CHAPTER-1

Introduction

The concept of mental retardation can be traced far back in history as the therapeutic Papyri of Thebes (Luxor), in Egypt around 1500 BC. These documents refer to mental retardation as disabilities of the mind and body due to brain damage (Sheerenberger, 1983). The knowledge base of the concept of mental retardation dates back to 18th century. Before this period, the concept was mysterious and people around the world held a variety of attitudes and perceptions toward the persons with mental retardation (Smith et al, 1994). Some of the first literacy references to persons with mental retardation appear in a Greek work dated 1552 BC. In this work, persons with mental retardation were called monsters (Gearheart and Litton, 1975). In Spartan times Lygcurgus (900 BC), the Spartan lawgiver prescribed death for ‘idiots’ in an attempt to keep their society free of defects. This process was usually effected by throwing off the defected from cliffs or drowning them in the Eurotas River (Barr, 1913). In the fourth BC there are records of wealthy Romans such as Seneca, keeping persons with mental retardation in their homes to amuse visitors. By the second century AD, individuals with disabilities including children who lived in the Roman Empire were frequently sold to be used for entertainment or amusement.’ Beyond the amusement value, they performed household duties usually without remuneration (Barr, 1913).
During the reign of Edward I in England (1272-1307) the properties of persons with mental retardation were reverted to the Crown (Clarke and Clarke, 1965). The Aztec King Montezuma (1520) had a large collection of defective people and housed them after the manner of a modern park zoo (Horsfield, 1940). Certain developments resulting from the ‘Renaissance’ of the 15th and 16th centuries created a new social atmosphere that would have direct implications for the persons with mental retardation. (Batshaw, 1993).

Throughout the ancient history, different patterns of treatment developed among western societies such as treating these individuals as clowns, buffoons and court jesters, perceiving them as demons or as persons capable of receiving divine revelations. Mild forms of retardation were blended into society without too much of difficulty (SPASTN, 2000).

The dawn of Christianity led to a decline in these barbaric practices and initiation of a movement towards care for the less fortunate. In fact, all the early religious leaders like Jesus, Buddha, Mohammed and Confucius advocated human treatment for the persons with mental retardation (Sheerenberger, 1983). The birth of ‘sensationalism’ and the revolutionary changes both in Europe and America are the most significant features of the eighteenth century. Philosophers like Locke and Rousseau have established new social attitude and practice regarding human development. The special education system and issues for individuals with disabilities occurred in Europe in the early 1800s. Marked improvements in treatment occurred in the 19*
century with Itard's (1774-1838) description that children with mental retardation could gain cognitive skills through education. His student Seguin (1812-1880) built on this observation by developing a curriculum for children with mental retardation and setting up residential schools that focused on behaviour management and sensory motor training (Batshaw, 1993).

During 1860-1890 urbanization and industrialization brought national transformation in United States and at this period there was a critical change in attitude towards the possibility of reintegrating those with mental retardation into the community. During 1890-1925, a number of events caused a dramatic change in social attitudes, mostly favourable to the needs of the persons with mental retardation. Custodial institutions were designed to serve as training centres from which individuals would leave to return to community settings. The Eugenics' movements began affecting many persons through sterilization, segregation and limitation on immigration.

By 1900, it was accepted that individuals with retardation could learn, but with significant cognitive deficits. The realization that a cure was not possible led to a half century of pessimism. During this time, the educational programmes were deemed of little value and residential institutions became primary, warehouses for individuals with retardation (Sheerenberger, 1983). During this time, the mental test was developed as the major trends of early 1900s. In 1905, Alfred Binet and Theodore Simon developed an instrument designed to be used in French schools to screen those who needed special
educational services. Milder forms of retardation were recognized during this period.

Social attitudes towards Persons With Disabilities changed to some extent after World War II and vocational rehabilitation was established. In 1922, Special education took a tremendous step as a bonafide professional field to train special educators. During this period many important developments took place both in social and physical sciences. Important standardized scales were developed to measure the social maturity and intelligence such as a) Vineland Social Maturity Scale (VSMS) by Doll in 1935 and Wechsler Intelligence Scale of Children (WISC) by Wechsler in 1949 (Smith, et al 1994). As 1950s began, the field of special education went through notable changes. Over the years, social attitudes toward people with mental retardation changed from fear and revulsion to tolerance and compassion.

The concept of ‘Normalisation’ originated during 1950s in Scandinavia, which argued about normalization of lives of the Persons With Disabilities and an integration of their special services into those of the welfare society (Bank Mekkilson, 1964). During this period, the nature-nurture issue seemed to be the best answer by those arguing on the importance of interaction between heredity and environment.

The shift in United States towards a community life for persons with disability took place in the 1960s and was manifested into 1969 report from the President’s committee on mental retardation ‘changing patterns in residential
services for the persons with mental retardation’ (Kugel and Wolfensberger, 1969). Later, concepts were brought into international domain in 1970s and have since then been developed further. In 1970s, a number of policy documents were drawn up highlighting the rights of persons to be part of the society. Much legislations regarding disabilities were passed during this period.

In 1980s, three features emerged such as (a) an eagerness to increase the services and to maximize their quality, (b) an understanding of the necessity to re-evaluate constantly all actions and (c) recognition of a need for educational reforms and restructuring. As a consequence, the concept of Community Based Rehabilitation was formed during the decade. As reported by O’Toole and McConkey (1995) it was a fundamental shift from the narrow focus on disability alone to an issue of relevance to the whole community including people with disabilities (Lysack and Kaufert, 1994). This change was the transition from institution based services to community based services.

The new approach called Community Based Rehabilitation (CBR) was upheld by World Health Organisations (WHO) and other UN agencies in the early 1980s, as an alternative service option for the rehabilitation of Persons With Disabilities in developing countries who had no access to services (WHO, 1981). Community Based Rehabilitation interventions were shifted from institutions to the homes and communities and carried out by minimally trained people such as families and other community members (WHO, 1989). It has been promoted internationally for more than twenty years as the core
strategy for improvement of the quality of life of Persons With Disabilities (Annika and Nilsson, 2002). The International Year of the Disabled in 1981 was the occasion when this position became public. During the Decade of Disabled Persons (1992-2002) the United Nations prepared the Standard Rules for Equalization of opportunities, which offered global strategy to the international community.

Since 1983, there has been a significant paradigm shift within the field of mental retardation. The shift relates to the concept of mental retardation and also the expression of the functional impact of the interaction between the limited intellectual and adaptive skills and the person’s environment (Baumister, 1987, Bruininks, Thurlow and Gilman, 1987, Greenspan and Granfield, 1992, Hawkins and Cooper, 1990, McFadden and Burke, 1991, Sheerenberger, 1983). During eighties and nineties there was a substantial growth in the number of CBR programmes in different developing countries. Along with the quantitative growth, there were also major changes in the way it was conceptualized (Thomas and Thomas, 1999a).

In the nineties, with the increasing conceptual shift in emphasis to accept the disabled person in the community, and to promote better human rights, the definition of Community Based Rehabilitation changed, as reflected in the 1994 Joint Position Paper of ILO, UNESCO and WHO. This classification is not linear anymore and explains the degree of interaction of the
health condition and the contextual factors simultaneously on participation. (Thomas and Thomas, 1999b)

CBR was viewed as a philosophy of care that inevitably embraces many forms of services (O’Toole, 1991) and directed towards the whole community as well as the individual members who happen to have a disability (Tjandrakusuma, 1998). It is not to normalize disabled people to fit into a restrictive, unjust and disempowering society but it is to join the struggle of other marginalized people to transform the social order into one that every one weak and strong, rich and poor, disabled and nondisabled will enjoy equal opportunities and respect (Werner, 1987).

CBR is a process using the existing and local resources in the rural community and it leads to restoration of clients at their optimal level of function. It also tries to integrate a network of services available for the disabled, through the programme of the disabled, his family members, and support groups and others whose involvement should be essential to support the disabled person to function in a way that is most accomplishing to their needs. The strategies were fabricated in such a way that was technically, administratively and economically maintainable using local and national resources (Helander, 1993 b).

Earlier, Community Based Rehabilitation had characterized as a set of rehabilitation interventions comprising the application of basic, secondary and tertiary level of physical and functional rehabilitation techniques, and it was not uniform in approaches. Recently there are certain regularized, professionalized

Indian Scenario

Manu Smriti, the ancient charter of social conduct impelled people to spare a part of their material resources to support the daily livings of their unfortunate fellow beings (Prabhu, 1963). Dharmashastra called upon all households to look after the weak and Persons With Disabilities and those who did so were ensured a place in heaven (Kuppuswamy, 1977).

In the ancient times some jobs were specially marked for Persons With Disabilities. Persons with hearing and speech impairments were preferred as attendants by kings and nobles (Narasimhan and Mukherjee, 1986). Persons with visual impairment were trained in flower garland making and vocal and instrumental music. Among Muslims, the persons with visual impairment were trained to teach and recite Holy Quran. Persons with orthopaedic disabilities were considered normal for a variety of jobs. Those who had severe deformities such as dwarfism were treated as clowns. During the period of British colonization in India, large scale missionary activities started with official patronage. These charity based Organisations worked with the beneficiaries and they had complete control over the inmates of the institutions.
The beneficiaries were held as ‘tabula rasa’ as if they had no language, culture and preferences (Dalai, 2002).

Disability rehabilitation in India is primarily considered to be a responsibility of the family. Those who were restricted by disability did not feel handicapped in a joint family system. Attitude of the society towards Persons With Disabilities is ambivalent. There is a belief in divine punishment in all religions and people tend to accept the condition of disability as something they deserved. Disability is held to be a punishment for the sins of previous births and one is called upon to accept it as divine retribution (Dalai, 2002).

Urbanisation and Industrial growth brought about a change in the concept and place of work. Persons With Disabilities were perceived as nonproductive members of the society. Such residual attitudes were being reinforced as post colonial developing countries continued to support policies and practices of the Christian missionaries (Mellory, 1994).

In post independence era, welfare approach was followed for the social development programmes. This has led to a phenomenal growth of centralized and institutionalized services for the welfare of Persons With Disabilities in the first two decades of independence. The ministries of social welfare of central and state governments played a major role in framing policies and programmes and infrastructure development. A National Council of Handicapped Welfare was set up to frame policy guidelines for the entire country and to prioritise disability programmes. Four national institutes for four types of disability-
blindness, orthopaedically handicapped, hearing impairment and mental retardation were established. Both the central and state governments initiated a large number of welfare schemes and enacted laws to monitor the functioning of governmental and non-governmental organisations. The government also set up eleven regional vocational training centres. To ensure uniform standards in technical courses in the field of rehabilitation for the disabled, Rehabilitation Council of India was set up (SPASTN, 2000). During this period most of the rehabilitation services in India followed the biomedical model in which hospitals and primary health centres played a key role. Persons With Disabilities were treated as passive recipients of welfare services.

In 1980s, there was an ideological shift in the developmental planning— from welfare to human resource development. The Decade of Disabled Persons (1983-92) marked another shift in the disability rehabilitation through community based support services. Many major projects were funded by international agencies. The government found it an easy way to generate much needed rehabilitation measures (Dalai, 2002).

The enactment of Persons With Disabilities Act (1995), ensured equal opportunities, protection of rights and full participation of people with disabilities in all spheres. In last two decades, Community Based Rehabilitation approach has been promoted as the most viable and practical solutions for the massive problem of disability in India, through both the government and nongovernmental organisations.
The global estimates indicate that ten percent of the world population suffers from disabilities. Among them around four hundred or more millions of the disabled were estimated to be in developing countries (Helander, 1993a). Exact statistics on Persons With Disabilities are difficult to obtain since many families are unwilling to report disability because of the negative attitudes towards disabled people in most communities, but village surveys in different parts of India indicate that up to 10 percent of the population are Persons With Disabilities (Janet Seeley and 2001 Thomas and Thomas, 2002).

In developing countries, the governments have limited resources and their needs in the field of rehabilitation of Persons With Disabilities were for establishing wider coverage of interventions rather than for providing quality services. The CBR approach is viewed as a possible method to increase the coverage in these countries to address the needs of government with limited resources and not as a consumer movement evolved out of the needs’ of the Persons With Disabilities (Thomas and Thomas 1999a).

Various researchers claim that the CBR is a vital approach for the rehabilitation of Persons With Disabilities irrespective of their impairments. Through the intervention activities of CBR programme the independence and functionality of the children with mental retardation can be maximized and the extra burden and constraints of the families can be minimized.

CBR programme of Bangladesh Protibondhi Foundation started in 1996 with door to door survey in a number of villages in Kisho region. Along with professional evaluation for screening and diagnosis of disability and service
delivery to the disabled children, clubs were formed by parents, teachers and local people. Micro credit and savings programme were introduced among the families of disabled. This is a unique example of successful CBR programme (Zaman, 2003).

Researchers like Myezwa (1995) and Vanneste (1997) report that the children with intellectual disabilities are least benefited by the CBR programme. Finkenflugel et al (1996) has reported from his study that the role of stakeholders (Person with Disabilities, family members, family trainers, CBR personnel) has not been explicitly linked to the specific objectives of CBR projects.

Regarding the programme delivery of CBR approach O’Toole (1988) has commented that the intervention programme may become too highly child focused and overlook the wider needs of the family as a whole. Dalai et al (2000) reported from the evaluation study that the CBR programme has not fulfilled their promises. These contradictory views need verification and if found true suitable rectifications need to be planned and executed. To propose the changes if any in the programme implementation, the present study was planned and conducted.

Objectives of tile study

The overall objective of the study is to assess the impact of Community Based Rehabilitation (CBR) programme on children with mental retardation and their caregivers in the rural areas.
The specific objectives of the study are,

1. to understand the CBR programme for children with mental retardation and its implementation aspects.
2. to know the background of the children with mental retardation benefited by the programme.
3. to identify the reported etiological factors associated with the mental retardation of the children
4. to assess the impact of CBR programme on various dimensions of adaptive behaviour of children with mental retardation.
5. to ascertain the differences in the perceived problems of the caregivers of children with mental retardation on their intervention through CBR programme.
6. to find out the problems and difficulties experienced by the CBR personnel in programme delivery and
7. to suggest measures appropriate to the study area to strengthen the reach of the programme to the target group.

Definition of Terms

‘Community Based Rehabilitation’ is a strategy for improving service delivery for providing more equitable opportunities and for promoting human rights of the disabled people (Helander, 1993a).

As per the definition given by ILO, UNESCO, WHO, Joint position paper, (1994) Community Based Rehabilitation (CBR) is “a strategy within
the community for the rehabilitation, equalization of opportunities and social integration of all children and adults with disabilities”.

**CBR programme** in the study refers to the approach implemented by the Government of India through the scheme ‘National Programme for Rehabilitation of Persons with Disabilities’ (NPRPD).

The term ‘**Impact**’ refers to the effect of the intervention on specific measurable traits.

**Rural** areas refer to the settlements under the governance and jurisdiction of notified Panchayats.

The expression ‘Rural’ is being recognized as the area that is sparsely settled or places away from the influence of large cities and towns. Such areas are distinct from more intensively settled urban and suburban areas, and also from unsettled lands such as outback or wilderness. People live in villages, on farms and in other isolated houses (www.wikipedia.org).

The term ‘**Mental Retardation**’ was adopted from the Persons With Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 to refer the study group.

‘**Mental Retardation**’ refers to significantly subaverage general intellectual functioning resulting in or associated with concurrent impairments in adaptive behaviour and manifested during the developmental period (Grossman, 1983). This definition has also been adopted by the Government of India and Government of Tamil Nadu for defining and classifying the persons with mental Retardation under the CBR programme.
Significantly subaverage’ refers to two standard deviations below the mean obtained from standard intelligence tests.

The degree with which the individual meets the standards of personal independence and social responsibility expected of one’s age and cultural group is referred to as adaptive behaviour.

‘Developmental Period’ is the period of time between conception and the eighteenth birthday of the person.

The term ‘Children with Mental Retardation’ in this study refers to the children with mental retardation in the age group of 3-15 years or otherwise known as children under the ‘Childhood years’. This age group classification is adopted from the NPRPD programme of Ramanathapuram District.

The word ‘Caregiver’ is known as an adult family member or other individual who is an informal provider of in-home or in community care to an individual (www.skvwaves.lib.ks.us).