CHAPTER 6
ROLE OF CIVIL SOCIETY

India has a great tradition of voluntary service and in spite of rapid changes the urge to serve fellowmen is still widespread. It has been part and parcel of the cultural heritage of India from time immemorial to provide help and sustenance to the persons with disabilities. However, the rise of Non-Governmental Organisations (NGOs) has gained momentum during past couple of decades and its impact on the society perceptions and public policy in our country. The sphere of activities of the NGOs helps "empowerment\(^1\)" of the disabled (Lang 1994:6). It aims at helping patients to achieve maximum possible physical and psychological fitness and regain the ability to care for themselves. It offers assistance with the learning or referring of skills required in routine activities, with occupational training and guidance as well as with psychological re-adjustment. The process of empowerment of disabled persons involves basically three aspects. They are physical empowerment, vocational empowerment and psycho-social empowerment. These three aspects are so interlinked that any type of compartmentalisation between them is not desirable.

During the past couple of decades, extensive research has been conducted in developed and developing countries regarding the role of the NGOs and governmental organisations for the empowerment and social integration of disabled person. India also witnessed during the last few decades a proliferation of studies and surveys concerning the problem of disability. This Chapter concentrates on the role of international and domestic NGOs with regard to harmonisation of the Convention and also the programmes and policies launched by Government of India by way of implementing the same in collaboration with civil society at the grass root level.

\(^1\) The word "empowerment" is the process of facilitating a person’s ability to live and work as normally as possible.
6.1 Meaning and sphere of activities of NGOs

By their very nature, NGOs are very heterogeneous entities and range from large bi-lateral funding agencies operating in many countries to very small organisations operating at village level, whose function is to provide for the immediate needs of their members. The latter are sometimes referred to as grassroots organisations. Some even debate whether grassroots organisations are indeed NGOs. For example, Jenny Pearce has argued that grassroots organisations differ from NGOs in three different ways (Pearce: 1992). First, grassroots or people’s organisations are comprised of individuals who are bound together by particular interests or common characteristics, such as class, gender, cultural identity and even disability. In contrast, the social composition of intermediary NGOs is generally comprised of middle class individuals, who for a multiplicity of reasons and motivations, have elected to work on behalf of or with the poor. Secondly, grassroots organisations invariably have limited yet quite specific aims and objectives. In contrast, NGOs act as intermediaries whereby they provide a link between bilateral and multi-lateral funding institutions and grassroots organisations. Thirdly, ultimately grassroots organisations are accountable to their members, whereas, NGOs, despite rhetorical statements to the contrary, are ultimately accountable to their funders.

The UN Economic and Social Council (ECOSOC) defines a non-governmental organisation as any internal or national organisation which is not established by inter-governmental agreement. This broad term encompasses private voluntary organisations, community groups, professional and trade associations, labour unions, academic and scientific organisations and others (Chandra 2000:157). However, there is a shift of focus from the institutional care to community participation, as it indicates the rapidly growing social awareness for the rights and equitable status of disabled community.

In a developing country like India, voluntary action is a three stage process. First, it is based on social conscience which has been defined by Beveridge in his work,
“Voluntary Action” as “the feeling of discomfort on the part of the people in comfort about the people in discomfort”. Second, voluntary action has emerged from social consciousness generated by organised interest groups of people who are committed to people-centered approach. Third, organisations of various target groups, particularly from among the weaker sections, have emerged. The membership of these groups of associations generally cut across traditional boundaries of caste and occupational groups (Lawani 1999: 35-36)

After independence, voluntary action changed in its approach and structure. The issues covered by the voluntary activists during this period were also of different type. Even the parties involved in the voluntary sector were different. After independence India was declared to be a “Welfare State”. The government undertook welfare schemes under various plans and policies. Besides, it has encouraged voluntary organisations to undertake social welfare programmes under the grant-in-aid programme and set up autonomous bodies like Central Social Welfare Board and Indian Council of Social Welfare etc.

The decade that followed India’s independence marked a phenomenal increase in the number of voluntary agencies in the country; they expanded their activities to cover practically every field of social welfare. Provision of welfare services, since the beginning of the first plan has been a co-operative venture between the State and voluntary organisations. The planners in India have all along emphasised the role of voluntary agencies and have recognised services rendered by them in various fields. During the First Five Year Plan, the Central Government established the Central Social Welfare Board in 1953 with the main object of assisting voluntary agencies in organising welfare programme for women, children and physically handicapped. The Central Social Welfare Board in collaboration with the State Government organised State Social Welfare Advisory Boards in each State and union territories. With the establishment of the Central Social Welfare Board, the voluntary organisation got an unprecedented

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2 The expression “voluntary action” is usually related to social change, a protest against prevailing system. It has an element of discontent in its expression. In contrast, voluntary organisations are service oriented entities.
support from the government on a systematic basis. It has so far given grants over ten crore rupees and as many as 6000 voluntary agencies all over the country have benefited from its grant-in-aid programmes. The Board, besides giving assistance to the already existing agencies, helped in establishing many new ones (Panigrahi 2004: 73)

Mainly the activities of NGOs would fall in the following three broad categories

- Service institutions organised by handicapped individuals and parents/relatives of the handicapped individuals and by others on humanitarian considerations;
- Advocacy organisations at the State and national levels and
- International agencies and organisations.

(i) Service institutions: In a large number of cases, the organisations were created in order to help a handicapped kith and kin, although many other children having similar handicap were also provided services. Some of these have in due course of time, developed into large organisations of repute. Relatives, particularly enlightened and resourceful parents, have taken a lead in rehabilitating their children which has resulted in setting up of registered societies/trusts which render services to the handicapped people. Besides, non-profit organisations have also been established with philanthropic and humanitarian considerations. These service organisations are responsible for bulk of the services provided to the handicapped persons. The range of services provided by NGOs is very wide and includes prevention, early detection, physical restorative services, education, training, placement, awareness creation, psycho-social rehabilitation etc.

Although national institutions in different areas of disability have been set up by the Government of India for the purpose of evolving model services and conducting researches, Mahavir Viklang Kendra, Jaipur, has gained worldwide acclaim through fitment of ‘Jaipur Foot’. Nevedic Prosthetic Centre, Chandigarh has developed artificial arm which is very useful particularly in areas where agricultural accidents are very high resulting in loss of arms. Many other orthopaedic fitment centres and hearing aid fitment centres exist
in voluntary sector. Thakur Hari Prasad Institute of Mental Retardation, and the All India Confederation of the Blind have been operating rural rehabilitation programmes for some years. The Pune District Leprosy Committee, Hind Kushta Nivaran Sangh and some other organisations have also taken up several service delivery programmes for leprosy cured people in rural areas.3

(ii) Advocacy organisation: As voluntary efforts began to grow in the post-independence period, there was a desire to set up national and State-level associations. The first such organisation was the National Association for the Blind set up in 1952. This was followed by the establishment of several national agencies such as the National Federation of the Blind, the All-India Confederation of the Blind, the All-India Federation of the Deaf, The All India Deaf and Dumb Society, Convention of the Teachers of the Deaf in India, the Fellowship of the physically handicapped, Bombay, the Federation of the Welfare of the Mentally Retarded, New Delhi and National Forum of the Parents of the Mentally Handicapped, Hyderabad. Some of them have taken up the cause of advocacy, others have taken up both. Advocacy by the organisations has led to initiation of some of the programmes such as special recruitment drive for the disabled and realisation that the disabled should have a say in decision-making from them. As a result, the disabled and parents of the mentally retarded children have been given representation in various bodies and committees of the Government. Disabled Rights Group (DRG), a newly set up organisation is devoted solely to advocacy.

(iii) International agencies and organisations: The role of international organisations has immense value in providing services, funding and support to national and local NGOs. In this regard organisations such as Christian Aid, OXFAM, ACTIONAID, USAID and various agencies of the United Nations

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3 Many of the organizations work only for one category of the handicapped and cover many aspects of their rehabilitation. Some of the organisations work for more than one category of the handicapped. The number of such organisations is, however, very small.
such as UNICEF, WHO, ILO and UNESCO are not only providing funding, but also implementing programme at various levels.

6.2 Policy and programmes of the NGOs for the disabled.

Since independence, the government of India has accepted the responsibility towards ameliorating the lot of the disabled section of the society and formulated from time to time, various schemes and programmes for their welfare and rehabilitation. NGO sector is a vibrant and growing one. It has played a significant role in the provisions of services for persons with disabilities. Some of the NGOs are also undertaking human resource development and research activities. Government has also been actively involving them in policy formulation, planning, implementation, monitoring and has been seeking their advice on various issues relating to persons with disabilities. Interactions with NGOs have enhanced on various disability issues. Networking, exchange of information and sharing of good practices among NGOs are encouraged and facilitated. The following programmes are undertaken by the Government:

(1) A directory of NGOs working in the field of disability is being prepared properly mapping them by geographic regions along with their major activities. For NGOs supported by the Central/State Governments, their resource position, both financial and man power will also be reported. Disabled persons organisations, family associations and advocacy groups of parents of disabled persons shall also be covered in the directory identifying them separately.

(2) There are regional/State imbalances in the development of the NGO movement. Steps are taken to encourage and accord preference to NGOs working in the underserved and inaccessible areas. Reputed NGOs are also encouraged to take up projects in such areas.

(3) NGOs are encouraged to develop and adopt minimum standards, codes of conduct and ethics.
(4) NGOs are provided opportunities for orientation and training of their human resource. Training in management skill which is already being provided, will be strengthened. Transparency, accountability, procedural simplification etc. will be guiding factors for improvement in the NGO-Government partnership.

(5) NGOs are also encouraged to mobilize their own resources to reduce the dependence on grants-in-aid from the Government and also to improve the availability of funds in the sector. Tapering of assistance in a schematic manner will also be considered so that the number of NGOs to be helped within the available resources could be maximised.

The NGO schemes and programmes for the empowerment of persons with disabilities are analysed in this section under the following heads:

6.2.1 Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP Scheme)

The main objective of the scheme\(^4\) is to assist the needy disabled persons in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances that can promote their physical, social and psychological rehabilitation, by reducing the effects of disabilities and enhance their economic potential. The aids and appliances supplied under the scheme is ISI.

The quantum of assistance and income limit under the ADIP Scheme is as follows:

<table>
<thead>
<tr>
<th>Total Income</th>
<th>Amount of Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Up to Rs 6,500/- per month</td>
<td>(i) Full cost of aid/appliance</td>
</tr>
<tr>
<td>(ii) Rs 6,501/- to Rs 10,000/- per month</td>
<td>(ii) 50% of the cost of aid/appliance</td>
</tr>
</tbody>
</table>

The scheme is implemented through implementing agencies such as NGOs, National Institutes under the Ministry of Social Justice and Empowerment and ALIMCO (a PSU). As per Results Framework Document (RFD) for Ministry of Social Justice and

\(^4\) See Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP Scheme), Government of India, Ministry of Social Justice and Empowerment, New Delhi.
Empowerment (2010-11), of the priority areas of action, ministry decided to release grant-in-aid of Rs. 100 Crore under the ADIP Scheme and Rs. 120 Crore under DDRS to provide rehabilitation services to about 2.30 lakh persons with disabilities (Government of India 2010-11).

Budget allocation and release of funds to implementing agencies under ADIP Scheme is as shown in Table: 3

<table>
<thead>
<tr>
<th>Sl No.</th>
<th>Financial Year</th>
<th>Budget Estimate (Rs. In Crores)</th>
<th>Amount Released (Rs. In Crores)</th>
<th>Percentage Expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>2003-04</td>
<td>57.00</td>
<td>55.00</td>
<td>96.4</td>
</tr>
<tr>
<td>2.</td>
<td>2004-05</td>
<td>60.00</td>
<td>63.18</td>
<td>105.3</td>
</tr>
<tr>
<td>3.</td>
<td>2005-06</td>
<td>60.00</td>
<td>57.91</td>
<td>96.5</td>
</tr>
<tr>
<td>4.</td>
<td>2006-07</td>
<td>71.20</td>
<td>67.59</td>
<td>94.9</td>
</tr>
<tr>
<td>5.</td>
<td>2007-08</td>
<td>70.00</td>
<td>49.08</td>
<td>70.1</td>
</tr>
<tr>
<td>6.</td>
<td>2008-09</td>
<td>79.00</td>
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<td>-----------</td>
</tr>
</tbody>
</table>

Funds released under ADIP (Rs in Crores)

<table>
<thead>
<tr>
<th>Name of implementing agency</th>
<th>2004-05</th>
<th>2005-06</th>
<th>2006-07</th>
<th>2007-08</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIs</td>
<td>18.89</td>
<td>9.32</td>
<td>23.06</td>
<td>9.13</td>
</tr>
<tr>
<td>ALIMCO</td>
<td>24.27</td>
<td>24.27</td>
<td>28.00</td>
<td>19.62</td>
</tr>
<tr>
<td>NGOs</td>
<td>20.02</td>
<td>24.32</td>
<td>16.53</td>
<td>20.33</td>
</tr>
<tr>
<td>Total</td>
<td>63.18</td>
<td>57.91</td>
<td>67.59</td>
<td>49.08</td>
</tr>
</tbody>
</table>

Source: ADIP Scheme, (applicable w.e.f. April 2005), Ministry of Social Justice, New Delhi.
6.2.2 Deendayal Disabled Rehabilitation Scheme to Promote Voluntary Action for Persons with Disabilities.

To facilitate delivery of various services to persons with disabilities by voluntary organisations, the Ministry of Social Justice and Empowerment is administering DDRS Scheme and providing grants-in-aid to NGOs for the following projects:

(i) Vocational training centres
(ii) Sheltered workshops
(iii) Special schools for persons with disabilities
(iv) Project for cerebral palsied children
(v) Project for pre-school and early intervention and training
(vi) Home based rehabilitation programme/home management programme
(vii) Project for rehabilitation of leprosy cured persons (LCPs)
(viii) Project relating to survey, identification, awareness and sensitization.
(ix) Project for community based rehabilitation
(x) Project for human resource development
(xi) Seminars/workshops/rural camps
(xii) Project for legal literacy, including legal counselling, legal aid and analysis and evaluation of existing laws
(xiii) Environment friendly and eco-promotive projects for the handicapped
(xiv) Grand for purchase of vehicles
(xv) Construction of building
(xvi) Grant for computer
(xvii) Project for low vision centres
(xviii) Half way home for psycho-social rehabilitation of treated and controlled mentally ill persons
(xix) District disability rehabilitation centres (DDRCs)

The maximum level of support could be up to 90 per cent of the eligible amount of grant for the project.
6.2.3 Vocational training and employment services

In recent years, many NGOs emerged on the scene to provide vocational training and other placement services to the disabled persons in India. Despite Government's concerns for the jobs and reservation for the disabled persons, yet the scenario remained unsatisfactory. Therefore NGOs are rendering very useful role in this regard.\(^5\)

In the field of education, there are many organisations rendering their services for the disabled in India. This has included variety of services such as Teacher's training, School and educational services.\(^6\)

There are various organisations rendering various services to the disabled on the social sphere. Many NGOs are providing sheltered homes in various regions of India to the disabled persons. Such NGOs are Praja Seva Samithi, Viswa Karuna Sangam, Lokviswas School for the handicapped kids, care home for disabled children, Anantha Sevasram, Saint Louis Institute for the deaf and blind, Pope Paul Mercy Home etc. are few of the long list of NGOs providing shelter and residential facilities to the disabled persons in India. However, most of the NGOs are devoted to the mental retarded category.\(^7\)

In the sphere of health, various NGOs do provide the therapeutic/counseling services to the disabled in India. Such NGOs are Priyadarshini Service Organisation, Blessing, Guru Nanak Home for handicapped Children, Santhal Paharia Sewa Mandai, Akshay Pratisthan, Prem Ashram, Seva-in-Action, Missionaries of Charity etc.

Securing employment is the ultimate objective of all rehabilitation programmes for the disabled population. The disabled population is lagging far behind the general

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\(^5\) Few of such NGOs are the society for rehabilitation of physical, mentally background, Daddy's Home, Cheshire Homes India, Gandhi Niketan workshop for handicapped, Gurukrampa, Mangalam, Satya Yothi, Amar Yoti, National Centre for Disabled etc. Promotion in employment is the pioneer NGOs in this regard.

\(^6\) The main NGOs which are rendering services in this regard are Saint John's Handicapped Institution, Srinivasa Mahila Mandal, Sneh Niketan, Saheed Memorial Society, Vikalang Kalyan Sewa Sanshan, Blind Social Welfare Society, Pingla Ghar, Hitkari parisd etc.

\(^7\) Data obtained from the Directory of Institutions working for the disabled in India, Ministry of Welfare, Govt. of India, New Delhi.
population in education and training and this has created additional handicaps in securing employment. It is not the specific physical or psychological barriers alone which restrict their opportunities to secure job. The attitude of employers, co-workers and the general public has also considerably aggravated the problem. Realising the difficulties faced by the disabled in competing with the general population in securing work, the Central as well as State Governments has devised special measures to promote their employment. A multi-pronged approach has been adopted to create conditions in which the handicapped can reasonably compete with others for jobs. The important programmes designed to promote their employment are: reservation of jobs in the public sector; establishment of Special Employment Exchange and Special cells in Government Exchanges to promote placement in jobs; and establishment of Vocational Rehabilitation Centres to arrange for assessment, training and placement. A scheme of assistance to voluntary organisations for training and employment of disabled persons, including establishment of sheltered workshops (Narasimha and Mukherjee 1986: 62).

6.2.4 Social integration

Similar to the All India Federation of Deaf, there are other all India organisations working for different groups of handicapped. Special mention may be made here of the National Association for the Blind, Bombay, and the National Federation of the Mentally Retarded, New Delhi. The National Association of the Blind does multifarious activities for the education, training, recreation and social integration of the blind. This is the only organisation which seeks the total rehabilitation of the visually handicapped taking into consideration all aspects of their cultural, social and economic life. The association is the pioneer organisation which started sending blind children to normal schools where they are taught through specialised equipments and with the help of resources teachers.

The basic idea is to promote social integration of the blind with the disabled, helping the able bodied understand the problems and potential of the disabled classmates. It also tells the world that the blind too, along with the other handicapped can work in any normal situation if given an opportunity. Most of these schools promoting such integrated education are located in Bombay and a few in other major cities. Similar schools where
the deaf children attend normal schools are located in New Delhi and some other States too, thanks to the initiative taken by voluntary agencies (Nair 1981:140).

Two decades ago in January, 1980, the National Association for the Blind, gave a lead to the rest of India by starting the first ever agricultural and rural training centre of the blind at Phansa in Gujarat.8

In South India, the Helen Keller International, Madurai, has developed a mobile rehabilitation team which collects the rural blind belonging to a group of villages and trains them in elementary farm occupations and rural jobs. The training enables the blind to help the family on the farm and non-farm jobs. In a country as vast as India, and with a great rural population, the experiments conducted in Phansa and Madurai need to be emulated in the rest of the rural India.

In the field of mental retardation also, there are many institutions for the education and training of the mentally retarded children and adults. At the national level there is the National Federation of the Mentally Retarded. There are several schools for the educable and trainable mentally retarded children, but their number is small and the facilities are available only in the cities and towns. For the orthopaedically handicapped, there are fewer institutions than for the deaf or the blind. For the production of artificial limbs and appliances, voluntary institutions are doing creditable work. Mention may be made here of the Rehabilitation Centre of the Bhagwan Mahaveer Viklang Sahayata Samiti in Jaipur. Here at Jaipur, they make a variety of shoes and legs, all custom made, to suit the orthopaedically handicapped who have to work in a rural background. The treatment and fitting of the limb is free at the centres for all patients.

8 It acquired an estate of 240 acres and several facilities like dairy sheds, irrigation tank, wells etc. With the help of the Royal Commonwealth Society for the Blind, the Phasa project started training the blind in agriculture, horticulture, animal husbandry, dairy, poultry farming, fish culture and the like. The idea was to train the rural blind in different agro-based pursuits.
6.2.5 Medical rehabilitation

Medical rehabilitation programmes are limited to major urban areas in the country. Broadly speaking, the centres providing medical rehabilitation of varying degrees can be grouped into three categories: major rehabilitation institutes; rehabilitation centres; and small rehabilitation units. There are about 10 major rehabilitation institutes in the country which are designed to be raining institutes for the development of manpower in the field of rehabilitation. In addition, they are the only organisations in the country conducting applied as well as basic research for the development of appropriate rehabilitation programmes. Service is essentially meant to be incidental to training and research. But, for a variety of reasons, they are required to serve a large number of disabled persons. Located in major cities, the pressure of the disabled population on these centres is high, and they are unable to refuse the direly needed calls to service. Consequently, they are over crowded and with service activities and the quality of their service is diluted. In the absence of well conceived rehabilitation programme in the country, training programmes in these institutions have become adhoc and have remained stagnant. Manpower development is on a small scale in comparison to the needs of a vast country like India. Over the past two decades, their contribution to research leading to the development of rehabilitation models suitable to Indian conditions has been insignificant. Only occasionally have they achieved some success in the development of appropriate aids and appliances suitable to the Indian disabled population.

The service provided in these centres continues to be based on western model. But the method, techniques, equipments, etc have remained traditional and have not been updated. They are untouched by recent innovatives in the field of medical science in the developed countries. Most of them still do not attempt to admit severely disabled groups. There are no prospects for the multiple-handicap group to get admission in any of these institutions. In government institutions, a large number of mild-category-handicaps are looked after to the neglect of the moderate and severe groups. Consequently, genuine cases are denied adequate attention and are forced to seek admission in private rehabilitation centres. Considering the expenditure incurred by the government on these institutions, the service facility available to the deserving and genuine handicapped
groups is meager. However, these major rehabilitation institutes are conscious of the need to provide comprehensive services to the disabled population. They are utilised by the government and the voluntary agencies to train new categories of manpower and to try out new approaches for rehabilitation. With all their shortcomings, they still constitute the major resource in the field of rehabilitation in the country.

The small rehabilitation units are predominantly found in the voluntary sector, and occasionally in a government hospital. They cater only to the mild categories of handicaps and their services are restricted to simple intervention programmes. These units are designed to provide only fragmented services. They have no long-term policies and programmes and find it difficult to secure the services of qualified professionals.

The rehabilitation units in the voluntary sector are more humane and considerate of the handicapped population than the government set up. However, the quality of service offered by them is generally far below standard and fragmented. All the three types of rehabilitation centres suffer from some common deficiencies. In brief, all of them are situated in the major urban areas and do not provide services for the rural population. Often, all the three types of rehabilitation centres are found in the same area, both in the government and in the voluntary sector.

There is an inordinate delay in the supply of aids and appliances to the needy population. This has resulted in a huge backlog in supply of braces, artificial limbs, hearing aids, wheel chairs, etc. The bulk of them do not have the resources or the time to train handicapped persons after fitment in the use of the aids and appliances. Only in some institutions is this training possible. Nearly all of them lack follow-up programmes to ensure that the treatment and counseling given to the handicapped individuals is clearly understood and followed. They are not aware of the results of their diagnosis and treatment. There is hardly any feedback between the handicapped individual and the rehabilitation centers once the individual leaves the centre. There is no system of continuous contact between the centre and the patient. Even where such an after care service exists, there is no documentation to assess the quality. This greatly affects the confidence of the handicapped individual in the adequacy of the services he receives from the centre (Panigrahi 2004:94-95).
6.2.6 Educational facilities

Even in the pre-independence era, the voluntary sector played a dominant role in the establishment of schools for disabled children. Education of the handicapped being a State subject, the Central Government has not played a major role in establishing special schools. The States have also lagged behind in opening new special schools during the past 50 years, except in a few places. Municipal authorities and other local government organizations have displayed a lack of concern for the education of the handicapped children. It is the voluntary organisations that continue to take the major initiative in opening special schools in the country.

However, despite the steady growth of special schools in the voluntary sector in the country over the past 50 years, their coverage is totally inadequate compared to the needs. The bulk of these schools are found in major cities and even among the urban population the schools are distributed unevenly. It is common to find a duplication of schools in the same geographical area, with no coordination among them. In fact, there is rivalry among the voluntary organizations in some places, leading to a multiplicity of special schools in the same area. They cater mostly to the elite group who can afford to pay for their services. Most of the special schools were started by parents themselves who had handicapped children and found no institution which could admit them. The special schools were started to support their own kind, and continue to be elitist in character. On the other hand there are virtually no special schools in the rural areas.

The Ministry of Welfare provides generous financial assistance to voluntary organisations to establish and run special schools for the disabled children. The assistance includes grants for the construction of buildings to the extent of 90 per cent of the estimated cost, subject to overall financial ceilings which are raised with increase in the cost of living. Grants are also given for maintenance of the institutions, i.e. Expenditure on staff, purchase and renewal of furniture and equipment, maintenance of hostels, transportation costs etc.

Most of the special schools are based on the western pattern, and even copy western books and other educational materials. There is an exaggerated emphasis on academic education to all groups of handicapped children irrespective of the ability of the child to receive such education. Parent counseling does not find a place in the curriculum
of most of these special schools. Even if counseling is attempted it is done as a mere formality, and parents are met occasionally in groups without any purpose. Stimulation programmes are not found in a large number of special schools. The entire approach to education of handicapped children is non-professional in character.

One of the main reasons for the unsatisfactory quality of education in the special schools is the lack of professional manpower. Till recently, there were no regularly organised training programmes. However the Government of India has recently established four national institutions in each area of disability: visual, hearing, mental and locomotor. These institutions are organising regular programmes for the training of teachers. These programmes have received wide acceptance throughout the country, both among the government as well as voluntary organisations, and there is a great demand for admissions to these training programmes.

Till recently, there was no attempt to standardise curricula in the special schools. Professionals who joined these schools in the past adopted the same methods of teaching and curriculum which they had acquired during their training in the developed countries. They have never joined hands to evolve a common curricula or integrated text books or methods of teaching in the special schools. If the special schools in the voluntary sector made exaggerated claims in the quality of education they provide, special schools run by the government are equally poor in quality. Most of them suffer from a lack of dedication and commitment. They are rigid, and far less flexible than the voluntary sector in their approach to understanding and tackling the growing needs of handicapped children.

A large number of handicapped children do not suffer from any learning disability, and can receive education in regular schools. This is true not only of those suffering from locomotor handicaps, but also of other handicaps such as deafness and visual impairment. So the emphasis is on ‘Integrated education’. Moreover, the Convention also speaks on inclusive education in order to reduce the isolation of

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9 In 1974, the Central Government introduced a scheme called ‘Integrated Education of Disabled Children’. Initially the scheme was a centrally sponsored one, with complete assistance from the Centre to the States to implement the scheme. After five years, the funding pattern of the scheme was changed, and from 1979 to 1981, expenditure on the scheme was shared equally between the Central and the State governments were required to contribute half the expenditure. During the International Year of Disabled Persons, the financial pattern was changed once again, since then the Central Government has given 100 percent financial assistance to the States to provide integrated education to handicapped children in normal schools.
handicapped children and to promote the psychological acceptance of these children by the normal school going population.\textsuperscript{10}

Despite 100 per cent financial support from the Centre, only few States have implemented the scheme. The scheme of integrated education has virtually remained a non-starter. There has been no clear assessment of the actual needs of handicapped children while placing them in regular schools along with normal children. The problems in the rural areas, particularly the scattered distribution of handicapped children, transport difficulties, need for pre-school training, parental attitudes, etc. have not been recognised. The present concept of integrated education in India envisages a provision of special teachers and other facilities are meant to be provided in circumstances where the strength of the disabled children justifies them. When the number of children in such normal schools is small less than eight to ten, provision of such facilities is costly and is avoided. However, it is not totally desirable to dispense with special teachers and related facilities and allow the scheme of integrated education. In theory, the arrangement appears fine, but in actual practice it is unworkable. Other important hurdles in the implementation of the scheme are a dearth of qualified teachers for dealing with disabled children in regular schools. Despite attempts made by the National Council of Education, Research and Training (NCERT) to start teachers training programmes, no substantial programme for training of such teachers has emerged. There is also lack of coordination between the Ministry of Education and the Ministry of Welfare in building up facilities for the training of teachers in special education. The University Grants Commission has selected certain Universities to organise and conduct teachers training programmes. The NCERT and its Regional Colleges are also creating more infrastructures for training teachers in special education.

\textsuperscript{10} 1000 NGOs across 29 States are involved in providing support to Inclusive education. These include Arushi in MP, Spastics Society of Eastern India, Kolkata, Sri Ramakrishna Mission Vidyapith, Coimbatore, National Association for Blind, Mumbai and other renowned NGOs. NGOs also provide technical assistance for planning of inclusive education, awareness generation, community mobilisation, early detection, identification and assessment of children with special needs and preparation of individualized educational plan, development of training materials, man power development, with a special focus on in-service teacher training and training of key resource persons and provision of essential assistive devices (aids and appliances). For more details see Annual Report 2009-10, Department of Higher Education & Literacy Department of Higher Education Ministry of Human Resource Development, Government of India.
While the limited facilities available in urban areas in the country offer poor quality education to handicapped students, even these limited facilities are practically non-existent in rural areas. Handicapped children suffer seriously in rural areas for want of any special or integrated school. Neither the State Governments nor the Voluntary Organisations have shown any concern for the disabled children in rural areas. It is concluded with regret that there seems to be no clear policy as to how to educate handicapped children in rural areas and bring them into the mainstream of society. This remains a big question mark which remains unresolved.

6.3 International and domestic NGOs

This section intends to look into the role of international and national NGOs in the implementation process. In the international level Inclusion International is covered.

6.3.1 Inclusion International (II)

Inclusion International is a global federation of family based organisation advocating for the human rights of people with intellectual disabilities worldwide. For over 50 years it has been committed to the promotion of these human rights and now represents over 200 member federations in 115 countries throughout 5 regions including the Middle East and North Africa, Europe, Africa and Indian Ocean, the Americas and Asia Pacific.11

- Objective

With its member societies, II acts as an agent for change on the basis of four main principles affecting the lives of people with an intellectual disability and their families.

(i) Inclusion in all aspects of every day society
(ii) Full citizenship which respects individual human rights responsibilities
(iii) Self determination in order to have control over the decisions affecting one’s life
(iv) Family support through adequate services and support network to families with a disabled member.

- Role in the negotiation process of the Convention.

11 For further information see http://www.inclusion-international.org/
The success in influencing the text of the Convention was the result of their combined efforts around the globe. All their key issues were addressed. Most important was the recognition of the family, the right to education, living in the community and legal capacity. II achieved their goals by developing clear positions to share with other disability organisations and governments, by having self advocates involved in the negotiations and by taking advantage of the close relationship between their members and governments. Presently II is collaborating with other disability organisations in the CRPD Forum to monitor and implement the Convention.

- Priorities and initiatives

II's strategic plan is based on the Millennium Development Goals as a framework to address poverty and exclusion of people with intellectual disabilities and their families. This framework has helped to draw attention to the cross cutting issues of exclusions and it has enabled their members to work in areas where in the past people with intellectual disabilities and their families have been ignored.

At the II World Congress in Acapulco in 2006, families and self advocates identified five priority issues that required special attention in order to address exclusion and poverty. Education is a key determinant of poverty and exclusion for individuals and for families; the structural causes of extreme poverty (development policy that excludes the people with disabilities); policies that ignore and undermine the role that families play in promoting and supporting inclusion of people with intellectual disabilities; acceptance of the right to make decisions and of legal capacity is a fundamental issue for people with intellectual disabilities and exclusionary policies that separate people with intellectual disabilities from their communities in institutions.

Over the past two years since the World Congress in Mexico, II has been building on a two track agenda; on the one hand building on the work of their members that was done on poverty and exclusion and on the other hand contributing to the development and future implementation of the Convention. In order to effectively contribute to global processes such as the Convention and poverty reduction initiatives, II has engaged in initiatives that strengthen the capacity of member organisations on the Convention; build opportunities for exchange of information between member organisations and with other disability groups and development resources and tools for use by their membership.
In 2009 and 2010 II was focusing on the implementation of the Convention as a tool for addressing poverty and exclusion generally and with specific attention to these priority issues. The Convention according to II is meant to enable inclusion by reaching beyond entitlements and seeking to address the systemic causes of exclusion in society.

- Full inclusion of people with disabilities in society

Celebrating the largest event in the history of II, 2,700 people with intellectual disabilities, family members, policy makers and professionals from more than 80 countries gathered under the slogan “Transforming Global Rights into Action” at the 15th World Congress of Inclusion International from 16 to 19 June 2010 in Berlin. The main objective was to discuss and advance the implementation of the Convention worldwide and to pave the way for an inclusive society. The congress provided a platform for all stakeholders to exchange experiences and innovative ideas. A central topic of concern for all participants proved to be legal capacity; the right to make one’s own decisions, including the right to political participation. Inclusive education, both in school and life-long learning was another major topic, as was work including getting a job, getting the support to do it and learning new skills and training. Full citizenship, the empowerment of self advocates and living independently in the community were among other main issues under debate. Many presentations and workshops highlighted the importance of advancing the implementation of the Convention; its ratification was pointed out as just a starting point and countries need to build on it. The monitoring of the implementation of the Convention should be done by different actors including independent national monitoring bodies and civil society, especially those organisations representing people with disabilities and, very importantly, by people with disabilities themselves.

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12 The World Congress of Inclusion International 2010 was organised by Inclusion International (II), Inclusion Europe (IE) and Lebenshilfe. IE is the European voice and representation of over 60 member organisations of people with intellectual disabilities and their families. Founded in 1988, IE has a 20-year track record of successful operation and defending the rights of its constituency. For more details on IE visit http://www.inclusion-europe.org. Lebenshilfe is a registered, non-profit organisation devoting itself entirely to people with intellectual disabilities and their families throughout Germany. It is politically and denominationally independent. For more information see http://www.lebenshilfe.de/
At European level, the UN Convention is already influencing the European Union’s policies but needs to be better known and the requirements of the Convention need to be further recognized. So far, all EU Member States have signed the UN Convention and 13 have already ratified it. The remaining Member States are preparing for its ratification. The EU Disability Strategy 2010-2020 is being prepared to ensure a solid and strong link between the Convention and the main political programmes of the EU 2020 Strategy.

People with intellectual disabilities had a major influence throughout the congress. More than 850 participants had an intellectual disability themselves. Many of them spoke in sessions about their personal experiences as self advocates and encouraged others to stand up for their rights. Thus it is to be understood that it is not only people with intellectual disabilities but persons with disabilities should also play a key role in monitoring activities of the Convention. In addition to this, adequate individual support should be provided to ensure their capacity to fulfill this.

6.3.2 Human Rights Law Net work

In the national level, a study of the Human Rights Law Net work (HRLN), an NGO which is a collection of lawyers and social activists dedicated to the use of legal system to advance human rights is made.13

- Mission

Their mission includes:14

(i) To protect fundamental human rights, increase access to basic resources for marginalised communities, and eliminate discrimination.

(ii) To create a justice delivery system that is accessible, accountable, transparent, efficient and affordable, and works for the underprivileged.

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13 HRLN collaborates with social movements, human rights organisations, and grass-roots development groups to enforce the rights of children, dalits, people with disabilities, farmers, HIV positive people, the homeless, indigenous people, prisoners, refugees, religious and sexual minorities, women, and workers, among others. HRLN provides pro bono legal services, conducts public interest litigation, engages in advocacy, conducts legal awareness programmes, investigates violations, publishes ‘know your rights’ materials, and participates in campaigns.

14 Information regarding HRLN is incorporated based on e-mail to the author (Sharma, Deepak Krishna:2010)
(iii) To raise the level of pro bono legal expertise for the poor to make the work uniformly competent as well as compassionate.

(iv) To equip through professional training a new generation of public interest lawyers and para-legals who are comfortable both in the world of law as well as in social movements to refine legal concepts and strategies.

(v) To work towards an increased awareness of rights as universal and indivisible, and their realisation as an immediate goal.

- Objectives

(i) Articulate an alternative constitutional law based not on property but on universal human values.

(ii) Introduce a broader ideological mooring for legal work as part of an overall process to bring about social change in which legal campaigns and social movements collaborate.

(iii) Incorporate international human rights principles in Indian law and, in turn, influence constitutional law in foreign jurisdictions through the development of innovative and path-breaking case law in India.

(iv) Build close links between legal networks in India and human rights law groups abroad, both in the development of law as well as programmatically.

(v) Campaign for wide ranging reforms of the legal system, particularly with respect to State funded legal aid for the poor, so that the State takes more responsibility for legal services and allocates more resources for legal aid.

(vi) Bring human rights law education in India into the main stream.

(vii) Build alliances between the judiciary and rights based initiatives to sensitize the judicial system to a more inclusive understanding of human rights and to an increased awareness of human rights law and practices in different parts of the world.

- Strategies

HRLN defends human rights by opposing violations, strengthening enforcement mechanisms, sensitising the public, and campaigning for constitutional and legal reform.
HRLN has developed effective and innovative solutions to achieve its aims and from 2001, has been building specialized initiatives around issues. Recognising the potential of effective partnerships, HRLN works closely with human rights and development organizations within and outside India. HRLN units in various States use the following strategies:

(i) Legal Aid and Public Interest Litigation

The nationwide network offers quick response and pro bono expertise to those who have little or no access to the justice system. HRLN lawyers offer legal representation and advice to people who cannot afford legal representation. HRLN is part of the access to justice movement.

Over the past decade, the Network has made a critical transition from individual litigation in the lower courts to filing public interest petitions in the High Courts and in the Supreme Court. Their experience is that a decisive and professional intervention at the level of the Supreme Court can bring about changes in retrogressive State policies and bring relief to millions.

However, increased litigation in higher courts does not mean that HRLN has in any way reduced its emphasis on individual cases. It is necessary for lawyers and paralegals to simultaneously be engaged in routine work, because it is through such cases that HRLN learns its orientation and retains its compassion. Universal principles are often derived from simple individual cases. A judicious mix of work in the trial courts and class action petitions in the superior courts forms the complement of HRLN’s legal work.

Broadly, HRLN’s principle is to never turn away an indigent person, but there remain basic guidelines for litigation. Cases of employers against employees, men against women and landlords against tenants are generally not accepted.

(ii) Legal education

Asserting everyone’s right to access and everyone’s ability to understand the law, they attempt to demystify legal terms, concepts and procedures so that everyone, especially those neglected by the system of justice can find themselves more included.
Law can then be the framework for liberation rather than of oppression by the elite. To do this HRLN takes legal education as a mission. It continuously campaigns to broad constituencies for better understanding about the law and the judicial system through different channels in the variety of Indian languages, and through material that is focused on its target audience.

(iii) Advocacy
In courts, in media, and in various public and legislative fora, HRLN is a strong advocate for laws and policies that promote and defend human rights. In crucial areas where legislation is lacking or requires amendment; HRLN has been at the forefront of efforts to formulate laws and policies.\textsuperscript{15}

(iv) Investigation, monitoring and crisis response
HRLN members are routinely called upon to conduct and participate in fact findings. In many cases the filing of petitions in courts has been a follow up to the monitoring and documentation of violations. Crisis response takes many forms.

(v) Campaigns
There is today a direct link between the public interest petitions done by HRLN and the campaigns it participates in and convenes. The latter creates awareness about the issues, facilitate the dissemination of the orders passed by the courts, and make the process for change participatory. This tells the judiciary that society is concerned about the outcome of the cases, and therefore makes the judiciary more responsive to the needs of civil society.

(vi) Disability rights
Despite the enactment of special legislation, the disabled in India continue to battle ignorance, insensitivity and resistance to the enforcement of their most basic human rights. To provide access to the legal system and improve facilities for persons with all types of disabilities, the Disability Rights Initiative (DRI) provides legal aid and takes up high-impact Public Interest Litigation. The

\textsuperscript{15}The Report Harmonizing Laws with the UNCRPD is a project organized by the efforts of Human Rights Law Net Work, The Deaf Way Foundation and National Association of the Deaf.
network also engages in out of court advocacy, conducts research and publishes ‘Know Your Rights’ material.

• Recent developments

In a landmark judgment, the Supreme Court on March 10th, 2010 has upheld the rights of persons with cerebral palsy to employment. Hon’ble Supreme Court observed about this case in its judgment:

this case is not one of the normal cases relating to a person’s claim for employment. This case involves a beneficial piece of social legislation to enable persons with certain forms of disability to live a life of purpose and human dignity. This is a case which has to be handled with sensitivity and not with bureaucratic apathy, as appears to have been done as far as the appellant is concerned.

The case involved a person with cerebral palsy in Jammu and Kashmir. He completed his B.Sc and was offered employment under a scheme of the Government of Jammu and Kashmir known as a Rehbar-e-Taleem, which literally translated means, a Teaching Guide. In spite of having stood first in the merit list, this person was not given an employment letter on the basis of a complaint filed by a person who stood fourth in the merit list and who questioned his appointment on the ground of his disability. Aggrieved at not being given the letter of employment in spite of standing first in the merit list, he approached the High Court where his plea was dismissed. Further aggrieved by this decision of the High Court he appealed against the order in the division bench, which in an unusual approach examined petitioner in court, and finding him lacking, passed an order upholding the order of the single bench. Petitioner approached Supreme Court for setting aside the order of the High Court and appealed for his employment. Finally the Supreme Court upheld the petitioner’s right finding that High Court has violated Section 22 and 27 of the 1998 Act.

6.4 Assessing NGO performance and accountability

Despite the exponential growth of NGO activity during the past decade, there are still questions regarding their effectiveness in achieving their stated objectives. Allied to this there is also a related debate regarding to whom NGOs are in fact accountable. Both

16 Syed Bashir-ud-din Qadri v Nazir Ahmed Shah & Ors. (Civil Appeal No. 2281-2282 of 2010).
these debates are of major concern to the development of the argument vis-à-vis empowerment and participation of poor and marginalized groups. It could be argued that failure of NGOs in achieving their objectives can be partially attributed to the inability to comprehend the processes and dynamics of social transformation. (Lang 1994:1) The evaluation of NGOs' effectiveness is indeed a problematical exercise, not least because there are few, if any, universally agreed criteria upon which such evaluations are and can be premised. In many instances, and certainly the case in some of the evaluation reports of disability projects in India, such evaluations tend to be instruments of propaganda. The aim is to impress donor agencies regarding the usefulness of the NGO's activities, (thereby providing evidence that the project of the NGO is of paramount importance, is indispensable, and warranting further financial support), rather than to critically analyse the strengths and weaknesses of the NGOs' activities.

Edward and Hulme are of the opinion that there is increasing evidence that NGOs do not perform as effectively as had been assumed in terms of poverty-reach, cost-effectiveness, sustainability, popular participation (including gender), flexibility and innovation. In terms of service-provision, there is certainly evidence that NGOs are able to provide some services more cost-effectively than governments (Edward and Hulme: 1995).

In agreement with Edward and Hulme, Nyoni maintains the opinion that many NGOs have failed in the mandate to alleviate poverty and to act as facilitators for the empowerment and social transformation of the poor, because their own internal structures tend to be hierarchical, not democratic. If NGOs cannot listen to those who work within their organization, then it is not at all surprising that they fail to listen to the view and interests of the beneficiaries of their services? Nyoni thus states that, most development agencies are centres of power which they try to help others change. But they do not change themselves. They aim at creating awareness among people yet they are not themselves aware of the negative impact on those they claim to serve. They claim to help people change their situation through participation, democracy, and self-help and yet they themselves are non-participatory, non-democratic and dependent upon outside help for their survival (Nyoni 1987: 51-56)
A further intractable problem continually faced by NGOs is accountability. This concept is generally understood to refer to the manner by which individuals and organisations report to identifiable and recognised authorities for the activities they perform. Both international and indigenous NGOs have multiple accountabilities. They are accountable “downwards” to their collaborating partners, those who are beneficiaries or client group of the services they provide. In addition they are accountable “upwards” to donor agencies and the government of the host countries in which they are operating. From a legal perspective, NGOs are solely accountable to their board of trustees. However from a more ethical standpoint many NGOs consider themselves to be accountable to their beneficiaries, especially for those that endorse a “people-centered” approach and ideological stance to development. Commenting upon the complexity of relationships that NGOs encounter in relation to multiple accountabilities, Brett states, “The NGO acts as an intermediary between the donor and the consumer and market competition is excluded”. The agency relationships involved are complex, and include those between NGOs and donors, consumers, home and host country governments and between managers and workers. They can also include those between foreign and local NGOs where the former sub-contract out to the latter. Since each of these has differing and conflicting interests and leverage, difficult problems of monitoring and enforcement arise (Brett 1993:269-303)

6.5 Summing Up

Although the ultimate responsibility of empowerment of the persons with disabilities rests with the government, but finally the social integration and their genuine empowerment depends on the positive approach of the society in which they live. Therefore, unless and until the social perception toward disability changes positively, empowerment of the disabled would be a difficult task. NGOs are an important watchdog of democracy as they provide a platform for citizen’s action, an essential counterweight to the State and cardinal instrument of the civil society. There are acknowledged shortcomings in the capacity of the disability NGO sector to grow into an expanded role, both in its own right and as a partner of government. Many NGOs have links with public agencies, predominantly for contracting out of services, technical assistance and training.
While results have in many cases been positive, there remain concerns about weak monitoring of NGO performance and accountability for use of public funds. Consultation between the public and NGO sectors on disability policy issues also remains underdeveloped, both at the centre and in most States. In addition, the monitoring and evaluation role for NGOs seems one that could be developed within public interventions. Despite the criticism of activities and involvement of the NGOs, many of them have poured funds for the good of the disabled people. In fact, NGOs have contributed where government expressed its inability for actions.