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# Chapter I

# Background to the Study

It is estimated that persons with disabilities constitute 10% of the total population of any developing country. It is often said that this is a sizable and invisible minority which is neglected and marginalised since ages. They are perceived as objects of charity and pity. They are viewed as a problem rather than as a priority. Potential barriers such as environmental, legal, cultural, institutional and societal; crippling negative attitudes, stigma, discrimination, seclusion, prejudice, ignorance and fear impoverishes and reduces them to lesser or sub-human beings. The apathy of the state and society further worsens the situation. Earlier approaches to disability and development were charity and relief oriented which isolated them and made them dependent. Legislation enacted for the development of this section has many gaps. Moreover they remain in the Gazette of India without effective implementation. A well known disabled activist rightly remarks that they are unseen, unheard and unaccounted for in the developmental process.

#### BASIC CONCEPTS

It is important to understand the basic concepts of disability from various dimensions before going into minute details, since the concept of disability is subjective, psychological, social, contextual, cultural and sensitive. There are dozens of definitions, which describe disability in different ways but none of them provides a standard and comprehensive definition to the term. Each definition ranges from the very narrow to the very broad, from the medical to the social, from the cultural to the local, from one intended to integrate them into society to one for exclusion and segregation. This particular chapter focuses mainly on the medical perspective of disability. It also makes an attempt to understand disability from psychological, socio cultural and medical dimensions. The attempt is also to understand disability from different perspectives like social, sociological, political, socio economic, religious, cultural etc.

Various agencies and pioneers of the sector have attempted to provide a working definition to disability and related concepts. The International Classification of Impairment, Disability and Handicap [ICIDH] is one such attempt made by World Health Organisation [WHO] in 1980 to provide a base to initiate discussions, deliberation, debate, thought process and a frame work to re-coin a most appropriate, comprehensive, contextual and socio-cultural definition to disability and related concepts.

WHO defines impairment, disability and handicap and provides a base for distinguishing these three terms in a scientific way since these three terms have linear connections with each other. Thus it is important to proceed in an orderly manner to understand the basic concepts. WHO has a mandate to develop a global common language in the field of health. In 1980 WHO implemented an International Classification of the Consequences of Disorders [ICCD] and International Classification of Impairments, Disabilities and Handicaps [ICIDH]. This classification has been widely used but at the same time criticised as being too medical and individual. The feedback was taken into account in the revision of the classification of the concepts in 1996 and 2001.

WHO's classification of impairments, disabilities and handicaps define functional ability using impairment, disability and handicap as central concepts (WHO 1980 and revision 1996). The relationship between impairment, disability and handicap has been defined as follows:

- Impairment refers to organ level functions or structures.
- Disability refers to person level limitations in physical and psychocognitive activities.
- Handicap refers to social abilities or the relationship between the individual and society.

ICIDH classification of impairments, disabilities and handicaps and International Classification of Disorders and Health [ICDH] of WHO, Geneva, Division of Mental Health and Prevention of Substance Abuse, 1977; Defines these terms and their relations in the following way:

- Impairment is an abnormality of psychological or physical functions or of appearance.
- Disability is an interference with the performance of an activity by an individual in relation to the immediate environment.

• Handicap is a societal disadvantage for a given individual that limits or prevents the performance of a social role or participation. The following case study will help us to understand these terms more clearly.

**A.Impairment:** Following are the operational definitions provided by various agencies, which will help in re-framing the definition of the concept of impairment.

- **1.** Impairment is any loss or abnormality of psychological or anatomical structure or function [WHO].
- **2.** A significant loss or deficiency in physical or mental faculties would be known as impairment [North Carolina General Statute 122C-3 12a].
- **3.** Impairment is long lasting or permanent and it could be a physical or mental problem or defect [Robert Levi].
- **4.** As per functional limitations, impairment may be defined as a specific reduction in bodily functions that one described at the level of person [Einar Helander].

From the above mentioned definitions, it can be concluded that;

- 1. Impairment is a long lasting or permanent problem or defect.
- 2. It can be physical, mental, sensory, intellectual, or psychological in nature.
- **3.** It can be congenital or acquired.
- **4.** It is loss or abnormality of structure or function of Psychological or Physiological nature at organ level.
- **5.** Impairment cannot be cured completely but its degree can be reduced through medical restorative services.
- **B. Disability:** Since the concept of disability is subjective and psychological, societies have defined this term in their own way. Distinction is made between disabled and non-disabled on the basis of appearance, behaviour, functional limitation and restriction of activity. Significant profound deviations of physical and mental faculties from the fixed standard of an individual, resulting in appreciable and substantial difficulty in performing functions in a social adjustment, would be perceived as a disability. The following few operational definitions provided by various agencies and individuals will be helpful to understand, re-visit and re-define this concept:
  - **1.** Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being [WHO].

- **2.** A person who in his/her society is regarded as disabled because of a difference in appearance and/or behaviour [Einar Helander].
- **3.** Disability is the loss or limitation of opportunities that prevent people who have impairments from taking part in the normal community life on an equal level with others due to physical and social barriers [V. Finkelstain & S. Ferench].
- **4.** A disability means an inability to perform a normal bodily or mental process. It could either be complete inability to do something (such as walking) or it can be a partial inability to do something (such as one can lift weights but not heavy ones) [Disability discrimination Act of British Government-1995].
- **5.** An individual is considered as disabled if his/her physical mental impairment substantially limits one or more major life activities [Americans with Disabilities Act [ADA]-1990].
- **6.** Disability in relation to a person means a total or partial loss of a person's bodily or mental function or a total or partial loss of a part of the body [Disability Discrimination Act of Australia-1992].
- **7.** A person with disability is an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognised physical or mental impairment [International Labor Organisation [ILO].
- **8.** Any person who is unable to ensure for himself/herself, wholly or partly, the necessities of a normal individual or social life including work, as a result of deficiency in his/her physical or mental capability [Planning Commission of India].
- **9.** A person with disability is one who in his/her society is regarded or officially recognised as such because of a difference in appearance and/or behaviour in combination with a functional limitation or an activity restriction [North Carolina General Statute 122C-3 12a]
- **10.** Long-term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community [Department For International Development [DFID].
- 11. "A physical or mental impairment which has a substantial and long term adverse effect on a person's ability to carry out normal day to day activities [Disability Discrimination Act UK-1995].

# Considering the above-mentioned definitions, it can be said that:

- **1.** Disability is a difference in appearance or behaviour of an individual.
- **2.** Disability is any restrictions or lack of ability of an individual to perform an activity in a normal range.
- **3.** Disability is a specific reduction in bodily functions that are described at the level of the person.
- **4.** Disability is contextual, cultural, episodic and perceived.

- **5.** Disability is social, psychological, subjective, permanent or temporary.
- **6.** Disability is not just individual pathology but a societal problem.
- **C. Handicap:** There has been some controversy also in the use of the word handicap. This word has been in use for a very long time. For some time it was believed that the word disabled would be preferable. Now it is preferred to use the phrase "person with disability". The term handicap was used previously in reference to persons with disabilities. Many people working on disability and rehabilitation feel that this is not a socially acceptable and politically correct language, since all people with disability are not handicapped. The word also has a negative connotation. Otherwise only a small proportion of the total persons with disability are handicapped, since they are dependent on others and need constant care. The term handicap was used in Europe during ancient times to indicate beggars who used to beg by holding their caps in the hands. That is how the term came into existence. Usually those beggars were persons with disabilities. Thus this term continued to indicate persons with disabilities. Attempts have been made to re-define this term for the sake of conceptual clarity. A few such definitions are examined below:
  - 1. A Handicap is a social disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual [WHO].
  - 2. The term handicap means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between persons with a disability and the environment. The purpose of this term is to emphasise and focus on the shortcoming in the environment and in many organised activities in society [United Nations [UN] Standard Rules-1999].
  - **3.** A person is handicapped when he or she is denied the opportunities generally available to the community that are necessary for the fundamental elements of living, including family life, education, employment, housing, financial and personal security, participation in social and political groups, religious activity, intimate and sexual relationships, access to public facilities, freedom of movement and the general style of daily living [Captan. HJM. Desai].
  - **4.** Handicap refers to a situation when physical and social barriers put persons with disabilities at a disadvantage and hinder their ability to fully participate in society. A person with a disability is not "handicap" but is handicapped by attitudinal, physical, and other barriers that society fails to remove [North Carolina General Statute 122C-3 12a].

From the above mentioned definitions of the concept handicap can be summarised as follows:

It is not an individual who is handicapped, but the society which makes an individual so by creating potential barriers like physical, mental, economic, social, health, architectural, political, religious, legal, institutional and cultural. It is society as a whole which is responsible for the handicap in the situation of a person with disability. Negative attitudes, prejudices and discrimination of society make a person handicapped. A prolific English author named Tony attempts to tell who is disabled in the following way.

# Policies Relating to Disability

India has a long experience of policy and practice with respect to disability, including collection of census information on disability from as early as 1872, and special schools and institutions operating since the 19th century. Like many countries, it also had specific provision for people with mental illness and retardation under the Indian Lunacy Act of 1912. The Constitution of India acknowledged also general state obligations to PWD in Article 41, and the State List under "Relief of the disabled and unemployable". Subsequently, specific measures such as employment concessions were introduced from the 1960s. However, it was not until the 1980s that policy commitment to full participation of PWD in Indian society evolved. The outcomes of this policy shift were realized in several key pieces of legislation: (i) the Mental Health Act, 1987; (ii) the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PWD Act); (iii) the Rehabilitation Council of India Act, 1992 and amended in 2000 (RCI Act); and (iv) the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (National Trust Act). The cornerstone among these is the PWD Act, which is discussed in the following section.

The Persons with Disabilities Act: The main provisions of the PWD Act are outlined in Box 7.1. It seems clear that the Act is informed by approaches beyond a pure medical model, in that many aspects of PWD lives are addressed, including societal attitudes. At the same time, the direct linkage in the Act between definitions of disability and entitlements necessitates a definition of disability which derives from threshold levels of physical and mental impairment which are defined in a largely medical sense. While the philosophy of the Act therefore represents a major step forward in disability policy in India, its underlying philosophy can be considered a hybrid between medical and social models of disability.

Broadly, the entitlements and commitments towards PWD under the Act can be divided into two main groups: (i) entitlements which are absolute and thus in nature of legal rights. Some of these existed as rights prior to the Act but were

reiterated or strengthened in the Act itself (and have in some cases been refined subsequently); and (ii) commitments that are given either in rather general terms or with the explicit proviso "within the limits of [governments'] economic capacity and development". These can be described as "contingent entitlements" under the Act and are not unqualified rights. The division is not entirely clear cut, as subsequent jurisprudence has in some cases strengthened general commitments. In a number of cases, follow-up action is also anticipated by states or other relevant authorities.

Despite the PWD Act being a ground-breaking piece of legislation, there remain a number of policy shortcomings in its design that are worth highlighting. These include both general issues which apply to several areas of the Act, and others which relate to specific sectoral heads. A number of them were raised by GoI's own Amendment Committee in 1999, but have not subsequently found their way onto GoI's agenda.

- (i) General Policy Issues in PWD Act: Some of the cross-cutting policy issues with respect to the PWD Act include:
- the Act covers only designated groups of PWD, which is by no means completely inclusive of categories of disability. This is in part driven by the linkage in the Act between the relevant legal definition of disability and the entitlements under the Act that flow from that. There is a natural reluctance on the part of policymakers to commit to entitlements for a wide group in the face of limited financial and other resources. Nonetheless, there is no reason in principle why the definitional and entitlement aspects of the Act need be completely synchronized. Providing for a more inclusive definition of disability while retaining more restrictive entitlements by disability type has been proposed by the Amendment Committee for the PWD Act.

The Committee proposed expansion of the Act's definition of disabilities to include multiple disability, autism, thalassemia, haemophilia, filiariasis, cerebral palsy and moderate/severe speech impairment. It also provided a more precise definition of mental illness, which in the current Act is vaguely defined as "any mental disorder other than mental retardation". These proposals seem eminently sensible. On the latter point, amendments to the Act proposed by the Ministry in 2006 also represent a step forward in trying to have a more workable definition of mental illness.

• a second overarching policy issue with the Act relates to commitments which are subject to the "limits of economic capacity and development" of the relevant authorities. The formulation represents an attempt to balance policy commitments and fiscal and institutional realities.

While the approach is reasonable, the Act fails to outline any process for determining broadly what are the appropriate levels of policies and

interventions which might be expected at different levels of economic development within India. This could not, of course, be a very precise process, but without some indication of what are reasonable expectations of states at different levels of economic development, it is difficult to know what constitutes reasonable compliance effort on the part of the authorities. As a result, what are justiciable rights in sections where this proviso is used remains quite uncertain. The uncertainty is significant, as this approach is used in important sections such as identification of PWD, prevention and treatment of disability, and access rights of PWD. In the absence of a process for benchmarking reasonable performance by states on the contingent entitlements of the Act, the courts have become the main point of reference for PWD to enforce performance by governments. In this respect, the courts have sought to promote the rights of PWD in a variety of areas.

The courts have tried to balance PWD entitlements with fiscal concerns. However, the resources and time needed to access the courts effectively are significant, and are likely to exclude many PWD.

- the above point raises the wider one that the Act's entitlements and commitments are supported by a weak enforcement mechanism. The institution mandated with monitoring compliance with the Act the Office of the Commissioner has weak powers. The Commissioners' office has authority to look into deprivation of PWD rights and on implementation of various rules, laws etc. which have been developed to promote the welfare and rights of PWD. The fundamental limitation of the office is that its only legal sanction in case of a breach is to "take up the matter with the appropriate authorities". The Office does not itself have enforcement powers of a court or administrative tribunal. It can and does make orders, but can not enforce compliance. As such, its effective powers are either "naming and shaming" or encouraging referral to the court system. While these have been effective remedies in some cases, there are clear limitations. This issue is discussed in the institutions section.
- the overall approach of the Act has rather limited roles for actors outside the core administrative framework, including NGOs/DPOs, civil society, PWD themselves and PRIs. There is no explicit role for PRIs mentioned, though the Act was passed after the 73rd Constitutional amendment. With respect to the NGO sector, it is mentioned at several points as either a point of consultation (e.g. on formulation of PWD rehabilitation policies) or as a potential implementer (e.g. on disability research and training of teachers). However, the overall policy and delivery model remains a rather traditional administratively-driven mechanism, with limited sense of genuine partnership in policy development and service delivery between the public and non-public sectors. Perhaps most notable of all is that DPOs are not mentioned in the Act at all, nor any obligation for governments to consult directly with PWD when developing policies, designing interventions or monitoring performance. The

assumption of the Act appears to be that disability NGOs will act as conduits for PWD views and action.

- (ii) Sectoral policy issues in the Act: There are also several sector-specific policy issues worth noting. They include:
- Employment: With respect to public sector employment, the Act provides for 3 percent of "identified posts" to be filled by PWD. The current list of posts (identified only in 2001) is restrictive, arbitrary and based purely on impairment, without consideration of personal or environmental factors. There are also no sanctions for non-compliance. This is discussed further in Chapter 6. The overall approach is one that is not considered good practice internationally, even in systems where a quota approach is used. A second feature of the quota policy is that it applies only to three disability types locomotor, visual and hearing, with a 1 percent reservation for each. Thus even the full disability categories of the Act are not included in the reservation policy.
- Education: While the thrust of the Act to ensure that CWD are in school is clear, its guidance on the most appropriate type of education and who should take the decisions on that issue is less so. The Act provides that education of CWD should be in "an appropriate environment". However, it has a multiple track of promoting integration of CWD into regular schools, setting up of special schools, and home-based education. While the different approaches need not be contradictory, the Act provides limited guidance both on which approach should be considered preferable and on who is to take and enforce decisions on what is considered an appropriate educational environment for individual children. Subsequent policies have provided some more guidance on the issue, but whether it remains the right of parents where to school their children is unclear.
- Health: Apart from being subject to the economic capacity proviso, the provisions of the Act in the area of health are very limited. Perhaps the most notable point is that the obligations of the authorities are so generally phrased that they are difficult to interpret in terms of enforcement. Thus, the authorities should pursue "various methods for preventing disabilities", "take measures" for promoting pre-, peri- and post-natal care, and "create awareness" of disability issues. The combination of the economic capacity proviso and such general language makes it difficult to consider the provisions on prevention and early detection of disabilities as more than statements of intent. The fact that the subsequent jurisprudence on health issues relates almost entirely to issues of custodial treatment of mental health patients and their capacity in personal law seems to support this conclusion.

As of 2006, the Ministry has proposed a number of amendments to the PWD Act which are under consultation. The general areas for proposed revision are:

- revision of definitions of a number of disabilities, including mental illness, cerebral palsy, low vision, mental retardation and other impairments. For several of the conditions, a positive element of the proposals is that they take into account more explicitly the impacts of impairments on functions and activities of daily living. On the other hand, there is a question as to whether the Act itself is the most appropriate place for precise medical and other definitions of disabilities, or whether the implementing Rules may give more flexibility in adjusting definitions over time.
- revised provisions on the institutions responsible for various areas of implementation and oversight of the Act. Some of this is (appropriately) moving precise definition of institutional composition and other details into the implementing Rules. Others make the mandate of bodies such as the central Coordination Committee more general and overarching in nature.

Box: Key entitlements and commitments under the PWD Act, 1995

The PWD Act has both binding entitlements and more general commitments. The key provisions are:

Education: The following are binding on Government (i.e. not subject to economic factors):

- Governments shall ensure that every CWD has access to free education "in an appropriate environment" until the age of eighteen.
- Governments "shall initiate or cause to be initiated" research by public and non-governmental agencies for development of both assistive devices and special learning materials for CWD in order to promote equal opportunity in education.
- Governments shall ensure teacher training that produces "the requisite manpower" for teaching of CWD both in special schools and integrated settings.
- all public educational institutions and other receiving aid from Government shall reserved not less than 3 percent of seats for PWD (i.e. for PWD over 18 years).
- government should prepare a "comprehensive education scheme" for CWD which includes transport or financial incentives, barrier free access, supply of book, uniforms and learning materials to CWD, adjusts the examination system as necessary, adapts curriculum for CWD.

Employment: The Government shall:

- identify posts for PWD in public establishments and update the list every three years.
- reserve not less than 3 percent of identified posts for PWD, with 1 percentage point reserved for people with blindness/low vision, hearing impairment, locomotor disability or cerebral palsy respectively (though any department or establishment can be exempted by notification).
- every employer should have a record of all PWD employed in that establishment.
- Governments and local authorities shall formulate schemes for promotion of employment of PWD which may provide for training of PWD, relaxation of age limits in employment, measures related to OHS, provisions for financing such schemes etc.
- Reservation of not less than 3 percent in all poverty alleviation schemes.
- "within the limits of their economic capacity and development", Governments shall provide incentives to both public and private sectors for employment of PWD with a target of at least 5 percent of their workforce to be PWD.

Prevention and early detection of disabilities: All commitments in this area are given with the proviso "within the limits of their economic capacity and development". With proviso, Governments should:

- Undertake surveys on causes of disability.
- Promote "various methods" for preventing disabilities.
- Screen children at least once a year for identifying at-risk cases.
- Provide facilities for training PHC staff.
- Conduct or sponsor awareness campaigns on hygiene, health and sanitation, and on causes and prevention of disabilities.
- "take measures" for pre-, peri- and post-natal care of mother and child.

Affirmative Action: Governments shall frame schemes for:

- Provision of aids and appliances to PWD
- Preferential allotment of land for housing, business, recreation centres, special schools, research centres, and factories run by PWD entrepreneurs.

Non-discrimination in access: All commitments in this area are given with the proviso "within the limits of their economic capacity and development". With proviso, Governments should:

- Adapt all forms of transport to make them accessible to PWD.
- Provide for a variety of assistive devices in the built environment, including auditory signals, ramps in public buildings and health facilities, Braille signage, accessible curbing, marked zebra and railway crossings, warning signals as appropriate etc.
- in the area of education, the proposed revisions aim to give a more specific obligation to states and local authorities to develop IE strategies and schemes. This increases consistency with initiatives under the lead of MHRD.
- other sectors such as employment attempt to spell out more precise obligations of employers and mandates of institutions. However, it is not clear how the proposed revisions will result in more effective functioning of actors such as Special Employment Exchanges.
- strengthened provisions on regular gathering of data on the socio-economic status of PWD.

# Need and Importance of Aids and Appliances

#### **Mobility Aids**

When walking is impaired due to locomotor disability, different types of mechanical appliances such as Parallel Bars, Walkers, Crutches, Sticks/Canes, Braces/calipers will be of great help. They provide support, protection and balance during movement from one place to another. Different walking appliances are required dependent on the severity of the disability, the age of the person affected, and the stage the rehabilitation has reached.

#### Types of Walking Aids

1	Parallel Bars	<ul> <li>Immovable</li> <li>Very Stable</li> <li>Disabled people should begin walking training with these</li> </ul>
2	Walkers	<ul> <li>Contacts the ground in 4 places at the same time</li> </ul>

3	Crutches	<ul> <li>Stable but slow</li> <li>Good for balance and weight-bearing on the hands, forearms and underarms</li> <li>Two points of contact, therefore less stable than a walker</li> <li>Allows faster movement</li> <li>Weight-bearing throughout the hands/elbow</li> </ul>
4	Sticks/Canes	<ul> <li>Least stable walking aid</li> <li>High sticks can help with balance problems</li> <li>A shorter stick will make the child use his weak leg and therefore help to strengthen muscles good for psychological support.</li> <li>Good for psychological support</li> <li>Sticks should b used on the opposite side of the weak leg</li> </ul>
5	Braces/calipers	Aids that help to hold the legs or other parts of the body in functional positions:  • They provide support to a wak joint, for example, in post-polio residual paralysis  • They provide help in controlling joint movements, for example, in cerebral palsy and hemilplegia  • They help prevent or correct deformity or contracture, for example in club foot or disability conditions due to polio

# **Wheel Chairs**

Appropriate Wheel Chairs

These guidelines focus on appropriate wheelchairs. Manual wheelchairs are here defined as,

- Wheelchairs propelled by the user pushed by another person. A wheelchairs is appropriate when it.
- Meets the users needs and environmental condition

- Provides proper fit and postural support;
- Is safe and durable;
- Is available in the country :and
- Can be obtained and maintained and services sustained in the country at an affordable cost.

#### Users of wheelchairs

The term "users" refers to people who already use a wheelchair or who can benefit from using a wheelchair because their ability to walk is limited. Users include:

- Children, adults and the elderly;
- Men and women and girls and boys;
- People with different neuromusculoskeletal impairments, lifestyles, life roles and socioeconomic status; and
- People living in different environments, including rural, semi-urban.

Users represent a wide range of mobility needs, but they have in common the need for a wheelchair to enhance their mobility with dignity.

#### Need for wheelchairs

About 10% of the global population, i. e. about 650 million people, have disabilities studies indicate that, of these, some 10% require a wheelchair. It is thus estimated that about 1% of a total population- or 10% of a disabled population – need wheelchairs, I.e. about 65 million people worldwide.

In 2003, it was estimated that 20 million of those requiring a wheelchair for mobility did not have one. There are indications that only a minority of those in need of wheelchairs have access to them, and of these very few have access to an appropriate wheelchair.

# Rights to Wheelchairs

States parties to convention on the rights of persons with disabilities have the obligation "to take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities". This is a commitment to provide mobility aids, such as wheelchairs, that make personal mobility possible. In 1993, the standard rules on the equalization of opportunities for person with disabilities expressed the same commitment, demanding that countries ensure the development, production and servicing of

assistive devices for people with disabilities in order to increase their independence and to realize their human rights.

These two important international declaration create rights to wheelchair because it is universally recognized that at appropriate wheelchair is a precondition to enjoying equal opportunities and rights and for securing inclusion and participation. Personal mobility is an essential requirement to participating in many areas of social life and wheelchairs are for many the best means of guaranteeing personal mobility.

Independent mobility makes it possible for people to study, work, participate in cultural life and access health care. Without wheelcharis, people may be confined to their homes and unable to live a full and inclusive life. We know that eliminating world poverty is not possible unless the needs of those with disabilities are taken into account. Without wheelchairs, these individuals are unable to participate in those mainstream developmental initiatives, programmes and strategies that are targeted to the poor, such as ae emobidied in the Millennium Development Goals, the Poverty Reduction Strategies and other national developmental initiatives.

It is a vicious circle lacking personal mobility aids, people with disabilities cannot leave the poverty trap. They are more likely to develop secondary complications and become more disabled, and poorer still. If they are children they will be unable to access the educational opportunities available to them, and without an education they will be unable to find employment when they grow up and will be driven even more deeply into poverty.

On the other hand, access to appropriate wheelchairs allows people with disabilities to work and participate in mainstream development initiatives that will reduce their poverty. Similarly, a wheel chair can enable a child to go to school, to gain an education and, when the times comes, to find a job.

#### Benefits of Wheelchairs

Wheelchair provision is not only about the wheelchair, which is just a product. Rather, it is bout enabling people with disabilities to become mobile, remain healthy and participate fully in community life. A wheelchair is the catalyst to increased independence and social integration, but it is not an end in itself.

Combined with adequate user training, an appropriate wheelchair can serve to reduce common problems such as pressure sores, the progression of deformities or contractures, and other secondary conditions. A whellchair with a proper cushion often prevents premature death in people with spinal cord injuries and similar conditions and, in one sense, is a life-saving device for these people. A wheelchair that is functional, comfortable and can be propelled efficiently can result in increased levels of activity. Independent mobility and increased physical function can reduce dependence on others. Other benefits, such as improved respiration and digestion, increased head, trunk and upper extremity control and overall stability, can be achieved with proper postural support. These factors combined serve to increase access to opportunities for education, employment and participation within the family and the community.

A wheelchair often makes all the difference between being a passive receiver and an active contributor. Economic benefits are realized when users are able to access opportunities for education and employment. With a wheelchair, an individual can earn a living and contribute to the family's income and national revenue, whereas without a wheelchair that person may remain isolated and be a burden to the family and the nation at large. Similarly, a wheelchair that is not durable will be more expensive owing to the need for frequent repairs, absence from work and eventual replacement of the wheelchair.

For society, the financial benefits associated with the provision of wheelchairs include reduced health care expenses, such as those for treating pressure sores and correcting deformities.

#### Challenges for Users

Users face a range of challenges, which must be considered when developing approaches to wheelchair provision.

Financial Barriers: Some 80% of the people with disabilities in the world lie in low-income countries. The majority of them are poor and do not have access to basic services, including rehabilitation facilities. The ILO reports that the unemployment rates of people with disabilities reach an estimated 80 per cent or more in many developing countries. Government funding for the provision of a wheelchair is rarely available, leaving the majority of users unable to pay for a wheelchair themselves.

Physical Barriers: As many users are poor, they live in small houses or huts with inaccessible surroundings. They also live where road systems are poor, there is a lack of pavements, and the climate and physical terrain are often extreme. In many contexts, public and private buildings are difficult to access in a wheelchair. These physical barriers place additional requirements on the

strength and durability of wheelchairs. They also require that users exercise a high degree of skill if they are to be mobile.

Choice: Users are rarely given the opportunity to choose the most appropriate wheelchair. Often there is only one type of wheelchair available (and often in only one or two sizes), which may not be suited to the user's physical needs, or practical in terms of the user's lifestyle or home or work environment. According to the Convention on the Rights of Persons with Disabilities, "States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities . . . by facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost".

#### Wheelchair Provision

Wheelchair provision usually includes the design, production and supply of wheelchairs and delivery of wheelchair services. Wheelchair provision can only enhance a wheelchair user's quality of life if all parts of the process are working well. This includes ensuring users have access to:

- 1. Wheelchairs of an appropriate design
- 2. Wheelchairs that have been produced to appropriate standards
- 3. A reliable supply of wheelchairs and spare parts; and
- 4. Wheelchair services that assist the user in selecting and being fitted with a wheelchair, provide training in its use and maintenance, and ensure follow-up and repair services.

#### Types of Wheelchair

No single model or size of wheelchair can meet the needs of all users, and the diversity among users creates a need for different types of wheelchair. Those selecting wheelchairs, in consultation with the user, need to understand the physical needs of the intended user and how he or she intends to use the wheelchair, as well as knowledge of the reasons for different wheelchair designs.

The ability to adjust or customize a wheelchair to meet the user's physical needs will vary, depending on the type of wheelchair. Often, wheelchairs are available in available in at least a small range of sizes and allow some basic adjustments.



For long-term users, a wheelchair must fit well and provide good postural support and pressure relief. A range of seat widths and depths, and the possibility to adjust at least the footrest and backrest height are important in ensuring that the wheelchair can be fitted correctly. Other common adjustments and options include cushion types, postural supports and an adjustable wheel position. Highly adjustable or individually modified wheelchairs are designed for long-term users with special postural needs.

#### Stakeholders and their Roles

Policy planners and implementers are directly involved in the planning, initiation and ongoing financial, advisory and legislative support of wheelchair provision. The role of policy planners includes the following:

- Wheelchair provision policy is developed in consultation with other stakeholders, aiming at effective measures to ensure personal mobility with the greatest possible independence for people with disabilities. This includes:
  - ❖ Facilitating the personal mobility in the manner and at the time of their choice and at an affordable cost;
  - ❖ Access to wheelchairs, including making them available at an affordable cost;

- Providing training in mobility skills to people with disabilities and to rehabilitation personnel; and
- ❖ Encouraging entities that produce wheelchairs and other mobility aids within the country.
- Standards for wheelchair products, service delivery and training are adopted, promoted and enforced.
- Measures are taken to ensure that wheelchair provision is equitable and accessible to all, including women and children, the poorest and those in remote areas.
- Wheelchair services are developed as an integral part of health care structures and in co-ordination with associated services, such as rehabilitation, prosthetic, orthotic and community-based rehabilitation services.
- Sustainable funding policies for wheelchair provision are developed.
- Wheelchair user groups and disabled peoples' organizations are involved at every stage from planning to implementation.

According to UN Standard Rules and the Convention, it is the primary responsibility of countries to make wheelchairs available at an affordable cost. Ensuring the availability of wheelchair services within a country does not necessarily mean the direct provision of services by the Government. Nevertheless, the Government can work closely with non-governmental and international non-governmental organizations, development agencies, user groups and the private sector to develop national policies and a provision system. Furthermore, in developing the policy one needs to ensure that wheelchair services are cohesive and closely linked with national health and rehabilitation strategies.

# Users, families and caregivers

Users and their groups are at the centre of developing and implementing wheelchair provision. They can help ensure that wheelchair services meet their needs effectively.

#### The role of users includes:

- Participating in the planning, implementation, management and evaluation of wheelchair provision;
- Participating in the development and testing of wheelchair designs;
- Working within wheelchair services in clinical, technical and training roles; and

Supporting and training new uers.

Some users permanently rely on members of their family to assist with day-to-day activities of living, while others may be more independent. Where a family member or caregiver is responsible for assisting a user on a daily basis, such as a parent of a child with cerebral palsy, he or she should also be involved in all the roles listed above for users. Family groups for parents, siblings and other relatives of children with disabilities are encouraged to undertake the activities listed.

# **Hearing Aids**

Hearing impairment (HI) of any degree has a profound effect on children: it delays development of speech, slows educational progress, and leads to being stigmatized. In India, 15.93% of the school going population (6- 14 years) are at risk of having a hearing disorder. The National Sample Survey Organization estimates, that the prevalence of speech disability is 8.3% in the urban areas and 8.9% in rural school going children. This estimate may be on a lower side as the data is collected by the primary school teachers and social workers. These workers often miss or ignore lower degree of hearing loss, especially in the absence of an objective tool or scale to measure or document the hearing loss. Most of the studies in India indicate a higher prevalence and incidence of hearing impairment in the rural population as compared to the urban residents. If taken together a total of 25% of Indian children under the age of 14 require the consolation of an audiologist and a speech language pathologist (ASLP).

In a broad sense the term audiological re/habilitation or aural re/habilitation refers to a wide range of modalities and activities used by an ASLP to maximise the child's ability to live and communicate with the speaking world around him. As usually observed in clinical practice most of the parents and other family members of children with HI prefer waiting for the child to speak till she/he grows beyond two to three years and then take the child for medical consultation. The audiologist who is a healthcare professional specializing in identifying, diagnosing, treating and monitoring disorders of the auditory and vestibular system portions of the ear is often approached at a quiet later age. Studies over the past decade have shown considerable variability in the age of identification, diagnosis, and intervention among specific settings and geographic areas.

In India aural rehabilitation is initiated by the parents hence gets significantly delayed. Specifically, the mean age of identification by parents and hearing aid fitting were both later than the Joint Committee on Infant Hearing, 2007 targets (14). The Joint Committee on Infant Hearing recommends identification of hearing loss by 3 months and commencement of intervention by 6 months of age. In eastern India children with HI are detected at a mean age of 3.03 years (SD: 1.3) and aural habilitation commences by a mean age of 7.38.

Most hearing loss in adults is permanent (not correctable by medication or surgery), but in many cases a hearing aid will help. How much a hearing aid helps will vary by the individual, the degree of hearing loss and the listening environment. In some cases, testing may indicate referral to an otolaryngologist (ear, nose and throat specialist) for possible medical or surgical correction for the hearing loss.

Everyone experiences increased difficulty hearing in the presence of noise, and this is usually worse for someone with hearing loss. However, properly fit hearing aids can provide significant benefit in this situation.

State-of-the-art directional microphone hearing aids can noticeably improve your ability to hear sounds in front of you compared with those behind you (improved signal-to-noise ratio). This can be helpful in a busy restaurant, for example, where the voices behind you are louder than those across the table from you.

# Type of Hearing Aids

Hearing aids are available in several styles outlined below. The best type for you depends on your hearing loss, ear anatomy, life style and demands on your hearing. After the hearing evaluation, the audiologist can help make this choice. Below are the four major styles of hearing aids:

**Behind-the-ear (BTE):** This type of hearing aid fits over the top and back of your ear. It is held in place by an ear mold that fits into your ear canal directing sound from the hearing aid toward your ear drum. It is easy to manipulate, and all the advanced circuit types can fit in this model. The battery life averages 14 days.

**In-the-ear (ITE):** This style fills the bowl and canal of the ear, however, there is no external piece sitting on top of your ear. Like the BTE, it is easy to operate and most advanced circuit types fit in this model.

**In-the-canal (ITC):** This style fits mainly in your ear canal and is noticeably less visible than the BTE or ITE. Because it is smaller, it may be more difficult to manipulate, and not all circuit types will fit into this model. The battery life is less as the battery is smaller (10 to 12 days).

**Completely-in-the-canal (CIC):** This type of hearing aid fits deeply into your ear canal and is virtually invisible. Because it is so small, not all circuit types can be accommodated, nor is it a good choice for severe and profound hearing losses. The battery life is about five days

# **Visual Impairments**

The term *visual impairment* describes a wide variety of conditions that affect vision abilities. We use the term to denote mild to most severe vision loss, rather than to defects in the eye itself. According to the Individuals with Disabilities Education Act (IDEA) of 1997, a visual impairment refers to "an impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness." Sight impairment terminology can sometimes be confusing. Most people classified as "blind" have a visual sense of lightness or darkness, as well as an ability to see some shapes and images. To avoid confusion, you should know the following terms commonly used to designate degrees of visual impairment:

- **Totally blind**. This term usually implies little or no visual sensitivity to light at any level. This condition is rare, and people who are totally blind typically have severe physical damage to the eyes themselves or to the visual nerves.
- **Legally blind**. A legally blind person has a visual acuity of 20/200 or less in the better eye, after correction. This means that what an individual with normal (20/20) vision sees at two hundred feet, the legally blind person cannot see until he or she is within twenty feet. In addition, a person can be classified as legally blind if she has a field of vision no greater than twenty degrees at the widest diameter. (A normal field of vision is close to 180 degrees.) Only about 20 percent of legally blind people are totally blind. Legally blind individuals typically use Braille and visual aids.
- **Low vision**. People with low vision can read with the help of large-print reading materials and magnifying objects. They may also use Braille.
- **Partially sighted**. Partially sighted individuals have less severe loss of vision than people in the other three categories. A person with partial sight may be able to see objects up close or far away and with corrective lenses may be able to function at normal levels.

Visual impairment in general affects four main functional areas: Orientation/mobility, communication, activities of daily living (ADL) and

sustained near vision task. Early intervention and special education can balance the negative effects of visual impairment. In many cases environmental adaptations, vision training, follow up for ensuring compliance, coordinating with stakeholders, removing myth and misconception and counseling would help in empowering the individual and/or enhancing functional residual vision. The effect of low vision is not same for all people and the following assessment needs to be compiled for each individual before embarking upon the decision of assistive devices:

- Extent of vision: Near and distance visual acuity
- Size of the visual field [if relevant]
- Effect of light and glare
- Extent of recognition and naming of colors
- Extent to which contrast affects their activities
- Extent of use of vision for different activities and purpose in the environment
- Extent to which a person sees and recognizes an object depends, amongst other on: Familiarity of the object; light; size; distance; contrast; color; detail or simplicity of the object
- Age, socioeconomic conditions, literacy status, and level of motivation Special Assistive Devices for the Visually Impaired

Assistive devices for the visually impaired can be broadly divided into the following categories: Education, mobility, vocational, daily living devices, low vision devices, and psychological test for vocational assessment and training. *Education devices* 

Braille duplicators and writers, for example, Brailler and thermoform machine to convert material into Braille; Writing devices: Braille slates, Taylor postcard frame, pocket Braille frame; Braille paper; talking books and tape recorders: Material recorded on cassettes has emerged as the most popular mode of imparting education; Reading machines: Kurzweil reading machine, which reads typeset or typewritten text and turns it into speech; Braille computers: Braille Windows, Index Braille, Braille'n speak helps individual while working with personal computers; Mathematical devices: The Taylor arithmetic frame, abacus, talking calculator, spur wheel helps in learning mathematics; Geography and science devices: Sensory quill and three-dimensional raised maps help in learning geography, human physiology, zoology, and botany.

#### Mobility devices

Canes (symbol canes; guide canes; long canes; electronic travel devices), mobility show-card, mini beeper.

#### Vocational devices

Goniometer, attachment to lathe, spot welding, continuity tester, Braille micrometer.

# Daily living devices

Daily living devices can be further classified into five broad categories namely, clocks and watches, games and puzzles, sports, kitchen equipment and personnel devices.

#### Low vision devices

Low Vision devices can be further divided into two types: Optical devices, which use lenses to magnify objects and non-optical devices and techniques, which make objects easier to use. A third category is electronic magnifier which is sometimes subsumed under non-optical devices. These devices include telescopes (telescopic spectacles, hand held, tele-bifocal spectacles), visualtek, schmidt reader, magnifying lenses (fixed focus; variable focus stand; half cylindrical rod; hand magnifier; folding; high plus spectacle; half eye spectacleprism glasses; clip on magnifier), microscopic spectacles, visolett, fluorescent reading lamps, tinted lenses. Electronic magnifier/adaptive technology in the form of closed circuit television (CCTV), computer software (JAWS, MAGIC, text Braille software), speech synthesizer, talking books, overhead projector. [25–28] Psychological assessment tests and training program is designed to develop a person's skill potential to the extent possible. These include Minnesota rate of manipulation test; Pennsylvania bi-manual work sample; Purdue pegboard; Crawford small parts dexterity test; Stanford-kolhs block design test for the blind; Blind learning aptitude test.

New initiative on low vision services in approved 11<sup>th</sup> five-year (2007-12) plan under NPCB

Strengthening Low Vision service is one of the thrust areas under 11th five-year plan under NPCB in addition to ongoing activities. Regional Institutes of Ophthalmology (RIO) and government medical colleges are being developed as Low Vision units in a phased manner. Financial assistance for Low Vision devices like high plus spectacles, hand held magnifiers, stand magnifiers, telescope, video magnifiers [closed circuit television], absorptive lenses; field expanding devices are being provided by NPCB especially for poor patients. Eye surgeons working in public sector are being provided seven days orientation training on Low Vision services and financial support is borne by the GOI. Technical guidelines and comprehensive resource on Low Vision services is being developed involving all stakeholders for reference and dissemination. Improving quality of life of persons suffering from visual impairment involve patience, perseverance, multi-disciplinary approach with efficient coordination amongst stakeholders including medical, paramedical, social/psychological and educational professional. The gap between need and availability of Low

Vision services is known globally, however, a beginning has been made by the GOI to address this issue and fruitful results will be evident in times to come.

#### Government Rehabilitation Services

The Ministry of Social Justice & Empowerment is the nodal agency of the Central Government that promotes services for the people with disabilities through its various schemes.

# **Objectives**

The primary object is to promote services for people with disabilities through government and non government organizations, 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 and nongovernment organizations.

- District Rehabilitation Center (DRC) Project
- Regional Rehabilitation Training Center (RRTC)
- National Information Center on Disability & Rehabilitation (NICDR)
- National Council for Handicapped Welfare
- National Handicapped Finance & Development Corporation
- Assistance through Overseas Development Administration, UK
- Training in the UK under the Colombo Plan
- UNICEF Assistance in collaboration with the Government of India
- National Awards

#### District Rehabilitation Center (DRC) Project

The District Rehabilitation Center scheme was launched in early 1985 to provide comprehensive rehabilitation services to the rural disabled. This was done in collaboration with the National Institute of Disability and Rehabilitation Research (NIDRR), Washington, U.S.A. A Central Administrative and Coordination Unit (CACU) for coordinating and administering the activities of DRC was set up.

The aims and objectives of the DRCs include surveys of disabled population, prevention, early detection and medical intervention and surgical correction, fitting of artificial aids and appliances, therapeutic services - physiotherapy, occupational therapy and speech therapy, provision of educational services in

special and integrated schools, provision of vocational training, job placement in local industries and trades, self-employment opportunities, awareness generation for the involvement of community and family to create a cadre of multi-disciplinary professionals to take care of major categories of disabled in the district. At present, 11 DRCs function in 10 States in India.

# Regional Rehabilitation Training Center (RRTC)

Four Regional Rehabilitation Centers have been functioning under the DRCs scheme at Mumbai, Chennai, Cuttack and Lucknow since 1985 for the training of village level functionaries, training of DRC professionals, orientation and training of State Government officials, research in service delivery and low cost aids, etc. Apart from developing training material and manuals for actual field use, RRTCs also produce material for creating community awareness through the medium of folders, posters, audio-visuals, films and traditional forms.

#### National Information Center on Disability & Rehabilitation (NICDR)

A National Information Center 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 the disabled 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 computerized data so far collected relates to institutions/professionals working for the disabled, 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 the publication of awareness-generation material/journals, hold Seminars/Workshops, organisation of Film Festival/Exhibitions, production of films, etc. UNICEF assistance is obtained for different activities on awareness creation.

# **National Council for Handicapped Welfare**

# **Objectives**

- Ensure a coordinated and comprehensive approach to research, training and services for the disabled 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 disabled persons
- Ensure people's participation in the rehabilitation of the disabled

# National Handicapped Finance & Development Corporation

The Government has set up the National Handicapped Finance & 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.

# Assistance through Overseas Development Administration, UK

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

# Training in the UK under the Colombo Plan

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

#### 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

• 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
- The Economic and Social Commission for Asia and the Pacific (ESCAP): The Economic and Social Commission for Asia and the Pacific at the 48th session, held at Beijing in 1992, adopted its Resolution No. 48/3 which proclaimed the period 1993-2002 as the Asian and the Pacific Decade of Disabled Persons, with a view to give fresh impetus to the implementation of World Program of Action concerning disabled persons in the ESCAP Region beyond 1992. India is a signatory to the ESCAP Resolution. It had hosted UNESCAP Technical Workshop on the Production and Distribution of Indigenous Assistance Devices at Madras from 5 to 14 September, 1995, in which representatives of about 22 countries participated. India has been in the forefront of the international movement towards protecting the rights and interests of persons with disabilities. India was also an active partner in the International Year of the Disabled Persons; UN Decade of Disabled Persons; SAARC Year of Disabled Persons, 1993 and ESCAP.

#### **National Awards**

On the occasion of the World Disabled Day every year, the President of India gives away National Awards to:

- The Best Employee
- The Best Employer
- The Best Individual
- The Best Institution
- The Best Placement Officer

#### Social services and people with disabilities

There are also likely to be challenges for both the *market and governments in direct service provision to PWD*, at least where service provision is disability-specific and not simply a factor in a PWD accessing general services. This is driven by the characteristics of the group of disabled people. First, while by no means negligible, they are a relatively small share of the population. With respect to service provision, the (still smaller) size of particular sub-groups of PWD also matters, e.g., where disability-specific aids and appliances are needed. As a result, PWD are likely to be a dispersed group for providing services. Second, PWD and the households in which they live are poorer than average, so that their appeal for the commercial sector is relatively limited (though may be higher for some segments of the market such as NGOs). Third, even where supply-side issues can be overcome (e.g., cities), there may be significant demand side issues. These could include lack of interest in services for disabled people (e.g., lower demand for schooling relative to other children),

greater problems in physical access to goods and services for PWD, or simply the poverty constraints already noted.

When both "arms-length" relationships (market and government) fail, then people as groups may be able to take care of some types of market failures. In the case of disability, local communities may provide a service that is too difficult or expensive for the market or government to provide (e.g., this may explain some of the success of community-based rehabilitation for PWD in India and elsewhere). They can be more precise in their appraisal of the extent and consequences of a person's impairment. Care of a PWD will not be overprovided by family or community, and is not prone to exploitation in the same way as a public program. The "insurance" in this case is implicit in the expectations of reciprocity among family members and of the community at large – both of which are very different in different cultural environments.

If effective household and/or community support is dependent a sense of reciprocity with the PWD, the most vulnerable PWD are those who do not have a sufficient support system within their community. This may be either because their connections to those with resources are few or weak (which may be driven by reasons such as social stigma, caste, age or gender), or because the people they can depend on (typically their family) are very poor themselves. There can thus be two weaknesses of social action – one that is driven by the absence or thinness of networks of reciprocity, and one that is driven by the limited capacity of social networks to provide support. There are reasons to expect that the lives of PWD are characterized by both these weaknesses more than average. Empirically, a typical feature of disability in all countries appears to be more limited social networks (in particular due to stigma) and higher household poverty. The effectiveness of social action in both promoting opportunities and providing basic social protection for PWD is thus likely to be unusually constrained.

What is the role of government in the context of community-provided care (either by informal community institutions or the family? The direction of help may be two-way. Firstly, governments may choose to help the disabled for the sake of alleviating poverty – not only for the PWD but for the entire support system if care-takers are themselves poor. Secondly, government programs for PWD may be able to use the greater and more detailed information available in the community in the identification of beneficiaries and, possibly, the extent of entitlement.

In the light of the challenges that face market, government and social action in the field of disability, what combination of interventions seem sensible for trying to address different forms of failure? There is not is simple answer to this question. Different combinations appear more appropriate for different aspects of PWD lives (e.g., employment versus education), for PWD in different settings (e.g., urban/rural), and also for people

with differing types of degrees of disability. For example, government and market action may be easier in urban areas with concentrated populations of disabled people, while collective action may be more readily mobilized in rural settings among groups where social cohesion is strong. The approach also needs to take account of binding commitments of the state to PWD – e.g., where legal rights have been guaranteed to PWD. Overall, a clear message of the report is that there will remain a critical role for the public sector in the disability field for a variety of reasons, a role that the experience of countries at all levels of income suggests is never able to be bridged fully by the actions of non-state actors. The rest of the report deals with the issues outlined above in turn.

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

It has been the constant endeavour of the Government to provide the disabled persons with aids/appliances at minimum costs. The requirement for providing of aids/appliances, which are essential for the social, economic and vocational rehabilitation of the disabled persons, has come into sharp focus, particularly after the enactment of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, which came into force in 1996.

Various surveys conducted from time to time have made it clear that India has a very large number of disabled persons. Many of them come from low-income groups. Disability restricts their opportunities for leading functionally productive lives. From the application of modern technology, there have emerged a number of aids, which can reduce the effects of disabilities and enhance the economic potential of the disabled. To illustrate a wheel chair, an artificial limb, crutch, a brace, a splint can greatly improve the mobility of physically disabled individual. Similarly, with the help of a powerful hearing aid, persons with some residual hearing can be helped to carry on many activities of daily living. Low vision aids can help the persons with substantially reduced vision to read, print and undertake other activities resulting in their rehabilitation. However, large number of disabled persons are deprived of the benefits of these appliances because of their inability to find funds to purchase them.

In the light of the Government's growing stress on helping disabled persons and in bringing the aids and appliances within their reach, it has been decided to continue the ADIP Scheme and modify it in such a way that it becomes more user-friendly and the needy are not deprived of aids/appliances, which are essential for their social, economic and vocational rehabilitation. If they can, thereby, become earning members they would be much closer to achieve

economic self-dependence and also be able to live and pursue their activities with dignity.

# The Scheme and its Objectives

The Scheme aims at helping the disabled persons by bringing suitable, durable, scientifically-manufactured, modern, standard aids and appliances within their reach. The estimates, according to Sample Survey conducted by NSSO in 1991, indicate that there are about 16.15 million persons with various types of disabilities in the country. Their disabilities restrict the opportunity for their economic and social growth. In addition, about 3% of the children below 14 years of age suffer from delayed development. Many of them are mentally retarded and cerebral palsied and require some aids/appliances to attain the capacity for self-care and independent living.

The main objectives of the Scheme 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 shall conform to BIS specifications to the extent possible.

#### **Definitions**

Definitions of various types of disabilities as given in the Ministry of Welfare's (Now Ministry of Social Justice and Empowerment) O.M.No.4-2/83 – HW.III dated 6th August, 1986 as amended from time to time will be applicable.

#### Scope

The Scheme will be implemented through the implementing Agencies as listed in the following Para. The Agencies will be provided with financial assistance for purchase, fabrication and distribution of such standard aids and appliances that are in conformity with the objectives of the Scheme. The implementing Agencies will take care of/make suitable arrangements for fitting and post-fitting care of the aids and appliances distributed under ADIP Scheme. The scope of the Scheme has been further enlarged to include use of mass media, exhibitions, workshops etc., for exchange of information and promoting awareness and distribution and use of aids/appliances.

The Scheme shall also include under its ambit, medical/surgical correction & intervention, which is essential prior to fitment of aids and appliances. The cost could range from Rs. 500/- for hearing & speech impaired to Rs.1000/- for visually disabled and Rs.3,000/- for orthopaedically disabled.

#### Eligibility of Implementing Agency Under The Scheme

The following agencies would be eligible to implement the Scheme on behalf of Ministry of Social Justice and Empowerment, subject to fulfillment of laid down terms and conditions:

- i. Societies, registered under the Societies Registration Act, 1860 and their branches, if any, separately.
- ii. Registered charitable trusts.
- iii. District Rural Development Agencies, India Red Cross Societies and other Autonomous Bodies headed by District Collector/Chief Executive Officer/District Development Officer of Zilla Parishad.
- iv. National/Apex Institutes including ALIMCO functioning under administrative control of the Ministry of Social Justice and Empowerment/Ministry of Health and Family Welfare.
- v. State Handicapped Development Corporation.
- vi. Local Bodies Zilla Parishad, Municipalities, District Autonomous Development Councils and Panchayats.
- vii. Nehru Yuvak Kendras.

Grant-in-aid under the Scheme will not be given for commercial supply of aids/appliances.

The NGOs should preferably possess professional/technical expertise in the form of professionally qualified staff (from recognised courses) for the identification, prescription of the required artificial aids/appliances, fitment and post-fitment care of the beneficiaries as well as the aid/appliance.

The NGO should also preferably possess infrastructure in the form of machinery/equipment for the fabrication, fitment and maintenance of artificial aids/appliances to be given to a disabled person under ADIP scheme.

Implementing Organisations should network and establish linkages with medical college /district hospitals/rural hospitals/PHCs/fitment centres of ALIMCO/DRCs/any other professionally competent agency to acquire/avail the requisite infrastructure for fitment and maintenance of aids/appliances distributed under ADIP Scheme available with these bodies. The Implementing Agencies shall also avail of the professional/technical expertise of abovementioned agencies for fitment and post fitment care of the beneficiaries as well as aids/appliances. National Institutes, fitment centres of ALIMCO and DRCs functioning under the administrative control of Ministry of Social justice and Empowerment shall also assist DRDAs and other autonomous organisations to develop requisite manpower and infrastructure over a period

of time to provide satisfactory service to the beneficiaries under the Scheme. Such organisations while applying for the grant under the Scheme shall produce sufficient proof of linkages with the professional agencies preferably in the form of a Memorandum of Understanding.

#### **Eligibility of Beneficiaries**

A person with disabilities fulfilling following conditions would be eligible for assistance under ADIP Scheme through authorised agencies.

- i. He/she should be an Indian citizen of any age.
- ii. Should be certified by a Registered Medical Practitioner that he/she is disabled and fit to use prescribed aid/appliance.
- iii. Person who is employed/self –employed or getting pension and whose monthly income from all sources does not exceed Rs. 8,000/– per month.
- iv. In case of dependents, the income of parents/guardians should not exceed Rs.8,000/- per month.
- v. Persons who have not received assistance from the Government, local bodies and Non-Official Organisations during the last 3 years for the same purpose. However, for children below12 years of age this limit would be 1 year.

# Quantum of Assistance to Disabled

Only those aids/appliances which do not cost less than Rs.50/- and more than Rs.6000/- are covered under the Scheme. However, for visually, mentally, speech & hearing or multiple disabled, the limit should be Rs. 8000/- during their study period upto XII standard. The limit will apply to individual items of aid and where more than one aid is required, the ceiling will apply separately. The amount of assistance will be as follows:

Amount of assistance on the base of total income				
Total Income	Amount of Assistance			
Upto Rs.5,000/- per month	Full cost of aid/appliance			
Rs.5,001/- to Rs.8,000/- per month	50% of the cost of aid/Appliance			

Further, travelling cost would be admissible limited to bus fare in ordinary class or railway by second class sleeper subject to a limit of Rs.250/- for beneficiary irrespective of number of visits to the centre and a Certificate from Doctor or Rehabilitation Professional, travel expenses subject to the same limit would be admissible to an attendant/escort accompanying the beneficiary. The beneficiary should attend the Rehabilitation Centre nearest to his/her place of residence, except in the North-Eastern Region where he may be allowed travel cost for travelling outside the Region till such facilities become available within that Region.

Boarding and Lodging Expenses at the rate of Rs.30/- per day for maximum duration of 15 days would be admissible, only for those patients whose total income is upto Rs.5000/-per month.

# Types of Aids/Appliances to be Provided

The following aids and appliances may be allowed for each type of disabled individual. However, any other items as notified from time to time by the Ministry of Social Justice and Empowerment for the purpose will also be allowed

#### **Locomotor Disabled**

- i. All types of prosthetic and orthotic devices.
- ii. Mobility aids like tricycles, wheelchairs, crutches walking sticks and walking frames/rotators.
- iii. All types of surgical footwears and MCR chappals.
- iv. All types of devices for ADL (activity of daily living)

# Visually Disabled

- i. Learning equipments like arithmetic frames, abacus, geometry kits etc. Giant Braille dots system for slow-learning blind children. Dictaphone and other variable speed recording system. Tape recorder for blind student upto XII standard.
- ii. Science learning equipments like talking balances, taking thermometers, measuring equipments like tape measures, micrometers etc.
- iii. Braille writing equipments including Braillers, Braille shorthand machines, typewriters for blind students after the XII class. Talking calculators, Geography learning equipment like raised maps and globes
- iv. Communication equipments for the deaf-blind. Braille attachments for telephone for deaf-blind persons.
- v. Low vision aids including hand-held stand, lighted and unlighted magnifiers, speech synthesisers or Braille attachments for computers.
- vi. Special mobility aids for visually disabled people with muscular dystrophy or cerebral palsy like adapted walkers.

#### **Hearing Disabled**

- i. Various types of hearing aids.
- ii. Educational kits like tape recorders etc.
- iii. Assistive and alarming devices including devices for hearing of telephone, TV, doorbell, time alarm etc.
- iv. Communication aids like portable speech synthesizer etc.

#### **Mentally Disabled**

- i. All items including in locomotor disabled.
- ii. Tricycle and wheel chair including the modifications to suit the individual.
- iii. All types of educational kits required for the mentally disabled.
- iv. Any suitable device as advised by the Rehabilitation Professional or treating physician.

# **Multiple Disabled**

i. Any suitable device as advised by Rehabilitation Professional or treating physician.

# Aids and Appliances Scheme:

Government of Karnataka has introduced the scheme on 20.07.1964 with a view to provide economic, social and job oriented rehabilitation programmes for economically backward people with various kinds of physical disabilities. Accordingly, Government has made provisions for purchasing Aids and Appliances. During 1992 the Government has revised the order and approved various financial assistances for purchase of Aids and Appliances for the reduction of poverty of persons with various disabilities. The programme is implemented in 30 districts in the State.

The programme intends to:

- ❖ Provide Spectacles for blind and partially blind people after testing or contact lens through surgery and provide white sticks.
- ❖ Provide hearing aids for totally or partially deaf people after due tests.
- ❖ Provide artificial clutches, Wheel Chair or Tricycle for mobility of physically challenged persons.
- Provide learning aids to mentally retarded children/adults after conducting due tests.

Though the scheme was introduced in the year 1964 no significant progress could be made for lack of funds and the scheme is being implemented rigorously from 2004-05 onwards.

#### Purpose of the scheme:

To help the needy physically handicapped persons to acquire good quality, durable and technically designed modern aids and appliances and through these equipments their physical, social, economic and emotional rehabilitation processes could be hastened resulting in joining the mainstream of the society.

# Guidelines for the implementation of the Scheme:

The District Officer for the welfare of Physically Handicapped and Senior Citizens shall identify beneficiaries through organizing health camps. The Medical experts shall conduct medical examinations of the physically handicapped persons and recommend the kind of aids and appliances required for them. After scrutinizing the eligibility criteria of the beneficiaries, proposals shall be submitted to the Head Office. At Head Office level, tenders will be called for the supply of Aids and Appliances as per K.T.P.P.Act and after identification of Contractors the Aids and Appliances shall be supplied to districts. However, since two years the district offices have been directed to procure and supply the aids and appliances to the beneficiaries.

# Progress Under the Scheme - Physical and Financial

Sufficient funds were allocated under this scheme only after 2006-07. A sum of Rs. 8.91 crores has been spent for purchase and supply of various types of Aids and Appliances to 40390 beneficiaries in the state.

# Eligibility/Parameters:

The following categories of physically handicapped are eligible to receive assistance under this scheme:

- a. The physically handicapped person should be a resident of Karnataka or should be residing in Karnataka for a minimum of 10 years (Residential Certificate issued by concerned Tahsildar or Educational Certificate to be produced).
- b. The nature of physical handicap to be certified by experts not below the rank of Orthopaedician/Eye Specialist/ENT Specialist.
- c. Preference to be given to the physically handicapped people who are employed or self employed or who are interested in self-employment. However, their income should not exceed Rs.11,500 per annum for persons residing in rural areas and Rs. 24,000 per annum for the persons residing in urban areas.
  - i. 50% of the costs of aids and appliances has to be paid for the physically handicapped whose income exceeds Rs.17,500 per annum.
  - ii. Subsidy amount will not be payable to the physically handicapped person whose family's annual income exceeds Rs.17,500
- d. Persons who have already received financial assistance under this scheme from any Government/Local Institutions/any Societies are not

eligible to receive financial benefits under this scheme. (In this regard an affidavit has to be furnished).

#### Study and Evaluation of the Aids and Appliances Schme:

The specific objectives of the evaluation study are:

- 1. To evaluate the process of implementation of the entire scheme.
- 2. To study the impact of the scheme on the economic development, employment generation, earnings and level of living of the religious minorities.
- 3. To study the organizational and administrative problems if any in the implementation of the scheme.
- 4. To suggest measures for the better implementation of the scheme.

### Methodology:

With a view to facilitate the broader understanding of the underlying issues in the Programm, the information is obtaind from a wide variety of stakeholders like the beneficiaries, officials working at various levels in the administrative hierarchy with different levels of leverage to power and control.

#### Tools and Techniques of Data Collection:

■ Interview Schedule for the Beneficiaries

With a view to capture the implementation process and analyse the benefits and impacts of the programmes implemented, a separate interview schedule for the beneficiaries was canvassed under the study. While in most of the cases the beneficiaries have responded to the queries in certain cases due to severe disability or the age factor the family members have provided the required feedback.

Informal discussions with key informants

The information on the various aspects of the present study was also collected through informal discussions with the key informants.

Group Discussions

The project staff and the key professionals has held group discussions at various levels to capture qualitative insights into the study.

#### Sample size Covered:

The total number of beneficiaries covered under the study is 990 and they are spread over 10 different districts representing the state.

S1.	Name of the District	Illustrative	No. of
No.		List of Taluks	Beneficiaries
			Covered
		Hosakote,	
	Bangalore Rural &	Magadi,	
1	Urban	Nelamangala	50
		Gelgaum,	
		Ramdurg,	
2	Belgaum	Hukkeri	115
		Humnabad,	
3	Bidar	Basavakalyan	100
		Holalkere,	
4	Chitradurga	Hosadurga	114
		Dakshina	
		Kannada,	
5	Dakshina Kannada	Puttur	95
		Jagalur,	
		Harapanahalli,	
6	Davanagere	Channagiri	100
		Gulbarga,	
7	Gulbarga	Shahpur	92
		Belur,	
		Holenarsipura,	
		Arakalgud,	
		Sakaleshpura,	
8	Hassan	CR Patna	98
		Nanjangud, T.	
		Narsipura, HD	
9	Mysore	Kote	121
		Shimoga,	
10	Shimoga	Bhadravathi	105
	Total		990

# **Duration of the Study**

The study was carried out during January 2012.

# Structure of the Report

The evaluation report is presented in five broad chapters. The first chapter sets the backdrop for the present study and outlines the study objectives. The second chapter is further set to provide the backdrop by a review of the performance of the programme . This is analysed against the total target population in the state and across the districts. The third chapter outlines the characteristics of the the socio-economic background of the beneficiaries. Further, the various aspects of the programme implementation i.e. identification of the beneficiaries, nature of the appliances provided, impact of the programme is also analysed. The fourth chapter outlines the perceptions of the other stakeholders and the issues in the implementation of the programme . The fifth chapter provides a summary of the study and also lists the recommendations for the future implementation of the programme.

# Chapter – II

# Socio-Economic Background and Perceptions of the Beneficiaries About the Programme

The present chapter attempts at analyzing the socio-economic background of the beneficiaries of the aids and appliances programme. The analysis will help in evaluating the certain intended objectives of the programme such as the benefits to be provided to the economically weaker sections and that the programme should help in the economic betterment of the target groups. The chapter also analyses their perceptions on the different aspects of the programme such as the source of information, role of the different stakeholders in extending the benefits of the programme, the perceived advantages and disadvantages and the impact of the programme as well.

#### Sex of the Beneficiaries:

	Frequency	%
Female	178	17.98
Male	812	82.02
Total	990	100.00

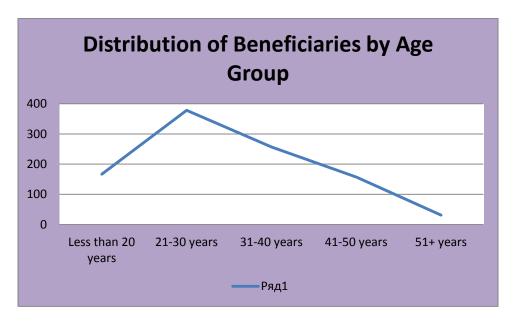
Of the total beneficiaries, most of them are found to be male, while the female beneficiaries account for a smaller percentage. They account for 82.02 and 17.98 per cent respectively. Thus, more of the male beneficiaries are found to be accessing facilities under this programme.

# Age of the Beneficiaries:

Age Group [No. of Years]	Frequency	%
Less than 20 years	167	16.87
21-30 years	378	38.18
31-40 years	257	25.96

41-50 years	157	15.86
51+ years	31	3.13
Total	990	100.00

Nearly 40 per cent of the beneficiaries are reported to be in the age group of 21-30 years followed by those in the 31-40 years. Both these age groups together account for more than 63 per cent of the total beneficiaries. The next best represented age group is those aged less than 20 years. They account for 16.7 per cent. The older age groups account for 3.13 per cent of the total. Thus, these programme is found to be assisting those in the younger age groups and thus, may be useful in improving their economic conditions. The fact that a good percentage are less than 20 years is also found to be helping the students and thus, helping them to compete with the other children of their age groups.



#### **Educational Background:**

The educational background of the beneficiaries is broadly analysed at three levels viz., illiterates, up to High School level and college education. The findings of the same are presented in the following table:

S1.	Educational level	Frequency	Percentage
No.			
1	Illiteracy	444	44.85
2	Up to High School level	458	46.26

3	Up to PUC level	64	6.47
4	Up to Degree level	24	2.42
	Total	990	100.00

The illiterates account for more than 40 percentage of the beneficiaries [44.85%] and the percentage of literates is 55.15%. The high percentage of illiteracy among the beneficiaries is due to the low socio-economic levels of the households.

The beneficiaries with college education account for less than 9 per cent of the beneficiaries.

The low achievements could be due to the physical or other disabilities which might have prevented them in accessing or utilizing the educational facilities either in the village or town.

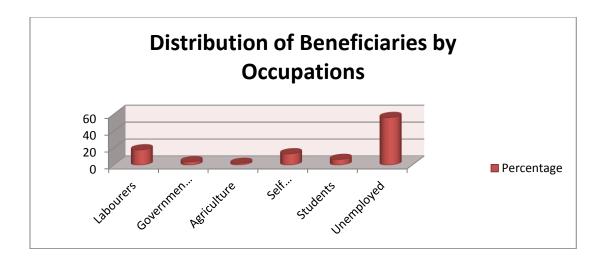
#### Occupation of the Beneficiaries:

The unemployment among the beneficiaries is found to be high. A fair percentage of beneficiaries are engaged in various vocations in spite of their disability.

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S1.	Occupation	Frequency	Percentage
No			
1.	Labourers	178	17.98
	Government	38	3.85
2	Service		
3	Agriculture	20	2.02
3	Self	132	13.33
	employment		
4	Students	66	6.66
5	Unemployed	556	56.16
	Total	990	100.00

The unemployment among the beneficiaries is found to be high. This is as high as 56.26%. A fair percentage of physically handicapped persons work as labourers. They account for 17.98 percent out of the total beneficiaries. About 3.85 percent are reported to have secured Government appointment.



It is found that few of them are working as Village Rehabilitation workers (VRW). A good percentage is found to be self employed 13.33 per cent. The beneficiaries who are reported to be self employed are engaged in petty business and in certain cases they are said to be gainfully employed after the provision of Aids/Appliances. About 6.69 per cent of the beneficiaries are found to be students.

Thus, the large number of beneficiaries are continuing the remain unemployed is perhaps due to the severity of the disability. This is further reflected in terms of their perceptions on the impact of the programme. Of those who are said to be employed, they are found to be engaged in those occupations which are not highly remunerative.

#### **Economic Status**

Category	Frequency	%
BPL families	976	98.58
APL families	14	1.42
Total	990	100.00

With a view to understand the economic standing of the households the beneficiaries were asked to state whether they belonged to BPL/APL category. Almost all the beneficiaries are reported to be belonging to BPL category. This is true of both rural and urban households. A small percentage of APL category have also found to have availed the benefits under the programme.

# **Religious and Caste Background**

Category	Frequency	Percentage
SC/ST	332	33.54
OBC	223	22.52
Minorities	58	5.86
Others	377	38.08
Total	990	100.00

Excluding a small percentage of the beneficiaries (Minorities account for 5.86%) the rest of them have said to be Hindus. Further, about a third of the beneficiaries (33.54%) are reported to be belonging to SC/STs. The beneficiaries belonging to OBC and others are of the order of 22.52 per cent and others 38.08 per cent. This indicates that more than 60 per cent of the benefits have been availed by socially marginalized groups, and the benefits of this programme may be helpful in the development of physically handicapped among these communities.

#### **Nature of Disabilities**

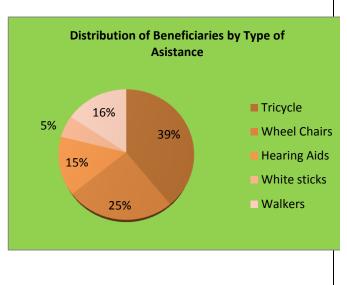
With a view to help in the better understanding of the programme, the respondents were asked to state the nature of their disability. The results of the same are analysed below:

Nature of Disability	Frequency	Percentage
Physical disability	791	79.90
Hearing impaired	145	14.65
(including dumb)		
Blind	54	5.45
Total	990	100.00

Majority of respondents were found to be physically disabled whose percentage is 79.90%, while the people with hearing disability are at 14.65%, the percentage of blind is 5.45.

#### Aids & Appliances provided

Type of	Frequency	Percentage
Assistance		
Tricycle	387	39.09
Wheel	249	25.15
Chairs		
Hearing	145	14.65
Aids		
White	54	5.45
sticks		
Walkers	155	15.66
Total	990	100



The type of assistance provided under the programme corroborates well with the nature of the disability confronting them. Thus, it is found that nearly 40 per cent of the beneficiaries have been provided with a tricycle and about 25 per cent with a wheel chair. The beneficiaries provided with the hearing aids is 14.65 per cent and that with white sticks is 5.45 per cent. About 15.66 per cent are said to be provided with walkers. The pattern of assistance is not the same across the different districts and is found to reflect the demands from the target population. These equipments have helped most of them in gaining employment and few are self employed.

The study documents the good and the bad experiences under this programme. About 18 of the children studying in the deaf school have been provided with hearing aids and the children are continuing to use them. Thus, these equipments have helped in their education. The wheel chairs provided in the districts of Mysore and Shimoga are reported to be in good condition. However, in certain places it is reported that the wheel chairs have not been useful because of the geographical terrain and other factors.

The present study has also come across stray cases wherein the beneficiaries have not been supplied with the appliaances.

Barring few exceptions, from the physical verification it is revealed that the appliances provided are being used. The issue is related to the hearing aids provided under the programme. The reasons for non-usage of the hearings aids are the poor reception of the hearing aids. Further, the beneficiaries were enquired about the investments made towards its maintenance. It was found

that the issue was relevant only in the context of the tricycle or the wheelchairs. It was found that a small amount [upto Rs.250/-] over a period of time was spent towards minor repairs.

With a view to understand the role of the institutions in the provision of appliances to the beneficiaries, the study attempted to enlist such institutions. The tricycles are also said to be provided through the SSA to the school children. This is based on the assessments done at the district level and the availability of resources. It is found that organizations such as the Rotary Club, Lions Club, a Jain organization [based in the Bangalore City] is reported to be extending such facilities on a cost sharing basis. The role of the other institutions in places other than the Bangalore city was not found to be very significant in extending facilities to the disabled.

### Appropriateness of the Aids and Appliances:

One of the objectives of the scheme is to provide the aids and appliances which will enable them to overcome their disability, improve their economic well being and thus improve their social status. The role of the appliance need not be exaggerated in view of the envisaged goal and objective of the programme.

S1. No.	Particulars	Frequency	Percentage
1	Suitable appliance	824	83.23
2	Not suitable	85	8.59
3	Could not specify	81	8.18
	Total	990	100.00

More than 80 per cent have reported that appropriate appliance has been provided under the programme. Thus, the role of the health camps comes into the picture. However, a smaller percentage have said that they have been provided with not appropriate appliances [8.59%]. Thus, this might have caused more harm or damage to the individuals. It is necessary to initiate appropriate action to ensure that the appropriate appliances are provided to them.

# **Knowledge of the Programmes:**

All the beneficiaries have informed that they are aware of the schemes, programmes and the benefit extended by the Government of Karnataka for the

welfare of the disabled/challenged. The knowledge of the programmes varied depending on the place of stay and their educational backgrounds. A small percentage of the beneficiaries did show great interest in listing out most if not all the programmes of the department. The programmes listed out by them are:

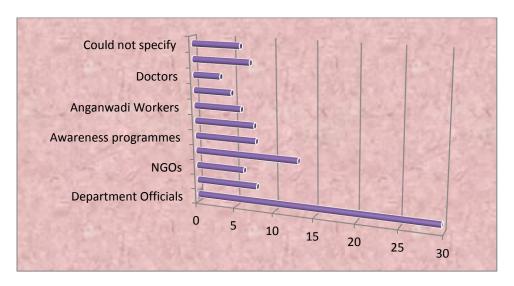
- 1. Special Schools Deaf and Blind Children
- 2. Scholarship to disabled children
- 3. Reservation for the disabled in government programmes [3%]
- 4. Concessions in travel
- 5. Observation of the Disabled Day
- 6. Sports and Cultural Activities at the districts

# Source/s of information about the Aids & Appliances scheme:

The sources of information listed out by the beneficiaries are listed in the following table:

Sl. No.	Particulars	Frequency	%
1	Department Officials	331	29.74
2	Elected representatives	87	7.82
3	NGOs	69	6.20
4	Press	145	13.03
5	Awareness programmes	87	7.82
6	Local leaders	85	7.64
7	Anganwadi Workers	67	6.02
8	Relatives & Friends	54	4.85
9	Doctors	39	3.50
10	Others	81	7.28
11	Could not specify	68	6.11
	Total	1113	100.00

The key source of information for the disabled has been the departmental officials. They are found to account for nearly 30 per cent of the total responses. The few officials listed out by the beneficiaries are the Village Rehabilitation Workers, The Child Development Project Officer, Anganwadi Workers, Medical Officers etc.,



The few other important informants includes press, awareness programmes, local leaders, NGOs etc., [see Table].

Thus, the department personnel together with other stakeholders such as the Doctors, NGOs, the Kin and the non-kin network are found to be involved in popularizing the programme as also availing the benefits.

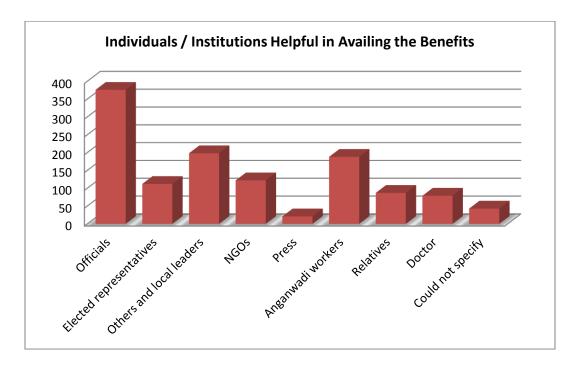
# Individuals/Institutions Helpful in Availing the benefits:

S1.	Details	Frequency	Percentage
No.			
1	Officials	376	30.67
2	Elected	112	9.14
	representatives		
3	Local leaders	198	16.15
4	NGOs	122	9.95
5	Press	21	1.71
6	Anganwadi	188	15.33
	workers		
7	Relatives	87	7.10
8	Doctor	79	6.44

9	Could	not	43	3.51
	specify			
	Total		1226	100.00

It is found that the Officials are also reported to be helpful in availing the benefits. This has been reported by 30.67 per cent of the beneficiaries. It must be noted that they are the key functionaries in disseminating information about the programme. The two other functionaries who are reported to have been helpful are the local leaders [16.15%] and the anganwadi workers [15.33%]. A smaller percentage have also indicated the role of the NGOs and the Doctors under this programme. The role of the press in this regard is found to be quite minimal [1.71%].

Thus, different kinds of individuals/institutions are found to be helpful in availing the benefits. Hence, it is important that they are oriented on the different aspects of the programme.



#### **Eligibility Criteria for Availing the Benefits:**

With a view to help in the effective implementation of the programme, the Government has laid down certain criteria for the extension of benefits under the programme. The following table explains the awareness on the various criteria laid down under the programme:

S1. No.	Details	Frequency	Percentage
1	Disability	350	13.29
2	Medical Certificate	514	19.51
3	Identity cards	527	20.01
4	Income certificate	326	12.38
5	BPL card	458	17.39
6	Photos	205	7.78
7	Ration Card	236	8.96
8	Could not specify	18	0.68
	Total	2634	100

The three important criteria pointed out by the beneficiaries are the identity cards [20.01%], the Medical Certificate [19.51%], BPL card [17.39%] and the income certificate [12.38%]. A good percentage of them have also referred to the other documents such as the photos which is submitted along with the applications.

# **Furnishing of Documents:**

S1. No.	Particulars	Frequency	Percentage
1	Furnished all the documents	812	82.02
2	Unable to furnish all the documents	42	4.24
3	Could not say	136	13.74
	Total	990	100.00

More than 80 per cent of the beneficiaries have said that they furnished all the required documents such as the BPL card, the income certificate, residential proof certificate, photos etc., along with the application. A smaller percentage have said that they were unable to produce all the documents at the time of submission of application.

# Awareness of Benefits given under this Scheme:

S1.No.	Details	Frequency	Percentage
1	Tricycle	405	29.98
2	Wheel Chair	397	29.39
3	Hearing aid	136	10.07
4	White stick	288	21.32
5	Crutches	45	3.33
6	Could not specify	18	1.33
7	Do not know	62	4.59
	Total	1351	100.00

The awareness of various aids and appliances provided under the scheme to the physically handicapped is around 95 per cent. The three important aids pointed out by the beneficiaries are the tricycle, wheel chair and the white stick. This may be because of the increased provision under these three categories. The beneficiaries who could not specify /do not know is around 6 per cent.

# Perceptions on the Advantages and Disadvantages of the Scheme

With a view to understand the impact of the programme on the beneficiaries and their households, they were asked to list out the advantages and the disadvantages as a result of availing the benefits under the scheme. The perceived advantages and the disadvantages are analysed in the following section.

# **Advantages**

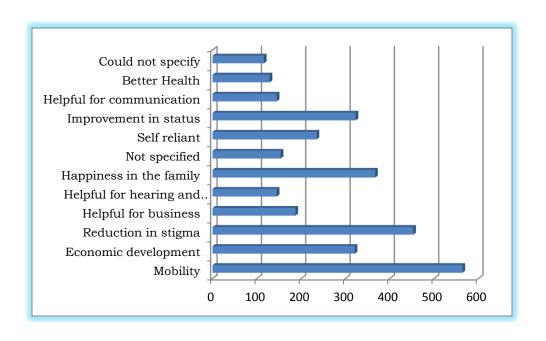
Sl. No.	Particulars	frequency	Percentage
1	Mobility	564	17.97
2	Economic development	321	10.23

3	Reduction in stigma	453	14.43
4	Helpful for business	187	5.96
5	Helpful for hearing and understanding	145	4.62
6	Happiness in the family	367	11.69
7	Not specified	154	4.91
8	Self reliant	235	7.49
9	Improvement in status	323	10.29
10	Helpful for communication	145	4.62
11	Better Health	129	4.11
12	Could not specify	116	3.70
	Total	3139	100.00

The most frequently perceived advantage of the programme is the mobility gained as a result of the provision of these aids/appliances. This is true for both the physically challenged and the visually impaired. It is learnt that in many cases these individuals were confined to a limited space in the household and did not have an opportunity to move around on their own. On the contrary as a result of this assistance they are able to move around. This mobility is found to have resulted in further changes viz., helpful for business [5.96%], happiness in the family [11.69%], self-reliant [7.49%], improvement in status [10.29%] and better health [4.11%]. Thus, the programme is found to have resulted in a multiplier effect.

The hearing aids is reported to have helped individuals in their communication and in their ability to hear and understand.

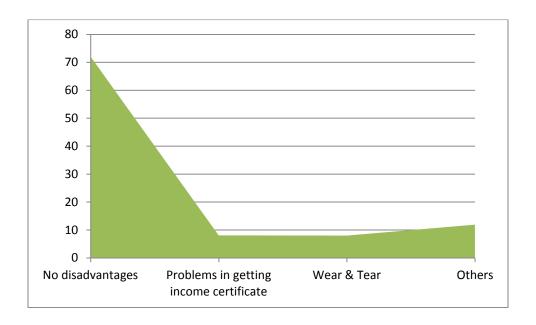
The economic development and the reduction in stigma are the two other advantages perceived by the individuals [see Table]. Thus, the programme is found to have resulted in bringing about changes in the community about the disabled.



#### **Disadvantages**

S1. No.	Particulars	Frequency	Percentage
1	No disadvantages	867	72.07
2	Problems in getting income certificate	97	8.06
3	Wear & Tear	96	7.98
4	Others	143	11.89
		1203	100.00

Most of the beneficiaries have reported that the aids and appliances provided under the scheme have not given rise to any disadvantages. The percentage is as high as 72.07 per cent. One of the disadvantage perceived is the wear and tear of these appliances. This has been reported by 7.98 per cent of the beneficiaries. This is true of any of the aids and appliances provided. This raises the critical question of the quality of the aids and their regular maintenance. These problems are bound to get compounded as a result of their poor economic background and their inability to stand on their own. In few cases, the beneficiaries explained the huge amounts that they had to spend to maintain the appliances. This gets compounded in the absence of good roads, the rugged terrain etc.,



The other general problem reported by the beneficiaries is the problem in obtaining the income certificate. These are highly generic problems and which are outside the purview of the implementing agency.

The few other disadvantages pointed out by the beneficiaries are the delay in the provision of the aids, lack of communication after the submission of the applications, problems in obtaining the medical certificate, lack of regular health camps, the attitude of the personnel at different levels etc.,

# **Problems Confronted in Availing the Benefits:**

With a view to help in creating a road map for the implementation of the programme in the future, the beneficiaries were asked to list out the problems confronted by them in availing the benefits.

S1. No.	Description	Frequency	Percentage
1	No problems	546	28.8
2	Reaching the district	286	15.1
3	Financial problems	176	9.3
4	Delay in receipt of benefits	259	13.6

5	Transportation	378	19.9
6	Lack of proper communication	167	8.8
7	Others	87	4.6
	Total	1899	100.0

It is interesting to note that nearly 30 per cent of them have said that they did not confront any problems in availing the benefits under this programme. This may be because they might have participated in the health camp and in certain cases the benefits might have been passed on immediately. This is not so for large majority of the beneficiaries.

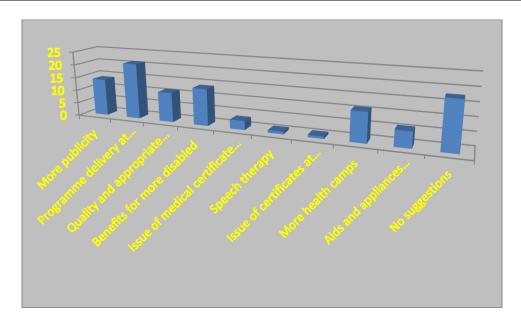
At the first instance, the critical problem faced by them is lack of adequate transportation. The problem gets compounded in the case of severe disabilities both for the physically and visually impaired. This has been reported by nearly 20 per cent of the beneficiaries. Many of the beneficiaries have been critical of the fact that they had to reach the district to fulfill all the procedures. This has been reported by about 10 per cent of the beneficiaries. About 9.3 per cent of them have said that they had financial difficulties. This is because, the fact that many of them are illiterates, they have to be accompanied by other people and as a result, there is increased expenditure. It was also reported that for a number of reasons they will be required to make repeated visits which again adds upto the cost. These issues need to be considered in the future planning of the programme.

# Suggestions for improvement of the scheme

The three important suggestions made out by the beneficiaries for the improvement of the programme are giving more publicity [14.02%], programme delivery at the GP or at the taluk level [21.07%] and the extension of benefits for more no. of disabled [13.89%]. These three suggestions are found to be quite reflective of the problems or issues in the implementation of the programme. This is quite well corroborated by the fact that the total number of beneficiaries covered by the programme till date is only around 40,000. In the same way, the programme is implemented by the district offices of the department which is coming in the way of accessing the benefits.

S1. No.	Particulars	Frequency	Percentage
1	More publicity	324	14.02
2	Programme delivery at GP/Taluk level	487	21.07

3	Quality and appropriate instruments	258	11.16
4	Benefits for more disabled	321	13.89
5	Issue of medical certificate at the Taluk Hospital	77	3.33
6	Speech therapy	22	0.95
7	Issue of certificates at districts for deaf	19	0.82
8	More health camps	254	10.99
9	Aids and appliances according to the needs of the physically disabled	136	5.88
10	No suggestions	413	17.87
	Total	2311	100.00



Many other suggestions made out by the beneficiaries are related to the strategies of the implementation of the programme and it is worthwhile to consider them in the future implementation.

# Perceptions on the Coverage of the Programme:

On the query related to the coverage of the programme at the village level, most of the beneficiaries have said that the disabled have been covered through the present programme. On further enquiries at the villages it is found that there are many more disabled individuals who would be expecting the benefits of the programme. This is inspite of the fact that some of the disabled are currently being provided with the required appliances by the civil society. It is also found that the activities of the civil society is further strengthening the programme implementation by the department. Thus, it is found that some of the beneficiaries who have been provided with crutches are being provided with artificial limbs by the civil society. This further points out the limitations of the community based rehabilitation of the disabled.

# Receipt of Benefits to the Other Members in the Beneficiary Households:

Generally none of the other members in the beneficiary families have availed the benefits under the scheme. In the entire study, this was noticed in a very very small percentage of the households and further, it was found that they genuinely required it.

### Receipt of Benefits by Beneficiaries - No. of Times:

Excepting a very negligible percentage of the beneficiaries, the rest of the beneficiaries have not accessed the facilities for more than once. Even in those cases, the beneficiaries were forced to access the facilities as the old appliance had to be replaced.

#### Impact of the Programme:

The impact of the programme is being analysed on five different parameters and the results are presented in the following table:

S1. No.	Indicators	Go	ood	Satisfactory		Not Satisfactory	
		Freque ncy	Percen tage	Freque ncy	Percen tage	Freque	Percen tage
1	Quality of Life	88	8.89	745	75.25	157	15.86
2	Mobility	457	46.16	365	36.87	168	16.97
3	Economic Status	38	3.84	405	40.91	547	55.25
4	Social Status	97	9.80	378	38.18	515	52.02
5	Empowerment	136	13.74	337	34.04	517	52.22

Quality of Life: About 75.25 per cent of the beneficiaries have indicated satisfaction on a three point scale. Only 8.89 per cent have said that it is good. The rating on this indicator is found to be highly relative. The changes pointed out by the beneficiaries is as compared to the previous experiences and thus, they have pointed out a significant change as compared to other aspects of life.

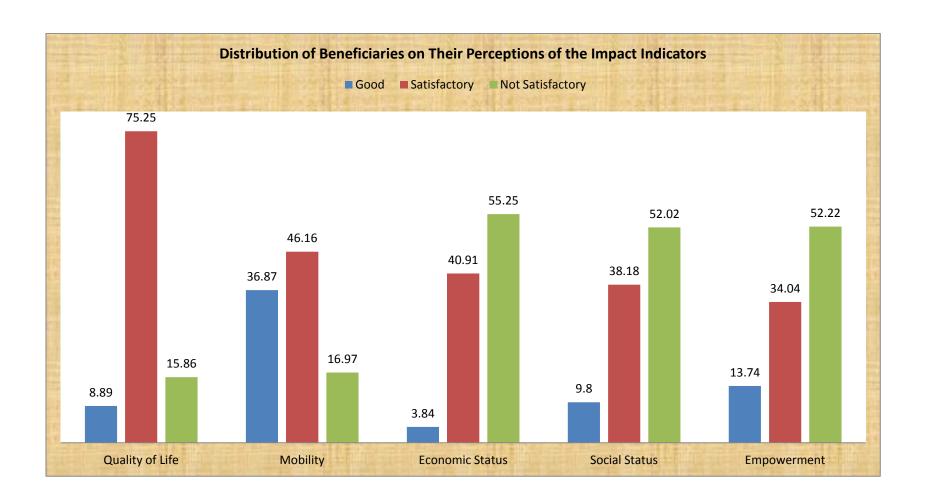
Mobility: Nearly 50 per cent have indicated good as far as mobility is concerned. This is because the aids/appliances have expanded their space and they are found to be accessing the different places as a result of this. However, about 36.87 per cent have expressed satisfaction, while 16.97 per cent have not expressed any satisfaction in this regard. This is because, the beneficiaries have said that there is need to provide better appliances such as the motorized tricycles, digital walking sticks which will further help in their mobility.

Economic Status: On the economic front, the satisfaction seems to be the lowest. About 55.25 per cent have said that they are not satisfied on the changes on the economic front. This is because of the limited opportunities that they are able to while other things remain the same. This also speaks of the importance of the forward linkages with various other programmes implemented by them. However, about 3.84 per cent have indicated happiness on this front as well. These individuals could be those who had already ventured into business avenues and the provision of the appliances perhaps has expanded their horizon or has made commuting more easy.

Social Status and Empowerment: More than a third of the beneficiaries have indicated satisfaction on the social status and the empowerment process which has begun in their lives. The fact that more than 50 per cent have not indicated satisfaction on the changes on both these aspects reveals that while the changes on these fronts are low, it has started happening. Further changes could be forthcoming only in the event of changes being effected at the individual level and at the societal level. This perhaps even includes counseling and therapeutic treatments.

Thus, the above analysis reveals that the programme has benefitted the physically, visually and the hearing impaired living in the rural and the urban areas of the selected districts. The programme has benefitted relatively a higher percentage of the male members than the female and has benefitted the BPL and socially marginalized groups.

The beneficiaries are found to have a good understanding about the programmes for the disabled in general and in particular the aids and appliances programme. While the officials have taken a lead role towards creating awareness and helping them in accessing the benefits, the local leaders, elected representatives, doctors and the civil society organizations have also played an important part at this stage of the programme.



The programme has not only resulted in widening the space – physical and social, but is also reported to have resulted in enhanced earnings for the individual and the household, but also in enhancing the social status and in overcoming the stigma.

It is interesting to note that the programme benefits are not being concentrated in a certain percentage of the households. On the other hand, there is increased demand for the aids and appliances and the civil society organizations are found to be supplementing the governmental programme.

#### Chapter III

# Key Result Areas / Issues in the Implementation of the Programme

While the programme is said to be under implementation since sometime, it is being effectively implemented for the past three years with adequate financial support. The experiences and the feedback has raised several issues concerning the implementation and the reach of the benefits to the eligible beneficiaries. The present study has tried to provide answer to some of these questions as well.

The present study has attempted at gathering qualitative insights about the various aspects of the programme implementation through the consultations with the community leaders, the elected representatives and the civil society organizations. The key issues that have emerged out of such discussions is also presented in this chapter.

#### A. Feedback from the Consultations:

	1	
S1.	Issues	Observations
No.		
1	Identification of the Beneficiaries	<ul> <li>Elected representatives and the school teachers were involved in the identification of beneficiaries</li> <li>Information on the health camps is shared through the elected representatives, pamphlets, organizations meant for the welfare of the disabled. E.g., Nageshwara Angavikalara Self-help Group, Nagaranavile village, C.R. Patna Taluk.</li> <li>While generally the beneficiaries are identified through the health camps, a certain percentage of the beneficiaries are also obtaining the services by directly approaching the department.</li> <li>VRWs are actively engaged in the identification of the beneficiaries. The factors influencing his involvement are that they are making use of this opportunity to provide the required services to the disabled at the village level.</li> <li>NGOs to a certain extent are helping the physically challenged to avail benefits under the scheme.</li> <li>The beneficiaries of the programme are futher working towards popularizing the programme</li> </ul>

		and are also helping the disabled in availing the benefits.
2	Department related Issues	The disabled have reported to be facing severe transportation problems in reaching the district / taluk place in order to obtain the relevant documents.
3	Problems	<ul> <li>The programme is said to have resulted in the agents in the provision of services.</li> <li>The programme is said to suffer from poor financial assistance.</li> <li>The appliances provided under the programme are said to have certain problems. Hence, it is suggested that the cost per appliances be revised in order to provide better equipments or appliances.</li> <li>The programme is said to have benefitted a certain percentage of the disabled, while a large majority are yet to receive the benefits. Because of the limited financial allocations, the beneficiaries are forced to follow up with the departments and thus resulting in problems.</li> <li>The major problem faced by the beneficiaries is the absence of communication on the status of the application submitted by them. Hence, the suggestion made by most of the disabled persons is that there should be a office at the taluk level which can respond to their queries or doubts.</li> <li>There is the general apathy among the officials concerned.</li> <li>There are also cases wherein the benfits are provided to individuals with better political clout etc.,</li> <li>One of the problem is securing the income certificate from the Revenue Department</li> <li>Obtaining medical certificate is also found to be posing problems to the beneficiaries.</li> </ul>
4	Impact	<ul> <li>The programme has helped in becoming self-reliant. E.g. Opening of a shop</li> <li>The beneficiaries have formed their own groups in order to provide service to the community. E.g. An organization has been established in Didiga village, C.R. Patna Taluk which is said to be involved in social services</li> </ul>

5	Appliances	such as the provision of the drinking water in the jathre, camps etc.,  • The beneficiaries themselves are said to be helping the other disabled either old aged or younger ones in availing the benefits of the programme.  • The programme has resulted in the easy movement and lesser dependence on others.  • The hearing aids and the provision of spectacles has helped in communication and the visions.  • Upon the receipt of the benefits, the beneficiaries are reported to have taken up to goat/sheep rearing activities.  • Beneficiaries have reported of changes in their social status considerably and people have started accepting them. Thus, this is said to be resulting in social changes also.  • The equipments provided are found and reported to be of reasonably good quality.
		However, due to the constant usage of the same over a period of time they are found to be lacking in maintenance. There is also a feeling that the quality of equipments are reported to be substandard and wear and tear occurs very soon. Thus, it is a mixed bag.  • The beneficiaries have said that they experienced certain difficulties due to lack of awareness of traffic rules, about the ways and means of maneuvering the vehicle etc.,
6	Suggestions	There is need to establish forward linkages this programme. Thus, they have expressed that the Department can take initiative to impart skill development training programmes, entrepreneurial awareness and development programmes and provision of loan or financial assistance to enable them to become self-reliant and thus, empowered.

# B. Key Result Areas:

1	Is there awareness among the disabled about the aids and appliances programme?	The study has revealed that, the disabled in particular has good awareness about this programme and in general about various other programmes such as the 3 per cent reservation in various developmental programmes, the concessions provided by the Government for the disabled etc., However, the discussions with the disabled has revealed that they are accessing the benefits provided by the non-governmental institutions as well.
2	Are the aids and appliances provided as per the needs and measurements of the disabled?	The discussions with the beneficiaries, the beneficiary households and the review of the documents has revealed that the aids and appliances are being provided upon the recommendation of the appropriate medical personnel and these personnel are also recommending on the basis of the merits of the case.
3	Are the disabled participating with all the necessary documentation to the health camps?	The discussions has revealed that the requests or the applications are made not only through the health camps held for this purpose, but at other times as well. Those who have submitted the applications during the health camps are reported to have submitted the necessary documentations. However, the discussions with the district authorities has revealed that a good percentage also turn up without proper documents. But the same is submitted subsequently. On this issue, the disabled have said that due to the paucity of time they have difficulties in submitting all the required documents during the camp. Hence, the health camps need to be organized with sufficient advance notice and with sufficient publicity.
4	Are the parents/guardians facing problems in providing the required documents?	The parents / guardians have reported the general administrative problems, the apathy and the delay in obtaining the required documents such as the income certificate etc., The problems become more severe in case of the households who do not have a permanent place of residence. It is reported that

		individuals with hearing impairment are put to hardship in procuring the required certificates because of lack of personnel at the taluk level.
5	Are the beneficiaries belonging to BPL families only submitting the income certificates?	The income certificate is said to be collected from all the applicants under the programme.
6	Are the Aids and Appliances being used by the beneficiaries? Are there changes in the beneficiaries regarding the quality of life, mobility and the standard of living?	Almost all the disabled contacted for the purposes of this study is found to be using the aids and appliances provided through the programme. This is because, they have been able to overcome the problems that they were confronting to a certain extent, if not completely. While some of them have spent certain amount towards the maintenance of the appliances, very few have discarded its usage.  It is interesting to note that the major benefit or advantage of the scheme is that it has helped in the mobility of the disabled. This mobility in certain cases has resulted in enhanced earnings and in turn, in the quality of life. However, it is found that the participation of the other line departments and the forward linkages with other programmes would have resulted in greater impacts on all these three aspects.
7	Are the eligible beneficiaries being selected? Are all the eligible beneficiaries being given orders and provided with the appliances?	While the eligible beneficiaries are being selected for the provision of benefits, the
8	Are the beneficiaries assisted under this progamme are all below the poverty line? If no, suggest corrective measures?	It is found that the most poor and the needy are accessing or using the facilities provided under this programme. The households who are economically relatively better off are able to access the benefits provided by others through their contacts etc., However, the greatest impediment for this class of people is the lack of an agency at the taluk/block/GP

9	Are the beneficiaries	level which would have helped them in accessing the available facilities. In view of these difficulties, it is suggested that the Grama Panchayaths be involved in this programme and the applications can be received and forwarded by these grassroot level institution.  By and large the beneficiaries are aware of the
	aware of the yardsticks stipulated under this programme?	yardsticks stipulated under this programme. However, there are certain misnomers as well. They have listed the photos as an yardstick.
10	Have the beneficiaries received the benefits for more than once under this programme?	No. Instances of benefits being accessed by the same beneficiaries for more than once was not noticed in the field. However, it has been expressed by few of the implementing officers, the individuals staying outside but belonging to Karnataka are also managing to obtain the benefits. Under such circumstances, it is likely that these benefits are reaching the already benefitted once.
11	Is there need for changing the mode of implementation of the programme?	The Department is the line agency [term used in Public Administration] functioning under the Secretary of the Department of Women and Child Development. Secondly, the Department does not have dedicated personnel working below the district level. In view of this limitation as also the problems faced by the Disabled, alternatively the programme could be implemented by the CDPOs office at the Taluk level. The implementation is expected to get strengthened as the anganwadi workers and the supervisors work under the control of the CDPOs. This is expected to strengthen the efforts of the department to take the department close to the people through the VRWs. This could be considered till such time that the District Rehabilitation Centres are established in all the districts of the State.
12	What are the problems confronted by the	1. Organizing health camps is found to be a difficult task. The reasons
	District Disabled Officers in the implementation of the programme?	are: (a) The vacancy at the level of Medical Officers in the PHCs. (b) Non-availability / acute shortage of specialized doctors like

13	Problems in the distribution of the	1 1 1 1
	distribution of the appliances at the district level?	

Is there a role of the other departments in the programme implementation? If yes, what are the problems and list the solutions?

With view achieve to economic improvements and empowerment of the disabled, there is need to establish forward schemes linkages with other programmes implemented by the Department / Corporations. The beneficiaries of the aids and appliances scheme need to be informed about the various other programmes viz., selfemployment schemes, direct loan schemes, development programmes and adequate number of these beneficiaries need to be covered under these programmes.

#### Problems:

- 1. Currently not many of the beneficiaries of these programmes are covered through the other programmes.
- 2. The goal of the programme is achieved in a very limited way.

#### Solutions:

- 1. Sensitization and awareness programmes for the other line department officials, the bankers and the elected representatives including the Department of the Disabled.
- 2. Pro active role through the VRWs and the MRWs.

#### **Chapter IV**

#### Observations and Recommendations

To be born into rural poverty in India is to began life with a handicap. For it often means a helpless and stoic acceptance of a variety of social ill-hunger, disease, squalor, illiteracy and a daily battle for the basic necessities of life. If in addition, a person belonging to this large segment of the rural poor is born with, or due to some unfortunate circumstances acquires, a disability, then he or she must face life with double handicap. Every problem that confronts the able-bodied, afflicts the disabled person in a more intense and chronic form.

The rural disabled are at a disadvantage when compared with their access to resources, employment opportunities and rehabilitation is severely restricted. They often comprise the most neglected, marginalized and unlettered of their community. They are usually denied education and the right to enjoy normal social interactions and relationships. Families rarely take the trouble to educate their disabled daughters and disabled women are not given a change to find fulfillment in marriage and motherhood. Employment opportunities for the uneducated and untrained disabled are so limited that the disabled person is considered a burden on the family, a drain on their meager finances.

Some estimates say that almost 70-80% of Indians with disabilities live in rural areas while most of the country's rehabilitation centers are situated in urban areas. To transport the disabled person to these centers for appraisal, treatment or training is an expensive process, involving not only the cost of travel but also the loss of daily wage for the escort. It has now been established that segregation of the disabled into protected environments and special institution is not only dehumanizing but also prohibitively expensive, allowing only a very small percentage to avail of the facilities.

Keeping the special problems of the rural disabled in mind, and given the increased skepticism about the efficacy of institutional care, there has in the last decade or so, been a shift to community based rehabilitation (CBR) in India, as elsewhere in the developing world. CBR is a process of motivating and providing inputs-which could be medical, technical or social-to the community to take care of its disabled. To put it very simply, it is a system of enabling the rural disabled in their community and through their community.

While this movement saw the closure of many gigantic institutions in the West, in Tamil Nadu the interpretation of CBR has been twofold. The first has been the sensitizing and training in even simple, uneducated members of the community by specialists and professionals so that they can spread awareness, impart therapy and even construct and repair mobility appliances like

crutches, calipers and wheelchairs. The community makes an ongoing effort to accept and integrate the disabled into the mainstream of daily life. The second aspect has been the reaching out into rural communities to identify areas which require technical assistance or help by referral to rehabilitation institutes.

Rehabilitation involves combined and coordinated use of medical, social, educational, and vocational measures for training or retraining the individual to the highest possible level of functional ability. The three main strategies for rehabilitation of disabled are institution-based, outreach, and community-based.

In general, rehabilitation encompasses the following:

- Early detection, diagnosis, and intervention
- Improve, facilitate, stimulate and/or provide services for people with disabilities, their families and attendant
- Medical rehabilitation i.e., management of curable disability and lessening the disability to the extent possible
- Social, psychological, and other types of counseling and assistance
- Training in self-care activities including social graces, etiquette, mobility, communication, and daily living skills with special provisions as needed
- Provision of technical, mobility and other devices
- Specialized education services
- Vocational rehabilitation services including vocational guidance, training, open placement, and self-employment
- Certification of degree of disability and provision of available concessions/benefits
- Community awareness, advocacy, empowerment
- Follow-up

In the backdrop of this, the present chapter attempts at summarizing and recommending changes for the effective implementation of the programme.

# Observations on the Implementation of the Programme:

- 1. Geographical Coverage: The Aids and Appliances programme is implemented throughout the state. The benefits of the programme has reached the disabled living in certain remote villages of the state as well.
- 2. The programme benefits have reached the rural and the urban poor and the marginalized communities as well.
- 3. A large majority of the beneficiaries under the programme has been provided with either a wheel chair or a tricycle. The rest of the beneficiaries are provided with a hearing aid or a walk stick and walkers also.
- 4. The programme has resulted in bringing about changes at the individual and the community level as well. While the individual has been able to redefine his space both geographical and social, at the community level the disabled are received and accepted and there are changes in the perception of the community about the disabled. It is interesting to note that it has impacted the health of the individuals as well.
- 5. There is a increased awareness among the disabled about the various programmes and concessions provided by the government. There is good awareness concerning the different aspects of the aids and appliances programme such as the criteria for availing the benefits, the documentation, the type of assistance etc.,
- 6. The officials under the programme is found to have played a critical role in the implementation of the programme. They are not only involved in disseminating information, but also helping the disabled in getting the required benefits.
- 7. Under the present set up, the district offices are trying to procure the appliances with governmental agencies or procure the same from private agencies after observing KTTP Act.
- 8. In general, the aids and appliances provided are being used by the beneficiaries.
- 9. Excepting a very small percentage, there is no cornering of the benefits by the individuals or households.

#### Recommendations:

#### Administration Oriented:

- 1. While there is a thinking that the Department proposes to establish the District Rehabilitation Centres in all the districts of the State, as an interim measure it is suggested that the programme at the Taluk level be implemented through the Child Development Project Officers and their assistants. This is further expected to help in taking the programmes to the door step of the disabled.
- 2. The Department may consider the revision on the unit cost of the aids and appliances.

- 3. There is an urgent need to consider a revision on the income ceilings prescribed under the programme.
- 4. The Department shall take steps towards filling up the posts of VRWs which is expected to strengthen the implementation of the programme.

#### Identification and Selection of Disabled:

- 1. The Department may evolve strategies towards wider dissemination of the programme and the criteria laid down under the programme.
- 2. The Department should also focus on all kinds of orthopedic problems.
- 3. With a view to help the district offices in the task, the Department may establish Mobile Vans with adequate personnel and equipments to hold the camps on a quarterly basis.
- 4. The Department shall initiate steps towards making it compulsory for the medical officers to provide disability certificates at the village level.
- 5. The Department to review the functioning of the Medical Authority and initiate appropriate action towards its effective functioning.
- 6. The Health Department should also inform the cases of disability arising out of various reasons to the Department.

# Provision or Supply of Aids and Appliances:

- 1. The Government shall revise the total financial allocations and the unit cost in order to make it a successful demand driven programme.
- 2. The Government shall take steps towards creating adequate godown facility to store the aids and appliances and supply the same up upon the receipt of the applications.
- 3. The Government shall take steps towards providing modern gadgets such as the battery operated wheelchair, motorized wheelchair, digital walking sticks and improved hearing aids.
- 4. The Government shall take appropriate steps towards the maintenance of the appliances through a community-based approach.
- 5. There is urgent need to bring in the counseling and therapeutic methods into the programme. These add-ons are expected to make the programme more effective.
- 6. The Department shall initiate early action towards reviving the sound library in order to help the students.

# Convergence with other Programmes:

1. The programme shall be implemented through an integrated approach through the participation of the line departments. The beneficiaries of this programme shall be covered in the other employment oriented programmes to bring about economic improvement and empowerment among the disabled.

## Capacity Building Programmes:

1. The Department shall take appropriate steps towards organizing orientation programmes for the personnel at all levels.

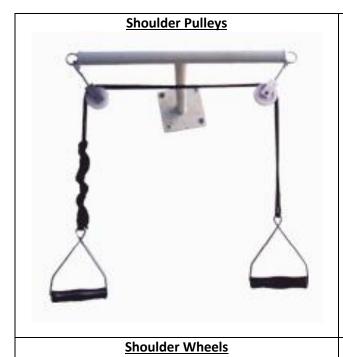


## Walking Aids & Crutches and Walking Sticks



























## **Worth Trust**

Worth Trust in Katpadi, Vellore have been identified as the nodal agency for the Tamil Nadu Government's Ministry of Welfare and in many ways their experience has been an example, though in no way typical, of North Arcot Ambedkar district's venture into CBR.

Initially, Worth followed the institutional method. Village children affected by polio would be referred for admission into their transitional school, which had a hostel attached. The children would remain here for a couple of years undergoing physiotherapy and corrective surgery it necessary and be taught to take care of their physical needs independently. Once worth decided to take rehabilitation into the community so that many more people could benefit from their expertise ad resources, the focus of their activities shifted. They went into Gudiyattam, Senur and Kalinjur villages of North Arcot district, to spread awareness about polio and the importance of immunization, to dispel superstitions about the nature of disability, to suggest ways to prevent disability by better health monitoring and increased safety standards and to convince people that the disabled were capable of leading productive, useful and independent lives.

The awareness campaign included talks to women's groups, dialogue with respected members of the village community like school headmasters, teachers and village headmen. It was possible to coordinate with government agencies to ensure that immunization worked in tandem with growing awareness. In the field of community health, other NGO's in Tamil Nadu, like the Thirumalai Charitable Trust, Ranipet, have enthused village volunteers to employ media as diverse as therukoothu (street theatre), kalakshepam, villupattu (folk song) and puppet shows to communicate messages of gender equality, nutrition, breast-feeding and alcohol abuse to rural audiences. Awareness generated from within in the community rather than from outside, scores significantly in terms of credibility and acceptance and any of these media could be used effectively as a means of communication about disability.

The combined efforts of the government, of Worth and other NGO's and medical institutions reaching out into the community, saw a decline in the incidence of polio in several rural pockets of North Arcot district. Follow-up by social workers reveals that there has been more consistence use of calipers and more encouraging figures of disabled children rehabilitated by Worth have gone on to complete post-graduate degrees and found jobs while many of the rural disabled have completed technical training courses rub by Worth and have found employment as turners, machinists, draughtsmen and also in the field of electronics. Rehabilitation of the child is now a must shorter process, involving less expenditure and also must less time spent away from the family. After their children are fitted with calipers, the parents are trained how to given therapy at home and perform the stretching exercises necessary to prevent

contractures. Children are admitted into the local village schools near their homes and are treated n CMC Hospital, Vellore, as outpatients.

Several panchayats have offered the premises of the local schools as centers where village women, trained by Worth therapists, provide physiotherapy to disabled children. The families of those children requiring corrective surgery are given the option of scheduling the surgery during the school's vacation time, which is also fortunately the slack time for agricultural work. The families can stay at Worth and be with the children during surgery. While Worth's focus was mainly on those suffering disability due to polio, they also identified people with other disabilities like cerebral palsy, hearing, speech and vision impairments and referred them to the concerned agencies for help.

While purists who favour the community-based approach prefer to create a situation where the community undetakes all aspects of rehabilitation, Worth and several other NGOs have realized that this is impractical and unrealistic. It is not always possible to find the rural community self-sufficient in the many resources required to help the disabled.

Take the example of Seenu, who is now learning tailoring in a vocational rehabilitation programme for the disabled run by CMC's Rehabilitation Institute and the Mary Vergese Trust. For two years, Seenu's family placed him as an apprentice to a tailor in his village in the hope that he would learn tailoring. Seenu's employer, however, had neither the inclination, the time, nor the skills required to train the young man properly and after two years Seenu was basically still stitching buttons and hooks. Encouraged by social workers from CMC, he accepted the offer of being housed temporarily in Vellore and is undergoing a structured programme which teaches him the basics of tailoring in a systematic way and will be helped to become self-employed by being given a load to purchase a sewing machine. Taking a more holistic view of the situation, part of his training also includes lessons in reading, writing and simple number work Wroth Trust also brings people from the rural areas to their center at Katpadi for technical training.

Most modern rehabilitation aids and mobility appliances are totally unsuitable for rural Indian conditions. Wheelchairs and tricycles are a legacy of a totally alien table-and-chair culture of the western world. Rural Tamil Nadu has a totally different social milieu as does most of rural India. It is quite literally, more down to earth, with sleeping, cooking and toilet facilities all being at floor level making the wheel chair user a total misfit in the home. The wheelchair user finds it not just difficult, but sometimes even dangerous to negotiate the sandy, uneven mud lanes in the villages independently. This is a problem that would not trouble a westerner, who has access to paved ad tarmaced roads. Calipers which require special fittings and have to be taken back to the point of manufacture for repairs have the built-in disadvantage that they may be discarded once they are broken.

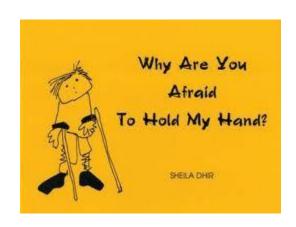
Several NGOs are encouraging village artisans to improvise their own calipers, crutches ad wheelchairs from locally available materials like wood, cane, PVC pipes and cycle components. Some amount of technical expertise has to be imparted to ensure that the improvised aids do no harm to the disabled person. Law wheelboards and trolleys are as good at making the paraplegic mobile as the more sophisticated wheelchair. The Little Brothers of Jesus, a group of Belgian priests, live and work in the rural communities of Senji, Tamil Nadu. When the villagers, belonging to very poor, down-tradden communities, shared their anxiety about their disabled children with them, the Brothers directed them to CERTH in Pondicherry. A group of men nominated by the village community received training in constructing inexpensive PVC calipers in Pondicherry and returned to the village with the ability and confidence to make them for their disabled children. In Gudiyattam village, Worth encouraged a number of people to make crutches from locally available materials mainly wood.

Superstition and the consequent discrimination of the disabled needs to be eradicated if they are to lead useful lives. This is another area which NGOs can tackle effectively. Training key members of the community to spread awareness has a chain reaction and the best possible spillover effect of raising the standards not just of the disabled, but of the community as a whole. For instance, when parents of disabled children are motivated to educate their children, parents of the able-bodied also receive the message that education is vital.

While using a community-based approach to rehabilitation, Worth has found that the model successfully used in one community cannot be replicated in another, for each community has its own cultural protocol and social norms. In many rural communities, mental retardation is not viewed as a disability requiring special intervention because they place a high premium on physical work and the mentally handicapped person can still perform a full day's physically taxing agricultural labour. Again in some rural communities of North Arcot district, where the main source of livelihood is beedi-rolling, requiring mainly finger dexterity, locomotor disabilities of the lower limbs are viewed less seriously.

In some villages, any form of disability is considered as divine retribution and a signal of God's wrath with the erring family. In these cases there may be a great deal of resistance against rehabilitation which is construed as interference with what God has ordained. Some communities feel that the most 'humane' solution to disability is extermination of the baby immediately after birth while others believe in a policy of complete protection, strictly confining their disabled to the home in order to shied them from the ridicule of the community.

The approach used in each community must therefore be fresh, open-minded and sensitive. Preconceived notions and rigid equations that presume that there is only one correct solution to the problem of rehabilitating the rural disabled can sabotage the whole exercise of community-based rehabilitation.



## Attitudes are the <u>Real</u> Disability

