A SITUATION ANALYSIS OF DISABILITY IN NEPAL

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BACKGROUND

Disability is present throughout the world, in all nations and all races. It is found not only in human beings but in animals as well. It is either congenital (from birth) or acquired due to accident or as the result of disease. It occurs in all ages from birth to old age. In fact, disability is a human reality. Disability is mentioned even in mythological and religious books.

According to Hindu mythology, the God Ganesh, Son of Lord Shiva, is an ideal example of disability and of corrective surgery. After the head of the God Ganesh was severed by his father for some misdeed, it was repaired by grafting the head of an elephant on his neck. Ganesh, with the elephant head, is a very highly revered god and is worshipped by millions of Hindus every day for success in their endeavours.

Disability in the past was taken as the punishment by a god for some sin committed in the past life. Several religious leaders and saints have possessed mystic and healing powers, which have led to the cure of disabilities.

In the past, medical science was insufficiently developed, so the people accepted disability as part of their fate and reconciled to live with it. Now, with the advancement in science, many disabilities can either be minimized or cured. "It has been observed that approximately fifty percent of disabilities are preventable" (Steward, 2001). Government and non-government organizations are trying to prevent available disabilities and use the slogan "Act today to prevent disability tomorrow" (Prasad, 2003). The prevention of disability has gained momentum more since the International Year of Disabled Person 1981.

There is an increase in the longevity of humans in almost all countries due to control and cure of infectious diseases by the use of antibiotics. The number of people of age 72 and above, are gradually increasing and those with disability have to bear their problems proportionately longer. In Nepal, the number of people of the age 80 and above were 3009,983, representing two percent of the total population in 1981. "In 2001, the number increased to 569,248 (2.45 percent). Naturally, the total number of people with disability of all ages has also increased" (CBS-NPC, 2001). Due to poverty and illiteracy, disabled people are leading a miserable life. In an economically weak and developing country like Nepal, disability management is a big problem. Social concept towards disabled persons has gradually changed. Members of society have become more sympathetic towards the cause of disability. His Majesty's Government (HMG) of Nepal is also more conscious about disability and is gradually taking steps to improve the disability situation.
DEFINITION OF DISABILITY

The words impairment, disability and handicapped are frequently used in connection with disability but they are not interchangeable. Somehow, people are not clear about their application. It would, therefore, be pertinent here to attempt to give appropriate definitions of these words in order to remove any misunderstandings that may otherwise arise in the minds of the people.

Impairment is a loss or abnormality of anatomical structure or psychological, physiological function.

"Disability is defined as any restriction or lack (as a result of any impairment) of ability to perform an activity in the manner or within the range considered normal for the human beings" (ed. Lennard J. Davis, 1997).

Handicapped implies a disadvantage for a given individual resulting from any impairment and disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors for the individual. An example will illustrate this point. A girl got a scar on her face as a result of an injury in early childhood. Such a scar did not immediately produce any disability at the time, but the moment she attained a marriageable age it turned into a handicap, as it came in the way of her being accepted.

There are three words frequently used in relation to disability: prevention, rehabilitation and equalization of opportunities. It would be appropriate to define these words as well.

Prevention means measures aimed at preventing the onset of physical, sensory or mental impairments (primary prevention) or preventing the progress of such impairment when it has occurred.

Rehabilitation means a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing him or her with tools to change or improve his or her own life. It can involve several measures intended to compensate for a loss of function or functional limitation (for example, by means of technical aid) and other measures, which facilitate social adjustment or readjustment.

Rehabilitation involves early detection, diagnosis and intervention (medical care and treatment) specialized education, training for self care, mobility, vocational training, employent, marriage etc.

Equalization of opportunities means the process through which the social system in general such as the physical and cultural environment, housing, transportation, social and health services, educational and work opportunities, cultural and social life including supports, recreational facilities, marriages, are made accessible to all including the disabled.

TYPES OF DISABILITY AND THEIR DEFINITION

There are several types of disabilities. Different countries have classified these disabilities in different ways depending on their economic, social and
cultural status. Economically developed countries have made the definition of disabilities more liberal. Developing countries, on the other hand, have made the definition less liberal. WHO has recommended various definitions, suggesting that countries can adopt any of these definitions for providing services to a disabled person.

There are several types of disabilities, but in Nepal, for the purpose of providing various services, HMG/N has officially recognized only five types of disabilities. These are:

i. Physical disability (Locomotors)

ii. Visual Disability
   a. Blind
   b. Visually impaired

iii. Mental Disability (Mental Retardation)

iv. Auditory Disability
   a. Deaf
   b. Hearing Impaired

v. Mental Disease (Mental illness)

I. PHYSICAL DISABILITY (LOCOMOTOR)

a. Blind: A person, who is either unable to count fingers shown from a distance of ten feet or is unable to read the first line of SNELLEN's Chart even after getting medical and surgical treatment for the eye disease or with the aid of corrective glasses, will be considered to be Blind.

b. Visually Impaired: A person, who is either unable to count fingers shown from a distance of 20 feet or is unable to read the fourth line of SNELLEN'S chart even after getting medical and surgical treatment for the eye disease or with the aid of corrective glasses, will be considered to be Visually Impaired.

II. MENTAL DISABILITY (MENTAL RETARDATION)

"A person, who before reaching the age of 18 is unable to perform work, consistent with the age or the environment, will be considered as Mentally Retarded" (AWMR, 1980).

III. AUDITORY DISABILITY

a. Deaf: A person, who is unable to hear a sound of 80 decibels (dB) or above, cannot speak clearly or cannot speak at all or can only communicate with sign language, will be considered Deaf.

b. Hearing Impaired: A person, who can hear a sound of intensity between 65 dB and 80 dB and above and cannot speak clearly or
has to use hearing aid for hearing speech, will be considered to be  
Hearing Impaired.

iv  MENTAL DISEASE (MENTAL ILLNESS)

A person, who due to mental weakness or abnormality from birth or 
caused as the result of accident or some disease, is unable to perform daily living 
activities will be termed as suffering from Mental Disease (Mental Illness).

CLASSIFICATION OF DISABILITY

i.  Severely Disabled: A person, who has lost both lower limbs or is unable 
to move the lower limbs, or has lost both upper limbs or is blind in both 
eyes, or is unable to work due to visual impairment, or has lost one 
lower limb or is unable to walk or needs wheel chair for mobility or is 
defeated or is hearing impaired or is mentally retarded will be called 
 Severely Disabled.

ii. Profoundly Disabled: A person, who is severely disabled and is unable 
to perform daily activities without continuous support of another person, 
will be called Profoundly Disabled

The types of disability, their definitions and classifications, as mentioned 
above, have been approved by the Ministry of Women, Children and Social 
Welfare (MoWCSW) and have been published in the Nepal Gazette.

DISABILITY CONCEPT IN NEPAL

EARLY PERIOD

In spite of the best possible efforts, no documents or evidence, such 
as stone inscriptions etc. have yet been found to authenticate the policies or 
programmes relating to the welfare of the disabled undertaken by any 
government in Nepal prior to 1968 A.D., when the Nepal Disabled and Blind 
Association were established. Nor were any fruitful results achieved from 
consultations with a number of eminent historians, archaeologists, teachers 
and social workers. Almost all the books, historical documents and stone or 
other inscriptions, available so far, have only mention about the political or 
religious activities undertaken.

In spite of this, we need not necessarily conclude that no such welfare 
works were rendered in that period.

Human beings are, by nature, humane and therefore kind and generous. 
They prefer to live in groups and communities helping each other. From the very 
beginning, they have been known to be aiding, according to their capacity, the 
poor, destitute, orphan, disabled, sick and other needy people. Although the world 
has now become very materialistic and self-centered, there are still generous and 
kindhearted persons who are inclined to help the needy in their communities. 
Their respective religions have also provided the much needed motivation and 
inspiration for them.
The people of the Kingdom of Nepal, too, are fortunate to obtain such inspiration from the respective religions they follow, such as Hinduism, Buddhism, Jainism and several others, which propagate teachings that philanthropic and charitable works lead them to salvation or moksha. It is generally believed that you will be a recipient of a happy or better life in your future birth in return for rendering social services for the benefit of the poor, sick, destitute, disabled, downtrodden and underprivileged or neglected members of the community. People, are, therefore, known to set up, from the very early days, public wells (Kuwa), stone taps (Dhunge dhara), resting places (Chautara), and guest houses (pati, paiwa, sattal and dharmashala) for the common use of pilgrims and travellers. They are known to establish charitable trusts called aushadhalayas (dispensaries): provide homes for children, managed under a unit known as orphanges (anathalaya): provide for the elderly citizens and managed under a unit called briddhashram (home for senior citizens): provide food and other essential items to the needy like pilgrims, mendicants, ascetics, disabled etc and managed under an arrangement known as sadabarta (chairity); manage charitable hostels like sanskrit pakshala (hostel for Sanskrit students offer free food and lodging): and impart education to children under the management of village schools (like pathashalas).

INSTITUTIONALIZED SOCIAL SERVICE

Similarly, several types of organizations or provisions are found to have been made many co-operative or welfare activities since time immemorial, and it is often difficult to trace dates or periods when such establishments or organizations came into being.

Such co-operative or welfare activities are in a way the institutionalized social services carried out under the foundations known as guthis or trusts supported by land grants put forth by the government or the people or groups involved.

The activities are aimed at supporting various kinds of social traditions or customs related to birth, marriage, death etc. or to community services such as religious functions, maintenance of public utility services or structures such as those mentioned above.

The Guthis or trusts under which these activities are managed are found to be of three types. The are raj guthi, chuut guthi and niji guthi. The Raj guthis is a national or official trust supported wholly by the state, generally meant to carry out religious functions. It is autonomous and managed under the strict supervision of the government. The Chuut guthi is a semi-autonomous or semi-official trust, managed under the rules laid down by the government. The niji guthi is a voluntary trust formed with an endowment made by private individuals, strictly for carrying out social activities, such as those mentioned above or for the care of shrines, temples, bridges, roads or utility provisions.
SOCIAL WORK FOR THE DISABLED PEOPLE BEFORE 1951
(BEFORE THE ADVENT OF DEMOCRACY)

In the early years of the Shah dynasty, when political stability was the concern of kings, the establishment of peace and security in the country were the priority of the government. Little was done to help the disabled. "But various types of Guthis—Raj Guthi, Chhut Guthi and Niji Guthi were already in existence as mentioned earlier. In addition to providing social and community services, they also provided welfare services to disabled people" (HMG/N, 1977).

During the 104 years of the Rana regime (1847-1951), which ended after the advent of democracy during the reign of His Majesty King Tribhuvan Bir Bikram Shah Dev all the powers of government were in the hands of Rana prime ministers. They were afraid of losing their powers, so an autocratic rule came to be established. They were scared of providing people with education for fear that the people, once educated, would become increasingly aware of their rights and responsibilities which might start a revolution. They were not in favour of allowing even social or religious organizations to be established in the country for fear that they might be instrumental in causing political awareness and mass agitation. Equally, they did not allow any meeting or gathering of people or even the founding of libraries and reading rooms. In 1931, a group of 46 people, including the poet laureate Laxmi Prasad Devkota, submitted a request for permission to open a library in Kathmandu for the use of the general public. All members of the group were penalized and made to pay a fine of Rs. 100 each.

However, during the reign of His Majesty King Tribhuvan Bir Bikram Shah Dev, two organizations for social services were established by two social workers, one in 1926 during the prime ministership of Chandra Shumsher Rana, by Tulasi Mehar Shrestha and later, the second by Daya Bir Singh Kansakar. Sri Tulsi Mehar, a staunch follower of Mahatma Gandhi of India, established a social organization called "Shree Chandra Kumdenu Charkha Pracharak Mahaguthi." The aim of these organizations was to train people to make hand-spun thread and hand-woven cotton clothes, to make themselves self-dependent and also to reduce the import of cloth from other countries. This was considered, by the Rana rulers, as the beginning of a social organization which might lead to a mass movement of the people. Tulasi Mehar was arrested in 1932 and sent to prison. Later, his release, he went to India. On his return from India, he established "Nepal Gandhi Ashram Nidhi." in 1951, soon after the dawn of democracy in Nepal. The main purpose of establishing this institution was to provide help to destitute people in their home and community based trade (Community Based Rehabilitation, CBR).

Later in 1972, the two above-mentioned institutions were merged into one which came to be called "Nepal Charkha Pracharak Gandhi Smarak Mahaguthi." This institution has today large assets, which are being used to operate various community development programmes, especially schools for needy and downtrodden children and institutions for socially exploited and destitute women.
These two serious attempts to initiate social services for the benefit of the people were suppressed and thwarted during the Rana regime. As a consequence, it became increasingly difficult for anyone to organize and establish even social institutions to help deliver welfare services to members of society. Those who dared to do so were made to suffer bitter consequences during the autocratic rule of the Ranas.

In 1947, a group of five people led by Daya Bir Singh Kansakar was fortunate to be permitted to establish an institution called "Paropakar Aushadhalaya" (Charitable Medical Trust). They were allowed to raise funds by installing donation boxes in appropriate public places. These donations were used for the purchase of medicines for the treatment of those who were sick but unable to afford the cost of medical treatment. This institution was registered under the Company Act of 1947.

CHANGE IN THE CONCEPT DISABILITY

"Disability has been seen as eccentric, therapeutically oriented, out-of-the-mainstream and certainly not representative of the human condition—nor as race, class, or gender seem representative of that condition" (CBS-NPC, 2001). In the course of the last 300 years the concept of society towards disabled persons has gradually changed. It has developed from neglect and hatred to charity-based welfare work.

The previous concept that disabled persons should change according to their environment is no longer valid. The new concept is that the environment should change in accordance with the needs of disabled persons. This is in line with the concept of equal opportunity for disabled persons in society.

In many ways, it reflects the general living conditions and social and economic status of the people. There are many specific circumstances like ignorance, neglect, superstition and fear, throughout the history of disability, that have isolated persons with different abilities and delayed their development. The paradigm has, now changed to inclusive, equality-based, barrier-free and right-based society for persons with disability.

Through education and rehabilitation, persons with different abilities have become more active and have turned into a driving force in the future development of the disabled population. Organizations (self-help organizations) of persons with disabilities and of their parents, families and advocates have been formed to advocate better conditions for disabled persons.

EXPECTATIONS OF DISABLED

In Nepal, a very large majority of disabled persons is drawn from economically weak communities who have not been so fortunate as to acquire education. Their contact with the outside world being limited, their aspirations are not high. Gradually, over the last two decades or so, mainly due to the growth of information technology, the availability of television, computers, radios and other means of mass communication, the disabled persons in Nepal are becoming acquainted with the facilities available to their counterparts in other countries. Due to financial and educational constraints their aspirations are very often
limited. Even then, they still expect to receive better education, job opportunities and better living conditions. Because they hail from the poor families, most of them desire to be economically rehabilitated in the society. They expect the following facilities to be made available to them in Nepal:

(A) **EDUCATION**

They want to receive good education, for which they expect the government to make arrangements for free education and provide educational materials free of cost, open more schools, either integrated/inclusive or special, for higher education.

(B) **VOCATIONAL TRAINING**

Persons with disabilities expect to obtain vocational training for skill development, which can help them to secure profitable jobs. They would like, at last, one centre for vocational training for the disabled in each of the five development regions in the country. It is important that after the completion of training, their qualifications should be recognized by the government, so that they may be able to get jobs in the government or in the private sector. One such vocational training centre in each district will help them to acquire skills and enable them to get settled in the society.

(C) **LEGISLATION**

The legislation for disabled persons, which was enacted in 1982 (BS 2039) but never implemented, has now become out of date. This should be amended or a new legislation be enacted. Persons with disabilities would like to have a new legislation, which will assure them of the rights and benefits that are enjoyed by disabled persons in other countries.

(D) **JOB RESERVATION**

By means of legislation, a certain percentage of jobs in the country must be reserved for persons with disability. Some of the blind and disabled persons have been employed but that is not enough.

(E) **JOB PLACEMENT**

The persons with disability feel that HMG/N has not taken any interest in creating jobs for them. They expect the social welfare council and the ministry to have a job placement cell with trained staff to arrange jobs for qualified and trained disabled persons.

(F) **LOAN REHABILITATION**

The majority of trained persons, who have developed skills for employment, are unable to start self-employment trades due to lack of finance. They expect the government to provide loans, at a nominal rate of interest, to enable them to launch their own trade or business.

(G) **EQUAL IN OPPORTUNITIES**

Disabled persons expect to have equal opportunities in all spheres of life, like any other person in the country. They expect that government and non-
government agencies do not discriminate against them, especially, on the basis of their disability.

(H) HOME FOR DISABLED PERSON

There are hundreds of thousands of disabled persons in the country who are profoundly disabled and who need constant help from another person for their daily activities. They need help even for taking food, sitting, walking and for using a toilet. For such person a Home for the Disabled is required in the country. In the legislation of 1982 for disabled persons, it is mentioned that one home for disabled persons may be established in each development region. But so far no action in this direction has been taken.

(I) DISABILITY ALLOWANCE

Persons with severe disabilities are often neglected both by the society and the families, because most of them hail from the lower economic strata. They face serious problems from the point of daily living. They must, in fairness, receive a disability allowance not only at the age of 16 but as soon as they become severely disabled.

Today, there is a radical change in the thinking. It is now felt that the presence of a large number of disabled persons is responsible for the poverty of the country. This change in thinking emerged because disabled persons cannot make their contributions to the developmental and economic activities in the country, and that has led to poor economic growth. Due to disability, not only the disabled persons themselves but also other members of their families are adversely affected and are unable to contribute effectively to the developmental activities of the nation. It is, therefore, important that a good national policy should be formulated for the management of the crises caused by disability.

WORKS CITED


