SURVEY OF LITERATURE
2. Survey of Literature

In this chapter the researcher thought that it would be more helpful to report the findings of scanning literature according to the following multifold approach, i.e,

1) A) Disability, handicap and Orthopaedical handicap or locomotor disability.  
   B) Prevalence of the incidence of handicap in the Indian Scenario.

2) Rehabilitation and the Indian scene.

3) Orthopaedically handicapped’s Adjustment and Well being:
   A) Theories of the impact of disability on adjustment.
   B) Lower limb amputation, its impact and
   C) Coping with amputation.

1. A) Disability, handicap and Orthopaedical handicap or locomotor disability.

Any sort of human disability is basically understood as an impairment of physical and mental function that interferes with the performance of activity of an individual within a given social and economic environment. The WHO [World Health Organization] has defined the terms ‘Impairment’, ‘Disability’ and ‘Handicap’ in 1980 through the publication of the International Classification of Impairment, Disability and Handicap (ICIDH) which is a manual of classification relating to consequences of disease and trauma.

Table 2.1.: The ICIDH Model [WHO 1980]

| Impairment: | Any loss or deviation of physiological or anatomical structure or junction of an organ or body part (organ and body dimension), a physiological disorder or injury; |
| Disability: | A disability reflects any limitation or lack of ability that a person experiences in performing an activity in the manner or within the range considered normal for a person, in other words, a limitation of learning, speaking, walking or some other activity (individual activity); |
| Handicap: | Loss or limitation of opportunities to take part in the life of the community on an equal level with others; an inability to accomplish something one might want to do. The term emphasize the focus on shortcomings in the environment and in many tasks and activities, example in education, occupation, information or communication (social dimension). |

Colloquially speaking “disability means something that incapacitates or disqualifies”. More specially disability refers to any limitation experienced by the impaired individual of similar age, sex and culture. It leads to a limitation of physical function whether orthopaedic, sensory or affecting any other specific organ. The effects of disability are seldom confined to particular pathological condition. In a majority of the cases they extend beyond it embracing the psychological, educational and vocational aspects as well. A demarkation is usually made between physical disability and mental disability. The present study is concerned with physical disability.

Physical disability, according to the department of social welfare, Government of India, includes impairments caused by congenital anomaly (e.g. clubfoot, absence of some parts of the body etc.), impairments caused by diseases (e.g. poliomyelitis, bone tuberculosis etc.), and impairment from other causes (e.g. cerebral palsy, amputation and fracture of bones etc.). Thus physical disability is not necessarily something that is physically imposed, recognized or caused, or only manifested physically or psychologically; nor is it a malformation or malfunction. It may refer to the variation in physique with which usually a highly negative connotative value is associated.

The word handicap is used to describe the disadvantages imposed by an impairment or disability upon a specific person in his cultural pattern, or in his psychological, physical, vocational and community activities. Thus, handicap may be conceived as a social condition imposed on the disabled individuals. This imposition has its roots in the negative value emanating from different sources such as imposed by the society, imposed by the person himself and imposed by a value that has important repercussions on the personality of the handicapped individual.

The disabled have to adjust themselves to their own disabilities as well as their uncongenial social surroundings. It appears that they are called upon to bear a double burden, psychosocial handicap in addition to their very own specific handicap (Sen, 1988).

The present study deals with orthopaedical handicap or locomotor disability caused by transtibial or transfemoral amputation generated by need for protection of lives of trauma victims. The researcher here further decided to restrict her study domain to the
lower limb amputees in between the ages of 16-22 years, i.e. the late adolescence and young adults whom she labeled as orthopaedically handicapped youths.

B) Prevalence of the incidence of orthopaedical handicap in the Indian Scenario
As regards to prevalence of the incidence of orthopaedical handicap, the main findings of the National Sample Survey Organization (NSSO) reported in 2003 December (the 58th round of survey) showed that number of disabled persons with loco motor disability was 483 per thousand disabled persons having other kinds of disabilities also. The report considers separately males and females in rural and urban areas.

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>2002 Numbers</th>
<th>% to all disabled</th>
<th>1991 Numbers</th>
<th>% to all disabled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual Blindness</td>
<td>2,013,400</td>
<td>10.88</td>
<td>N.A</td>
<td>N.A</td>
</tr>
<tr>
<td>Low Vision Both</td>
<td>813,300</td>
<td>4.39</td>
<td>N.A</td>
<td>N.A</td>
</tr>
<tr>
<td></td>
<td>2,826,700</td>
<td>15.28</td>
<td>4,005,000</td>
<td>24.79</td>
</tr>
<tr>
<td>Hearing</td>
<td>3,061,700</td>
<td>16.55</td>
<td>3,242,000</td>
<td>20.06</td>
</tr>
<tr>
<td>Speech</td>
<td>2,154,500</td>
<td>11.65</td>
<td>1,966,000</td>
<td>12.17</td>
</tr>
<tr>
<td>Locomotors</td>
<td>10,634,000</td>
<td>57.50</td>
<td>8,939,000</td>
<td>55.33</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>994,600</td>
<td>5.37</td>
<td>N.A</td>
<td>N.A</td>
</tr>
<tr>
<td></td>
<td>1,101,000</td>
<td>5.95</td>
<td>N.A</td>
<td>N.A</td>
</tr>
<tr>
<td>Mental Illness Both</td>
<td>2,095,600</td>
<td>11.33</td>
<td>N.A</td>
<td>N.A</td>
</tr>
<tr>
<td>All</td>
<td>18,491,000</td>
<td>100.00</td>
<td>16,154,000</td>
<td>100.00</td>
</tr>
</tbody>
</table>

[Source: NSSO Rounds 47th in 1991 and 58th in 2002]

Note: The percentages may not add up to 100% as multiple disabilities were also recorded for a large number of disabled persons.
Also referred to as orthopaedically handicapped, these persons have lost or lack the normal ability to execute distinctive activities associated with moving self and objects from one place to another. Loco motor impairment leads to substantial restriction of the movement of bones, joints or muscles and limbs. Some common conditions giving rise to locomotor disability could be poliomyelitis, cerebral palsy, amputation, injuries of spine, head, soft tissues, fractures, muscular dystrophies etc.

Loco motor impairments can be classified as: congenital and acquired. Congenital and developmental examples are cerebral palsy, meningocele, meningo myelocele, phocomelias and congenital dislocation of hips. The acquired loco motor impairments can be grouped into infective and traumatic. The infective may be due to tuberculosis of spine or other joints, chronic osteomyelitis, septic arthritis, acute poliomyelitis, G.B. syndrome, leprosy, encephalitis, AIDS etc, the traumas being accidents (traffic, domestic, industrial, agricultural, fall from heights, bullet injuries, explosion, violence, sports injuries), natural catastrophes like; earthquakes, floods, etc.*

While incidence of loco motor disabilities were reported to be lesser in West Bengal and other Eastern States of India as compared with other states, a reported decline in number was noted in 2002.

* From now onwards "orthopaedically handicapped", " locomotor disability" and " leg amputees" will be used interchangeably in this write-up.
According to the NSSO 58th round (2002), nearly 10.6 million persons constituting 57.50% of all the disabled population (18.49 million) in India were loco motor impaired. The reported loco motor impaired persons as per the NSSO survey have shown a significant increase from 8.93 million in 1991 to 10.6 million in 2002. The increase could be probably due to increase in traumatic impairments especially accidents due to increasing vehicular traffic movements, industrial accidents and other occupational hazard accidents. The proportion of loco motor disabled persons to all disabled persons has all marginally increased from 55.3% in 1991 to 57.50% in 2002. Of the total loco motor-impaired persons nearly 37.61% were females and the rest 62.39% were males in 2002. Gender variation in the loco motor impairment could be explained to the nature of work undertaken by the males, which have more potential of accidents. Hence loco motor impairment caused by occupational and traffic accidents are gender specific, particular more likely for males in India. (Refer Table no: II.2 and figure no: II.1)

<table>
<thead>
<tr>
<th>Locomotors Disability</th>
<th>2002</th>
<th>1991</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Rural</td>
<td>4998</td>
<td>2983</td>
</tr>
<tr>
<td>Urban</td>
<td>1635</td>
<td>1016</td>
</tr>
<tr>
<td>Both</td>
<td>6633</td>
<td>4000</td>
</tr>
</tbody>
</table>

[Source: NSSO Survey rounds 47th and 58th, 1991 and 2002.]

(Prevaleance rate is per 100,000 persons).

Loco motor Impaired Persons prevalence rate:*

The prevalence rate for the loco motor impaired persons (number of loco motor impaired persons per 100,000 persons) in India has marginally come down from 1074 to 1046 for rural areas and from 962 to 910 for urban areas during 1991 to 2002. The prevalence rates were substantially higher among the males as compared to the females both in rural and urban areas for 1991 and 2002. This indicates that gender

* The present study dealt with urban and suburban sample, not anyone from the villages.
specific vulnerability exists for locomotor impairment of males due to their nature of work activity, which increases their mobility over space and increases their chances of occupational and traffic accidents.

**Locomotor Impaired persons Inter-state prevalence rate:**
The prevalence rate of loco motor Impaired males has depicted marginal declining trends in majority of the states both in case of rural and urban areas during 1991-2002.

In the case of rural areas significant decline in 2002 as compared to 1991 was recorded for Andhra Pradesh, Karnataka, Chhattisgarh and Rajasthan. The prevalence rates among the loco motor impaired males in rural areas were lowest for Jharkhand, West Bengal and all Eastern states. Higher prevalence rates were recorded in Uttar Pradesh, Punjab and Himachal Pradesh. Medium level prevalence rates for male loco motor impaired persons among the rural areas were found in Kerala, Tamil Nadu, Gujarat, Maharashtra, Bihar, Uttarakand and Haryana.

In case of urban areas loco motor impaired males recorded declining trends for prevalence rates in Andhra Pradesh, Maharashtra, Punjab. The prevalence rates among loco motor impaired males were lowest in case of Karnataka, Andhra Pradesh, Orissa, Jharkhand, and all Eastern states. Uttar Pradesh and Kerala recorded highest prevalence rates for loco motor impaired males in urban areas.

The prevalence rates for loco motor impaired women has increased marginally during 1991 to 2002 in all the states uniformly. Loco motor impaired women recorded lower prevalence rates both for rural and urban areas in all states compared to male counterparts in 2002. Orissa was the only state that recorded higher prevalence rate for loco motor impaired women in 2002 as compared to 1991. All other states except for Punjab had prevalence rates of less than 1000 for loco motor impaired women. In the case of urban areas loco motor impaired women also recorded lower prevalence rates for all states except for Chattishgarh.

The most significant part of the report was that among the different types of disability the prevalence of loco motor disability was highest in the country. It was 1046 in the rural and 901 in the urban per 10,00000 persons. This was followed by visual
2.2. Rehabilitation and the Indian scene

Attempts to provide rehabilitation to the individual from all angles — i.e. support from every possible corner in the life of the disabled individuals (physical, psychological, social, economical, vocational, sexual, spiritual) is the essence of holistic rehabilitation.

The classification of functioning Disability and Health (ICF) (WHO, 2001) provide a standard language and a universal and globally accepted framework and classification that comprehensively addresses human experience in relation to functioning and health which is essential to understand before thinking about rehabilitation. Therefore, the First step, however, while providing rehabilitation to any kind of disabled individual is to understand nature of disability. Geertzen, (2008) mentioned that the ICF is the successor to the International Classification of Impairment, Disability and Handicap (ICIDH) (WHO, 1980).

The ICIDH was a result of the traditional medical model of thought. A disease or trauma leads to impairment and subsequently to disability and handicap. The disadvantage, however was that there was no causal relationship shown in this sequence. The diagnosis of the unwanted interference alone does not explain what patients can do, what their prognosis is and what their needs are. There was a requirement for a unified and standardized international language for describing and classifying health domains and health-related states. There was also a need to provide a common framework for health outcome measurement, for both individual, as well at population level. With respect to the patient the ICIDH was a negative model, whereas the ICF has a positive approach by classifying health by accounting for function. In short: there was a transition from the biomedical model (ICIDH) to a bio-psycho-social model (ICF).
Advantages of the ICF are, as mentioned, the common language (internationally), common terminology (in publications), and the possibility for data research and for benchmarking (code-system for information for insurance companies). An example of the common language of the ICF is, for instance, assessing the expectations of the patient and also of the rehabilitation team during the rehabilitation process. This is practical not only for goal setting but also for the reviewing and evaluation of the rehabilitation process and in setting renewed goals.

The ICF framework consists of three components: a) Body function and structures which refers to physiologic functions and anatomical parts. The loss or deviations from normal body function and structures are referred as impairments, b) activity which refers to task execution by the individual. Activity limitations are difficulties the individual may have in executing activities, and c) participation, refers to involvement in everyday situation. Participation restrictions are problems the individual may experience with such involvement. These three components are summarized under the umbrella terms: Functioning, Disability and Health. The three components are related to and may interact with the Health condition and to the Personal factors and Environmental factors (Fig.2.2)

Fig.2.2.: ICF Framework.

[ Source: World Health Organization, 2001]
Looking at the ICF-model one can see that there is a distinction between capacity and performance. Capacity is what one can do under the best circumstances. Performance is what one has to actually do in their day to day life. Performance includes the choices one make about what they do really and how they do it; and this performance might not equal capacity. This is the same for both disabled and non-disabled persons.

Pattston (2007) introduced a new language of Constructive Functional Diversity (CFD). The common trait of existing language in impairment and disability is negative and comparative; the focus of the new language is constructive when it is carefully considered and meant to be helpful. CFD has four core elements:

1) Modes—how human beings function
2) Outcomes — why they function
3) Value or desired state — the level of importance placed on function
4) Capacity (or actual state) — the level of ability to function.

He did not include sexual and cultural function as they involve all of the listed mode functions.

CFD outcomes move from a focus on ‘doing’ to a focus on ‘being’. According to Pattston all function is motivated by a desire to achieve a particular outcome, they being: task, job, occupation, role, meaning, and utility purpose.

Value or desired state and capacity or actual states are the dynamic, changing element of CFD. Value changes all the time for individual, groups, cultures and society, for both modes and outcomes. The match or mismatch in value and capacity would therefore determine the level of functional synergy. He proposed further that people with common function are more likely to have higher levels of function synergy than people with unique function because the capacity of common function matches the value of common function. For example, the ability to walk (CFD motor mode) matches the high value of walking. Again CFD questions the legitimacy of the value of function and its outcomes, including roles, as they are typically now held by individual and society. While capacity may be impossible, difficult or unreasonable to change, value is relatively abstract and variable and (can be changed and does change)
Survey of literature

quite fluidly in individuals and groups. Hence one can change functional synergy by individually or collectively deciding to value a mode or outcome of function differently. He noted that his proposition fundamentally has been different to the ideology of Social Role Valorization (SRV) formulated in 1983 by Wolfensberger. The latter suggested that “SRV suggests that...... it is most useful to seek positive valued roles for the devalued people and groups. Further it suggests that such role revalorization may be considerably more effective than other means of assisting people in devalued states. Consequently SRV suggests that enhancing competency and image (of the person and their surroundings) will result in positive roles being made a possibility for devalued people”.

Pattston while proposing the model of CFD opined that it has a potential to have several benefits in functional reconfiguration (i.e. rehabilitation) settings for both clients and professional (i) it can create the opportunity to people not to join the group of stigmatized people that they have feared so long (dysfunction phobia) .On the contrary it creates opportunity for a person with functional realignment (i.e. with acquired impairment) to perceive their situation from a position of value rather than stigma. (ii) Motivation is a highly complex process and some people demonstrate higher motivation than others to reconfigure function (rehabilitate) after a traumatic incident.

According to CFD model if someone has lost capacity to function in a mode or outcome area that they highly valued, the impact will be greater than if they placed low value on the functional area. If the person realizes it will be impossible to regain that capacity internally, and isn’t satisfied with the use of functional enhancements, this will affect motivation. The option for successful reconciliation, therefore are:

(a) to change the internal value placed on the affected area of function; and/or
(b) to raise the internal value in another area of function where capacity has been unaffected.

(iii) it was also suggested that CFD fosters client-centered practice i.e. clients can direct the reconfiguration (i.e. rehabilitation) process by exploring a dynamic landscape of functional modes, outcomes, value and capacity (internal and external). There can be a choice whether measurement or interpretation are determined subjectively (by the client) or objectively (by the professional) as this is a new
proposition. Pattston himself have suggested some very wise research options as well as opportunities.

To the present investigator Pattston’s model and approach appear to be highly promising and beneficial for awkward trauma victims, like the lower limb amputee victims after an accident. However, it seems that it is yet to receive recognition and being used in its full form in more advanced countries.*

In India, especially in the eastern region, the issue of holistic rehabilitation is a far cry. Here, vocational rehabilitation seems to be only considerable idea. But even successful vocational rehabilitation presupposes the notion of holistic rehabilitation. Vocational rehabilitation is by definition a multidisciplinary intervention in a process linked to the facilitation of return to work or to the prevention of loss of the work. Clinical staff (general practitioner, specialized physician) in contact with a person who has lost his job or who is yet to decide about it in life must promote vocational rehabilitation. Medical rehabilitation for those with disabilities, whether new or old, has to be followed without delay by vocational rehabilitation. It is even better if these two intertwined processes are overlapping. They involve many professionals including physiotherapists, occupational therapists, psychologist, vocational trainers, job counselors, teachers, case-managers, job placement agencies. Reality lies here far beyond this truth.

It is a generally shared opinion that rehabilitation is not (yet) ‘fully person centered’ and that it should be more. Gzil et al. (2007) pointed out that (i) The History of rehabilitation is complex with several stages and paradigm shifts. Furthermore, these paradigms do not succeed one another but overlap. It would therefore be erroneous to reduce the history of rehabilitation to merely a shift ‘from a medical approach to a person-centered approach’. (ii) Several proposal of how to make rehabilitation more person-centered are found within the literature. However, none of these appears

* The present researcher opined that in a country like India, (especially its Eastern parts) a dearth of several awareness among not only the masses but also the medical personnel as well as the rehabilitation officers (who are very few in number) exists. As such, the author felt keenly a need to introduce CFD model at the very root of awareness programs using CFD terminology and their meanings via the use of mass media here.
satisfactory with each leading to theoretical and practical difficulties. (iii) Although person-centeredness has unquestionably contributed to the overall progress of rehabilitation, it is not certain that more person-centeredness is the solution to current challenges to rehabilitation. Therefore, the current concept of rehabilitation is at least as syncretism as the notion of person-centeredness. It combines several paradigms belonging to chronic disease and disability. Also, it can be observed that somehow rehabilitation (in the broad sense) appeared to follow a 'shift from an acute illness, curative model to one that acknowledges the long-term nature of the career of chronic illness or disability'. Tracing back to its origins, it can be seen that rehabilitation started to constitute itself as such by differentiating itself from a curative medicine, that is to say an acute-care focused medicine. It seemed as if rehabilitation had then been constituted for the second time, by differentiating itself, this time, from re-adaptation and re-education medicine.

As McPherson and Sobsey (2007) observed, 'rehabilitation originally suggested a restoration to a formal state of typical function. Today, rehabilitation no longer requires a preconceived standard of potential for typical function to determine eligibility for services or to establish treatment goals'.

Rehabilitation, strictly speaking, is therefore distinct from a model (the parsonian model of re-adaptation and re-education) which could be qualified as an impairment-focused one.

Rehabilitation as such has never been disease-oriented. These are indications that there is no contradiction in principle between person-centeredness and medicine, nor is there any between person-centeredness and rehabilitation. Again, much depends on how person centeredness is defined. The traditional medical approach can in fact be considered as person centered. The move towards an emancipator interpretation of person centeredness is a general move which is affecting medical care as it is affecting rehabilitation.

These analyses demonstrated that the founding concept of rehabilitation and the unifying thread of its history is not the idea of person-centeredness (towards which the history of rehabilitation would be oriented), but the notion of disability (which never ceased to be re-conceptualized through the second half of the 20th century.
From an ethical point of view, person-centeredness allowed rehabilitation to acknowledge that disabled persons are full fledged citizens and persons that they not only have needs but also thought, emotions and that even though they come across difficulties, they posses a certain quality of abilities. Person-centeredness thus generated practices that are more respectful of individual’s needs, particularities and preferences. It facilitated disabled person’s voice to be heard, their expertise and competence to be acknowledged.

From a technical and pragmatic point of view, person-centeredness made it possible to break with the medical discourse monopoly on disability and allowed to acknowledge, there was a time for care, which was distinct from the time for medicine. By making this possible, it did lead to clear medical acknowledgement of other health professionals part and know-how. It also allowed acknowledging that individuals were not isolated, that they are social beings who need the presence of people around them, people who must be trained and informed about their needs. Person-centeredness also enhanced professional acknowledgement that disabled persons were individuals (and individuals who were different from one another) whose needs and strengths were variable in time. Therefore, person-centeredness probably led (or may lead) to improvement in intervention effectiveness/ efficiency. Person-centeredness did not first appear in the area of rehabilitation but in the clinical psychology and counseling fields (Rogers, 1961). Only, in a second stage, were certain ideas contained under the term person-centeredness applied to rehabilitation.*

India is a developing country just as it gropes painfully the developmental processes, (development is a change and change is painful with some uncertainty), the challenges of rehabilitation of people with Locomotor disability (as with other kinds of disabilities also) has not yet met the desired level.

* To the present researcher it seemed that CFD Model coupled with the concept of person-centered rehabilitation can play a great positive role in a developing country like India where a lot is yet to reach in the Rehabilitation Scenario.
2.3. Orthopaedically Handicapped's Adjustment and Well-being:

A) Theories of the impact of disability on adjustment

Numerous authors have developed theoretical statements which started in the second decade of last century by Adler in (1917) regarding the impact of physical disability upon social and emotional adjustment. Although considerable thought has been given to this problem, little concrete research in support of any of the theoretical positions has been undertaken or completed. Since there is little experimental verification and since no attempt has been made to interpret theory in terms of degree of disability, length of period of disability in the development of individual, congenital disability versus acquired disability and other pertinent factors, little can conclusively be stated. Yet the consideration of following theories might be of some help. (Cruickshank, 1948)

At this juncture it would probably be more helpful to consider the fact that the impact of loss of limbs due to amputation because of some disease having being suffered by the amputee in the past is quite different from the individual who had been healthy and happy prior to suffering loss of limb due to amputation because of trauma. The former sighs with relief from pains while the later experiences disbelief and acute psychic agony. The present study is concerned with the adjustment problems and well being of the latter group.

a) Field Theory

As Cruickshank reported two types of problems are to be observed in the handicapped individual from this point of view:

i) Adjustive problem which might occur in the normal developmental progress of any individual who is simultaneously striving for expansion of self and for self-concept already developed, and

ii) Adjustment problem which are solely resultant from the fact that a handicap has been inserted suddenly between the goal and the self desire to achieve such a goal.

In spite of artificiality of such a proposition, it points out the failure to recognize the duality of the problem. What actually happens is that the adolescent and the young
adults, during normative developmental processes, make efforts to integrate the crippling condition and their understanding of it into their life space. As because the amputee attempts to control an inadequacy in adjustment in a new social situation (different from that of an old situation which no longer holds value for him). The handicapped individuals’ personality in the course of his attempts to adjust faces a barrier to successful adjustment which is the physical handicap – irremediable. The normal personality tries to develop substitute satisfaction which contains nearly the same positive value as the originally desired situation. For a handicapped individual substitute satisfaction comparable to the original goal region is rarely possible. Thus, handicapped individuals’ personality, in addition to the possibilities of escaping the life space into unreality or retreat into protect the self, has added negative possibility of developing substitute satisfaction within the old situation life space. Thus, the handicap sets into operation in a vicious cycle. While no experimentation has been undertaken to taste the adequacy of the hypothesis Lewinian Field Theory may explain the problem of adjustment faced by many disabled children and young people.

b). The theory of Organic Inferiority as developed by Adler (1917) has close relationship to the problem under consideration. Although not much empirically validated but stimulating further thoughts has largely been supplanted by other ideas. He originally hypothesized and assumed an undetermined but specific neurological basis between organ inferiority and behavior mechanism of a compensatory nature. In later writings, the psychic need for control of inferiority of whatsoever kind was added. However, to completely discount Adler’s contribution would be a mistake, (Crookshank, 1936; Dreikurs, 1943). Because according to him the life style of each individual is not only influenced by disability but in turn determines the final effect of any physical disability.

Each handicapped individual formulates his own response to his disability in accordance with his life style, which can only be determined through dynamic investigation. What the individual does with the disability, individual courage and social interest, or the lack of them, determine whether a disability permits a good adjustment or leads to permanent failure.
However, Allen and Pearson, (1938) held that the behavior problem of young adults and children are directly related to faulty social attitudes towards them rather than to the person’s inability to encompass psychologically the physical disability by *per se*.

c) **Freudian theories and body Image.**

Numerous writers have looked to the writings of Freud as a basis for their concepts regarding physically handicapped individual. Chief among them were Schilder, (1950). The latter saw a direct relationship between the perception of the body image and action. According to him when an individual’s orientation concerning left and right is lost in respect of own body, there is also a loss of orientation in regards to the bodies of other persons. The postural model of one’s own body is connected with the postural model of the bodies of others. Thus, experiences of one’s own body image and experience of the bodies of others are closely interweaved with each other. According to Bender and Silver, (1948); a disturbance in the body image may occur in the development of the individual or at any level in the perceptual or integrative growth of the person.

Machover (1949), reported on the drawing of 20 orthopaedically handicapped individual. She opined that the preliminary findings were notable, and that individual projection of the disability into their drawings of self varied according to the basic personality of the individual afflicted, the degree of disability and the duration of confinement after trauma were *important features* of the individual's reaction to loss of limbs. Both qualitative and quantitative researches are needed for verification of this theory. Further, it is important to see that for the physically handicapped individual the normal transition from the pleasure principle to the reality principle is frequently impossible because of the individual’s inability to participate in normal activities. The commonness of narcissistic pleasures among the handicapped persons was also stressed by author. The person is different by reason of disability, and as such through such experiences as the necessity for due physical exertion, pain, misfortune fear and other factors associated with the disability itself. The disabled person considers himself in the position of uniqueness and narcissism. Also, unfavorable familial relationship as well as unfavorable culture - person relationships are basic to compensatory behavior. The individual comes to feel inferior and unconsciously over compensates so as to achieve psychic stability. Keeping with Freudian concept he
Survey of literature stressed the importance of close and intimate relationship between the individual and his caring adults. The individual, further, considers the care givers including the parents as the source of all the satisfaction as well as may be blaming other individual for his misfortune. This result in ambivalence since the emotions related to both roles in the same situation are distinctly different. Conflict and maladjustment ensue when the individual is unable to rationalize the two opposing point of view confronting him. Often, when a satisfactory solution is not reached, the handicapped person is noted to resort to hypochondriacal solution as a compensatory mechanism. The close relationship between the defect and the body structure increases the ego libido. As the individual feels rejected by the parent, by his peers, by the culture, the importance of this relationship becomes greater. As the need to protect the defect, the body, and, in fact, the ego itself becomes more apparent, hypochondriacal solutions are often used.

In general, Cruickshank (1948) reported some important points namely

1) Parental attitude or attitudes of care givers at the home front having found as basic in the development of healthy adjustment among the handicapped.

2) Psychoanalytically, the ego loss due to a somatic defect resolves itself in emotional compensatory behavior.

3) Kubie, (1945) in the same frame of reference pointed out that the psychosocial impact of the handicapped condition will be the result of the four factors-reality, conscious fantasy, unconscious fantasy and feeling.

Barker (1948), and his associates have summarized the theoretical assumptions which are proposed as etiological problems in individuals with physical disabilities. One point is to be remembered here that these assumptions were developed mostly in connection with condition of disability present since birth and those occurring in early childhood. So the present researcher exercised caution while thinking of these assumptions in connection with the incidence of lower limb amputation in late adolescence and young adulthood. However, some of them could be seen as applicable to present target group were as follows.

1) Compensation for inferiorities

2) Easy narcissistic satisfaction deriving from pain and uniqueness

3) Lack of normal plan and expressive actions

4) Easy cathexis to disabled part
5) Unrelated anxieties transferred to bodily handicap
6) Blame of parents (displaced aggression)
7) Feeling of guilt for hostility towards parents and other care givers
8) Body image at variance with reality
9) Efforts to achieve social acceptance
10) Dependant, demanding apathetic behavior deriving from protective situation
11) Variable, conflicting behavior in response to variable, inconsistent attitudes of others
12) Goals beyond achievement possibilities due to pressure from family and physical, social and economic restrictions
13) Conflict between withdrawal and compensatory tendentious.
14) Acceptance of disability as a punishment for sin
15) Retaliatory behavior for unjust treatment by fate
16) Self concept
17) Degree of acceptance of disability by disabled person
18) Value system of disabled person and his associates
19) Cultural role of the disabled person
20) Intergroup dynamics

(Calark, 1934; Wertz; Adler, 1917: Allen and Pearson, 1938; Winkler; Schilder: 1950)

B) Lower Limb amputation, its impact.
As per medical encyclopedia amputation is the intentional surgical removal of a limb or body part to remove diseased tissue or relieve pain. Amputations can be either planned or emergency procedures. Injury and arterial embolism are the main reasons for emergency amputations. The operation is performed under regional or general anesthesia by a general or orthopaedic surgeon in a hospital operating room.

Details of the operation vary slightly depending on what part is to be removed. The goal of all amputations is two fold: to remove diseased tissues so that the wound will heal cleanly and to construct a stump that will allow the attachment of a prosthesis or artificial replacement part. The surgeon makes an incision around the part to be amputated. The part is removed, and the bone is smoothed. A flap is constructed of muscle, connective tissue, and skin to cover the raw end of the bone. The flap is
closed over the bone with sutures (surgical stitches) that remain in place for about one month. Often, a rigid dressing or cast is applied that stays in place for about two weeks.

As regards to the aftercare of amputee patients the followings may be noted. Recovery from surgery takes about six weeks. Rehabilitation, however, is a long and arduous process, especially for above-the-knee amputees. The doctor and the physical therapist decide how soon after surgery the patient can begin to exercise, and several sessions each day may be recommended. In addition, psychological counseling is an important part of rehabilitation. Many patients experience a sense of loss and grief when they lose a body part. Others are bothered by phantom limb syndrome, where they feel as if the amputated part is still in place. They may even feel pain in the limb that has been removed. Many amputees benefit from joining self-help groups and meeting others who are also living with amputation. Addressing the emotional aspects of amputation often speeds the physical rehabilitation process.

C) Coping with amputation

Amputation poses challenges on many levels: physical, emotional, social, spiritual and financial and may affect one’s ability to think clearly and solve problems. Emotional responses to amputation are different for every individual and their family. It is common, however, to feel a sense of grief and loss. How people respond to their amputation depends upon their unique make-up (personality, values and attitudes), previous life experiences, their support system, and the meaning they give to their amputation.

Besides the above, the followings given below complicates the adjustment to leg amputation.

According to Pattston, (2007) common people as well as the disabled suffer from what he has labeled “Dysfunction phobia”. According to him, values, beliefs and attitudes that condition people from birth are subconscious and conscious and most often, due to them, people respond to impairment and disability in a negative way. The usual reactions to the encounter of impairment or disability include sadness, a focus on loss, pity, denial and even shock, horror and devastation. In a study, he asked
participants to tell him how they would react waking up the next morning with a number of difficult changes such as having different hair colour, being rich and famous, being the other gender, having a different sexual performance coming from another race and having only 50\% of ones physical, intellectual or emotional capacity. The first five changes are highly unlikely to happen overnight but the last change is possible even statistically likely in some cases to happen unexpectedly and involuntarily. People's responses to first five changes, at worst is uncertainty but in response to a suggestion of 50\% reduction in capacity, most of the people reported that they would hate it and be fearful with few exceptions. Additionally, people are conditioned to belief that impairment is 'wrong' and unnatural which understandably contributes to dysfunction phobia. It is further exacerbated by the long history of social exclusion, devaluation, poverty and discrimination experienced by disabled people, which people witness with distress, but without the realization that they individually and collectively cause it, oppression and discrimination against disabled people is often called abilism (or disabilism). Abilism is the institutionalized belief that being non-disabled is better or more natural than being disabled.

The average person lives in denial that at any time they could have a car accident or stroke and become paralyzed or brain injured or become depressed or loose sight. Pattston believed that this denial causes society to fall to provide support, remove barriers and challenge discriminatory attitudes towards the things that dis-able. A non disabling society potentially benefits all people and not just those perceived as needing the intervention. Pattston further suggested that the root fear relates to the inability to cope rather than the change or loss of function as human being are infinitely adaptable. Disabled people adapt when adequately supported and newly impaired people share this potential. Pattston proposed that such a trend of thought at the beginning of a rehabilitation process could impact in terms of client directed practice, giving a totally different potential focus-adaptation-as well as or instead of restoration.

It is not just non-disabled people who exhibit dysfunction phobia – many people who are impaired either fear or dislike their own functional defect and/or the possibility of a further loss of function. Disabled people often apologize for their inability to do things, or for their need of support. Some may even discriminate against others with
the same or different impairment (e.g. physically disabled people often do not want to associate, or be associated, with intellectually disabled people). Thus, young adults, with acquired impairment as a result of accident may be desperate to return to their communities or workplaces, but are terrified about appearing in public as a ‘disabled person’. Desmond et al. (2008) investigated associations between post-amputation phantom and residual limb pain and prosthesis satisfaction, activity restriction and psychoadjustment to amputation among lower limb prosthesis users. Eighty nine people with a lower limb amputation completed a postal survey. Characteristic of phantom and residual limb pain, prosthesis satisfaction, activity restriction and psychoadjustment to amputation were assessed using the Trinity Amputation and Prosthesis Experience Scales (TAPES). Comparisons of those who experienced residual and/or phantom limb pain in the preceding assessment with those who did not reveal significant differences in prosthesis satisfaction, psychoadjustment but not in activity restriction. Overall, it is important for clinicians to ascertain the type and level of pain that the person is experiencing and to separate the experiences of the pain from the experiences of the prosthetic limb. The role of a psychologist – counselor therefore seems to be of utmost importance from the very moment a trauma victim is brought to hospital

People may experience feelings of anxiety, anger (directed towards self, family or caregivers), depressed mood, shock, denial, ambivalence, hopelessness, helplessness, numbness and disconnection. Some people report feelings of relief as their amputation was expected and resulted in freedom from pain with improved function. These feelings can be frightening and overwhelming and people often believe they are going crazy. This is not so! People often compare their feelings to being on a roller coaster ride. Like a roller coater, they feel they have little control over their lives. They may experience “high and lows” ranging between optimism and despair. The ranges of feeling one may experience are normal and expected and are part of the healing process. These new feelings may affect how one normally copes with daily living. For example, many people read as a way of coping with stress. After an amputation, it is common for people to find it difficult to concentrate. If reading is a way of coping with stress, they may not be able to use this to help them. The individual may need to develop new ways of coping to help with feeling and stress related to his amputation. These intense feelings will settle over time (Mukherjee et. al. 2008)
In order to understand better how trauma victim experiences amputation and subsequently successfully or unsuccessfully copes with the loss of lower limb it will be helpful to consider Zigmond’s Model (Zigmond, 1996) Figure 2.3.

[Found in chapter ‘Psychological Impact of Amputation’ by Barbara Engstrom, Catherine Van de Ven (1999)]

According to Zigmond, there are therefore many levels at which the difference an amputation creates needs to be acknowledged and adjusted to. When adjustment has occurred the amputee is able to meet the demands and challenges of amputation and a state of maintenance is achieved. Also the meaning of the amputation in term of losses and gains or pros and cons the amputee needs to be taken into account, and accordingly why some people appear to cope easily with amputation, while others grieve to a greater extent or become depressed, becomes meaningful. Expressed in terms of the above model the differences some people face may be less significant or easier to adjust to themselves than others. Losses can be functional, occupational or interpersonal or more subtle losses of identity or body image.
It seems to be worth mentionable here that unlike the victim of a sudden unforeseen trauma, the amputee who comes to amputation of a limb that has caused him a great deal of difficulty over many years, reacts to the operation with relief and rapid acceptance. Such a person has experienced considerable gains to outweigh the loss of the limb and the differences that must be adjusted to are not difficult to acknowledge and accept. But a trauma victim experiencing amputation usually experiences a profound sense of their own mortality and is disturbed by their new body image. They are also troubled by others' view of them as disabled. These losses may then outweigh the functional gains and depression may result due to trauma. The results suggested that the patients who have had amputation due to malignancy differed from traumatic amputees in their adjustment to amputation. The former provided evidence of better adaptation to disability. This conjecture received empirical support as reported in an article by Boyle and others “Adolescent adjustment to amputation” (2006). They compared adolescent who underwent limb amputation due to cancer and compared them to data obtained from 8 patients with amputation after trauma. Thus, the processes that leads to an amputee’s understanding of his amputation and the adjustment required or losses or gain resulting from it, are complex and idiosyncratic.

In the above context it appeared that the special problem experienced by trauma amputation victims might be displayed in the following way.

i) Phantom limb sensation which refers to the very real feeling that the missing limb is still present. It is the normal feeling that amputees have after surgery, and it is so real. Another problem is phantom limb pain. This is the actual pain that is perceived as coming from the removed limb. The intensity, type, and duration of phantom pain varies from person to person. Happily, both phantom sensation and phantom pain usually decrease.

ii) Another problem is their greater tiresomeness while walking as compared with normal individuals due to their remarkably greater oxygen consumption.

iii) A minority of amputees experience denial in relation to accepting their impairment (i.e. the reality that their limb is missing). Where this occurs, it can be an attempt to return to what is known and familiar, perhaps in the face of unbearable levels of anxiety. In such cases, phantom sensation may play a
role in reinforcing the denial. This degree of denial may lead to serious problems. Such a disconnection with reality may indicate some underlying psychosis and if this state persists for more than a few days and the amputee is not responding to counseling a psychiatric assessment should be requested.

iv) It is more common to experience denial in relation to disability that is accepting the 'difference' in physical function. This can be manifested in amputees who persistently 'overdo it' in relation to physical activity and can lead to problems with blistering or trauma to the skin on the residual limb.

v) Some amputees may only understand the difference amputation is going to make to their lives when they start learning to walk again and realize the extent to which their function is compromised. Any amputee who has been assured pre-operatively that their 'new leg' will be 'as good as old' may have greater difficulty adjusting to the reality of prosthesis.

vi) Handicap is affected by many factors and not an inevitable consequence of amputation. Many amputees may only become aware of possible handicaps (for example, jobs or hobbies they are no longer able to do) following discharge from hospital or from rehabilitation services.

vii) Amputees may also notice social issues living as a person with a disability, such as some friends treating them differently. These issues can be difficult to adjust to when individual have spent much of their lives with the identity of an able-bodied person.

Maguire and Parkes, (1998) noted that the loss of body parts as in amputation can give rise to grief for loss of body image or function, or both anxiety, depression and sexual problems are related to the magnitude and type of loss as well as the personal vulnerability of the patient. Both avoidance of an obsessive preoccupation with the loss can be problematic. Burger and Marineck have reported, (2007) that individual, after lower limb amputations, have problems returning to work. Many have to change their work and/or work only part time. Therefore, vocational rehabilitation and counseling should become a part of rehabilitation program for all subjects who are of working age (as the case of subjects in the present study) after lower limb amputation.
As such better co-operation between professionals like rehabilitation team members, implementing bodies, company doctors and the employers is necessary.

Denas, McFadyen and Rowe (2008) measured activity restriction after lower limb amputation and quality of life enjoyed by the amputee’s population. It supported increasing physical activity in this patient group, so long as social interaction is not compromised. Creating and positively reinforcing awareness within the rehabilitation team about the importance of the amputee patient’s reintegration into social networks is paramount and should not be overlooked.

Geertzen, in his article “moving beyond disability”, (2008) firstly suggested a change in focus from disability or impairment to the broader perspective of the overall health of individuals with disabilities, the so called holistic approach, towards the life of the individual. It is an approach in which all members of the multidisciplinary rehabilitation team work with the goal of a better quality of life for their patients. This is in line with the ICF (International Classification) of functioning, disability, and health. The author further reported that difference between able and non disabled persons in respect to sexuality and the need to express ones sexuality is absent but in many countries there is still a taboo on the discussion of sexuality and speaking about a disabled person’s sexuality is even greater a taboo. The first publication that deals with satisfaction of amputee patients with their sexual life was that of Ide et al; (2002). Thirty percent of the amputees surveyed were not satisfied with their sexual life according to this article. A few of his conclusions and observations were:

- There was a need for medical professionals to set up opportunities for psychological support for amputees;
- It was regrettable that no respondent in the study talked about sexual issues with (medical) professionals.

Takamine, (2008) initiated the concept of barriers while thinking about persons with disabilities. According to him there are many boundaries in society. There are geological boundaries, cultural boundaries, national boundaries and others. For persons with disabilities, there are other types of boundaries such as physical, informational and social boundaries. Takamine in Japan defined boundaries as
barriers which prevent persons with disabilities from accessing and enjoying services, information activities in the society in which they live. He further pointed out that until and unless the society strives to remove social boundaries for persons with disabilities their human rights will not be protected.

Generally, four types of barrier are recognized: physical barriers, information barriers, institutional barriers, and attitudinal barriers. Physical barriers include inaccessible built environments (steps, toilets, narrow passages, etc.), as well as inaccessible public transportations, including buses, railways, airplanes, etc. Public laws, rules and regulations often restrict education and training as well as employment opportunities for persons with disabilities. Attitudinal barriers are most common and difficult to redress. In many countries disability is considered as stigma (a curse from ancestors). Persons with disabilities have been perceived as having no ability, and being asexual. The present study deals with the attitudinal barriers.

Furthermore, it is important to note here that Gray et al in USA, (2008) have developed a subjective measure of environmental facilitators and barriers to participation of people with mobility limitations.

Callaghan, Condie and Johnston (2008) in Scotland U.K. found that among 800 lower limb amputation performed each year 20% do not use their prosthesis, and 20% only occasionally use it. This finding has implication for patients well-being and health care cost efficiency. Knowledge of how psychological variables determined a prosthetic use and activity limitation is valuable because it raises the prospect of being able to identify patients whose psychological profiles render them more at risk of not rehabilitating successfully with prosthesis, in this case those who perceived symptoms as fluctuating and treatment to be ineffective. Such information could also inform the formulation of elements of psychological care aimed at increasing the number of patients making effective use of their prosthesis and achieving improved activity after discharge from hospital.

The loss of a limb is a traumatic and far-reaching event and often represents a struggle for survival, psychosocial adaptation and re-defining of self. In a case study presentation, Grobler, (2008) in South Africa, explored a patient’s relationship with
Survey of Literature
disability by means of a comprehensive model in understanding and accessing the trauma journey. The patient was a 19 years old black with a bilateral transfemoral amputation. During their conversation by using projective techniques the author realized that the amputee was confronted with "making sense" out of a situation and his relationship with disability. According to Kohl (1984), in the process of re-evaluation of life 'an examination of one's life is made, which evolves into a balance sheet of right and wrong deeds that serves as a basis of determining future goals'. Successful resolution of this psychosocial issue leads to 'the reattachment to life's meaning with a positive sense of self-worth and a potential for fulfillment'.

In the process of re-defining himself, the patient had to resolve the psychosocial issue of body image. Shontz (1974) refers to the unique situation of persons with limb loss of having three body images; one with prosthesis, one without it, and the pre-injury intact body.

Erik Erickson (1968) who refers to the developmental stage that the subject finds himself in during adolescence and young adulthood as the task of achieving ego identity and avoiding role confusing. As a young adult in grade 11, this individual had to establish a social identity, career identity and a sexual identity. It is in particular his fear of rejection by an intimate partner that might result into isolation.

One point which clearly emerges until now is that the immediate social surrounding and attitude of human being in that surrounding around the lower limb amputee are extremely important for their prognosis in a positive way. A survey of psychosocial problems in the families who view the amputee as the burden, inter parental marital adjustment and maternal neuroticism was done by Singhi et al (1990). The findings pointed out existence of greater financial stress, frequent disruption of family routine and leisure, poor social interaction and their ill effects on the physical and mental health as compared to families of control subjects. Social burden was significantly higher in group with physical disability socio-economic and educational statuses of the parents were lower and generated more burdens. The neuroticism scores were also significantly higher for physically disabled families and marital adjustment scores lower in families with disabled children. The authors suggested that appropriate
management of these problems should be incorporated as part of the rehabilitation programs.

Biographies of illustrious figures with disability and handicap have shown effective tackling of problems related to their mental strength, personality adequacy and psychosocial barriers. This had helped them to prove their worth and competence. Particularly, in respect of physically handicapped individual, quite a few of them have earned credit in the areas of Mountaineering, Aquatic sports, Channel Swimming, Athletics, and as a productive member in the Indian Parliament.

The proportions of handicapped employees have started growing with observable speed under the support of government policies at the State and Central levels. Even then a direct interaction with recent amputees (at least 2 months have passed after the amputation and initial pain has subsided revealed one horrifying fact. In the cold and impersonal climate of the hospital they very clearly felt the urgent need to pour out their hearts to a caring and listening soul but unfortunately the hospitals here are devoid of counselors specially meant for helping individual trying to cope with loss of a limb. Also it was so that no rehabilitation officers have visited them even after 2 months of hospitalization. As a result psychosocial problems were brewing in them. They needed badly psychotherapeutical advices and guidance to get rid of adjustment problems and personality inadequacies .Youth is a special phase of life when individual begin to contribute to self and society but orthopaedically handicapped youth with locomotors disability (16-22 years of age covering late adolescence and early adulthood) tended to experience self restriction instead as manifested by their initial semi structured interview (vide chapter v : Results and Discussion). In this connection it was noted that they were more hopeless and more externality oriented in an earlier study ( Mukherjee et.al, 2001 ) In a later more exhaustive study sponsored by University Grant Commission during the year 2003-04-05 a group of 100 orthopaedically handicapped youths and their 100 normal counter parts were approached with measures of: Tyler’s Behavioral Attributes of Psychosocial Competence, Hopelessness, Self-esteem, Perception of communication Satisfaction (while talking with mother and father) Loneliness, Happiness, Life-Satisfaction, Perceived Social Support as well as “ charms in family life” perception. The findings clearly pointed that remaining in the city life as neglected and unattended cases
orthopaedic disability (of stable restricted movements) the leg amputees learnt to rationalize their deviations from the mainstream of urban style of life and its norms, due to their ‘personality in adequacy’ as the victim of social neglect due to their ‘bad luck’. Consequently, they, for coping with the stress of socially stigmatized life, picked up certain strategic self-defense to remain alive. In course of time, they learnt from others’ behavior and attitude about their unwritten low social worth and status and of their future uncertainties. Here the entire situation appears to be quite different from the rehabilitation attempts abroad in more developed countries.

Moved by the hapless plight of the young ones when they are struck by a trauma and loose lower limb as a result of amputation and continue to suffer from locomotor disability the present investigator- a budding Applied Psychologist undertook to examine young lower limb amputees in terms of:

1. The nature of differences if any in some selected psychosocial variables, from their normal counterpart in society and

2. To reveal the extent to which these psychosocial variables contribute to their sense of subjective well-being, because, until and unless an individual feels and tells himself that “I am well ” it is not realistically possible for him to positively approach life-problems.

3. Furthermore, the investigator decided to unravel the real rehabilitation situation facing the leg amputees here.