CHAPTER - 6

COMMUNITY BASED REHABILITATION (CBR)
6. COMMUNITY BASED REHABILITATION [CBR]

Introduction:
In the earlier chapters and sections, basic concepts, issues, approaches, models, perspectives, responses and strategies to disability and development have been discussed. It could be noticed that disability is not a problem of an individual but a problem of the entire society because of the potential barriers created by the social system, which hinder the holistic development of Persons With Disabilities. It is a complex issue, coupled and compounded with a complex phenomenon. Disability is subjective, psychological and social since the concept of disability assumes a different status depending upon various related factors. One must agree that it is a priority issue that needs to be addressed. There have been different approaches to deal with the issues of Persons With Disabilities. There is a paradigm shift from charity to rights mode, dependence to independence, compassion to opportunity, exclusion to inclusion, discrimination to non discrimination, inequality to equality and rehabilitation to development. The new thinking, perspectives, approaches, and responses are moving towards holistic development of Persons With Disabilities in order to create an enabling environment for Persons With Disabilities to secure, realise, exercise their rights and discharge their duties as equal human beings in their respective societies. This section provides a base for discussing various issues of community based rehabilitation [CBR], as an approach, phyllosaphy, strategy, model and response to disability and development.

6.1. UNDERSTANDING COMMUNITY BASED REHABILITATION

In this section the focus is on understanding Community Based Rehabilitation (CBR). It does not try to define CBR, as it has become apparent in recent years that CBR defines definition. Its simplicity and complexity have led to confusion about what the meaning of CBR is. The starting of CBR is simplicity itself with the delivery of primary rehabilitation therapy to Persons With Disabilities in their communities. The complexity of CBR is the current concept that CBR programmes should be multi-sectoral (or multi-disciplinary) so that they can provide assistance in all the areas which are central to improvement of the quality of life of Persons With Disabilities. This complexity recognises the need for close coordination, collaboration and cooperation between governmental and non-governmental organisations of all types and at all levels.

Paradigms in rehabilitation and disability service delivery in economically developed countries are currently being challenged and reviewed. An analysis of rehabilitation and disability literature coming up from these countries identify a number of issues of concern. Utilising a systems framework, adapted from the work of Urie Bronfenbrenner, the analysis indicates that certain aspects of current paradigms, may have adverse impacts on Persons With Disabilities. It was determined that new paradigms should be explored. Analyses of the current trends that are relevant to the disability sector have revealed a number of important directions, particularly the significance of the community paradigm. CBR, a disability service delivery approach which has arisen in developing countries, was proposed as an approach which was consistent with the identified trends and the community paradigm, and which constituted a constructive response to the identified concerns.

It was noted however, that CBR lacked a strong research base and that fundamental principles have not been clearly elucidated. Based on the existing literature, a detailed
description and analysis of CBR was undertaken, and strategies, benefits and limitations of
the approach were documented. The description of the parameters of CBR resulted in the
elucidation of an evolutionary process, and the identification of key principles. It was
proposed that the defining concept of CBR is 'engagement' between Persons With
Disabilities and their local communities. This concept was seen as having greater import,
beyond the traditional contexts in which CBR has traditionally been employed. The possible
application of CBR to economically developed countries was considered at a theoretical
level. In order to explore the potential of the notion of engagement, two multi-phase,
qualitative studies were devised and conducted in South East Queensland by International
Disability and Development Consortium (IDDC).

The inductive phase of the research involved two studies, both of which resulted in the
development of a model that consisted of five bipolar axes. This 'model for enhancing
engagement', described the process by which engagement between users of human
services (specifically Persons With Disabilities) and their local communities might be
maximised. The subsequent deductive phase of the research consisted of an exploration of
the potential utility of this model through the two studies. Within the limitations of the
qualitative design, the research indicated that the model had practical utility in the current
context. In order to confirm concepts within the model, and consider its congruence with the
field of CBR, a final phase of verification was employed. This phase drew data from other
sources to provide a degree of confirmation to the concepts within the model. The primary
outcome of the research was the development of 'model for enhancing engagement'
between Persons With Disabilities and their local communities. This model was described
and its potential application was considered at a conceptual level.

Three subsidiary outcomes were also seen as contributions of the research. First, a
descriptive and conceptual framework, based on the work of Urie Bronfenbrenner, was
developed and applied in the current studies which may have further utility. Second, a
detailed analysis of the CBR literature resulted in the documentation of an evolutionary
process in CBR, the identification of key principles, and the proposal of the notion of
engagement. Third, a comprehensive, multi-phase, qualitative research process has been
devised for the research which meets requirements for rigorous and effective data
presentation.

Many different agencies are now reviewing their experience from many years of support to
CBR. These evaluations were expected to feed into the global review that was being planned
by the World Health Organisation's Disability and Rehabilitation Unit in October 2002. The
following are some personal reflections from the IDDC co-ordinator, Sue Stubbs on CBR.
They are drawn from 10 years of experience working for Save the Children UK as Disability
Advisor, but they are personal perspectives, and do not represent the views of Save the
Children UK. "The basic concept inherent in the multi-sectoral approach to CBR is the
decentralisation of responsibility and resources, both human and financial, to community
level organisations. In this approach, governmental and non-governmental institutional and
outreach rehabilitation services must support community initiatives and organisations.

For the multi-sectoral approach to CBR to be successfully translated into action, both
governmental and non-governmental service capacities need to be improved in most
countries of the Asian and Pacific region. Of special importance is improvement of the
capacity and skills for facilitating community involvement. Such improvement and related
activities must be closely coordinated to ensure the optimum use of scarce resources. In
accordance with the multi-sectoral concept, systems are developed, at the community level
and among governmental and non-governmental organisations that interact and reach out to

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each other. Another factor for the success of the multi-sectoral approach is the empowerment of the community to assume responsibility for ensuring that all its members, including those with disabilities, achieve equal access to all of the resources that are available to that community, and that they are enabled to participate fully in the social, economic and political life of the community. This approach ensures that what is done in the name of CBR actually fits into the reality of the community and is owned by the community”.

CBR in context:
Placing CBR within a human rights framework can be very helpful in giving it a solid foundation, and clear set of goals. For example: CBR without a clear human rights framework could concentrate on delivering therapies and equipment to Persons With Disabilities. This could have temporary benefits, but will not necessarily result in Persons With Disabilities being empowered. This approach does not try to remove the barriers to participation in society – so a disabled person may have callipers but still be refused access to school or job. CBR with a clear human rights framework would create a strategy to address the comprehensive rights of Persons With Disabilities, working alongside other useful strategies.

The provision of therapy, aids and equipment could be a part of this, but with the aim of promoting full human rights. The few reflections below on Inclusive Society show how CBR can fit into a framework based on the Convention on the Rights of the Child. In such a framework, strategies such as Inclusive Education, and the development of Disabled people’s and Parents Organisations [DPOs] are also important along with welfare and inclusion CBR, outreach and Institution-based rehabilitation. It is common to find that any programme related to disability located in a community is called ‘CBR’. However, there are some fundamental differences in approaches that have very different outcomes:

1. In Institution-based rehabilitation, the locus of control is based in the institution. This service meets a small number of needs of a small number of Persons With Disabilities. This is at best a limited approach, and at worst it can abuse the rights of Persons With Disabilities.
2. Withoutreach, the locus of control is still based in the institution, but more people can be reached but there will be limits according to distance from the institution, and according to whether the needs of the Persons With Disabilities are similar to what the institution offers.

With CBR, the locus of control should be with the community. So the starting point is exactly the opposite. The Persons With Disabilities, family and community members decide what their priorities are, and then work together with local organisations and government institutions, in order to access relevant and appropriate services. Institutions have an important role as referral agencies. The difference is that they respond to needs rather than dictate them. In practice, many programmes are in transition between these different models. Some key questions are:

- Who should have control in deciding what Persons With Disabilities need?
- How can very poor and marginalised people develop more awareness and control?
- What sort of partnerships and support can help develop that control?
- How can existing human, material and financial resources within communities be ‘unlocked’?

What CBR is Not: Sometimes it is useful to think about what something is not, rather than what it is.

- What CBR is not a rigid or a blue-print approach which only focuses on the physical or medical needs of a person;
- Why only a long-term residential care delivering a service to Persons With Disabilities as passive recipients?

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• Why only an outreach from a centre providing rehabilitation training in isolation?
• Why only surveys on disability with no action?
• Why limited to one sector?
• Why an approach which is determined by the needs of an institution or group of professionals where Persons With Disabilities have to travel to a remote centre or institution to meet their needs?
• Why segregated and separate from services for other people?
• Why an approach with a narrow concept of ‘rehabilitation’ or a short-term fix?

What CBR is: It is integration into existing services and promoting the social inclusion of Persons With Disabilities. It is an approach with a broad concept of ‘rehabilitation’, a long term strategy for centres/institutions to respond to the needs of Persons With Disabilities and an approach which requires that the needs of Persons With Disabilities Social, Medical and the new ‘Economic’ be met in the community.

Models of CBR: There is much confusion as to what is meant by saying that this programme follows a medical model, and that programme follows a social model. Some are now saying that they follow a mixed model. From the perspective of this research, the difference between the two models is that there are two different starting points, two different sets of values, assumptions, beliefs, and so it is not possible to really have a mixed approach; how can some one start out on a journey from two different places at the same time?

The social model:
• Believes that all people are different, but some people are made disabled by the ‘barriers’ in society; ignorance, lack of access to resources, discrimination etc.
• Puts energy and effort into removing the barriers in society that exclude Persons With Disabilities
• Acknowledges the full human rights of Persons With Disabilities, including the right to appropriate therapies, medical treatment, aids and equipment if needed. But Persons With Disabilities themselves (and their family) should be able to make informed decisions about what they need
• It is not against Persons With Disabilities having therapy, or reducing the impact of their impairment (physiotherapy, wearing spectacles). This should be their choice.
• Argues that any individual requirements should as far as possible be available within mainstream structures. So for example, disabled person’s rehabilitation needs should be available within the mainstream health service, education should be inclusive etc.
• Places the locus of control with disabled persons themselves
• Measures success by how many disabling barriers are removed in society

The Medical Model:
• Believes that Persons With Disabilities are ‘abnormal’ or sick, or in need of treatment to fix them so that they can become as ‘normal’ as possible.
• Puts energy and resources mainly into trying to cure the person, or make them live and act as if they did not have impairment. E.g. forbidding profoundly deaf children to use sign language, forcing persons with physical disabilities to ‘walk’ or ‘stand’ even if they feel much more comfortable in a wheelchair.
• Will perceive Persons With Disabilities who have permanent impairments that cannot be ‘improved’ as tragedies or failures of the system
• Does not try to remove discriminatory barriers, or change society’s attitudes or behaviours.

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• Places the locus of control with doctors and professionals who make decisions about disabled person's bodies.
• Regards 'success' as making a disabled person as 'normal' as possible.

The Economic Model:
• Believes that people exist to serve the economy, not the economy to serve people
• Decides people's worth based on their capacity for economic productivity
• Will only justify responding to disabled person's needs 'where resources allow'.
• Perceives Persons With Disabilities as an economic burden on society
• Refuses to acknowledge the economic productivity potential of the majority of disabled persons, if barriers to accessing employment were removed – prefers to 'write disabled persons off'
• Does not appreciate the added value and richness of embracing people with all types of 'difference' within a society
• Believes that Persons With Disabilities' basic needs such as mobility aids, Braille equipment, hearing aids etc. and accessible accommodation are 'special needs' and should be provided by charities, rather than being rights provided by governments
• Classes disabled persons as too poor to be worth investing in (along with the poorest countries)

The following are the three legs of a stable CBR programme:
1. Financial support
2. Technical and management support
3. Commitment and capacity from both the community and the partner agencies

If any one of these 'legs' is missing, the stool will topple over! Stable CBR programme needs not only financial support but also technical and management support. In reality, it is well known that there is a wide range of opinions about what CBR actually is. Also, in practice, projects and programmes that are called 'CBR' can cover just about anything that is disability-related. There is a wide range of diverse understanding on CBR, it's approaches and philosophy among various agencies such as IDDC members which is a positive aspect and enriches the learning process. But underneath the wide range of practical and philosophical expressions, IDDC members believe that CBR does have some important and relevant essential components and qualities that distinguish it as a strategy from the two main alternatives in poor communities: a) Institution-based rehabilitation and outreach services – usually urban based are inaccessible and expensive, b) Local traditional coping strategies; these can be built on and developed, but communities do not of themselves have sufficient knowledge, skills, and positive attitudes to really offer appropriate help and support.

The core ingredients of CBR include:
• Being Community-Based: This means that the locus of control and action should be in the local community – Persons With Disabilities themselves, their families and community members. It does not mean 'community-enclosed' – although it is estimated that 80% of rehabilitation needs can be met within the local community, there is also the need for referral to district and national level services for some people and for training and support. Some of the important ideological issues will throw some light on the concept of CBR.
• Rehabilitation: This term has been heavily criticised by Persons With Disabilities because of its negative connotations and its lack of association with equalisation of opportunities and the removal of barriers in society. WHO and UN agencies have tried to rectify this situation by stressing that CBR does include the measures to bring about social inclusion. The new concept of Rehabilitation underlines the importance of co-
ordination of aspects related to medical, social, educational, vocational training and income generation issues.

- **Cultural compatibility**: This means that CBR can respond flexibly and build on existing community traditions, structures, networks and activities such as the extended family, local committees, informal and non-formal education practices etc.

- **Utilisation of local resources**: CBR programmes globally have developed ingenious ways of utilising local resources – people, material and finances. Low cost aids and equipment can be produced from local material by local people and CBR programmes can empower Persons With Disabilities and parents to take an active role in their communities and in CBR implementation.

**Importance and Relevance of CBR:**

**Human Rights and CBR**: Human Rights are often understood in a very limited way. In reality ‘rights’ refer not just to the civil and political rights but also the right to have basic human needs met, such as the right to life, food, shelter, staying with one’s family, and the right to develop as a human being. This is particularly important in relation to disability, because a majority of Persons With Disabilities are still struggling to access these very basic human rights. 70% of Persons With Disabilities and as many as 87% of the world’s children with disabilities live in the poorer countries of the ‘South’. CBR needs to be seen in the context of general human rights instruments such as the UN Convention on the Rights of the Child, which is legally binding. Article 2 (non-discrimination), and Article 6 (Right to Survival and Development) are basic principles underlining all other rights, and for children with disabilities, CBR can be an efficient strategy to meet these rights.

For a child with cerebral palsy born into a poor community, the right to survive, develop, have sufficient food, shelter, and the opportunity to develop basic functioning and basic daily living skills must be realised. These basic rights are the foundations on which all other rights (the right to express their views, participate in society and access education etc) stand. Article 28 states that all children have a right to education, but for a child with disabilities, even if the schools are inclusive and accessible, the Right to Education is meaningless if the child with disabilities is hidden in a inner room, or is dying of malnutrition because the mother lacks the information on the proper sitting position to enable the child to swallow. Article 9 stresses on the right of the child to remain living with their family, a right that is often denied to children with disabilities. CBR is again a strategy that fully supports this right. For adult Persons With Disabilities, CBR programmes are often the means through which they are able to find support, access essential aids and equipment, combat discrimination in the local community, and gain access to employment and participation in the wider activities of society.

**Poverty Eradication and CBR**: Governments and International Agencies throughout the world agree that the primary aim of development co-operation should be eradication of poverty. How does CBR combat poverty? Persons With Disabilities are amongst the poorest of the poor, and poverty alleviation cannot be achieved without including Persons With Disabilities. Poverty is both a cause and a consequence of disability. A World Bank Report stated that Persons With Disabilities constitute as many as 16% of the population in extremely poor communities. Disability affects not just the person, but the whole family and therefore a much larger percentage of people are directly affected by disability. Other reports suggest that only 2% of Persons With Disabilities have access to rehabilitation and appropriate services.

Without essential support, services and rehabilitation, a person with disabilities is frequently unable to contribute economically and may also not be able to care for himself or herself, thus becoming an economic burden to their family. Negative attitudes in the community also mean that often family members are denied education, employment and participation, thus...
creating a cycle of exclusion and increased poverty. A local CBR programme can enable person with disabilities to maximise their functioning, gain confidence and skills to be able to contribute to family life and also find employment. The vast majority of Persons With Disabilities particularly in poorer countries have only mild to moderate impairments and sometimes with very little support, and very simple aids and equipment, can then fully participate and contribute to their family and community. When CBR is in place, the family into which a child with disabilities is born can be supported from the start through participation in Parents Organisation, training in simple exercises and activities of daily living skills through CBR home visits, day care facilities, awareness-raising programmes in the community etc. This can prevent marriage break-up, siblings dropping out of school to care for the child, mothers being over-burdened, families spending all their assets seeking cures that will not work, and the inevitable descent into poverty and exclusion. Although in the short term, CBR needs investment, in the long-term, it can be a cost-effective strategy, as it specialises in fully utilising the local resources of people (families and volunteers) and materials (low cost appropriate aids and equipment). Because CBR emphasises integration within mainstream services, not top-down expensive parallel systems, it can maximise financial inputs.

**Analysis of the Current Situation:**

It is recognised among IDDC members that despite the wide adoption of the CBR approach by many UN agencies and international non-governmental organisations during the last two decades, and its great contribution to the well being of Persons With Disabilities, it remains mainly an NGO supported, small-scale programme with limited involvement of governments. From the point of view of the IDDC members, among other factors for this limitation stand the two most prominent ones:

1. The lack of endorsement and adoption by the service providers, authorities and training institutions, which means in other terms the lack of governmental support and involvement. Even in the case of some of the countries where CBR is officially recognised and adopted at the national level, it is not yet fully put in practice in terms of allocation of resources, setting disability as priority, etc.

2. The lack of endorsement and support from most of the official representatives of the beneficiaries, who are DPOs. This is mainly due to the lack of understanding and awareness about the real meaning of CBR and its major contributions to the rights-based approach and the empowerment of Persons With Disabilities and their families especially at grass root level.

An analysis made by the IDDC CBR Task Group has shown that the main barriers hampering the governments’ involvement in promoting the CBR approach were:

- Lack of understanding of the concept
- Rapid turn over of Civil servants
- Acceptance of CBR as a valid intervention
- Finance/Prioritisation
- Poor Management/planning of CBR
- Inter Ministerial Rivalry - Lack of communication
- Limited marketing of CBR as a cost effective and economic solution to disability and rehabilitation.
- Evidence based facts not made available
- Lack of co-ordination between Government and NGOs
- Absence of coherent community level strategy
- Limited competence and capacity of decentralising services
- No models of good practice

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• Social welfare department often has a weak structure at community level
• Government preoccupied with basic needs
• Governments do not include disability as a cross cutting issue

It was also agreed that interventions with the government should be aiming at producing the following changes:
• Better understanding of the concept of CBR
• Convince the government of cost effectiveness of CBR; number of people covering economic impact.
• Reallocation of resources; ensure Government understanding the reality of costs involved
• Decentralisation of Government's approach to CBR
• Government to understand/address disability as a cross cutting issue
• Improve specialised disability services but also to develop pools for effective inclusion.
• Encourage Government to recognise the value of using CBR methodologies for including other marginalised groups.
• If possible to work with the ministry with the best potential co-ordinating role (with Ministry of Community Development, if existing)
• Government to co-ordinate/back up and use existing resources but not to manage CBR programmes
• Formalising and recognising role of CBR

The group has also recognised the importance of adopting advocacy strategies while targeting governments to produce the above mentioned changes. In this respect they addressed the need to develop tools/evidence/projects to support their advocacy, such as:
• Regional co-ordination of CBR strategies planning and management
• Evidence generation on statistics for cost effectiveness
• Sharing of Evaluation materials
• Develop advice/recommendations on the value of CBR programmes on economy of countries
• Empower DPOs to be able to advocate for CBR activities at local Government levels and ensure DPO’s clear understanding of the concept
• Influence Government from bottom up to top down
• Improve technical capacities for ways to include Persons With Disabilities.
• Look at planning methodologies
• Allocate a percentage of funding of NGOs to work with Government.
• Encourage NGOs to work in collaboration with Government and vice versa
• Reallocation of funds e.g. NGO\'s to initiate a programme and Government to fund sustainability of programmes.
• Establish co-ordination meetings between ministries about CBR by supporting local Government to fund sustainable programmes.
• Establish co-ordination meetings between Ministries about CBR by supporting local NGOs to advocate/select local projects as models of good practice and ones that are co-ordinating at national level to local level.
• Creative ideas for co-ordinating but not dominated by one ministry.
• Influence policy makers/donors to allocate resources to CBR

The second major area, which was identified by IDDC member group as focus for their future work to promote CBR, is related to the lack of full involvement and support of most of the DPOs worldwide. In this respect the task group recognised the need to work in close collaboration with DPOs and encourage all UN agencies and governments as well as NGOs to work in partnership with DPOs at all levels.

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Meaning/Definitions:
The starting point for understanding CBR is the following approach agreed to in 1994 by ILO, UNESCO and WHO, which provides a base for understanding the concept of CBR but the definition is not comprehensive and contextual.

There are a number of working definitions which are discussed in the section.

1. Community-based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all Persons With Disabilities. CBR is implemented through the combined efforts of Persons With Disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services. [ILO, UNESCO and WHO]

2. CBR is a strategy for improving service delivery, equalisation of opportunities and promotion and protection of human rights of Persons With Disabilities [UNDP]

3. CBR is a serious effort towards de-institutionalising, de-professionalizing and de-mystifying the rehabilitation services for Persons With Disabilities. [UNO]

4. CBR is a process of democratisation of rehabilitation of Persons With Disabilities that is rehabilitation for the /of/by/with in community.[SRMAB]

5. CBR is a manual training programme described in the community to rehabilitate the needy people of that community.[IAR India]

6. This approach to CBR is multi-sectoral and includes all governmental and non-governmental services that provide assistance to communities. Many of the services which can provide opportunities for and assistance to Persons With Disabilities are not traditionally considered relevant to CBR programmes and Persons With Disabilities. Examples include community development organisations, agricultural extension services, and water and sanitation programmes.

In the ILO-UNESCO-WHO approach to CBR, the phrase "within community development" is understood to be the following strategy recommended by the UNO; ... “the utilisation, (in an integrated programme) of approaches and techniques which rely on local communities as units of action and which attempt to combine outside assistance with organized local self-determination and effort, and which correspondingly seek to stimulate local initiative and leadership as the primary instrument of change”. In the CBR context, community means: (a) a group of people with common interests who interact with each other on a regular basis; and/or (b) a geographical, social or government administrative unit.

Principles:
The strategies of CBR may differ depending upon context, culture, geography, resources, state, situation, need and other related factors but the basic, fundamental and underlying principles are same wherever it is. The basic principles of CBR are as follows:

1. Wider coverage: A CBR programme should cover a large number of Persons With Disabilities and address their issues both at micro and macro levels. A micro level CBR initiative should have its extensive impact at macro level and reach Persons With Disabilities, family members and communities as many as possible.

2. Cost effective: CBR programme should be cost effective so that it is affordable to Persons With Disabilities. The investment made for a CBR programme should cater to the needs of a large number of Persons With Disabilities so that it can be cost effective. The underlying principle is few services to all as against all services to few.

3. Community participation: A CBR programme should involve the community at all levels of the programme right from designing, planning, implementing, monitoring and evaluation stages. The participation and involvement of Persons With Disabilities at all levels of the
programme mentioned above is most essential and desirable since they are the primary stakeholders of the programme. They are in the best position to understand their own needs, issues, problems, strengths, limitations, opportunities and threats.

4. Social inclusion: CBR approach should strive for the inclusion of Persons With Disabilities in all spheres of community/social life. It should not exclude or isolate Persons With Disabilities in any manner. Institutionalisation and custodialisation is strongly rejected and opposed by Persons With Disabilities and their movement is against these attempts.

5. Solidarity: CBR should strive for achieving the social solidarity between all marginalised groups, larger society and community and Persons With Disabilities. Persons With Disabilities should support other marginalised groups and seek their solidarity to disability movement. Disabled community should support the larger development process of the community and society.

6. Human rights perspective: CBR should have rights perspective rather than charity perspective. It should address basic issues rather than symptoms. It should consider disability as a development and human rights issue rather than medical rehabilitation issue alone. It should ensure equalisation of opportunities, rights, entitlements and dignity.

7. Dignity of the individual: CBR should recognise the dignity of the individual. It is very important to understand that a Person With Disability is an individual with human dignity rather than a case, patient and object. She/he is a human being first and then disabled or non disabled. The basic human individuality must be respected and opinion of the individual should be respected. The individual informed decision should be final in the rehabilitation process.

Programme Criteria:
The development and implementation of CBR programmes should be based on the following criteria:

1. Persons With Disabilities must be included in CBR programmes at all stages and levels, including initial programme design and implementation. In order to give significance to their involvement, they must have distinct decision-making roles.

2. The primary objective of CBR programme activities is the improvement of the quality of life of Persons With Disabilities.

3. One focus of CBR programme activities is working with the community to create positive attitudes towards Persons With Disabilities and to motivate community members to support and participate in CBR activities.

4. The other focus of CBR programmes is providing assistance for people with all types of disabilities (physical, sensory, psychological and mental); for people of all ages, including older people; people affected by leprosy; people affected by epilepsy; and other people who may be identified by the community as needing special assistance.

5. All activities in CBR programmes must be sensitive to the situation of girls and women. This is because in many communities throughout the Asian and Pacific region women are not treated equally. When they are disabled, the problems that they face in life are doubled. Furthermore, women are usually the primary family care-givers for all Persons With Disabilities.

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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. 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. Flexible, local programmes will ensure community involvement and result in a variety of programme models which are appropriate for different places.

7. CBR programmes must coordinate service delivery at the local level. Community members seldom understand the different roles and specialisations that are part of providing assistance to Persons With Disabilities. They tend only to see the problem of disability and only want access to “one window” for help. They may focus only on where to go and who to see about a specific “problem”, rather than understanding the totality of what constitutes a fulfilling life for a community member who has a disability.

The Components of Community-based Rehabilitation Programmes:
The components of a CBR programme should include:

1. Creating a positive attitude towards Persons With Disabilities: This component of CBR programmes is essential to ensure equalisation of opportunities for Persons 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.

2. Provision of functional rehabilitation services: Often Persons 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 following areas of rehabilitation:
   - Medical
   - Eye care service
   - Hearing services
   - Physiotherapy
   - Occupational therapy
   - Orientation and mobility training
   - Speech therapy
   - Psychological counselling
   - Orthotics and prosthetics
   - Other devices

3. Provision of education and training opportunities: Persons With Disabilities must have equal access to educational opportunities and to training that will enable them to make 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:
   - Early childhood intervention and referral, especially to medical rehabilitation services
   - Education in regular schools
   - Non-formal education where regular schooling is not available
   - Special education in regular or special schools
   - Sign language training
   - Braille training
   - Training in daily living skills
4. Creation of micro and macro income-generation opportunities: Persons 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 Persons With Disabilities.

5. Provision of care facilities: Often, people with extensive 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 to families who either work or need time off for other activities.

6. Prevention of the causes of disabilities: Many types of disabilities 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 early intervention 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.

7. 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.

Strategies:
It should be noted that the specific strategies of a CBR programme may differ according to various variables but the global strategies should be same for any CBR programme. The global strategies include:

- A CBR programme should strive for generating awareness in community in order to raise the level of awareness and changing the attitudes of the community and other stakeholders towards Persons With Disabilities.
- A CBR programme should work towards building the capacity of all the actors concerned in order to manage a CBR programme for Persons With Disabilities in their community.
- There should be constant attempts to network, leverage and establish linkages with state, local institutions, agencies, organisations, development agencies and DPOs in order to build a strong anti poverty movement.
- A CBR programme should promote people centred advocacy in order to encapsitate Persons With Disabilities, families and communities in order to put constant pressure on the state to ensure effective implementation of schemes and programmes.
- Influencing policy and programmes in order to make every development initiative of the state and development agency inclusive of Persons With Disabilities.
- There should be a clear bias in favour of most poor and marginalized in order to promote equity of all Persons With Disabilities. It is an established fact that there is disparity with in disability sector where few category of Persons With Disabilities
suffer from dense marginalisation. CBR should strive for reducing the disparity of these sections.

- There is a great need to organise Persons With Disabilities into Self Help and Advocacy Groups [SHAGs] in order to enable them to raise, discuss and address their own issues and issues concerning all the people of the community/society.
- There should be conscious attempts to transfer both technical and managerial skills to Persons With Disabilities, families, communities and service providers in order to ensure sustainability of the programme in a long run.
- CBR programme should strive for activating existing infrastructure and facilitate the process of inclusion of Persons With Disabilities in all spheres and walks of life.

The resources, skills and initiatives to start and sustain CBR programmes require the cooperation and collaboration of eight relevant sectors:

A. Persons With Disabilities;
B. Families of Persons With Disabilities;
C. Communities;
D. Governments (local, regional, national, international);
E. NGOs, local, regional, national and international organisations, and organisations of Persons With Disabilities;
F. Medical professionals, allied health science professionals, educators, social scientists and other professionals;
G. The private sector (business and industry).
H. Disabled people's organisations [DPOs] and Self and Help and Advocacy Groups SHAGs;

The roles of these stakeholders in a CBR programme are discussed in the next section of this chapter.

Source:

6. COMMUNITY BASED REHABILITATION [CBR]
6.2. THE ROLE OF STAKEHOLDERS IN CBR

The initiative to start CBR programmes and to facilitate their development may come from any one of the following groups. However, the effectiveness of CBR and the long-term development and sustainability of any CBR initiative will require the coordination, involvement and collaboration of all eight groups. The eight groups and their suggested roles are as follows:

A. Persons With Disabilities: Persons With Disabilities can and should contribute at all levels of CBR programmes in every position within a programme. The involvement of Persons With Disabilities in a CBR programme should be at all levels beginning from designing, and planning, to implementing, monitoring and evaluating the programme which facilitates full inclusion of Persons With Disabilities in all spheres of life. They know what the effects of local conditions are on themselves. They are likely to have a good understanding of those effects on their peers with disabilities. They also know what impairment really means in the context of their family, community and nation. This knowledge enables them to be very effective members of a CBR team. They can be more effective than non-disabled people as role models and counsellors for other Persons With Disabilities. Persons With Disabilities have an important role in community education. As community educators, they serve as living examples of Persons With Disabilities that make a significant contribution, provided that they are given the opportunity and the right type of assistance. CBR programmes should also facilitate the development of SHAGs of Persons With Disabilities at the community level. The disability activists rightly remark that “we are in a best position to understand our own needs, issues, problems, pain, sorrow, sufferings; and suggest appropriate intervention to address our own issues than anybody else on the earth” This is true because they undergo the real effects and trials of impairment and social attitudes and conditions.

B. Families of Persons With Disabilities: Families have the primary responsibility of caring for all of their members. They are the first line of support and assistance for Persons With Disabilities at the local level. As such, families must be included in CBR programme activities. Where the individual with a disability is not able, for whatever reason, to speak for himself or herself, a family member should represent him or her and should be considered a legitimate member of Persons With Disabilities’ organisations. Members of families with experience in caring for Persons With Disabilities are the people who most often initiate CBR programmes and are, or prove to be, the most effective contributors at all levels.

C. Communities: Community members should be involved in CBR programmes at all levels because they already know the local environmental conditions, the local economy, the local political situation and how to work with them. They also know about the accessibility, availability and effectiveness of locally available rehabilitation services, who in the community cares enough about other people to become a programme leader or worker; and, which community members have the knowledge and skills for training others in micro-economic activities. They are the people most likely to want to live, work and stay in the community. Community involvement usually requires the agreement and approval, both formal and informal, of the community leaders. Since CBR is contextual, culturally compatible and flexible, it is very important to involve communities at all levels and all stages of a CBR programme due to better understanding of the situation, context and conditions. The long term sustainability of the programme largely depends on the communities.
D. Governments (local, regional, national): Governments have the most important role in the development and sustainability of CBR programmes. Their cooperation, support and involvement are essential if CBR is to cover the total population and be sustainable. They should implement and coordinate the development of the entire programme structure, including the development of the referral system, as well as the activities within the community. They also should provide resources for non-governmental organisations (NGOs) and community activities. Finally, they should ensure that discriminatory legislation is changed and that the rights of Persons With Disabilities are guaranteed and protected through appropriate policies, legislations, schemes, programmes and institutions.

E. Non-governmental organisations, local, regional, national and international: Organisations including NGOs, DPOs, CBOs, disability and development agencies, international development and funding agencies and organisations of Persons With Disabilities; are often able to provide resources and skills to facilitate the development of new programmes, especially in areas where none exist. They can develop new approaches to CBR and provide training programmes to government employees, CBR workers, Persons With Disabilities, families, and community members. NGOs are effective in facilitating the development of community members as CBR programme leaders. They are often best able to provide long-term care facilities for those people with extensive disabilities whose families cannot or will not look after them. The role of external agency is that of a catalyst in order to initiate the change process and facilitate the local community including Persons With Disabilities and families to manage and continue the same in a long run.

F. Medical professionals, allied health science professionals, educators, social scientists and other professionals: Professionals are often in a position where they can, as trainers and educators, facilitate the development of new programmes by making their knowledge and skills accessible to community members and CBR programme workers. They can also ensure that they support community efforts by making themselves available and accessible on a referral basis. When they are in government service, they can advocate and promote the development of CBR programmes as an effective way to provide local-level services quickly.

G. The private sector (business and industry): The private sector has a social obligation to return some of the benefits of its operations to the communities that support it. In the past, this support has largely taken the form of charity. Charity occurs when donors "give" whatever they feel is needed or appropriate to Persons With Disabilities. This approach of assisting Persons With Disabilities is no longer appropriate and needs to be changed. Supporting CBR programme activities eliminates the need for charity. CBR support is a much more appropriate way of directing resources to communities and Persons With Disabilities. By supporting CBR programmes, the private sector receives credit for its social involvement while being guaranteed that its support is put to effective and efficient use. Who but trained, knowledgeable community members would know what is most needed by the people of their own community?

H. Disabled People’s Organisations [DPOs] and Self Help and Advocacy Groups [SHAGs] of Persons With Disabilities: In the last ten years Persons With Disabilities have organised themselves into their own organisations in 100 countries. Disabled People’s Organisations [DPOs] are those controlled by a majority (51%) at the board and membership levels by Persons With Disabilities themselves. Disabled People’s International (DPI) considers the role of DPOs to be the most fundamental issue for the disabled person’s movement. The World Programme of Action Concerning Disabled Persons concurs in paragraph 28: The role of these organisations includes providing a voice of their own,
identifying needs, expressing views on priorities, evaluating services and advocating change and public awareness. As a vehicle of self development, these organisations provide the opportunity to develop skills in the negotiation process, organisational abilities, mutual support, information sharing and often vocational skills and opportunities. In view of their vital importance in the process of participation, it is imperative that their development be encouraged. (WPA, p. 8) This paragraph outlines the role of organisations of Persons With Disabilities, which will be discussed in this section. First, however, as a background, it is important to define DPOs, to describe the worldwide situation of Persons With Disabilities, and to discuss the evolution of key philosophical tenets of the Persons With Disabilities' movement. The role of DPOs is summarised below:

1. **Self-representation** — DPOs believe that Persons With Disabilities are their own best spokespersons. DPI's motto is, "A voice of our own". This premise is the backbone of the movement. Medical and social work professionals, and extended families, have spoken for Persons With Disabilities for too long. In the words of Ed Roberts, a disabled American, "...when others speak for you, you lose." (Roberts, 1983, p. 7) Persons With Disabilities believe that they best know the needs and aspirations of Persons With Disabilities. They will represent themselves to governments, service providers, the United Nations and the public. As mentioned earlier, Persons With Disabilities redefined themselves as citizens with rights, not as patients and clients of professionals, nor as beggars asking for hand-outs. As the National Council of Disabled Persons of Zimbabwe (NCDPZ) believes, "Our role is to act as a voice of Persons With Disabilities. We are a 'civil rights' organisation of the disabled formed to conscientize Persons With Disabilities about their rights and to fight for the right to access to all community services". (NCDPZ "A Voice", 1983, p. 1) To assert their rights, Persons With Disabilities believe that all disability groups must be united into national DPO, and of course, DPI, an international united front. As Jim Derksen urged disabled Canadians in 1975: "Let us reason together, let us deliberate on our problems and needs, let us consider our abilities, and when we have agreed on the problems and solutions let us articulate our opinions and ideas in a strong and united voice." (Derksen, 1975, p.1a)

2. **Identifying grassroots needs**: DPOs arise in response to a group of people's perception that there are barriers to participation of Persons With Disabilities in society that need to be addressed. These organisations are based on the needs and aspirations developed by the disabled grassroots community. The Persons With Disabilities who start such organisations are usually educated and are better off financially than the majority of disabled persons in their countries. Their educational advantage causes these disabled persons to identify and analyze the barriers that bar the participation of Persons With Disabilities in society. They have learned the tools that the rest of society uses and they turn them towards the benefit of all Persons With Disabilities, who are in some developing countries, 99% illiterate. Furthermore it is Persons With Disabilities who must identify their own needs and ways to meet them. Paulo Freire explains in Pedagogy of the Oppressed: "... those who recognise, or begin to recognise themselves as oppressed must be among the developers of the pedagogy. No pedagogy that is truly liberating can remain distant from the oppressed by treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption." (Freire, 1970, p. 39) Indeed, Persons With Disabilities and their organisations identify the forces that oppress them, and organize to overcome those forces -- physical and attitudinal barriers. DPOs around the world have forged mechanisms to hear from the grassroots disabled constituency. There are three ways this can be accomplished.

a. **Organising local chapters**: DPI's members have made it a priority to establish local chapters of their organisations throughout their countries. This is important, not only to build

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the infrastructure of their organisations, but to solicit and represent the views of all Persons With Disabilities in a country. In countries such as Argentina DPO realizes that it must reach out into the rural areas beyond Buenos Aires to help Persons With Disabilities organize. Through outreach the needs and aspirations of rural Persons With Disabilities are learned. In Zimbabwe the National Council of Disabled Persons (NCDPZ) started a rural outreach program in 1984. It sends development workers into rural areas to locate Persons With Disabilities. They meet with local chiefs and village leaders to discuss the need to locate and to integrate Persons With Disabilities into everyday life. In the process of organising local chapters Persons With Disabilities previously hidden away in the community are discovered and so are their needs and aspirations: "Rural members usually meet in small groups or SHAGs which form part of the branch. Members try to locate Persons With Disabilities in their villages and introduce them as new members. They inform their branch secretaries of children or adults in need of treatment and education. Sometimes a branch is able to refer these people to suitable hospitals or schools themselves; if they are unable to do this they request help from the headquarters office of NCDPZ." (NCDPZ, ca. 1984, p. 2)

b. Open forums: DPOs also hold open forums to discuss issues of concern to Persons With Disabilities. Over the last ten years the Coalition of Provincial Organisations of the Handicapped (COPOH) in Canada has held six forums on various issues. Some 100 Persons With Disabilities have attended each forum along with government officials, business people and members of the community. The forums have dealt with barriers to disabled persons' participation in employment, transportation, rehabilitation and independent living. (Driedger, 1986, pp. 9-10). The forums help disabled Canadians to identify the barriers to their participation in each area and formulate strategies for changes. For example: The first forum held in Winnipeg in 1978 focused on employment. Persons With Disabilities affirmed that employment was a right of every citizen in society. And Persons With Disabilities agreed that working in the community with all other citizens was the best option for them. (Driedger, 1986, p. 9)

c. Democratic representation: Both the forums and outreach activities of DPOs provide direct input from grassroots Persons With Disabilities. Democratic representation also provides another kind of input which is more indirect. DPOs, by definition, are controlled at the board and decision-making levels by Persons With Disabilities. People are elected to the decision-making bodies of organisations by their membership. Thus, the Persons With Disabilities elected to DPO boards represent those people's concerns to governments, service providers and the public. Rank Bowe, an American disabled advocate explains the process of representation: "Before I can represent a group of people, I must first consult with them. This process involves sharing with these people my knowledge or expectation that certain issues among the many which concern these people are likely to become subject to public debate in the near future. I must solicit from these individuals informed opinions on these issues and receive from them instructions to represent these views. These instructions constitute my authority as a representative." (Bowe, 1980, pp. 13-14). As a genuine representative, he or she then returns to report to the group, "In order to complete my work as a genuine representative, I must then return to my group and represent to these people the views, decisions and other deliberations of the people with whom I met on the group's behalf." (Bowe, 1980, p. 14). This is how the system of representation would ideally work. Indeed, the views of the group are represented by individuals to other bodies. DPI is the international manifestation of such a representative system.

3. Representations to government service providers, and U.N. bodies: DPOs fulfil the role of a vehicle to represent the needs of Persons With Disabilities to decision-makers and service-providers at the local, national and international levels. Their representatives make
presentations to decision-makers. In the case of DPI it’s members are cross disability DPOs, and thus decision-makers can hear a united voice. In the past, in many countries, before the advent of cross-disability groups, many uni-disability groups would present their varying points of view without consulting other groups of Persons With Disabilities. Government found it difficult to know which group to give priority to in the consultation process. As O’Rourke of the American Coalition of Citizens with Disabilities (ACCD) stated: “For a long time it was a big problem with disabled groups in America because when the legislation was brought before the Congress, perhaps forty different groups would go to Congress. Each had a different position… It became very difficult for the people within the government themselves to make decisions.” (O’Rourke, 1978, p. 51). The American disabled citizens formed a cross-disability coalition to surmount this problem. Forrester, of the Combined Disabilities Association in Jamaica reiterates the important role of organisations in the consultation process: “It is more convenient and advantageous to make representatives to government concerning change or to lobby political leaders as associations, since politicians are more liable to act where they perceive that proposals are being made by associations rather than individuals”. (Forrester, 1985, p. 7). Indeed, government planners can discover what the majority of Persons With Disabilities want. Too often priorities are set in social services that have little to do with the actual needs of Persons With Disabilities. It, thus, is good economic and policy planning to include disabled persons in the planning process because they are the ones that best know the needs of Persons With Disabilities: “Most frequently in the past, programs, even in America, were designed by people who themselves were not very close to the problem. Persons With Disabilities themselves often know how to deal with situations when people who are not disabled need to think about how this problem should be handled. This thought itself is still only theory because they are not disabled themselves, and lacking experience they have difficulty coming up with simple solutions.” (O’Rourke, 1978, p. 50)

4. Evaluating and monitoring services: Since Persons With Disabilities themselves best know their own needs, DPOs play a role in evaluating and monitoring services. This process would perhaps take place more often in developed countries, where there were more services, than in developing countries. It would also happen more often in countries where there was an expectation from their citizens that their social needs should be served by government as a right. This attitude appears in countries such as Canada and Sweden where their social welfare states provide subsidized medical care and technical aids. The monitoring of services takes place in Sweden through HCK, its cross-disability organisation. In Canada, the Coalition of Provincial Organisations of the Handicapped (COPOH), as its first lobbying effort, worked to obtain accessible public transit services for Persons With Disabilities in 1975. (Driedger, 1983, pp. 9-12). The group perceived that there was a need for Persons With Disabilities to have the same right to affordable, public transit as other citizens: “The City of Winnipeg now provides a public transportation system, available to all non-handicapped persons who wish to use it during hours of operation. It is therefore an established city policy: a) to make public means of transportation available; and, b) to charge only a minimal fare to the user.” (Jim Derksen quoted in Driedge, 1983, p. 10).

5. Self-development: DPOs play a role in the development of Persons With Disabilities’ skills in the negotiation process, organisation, management, and proposal and letter-writing. They also provide a forum for mutual support, while the above skills are being developed. Organisations give Persons With Disabilities the opportunity, through being volunteer committee members or salaried employees, to learn skills which would benefit them in the open employment market. Indeed, much of the skills training have taken place in local and national organisations where Persons With Disabilities learned new skills because they had

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to do those things at the time to further the aims of their organisation. There was no one else to take on these jobs, especially when groups started out with few monetary resources.

The skills development of Persons With Disabilities in the developing world is one of DPI's main aims. DPI established a Self-Help Leadership Training Program in 1982 for this purpose. DPI has raised monies from agencies such as the Canadian International Development Agency and the UN Trust Fund to help fund these seminars. Since 1982, DPI training seminars have been held in Africa, Asia, Latin America and the Caribbean. These week-long seminars deal with budgeting, management, fund-raising, writing letters, project proposals and reports, and establishing local self-help businesses. Similar seminars are taking place in some developed countries on the initiative of local and national organisations of Persons With Disabilities. In June 1987 the Saskatchewan Voice of the Handicapped, a provincial member of COPOH, hosted a seminar focussing on leadership training.

6. Mutual support and solidarity: DPOs, at all levels, are a vehicle for mutual support and solidarity. Persons With Disabilities who belong to these groups find that they have a common purpose, that of promoting their right to live as citizens in society. This common purpose engenders feelings of mutual support and solidarity in a common cause. Indeed, the DPI Development Program Evaluation discovered that Persons With Disabilities, who were given the opportunity to meet and discuss issues of concern with each other, experienced this.

7. Vehicle for self-help projects: DPOs play the role of initiators of self-help projects aimed at integrating Persons With Disabilities into the mainstream of society. The projects have been initiated in two main areas: independent living and employment. In the U.S., Canada and the United Kingdom organisations have investigated the need for independent living of Persons With Disabilities in the community like everyone else. Organisations controlled by Persons With Disabilities, called independent living centres, have arisen to ensure that Persons With Disabilities live as independently as possible. In some cases, as in the United Kingdom, the development of these centres is spearheaded by cross-disability DPOs at the local level. The centres were needed to fill gaps in services that Persons With Disabilities identified. They needed to live independently in the community: "They [independent living centres] are needed because they are a practical and imaginative way of correcting the historical omission of Persons With Disabilities in the past, and to ensure that future service developments correspond to disabled person's legitimate aspirations". (Davis, 1983, p. 4) Indeed, independent living centres which are controlled at the board level and managed by Persons With Disabilities can identify what are the real needs of Persons With Disabilities.

The first centre was initiated in Berkeley, California in the early 1970's: After graduating some disabled students realised that once they left the university they would no longer have access to the services they depended upon in order to live in the community. They required such services as attendant care and accessible transportation. To solve this problem, they organised cooperatively to guarantee the provision of the services they required. (Driedger and D'Aubin, 1985, p. 51). This centre, and others in the U.S. and Canada, were established by groups of individuals who saw that their needs were not met by existing service agencies. These centres, depending on the local situations, provide accessible housing with attendant care, advocacy, peer counselling and information on existing services. Many DPOs, mostly in the developing countries, have also initiated self-help employment projects. These businesses have proven immensely successful in terms of job skills training for Persons With Disabilities, demonstrating that they can work as efficiently as non-disabled people, providing a living for Persons With Disabilities, and in making a profit, which is often used to fund the

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self-help organisation. All of the above elements are present in DEEDS, Industries run by the Combined Disabilities Association in Kingston, Jamaica.

This is a factory that employs 50% disabled workers and 50% non disabled workers. Thus, it is not a sheltered workshop. The Board of Directors consist of Persons With Disabilities and non disabled business people. The factory produces wooden toys and gift items, which it markets in the U.S. and other places. It has proven to be a successful business venture which is reflected in the quality of the products and its economic viability. Profits go towards financing the projects of the Combined Disabilities Association. (Forrester, 1985, p. 7) In Guyana, the Coalition of Citizens with Disability has embarked on a chicken hatchery cooperative project. Again, Persons With Disabilities are employed in this venture. In Mauritania, Persons With Disabilities learn sewing, embroidery, secretarial skills and rug-making in training centres. These centres also market the products, thus providing a living for the Persons With Disabilities at the centres.

8. Networking mechanisms: Organisations provide the opportunity for Persons With Disabilities to share ideas and information, especially at the international level. DPI has played an important role in facilitating information-sharing among DPOs from different countries. DPI's Leadership Training Seminars and regional meetings of World Congresses provide forums for formal and informal information exchange. For example, delegates from the organisation in Guyana attended a Training Seminar in Barbados in 1983 and returned home inspired to create a cross-disability organisation in their country. After Guyanese delegates attended another DPI Leadership Training Seminar in Barbados in 1985, they returned home to start a chicken hatchery cooperative run by Persons With Disabilities.

9. Promoting Public Awareness: Organisations of Persons With Disabilities also create public awareness about the needs, aspirations and abilities of Persons With Disabilities. This awareness is promoted through many of the activities of DPOs: lobbying government, monitoring service agencies, publishing a newsletter, speaking in the national media, conferences, etc. For example, the Council of Disabled Persons in Zimbabwe promotes awareness about the needs and abilities of Persons With Disabilities and the need for their integration into community through its Outreach Program as described earlier. Village leaders are sensitised to begin looking at including Persons With Disabilities in community life.

Many organisations undertake specific "public awareness" campaigns which are usually carried out in the media (radio, newspapers, and television) or in the schools with children. Organisations often operate speakers' bureaus which send Persons With Disabilities out to speak at community events. Others have school programs, which promote awareness. In Canada, the Manitoba League of the Physically Handicapped in conjunction with the Mennonite Central Committee ran such a program. Persons With Disabilities spoke to school children about issues of Persons With Disabilities. The premise behind such a program is that children will be exposed to a disabled person and hear that person's point of view. Many children do not have this opportunity when they are young. Children's attitudes about Persons With Disabilities often have not had the chance to become as negative as those of adults, who may often view Persons With Disabilities as "sick", "helpless", and "childlike".

Finally it can be summarised that DPOs play many roles at the local, national and international levels for Persons With Disabilities, governments, service providers and the general public. In many cases, the organisations of Persons With Disabilities are the best vehicle to carry out the aspirations of Persons With Disabilities. After all, Persons With Disabilities, from their own personal experiences best know their needs, aspirations and
abilities. One of the main themes of the World Programme of Action is the importance of DPOs. It calls upon governments to encourage their development and utilise their expertise.

Having attempted to outline the role of DPOs in promoting meaningful and effective inclusion of Persons With Disabilities through a CBR programme, now let us understand the role of SHAGs at village level in rural areas. SHAGs have been playing a key and instrumental role in providing services, promoting inclusion, generating awareness, lobbying, and advocating for their own rights and promoting holistic development of their own community where they live. It is important that a CBR programme should facilitate the process of organising Persons With Disabilities and their families into SHAGs at village level and federate them at block and district level in order to ensure sustainability of the programme and disability movement.

Source:
6.3. SOME CONTROVERSIES IN CBR

This chapter aims to present a brief introduction to the concept and evolution of CBR including an overview of the changes that have taken place in the last decade. It discusses some controversial issues concerning CBR in developing countries, with particular reference to South Asia and India. The points for discussion are framed around 5 questions, namely:

1. Who should start CBR programmes?
2. Will the predominance of the social model lead to rehabilitation needs being ignored?
3. Is CBR expensive?
4. If so, for whom?
5. Can it realistically depend on volunteers and can it help all Persons With Disabilities?

The points raised are based on the work experience of various people of disability sector over the last decades. The section concludes with a recommendation that research into these areas is required to establish constructive progress.

Introduction

CBR was promoted by the World Health Organisation (WHO) and other UN agencies in the early eighties, as an alternative service option, for the rehabilitation of Persons With Disabilities in developing countries, who had no access to services (WHO, 1981; UN, 1983). Since these countries had limited resources to provide high quality institutional services, the emphasis was on developing a method, which provided wide coverage, at costs that were affordable to the governments of these countries. In CBR, interventions were to be shifted from institutions to the homes and communities of Persons With Disabilities, and carried out by minimally trained people, such as families and other community members, thereby reducing the financial costs (WHO, 1989). In the early eighties, CBR was conceptualised and evolved primarily as a service delivery method with a medical focus.

WHO recommends that it be integrated into the primary health care (PHC) system that was already well established in many developing countries. The International Classification of Impairments, Disabilities and Handicaps (ICIDH), published in 1980 by WHO, also encouraged a medical approach to rehabilitation (WHO, 1980). As a result, the early CBR programmes tended to focus on restoring functional ability in disabled individuals, in order to 'fit' them into their community. This was a sort of community located rehabilitation. During the eighties and the nineties, there was a substantial growth in the number of CBR programmes in different developing countries. Along with the quantitative growth, there were also major changes in the way it was conceptualised (Thomas and Thomas, 1999). One of the early changes was the shift from a medical focus to a more comprehensive approach.

With the realisation that stand alone medical interventions did not complete the rehabilitation process, CBR programmes gradually began to add on interventions such as education, vocational training, social rehabilitation and prevention. Along with this came the recognition that CBR needed to deal with issues relating to Persons With Disabilities' lives at all times, and to change not only the disabled individual, but the context in which he or she was located. Changing contextual factors involves helping non-disabled people in the community accept Persons With Disabilities, promote their social integration, and equalise their opportunities to access education and employment, in the same way as non-disabled people. Protection of the rights of Persons With Disabilities, and empowerment of the community to manage their programmes are other aspects of the contextual changes. These require involvement from the community, both before, during and after the formal programme phase if a philosophy of sustainability is to be embraced. Thus, CBR today, follows a social, rather
than an exclusively medical model, but there are still many questions to be answered before CBR can be implemented effectively. It may need two or three more generations before CBR becomes part of the established culture and therefore sustainable. The following discussion deals with some of the questions that need to be addressed.

**Should CBR be initiated before community expresses its need or only when there is an expressed need?** In the earlier years when CBR was a form of service delivery, this question was irrelevant. Today, however, CBR is viewed as a development process, and the question of whether CBR should be imposed by outsiders or initiated by the community, is debated widely. In the earlier years, CBR tended to be a form of ‘community therapy’, where services were physically shifted to the community, but the clients remained passive ‘beneficiaries’ (Wirz, 2000). Subsequently, some CBR programmes have changed to a community development approach, disabled persons and their families are actively involved in all issues of concern to them. However, many feel that the initiation of programmes remains in the hands of the ‘external’ facilitators because the level of awareness required for needs to be constructively expressed require development, but that the ultimate goal should be full ownership of the programme by the clients. As it is conceptualised today, ‘community participation’ is a central and essential tenet of the social model CBR. In practice, however, most CBR programmes in South Asia find it difficult to achieve this goal (Thomas and Thomas, 2001) and the challenge of promoting community initiation remains.

Usually, it is assumed that communities are homogeneous, cohesive and mutually supportive entities, but in reality, it does not appear to be so. They are, in most instances, quite heterogeneous, with wide difference in socio-economic status, educational status, religion, ethnicity and so on (Boyce and Lysack, 2000). This diversity sometimes causes friction and affects services, because different groups in a community have widely differing needs and priorities. Usually the needs of Persons With Disabilities, who are in a minority, are not considered to be a priority by others [Thomas and Thomas, 2001]. Given this background, how does one define the ‘community’ in a CBR programme? Does it comprise only of the primary clients, i.e. the Persons With Disabilities and their families? Or, does it include the larger community? If the latter, then is it reasonable to expect members of community at large, to share their resources with Persons With Disabilities?

Poverty is a major barrier to participation in development programmes, as people have other pressing needs to be fulfilled before they can take charge of their programmes. Corruption and cornering of wealth by vested interests is another issue that mitigates against participation by all. People in developing countries also have difficulty with decentralisation and ‘bottom-up’ practices due to a cultural reluctance to take charge of their own affairs. Local communities usually benefit from the Government as a permanent role, and resist suggestions about taking charge of programmes on their own (Thomas and Thomas, 2000, Boyce and Lysack, 2000, Dalal, 1998).

Consequently, the issue for debate among planners today, is whether: CBR should be initiated in a community by an external agency, or whether one should wait for the local communities to start CBR on their own? The votaries of the former opinion advocate starting services for disabled individuals without waiting for community participation, as it may take a long time, and in the meantime, the needs of many disabled persons would remain ignored. They argue that community ownership of the programme, where people take on the responsibility for planning, implementing, sharing the risks of and monitoring their programme, is unlikely to be achieved in the foreseeable future. There is also a suspicion in the minds of many people, that the rhetoric of ‘community participation’ is used by governments as a ploy to abdicate their responsibility, because the taxes collected are spent...
on causes other than development. The opposing argument is that CBR is a developmental issue and as such, it needs to be initiated by the concerned groups themselves, who in this case are Persons With Disabilities and their family members (Miles 1999, Wemer, 1995). If it is externally initiated, the clients will continue to be passive recipients of services, with expectations of charity, without the initiative to manage their own affairs and to contribute to society.

Since people in developing countries are largely ignorant about consumer or ownership of development programmes, it is not feasible in most instances to begin the programme with full ownership by the communities (Thomas and Thomas, 2001). There is however, a possibility of striking balance between the two opposing arguments. CBR programmes will to motivate the local community to participate in their development to begin with, and over time, to shoulder the responsibilities of the programme. In this process, the community will gradually acquire the skills to take over their programmes as well. (Thomas and Thomas 2001).

**Will the Social Model of CBR ignore the real Rehabilitation needs of PWDs?** When CBR was initially promoted by WHO, it was to be integrated into PHC system, and thus many early CBR programmes followed a medical model which came in for criticism in the eighties as not being sensitive to all the needs of Persons With Disabilities (Lang, 2000). As a result, most CBR programmes evolved subsequently as separate programmes addressing an array of needs, in a comprehensive manner. The perception then, was that unless a special focus was given to disability, the 'specialised' needs of Persons With Disabilities would remain unmet (Thomas and Thomas, 1998). However, with the shift from a medical model to the social model, the emphasis today is on integrating disability into development processes. According to votaries of this model it is more cost-effective, and promotes better social integration, by ensuring that Persons With Disabilities have access to the same benefits and services as others in the community, unlike a 'specialised' CBR programme that concentrates on Persons With Disabilities and may actually isolate them from the mainstream (Scott, 1994). Community participation is likely to be greater in a programme that benefits the majority, rather than a minority group. At the same time, people fear that unplanned integration of disability into other development programmes can ignore rehabilitation needs, such as mobility, special education, vocational rehabilitation and so on. In turn, this can contribute to increased marginalisation of Persons With Disabilities, rather than their integration into the mainstream (Jones, 1999).

The last few years have witnessed attempts to integrate disability into community development projects that showed some tangible benefits, for Persons With Disabilities from the integration (Scott, 1994, Liton 2000, Thomas, 2000). Many problems were also encountered in this process. Lack of organisational ability and knowledge about disability, part of community development organisations act as a major barrier to integration. Disability is seen as a 'specialist' issue, and hence organisations feel that they do not have the expertise to deal with it (Jones, 1999, Thomas, 2000). Further, Persons With Disabilities tend to be recognised only by their disability and not by any other parameter such as gender, poverty level, ethnic status and so on. This results in their exclusion from the benefits of integration in a development programme. Lack of mobility, education and skills in Persons With Disabilities prevent them from being a part of development programmes, while expectations of charity and poor motivation on the part of Persons With Disabilities, contribute to their exclusion (Thomas, 2000). Integration of disability issues into development programmes implies high degree of co-ordination and collaboration between different sectors such as health, education, employment and so on. Often, such co-ordination works better at local, 'grass-root' levels, but fails at higher regional or national levels.

6. COMMUNITY BASED REHABILITATION [CBR]
Difficulties in multi-sectoral collaborations can be due to many reasons. In developing countries, programmes tend to be 'porous' and as a result, the different players in the field take time to trust each other (Thomas and Thomas, 2001). Secondly, there are differences in the management culture of government organisations and non-government organisations (NGOs), with the government operating in a top-down manner while the NGOs are usually 'bottom-up' and democratic in their management style. These differences can become a barrier to effective collaboration. Thirdly, under the cover of 'collaboration', members often try to gain control over each other rather than to work towards a common goal, and hence multi-sectoral collaborations get submerged in power and control issues between the different sectors. Lack of commitment to the goal from all partners, can also be a problem in multi-sectoral collaborations. Usually, a powerful minority controls the process while the rest are passive participants. As result, in many instances the decisions are finalised by the minority and the majority is left to merely endorse them. These issues need to be addressed and service development should be based on a comprehensive model, which includes both medical and social perspectives. This is more likely to meet the needs of Persons With Disabilities. Until such time however, it may be more realistic to pursue a plan that is most feasible in a given context, focusing on the goals of the programme as the central issue at all times.

Is CBR Expensive? If so, for whom? CBR was promoted to achieve wider coverage, at costs that are affordable. This was to be achieved by shifting rehabilitation interventions to families of disabled persons, thus reducing the financial expenses on institutions and personnel, and consequently reducing the unit cost of rehabilitation. To date, very little evidence has been gathered to verify or reject the perception that CBR is a cheaper rehabilitation option in remote rural settings, where costs in terms of time and transport have to be considered. However, even if CBR does reduce the financial costs of the service provider, a question, which must be addressed, is, who carries the burden then? In reality, the costs to consumers in terms of their efforts, time money, may turn out to be much higher than what it is generally believed to be (Thomas and Thomas, 1998). The 'cost effective' aspects promoting community-based interventions lie in the utilisation of community resources. These, often involve different community members who volunteer their time and efforts, to help and support disabled and their families. The volunteers are often family members themselves in which case another aspect for consideration might be the 'emotional cost' of this involvement. How to measure emotional costs, how to value or cost life itself, is difficult to contemplate, and how such information can be compared with a financial budget seems an impossible task.

The point then is, are the consumers are ready to take on additional burden of the costs of CBR interventions? Secondly, even if they are willing to do so, can they afford to do so? Many families in developing countries, who are struggling for their daily survival, feel that it is a waste of effort and money to address the rehabilitation needs of their children with disabilities, preferring instead, to spend on other children without disability in the hope that they would support them in old age. In an environment of increasing competition for resources, their reasoning is that unless the other children are well placed, they may not be in a position to support their disabled sibling in the future, especially since few protective social security schemes are available in most of the countries (Einar, 2001). Until some of these issues are addressed, it is unlikely that consumers would be ready to bear the costs of rehabilitation programme on their own.

Is CBR the answer for all Persons With Disabilities or only for a select few? It is estimated that 70% of Persons With Disabilities could be helped at the community level,
while the remaining 30%, comprising of people with severe and multiple disabilities, require specialist interventions that are not available in the community (WHO, 1981). Evaluations of CBR programmes in eighties and early nineties endorsed this view (Helander, 1999). With the change towards a social model that emphasised equity and integration, CBR as it evolved subsequently, began to address the need to include all Persons With Disabilities within its ambit of services. In reality, however, the desired level of equity has not been achieved, leaving out some sections of Persons With Disabilities. It is estimated that about 20% of the disabled population that requires interventions from a CBR programme are people with severe disabilities, many of whom would also have multiple disabilities (Rajendra, 2001). In poorer communities, the percentage of people with severe disabilities is low, as the families may not seek help for their survival. In some communities, mortality of children with disabilities reaches almost 80%, to a 'weeding out' phenomenon (Rajendra, 2001). However small their number may be, CBR programmes face many difficulties in dealing the impairment aspects of severe disabilities. Many programmes initiated by external agents, need to build a rapport with the community and show quick results. They often achieve this by working mildly and moderately disabled persons. As a result, people with severe disabilities tend to be left out from the interventions. Most CBR programmes also do not have personnel who are adequately trained to deal with this group. Sometimes, in the process of promoting 'community participation and 'rights' of disabled persons, the important needs of severely disabled persons get neglected. As yet, there are no valid methods to effectively address the needs of this group at the community level.

Women with disabilities are another group whose needs are not addressed by CBR programmes, particularly in traditional cultures. Although disability leads to segregation of both men and women, women with disabilities face certain unique disadvantages, such difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services which are dominated by male service providers (Thomas, 2001). Concerns of women with disabilities also tend to get neglected, in organisations of Persons With Disabilities that are usually dominated by disabled men. Even in women's organisations in developing countries they are first considered as disabled and then only as women. CBR programmes will need to develop appropriate strategies to address issues related to traditional, social and cultural perceptions. Strategies, such as awareness building, are needed to dispel misconceptions about disabled women’s gender roles, along with skills development training, to carry out their tasks and home adaptation where feasible. Training of women and CBR staff, provision of educational and employment opportunities for women with disabilities, sensitisation of women’s organisations and DPOs to include the issues of women with disabilities in their agenda, can all help to reduce the inequality between women and men with disabilities.

Can Volunteers in CBR ‘afford’ to volunteer? In an international workshop on CBR in 1998, participants from twenty CBR projects were asked to identify the major challenges facing them. Problems linked with community volunteers were identified as one of the significant issues by almost all the participants. The problems had to do with difficulty in finding new community volunteers, fast turnover of volunteers, need for additional resources for continuously training new volunteers, lack of motivation among volunteers, and need for paying incentives or small salaries to volunteers (Deepak and Sharma, 2001). The role of community volunteers is perceived as one of the major issues for CBR projects in different parts of the world, particularly in the light of current emphasis on ‘community participation’. There are examples of CBR programmes that have successfully used volunteers (O'Toole, 1995), but these probably are the exceptions, rather than the rule. The point of debate is can there be true voluntarism in developing countries where a majority of the population cannot afford to ‘volunteer’? The dictionary defines ‘volunteer’ as a person, ‘who voluntarily
undertakes, or expresses a willingness to undertake a service while having no legal concern or interest'. Thus, the term has a dual connotation, that of, 'own free will' and of 'without interest or payment'. Though the term 'volunteer' is used often in CBR, in reality, it covers a variety of identities and roles that do not conform the definition of the terms. Thus, there may be persons who have the time to dedicate to their chosen task, or may have some time in specific periods of the month or year, or may be available only for a limited period of time. In the last decade, with a move to market economies in many developing countries, most people needed to be paid employment to survive and are therefore less able or willing to volunteer. Those who do volunteer, often use their training and experience as a stepping-stone to paid employment. Under these circumstances, expectations of free work over a long period of time from volunteers, in the same way as paid CBR workers, may not be realistic or sustainable.

To conclude, after more than two decades of CBR in different parts of the world, many people believe that it may be an appropriate approach for Persons With Disabilities, in developing countries. But many controversies and questions remain about different aspects of CBR. If sufficient attention and resources are allocated to research in this field, it is possible that some of these questions may be answered in the coming decade.

Source:
6.4. LIFE CYCLE OF A CBR PROGRAMME

In the earlier sections it was attempted to understand the concept of community-based rehabilitation in the context of disability. One is convinced that CBR is one of the best and effective solutions for the development of Persons With Disability in India and other developing countries not just because of its cost effectiveness but also its over arching other advantages. This particular section deals with the processes involved in the planning, implementation, monitoring, perspective building, review, evaluation and holistic development of a CBR programme for Persons With Disability right from the beginning. This is a sincere and serious attempt to summarise the learnings of different CBR programmes, which have been initiated, implemented in different parts of this country. This is not a mere theory but actual grassroot experiences of Persons With Disabilities, care givers, CBR practitioners, professionals and activists who have been involved actively from the stage of conceptualisation, designing, planning, implementing, monitoring and evaluation. The best practices are documented during the process of implementation of CBR programme. The different stages of a CBR programme implemented and passed through in various organisations which implemented such programme are captured in this section. The processes which are followed in different projects in different parts of this country are summarised as follows:

Selection of target area: Selection of target area is the first and foremost step in the process of developing a CBR programme. To define a target area; it generally refers to an area where the agency actually carries out its operation which includes selection of target group, implementation of planned activities, interaction with community, provision of services to community, awareness generation, organising community into groups, and monitoring and evaluation of planned activities for the development of a particular community. In other words target area refers to a village/slum or a group of villages/slums where the actual work is carried out in order to fulfil the set aims and objectives of the agency to realise its vision and mission. Since this is the key step involved in the process of development of a CBR programme, selection is to be done very carefully. Following indicators will help to select a target area: level of poverty, available facilities, proximity to town, prevalence of disability, incidents of disability, existence of agencies, infant mortality rate, maternal mortality rate, frequency of outbreak of epidemics, drought prone, basic infrastructure, access to Government schemes and programmes, causative factors of disabilities and any other factor which are specific to that particular area.

Situational analysis: Once target area is selected it is important to undertake a situational analysis of the target area in order to write a proposal. This can be done in selected villages through sampling. The secondary literature needs to be reviewed in order to collect secondary data about the target area which is available in the form of publications, books, unpublished material, ledgers, registers, newsletters, journals, periodicals, reports, magazines and other forms. Primary data can also be collected in the sample villages by following both the conventional and participatory approaches based on various factors. Sampling must be drawn considering various variables, which affect the lives of that community. The variables include; proximity to cities and town, size of the village, rural and urban, caste, incidence and prevalence rate, density of population, general development and backwardness and other variables which are specific to that region.

Proposal development: Many agencies have their own proposal formats according to their funding policies and statutory requirements. It is important to note that proposal should be comprehensive, brief, clear, specific and relevant. Use of jargons, acronyms and unknown...
terms should be avoided. The objective should be defined clearly and specified how it will be achieved. Explanation should be provided how the issue falls in the purview of the agency. A comprehensive proposal format is presented as annexure No. D.1 which can be modified accordingly.

Selection of implementing team: Implementing team refers to a team of members who are directly or indirectly responsible for implementing the planned activities. Implementing team can be broadly classified into management, technical or professional team, mid level functionaries, grass root level workers and volunteers. While selecting a team of grass root level and mid level functionaries team following things should be borne in mind: The team members should be tenth plus or minus passed candidates for grass root level staff, twelfth plus or minus for mid level functionaries. There is no need to be rigid on educational qualification. Their attitude, aptitude, interest, knowledge, skills, commitment and other essential aspects of the work need to be assessed as skills and knowledge can be improved but not attitude and commitment. It does not matter if the educational, knowledge, skill level is poor, as they can be enhanced through education, training and reading appropriate books. Poor attitude and commitment can pose a problem. Preference should be given to candidates with disabilities and caregivers of Persons With Disabilities. It is advisable that volunteers, grass root level workers and mid level functionaries are selected from the target area so that they have a good understanding of socio, economic, political, cultural situations of that target area which is essential to work with the community.

Sensitisation and Orientation: Once implementing team is selected they need to be sensitised about the issue. An orientation programme should be conducted to make them understand about following:

a. Basic issues of disability and development: Attitudes, discrimination, exclusion, prejudices, poverty, disability and development

b. Basic concepts and perspectives of disability and development: Impairment, disability, handicap, rehabilitation, and models of disability, rights, responses and approaches

c. Orientation on disability: Orientation to Disability, types of disability, categories of disability, specific condition of disability, and degree of disability needs to be provided. They need to be sensitised about attitudes, conditioning, empathy, approach, needs, problems, limitations, potentials of Persons With Disabilities and other factors which play a major role in the development of Persons With Disability through community based rehabilitation approach. Help needs to be provided to them to develop sensitivity and positive attitudes toward Persons With Disability.

Enumeration of Persons With Disability: There are different approaches to enumerate/identify/survey Persons With Disability. One can use any one method or all approaches in different villages. Identification can be done through implementing team and a group of volunteers who live in the same village. If the volunteers are Persons With Disability it would be excellent. The volunteers need to be sensitised and oriented to essential issues of identification of Persons With Disability. Enumeration can be done through following ways:

a. Key informant survey: This method includes gathering information about prevalence of disability through key informants like formal and informal leaders, teacher, Anganvadi worker, health worker, Postman, Panchayat member and other key people of that village. A meeting with these informants should be organised and introduction to self, organisation, aims and
objectives of the organisation, aims and objectives of the project, role of the organisation and concerned self, role of community, Persons With Disability, care givers, state and other stakeholders should be clearly explained. No false assurances should be made and it should be explained that the organisation is there to help them to solve their own problems and issues. Discussions about Persons With Disabilities and their issues in that community should be held and a list of Persons With Disabilities living in that community collected. Once list is collected the house of that particular person needs to be visited and necessary information should be collected. A simple format can be used for survey. [Refer annexure No. D.2 for survey format.]

b. Door to door survey: This is general survey where every house is visited and information is collected. Same format along with additional format for families of Persons With Disabilities can be used.

c. Rapid Rural Appraisal [RRA]: This includes collecting information about prevalence of disability in a tabulated format. This is a quick process where lot of information is collected in a short period with less number of enumerators.

d. Participatory Rural Appraisal [PRA]: This can be conducted in sample villages in order to make a situational analysis of the entire target area. Along with identification needs assessment can also be done. Generic needs of Persons With Disability can be collected which may include education, employment, assistive devises, therapeutic services, social inclusion, marriage, recreation, social security benefits, group membership, access to buildings, public places and other services, social communication, awareness, political process and religious aspects and medical interventions. [Refer annexure No. D.3 for needs assessment proforma].

It is not always necessary to collect data of Persons With Disability through a systematic data collection method. Many agencies identify an active volunteer preferably Persons With Disability and motivate him/her to identify all Persons With Disability of a particular village and have a get together for the Persons With Disability. A process is initiated to organise them into Self Help and Advocacy Group [SHAG] and raise their issues in the group meeting and thus the needs assessment is done. Once group is established in the village Persons With Disability and their family members will come on their own and enquire about the group. They come with issues of their children and seek advice to solve it. This involves direct implementation of programmes without collecting data the formal way.

Awareness generation: Any CBR programme should be initiated with awareness movement. Mass awareness movement should be launched to sensitise, orient, break barriers and get informed about disability issues. Community should be sensitised, which includes Persons With Disabilities, their family members, and general community. Sensitisation can be done in different ways. Depending upon the need and context various methods can be used. Some of the methods are wall writing, community meeting, role-play, street play, film show, posters, puppetry, handouts, family visits, story telling, songs, Kērthana, and other traditional methods. Local mass communication media should be used effectively to raise awareness in that community. Since changing attitudes is a tough job and dead slow process this will be an on going activity through out the project span and after withdrawal also. Awareness generation programmes should target to changing attitudes and providing information about rehabilitation of Persons With Disabilities and prevention of disabilities. Prevention of disabilities is also an objective of any CBR programme thus awareness on prevention is also essential.

6. COMMUNITY BASED REHABILITATION [CBR]
Community organisation: Community should be organised into different groups as per the need. Community organisation aims at organising community into group so that it can function as integrated unit to achieve set objectives, which facilitate multidimensional development of that particular community. These community groups include SHAGs of Persons With Disabilities and their caregivers, parents groups, students groups, youth groups, mahila mandals, teachers groups, village leaders groups, service providers groups and any other group, which is relevant for the purpose. Following note will provide an idea on Self-Help and Advocacy Group [SHAG] of Persons With Disabilities.

The group members should be facilitated to formulate a constitution for their group. Ownership of any group should not be taken by the external agency. The ownership of any community based group should lie with the members. Implementing teams are only catalysts or change agents or facilitators to assist the change process. The members should be facilitated to raise and discuss the issues of Persons With Disabilities. Issues include, negative attitudes, environmental barriers, access to schemes and programmes and services, education, livelihood, marriage, recreation, companionship, housing, land and property, identity, assistive devises, therapeutic services, medication, medical services, pension, concessions, water, road, transport, sanitation, electricity, communication, environment and other issues which affect the lives of Persons With Disabilities and other community members. The issues should be prioritised according to the urgency. Issues like assessment, treatment, medication, assistive devises, which empowers the group, should be tackled first. Once the issues are raised and discussed in the meeting, responsibility should be shared to tackle the issues. Issues can be raised through individual needs and problems, which form the issues for the group. The resolutions passed to tackle the raised issues should be executed and status of the issue should be shared in the next meeting. Anything and every thing with regard to development of Persons With Disabilities should be discussed and tackled through group. Group must be a key player in everything that is done. There is nothing without group. This helps in strengthening the group. Meeting should be driven by issues rather than by solution. Issues help the members to unite together and sustain the interest of the members towards the group.

Self-Help and Advocacy Group [SHAGs] of Persons With Disabilities: Literary meaning of SHAGs is a group to help themselves. SHAGs can be termed as a group of like minded persons affected by one or more issues but whose cause is similar and whose objective is to help themselves. The primary objective of SHAG may be helping themselves but the ultimate objective is to promote the development of entire society.

Objectives: Organising self, lobbying, pressurising, influencing, self-help, promoting integrated development, tackling and addressing issues, rising and discussing issues, drawing the attention of community and policy makers regarding their own issues, availing entitlements, fighting for rights, promoting and protecting their rights and raising awareness in the community regarding their issues.

Characteristics: Smallness, voluntary and homogeneity are the salient features of SHAG.

Principles: The fundamental principle on which this concept is based is “all for one and one for all” or “all for me and I for all”. The other principles are co-operation, mutual-exchange, participation, shared responsibility, collective action and mutual respect.

Merits: Provides a forum for discussion, recreation, sharing, ideas, choices, support, help, power, education, opportunities and ventilation.
Sucesses: There is a wrong notion about SHAG that it is a savings and credit group among people since most of the groups are engaged in just credit activities, but it is not true. There are few SHAGs, which became credible voluntary organisations. Many SHAGs are managing banks, co-operative societies, rural development projects, milk dairies and small-scale industries. They are instrumental in promoting peace and harmony, ecological balance, literacy co-operative movement and rights of marginalised section.

SHAGs for Persons With Disability is not a new concept. If SHAG empowers other marginalised it can also empower Persons With Disability. This concept is very much applicable to Persons With Disability with some modifications. Principle caregivers represent severely and under aged Persons With Disability, in other words their family members will represent those who cannot represent themselves. They need to carry out different activities. Activities sustain their interest. It should be an action or activity oriented group rather than ideology-oriented group. Possible activities are: managing day care centre, educating children with disability, special coaching classes, providing therapeutic services, reviewing the progress of children with disability in their meetings, helping them to avail social security schemes, taking for referral services, admitting the children to regular schools, lobbying with local administration, raising awareness, promoting savings, providing loans, encouraging members to contest for local body elections, pressurising family members to provide proper care to Persons With Disabilities, organising different events like sports, drawing, drama, dance, music etc, organising exposure visits, observing national festivals, protecting environment, helping other marginalised sections like aged, widow, women, daliths and others to avail social security schemes, taking up the issues like water, transport, sanitation, electricity, communication, untouchability, bad governance and other mainstream issues and community health activities, participating in community development, contributing to the development of society, community and nation. These village level SHAGs can be federated at Panchayat, hobli, taluk, district, state and country level to form a strong confederation of Persons With Disabilities to influence, lobby and pressurise policy makers. More and more SHAGs of Persons With Disability need to be formed in order to promote their self-empowerment. There are about more than 5000 SHAGs of Persons With Disabilities functioning effectively in its true sense of self help in the different parts of the country.

Training and human resource development: Building the capacity of implementing team is an essential component of any CBR programme. Team should equip themselves to tackle the issues that come up in the course of implementation. Training curriculum should include issues on attitudes, basic concepts, basic issues, advocacy, communication, leadership, legislations, social skills, planning, organising, social or community mobilisation, networking skills, group management, facilitation skills, leveraging, services, rights and entitlements, medical rehabilitation, preventing, monitoring, review, evaluation and transferring skills or building the capacity of other stakeholders to tackle the issues. Training can be imparted in one stretch or in different phases. The training, which is imparted in phases, has proved effective since it provides ample time to practice the skills and knowledge gained through training. Sending staff for different refresher courses helps them to upgrade and update their skills and knowledge according to the changing trend of disability sector across the globe. Attending workshops, meetings, seminars, short-term training programmes, exhibitions and other events on disability and development enable them to broaden knowledge and skill base.

Professional's role: Disability is more a socio, economic, political and cultural issue but the role of medical rehabilitation cannot be ignored since this enables the person to improve their functional abilities. Medical rehabilitation is an important component of any CBR programme but it should not be whole and sole component. The role of medical rehabilitation in the trend
of human rights perspective cannot be ignored. Bringing disability under human rights perspective brings a new and holistic approach to disability and development but it should not sideline the timely and appropriate medical intervention. In a CBR programme, technical team constitutes of a physiotherapist, speech therapist, occupational therapist, orthotist, special educator, social worker and community organiser. There are different ways to bring the inputs of these professionals into the project: recruiting the team on full time basis, hiring them on part time basis, networking with specialised institutions, sending existing staff for technical training, block placement of students and volunteers. Once the selection of these people is over they should be sensitised towards attitudes, issues, perspectives, and human rights aspects. This is very important to prepare them to speak the language, i.e. psychosocial model of disability and human rights perspective of disability. Recruiting outside technical team for time being is good but one cannot depend only on outside technical team and it will not be a permanent solution for medical interventions. Sending the team members who graduate and have appropriate educational qualification and who would like to continue with project for a long time will be more appropriate.

Planning individual interventions: The main objective of the project is to improve the quality of life of Persons With Disabilities and facilitate them to empower themselves to secure, realise and exercise their rights and duties to life of dignity. Planning and implementing interventions is an essential component of the project. Individual intervention can be planned in different ways. Needs assessment done along with identification, issues raised in the meetings of SHAGs of Persons With Disabilities, survey and data collection will provide a base to plan individual interventions. Case study is a good and effective methodology to plan concrete interventions for individuals. Careful and complete study and observation of an individual will help to understand the needs, limitations, strengths, issues, aspiration, ambitions and interventions for that individual and will help to build a rapport. This rapport can be used to organise them into SHAGs. Case study is not a one-time process and continues till work with the individual goes on. Case study is a systematic process to understand the person. [Refer annexure No. D.4 for case study proforma].

Intensive interventions: It has already been discussed that issues or needs of Persons With Disabilities should emerge in self-help group meetings. Once the needs or issues emerge from series of meetings, consultations and dialogues; the role of different stakeholders needs to be decided to tackle the issues. The role of being only a facilitator or catalyst needs to be remembered. The role of project personnel is not to offer solutions but seek their suggestions to solve their own issues. Attempts will be made to change the system, which will suit the diverse needs of Persons With Disabilities and cater to the needs of all Persons With Disabilities. The programme should be initiated with medical interventions. Once the efforts are made to improve the mobility, communication, self care, functional abilities, accessibility and social skills; the next step will be to include the children with disabilities into mainstream education system. The existing infrastructure should be prepared to include the children with disabilities into their system. Preparations at schools should be made so that children with disabilities will have easy access to these schools. Capacities of the teachers of these schools should be built through training programmes, meetings, workshops and school visits so that they can handle children with disabilities. The schools should be equipped with appropriate teaching and learning aids so that learning will be interesting to not only children with disabilities but also other children without disabilities. Livelihood is an important issue of any marginalised group; disability is no exception. This is an issue, which has to be addressed effectively. Livelihoods of Persons With Disabilities in a CBR programme assumes top priority since economic development or economic independence of Persons With Disabilities automatically gives them respect, dignity, increases self esteem, confidence and acceptance of the family and community better.
Livelihoods in a CBR programme mean skill building, financial assistance and placement services. Prevocational training equips the candidates to undergo a particular vocational training. Vocational training can be imparted through regular vocational training centres, special training centres, local artisans like blacksmith, goldsmith, cobbler, carpenter, potter, weaver, tailor, automobile repairer, TV radio repair, motor winder, agriculturist, Seri culturist, petty shop owner and other artisans specific to that region.

After successful completion of the vocational training help needs to be provided to avail loan for the self-employment, which can be through local banks, financial institutions, disability welfare department, schemes and programmes general and particular to Persons With Disabilities. SHAGs of Persons With Disabilities can also lend to start self-employment projects. Educated youth can be placed in public and private sectors. Majority of Persons With Disabilities are engaged as daily wage labourers. It is important to convince the community and employers in particular that Persons With Disabilities can also be engaged in all types of meaningful and gainful livelihood opportunities depending on type of disability, degree of disability, interest and aptitude of that particular individual. When livelihood options are thought about the stereotype options like recanning, telephone booths, candle making, file making, agarbatti making and other occupations are taken into consideration. Persons With Disabilities are no different from others in all respects thus livelihoods should not be an exception. They need a meaningful and gainful livelihood options like anybody else to lead a life with respect and dignity in their society or community. Many Persons With Disabilities have demonstrated that they can also engage in all sorts of meaningful and gainful occupations. One can see Persons With Disabilities as wage labourer to white-collar jobs across the country and globe.

Entitlements: Persons With Disabilities should be helped to access or avail various social security schemes or entitlements, which are meant for them. The entitlements include, free or concessional bus passes, train passes, flight passes, scholarship, pension, insurance, loans, assistive devises, schemes, concessions, relaxations and programmes which help Persons With Disabilities to enhance self confidence level.

Perspective building: Perspective building exercise will help to have a long term perspective in line with the long term aims, objectives and goal. Perspective building exercise can be had in different intervals of the project span. It can be begun with the project initiation. A perspective building exercise can be had immediately after the situational analysis of the target area. Keeping the situational analysis as a base for the interventions, a project should be designed with clear-cut long-term perspective. The strategies, interventions, time frame, components and monitoring mechanism should be specified to ensure appropriate interventions. Second perspective building exercise can be held after the mid term review. This will help to incorporate the learnings of the review. Persons With Disabilities, care givers, external consultants, different stakeholders and other members could be included in the exercise. The third can be after few years preferably three years after mid term review. Incorporation of all the learnings and opinions of each and every member needs to be ensured in the perspective building process. The last exercise will be just before the withdrawal of the project. This will help the community and Persons With Disabilities to sustain and carry forward the great work that has been initiated. Perspective should clearly spell the strategies, interventions, roles of different stakeholders, monitoring mechanism, time frame and approach. This should also speak about vision, mission, change, impact and sustainability of the programme.
Networking, leveraging and alliance building: There is a great need to network, leverage and build alliance with different agencies, stakeholders and individuals to enhance the coverage and efficacy of the programme. Networking is necessary to exchange information, knowledge, skills, resources and influence and lobby with the state. Networking can be done with local NGOs, clubs, individuals, Government departments, CBOs, movements, campaigns, volunteers, hospitals, institutions, PRIs, banks, corporates, cooperative societies and other agencies and individuals who can contribute to the success of the programme.

Advocacy: Advocacy is an important strategy to influence, lobby, pressurise and activate existing Government infrastructure. It is important that Persons With Disabilities play key role to advocate for themselves. Advocacy can be right from village to country level and with different players like family, community, society, state, development agencies, corporates and other unilateral, bilateral and multilateral agencies.

Monitoring and evaluation: It is important to monitor a CBR programme effectively in order to achieve desired end results. An effective monitoring mechanism will decide the effectiveness and efficiency of a CBR programme. Monitoring in this context refers to keeping track of the planned activities in order to realise the vision and mission of the organisation in accordance with the aims and objectives of the CBR project. There are different ways to monitor a CBR programme. Some important ways of monitoring include, meetings, reporting, documentation and field visits. Monitoring is required at two levels; one at the project level and second at the individual level. The progress of the programme largely depends on the progress of the individuals. Monitoring mechanism can be designed at both the levels in order to balance the progress of both individuals and programme as a whole.

Meetings: Planning and review meetings can be conducted at different levels. The frequency of the meetings can be varying depending upon the level of meetings. Meetings can be weekly, fortnightly, monthly, quarterly, half yearly and annual. The annual plan needs to be divided into half yearly, quarterly, monthly and weekly basis in order to keep track of the progress. In the beginning of the project period weekly meetings can be organised for grass root level workers since intensive interventions need to be planned. Monthly meetings can be organised at the project level for all the team members in order to plan for the next month and review the work of previous month. Review and reflections should be continuous and not annual or half yearly features. Constant review and reflections will help the team members to make appropriate changes according to the lessons learnt. Meetings can be at different levels depending upon the need and importance of the outcomes of the meetings. The different levels include, grass root level workers, mid level functionaries, professional/technical team, members of community based organisations/groups, management, board members of the organisation, consultants and other stakeholders. Following are some of the patterns followed in different projects to plan and review the progress: Annual meeting for annual review and reflection for the entire implementing team, half yearly meeting for planning and review for the entire team, quarterly meeting for some members on some subjects, monthly meeting for entire implementing team to plan and review monthly planning and review, monthly meetings for technical team to review the individual progress, weekly, fortnightly, monthly meetings for grass root level workers to review and plan individual and project progress, monthly meetings for mid level functionaries to review and plan. Some of these meetings will be at project level and some will be at cluster levels.

Reporting: A good and effective reporting system should be put in place to keep track of the planned activities. Appropriate reporting formats will help the team to prepare systematic reports. Designing appropriate reporting formats will save time of reviewer and reporting
person. The type of reporting formats depend upon the nature of the project, nature of the interventions carried out and level of interventions. The frequency of the reporting will be weekly, fortnightly, monthly, quarterly, half yearly and annually. The NGOs are expected to submit their half yearly and annual reports to the donor agency. The information gathered from different stakeholders should be fed into this and thus a comprehensive report should emerge at the project level for the donor agency. This bottom up approach should be followed both in planning and reporting processes. Plans should emerge from community, groups, grass root level workers and implementing team so that a comprehensive plan emerges at the project level.

**Documentation and records:** Appropriate records will help the project to monitor the progress effectively. These records will serve as reference material for external and internal reviewers. Constant update of these records will help the implementing team to analyse the situation correctly. The important records include, individual case file, event register, reports, plans, filled review formats, movement register, registers and books to record different events and statistics, cash book, receipt book, meeting minute book, perspective documents, appraisal documents, review reports, evaluation reports and other important and essential documents according to the need and nature of the interventions of the project. Constant update of records and timely recording of the information into the appropriate records will help the project to review and monitor the interventions effectively and efficiently.

**Field visits or physical monitoring:** Field visits will help the reviewer to understand the ground realities. Some times the reports and records may not give appropriate and correct information about the progress of both individual and project. Frequent field visits will provide opportunities to the reviewer to interact directly with Persons With Disabilities; care givers, community and other stakeholders. It is important to involve every stakeholder in the monitoring process like planning and review and reflections process. Rapport with these stakeholders will help to gather appropriate and correct information. This monitoring system is like policing the implementing team. The presence of a particular member of the implementing team is recorded in a book called movement register and that book will be kept in project head’s custody. Reviewer can follow the movement register and understand the movement/presence of staff in the field.

**Evaluation:** Evaluation refers to collection, processing, tabulation, bifurcation, analysis, generalisation and inference of primary data in a given geographical area. Evaluation helps the project to understand the progress of the interventions carried out. Evaluation should give information about direction, speed, coverage, reach, and other aspects of the project. Evaluation can be conducted at different levels of the project span. The important levels include pre evaluation which will be conducted before undertaking any interventions to have base line data, midterm evaluation which will be conducted in the middle of the project span and post evaluation normally at the end of the project span. Different methodologies can be applied in the evaluation process. The important methodologies include, case study, *Focused Group Discussion* [FGD], interview, *schedule*, questionnaire, FRA, record review, review of secondary literature, technical assessment and other methods. The evaluation is conducted at different levels. The levels include, Persons With Disabilities, care givers, community members, volunteers, implementing team, management team governing board, service providers, technical team and others. Appropriate monitoring indicators should be developed to assess the impact of the interventions. Review is done against these monitoring indicators developed by various stakeholders of the project. Monitoring indicators can be input indicators, output indicators, process indicators, coverage indicators, outcome indicators, impact indicators and qualitative indicators. [Refer annexure No. D.5] for monitoring indicators.

6. COMMUNITY BASED REHABILITATION [CBR]
List of proposed activities: Here is a list of proposed activities which can be undertaken in a comprehensive CBR programme. This list is only suggestive and illustrative and not exhaustive. This is taken from different CBR programmes implemented in the different parts of this country by various organisations. These activities are not in chronological order and can be undertaken at a time or one after the other or hand in hand depending on the nature of the project and situation of the target area.

List of activities
Awareness programmes: Awareness on various issues and aspects of disability and development targeting different segments of the community using various methods like wall writing, community meetings, film shows, slide shows, puppetry, street theatre, role play, songs, story telling, hankath, poster, handbills, media, family meetings, school visits, sessions, lecture, demonstration, camps and other appropriate methods which are specific to that area.

Prevention: Immunisation to children against six killer diseases, immunisation to pregnant women against tetanus, antenatal care, health education on nutrition, timely and appropriate treatment for infectious and non infectious diseases, proper and timely medical check up of pregnant women, ensuring access to iron tablets, vitamin A tablets, nutritious diet of ICDS and other appropriate measures.

Early detection and identification: Identification of Persons With Disabilities through key informant survey, door to door survey, RRA, general survey, family visits, secondary data and other relevant data collection methods.

Processing of data: The data collected for the identification of Persons With Disabilities using various methods, should be processed and analysed to plan appropriate interventions. The data should be disaggregated with following details: type of disability, condition and degree of disability, age, gender, needy and most needy, percentage and other relevant details which are necessary for planning.

Needs assessment: The primary needs assessment is done by the grass root level workers through interviews, case studies, meetings of SHAGs, family visits and meetings to collect the general needs of Persons With Disabilities and specific medical needs is assessed by professionals.

Formation of SHAGs: Persons With Disabilities and their caregivers are organised into SHAGs to raise, discuss, tackle and address the issues of Persons With Disabilities.

Community organisation: The community in general will be organised into specific groups like parents, teachers, youth, women, leaders, service providers, women with disabilities, men with disabilities, children with disabilities, peer groups and other groups depending upon the need of the region.

Medical interventions: Activities to address the medical needs like, medical surgery, corrective surgery, cataract surgery, medication for persons with epilepsy, mental illness, medical assessment, X-ray, medical treatment and appropriate medical interventions.

Medical certification: Medical/disability certificate is a basic document, which provides a legal identity to Persons With Disabilities; if the degree of disability of an individual is 40% and above he/she is entitled to medical certificates. This basic document is necessary to avail social security schemes and other benefits of the Government meant for Persons With Disabilities. It does not mean that work is taken up with only those whose disability is 40%
and above. It is mandatory to a CBR programme to work with all those who need services. Medical certification is done through camps and directly visiting the appropriate authority. There is a provision of issuing ID cards in some states. Person should have either a medical certificate or ID card depending upon the rules, regulations and statutory requirements of the states.

**Therapeutic interventions:** Therapeutic interventions like, Physiotherapy for persons with locomotor disability, speech therapy for speech and hearing disabilities, occupational therapy for different category of disabilities, self care training for those who need skills, orientation and mobility training for visual disability, special education for those who need different skills and other appropriate therapeutic interventions.

**Assistive devises:** Assistive devises include, crutch, calliper, wheel chair, tricycle, brace, artificial limbs, gaiter, special seating chairs, upper and low level trolleys and appropriate equipments for persons with mobility impairments; mobility/white cane, magnifying glasses, low vision aids, spectacles and appropriate devises for persons with visual impairments; hearing aid, communication chart and other appropriate devises for persons with communication impairments. The list is not exhaustive but suggestive.

**Educational activities:** Integration to regular schools, non formal education, home based education, special education, preparation of teaching and learning materials, coaching classes, teaching Braille, lip reading, sign language, teacher training programmes and appropriate activities which enable the children with disabilities to get educated.

**Camps:** Camps can be conducted for various things such as assessment, certification, assistive devises and to get entitlements. There is an approach called single window approach where assessment, certification, measurement for assistive devises, income certificate, bus passes, scholarship and other entitlements are availed in the same place and same day.

**Entitlements:** Helping Persons With Disabilities to avail entitlements like, pension, scholarship, bus passes, train passes, loans, flight passes and other benefits offered by the concerned Government.

**Training programmes:** A series of capacity building exercises like training programmes, seminars, workshops, refresher courses and in-service training programmes for implementing team, training for parents, leaders, teachers, Anganvadi workers, ANMs, doctors, PRI members, youth and women group members on disability and development could be provided to enable them to take over the programmes.

**Exposure visits:** Seeing is believing. It is necessary to take implementing team and community members to visit different programmes implemented at various places to see and learn different aspects of disability and development. Taking members and leaders of SHAGs to different places for exposure to see successful SHAGs will be a motivating factor for them and learnings and best practices will be incorporated in their processes.

**Livelihood activities:** Activities for economic empowerment such as prevocational training, vocational training, self-employment loans, placement services, career guidance workshops and other relevant activities can be taken up to make them economically independent.

**Access:** Programmes to make physical environment accessible to Persons With Disabilities is essential. The activities may include, building ramps, railings, warning blocks, signatures, auditory signals, visual signals and other essential activities and modification and adaptations should be undertaken to make physical environment accessible.
Community based institutions: Community based centres such as day care centres for severely disabled, evening classes, information centres, resource centres, assessment centres, therapeutic centres, referral centres, games/play centres, vocational training centres and production centres can be initiated by the agency but the ownership should lay with community, right from the beginning so that it is easier to hand over the centre to the community when the external agency withdraws itself from the target area thus sustainability is ensured.

Political participation: It is important to ensure that the Persons With Disabilities participate in the political process of the state at various levels right from village Panchayat to general elections of the country. They should ensure that the agenda of Persons With Disabilities is included in the manifesto of the political party and candidate. It should be ensured that Persons With Disabilities exercise their vote with dignity and they can be encouraged to contest in elections. It should be noted that agency should be non political. It should not have affiliation to any political parties. Even Persons With Disabilities contest independently in the elections.

Advocacy initiatives: Different advocacy initiatives can be planned and implemented along with the community. Advocacy should be people centred and not agency centred. Advocacy can be at different levels right from the family to national level. Advocacy can be against state, community, unilateral, bilateral and multilateral agencies, international development agencies and state owned and state undertaking establishments. Mobilising large number of people particularly Persons With Disabilities is very important to demonstrate the strength of the disability sector.

Source:
1. SRMAB [1998] "Perspective document of Sourabha CBR project" ActionAid India, Kanakapura, Bangalore, unpublished

Conclusion:
This research makes a serious and sincere attempt to review the existing literature on CBR extensively. Many research reports, position papers, review reports, evaluation and impact assessment reports and perspective documents in India as well as across the globe have been referred to. Having attempted to review the extensive literature it is very important to cross verify it with the ground realities. There may be dozens of definitions provided by various agencies to this term or concept. The one revised definition of ILO, WHO and UNESCO seems to be more appropriate which needs further examining in the light of the fact that the concept of rehabilitation has limited meaning or negative connotation. After considering all the dimensions, issues, factors and facts the suggested working definition of CBR is as follows: “CBR means a set or combination of strategies within community development, for rehabilitation, equalisation of opportunities, promotion of holistic development, empowerment, full participation, inclusion and protection of human rights of all

6. COMMUNITY BASED REHABILITATION (CBR)
Persons With Disabilities through a combined, coordinated, concerted and collaborative efforts by all the stakeholders including, disability sector, state, private sector and NGOs”.

Global trends vis-à-vis the ground realities: CBR for Persons With Disabilities in a remote village of India means a process of facilitating enabling environment for inclusion, empowerment, full participation, promotion and protection of human rights, equalisation of opportunities, provision of services to attain self actualisation and human dignity. The questionnaire sent to pioneers indicates some key words for redefining this concept which include, “inclusion, rights, opportunities, participation, poverty reduction, empowerment, access, barrier free environment, equality, equity, right attitude, coordination, collaboration, inclusive approach, comprehensive approach, combination of strategies, acceptance, holistic development; multisectoral, dimensional and disciplinary approach and contextual model”. The primary data points out that 62% of respondents strongly feel that identity, dignity, human rights, inclusion, solidarity, wider coverage, participation, equity and need based should be the key principles of any CBR initiative.

62% respondents with and without disabilities strongly agree that policy influencing and advocacy; community awareness and organisation; networking, leveraging, linkages and alliance building; capacity building, transfer of skills; inclusion and empowerment should be the key strategies of any CBR approach. 79% say that awareness building, changing attitudes, poverty reduction, basic rehabilitation services, specialised interventions, medical interventions, prevention, livelihoods, education, and formation of SHAGs, strengthening disability movement, political participation, skill building and development activities should be the key components of a CBR programme. 64% respondents with and without disabilities strongly feel that the social or rights model with an optimum balance of medical, basic rehabilitation and specialised services and rights will be an effective and comprehensive model of CBR. 92% respondents with disabilities and communities strongly feel that community can manage a CBR programme after 7-8 years of external financial and technical support to an extent of 62% and 35% respectively according to Persons With Disabilities and community’s response.

45% of the pioneers feel and 31% strongly feel that the 5-7 years should be desirable to facilitate the process where community takes over and manages the programme. 50% of the pioneers strongly feel that community taking over and managing a CBR programme means that community facilitates the process of inclusion effectively. This fact was further substantiated by saying that 100% Persons With Disabilities, families and communities strongly feel that they have a role and had role right from planning to evaluation and contributed to the extent of 66% in the success of the CBR initiative. 98% respondents with disabilities and communities strongly feel that CBR is one of the effective and best approaches to disability with significant impact in the region. It is evident from the primary data that 62% of the pioneers, 99% of Persons With Disabilities, their families and 100% communities strongly feel that intensive micro CBR initiative should have extensive impact at macro level. The fieldwork substantiates the fact that the CBR programme has its extensive impact on neighbouring blocks and through the district. This was further reinforced with the strong agreement of 99% of Persons With Disabilities and families, 100% of the community respondents, that the CBR initiative had its extensive impact across the block and neighbouring blocks.

100% Persons With Disabilities and families, communities and 48% pioneers feel and 36% strongly feel that community based institutions should be one of the components of any CBR for intensive and respite care of needy. 50% pioneers strongly feel that IBR and CBR can be complementary to each other. 57% of the pioneers strongly feel that CBR is not just a
compulsion but one of the better options to a country like India due to its overarching advantages over other approaches. As far as the role of different stakeholders is concerned, primary data reveals that Persons With Disabilities have first, family second, community third, external agency fourth, state fifth, professional sixth, donor agency seventh and private sector eighth place. 99% Persons With Disabilities, families, 100% communities and 57% pioneers strongly feel that state has a prominent and primary role in facilitating the process of change and inclusion of Persons With Disabilities. Majority of respondents with and without disabilities strongly feel that SHAGs and DPOs have a key role in this process. 72% of the respondent stakeholders feel that politicisation of the issue of disability with active participation of Persons With Disabilities in the state politics would bring significant changes in the sector in general and in the lives of Persons With Disabilities in particular. 100% of the respondents with disabilities and families, 83% respondents of communities and 40% pioneers feel and 43% pioneers strongly feel that exclusive SHAGs of Persons With Disabilities are essential to address the issues at grass root. This has been proved through effective functioning of more than 25 SHAGs of Persons With Disabilities and families in the target area.

Exclusive SHAGs of Persons With Disabilities are essential in a CBR programme. It does not hamper the process of inclusion with the strong agreement of 40% of the pioneers during the research. This fact was substantiated with the ground reality that 82% of the respondents with disabilities and families are associated and linked with SHAGs at village and federation at block level which accelerated the process of inclusion effectively. However few pioneers feel that these homogeneous groups may be counter productive due to various reasons and lead to exclusion. It is evident from both primary and secondary data that a CBR programme should have four elements or imperatives namely Poverty reduction, Rights, Inclusion and Equalisation of opportunities. The key principles should be identity, human dignity, human rights, individuality and inclusion. It is evident from the primary and secondary data that CBR is not only a compulsion but a better option for a developing country like India due to its overarching advantages over other approaches with a strong agreement by 64% of the respondents. 79% of the respondents strongly feel that CBR is not a single approach in itself but includes a set/combination of strategies, approaches, responses and solutions with adequate flexibility and space for innovations depending on the context and culture. 64% respondents strongly feel that a CBR initiative should cover or include all Persons With Disabilities with different categories and degree without excluding a single person in a given target area. 79% strongly feel that medical rehabilitation component should be an essential and desirable service component of health care system of the state at all levels depending on the specialisation.