DISABILITY IN INDIA: AN APPRAISAL OF PERSPECTIVES AND POLICIES

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MASTER OF PHILOSOPHY

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CERTIFICATE

Certified that the dissertation entitled ***DISABILITY IN INDIA: AN APPRAISAL OF PERSPECTIVES AND POLICIES*** *submitted by* ***MAHNAZ ULFATH*** *is in partial fulfilment of the requirement for the award of the degree of* ***Master of Philosophy*** *of this University. The dissertation has not been submitted for any other degree of this university and is her own work.*

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Dedicated to my grandmother

Muslima Khatoon

Acknowledgement

I remember and thank
my teacher Rama Baru for
the strength and confidence,
which I know I would not have got otherwise.

My parents and sisters
for being there
when I needed them.

For the love and hot coffee
my friends, room mates poured in excess.

My thanks goes to Chandan, Raju and Govind,
who arduously typed my dissertation.

For the spirit
which kindled the cause
my grandfather --
who is always with me.

And Sumit
who is my all.

Mahnaz Ullah

A Question

The white linen like logic
stained by the rape of heart.
I wash it with tears
Since Adam was flouted.
Can't I have another?
Or shall I wash
Reasons' dirty linen
till the last amongst us is gone?

An itenerant word
in the state of an irate pupil.

The chasm widens
between me and me.
an appendics existence.
Tinder dry
depending on a match stick.
Light the stick, please.

Persons with disabilities challenge the world community to grow - to build emotional intellectual and practical bases for a society which advances the freedoms, address the needs and facilities the contributions of all peoples.

- UN Secretary General Boutros
Boutros-Ghali.

INTRODUCTION

The thread that binds three gifted individuals at different periods of time, Surdas, Bethoveen and Stephen Hawkins, is that all of them were disabled. No one will even doubt the contribution of these personalities to poetry, music and science. Their talent overshadowed their disability and society remembers them for the former rather than the latter. Ideally this should be so for all individuals, gifted or otherwise. However the experience of most disabled individuals is mainly one of discrimination.

I wanted to research on the topic of disability because of a very personal interest. I grew up in a family consisting of a visually impaired grandfather who to me was 'normal' in every aspect. From an early age I realised that how one views disability is largely shaped by society attitude to it. I hope my dissertation, would be a little step towards bringing and understanding how societies have viewed and treated disabled people.

Disability is an area which has been largely under researched. Some studies have focused on problems faced by disabled people and the rehabilitation programmes designed for them. However there are few studies which have tried to look at the magnitude of the problem, the programmes and policies available and their limitations. We believe that in order to make any meaningful intervention one needs to take an interdisciplinary approach to disability whereby different aspects of their lives are addressed.

In this dissertation I seek to view and locate disability within an interdisciplinary perspective based on an understanding of the prevalence of disability, its causes, types and geographical distribution. This is necessary in order to understand disability within not as an individual problem but seeks to take a comprehensive view. This kind of an approach becomes essential while planning any intervention for disabled persons. Much effort has been put into the rehabilitation and prevention without adequate attention to curative inputs. The discipline of public health stresses the need for an integrated approach to tackling any health problem in a community. We feel that this kind of approach to even deal with disability could help in evolving a more suitable policy for the disabled.

This dissertation has five chapters the first one deals with the various theoretical approaches to viewing disability.

The second chapter analysis the prevalence and incidence of disability, its causes and geographic distribution based on the two National Sample Survey on physical disabilities conducted in 1981 and 1991. The prevalence rate, treatment, interstate variation, the rural urban divide has been analysed.

The third chapter reviews the government policies regarding disability from the Ist to VIIIth plans and locates the role of the service sector both before and after independence and marks the shift from individual-based-care to community-based-rehabilitation.

The fourth chapter views the legislative aspects of disability and states the importance of rights for the disabled.

The last chapter deals with necessary intervention and seeks to arrive at a conclusion.

As far as the number of disabled persons is concerned there are several estimates available. According to a World Health Organisation approximately 10 per cent of the Indian population is disabled which numbers to about 90 million people.

While the percentage of disabled may appear small one must keep in mind that they are part of a family which also bears the burden of caring. According to a rough estimate more than 40 per cent of the population would consist of families of disabled who are deeply affected emotionally, socially and economically (VHAI).

Within this a vast majority (about 80%) of the disabled live in rural areas of our country where access to services is negligible. Studies show that there is a paucity of services and 0.2 per cent have access to rehabilitative services. Furthermore, while 80 per cent of the disabled population lives in the rural areas, the services are mainly urban based and only 2 per cent of the rural and 5 per cent of the urban disabled population have access to services.[1] Major physical disabilities affecting our population are a (1) locomotor disability, (2)visual disability (3) communication disability, including speech and hearing.

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1 Alkazi, R.M., State of India's Health, Voluntary Health Association of India.

As far as preventive programmes are concerned the government has given special attention to eradication of polio and blindness. This concern has been translated into two national programmes; the former under Universal Immunization Programme and latter under National Blindness Control Programme.

Four years before the year AD 2000, the year for which so many targets have been set; to eradicate polio, to reduce the incidence of blindness to 0.3%, to achieve universal immunisation, the list is endless. Are we anywhere near achieving these targets?

There is a growing awareness in the country about the needs of disabled people, as was articulated in a small way by the Disabled Rights Group. They have brought the concern of disabled to the fore and articulated their interests. However this is just a beginning in the long haul for equal rights.

It is well recognized that over 70 per cent of these disabilities are preventable, where disabilities treatments and rehabilitative service are required.

CHAPTER ONE

SOCIAL CONSTRUCT OF DISABILITY

This chapter seeks to review the different theoretical approaches within which disability has been viewed and its impact on policy formulation.

Even as the writing of history has expanded wide enough to include those who are at the lower rungs of the social ladder, it has continued to ignore almost completely, those who are at its very bottom, the "dregs of society', those who existed on the periphery, or even outside society.

These lowest 'classes', to use the team in a non-Marxian sense, constitute the marginal groups like the disabled. They have no permanent place or role in society, and no defined position in the process of production. They remain outside the pale of the mainstream society's terms of reference, either deliberately, or having been pushed there by their perceived "separateness". In straightforward terms, disabled, are those about whom very little is known; indeed, about whom there is very little urge to know.

Disability is a condition which is largely shaped by how society views it. Through history one finds that people sought to explain why disability occur from a religious viewpoint. Some study shows that these people were normally not isolated but accommodated within the community despite their differences.

Some anthropologist have tried to study how disability is viewed in tribal societies.

Evans-Pritchard in Witchcraft Oracles and Magic amongst the Azande, demonstrate that disability is a social construct. He explains that in societies dominated by religion or magic disability is likely to be perceived as punishment by the gods or individual disabled people to be seen as victims of witchcraft. He cites the example of the Wapogoro tribe among the Red Indians who do not isolate the epileptics but through their belief system are accommodated.

Michael Oliver in Social Work with Disabled People[1] defines impairment as 'individual limitation' and disability as 'socially imposed restriction'. Vic Finkelstein in Attitudes and Disabled Persons: Issues for Discussion, illustrates in a rather interesting and amusing article, that if the physical and social world were adopted for wheelchair - users their disabilities would disappear and able-bodied people would become disabled. According to this model, blindness is an impairment but lack of access to written information is a disability- a socially determined state of affairs which could be solved by more extensive braille production, more money to pay for "readers" and the greater use of taped material. Similarly, not being able to walk is an impairment but lack of mobility is a disability, a situation which is socially created and could be solved by the greater provision of electric wheelchair, wider doorways and more ramps and lifts. This constitutes a social model of disability, where constitutes a social model of disability,

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1 Oliver Michael, Social Work with Disabled People, London, Macmillan, 1983.

where disability is viewed as a problem located within society rather than within individuals who happen to have impairments.

Thus the way to reduce disability is to adjust the social and physical environments to ensure that the needs and rights of people with impairments are met, rather than attempting to change disabled people to fit the existing environment.

Accounts from some societies suggests that individuals with certain kinds of impairments or biological characteristics may not be considered human. On rather they may be a point at which such an individual's humanity is in doubt. In many northern countries, the Abortion of a defective fetus is considered more acceptable than that of a "normal" one, suggesting that the "human" status of an impaired individual is more negotiable.

The debate about whether severely impaired individuals/infants or even adults should be alive also involves the attribution of humanity, as the revealing term "human vegetable" implies.

In many societies, birth defects are more likely to be seen as inhuman than defects acquired later in life. Essentially disability is seen as an aberration.

The second approach is based on the work of Turner (1967),[2] where he develops the concept of "liminality". This has recently been used to explain the social position of disabled people in all post industrialised societies. According to Murphy,

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2 Turner, V., The Forest of Symbols: Aspects of Ndembu Ritual, New York: Cornell University Press, 1967.

> The long term physically impaired are neither sick nor well, neither dead nor fully alive, neither out of society nor wholly in it. They are human beings but their bodies are warped or malfunctioning, leaving their full humanity in doubt. They are not ill, for illness is transitional to either death or recovery ... . The sick person lives in a state of social suspension until he or she gets better. The disabled spend a lifetime in a similar suspended state. They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people.[3]

The third approach is the "surplus population thesis", and here the authors argue that in societies where economic survival is a constant struggle, any weak or dependent members who threaten this survival will be dealt with. Thus disabled children may be killed at birth, disabled adults may be forced out of the community and disabled old people simply left to die.[4]

"The surplus population thesis" can be substantiated by citing a few ethnographic studies. Rasmussen in his book People of the Polar North, cites an example of an Eskimo man and one of his wives who were badly burnt in an explosion. The wife was simply left to die, but the husband, if he recovered might again make an economic contribution, and so was saved.

According to Nancy Scheper - Huges describes how impoverished women in northeast Brazil neglect these "poor little critters" and compares them to Nues "crocodile infants" and Irish "changelings", all excluded from the realm of humanity.

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3 Murphy, R. The Body Silent, London: Dent, 1987.

4 Rasmussen, K., People of the Polar North, Philadelphia: Lippincott cited in Michael Oliver's, The Politics of Disablement, p.21.

"The Sickly, Wasted, or congenitally deformed infant challenges the tentative and fragile symbolic boundaries between human and nonhuman, natural and supernatural, normal and abominable"[5]

Work is central to industrial societies not simply because it produces the goods to sustain life but also because it creates particular forms of social relations. Thus anyone unable to work, for whatever reason, is likely to experience difficulties both in acquiring the necessities to sustain life physically, and also in establishing a set of satisfactory social relationsips.

Disabled people have not always been excluded from working but the arrival of industrial society has created particular problems; disabled people often being excluded from the work process, because of the changes in methods of working and the new industrial discipline continuing to make meaningful participation in work difficult, if not impossible.

Michael Oliver in his book, The Politics of Disablement, analyses how with the seclusion of the disabled in the Capitalist society, gradually leads to the concept of asylum and institution; thus further segregating the disabled.

"The onset of industrial society did not simply change ways of working, but also had a profound effect on social relations with the creation of the industrial proletariat and the gradual erosion of existing communities, as labour moved to the new towns."[6]

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5 Scheper - Hugher, Nancy Death without weeping: the violence of Everyday life in Brazil, Berkeley, Los Angeles, London: University of California Press.

6 Michael Oliver, The Politics of Disablement, Macmillan, London, 1994.

Industrialisation had profound consequences for disabled people therefore both in that they were less able to participate in the work process and also because many previously acceptable social roles, such as begging or "village idiot" were disappearing.

The new mechanism for controlling "economically unproductive" people was the workhouse or the asylums and over the years a whole range of specialised institutions grew up to contain this group. These establishments were undoubtedly successful in controlling individuals who would not or could not work. "They also performed a particular ideological function standing as visible monuments to the fate of others who might no longer choose to subjugate themselves to the disciplinary requirements of the new work system."[7]

There were problems too in that it was soon recognised that these institutions not only created dependency in individuals but also created dependency group.

It is pertinent to note that in pre capitalist societies ethnographic studies have shown that while disability may have been viewed as an aberration, this did not lead to the segregation of the disabled persons. It is with the rise of capitalism that the need to segregate disabled arose since they were viewed as "unproductive" labour.

Finkelstein explains that there are indeed, strong economic reasons for the exclusion of disabled people and it is the embodiment of these social and economic relations under capitalism which has led directly to the exclusion of disabled people within capitalist societies.[8]

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7 Ibid.

8 Finkelstein, V., Attitudes and Disabled People: Issues for Discussion, cited in The Politics of Disablement, p.27.

He goes on to state that the disabled are being gradually excluded from the capitalist work force.

His theoretical approach which is a historical materialistic one is couched in terms of three phases of historical development. Phase one corresponds to Britain before the industrial revolution; that is feudal society. Phase two corresponds to the process of industrialisation when the focus of work shifted from the home to the factory; that is the capitalist society. This takes us up to the present day, and phase three refers to the kind of society to which we are currently moving towards.

The economic base in phase one, agriculture or small sale industry, did not preclude the great majority of disabled people from participating in the production process, and even where they could not participate fully, they were still able to make a contribution. In this era disabled people were regarded as individually unfortunate and not segregated from the rest of society. With the rise of the factory in Phase two, many more disabled people were excluded from the production process for;

"The speed of factory work, the informed discipline, the time keeping and production norms all these were a highly unfavourable change from the slower, more self-determined and flexible methods of work into which many handicapped people had been integrated.[9]

As Capitalism developed, this process of exclusion from the workforce continued for all kinds of disabled people.

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9 Ryan and Thomas, The Politics of Mental Handicap, Hamondsworth: Penguin, 1980, Cited in Oliver, M. The Politics of Disablement p.101.

By the 1890s, the population of Britain was increasingly urban and the employment of the majority was industrial, rather than rural. The blind and the deaf, growing up in slowly changing scattered rural communities, had more easily been absorbed into the work and life of those societies without the need for special provision. Deafness, while working along at agricultural tasks that all children learned by observation with little formal schooling, did not limit the capacity for employment too severely. Blindness was less of a hazard in uncongested familiar rural surroundings, and routine tasks involving repetitive tactile skills could be learned and practised by many of the blind without special training. The environment of an industrial society was however different.

Changes in the organisation of work from a rural based, cooperative system where individuals contributed what they could to the production process, to an urban, factory-based one organised around the individual waged labourer, had profound consequences. "The operation of the labour market in the nineteenth century effectively depressed handicapped people of all kinds to the bottom of the market"[10]

As a result of this, disabled people came to be regarded as a social and educational problem and more and more were segregated in situations of all kinds including workhouse asylums, colonies and special schools, and out of the mainstream of social life. The emergence of Phase three, according to Finkelstein, will see the liberation of disabled people from the segregative practices of society largely as a

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10 Morris, P., Put Away, London : Routledge and Kegan Paul, 1996.

consequence of the utilisation of new technologies and the working together of professionals and disabled people towards common goals.

For Finkelstein, disability is a paradox involving the state of the individual (his or her impairment) and the state of society (the social restrictions imposed on an individual). By adopting a three-stage evolutionary perspective he sees the paradox emerging in Phase two. In phase one disabled individuals formed part of a larger underclass but in phase two they were separated from their class origins and become a special, segregated group, whereby the paradox emerged and disability came to be regarded both as individual impairment and social restriction. Phase three, which is just beginning, sees the end of the paradox whereby disability comes to be perceived solely as social restriction.

While it is certainly true that the emergence of capitalism has profound effects on social relations generally and that many acceptable social roles and positions disappeared, and that this directly affected disabled people in many instances, it is difficult to assess whether these changed affected the quality of the experience of disability negatively or positively, largely because history is silent on the experience of disability.

If we review some studies done on disability one finds that three major theoretical approaches to our understanding of how disability is viewed and the problems faced by disabled persons.

The various approaches to disability.

(1) Functionalist approach (Comte's positivist model)
(2) Psycho-social model (stigma - negative image)
(3) Medical Approach.

Auguste Comte provided an evolutionary approach aimed a providing an understanding of the development of human history. He suggested that the human intellectual process could be understood in terms of three stages of development; the theological, the metaphysical and the positivistic stages. This model suggests that there has been a shift from a religious interpretation of reality to a more naturalistic one and finally to a scientific way of understanding both the natural and social worlds: each branch of our understanding passes through three different stages : the theological or fictitious stage; the metaphysical or abstract stage; and the scientific or positive stage.

Comte's model has been used to understand disability and mental retardation at various stages. This suggests that care was initially provided was based upon a philosophy of compassion linked to religious and philanthropic perspectives, then services were provided upon the philosophy of protection, both for the disabled individuals and society, and finally care was provided on the basis of optimism, linked to the development of new scientific and pedagogic approaches to the problem mental handicap.

Comte's model has also been used to illustrate changing patterns of prejudice in respect of people with epilepsy :

"increasing rationalism did not ameliorate social prejudice against epileptics - it merely caused one form of prejudice to be substituted for another. He was no longer isolated as unclean, as a ritually untouchable person, but instead he was isolated as insane, and placed in institutions where he was subjected to extremely substandard conditions of life. However later evidence suggests that further rationalisation and increasing knowledge of the causation of epilepsy, separating it from insanity, may lead

to improvements in social conditions for epileptics - as the culture catches up with findings of the scientific community.[11]

This was in keeping with Comte's view that in the positive stage of development of societies, the rationality of men will prevail in creating better conditions and located his options for the disabled as well.

During the post industrialisation period which was marked by dramatic changes in social relations the focus on disability shifted to the individual and on the functional limitations of the disabled individual at the physical, psychological and social levels. This gets reflected in a fragmented approach to the question of disability where the physical impairment can be treated with medical technology, the psychological dimension through counselling and the social through provision of institutional services.

While medical technology does play an important role in correction of disabilities this approach is limited by its emphasis on merely correcting the physical dysfunction. Therefore undue emphasis is given to corrective surgery and a host of preventive technologies.

This approach, ignores the experience of illness and disease and neglects issues of prevention. In addition many of the major disorders in modern society have no known biochemical cause or are unresponsive to medical treatments. Finally, this approach

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11 Pasternak. J. 1981. "An analysis of Social Perceptions of Epilepsy : Increasing Rationalisation as seen through the Theories of Comte and Weber", Social Science and Medicine, Vol. 51E, no.3.

ignores the influence that cultural, or even subcultural factors, may have upon the disease process.

Despite these well-known criticisms, it remains true that in the twentieth century, we have seen an increasing medicalisation of society. Medicine has acquired the right to define and treat a whole range of conditions and problems that previously would have been regarded as moral or social in origin.[12] There have, of course been substantial gains from this medicalisation of disability, which has increased survival rates and prolonged life expectancies for many disabled people as well s eradicating some disabling conditions. But the issue for the late twentieth century is not one of mere increase in expectancy of life but an improvement in overall quality of life of disabled persons to lead socially productive lives with rights like any other citizen.

This highly individual approach to viewing disability has far reaching consequences in the day to day lives of people. In Pride Against Prejudice: Transforming Attitudes to Disability, Jenny Morris narrates her personal experience of being disabled and negates the theory of medicalisation.

> Academics and professionals play a key role in influencing the meaning which non-disabled people give to disability and in determining the policies and services which affect our lives. The models of disability which most commonly inform this role are the "personal tragedy" and medical models of disability. Those who subscribe, consciously or unconsciously, to these models view disabled people as individuals whose experience is determined by their medical or physical condition. Someone who is blind is thus viewed as experiencing of the professional to mitigate the difficulties caused by not being able to see. The individualist

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12 Courad, P. and Schneides, J., Deviance and Medicalisation: From Badness to Sickness (St. Louis: Mosby), 1980.

assumption which are at the heart of this definition of disability also encourage a particular psychology of disability. By this I mean that disabled people's behaviour is often interpreted in terms of individual pathologies. Our justifiable anger about our apprehension is interpreted as a self-destructive bitterness which arises out of a failure to "accept" our disability. Our difficulties in getting access to the resources we need to live independently are treated as a "lack of motivation" or similar individual inadequacies.

The medical and 'personal tragedy' models of disability and the attitudes which go with them are a very "important part of the powerlessness experienced by disabled people in their relationship with those professions whose role is so important to the quality and nature of our daily lives. Disabled people - in their struggle to assert their autonomy and to counter their powerlessness - challenge these attitudes in their day-to-day contact with those who have power over us.[13]

One of the pioneers in exploring how societal attitudes play an important role in the way disabled people are treated is Goffman's work on stigma. His work marks the shift from a purely psychological explanation to a socio-psychological one.

The term "Stigma" refers to the persistent trait of an individual or group which evokes negative or punitive responses. Thus, disabling conditions are stigmatizing to the extent that they evoke negative or punitive responses; and a major concern for social scientists has been to illuminate both the cause and forms of these responses, as well as their impact on the lives of disabled people. In his classic work on stigma, Goffman offers a rich exposition of the causes, forms and effects of stigma in American society. He argues that stigma is best explained by reference to the notion of deviance, that is , deviation from prevalent or valued norms; but importantly he demonstrates that deviance is not an inherent properly and, in effect a person is not a deviant until his acts or

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13 Morris J., Pride Against Prejudice: Transforming Attitudes to Disability, The Women's Press, 1993. p.180.

attributes are perceived" as negatively different. Although Goffman is interested in all types of stigma, he repeatedly refers to the experience of people with disabilities in order to build his arguments.

By taking a stigma/deviance approach, Goffman brings to light the overriding theme of subsequent social science research that it is not the functional limitations of impairment which constitute the greatest problems faced by disabled individuals, but rather societal and social responses to it.

A review of studies on disability in India have largely focused on themes regarding rehabilitation, integration, education and policy.[14] After 1981 (year of the disabled) some studies focused on shift in policy specially after the concept of Community Based Rehabilitation (CBR) was initiated.[15] However none of these studies have taken a comprehensive view of disability by exploring the linkages between the causes, prevalence, distribution of disability and policy outcomes for the disabled. Our review of available studies clearly demonstrates that only some aspects of disabled lives are focused and there is a lack of an integrated approach which would address the links between the need for a theoretical approach, characteristics of the disabled and policy outcomes.

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14 Advani Lal, R.S. Pandey, Perspectives in Disability and Rehabilitation; S.P. Murthy, Cyn Gopalan, Work Book on Community Based Rehabilitative Services; S.N. Gajendragadkar, Disabled in India; S. Krishnaswamy, The Demography of the Disabled And the Handicapped in India; Baquer Ali, Disabled, Disablement Disablism.

15 T.N. Chaturvedi, Administration for the Disabled, Policy and Organisational Issues.

The objective of this dissertation would be to analyse the different theoretical approaches for understanding disability; and find trace of it as to how it shapes policy for disabled.

The analyse the characteristic of the disabled people, based on the NSS survey.

The review the evolution of government policies and legislations for the disabled, in independent India.

There is debate on need to improve the lives of disabled - one needs to take an integrated view rather an individualist one Planning services for disabled has to take into account the preventive, curative and rehabilitative component as an integrated whole. In order to do this one needs to get an ideas of the prevention, cause and types disability, the rural-urban, interstate distribution. One also need, to review the theoretical and social construct of disability itself which would largely dictate policy interventions. Most studies in the area of disability have focused either on rehabilitation programmes or the psychological problems faced by disabled people. There is clearly a paucity of studies which locates disability in a wider socio-economic context and sees the necessity to examine an integrated approach where the preventive, curative and rehabilitative services reach the community in which disabled persons live. Our study explores the interphase between the social construct of disability, its demographic details and policy outcomes, in order to comment on the lack of a coherent policy for disabled.

CHAPTER TWO

CHARACTERISTICS OF DISABLED IN INDIA

According to WHO estimates 10 per cent of the Indian population consists of disabled people. In the number is 90 million which is very large. However this estimate does not give us any indication of types, its distribution according to sex, states and urban/rural areas. There is no breakup showing causes and age. Given a large country like ours - for any effective and meaningful policy a strong data base is needed. In fact our effort in this chapter is to throw light into the characterises of disabled population through an analysis of NSS conducted over two rounds.

It analyses the 36th round and the 47th round of the NSS report covering a time period of one decade between 1981 and 1991 respectively. It deals will the prevalence rates, types of disabilities, inter state distribution and the rural-urban distribution.

A Report on Disabled Persons in India; Journal of the National Sample Survey Organisation; 47th Round, Report number 393 Department of Statistics, Ministry of Planning Government of India, July-Dec. 1991.

A demographic profile of the disabled and the handicapped, people of India was conducted by the NSS in 1991 with regard to the types, size, causes, age at onset, marital status, educational level, living arrangements along with the incidence and prevalence rates of physical disabilities only.

Sample size

At the all India level, 39271 households in the rural area and 17,489 households in the urban area were surveyed from 4,373 villages and 2,503 urban blocks. The number of disabled persons enumerated in rural and urban India was 42,400 and 18,833 respectively. According to the survey estimates, the number of physically disabled persons in the country was 16.15 million during July to December, 1991. They formed about 1.9% of the total estimated population. Which was obtained by using 1991 census population projected for 1st October, 1991.

In 1981, the estimated total number of disabled persons in India, according to the NSS, is 11.94 millions. This survey covered 5,409 villages and 3,652 urban blocks in which 81,858 households in the rural area and 56,462 households in the urban areas were contacted to collect data. In all, 4,49,802 and 2,96,852 persons were enumerated in the rural and urban areas respectively. Thus, the disabled population comprises of 1.8% of the total population in India. Of all the disabled population, 81% live in rural areas, and 19% live in urban area.

Rural-Urban Distribution

According to the NSS data, the prevalence of physical disability covering visual, hearing and speech and locomotor disability was more in the rural area as compared to the urban area.

As regarding the inter-state variations, Punjab has the highest rate of with 2936 per 1000 persons. This is closely followed by 2870 per 1000 in Himachal Pradesh.

This is followed by Maharashtra with 27 per 1000, Andhra Pradesh with 24.9, Tamil Nadu 23.7, Orissa 23.0 per 1000 population.

In comparison with the NSS of 1981, Punjab has the highest rate with 26 physically disabled per 1000 population. This is closely followed by Andhra Pradesh with 24 per 1000 population.

The reason for a higher percentage of disabled persons in the rural area could be attributed to the fact that about 75% of India's population reside in the rural area.

Incidence Rate

An analysis of both the round of NSS data of 1981 and 1991 show a trend that it is mostly the agriculturally progressive states, which have a high rate of physical disabilities, locomotor disability, in the rural area. In Punjab and Haryana this has been due to mechanisation of agriculture which has contributed to physical disability, as demonstrated by a study conduced by Dinesh Mohan in the Economic and political Weekly, Vol XXII, No. 13, Review of Agriculture, March 28, 1987.

There has been a callous neglect ad disregard of the health of the people of India with regard to policies concerning pesticide import, rise of disability in the rural area, as observed by him. His study of this area shows that

a) There is a significant statistical co-relation between the technologies involved in the green revolution and prevalence of the following disabilities in India: amputations, dysfunction of joints, deformities, and visual disabilities.

b) There is overwhelming evidence from animal experiment that pesticides can cause mutations and congenital deformities.

c) Some evidence exists that pesticides can cause deformities of limbs and visual disabilities in humans even when taken in low doses.

d) there is enough evidence that agricultural technology like threshers result in amputations of a large number of agricultural workers.

e) Pesticides which are banned or highly restricted in other countries are being imported to India and also being manufactured locally.[1]

Based on the above evidence a hypothesis is formed that those states which have more intensive pesticide use have a higher prevalence rate joint dysfunction, limb deformities and visual disabilities and those states which have a higher rate of use of technologies like tractors and threshers have a higher rate of amputations.

Types of Disability:

The physical disabilities can be categories into the various sort;

a) locomotor disability

b) visual disability

c) Communication disability, both hearing and speech

d) Speech disability

e) hearing disability

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1 Dinesh Mohan, 'Review of Agriculture', Economic and Political Weekly, vol.xxii, no.13, March 28, 1987.

According to the NSS, it was observed that among the different types of disability the number of persons having locomotor disability was highest in both rural and urban areas followed by the number of persons with visual disability and hearing disability.

The major cause of physical disability was due to polio.

Reasons deduced is due to ill-equipped rural health service and no proper prevention measures.

Sl. No.	Type of Disability	Numbers			
		Rural	Urban	Rural	Urban
1.	Locomotor	4342	1985	680	2132
2.	Visual	2908	566	3335	670
3.	Hearing	2477	542	2573	669
4.	Speech	1366	388	1499	467

No. of persons disabled in (000's)

Source: Government of India : *Sarvekshana - Journal of the NSS*, New Delhi, July-October, 1991.

Prevalence of Physical Disability

In the country as a whole, the prevalence of physical disability was 2.0 per cent in the rural population and 1.6 per cent in the urban population; according to the 1991 survey between the two sexes, the prevalence of disability was marginally higher among males than among females. the rate for males was 2.3 and 1.8 per cent while that for females was 1.7 per cent and 1.4 per cent in rural and urban India, responsibility.

The inter-state variations in prevalence rate are significant in both the sectors. In areas it was as low as 1.2 per cent in Assam, to as high as 2.9 per cent in Punjab. While in the urban area, ranged from 1.1 per cent in Rajasthan had the lowest prevalence of 1.1 per cent and Orissa has the highest 2.0 per cent (See table).

The prevalence rates among males are higher than among females in all the states.

Incidence of physical disability

The incidence of physical disability in population, that is the number of persons who had suffered physical disability by both or otherwise during the specified period of previous year (365 days preceding the date of survey July-Dec. 1991) per 100,000.

At the all-India level, 90 per 100,000 persons were born or otherwise became disabled during the reference year in the rural sector.

In the urban sector, this figure was a little lower 83 per 100,000 persons. As in the case of prevalence rate, the incidence rate is also observe to be higher among males than that among females. The rates among males were 99 and 90, respectively in rural and urban India as against 81 and 75, respectively among females. In this respect, the states also exhibit the same feature.

The State-wise difference are quite highranking from 30 to 171 per 100,000 persons in rural India and from 46 to 144 per 100,000 persons in urban India. Assam reported the lowest incidence rate and Tamil Nadu the highest rate in both the sectors. The states other than Tamil Nadu which showed high incidence rate of physical disability

in rural areas are Punjab 156, Andhra Pradesh 132, Mothy Pradesh 121, and Maharashtra 107.

In the urban areas, Orissa 141, Maharashtra 98 and had a relatively high incidence of physical disability. Contrary to the general pattern, rural areas of Andhra Pradesh and Mothy Pradesh and urban area of Assam, Orissa and Tamil Nadu reported a higher incidence of disability among female than males during the year.

Prevalence of Physical disability: A Comparison Between NSS 36th (1981) and 47th (1991) Round

The first comprehensive survey on physical disability was called out in the NSS 36th round (July-Dec. 1981) and its follow-up survey in NSS 47th round (July-Dec. 1991).

The concepts, definition and survey procedures were the same in both the rounds. It is, therefore worthwhile to see the changes in the prevalence and incidence of physical disability in the population since the incidence late of physically disabled persons as a whole is not available for NSS 36th round, only the prevalence rate as obtained from these rounds are presented for each sex separately for rural and urban India.

Prevalence of physically disabled persons per 100,000 persons obtained from the NSS 36th and 47th round.

Sector	36th round (July-Dec. '81)			46th round (July-Dec. '91)		
	Male	Female	Total	Male	Female	Total
(1)	(2)	(3)	(4)	(5)	(6)	(7)
Rural	2045	1632	1894	2277	1694	1995
Urban	1532	1297	1420	1774	1774	1579

Source: Government of India, *Sarvekshana*, NSS.

The results reveal that in both sectors of India, the prevalence of physically disabled persons for male as well as for female increased marginally over the periods 1981 to 1991. the rural-urban as well as male-female pattern in the prevalence rate is found to be similar in both the rounds.

Visual disability

The cause of visual disability was nt known to about 16 and 13 per cent of the visual disability in rural and urban India respectively. About 27 and 21 per cent reported "old age" or the cause of visual disability in the rural and urban India respectively. Further cataract, the incidence of which is generally high in old age, was found to be the cause in about 24 and 28 per cent cases respectively in the rural and urban sections. Thus, the distributions of disabled person by age at onset of visual disability and by probable cause of such disability suggest that the visual disability is essentially an old age problem. In most of the major states, 40 per cent or more reported "old age" and "cataract" as the cause of visual disability in both the sectors.

The prevalence rate was higher in rural India as compared to that in urban India for males as well as females. Between the two sexes, the prevalence of hearing disability was higher among males 493 than among females 435 in rural India, while in urban India, it was higher among females 355 than among males 325. The male female and urban-rural pattern observed above for all India were noticed in most of the major states. In the rural areas, the highest prevalence rate was reported by Himachal Pradesh -1108, followed by Tamil Nadu 723, 0-698, Andhra Pradesh 660.

The highest rate in urban areas were reported by Orissa 548, followed by Tamil Nadu 518 and Andhra Pradesh 501. In the urban areas of Himachal Pradesh which reported the highest prevalence rate in the rural areas, the rate was as low as 237. In no other state, the rural-urban difference is that large. It may be mentioned that Rajasthan has the distinction of reporting the lowest prevalence rate of hearing disability in both the sectors-271 and 196 in rural and urban sectors respectively.

Incidence of Hearing Disability

While the incidence rate among females was 14 in both the sectors, that among males was 16 and 11 in the rural and urban respectively.

Tamil Nadu has the highest incidence rate in both the sectors-42 and 29 for rural and urban areas respectively. The lowest rate of incidence was found in Bihar 3 and 1, respectively for rural and urban areas. The statewise variations in incidence rate appear to be rather large.

At the all India level, about 61 and 65% reported the onset of hearing Disability at ages 60 years and above in the rural and urban sectors respectively. In both the sectors, the onset of hearing disability in each quinquennial age-group upto 30-34 years was quite low and almost of the same order, around 1%. The result indicate that the hearing disability is mainly a problem of old age like visual disability.

The state-level results quecally conform to the all- India pattern. It may be mentioned that number of sample persons of age 60 years and above with hearing disability was very small for many states. The state level results are, therefore, not expected to be reliable enough.

In about 26 and 21 % cases of hearing disability in rural and urban India respectively, the informants were ignorant of the cause of hearing disability. About 23 to 26% reported "old age" as the cause of hearing disability of the other reasons, ear discharge and other illness were identified as the cause by a comparatively large proportion of persons with hearing disability. It may be noted that even in the year 1991 about 1 % of the disabled (hearing) persons reported "german measles/rubella" as the cause of hearing disability. Most of the states exhibit the same pattern as is observed for all India.

Speech Disability

It is found that during the second half of 1991, 273 per 100,000 persons in rural India had a speech disability. The corresponding numbers in urban India was 23 percent. The male-female difference was considerably high and a higher proportion of males had speech disability than females out of 100,000 males, 333 and 285 had speech disability in the rural and urban sector respectively.

On the other hand, 208 and 132 females per 100,000 had speech disability in rural and urban India respectively. The states also reveal a similar pattern. Among the major states, the prevalence rate was highest in Himachal Pradesh 457, followed by Kerala 414, Karnataka 353 in the rural sector. In the urban sector, the highest prevalence rate of speech disability was observed in Andhra Pradesh 359 followed by Kerala 327, Tamil Nadu 306 and others.

Incidence of Speech Disability

In India 5 per 100,000 persons were born or otherwise affected by speech disability in a year. Further, proportionately more males were affected than females

during the year. Among the states, the incidence late per 100,000 persons was highest in rural Tamil Nadu 13 and urban Kerala 17.

Cause of Speech Disability

About 20 and 17 percent in rural and urban India respectively, did not know the cause of speech disability. Among the reported causes, paralysis and other illness were the major ones. As high as 41 and 45 percent of cases reported paralysis and other illness" as the cause in the rural and urban sectors respectively.

About 9 percent had developed speech disability due to mental illness/retardation. It may be worth nothing that contrary to visual and hearing disabilities, only 2 percent reported old age as the cause of speech disability.

Locomotor Disabilities

The survey estimated 8.04 million persons as having locomotor disability in the country of them, about 6.29 million lived in the rural areas and 1.75 million in the urban areas. Further about 2 percent of those who had locomotor disability (two or more types of locomotor disability) in both the rural and urban sectors.

Prevalence of Locomotor Disability

Compared to other type of disability the prevalence of locomotor disability per 100,000 person was the highest. The rate was as high as 1074 and 962 in rural and urban India. Among males, the prevalence was much higher than among females : 1345 and 1170 for males as against 784 and 728 for females per 100,000 in rural and urban areas respectively.

Among the states, the prevalence of locomotor disability was highest in Punjab 1974, per 100,000 in the urban sector. The lowest prevalence rate was in Assam in both

the sectors- 419 and 424 in rural and urban sector respectively. Interesting, Assam is seen to be the only state where the prevalence of locomotor disability was proportionately more, though marginally, among the urban population than that among the rural population.

Incidence of Locomotor Disability

It is found that the incidence rate in a year was almost same in both in India - 53 and 52 respectively. Further, the rate among males 64 though same in both the sectors, was higher than among females 42 and 39 in rural and urban respectively. In the different states, the incidence rate among males were, in general, also higher than that among females.

The over all incidence rate of locomotive disability was highest in Punjab 99 for rural sector and in Orissa 89 for urban sector.

Cause of Locomotor Disabilities

Polio was found to be the major reason for locomotor disabilities. About 33 and 35 per cent of the persons with locomotor disabilities reported "polio" as the cause at the all India level in the rural and urban sectors respectively. The next in importance was the cause "burns and injuries" accounting for 23 to 24% respectively. Contrary to the results relating to visual and hearing disability, the percentage of persons who acquired locomotor disabilities due to "old age" was a low as 4 to 5 per cent at the all India level.

In this context, it may be mentioned that the incidence of locomotor disability due to causes like, stroke, arthritis, cardio respiratory diseases, was generally higher at the older age than at the younger ages. It is worth noting that in India, about 2 to 3 per cent of the disabled persons reported leprosy as the cause of locomotor disability such cases

were highest in rural Tamil Nadu 8 per cent in urban Orissa 18 per cent and West Bengal 9 per cent.

Prevalence and incidence of locomotor disability - a comparison between NSS 36th and 47th rounds

It is found that the prevalence rate had increased substantially over the decade 1981 and 1991 in both the rural and urban sectors. The incidence was more in the urban than in the rural areas. Further, the prevalence rate had increased for both the sexes over the decade. While, the increase in the rate among rural females was higher than among rural males, the picture was just the opposite in urban India.

On the other hand, the incidence rate, as whole, remained stable over the period 1981 and 1991. Also, the incidence rate had remained this same for both males and females in the rural areas.

In the urban areas, the rate among males had increased slightly; although, among females it had decreased marginally.

A SUMMARY OF THE REPORT ON THE SURVEY OF DISABLED PERSONS, 1981

During the International year of Disabled Persons (1981) the Ministry of Social Welfare, Government of India, took the initiative to survey the extent of disability in India. At the Ministry's request, the NSS Organisation conducted a country-wide sample survey on disabled persons to arrive at reasonably accurate estimates of the incidence and prevalence of disability in the country.

The NSS organisation collected information on certain types of physical disabilities, where disability was defined in a careful and graded by a group of experts so as to minimise investigator bias.

The survey covered almost the entire area of the country covering 5409 sample villages and 3652 Urban blocks. All the States and 5 Union Territories participated in the survey. The survey covered three types of disabilities - visual, communication and locomotor disabilities. Mental disability was specifically excluded from the survey.

The following definitions were adopted for the survey.

i) Visual Disability:

A person was treated to be visually disabled if he/she did not have light perception both eyes taken together or if he/she had light perception but could not correctly count the finger of a hand (with spectacles) from a distance of three mt. in good day light.

ii) Hearing Disability:

A person having one ear with normal hearing ability and the other was total loss of hearing ability, was treated as normal and not disabled. Hearing ability was judged without the use of hearing aids.

The following persons were classified as disabled:-

a) Those who cannot hear at all (not hearing loud sound such as thunder and under standing only gestures);

b) Those with profound hearing loss (hearing only loud sound such as thunder and understanding only gestures);

c) Those with severe hearing loss (hearing only words shouted at or hearing if the speaker is in front) and

d) Those with moderate hearing loss (having hearing disability to such an extent that they usually ask to repeat or like to sec the face of the speaker or feel difficulty in conducting telephone conversation or in hearing whispers).

iii) Speech Disability:

In addition to those who cannot speak at all, persons having the following defects were considered disabled:-

a) Speak Unintelligibly,

b) Stammering,

c) Speaking with abnormal voice and

d) Other speech defects (nasal voice and articulation defects).

iv) Locomotor disability:

By locomotor disability was meant an individual's inability to execute distinctive activities associated with moving both himself and objects from place to place. The loss on lack of normal ability of an individual associated with moving both himself and object from one place to another can occur due to

a) Paralysis of the limb or body,

b) Deformity of the limb,

c) Amputation,

d) Disfunction of joint or the limb and

e) deformity in the body other than in the limb (deformity in spine, deformity in the neck)

The hunch-back and dwarf were also included under locomotor disability.

The Prevalence Rate:

The number of persons having the disability per 1 lakh population.

The Incidence Rate:

The number of persons who became disabled during 365 days preceding the date of survey per 1 lakh population.

Overall Estimates:

The survey arrived at an estimate of 12 million persons having at least one or the other disabilities which constitute about 1.8% of the total population of 680 million. About 10% of these physically disabled are reported to have more than one type of physical disability. Considering each type of disability separately, those having locomotor disability constitute the maximum number (5.43 million) followed by those with visual disabilities (3.47 million) and hearing disabilities (3.02 million) and speech disabilities (1.75 million).

The distribution of the total disability by type of disability and by their rural, urban and sex wise break up is given in the table.

Incidence of Disability:

The survey also estimated the number of persons who became disabled during the year preceding the date of the survey as follows:

No of disabled (in 1000's) during the year preceding the date of Survey.

S.No.	Type of disability	Total	Rural	Urban
1.	Locomotor	366	279	87
2.	Visual	249	201	48
3.	Hearing	109	85	21
4.	Speech	25	18	7

Source : *Sarvekshena*, NSS, 1981, Government of India.

It may be seen from the above that the incidence of disability in the preceding year constituted 6.4%, 6.9%, 3.4%, 1.3% in the rural areas; and 8.0%, 8.5%, 3.9%, 1.8% in the urban areas respectively of the total prevalence of locomotor, visual, hearing and speech disabilities.

Congenital Cases:

The survey also has come up with separate prevalent rates in respect of congenital cases [disability from birth] for visual and communication disabilities. In respect of the visual disabilities, they constituted 5% and 8% respectively in the rural and urban areas of the total number of visually handicapped whereas in the case of hearing disability they constitute 30% in the rural and 28% in urban areas. For the speech disability, the corresponding proportion is 77% and 67% in the rural and urban areas. The proportion of congenital cases was seen to be less for all types of disabilities for female as compared to males, except for speech disability.

Age Group-wise distribution:

Generally the prevalence rate is seen to increase with the age and is maximum in the age group of 60 years and above for all types of disabilities, except in the case of speech disability. In speech disability the maximum rate was found in the age group

5 to 14 years. The rate however, shows a jump even from the age of 40 years and above. This finding gives a clue to the age group which needs special attention for the treatment of the disabled.

On-Set of Disability:

An overwhelming proportion of the disabled population in the age group of 60 years and above was found to have developed disability from the age 45 and above in respect of all disabilities, once again indicating the need to pay special attention to this population in the age group.

Visual disability

The prevalence rate for visual disability is estimated at 553 for the rural sector and 356 for the urban sector. The prevalence rates for men and women are 444 and 676 respectively in the rural area and 294 and 425 respectively in the urban sector. The Survey reveals a large variation over the States in the prevalence of visual disability among the population both in the rural and urban sector.

Applying these rates to the 1981 census, it is estimated that 11.93 lakhs men and 17.13 lakh women in the rural areas and 2.49 lakh men and 3.17 lakh women in the urban areas suffer from visual disabilities.

The following table gives the prevalence rate of visual disability by age group:

	0-4	5-14	15-39	40-59	60s Above	All ages
1. Rural	39	66	117	585	5863	553
2. Urban	25	87	117	385	4156	356

Source : *Sarvekshna*, Government of India, 1981.

The prevalence rises steadily with increasing age both in rural and urban areas. It is very high in the age group of 60 and above and not very significant in the younger age groups. The estimated prevalence of congenital blindness is given in the following table.

	Having light perception			Having no light perception		
	From Birth	Not From Birth	Total	From Birth	Not From Birth	Total
RURAL	8	325	333	22	197	219
URBAN	8	212	220	21	114	135

Source : *Sarvekshna*, Government of India, 1981.

Thus it is seen that only about 30 out of 553 visually handicapped persons suffer from the disability from birth in rural areas whereas the corresponding figure for the urban areas is 29 out of 335. Similarly in the age group 0-4 the number of visually handicapped is only 39 in rural areas and 25 in the urban areas.

For the country as a whole, the incidence rate of visual disability is estimated at 38 per one lakh population for the rural sector and 30 for the urban sector. The rate for rural males was 32 while that for the rural females was about 45. The rate for urban males was 23 and for urban females it was 38.

The incidence rates of visual disability in various age groups are given in the following table:

Age group (yrs)	M	F	Total	M	F	Total
(1)	(2)	(3)	(4)	(5)	(6)	(7)
0-4	6	13	9	5	3	4
5-14	4	1	3	2	3	2
15-39	3	4	4	6	2	4
40-59	32	49	41	31	58	43
60 & above	361	485	422	284	473	381
All Ages	32	45	38	23	38	30

Source : *Sarvekshna*, Government of India, 1981.

The incidence rate is very high for the age group of 60 years and above. Incidence among the other age groups is much less while the incidence among children aged 0-4 years is slightly higher than the incidence in the other age groups.

The age on-set of visual disability takes place predominantly after the age of 45. The following table gives the distribution per thousand persons aged 60 years and above by age groups at the on-set of the disability:

On-Set of disability having no light perception (Age-Years).

	0-4	5-14	15-29	30-44	45-59	60 & above	All ages
	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Rural	33	53	30	43	229	612	1000
Urban	29	45	24	47	253	602	1000

Source : *Sarvekshna*, Government of India, 1981.

The survey also conducted information on the probable causes of disability for those who are not born disabled. The following table given the distribution for one thousand persons by cause of disability:

	Cataract (1)	glaucoma (2)	Corneal opacity (3)	Others (4)	Not known (5)	All cases (6)
I. Having no light perception						
	(1)	(2)	(3)	(4)	(5)	(6)
Rural	198	78	152	36	536	1000
Urban	156	64	246	61	473	1000
II. Having light perception						
Rural	243	46	46	26	639	1000
Urban	285	59	40	35	581	1000

Source : *Sarvekshna*, Government of India, 1981.

The above table clearly indicates that about 54% of the people in the rural areas and 47% of the people in the urban areas did not know the cause of their disability. Out of the cases mentioned cataract, glaucoma, corneal opacity are the main ones both in the rural and urban areas.

At the all India level about 50% of the visually disabled in rural areas and 30% in the urban areas did not take any treatment for the disability. Of those who did not take any treatment, 50% reported that they could not take any treatment because of the expense and inconvenience. Between 20 to 30% of these respondents also felt that treatment was not necessary.

Hearing Disability

Children in the age group 0-4 were excluded from the purview of the survey on hearing disability because it was felt that the information amongst children of this age group would be incomplete and unreliable. Therefore the information on hearing disability contained in this chapter relates to all age groups excluding the age group 0-4.

The prevalence rate of hearing disability for the rural population is estimated at 553 for one lakh population as against 390 for the urban population. The rates for males and females were 595 and 510 respectively in the rural areas and 386 and 395 respectively in the urban areas. This is a large variation in the prevalence of hearing disability over the states in both rural and urban areas.

In comparison to the locomotor and visual disabilities, the prevalence rate for hearing disability from birth is high. About 188 persons and out of 553 in the rural areas and 108 out of 390 in the urban areas suffer from the disability from birth. There are large variations in the rates of hearing disability.

The following table gives the prevalence of hearing disability in various age groups:

	5-14	15-39	40-59	60s Above	All ages
Rural	314	518	614	2628	553
Urban	244	208	434	2366	390

Source : *Sarvekshna*, Government of India, 1981.

The prevalence rate rises with increase in age, the highest rate being registered for the age group 60 years and above.

The incidence rate of hearing disability is estimated at 19 for one lakh population for the rural Sector and at 15 for the urban sector. The incidence rates for the males and females are same in both the rural and urban areas of the country. The incidence rate are striking by high for the age a group of 60 years and above, than for the other age groups for both males and females and in both urban and rural sector.

The following table gives the incidence rates of hearing disability by sex and age for rural and urban sectors:

	Rural			Urban		
Age group yrs	male	Female	Total	Male	Female	Total
5-14	14	11	12	6	7	7
15-39	7	3	5	5	7	5
40-59	16	16	16	16	9	13
60 & above	135	135	135	147	122	134

Source : *Sarvekshna*, Government of India, 1981.

The on-set of hearing disability bears a close resemblance to the on-set of disability among the visually handicapped. At the all India level about 60% in the rural sector and 57% in the urban sector reported the on-set of disability at the age of 60 years and above. About 26% of the hearing disabled in the urban and rural areas reported the on-set of disability in the age group 45-59.

The following table indicates the major causes of hearing disability:

	Ear Discharge	Not known	Illness	German Measles	Others	Total
	(1)	(2)	(3)	(4)	(5)	(6)
Rural	174	528	215	6	77	1000
Urban	137	492	246	10	115	1000

Source : *Sarvekshna*, Government of India, 1981.

Ear discharge and illness, accounted for the bulk of the disability among the hearing handicapped. German measles is not a significant cause for the disability. About 53% in the rural sector and 49 percent in the urban sector did not know the cause of the disability.

Between 40-65% of the hearing disabled did not take any treatment. Of those who did not take any treatment, about 37% in the rural sector and 31% in the urban sector could not afford treatment; while 35% and 38% in the rural and urban sector did not consider treatment necessary.

Speech Disability

As in the case of hearing disability, the Survey did not cover children in the age group 0-4 years as it was felt that the information on prevalence of speech disability among this age group would be incomplete and unreliable. The estimated number of persons having speech disabilities for one lakh population aged 5 years and above in 304 in the rural sector and 279 in the urban sector. There is wide variation in the prevalence of speech disability across states for both rural and urban areas. For men the prevalence rate was 379 in the rural sector and 342 in the urban sector. For women the rates were 228 and 207 in the rural and urban sectors respectively. Speech disability from birth is considerably high. It was estimated at 234 for one lakh population in the rural areas and at 186 in the urban areas.

The distribution of speech disability in the various age groups in given in the following table:

	Persons				
	5-14	15-39	40-59	60 & above	All ages
Rural	411	274	220	285	304
Urban	429	236	166	282	279

Source : *Sarvekshna*, Government of India, 1981.

The prevalence is fairly high in the age group 5-14 yrs. The prevalence falls steadily over the age groups 15-39 yrs and 40-59 yrs and then rises slightly at ages 60 and above.

The incidence rate of speech disability was about 4-5 for one lakh population for both rural and urban sectors. The rate for males is about 6-7 in both in the sector is about 6-7 in both in the sectors for females was about 2 to 3. The incidence rate of speech disability by sex and age for rural and urban areas is given in the following table:

	Rural			Urban		
Age group	Male	Female	Total	Male	Female	Total
5-14	3	1	5	8	2	5
15-39	2	1	1	1	1	1
40-59	6	3	4	12	5	8
60 & above	17	10	13	45	12	28

Source : *Sarvekshna*, Government of India, 1981.

The age pattern of on-set of speech disability for rural and urban areas are similar. Nearly 50% of the disability are reported to have started at the age of 60 yrs and above and over 20% between the ages 45-59 yrs. The distribution pattern of the speech disabled by age at on-set of disability is given in the following table:-

Age (years) at on-set

	0-4	5-14	15-29	30-44	45-59	60 & above	Not known	All ages
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
Rural	55	59	33	48	223	475	107	1000
Urban	12	73	8	48	229	493	137	1000

Source : *Sarvekshna*, Government of India, 1981.

About 84% of those who suffer from speech disability are not aware of the cause. About 11% reported illness as the main cause. Voice disorders and cleft palate are responsible for a small percentage of speech disability (4%).

LOCOMOTOR DISABILITY

The number of persons having locomotor disability for one lakh population is estimated at 828 for the rural areas and at 679 for the urban areas. The rates for males and females in the rural areas is estimated at 1047 and 597 respectively, and in the urban areas at 800 and 544 respectively. A large variation in the prevalence of locomotor disability over the state is observed for both rural and urban areas of the country.

The prevalence rates for different types of locomotor disability that is paralysis, deformity of limb, amputation and disfunction of joints is presented in the following table:-

Persons

	Paralysis	Deformity of limbs	Amputation	disfunction of joints
	(1)	(2)	(3)	(4)
Rural	195	350	65	169
Urban	183	276	53	126

Source : *Sarvekshna*, Government of India, 1981.

Deformity of limbs followed by paralysis, disfunction of joint and amputation contribute to locomotor disabilities in that order.

The distribution of persons having locomotor disabilities in different age groups is given in the following table :-

Persons

	0-4	5-14	15-39	40-59	60 & above	All ages
	(1)	(2)	(3)	(4)	(5)	(6)
Rural	435	676	641	110	2617	828
Urban	540	718	482	730	2246	679

Source : *Sarvekshna*, Government of India, 1981.

The prevalence rate is substantially higher for the age group 60 and above than for the other age groups. In all the age groups both in urban and rural areas the prevalence is more or even less.

The incidence rate of locomotor disability was 53 for one lakh population in the rural areas and 54 in the urban areas. The incidence rate for males and females in the rural areas are 64 and 42 respectively while in urban areas it was 61 and 47 respectively. The incidence is substantially higher in the age group 60 and above and in the age group 0-4 compared to the incidence in the other age group.

The age patterns of the on-set of various locomotor disabilities in the rural and urban areas are given in the following table :-

	RURAL				URBAN			
Age (yrs) at on-set of disability	Paralysis	Deformity of limbs	amputation	Disfunction of joints	Paralysis	Deformity of limb	Amputation	disfunction of joints
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
0-4	46	56	7	8	27	72	27	9
5-14	29	93	31	19	20	63	42	17

15-29	15	78	95	33	12	48	134	22
30-44	49	144	238	53	35	77	332	56
45-59	279	283	272	268	277	259	260	262
60 & ABOVE	571	344	283	612	625	474	205	633
Not recorded	11	2	74	7	4	7	-	1
All ages	1000	1000	1000	1000	1000	1000	1000	1000

Source : *Sarvekshna*, Government of India, 1981.

About 55% of disabilities due to paralysis in the rural areas and 66% of the similar disabilities in the urban areas were attributed to cerebral palsy, polio, and stroke. Injuries, burns and polio were primary causes of deformity of limb in both rural and urban areas while injuries, burns and leprosy were the primary causes of amputation in both rural and urban areas. Slightly higher than 60% of disabilities due to disfunction of joints were attributed to injuries, burns and illness other than polio, leprosy and stroke in both rural and urban areas. It may also be noted that slightly lower that 30% of cases of disabilities due to paralysis and deformity of limb in the rural areas and slightly higher than 40% of similar disabilities in the urban areas were attributed to polio.

A large proportion of persons with locomotor disability received treatment, than persons with other disabilities. Only 30% in the rural areas and about 15% in the urban areas did not receive any treatment. Of those who did not receive treatment between 40 to 50% in the rural areas and about 30% in the urban areas considered the treatment expensive while 10 to 15% considered the treatment as not necessary.

ESTIMATED NUMBER (IN 00) OF DISABLED PERSONS BY TYPE OF DISABITY IN THE RURAL AND URBAN AREAS

TYPE OF DISABILITY	RURAL			URBAN		
	MALE	FEMALE	PERSONS	MALE	FEMALE	PEROSNS
(1)	(2)	(3)	(4)	(5)	(6)	(7)
physical disability	5496	4176	9672	1300	967	2267
visual disability	1193	1715	2908	249	317	566
with no light perception	443	706	1149	105	110	215
with light perception	747	1001	1748	144	206	350
hearing disability	1366	1111	2477	288	254	542
speech disability	870	486	1366	255	133	388
locomotor disability	2814	1528	4342	679	406	1085

It may be seen from the above that

i) Prevalence of disability was more in the rural areas (about 81%) than in the urban areas about (19%)

ii) that it is more among males (57%) than among females (43%)

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 VISUALLY DISABLED PERSONS BY CAUSE OF DISABILITY SEPARATELY FOR EACH TYPE OF VISUAL DISABILITY IN THE RURAL AND URBAN AREAS.

cause of disability	rural		urban	
	visual disability		visual disability	
	with no light perception	with light perception	with no light perception	with light perception
(1)	(2)	(3)	(4)	(5)
visual disability	86	115	28	48
hearing disability	46	39	10	21
speech disability	14	4	2	7
locomotor disability	172	107	35	87

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 VISUALLY DISABLED PERSONS BY TYPE OF TREATMENT TAKEN SEPARATELY FOR EACH TYPE OF VISUAL DISABILITY IN THE RURAL AND URBAN AREAS.

cause of disability	rural		urban	
	visual disability		visual disability	
	with no light perception	with light perception	with no light perception	with light perception
(1)	(2)	(3)	(4)	(5)
glasses only	11	43	8	78
medicine only	271	194	408	254
surgical operation	154	174	225	289
others	70	50	71	54
no treatment taken	494	539	288	325
total	1000	1000	1000	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 VISUALLY DISABLED PERSONS BY TYPE OF TREATMENT TAKEN SEPARATELY FOR EACH TYPE OF VISUAL DISABILITY IN THE RURAL AND URBAN AREAS.

cause of disability	rural		urban	
	visual disability		visual disability	
	with no light perception	with light perception	with no light perception	with light perception
(1)	(2)	(3)	(4)	(5)
place where treatment available not known	49	19	24	23
place of treatment known but treatment expensive	460	499	537	415
treatment not deemed to be necessary for:				
economic independence	163	173	106	166
personal independence	82	140	63	156
others reasons	246	169	270	240
all reasons	1000	1000	1000	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

PREVALENCE RATES (PER 1,00,000 AGED 5 YRS. & ABOVE POPULATION) OF COMMUNICATION DISABILITY BY SEX AND TYPE OF DISABILITY IN THE RURAL AND URBAN AREAS.

type of communi-cation disability	ural			urban		
	male	female	persons	male	female	persons
(1)	(2)	(3)	(4)	(5)	(6)	(7)
hearing	595	510	553	386	395	390
speech	379	228	304	342	207	237

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 DISABLED PERSONS AGED 5 YEARS AND ABOVE HAVING HEARING DISABILITY BY CAUSE OF DISABILITY IN THE RURAL AND URBAN AREAS

ares	cause of disability							all causes
	german measles	noise induced hearing loss	ear discharge	following			others and not known	
				illness	injury	medical and surgical intervention		
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
rural	6	23	174	215	40	14	528	1000
urban	10	30	137	246	55	30	30	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 DISABLED PERSONS AGED 5 YEARS AND ABOVE HAVING SPEECH DISABILITY BY CAUSE OF DISABILITY IN THE RURAL AND URBAN AREAS

ares	cause of disability						all causes
	voice dis-order	cleft palate	following			others and not known	
			illness	injury	medical and surgical intervention		
(1)	(2)	(3)	(5)	(6)	(7)	(8)	(9)
rural	6	23	215	40	14	528	1000
urban	10	30	246	55	30	30	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 DISABLED PERSONS (AGED 5 YEARS AND ABOVE) BY TYPE OF TREATMENT TAKEN FOR EACH TYPE OF COMMUNICATION DISABILITY IN THE RURAL AND URBAN AREA.

type of treatment	rural		urban	
	hearing disability	speech disability only	hearing disability	speech disability only
(1)	(2)	(3)	(4)	(5)
surgical operation	11	15	28	48
allopathic treatment other than surgical operation	337	287	488	384
others	69	53	65	75
no treatment taken	583	645	419	493
total	1000	1000	1000	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION FOR 1000 PERSONS (AGED 5 YEARS AND ABOVE) HAVING COMMUNICATION DISABILITY WHO TOOK NO TREATMENT BY TYPE OF DISABILITY AND REASON FOR TAKING NO TREATMENT FOR RURAL AND URBAN AREAS.

reason for taking no treatment	rural		urban	
	hearing disability	speech disability only	hearing disability	speech disability only
(1)	(2)	(3)	(4)	(5)
place where treatment available no known	92	160	51	152
treatment expensive	366	287	312	180
treatment not deemed to be necessary for				
economic independence	180	180	152	166
personal independence	168	177	229	299
others causes	194	196	256	203
total	1000	1000	1000	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 DISABLED PERSONS (AGED 5 YEARS AND ABOVE) WITH HEARING DISABILITY WHO WERE ADVISED HEARING AID BUT NOT ACQUIRED ANY HEARING AID BY REASONS FOR NOT ACQUIRING THE AID IN THE RURAL AND URBAN AREAS.

areas	reasons for not acquiring any hearing aid						percentage of persons with hearing disability who were advised aid out of those who took treatment
	aid not available	aid too expensive	aid not deeme to be necessary for		others	total	
			economic independece	personal independence			
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
rual	15	560	79	143	203	1000	10
urban	13	518	107	126	236	1000	13

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

PREVALENCE RATES (PER 100,000) OF LOCOMOTOR DISABILITY BY SEX AND TYPE IN THE RURAL AND URBAN AREAS

type oflocomotor disability	rural			urban		
	male	female	persons	male	female	persons
(1)	(2)	(3)	(4)	(5)	(6)	(7)
paralysis	246	141	195	214	149	183
deformity of limb	444	250	350	325	221	276
amputation	100	28	65	83	20	53
dysfuntion	200	137	169	136	115	126
at least one type[1]	1047	597	828	800	544	679

1including hunch-back, dwarf and types other than those shown in the table.

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 DISABLED PERSONS BY CAUSE OF DISABILITY SEPARATELY FOR EACH TYPE OF LOCOMOTOR DISABILITY IN THE RURAL AND URBAN AREAS.

cause of diability	rural				urban			
	paralysis	deformity of limb	amputa-tion	dysfunc-tion of joints	paralysis	deformity of limb	amputa-tion	dysfunction joints
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
cerebral palsy	152	26	--	--	99	32	--	--
following injuries and burns	21	267	219	423	20	223	276	416
following medical and surgical intervention	5	17	30	20	10	19	24	29
following illness:								
polio	277	291	--	80	436	434	--	120
leprosy	2	75	124	12	3	32	77	12
stroke	124	15	--	20	112	12	--	24
others	191	159	278	236	161	130	408	202
other causes	228	150	349	209	159	118	212	187
call causes	1000	1000	1000	1000	1000	1000	1000	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 DISABLED PERSONS BY TYPE OF TREASTMENT TAKEN SEPARATELY FOR SELECTED TYPES OF LOCOMOTOR DISABILITY IN THE RURAL AND URBAN AREAS

type of treatment	rural			urban		
	male	female	persons	male	female	persons
(1)	(2)	(3)	(4)	(5)	(6)	(7)
surgical operation only	11	26	33	19	41	63
physiotherapy/occupation therapy only	29	32	32	45	40	36
aid/application only	139	83	107	168	133	151
sugical operation and physiotherapy/occupation therapy	1	3	6	7	6	21
phgysiotherapy/occupation therapy and aid/appliance	1	4	7	6	8	11
surgical operation, physiotherapy/ occupation therpy and aid/applicance	1	2	1	7	7	6
other allopathic treatment	530	419	421	584	494	467
others	53	58	78	44	52	84
all types	770	629	686	894	786	845
no treatment	230	371	314	106	214	155
total	1000	1000	1000	1000	1000	1000

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

DISTRIBUTION OF 1000 DISABLED PERSONS WHO TOOK NO TREATMENT BY REASONS FOR TAKING NO TREATMENT SEPARTELY FOR SELECTED TYPES OF LOCOMOTOR DISABILITY IN THE RURAL AND URBAN AREAS.

reasons for taking no treatment	rural			urban		
	male	female	persons	male	female	persons
(1)	(2)	(3)	(4)	(5)	(6)	(7)
place where treatemtn available not known	82 (8.21)	119 (11.9)	62 (6.2%)	71 (7.1)	87 (8.7)	35 (3.5)
place known but treatment expensive	492 (49.2)	370 (37)	475 (47.5)	310 (31.0)	272 (27.2)	374 (37.4)
treatment not deemed to be necessary for:						
economic independence	132 (13.2)	126 (12.6)	155 (15.5)	79 (7.9)	103 (10.3)	199 (19.9)
personal independence	37 (3.7)	97 (9.7)	85 (8.5)	47 (4.7)	112 (11.2)	88 (8.8)
other reasons	187 (18.7)	216 (21.6)	149 (14.9)	266 (26.6)	298 (29.8)	259 (25.9)
treatment taken for other locomotor disability	70 (7.0)	72 (7.2)	74 (7.4)	227 (22.7)	128 (12.8)	126 (12.6)
all reasons	1000	1000	1000	1000	1000	1000

Note : Figure in brackets represent percentages

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

Estimated number (in '000) of disabled persons by type of disability and sex

All-India (in '000)

type of disability	rural			urban		
	male	female	persons	male	female	persons
(1)	(2)	(3)	(4)	(5)	(6)	(7)
Physical disability*	7442	5210	12652	2078	1424	3502
visual disability	1539	1796	3335	308	362	672
hearing disability (5 years and above)	1409	1164	2573	339	330	670
speech disability (5 years, and above)	942	557	1499	296	169	467
hearing and/orspeech disability (5 years and above)	2009	1490	3499	557	426	983
locomotor disability	4396	2411	6807	1370	762	2132
estd.(000) total persons (ba sed on 1991 Census Population)	326820	307537	634357	634357	117121	221761104 640

*at least one of (i) visual, (ii) hearing, (iii) speech and (iv) iccomotor disability.

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1991.

Table 2.1.1 : Number of disabled persons per 100,000 persons by sex

state/u.t.	rural			urben		
	male	female	perosn	male	female	persons
(1)	(2)	(3)	(4)	(5)	(6)	(7)
Andhra Pradesh	2640	2354	2498	2092	1712	1903
Assam	1408	947	1200	1390	948	1186
Bihar	1973	1125	1573	1740	1071	1436
Gujarat	1786	1557	1676	1720	1566	1648
Haryana	2290	1665	1988	1603	1105	1371
Himachal Pradesh	3580	2157	2870	1268	995	1144
Karnataka	2368	1891	2151	1662	1307	1494
Kerala	2280	1636	1945	1927	1587	1755
Madhya Pradesh	2281	1794	2051	1805	1113	1475
Maharashtra	2437	1927	2700	1787	1408	1610
Orissa	3191	2166	2306	2025	2077	2049
Punjab	3418	2384	2936	2025	1558	1807
Rajasthan	2141	1355	1767	1594	1168	1126
Tamil Nadu	2541	2201	2372	2075	1669	1874
Uttar Pradesh	2269	1441	1879	1779	1210	1519
West Bengal	2069	1484	1788	1690	1283	1505
All-India	2277	1694	1995	1774	1361	1579

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1991.

TABLE (2.PER 1000 DISTRIBUTION OF HOUSEHOLDS WEICE REPORTED AT LEAST ONE DISABLED PERSON BY NUMBER OF DISABLED PERSONS IN THE HOUSEHOLD AND AVERAGE HOUSEHOLD SIZE

state/u.t.	rural			average hh. size	p.c. of hhs. with at loast one disabled person	Urban			average hh. size	p.c. of hhs. with at least one disabled person
	number of disabled persons					no. of disabled persons				
	1	2	3 or more			1	2	3 or more		
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
Andhra Pradesh	914	81	5	4.9	9.96	922	69	8	5.3	7.67
Assam	951	47	2	5.6	5.61	972	25	3	6.0	4.86
Bihar	934	63	3	6.0	7.45	914	84	3	6.8	6.67
Gujarat	936	59	5	6.0	8.30	929	65	6	5.7	7.72
Haryana	900	97	4	6.7	9.73	915	71	4	5.5	5.78
Himachal Pradesh	892	105	3	6.3	13.62	917	79	4	4.8	3.98
Karnataka	923	70	7	6.1	10.06	929	63	4	6.1	6.38
Kerala	934	63	3	5.6	8.59	923	73	4	5.9	7.73
Madhya Pradesh	914	82	5	6.3	9.94	923	73	4	6.5	6.95
Maharashtra	901	95	4	5.6	9.64	919	75	6	5.4	6.81
Orissa	933	66	1	5.3	10.48	923	66	10	5.3	6.79
Punjab	882	113	4	6.3	13.95	913	82	5	5.6	6.63
Rajasthan	913	84	4	6.6	8.55	923	72	5	5.4	6.70
Tamil Nadu	913	83	5	4.5	9.09	926	70	4	5.0	7.12
Uttar pradesh	925	72	3	6.3	9.25	925	72	5	6.5	7.21
West Bengal	934	60	6	6.0	8.13	945	54	1	5.6	5.77
All-India	920	76	4	5.8	9.15	925	70	5	5.8	6.76

Source : National Sample Survey, Government of India, *Sarvekshana*, July-December 1981.

CHAPTER THREE

ROLE OF THE SERVICE SECTOR - GOVERNMENT AND NGOs IN PROMOTING WELFARE OF DISABLED AND REVIEW OF PLANNED DOCUMENTS

In this chapter an attempt will be made to trace the development of social services for handicapped persons by both voluntary and government agencies in this country. In this review we will be focusing from pre-independence period to the present in order to assess their contribution, of services provided and the social services. Review the functions they are performing currently in relation to what could ideally be their tasks, identify the areas where there are wide lacunae between needs and the services provided, and suggest directions in which they could move for more effective and comprehensive fulfilment of felt needs. The review of the planned documents have also been analysed.

From Charity to Rehabilitation

Voluntary effort in the course of the underprivileged, including the handicapped, (for the propose of this dissertation, the term "handicapped" will be used in a restricted sense to include the physically handicapped and the mentally deficient only. It will not cover the socially handicapped or any other group) began with a definite religious undertone, and religion has retained some of its motivating force, although several other motives have increasingly come into the picture. Beside Hinduism, with its castes and joint family systems, the other religious prevalent in India also enjoined upon their followers their duty towards their less fortunate brethren. Hence, temples and places of

pilgrimage, individual and community charity, have traditionally given succour and shelter to the poor and destitute, the sick and the disabled, the aged and the infirm.[1]

Throughout the Muslim world, giving alms to the disabled is a social obligation.

With the advent of British colonialism, Christian missionaries tried the other religious groups in starting services for the handicapped.

However, the emphasis earlier was on providing food, shelter and clothing to the needy, rather than on their rehabilitation. If we look at the history the traditional cultural concept of "Karma" encouraged the belief that an individual was disabled because he was paying for his past sins, and efforts to improve his lot would mean tinkering with divine justice.

In the 18th century, social consciousness and intellectual awakening in the wake of western influences and world economic changes led social reformers in India to think in terms of positive action for the welfare of the disabled. Towards the end of the 19th century, the first two voluntary bodies for the handicapped came into being.[2]

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1 Baig, Tara Ali, "Social Administration in Voluntary Social Welfare Agencies", Encyclopedia of social work in India, vol.II, Publications Division, Ministry of Information and Broadcasting, New Delhi 6, 1968, p.235.

2 Taylor, Dr. Wallace W. and Taylor, Dr. Isabelle W, Services for the Handicapped in India, International Society for Rehabilitation of the Disabled, New York: 1970. p.8.

Voluntary Institutions for Handicapped Persons During the Pre-Independence Period.

Sl. No.	State/City	Year of Establishment	No. of Institutions	Type of Institute
(1)	(2)	(3)	(4)	(5)
1	Madras	1853	1	Mentally Handicapped
2	Benares	1884	1	Blind
3	Lahore	1906	1	Blind
4	Madras	1850	1	Idiot "Asylum
5	Dhar in M.P.	1436-69	1	Mental" Hospital
6	Goa	1531	1	Mental Hospital
7	Agra near Secundra	1837-38	1	Lepers
8	Allahabad	1826	1	Blind
9	Almora	1875	1	'Lame', 'Blind' and 'indigent'
10	Amraoti (Seyderabad)	1882	1	Lepers/Blind poor
12	Amritsar	1861	1	"Idiot"
13	Benaras	1824	1	Blind
14	Dehradun	1903	1	Blind
15	Bombay	1866	1	Blind Ophthalmic Hospital

Source : Disability care and Education in 19th Century India: Some Dates, Places and Documentation. M.Miles.

In 1983, a school for deaf children was started at Bombay and in 1986, an institution for the adult blind came up at Amritsar. The Davil Sassoon Infirm Asylum founded in 1865, and other similar institutions, provided shelter to the infirm and crippled. But it was as late as the 1940s when the first organisations specifically meant

for the orthopaedically handicapped came into being. The T.K. Polio clinic at Ahmedabad in 1943, and the Society for the Rehabilitation of crippled children in Bombay, which founded the Children's orthopaedic Hospital in 1947.

Christian missionaries made the first organised effort to control leprosy by establishing a colony in Calcutta in the early 1900s.

An institution established in 1934 in Ranchi was the first to provide services for the mentally retarded, followed by the Home for mentally Deficient children started in Bombay by the Children's Aid Society in 9141.

A few scattered institutions for the handicapped, therefore existed well before Independence. But there was little involvement at the governmental level, and no particular policy or programme governed the country as a whole. Though there was no nationwide plan to provide disability services, the presidency governments gave financial aid and other assistance to institutions serving people with disabilities, from the early 19th century, onwards.[3]

State Initiative for Welfare of the Disabled

A planned approach on a rational and scientific basis for the welfare and rehabilitation of the handicapped did not emerge until 1945. Here again no government action concerning the services for the handicapped was taken until India became free.

Before 1947, only voluntary bodies had provided the basic services for the blind, the deaf and dumb, the orthopadically handicapped and the mentally retarded. After independence planned initiative for the disabled rested with ministry of social welfare.

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3 Miles. M., Disability Care and Education in 19th century India : Some Dates, Places and Documentation; Action aid Disability News, vol.5, no.2, Supplement, 1994

The programmes focused on schemes like scholarship, giving aids and appliance, without any major programmes for the disable.

The role of the education, health and labour ministries was much less. The education ministry contribution towards the disabled initially restricted itself to provision of scholarships. It is only during the eighties, after 1981 year of the disabled, that special education schemes were initiated. The ministry's role in prevention of disabilities was restricted to two programme viz. NBCP and later polio prevention under the UIP.

In the following section we undertake a detail review of government policy towards the welfare of disabled.

The first plan shifted emphasis from charity to rehabilitation.

In the second plan emphasis was laid on education and employment with programmes for scholarships for the handicapped students and a plan for setting up a chain of special employment exchanges for the disabled. Under the Third Plan, the state encouraged development of facilities for vocational training and expansion of employment opportunities for the disabled and better co-ordination between public and private organisations to promote there objectives. Though the emphasis tended to vary in the subsequent plans as well the only well-defined policy and plan of action for the disabled was only formulated only during the International Year of Disabled persons. (IYDP)

Today the situation is several times brighter that it was three decades ago, whether in terms of education, employment, or a more humane attitude towards the disabled, but their is hardly any room for complacency. The task ahead is stupendous and we require enormous resources and political will to carry out definite decisions which alone can put the handicapped alongside the rest of the community.

When India became independent, ambitious plans for a welfare state envisioned a primary role at the policy level for the government with a greater room for action by voluntary agencies. The magnitude of the task made it clear that voluntary effort alone could provide the quality and quantity of services needed for the gigantic task of the welfare and rehabilitation of the disabled. Thus began the close partnership between the government agencies and the voluntary agencies. Today there are several voluntary agencies getting assistance from government agencies and the Central Social Welfare Board (1953) in the various programmes for the handicapped.[4]

The formation of the Board in 1953 was a recognition of the fact that the voluntary organisations had come to stay in many ways. The voluntary agencies enjoyed the prerogative of a certain flexibility of action, willingness to experiment and a close personal touch with the clientele which government agencies do not have.

Most of the national voluntary organisations for the disabled have appeared relatively recently. Only one is century old. More than half have their headquarters in Delhi and the rest are located in Bombay, Calcutta and Madras.[5]

Much of the financial support for these voluntary organisations comes from a variety of sources like donations, membership of institutions, sales proceeds, government grants, international aid, fund raising campaigns, and affiliation fees from their branches.

There has been a shift in emphasis in the programmes of services offered by different voluntary agencies in the country. The change in emphasis has ben from :

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4 Chaturvedi, T.N. Administration For the Disabled : Policy and Organisational Issues, Indian Institute of Public Administration, New Delhi, 1981.

5 Ibid.

(a) Social reform to social welfare services;

(b) Institutional approach to community based welfare services;

(c) Special institutions and schools for the handicapped to integration in regular schools;

(d) Free services to the charging of token fees and

(e) curative and rehabilitative services to preventive services.

A review of the Planned Document reveal that the bulk of input for the disabled has been under the ministry of social welfare. The role of Health and Education is minimal and its only after 1981 (year of the disabled) does it gain any importance with these two ministries. The policy review indicates the separateness with which the issues of disability is handled in this country.

The First Five Year Plan devoted a whole chapter to Health which included family planning, but did not mention the issue of disability. The section on social welfare, does mention about rehabilitation of all "weak, handicapped". It stated that the total number of afflicted persons in India has hardly ever been correctly estimated. This is due to defective enumeration, lack of definitions, and the desire of persons to avoid publicity to their handicaps.

Education

In September 1955 the Ministry of Education constituted a National advisory council for the education of the handicapped. The factions of this council are to advise the central government on problems concerning the education, training and employment and the provision of social and cultural amenities for the physically and mentally

handicapped, to formulate new schemes and to provide liaison with voluntary organisations working in this field.

The watershed is 1981 - the year of the disabled

The past eight year have been important for the development of welfare services since they signified participation by the state not only in the sphere of statutory enactment but also in the organisation of basic services for education and rehabilitation of the handicapped and the extension of welfare services for women and children in rural areas.

Critique

1. No integrated effort has been made so far
2. Disability has been dealt only as a welfare service, instead of making an indepth study about the causes, prevention and treatment.
3. The magnitude of disability is still not known, correctly.
4. Assistance is given only in the form of scholarship and reservation. Disabled people as a potential labour force, is not recognised.
5. There is absence of statistics and lack of information.

Social welfare

During the past three decades of planned development, social welfare as a plan component has acquired great significance, as evidenced by its widening interface with Government and increasing participation by voluntary agencies. Up to the close of the Fourth Plan, most of the programme were curative or ameliorative in nature. From the Fifth Plan onwards, emphasis has been on the promotion of preventive and developmental services.

Greater attention was paid to the effective implementation of various education, training and to habilitation programmes for physically handicapped persons. The rates of scholarships to the handicapped were revised upward with effect from 1982-83 a new scheme of 'Assistance to disabled persons for fitting of aids and appliances' was introduced in 1981 on the occasion of the International Year of the Disabled for the economically weak disable person. In addition to the special employment exchanges for the handicapped, special cells were set up in the normal employment exchanges to facilitate proper placement of the handicapped.

Welfare of the handicapped: The main thrust in the programme for welfare of the handicapped will be on prevention of disabilities and development of functional skills among the handicapped. a large number of disabilities are preventable, if timely measures are taken in the areas of health and nutrition and accident prevention. Besides strengthening the activities of immunisation prophylaxis against diphtheria, whooping cough and tetanus, nutritional anaemia and blindness due to Vitamin 'A' deficiency and vaccination against polio and typhoid and the provision of nutritional supplements, education in health and nutrition will be given priority, but never received it. Suitable measures to prevent and control disabilities caused by accidents will be taken. A programme of mass education for early identification of disabilities and the symptoms causing them will be intensified.

Simple, durable and inexpensive aids and appliances would be made available to handicapped persons so that they can become functional and useful citizens. The National Institute for Rehabilitation, Training and Research (NIRTR), earlier known as National Institute of Prosthetic and Orthotic Training (NIPOT), will continue to conduct training

courses for prosthetic and orthotic technicians, multi rehabilitation assistants, doctors and other professionals. When awarding scholarships to handicapped persons, stress would be laid on vocational training, which has better employment potential training schemes would be so devised as to impart adequate vocational skills leading to employment in the open market or to self-employment. Sheltered workshops for the severely handicapped will seek to supplement those efforts. Suitable arrangements are envisaged for organising supply of raw materials and for marketing their products. Employment exchanges with registration of 150 or more handicapped person Incentives would continue to encourage disabled workers to improve their standard of performance to persuade employers to accept physically handicapped persons. The scheme of District Rehabilitation Centre (DRC), which aims at providing comprehensive and integrated care services to the handicapped individual from early childhood till he is rehabilitated in the community, is being taken up at present on a paid basis. Further expansion would be taken up after the programme is evaluated. Grants-in-aid will continue to be given to voluntary organisations for purchase of equipment and improvement of standards of services for the handicapped.

The activities of the four national institution for the handicapped, i.e, one each for the visually handicapped, orthopaedically handicapped, hearing handicapped and mentally handicapped, working in the field of training, research, vocational guidance and development of suitable service models for the disabled, would be strengthened, based on the latest research and developments taking place, both inside and outside the country. These institutes would continuously evaluate the existing technology and explore new methodologies for promoting the optimum utilisation of the capabilities of the

handicapped so that their occupational options are widened, with resultant improvement in their social independence.

Under 'Social Welfare' sector, preventive, development and rehabilitative services are provided to the socially and physically handicapped as well as to the vulnerable and weaker sections of the society. These services have developed gradually and the inputs increased steadily during the successive plan periods. In the First Five Year Plan, a provision of Rs.4.00 crores was made and the amount was placed at the disposal of the Central social Welfare Board, set up in 1953 for encouraging voluntary organisations, especially in the field of women and child welfare. It gave grants-in-aid and technical assistance to the voluntary organisation. It also started Welfare Extension Projects' for providing welfare services to women and children in rural areas.

The Second Plan with an approval outlay of Rs. 19 crores witnessed the participation of Central and State governments in addition to the activities of the Central social Welfare Board. The scope of social Welfare was widened so as to include and promote additional activities for welfare of women and children, like welfare of women and children like welfare extension projects in urban and border areas, condensed courses of education for adult women and socio-economic programme. For tackling the problem of juvenile delinquency, beggary and vagrancy and immoral traffic in girls and women, the Central Government sponsored various 'social defence' schemes and the State Governments were encouraged to implement them with necessary financial support. Special programme were introduced for the education, training and rehabilitation of the physically handicapped.

In the Third Plan, the State Government and the voluntary organisations were associated closely in drawing up the plan with an outlay of Rs.31 crores. While providing services, effort was directed in particular towards sections of the community which needed special care and protection. The object was to replace individual haphazard relief and charity by organised and sustained activity for education, welfare and rehabilitation with the general support of the community. The resources provided were utilised both for expanding the existing services and for assisting voluntary organisations to continue their activities. To this extent, development of new services tended to be limited.

The effort so far was mainly directed to the provision of some basic curative or ameliorative services. The preventive and developmental aspects which are more effective and economical in the long run did not receive adequate attention. The major thrust in the Fifth Plan with an outlay of Rs.83 crores was on the expansion of preventive and developmental programmes. During this period, child welfare was given the highest priority. To ensure healthy growth and development of children and reduce infant and maternal mortality rates, the scheme Integrated Child Development Services (ICDS) was launched on an experimental basis to provide a package services consisting of supplementary nutrition, immunisation, health check-up referral services, nutrition and health education and non-formal education to children in the age-group 0-6 and pregnant and nursing mothers in rural, urban and tribal areas.

In spite of these achievements, certain deficiencies in programme planning and implementation need to be remedied in order that the effectiveness of social welfare schemes can be enhanced. There has been a tendency to depend on schematic patterns in the implementation of the schemes by government or voluntary organisations leaving

little room for flexibility or ability to respond to the requirements and variations in local situations. The involvement of local community in planning and programming has been inadequate and their participation has been lack of integration of services at the beneficiaries level.

The development of welfare services between States has varied considerable and the backward States where the need is greater have suffered both from lower financial allocations and weak administrative machinery which have been further accentuated by frequent transfers at the policy-making levels. The field machinery for supervision has been weak. Absence of professionally trained manpower both at decision-making levels and supervisory levels has affected the quality of services.

Voluntary organisation have concentrated and developed only in some States and that, too, in selected areas within States for extending certain types of welfare services. The grant-in-aid programmes have not been able to promote and develop voluntary organisations in remote and backward areas with the result that the existing disparities have been aggravated and central funds have flowed more to areas already having strong administrative machinery and infrastructure to utilise machinery and infrastructure to utilise the funds. Women's organisations specially at the local level in rural areas have not been promoted.

While development of services for children have shown an increase, those for the physically handicapped have remained extremely inadequate and little has been done to bring the handicapped in the mainstream of national development through integrated programmes of educations.

The linkage of social welfare programmes with economic programmes has not materialised except in a very limited way and many economic projects have been launched, particularly in rural areas without proper consideration of the social impact or the social service needs of women and children. There is lack of coordination between the State Governments and the State Social Welfare Boards in programme planning and implementation. Such coordination has assumed urgency in view of the proposed expansion. Monitoring of programme performance of even the important schemes continues to be in terms of financial achievements rather than physical performance related to the objectives of the schemes.

Absence of statistics and lack of information about the performance of different schemes comes in the way of planning and implementation of welfare programmes. It would be necessary for the Departments of Social Welfare at the Centre and in the States to consider in detail how this weakness can be remedied. Research and survey of major social problems should be sponsored by organisations like the Social Science Research Council. The machinery for collection of statistics and for research needs to be improved and statistical cells established in the Central and State departments of social welfare and the Central and State Social Welfare Advisory Boards. It would be desirable to organise training and orientation courses for officers at various levels in collaboration with the existing social legislation is necessary to assesses to what extent the laws have functioned as instruments of directed social change and to identify the problems of their implementation. A detailed analysis of the level of development of welfare services, whether by Government or by voluntary organisation should be prepared in each State

at regular intervals and the gaps identified. The supervision of programmes at the field level should be effective in order to raise the standards of service.

Public opinion in favour of legislation for the disabled through publicity and propaganda is necessary. It is, therefore, proposed to assist voluntary organisations in this regard.

Programmes/Schemes for Disabled Across Plan Reviews

SOCIAL WELFARE	EDUCATION	HEALTH
District Rehabilitation Centre (DRC)	1995 Education for Handicapped	Prevention
Setting up of NGOs	Training	Nutrition
Scholarships	Employment exchange	Accident prevention
Aids and appliances	Cultural activities	Immunisation
Training	Scholarships	Vitamin Prophylaxis against whooping cough, diphtheria, tetanus, nutritional anaemia, blindness, polio, typhoid.
Placement cell	vocational training	
Sheltered workshop	NGOs for special education	Health education
Grant in Aids for supply of raw material		
Welfare Extension Projects for Women and Children		
Social defense scheme		

Source : Government of India, Plan Document of Various Years.

National Programme for Control of Blindness

This was the only programme dealing with disability control. The launching of the Trachoma Control Pilot Project in 1956 under the Indian Council of Medical Research was the first step taken in the direction of prevention of blindness in India.[6] The National Trachoma Programme was initiated in 1963 on the basis of experience gained in the pilot project.[7] Punjab, Haryana, Rajasthan, Uttar Pradesh and Karnataka were the states in which this programme was mainly implemented. It was implemented on a lesser scale in Madhya Pradesh, Bihar, and Jammu and Kashmir.

Activities of the Programme

The main activities of the programme was distribution of tetracyclines ophthalmic ointment and imparting of health education through specially trained para-medical trachoma workers located at Primary Health Centre (PHC).

The control strategy was revised in 1969-70 to integrate the programme with the general health services.[8] In areas which came under the malaria maintenance phase, the separate staff was withdrawn and the programme was carried on through basic health workers. In the rest of the affected areas, a health education assistant at the PHC level and a Health Education officer for each group of a PHCs at the district level was posted to assist the medical officers of the PHCs and the Chief Medical Officer of districts in carrying out the programme. Subsequently, except for Nagaland, Orissa, Sikkim, Tamil

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6 D. Banerjee, Health & Family Planning Services in India, Lok Paksh, 1985.

7 Government of India, Director General of Health Services, Health Statistics of India, 1982.

8 Government of India Directorate General of Health Services, 1961.

Nadu and West Bengal, all the states and union territories were covered by the National Trachoma Control Programme (NTCP), because in all of them trachoma was found to be highly endemic.

A sample survey carried by the ICMR at 7 centre in 1973 gives an estimate of about 9 million blind and 45 million persons with lesser degrees of visual impartment in India.[9]

According to this survey, the major cause of blindness in due to cataract.[55.0%]

Taking note of the findings of the survey, the central council of Health and Family welfare, meeting in 1975, recommended expansion of the National Trachoma control programme to include the following strategy for prevention and control of blindness.[10]

a) Dissemination of information about eye care with particular emphasis on ocular health of children, both pre school and school going, and all other valuable groups, through all media of mass communication.

b) Creation of awareness among teachers, social workers and students concerning eye-care, including the role of nutrition.

c) Argumentation of ophthalmic services by employing the "Extended Eye Camp" approach, so that treatment can be provided in the shortest possible time.

d) Establishment of a permanent infrastructure for community oriented eye health care at the peripheral, intermediate and central level.

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9 Government of India Directorate General of Health Services, 1981.

10 Government of India, Directorate General of Health Services, 1981.

In 1976, the National Trachoma Programme was renamed the National Programme for Prevention of Visual Impairment and Control of Blindness. Later in 1981 the name was again changed, this time to National Programme for Control of Blindness.[11]

In view of the National Programme for the Control of Blindness having been put under category No 1, and 100% control sponsored scheme, the National Committee recommended that a revised plan of action be drawn for quick implementation. The following is the summary of the draft proposals for the revised plan of action:-

1. For better implementation and better co-ordination of the programme between the states and the centre, it is proposed to create and strengthen ophthalmic cells of the states and at the Centre.

2.a) Decentralisation for the responsibilities & flexibility in the implementation of the National Programme at the state level under the overall guidelines prescribed by the National Committee.

b) This shall include the purchase of indigenous equipment, development, training and employment of staff, etc.

3.a) Supply of equipment at all levels to be regulated according to the needs and available manpower for its utilisation.

4.a) concerted efforts for the clearance of the backlog of cataract in the next 5 years.

b) Maximum utilisation for the existing manpower.

c) Suitable incentives for extension work in rural areas.

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11 Government of India, Directorate General of Health Services, 1981.

d) Involvement of the voluntary and non-governmental organisations for greater participation in the programme with liberal financial assistance.

5. A concerted effort to combat nutritional blindness due to infection particularly in the younger age group.

6. A concerted effort for early detection of visual defects and development of suitable treatment & referral system.

7. Development of intra-structure at Taluq and district hospitals and strengthening of the district set up for Ophthalmic care.

8. To experiment models for comprehensive eye care at district level.

9. Creation of a Central Ophthalmic instrument workshop for the servicing, maintenance and repairs and training of technicians therefor.

10. Creation of Central information cell for the proper monitoring and evaluation of the various activities under the programme.

11. To develop a calendar for the plan of action at various levels.

But the drawbacks are many.

1. It is a techno-centric approach

2. It concerns with the surgical aspect but there is no mention of rehabilitation. It is only interested in reducing number, being the major motive.

Policies and Issues Regarding the Universal Immunisation Programme (UIP)

The National Health Policy for India has given high priority to health care of women and children and has included immunisation as one of the priority programmes requiring special attention in the immediate context for enhancement of child survival.

Moreover, according to the policy statement, primary health care, including immunisation as one of its essential components, has been accepted as the strategy for achieving the policy goals.

Legitimisation for according such high priority was based on the morbidity, mortality and complications following vaccine preventable diseases (VPD) among children. In the absence of national epidemiological surveys conducted in the country on VPDs, the main source of information was reported data from various health institutions all over the country. In the memorandum of understanding of the government of India with UNICEF, the prevalent situation on VPDs was described as follows:

About two million children die or become disabled due to six VPDs annually. About 500 children are paralysed daily by poliomyelitis, 2,50,000 new born die annually of neonatal tetanus (NNT), 2,00,000 children die of measles, some 4,00,000 children die of tuberculosis and 1,50,000 die due to whooping cough. The aftermath of measles results in severed malnutrition, and bronchopneumonia. Tetanus also takes a heavy toll of lives in older children.

Prevention of the occurrence of vaccine preventable disease will not only reduce morbidity and mortality, but also prevent handicaps arising due to poliomyelitis. It has been reported that about 2/3 lameness amongst children is due to poliomyelitis.

The true picture of the magnitude of the problem due to 2 major VPDs, NNT and poliomyelitis was made available in India in 1981-82. Sample surveys conducted in 1981 ad 1982 in 11 States revealed the neonatal tetanus mortality rate to be 13.3/1000 live births in rural areas and 3.2 in urban areas. The incidence rate of paralytic poliomyelitis was estimated to be 1.6 and 1.7 per thousand children in the 0-4 year age group in urban

in urban and rural areas respectively. It is projected that in the absence of the Immunisation Programme, around 40 million cases with 1.5 million deaths occur due to VPDs annually.

Against the goals specified for immunisation coverage in the National Health Policy, EPI which was in operation since 1978 showed very slow progress, which clearly indicated the need for accelerating the pace for improving coverage with quality services. Recognition of the potential of immunisation as a cost effective technology for children survival had resulted in the extension of EPI with the aim for providing universal immunisation by 1990 under the UIP. Members of the Task Force constituted by Government of India under the chairmanship of Shri R.P.Kapoor, to prepare a plan of action to achieve the objectives of UIP, felt that successful implementation of the project will:

1. greatly reduce the morbidity and mortality among children and will enhance the child survival rate;
2. establish an active interaction between mothers and primary health care functionaries;
3. constitute an important step in journey towards health for all by 2000 AD; and
4. be the leading edge of primary health care and could be the entry point for a continuous system of delivery of a package of MCH services.

Policy planners believed that immunisation, prophylactic treatment against nutritional deficiencies and oral rehydration therapy against children diarrhoea, are the most simple, cost effective package of health services which will enhance child survival

and prevent avoidable disability long before significant improvement in the level of economic development could be achieved. The high priority accorded to the Immunisation Programme by the government of India is reflected in the fact that it has been included under one of the seven National Technology Missions.

In the final analysis, the objectives of the mission for the Universal Immunisation programme are to:

1. Reduce morbidity and mortality due to diphtheria, tetanus, poliomyelitis, tuberculosis, and measles among infants.
    a. Reduce mortality due to residual polio paralysis to less than 0.5 per 1,00,000 population;
    b. Reduce the neonatal tetanus mortality rate to less than 1 per 1000 live births.
2. Reduce mortality due to tetanus amongst pregnant women.
3. Achieve self-sufficiency in vaccine production.

Policy planners may display a great deal of confidence and make believe that the package is an 'opportunistic marvel'. Yet there are many issues raised by critics of the programme who question the wisdom in launching such a costly mega venture. They fear that the fanfare with which the programme has been launched may ultimately misfire. They feel that UIP like the Family Planning Programme is hijacking the space from various other programmes needing greater attention and high order of priority.

It has been argued by some that the premise on which the programme had been built is totally untenable. There is no epidemiological evidence to support the contention

that control of six vaccine preventable diseases will make any dent in infant mortality. Six VPDs form a very small proportion of diseases which cause death, illness and disability in children below five years of age.

Forgetting for a moment that the six VPDs pale into insignificance when looked at against the backdrop of total health problems viz. poverty, malnutrition, tuberculosis, leprosy, diarrhoea, dysentery, cholera, worm infestation, acute respiratory infection, anaemia, etc., the question has also been raised as to how and why immunisation is chosen as the most effective method in controlling the six VPDs. Knowing fully well that causation of disease is multifactorial, relying totally on one single tool to control the disease has not been accepted as a sound policy. For example, tuberculosis is best controlled by interrupting transmission in adults; yet, the government, instead of revamping the national tuberculosis control programme, is relying on B.C.G. vaccination which gives very little protection.

Various questions have been raised regarding the immunisation schedules recommended for India also. There is a feeling that a large number of issues related to the schedule of immunisation, doses, and type of vaccine should have been resolved before launching such a massive programme. Similarly, the number of doses of polio vaccine has also been under debate - whether it is enough to give there has been doubt expressed regarding the rationale of fixing of the age group for it is based on epidemiological observations or is it the acceptance of inability to cover all the preschool children and, therefore, the target group has been scaled down to one year.

Besides, several studies have shown that even with more than 85% coverage and vaccine efficacy of more than 95%, cases of poliomyelitis have still been occurring in

those areas. Many are, therefore, recommending that there is a need to revise the policy regarding expected coverage level and suggesting that it should be extended to 100%.

Another issue raised by many regarding the programme is that, apart from being a vertical programme, the total overall programme details including strategies, operational details, norms of resource allocation, etc. follow a uniform pattern throughout the country. No consideration has been given to epidemiological and ecological profiles, organisational and managerial capabilities and preparedness or limitations in terms of the general economic development status of different States. It is a well established fact that socio-economic variations between the States or even within the same State influence the implementation of the programme and achievement of results.

CHAPTER FOUR

CONTEMPORARY DEBATE AND EMERGING TRENDS: LIBERAL VIEW

The present chapter gives a descriptive and analytical review of the existing legislation concerning disabled persons in India. It tries to locate the various rights which existed for the disable in the pre-independent era and tracing it to the present, with the passage of the only bill for disabled in July'95

The world for, and of, the disabled is changing at a rapid pace and the aspirations as well as the expectations of people are also changing. Advances in medical and surgical sciences; breakthroughs in technology; greater understanding of the causes of disability and improved methods of coping with it, increasing consciousness of civil rights and the emergence of people with disabilities displaying skills and knowledge to improve their own lives are some of the factors which have contributed to the new thinking that, the disabled deserve a dignified status in society on the same terms as non-disabled.

The present chapter gives a descriptive and analytical review of the existing legislation concerning disabled persons in India.

In the process, some basic issues confronting the rehabilitation of the disabled are highlighted and a few suggestions made, considering their core needs.

For the disabled, among other things factors such as the levels of social development; economic advancement, concept of social security and social welfare policies, availability of voluntary agencies, and the economic and social problems and

priorities-all these considerably influence the enactment and implementation of the legal provisions in their favour.

Human rights movement has boldly shifted the attention from provision of charitable services to protecting their basic right to dignity and self-respect. In the new scenario, the disabled are viewed as individuals with a wide range of abilities and each one of them willing to utilise his potential and talents. Society, on the other hand, is seen a the real cause of the misery of people with disabilities since it continues to put numerous barriers as expressed in education, employment, architecture, transport, health and dozens of other activities.

In a country like India the numbers of the disabled is so high and resources so scarce and the attitudes so damaging, it is legislation which can bring about changes. Although legislation alone cannot radically change the fabric of society in a short span of time, it can, nevertheless, increase accessibility of the disabled to education and employment, to public building and shopping centres, to means of transport and communication. Impact of well-directed legislation in the long run would be profound.

Legislation in Post-Independence India

Until 1947 when India became politically independent, most of the approaches to wards the disabled adopted by the government were inspired by the concept of charity. Christian missionaries, and the wives of the rich and influential, were laying the foundation of voluntary work but the focus of all such activities was compassion for the unfortunate brothers and sisters. A legacy which stubbornly survives to this day.

It was the First Five-Year Plan that attempted to change the emphasis of programmers for the disabled from charity to rehabilitation. It stressed the importance

of education and employment. Later on, other Five-Year Plans encouraged the development of facilities for vocational training and job opportunities. The impact of this kind of thinking has remained somewhat subdued and low-key, largely because of scarcity of resources and the absence of official enforcing mechanisms.

Many schools and institutions throughout India for creating opportunities to educate the disabled and to provide for there employment and shelter emerged because of the voluntary sector and supported by the Central and States governments. The number of disabled persons benefitting from the sum total of such initiatives remained negligible when seen in the context of their total population. The emphasis in such initiatives was to provide relief. The policy makers and the social workers did not, until recently, realise that people with disabilities had the potential to be economically independent and earn a living. The private sector's record in this respect has been disappointing. The need to protect the rights of the disabled through suitable legislation gradually became clear and obvious.

The Constitution of India

The Indian Constitution had come into force in 1950. The first Prime Minister of India, Jawaharlal Nehru, a trained barrister declared that "the fundamental Rights should be looked upon not from the point of view of any particular difficulty of the movement but as something you wish to make permanent in the Constitution".

The constitution maintains a list of fundamental Rights and declares in its Preamble that "a civilised community has to behave in a civilized manner, not only among themselves but also towards others with when they come into contact." Civilised manner connotes certain norms, conventions and behaviour patterns. These Fundamental

Rights are for all citizens of India, but the disabled cannot claim some of these rights without the government introducing amendments to the Constitution:

* Right to Equality

(Articles 14-18)

* Rights to Freedom

(Articles 19 & 358)

* Right of Protection against Conviction

(Article 20)

* Right to Protection against Arrest and Detention

(Articles 22)

* Right to Protection against Exploitation

(Articles 23-24)

* Right to Freedom of Religion

(Article 25-28)

* Cultural & Educational Rights)

(Articles 29-30)

* Right to Constitutional Remedies

(Articles 32, 33, 359)

The Indian Constitution established the principle that people with disabilities are entitled to same social, economic and political rights and privileges as other citizens of India. It confers certain Fundamental Rights which can be enforced by the courts. It also lists Directive Principles for the State to follow and implement. The Constitution, barring

a few exceptions, did not make any specific legislative provisions about the rehabilitation and total integration of the disabled in society. The government's efforts to organise an accept able arrangement for social security of the disabled have been rudimentary and half-hearted.

The Quota System

The government had also made a provision for quota system for the education and employment of the disabled and as early as 1971 two per cent posts were reserved for people with disabilities. Enforcement of such a quota system has never been followed. As far as the private sector is concerned, there is no obligation for it to provide employment to people with disabilities. There have been limited opportunities for self-employment to people with disabilities. Even in the government sector the implementation of quota system has not been vigorously followed.

The Hindu Marriage Act of 1956, a giant legislative step in every ways, permitted mental illness or leprosy as sufficient grounds for obtaining divorce or separation because both these disabling conditions were regarded as incurable.

Travel concessions for those with severe activity restriction were also made available but, following medical definitions of disability, the procedures to obtain a certificate which entitled the disabled such concessions became too cumbersome because of the over-enthusiasm of bureaucracy to make savings for the government.

Anti-Discriminatory Legislation

Without defining untouchability, for it is meant to denote different practice in different parts of India, the Constitution has abolished it and discrimination on grounds of untouchability is forbidden. Those practising such discrimination are punishable in

accordance with law. Yet there is no law to protect the disabled against discrimination experienced by them in daily lives, although their rights are clearly established in the Constitution.

Earlier Efforts to Have a Law for the Disabled

The list of individuals, voluntary organisations, government officials and professionals, who had shown, during past 50 years, their profound concern at the failure of existing legislation to address all aspects of the lives of people with disabilities, is long and impressive. Each in his/her own way has attempted to make the world a better place for the disabled. Often without the facilities of modern technology, they created methods to educate the disabled; opportunities to find them employment and shelter; health facilities to prevent, identify, diagnose, treat and rehabilitate; They mounted publicity campaigns aimed at changing attitudes and actions considered harmful to the disabled.

An important milestone is the effort Mrs Indira Gandhi, as the Prime Minster of India, had made in 1971 to bring a comprehensive legislation in the fields of education, employment and social security.

The 1981 Draft Bill

The government had appointed a Committee to suggest and recommend measures for the security and rehabilitation of the disabled persons. The Draft Bill namely the Disabled Persons (Security and Rehabilitation) Bill 1981 was intended to provide security, employment, education, training and rehabilitation of the disabled persons and for "matters connected therewith or incidental thereto", It recommended the establishment of the central Council for the disabled to promote their welfare. It was further

recommended that under the Central Council there would be State Councils for the Disabled.

The Bill recommended reservation of not less that five per cent of posts for the disabled in all categories. The Central government was expected to appoint registering authorities for the purpose of registering disabled people for employment. Any disabled person with prescribed qualifications was eligible for registration. All employers were expected to maintain records of appointment of disabled persons and contravening of the Act in this regard was punishable with imprisonment and/or fine.

The State government was expected to make suitable arrangements for imparting free and compulsory education for all disabled children until they reached the sage of 16. Those refusing to admit disabled children for education on the ground of their disability were punishable with imprisonment and/or fine.

All institutions for the disabled were expected to obtain a licence from the government. The person or persons in charge of the care of the disabled had to ensure the well-being of disabled persons and to prevent physical pain, humiliation and mental suffering of the disabled in their care. The government was expected to maintain homes for the severely disabled but at the same time it had to provide advice and counselling to family members to support management of the disabled at home.

The Bill also recommended the appointment of a Chief Commissioner, supported by a team of commissioners, to coordinate all work of the disabled, keep an eye on utilisation of funds, to safeguard the interests of the disabled and to periodically report to the governments about the progress made. In addition to the above recommendation,

the Bill had worked out a system for funding the recommendations from the Central and State government annual budgets.

While going through the Draft Bill, the Ministry of Law, of Government of India make a specific comments on most of the provisions of the Bill, it only questioned the clause dealing with reservation of posts. It pointed out that the Parliament was not competent to enact a law relating to the State Public Services. In addition, Article 16 of the Constitution does not contemplate reservation of posts in favour of the disabled. Instructions and are not strictly in conformity with the provisions of Article 16. The Bill was never enacted by Parliament.

The Baharul Islam Committee

The Government of India kept receiving a number of representations regarding bringing out legislation for the handicapped. in November 1987 the government, with Mr. Rajiv Gandhi as its Prime Minister, appointed a Committee under the chairmanship of Mr Baharul Islam, MP, formerly a judge of Supreme court of India, to consider legislation for the handicapped, specially for their employment. The Committee submitted its report in June 1988 giving in detail the scope, objective and general scheme of legislation for the handicapped covering various aspects of prevention, rehabilitation, social security and welfare of the handicapped. The committee gave special attention to opportunities of employment for the disabled. For those who cannot be employed or self-employed, because of the nature and degree of disability, the committee felt that the law should provide them with a protective environment and thus eliminate their age-old exploitation and/or neglect by society.

Suggested Amendments to the Constitution

In order to make sure that there were no legal obstacles to the disabled enjoying the same rights as the non-disabled, the Committee recommended that amendments must be made in Articles 15(3), 15(4), 16(4), and 46. It was felt that suggested amendments would ensure equality of opportunity for the disabled with other citizens of India and no one would be discriminated against on the grounds of disability.

The enactment of the bill "Persons Disabilities, (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, marks an encouraging step in the dismal world of legislation for the disabled.

CHAPTER FIVE

DISCUSSION AND CONCLUSION

I wanted to research on the issue of disability for a very personal interest that began from my very childhood. I grew up in a family consisting of a visually impaired grandfather. His "separateness" in physical form was never felt by us because he was "normal" in every aspect, and led an independent life. It is attitude and accommodation which finally counts in dealing with disability.

In a country like India, the quantum of disability is quite high as shown by the NSS in their two rounds of survey between 1981 and 1991. The evidence from the International Year of Disabled Persons (IYDP) (1981) is that governments are seldom ignorant of the fact that disability is a **problem**, but they do not consider it a **high priority**, and this reflects the feeling of the general population as reported in the literature of at least 30 developing countries surveyed recently.[1]

A NSS of locomotor, visual hearing and speech disabilities in India discovered 1.8 per cent of the population having these disabilities. The WHO estimate of disabled people in India is estimated to about 10 per cent of the population, which figures as 90 million people.

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1 Miles, M., Attitudes Towards Persons with Disabilities Following IYDP (1981). Mental Health Centre, Mission Hospital Peshwar, for National Council of Social Welfare, Government of Pakistan, Islamabad, cited in M.Miles, 'Where there is no rehab plan,' Monograph, Peshwar, Pakistan: Mental Health Centre p.5, 1983.

International estimate of Disability

A lay survey in Venezuela discovered approximately one per cent of the population disabled.[2] A slightly lower percentage of 0.7 per cent is reported by a paediatrician during his informal but detailed study in Nepal.[3] An extensive "Key Informant" survey in Bangladesh produced a similar result 0.8 per cent of handicapped children,[4] and Rohert Serpell[5] gives a figure of 0.5 per cent for "easily identifiable" children with disabilities, based on Ministry of Education survey in Botswana.

Impairments of the mind, the senses, and the motor functioning of the body are universal. Everywhere there are people who must live with biological defects that cannot be cured and that inhibit, to some extent, their ability to perform certain functions. But the significance of a deficit always depends on more than its biological nature, it is shaped by the human nature, it is shaped by the human circumstances in which it exists.

A preliminary common sense definition of disability might be that it is a lack of limitation of competence. We usually think of disability in contrast to an ideal of normal capacity to perform particular activities and to play one's role in social life. Sickness also inhibits ability, but we distinguish between sickness, which is temporary (whether ended

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2 Hindley Smith R., A preliminary report on a Survey concerning the possibility of proving simplified rehabilitation service at the primary health care level in Latin America. The Disabled in Developing Countries, Occasional Papers no.XLI, The Commonwealth Foundation, London, 1976.

3 Richardson, S.A., Physical Impairment, Disability and Handicap in rural Nepal. Development Medicine and Child Neurology, 1983, 25, pp.717-726.

4 Ahmadullah Mia et al., Situation of Physically handicapped children in Bangladesh, a field survey, Institute of Social Welfare and Research, University of Dacca, 1979.

5 Serpell, R., Childhood disability in Botswana, A Report for UNICEF and the government of Botswana, 1982.

by healing or death), and disability, which is chronic. In principle, disabled people cannot be cured; they may be rehabilitated. Disability is used to refer to limitations resulting from dysfunction in individual bodies and mind. By metaphoric extension, we speak of social disabilities such as poverty or race. But the core meaning of disability for most of us is a "biopsychological" one. According to Susan Reynolds Whyte and Benedicte Ingstad, blindness, lameness, mental deficiency, chronic incapacitating illness - are" prototypical disabilities".[6]

The concept of disability needs to be located within the socio-economic matrix and what are the different theoretical approaches within which it is viewed. Our review shows that the dominant theoretical approach during this century has been the psychological which has focused largely on the 'normal' and 'abnormal' imagery. Disability within this approach is highly individual-centred, as a result, the emphasis is more on how the individual can be helped to adjust to the mainstream. Much of the social work practice with rehabilitation of the disabled has been from this perspective.

The socio-psychological approach as put forth by Goffman tends to locate the disabled individual within the context of society which generates the notion of stigma. The historical materialist model goes, even a step further and located disability and views on disability within the context of changing society. (Finklestein's work)

Given the dominance of the psychological and a socio-psychological approach the focus has largely been on individual, who is disabled and the problems he/she might face in adjustment to the norms of society. It does not address the links between the

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6 Benedicte Ingstad and Susan R.Whyte, Disability and Culture, University of California Press, 1995.

nature of society and position of disabled persons nor does it provide us insights into which classes do the disable belong to.

If the major paradigm is a psychological or a socio-psychological the clearly the nature of interventions also stem from it. One approach has been to medicalize disability and therefore divorce it from its social context. The cartesian approach where the emphasis is on correcting functional dysfunction.

The limitation of these approaches is clear, therefore the need for a more comprehensive approach is felt. Disability needs to be studied over time and in context, as a socially transforming and changing process, and as not a static characteristic of an individual, is stressed in the dissertation.

Therefore the need for a comprehensive approach to looking at disability is stated, which does not negate the importance of the individual. Disability is viewed within an interdisciplinary approach where the quantum, causes, distribution and treatment patterns are analysed in order to really have meaningful policy intervention.

India has made substantial improvements in the living conditions of her people since Independence. However, a vast number of them still remain impoverished at the lowest rungs. Variedly described as the "down-trodden", "the weaker sections", or in a rather tight economic terminology as the "people below the poverty line", this huge population comprises several layers and categories. Among these marginalised people, the handicapped constitute a sizeable sections. Extreme forms of poverty, and inability to participate in gainful economic activities, make them vulnerable to a grim situation of dependence on a society, which has not been prepared to shoulder such gigantic responsibilities.

Consequently, the handicapped are found as small clusters in every class of the wider social spectrum, and as a segregated community group, that bear untold sufferings.

There sustenance, overall rehabilitation, raising of their standard of living need a much larger resource base and support system, as well as a high degree of social awareness and concern.

As the National Sample Survey (NSS) in 1981 and a decade later in 1991, vividly point out the lacuna existing in the system. An analysis of the NSS data shows that in terms of numbers, locomotor disability figures first in the list. It affects the rural area more than the urban one. The major cause of it is due to polio. The National Programme that deals with its is the UIP, but after the onset of the disability there are no governmental programme for handling it. In a study conducted by Dr.Rama Baru[7] on rehabilitation of disabled children conducted in the urban slums of Visakhaptanam in Andhra Pradesh and other was located in a rural setting in Harayana, the study reveal that though the parents felt treatment was needed for their disabled child/children but were unable to take time off from work; since they were daily wage labourers. Taking their child to a hospital would mean a cut in that day's work. One of the worker remarked that "the choice is between feeding all my children or treating a lame child". It was clear that poor socio-economic conditions proved to be a major constraint on parental involvement in the programme, and, nearly 50 to 60 per cent of the identifyied cases dropped out.

The study revealed that although the civil hospital had two orthopaedic surgeons, they refused to perform correctional surgery. The district hospital did not have the

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7 Baru, R., 'Rehabilitation of Disabled Children: Lessons from Two Community Projects', Indian Journal of Social Work, vol.L, no.2, April 1989.

required specialists (Burrett,1987)[8]. Therefore, all the cases had to be referred to hospitals in Delhi, of which, Kalavati Saran Children's Hospital, All India Institute of Medical Science and Safdarjung Hospital were most frequented. Once again, many parents had to spend time and money to attend to their children.

The Thirty-Sixth round of the National Sample Survey, conducted during 1981, showed that a fairly large percentage of persons with communication, locomotor and visual disability in rural and urban areas did not take treatment because it was too expensive. In both rural and urban areas, only a small percentage of disabled people were not aware of the availability of treatment. Although specialist services in government hospitals are given free of cost, incidental expenses like transport costs, boarding, lodging and loss of daily wages, takes a toll on the family income. During 1981, the central government had introduced a scheme to distribute hearing aids and callipers, free of cost, to persons earning a monthly income of below Rs. 1000/-. However, there were a number of instances when specialists working in government hospitals would charge patients for the required aid even if they were entitled to it free of cost.

Thus, for many who came from rural areas, the process of assessment of treatment was often prolonged and expensive.

In an extensive survey of similar projects in Asia, Africa and Latin America, Miles[9] points out that many of them have been implemented from 'above' with little understanding of local needs and problems (Miles 1984). In addition, there has been little

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8 Burrent, G., 'Paralytic Poliomyelitis: A Tragedy on the Rise', Medico Friend Circle Bulletin, no.130.

9 Miles, M., Where there is no Rehab. Plan, Monograph, Peshawar, Pakistan Mental Health Centre.

effort to cooperate with and coordinate the existing structures like primary health centres, hospitals or community centres which could play a vital role in treatment, management and follow up service for disabled children.

The government has intervened only after the disability has set in, with no prior preventive measures. The "technological fix" approach seems to be the only solution so far. The only National Programme catering to the needs of the disabled in the nature of prevention is the Universal Immunisation Programme and the National Blindness Control Programme.

As has been stated these are vertical programmes which are not integrated and therefore lose a lot of validity in terms of implementation.

The whole question of access to treatment is a major problem. The issue of availability for treatment at the Primary Health Centre, exposes the working of the General Health Services. The infrastructural problem coupled with the general lack of concern poses formidable problems. Specialist services are located only at the District Hospital and Medical College Hospitals showing the urban bias.

Regarding education of disabled, as per the 1991 NSSO, 70 per cent of the physically disabled persons live in the rural area and 46 per cent in the urban area are illiterates; literates being those who could read and write a simple message with understanding. For the general population, illiteracy, as per 1991 census, is about 48 per cent. The gulf between the disabled and the non-disabled is obvious, only 4 per cent of the disabled in rural and 12 per cent in urban India have reported educational level as "secondly and above."

The infrastructure available for education in its present form would not be able to take care even of the annual addition to the educable age-group. Besides, standards of

teaching are generally low. One of the main reasons is lack of quality teachers. In order to attract them good salary scales and regular payment are a must. Most of the special school are run by NGOs with assistance from Central and State governments.

The grant-in-aid scheme of the Central and State Government should provide for regular disbursements of teacher's salaries at scales not inferior to those in ordinary schools. Special training should rather bring them better salary scales or additional special pay. These are lacking. The curriculum, too, needs to be given a fresh look. 'A plus' curriculum is a must which is generally absent in many of the schools. This results in children not being well prepared to meet the challenges of life on leaving such schools. Another great disadvantage of being in secluded and sheltered environment which may turn out to be a disadvantage in social adjustment later in life.

The National Policy on Education - 1989 which has a chapter an education of the handicapped, advocated the approach of providing integrated education. But this has not been effectively implemented.

Disability has not been viewed in a comprehensive manner. It is dealt by the Ministry of Social Welfare in absolute isolation with the Ministry of Health or the Ministry for Education. The issue of disability seems to be fragmented and divided into various sections in the ministry. The fragmented view of disability will give a fragmented policy. Therefore a careful blending of the Health Service with the Department of Social Welfare and Department of Education is very imperative.

The WHO introduced its Community Based Rehabilitation (CBR) scheme in 1976. Of late the scheme has achieved some publicity and generated a great deal of activity, but the question of practical results in terms of rehabilitating disabled persons remains moot.

Briefly, CBR is a systematised approach to helping disabled persons within their own community, making the best use of local resources, and helping the community become aware of their responsibilities. Responsibility is also given to the disabled themselves as they are part of the community.

Basic concepts of CBR

1. The service to disabled persons should reach them in their own communities.

2. The local community should, from the beginning, be involved in service delivery to disabled persons. The community should recognise the needs for becoming contributing members if the required opportunities are extended to them.

3. Stress should be laid on equal opportunities for disabled and non-disabled persons, depending on their aptitude, merit and training.

4. It should be made clear to disabled persons that they are being regarded both as recipients of service as well as contributors to community welfare.

5. Mainstreaming of all activities should occur so that the responsibility for disabled persons becomes a part of the community's responsibility for its members, regardless of disability.

6. Disabled persons must be encouraged to do maximum for themselves as well as other disabled persons and their families. In fact, where disability is concerned, they should play a leadership role.

7. Local resources should be tapped to a maximum. Specialised service or agencies extending services shall play only a supplementary role in the service-delivery mechanism and only when services are not available locally.

While the concept of CBR is positive - lack of integration between preventive, curative and rehabilitative services makes it ineffective.

The Concept of Activism as in Britain

If the disabled people could not get issues on to the political agenda through the normal process of political participation, then this raises the issue of the avenue of pressure-group activity.

From the mid-1960s onwards in Britain, it was clear that despite rising affluence, a numbers of groups were not sharing in the new material end social benefits that were being created, and that traditional political activity was not even getting these issues on to the political agenda. This resulted in the creation of new kinds of pressure groups who were likely to campaign around single issues of one kind or another. Groups like Shelter and the Child Poverty Action Group are examples of these, and specifically, in the area of disability, the Disablement Income Group is the most prominent example. The establishment of these groups was a reaction to what was perceived to be the fraudulent character of British democracy. There were of course special conditions which explained the new expression of protest. Public expectations has been running high. The policies of successive governments had been built to relatively full employment and steadily increasing national wealth. This meant that the views and interests of workers, pensioners and others were believed to weigh move heavily then they had done before the war in the conduct of national affairs... Some groups - like the elderly, one-parent families and sick and disabled people, were observed to have been left behind in the race for prosperity.[10]

The myriad of disability - specific programme and policies, the segregation of disabled people, the inability to gain access to organised society, to experience an integrated and adequate education, to obtain meaningful employment, and to socially interact and participate has resulted in a politically powerless and diffuse class of people who are unable to coalesce with other groups of disabled people on common issue, to vote, to be seen or heard. This class has accepted the stigma and caste of second hand

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10 Townsend, P., Democracy for the Poor, Forword in McCarthy, cited in M. Oliver's, The Politics of Disablement, Macmillian, London, 1994, p.104.

citizenship and the incorrect judgement of social inferiority.[11] In the Indian scenario too, activism would help to create consciousness among the people and help improve the life of disabled.

Keeping all this in mind, for a coherent intervention for the disabled, government and non-governmental agencies should work in tandem. The role played by the WHO and UN and a host of other agencies, is commendable. Much has been done though, yet, much more needs to be done. An assessment of the performance and the consequential shortfall in respect of this performance is to be made by the researchers only.

The instant piece of research is only to suggest the need for greater and more comprehensive research. The preliminary ground is traversed at the moment, for this is just the commencement of the journey. Milestones are beckoning us in the form of a challenge to the "incredible human capabilities". It is to be seen when and how we measure up to this task.

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11 Funk, R., Disability Rights: From Caste to Class in the Context of Civil Rights in Gartner and Joe (eds), cited in M. Oliver's, The Politics of Disablement, Macmillan, London 1994, p.102.

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