CHAPTER I

INTRODUCTION

1.1 The Disabled

The phenomenon of disability has agitated the minds of the people since the dawn of civilization. The term ‘disabled’ suggests a state of helplessness, something which falls short of the norm or standard, viz, physical fitness. Every individual suffers from some physical limitation or other, which renders him incapable of performing certain task. On the other hand there is no individual however severely disabled, who can not undertake some activities. It is often forgotten that despite his or her permanent disability such an individual still possesses residual resources which are intact, and capable of taking a fresh task. Infact ‘physical fitness’ itself is a relative term. It is the functional capacity of the individual for a task. It has no real meaning unless the task or the job, for which the fitness is to be judged, is specified. Generally the terms ‘disabled’ and ‘physically handicapped’ are used in an identical sense, but the expert interpretation of these are quite unique.
Defining disability is by no means an easy task. Many definitions have been advanced, founded on diverse values, and the theoretical underpinnings (Hahn, 1988:39-47). Traditionally, disability has been examined from medical clinical approach that focuses on functional impairments; or from psychological approach with its orientation on psychological disturbances; or from economic- vocational standpoint that stresses vocational limitations arising out of physical, mental or sensory impairments; or from system analysis approach which view the phenomenon of disability in systemic terms; or from minority group perspective, which seeks to justify analogies between the disabled and other minorities; or from human rights paradigm which views legal measures as constituting the fundamental framework by which mechanism for equality of opportunity can be ensured. (for details see chapter II)

1.2 Review of Literature

Here attempt has been made to review the relevant writings of recognized authorities and research studies conducted on the various aspects of disability in India as well as in other parts of the world to supplement this study. The following pages contain citation of information and studies related to the present research endeavour on disabled people.

The well known North America anthropologist Benedict undertook one of the first anthropological studies on ‘disability’. In her paper,
Anthropology and the Abnormal, published in the Journal of General Psychiatry in 1934, Benedict argues that rather than dealing with questions like why abnormalities occurred or how they could be treated, the whole notion of abnormality as a cultural phenomenon should instead be put under scrutiny (Benedict 1934: 59-80).

Several studies were made on the school children in different parts of India to assess their I.Q. level. Kamath (1938) studied 1074 children and adolescents from Bombay- Karnataka area and found that nearly 4 per cent of those studied had an I.Q. below 70. Ganguly (1962) while studying a selected sample of children from 39 Calcutta schools found that there are 70 ‘dull backward’ cases per thousand school children. Kuppusamy (1968) conducted a survey on the same line taking a carefully selected sample of 991 children going to the middle schools, and found that 1.4 per cent of them had an I.Q. below 70. A fairly large scale study was carried out on school children in the city of Nagpur by Verma (1968), and studied a total of 3114 students from the primary schools, 4554 from the middle schools, and 1338 from the high schools. Among these students the prevalence of mental retardation was found to be 1.70 per cent, 0.30 per cent, and 0.08 per cent in the primary, middle and high schools respectively.

Hanks and Hanks (1948), in their paper, The Physically Handicapped in Certain Non-Occidental Societies, sought to determine the social factors that influenced the status of persons with disabilities in Asian, traditional
North America, Pacific and African cultures (cited in Armstrong & Fitzgerald, 1996:253). Their methodological approach involved, what has been termed as 'armchair anthropology'; the tendency to seek some sort of general cultural interpretation through a comparative analysis of a range of ethnographic material provided by other field workers. Although, such comparative accounts provide important insight into the diversity of cultural attitudes, practices and values associated with various ‘disabilities’, the piecing together of ad-hoc reference from a diverse and often incompatible range of sources does not allow for a truly in-depth analysis of what it means to be ‘disabled’ within a specific culture. Nor do such accounts incorporate the full meaning of culture as an anthropological concept.

Despite the obvious potential, the impact of anthropological research on disability studies continues to remain relatively negligible. A small number of anthropologists have pursued an interest in disabilities since the late 1960s, but a very few have contributed a uniquely anthropological perspective to broaden the study of disability. The work of Murphy (1990: 131) is a significant exception in this regard. Through is autobiographical account of living with a deteriorating physical disability, Murphy contributed the anthropological concept of liminality to our social and cultural understanding of disability. Drawing on Gennep and Turner’s use of liminality as a term to describe the ‘betwixt and between’ status of
initiates during rituals, Murphy argued that people with disabilities experience a similar ambiguous and socially removed state. Some anthropologists have focused on particular type of disability, such as deafness, blindness, or intellectual impairment and sought to discover the social and cultural factors that influence the experience of being disabled in such ways, while others have attempted cross cultural analysis and used these to reflect on the diversity of cultural interpretations of disability and problems associated with universalizing western biomedical practices. Despite the slow but steady growth in ethnographic interpretations of disability, the potential impact of anthropological findings on debates within disability studies continues to remain somewhat limited. The first socio cultural attempt to understand and analyze the experiences of people with disabilities from their own perspective was undertaken by the North American anthropologist, Edgerton. Focusing specifically on the experiences of people with intellectual disabilities, Edgerton argued that despite the enormous amount of literature in this field, nearly all of it was from the perspective of social workers, psychiatrists and other medical specialists. He sought to counter these overtly quantitative and statistical accounts through his numerous socio-cultural studies that aimed to provide an insight into the reality of being intellectually disabled in a western culture (Edgerton, 1963: 372). However, Edgerton was primarily concerned with how mildly intellectually disabled people coped with life on ‘the outs’
(as life outside the institution was called), and how they adopted to living in the community. He tried to portray the interconnected effects of institutionalization, stigma, incompetence and labeling, and concluded that these deinstitutionalized people relied heavily on the support of 'non-retarded benefactors' in order to successfully cope with life outside the institution. Edgerton also gave the view that such people accumulated personal belongings to give the appearance of normality, invented biographies that hid their hospitalization, and often stated that unlike the severely intellectually disabled; they had been wrongly institutionalized and labelled as 'retarded'.

However, an interest in the role of cultural meanings in the anthropological study of intellectual disability was stimulated by the seminal work of Bogdan and Taylor. Like Edgerton, Bogdan and Taylor emphasized the usefulness of qualitative research methods; but whilst acknowledging the devastating stigma associated with being labelled intellectually disabled, Bogdan and Taylor did not accept Edgerton’s argument that this stigma was a result of being innately incompetent and retarded. In their book, *Inside Out: The Social Experience of Mental Retardation*, it has been claimed that the ‘scientific aura’ surrounding the term ‘mental retardation’ hides the ‘subjective moral and cultural value judgements’ associated with it. For them, the term ‘mental retardation’ tells us about society, and the methods by which people who do not fit the
increasingly complex demands of modern industrialization are perceived, categorized and administered (Bogdan and Taylor, 1982: 5-9).

Nagi (1965) tried to work out a way in which terms like impairment and disability as well as other nomenclatures are explained in such a manner that not only are the terms differentiated, but also can be put into a clear and coherent relationship with each other. Thus, Nagi makes a distinction between the following:

(a) Active pathology or disease processes;
(b) Impairment;
(c) Functional limitations;
(d) Sickness and illness;
(e) Disability.

Figure 1: Nagi's Conceptual Framework

![Diagram showing Nagi's Conceptual Framework]

Source: Cited in Kama, 2001:198
The Above figure indicates how the disease and disablement concept defined by Nagi can be linked together. The power of this scheme is indicated by its allowing the area of interest (covered by rehabilitation) to be elaborated with fair accuracy. In other words, rehabilitation procedures operate on most impairments (anatomical and physiological abnormalities), all functional limitations (limitations on the individual’s ability to perform his or her usual task and delegations) and all ‘illness’; which do not correspond to disability. Disability, sickness and illness are all patterns of ‘behaviour’, but only that of disability is consequent on impairments and functional limitations.

A survey carried out by Jordan (1968) to understand the social attitude towards disabled people in developed versus developing societies. The survey reveals that affluent societies have more positive attitude towards the physically disabled than that of the societies of poorer third world countries. However, the data provided by the survey do not yield sufficient information about the social processes involved in the integration or segregation of the disabled within their societies. A large scale community study done at Nagpur by Verma (1968) on mental retardation, where a sample of 30,326 individuals belonging to 4696 families were screened. The study showed that one out of every eight families studied, had a suspected case of mental retardation in it. In the age range of 8 to 15 years the prevalence of mental retardation was 4.20 per cent, while it was
1.60 per cent in the population between the ages of 16 to 22 years. Another similar study conducted by Gupta and Sethi (1970) at Lucknow, concluded that the overall prevalence of mental retardation in the community is 23.3 per thousand. This indicates that there are nearly 13 to 18 million individuals in India who are mentally retarded.

Anderson (1973) carried out an intensive study of ninety nine moderately or severely disabled children, who are being educated in ordinary primary schools. Interviews with parents and teachers were also carried out and a control group of ordinary class mates of the disabled children were also examined. Here the researcher tried to highlight the educational issues which are confronted by the disabled children, their families and the educational and social services which help them to cope with education and also with life. One of the great merits of the said study is that it recognizes that there is no one way to achieve integration. It presents in some detail many examples of different ways of solving the problems of providing adequate educational services in different contexts and using different resources.

Few studies have been undertaken in the sphere of employment of the blind persons in open industries. The study undertaken by the Blind Relief Association in 1975 to know the attitudes of the employers towards employability of the blind employees within their organization concludes that the blind either work equally or even more efficiently than their sighted
colleagues. Yet, the employers are reluctant to employ them. An attempt was made by Ramachandran and his colleagues to conduct a feasibility survey for the employment of the blind as physiotherapists. He concludes that the blind can successfully undertake this profession. Regarding adjustment of the blind in the society, Nagpal of Delhi university, as a part of his M.Ed. thesis, worked on this topic but her conclusion could not be considered as they are based only on 10 respondents.

Biswa (1980) studied the incidence of mental retardation in relation to the background factors like characteristics of parents, caste, community, occupation and income, sibling order, and other relevant factors of the family history of mentally retarded children. The study revealed that mental retardation is inversely related to socio-economic status of the children, marital relations of the parents are not healthy, mostly these children are unwanted and rejected by the parents, frequency of premature death of the parents are higher in case of retarded as compared to normal children and the retarded children mostly come from joint families where generally a healthy and happy atmosphere is wanting.

Zola, who himself suffers from physical disability lived for 10 months or so, in a Dutch village built for the physically disabled. Zola (1982) maintains that in the United States and in Holland physically disabled people are viewed as infants or children and are not granted the status of valid adults. He notes the difference pointed out by the disable in
the Dutch village between 'valid' people and 'invalids'. The study indicates that the availability of rehabilitation service and social programmes have not ensured the social integration of disabled adults even in western societies.

According to Fine and Asch (1988:3-12) there could be a set of common assumptions regarding the public perception of disability. These assumptions are; it is often assumed that disability is located solely in biology and thus disability is uncritically accepted as an independent variable. The disability and the disabled individuals are considered to be synonymous and the cause of other behaviour and attitudes. Secondly, whenever a disabled person is confronted with problems, it is taken for granted that the problems originate from his/her impairment. Thirdly, the disabled individual is visualized as a victim. Fourthly, disability is supposed to be linked with the disabled individual's self concept, self definition, social competition and reference group; and finally, disability is viewed as a synonym for needing help and social support.

Shankar (1991) studied the physically and mentally retarded children living in a number of residential institutions in an around Delhi. The data collected from few such institutions like children's home, jail, the centre for the deaf and dumb and the saket, the home for the physically disabled children and so also the orphans in some orphanages, revealed the various problems faced by the disabled children in their day to day life. A study
carried out by Annapurna (1997) on the problem of stressful effects on family in rearing and managing mentally disabled children. She did her study with a sample of 60 families from Chandragiri Mandal in Chittoor district. Information on family resources, coping, functioning, integration, burden, satisfaction and problem behaviour in children with mental retardation were treated as key ingredients for the study. The age group of children with mental retardation chosen for inclusion in the study was 6 to 18 years, which represents childhood, late childhood and adolescence. Interviews were carried out with 60 fathers, 60 mothers and 60 significant other persons in the family, predominantly grandparents and siblings. All these groups experienced burden on the family, perceived disruption in family functioning, lowered family satisfaction and perceived behaviour problems affecting family life.

Whyte has spent many years researching the meaning of disability within East African cultures, although in this particular example her focus is on the Nyole people of rural Uganda. Whyte emphasizes the connection between local notions of personhood, agency and self, arguing that interpretations of competency and sociality take on different forms in different cultures. Nuttall, on the hand, has studied the Inuit people of Greenland in order to disentangle the effects of non-indigenous models of intellectual incompetence on local Inuit models of personhood. Their elaborate social and moral codes, as well as their concept of personhood,
reflect this interdependent relationship, emphasizing the importance of a 
seal diet to physical and spiritual wellbeing, the skills as a hunter necessary 
to maintain such a diet and the knowledge of places and persons within 
their society is embedded. The Inuit emphasize continuity between the 
social, natural and supernatural worlds and whilst they recognize different 
levels of incompetence, do not exclude individuals on the basis of these. 
The emphasis on disability studies on the ‘disabled’ body in opposition to 
‘able-bodiedness’, and on disability as a physical and/or sensory rather 
than an intellectual experience, also has problematic implications for those 
whose impairments are intellectual. As Chappell (1998:212-216) argues, 
intellectually disabled people have been marginalized within the discourse 
of disability studies due to this emphasis on the body. It is, she claims, one 
of the consequences of including all forms of impairments within a singular 
analytical category as ‘disabled’. Rather than critiquing the social model in 
total, Chappell suggests that the particular experiences of intellectually 
disabled people should be included within this model of disability, along 
with all those other variables such as age, gender, ethnicity, class and 
sexuality which make the experience of disability diverse and specific.

Karna (2001) in his study has made a comprehensive examination of 
the problems of the disabled in historical, cultural, and political 
perspectives. He has gone in to each aspect of the problem to great depth. 
He has looked at the theoretical issues involved, the popular notions of
disability and disability and human rights. The study also tried to examine the movements for eradication of discrimination based upon disability through affirmative action etc. Krishna at al. (2001) explain the fact that one in every four families worldwide has a relative with disability or in other words more than 500 million persons; i.e. 10 per cent of the world’s population suffer from some type of disability. It also explains in detail the United Nations document viz, families and disability, human rights and disabled persons, and world programmes of action concerning disabled persons; and UNESCO’s legislation pertaining to special needs.

The study by Rao and Mohan (2003) on mentally disabled children in Dakshinya Institute for the Mentally Handicapped, Guntur, tried to focus on family history, motor problems, behaviour problems, assets problems of mentally disabled and programmes that are required for mentally retarded individuals. The study revealed that out of 110 mentally disabled children studied, 15 have family history of mental retardation. The boys and girls studied under this research were found to have 14 and 15 motor problems respectively. It is also brought to light that these individuals have 47 behaviour problems and 22 assets problems.

A study was carried out with a team of researchers headed by Klasing (2007) in a few villages in Rajasthan and Andhra Pradesh to understand the problems of the disabled people in rural India. Klasing reports that there are insurmountable physical and social barriers that the
people with disabilities confront in rural parts of our country. The research found a profound denial of schooling to children with disabilities. In Andhra Pradesh 62 per cent of the disabled respondents never been to school while the Rajasthan survey found that 53 per cent of the disabled were illiterate. In the same study it was also found that in Andhra 51 per cent of those who had disability and were of working age had absolutely no opportunity to works and were fully dependent on the members of their families; in Rajasthan the figure was 62 per cent. However, with few exceptions, they had uncertain low-end work, barely averaging 7 to 10 days a month with niggardly ways.

1.3 Objectives of the Study

The Study would aim to examine the following:

(i) To have an idea on the overall situation integral to the disabled in Assam with particular reference to Guwahati;

(ii) to categorize the disabled;

(iii) to know the perception of the disabled towards life;

(iv) to explore the hindrances faced by the disabled;

(v) to understand the role of parents/guardians towards the disabled;

(vi) to study the socio-economic conditions of the disabled for taking or non taking institutionalized education;

(vii) To know the activities undertaken by the voluntary organizations for
the welfare of the disabled;
(viii) to examine the problems faced by the voluntary organizations in carrying out welfare activities for the disabled;
(ix) to explore the views and opinions of the community members towards the disabled and the organizations working for the disabled,
(x) to understand the contributions made by the government for the upliftment of the disabled.

1.4 The Study Area

The study was conducted in the Guwahati city. Situated on the banks of the mighty Brahmaputra River, this fast growing metropolis of Assam is the gateway to the Northeast region of India. The city’s population break up is cosmopolitan in nature as people from the neighbouring states have also settled here (for details see chapter III).

Guwahati was considered for the study as most of the disability rehabilitation centers of Assam are situated here and within the city limits. The Composite Regional Centre (CRC), under the ministry of Social Justice and Empowerment, situated at the Guwahati Medical College Hospital, offers rehabilitation services to the persons with various disabilities. The Sishu Sarothi and Ashadeep are institutions run by non-governmental organizations, provide special education to the mentally retarded children along with rehabilitation and training to the children with
cerebral palsy and associated multiple disabilities. The Guwahati Blind High School, Bassistha is a government run institution and provides special education for the blind children from class I to the High School Leaving Certificate Examination conducted by the Board of Secondary Education, Assam. The Government B.D.S. Deaf and Dumb School, Kahilipara, is yet another pioneer institution providing education to the deaf from the preparatory class to the High School Leaving Certificate Examination. Apart from all these institutions, Director of Social Welfare, Government of Assam; All Assam Disabled Persons Association, Kamrup; Pragati a confederation of NGOs and thirteen other NGOs working in the disability sector in the city.

These institutions and organizations are providing their invaluable services not only to the disabled people in Assam but to the entire Northeast India. It is pertinent to note that apart from Assam, the other states of this region have either limited or no infrastructure at all to provide rehabilitation services to the persons with various disabilities. Another factor for the people from the entire Northeast region to bring their wards to Guwahati for various rehabilitation programmes, is the distance from their respective states, which is nearer to any other centre in India and also the quality of services provided by these city based institutions are as good if not better than the services provided by similar institutions in other parts of India.
It is important to mention here that the present research encompasses those disabled persons who are enrolled or in anyway associated with the rehabilitation centre considered for the study, as it is practically very difficult for the researcher to come in contact with numerous disabled persons living in all possible areas of the city. Moreover, the research includes only those disabilities for which there are specific institutions for education and rehabilitation programmes located in Guwahati city. Therefore, the persons who are blind, deaf, and mentally retarded have been included in this study.

1.5 Methodology

The investigator has adopted various methods and techniques used in Anthropology for collection of data. For the intended research, both qualitative and quantitative data have been collected depending on the methods used by different social scientists like observation method, survey method, interview method, case study method etc. Statistical data have also been collected by the investigator from the local NGOs working in this sector. The investigator intends to visualize the importance of the problem in Guwahati city. Some in-depth case studies and life history of the respondents were collected, mainly from the disabled persons, their parents/ guardians, family members and their teachers. Data has been collected from the local NGOs and institutions dealing with disabilities.
For the purpose of collecting secondary data, intensive library work has been done and collected data from various sources like books, dissertations, research journal, published and unpublished documents etc. Information on the various aspects of disability issue have been accessed from the District Library, Nabin Chandra Bardoloi Hall, National Institute of Public Cooperation and Child Development (Regional Centre, Guwahati), Assam Administrative Staff College, Suryakumar Bhuyan Library at Cotton College, K.K.Handique Library at Guwahati University etc. The internet has also been accessed to gather relevant information. Records of the NGOs, organizations within the vicinity of Guwahati city have been collected. Systematically arranged, tabulated and analyzed data so collected has helped not only in having a clear view on various aspects of disability but also the socio-cultural atmosphere of the study area.