CHAPTER - 5

CHALLENGES VERSUS RESPONSES
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Introduction:
It is estimated that there are about 600 million Persons With Disabilities in the world. Out of this 420 million [70%] live in developing countries. 336 million [80%] of them live below poverty line. These facts are also true of India. Persons With Disabilities constitute 5.21% of the total population and 80% of them live below the poverty line. It is quite often remarked that they are a sizable invisible minority of this country and are neglected and discriminated since ages. There are several social, political, cultural and environmental reasons for such discrimination. Welfare, charity and relief oriented approaches to disability and development result in making them dependent, alienation and self-estrangement. A combination of these factors attribute to the powerlessness, exclusion, degradation, dehumanisation, marginalisation and ostracisation of these people.

This particular chapter deals with the historical overview of rehabilitation and different approaches, and responses to disability and development right from the beginning. The term rehabilitation literally means restoring optimum levels of functional ability of a person and other related factors in the communities. Different agencies and pioneers have defined Rehabilitation in different ways. Following are some of the important definitions of this term which can be examined in the context of holistic development, empowerment and meaningful and effective inclusion of Persons With Disabilities.

5.1. REHABILITATION

The original meaning of the term `rehabilitation' is "to restore a person's dignity and/or legal status", and now as before this seems adequate. But the scope of the term has changed a development that has been noticeable in the industrialised and developing countries over the last 40 years, in phases suggested below.

Phase 1: Concept focusing on Persons With Disabilities individual: An example of a definition focusing on the individual is the WHO definition of rehabilitation (1969) offered by an expert group "... the combined and coordinated use of Medical, Social, Educational and vocational measures for training or re-training the individual to the highest possible level of functional activity". Taking advantage of the welfare system it is reported from Holland that about 13% out of the labour force, or some 9,00,000 out of six million, are registered as unable to work for mental or physical reasons. In 1990, 116,000 people were recognised as disabled. For one third of those, the cause was stress. The people at work in Holland support a large number of non-workers. For every 100 workers there are 86 others who receive disability pensions or other government grants because of unemployment in the industrialised countries. The system is now under reform. The same is true of the Scandinavian countries. Sickness benefits based on self-declared inability to work, which amounted to 80-96% of the take-home salary, are cut. In several countries in northern Europe, the average annual time on sick leave was about weeks until a few years ago - the healthiest countries in the world had the most people off sick. The welfare system has not only tempted workers to stay home when just feeling "tired", it has also been taken advantage of by employers who, when their profitability is somewhat close to the margin, have deliberately moved large groups of workers over to the benefit system. The scenario in developing countries is reverse in the sense that a small portion of Persons With Disabilities have access to state social security programmes and a large number of Persons With Disabilities have been striving to get employment.
Phase 2: Concept recognising the importance of physical barriers in the environment: Professionals early on recognised the role that environment plays in rehabilitation. This was of particular importance for people with moving problems. They encounter difficulties climbing stairs, passing through narrow doors or passages, using ordinary bathrooms and kitchens or public means of transportation, or moving outdoors on steep hills or in the terrain. Other problems concerned people with impaired vision, having difficulties in crossing roads, entering transport facilities, orientation in shops, receiving information via newspapers etc. People with hearing difficulties were at a disadvantage in road traffic, communicating in shops, public offices and courts. As these problems were realised, rehabilitation programmes in the industrialised countries started including interventions aimed at adapting the environment. New architectural norms for housing were issued. Buses, metros and trains and entrances to public buildings were specially designed. Special traffic signals were provided for people with poor vision. Braille signs were put up in elevators and interpreters were provided for deaf people. Until now only a few industrialised countries have more or less completed these changes. For others the main efforts are still to be made. But today these adaptations in the physical environment for each individual, as well as general change are considered an integral part of a rehabilitation programme. The situation in developing countries is pathetic since almost all public places and transport are inaccessible to Persons With Disabilities even today.

Phase 3: Concept related to equalisation of opportunities: This term was introduced in 1981, and to quote the definition, which appears in the Manifesto of Persons With Disabilities people's International [DPI] "Equalisation of Opportunities means the process through which the general systems of society, such as the physical environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all". Regulations or laws excluded children with disabilities from inclusive schooling; others barred adolescents and adults from access to vocational training and jobs. There was reluctance to socially integrate Persons With Disabilities into public services, housing, transportation, leisure, sports, workplaces, etc. Authorities often sought "special" solutions in terms of separate facilities for living, sheltered workshops for work, special medical, educational and vocational services away from the mainstream, and so forth. The concept of equalisation of opportunities served to draw attention to the widespread discrimination experienced by all Persons With Disabilities in all societies. The World Programme of Action Concerning Persons With Disabilities (U.N. 1982) and the U.N. Standard Rules on the Equalisation of Opportunities for Persons With Disabilities (1994) are now major global policy instruments.

Phase 4: Concept focusing on human rights: The term 'equalisation of opportunities' is cumbersome and is poorly understood by many people in the developing countries. It does not fully express the new orientation sought. Opportunities should be provided in any case on an integrated basis and not separate from the "mainstream." The term reflects the development debate during the 1970s and 1980s. At that time, more equitable opportunities and full participation were sought for many disadvantaged groups, such as women, minorities, special ethnic groups, the rural poor and slum-dwellers. The concept was applied also to Persons With Disabilities. Another important concept - which is not identical with the preceding one - relates to "equal access to and distribution of resources". New mottoes were created, e.g. "new economic order," "health for all," "education for all". The vital question of human rights for Persons With Disabilities is being considered having gone beyond these concepts. Compared to the terms mentioned above, "human rights" is a much more general term, and it is better known worldwide. Also, it expresses more fully the direction sought for development programmes in favour of Persons With Disabilities. For what appears to be
political reasons, the term human rights were for a long time not sufficiently promoted. But in
the wake of constitutional reform and democratisation - many governments of developing
countries have become more receptive to proposals that openly promote human rights.
Efforts to promote and protect the human rights of Persons With Disabilities are seen as one
of the corner stones of the Community Based Rehabilitation [CBR] strategy. Such rights are
described in the UN Universal Declaration of Human Rights, as well as in the constitutions of
most countries. These legal instruments spell out number of rights that apply to "all citizens."
To conclude, this research has chosen in this work to widen the term rehabilitation to
encompass
• all interventions/training provided to Persons With Disabilities individual,
• all changes/adaptations in his/her own local physical environment,
• all general changes needed in the environment in order to diminish or eliminate barriers
for Persons With Disabilities,
• equalisation of opportunities provided on the basis of integration and inclusion,
• promotion and protection of human rights and empowerment.
The operational definitions of 'rehabilitation' are discussed below:
1. Rehabilitation is a process of enabling a Person With Disability to reach or maintain
optimum physical, sensory, intellectual, ophthalmic, social and self actualisation levels
with appropriate education, training, assistive devises and appropriate access. [UNO]
2. Rehabilitation is a process of change that occurs in an individual towards better quality of
life and better social acceptance in his/her community. [Thomas and Thomas 2004]
3. Rehabilitation is a process of restoring the optimum abilities of a person to lead a life with
dignity. [NCDD]
4. Rehabilitation includes all measures aimed at reducing the impact of disability for an
individual, enabling him or her to achieve independence, social integration, a better
quality of life and self-actualisation. [Einar Helander 1993]
5. Rehabilitation includes not only the training of Persons With Disabilities but also
interventions in the general systems of society, adaptations of the environment, protection
of human rights and empowerment. Protection of human rights is an obligation for the
authorities of each country, for its communities and for every citizen. Persons With
Disabilities shall have the same rights to a life in dignity as others, and there must be no
exceptions. Special attention may be needed to ensure the following: Access to health
and social services; to education; ability training and income generation opportunities; to
housing, transportation and to buildings; to information; to cultural and social life,
including sports and recreational facilities; to representation and full political involvement
in all matters of concern to them. Finally any measures, actions, activities and
interventions carried out to empower Persons With Disabilities are the part of
rehabilitation process.

Source:
1. Einar Helander (1985) "Prejudice and Dignity" [A handbook for CBR practitioners on An Introduction to
CBR] United Nations Development programmes (UNDP), New York, USA.
2. www.asksource.org
3. www.iddc.org.uk

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5.2 THE CONVENTIONAL SYSTEM

This section deals with the conventional, still existing system for rehabilitation. The description is based on visits made to a large number of institutions working with Persons With Disabilities and secondary literature reviewed for this research. It also draws on the discussions with central and local authorities, professionals, representatives of organisations for and of Persons With Disabilities, international development and donor organisations and local non-governmental organisations; experience gathered during the visits by Einar Helander to several hundreds of centres, institutions, schools, training centres, hospitals and so on, as well as to hundreds of small rural communities and marginal urban settlements. The description is also based on the reports and documents which were received and insights obtained from interviews with Persons With Disabilities and their families in their homes.

1. Policy approaches: The first subject for review concerns policies of interest to Persons With Disabilities. Each country has a number of general policy statements, of which the constitution is the most important. Often the constitution was adopted after decolonisation, formulated in modern terms and revised in the light of more recent reforms. The constitution generally lays down the rights of all citizens: to education, to work, to public services, to freedom of association and expression, to legal protection, and so on. It may sometimes include passages relating to Persons With Disabilities, where it is stressed that they share the same rights or that they should be given the special services they need. The activities of each government sector are regulated by specific laws, decrees, and rules or similar, based on the constitution. To give an example, the parliament, at the initiative of the Ministry of Education, may approve policies and legislation governing education, training of teachers, curricula and examination procedures. These instruments may include guidelines on how to educate children with disabilities and adults. Some policy documents are specific and exclusively concern Persons With Disabilities. For example, numerous countries provide welfare contributions and/or assistance in the form of transport facilities or higher school allowance rates for children with disabilities. Many have also special labour regulations such as quota legislation or sheltered-workshops, subvention schemes in respect of orthopaedic appliances, and so forth. Or the country’s social security system may provide for workmen’s compensation, rehabilitation services, etc. Finally, there exists today a wide range of international resolutions, conventions, declarations that may or may not have been ratified and implemented by a particular country. However, policies related to Persons With Disabilities often fail to achieve their goals. This is because:

(a) implementation of such policies is inadequate or non-existent. Most governments have not done enough to inform their citizens about their rights and their duties. In addition, there is a deficiency of administrative, political and service structures to ensure the implementation/enforcement of the relevant policies;

(b) policies related to Persons With Disabilities are seldom integrated and consistent because of the lack of clearly defined general political objectives in this area.

2. Planning approaches: Few countries have any detailed medium or long term plan as to how needs of Persons With Disabilities are to be met. Some of the plans often fail to address the problems as a whole in a realistic way. Nor have they set precise targets in terms of population coverage. External donor or development organisations which set up or contribute to services - sometimes in co-operation with the government or with a national non-governmental organisation - are not receiving enough guidance. The lack of government planning contributes to the haphazard and uncoordinated use of the resources set aside for Persons With Disabilities. External initiatives clearly suffer from a lack of co-ordination at the national level. As a matter of fact, some countries have attracted over a hundred different

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small projects each, most of which are planned and executed in ways that leave much to be desired. With a clear plan to follow, governments could redirect the use of external funds. Better planning will yield long-term benefits, as services and other facilities will be set up, which are economically and professionally maintainable. In addition one would expect that they will better fit into the pattern of general socio-economic and human development.

3. Types and structures of conventional services: It is an attempt to review the types and structures of existing services. The conventional systems of services exist in many different forms like:
- rehabilitation centres, usually for one category of Persons With Disabilities;
- orthopaedic workshops, some also produce wheelchairs, crutches or ADL appliances;
- outpatient clinics for physiotherapy and occupational therapy;
- ordinary hospitals, which may have a physiotherapy department designed for acute patients (with fractures, stroke, post operative treatment, etc.);
- rehabilitation hospitals, sometimes with their own department of orthopaedic surgery, an orthopaedic workshop and wards;
- special schools or integrated special classes and/or ADL training centres, e.g. for blind, deaf, physically disabled or mentally retarded children;
- vocational centres, almost none of which have facilities for assessment, so the main thrust is for training;
- sheltered workshops and co-operatives for Persons With Disabilities;
- psychiatric hospitals, where one might find large groups of mentally retarded, autistic or epileptic children/adults, and patients with chronic mental illness;
- leprosaria, for patients undergoing leprosy treatment. Some of them are sent home after the treatment, others remain for a lifetime;
- orphanages, where most children stay for only a short while (before being adopted). But children with disabilities often remain until they have reached maturity, because few people want to adopt them;
- beggars' homes or detention centres, where disabled beggars (after being rounded up by the conventional system- and removed from the streets) may stay for very long periods of time;
- rehabilitation services, which form part of another activity, e.g. those of an ophthalmologic assistant in a district hospital, who may train blind people, or that of a bicycle manufacturer producing wheelchairs. The services are provided either in boarding or in day centres and mostly to be found in the capital. Some have made attempts to set up an outreach programme.

4. Origin and funding of conventional services: The beginnings of some of the services go back to the 19th century. But most of them are the result of expansion since World War II. Many early services for Persons With Disabilities in developing countries were started by religious organisations. Missionaries and others observed the large number of Persons With Disabilities everywhere and began looking for ways of helping them. They called experts and professionals to design services and, in the early phases of development, these services tended to be copies of institutions in the industrialised countries. Such services multiplied and became the standard pattern. In the years to follow, one trend was to train nationals in certain well-established centres in the industrialised countries. Some of the returning professionals successfully convinced their governments to set up or, at least, to support a national centre in the capital. In a handful of countries, the government created decentralised services, e.g. on a regional basis. Many non-governmental organisations followed suit, providing special services for small groups of Persons With Disabilities, the majority of them children. Support also came from multiple and bilateral donors. Today, thousands of different service providing projects receive external funds. The funding of existing services is mixed.

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In the beginning, many facilities were built and equipped by funds provided by foreign donors, and the personnel consisted of the major part of expatriates. Most donors now try to create, or get in contact with, a local organisation prepared to take over management and funding of the services. Nationals later on often replace expatriate staff, which helps to reduce costs. After a while, the national or local governments may start contributing funds, on an initially rather symbolic scale. Some services have been set up by social security funding, but in most developing countries these cover but a small proportion of the population. It is not easy to calculate the amount of funds currently used for providing services for Persons With Disabilities in the developing countries. The total amount spent by external contributors (multi-lateral, bilateral and international NGOs) is at least US$ 300-400 million annually. National governments, social security systems and NGOs spend probably over US$ 100 million for rehabilitation annually. This would bring the total to something in the order of US$ 500 million a year. But this is a conservative estimate. Using another approach, one could, for instance, calculate that about 2 million Persons With Disabilities receive services (funded either by local or external donors or by their own government) at an annual cost conservatively estimated at US$ 500. Then the total comes to US$ 1,000 million per year.

5. The gap between needs and available services: To judge from country visits by Einar Helander and reports, the number of Persons With Disabilities throughout the developing countries known to receive organised, active rehabilitation functional training, receiving special education or undergoing preparation for jobs was estimated to be about two million in 1998. In other words, about 3% of the requirements for rehabilitation calculated have been met. Others were given care by the family, a proportion of who were receiving effective "spontaneous" training. Still others had been integrated in local schools or were earning an income. In the past few decades, the provision of rehabilitation has been lagging behind the population growth in many developing countries, where the combined effects of economic stagnation, high birth rates and structural problems tend to widen this gap. Still others stay in institutions, which have little to do with rehabilitation and more with "storage". The following three factors may help to explain what gave rise to this gap of some 97%.

(I) Costs: Cost estimates in a number of conventional rehabilitation centres of acceptable quality in developing countries vary between US$500 and US$5,000 per Person With Disability per year. Based on this, the annual cost (including capital costs, administrative overheads, etc.) could reasonably be assumed to average roughly US$ 1,000 (or about US$ 3 per day). If conventional services were to be provided for all those persons with moderate and severe disabilities, conservatively estimated at 70 million, who need rehabilitation programme, the price tag would amount to some US$ 70 billion annually. This has made many decision-makers reluctant to embark on anything but small-scale services.

(II) Personnel: In a large number of developing countries, there is a serious shortage of professional personnel. Many countries lack schools, while in others trained personnel "disappear" into the private sector or immigrate to countries which offer better salaries or career prospects. In most countries the professionals remain in the capital and prefer to work in institutions. In addition, the "early expatriates" may have contributed to the problem. When their profession was introduced in the developing countries, they frequently insisted that there should be no change in personnel policies, in distribution of tasks between various categories of personnel (working as teams), in duration of training, and in curricula. This considerably increased the price for providing rehabilitation. It is hard to conceive of a better way of blocking the setting up of public services for 50 Persons With Disabilities in the developing countries; and a more effective instrument to make governments delay even the necessary policy decisions.

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(iii) Public perceptions: The service gap is partially due to the perception that rehabilitation does not bring about any significant change in the life situation of Persons With Disabilities, that services are very costly and they require a large number of qualified professionals. At the origin of this perception is that, for a small group of severely disabled individuals, the situation is too grave to allow for more than marginal improvement. Some conventional institutions, which concentrate on functional training and segregated special education, have also had a part in forming such perceptions. Many of them have not had appropriate programmes for the social and vocational integration of their clients; in such centres Persons With Disabilities remain "for ever". Another part of the explanation of the lack of services is prejudice. Persons With Disabilities are a low status group with few "political resources", subjected mainly to charity-generated care, and this has slowed down the provision of the public services needed. The international efforts to provide services for Persons With Disabilities in the developing world have had a significant influence. The importance of what has been done by all those dedicated workers who, in spite of all the negative reactions and the difficulties encountered, managed to get a service off the ground must be recognised. Their achievements may be summarised as follows: They demonstrated that Persons With Disabilities are able to take care of themselves, to learn as well as teach others, to work and to earn an income; they created awareness of the fact that disability is a common problem and that next to nothing has been done about it; they encouraged nationals (governments and NGOs) country or the location. Helander feels this to be immaterial. The situation varies, of course, considerably from country to country. But when it comes to type of problems they do not differ much. Nor are the situations described in the following text unique to rehabilitation. Many other development projects (e.g. in agriculture, education, health and transport) have their share of similar problems.

6. Several important problems with the conventional system: The relationship between the family and the Persons With Disabilities is often broken, and those admitted to a centre have no way out; the costs are very high, and there are few chances for the system to be taken over by national authorities/NGOs without a major loss in quality, so the donor has no way out. "Tie the hands of the children so the personnel can watch TV in peace". In 1989 a UN expert visited a centre for mentally retarded in an Asian developing country and reports the following: "... there is no consistent program of activities proposed to the children: besides eating and bathing, there are no activities where the children are actively involved; they are placed in a large room, without any stimulation of any kind, where they spend their time moving around, or sleeping on the floor, or indulging in self-stimulatory behaviour, until next feeding-time or bathing-time. Moreover, there is no furniture in the room besides a floor-rug. In order to prevent self-stimulatory behaviour, some of the children are either tied down all day long in their beds, or have their hands tied back. Occasionally, one of the care-takers interferes to take one or two children to the bathroom. Two or three times over a period of three months, the children were taken to the "club-room", another room on the same floor, over-equipped with decorative items and dolls. This room contains a video-set, but it was noticed that the video-system was never used; instead, regular television programs were put on for the pleasure of the care-takers." The relationship between the care-takers and the children is very distant: there is no corporal contact other than for punishment purposes, or for accompanying the child to the bathroom or to his bed." Other remarks in the same report are: "... The services offered ... are merely at the level of boarding. No attempt has been made at implementing any systematic educational training program to clients. The staff directly involved with the children is not competent. There does not seem to be any control or follow-up of the staff performance" ...There is no clear-cut job-description to identify the proper responsibilities of each of the personnel, a factor which is
greatly responsible for the general chaotic atmosphere. "The total lack of parental involvement in the training process of the clients: some of the children have been institutionalised for years [average time 8 years and 3 months] without any parental visit."... The structure of the programs for another institution in the same country was designed to fit the needs of the teachers for frames and forms rather than the actual priorities and needs of the children they are supposed to serve. In addition, there does not seem to be any planned program for the future of the clients served today."

"Abuse in an institution" A physically disabled expatriate went to an African country and through contacts in his home country obtained funds to open a "home" for disabled adolescents. He rented a large villa and had some simple boarding houses set up on the land. After a few years had "collected" a dozen disabled boys, who were lodged and fed. He employed some help to look after them, but there was no rehabilitation programme. By court order, he had also been made custodian of four or five young male criminals, who were out of jail. These were not disabled. One day the expatriate suddenly had a fatal accident. The local church, which had given some economic support to the "home", decided to take it over and employed a young couple to look after the boys. When they went through the belongings of the expatriate, they came across his diary. In it he had recounted his sexual experiences in great detail with all those who had been in his care. Interviews with the boys confirmed the story. The boys said that they had never dared to say anything or complain, for the expatriate had threatened them of being thrown out to the street or sent back to jail. Besides they did not think that anybody would believe them - the expatriate had an excellent reputation and good connections with a number of high-ranking officials.

Following instance explains some of the problems encountered by orthopaedic workshops. Many people ask why this technology is so rarely functioning well, while highly sophisticated manufacture of computers, television sets, cars, ships, jewellery, watches and so on in some of the same countries are done with excellent quality. This may be explained by the following facts:
- training is inadequate, supervision and quality control (by professionals and by the Persons With Disabilities who receive the appliances) are lacking; one of the main problems is the lack of understanding of biomechanics such as alignment.
- staff is not well paid and hence not well motivated for the job;
- presence of severe production problems, such as lack of materials and spare parts, rehabilitation materials and assistive devises.
- breakdown of machinery, power and water cuts, with the personnel eventually acquiring a resigned attitude to work; control of the means of production is to a large degree out of their hands;
- costs are high; very few people can afford to pay for their appliances, even if only in part; the subvention system often breaks down or is inadequate;
- the authorities who should help to correct problems and provide/import materials and spare parts consider this activity as a low priority, so the delays are long - sometimes years.

"On orthopaedic workshops" Einar Helander visits over one hundred orthopaedic workshops, in some sixty developing countries. Millions of dollars have gone into equipping them as well as into the training of thousands of technicians, who should be able to do a good job. No other technical area of rehabilitation has received so much external support. Yet the output of these workshops is lamentably low, very often not more than 10% of the potential output, some of the products being of acceptable quality, others a far cry from it. And another big problem is alignment - a poorly understood subject. The picture that presents itself is almost invariably that of a very run-down building, full of old, costly machinery, most of it in a state of disrepair; and with technicians who for many reasons are unable to master the technology.

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There are some good examples, such as the highly effective and attractive workshop managed by expatriate staff that Helander sees in an African country. Another one, in Latin America, that had an excellent staff and well-kept machinery in spite of a leaking roof. "The building had not been repaired since they moved in 25 years ago, so the floor was covered by five centimetres of water, and we had to step on bricks placed here and there to move about. But this Centre had no materials for the appliances because government "savings" measures and inflation had reduced the budget to well-nigh zero. About the fact that they spent most of their time producing spare parts for private vehicles - a way of complementing their meagre salaries of a few US dollars a month. Here the machines were in very good order. This was meant for military for their soldiers. This one was highly efficient and low-cost, turning out excellent products, with a network of 20 annexes covering the whole of the country. It was all paid for through the army budget. In another workshop visited by Helander in Asia, they made no secret of the inadequate machinery and inefficiency of the workshop. And yet another one comes to mind - a workshop run by a leading physician in another Asian country had the idea of producing all the required modules for the entire country in a central industry, from where they were then sent out to annexes for fitting and local alignment. Although run by a retired general, the undertaking turned out to be a costly flop. There are some examples of efforts to manufacture appliances using low-cost technology, e.g. by having them produced by local blacksmiths or by introducing production relying exclusively on simple tools/equipment that can be totally controlled, requiring no or few external inputs. These techniques are as a rule more productive than the "conventional" ones.

"Some do it expensively, with not much result" This is a vocational training unit for about 25 mentally retarded adolescents in an Asian country. Some of them come from the neighbourhood and go home every day by a special bus. Others come from far away and are boarding. The trainees are taught carpentry. They have four well-trained instructors. The Centre is equipped with several expensive pieces of woodworking machinery. But these are not used, for the trainees could not learn how to operate them, and besides, they were potentially dangerous. The training consists of sawing and drilling by hand and of polishing various pieces of wood with emery paper. These are then painted and sold as part of a toy set used in nursery schools. The vocational training project had been going on for three years. During this period, just one of the trainees had been placed in a job. However, in order for the boy to get the job, one of the teachers was sent along for four months to help him adjust to the job. The annual cost of training was US$4,000 per trainee. These costs were covered by donations, mostly from external sources. Unfortunately, the experience has not been very positive.

"Training for training's sake?" "In this African country, the government has set up several vocational training centres for Persons With Disabilities. The one I was shown was housed in some extremely spacious buildings; one could easily have had 200 trainees here. As it was, the total came to not more than about forty. "As usual", the Persons With Disabilities were trained along conventional lines. The deaf boys and girls did carpentry. The blind youths were making baskets, and the physically disabled were learning how to sew. As regards the carpentry, the products were of such poor quality that there was no way they could ever induce anybody to buy them. The tables or chairs had uneven legs, surfaces scratch marks, etc. The basket-weaving was done with acceptable quality, but selling these baskets would earn a hard-working Persons With Disabilities not more than one US dollar a day. Those who did sewing turned out fine products. But with a sewing machine available in so many households nowadays, the prospects of earning an income from this activity are nil. The government's austerity programme did not allow the vocational training centres in that country to operate for more than about eight months last year. The trainees were sent home

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to wait for the next budget year to come around. Though idle over all these months, the teachers' jobs were protected by law and they continued to draw their pay.

“Cooperatives” Review of economic co-operatives for Persons With Disabilities was carried out in 1985. It was estimated that there existed 400-500 such cooperatives, employing some 8,000 to 10,000 members, in the developing countries. Most of these were situated in Asia, predominantly in India. However, a large proportion of them were “dormant”, and most of them experienced a quickly diminishing membership. One has seen about 50 such co-operatives in some 30 countries. Some of these counted a few non-Persons With Disabilities among their members. Almost none of them had lived up to the expectation of providing their members with an income sufficient to support themselves or their families. A large proportion of them had for years been receiving subventions, or had subsisted on “charity income” from sales of goods ‘manufactured by Persons With Disabilities' organised on special occasions. The most common problems mentioned were: selling the products, low productivity of the members, products of insufficient quality, and high travel costs. Many of the co-operatives were conceived with the idea of providing "rehabilitation services", but more often than not the idea came to nothing. The review referred to above describes a number of co-operatives, but cites just one example of a successful enterprise, i.e. a co-operative in Ethiopia. The visitor saw five or six more where the members were able to earn an income comparable to that of a non-Person With Disability.

7. Analysis of the Conventional System: In the following part of this section, attempts are made to analyse some factors associated with the problems of the conventional system of rehabilitation. Intention is not to criticise the pioneers of rehabilitation. The shortcomings of the system did not become evident until after several years, and many people believed that they would be able to overcome the problems with time and patience. Besides, there were no alternatives. This research has chosen to comment on nine different factors which are drawn from the Helander's "Dignity and Prejudices" - all interrelated. These factors are:

(a) The charity factor: The charity factor is a historical one, but continued reliance on charity may be doing more harm than good. Services for Persons With Disabilities in the developing countries continue to be to a large extent concentrated in the private sector, funded by contributions collected by charity organisations. The result is a system in which the role of the government is very small or nil. Consequently Persons With Disabilities in the developing countries rarely see public services set up to meet their needs. This has created a dependency on charity organisations, either national or international. These in their turn use lotteries, telethons, mailing, etc. as approaches, often painting a picture of Persons With Disabilities that many characterise as over-emotional. In some developing countries one can see the involvement of some rich people who in reality pay very low taxes or no taxes at all. Some of these will "tax themselves”, for example by providing funds for a project concerned with children with disabilities. The presence of charitable funding is one of several different explanations why so many governments in the developing countries fail to provide even the most essential services for Persons With Disabilities. For other "vulnerable groups" the situation is similar. Governments know that these groups are likely to attract external funds from concerned donors. Also, they might have the perception that rehabilitation is costly and not effective, and hence undeserving of public funds. To be “charitable” is mostly seen as a positive trait. It demonstrates kindness and willingness to help less fortunate people. But charitable action in favour of Persons With Disabilities is mostly "charity at a distance": providing funds while avoiding true personal contact. It is often poorly organised, unreliable in the long run, and on a scale not large enough to achieve what is needed. Gross injustice can never be corrected by petty charity. Some organisations are known to project images of Persons With Disabilities that create feelings of guilt or pity, serve to reinforce fear,
distancing and stereotyping. This type of action has developed into a pattern, as well-meaning people all over the world in the advertising and the information field have learned how to exploit the charitable emotions of the people in the industrialised countries. People donate large amounts, responding to dramatic television images showing helicopters landing at sunrise, yellow bulldozers flattening out the landscape, tent cities with mountains of blankets and canned food, and energetic young doctors seriously administering blood transfusions, their white coats flapping in the wind. One month later most is forgotten. The consequences for Persons With Disabilities are serious. Their services need to be permanent; nothing must be hasty or likely to be forgotten next month. When the enthusiasm of donors is short-lived, Persons With Disabilities become "victims" of charity. There is no reason why Persons With Disabilities should not have public services, financed with government funds - just like all other groups of people with "special needs". Closely connected with this dependency on charity is the difficulty of getting out of emotionalism when it comes to evaluating the conventional system. Attempts at a rational review of how funds are spent and with what results frequently meet with a considerable amount of resistance. In the long run, such attitudes to accountability will lead to a loss of credibility among people who have been willing to contribute.

(b) The attitudes and policies concerning financing: Some of the problems are related to attitudes or policies concerning financing. In countries where the government is responsible for the institutions, it is not infrequent to observe a "contraction" in periods of economic restructuring, with curtailment of the funds allocated for social services, including rehabilitation centres. As a consequence, the number of disabled "clients" admitted to such centres, whose funds may not allow them to stay open for more than a few months a year, is reduced. In some countries, the personnel belong to the civil service and will be retained even if there is nothing to do. When it comes to projects financed by external donors, one can observe that it has become customary for donors to start by insisting that they will themselves implement the project in question. After having paid considerable amounts over several years, the donor most often arranges for the project to be "taken over by the nationals". In most cases this has meant the future fund-raising is left to a national NGO. Most of these lack the necessary connections and the fund-raising capacity of the expatriates. Therefore, the situation following such transfers has tended to deteriorate quickly. Buildings are soon in a severe state of unrepair, electricity and water cut, professional staff forced to leave. The situation may slowly approach a point where there is barely enough to clothe or feed the "inmates". Why have so many donor projects gone wrong? It seems that many international organisations prefer to support action where a lot of money can be dispensed in a hurry, with high visibility and no intention of sustaining long-term effects. Fortunately enough, international donor agencies exist which have understood that one needs to stay on and continue to economically support what has been started until the services are financially maintainable using national resources. The conclusion is that one should try to reorient the long-term role of donors. The charity approach should disappear, and contributions from the outside should be directed toward co-operating with the government in implementing the national rehabilitation plan. Rehabilitation should be an integrated part of a general community development programme. Community-based services, as opposed to institutions, will then have "grassroots", and local people who have initiated their own projects are better able to sustain them in times of austerity.

(c) The indiscriminate transfer of Western technology and types of professionals: To put it in a nutshell, this transfer has not been very successful, for a number of reasons: - some technologies do not fit well with the priorities and realities of the developing countries, while other parts are culturally not compatible; - the effort to train personnel and to create rehabilitation teams after Western models has largely failed to give the expected results.
because of an inadequate understanding of how one can set up appropriate service delivery systems and rely on community self-management. A thorough rethinking is called for to start with, it is necessary to analyse the needs. Then, building on existing local experience, the tasks should be described and shared out realistically as part of a decentralised delivery system. Dissemination of appropriate technology - built on already existing experience - is needed; not transfer of Western technology. Further, new strategies concerning the personnel at all levels in such a system have to be developed. Relevant educational objectives should be formulated and facilities set up for training such personnel, without attempting to copy Western models. Finally, the system should be evaluated and - whenever necessary - better adapted to local conditions.

(d) The vested commercial interests: There are many organisations that, against a fee or against a certain percentage of the funds provided for the particular purpose, offer services to plan and/or execute projects, to construct and equip buildings and/or recruit personnel for rehabilitation. Comments on the "Jerry Lewis Muscular Dystrophy Association Telethon" made by Evan J. Kemps, Jr., Executive Director of the Disability Rights Center, USA, who himself has a disability caused by a neuromuscular disease; "The very human desire for cures for these diseases can never justify a television show that reinforces a stigma against Persons With Disabilities...With its emphasis on "poster children" and "Jerry's kids," the telethon focuses primarily on children with disabilities". This stereotype, insensitive and indifferent attitude further worsens the situation and reinforces the stigma and negative crippling attitudes of the general community. The innocence of children makes them ideal for use in a pity appeal. By celebrating children with disabilities and ignoring disabled adults, it seems to proclaim that the only socially acceptable status for Persons With Disabilities is their early childhood. The telethon emphasizes the desperate helplessness of the most severely disabled. In doing so, it reinforces the public's tendency to equate handicap with total hopelessness. When a telethon makes disabling conditions "Consultant Services" are primarily interested in large-scale projects and do not question the concepts, the usefulness or the cost-effectiveness of the programmes in question. They have an interest in keeping the business going and will certainly not welcome a change. One might also find that certain projects include training of personnel directed at the exclusive use of specific Western techniques, which necessitate the import of components or supplies. This ensures continuous sales from a particular exporting company. Attempts to change such technology meet with resistance.

(e) The apartheid of service delivery: The goal of rehabilitation is the social integration of Persons With Disabilities. Unfortunately, many of the activities of the conventional system have been counterproductive and have promoted segregation. Persons With Disabilities are often kept in boarding institutions in far-away places for years, losing all contact with their families and their communities. Whenever education, vocational training or jobs are provided, a parallel system is often created. This is not done out of concern for the special needs of children with disabilities and adults. The main reason seems to be the wish to keep them separate, so they will not interfere with the training given to non-disabled pupils or trainees, or will not negatively influence the work performance of non-disabled employees. Furthermore, services are fragmented, with components aimed at various groups of Persons With Disabilities delivered separately. Services at home, at school, concerning vocational aspects; the elderly, for example, mostly have each their own separate system. Services are not distributed properly. Most of them are located in the capital, with the remainder in other large cities. Rural services are rare, even in countries where between 70 and 80% of the population lives in villages. Services are costly, reflecting high building, equipment and personnel costs. In addition, many of these institutions and their personnel are underutilised. In a centre that could easily receive hundreds, one might find not more than 25-50 people.

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(f) The lack of parental and community involvement including representation of Persons With Disabilities: There are many examples of parents who leave their child with disability in an institution, never to return. Some such infants or children are secretly left on the doorstep of a centre or an orphanage in the early morning hours, leaving the centre no other choice but to take care of them. Rich parents may "export" their child with disability to another country and pay huge sums for "lifetime care". These are examples of parental attitudes. Examples of lack of co-operation between institutional staff and parents have been given elsewhere such attitudes are not easy to change. All rehabilitation systems must build on full family involvement. Parental education should therefore be a standard component of any system. Persons With Disabilities who have been institutionalised for a long period of time will find it difficult to return to their communities. This is particularly true of children. Social integration can come about only if the community accepts its disabled members, takes an active role in their rehabilitation and makes an effort to re-integrate those who have been away in an institution. Persons With Disabilities who remain in their respective communities are today seldom consulted about their views of services provided for them. All communities should find ways and means of affording them adequate representation and influence and developing their political capacity.

This is not an easy task, considering that many of them are unable to take care of themselves, to move about or to communicate, in addition to lacking schooling and employment. There are two ways in which Persons With Disabilities can be represented in matters that concern them. The first is through their direct participation in political bodies such as parliament/congress, local and district councils, political parties, women's and youth organisations, labour unions and social security boards. The second is by forming their own organisations to act as pressure groups. Needless to say, all Persons With Disabilities cannot be represented in such organisations. Their parents, for instance, should represent children. Normally, organisations of this type will have very little say unless they form a national union or federation. Where this is the case, they may be officially recognised by the authorities as partners in the policy-making, planning and implementation processes concerning services for Persons With Disabilities. At present, groups of Persons With Disabilities have limited direct or indirect representation in the developing countries. In some countries, the regulations in force require, legal recognition of such organisations, limit their number, and place them under government tutorship. There are examples of governments dissolving some such associations by special decree, which is equivalent to denying Persons With Disabilities freedom of association.

In many instances it is the government that appoints the chairmen and executive officers from among the ranks of non-disabled professionals. Organisations of Persons With Disabilities are often split up into small groups, making them powerless. There are numerous problems related to their internal cohesion and administrative capacity. Most such organisations are only present in the capital or in the big cities. Very few associations have been organised in rural settings. Unions or federations are uncommon, a fact that has seriously weakened these organisations' potential role as advisors or partners of the government. Where organisations exist, they are not very representative, with "normally" just a handful of young men, either physically disabled or blind. Among their members are seldom any women or elderly persons, other groups of Persons With Disabilities and parents are often under-represented. Today Persons With Disabilities and their families are, generally speaking, powerless, lacking political influence in their own society and with little or no say in matters of immediate concern to them.

(g) The lack of a credible evaluation system: The evaluation systems applied by most organisations involved in conventional rehabilitation are either non-existent or superficial.

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(h) The structuring of the conventional system: The problems associated with the structuring of the system into its various levels: macro-level, intermediate level and micro-level, are already mentioned in the Introduction. The conventional system operates mainly on the intermediate level, with the macro-level (the government, the legislative and executive bodies) being mostly involved in providing symbolic policies, plans and services. At the micro-level communities and families have rarely been the conventional system engaged in any activities. The inputs from external resources - such as development/donor agencies - contribute for the most part to strengthening the intermediate sector, leaving the government believing that this is how the problems related to Persons With Disabilities will finally be resolved. What is more, these inputs do not lead to community involvement, creating, as they do, the impression that families and communities have no part to play but merely to wait for the institutions to eventually acquire enough capacity to address the totality of the needs. Structured that way, the system contributes to passivity on the macro and the micro-level. What has been missing is a willingness to challenge the system as such, to point out that the conventional approach will not and cannot succeed in meeting more than a tiny proportion of the needs and to insist that it is conceptually wrong, unrealistic and has serious side effects.

(i) The lack of legal protection and human rights: It is a fact that most national constitutions accord all citizens a number of rights. These include the right to education, employment, services, personal property and so forth. But there are many examples of disabled citizens being deprived of these rights. They are often refused entry to the local school; not accepted for vocational training; not given employment, even if fully qualified. They rarely receive legal assistance when their property or their land is stolen or when they suffer physical, psychological, economic or sexual abuse in institutions. What is needed is not so much more laws to protect Persons With Disabilities but application of the existing ones. To provide such protection is major challenge for any rehabilitation programme.

The beginning of the end of the Conventional System: In the late 1960s and 1970s experts were beginning to express concern about the effectiveness of the conventional system. One such clear expression of criticism of the way services for rehabilitation were developed was the report of meeting of experts held in Killarney, Ireland, on 21-24 September 1969; the report states that: "...it is obvious that the pace at which personnel were being trained and other necessities for rehabilitation services were being developed was not adequate to meet the current problem and certainly incapable of coping with the predictable growth in the number of persons requiring professional help..."...it is possible that an objective analysis of methods of delivering rehabilitation services will suggest measures which can serve to provide at least the most essential assistance to large numbers of people with the resources available now or in the immediate future".

Experience in the less developed areas makes it clear that essential help may be given to Persons With Disabilities in ways which are often different from those methods established for use in industrialized and economically developed areas but are consistent with the available resources and the cultural, social, and educational patterns of the developing countries... "...it may be possible to identify forms and patterns of services which by requiring fewer trained personnel, less advanced levels of training, simple facilities, etc., may enable the delivery of essential services to be expedited and expanded." Having reviewed the conventional system, the experts suggested in principle: - a change of technology, - a new service delivery system, and - new types of personnel. They did not, however, propose any practical solutions. To find these was left to others, and it is easy to see why.

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A solution was being sought to a problem that had the appearance of being intractable. The only existing system was the "conventional" one, and it certainly did not easily lend it to the changes discussed by the experts. In spite of all that was said in Killarney, experts and organisations still went on claiming that the only hope for services in the future lay in the extension of the existing pattern. Well knowing that there were insurmountable problems associated with the conventional system, they had in reality concluded that rehabilitation in the developing countries is not feasible in our times. The following summary of the situation was given in a 1976 WHO document. "...rehabilitation services are practically nonexistent or grossly inadequate in developing countries; there is an apparent lack of national planning and coordination of services (medical, educational, vocational, and social, etc.) in most countries, medical rehabilitation services have usually concentrated on institutional care, with a low turnover of patients at a high unit cost; when advanced rehabilitation services and technology have been introduced in developing countries, the result has often been discouraging or a complete failure." These judgments are still valid 23 years later. A recent UNESCO document states that: "The stark reality is that the great majority of children and young people with special education needs do not receive an appropriate education, if they are offered any education at all."

In the last few decades, the ranks of Persons With Disabilities in the developing countries needing rehabilitation have annually increased by over two million people. The resources available have remained more or less static. Thus in reality the situation has rapidly deteriorated. We have on our hands a growing moral, social, health and economic problem of vast proportions, which we are incapable of dealing with by using the spending on development programmes funded by the industrialized countries that is at present estimated at a total of US$ 50 billion. Based on the estimate of US$ 300-400 million, the amount spent on programmes related to Persons With Disabilities is not more than 0.6% to 0.8% of the total. Only 0.3% of the UNDP budget for the period 1988-91 as used for projects concerning Persons With Disabilities, and other UN agencies spent an even smaller percentage of their regular budgets for that group. Evidently, rehabilitation programmes do not rank high on the list of development priorities. A UNESCO document reports from a study carried out in 13 African countries in 1983. These countries had a total population of 107 million.

The number of children with disabilities receiving special education was 13,067. [Children with handicaps at school in Southern and Eastern African countries UNESCO, Paris, France, 1983] Another example appears in E. Kleinberg: Special under visioning for blind barn utvecklingsländerna fron 1975 till 2000. (SHIA, Stockholm, Sweden, 1987) estimates that in sub-Saharan Africa, the proportion of blind children receiving special education has increased from about 1% (1970) to 1.6% (1985), a very marginal increase. During the same period, primary school attendance has gone up from about 30% to about 50%. Many centres with funding problems have tried to create sheltered workshops, hoping that this would help to pay for their running costs. It appears, however, that this effort almost invariably fails.

These tendencies have been described by many others. T. Johnson quotes several reflections in this vein, among them those of Chambers and Hartman, who write that children with disabilities "interfere with instruction" and "absorb the energies of the teacher and make so imperative a claim upon her attention that she cannot under these circumstances properly instruct the number commonly enrolled in a class". Chronbach remarks that intelligence tests have frequently been used as an instrument to drop children "by the wayside or to vegetate in an under demanding slow classroom". Johnson states that "the schools these children are de-selected from are characterised by a rigid examination-oriented system with the main task of identifying children with potential for a further academic career", and he ends with a UNESCO quote: "This elitism, that is still frequently advocated, seems to justify the

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educational institution in rejecting in some cases over one third or even half of the children entrusted to it. Such wastage would not be tolerated in any other sector of activity. "J. G. Chambers and W. T. Hartman: Special Education Policies. Their History, Implementation, and Finance, Temple University Press, Philadelphia, USA, 1983"

**Source:**
2. www.asksource.org
3. www.ich.ucl.ac.uk

5.3 A HISTORICAL OVERVIEW OF REHABILITATION

Having attempted a review of the global situation of Persons With Disabilities, the research will now look at the historical perspective. There are four principal reasons for this:
- to better understand the situation described in the previous chapters;
- to see what lessons can be drawn from the past;
- to identify and apply positive experience while avoiding duplication of mistakes;
- to review the major concepts related to Persons With Disabilities and to choose the most advanced and most humanitarian principles to guide the implementation of rehabilitation in the developing countries.

Over the centuries, prejudiced beliefs, attitudes and behaviour of non-disabled people have largely determined the quality of life and the fate of Persons With Disabilities, and they still do. Reactions to the presence of human beings with disabilities may be grouped under six main headings:
1. Elimination - getting rid of them;
2. The poorhouse - removing them from the view of the non-disabled;
3. Institutional care - providing care for them on a segregated basis;
4. Integration - encouraging a pro disabled environment;
5. Self-actualisation and empowerment;
6. The right to public services;

The elements of each of them are as follows.

1. **Elimination:** As a reaction to disability, elimination is characterised mainly by the premature death of a person with disabilities - a fate shared by millions of them. For the purposes of this research, the term "premature death" indicates that the death was not directly related to disability or to its causes. This would, for example, be true in the case of an infant dying from a severe, disabling malformation of the heart. Premature death in our context has been brought about by other human beings, either directly or indirectly. The most infamous example of "premature death" is the systematic killing of persons with mental disabilities during World War II in Nazi Germany. At the Nuremberg Trial of war criminals, it was estimated that 300,000 people with such disabilities had fallen victim to Hitler's euthanasia programme. Even in present days, the survival of Persons With Disabilities is jeopardized by widespread prejudice among non-disabled people. The behaviour borne out of such prejudice has led, and still leads, to premature death caused by negligence or by intent, as described in the following document on the situation in a developing country: "Before the advent of hospitals, child welfare and maternity clinics, women gave birth in their ancestral homes. Before a newborn baby was officially announced, he was thoroughly examined for any visible defects of the body. A baby with any physical defect was promptly
eliminated. The family was informed that the baby was still-born. Congenital deformities were, therefore, not much of a social problem".

Negligence of females with a disability is in some countries more pronounced than that of males. Misinterpretation of Darwinian Theory - and in particular of the phrase "survival of the fittest" - has contributed to the belief that it is somehow in the best interests of societies to let the most vulnerable to go under. In present days, elimination is practiced in many industrialised countries, where it is culturally and legally acceptable to diagnose the presence of a defective foetus by amniocentesis or similar techniques and to grant permission for an abortion should the diagnosis be positive. In several countries, murder of an infant or child with a congenital defect sometimes leads to nothing more than a suspended sentence and the public at large appears to be strongly in favour of such judgments. Recently, it was proposed (in a European country) to legalise infanticide committed during the first three days after the birth of severely handicapped baby, a practice said to exist already clandestinely, on a limited scale. On the other hand, arguing in favour of the view that "parents of severely disabled newborn infants should be able to decide, together with their physician, whether their infant should live or die," sometimes meets with strong opposition.

2. The poorhouse: The "poorhouse approach" is an attempt to help the "impotent," "lame" or "feeble-minded," as well as unemployed and aged individuals, orphans and other groups of destitute, without any source of income. The first poorhouses in Europe were set up by municipal action in the early 16th century, at a time when the medieval economic system was on the decline and the needs of the poor could not be met by charitable, religious organisations. The motive behind the creation of poorhouses does not appear to have been mainly charitable. Rather, it was the fear that vagrants might spread disaffection and that some might be recruited as mercenaries in rebel armies. To save costs, the local authorities in many communities gave the aged and those unable to work a license to beg. Not until very recently did the poorhouse disappear as a component of European and North American municipal structures, which raised "poverty taxes" to cover costs for the subsistence of the poor and the undesirable. These taxes supported many different groups, such as Persons With Disabilities, with unusual behaviour or appearance, chronic alcoholics, criminals released from prison, the severely ill, members of certain ostracised ethnic groups, people thought to be carriers of communicable diseases (including epilepsy and organic brain disorders), orphans, or others who simply happened to be jobless. There are many interesting features to the poorhouse approach. The obligation "to put the poor to work" was instituted in England in 1601. This was thought to contribute to rehabilitate the poor. Working conditions in the poorhouse were designed to act as deterrents to taking advantage of the system. Paupers had to wear special uniforms or garments. In some countries they were made to wear a large red or blue, plainly visible letter "P". They were denied the right to vote and were subject to harsh discipline.

By the middle of the 19th century, the repressive "poorhouse" system started crumbling, helped by such factors as the development of democracy, humanitarianism, social security and more scientific approaches to dealing with poverty. But many of the attitudes associated with the poorhouse approach have persevered into present days, even among some highly educated people. Poverty is not infrequently thought to be a sign of God's disapproval. Many non-disabled people still prefer to make voluntary contributions or pay taxes in order to have poor Persons With Disabilities removed from their sight and cared for by custodial staff. Today, the poorhouse as an approach is rare in developing countries, high costs being one of the main reasons, so it seems. Communities generally accept to have a certain number of marginal people living amidst them - persons with mental illness, beggars, jobless and destitute people, and others. Also, there often exists a limited welfare system: families,
friends or neighbours taking care of their needs in terms of food, clothing and shelter. Mental hospitals in these countries sometimes function as a type of poorhouse, in particular for those affected by mental retardation or disease.

3. **Institutional care**: The first large-scale institution for Persons With Disabilities in Europe seems to have been the "Hotel des Invalides", built in Paris between 1670 and 77 by King Louis XIV; it was designed specifically for disabled and aged soldiers. Eventually it housed 7,000 such veterans. This institution still exists today, though on a much smaller scale. Institutions have also existed for centuries in several developing countries. In Sri Lanka, for example, King Buddhadas built a very large institution as early as in the fourth century. Later on, about 200 years ago; institutional care for "civilians" began to emerge as a "specialisation of the poorhouse." The "inmates" were divided into distinct groups and sent to separate boarding institutions, among them institutions for various groups of Persons With Disabilities. Detention and charity were combined with rehabilitation, special education, and therapy, vocational training and sometimes with a job in a segregated, "sheltered" surrounding. New technology too began to emerge, such as characters in relief for blind people, a system used by label Valentin Hauy in 1784.

This inspired the creation of the first specialised school for blind children in France. Louis Braille in 1824 invented the system, now used by millions of blind people. As countries became more affluent they tended to improve the image of such specialised poorhouses by ensuring a higher density of personnel, increased freedom to visit the neighbourhood, and less conspicuous signs of charity. Detention was enforced by creating psychological dependency rather than by locking doors. In many places, the segregated institutions improved the technical rehabilitation programme. In the "centres of excellence", Persons With Disabilities were well "looked after." They developed many of their abilities and skills to become more mobile, more advanced in communication, better educated, and more productive at work. More was done to assist them in finding their way back to their families or in trying to lead an independent life. Yet, up to present days, institutions have continued to be the subject of heavy and justified criticism.

A few years ago, the United States Supreme Court noted the undisputed facts about a large, well-known institution for persons with mental retardation: "Conditions ... are not only dangerous, with the residents often physically abused or drugged by staff members, but inadequate for the 'rehabilitation' of the retarded. Indeed the court found that the physical, intellectual and emotional skills of some residents have deteriorated." Institutions are still the dominant type of facility for rehabilitation in the developing countries. The most common clientele are children receiving schooling and functional training. In addition, there are a number of facilities that provide orthopaedic appliances and gait training. Others aim at preparing people for employment or offer them sheltered work. The establishment of day-care facilities for Persons With Disabilities began mainly after World War II. Such facilities provide a better solution than residential, totally segregated institutions. Day care can do much to support families, who for several reasons are unable to take full care of their own disabled members. This step was followed by attempts at integration.

4. **Integration**: The conceptual evolution towards social integration and de-institutionalisation is the outcome of a gradual change in a number of factors, the most important of which are new medical inventions, lack of an adequate number of professionals or of effective remedies, economic necessity, the reactions of millions against authoritarianism, colonialism and paternalistic attitudes, and finally the growing influence of Persons With Disabilities and parent groups. At the end of World War II, millions of disabled veterans returned home, stayed there and were integrated in main-stream community and family life.

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It is true, a number of veterans' hospitals and other facilities were set up to help with medical care and rehabilitation, but the idea of keeping all disabled veterans in institutional settings, i.e. creating a sort of large-scale 'Hôtel des Invalids', did not seem practical. Thus social integration became the solution, but out of economic necessity rather than choice. It did not cause any major problems, nor did it lead to lower-quality results. The next decade, with the economic situation improving in a number of Western countries, marked the onset of a period of escalated construction of new institutions for Persons With Disabilities. This development was paralleled by a tendency among a growing number of parents to prefer to keep their children with disabilities at home. Increasing prosperity, better housing conditions and higher levels of education made this possible. Day-care facilities and mobile specialists later helped many such families.

The 1950s saw the beginning of a great revolution in psychiatry. This was precipitated, among other things, by the invention of new psychotropic drugs which simplified the care of patients with chronic psychosis. In fact, they recovered to such an extent that, given a community psychiatric service as a supporting structure, many could be sent home or be admitted to halfway houses. In all industrialised countries, the majority of closed wards for the severely mentally ill people were opened up. Several hundreds and thousands of patients were discharged to live outside the institution, either temporarily or permanently. Economic constraints were a major contributor to this change. In the decades before 1960, tuberculosis accounted for the majority of deaths in institutions for Persons With Disabilities and in hospitals for the chronically ill. With the invention of new drugs and the availability of BCG-vaccination, the death toll from tuberculosis declined considerably. With the Persons With Disabilities living longer, specialised institutions and hospitals became overcrowded.

The lack of funds did not permit the further expansion of existing facilities. So, in order to make room for new patients, the least disabled had to be discharged and sent home. Their needs for care had to be met by day-care centres rather than by closed wards. The "space problem" was an interesting phenomenon. Initially, doctors were put on the defensive, apologising to patients and their families, and blaming the politicians for not raising taxes to pay for the institutions "needed". Later on, attitudes changed. The merits of social integration were discovered, and going home became part of an active and planned effort. Another factor contributing to this change was the emergence of self-care programmes. These were set up either to cope with the shortage of professionals or because the therapy provided by the professionals failed to produce the desired results. Alcoholics Anonymous, which was started because most professional programmes had turned out to be a failure, is an excellent case in point. Alcoholics felt that they could do better on their own, and they started group therapy sessions on a regular basis.

Today they have local organisations in almost every country. Another movement that made its appearance in the period between the fifties and the seventies was the so-called "therapeutic community," encouraging mentally ill patients to become more independent, or totally independent, of professional care-providers. These two examples of rebellion are not indicative of the search for true social integration. Rather than breaking new ground, they continued to follow the old pattern of bringing together segregated groups of Persons With Disabilities. However, their challenging the authoritarianism exercised by professionals has been an important element in the development of the self-care concept. De-institutionalisation was furthered by other factors. One was the rapid increase in the number of elderly Persons With Disabilities in industrialised countries, which strained all care facilities to the utmost. The professionals became over-extended and had to find solutions to cope with their daily workload. Physiotherapy departments started encouraging self-treatment of chronic conditions, using simple training packages for in and outpatients suffering from

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stroke, arthritis, back disorders and other complaints. Parents of children with cerebral palsy were visited at home at monthly intervals and given instructions and demonstrations on how to proceed with the training themselves. Many rehabilitation professionals changed their roles from that of therapy providers to teachers of self-therapy. The authorities, recognising the benefits of the new trends, began to promote these efforts by providing economic and organisational support. When scientists began reviewing the results of such "home rehabilitation/self-care," they found them to be equivalent or even superior, in some respects, to the results obtained by institution based rehabilitation.

It was then recognised that the frequency of emotional and behavioural disturbances not primarily caused by the particular disability was higher in children with disabilities treated in residential institutions than in those trained at home. These disturbances were interpreted as side effects of the segregation typical of long-term institutional care. Many of the problems that disabled adults encountered in their contacts with non-disabled people; for example, in finding and retaining a job; could be attributed to their earlier segregation. Children receiving long-term care in boarding institutions often develop a special language (argot), which further impairs their ability to communicate with outsiders.

Family integration and integration with a non-disabled peer group have been shown to diminish or eliminate such undesirable side effects. Integration and home self-treatment (or treatment by a family member) of Persons With Disabilities, under the supervision of professionals, is now an accepted method and has proved to be an effective and preferred approach. With family integration as the starting point, many countries have embarked on efforts to further social integration, including integrated housing, schooling, vocational training and jobs, sports and recreational facilities, and so forth. Large-scale programmes were introduced to eliminate physical barriers in the environment such as providing accessible public buildings, transportation and housing for people with mobility problems. All-round social integration has yet to be achieved. And prejudice is the main obstacle on the road to this goal.

In the most developed countries, long-term institutionalisation of Persons With Disabilities is now considered a second-choice solution; to be applied only to those for whom no other approach is possible. Social integration is, however, achieved only in part. The approach faces many an obstacle, including the predominantly negative attitude adopted now as before by non-disabled people, and by a number of professionals. Another sizeable hindrance to implementing integration is the fact that some governments have contented themselves with closing down institutions, especially those for persons with mental illness, without providing the necessary resources for community level care. Given the general downward trend in social welfare allowances, this has given rise to an alarming phenomenon - the appearance of large groups of "homeless people". The majority of them belong to the groups of the mentally ill, drug addicts and alcoholics. There is no doubt that the change from institutional care to community care and integration cannot be brought about without real community involvement and adequate networks of local care providers. This staff must not only be easily available but must, moreover, make frequent home visits to provide all necessary follow-up action.

Furthermore, the community should make adequate provision for all daily needs such as rent, food and clothing, and set up at least a simple programme of daily activities. Finally, the very active role played by the "consumers" needs to be acknowledged, particularly in the industrialised world. Organisations of Persons With Disabilities and organisations of parents have firmly established themselves in the past thirty years. They are increasingly consulted by governments and local authorities in matters of policies and programmes targeted at

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them. Their effectiveness in lobbying for human rights and equal opportunities is growing, leading sometimes to successful "rebellion" against inadequate programmes, paternalism and prejudice. In many developing countries, the social integration approach has been there from the very beginning. As specialised facilities are scarce, most Persons With Disabilities stay with their families and in their communities. For most of them life is not easy, though some of them do receive "spontaneous" rehabilitation from the family. It would appear that more Persons With Disabilities have received effective rehabilitation through their families than through institutions, and that they have remained socially integrated as a result.

5. Self-actualisation and empowerment: Self-actualisation implies that each person with disabilities should be able to fulfil his or her need for taking an active part in society and for living a life with dignity, independence and with self-esteem. This is the ultimate goal that rehabilitation aspires to - a goal not sufficiently acknowledged at the present time. For a better understanding of the term "self-actualisation", it may be useful to review the basic concepts of human need, as described by Maslow. In his "Theory of motivation" he describes five levels of human needs (material and non-material), as illustrated below. The needs are presented in ascending order of their importance:
- Physiological needs are the essentials needed for survival, such as food, water, air, sleep.
- Safety/security needs are those of security and protection against danger.
- Social needs are those of belongingness, affection and love.
- Esteem needs are those of self-esteem (self-respect) and esteem by others (recognition).
- Self-actualisation needs are those of self-fulfilment, to realise one's own full potential.

Most inquiries into needs of Persons With Disabilities in the past have been very limited. The full scope of the needs of Persons With Disabilities has to a large extent been neglected. It has been more or less presumed that one's basic material needs are satisfied, conventional rehabilitation services and opportunities are provided, the Persons With Disabilities have "reached the highest possible level of ability" - all needs have been met. This view is too superficial to be acceptable. Esteem needs and self-actualisation too have to be satisfied, and a more dynamic, holistic approach is necessary.

Let us apply Maslow's theory to sum up the situation of Persons With Disabilities. The actual survival of disabled individuals was and still is threatened in many ways. The poorhouse and, later on, institutional care, were approaches designed to protect the survival of Persons With Disabilities and to provide the physiological needs for water, food, shelter, clothing and safety. This is as far as things have reached today for most Persons With Disabilities in the industrialised countries - not so in the developing ones. The feeling of belonging, of receiving attention and love, comes more easily to Persons With Disabilities who live in the midst of their families and friends. The integrated approach offers ways of better satisfying these needs. Nevertheless, most organisations working for Persons With Disabilities in the developing countries have concentrated on the residential institutions. Esteem and self-actualisation needs can only be fulfilled if Persons With Disabilities live in the community, share the same rights and play a proper, meaningful role in their respective societies. The subject of empowerment is another important goal to enable Persons With Disabilities to exercise their political rights. This subject is dealt in detail in Chapter 6. In the industrialised countries, the social integration approach is slowly replacing institutional care. Nobody disputes the fact that for some Persons With Disabilities no solution other than institutional care can be found. All their relatives may abandon children with disabilities or adults. Their disability may be so serious that care is needed round-the-clock. The care may prove too costly or involve technical equipment that is difficult to handle at home. Behavioural disturbances may become so severe that they are too much of a burden for a family to cope

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with. But, in reality, early intervention programmes, such disturbances are rare. In several countries, it has been possible to reduce institutional care to a minimum. So the questions arise: Is there a way to avoid repeating the mistake of having an institutional system installed as the only model for services in the developing countries? Is there a way whereby priority can be given to a system building on social integration?

6. The right to public services: The first actions in Europe to assist Persons With Disabilities - during the medieval period - were set up by religious organisations. In the 16th and 17th centuries - when this system was breaking down - it was replaced by the poorhouses installed by local authorities. Later on, a number of private initiatives emerged, for example the development of special education for blind and deaf children, "homes for persons with mobility impairment" and so forth. In the 20th century, in the industrialised countries, numerous services were created in the private sector, financed by voluntary organisations - reflecting the growing influence of associations of parents of Persons With Disabilities and the availability of donated money. This is the pattern most commonly copied in the developing countries. But in the last few decades, this tendency has been subject to severe criticism in the industrialised countries. The question is: Why should Persons With Disabilities dependent on charity? Why can they not have public services like everybody else? Why are not all schools for children with disabilities managed by the education department or by local authorities, just as "normal schools" are? Persons With Disabilities argue that they are treated as beggars and become dependent on charity. So, in the more advanced societies, the services of private charitable organisations, along with economic contributions to disabled individuals, are in the process of being taken over by the public sector. Social security and other government systems increasingly take care of the economic side, including subventions and pensions. In the developing countries, it is common to see Persons With Disabilities begging. In many ways the culture and social stratification of many societies legitimise the dependency on begging and charitable action. But, in the long run this will diminish and disappear. Persons With Disabilities in the developing countries will, like their brothers and sisters in the industrialised world, demand that the authorities step in and replace charitable action by public services and social security.

Lessons to be learned from the positive experiences of the past indicate that a rehabilitation programme in developing countries should incorporate a number of priorities:

- Functional training approaches based on the modern technologies of self-care and homecare. To succeed, one must obviously try to demystify the technology, so as to make it easy to understand and to apply. Families and communities need to be mobilised to provide the care and rehabilitation needed.
- A system of schooling that is accessible to the children with disabilities where they live emphasising inclusive education.
- Total social and economical integration coupled with a programme of community preparation aimed at ensuring equal opportunities, better recognition, more positive attitudes and the disappearance of discriminatory behaviour towards Persons With Disabilities.
- Less paternalistic and authoritarian attitudes among professionals involved - in the supervision and in referral care systems.
- Interventions in the environment to reduce or to eliminate physical, psychological, cultural, social, and economic barriers.
- Increased respect for the human rights of Persons With Disabilities.
- Efforts that promote self-actualisation and empowerment, defining new roles for Persons With Disabilities to look after their own interests and to influence society as a whole through their own organisations or interest groups. This would liberate them from the
influence of power structures not of their own making and allowing them a life in dignity, on an equal basis with all other members of the common human society.

- Far greater emphasis on adequate organisation of service delivery - leaving behind a system characterised by costly fragmentation, underperformance, and lack of co-ordination. The activities concerning homes historical perspective cannot be achieved without government involvement. Concepts described in this chapter are poorly understood and even less applied, in real life. Few people who have heard of the principles of social integration and self-actualisation have tried to implement them. Innovative ideas call for innovative solutions; it is not adequate to go on with the conventional system, thinking that next time around perhaps it will not fail. In order to be innovative one needs to experiment with new strategies. There is a need to find better solutions, which integrate the most advanced and humanitarian principles into the design of the rehabilitation system.

Source:
2. www.asksource.org
3. www.lddc.org.uk
4. www.ich.ucl.ac.uk

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5.4. STATE RESPONSES TO DISABILITY IN INDIA

Policy and Institutional framework: In several respects, India has a well-developed policy and institutional framework for Persons With Disabilities given its income level. There is a well-developed framework of legislation, consisting of four core disability-specific acts: (i) the Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (Persons With Disabilities Act); (ii) the Mental Health Act, 1987; (iii) the Rehabilitation Council of India Act, 1992; and (iv) the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (National Trust Act).

The Persons With Disabilities Act is the core legislation with respect to disability. Its philosophy is one of integration of Persons With Disabilities into mainstream life, in addition to a focus on prevention of disability. It thus proceeds from a social rather than medical model of disability. In many respects, it is the policy benchmark around which both Government and non-government sectors evaluate progress on inclusion of Persons With Disabilities. In addition to establishing the institutional framework for promotion of the interests of Persons With Disabilities, it mandates programs in a number of key areas, including prevention and early detection of disability, inclusive education, training for Persons With Disabilities, health, employment (e.g., 3% quota for Persons With Disabilities in government employment), social security, and anti-poverty programs (e.g., a 3% reservation for Persons With Disabilities in all anti-poverty programs).

Ministry for Social Justice and Empowerment [MSJE] is the nodal ministry for the welfare of Persons With Disabilities at the central level which coordinates with other related ministries and departments for the implementation of disability related schemes and programmes. It is responsible for policy formulation and supervision with respect to disabilities. Several other Ministries also deal with disability-related programs and issues, including Health, Personnel, Human Resource Development, and Urban and Rural Development. In addition, under the authority of MSJE a wide range of national, regional and local institutions and centres are functioning such as the six National Institutes for specific disabilities, and the Rehabilitation Council of India, which provide technical support. There is also a decentralised structure of the Ministry from the state down to the block level.

Even though the MSJE is the key nodal ministry at the central level but in some states the welfare of Persons With Disabilities has been promoted by the other related ministries for example Ministry for Women and Child Development at the state level and ICDS at block level in the state of Karnataka. The institutional arrangements make inter-Ministerial/agency coordination a challenge in terms of overall policy development, implementation, and coherence. The various institutions, departments, organisations, schemes, programmes, facilities and new initiatives promoted by the MSJE are as follows:

Institutions of Central Government:
The government of India has established a number of institutions as autonomous bodies under The Ministry of Social Justice and Empowerment to promote the development, welfare, and protection of rights of Persons With Disabilities which are as follows:

National Council for Handicapped Welfare: Government has set up National Council for handicap welfare with following objectives:
- Ensure a coordinated and comprehensive approach to research, training and services for Persons With Disabilities population.
- Evolve a National Plan of Action. Review legislative, administrative and other measures for the welfare of disabled.
- Evolve policy guidelines for the welfare and rehabilitation of the Persons With Disabilities.
- Ensure people's participation in rehabilitation of Persons With Disabilities.

**National Information Centre on Disability and Rehabilitation (NICDR):** National Information Centre on Disability and Rehabilitation was set up under CACU in 1987 to provide a database for comprehensive information on all facilities and welfare services for Persons With Disabilities within the country. It also acts as a nodal agency for awareness creation, preparation/collection and dissemination of materials/information on disability relief and rehabilitation. The computerised data so far collected relates to institutions/professionals working for Persons With Disabilities, aids and appliances, scholarships, national awards and physical/financial performance of DRCs/RRTCs. It publishes the Indian Journal of Disability and Rehabilitation. The Media Cell is responsible for publication of awareness-generation material/journals, hold Seminars/Workshops, organisation of Film Festival/Exhibitions, production of films, etc. Assistance from UNICEF is obtained for different activities on awareness creation.

**National Institutes:** Six National Institutes under Society Registration Act of 1980 which are autonomous bodies were established under the MSJE, Government of India. These institutes were established in late 70s and early 80s to promote the development of Persons With Disabilities. The six national institutes include, National Institute of Orthopaedically Handicap [NIOH] - Kolkota, National Institute of Visually Handicap [NIVH] - Dehradun, National Institute of Hearing Handicap [NIHH] - Mumbai, National Institute of Mentally Handicap [NIMH] - Secundrabad, National Institute of Physically Handicap [NIPH] - New Delhi and National Institute of Rehabilitation, Training and Research [NIRTAR] - Cuttack.

The aim of these national institutes is to promote rehabilitation, prevention, education, human resource development, research and training in the field of disability and development. Apart from these six institutes under the Ministry of Social Justice and Empowerment there are many other institutes under the Ministry of Health and Family Welfare which are functioning for the development of Persons With Disabilities. They include, National Institute of Mental Health and Neuro Science [NIMHANS] - Bangalore, All India Institute of Speech and Hearing [AIISH] - Mysore and other hospitals also provide medical rehabilitation services.

**Rehabilitation Council of India [RCI]:** The Government of India set up Rehabilitation Council, as a registered society under the Societies Registration Act, 1860. Thereafter, this was converted into a statutory body under the Rehabilitation Council of India Act, 1992. It came into force w.e.f. 31st July, 1993. This is under the administrative control of Ministry of Social Justice and Empowerment. The objectives of this council are:

- to regulate the training policies and programmes in the field of rehabilitation of Persons With Disabilities
- to prescribe minimum standards of education and training of various categories of professionals dealing with Persons With Disabilities
- to regulate these standards in all training institutions uniformly throughout the country
- to recognise institutions/universities running degree/diploma/certificate courses in the field of rehabilitation of Persons With Disabilities
- to recognise foreign degree/diploma/certificate awarded by universities/institutions on reciprocal basis
- to maintain central rehabilitation register of persons possessing the recognised rehabilitation qualification and

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to encourage continuing rehabilitation education in collaboration with organisations working in the field of disability.

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities: This trust was established under The National Trust for welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 which came into force w.e.f. 30th December, 1999. The National Trust supports programmes which promote independence, facilitate guardianship where necessary and address the concerns of those special persons who do not have their family support. The Trust also seeks to strengthen families and protect the interest of persons with autism, cerebral palsy, mental retardation and multiple disabilities after the death of their parents. The Trust is empowered to receive grants, donations, benefactions, bequests and transfers. It is exempted from income tax.

National Handicapped Finance and Development Corporation (NHFDC): The Government has set up the National Handicapped Finance and Development Corporation with an authorized share capital of Rs. 400 crore to make the Persons With Disabilities self reliant, economically productive and to bring them into the mainstream of economic activity. The Corporation provides soft loan to set up cottage industries. The objectives of NHFDC include providing concessional finance for a wide range of activities including self-employment ventures, upgrading of skills, assistance for infra-structural activities which support economic pursuits, loans for education etc. Assistance is given to Persons With Disabilities who are below double the poverty line. NHFDC functions as an apex financial institution for routing funds through the channelising agencies authorised by the State Governments/UT Administrations. NHFDC has also introduced a new "Micro Financing Scheme" under which assistance to Persons With Disabilities is provided through NGOs.

Artificial Limbs Manufacturing Corporation [ALIMCO] of India, Kanpur: The Artificial Limbs Manufacturing Corporation of India (ALIMCO) was registered under Section 25 of the Companies Act, 1956 on 25th November 1972 as a Government company not for profit. Objectives of this corporation include:
- manufacturing orthotics/prosthetics and rehabilitation aids required by Persons With Disabilities in the country
- training orthotic/prosthetic technicians and engineers to carry out research and development in the field of orthotics and prosthetics. The Corporation's factory at Kanpur is equipped with sophisticated plant and machinery required for such manufacturing. As a back-up for production, the factory also has a well equipped tool room. Production is planned in a scientific manner. The quality control department ensures that the products of the factory are in keeping with the specifications laid down by the Bureau of Indian Standards and other International agencies. The Corporation has a quality control laboratory (QC Lab) with sophisticated test equipment required for checking the quality of incoming material as well as testing the finished products of the corporation. The QC Lab is recognised by the Bureau of Indian Standards as a certifying agency for the quality of material used by other manufacturers in North India.

During the year 1999-2000, ALIMCO achieved an all time record of overall turnover of Rs. 2354.86 lakhs, highest ever production of Rs.1792.83 lakhs much beyond the laid down targets, and a record cash profit of Rs.370.46 lakhs. The Corporation has achieved more than 57% increase in value of production and more than 26% increase in overall turnover over the corresponding figures of the last year. The company has achieved substantial increase in the production of various categories of Aids and Appliances ranging from 28% to

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205% without any increase in person-power and by increased capacity utilisation. Apart from cash profit of Rs.370.46 lakhs, the Corporation has for the first time earned a net profit of Rs.43.81 lakhs, which was to be ploughed back into Corporation's activities. Four Auxiliary Production Centres of Artificial Limb Manufacturing Corporation of India (ALIMCO) are being set up to expand the production capacity and for easy availability of quality aids and appliances.

National Commission for Persons With Disabilities [NCPD]: Government of India constituted a national commission for Persons With Disabilities with its resolution No. 16-8512003-N1-111 (DD) - dated the 16th October, 2003, at New Delhi. The Government of India, being sensitised to the special problems of Persons With Disabilities and to the need for ensuring a life of dignity for them and of ensuring their full participation in civil society, has enacted the Persons With Disabilities (Equal Opportunities, protection of Rights and Full Participation) Act, 1995, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 and the Rehabilitation Council of India Act, 1992, and has been implementing several schemes through a multi-sectoral approach involving civil society, voluntary organisations and departments of the Government.

And whereas, considering the large number of Persons With Disabilities in the country and the magnitude of disability issues with all their ramifications, a need has arisen to take a holistic view of the problem. Now, therefore, it is resolved to constitute a Commission to be called the National Commission for Persons With Disabilities, with its headquarters at New Delhi to aid and advise the Government regarding disability and rehabilitation matters and to make recommendations to it in this regard; and monitor the violation of human rights of Persons With Disabilities. The Commission shall consist of nine members, including a Chairperson, two full time Members, a Member-secretary and five Associate Members; and the Chairperson. The full time members and the Associate Members shall be persons of eminence and involved in the rehabilitation and advocacy for the rights of Persons With Disabilities.

Schemes and Programmes:
District Rehabilitation Centres [DRC]: The Government of India launched the District Rehabilitation Centre Scheme in early 1995, to provide comprehensive rehabilitation services to the rural disabled right at their door steps. The scheme, at present, is operational at 11 different districts of the 10 states of our country. The services provided in the scheme include - Prevention and Early Detection, Medical Intervention and Surgical Correction, Fitment of Artificial Limbs, Aids and Appliances, Therapeutic Services, Training for acquiring Vocational Training, Job Placement etc. One such centre has been functioning in Mysore District of Karnataka.

Regional Rehabilitation Training Centres (RRTCs): Four Regional Rehabilitation Training Centres (RRTCs) have also been set up at Chennai, Cuttack, Lucknow and Mumbai for training and person-power development in the field of rehabilitation particularly for the DRCs. The RRTCs also have been conducting training programmes for Communities, Parents and even for Persons With Disabilities themselves.

District Disability Rehabilitation Centres [DDRC]: For initiating rehabilitation services throughout the country, 149 DDRCs have been initiated in the identified districts, which will provide core rehabilitation services and also facilitate convergence with other developmental programmes. Almost all district centres are already functioning. Others are at the threshold of being launched. It has been decided to involve NGOs and experts working in the area of disability for monitoring and facilitating early setting up of district centres.
National Programme for Rehabilitation of the Persons With Disabilities [NPRPD]: A Complementary scheme to the DRC namely - National Programme for Rehabilitation of the Persons With Disabilities has been formulated as a State Sector Scheme. Through this scheme, rehabilitation services are being provided right from the grass root level up to the state level involving community and the other existing organisations. The scheme commenced in 1999-2000. 74 districts are expected to be covered in 2000-2001 wherein services will be provided at Gram Panchayat, Block, District and State level. Government of Karnataka has initiated CBR programmes in many blocks of Karnataka. These programmes are short term initiatives and provide services like certification, assistive devises, medical interventions, education and facilitate Persons With Disabilities to organise into Self Help and Advocacy Groups [SHAGs].

Composite Regional Rehabilitation Centre for Persons With Disabilities [CRRCs]: Five Composite Regional Rehabilitation Centres (CRRCs) are being setup in different parts of the country to provide services for different kinds of disabilities and for creating infrastructure for training and person-power development, promoting research and generation awareness. The basic objective of setting up Composite Resource Centres (CRCs) is to create the infrastructure required for training and person-power development, research and providing services to Persons With Disabilities, particularly in those parts of the country where infrastructure is lacking at present. The Centres would be expected to function as outreach Centres of National/Apex Institutes, presently functioning under the Ministry and will facilitate the process of capacity building at local levels, in regions where they are being set up. The proposed centres would also carry out the following objectives:

- to serve as Resource Centre for rehabilitation and special education of Persons With Disabilities
- to start with, short term and orientation courses will be taken up.
- to establish linkages with existing medical, educational and employment services, following the principles of CBR and offer extension services in the rural areas.
- to develop strategies for delivery of rehabilitation services suitable to the socio-cultural background of the region.
- to undertake designing, fabrication and fitment of aids and appliances.
- to undertake services of education and skill development leading to enhancement of opportunities for employment, rehabilitation, mobility communication, recreation and integration in society.

Land required for the Centres are being provided by the State Governments. First such Composite Regional Rehabilitation Centre has started functioning at Sri Nagar and the foundation stone for the permanent construction of CRC has been laid by MOS (SJ&E) at Sri Nagar on 29th June 2000. The second Composite Regional Centre has started functioning at Lucknow since 26th August 2000.

Regional Rehabilitation Centres for Persons With Spinal Injuries and other Orthopaedic disabilities [RRCs]: Four Regional Rehabilitation Centres (RRCs) for persons with Spinal Injuries and Orthopaedic disabilities are being setup as a Centrally Sponsored Scheme on 90:10 Centre:State sharing basis. These Centres would provide facilities for treatment and rehabilitation services to the spinally injured and persons with other orthopaedic disabilities. The Indian Spinal Injuries Centre, New Delhi, a Centre of Excellence will provide the required technical support for setting up of these centres and will also function as Referral Centre. State Governments are providing land for construction of the permanent Centre as well as temporary accommodation for immediate setting up of the RRCs. Various services to be provided by the Centre will include, Diagnostic Facilities, Equipped Physio-Occupational Therapy, In-patient bed facility, Minor Operation Theatre,

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Artificial Limbs and appliances fitting centre, Vocational Training, Teaching and Training to health personnel and community workers.

**Economic Assistance by Public Sector Banks:** All orphanages, homes for women and Persons With Disabilities as well as institutions working for the welfare of the handicapped, are given loans and advances at very low rates of interest (4% under DRI) and a subsidy of 50% up to a maximum of Rs. 5,000/- is also admissible. State Governments/Union Territories also give concessions/facilities such as reservation in jobs, scholarships, old age pension, free travel in buses, etc.

**Funding scheme for special schools:** This is a grant-in-aid scheme for voluntary organisations to develop institutes that serve to provide educational and social opportunities for Persons With Disabilities.

**Relief Assistance under Bilateral Agreements:** Ministry of Social Justice and Empowerment operates the Bilateral Agreements entered into, by the Government of India with the Government of USA, UK, Sweden, Switzerland and Germany. Objectives of this scheme are to provide duty free entry into India of donated supplies for relief and rehabilitation of poor and needy without discrimination of caste, creed or race. Organisations which are charitable in nature and not running on profit should be engaged in rehabilitation of the poor and needy and other weaker sections irrespective of caste, creed, colour, gender, religion etc. The donee organisation should be recognised under the Bilateral Agreement and should be registered under Societies Registration Act or registered as a charitable institution with State/Union Government. It should be registered under FCRA by Ministry of Home Affairs, if funds are also received by the said organisations from abroad. The source of income must be known.

**Grant-in-Aid Schemes:**

**Assistance to Voluntary Organisations for Disabled:** The scheme was started with a view to provide assistance to voluntary organisations working in the field of handicapped welfare. It is a comprehensive scheme to cover different areas of rehabilitation - physical, psychological, social and economic. Financial support is given up to the extent of 90% of the total project cost (up to 95% for the rural areas), for recurring items like staff salary, maintenance charges, contingencies and non-recurring items like construction of the building, Rs. 5 lakhs is provided. Financial assistance is given for such projects as vocational training centres, special schools, counselling centres, hostels, training centres for personnel, placement services, etc.

**Assistance to Persons With Disabilities for Purchase/Fitting of Aids/Appliances [ADP]:** The main objective of the scheme is to assist needy Persons With Disabilities in procuring durable, sophisticated and scientifically manufactured aids and appliances that promote their physical, social and psychological rehabilitation. The scheme is implemented through centres run by the companies registered under Companies Act, registered societies, trusts or any other institutions recognised by the Ministry of Social Justice and Empowerment for the purpose. A large number of governmental and non-governmental agencies are engaged for the implementation of the scheme. Aids and appliances such as wheelchairs, crutches, callipers, hearing aid, Braille slates, etc. are given to different categories of Persons With Disabilities. Indian citizens possessing a certificate from a registered medical practitioner can benefit under this scheme. Persons With Disabilities in need of aids and appliances are given travel allowance subject to a limit of Rs. 150/- for visiting the implementing agencies' centre. The boarding and lodging expense at the rate of Rs. 10 per day subject to Rs. 150/- per beneficiary is also admissible in cases where the income of such persons is less than Rs.

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1200/- per month. According to the scheme, aids and appliances up to the value of Rs. 3600/- are distributed to Persons With Disabilities free of cost if the monthly income of Persons With Disabilities is up to Rs. 1200/- and at 50% of the cost is provided if it is between Rs. 1201/- and Rs. 2500/-.

**Assistance to Voluntary Organisations for the Rehabilitation of Leprosy-Cured Persons:** India has a large population of leprosy-affected persons; the figure is estimated to be 4.50 lakhs. The scheme is designed to provide financial assistance to NGOs in a phased manner for the rehabilitation of leprosy-cured persons both in rural and urban areas. Assistance is given up to 90% of the project cost. Programmes like awareness generation, early intervention, educational and vocational training, economic rehabilitation, social integration, etc. are undertaken under the scheme.

**Assistance to Organisations for Persons with Cerebral Palsy and Mental Retardation:** Under the scheme, assistance is given to NGOs up to the extent of 100% for running training courses for teachers in the area of cerebral palsy and mental retardation. Both recurring and non-recurring items are considered for sanction.

**Establishment and Development of Special Schools:** The scheme envisages providing assistance to the NGOs up to the extent of 90% for establishment and up gradation of special schools in the four major disability areas - orthopaedic, hearing and speech, visual and mentally retarded. Priority under the scheme is given to setting up of schools in districts where there is no special school at present. Both recurring and non-recurring expenditure is supported.

**The Integrated Education Scheme:** The scheme of Integrated Education was initiated with the help of ministry of human resources development in order to educate children with disabilities in regular schools. The scheme provides financial assistance to voluntary agencies to implement this scheme. One resource teacher is for at least 8 children with disabilities and assistance is also given for assistive devises, teaching and learning aids and resource centres.

**Science and Technology Project in Mission Mode on Application of Technology for the Welfare and Rehabilitation of the Handicapped:** The objective of the scheme is to coordinate and fund the research projects for generation of new technology in terms of development of assistive devices for large scale use by Persons With Disabilities. The focus of S&T Mission Mode scheme is to design, develop and standardise new and innovative assistive devices. Leading research institutions are encouraged to undertake research on better materials, design and technology for fabricating high quality modern state of the art assistive devices. Several products have been successfully developed. To name a few; plastic aspheric lenses for the low vision persons, B.K. Prosthesis, inter-pointing Braille writing frame, PU Foam foot, multifunctional wheelchair, feeding aid for spastic etc. are a few developed under the Mission Mode. 100% funding is provided to the research/scientific institutions through Rehabilitation Technology Centre.

**Training in the UK under the Colombo Plan:** Every year, officers/NGOs are sponsored to undergo training in the UK under the Colombo Plan. The officers are nominated from Central Government, State Governments, National Institutes and from non-governmental organisations that are actively engaged in providing welfare services to the handicapped and disadvantaged.

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UNICEF Assistance in collaboration with the Government of India: The Master Plan Operation (MPO) 1991-95 was launched in 1991, with the help of UNICEF, to prevent childhood disabilities in India. The Master Plan of Operation short listed the following components of programs as major areas of activities:
- Strengthening and integrating disability prevention and rehabilitation in existing government services at the community level.
- Support for communications, including audio-visual and print media for advocacy, information and training.
- Support to research and planning, especially to studies which promote interventions that can be taken up by the community in rural areas and/or urban slums.
- Support for innovative projects at the community level, particularly those being run by NGOs.
- Monitoring and evaluation of ongoing programs. Objectives of the Master Plan of Operations (Bridge Program) 1996-97 also include other thrust areas such as the convention on the rights of the child. National Plan and State Plan of Action for the prevention, early detection and intervention of childhood disability.

Assistance through Overseas Development Administration, UK: Urban Based Community Rehabilitation programs have been taken up in the cities of Calcutta, Bangalore and Visakhapatnam under the Overseas Development Administration of the United Kingdom (ODA).

Employment of Handicapped: Objectives of this initiative include provision of assistance to Persons With Disabilities in getting gainful employment either through Special Cells in normal Employment Exchanges or through Special Employment Exchanges for physically handicapped persons. This scheme is implemented through Labour Department of State Governments/UT Administrations. Up to 100% financial assistance is provided in the case of Special Cells, and 80% in case of Special Employment Exchanges to State Governments/Union Territory Administrations.

National Awards for Persons With Disabilities: The Ministry of Social Justice and Empowerment has been giving National Awards since 1969 on the International Day of Persons With Disabilities i.e. 3rd December every year. The President of India gives the awards to outstanding personalities in the field of disability and development. The Awards are given in different categories, namely best employer of disabled, outstanding employee, placement officer, best individual, institution, barrier-free environment, creative Persons With Disabilities and National Technology Awards to those involved in the rehabilitation and welfare of Persons With Disabilities. Institution of Awards has created awareness amongst the Persons With Disabilities both in public and private sector and brought them to the mainstream.

New Initiatives:
Directory of Assistive Devices: Directory on Assistive Devices on Educational Tools and Barrier Free Features for Persons With Disabilities containing information on availability of assistive devices and barrier free features was formally released by the Hon'ble Minister of State for S J and E on the 'World Disabled Day', the 3rd Dec., 2000. A revised edition of the Directory with great details, especially on Barrier Free features is being brought out shortly.

Sensitizing the probationers at LBSNAA: To sensitise the future administrator of the country, two 1-day seminars were held at LBSNAA on 28th October, 99 and 14th October, 2000 on disability issues. These programmes included both classroom intervention and field visits.

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Development of new assistive devices: Major strides have been made in the development of State of Art assistive devices through the scheme of S&T Project in Mission Mode. Major developments of assistive devices included commercial production of Plastic Aspheric Lenses, and Development of Motorised wheelchair.

Educational support programme: A project to support children with disability with education and other supplementary services is being funded by UNDP and is being implemented in ten blocks each in Karnataka and Uttar Pradesh. A two day workshop of representatives of two State Governments, Janshala and NIMH was held in which detailed activities to be undertaken upto March, 2001 were worked out. The total duration of the project was 3 years with a funding of $ 1 million.

Identity Cards for Persons With Disabilities: Guidelines for issuing Identity Card to Persons With Disabilities by the respective States/Union Territories have been issued by the Ministry, after consultation with State Governments/NGOs as well as concerned Ministries.

NIDRR Project: An agreement has been signed with NIDRR, USA for supporting various applied research projects including modernisation of ALIMCO. Professionals from USA have already given hands-on training to professionals at ALIMCO on production/process modernisation. A team of experts on Mobility Aids from NIDRR visited India and interacted with ALIMCO, IIT - Delhi and CEERI on 19th December 2000.

Concessions and relaxations:
Concessions on Railways: Railways allow Persons With Disabilities to travel at concessional fares up to 75% in the first and second classes. Escorts accompanying blind, persons with orthopaedic and mental disabilities are also eligible to 75% concession in the basic fare.

Air Travel Concessions: Indian Airlines allow 50% concession fares to blind persons on single journeys.

Postage: Payment of postage, both inland and foreign, for transmission by post of 'Blind Literature' packets is exempted if sent by surface route.

Customs/Excise: Braille paper has been exempted from excise and customs duty provided the paper is supplied direct to a school for the blind or to a Braille press against an indent placed by the National Institute for the Visually Handicapped, Dehradun. All audiocassettes recorded with material from books, newspapers or magazines for the blind are exempt from custom duty. Several other items have also been exempted from customs duty if imported for the use of a Person With Disability.

Conveyance Allowance: All central government employees who are blind or orthopaedically handicapped are granted conveyance at 5% of basic pay subject to a maximum of Rs. 100 per month.

Educational Allowance: Reimbursement of tuition fee of physically and mentally handicapped children of the Central government employees has been enhanced to Rs. 50/-. Income Tax Concession: The amount of deduction of income tax from total income of a person with blindness, mental retardation or permanent physical disability has been increased to Rs. 40,000/-. 

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Award of Dealership by Oil Companies: The Ministry of Petroleum and Natural Gas has reserved 7.5% of all types of dealership agencies of the public sector companies for the orthopaedically handicapped and blind persons. However, persons with visual handicap are not eligible for LPG distribution. Similarly, the Ministry has also reserved 7.5% of such dealership/agencies for defence personnel, and those severely disabled either in war or while on duty in peacetime.

Posting: Candidates with Physical disabilities, appointed on a regional basis are given as far as possible, appointments as close to their native place.

Apart from the programmes of the union GOVT of India, there are specific schemes and programmes which are implemented by the state GOVTs according to their economic capacities. These programmes include; pension for Persons With Disabilities, free/concessional fare in state transport, unemployment allowance, micro CBR programmes, self-employment loans, vocational programmes, scholarship for students with disabilities, insurance for severely and profoundly disabled people, grants for setting up of small business, marriage allowance, reservation/quota in public sector employment, higher education, assistance for assistive devises and other concessions, relaxations, schemes, programmes and activities have been implemented along with general development programmes.

Key issues in implementation: Some key issues with respect to implementation of policies and institutions under the Act include:

- the definition of disability is not comprehensive, so a number of seriously disabling conditions are not included
- even for the disabilities included, the definitions included in some cases are not operationally useful (e.g. mental illness is defined as "any mental disorder other than mental retardation")
- in practice, the functioning of the Commissioner for Disability has been under-resourced, partial, as it reaches lower levels of the system (e.g. many states have Commissioners who perform the function as an additional task), and with weak enforcement powers, often low and the relative influence of disability institutions very variable across states.
- it remains unclear how the commitments and entitlements under the Act relate to the fiscal possibilities of the public sector at different levels, nor is there an overview to date of the fiscal impact of its implementation. In recognition of some of these shortcomings, amendments to the Act were proposed by a Government committee in 1999, but their status is unclear. More immediately, GOI is establishing a Disability Commission with status equivalent to the Human Rights Commission and others in response to concerns from many quarters that disability issues are not receiving sufficient profile.

Despite such concerns, there are examples of states where substantial improvements in the operation and priority of policies and programs for Persons With Disabilities have been made. These include not only the more developed southern states like Karnataka and Tamil Nadu, but also states such as Rajasthan, which is considered to be very progressive despite its low income level.

Access to services and programs for Persons With Disabilities: The current situation of access to services for Persons With Disabilities exhibits both the legacy of separate programs and the more recent emphasis on mainstreaming them into general programs. While the more recent approach includes a continued emphasis on specific services for Persons With Disabilities (e.g. rehabilitation, institutional and community-based), increasing
access for them to regular social services is seen as the key to improving outcomes, both in terms of prevention of disability and in terms of better outcomes. The overall policy direction was introduced in the Ninth Five Year Plan and built upon in the Tenth. However, while the need for inclusive social services and policies has been increasingly recognised, there remain serious concerns on implementation in a number of areas.

**Sectoral policies and programmes:** This section outlines some of the main sectoral policies and programs related to Persons With Disabilities, focusing on programs identified by both Government and NGOs as key areas during the scoping mission for the study. There is also a range of cross-cutting issues in policy and service delivery. Access to services is a key example. Persons With Disabilities face major barriers in physical access, in the form of lack of wheelchair accessible ramps and elevators, unavailability of transportation, stairs and narrow doorways in public facilities, all of which limit their access to services. The Persons With Disabilities Act provides specific instructions on this, and the guidelines have been addressed by Ministries such as Urban Development. India also has several programs to enhance the availability of low-cost, appropriate technology both in rehabilitation and access. The development of appropriate technology is the mandate of the Council for the Advancement of People's Action in Rural Technology (CAPART) and other organisations. CAPART also has a strong emphasis on integrating the needs of Persons With Disabilities in its programs. However, establishment of a barrier-free public environment remains a distant reality to date.

(a) **Health care:** Health care is critical to the disability agenda in terms of prevention of disability, rehabilitation, and the often greater-than-average health care needs of Persons With Disabilities. As with other sectors, there is a dual need to focus both on specific programs for Persons With Disabilities and to prevent/minimise disability, and on promoting the access of Persons With Disabilities to mainstream programs. There is also a need to understand better the role of health services in contributing to disability, through poor or untimely treatment. A fundamental issue is also the dominant role of the private sector in health financing and service provision in India, and the implications of access to services for Persons With Disabilities and the role of the public sector in the face of market failures. Access to health services for Persons With Disabilities is an under-studied area. However, the available evidence suggests that it is a serious concern, particularly for women. A range of national programs with direct bearing on prevention of disability, including Leprosy Eradication, Blindness Control, Iodine Deficiency Disorders Control, Mental Health, and Universal Immunisation have been proving little effective in the recent past. For some of them, there has been clear progress in recent years on prevention of disabling conditions (e.g. the share of people with locomotor disabilities caused by polio fell by around 10% between the 1991 and 2002 NSS rounds). This underlines the evolving nature of disability in the population. Just as with health status in the general population, the causes and composition of disability can be expected to change over time, as disability shares from malnutrition and infectious/contagious diseases fall, and shares of other disabilities such as locomotor increase due to reduced mortality rates and rising life expectancy.

(b) **Education:** As in many countries, the trend in education for Persons With Disabilities in India has been towards inclusive education in mainstream schools wherever possible. The revised National Policy on Education and Plan of Action in 1992 recommended integrated education for Persons With Disabilities, i.e. those children with mild and moderate disabilities should be in regular schools. The policy was reinforced by the Persons With Disabilities Act - which included a 3% reservation for children with disabilities in all educational institutions run or funded by Government - and by the DPEP emphasising on reducing disparities in enrolment. The Rehabilitation Council of India also implements a national teacher training
program, and states are beginning to include training on integrated education in their general teacher training programs. In addition, there are guidelines on construction promoting physical access for Persons With Disabilities. Although integrated education had been a national objective for over five decades, when various experiments (e.g., by the Royal Commonwealth Society for the Blind) were initiated, IE received a substantial boost through the DPEP. From a few IE pilots across the country, IE has since grown to cover over 2,000 blocks across 18 states. DPEP guidelines clearly state that “DPEP will fund interventions for IED of primary school going children with integrable and mild to moderate disabilities”.

To some extent this has been achieved through surveillance, early detection and awareness building across communities, improved in-service training with a special focus on children with special needs, other logistical and resource support, ensuring barrier free architectural design, and provision of educational aids and services. SSA has built on the experiences of DPEP, scaling up efforts across the country. The SSA also provides for an integrated and inclusive education policy, emphasizing a “zero rejection policy” to ensure universal primary education. It also commits the government to provide aids, appliances, barrier free schools, and training of teachers in sensitivity issues and on special curricula. There remains, however, a criticism that the allocated resources are inadequate to meet country’s needs, and that the modes of service delivery need to be revisited. There also remains limited consolidated analysis in both fiscal terms and with respect to specific interventions of the most cost-effective and sustainable ways of meeting the policy commitments under Sarva Shiksha Abiyan [SSA] for children with disabilities.

Despite the significant progress in inclusive policies, evidence on outcomes to date with improving attendance among children with disabilities suggests that there is a long way to go. The 2002 NSS data on education enrolment and illiteracy among children with disabilities are sobering, indicating both low average enrolment and high variability by type of disability, with the situation of blind and mentally ill children particularly difficult. There are also notable patterns by rural/urban location, though gender ratios in enrolment are surprisingly close, giving anecdotal evidence on the situation of disabled girls and general gender enrolment ratios. The summary data are presented in [Table 5.1]:

Table 5.1 Education indicators by type of disability, 2002:

<table>
<thead>
<tr>
<th>Type of disability</th>
<th>Enrolment rate for 5-18 yrs.</th>
<th>Literacy rate 5-18 yrs.</th>
<th>Girl/boy enrolment ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blindness</td>
<td>9.5%</td>
<td>38%</td>
<td>95%</td>
</tr>
<tr>
<td>Hearing disability</td>
<td>20.3%</td>
<td>42%</td>
<td>96%</td>
</tr>
<tr>
<td>Speech disability</td>
<td>47.2%</td>
<td>35%</td>
<td>106%</td>
</tr>
<tr>
<td>Locomotor disability</td>
<td>29.2%</td>
<td>59%</td>
<td>105%</td>
</tr>
<tr>
<td>Mental illness</td>
<td>16.7%</td>
<td>22%</td>
<td>99%</td>
</tr>
<tr>
<td>All children with disabilities</td>
<td>26%</td>
<td>49%</td>
<td>94%</td>
</tr>
</tbody>
</table>

Source: NSS, 58th round.

(c) Employment: There is a range of public policies and institutions to promote employment among Persons With Disabilities. The Persons With Disabilities Act mandates a 3% quota in public employment for Persons With Disabilities, with the aggregate quota divided in turn between those with locomotor, hearing, and visual disabilities. The Act further sets a target of 5% of the workforce for Persons With Disabilities in the non-public sector, though the incentives anticipated in the Act have never been elaborated. Apart from the Persons With Disabilities Act, there are a range of more specific efforts to include Persons With Disabilities

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in areas like VET, and establishment of a network of Special Employment Exchanges for Persons With Disabilities and special units for Persons With Disabilities within regular Employment Exchanges throughout the country.

In spite of such policies, labour force participation and employment rates among Persons With Disabilities are much lower than among the general population, and highly variable by type of disability. The wages of Persons With Disabilities and disability-wise rate of employment is far lower (e.g. around 9% for the blind), and exhibit large variations by gender (men’s employment rates are 3.5 times those of women). Even among those in employment, rates of regular/full time employment are said to be significantly lower. The situation in the formal sector appears particularly problematic, e.g. a 1999 NCPEDP survey of the top 100 companies in India found that Persons With Disabilities comprised only 0.4% of their workforces, with public enterprises around 0.5%, private around 0.3%, and multi-national enterprises a mere 0.05%; quotas for employment of Persons With Disabilities are often not met, and there have recently been well-publicised cases of exclusion of qualified Persons With Disabilities from the IAS and other positions. The success of specific interventions like the Employment Exchanges has also been limited to date, with just over 4,000 Persons With Disabilities annually placed by exchanges nationally during the 1990s.

The extent to which low LFP and employment rates are driven by different factors; including societal attitudes and discrimination; skill levels among Persons With Disabilities, and constraints on employment in different occupations due to the nature of disabilities, is not well understood. While existing research provides insights (e.g. that women with disabilities are significantly more likely than men to lose their job due to the onset of disability), the area is under-researched. A further important element of the labour and employment story with respect to Persons With Disabilities is workplace injury and its contribution to preventable disability. NSS data from 2002 indicate that around 37% of currently disabled were working prior to their disability. At the same time, relatively little reliable information is available on the nature and incidence of workplace injury in India, or the effectiveness of occupational health and safety standards in helping to minimise it.

(D) Social protection and anti-poverty programs: The Persons With Disabilities Act includes promotion of the social security needs of Persons With Disabilities as one of its core areas. There are a range of specific social protection schemes for Persons With Disabilities, as well as different forms of disability insurance, public and non-government. However, for all programs, evaluations are scarce, even in terms of reliable estimates of the fiscal costs of programs at central and sub-national levels. Disability insurance for civil servants and private sector workers covered by the Employers’ Pension Scheme is part of their wider social security packages. Previous Government initiated a social security scheme for the unorganised sector, which includes an integrated package of pension, health and workplace injury insurance. The various disability insurance initiatives have an important link to the design of broader health insurance, given the policy choices surrounding whether to insure people for a package of health services or for the disabling events itself. The broader social protection program for Persons With Disabilities is the centrally-sponsored non-contributory pension for Persons With Disabilities, which is targeted on Persons With Disabilities under the Act who have incomes below a certain level. Government of India provides a standard monthly amount per beneficiary under the program, which can be topped-up from states’ own resources. These programs are administered at state level and a significant degree of variation in coverage and efficiency is likely. To date there is relatively limited reliable evaluation of the incidence and impact of the scheme, with preliminary work done in states like Karnataka suggesting concerns with both inclusion and exclusion errors, and Planning Commission assessments.

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Attitudes towards Persons With Disabilities: Discussions of disability in India stress the negative societal attitude to Persons With Disabilities. This is variously put down to religious, cultural, political and other reasons. There are assessments of attitudes to specific disabling conditions such as leprosy and mental illness in the context of national programs and initiatives.

The MSJE is the nodal agency of the Central Government that promotes services for the Persons With Disabilities through its various schemes. The primary objective is to promote services for Persons With Disabilities through government and non government organisations, so that they are encouraged to become functionally independent and productive members of the nation through opportunities of education, vocational training, medical rehabilitation, and socio-economic rehabilitation. Emphasis is also placed on coordination of services particularly those related to health, nutrition, education, science and technology, employment, sports, cultural, art and craft and welfare programs of various government, unilateral, bilateral and multilateral agencies, UN agencies, international development and disability agencies and non-government organisations.

Source:
3. www.disabilityindia.org
4. www.socialjusticeandempowerment.nic.in

5. CHALLENGES VERSUS RESPONSES
5.5. VOLUNTARY ORGANISATIONS AND DISABILITY SECTOR IN INDIA

Voluntary sector; which is popularly known as NGO or Non Governmental Organisations; is a key player in promoting and protecting the human rights of Persons With Disabilities in India. This sector can be broadly classified into six categories according to the nature of work these organisations carry out in order to create enabling environment to empower Persons With Disabilities. They are:

A. International donor agencies promoting general development.
B. International donor agencies promoting disability and development.
C. National development agencies promoting general development.
D. National development agencies promoting disability and development.
E. Disabled Persons' Organisations [DPOs] or The Self Advocacy Organisations.
F. Community Based Organisations [CBOs] promoting general development.

Every organisation has its own strengths and limitations. The perspectives, strategies, approaches, models and responses to disability and development differ from one set of organization to the other. Disability sector in India applies a wide range of strategies and approaches for the empowerment of Persons With Disabilities. The strategies range from narrow medical model to wider social or rights based model.

A. International donor agencies promoting general development:
A wide range of international donor agencies have been promoting general development in the country. The ultimate aim of these agencies is to eradicate poverty and empower poor and marginalised in order to access their rights and entitlements and exercise their rights and discharge their duties to life of dignity. The focus of these agencies varies depending upon the priority of the agency. The key issues covered are women, children, tribal people, dalith, minority, education, health, environment, governance and other socio economic political and cultural issues of the society. Few agencies have been addressing issues affecting the lives of Persons With Disabilities. Disability is a priority agenda in the wider development spectrum for few agencies. This section summarises the significant contribution made by these agencies in promoting and protecting the human rights of Persons With Disabilities.

Action Aid: Action Aid is an international donor agency which has been undertaking pioneering work in the field of disability and development. Headquarters of this agency is based at New Delhi and they operate through 14 regional offices based in different states across the country. Action Aid works through NGOs, CBOs and local organisations and promotes direct initiative depending upon the need and availability of credible local agencies. Disability is a cross cutting issue along with women and children. It also recognises disability as a special group for focused interventions. Twin track approach is applied to disability and development which promotes both exclusive disability specific initiatives and inclusive development initiatives where disability is included with development. 10% of its total outlay is earmarked for disability and development. Disability friendly HR policy makes provisions for recruitment and training of staff with disabilities and a barrier free environment to discharge their duties to the best of their potentials. Action Aid advocated and popularised the concept of CBR in India through initiating and promoting 16 CBR initiatives across the country in 1990. Before that it supported 45 institutions working with Persons With Disabilities across the country. Action Aid applies rights based approach to disability and development where CBR initiatives are implemented with rights based focus.

Department for International Development [DFID]: DFID is a department of British Government with a aim to promote general development in developing countries. It operates
in India towards achieving the Millennium Development Goals [MDG]. One of the goals is to eradicate extreme poverty and hunger by 2015. It works with NGOs and the state to promote general development in the backward regions of India. Disability is a priority issue to DFID which is well articulated in the position paper of DFID titled “Poverty and Disability, Disability and Development”. It advocates for a twin track approach to meet the specialised needs to cope with various impairments and meet the general needs to ensure equalisation of opportunities and full participation of Persons With Disabilities across the spheres of life. It has been making serious attempts to include disability with development through an initiative called PACS. Poor Area Civil Society [PACS] is an initiative implemented in 100 poorest districts of MP, Bihar, Jharkhand, Chattisghad, Uttar Pradesh and Uttaranchal. This initiative is also focusing on disability through promoting disability specific projects with a clear mandate to include disability in general development initiatives. Apart from this initiative nothing much has been done with regard to the rights of Persons With Disabilities. The position paper is yet to be translated into reality in letter and spirit.

Voluntary Service Overseas [VSO]: VSO is an international development agency which works from its New Delhi based office. The main objective of this agency is to build the capacity of various development agencies in various aspects. It places its volunteers who are technical experts in different fields and enable national development agencies and community based organisations to upgrade and build their skills to implement the development initiatives effectively. Disability is a priority agenda of VSO who are making attempts to build the capacity of disability agencies to develop human resource through transfer of skills by placing its volunteers who are the experts of disability sector. Apart from the two international donor agencies there are agencies like Save the Children Fund [SCF], Oxfam GB, Care, Plan, Child Relief and You [CRY], US Aid, America India Foundation, Catholic Relief Services [CRS], Christian Aid, Christian Children Fund [CCF], and a whole lot of international development agencies that have been working in India promoting general development. Many of these agencies are not aware of disability at all and few of these agencies have position paper on disability but it still has to be translated into reality. It is very important that these agencies realise that unless they include disability at organisational level and field level the development and empowerment process facilitated by these agencies will be incomplete since they are excluding 20% of the most poor and marginalised from their work i.e. Persons With Disabilities.

B. International donor agencies promoting disability and development:
A wide range of agencies promote disability work through NGOs and other agencies. These international agencies fund only disability programmes and promote community initiatives. The important agencies include:

Association of Italian Felerio Organisation [AIFO]: AIFO is an Italian organisation based at Bangalore, who initiated their work with persons affected by leprosy. The objective was to eradicate leprosy and rehabilitate persons affected by leprosy. Now AIFO has moved to general disability field and promotes CBR programmes across the country. The salient feature of the CBR promoted by this agency is that of integration of persons affected by leprosy along with other category of Persons With Disabilities.

CBR Forum: CBR Forum is a branch of Caritas India which is based at Bangalore and promotes CBR programmes across the country. This agency promotes micro CBR initiatives through disability agencies. The duration of the initiative ranges from 3-4 years depending on the need and achievement of the organisation. All categories of Persons With Disabilities are covered through the initiatives.

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Christopher Blinden Mission [CBM]: CBM is another agency which promotes disability work across the country. The headquarters are based at Bangalore and works through disability organisations. It funds for promoting CBR initiatives and focus is on visual disability. This agency initially supported many institutions working with persons with visual impairment across to support education, vocational training and livelihoods. Now only CBR initiatives are being supported by the agency.

The Leprosy Mission [TLM]: TLM is another agency which promotes CBR initiatives across the country. The head quarters of the organisation is based at New Delhi and operates across the country. The agency initially worked with persons affected by leprosy. The organisation was initiated to eradicate leprosy and provide rehabilitation services to Persons With Disabilities and now promotes general CBR initiatives with a special focus on integration of persons affected by leprosy. This agency has created a good amount of basic infrastructure to provide medical and basic rehabilitation services to all categories of disabilities.

Handicap International [HI]: HI is an international agency based at New Delhi and promotes disability work across the country through disability organisations. It provides both technical and financial support to NGOs to promote disability work. The approach promoted by this agency is known as CAHD [Community Approach to Handicap in Development] an approach which emphasises on inclusion of disability with general development.

Leonard Cheshire International [LCI]: LCI is an international organisation which works through its Regional office, South Asia based at Bangalore. The regional office was set up to build the capacity of a wide range of Cheshire Homes located in different parts of the country. The Cheshire Homes are known for their intensive institutional care and basic rehabilitation services to persons with multiple and profound disabilities. LCI is not largely a donor agency but it facilitates its partners to raise resources both internally and externally. Now these Homes are not just limited to institutional care but are also moving out towards communities. LCI ROSA is facilitating its partners to initiate CBR programmes in neighbouring communities which is a bold step towards community approach.

Action on Disability and Development India [ADD]: ADD India is an international agency which operates through its Bangalore based office across south India. The philosophy and approach of this agency is to organise Persons With Disabilities into Self Help and Advocacy Groups [SHAGs] at village level and federating them at block, district and state levels. A large number of SHAGs of Persons With Disabilities and their care givers federated at various levels are functioning across the country. It is not a donor agency but largely a training agency which believes that disability is a development and human rights issue and building the capacity of national development agencies and community based organisations to include disability as a priority agenda with their development work. It focuses on building the cadres at grass root level and equipping them with appropriate knowledge, attitude and skills to facilitate the process of inclusion.

CBR Network: CBR network is an international agency which operates from Bangalore based South Asia office across the country. It promotes national disability agencies to initiate CBR programmes across the country. It works with state and facilitates initiation of CBR programmes across the country. The focus of this agency is on early detection and inclusive education. It was instrumental in initiating rehabilitation courses on various aspects of CBR through University of Bangalore. It has been striving towards inclusion of disability as a priority agenda in all the concerned departments of the state. It is not largely a donor agency.
but strives for developing the required human resource for the development of Persons With Disabilities.

C. National development agencies promoting general development: A wide range of development agencies are working in the country to promote general development. Most of these agencies promote integrated development which includes health, education, livelihoods, governance and environment and other developmental issues. The ultimate aim of these agencies is to eradicate poverty through empowering poor and marginalised. Many of these agencies focus on some particular social groups such as women, children, dalith, tribal people, minorities, persons with HIV AIDS and other most marginalised groups. Few development agencies have realised that Persons With Disabilities constitute a significant amount of the most marginalised and are making serious and sincere attempts to include them in the development process.

Rural Development Trust [RDT]: RDT is a national development agency which promotes integrated development in Rayala Seema region of Andhra Pradesh. This agency is in the forefront in including Persons With Disabilities in the process. It applies twin track approach to disability. It has promoted a significant number of Self Help and Advocacy Groups of Persons With Disabilities and facilitated these groups to access basic rehabilitation services and fight for their rights. It also ensures that all other components of development process include disability in order to ensure access to general needs of this group. It is a very good attempt towards inclusion.

Young India Project [YIP]: YIP works in Anantapur and other selected districts of AP. The main focus of this agency is to organise landless labourers into Self Help and Advocacy Groups in order to fight for their rights. It has included Persons With Disabilities in this process. It has promoted a large number of SHAGs of Persons With Disabilities and enabled them to access their rights.

Sammuha: This agency operates in the northern part of Karnataka and promotes integrated development. It promotes both exclusive CBR initiatives for Persons With Disabilities and integrated development initiatives where disability is a priority agenda. It has facilitated Persons With Disabilities to form groups and federated them at various levels to strengthen disability movement.

Lokjumbish: Lokjumbish is a quasi state body which promotes education. It focuses on literacy where inclusive education of children with disabilities is a priority agenda. It has been instrumental in promoting literacy rate of children with disabilities in a significant number of districts of Rajasthan.

Nava Bharath Jagruthi Kendra [NBJK]: NBJK operates in many districts of Jharkhand and promotes integrated development. It is another live example for promoting the process of inclusion of Persons With Disabilities with development. It promotes both integrated and disability specific micro initiatives to empower Persons With Disabilities. It has promoted a network of CBOs and NGOs where disability is a priority agenda.

It is a positive trend that development agencies are getting increasingly sensitised and are striving to promote the holistic development of Persons With Disabilities. This is not enough. Unless a large chunk of development organisations realise and include disability as a priority and focus agenda with development, empowerment of this section is a dream.
D. National development agencies promoting disability and development: A wide range of disability organisations have been working towards empowering Persons With Disabilities. Around 4000 such NGOs are operating across the country. Majority of these NGOs are uni disability agencies which focus on one single disability. These NGOs provide a wide range of services to Persons With Disabilities. The services include basic rehabilitation services like assistive devises, surgical interventions, treatment, medication, therapeutic interventions and other appropriate training services to improve the functional ability of Persons With Disabilities. Apart from medical interventions these NGOs also provide education, vocational training placement services and other appropriate need based services. The approaches to provide these services include institutions, day care centres, special schools, out reach services, respite care centres, and CBR. Now these NGOs are moving towards community approaches to reach more and more Persons With Disabilities. Most of these NGOs are based in urban cities or the periphery of cities and towns. Remote villages have no access to these NGOs. These NGOs are moving from uni disability to cross disability services and focus on inclusive approaches. The important uni disability organisations include National Association for the Blind [NAB] which operates through its many branches based across the country and provide services to persons with visual disabilities. A large number of Spastic Societies provide services to persons with cerebral palsy. Parent’s organisations and a large number of networks provide services to persons with mental retardation and mental illness across the country.

The important agencies which promote CBR and provide cross disability services include, Sri Ramana Maharishi Academy for the Blind based at Bangalore which initiated work with visual disability but moved to cross disability and has been implementing CBR in a wide area. Blind People Association is based at Ahmedabad and has been promoting CBR in many parts of Gujarat. Association of Persons With Disabilities [APD] is based at Bangalore and is implementing a number of micro CBR programmes in many parts of Karnataka. Mobility India is based at Bangalore which provides technical support to organisations which work with Persons With Disabilities. NCPEDP is based at New Delhi and provides livelihoods to Persons With Disabilities across the country and takes up activities of advocacy. All India Confederation of the Blind, Institute of Speech and Hearing, Vidhya Sagar, Deepshika, JM institute of Speech and hearing, Shishusarathi, Bethany Society, Ashagram trust, Amarjyothi Charitable trust, Akshay Prathishtan, ASTHA, Dish, Arushi, Seva In Action, Narendra Foundation, Nidan, SPARC, Action For Autism, Vikalang Kendra, Sankalp, Vishk and a large number of other agencies have been implementing CBR programmes along with institutional care to cross disability. These agencies have started networking with each other and promote disability networks consisting of disability agencies, development agencies and disabled people’s organisations across the country in order to demonstrate the strength of disability sector in India. The important disability networks which are active are include Orissa State Disability Network, Jharkhand network, MP network, Meghalaya network, Tripura network, Disability network Karnataka, AP network, National disability network and various networks of parents associations and psychiatric disabilities.

E. Disabled peoples' Organisations [DPOs]: Disability movement has been well placed in India in recent past. Persons With Disabilities and disability sector at large realised that disability movement should be led by Persons With Disabilities themselves. There are two streams of thoughts about disability movement. A discusses about organisations for Persons With Disabilities where as B insists on organisations of Persons With Disabilities. Now more and more organisations of Persons With Disabilities are emerging and working towards self empowerment. These organisations are also called self advocacy organisations. DPOs were instrumental in lobbying with the state to enact legislation for Persons With Disabilities and formulation of various policies for the development of Persons With Disabilities. The
important DPOs or self advocacy organisations include National Federation of the Blind with more than 60,000 members across the country. It is one of the oldest self advocacy organisations which has been working with disabilities. There are uni disability self advocacy organisations which advocate for both their own disabilities and general issues of disability sector. There are two schools of thoughts about self advocacy organisations. One school insists on unidisabilities and other school focuses on cross disability organisations. There is a moderate school which accepts both unidisabilities and cross disability self advocacy organisations to address disability specific and general issues of the larger disability sector. The other self advocacy organisations which are active in India are: Kerala Federation of the Blind, Karnataka Federation of Persons With Disabilities, Disability rights group, All India Confederation of the Deaf, All India federation of the deaf, Karnataka Parents Association of Mentally Retarded Children, Karnataka Association of Psychiatric Disabilities, Amarlothi disabled peoples Association, Disability network of Andhra Pradesh, Friends of Disabled, Family of Disabled, Kutch Vikalang Mandal, Lohia Viklang Samithi, Karnataka Welfare Association of the Blind and Tamil Nadu Federation of Persons With Disabilities.

Self Help and Advocacy Groups [SHAGs]: Apart from DPOs at macro level there a large number of SHAGs at village level are functioning effectively in the different parts of the country. A recent study conducted by a PHD researcher reveals that there are more than 5000 such groups are involved in providing rehabilitation services at village level across the country particularly in southern part of the country. These groups are instrumental in generating awareness, raising, discussing and addressing the issues at micro level concerning Persons With Disabilities. Most of the times these SHAGs are promoted by disability/development organisations as a part their development or disability initiatives. These SHAGs proved very effective in solving the village, panchayat, hobli, block and district level issues of Persons With Disabilities. SHAG is a grass root level support structure to promote; effective and meaningful inclusion, empowerment and holistic development along with promoting and protecting the rights of Persons With Disabilities at village level.

F. Community Based Organisations: A wide range of CBOs are also associated with disability movement and sector which include development organisations and disability specific organisations. CBOs are promoted by development agencies to ensure sustainability and continuity of development programmes and also to lobby with the state for speedy and effective implementation of policies and legislations. These development oriented CBOs also work in solidarity with disability sector and support disability movement. Apart from this a large number of Self Help and Advocacy Groups are promoted by disability and development agencies in villages and towns to promote the concept of self help among poor and marginalised which work at village level and provide services to their members. The members of these groups constitute of Persons With Disabilities and their care givers. They act as self advocacy, pressure and lobby groups at village. These SHAGs have been federated at various levels in order to combine the disability movement. These groups provide basic services, help to access state social security schemes, assistive devises, education, livelihoods, training and appropriate services. There are differences in opinion about promoting Self Help and Advocacy Groups of Persons With Disabilities. The first and fore most difference arises as one of the schools of thought argues that promoting exclusive self help organisations may result in exclusion of the marginalised from the main stream community and therefore integrated groups should be promoted where all marginalised people, both disabled and non disabled, can be the members. The other school of thought argues that exclusive groups are essential to have a forum to discuss their own issues and address them effectively. They also argue that it is like any other groups of the marginalised such as women, dalith, tribal people, youth, children and other disadvantaged groups which are homogeneous and only have members from that group. The other difference of opinion is

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that there should be unidisabilities groups and cross disability groups. The socially accepted trend and existing groups show that cross disability groups function well considering number of Persons With Disabilities in a given village and the basic issues being same to any category. These groups are making attempts to address the specific issues of different categories of disabilities. The experiences of many disability and development agencies prove that exclusive groups of Persons With Disabilities function better and sustain longer period. The integrated groups have a tendency to ignore the issues of Persons With Disabilities since this group is not vocal and assertive. These integrated groups have not yielded expected results and disintegrate soon before achieving the aims and objectives of the groups.

Responses to disability in Kanakapura Taluk
The situation of disability in Kanakapura was similar to that of any other part of this country. The base line survey and pre evaluation conducted by Sourabha CBR project before initiating this programme clearly indicates that the level of awareness among community, access to education, livelihoods, social security schemes, state programmes, health care services, poverty alleviation schemes, development, building, public places and other basic services, participation of Persons With Disabilities, prevalence and incidence of disabilities, access to basic rehabilitation services, political participation and equal opportunities and full participation in all spheres of community life in Kanakapura was in the same category as any other blocks in India with regard to status of disability.

As far as disability and development is concerned the situation has changed drastically. The dramatic change is reflected in the significant transformation observed in community, families and Persons With Disabilities. There is optimum utilisation of state programmes and schemes in Kanakapura block. The spectacular changes have facilitated the process of inclusion of Persons With Disabilities. These changes are due to the CBR programme implemented by a disability organisation. The agency implemented its interventions for ten years and during its implementation period facilitated a community structure to ensure its sustainability in the long run. The services and support system for Persons With Disabilities still exist in the block for Persons With Disabilities.

The programme started with a typical medical intervention for Persons With Disabilities approach. Later on education, vocational, livelihoods, awareness programmes, community organisation components were added to the programme to make it more comprehensive and effective. These additions have yielded desirable and good results in terms of increased level of awareness, positive attitude, and reduced rate of incidence of disabilities, enhanced utilisation of state schemes and programmes and resources, utilisation of poverty alleviation resources, increase in functional ability, mobility, communication, self care, social skills, education and vocational skills of Persons With Disabilities. Increased access to education, livelihoods, state schemes and programmes, increased self esteem, respect, dignity, confidence, self worth, self actualisation and decision making power is noticed. The strategies applied by this agency are discussed in the case study of Sourabha CBR project.

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The indicators of significant change observed in the community and Persons With Disabilities are shown in the following table.

Table 5.2 Indicators of change:

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Rate in percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness on disability in community</td>
<td>78</td>
</tr>
<tr>
<td>Access to education</td>
<td>62</td>
</tr>
<tr>
<td>Access to state programmes</td>
<td>97</td>
</tr>
<tr>
<td>Access to basic rehabilitation services</td>
<td>93</td>
</tr>
<tr>
<td>Access to livelihoods</td>
<td>78</td>
</tr>
<tr>
<td>Access to public places</td>
<td>89</td>
</tr>
<tr>
<td>Increased participation</td>
<td>68</td>
</tr>
<tr>
<td>Increased decision making</td>
<td>87</td>
</tr>
<tr>
<td>Increased role in development</td>
<td>46</td>
</tr>
<tr>
<td>Increased income</td>
<td>57</td>
</tr>
<tr>
<td>Increased functional ability</td>
<td>97</td>
</tr>
<tr>
<td>Increased self esteem, dignity, respect and confidence</td>
<td>86</td>
</tr>
<tr>
<td>Increased strength</td>
<td>59</td>
</tr>
<tr>
<td>Increased visibility</td>
<td>99</td>
</tr>
<tr>
<td>Increased participation in politics</td>
<td>29</td>
</tr>
<tr>
<td>Increased role in family</td>
<td>67</td>
</tr>
<tr>
<td>Increased role in community</td>
<td>57</td>
</tr>
<tr>
<td>Married life</td>
<td>69</td>
</tr>
<tr>
<td>Increased identity</td>
<td>72</td>
</tr>
</tbody>
</table>


Source:
2. www.actionaidindia.org
3. www.empowerpoor.org
4. www.vsoindia.org
5. www.cbrnetwork.org
6. www.cbm.org
7. www.aifoindia.org
8. www.tlmindia.org

Conclusion:
The attempts made to review the existing and ancient approaches to disability clearly brings out the fact that the term rehabilitation itself has a negative connotation which limits the scope of inclusion process only to those with acquired disabilities. The literary meaning of rehabilitation is restoring the previous condition. This term is perfectly suitable if disability is due to various factors after birth. But if it is by birth the term looses all the meaning because restoring the previous condition does not apply. Considering these facts the operational definition used in this research goes well with rights perspective which is as follows: "Rehabilitation is a process of enabling a person with disabilities to reach or maintain; optimum physical, mental, intellectual, sensory, ophthalmic and emotional functional abilities; social, cultural and self actualisation levels with appropriate education, training, assistive devises, removal of barriers and appropriate access". This definition covers wider aspects of disability, development and responses. In any manner no definition is perfect unless it is practical and realistic. This calls for a wider debate on this concept to have a comprehensive, holistic, effective and practical definition.

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Many of the institutional care centres, training centres and vocational training centres are in a way contributing to perpetuate crippling negative attitudes and stereo types. There are quite a few examples of these care centres which have contributed tremendously to empower Persons With Disabilities but the concern is that most of these centres are urban based and reachable to only a limited number of Persons With Disabilities as against the large number of unreached population. Secondly a large chunk of resources are spent on few in a situation where there is a resource crunch both in terms of human resource, money and material. The existing systems of rehabilitation have both merits and demerits.

Global scenario vis-à-vis the universe: The field work brings out the fact that 60% of pioneers, 79% respondents with disabilities, their families and 63% of communities strongly feel that any approach or system which facilitates the process of inclusion and empowerment of Persons With Disabilities is acceptable, no matter whether they are institutional care centres or community initiatives as long as they do not exclude, perpetuate stereo types and lead to disempowerment and impoverishment. 69% respondents with and without disabilities strongly feel that there is a great need to facilitate community based institutions and care centres for persons with severe and profound disabilities to provide services and care to ensure their meaningful and full participation, promotion and protection of their human rights by considering the basic principles of rehabilitation which does not exclude and discriminates them from any aspects of life.

The historical overview of rehabilitation groups the reactions into six categories which did not come one after the other into effect. The matter of the fact is that they exist even today in some form or the other. Elimination, poorhouse and institutions can be seen in different forms in this country even today. Persons With Disabilities strongly feel that custodialisation should be ended and attempts towards this process are strongly condemned. 100% Persons With Disabilities and family members strongly feel that rehabilitation process should take place in their own communities without creating isolation and breaking the bondage of family and community. 74% of pioneers and 100% respondents from the community reinforce this view strongly. The primary data clearly articulates that there is a greater need to diversify the resource base and resources for the development of Persons With Disabilities. Majority of the charity oriented schemes and programmes of the state, voluntary and private sector should be converted in to a long term sustainable development programme in order to make significant and sustainable changes in the lives of Persons With Disabilities.

India has a well developed institutional and policy framework for the development of Persons With Disabilities. There are four core disability related legislations which provide scope for holistic development, equalisation of opportunities, full participation and protection of rights. The Persons With Disabilities Equal Opportunities Act 1995 is the queen of all other legislations and policies which creates a base for empowering Persons With Disabilities. There are a set of institutions namely Rehabilitation Council of India, National Trust, National Institutes, National Commission and other institutions which are working for the development of Persons With Disabilities. The Judiciary of India is always positive and progressively has interpreted the constitution in favour of Persons With Disabilities. The key issues lie in implementation of these legislations. Most of these legislations, policies and programmes are in paper and are suffering from lack of or non implementation due to resource crunch and apathy towards the issue. The ground realities and facts reveal that 35% of Persons With Disabilities and 36% of communities are not aware of existence of these legislations and policies. 73% of communities and service providers are not aware of any of these legislations and policies. If this is the case in a region where a CBR programme has been implemented for 10 years and has a strong disability self advocacy group with active disability movement going on, one can imagine what the situation would be where there are no such interventions

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at all. In spite of various concessions, schemes, programmes and relaxations provided by the state only a negligible percentage of Persons With Disabilities and their families could access these facilities. 99% of Persons With Disabilities and their families have accessed these concessions and facilities; 99% of respondents with disabilities and 70% communities are aware of these facilities, in spite of external interventions. But the national facts show that less than 10% have accessed these facilities. 98% of the respondents with disabilities, their families, 66% communities and 69% of pioneers strongly feel that opportunities for Persons With Disabilities should be made available everywhere by integrating disability component with all the concerned ministries, departments, programmes, schemes, policies and institutions besides a separate division or department for Persons With Disabilities. 95% of respondents with and without disabilities strongly feel that there is a greater need to simplify the procedures and process to access entitlements of Persons With Disabilities. The majority of the respondents strongly feel that the services, support structures and coordination and implementing institutions should be decentralised and attempts should be made to ensure an accountable institution at the block level should hear the complaints and makes conscious attempts to redress the grievances filed by Persons With Disabilities.

Apart from the state there is a sub sector called NGO which is striving for the development of Persons With Disabilities in India. About 4000 NGOs are working for Persons With Disabilities most of which have been functioning as uni disability organisations which cater to the needs of one category of disabilities through institutional care centres. There is a shift from institution to community, uni disability to cross disability, medical approach to human rights approach in these NGOs. A large number of development organisations have excluded Persons With Disabilities from their purview of development. There is an increasing trend to include Persons With Disabilities with development. It is evident that NGOs have contributed significantly to the development of disability sector in spite of their limitations. There is a great need and opportunity for encashing and capitalising on the existence of thousands of development agencies with regard to inclusion of Persons With Disabilities in the development process. There is an increasing trend and realisation among Persons With Disabilities about the great need to create more and more organisations of Persons With Disabilities to address the needs of cross disability. The primary data substantiates the fact that 100% of Persons With Disabilities, their families, 83% communities and 43% pioneers strongly and 40% feel that Persons With Disabilities need exclusive groups to address their own issues effectively.

Majority of the respondents with and without disabilities strongly feel that there is a great need to promote more and more SHAGs at village in order to provide basic rehabilitation services, address issues and advocate for their own rights. Majority of the respondents strongly feel that facilitating Persons With Disabilities and their families in to exclusive SHAGs does not hamper the process of inclusion unless these groups focus only on issues concerning Persons With Disabilities which can be avoided through addressing the general development and social issues concerning all including those of Persons With Disabilities. The disability movement should be led by Persons With Disabilities themselves. 69% of the respondents with and without disabilities strongly feel that disability should be integrated within the general development work by international, national, regional and local development agencies, as well as CBOs, networks and human rights movements with adequate priority for meaningful inclusion. There is a great need to consider disability as a priority agenda by all development agencies including the international donor agencies, development agencies, funding agencies and NGOs for meaningful and effective inclusion of this section. 59% of respondents with and without disabilities strongly feel that there is a greater need to establish effective and clear linkages with voluntary, private sector and the state for ensuring maximum utilisation of financial, material and human resources for the development.
of Persons With Disabilities to avoid duplication of efforts. Effective convergence and synergies will definitely maximise the impact of minimum resources invested on the issue. 89% respondents strongly feel that voluntary sector and DPOs should not waste their time in criticising each other and there is a greater need to work in coordination without self centred and egoistic attitude.

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