and support organisations, which have a job-placement cell who work towards identification of potential employers and providing jobs.

Education
What are the provisions that have been made in schools to integrate children with disabilities? Everyone talks of inclusive education. But no one has really looked into the number of schools which have children with disabilities, or looked at the quality of education that these children are getting in these schools.

How many children with disabilities should be going to school? Of those, how many are actually going to school?

Creating an accessible environment
NOC (No objection certificates) are given by the city development authority to construct public buildings and spaces with no consideration for the needs for persons with disabilities. This continues to silently exclude us from participating. Can the concerned people be notified for ensuring that all new construction/ repair works undertaken takes into account of creating a barrier-free environment?

The Access Audit team in Bangalore has covered public buildings like the general post office, High court and BEL factory, which employs over 100 persons with disabilities. We have been encouraged by the results. This is surely a step towards working together in the right direction and bringing about a change. This kind of joint efforts must be made to deal with other issues like creating educational opportunities, accessing health programmes, employment, getting aids and appliances, and so on.

CONCLUSION

While Karnataka has a sensitive, accessible and responsive office of the Commissioner, much remains to be done towards getting persons with disabilities together, strengthening the disability movement, and ensuring that everyone, especially the poor are able to ask for their rights, live in dignity and be included in society with a better quality of life.

C. Mahesh

SUMMARY OF THE DISCUSSION AT THE FRIDAY MEETING
ON 28TH SEPT 2001

The major suggestions that the participants at the Friday Meeting agreed upon were firstly, that there was a need to sensitise all levels of personnel in different government departments throughout the country, on the Act. Secondly, education for children with disabilities was an important issue that needed to be actively promoted.

DISASTER AND DISABILITY

DISCUSSION LED BY

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INTRODUCTION

Oxfam India, works towards an equitable and just society free from hunger, exploitation and poverty by facilitating people-centred, responsive, transparent governance systems, ensuring basic rights and sustainable development. Oxfam India focuses on development work and humanitarian operations, functioning with the resources mobilised from India. Some key programmes include gram swaraj, sustainable livelihood, humanitarian action and disaster preparedness and basic rights. In the last three years, the organisation has been involved in programmes related to the Kargil conflict, the Gujarat earthquake and the Orissa flood, apart from other development initiatives.

DISASTERS

According to Webster's dictionary, a disaster is 'a grave occurrence having ruinous results'. The World Health Organisation defines a disaster as 'any occurrence that causes damage, economic destruction, loss of human life and deterioration in health and health services on a scale sufficient to warrant an extra ordinary response from outside the affected community'.

Disasters devastate. They leave a long trail of mortality and morbidity. Deaths, devastation and disabilities punctuate every disaster. Globally, 211 million people are affected by 'natural' disasters every year. Disasters set back the development process by decades. Two-thirds of the people affected are from countries of low human development index (HDI). Experts note that the poorest are becoming more exposed to disaster risks. Political insensitivity, increasing poverty, climate change and globalisation are the major factors that amplify the vulnerability and impacts of disasters.

India is a major theatre of disasters of various nature. Natural disasters like floods, earthquakes, cyclones and droughts; human made disasters like conflicts, communal riots and refugee situations and other disasters like fire, epidemics and transport disasters leave a long trail of mortality and morbidity. Disasters affect over 56 million people and kill over 5000 people in India, annually. The

annual economic loss on account of disasters is estimated at approximately US $ 1884 million. The impact of disasters is devastating. Social and economic progress achieved over decades of initiatives by the community and the advances in health and other developments can be significantly degraded and devastatingly reversed by disasters.

In India, floods affect 11 percent of the area. Of the cultivable area, an estimated 28 percent is drought-prone. India's 7,517 km coastline is a hub for cyclones and storm surges. The Himalayan region and Deccan plateau are vulnerable to earthquakes. Ethnic conflicts in the Northeast, the ongoing violence in Jammu and Kashmir and communal and caste riots have left generations on the run. India is also home for over 240,000 refugees. Over 30 million Internally Displaced People have been produced by country's ill planned "development programmes". Fire, transport and industrial disasters add to the lot. The breakdown of the public health system has resulted in the re-emergence of epidemics. Tuberculosis kills over half a million people in India every year.

Despite the recognition of the impact of disasters, the country lacks a humane national disaster management policy. The responses to disasters are often ad-hoc, characterised by a knee-jerk reaction, panic reactions and unprofessional attitudes.

Firstly, disasters cause impairment. Laser blinding and deafening light weapons to industrial disasters illustrates this. Secondly, disasters leave many as disabled. Landmines and earthquakes endorse this point. In the last decade, four million children have been disabled by war. Many children and adolescents in every war zone will suffer permanently from war injuries. Many of them are amputees. Neurological damage from head injuries and inaccessibility to prostheses, wheel chairs and other needs will make their rehabilitation a distant dream. Wars and conflicts amplified by an annual 700 billion US dollar global arms trade increase their number and misery. In Cambodia during 1993, landmines resulted in 700 amputations every month. Cambodia and Afghanistan are just two countries whose future is punctuated by the unending and inhumane legacy of landmines.Thirdly, disasters often leave survivors as handicapped. The tardy rehabilitation after the Latur (Maharashtra) earthquake in 1993, resulted in a many fold increase of stress and trauma. In the earthquake-hit areas, there are many paraplegics awaiting a humane response even after eight years. In Gujarat, eight months after the devastating earthquake, the future of amputees, paraplegics and others with special needs look uncertain.

Many factors influence and trigger disasters, including absolute policy, a defunct public health system, inadequate development policies, absence of disaster preparedness programmes and disaster management policies, government inertia, lack of a sense of direction in the voluntary sector, geographical incompatibility such as flood zones, fault lines and so on, and climatic changes such as global warming.

There is a growing concern about the way in which disaster management and rehabilitation programmes are conceived and implemented today. Post disaster rehabilitation programmes should be judged by its contribution to strengthening coping capacities of communities and by how it contributes to the long term developmental needs. While a swift action is a must, especially for the millions threatened by water-borne diseases in a post-flood scenario, or threat of starvation in a drought situation, today, the world realises that post-disaster programmes that does not leave a permanent positive change is not acceptable. Speed should not come in the way of breaking the cycle of destruction and vulnerability. Absences of a disaster management policy and the exclusion disaster- related disability in disability policies have amplified the sufferings.

THE WAY FORWARD

Disasters that lead to disability, and the plight of the disabled in disaster situations are an agenda that deserves a prominent place in the international humanitarian agenda. Reduced mobility means lesser visibility, lesser access and lesser voice. Translated in simple language, this means lesser survival chances.

To better the survival chances of people with special needs during disasters, and to address their long term needs call for:

• An informed debate that is the responsibility of every constituent of the civil society, especially the media, academicians, activists and other interest groups.

• A *"reality check"* by humanitarian agencies to ensure that disability is an integral part of their disaster response programme.

• Paradigm shift in disability and disaster related policy making, to endorse the needs and rights of differently abled people.

It is important that the world recognises disaster-affected people not as just passive victims, but as active survivors. Recognising that humanitarian assistance is not an act of charity but a survival right of the affected, may be the first step to break the poverty-vulnerability-disaster-disability cycle.

Striking at the root of poverty, is the best way to reduce the numbers of those who have to be lifted out of rubbles, floodwaters, drought and other such situations.

People-centric disaster management programmes, sensitivity by the government, humanitarian agencies and corporate houses alone, can ensure a better disaster recovery process.

Every disaster situation that we have to deal with today, calls for synergy between various actors involved in disaster management and disability issues.

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Dr. P.V. Unnikrishnan

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SUMMARY OF THE DISCUSSION AT THE FRIDAY MEETING OF 30TH NOVEMBER 2001

The debate between participants stressed the need for better planning and implementation of disaster programmes and rehabilitation. There was agreement that post-disaster rehabilitation programmes need to strengthen the coping capacities of communities, and contribute to the long term development needs of the community.

Rehabilitation Notes

STRATEGY FOR SELF-HELP GROUPS OF PEOPLE WITH DISABILITIES IN DEVELOPING COUNTRIES
Chhabi Goudel*

With the aim of minimising the differences between disabled people and others, the United Nations developed a manual on "self-help organisations of disabled persons" in 1991. Similar guidelines have also been produced by different organisations such as Action on Disability and Development, UK, and Rural Development Bank, Nepal. This paper for rehabilitation

development workers, will focus on self-help groups of disabled people by using local resources available in the community.

ESTABLISHMENT OF SELF-HELP GROUPS OF DISABLED PEOPLE

Step 1: Community or village entry

The role of the rehabilitation development worker is to inform the community and disabled people about the concept of self-help groups and encourage them to form a self-help group in their community. Once discussions have taken place, and all concerned have decided to form a self-help group, the group should approach the community executives for further action. Elected executives are the key people of the community; therefore they should be contacted from the beginning. In the meeting with the community executives, the aims, plans and activities of the group should be discussed and agreed upon. Only after agreement by the two parties should the formation of the self-help groups begin.

Step 2: Data collection of disabled people

Data can be collected in an informal way, by contacting key people in the village. Since the community executives know their community well, and know where disabled people live, it may not be difficult for them to identify persons with a disability. A forum that includes disabled people, community development workers, volunteers, social workers, health personnel and rehabilitation workers can decide the level and types of disability of each individual, and categorise them according to their impairments or disability. After collecting the statistics, all the disabled people should be called to a mass meeting in an accessible place. As much as possible, the village chairman, ward members, teachers, health staff, agricultural workers, volunteers, and social workers should also be invited to attend this meeting. Only after discussing the aims and objectives, can a self-help group be formed.

Step 3: Identification of the target group

After formation of the group, all group members should participate in identifying the target group. There are different types of disabilities, that can be categorised into 5 main types, namely, 1) blind people 2) deaf people 3) people with learning disabilities (here the parents must be involved) 4) physically disabled people and 5) people with multiple disabilities.

Step 4: Formation of self-help groups of disabled people

The process of forming a self-help group may vary according to the local situation and need. After collecting the statistical data, the situation of individual disabled people should be analysed carefully. Groups of a reasonable number of people should be formed, taking into account road conditions and severity, individual characteristics, group size and effectiveness. A guideline could be that people should not travel for more than half an hour to a group meeting. If there are more than 5 people in the group, there may be difficulties with planning, decision-making and travelling. If there are more than 5 members in a small geographical area, another group should be formed. In very remote areas, less than 5 people can make a group and even half an hour's travel may be viewed as too far for some disabled people. There are no hard and fast rules for distance. The meeting place should be accessible to all members so that they can meet and discuss their business.

Each group should have a co-ordinator or leader. Age, sex, race, religion or the type of disability should not restrict group membership. Those who have the experience and interest in helping in rehabilitation can be asked to form an advisory group. In forming self-help groups and advisory groups, advice can be taken from other organisations with previous experience. Such organisations

can also be encouraged to assist in the formation of other self-help groups in their own working area.

Strengthening Self-help Groups Of Disabled People

Step 5 : Meeting

The first meeting is an important process. Normally there should be many interactions, discussion (both positive and negative), and a conclusion made during the meeting. Formal meetings are usually held once a month to formalise decisions by passing the minutes of the meetings. Sometimes, self-help groups can meet in informal ways too. To run this process effectively, all members' opinions should be taken into account at all times, and therefore all members should be called for all meetings.

Meeting procedure

The secretary should consult the co-ordinator and then clearly inform the members about the date, time, place and agenda of the regular meetings. The time that is suitable for all members must be considered. The meeting should not be started until all the members are present. Points to be included in 'any other business' should be collected before the meeting starts. Once these points are collected and the meeting starts, no other points should be considered.

The collected points should be dealt with one by one, and the person raising the points should have a chance to explain them, while other members give their views later. The chairperson should have the freedom to prioritise the agenda.

Normally, for financial matters agreement from all the members is necessary, to avoid conflicts at a later date. For other matters, 51% agreement will be sufficient. The minutes of the meeting should be correctly recorded for future reference. At the end of the meeting, the secretary should read the minutes and if all are in agreement, they should be signed by all present. Executive members such as the chairperson, treasurer and secretary should be chosen by group members. This executive body decides about monthly savings, loan repayment and selection of applications. Extra ordinary meeting should be arranged if necessary.

Factors influencing the good running of the meeting
- The meeting place should be accessible for disabled people.
- The meeting place should be comfortable.
- The timing of the meeting should be suitable for all.
- Unacceptable language should be forbidden.

Step 6: Self-help group activities

After formation of the group, all group members should participate in the following tasks/activities.

6.1 Awareness raising

The first task of the group is to raise awareness among the general public, the government and disabled people themselves, by informing, publicising, discussing and sensitising.

6.2 Needs assessment

The needs of all members of the group, their status in society, potential in their family and so on, has to be analysed carefully through interviews and observations.

6.3 Confidence building

Disabled people have to become confident about their potential to change and have to be encouraged by sharing experiences, observations, endorsements, conscientisation, sensitisation, and disseminating information.

6.4 Training

Once the needs of individual members are identified, training for them has to be arranged through discussions, skills transfer, seminars, coaching, and field trips.

6.5 Motivation

All members should be aware of the aims of the group, what the group is, what its objectives and policies are. Members themselves should be able to motivate the community. If they are confident of the group aims, objectives and policies, they will be able to perform their task effectively.

They should know who the disabled/ disadvantaged are, what their physical, economic and social situation is, and what problems they face. They should also know what action is being taken by the government or NGOs, in this regard. These questions have to be examined carefully and discussed by all concerned.

6.6 Developing group Rules, Policies and Principles

Disabled people are usually neglected by themselves and also by their families, neighbours and community. Groups must take appropriate action to gain their rights, dignity and social security. National policies should be kept in mind when developing the group's policies and rules.

6.7 Establishment of savings and credit scheme

What is savings?

From the money earned today, a person can put aside some money for tomorrow, or next week. This is saving. This system has been employed from very old times.

Group saving

A self-help group collects funds by collecting monthly savings from the members and group activities. For development and sustainability of the organisation, a group fund is essential. After people get involved in an economic activity, they will also be involved in the self-help group for a long period of time. This is important for sustainable inclusion and economic development of the disabled people.

Loan

For economic activities, savings, grants, and loans are needed. A loan is an amount that can be taken from the bank for a certain period of time at a certain interest rate. Normally, people deposit capital as collateral assets in order to receive a loan. Loans are available everywhere to fulfil peoples' needs. A loan can be short or long term. A short term loan is preferred for a self-help group because it has some advantages, such as easy availability for income earning activity such as a business, for employment oriented activity such as training, for emergency medical treatment, or other disasters and for social or religious purposes such as marriages or funerals.

Loan repayment

This involves returning the money into the group account according to pre-arranged conditions. The group's aim is not only to earn money from the interest, but also to provide support to the members.

Interest rate

Interest is the negotiated amount of money, which must be paid by the borrower to the lender on top of the principal loan, before a certain date. It is fixed by an agreement between both parties. The group can decide the interest rate during their meeting, before lending any amount.

6.8 Drawing up an action plan

It must be based on the ideas and hopes of group members, along with the available technical and managerial knowledge, and practical experience. The action plan of each individual member in the group should be discussed and drawn up in the group. The advantage of this process is the maximum involvement of all members.

6.9 Involvement in social activities

Self-help groups can take part in social services such as services for individuals, groups or the community. Group members can also be involved in village development activities such as meetings, road construction/repair, school committees, health programmes, drinking water provision, agricultural development, forest development, industries and so on. In this way disabled people can gain respect and contribute their resources to the community. Disabled people can also be involved in the cultural activities in the community.

6.10 Networking

Groups can collect information on government welfare policies, and help develop co-operation between different sectors.

6.11 Problem solving

Groups often face problems which affect efficient running of the group because of lack of communication, or conflict. An analysis of what went wrong, how it happened and how it can be changed to prevent it from recurring, is important. It is important to 1)identify and understand the problems, 2)to suggest ways of solving the problems, 3) evaluate the suggestions, 4) choose the solutions that will best solve the problem, 5) make an action plan for carrying out the solutions, 6) implement the action plan, and 7) assess the result of the action plan.

CONCLUSION

Disabled people will benefit greatly from their own self-help groups as bank and private lenders are often beyond the reach of the individual. Therefore inclusion into self-help groups and a savings and credit scheme is very useful for disabled people. However, review of literature shows that it is difficult to include people with learning disabilities into the groups, hence in these cases, the families or parents can take part in the group.

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TRAINING OF PERSONNEL FOR CBR

Sheila Wirz*, Prue Chalker**

Over the past 20 years the interpretation of "CBR" has changed but it is our belief that the rationale of training for CBR has not. It is vital that the training issues are carefully explored if training is to be effective in the next decade. In this paper, we discuss some background issues, then share some results of a survey of training courses for CBR.

BACKGROUND

Training for what?

- Twenty years ago when WHO introduced their CBR training manual, the emphasis was on skills transfer to people in the community who would work with persons with disabilities and their families
- The second most important "manual" at that time was Disabled Village Children (DVC)
- Both DVC and WHO manual had an impairment basis for their very good manuals

Changes in recent years have meant that the training must have a greater emphasis upon issues such as:

- Problem solving: referral to specialists however desirable, may be impossible for reasons of cost or access.
- Including persons with disabilities and their carers in planning: the days of professionals knowing best and imposing a programme of intervention are over (this may work for the treatment of some impairments, but not for the management of disability). It is the person with disability or the carer who know the real needs and these must inform programme planning, not the perceived needs of the professional.
- Monitoring and evaluation: volunteers and professionals need to be able to show the benefit of their activity. Cost benefit may be unpopular with practitioners who feel that any friendly contact is helpful to a family but employers in times of market economy need to know the benefits.

The Impact of Disabled Persons' Organisations (DPOs)

- DPOs and other movements have changed the perception of services for disabled people
- The very idea of services "for" persons with disability is challenged firstly through the idea of services "with" them
- The claims of participation by DPOs in planning are sometimes less real than the rhetoric suggests, but are still a move in the direction of participation

Changes in Service Providers

- WHO has revised its classification of disability from Impairment, Disability and Handicap, to Disability, Function and Participation (ICIDH2), thus moving away from an impairment base towards inclusion/human rights as the basis for considering persons with disability.
- More people begin to understand the "social model" of disability which persons with disability have been trying to have accepted, for a number of years.
- The move from "medical model" services towards a "social model" of service provision which began in the North is more common in the South.
- The WHO section has changed its name to DAR (Disability and Rehabilitation) to reflect such changes in emphasis.

Changes in the availability of volunteers

- In the period (albeit the end of the period) of "iron rice bowl" policies in many countries of the South, it was easier to find community "volunteers" to undertake volunteer activities such as

becoming CBR workers. Such people often had a notional government job for which they were paid minimally but had little to do. They had a place in the community as a member of the "government cadre", more than basic education and feeling of responsibility to their communities.

- In the last 20 years, with a move to market economies, most people need paid employment to survive at all (with the need to pay school fees, medical care etc.) and are less able/willing to volunteer,

- Those who do volunteer often use their volunteer training and experience as a stepping stone to paid employment and are available to CBR for less time.

Changes in professional practice

- In the South, the majority of professionals working within the disability field, work in government posts for some time, but as pay decreases and the expenses of urban living (and their expectations) increase, most professionals spend more time in private practice now, than 20 years ago. The majority now behave as a minority did when Alma Ata was still a hopeful direction for most.

- Most countries of the South have a policy encouraging newly qualified professionals to work for 2 years or so in the rural community. In reality, this seldom happens as able/well connected graduates can buy their way out of such obligations and the likelihood of young idealistic professionals in community disability services has diminished.

- Professionals may still feel some training obligations to community services but are less likely to be intimately involved.

Who works in CBR now?

The term CBR has very specific connotations for some people. Perhaps it is better to consider "community disability services". This can include many components, such as:

- Human rights
- Rehabilitation services
- DPO activity
- Family centred therapy
- Income generation
- CBR workers in the community

The different interpretations need different training emphases.

METHODS AND RESULTS OF THE SURVEY

The methodology adopted in this project to explore training issues had two phases.

In **Phase 1** informal interviews were conducted with a range of informants engaged in CBR. The sample was opportunistic and all the interviews took place in London, and India, in and around Chennai, Banagalore, Calcutta and Delhi. Semi-structured interviews were also conducted with ten community disability service personnel from six countries, who had all undertaken post graduate training overseas. The purpose was to elicit their views on what factors contribute to effective CBR training. The information collected, informed the design of the questionnaire.

In **summary,** the main themes identified in the informal and semi- structured interviews in relation to CBR training were:

1. Creating positive attitudes to people with disabilities is crucial to the success of CBR, but this is rarely addressed in training.
2. There is insufficient involvement of people with disabilities and their families in planning and training for disability services.
3. There is an overemphasis on the transference of knowledge unrelated to the practical use of the knowledge.
4. Training concentrates on technical skills over creativity and problem solving skills.
5. Course teachers are usually institution-based practitioners with little knowledge of working in the community and the ethos of CBR. Training equips the participants for the delivery of services, as an extension of institution-based services, rather than CBR.
6. Training is often given in medical institutions giving 'mixed messages', about appropriate technology and ways of relating to clients.
7. Scant attention is paid to the community development/empowerment aspects of CBR in training.

The questionnaire has three sections.

Part 1 aimed to establish a profile of a CBR manager.

Part 2 sought to discover more about the conduct and content of trainings. **Part 3** asked about training materials used.

In **Phase 2** the questionnaire was distributed and the returns analysed.

The Sample: The questionnaire was sent to an opportunistic sample of forty-seven organisations in India. The questionnaires were addressed to the people who manage CBR programmes. The respondents reflect the diversity of activity and organisational structure involved in community disability services, from large organisations that started as institutions and currently promote CBR, to grass roots organisations that have always worked in the community. The data collected is based on 32 returns.

We also used the opportunity of the Friday Transaction Meeting in Bangalore on 30th March 2001 to engage a large group of experienced people to replicate some of the results from the survey. We chose to re-examine the data about what is taught and what is thought to be key skills by co-ordinators.

KEY RESULTS OF THE SURVEY

The results are presented in four sections, namely, profile of managers, questions relating to training issues, information on training materials and expressed need for further materials, the replication exercise and key points raised at the Friday Meeting of March 2001.

1) A profile of CBR co-ordinators

What was the professional background of the CBR co-ordinator?

Table 1 – professional background of CBR co-ordinator N = 29

Professional Background	Number	%
Special Educator	**5**	**17**
Community Worker	**5**	**17**
Social Worker	**5**	**17**
Teacher	**4**	**13**

Therapist	3	10
Rural Development	2	7
Business	2	7
Doctor	1	7
Nurse	1	3
Prosthetics/orthotics engineer	1	3

Those with an education background – special educators and teachers – represented the largest professional group, followed by community workers and social workers and then therapists. Two respondents replied that they had qualifications in rural development, two had business backgrounds, and two described themselves as CBR workers and were included under community worker. One respondent was a prosthetic/orthotic engineer and one was a nurse.

Is the CBR manager a person with disabilities?

Table 2 - Number of CBR co-ordinators who are/are not PWDs (N = 29)

	Number	%
CBR Manager - not a PWD	27	93
CBR Manager a PWD	2	7

Only two of the co-ordinators were people with disabilities. However, one large rural CBR programme that helped to initiate 17 locally run programmes, reported that 3 of the programmes are managed by persons with disabilities, and a parent manages one programme. One other respondent said that the chairperson of their CBR programme, was the mother of a person with disability.

Has the CBR co-ordinator had any CBR training?

Table 3 - CBR training of co-ordinators (N = 29)

CBR Training	Number	%
YES	20	69
NO	9	31

How long was the CBR training?

Table 4 - Length of CBR training (N = 20)

Length of CBR training	Number	%
< 1 month	1	5
1 – 3 months	9	45
3 – 9 months	4	20
12 months	3	15
> 12 months	3	15

A majority (69%) of co-ordinators had had some CBR training and most had received a qualification for this (85%), though for 59%, the qualification was a certificate of attendance. 45% had had training lasting from 1 to 3 months, 20% received 3-9 months of training and 30% 12 months or more than 12 months, of training.

One respondent said that CBR was included as part of his MSc. course in rehabilitation. Two other respondents who had taken courses in special education had had a CBR component as part of their courses. Three respondents' CBR training had been 'on the job', that is, a series of in-service training from experienced personnel, either as a short training, or by mentoring. One had had a certificate of attendance for this training. The two others had not been given a formal qualification. The majority (59%) had had CBR training during their current employment. Three of the respondents said that their course was accredited by the Rehabilitation Council of India, but one of these was an MSc. in Rehabilitation as mentioned above.

The high percentage of co-ordinators who had had some kind of CBR training was one of the surprising results of the survey.

Fifteen of the CBR co-ordinators had management training, 12 of whom had had some kind of formal training.

Table 5 - Length of management training (N = 12)

Length of management training	Number	%
< 1 month	**1**	**8**
1 – 3 months	**5**	**39**
3 – 9 months	**3**	**23**
12 months	**2**	**15**
> 12 months	**1**	**8**

We listed some of the tasks involved in running a CBR programme. This list was derived from interviews with CBR personnel and revised after the first draft of the questionnaire was piloted in India.

Is it necessary for a CBR manager to be skilled in any or some of these?

Table 9 – Necessary skills for CBR (N = 32)

CBR tasks	Not necessary	Useful	Advisable	Necessary	Highly desirable
Programme supervision	**0**	**0**	**2**	**6**	**24**
Training of CBR workers	**0**	**2**	**1**	**5**	**24**
People management	**1**	**0**	**2**	**5**	**24**
Community organisation	**0**	**1**	**2**	**10**	**19**
Community development	**1**	**0**	**2**	**10**	**19**
Record keeping	**0**	**0**	**2**	**11**	**19**
Financial management	**1**	**2**	**3**	**8**	**18**
Counselling for PWDs and					

families	1	3	1	10	17
Disability assessment	1	4	3	7	17
Advocacy	0	1	4	13	14
Organisation of self-help groups	1	1	8	8	14
Public education	0	5	2	12	13
Educational rehabilitation	1	5	4	13	9
Fund raising	2	4	7	10	9
Income generation	2	5	7	9	9
Therapeutic interventions	4	5	5	9	9
Vocational training	2	7	7	11	5

The tasks which had the highest agreement were programme supervision, training of CBR workers, people management, community organisation and community development. There was less agreement on disability assessment and very low agreement on therapeutic intervention.

The implications of this are examined in the next section on training issues.

2) Questions relating to training issues

We compared the results of the "highly desirable" tasks (Table 9) with the main topics taught on the longest of the courses given by the organisations.

Table 10 - Respondents ratings of highly desirable skills needed for CBR management compared with Main Topics of Courses

Skill deemed "highly desirable"	No. of respondents re skills N = 32	No. of respondents re courses N = 26
Programme skills	24	8
Training CBRWs	24	5
People management	24	5
Community organisation	19	6
Community development	19	5
Record keeping	19	4
Financial management	18	2
Counselling	17	8
Disability assessment	17	15
Advocacy	14	6
Self help groups	14	5
Public education	13	5
Educational rehabilitation	9	1
Fund raising	9	2

Income generation	**9**	
Therapeutic interventions	**9**	**15**
Vocational training	**5**	**3**
Causes of disability	**-**	**18**
Impairment groups	-	17

The topics most frequently covered in training by the majority of organisations were causes and prevention of disability, impairment groups, assessment and therapeutic interventions. These were the tasks for which there was little or no agreement about in terms of desirability for CBR.

The mismatch between what was considered important in CBR and what was taught on courses was not so surprising when we looked at who were the most regularly used trainers on courses. Therapists represent by far the largest group.

Table 11 - The most regularly used trainers on CBR courses (N = 26)

Teacher/trainer	Number	%
Physiotherapist	19	73
Speech therapist	**14**	**54**
Community worker	**13**	**50**
Person with disabilities	**10**	**38**
Occupational therapist	**9**	**34**
School teachers	**8**	**31**
Special educators	**8**	**31**
Health workers	**8**	**31**
Parent	**7**	**27**
Doctor	6	23

How long are the courses run by the organisations?

Table 12 – Length of CBR training (N = 26)

Length of course	Number	%
Up to 1 week	**8**	**33**
Up to 1 month	**11**	**45**
Up to 6 months	**7**	**29**
Up to 1 year	**6**	**25**
> 1 year	1	4

Some organisations run several courses of varying lengths. Within one organisation, course lengths may vary from one week to 6 months. One organisation offers a 14-month course. Courses are run for different groups, not just CBR personnel. For example, training courses may be for health workers, parents, people with disabilities, teachers, government health staff, pre-school teachers and social workers. Areas covered may include skills and strategies for inclusive education, handling children with cerebral palsy, counselling for parents, vocational training courses, and technical training, such as those for making of orthotic and prosthetic devices.

Essentially, a wide variety of training from informal 'on the job' training, to training of 6 months, or more, in length are offered by the organisations, for a wide variety of target groups. More formal training courses are offered to mid level workers and teachers, for example. More informal training may be given to the organisation's staff and volunteers, and parents' groups.

Not all organisations run their own training (N=26). Some rely on the 'parent' organisation or look to other local NGOs or international NGOs who run training courses relevant to the organisation's needs.

What were the teaching/learning experiences used during the course?

Table 13 - Percentage of organisations using particular teaching/learning experience (N= 26)

Teaching/learning experience	Number	%
Group activity	**24**	**92**
Demonstration	**20**	**77**
Discussion	**20**	**77**
Question and answer	**19**	**73**
Assignments	**18**	**69**
Observation	**17**	**65**
Brainstorming	**15**	**58**
Role play	**14**	**54**
Lectures	**13**	**50**
Tutorial	**9**	**35**
Peer teaching	8	31

These findings were interesting in the light of the published and anecdotal criticism of CBR training which indicated that most training was dependent on didactic teaching methods. Active methods figure highly in the majority of training courses with 92% of organisations saying that 'group activity' is a regularly used method, and 77% that 'demonstration and discussion' are also regularly used. 'Lectures' are only used on a regular basis by 50% of the organisations.

Where does training take place?

Table 14 – Location of training (N = 26)

Location of training	Number	%
Training institute	**16**	**62**
Community hall	**14**	**54**
'On the job'	**14**	**54**
School	**9**	**34**
NGO centre/office	**6**	**23**
Hospital	**5**	**19**
CBR centre	**1**	**4**
Health centre	**1**	**4**

DPO centre	**1**	**4**
Vocational training centre	**1**	**4**
Pre-school (Balwadis)	1	4

Several respondents emphasised that substantial parts of training were practically based and involved home visiting and working in the community. One respondent felt that it was very important that training takes place as close to the community where CBR activities will be undertaken as possible. "Trainees to feel comfortable and to relate training directly to the local experience."

What training materials are used?

Table 15 - commonly used manuals, graded by usefulness (N = 26)

Manuals	very useful	useful	not useful
Disabled Village Children	19	6	1
Training in the community for people with disabilities	7	14	5
Nothing About Us Without Us	11	9	2

Table 16 – Manuals found "very useful" by number of respondents using manual

Manual	No. of respondents
Joint Position Paper	4
The Standard Rules	4
Persons with Disabilities Act	4
Spastics Society of East India publications	3
Prejudice and Dignity	3
Handicap International Physical Therapy Assistant Manual	3
Helping Health Workers Learn	3
Teacher Health Care Workers	3
Training for Transformation	3
WHO manual on Cerebral Palsy	1
Where there is no doctor	1
Special Education for Mentally Handicapped Children	
Child-to-Child Manuals	1
Asia Pacific Disability Rehabilitation Journal	1
CBR News (Indian version)	1

   The need for additional CBR training manuals or texts.

Respondents were asked if there was a need for additional training manuals, and what areas should these cover. The following are a selection of responses

"Material for people who do not have reading and writing skills."

"Community development."   "Disability Rights."

"Community participation."   "Networking."

"Project management."   "Vocational training and employment."

"Building linkages with other sectors, for example, Education, Health & Hygiene and Agriculture."

"There is need for simple, good quality material about home training for persons with learning disabilities. Portage has too much text. More pictures and easy steps are needed."

"Assessment tools for children with learning disabilities are needed. The WHO assessment is too superficial and not detailed enough. The assessment/checklist in C. Miles' book is too long and complicated."

4) The Replication Exercise at the Friday Meeting of 30th March

The Exercise

The group at the Friday Meeting were paired. Group A consisted of thirteen pairs of CBR service providers plus one trio – 29 in all. Group B consisted of seven pairs of trainers – 14 in all.

Two sheets were prepared. Sheet 1 was given to Group A - people involved in CBR activity but not directly involved in training. This replicated the part of the questionnaire that had been answered by 32 respondents from the original survey and listed tasks involved in running CBR programmes. The 13 pairs and 1 trio were asked to rate the tasks as not necessary, useful, necessary and highly desirable.

We listed the same tasks and distributed them to Group B - those involved in training and asked were any of these were included as topics on their courses.

Through discussion the pairs/trio completed the questionnaire sheets.

Group A Results.

1. Group A rated 2 skills highly as had the 32 from the original survey. These were:
   • Programme supervision
   • People management
2. Although people management was not rated as highly in Bangalore (57%) as by the 32 (75%) it was still the second most highly rated skill.
3. The Bangalore group rated   counselling, public education, advocacy and disability assessment very similarly to the 32 from the original survey.
4. They disagreed strongly about training of CBR workers. This was rated highly by 75% of the 32 but only by 29% of the 14 pairs in Banagalore.
5. Areas that were not thought to be essential by ANY Bangalore respondents were income generation, therapeutic interventions and vocational training. These had been rated by 28%, 28% and 16% respectively of the 32 from the original survey.

Group B Results

Seven pairs completed the trainers' questionnaire. There was little similarity between the Bangalore group and the original survey respondents (N = 26).

	Taught by Bang. Grp x 7	Taught by Original Resps. X 26
• Training of CBRWs	100 %	19%
• Disability assessment	100%	58%
• Ed. Rehabilitation	100%	4%
• Fund raising	100%	8%
• Therapeutic interventions	100%	8%

The numbers were small in this replication exercise and we noted that they demonstrated much greater diversity in their responses than the original survey respondents (N = 32).

5) Keys Points raised at the Friday Meeting

The debate at the Friday Meeting discussed the ways the gaps identified in the study could be addressed. Participants felt that the conceptual understanding of CBR influences the way courses are designed, and that although there has been a shift in the philosophy of CBR from a charity orientated medical model to a rights based social model, this was not adequately translated into the curricula for training. Moreover, most courses use professionals as trainers, and this could lead to an over-emphasis on impairments in the training. The participants felt that it was important to incorporate certain non-specific skills such as advocacy, community organisation and so on into the training of CBR personnel. Another issue was that many of the existing courses are ad-hoc ones that have not carried out a task analysis of the personnel to be trained, in order to define their training requirements and design an appropriate curriculum. These gaps will need to be addressed in planning of future training courses for CBR personnel.

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WEBSITE FOR PERSONS WITH DISABILITIES IN INDIA
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3. CBR TRAINING NOTES
2001

FRIDAY MEETINGS

'Friday Meetings' were initiated to improve access to knowledge for development organisations, particularly those involved in non-institutional forms of rehabilitation. These meetings which are held on the last Friday of every odd month, such as January, March, May and so on, are a get-together of like minded people to debate themes related to application of different methods and development of skills, in this field. All those who are interested are welcome to attend. The meetings are always conducted at the same venue on the last Friday of odd months, between 2 pm and 5 pm. After an initial presentation on a theme, the emphasis is on discussion between the participants. The opinions generated here can be useful to people who are decision makers, researchers and interventionists.

Friday Meeting Transactions
Feedback Questionnaire

We would like to know from our readers if we should continue to publish Friday Meeting Transactions, since there are a large number of newsletters on CBR, dealing with practical application of principles, in the field today.

PLEASE TICK THE APPROPRIATE ANSWER

1.   Organisation or Individual (please tick)

Name:

Postal Address:

Telephone: Fax: e-mail:

2.   How useful is Friday Meeting Transactions to you?

100%   / 75% / 50% / 25%

3.   How many others read your copy of Friday Meeting Transactions?

1/2/3/4/5/6-10/ More than 10

4.   Should we continue to publish Friday Meeting Transactions?

Strongly agree/Agree/Not sure/Disagree/Strongly disagree

THANK YOU

Please mail the completed Questionnaire back to:
Dr. Maya Thomas, J-124 Ushas Apts, 16th Main, 4th Block, Jayanagar
Bangalore - 560 011, India.