Chapter: 1

Introduction

Disability stems from “The failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities, rather than from the inability of the disabled individual to adapt to the demands of society” (Hahn, H. 1986)

“Persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”

1.1 Disability

Persons with disabilities are one of the disadvantageous groups in all societies. A sizeable number of them are a subject to dispossession in many dimensions. Disability is manifested in many forms such as lowered ability to cope with some common life demands, or being a subject to social stigma and discrimination. These play a significant role in limiting the opportunities and creating barriers. Whereas disabled persons encounter many problems while trying to overcome various barriers or accessing the services. Disability means any restriction or lack of ability to perform an activity in the manner or within the range considered normal for human beings. It is a social construct i.e. a combination of biological condition of the individual and of the social status that the disability attaches to their existing biological condition. It can be conceptualized as a multidimensional experience for the person involved, a disability may be intellectual but it affects their social, psychological, physical and other aspects also. By and large, persons with disabilities bear the ordeal of physical limitations which do not let them perform certain tasks and be a part of mainstream. In addition to above, the present socio cultural milieu fixes a boundary which makes them handicapped (a disadvantage for the individual resulting in disability) outside the boundary, thus recognizing the role of physical, social and environmental factors affecting the disability. The World Health Organization (WHO) defines disability as an umbrella term, that provided a threefold medical model definition which included
impairment, disability and handicap. It says that impairment (loss or abnormality of psychological, physiological or anatomical structure or function) is a problem in body function or structure, disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she live. It results from an impairment and is a restriction or lack of ability to perform an activity within a range, considered normal. Whereas the concept of disability expressed in the preamble to the Convention on the Rights of Persons with Disabilities (2006) reflects a shift from a medical model to social model of disability. According to this the disability results from the interaction between persons with impairments, attitudinal or environmental barriers hindering their full and effective participation in society on an equal basis with others. According to The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, disability is built upon the principle of equal opportunity, protection of rights and full participation. It provides definitions of disabled person following the medical model. It includes hearing impairment, visual disability (Blindness, low vision), leprosy cured and locomotor disability and intellectual disability.

1.2 Demographic Trends on Disability

Global: The global estimates of disabled population according to ‘The World Disability Report 2011’ is 15 % and between 2 to 4 % of the population have severe disabilities. Similar results were of the first-ever UN global survey (10 October 2013, Geneva) of persons living with disabilities on, how they cope with disasters.

India: According to Census 2011 in India the total number of disabled persons were 26,810,557 out of that 55.8% were males and 44.1% were females. 52.42% females had disability in seeing whereas 47.57% males had the same. There were 52.8% males and 47.1% females who had hearing disability, whereas 56.1% males and 43.8% females had a speech disability, 61.9% males and 38% females had movement disability, 57.8% males and 42.1% females had mental retardation, Mental illness were found among 57.5% males and in 42.4% females, 55.3% males and 44.6% females had any other disability and 54.9% males and 45% females had multiple disabilities.

Chandigarh: According to Census 2011 the total number of disabled persons in Chandigarh are 14,796 out of that there are 8743 were males and 6053 were females. Further break up shows that there are 1774 persons who have visual impairment out
of that 1078 were males and 696 were females. There are total of 2475 people with hearing disability out of that there are 1268 were males and 1207 were females. In the category of speech impairment the total number is 961 out of that there were 562 males and 399 were females. There are 3815 people who have physical disability consisted of 2378 males and 1437 females. There are 1090 people who have intellectual disability out of that there were 683 males and 407 were females. Total number of persons who have mental disability is 756 out of that 445 were males and 311 were females. There are 1342 people who have multiple disability which consist of 775 males and 567 were females.

**Melbourne:** According to the Disability, Ageing and Carers: summary of findings report in 2012 by the Australian Bureau of Statistics (ABS) Victoria had an estimated population of around 3,64,900 persons who had a some kind of disability out of that 1,61,200 were males and 2,03,700 were females. Approximately 98,888 persons had intellectual and behavior disorders and there were 265,647 people who had physical disability which includes asthma, hypertension, back problem, arthritis, acquired brain injury, vision disorder etc.

1.3 Models of Disability

The model of disability is the conceptual framework that helps to comprehend various dimensions of disability. These also provide some insight into, why certain attitudes exist and how they are reinforced in the society. The two main models are the medical model and the social model. (Sullivan Katie, 2011)

**Medical Model of Disability:** Medical model is the cause behind the negative attitudes towards persons with disabilities, that is when they are seen as the faulty human beings and also the ones who are in need of treatment or rehabilitation (Oliver 1996). This model is also known as, an individual model or at times personal tragedy model because it is believed that the problems related to disability are exclusively within the concerned individuals or their impairment. Through this model, persons with disabilities at times viewed as feeble, defective and incapable of living on their own or fully participating in anything. It is presumed that they require the aid of medical professionals. When people with disabilities are seen as sick, there are chances that they get exemption from routine obligations which in turn tend to isolate them from the rest of the population. Thus creating low expectations from them, which may prove to be damaging to the ones with disabilities and also to society as a whole. The
overriding effect of the medical view of the disability, gives way to negative perceptions of disability which is reinforced, thus marginalizing the persons with disabilities. The medical model does not put any responsibility on the society to accommodate persons with disabilities, rather the thrust of this model is that they must adapt themselves to existing situation, for which they are normally helped by medical professionals who provide treatment and rehabilitation (Kapalan, 2000). Many disabled people internalize the negative message, that all disabled persons problems stem from not having ‘normal’ bodies. This internalized oppression can make disabled people less likely to challenge their exclusion from mainstream society.

**The Social Model of Disability:** In the 1970s, following the Civil Rights Movement in the United States, people with disabilities rallied for equal rights and access and adopted a new social model of disability. The social model does not accept disability as a medical condition. It does not view disabled as defective individuals, but as significant members of society, who have the right to full participation. (Sullivan Kathryn, 2011). This model says that components of disability include everything in the society that isolates and excludes person with disabilities. These may be discrimination, inaccessible buildings and transportation systems, segregated education, (Oliver 1996). The social model therefore prefers to fix the society to enable access, and reduce discrimination and negative attitudes in order to ensure that all can participate fully instead of looking for cure of disability within the individual. This model proposes that if there were no social and environmental barriers, there would be no disability. As it believes that disability is primarily a result of society’s response towards them and also of their experience of availing the health and welfare system which has gives them a feeling of socially isolation and oppressed. Through the social model, disability is understood as an unequal relationship within a society in which the needs of people with impairments are often given little or no consideration. People with impairments are disabled by the fact that they are excluded from participation within the mainstream of society as a result of physical, organizational and attitudinal barriers. These barriers prevent them from gaining equal access to information, education, employment, public transport, housing and social/recreational opportunities. (Carson Grant 2009). Thus the social model aims to achieve the acceptance by society of individual differences and maximize
independence in making choice and control of disabled people over their own lives. (Bigby & Frawley, 2010)

The International Classification of Functioning (ICF) also states variety of theoretical models to understand and explain disability and functioning, these models were:

**Moral model:** This refers to the attitude which says people are morally responsible for their own disability. It is basically seen as a result of sins of past or previous birth. In the Indian context sometime disability is believed to be result of one’s misdeeds and the concerned person has to bear the consequences.

**Professional model:** It puts forth a traditional response to disability issues and is seen as a result of the medical model. In this professionals follow a process of identifying the impairment and limitations thus take the needed steps to bring progress in the disabled person.

**Tragedy/ Charity model:** This model views persons with disabilities as victims of situations and who deserve compassion.

**Economic model:** This model explains disability as a person’s lack of ability to involve themselves in work. It also evaluates the degree to which impairment of a person’s disability effects productivity and the economic consequences for the individuals, employer and the state.

**Empowering model:** This allows the person with a disability and the family to decide the course of their treatment and the services prefer to take.

1.4 Intellectual Disability:

Intellectual disability is the contemporary term that describes the phenomenon known as learning disabilities, mental retardation, mental handicap, sub normality. There is always a group of people in every society who have lower than average intellectual capacity and poor adaptive skills. On the basis intellectual and adaptive capacity alone some people are marked different from others. This group is generally labeled as having intellectual disability. Intellectual disability includes both intellectual impairment and disability.

The International Statistical and Classification of Diseases and Related Health Problems (AAMR 2002) states by using the now redundant term mental retardation as a condition or incomplete development of mind which especially characterized by impairments of skills manifested during the developmental period, skills which
contribute to overall level of intelligence i.e. cognitive, language, motor, and social abilities. Retardation can occur without any special condition. The intellectual disability is concerned with the relationship between intellectual impairment and society (Bigby & Frawley, 2010)

The 1992 and 2002 AAMR definitions of mental retardation emphasizes on the role of supports in conceptualizing the nature and degree of intellectual disability. Intellectual disability is a complex and multifaceted concept and has undergone many changes in name, but has always referred to the developmental period. The expression developmental disability is much broader than intellectual disability, and may include people with epilepsy, cerebral palsy, autism or other disorders that occur in the developmental period. (Phillip, 2003) This definition includes three criteria: disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed (reading, writing, money concepts, language and self-determination), social (interpersonal, self-esteem, responsibility, follows rules and avoids victimization), and practical (daily living skills such as cooking, cleaning, hygiene) adaptive skills. This disability originates before age 18. It also refers specifically to a subset of the population with developmental disabilities, whose major functional limitations is predicated primarily by intellectual and cognitive limitations. Thus, it is possible for a person to have a developmental disability, but not necessarily an intellectual disability, such as a person with cerebral palsy who has normal intellectual functioning. However, a person with intellectual disability always has a developmental disability. (Elizabeth A. Perkins 2009).

According to the World Health Organization (WHO), (1992) Intellectual disability (mental retardation) is defined as a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities. Retardation can occur with or without any other mental or physical condition

Intellectual disability is defined as significantly sub average general intellectual functioning on standard psychometric tests together with significantly limitation in adaptive functioning in, at least two of the following skill areas — communication, self-care, home living, social/ interpersonal skills, leisure, use of community resources, self direction, functional academic skills, work, health, and

Children with intellectual disability can be subclassified according to severity, as mild intellectual disability (intelligence quotient (IQ) 50–70), moderate intellectual disability (IQ 35–49), severe intellectual disability (IQ 20–34), and profound intellectual disability (IQ < 20) (Shevell et al., 2003). Apart from this, for children less than 5 years of age the term global developmental delay is used and the term intellectual disability is usually applied to older children when IQ testing is valid and reliable (American Psychiatric Association, 2000).

1.4.1 Associated Co Morbidities: These are the additional disabilities found in Children with Intellectual disability

- Attention deficit hyperactivity disorder (ADHD): It is one of the most commonly diagnosed behavioral disorders of childhood. The core symptoms of AD/HD are developmentally inappropriate levels of inattention, hyperactivity and impulsivity. There are three sub types, Predominantly inattentive, Predominantly hyperactive impulsive, Combined Type i.e inattention, hyperactivity-impulsivity (Fowler, 2004).

- Vision Problems: Children may have range of visual problems from short sightedness to partial or total blindness. Some other problems include, drifting of one inward or outward, frequent blinking, seeing double or not seeing clearly, low vision. It also includes squint that is the misalignment of the two eyes as observed or diagnosed may also be there.

- Hearing Problems: It includes the degree of hearing of loss and the age of onset i.e when the loss manifested itself. Hearing impairment may lead to speech development, communication, language deficit, poor academic performance.

- Autism: It is a mental disorder characterized by a sever condition of uneven skill development primarily affecting communication and social abilities of a person marked by repetitive and ritualistic behavior. Autistic individuals have difficulty in communicating and socializing. A child with autism typically develops communication problems too. Speech is normally delayed and if it does develop it may be peculiar or echolalic (Towbin et al. 2002). It is a lifelong developmental delay often associated with mental retardation.
• Down’s Syndrome: Down’s Syndrome or mongolism occurs in one out of every 700 births. It accounts for about 10% of moderate to severe mentally retarded children. It is the common identifiable cause of intellectual disability. It occurs due to the presence to an extra chromosome 21. Which leads to delayed developmental milestones. (Roizen 2002) Down Syndrome (DS) and Fragile X Syndrome (FXS) These two syndromes are analyzed in detail in our country, since they are reported as the most frequent genetic causes of mental retardation worldwide (Lantigua Araceli 2008).

• Cerebral Palsy: It is characterized by chronic disorders of movement and posture. The orthopedic problems include discrepancy in skeleton growth, deformities of hand, feet, pelvic, dislocated or sublocated joints, contractures at joints. Other combination of characteristics that can be seen are: motor disorder, medical conditions, hearing disabilities, attention, language and perceptual deficits behavioral problems, mental retardation. It is a heterogeneous condition in its causation and manifestation and be put under a group of disorders caused by injury in developing brain, malformation of brain and blood vessels, neurological damage. The perinatal causes, such as birth asphyxia, sepsis (meningitis, encephalitis), intracranial bleeding, multiple births. Causes after birth include, infections, traumatic brain injury, post surgical vascular complications. According to the National Trust For the Welfare of Persons with Autism, Cerebral Palsy Mental Retardation and Multiple Disabilities Act, 1999, cerebral palsy means: a group of non-progressive conditions of a person characterized by abnormal motor control and posture resulting from brain insult or injuries occurring in the perinatal, perinatal or infant period of development.

• Constipation: Constipation was defined as follows: scybalous, pebble-like, hard stools in over a quarter of defecations in combination with a defecation frequency of less than three times per week during a 2-week period; large stools palpable on abdominal examination; or laxative use or manual disimpaction of feces (Veugelers et al., 2010).

• Drooling: Drooling was diagnosed when excessive intermittent or continuous salivation for over last six months was complained of by the guardian of the child.
- Epilepsy: Epilepsy was diagnosed if two or more unprovoked seizures 24 h apart after the neonatal period were present (Commission on Classification and Terminology of the International League against Epilepsy, 1989).
- Feeding difficulty: Feeding difficulty was defined as persistent inability to properly take food appropriate for his or her age over last 6 months.
- Behaviour problems: A child with intellectual disabilities may develop behavioural problems. A behaviour disorder implies a child causing trouble for others and harm to themselves. This includes tantrums, damage to public property, exhibit inappropriate sexual behavior etc.
- Spina Bifida: Some children with spins bifilda may also lead to intellectual disability. It means spinal cord has been damaged before birth. However malformation depends upon extent of damage. It can also lead to paralysis in both legs.

1.4.2 Causes of Intellectual Disability (Caregiver Manual. The National Trust)
- Before Pregnancy: These include conceiving a child at a very young or old age, Poor nutrition of girl child and young women, Family history of mental retardation.
- During Pregnancy: These cover malnutrition or lack of specific minerals during pregnancy, medication during pregnancy, radiation during first trimester, infectious diseases like German measles, repeated fits and high BP in pregnant women, accidents during pregnancy overexertation, addiction smoking, alcohol intake
- During Delivery: These are premature birth, prolonged labour, difficult labour, complication of forceps
- After Birth: Poor nutrition, accidents such as head injury, illness and head Injury

1.4.3 Historical Perspective of Intellectual Disability
The history of intellectual disability has passed through a very chaotic stages and can be in recapitulated under: i) Pre-industrialization phase: From the beginning of civilization to the beginning of industrialization period, people born with "abnormal" physiognomy were treatment under fear or even ridiculed at (which still continues in many societies and has even been reported in this study).
ii Industrialization phase: Although industrial revolution is associated with increasing financial gains and productivity, but ill effects are also a part and parcel of industrialization. Large scale migration to metropolitan cities has given rise to slums, poverty, diseases, and crimes. Families started valuing the productive members, those with vocational ability and started neglecting the non productive members who were not able to work. In this process the individual who had low intelligence were left out and were labeled as feeble-minded, degrading, and stigmatizing. iii) Humanitarian approach: In 1846, Dr Samuel Gridley Howe from Boston persuaded Massachusetts Legislature to appoint a commission to inquire into the condition of 'idiots'. He for the first time after survey and close study, observed that, "These are the proper subjects of education, they could be taught some kind of vocation and be made self-sufficient. This led to rise of state run schools for these persons. However, these schools were a failure because Howe and his fellows (Sequin and Wilbur) were too optimistic, unrealistic in expectations as they had expectations of restoring all 'idiots' to normal functioning. iv) Demonology of the defectives: The scientific developments of Darwinism, sociological approach, Mendelian theory of genetics, and Binet psychometric tests advocated, directly or indirectly said that feeble minded individuals, who could be easily identified and quantified, are risk to the society. Thus, the society started thinking ways to prevent feeble mindedness from occurring and also started working on ways to control those in whom it did occur. At that time segregation seemed to be the best method where feeble minded could be cheaply and wisely cared for along with prevention and societal protection. v) Period of John F Kennedy: In 1963, based on recommendations of President's Panel on Mental Retardation, JF Kennedy made a speech to the Congress of United States and asked for new resources to deal with the needs of people with mental retardation. Soon, almost every state launched special educational programs for these person .Presently the term Intellectual disability is being used instead of mental retardation. This transition in terminology is supported by organization like the American Association on Intellectual and Developmental Disabilities (AAIDD), International Association for the Scientific Study of Intellectual Disabilities (IASSID), and President's Committee for People with Intellectual Disabilities.(Chavan & Rozatkar, 2014).
1.4.4 Reactions of Family to the Birth of a Child with Intellectual Disability

Families are strong stable and integral part of the society as whole. They are primary units which provides care, nurturing, and socializing to its members. Families provide primary ecological context, within which individual functions and develops. Since every family expects to receive a healthy baby, the birth of a baby is normally anticipated with great eagerness and expectations of future. Whereas the birth of a child with disability turns out to be an extraordinary life altering event and the exuberance becomes muted. This situation is bound to make a qualitative difference to their lives. The presence of a member with mental retardation irrevocably changes the family unit and affects all individual members. Marika (1999) said that the parents, especially mothers of children with disability, have significantly more negative emotional state and also more depressive symptoms. According to (Dale 1996), parents rarely expect their child’s disabling condition thus breaking the news about disability is one of the most stressful tasks for medical professionals and on the other hand receiving the diagnosis is also a herculean task for the parents. The confirmation or diagnosis, whether at birth or later, often creates an immense crisis of changed expectations and hopes. The parents may experience intense reactions during the early days. The initial formal diagnosis whether at or after birth creates a crises situation they may experience panic, anxiety and helplessness, periods of indifference and anger, depression, apathy and bitterness (Vijesh & Sukumaran 2007). The mothers especially tend to have feeling of guilt, self-blame which includes, guilt, regret/self pity i.e. helplessness to change, feeling of inadequacy, may also include feeling of reproductive inadequacy (Carr 1988). Overall the parental reactions to the disability depend not only on the diagnosis but also the way the diagnosis is disclosed to them, has direct impact on their reactions towards their child’s disability. Most of the times the parents grieve not having a normal child as desired by them. This phase passes through following stages shock, denial, sadness, adaptation and reorganization (Fraser, et al. 1998). Signs of denial or failure to believe or accept the diagnosis become more obvious when they run from doctor to doctor for either reconfirmation of diagnosis or treatment. The parents may not realize they are running away from responsibilities also (Wright 1976).
1.4.5 Impact of Child’s Intellectual Disability on the Family

Parents of children with intellectual disabilities often face more stressful and emotionally demanding life than other parents (Norlin & Broberg, 2013). This is because having a child with mental disability calls for lot of adjustment and coping on the part of the family, though the impact is often individualized (Peshawaria 2008). Their presence in the family at times may give rise to disequilibrium, which is eventually followed by an adjustment to life with or without any undue stress. These stresses emerge and reemerge during the upbringing of the child and in the long run may also result in resentment and hopelessness due inability to change the situation. All this bring with it, the feelings of embarrassment, fear (due an uncertainty) and social isolation. Apart from this the caregivers face a wide range of problems such a emotional for example, mothers who are the primary care giver are more prone to lack of emotional well being and in some mothers their child’s disability even gives rise to resentment. Another problem that may come up is the marital conflict due to additional responsibilities related to child with disability. Rather parents who have a child with disability are more likely to be divorced or separated than those have children without disability (Dhar 2009), Financial strain resulting from visits to doctors, medication, transportation and other specialized services can also prove to be taxing for the families (Wei & Jennifer, 2012). Then there are some major issues that come with the normal siblings of the child with intellectual disability. These issues may be, lack of acceptance by siblings, they may experience feelings of bitterness and resentment towards their parents or the child with disability. Feeling of jealousy, neglect, or rejection may come up as they watch most of their parents’ energy, attention, money, and psychological support flow towards the child with special needs (Levy et al. 2010). Many siblings swing back and forth between positive and negative emotion). Impact on the lives of the grand parents is another issues of concern. They may find it difficult to cope with twin issues of crisis, such their own age and the pain of their grandchild’s disability. With all this they may have to deal with their own distress, anxiety and uncertainty (Findler 2014) Problems among the family members may arise due to behavior problems of the child with disability, (Peshawaria 2008). Some other problems that have indirect impact on the caregivers are the issues related to the child’s special school, their behavioral and life skill issues. Apart from these there may be social problems as put forth by Taylor et.al, (2010) that burden of care
giving is more related to societal rejection, social stigma, along with challenge of navigating a poorly coordinated and often nonresponsive service system. In addition to all this are individualized services which have to be provided to the child with intellectual disability due to their unique needs.

1.5 Social Support: Family Support (Informal) and State Support (Formal)

1.5.1 Social Support: Social support acts as a bridge between the family that needs support and the sources of support available. It plays a role of a shock absorber and is an important mediating variable in buffering of the stressful events, which means higher the social support, lower the level of stress, thus creating better fabric of understanding among the family members and the child with disability. (Eisenhower et al. 2005) It is the communication between the providers & the receivers that tends to reduce the ambiguity which sometimes arises due to crises and has positive effect on the overall functioning. (Albrecht and Adeleman 1987) Overall social support deals with different types of support and processes which manage a range of factors that further cater to the issues related to the relationships and ties with others (Ryff and Singer 2000). It helps parents to alleviate amount of stress associated with raising a child with disability.

Social support has three components, the existence of social relationships, the structure of one’s social networks, and the functions of social support (House, Kahn, McLeod, & Williams, 1985). Another two major significant aspects of social support, perceived availability of support i.e. the support that is available and the received support means to the actual occurrence of a socially supportive exchange.

Social Support includes both Family Support System (Informal) and State Support System (Formal)

The support required by the families could be formal or informal. Formal such as support from professionals, medical services, respite services or health professionals and informal support from siblings of the child with disability, relatives, grandparents or friends. This support maybe extended by them in the form of counselling, babysitting or help in the household tasks. There are two factors related to support that are significant. Social support is important for health and stress relief; it increases resilience, multiple joy, and softness sorrow, (Scoott, E. 2007). An important resource for coping with stress is social support, the presence of others in whom one can confide and from whom one can expect help and concern. (Burton, Westen & Kowalski, 2009). Peshwaria (2008) very rightly stated that family support
and institutional support (state support) are significant facilitator.

1.5.2 Family Support Systems: The care and responsibilities undertaken by caregivers on a daily basis is considerable, both in economic terms and its sociological impact. Perhaps the most important aspect of family caregiving is that it helps to maintain family structures, enables care recipients to remain in their home environment, and enjoy the benefits of receiving individualized attention (Perkins, Lynn, & Haley, 2007). After all, no one is more familiar with personal likes, dislikes, and mannerisms than their own family members who become their caregiver. Families having children with disability experience lot of stress. Many areas that affected are, family relationships, finances, and social and recreational life, household functioning, care giving demands and siblings (Marsh 1992). They tend to seek support from others which plays a vital role in the families’ hard work to adjust to the disability and respond to its members’ psychosocial needs (DeMarle and Le Roux 2001). Parents who can turn to their relatives or friends are likely to have less depression and better health and wellbeing. It also alleviates their loneliness and isolation and provide the rejuvenation to get back to their role of looking after their child with disability (Corey 2005). Help may be primarily in the form of friendship, emotional, counselling or visiting. It has been seen that supportive relationships outside of the family lead to better adjustment, specifically for mothers (Wyngaarden Krauss 1993). Those approached for support include spouses. (Llewellyn 2002) found that single parents are more dependent upon professionals and those living with spouse are more family oriented. Spouse can provide chores such as shopping, cooking, caring for a child with disability as and when needed. In fact the mothers who receives great support from their spouse experiences lower level of stress that leads to happy marital relations (Hassell et al. 2005) Salovita, Italinna (2003) put forth the importance of family resources and spousal support as important factor to alleviate some of their stress. Apart from this. (Strohm 2002) said attachment between siblings life becomes easier for parents and for children themselves. Sibling relationship is one of the long term relationship the child with a disability has. (Berk et al. 2001). Normally older siblings tend to develop sense of responsibility and be a good source of support for parents a. Siblings are essential members of family support systems. (Llewellyn 1995) Positive relations between siblings assure parents and they can turn to their other children for support which is readily available at their home.
Grandparents is another important source of support and play a crucial role in managing their grandchildren with disability. (Meyer and Vadasy 1986) Grandparents provide emotional and financial and manual help when ever required. They even take out their grandchild having a disability for outings and for recreational activities. Lastly relatives and close friends help in responding to the challenges faced by families of an intellectually disabled child. Support from extended families proved to be stronger predictor of families quality of life than family income. (Davis and Gavidia Payne 2009). The friends are someone who you can trust a most and with good friends one can share their private feelings and can express emotions which is a powerful stress reliever for caregivers having a child with disability. Support from friends could be practical or emotional and one can share a lot of feelings and even personal things with friends, how well parents manage depends upon the support, acquaintance and guidance they get from their familiar support networks, particularly close friends and extended family such as grandparents (Mayes et al. 2008)

1.5.3 State Support System (Formal)

State support (Formal social support) is given through professional service providers in the form of schemes and services such as respite care services and various programmes run by the concerned government’s itself and through the NGO’s. Partnership between parents and professionals is very essential for ensuring that the children receive every opportunity to achieve their full potential.

1.5.4 State Support Systems Available for Persons with Disabilities in Australia and India

1.5.4.1 Constitutional and Legislative Provisions and Schemes for Persons with Disabilities in Australia

There has been strong evidence of continuing, unmet needs of persons with disability in Australia in various areas. An inexhaustive list of issues related persons with disability and their caregivers include personal assistance and care, support to live independently, appropriate accommodation options, interpreting services, education aides, access to assistive technology, support to meet additional expenses, apart from this support for family carers, respite services. The Australian Government has taken a number of initiatives to foster respect for the rights of persons with disabilities, fight stereotypes and encourage awareness of the capabilities and contributions of persons with disabilities.
Provisions in the Australian Constitution:

The constitution reaffirming the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination. According to constitution people with disabilities are entitled to the same rights and the same opportunities as all other Australian citizens. Section 23 of the Disability Discrimination Act makes it unlawful to discriminate on the grounds of disability in providing access to or use of premises that the public can enter or use. After more than 10 years of negotiations, the Australian Government has introduced new standards for access to buildings for people with disability. The standards, approved by the Parliament in November 2010, which clarify how to ensure buildings, are accessible to people with disability and meet the requirements of discrimination law. With regard to education, it would be unlawful for an educational authority to discriminate in the admission and treatment of students and in the provision of all levels of education, training and vocational or educational assistance, including financial assistance. Sections 234 and 235 of the Commonwealth Electoral Act 1918 provide for certain persons with disabilities to seek assistance to cast their vote or vote outside of a polling booth.

Apart From This There Are a Set of Legislative Provisions at Both Federal and State Level (Victoria)

Legislations Pertaining to Persons With Disability in Australia:

Australian Human Rights Commission Act 1986: Aims to encourage an understanding, recognition, public discussion of human rights in Australia and to commence research and educational programs and other programs, on behalf of the commonwealth, for the purpose of promoting human rights, and to co ordinate any such programs undertaken by any other persons or authorities on behalf of the commonwealth. The commission also handles complaints on discrimination on the basis of age, race, pregnancy, impairment and physical, mental, intellectual or psychiatric disability.

Disability Discrimination Act, 1992 aimed to eliminate discrimination against people with disabilities, promote community acceptance of the principle that people with disabilities have the same fundamental rights as all members of the community
and ensure as far as practicable that people with disabilities have the same rights to equality before the law as other people in the community.

State Initiative:

**Disability Act Victoria 2006:** Commenced on 1 July 2007. It replaced the Intellectually Disabled Persons' Services Act 1986 and Disability Services Act 1991. The act provides for a stronger whole-of-government, whole-of-community response to the rights and needs of people with a disability and a framework for the provision of high quality services and supports for people with a disability. According to this act the definition of people with ‘intellectual disability’ is the ones who are over the age of five years and present with the concurrent existence of significant sub-average general intellectual functioning and significant deficits in adaptive behaviour each of which became manifest before the age of 18 years. It also defines ‘developmental delay’ as a delay in the development of a child which is attributable to a mental or physical impairment or a combination both and is manifested before the child attains the age of six years and results in substantial functional limitations. Another area covered is that people with a disability be given information to assist them to exercise their rights and make choices in decisions affecting their lives and the services under this act.

**The Australian Citizenship Act 2007** provides significant assistance and accommodation for persons with disabilities in the various processes surrounding their citizenship applications. No one in Australia is deprived, on the basis of disability, of the ability to obtain, possess or utilize documentation of their Australian citizenship or other documentation of identification.

**Schemes: Provisions in Australia**

**Disability Pension.** Person included for this scheme are permanently blind or have been assessed as having a physical, intellectual, or psychiatric impairment unable to work, or to be retrained for work, for 15 hours or more per week at or above the relevant minimum wage within the next 2 years because of your impairment

**Carer Pension:** Provides supplementary payment for carers who provide additional daily care and attention for someone with a disability or medical condition, or who is frail aged and provide additional daily care for a dependent child aged under 16 years, with a disability or medical condition, who lives with them. Apart from this it provides additional daily care for two dependent children with disabilities or medical
conditions, who do not individually qualify for Carer Allowance, but together have a substantial caring responsibility and live with them; or provide additional daily care for a person aged 16 years or over who has a disability, medical condition, or who is frail aged care must be provided in either your home or the home of the person you are caring for.

**Disability services case management**

Disability case management service aims to assist people with disabilities to become more independent and active in community life. Case managers establish a positive collaborative relationship with the person, and their support network, such as family members, and assist the person to identify, link with and organize the supports they need to deal with problems and achieve their goals. Case management involves a person-directed planning process. Support accessed through case management will be suited to individual needs and the needs of family and carers.

Aids & equipment: The Victorian Aids and Equipment Program (A&EP) provides people with a permanent or long-term disability with subsidized aids, equipment, home, and vehicle modifications. The program aims to enhance the independence of people with a disability in their own home, facilitate their participation in the community and support families and carers.

Disability supported accommodation: The department funds community service organizations to provide a range of supported accommodation services including group homes and community residential units for people with a disability. The support is based on the individual needs and promotes community participation, relationship building, skill development and maintenance. Accommodation is usually offered in shared housing with the residents supported by a team of staff who usually work according to a roster. Supported accommodation services are provided under the Disability Act 2006. Accommodation options for people with a disability include: support to live in their own home, or the family home through an individual support package. Outreach support to assist people to live more independently in their own home, support for younger people at risk of admission to residential aged care, shared supported accommodation that is an accommodation solution for people who require rostered support and is targeted to people with a disability with the highest support needs.
Futures for Young Adults: This is a post-school funded support is available through Futures for Young Adults (also known as FFYA). FFYA is funding provided by the Victorian Government to support young people to access further education, training, employment or other community options that help meet their transition goals. FFYA funding is provided for up to a maximum of three years from when young people with a disability leave school up until they turn 21 years of age.

Post-School Transition Support: The transition from school to adult life presents young people with a wide range of options, including further education, employment, vocational training, volunteering and other community-based activities. Young people who have disability support need, may find it difficult to access these options in the short or longer term and may need funded support from the Victorian Government.

Exploring the possibilities: The resource guide for exploring the possibilities provides a starting point for young people with a disability, their families and supporters to explore the range of options available.

Community Health Centre: The services offered vary between community health services, depending on the needs of the local area. Primary health services include: Counselling and support services, health promotion activities, medical and nursing services, dental health, allied health, including audiology, dietetics, exercise physiology, physiotherapy, podiatry, occupational therapy and speech therapy. Other services and supports include: Carer respite, disability services, rehabilitation programs, support for self-help.

Behavior Support Services: Behavior support services deliver systematic, environmental, educational and other therapeutic strategies to prevent the occurrence of behaviors of concern. Behaviors of concern are behaviors that are a barrier to a person participating in and contributing to their community and pose a risk to the health and safety of a person and the community. This include aggressive, self-injurious, anti-social or dangerous behaviors. Behavior support services are delivered by practitioners via departmental divisions, community service organizations (CSOs) or private practitioners. Within the department, practitioners includes a range of staff with tertiary qualifications in relevant disciplines such as, psychology, nursing, social work, speech pathology, and staff who have relevant behavioral training and experience. Behavior support services teams (sometimes known as Specialist Services
Teams or Behavior Intervention Services Teams) are committed to the use of non-aversive techniques that maximize quality of life and reduce behaviours of concern.

**Australian Disability Parking Scheme** includes Disability Parking Permit, which is recognized nationally. It has nationally consistent eligibility criteria and national minimum parking concessions to help to reduce the barriers for permit holders when travelling interstate. Permit holders can park in parking spaces showing the international symbol of access and can receive concessions in most public parking spaces where the sign or meter shows specific time limits. A disability parking permit is granted to persons when their ability to walk is severely restricted by a medical condition or disability and also to organizations that transport individuals who meet the eligibility criteria.

**Australian Disability Enterprises** are commercial enterprises enabling people with disability to engage in a wide variety of work tasks such as packaging, assembly, production, recycling, screen printing, plant nursery, garden maintenance and landscaping, cleaning services, laundry services and food services. Employees of Australian Disability Enterprises employ people with disability who find it difficult to work or maintain employment and enjoy the same working conditions as those in the general workforce.

**The Cinema Access Implementation Plan** and the establishment of the Accessible Cinema Advisory Group (ACAG) aims to assist Australians major cinema chains in converting to a digital based technology to significantly reduce barriers to people with disability. The main aim is to improve cinema accessibility for people who are deaf or hearing impairment, blind or vision impaired

**National Companion Card** brings together state and territory programs that enable eligible people with disability who require attendant care support to participate at venues and activities without incurring the cost of a second ticket for their companion. The cardholder needs to present the card to purchase a ticket or pay an entry fee and they can receive a ticket for their companion at no extra charge. Under this scheme, a cardholder may use their card in any state when on holidays or travelling.

**Disability Investment Group** The Australian Government has established a Disability Investment Group to explore innovative funding ideas from the private sector that will help people with disability and their families’ access greater support and plan for the future.
National Disability Advocacy Program provides organizations with funding to assist people with disability to overcome barriers that have impact on their daily life and their ability to participate in the community. This programme provides people with disability access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights and to enable them to participate in a community. As per this programme the primary aim is for advocacy agencies is to promote advocacy by assisting people to speak for themselves, but if they are unable to do so, an advocate speaks on their behalf.

Print Disability Services funds nine print disability service providers to produce alternative formats of printed material for people, who are unable to read, hold or manipulate printed material in standard form because of their disabilities.

Outside School Hours Care for Teenagers with Disability: Which was formerly known as the Extra Support for Children with Disability Program, is an Australian government’s initiative to increase outside school hours care and holiday care for teenagers with disability aged between 12 to 18 years. This activity provides quality outside school hours care for students ages 12 to 18 with disability and their parents and carers with time to work or participate in the community.

Leaders for Tomorrow is a new national program which aims to develop the leadership capacity of people with disability and provide up to twelve months of leadership support to two hundred people with disability to 30 June 2014. The aim of this scheme is to link people with disability with suitable training, and give support and mentoring to develop the skills and confidence to become leaders in business, community and government.

Helping Children with Autism (Autism Spectrum Disorders) It includes support for parents, families, carers and children from diverse cultural, linguistic and Indigenous backgrounds and living in rural and remote areas. Australian Government also committed to spend millions of dollars to address the need for services for children with Autism, their families and carers. This funding is ongoing. Following diagnosis families can contact autism advisor in their state who provides information regarding eligibility, available funding, early intervention and other support services. Children who would like to access early intervention funding of up to $12000 can access that funding if they have seen by an autism advisor and deemed eligible to access the service before their sixth birthday. Families who reside in an outer regional
or remote area may be eligible for a one off payment of $2000 to cover the additional expenses associated with early intervention services. There is a funding to support older children with autism as well. Even the parents can get funding to attend workshops, information sessions and to access online workshops.

**Employment For People With Disability:** The Victorian government is committed to ensuring its workforce is reflective of the community. This includes increasing the employment of people with a disability and actively promoting awareness and understanding among government employers to create inclusive and diverse work environments. People with a disability are encouraged to apply jobs in the Victorian Government. The disability employment advisory service (DEAS) aims to increase the number of people with disability who work in Victorian government departments. The service is designed to provide a supportive approach to employing people with disability. It helps to ensure staff have the knowledge and tools to engage and retain a diverse workforce.

**National Disability Insurance Scheme:** This scheme is big effort to provide support and services to people with disability, their family and carers with funding from all levels of government. NDIS support choice for people with disability their families and put people in control of care and support they receive based on need and also help them make informed choices. NDIS includes a comprehensive information and referral service, to help people with a disability who need access to mainstream, disability and community supports. NDIS gives people the peace of mind to know that if they have or acquire a disability that leaves them needing daily assistance with everyday life, or if they care for someone who has a disability, that they will be supported.

**Aids and Equipment Scheme:** Under this scheme people with a permanent or long term disability are provided aid, equipment, home and vehicle modifications on subsidised rates. This scheme aims to enhance the independence of people with a disability in their own home, facilitate their participation in the community and support families and carers.

**Some reflections on the future:**

**National Disability Strategy (2010-2020)** has set a ten year national plan for improving life for persons with disabilities, their families and caregivers in Australia. This new approach will assist in addressing the challenges faced by people with
disabilities, both now and in future. The strategy includes inclusive and accessible communities, the physical environment including public transport, parks, buildings, parks, buildings and parks. Economic Security in terms of jobs, business opportunities, financial independence and income support for those who are not able to work. Apart from this health promotion, early childhood education, care and vocational education for persons with disabilities are also there in the package.

1.5.4.2 Constitutional Provision, Policies, Legislations and Schemes for Persons with Disabilities in India

Constitutional Provisions: Primary idea behind all the fundamental rights assured in the Constitution of India is to keep in view the dignity and respect of every human being. Thus persons with disability have the same fundamental rights as the ones without disability. In the Article 4, the State shall promote with special care, the educational and economic interests of the weaker sections of the people and shall protect them from social injustice and all forms of exploitation. The Article 14 says that the State shall not deny to any person equality before the law or the equal protection of laws within the territory of India. Whereas according to Article 15, nothing in this article shall prevent the State from making any special provision for the advancement of any socially and educationally backward classes of citizens. Then the Article 41 declares that, the State shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement. The Article 46 on the other hand lays down an obligation on the State to promote with special care, the educational and economic interests of the weaker sections of the people, and protect them from social injustice and all forms of exploitation. The constitution says that the State shall make an endeavor to provide for free and compulsory education for all children until they complete the age of 14 years. Though the fundamental rights, do not have a specific mention of the physically handicapped or disabled, yet they do pertain to the socially, economically and educationally backward class of people. The Ministry of Social Welfare has already recommended that the disabled be treated equal to women and other weaker sections of the community.

The National Policy for Persons with Disabilities 2006: It came up as a response to the need to have a extensive document that would put forth all the decisions and
actions related to provisions for persons with disabilities. The policy further acknowledged that persons with disabilities are a significant human resource for the country and sought to create a milieu that shall not only provide them with equal opportunities for full participation as others and also protect their rights. For this the policy also ensured that they exercised their rights through various opportunities at an equal level as others. The policy recognized the existence of social barriers, thus supported the provision of equal opportunities in areas such as early identification and support, education, rehabilitation programmes, employment, social security, barrier-free environment, trained human resources, recreation, cultural options and access to appropriate aids and appliances. Similar initiatives were proposed in the area of education where emphasis is on that children would receive right to education from preschool years to post secondary and also be given vocational training. They shall receive this education by trained and qualified persons through a continuum of educational options ranging from regular schools, community based rehabilitation programmes to home-based programmes for children with severe disabilities, who choose to receive education in this mode. The policy made a special mention of access, care, protection and security, for protection of the rights of young children with disabilities. It also highlights the need to ensure that children with all levels of ability are included in accessing education, recreation, rehabilitation, health and other specialized services. Women with disabilities got a special recognition in this policy. Focus was on supporting programmes which will provide education, employment and rehabilitation, developed for the unique needs of women with disabilities. It also highlighted the need to protect women with disabilities against abuse and exploitation. The Ministry of Social Justice and Empowerment is the nodal agency to implement the provisions included in the national policy. It is supposed to coordinate the implementation of the policy in collaboration with other agencies including government, disabled people's organizations, NGOs working in the area of disability, representatives of family or parent associations and experts and professionals. The policy foresees a complete package of welfare services to the persons with disabilities. It also seeks to deal effectively with their multidimensional problems of the concerned group. In addition to legal framework an extensive set up has been developed in the form of six National Institutes: (i) National Institute for Visually Handicapped, Dehradun; (ii) National Institute for the Orthopedically Handicapped,
Calcutta; (iii) Ali Yavar Jung National Institute for the Hearing Handicapped, Mumbai; (iv) National Institute for the Mentally Handicapped, Secunderabad; (v) National Institute for Rehabilitation, Training and Research, Cuttack; and (vi) National Institute for Physically Handicapped, New Delhi. All the above institutes offer a variety of long term training programmes: three year degree courses in physiotherapy, occupational therapy, mental retardation.

**Legislations Pertaining to Persons with Physical Disabilities**

**Mental Health Act- 1987:** Mental health act was drafted by parliament in 1987 but it came into effect in all the states and union territories of India in April 1993. It consolidate and amend the law relating to the treatment and care of mentally ill persons, to make better provision with respect to their property and affairs and for matters connected therewith or incidental thereto. Health in this is defined as the state of complete physical, mental and social wellbeing and not merely an absence of disease or infirmity.

Salient features of the Act: Mental health act is divided into 10 chapters consisting of 98 sections.

Chapter I: Deals with preliminaries of the act, definitions and provides for change of offensive terminologies used in Indian Lunacy act 1912.

Chapter II: Deals with the procedures for establishment of mental health authorities at central and state levels.

Chapter III: It lays down the guidelines for establishment and maintenance of psychiatric hospitals and nursing homes. There is a provision for licensing authorities to process applications for license which have to be renewed every five years.

Chapter IV: It deals with the procedures of admission and detention of mentally ill in psychiatric hospitals.

Chapter V: It deals with the inspection, discharge, leaves of absence and removal of mentally ill persons.

Chapter VI: It deals with the judicial inquisition regarding alleged mentally ill persons possessing property and its management.

Chapter VII: It deals with the maintenance of mentally ill persons in a psychiatric hospital or psychiatric nursing homes.

Chapter VIII: It deals with the protection of human rights of mentally ill persons.
Chapter IX: It deals with the penalties and procedures for infringement of guidelines of the act.

Chapter X: It deals with miscellaneous matters not covered in other chapters of the act

Objectives of the Act:

- To establish central and state authorities for licensing and supervising the psychiatric hospitals.
- To establish such psychiatric hospitals and nursing homes.
- To provide a check on working of these hospitals.
- To provide for the custody of mentally ill persons who are unable to look after themselves and are dangerous for themselves and or, others.
- To protect the society from dangerous manifestations of mentally ill.
- To regulate procedure of admission and discharge of mentally ill persons to the psychiatric hospitals or nursing homes either on voluntary basis or on request.
- To safeguard the rights of these detained individuals.
- To protect citizens from being detained unnecessarily.
- To provide for the maintenance charges of mentally ill persons undergoing treatment in such hospitals.
- To provide legal aid to poor mentally ill criminals at state expenses.
- To change offensive terminologies of Indian Lunacy act to new soothing ones.

Procedure for admission and discharge of mentally ill: A mentally ill person (not a minor) may make a request for admission as a voluntary patient; in case of minor his guardian may make such request. Medical officer in-charge, on such request after enquiry, within 24 hrs, if thinks necessary may admit such person and shall discharge such patients on request by him or guardian as the case may be, unless he finds such discharge against patient's interests. Such cases will be referred to medical board, which if decides the same, then patient will be further admitted for a period not exceeding 90 days for treatment. A mentally ill may be admitted as inpatient on a request by friends or relatives. Such request should be supported by medical certificates to the effect. In such cases medical officer in-charge may admit the patient if he thinks necessary. Request for admission may also be made by a police officer if such mentally ill person is dangerous to himself or others. Such persons will be discharged by magistrate on request by friends/relatives or after they are certified to
be sane by the board of experts. Most of the sections of the act are in accordance with mental health act 1959 and the mental health (amendment) act 1982 of England and mental health act 1960 of Scotland with minor differences.

**Rehabilitation Council of India Act (1992):** It was amended in the year 2000. This act came into force as a rejoinder to the need to have standardization, by ensuring minimum standards, quality of education and training in the field of disability. This was to be done by prescribing minimum standards of education and training of various categories of professionals dealing with people with disabilities and regulating the standards in all training institutions equally in the country. It also provided recognition to the institutions/universities running degree/diploma/certificate courses in the field of rehabilitation of the disabled and withdrawal of recognition, wherever facilities are not satisfactory. The Act also prescribed disciplinary action against unqualified persons delivering services to persons with disability. Rehabilitation council of India has been delegated with the task to develop uniform syllabi for various rehabilitation courses, also to regulate and monitor services given to persons with disability. It maintains a central rehabilitation register of all qualified professionals and personnel working in the field of rehabilitation and special education. The act provides for regulation of the training policies and programmes in the field of rehabilitation of people with disabilities and recognize Vocational Rehabilitation Centers as human resource development centers and encourage Continuing Rehabilitation Education (CRE) for professionals trained and working in the field, in collaboration with organizations working in the field of disability. Training courses such as Foundation Course and Certificate Course, Diploma, Degree and Post Graduate Diploma courses, recognized by the Rehabilitation Council of India launched by distance education centers or are being run on regular basis are run by universities, training Institutes and NGOs. Professionals after completion of either of these courses are entitled for registration in the Central Rehabilitation Register maintained by the RCI and are thus eligible to practice. They must also at specific times undergo re-training by attending various training courses in order to renew their registration.

**The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995:** The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 is one of the important
legislation enacted by the Parliament in the history of disability movement in India. The paradigm shift from the welfare and charity approach to the right based has been summed through this landmark enactment. This act was passed in December 1995, and enforced in February 1996. It is guided by the philosophy of empowering persons with disabilities and their associates. The endeavor of the act has been to introduce an instrument for promoting equality and participation of persons with disability on the one hand, and eliminate discriminations of all kinds, on the other. It aims to protect and promote economic and social rights of people with disabilities. The act is divided into fourteen chapters.

In chapter one, the section 2(t) of the act, proclaims that a person with disability means ‘a person suffering from not less than forty percent of any disability as certified by a medical authority.’ The act covers seven disabilities which have been listed in Section 2, these include blindness, low vision, hearing impairment, locomotor disability or cerebral palsy, mental retardation, mental illness and persons cured of leprosy. Apart from this, the section also covers some other concepts related to disability.

Chapter four of the act covers provisions related to promotion of methods for prevention and early detection of disabilities by screening all the children at least once in a year to identify cases who are at risk. It includes surveys and research to investigate the cause of occurrence of disabilities, provision of facilities for training to the staff at the primary health centers, taking of measures for pre-natal, parental and post-natal care of mother and child, education of the public through the pre-schools, schools, primary health Centers, village level workers and anganwadi workers, sponsor awareness campaigns and create awareness among through electronic and print media.

In chapter five, the section 26,27 and 30 list out provisions for education of persons with disabilities which include access to free education till eighteen years, promotion of integration into the mainstream, schemes to conduct part time classes: for children who have completed class fifth but could not continue, for providing functional literacy for children in the age group of sixteen. Provision of non-formal education by utilizing the available manpower in rural areas after giving them appropriate orientation and lastly imparting education through open schools or open universities.
Whereas chapter six is on employment issues, under the section 32, 33, 38 cover identification and reservation of posts with periodic review and updatation of list at, interval not exceeding three years. Reservation of vacancies not less than three per cent with one per cent. each of the following category, blindness or low vision, hearing impairment, loco motor disability or cerebral palsy. Also formulate schemes for ensuring employment of persons with disabilities, and such schemes may also provide for training and welfare of persons with disabilities, relaxation of upper age limit, regulation of employment, health and safety measures and creation of a non-handicapping environment.

The act has an exclusive chapter eight, entitled non-discrimination in which sections 45, 46 and 47 prohibit discrimination on the basis of disability in the matter of public employment and in access to public facilities. The parallel reforms in service rules, building codes and motor vehicle standards have been tremendously slow. For this reason the, disability litigations are on rise but the positive element in the present situation is that disposal of disability discrimination cases both by courts and quasi judicial bodies is reasonably quick.

Chapter IX on Research and Manpower Development, promotes research in areas such as, prevention of disability, rehabilitation including CBR, development of assistive devices, job identification, on site modifications of offices and factories. Also to provide financial assistance to the universities, other institutions to carry out research purposes.

Overall the act puts forth the responsibility of the government at all levels including establishments under its control. It lays down precise measures to develop services and programmes, to bring in equality in the opportunities for enjoyment of right to education, work, housing, mobility and public assistance in case of severe disability and unemployment. To accomplish these responsibilities, a Central Co-ordination Committee and State Co-ordination Committees which represent major development ministries, members of parliament nongovernmental organizations for persons with disability and woman with disability, as a member have been envisaged in the multi-sector model. Furthermore, the institution of Chief Commissioner in the Centre and Commissioner for Persons with Disabilities in States has been proposed. Their mandate is to redress individual grievances, provide safeguards to the rights of persons with disabilities, monitor implementation of disability related laws, rules and
regulations, and oversee utilization of budget allocated on disability. These quasi-
judicial bodies are vested with the powers of a civil court. For grievance redressal in
case of violation of rights as given in the act, people with disabilities may move an
application to the chief commissioner for persons with disabilities in the Centre and
commissioner for persons with disabilities in the states

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental
Retardation and Multiple Disabilities Act, 1999: This Act provides for the
constitution of a national body for the Welfare of Persons with Autism, Cerebral
Palsy, Mental Retardation and Multiple Disabilities. Such a national body will be a
trust whose objects shall be as under:

- Enable and empower persons with disability to live as independently and as
  fully as possible within and as close to the community to which they belong.
- Strengthen facilities to provide support to persons with disability to live within
  their own families.
- Extend support to registered organization to provide need based services
during the period of crisis in the family of persons with disability,
- Deal with problems of persons with disability who do not have family support.
- Promote measures for the care and protection of persons with disability in the
  event of death of their parent or guardian.
- Evolve procedure for the appointment of guardians and trustees for persons
  with disability requiring such protection.
- Facilitate the realization of equal opportunities, protection of rights and full
  participation of persons with disability.

Reflections of Approaches and Programmes in the Last Four, Five Year Plans:

Ninth five year Plan (1998–2002): During this plan the approach and focus towards
persons with disability radically shifted from the welfare approach to the right based
approach. There was special emphasis on adopting an integrated, multi-collaborative
approach towards empowering the persons with disabilities and making them a part of
the mainstream. Strategies adopted for empowering them, during this plan were:

- Effective enforcement of a comprehensive legislation i.e. Persons with
- Reaching out to the neglected persons with disability in rural areas.
• Putting together the existing services in welfare of associated sectors to gain maximum benefits.
• Create facilitating environment for persons with disabilities to help them to exercise their full rights for equal opportunities and participation, by the efforts of both the government and non-governmental organizations.
• Put together, both financial and manual resources of all concerned for family/community based rehabilitation.
• Prevent disabilities through supplementary nutritional feeding for both children and expectant/nursing mothers, early detection and timely intervention
• Strengthen and expand special schools and vocational training programmes with barrier-free environment.
• Strengthen and expand the national institutes for persons with the disabilities
• Make provision for simple, strong and realistically priced aids and appliances and setting up of a National Trust to ensure total care and custodianship of those with Mental Retardation and Cerebral Palsy. For this the legislation, The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act 1999 was passed.

A broad set of activities covered by both the enabling legislations were as follows: issuance of disability certificates, prevention and early detection of disabilities, promotion of the idea of integration of students with disability in mainstream schools and removal of architectural barriers from institutions at primary level up to institution of higher education. It also included provision of incentives to private sector employers that ensured persons with disabilities constituted at least 5% of their workforce and lastly framing of a scheme for payment of an unemployment allowance to those persons with disability who despite their registration with a special employment exchange for more than two years have not been placed in any gainful employment.

**The Tenth Five year plan (2002-2007):** It took serious note of the slow pace of implementation of the enabling legislations and advocated a multi-sectoral and multi-collaborative approach to make the provisions of the Persons with Disabilities Act 1995 more effective through clear-cut delineation of responsibilities to the concerned ministries/departments. It was also documented that the ministry of social justice and
empowerment, being the nodal ministry, should make sure that the objectives of the act are fulfilled. Besides monitoring/reporting the progress on a regular basis, the concerned ministries/departments were to formulate detailed rules and guidelines for the same. To ensure adequate financial support to efforts to support the disabled, the tenth plan advocated the introduction of a ‘component plan for the disabled’ in the budget of various ministries/departments. The government has been encouraging education among persons with disabilities. Five hundred scholarships were provided every year during the tenth plan for higher and professional courses. The Ministry of Health and Family Welfare initiated a number of programmes for the prevention and reduction of the incidence of various disabilities.

**The Eleventh Five Year Plan (2007-12):** Thrust of this plan was to empower the persons with disability and give special attention to monitoring mechanisms. It aimed at inclusive growth. It expected to achieve inclusiveness through significant improvements in literacy/education, health, greater employment opportunities and sharper focus on disadvantaged group. Emphasis was on right based approach to empower the persons with disabilities. This plan was based on the Persons With Disabilities Act 1995, National Policy for persons with disability 2006 and UN Convention on Rights Persons with Disabilities, with a four pronged approach, that covered the following:

- To outline clear cut responsibilities amongst concerned ministries/departments.
- Detailed rules and guidelines to be formulated concerned ministry/department within six months of approval of plan.
- To ensure that each ministry/department reserves not less than 3% of the annual outlay for persons with disabilities.
- To set-up monitoring mechanisms at various levels and develop review systems.
- To upgrade the disability division of ministry of social justice empowerment into a separate department.
- To strengthen the office of the commissioner for better performance so and ensure different ministries/departments perform their function.
- Set up ‘National Institute of Universal Design’ to promote barrier-free environment.
• Raise income ceiling for assistance under Assistance to Disabled Persons Scheme to Rs. 10,000/- and enhancement to Rs 25,000 aids and appliances per person.
• Commercial and rural banks and National Bank for Agriculture and Rural Development (NABARD) to provide loans on a concessional basis
• Ensure that District Magistrate are responsible to provide disability certificate within 30 days of making an application
• Vigorous implementation of the comprehensive action plan for inclusive education of children and youth with disabilities
• Identify of jobs- with the help of disabled person organizations.
• Workout on backlog placements
• Incentives to promote employment of persons with disabilities in private sector
• Amend building bye-laws for barrier-free access.

The Twelfth Five Year Plan (2012-17): This plan too looks into three key aspects: Firstly recognition of the extent to which development, competence and emerging personal autonomy of persons with disabilities can be enhanced through realization of various agreed national and international convention and programmes. Secondly empowerment in terms of denoting the rights of persons with disabilities to respect their capacities and by transfer of their legal rights. Thirdly protection, acknowledging that persons with disabilities have un-evolved capacities as consequences of their disabilities and thus have right to protection programmes meant for persons with disability. The two pronged strategy adopted for persons with disability, under this plan included, Public awareness on disability rights and issues by stepping up of level of awareness of legislative provisions, development programmes. Secondly service delivery which includes, making large number of products, accessible public and information services, improving participation and completion rates of education at various levels, enhancing condition of health, nutrition and housing upto reasonable level, reducing disproportionate incidence of poverty and identifying exclusive implementation agencies.
The other areas covered were, empowerment of municipalities and panchayats to work for persons with disabilities. Review the existing legislations. Intensified efforts to cater to the needs and problems and the ones with severe disabilities.

**Some Programmes/Schemes**

**National Programme for Control of Blindness**: It was launched by the Ministry of Health & Family Welfare, Government of India in 1976. India was the first country in the world to have launched a national level blindness control programme. It is a 100% centrally sponsored programme. It was included in the Prime Minister’s 20-point socio economic programme in 1982. Main Objective of the programme are:

- Reduce the backlog of blindness through identification of treatment of blindness & visually handicapped.
- Develop eye care facility in every district.
- Develop human resources for providing eye care services.
- Improve the quality of services delivery.
- Secure participation of Voluntary organization in eye care.
- Enhance community awareness of eye care.

**National Program for Prevention and Control of Deafness (NPPCD)**: This programme started in 2006 with its pilot project run in 25 districts. The program is being implemented through National Rural Health Mission (NRHM). Main objectives of the programme are:

- Prevention of the avoidable hearing loss on account of disease or injury.
- Early identification, diagnosis and treatment of ear problems responsible for hearing loss and deafness.
- Medical rehabilitation of persons of all age groups, suffering with deafness.
- Strengthening of the existing inter-sectoral linkages for continuity of the rehabilitation Programme, for persons with deafness.
- Development of institutional capacity for ear care services by providing support for equipment and material and training personnel.

Following strategies have been adopted to fulfill the above objectives:

- Strengthening of the service delivery including rehabilitation.
- Development of human resource for ear care.
- Promote outreach activities and public awareness through appropriate and effective Information, Education, and Communication strategies with special emphasis on prevention of deafness.
- Develop institutional capacity of the district hospitals, community health centers and primary health centers, selected under the project.

The components of the programme include manpower training and development, capacity building, service provision including rehabilitation, awareness generation through effective Information, Education, and Communication activities.

**Assistance of Disabled Persons for Purchase /Fitting of Aids and Appliances:**
Disability restricts the opportunities for concerned individuals to lead a functionally productive life. Though with the application of modern technology, there have emerged a number of aids, which can reduce the effects of disabilities and enhance the economic potential of the disabled. Still a large number of persons with disability are deprived of the benefits of appliances because of their inability to find funds to purchase them. The main objective of the scheme is not only to assist the needy persons with disability to procure durable and scientifically manufactured modern standard aid and appliances but also to promote their physical, social and psychological rehabilitation by reducing the effects of disability through enhancement of their economic potential. The aids and appliances supplied must be ISI marked. A person with disabilities fulfilling following conditions are eligible for assistance under Assistance to Disabled Persons Scheme through authorized agencies. They should be an Indian citizen of any age and be certified by a registered medical practitioner they are disabled and fit to use prescribed aid/appliance. Apart from this they should either be employed/self-employed or getting pension The monthly income from all sources does not exceed Rs. 10,000/- per month. In case of dependents, the income of parents/guardians should not exceed Rs. 10,000/- per month. These persons should not have received assistance from the government, local bodies and nongovernmental organizations during the last three years for the same purpose. However, for children below 12 years of age this limit is one year. Only those aids/appliances which do not cost more than Rs. 6,000/-are covered under the Scheme. However, for visually, mentally, speech & hearing or multiple disabled, the limit is Rs. 8,000/- during their study period after IX standard. The limits applies to individual items of aid and where more than one aid is required, the ceiling is applied separately. The following aids and
appliances may be allowed for each type of disabled individual. For hearing disabled various types of hearing aids, educational kits like tape recorders/CD players, assistive and alarming devices including devices for hearing of telephone, TV, doorbell. Communication aids, like, portable speech synthesizer. For visually impaired, learning equipments like arithmetic frames, geometry kits. Giant Braille dots system for slow-learning blind children, Dictaphone and other variable speed recording systems, CD player for visually impaired student from X standard, Science learning equipments like talking balances, talking thermometers, measuring equipments like tape measures, micrometers. Braille writing equipments including braille writing equipments including braillers, braille shorthand machines, typewriters for visually impaired students from X class. Talking calculators, geography learning equipments like raised maps and globes. Communication equipments for the deaf-blind include braille attachments for telephone for deaf-blind persons. Low vision aids including hand-held stand, lighted and unlighted magnifiers, speech synthesizers or Braille attachments for computers. Special mobility aids for visually impaired people with muscular dystrophy or cerebral palsy like adapted walkers. Soft-ware for visually impaired persons using computers that are likely to cost more than Rs. 6,000/- may be procured and provided in exceptional cases subject to prior approval of ministry of social justice and empowerment on case to case basis. For all other devices ceiling is Rs. 6,000/-. Lastly for Persons with locomotor disability, all types of prosthetic and orthotic devices, mobility aids like tricycles, wheelchairs, crutches walking sticks and walking frames may be provided. Motorized tricycles for persons with locomotor disability that are likely to cost more than Rs. 6,000/- may be procured and provided in exceptional cases subject to prior approval of ministry of social justice and empowerment on case to case basis. Extent of subsidy would however continue to be Rs. 6,000/- for all other devices, ceiling is of Rs. 6,000/- for all types of surgical foot wears and MCR chappals. From the year 2007-08, a new approach was adopted for district wise allocation of funds to organize camps for person with disability for distribution of aids and appliance to ensure country wide coverage. This approach was taken further by promoting involvement of Red Cross Societies, District Disability Rehabilitation Centre’s and state government Corporation/Boards.

Deendyal Disabled Rehabilitation Scheme to Promote Voluntary Action for Persons with Disabilities: Thrust of this scheme is to facilitate delivery of various
services to persons with disabilities through voluntary organization. To facilitate delivery of various services to persons with disabilities by voluntary organizations, the ministry of social justice and empowerment is administering DDRS scheme and providing grants-in-aid to NGOs. It covers projects for:

- Cerebral palsied children
- Rehabilitation of leprosy cured persons (LCPs)
- Survey, identification, awareness and sensitization
- Community based rehabilitation and human resource development
- Legal literacy, including legal counselling, legal aid and analysis and evaluation of existing laws and seminars/workshops/rural camps
- Environment friendly and eco-promotive
- Low vision centres
- Vocational training centers
- Sheltered workshops and special schools
- Home based rehabilitation program/home management programme
- Grant for purchase of vehicle, computers and construction of building
- Half way home for psycho-social rehabilitation of treated and controlled mentally ill persons.
- District disability rehabilitation centers (DDRCs)

The maximum level of support could be up to 90% of the eligible amount of grant for the project. The guidelines of the scheme were revised in the year 2009.

**National Awards for Empowerment of Persons with Disabilities:** In this scheme awards are given, not only to the most efficient/outstanding employees with disabilities but also the best employer, best placement agency/officer, outstanding individuals, role models, outstanding creative disabled individuals and for outstanding technological innovation and adaptation of innovation to provide cost effective technology. Awards are also given to government sector, public sector undertakings and private enterprises for creating barrier free environment for the persons with disabilities, the best district in the field of disability rehabilitation, best local level committee of National Trust and to the best State Channelizing Agency (SCA) of the National Handicapped Finance and Development Corporation (NHFDC). Preference is given to the placement of women with disabilities, particularly from the rural areas.
and self employed women. The National Awards are presented in the following categories:

- Best employees/self-employed with disabilities with following sub categories: Blindness, low vision leprosy cured, hearing impairment, locomotor disability, Cerebral Palsy. They get Rs.25,000/- in cash, a citation, a certificate and a medal. In addition, 10 more awards i.e. one award in each sub-category, are given, which will carry a cash award of Rs.15,000/-, a citation, a certificate and a medal each. Seven awards are reserved for women with disabilities.

- Best employers and placement officer/agency with three sub categories, firstly the best employer who gets Rs.50,000/- in cash, a shield, a citation and a certificate. In addition, 5 more awards are given in the category with Rs.15,000/- in cash, a shield, a citation and a certificate in each case. One award is reserved for women. Secondly for the Best Placement Officer/Agency which gets Rs.25,000/- in cash, a shield, a citation and a certificate. In addition, 3 more awards are given in the category with Rs.15,000/- each in cash, a shield, a citation and a certificate. One award with the same composition is reserved for eligible woman applicant. Third sub category is of best individual and institution working for the cause of persons with disabilities, for the best individual gets Rs.1,00,000/- in cash, a citation and a certificate. In addition, 4 more awards (including one for the woman and two for the professionals in the field) are given in this category. Each award carries a cash amount of Rs.25, 000/-, a citation and a certificate. One award with the same composition is reserved for eligible woman applicant. The best institution gets Rs.1, 00,000/- in cash, a citation and a certificate. In addition, 5 more awards will be given in this category. Each award will carry a cash amount of Rs.25, 000/- each, a citation and a certificate. Thus, the total awards in this category are six.

- Role model awards is of Rs.50, 000/- each in cash. Two awards in this category are reserved for eligible women applicants.

- Best Applied Research Technological Innovation aimed at improving the life of persons with disabilities Rs.1,00,000/- in cash, a citation and a certificate.
- Development of new cost effective product for manufacture aimed at improving the life of persons with disabilities Rs. 50,000/- each, citation and certificate.
- Outstanding work in the creation of barrier-free environment for the persons with disabilities, a citation and a certificate.
- Best district in providing rehabilitation services, shield, citation and certificate.
- Best local level committee of national trust, shield, citation and certificate.
- Best state channelizing agency of national handicapped finance and development corporation, shield, citation and certificate.
- Outstanding creative adult persons with disabilities Rs. 50,000, citation and certificate.
- Best creative child with disabilities, one male and one female, Rs. 25,000 cash, medal, citation and certificate.
- Best Braille press, Rs. 10,000, citation and certificate.
- Best accessible website, Rs. 100,000, medal, citation and certificate.

**National Scholarships for Persons with Disabilities**: Under this scheme every year, 500 new scholarships are awarded for pursuing post matric professional and technical courses of more than one year duration. However, in case of students with cerebral palsy, mental retardation, multiple disabilities, profound and sever hearing impairment, scholarships are awarded for pursuing studies from IX std onwards. Advertisements inviting applications for scholarships are given in leading national/regional newspapers in the month of June and are also placed on the website of the ministry. Students with 40% or more disability whose monthly family income does not exceed Rs. 15,000/- are eligible for scholarship. A scholarship of Rs. 700/- per month to day scholars and Rs. 1,000/- per month to hostellers is provided who are pursuing graduate and post graduate level technical or professional courses. Rs. 400/- per month to day scholars and Rs. 700/- per month to hostellers is provided for pursuing diploma and certificate level professional courses. In addition to the scholarship, the students are reimbursed the course fee subject to a ceiling of Rs. 10,000/- per year. Financial assistance under the scheme is also given for computer with editing software for blind/deaf graduate and postgraduate students pursuing professional courses and for support access software for cerebral palsied students. Emphasis of the twelfth five year plan was on pre and post matric scholarships.
Incentive to Employer in the Private Sector for Providing Regular Employment to Persons with Disabilities: It is a central sector scheme for providing one lakh jobs per annum to the persons with disabilities with a proposed outlay of Rs 1800 crores, during the 11th Plan period sanctioned by the government. Under this scheme the government makes payment to the employer’s contribution to the Employee Provident Fund and Employee State Insurance for the first three years as an incentive, in return of employment of persons with disabilities with monthly wage up to Rs 25000/ per month.

Models to Promote Awareness about Accessibility features in Public Buildings: Funds are being provided to universities/Administrative Training Centers in the state/UT’s and State Secretariats for installing lifts to provide barrier free access to persons with disabilities.

Composite Regional Centers for Person with Disabilities (CRCs): This scheme is a part of overall strategy to reach out to persons with disabilities and facilitate the creation of required infrastructure and capacity building at Central, State and district level.

District Disability Rehabilitation Centre’s (DDRCs): The objective is to create infrastructure and capacity building at district level for awareness generation, rehabilitation, training and guiding rehabilitation professionals. This scheme is a joint venture of state and central government. The DDRC’s are funded through the Scheme for Implementation of the Persons with Disabilities Act 1995 for an initial period of three years and thereafter funding is made through the scheme of Deendyal Disabled Rehabilitation Scheme.

Technology Development Projects in Mission Mode: This scheme came up in 1990-91 with a view to provide suitable, cost effective aids and appliances by the application of technology to increase the employment opportunities and integration of the physically disabled in the society. In this suitable research & development projects are identified and funded for developing aids and appliances. It is implemented through the IITs, educational institutes, research agencies and voluntary organization. Financial assistance is provided on 100% basis. The four technical advisory groups monitor the selection and progress at different stages in areas of disabilities, namely orthopedic (including cerebral palsy), visual, speech and hearing and mental. All the projects recommended by the respective technical advisory groups.
are placed before the apex level committee headed by secretary, ministry of social justice and empowerment.

**National Institutes and Bodies Working For Persons with Disabilities and their Objectives:**

- National institute for Rehabilitation, Training and Research
- Pandit Deen Dayal Upadhyaya Institute for Physically Handicapped
- The National Institute for the Mentally Handicapped Manovikas Nagar, Benrempaly, Secunderabad, A.P.

Some Common Objectives of the above Institutes are:

- Manpower development to deal with various aspects of rehabilitation, training of personnel.
- Conduct, sponsor and coordinate research in the areas of identification, intervention, educational approaches, remedial teaching methods, jobs.
- Material development for education and public awareness and community education.
- Information, documentation and dissemination of the latest information and developments.
- Training of trainees and specialized professionals
- Manufacturing and distribution of such aids and appliances as are needed for the education, training, employment and rehabilitation of the disabled persons
- Undertake or sponsor such publications as may be considered appropriate.
- Educational programmes to strengthen persons with disabilities.
- Conduct, sponsor, co-ordinate or subsidize research on biomechanical engineering.
- Biomedical engineering for effective evaluation of special appliances or medical procedures or the development of new special appliances
- Service facilities including, strategies for early identification and rehabilitative procedures. Films and audio visuals on vocational training and job placement are being developed.
- Develop models of service delivery programmes for rehabilitation.
- Co-operate with national, regional or local agencies in research or such other activities as may be designed to promote the development of services for the disabled persons.
National Handicapped Finance and Development Corporation (NHFDC):
Incorporated by Ministry of Social Justice and Empowerment, Government of India on January 24, 1997 as an apex body with authorized share capital of 400.00 crore. It is wholly owned by government of India.

Objectives of NHFDC:

- Promote economic development activities, self-employment and other ventures
- Assist through loans and advances for economically and financially viable schemes or projects.
- Grant concessional finance in selected cases and extend loans to pursue general/professional/technical education for training at graduate and higher levels.
- Assistance for upgradation of technical and entrepreneurial skills.
- Set up training, quality control, process development, technology, common facility centers for rehabilitation/upliftment
- Assist the state level organizations
- Work as an apex institution to channelize the funds through the Corporation.
- Assistance for self-employed in marketing their finished goods and procurement of raw materials.
- Develop, operate and implement specific pilot programmes, projects and schemes to promote self-employment economic activities.
- Undertake evaluative studies, techno-economic and related surveys, preparation and appraisal of project reports and documents.
- Establish, maintain, subscribe or subsidize or become member of training institutions, research laboratories research institutions and experimental experiments.

The Rehabilitation Council of India: RCI is a statutory body under the Rehabilitation Council of India Act, 1992 which came into force on 31 May, 1993. The Council is responsible to regulate training policies and programmes, standardize training courses for professionals dealing with people with disabilities. It also prescribes minimum standard of education and training of professionals, regulate these standards in all training institutions uniformly throughout the country and recognize Institutions/Universities running courses in the field of rehabilitation of the
disabled. Another important function of the Council is to maintain a Central Rehabilitation Register (CRR) of persons possessing the recognized rehabilitation qualification. Only those professionals who are registered with the CRR are authorized to practice anywhere in India and it is a statutory

The National Trust: It is a statutory body under the Ministry of Social Justice & Empowerment, Government of India and set up under the National Trust for the Welfare of Persons, with Autism Cerebral Palsy, Mental Retardation & Multiple Disabilities Act 1999. Major objectives of trust are to ensure people with disabilities lead independent life with dignity. Secondly support & strengthen NGOs & other service providers and lastly appoint legal guardian to take care of the need of people with disabilities.

International Initiatives for Persons with Disabilities

Declaration on the Rights of Mentally Retarded Persons (1971) stipulated that people with intellectual disability have the right to enjoy equal rights as ones without disability. It also states that whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

Declaration on the Rights of Disabled Persons (1975) confirmed that disabled persons have the inherent right to respect whatever the origin, nature and seriousness of their disabilities be. They have the same fundamental rights as their other citizens of the same age, which includes the right to enjoy a decent life, as normal and full as possible without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, birth or any other situation applying either to the disabled person himself or herself or to his or her family.

The United Nations International Year of Disabled Persons (1981) marked the beginning of a decade in which serious attention was given to the issue of disability by the global community. The central principle of international year of disabled people was to initiate their full participation and equality, increase awareness of the benefits of the integration of people with disability in every aspect of political, social,
economic and cultural life. So far this year has created an awareness of disabled people and their needs never before seen in Australia.

The World Program of Action Concerning Disabled Persons, Declared in 1982, Was Followed by the United Nations Decade of Disabled Persons, 1983-1992. In 1982 General Assembly took a major step towards ensuring effective follow up to the international year by adopting, on 3 December 1982, the World programme of action concerning disabled persons. The programme restructured disability policy into three distinct areas: prevention, rehabilitation and equalization of opportunities. In broad sense implementation would entail long term strategies integrated into national policies for socio economic development and legislation eliminating discrimination regarding access to facilities, social security, education and employment. At the international level Governments were requested to cooperate with each other, the United Nations and non-governmental organizations.

The Proclamation on the Full Participation and Equality of People With Disabilities in the Asian and Pacific Region was adopted at the Meeting to launch the Asian and Pacific Decade of Disabled Persons, 1993-2002 held at Beijing in December 1992. The primary focus and goal of the Decade action was the expansion of opportunities for the full participation of people with disabilities in society and their equality in the development process. It was aimed at encouraging government, ministries and departments, NGOs, international organizations, including United Nations agencies and bodies, and committed individuals to take action to achieve these goals. It was hoped that there would be tangible results in villages, towns and cities of the region, with a significant improvement in the quality of the lives of people with disabilities, as a result of the impetus of the Decade.

Biwako Millennium Framework for Action Towards an Inclusive, Barrier-Free and Rights-Based Society for Persons With Disabilities (2002) Was the outcome of the high-level intergovernmental meeting to conclude the Asian and Pacific Decade of Disabled Persons. Biwako Millennium Framework sets out main beliefs, policy commands and recommendations for priority areas and strategies to further the goals of an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific region.

countries to do so. By ratifying the Convention, Australia has tied with other countries around the world in a worldwide effort to support the equal and active participation of all people with disability. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inbuilt dignity. Persons with disabilities are entitled to implement their civil, political, social, economic and cultural rights on an equal basis with others.

Despite all the above provisions in the form of state system still sometime it has been felt that the services are limited and persons with disability often report go to extraordinary lengths to meet eligibility criteria and receive the needed support. This process many a times leaves them feeling disgraced and humiliated also. At times they describe the system as difficult to navigate, even very slow and also unresponsive, in addition to all this are the endless forms. Some caregivers also expressed their unique set of frustrations which included, often being told to be positive while at the same time being forced to put up a desperate picture of their child and their needs in order to get maximum support. Indicates the need for individualized services for the caregivers.