CHAPTER - I

INTRODUCTION

Throughout the history of mankind people with disabilities have been a part of society. From the earliest recorded history people with disabilities have been ostracized, rejected and discriminated against. The greatest constraints on people with disabilities are environmental and social (Mackelprang and Salsgiver, 1996).

Birth of a handicapped child has long-term implications for the family. His or her presence is likely to slow down the gradual process of adjustment of the family members to the newcomer (Wilken, 1979; Bowley and Gardner, 1980). The parents of the disabled children, instead of having their responsibility lessened as their children grow up, are faced with an indefinite period of child care. The family is faced with the burden of care and management beyond the period required by a normal child. Most often the family members feel in some measure a sense of blame. Feelings of guilt are very natural and fairly common in such cases, though usually quite unfounded. It seems something of a slur on the family names a stigma and an embarrassment to all concerned. Sometimes, though this is rare, the parents find it hard to love their disabled child fully and they feel resentful and hostile towards the world and anyone who tries to help.
The problem, which a disabled person faces, has to be viewed from the physical, psychological, sociological and emotional planes (Wright, 1960; Bhatt, 1963; Bhatnagar, 1990; and Barua, 1996). The problem of the physically handicapped individuals is not only a problem that concerns the affected individuals, but also a social problem affecting the whole of society. The fate of the physically handicapped individuals is considered to be one of life-long dependency, and despondency, misery and squalor. The physically handicapped individuals pose a challenge to society. The problems of the physically handicapped are not only those caused by the disability *per se* but also those of adjustment in a world whose apathetic or hostile attitudes towards them magnifies their troubles and threatens their very existence as human beings. They have to face the peculiar and irrational attitudes that society has always displayed towards the physically inferior in the form of pity, sympathy, curiosity, embarrassment, repugnance, fear, indifference and avoidance.

The right to see is one of the precious gifts of nature and the deprivation of sight is one of the worst disabilities a human being can suffer. This human tragedy is further compounded with the economic repercussions not only on the afflicted individual but also on the family and imposes a particularly heavy burden on the society at large (Agarwal, 1978; Menon, 1981; and Madan, 1989).
Magnitude of the Problem of Blindness in India

Of the estimated 30 million blind persons (Visual Acuity > 3/60) in the world, 6 million are in India, one out of every five blind persons in the world is an Indian. Two major surveys were conducted to find out the prevalence of blindness in India. The first survey was done by the Indian Council for Medical Research (I.C.M.R.) on a national sample in 1974 and arrived at a figure of 1.38 per cent prevalence rate for the economically blind. In the second and the latest National Programme for Control of Blindness (N.P.C.B.) World Health Organization Survey (W.H.O.) (1986-89), the prevalence rate increased to 1.49 per cent (Present status of National Programme for Control of Blindness, N.P.C.B. 1993).

Epidemiology

In India as per the national survey results, it is estimated that there are 12.5 million economically blind persons (Visual Acuity > 6/60), of the total 80.1 per cent are blind due to cataract. The distribution of the remaining is 7.35 per cent refractive errors, 4.69 per cent aphakic blind, 1.70 per cent glaucoma, 1.52 per cent corneal opacity, 0.30 per cent trachoma and the remaining 4.25 per cent suffer from other causes. Out of the total 12.5 million economically blind persons, about 10 million are blind due to cataract. Prevalence of blindness is high in the States of Jammu and Kashmir, Madhya Pradesh
and Rajasthan. In absolute terms, more than two-thirds of blind persons are in Andhra Pradesh, Bihar, Madhya Pradesh, Maharashtra, Rajasthan, Tamil Nadu and Uttar Pradesh (Present Status of National Programme for Control of Blindness, N.P.C.B. 1993).

The comparative statistics and findings of the two major surveys are presented in Table-1. (Limburg, 1994).

**TABLE - 1**

Comparative data of the two major surveys ICMR, 1971 and the WHO/NPCB 1986, regarding the causes of blindness in India

<table>
<thead>
<tr>
<th>Causes of blindness</th>
<th>ICMR 1971</th>
<th>WHO-NPCB 1986</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cataract</td>
<td>55</td>
<td>80.90</td>
</tr>
<tr>
<td>Refractive errors</td>
<td>--</td>
<td>7.35</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>0.5</td>
<td>1.70</td>
</tr>
<tr>
<td>Injuries</td>
<td>1.2</td>
<td>--</td>
</tr>
<tr>
<td>Malnutrition</td>
<td>2</td>
<td>--</td>
</tr>
<tr>
<td>Other infections</td>
<td>1.5</td>
<td>--</td>
</tr>
<tr>
<td>Corneal opacity</td>
<td>--</td>
<td>1.50</td>
</tr>
<tr>
<td>Trachoma</td>
<td>5</td>
<td>0.40</td>
</tr>
<tr>
<td>Small-pox</td>
<td>3</td>
<td>--</td>
</tr>
<tr>
<td>Other causes</td>
<td>18.3</td>
<td>8.20</td>
</tr>
</tbody>
</table>

While the other causes of blindness went down, blindness due to cataract increased from 55 per cent in 1971 to 80 per cent in 1986. 7.35 per cent refractive errors are also an important cause of blindness.
in India. The WHO-NPCB survey of 1986 indicates that blindness is more prevalent in rural areas than in urban areas, more occurrence in females than males, more amongst the poor than amongst the rich.

India has a load of more than 13 million blind persons out of which nearly 11 million are blind due to refractive errors (Sharma and Limburg, 1995).

The eyes are a wonderful creation of nature and a master-piece of perfection. Eye-sight is one of the most precious possessions of man. To lose vision -- total or partial is a tragedy. If a man loses a leg he can walk with an artificial one, but if he loses the sight of an eye, it is forever. Without sight the world around is a closed book. This makes the blind person a burden on the community. Eyes are affected due to many factors. Most common among them -- accidents, infections, nutritional deficiency, refractive errors, cataract, glaucoma and some other problems (National Programme for Control of Blindness - India - Primary Eye Care Guidelines, 1987).

Eyes are important to us. It is with eyes that we see and understand the world. Like other parts of the body, our eyes need nutrition for healthy development and maintenance of proper sight. Deficiency in vitamin A results in several defects of the eyes. One of the defects is a condition called night blindness. In India, about 30,000 children become blind every year due to vitamin A deficiency.
Prevalence of xerophthalmia due to vitamin A deficiency is mainly caused due to inadequate intake of vitamin A in Indian children. Even among pregnant women the dietary intake of vitamin A is very low combined with delayed supplementary feeding and repeated infections are responsible for the development of vitamin A deficiency in infants. Malnutrition is closely linked to a country's level of economic development. Malnutrition is intrinsically a global problem affecting the individuals, the family and the community. Malnutrition is a problem that defies immediate solution. It has many roots: inadequate food supply, limited purchasing power, poor health conditions and incomplete knowledge and ignorance about the value of nutrition in one's diet. A majority of the visually handicapped individuals belong to the low socio-economic strata and underprivileged sections of the social hierarchy (Mishra and Negi, 1990). Some of the developmental problems like overcrowding, lack of clean potable water, bad personal and environmental hygiene are the other contributory factors in addition to the two most common problems encountered in developing countries -- mainly poverty and ignorance and both of them have a direct bearing on the burden of blindness (Thylefors, 1983, 1987). Poverty and illiteracy are the two main barriers and obstacles in the improvement of health status of any given country. Poverty may sometimes be the reason for a family for not seeking early treatment for trachoma, or an elderly person's not having a cataract operated upon, but more often lack of information, awareness
and motivation are the underlying reasons. Seventy-five per cent of the blindnesses encountered in developing countries are either preventable or curable if only existing knowledge and technology could be systematically applied. There is a vicious circle of blindness and poverty in many developing countries.

The concept of "avoidable blindness" has gained increasing recognition in recent years. Prevention is far harder to practise than to preach. However, prevention is a neglected and seriously underused service (Brewer and Kaklin, 1979; and Bhatt, 1996). This neglect is costly both to the society and the handicapped youth and their families, not only in money, but also in the tragic fact that a large fraction of the handicap occurring in youth can be prevented. Prevention can be achieved directly as a direct result of improved services, such as early identification of the disorder and proper medical treatment.

Helen Keller, the world's famous blind citizen has said, "If one-tenth of the money we now spend to support unnecessary blindness were spent to prevent it, society would be the gainer in terms of cold economy, not to mention considerations of the happiness of humanity". Thus, the cost of human loss is enormous if it is compared to that of preventing it.

A visual handicap is a potential health hazard posing a grave threat to the well-being of the individual. Kool and Singh (1983)
noticed that a person suddenly blinded normally develops reactions such as protest against unfairness of visual loss, anxiety and depression. The individual experiences a threat to his identity and finds it difficult to go out alone, thereby feeling more isolated. Kool (1981) in an observational study, reported a set of neurotic reactions and fear in blind persons, such as inadequate expression of emotional response, tendency to avoid responsibilities and social relationships, high anxiety related to the stress caused by blindness, tendency to feel more concerned about the affection of others towards them, yet unable to enjoy deep affection towards others, failure to understand concern about deep social contacts. The visually handicapped individuals suffered from fear of being watched and they, therefore, felt insecure.

Verma (1971), Kalaiah (1973), and Woods (1975) reported behaviour disorders in visually handicapped adolescents. They were maladjusted in the areas of home, social, and environmental adjustment. Their difficulty in adjustment to the seeing world was caused by the attitudes of the sighted people towards them, and thus they became socially withdrawn. They often became remote and unresponsive to people generally. They exhibited severe temper tantrums and they became aggressive occasionally.

Bhatt (1963) studied the impact of physical disability on the individual and society. The observations made were that disability affects both the individual’s social standing and his domestic happiness.
Disability produces pronounced changes. He at once feels that he is cut off from the rest of the world. He feels threatened, lonely, insecure, alienated and isolated. The handicap renders him incapable of leading a normal life as it interferes with his well-being. He is unable to develop the necessary skills and abilities through which he is able to satisfy his basic and psychological needs and thereby achieve a degree of adjustment. He is unable to gain mastery and control over the environment and develop and nurture satisfying interpersonal relationships that are very vital for his well-being. The handicapped individuals run a risk as their handicap hampers and disturbs their functioning and this further leads to maladjustment in other areas of life.

In the present study an attempt has been made to systematically explore and evaluate the subjective well-being, self-esteem, self-competence and social support experiences of the visually handicapped individuals by studying in depth their experiences on all the dimensions of well-being, self-esteem, self-competence and social support and by comparing their experiences with the experiences of the normal sighted individuals on the same dimensions. The study of these experiences will give us the estimate and impact of the magnitude of the problems and difficulties faced by the visually handicapped individuals in comparison with normal sighted individuals. The results of the comparative data and feedback of both the sample groups help us to have a fully
integrated view of their subjective well-being, self-esteem, self-
competence and social support experiences.

The visually handicapped individuals are substantially
disadvantaged compared with normal sighted individuals in the
experience of happiness, health, self-esteem, life satisfaction and in
having adequate and reliable social contacts all of which form the
important determinants of well-being. Subjective well-being includes
happiness, morale, life satisfaction and positive affect (Diener, 1984;
Vinokur and Caplan, 1986, and Taylor and Brown, 1988). Well-being is
conceived of in terms of the person's emotional and role functioning
ability, that is the ability to handle interpersonal role relationships,
problems and associated emotions. Accurate perceptions of the self,
the world and the future are essential for mental health. The well-
adjusted person is thought to engage in accurate reality testing and
possesses a view of the self that includes an awareness and acceptance
of both positive and negative aspects of the self.

Well-being is related to all aspects of psychological growth of the
individual - physical, perception, language, skills, intelligence,
sociability and social sensitivity, emotional maturity, learning, enduring
aspects of personality and cultural values (Sinha, 1990). In traditional
Indian conceptualization of the state of well-being, mental health
appears to be regarded as an essential aspect of health. The concept of
mental health is closer to that of psycho-social well-being.

Another
concept which is relevant and integral to well-being is that of competence. It refers to the individual's capacity to control and master the environment. It is the skill to deal with the environment in such a way as to satisfy needs as well as maintain a state of balance or equilibrium with oneself and the environment. The experience of well-being bolsters and enhances confidence and faith in one's abilities and this experience promotes and fosters the feelings of self-competence and self-esteem.

Self-esteem is defined as positive image of oneself based on a fair appraisal of one's assets and liabilities. It represents a longitudinal as well as a transactional cognitive phenomenon. Muhlenkamp and Sayles (1986) suggested that both self-esteem and social support are positive indicators of life-styles. An essential component of self-esteem is the value one holds of oneself, it follows that those with more self-esteem would consider it worthwhile to enhance their status of health. High self-esteem is one of the strongest predictors of subjective well-being.

The term self-esteem denotes an intrapsychic structure -- an attitude about the self which is a straightforward idea (a global positive or negative attitude towards the self). Self-esteem is typically treated as a multidimensional variable referring to the individual's overall feelings and conceptions of himself in terms of various qualities and attributes (Gecas, 1971; and Baumeister, et al 1989).
Individuals with high self-esteem generally show greater self-confidence and an orientation towards self-enhancing self-presentation than individuals with low self-esteem who exhibit a self-protective orientation. High self-esteem is associated with adaptive functioning and greater personal contentment. Low self-esteem frequently accompanies psychological disorders such as anxiety and depression and may be a causative and maintaining factor (Rosenberg and Pearlin, 1978; Chrzanowski, 1981; Demo, 1985; Robson, 1988; and Campbell, et al., 1991).

The family is generally considered an important context for the development of a child's self-concept. It is the place where one's initial sense of self is formed through intimate, intensive and extensive interaction with parents and other family members. Supportive behaviour on the part of the parents communicates a positive evaluation to the child who in turn internalizes this evaluation of his or her worth (Gecas, 1971; Gecas and Schwalbe, 1986 and Whitbeck, et al 1991). Having close parent-child relations which convey affection, love, emotional-closeness, acceptance and support are likely to develop positive orientation towards the self which will enhance self-esteem. These experiences foster higher self-esteem, low anxiety and depression and promote psychological well-being in young adulthood (Roberts and Bengtson, 1993; 1996). Individuals with high self-esteem are likely to engage in careers and marriages that are more rewarding and less
stressful. Thus, the idea of the importance of self-esteem promoting a sense of well-being cannot be underestimated.

Social support is an important factor in the development and maintenance of mental health. Social support is usually defined as the existence or availability of people on whom one can rely. People who love us let us know that they care about, value and love us. Social support is conceptualized as the information leading the subject to believe that he is cared for, loved and esteemed as a member of a network of mutual obligation. Support is also defined as any action or behaviour that functions to assist the focal person in meeting his personal goals or in dealing with the demands of any particular situation. Social support is an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient (Cobb, 1976; Tolsdorf, 1976; Shumaker and Brownell, 1984; and Thoits, 1982). Individuals having higher levels of social support, with close social ties, being more trustful of others and being satisfied with social contacts and who feel they have higher levels of perceived control report higher levels of well-being (Hibbard, 1985; and Schulz and Decker, 1985). Sarason, et al. (1983) reported that people high in social support are more involved in present and future social relationships, they have positive self-concepts, they are low in anxiety and they have a belief in their own ability to control aspects of their environment. People who have
few social supports are dissatisfied with their state of affairs and they are more likely to be anxious as they are emotionally vulnerable and they are more pessimistic about the present and the future. Thus, individuals with strong social support should be better able to cope up with major life changes than those with little or no social support as they may be more vulnerable to life changes, particularly undesirable ones.

Family support is defined as a feeling that a person is cared for and valued by other family members and that he or she can fall back on the family network in difficult times. In behavioural terms family support refers to emotional, instrumental and financial assistance obtained from one’s own family. Lack of family-based social support makes one susceptible to psycho-pathology (Procidano and Heller, 1983 and Dalal, 1995).

Social bonds are postulated as necessary in themselves for mental health as the absence or disruption of social bonds in itself causes emotional distress (Henderson, 1977, 1980; Turner, 1981; Rook, 1984b). Most people require to maintain a minimum level of social interaction with others, and that below the level the risk increases for the emergence of a number of psychiatric disorders. Although the view that social bonds and supportive interactions are important to a person’s health and well-being seems to have been widely shared, only recently has hard evidence on the subject been developed and assembled.
The purpose of this study is to identify and locate the problem areas and focus on the shortcomings and hardships experienced by the visually handicapped individuals in comparison with the normal sighted individuals. Taking into consideration the hypotheses that the visually handicapped individuals are low in their experiences of subjective well-being, self-esteem and social support, a scientific effort in the form of intervention programme is required to help the visually handicapped individuals to enhance and elevate their status of subjective well-being, self-esteem, and social support. This intervention is possible with the aid of suitable counseling techniques which will encourage the visually handicapped individuals to improve and benefit their lives by helping them to become self-reliant, self-sufficient and self-adequate.