PERSONS WITH DISABILITIES IN RURAL ANDHRA PRADESH: A COMPARATIVE STUDY OF DEVELOPMENT INITIATIVES OF THE STATE AND NON-STATE ORGANIZATIONS

DOCTOR OF PHILOSOPHY

IN

SOCIOLOGY

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BY

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CERTIFICATE

This is to certify that the thesis entitled **“Persons with Disabilities in Rural Andhra Pradesh: A comparative study of development initiatives of the state and non-state organizations”**, submitted by **Debasmita Chand** bearing Regd. No. **09SSPH01** in partial fulfillment of the requirement for the award of the degree of Doctor of Philosophy in Sociology is a bonafide work carried out by her under my supervision and guidance which is a plagiarism free thesis**.**

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DECLARATION

I hereby declare that the thesis entitled, **"Persons with Disabilities in Rural Andhra Pradesh: A comparative study of development initiatives of the state and non-state organizations"**, submitted by me under the guidance and supervision of **Dr. C. Raghava Reddy,** Department of Sociology, in partial fulfillment of the requirement for the award of the degree of Doctor of Philosophy in Sociology from University of Hyderabad is a bonafide research work which is also free from plagiarism.

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CONTENTS

Chapter -II: Theorising Disability

Chapter-III: The Society for Elimination of Rural Poverty (SERP): An overview

Chapter-IV: The Rural Development Trust (RDT): An Overview

Chapter-V: SERP and RDT: An Analytical Overview

Chapter-VI: Findings and Discussions

List of Tables

List of Figures

List of Abbreviations

ADD	Action on Disability Development
AIDS	Acquired Immuno Deficiecny Syndrome
APM	Assistant Project Manager
APMACS	Andhra Pradesh Mutually Aided Cooperative Society
APRPRP	Andhra Pradesh Rural Poverty Reduction Project
APSACS	Andhra Pradesh State Aids Control Society
APSHC	Andhra Pradesh State Housing Corporation Limited
ART	Antiretroviral Therapy
ATL	Area Team Leaders
BC	Backward Class
BMF	Biwako Millennium Framework
CA	Community Animator
CACU	Central Administrative and Coordination Unit
CBO	Community Based Organization
CBR	Community Based Rehabilitation
CC	Community Coordinators
CCC	Central Coordination Committee
CDW	Community Development Worker
CEO	Chief Executive Officer
CIF	Community Investment Fund
CIL	Centre for Independent Living
CRC	Composite Regional Centers
CRI	Critical Rating Index
CRP	Community Resource Person
CSW	Community Social Workers
DCC	District Coordination Committee
DDRC	District Disability Rehabilitation Centers
DMHO	District Medical and Health Office
DOTs	Direct Observation Treatments
DPM	District Project Managers
DPMU	District Project Management Unit
DRC	District Rehabilitation Center
DRDA	District Rural Development Agency
DRG	Disabled Rights Group
DRM	Disability Right Movement
DSDF	Disability Sangham Development Fund
EC	Executive Committee
EIF	Enable India Foundation
ESCAP	Economic and Social Commission for Asia and the Pacific
FVF	Fundación Vincent Ferrer
GoI	Government of India
GOs	Group Organizers
HRD	Human Resource Development
ICDS	Integrated Child Development Services
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
IDA	International Development Association
IEDC	Integrated Education for Disabled Children

Contd…

List of Abbreviations

ISI	Indian Standatd Institute
ISIC	Indian Spinal Injury Centre
MCP	Micro Credit Plan
MCSC	Mandal Community Support Cell
MIS	Management Information System
MNREGA	Mahatma Gandhi National Rural Employment Guarantee Act
MRO	Mandal Revenue Officer
MRP	Mandal Resource Person
MS	Mandal Samakhyas
MSJE	Ministry of Social Justice and Empowerment
MVS	Mandala Vikalangula Samakhya
NABARD	National Bank for Agriculture and Rural Development
NACO	National Aids Control Organization
NEDCAP	Non-Conventional Energy Development Corporation Limited
NFB	National Federation of the Blind
NGO	Non-Government Organization
NHFDC	National Handicapped and Finance Development Corporation
NREGS	National Rural Employment Guarantee Scheme
NSSO	National Sample Survey Organization
PD	Project Director
PHC	Primary Health Center
PIP	Participatory Identification of Poor
PoP	Poor/Poorest of the Poor
PRI	Panchayat Raj Institutions
PSUs	Public Sector Undertakings
PWDs	Persons with Disabilities
RDT	Rural Development Trust
RMC	Resource Mobilization Centre
RNTCP	Revised National TB Control Programme
RRC	Regional Rehabilitation Centers
SCs	Scheduled Castes
SERP	Society for Elimination of Rural Poverty
SHGs	Self-Help Groups
SPD	State Project Director
SPMU	State Project Management Unit
SSA	Sarva Shiksha Abhiyan
STDs	Sexually Transmitted Diseases
STs	Scheduled Tribes
TRC	Training Resource Centers
UIP	Universal Immunization Program
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
UPIAS	Union of Physically Impaired Against Segregation
USD	United States Dollar
VK	Vikalangula Karyakarthalu
VO	Village Organization
VS	Vikalangula Sanghams
WHO	World Health Organization
ZPP	Zilla Praja Parishad
ZVS	Zilla Vikalangula Samakhya

CHAPTER-I

DISABILITY: MEANING AND DEFINITIONS

CHAPTER-II

THEORISING DISABILITY

CHAPTER-III

THE SOCIETY FOR ELIMINATION OF RURAL POVERTY (SERP): AN OVERVIEW

CHAPTER-IV

THE RURAL DEVELOPMENT TRUST (RDT): AN OVERVIEW

CHAPTER-V

SERP AND RDT: AN ANALYTICAL OVERVIEW

CHAPTER-VI

FINDINGS AND DISCUSSION

CHAPTER-VII

CONCLUSIONS

CHAPTER-I

DISABILITY: MEANING AND DEFINITIONS

1.1 Introduction

Disability is a relative term in so far as different cultures define their norms of 'being' and 'doing' differently. Conceptions for disability are therefore highly contextual and subjective. Disability has been subjected to many definitions in different disciplines and for different purposes. It has been described from medical, sociological and political perspectives and definitions of disability have been developed and used in different contexts.

Among the many explanations on impairment advanced by different streams of knowledge, the medical model was dominant for a very long time. Medicalisation of impairment pre-supposed a normal body that is free from challenges. Standards of body and mind pronounced by medical scientific knowledge marked body as 'physiological-pathological' object and the defective ones were associated with 'degeneracy'. The bio-social notion that guided the medical paradigm objectified and categorized people as sick or healthy, mad or sane and justified the hierarchical standard for treating some bodies as abnormal and inferior (Reddy, 2011).

Institutional system of social control driven by the capitalist political ideology that emerged during the late 18th and early 19th centuries in the West took recourse to the medical scientific notions of normality and impaired bodies. This new 'bio-politics' created a docile body and relegated impaired bodies to the margins of 'social', ignoring the individual as an independent being capable of deriving and creating meaning and a social world of their liking. Correspondingly, the involvement of the medical profession in disability has added to the process of objectification and correction and in a way, medicalisation emerged as a key aspect in the social policies for persons with disabilities (Chand and Reddy, 2012).

1.1.1 Critique of Medical Model

The dichotomous and reductionist paradigm foregrounded in the medical approach, has been challenged by the social construction paradigm. The Disability Rights activists in North America and Europe began to oppose considerations which placed body at the center of explanation. They questioned the propositions of medical model which treat body as pre-social, an object and a 'physio-chemical product' (Rao, 2007). They claimed that, such an approach overlooked the self for body, thereby reducing body to a non-social entity. Taking roots during 1980s, the social construction model referred to as 'social model' strongly objected to the assumptions of body and normality as postulated in the medical model. It questioned the organization of biological difference into social constructions as 'normals' and 'non-normals'. It highlighted that barriers to participation of people with impairments are socially originated and rooted in power-knowledge relations.

The proponents of social model argued for looking at the social barriers that disable the impaired body rather than impairment. They believed that impairment-based constraints of an individual could be overcome not by subjecting the impaired body to correction, but by changing the way social environment was built and construed. Oliver, one of the key architects of the social model explained the separation of impairment and disability as 'primarily a pragmatic attempt to identify and address the issues that can be changed through collective action rather than medical or other professional treatment' (Michael Oliver, 1996 cited in Barnes and Mercer, 2003:67).

These contestations shifted the focus of discussion on abilities or lack of abilities from impairment and body to outside the body i.e. society. Paul Hunt (1966) argued that 'the problem of disability lies not only in the impairment of function... but also, more importantly, in the areas of our relationship with 'normal' people' (Paul Hunt cited in Barnes and Mercer, 2003). Several scholars of disability began to discuss the disabling socio-political barriers like architectural, attitudinal and occupational which excluded the impaired individuals from participating in the society (Reddy, 2011).

1.2 Building a Socio-Political Model of Disability

The manifesto of the Union of Physically Impaired Against Segregation (UPIAS) entitled 'Fundamental Principles of Disability' (1976) asserts that disability is the manifestation of social discrimination against the impaired. The UPIAS maintains that it is the society which disables physically impaired people and disability as a social construct is something external and imposed on the impaired, leading to isolation and exclusion of the impaired from full participation in the society. It equates such exclusionary practices with oppression and declares the disabled people as an oppressed group (Barnes and Mercer, 2003).

The social model argued to develop a model that delinked 'disability' from 'impairment' and treated these two as exclusive notions (Oliver, 1990). It defined impairment as the lack of a limb or part thereof, or a defect of a limb, organ or mechanism of the body and disability as a form of disadvantage which is imposed on top of one's impairment, i.e. the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments (UPIAS, 1976). This distinction between impairment and disability formed the basis for the construction of the social model. The line of causation was redirected from individual pathology to the outcome of social barriers and power relations. Thus, social model asserted that 'disablement has nothing to do with the body' and suggested the need for separation of impairment from the individual because impairment is 'nothing less than a description of the physical body' (Michael Oliver, 1996 cited in Tremain, 2006).

The social model is arguably the most powerful form which social approaches to disability have taken. The benefits of the social model have been shown in three main areas. First, the social model, called 'the big idea' of the British disability movement (Hasler, 1993), has been politically effective in building the social movement of disabled people and in generating a clear agenda for social change. Second, the social model has been an effective instrument in the liberation of disabled people by identifying the barriers that are to be removed. Third, this model has been psychologically effective in improving the self-esteem of disabled people and building a positive sense of collective identity (Davis, 2006).

The social model derives its strength from a series of dichotomies drawn in comparison to the medical model (Shakespeare, 2006). First, impairment and disability are two distinct constructs; impairment is individual, private and a personal tragedy while disability is structural, social and externally imposed. Second, disability as a social creation distinguished disability from individual deficit. Any reference as ‘persons with disabilities’ and an approach that seeks to count the number of people with impairments and attempts to mark ‘the body as numerical and calculable’ (Rao, 2007), is denounced by the social model. The social model fights for the removal of social barriers, enactment of affirmative legislations, enabling environment, equal rights for independent living with dignity. Finally, the distinction between disabled and non-disabled is one of political as disabled people form part of the oppressed group whereas the non-disabled people and organizations are sources, causes and contributors of oppression (Reddy, 2011).

The oppression and discrimination against the disabled is equated with that of gender, race, caste and class. In fact, disability as a form of discrimination cuts across all other forms of discrimination and assumes magnifying proportions. For instance, if impairment is considered as a disadvantage, an impaired woman is considered to have a double disadvantage and if she belongs to a deprived caste she then is considered to possess triple disadvantage. In a culture where being a daughter is considered a curse, being a disabled daughter is a fate worse than death. In Hindi the phrase, *Ek to ladki oopar se aapahij* which means, one a girl and that too disabled reflects the reality of a woman with a disability and the general attitude towards disabled women in India (Ghai, 2002). The community, family and individual strategies play an important role in negotiating disability. In India, women with disabilities face double discrimination due to the prevalence of traditional gender roles and expectations (Thomas and Thomas, 2002). Mehrotra (2006) argues that disability is not the primary disadvantage of women in India rather it becomes an additional burden on their marginalized gender position. Disabled women experience disability and gendered roles simultaneously. Although stereotyped to be incomplete, they are expected to fulfill all the gendered duties and are primarily taken to be working members of the society.

1.2.1 Critique of Social Model

Presenting a positive disability identity, the social model at the policy level helped in generating a political identity for persons with impairment to fight for affirmative initiatives. It gained wider acceptance among academia and activists and at the same time it was subjected to sharp criticism from a section of disability activists. The critics of the social model, though not opposed to its basic tenets, questioned the notion of separation of impairment from disability. They argue that impairment cannot be treated as something *a*social or pre-social. The attempt to view disability in isolation and neglect of the body were strongly contested for the basic reason that impairment means a lot to those who suffer from severe impairments and mental illness. Disallowing theoretical analysis of the body and the accompanying pain, suffering and emotional trauma, as proclaimed in the social model, only adds to the oppression (Galvin, 2003). They believe that 'the impaired body is part of the domain of history, culture and meaning and not an *a*historic, pre-social, purely natural object' (Hughes and Kevin Paterson, 1997). The critics of social model claim that impairment is still to be negotiated as it manifests its lack of function and other limitations which are real problems that cannot be ignored. The social model has been criticised for presenting a narrow perspective of impairment by considering largely the problems of physically impaired or orthopedically challenged people and excluding the people with learning difficulties, mental health problems and others who experience severe difficulties in dealing with their impairments (Reddy, 2011).

The social model so strongly disowns individual and medical approaches that it risks implying impairment as non-problematic. However, for those who have degenerative conditions which involve pain and discomfort, it is harder to ignore the negative consequences of impairments. It is argued that impairment is a much important aspect of many disabled persons' lives to be ignored and separated from their identity (Shakespeare, 2000). It is claimed that the social model valorises disability while impairment is marginalized or silenced.

Shakespeare (*ibid*: 162) argues that any approach 'that loses contact with the physical does no favour to the disabled...we have to have a position that recognizes difference and limitation and the very real problems which disabled people may have with their bodies and their lack of function'. Thus, it is argued that the body that bears the impairment apart from the social barriers of disability should be considered in approaching disability. On another count, the concept of barrier-free society is considered as utopia (Shakespeare, 2006). Removal of social barriers might enable an orthopedically challenged to overcome certain difficulties without subjecting to medical correction, but the problems of persons affected by congenital problems need medical interventions or corrections. Even if social barriers are removed, it will not help people with other impairments such as sensory and cognitive abilities to overcome the physical barriers.

Recognizing these limitations in both the medical and the social model, the World Health Organization (WHO) developed the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980s. It provides a conceptual framework for disability which is described in three dimensions: Impairment, Disability and Handicap. In the context of health experience, impairment refers to any loss or abnormality of psychological, physiological or anatomical structure or function whereas a disability refers to the restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Handicap is the disadvantage for a given individual resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual (WHO, 1980).

Impairment is considered to occur at the level of organ or system function. Assessment of impairment requires the judgement of mental and physical functioning of the body and its component parts according to accepted standards. Disability is concerned with functional performance or activity and limitations therein affecting the whole person. The definition of disability attempts to encompass those activities considered important in daily life. On the other hand, handicap focuses on the person as a social being and reflects the interaction with and adaptation to the person's surroundings. The definition of handicap attempts to classify those consequences which place that individual at a disadvantage in relation to their peers (World Bank Report on Disability, 2009).

This, however, received considerable criticism for its reliance on bio-physiological definitions of normality and for ignoring the social, economic, political, and cultural barriers in the environment. The disabled people's organizations questioned the ICIDH approach for its reliance on medical definitions of impairment and for disregarding the role of social and cultural factors in judging body and cognitive functioning (Barnes and Mercer, 2003). The ICIDH also received criticism for positioning impairment as the cause of both disability and handicap and for privileging the medical and rehabilitative interventions. Barnes and Mercer (2003) argue that 'the overwhelming clinical focus dictates strategies for individual adjustment and coping... and the ICIDH concentrates on diagnosing and treating the individual's limitation rather than looking at that person's social exclusion'.

Considering the criticism about the deficiencies in the ICIDH model, the WHO revised and renamed it as the International Classification of Functioning, Disability and Health (ICF). The ICF model is claimed to be an advanced model that incorporated both the medical and the social models to provide a coherent view of disability from a biological, individual and social perspective (WHO, 2001).

The main difference between the classifications given by the ICF model as against the ICIDH model is that, the ICF model emphasizes more on environmental factors in creating disability than the ICIDH model. It defines impairments as problems in body function or structure causing significant deviation or loss. In the ICF model, problems with human functioning are categorized in three interconnected areas viz. Impairment is considered as a problem in the functioning of the body or alterations in the structure of the body, for example, paralysis or blindness. Activity limitation is the difficulties in executing activities, for example, walking or eating. Participation restrictions are problems with involvement in any area of life, for example, facing discrimination in employment or transportation.

Thus, the ICF model replaced ‘disability’ with ‘activities’ and ‘handicap’ with ‘participation’. ‘Activity’ is defined as the execution of a task or action by an individual, and ‘participation’ as the ‘lived experience’ of the people in the actual context in which they lived (Mitra, 2006). It recognizes the complex interplay of biological and social factors contributing to a health condition that limit the activity and participation of the impaired persons. Further, it lays emphasis on the functional limitations which are biological and psychological in nature and the social constraints imposed on the impaired persons. Thus, it is often referred to as the ‘*bio psychosocial model of disability*’ also.

The ICF model suggests for interventions associated with impairment and to develop capabilities of individuals for activity. This model can also be used to understand and measure the positive aspects of functioning such as bodily functions, activities, participation and environmental facilitation. It adopts neutral language and does not distinguish between the type and cause of disability - for instance, between ‘physical’ and ‘mental’ health. ‘Health conditions’ are diseases, injuries, and disorders, while ‘impairments’ are specific decrements in body functions and structures, often identified as symptoms or signs of health conditions.

ICF contains a classification of environmental factors describing the world in which people with different levels of functioning live and act. These factors can be either facilitators or barriers. Environmental factors include: products and technology, the natural and built environment, support and relationships, attitudes and services, systems and policies. It recognizes personal factors such as motivation and self-esteem which can influence how much a person participates in the society. It further distinguishes between a person’s capacities to perform actions and the actual performance of those actions in real life, a subtle difference that helps illuminate the effect of environment and how performance might be improved by modifying the environment (The World Bank Report on Disability, 2010).

Disability is complex and multidimensional. Impaired individual's experience of disability depends not just on the functional limitations relating to his/her impairment, but also on the environment in which s/he lives. The UN Convention on the Rights of Persons With Disabilities (PWDs) defines disability as resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (United Nations, 2006). Attitudinal barriers range from assumptions about capabilities and dependency which can lead to over-protection and disempowerment through negative superstitious beliefs and practices towards persons with disabilities. Negative attitudes towards disability mean that persons with disabilities routinely experience discrimination within the family and community which can deny them equitable access to resources, services and opportunities for personal development.

Environmental barriers on the other hand, include those barriers that are built in the environment such as inaccessible public buildings and barriers relating to communication, including lack of information in accessible formats. A combination of environmental and attitudinal barriers within communities and institutions can lead to the persons with disabilities being effectively excluded from participating in social, civil and political processes. As a result of discrimination and social exclusion, together with their invisibility in the society, persons with disabilities suffer from low self-esteem, low confidence and low aspirations, which in turn, leads to poor participation in social, economic and cultural life. The type and severity of discrimination faced by persons with disabilities varies depending on the nature of their impairment, their environmental context and the interaction with other factors such as gender and age.

In India and South Asia, disability is largely seen as a product of cultural impediments such as beliefs and stereotypes as well as structural impediments like poverty, underdevelopment, illiteracy, unemployment and caste, class and gender barriers etc. PWDs are marginalized in education, employment, mobility and other significant areas of life. The meaning of disability in India is embedded in this basic struggle for survival and cultural understanding. Prevention and rehabilitation models continue to be relevant in such circumstances (Mehrotra, 2012).

1.3 Government Policies and Developmental Programmes

In order to provide equality, freedom, justice and dignity to all individuals and in the direction of evolving an inclusive society for all, including persons with disabilities, the Government of India (GoI) enacted the following legislations for persons with disabilities.

1. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, provides for both preventive and promotional aspects of rehabilitation like education, employment and vocational training, research and manpower development, while aiding in the creation of barrier free environments, rehabilitation of disabled, unemployment allowances for the disabled, special insurance schemes for employees with disabilities and the establishment of homes for persons with severe disabilities. The Act is the most comprehensive legislation enacted to ensure equal opportunities for disabled, allowing their full participation in nation building. Under the PWD Act, the Central Coordination Committee (CCC) was established with the Cabinet Minister of the central government as its Chairman. This committee reviews and coordinates the activities of all departments of the government and other governmental and non-governmental organizations which are dealing with matters relating to persons with disabilities. It also advises the central government on the formulation of policies, programs, legislation and projects with respect to disability. It monitors and evaluates the impact of policies and programs designed for achieving equality and full participation of persons with disabilities.
2. National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999 which has provisions for legal guardianship of the above four categories of disabilities and creation of enabling environment for independent living.
3. Rehabilitation Council of India Act, 1992 which deals with the development of manpower for providing rehabilitation services to the persons with disabilities. In addition to the legal framework, the Act also envisaged the

development of extensive infrastructure by setting up of national institutes to work towards the development of manpower.

Accordingly, seven national institutes specialized in dealing with impairment were set up. They are:

- Institute for the Physically Handicapped, New Delhi
- National Institute of Visually Handicapped, Dehradun
- National Institute for Orthopedically Handicapped, Kolkata
- National Institute for Mentally Handicapped, Secunderabad
- National Institute for Hearing Handicapped, Mumbai
- National Institute of Rehabilitation Training and Research, Cuttack
- National Institute for Empowerment of Persons with Multiple Disabilities, Chennai

Apart from the above mentioned institutes, the GoI has also set up the National Handicapped and Finance Development Corporation (NHFDC) to provide credit to persons with disabilities on concessional terms for undertaking self-employment activities. Panchayat Raj institutions at the village level, intermediary level and district level have also been entrusted with the welfare of persons with disabilities. The National Council for Handicapped Welfare was set up to frame policy guidelines for the entire country and to prioritize disability programmes. This council, comprising of central and state ministers and rehabilitation experts regulates the activities of the central and state governments and voluntary sectors. Most of the rehabilitation services in India follow the bio-medical model in which hospitals and primary health centers play a key role. Disability is viewed as a diseased state and the emphasis is on curing, correcting or attempting to ameliorate the problem so that PWDs become as ‘normal’ as possible.

As service providers, almost all the traditional organizations work with the idea of rehabilitation. The World Bank Report, 2010 defines rehabilitation as ‘a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments’. A distinction is sometimes made between habilitation, which aims to help those who acquire disabilities congenitally or early in life to develop maximal functioning and rehabilitation, where those who have experienced a loss in function are assisted to regain maximal functioning.

Rehabilitation targets improvements in individual functioning by improving a person’s ability to do certain basic daily chores independently. It also includes making changes in the individual’s built-in environment, at home, for example, installing a toilet handrail etc. Typically, rehabilitation occurs for a specific period of time, but can involve single or multiple interventions delivered by the rehabilitation workers, starting from the acute or initial phase immediately following recognition of a health condition through post-acute and maintenance phases. Rehabilitation involves identification of a person’s problems and needs, relating the problems to relevant factors of the person and the environment, defining rehabilitation goals, planning and implementing the measures and assessing the effects (The World Bank Report, 2010).

The rehabilitation measures can be grouped into, (i) physical rehabilitation (ii) educational rehabilitation and (iii) economic rehabilitation for a dignified life in the society focusing on working with the abilities of the disabled and mainstreaming the persons with impairments.

The physical rehabilitation strategies derive their mandate from the medical model and thus lay emphasis on the correction of the impairment. The efforts include, early detection of impairment and intervention through drug or non-drug therapies, counseling, strengthening capacities of persons with disabilities and their families, physiotherapy, occupational therapy, psychotherapy, surgical correction and intervention, vision assessment, vision stimulation, speech therapy and special education, and assisting persons with impairments in procuring durable and scientifically manufactured, modern aids and appliances of ISI standard.

Education for the disabled is seen as critical in their participation in economic and social life. In line with the spirit of the Article 21A of the Indian Constitution that guarantees education as a fundamental right and Section 26 of the Persons with Disabilities Act, 1995, free and compulsory education is to be provided to all children with disabilities up to the minimum age of 18 years.

Under the Sarva Shiksha Abhiyan (SSA) programme launched by the government of India, children with disabilities in the age group of 6-14 years are to be provided with eight years of elementary schooling. As part of SSA, a continuum of educational options, learning aids and tools, mobility assistance, support services etc. are being made available to students with disabilities. This includes education through an open learning system and open schools, alternative schooling, distance education, special schools, home based education, itinerant teacher model, remedial teaching, part-time classes and vocational education. Under the Integrated Education for Disabled Children (IEDC) scheme, children with disabilities in the age group of 15-18 years are provided free education.

The PWD Act, 1995 provides for 3 percent reservation in employment in the establishments of the Government of India (GoI) and Public Sector Undertakings (PSUs) against identified posts. The status of reservation in various Ministries/ Departments of the government against identified posts in Group A, B, C and D is 3.07 percent, 4.41 percent, 3.76 percent and 3.18 percent respectively. In Public Sector Undertakings, the reservation status in Group A, B, C and D is 2.78 percent 8.54 percent 5.04 percent and 6.75 percent respectively.

Moreover, the Government of India under the auspices of the Ministry of Social Justice and Empowerment (MSJE) set up the National Handicapped Finance Development Corporation (NHFDC) in 1997 to promote activities of economic development, provide self employment opportunities and to help the PWDs in pursuing general, professional/technical education. Loans are provided for amounts ranging from less than Rs.50,000/- to 5 lakhs and above with the repayment period, subject to a maximum of seven years (http://socialjustice.nic.in/)

1.3.1 The Ministry of Social Justice and Empowerment (MSJE)

The basic objective of the policies, programs, laws and institutions of the Indian welfare system is to bring disabled into the mainstream of development by making them self-reliant. Accordingly, it is envisaged that three percent of all resources allocated to poverty alleviation programs throughout the country, at both the central and state levels, are set aside for the disabled. The MSJE is entrusted with the welfare of the disabled. It carries out its activities through an infrastructure network of the national institutes and other departments. These institutes work in the fields of locomotors, visual, hearing and intellectual disabilities. The institutes provide rehabilitation services by undertaking vocational training programs and community awareness programs. Through outreach services, communities are made aware of prevention of disability, early identification, appropriate intervention and rehabilitation of the disabled. The institutions are also engaged in functional research activities in related applied areas.

MSJE also oversees the operation of four Composite Regional Centers (CRC) for persons with disabilities, four Regional Rehabilitation Centers (RRC) for persons with spinal injuries, one hundred District Disability Rehabilitation Centers (DDRC) and the Indian Spinal Injury Centre (ISIC). The Ministry has also put in place the National Programme for Rehabilitation of persons with disabilities which trains people from the grassroots level in the prevention of disability, recognition of its occurrence and rendering advice on appropriate referrals that can range from minor interventions available at primary and state level institutions that are able to provide sophisticated services.

During the 1980s, there was a shift in the policy frame from welfare to development where the disabled have now figured not as recipients, but as participants in the development process. This period witnessed the greater interest and participation of international Non-Government Organizations (NGOs) and the emergence of local NGOs in partnership with the government working at community level. In India, this phase saw groups being formed by disabled activists for claiming their political, legal and social goals by adopting a rights-based approach.

In 1990s, globalization further determined the course of the Disability Right Movement (DRM) in the Indian context, especially through larger international influences, stronger presence through local NGOs and greater possibility of networking and faster and productive information flow through the web. The DRM in India started only in the early 1990s. During this year, the Indian government organized a national seminar in New Delhi to discuss various issues concerning disabled citizens. The main need that emerged from the seminar was for a comprehensive legislation to protect the rights of PWDs. However, it was only after intense lobbying of the Disabled Rights Group (DRG) that the crucial legislation was passed in 1995 (Mehrotra, 2011).

1.3.2 Community Based Rehabilitation (CBR)

India's disability-related policies are moving away from medical rehabilitation towards a Community Based Rehabilitation (CBR) approach for the self-sufficiency and improvement of the status of the disabled through vocational training and education. In 1995, the government launched the District Rehabilitation Centre (DRC) scheme as a model of comprehensive rehabilitation services for the disabled living in rural areas. The scheme operates across 11 centers in 10 States. The program was launched in collaboration with the National Institute of Disability and Rehabilitation Research, Washington, D.C.

In conjunction with the DRC, a Central Administrative and Coordination Unit (CACU) was also established for coordinating and administering the activities of the DRC. The objectives of the DRC include surveying the disabled population, prevention, early detection and medical intervention and surgical correction, fitting of artificial aids and appliances, therapeutic services such as physiotherapy, occupational therapy and speech therapy, provision of educational services in special and integrated schools, provision of vocational training, job placement in local industries and trades, self-employment opportunities, awareness generation for the involvement of community and family to create a cadre of multi-disciplinary professionals to take care of major categories of disabled in the district (http://socialjustice.nic.in).

Most disability services in India are under the auspices of the government, but they also have a strong presence of the NGOs (Thomas and Thomas, 2002). In the rural areas, and among urban squatters, NGOs are promoting organizations of disabled people and their parents. They are also largely engaged in what is known as community rehabilitation programmes generously supported by the government and international agencies. All these efforts in the last two decades have contributed to popularizing the philosophy of community-based rehabilitation and raising the hopes of millions of persons with disabilities (Mehrotra, 2011).

1.4 State initiatives towards Persons with Disabilities in Andhra Pradesh

In the light of increased activism on disability rights, there has been a perceptual change in the approach of the state towards the PWDs. The welfarist mode of approach of the state towards PWDs has now changed to the rights mode approach emphasizing on equality, independent living, access and participation. As a result, the development agenda of the state has been reconfigured to include participatory approaches of the state for the PWDs. The state of Andhra Pradesh[1], initiated the component of disability as part of its larger programme of poverty eradication in the state.

For implementing the rural development project in a professional and accelerated manner, the Government of Andhra Pradesh has established the ‘Society for Elimination of Rural Poverty’ (SERP) in the year 2000 as an autonomous society under the Societies Act. The society was set up with a financial assistance of USD 260 million from the World Bank with an objective to initiate statewide community demand driven rural poverty alleviation programmes. The Society for Elimination of Rural Poverty works on six major components, one of which is disability. The component of disability relies on group approach similar to that of women SHGs. The PWDs in villages of Andhra Pradesh are mobilized to form groups, function on their own and work for their development with the financial assistance and support from the state.

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[1] The study was carried out before the bifurcation of the state of Andhra Pradesh into Telangana and Andhra Pradesh in the year 2014. The field site lies in Andhra Pradesh.

1.5 Non-state initiatives towards Persons with Disabilities in Andhra Pradesh

Generally, rehabilitation services are believed to be confined to cities and major towns while, such services are not available to people in rural areas and small towns. Even a majority of parents in cities and major towns are unable to access rehabilitation services due to lack of awareness, poor financial conditions and attitudes of family members towards their disabled children. One of the biggest challenges faced by the civil society is to provide rehabilitation services to those who are yet to receive them in villages and small towns. On the other hand, the role of NGOs in facilitating the development of persons with disabilities all over the country cannot be undermined. NGOs are actively involved in creating awareness, mobilizing resources and in actual delivery of support and services to persons with disabilities. The key role of NGOs lies in mobilizing community participation.

NGOs have made a significant contribution in the area of disability through the activities of early intervention, assessment, therapeutic services, parents' education, formation of self-help groups, etc. Their objectives also cover organizing training programmes for rural rehabilitation workers, special educators, teachers and parents. To promote meaningful, effective and sustainable action, both the government and the NGOs work in close partnership. NGOs involved in the development of persons with disabilities have been successful in India mainly for their ability to:

- Experiment freely with innovative approaches,
- Be flexible in adapting to local situations and responding to local needs,
- Enjoy good rapport with the community and can render micro-assistance to the disabled,
- To communicate at all levels, from the grassroots to the state/district level functionaries,
- Reach poor communities and remote areas with few basic resources or little infrastructure, and where government services are limited,
- Promote local participation in designing and implementing programmes by strengthening organizational capabilities,
- Operate by using appropriate technologies and streamlined services.

Self-help groups of disabled people have began to be recognized in few parts of the country as another institution to be consulted and represented at local level events. This is mainly occurring in the Southern part of India where NGOs are more engaged in social mobilization work, for example in Andhra Pradesh, Tamil Nadu and Karnataka (Mehrotra, 2013). The Rural Development Trust (RDT) is one such non-government organization located in Andhra Pradesh carrying out need based welfare and integrated programs of development for rural poor and needy, especially those belonging to marginalized and underprivileged sections, namely Scheduled Castes (SC), Scheduled Tribes (ST), Backward Class communities (BC) and Persons with Disabilities (PWDs) for the past 44 years. RDT has been working with persons with disabilities since 1985. The main objective of RDT towards the development of persons with disabilities is to enable them to have equal opportunities and rights and the capacity to access all the existing resources and services to lead a life with identity, dignity, respect and justice in the family, community and society.

1.6 Objectives of the Study

Given the background, the study aims at understanding the state and non-state initiatives towards the PWDs in rural Andhra Pradesh. The study attempts at describing the methods adopted and approaches evolved in the delivery of services to the PWDs. In its attempt, it draws comparisons between the state and non-state initiatives from the point of view of the target group i.e. persons with disabilities.

The specific objectives of the study are:

- To describe the functioning of state and non-state organizations in approaching and mobilizing PWDs in rural areas.
- To critically examine the impact of such initiatives from the point of view of the PWDs. This aspect explores the issues of identity, access and participation through an understanding of relations of persons with disabilities with their family members, neighbors, institutions at the village level and above after the initiation of the programme for the disabled.

- To discuss the differential approaches of the state and non-state towards PWDs and bring out the emerging concerns pertaining to the issues of development of the marginalized.

1.7 Research Strategy

The study aimed at understanding the state and non-state initiatives for the persons with disabilities selected the Society for Elimination of Rural Poverty (SERP) as the state initiative and the Rural Development Trust (RDT), a non-government organization as the non-state initiative, both of which work for mainstreaming and empowering the persons with disabilities. The SERP functions in all the districts of Andhra Pradesh whereas RDT works for the persons with disabilities in Anantapur district of Andhra Pradesh. The study was conducted in Anantapur district where both the programmes of development, i.e. of the SERP and RDT are implemented for a comparative understanding between the state and non-state development initiatives towards persons with disabilities.

1.7.1 Sample Selection

The basic unit of study is village to which persons with disabilities belong. In the case of state initiative, the villages were identified from the records available with the district authorities engaged in the initiative towards PWDs. In the case of RDT, the villages were identified with the help of the village level functionaries of RDT. The criteria adopted in the identification of the villages were a) successful functioning of SHG in the village b) functioning of SHG for the last five years and c) availability of local level functionaries.

It is important to mention that, both the state and non-state initiatives are functioning in Anantapur district for more than a decade. However, the villages where these two initiatives are operational do not overlap. In fact, RDT began its programme much earlier than the state. Thus, when SERP launched its programme, it excluded the villages where RDT has been functioning to avoid duplication of efforts. It was also observed that the PWDs were approached either by the initiatives of SERP or RDT across the district.

From those mandals[2] of Anantapur district where SERP has been functioning, three mandals were selected. From these three mandals, three villages from each mandal were selected for the study. Thus, under the state initiative nine villages were selected. The selection of the villages was random adopting the criteria of successful functioning of SHGs. The sample for the study on RDT was identified from the data given by the Disability unit of RDT. Villages were identified based on the inputs provided by the functionaries of RDT. The criterion adopted in the selection of RDT initiated villages was similar to that of the selection of villages under SERP.

Once the villages were identified, primary data were collected from the persons with disabilities located in each of these villages. All the PWDs from each of the villages were approached and data were collected from those who were accessible and willing to give responses. Family members and the functionaries of both state and non-state agencies were also approached for data collection.

Data were collected from a total of 72 respondents comprising of 30 respondents of SERP and 42 respondents of RDT. Family members and functionaries formed part of additional data, with whom the researcher interacted and discussed the issues related to the PWDs. The respondents were also met in their group setting. As the PWDs of every village selected for the study are members of SHGs, data were collected using focused group discussions with the SHGs. Focused group discussions also yielded significant data as the PWDs were more forthcoming in the group setting than at home. It was observed that the respondents were greatly influenced by their family members, particularly, their parents. This was witnessed during the course of an interview with the PWDs as there used to be a constant interference from the parents and family members while the interview was being held. The interviews were recorded using a voice recorder after taking consent from the respondents or their family members. The voice recordings were transcribed and analyzed. Data from the functionaries was collected during the travel to the villages, in their offices or in the villages.

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[2] Mandal is the administrative unit for about 10 to 15 villages. Mandals were carved out of Blocks in Andhra Pradesh.

1.7.2 Primary Sources

Data from the field were collected using semi-structured questionnaire, interview and focus group discussions. Socio-economic profile of the respondents was collected using the semi-structured questionnaire. In-depth interviews were carried out to collect data on roles, social relations, perceptions of the persons with disabilities with regard to the issues of impairment and ways to cope with it. Interviews with the family members and the field level personnel belonging to government and non-government organizations were also conducted. Focus group discussion helped in understanding the social, cultural, economic, political issues in general and issues of identity, participation specifically concerning disability in particular.

1.7.3 Secondary Sources

The necessary data were collected through secondary sources like government records on the persons with disabilities, functioning of the groups in terms of savings, conduct of meetings, participation, etc. Data available with RDT about its various programmes for the disabled like children attending special schools, aids and appliances distributed, PWDs employed in its units like book binding, handicraft, etc. were also used in the study.

1.8 Organization of the Thesis

The first chapter introduces the research problem by dwelling on the conceptual issues of disability. It also discusses the evolving notions of disability and the changing approaches of development towards PWDs over time. It presents the objectives and methodology adopted in the study. The second chapter critically engages with the theoretical understanding of disability through an elaborate review of literature on disability in general and in India in particular. It deliberates on the sociological issues of disability. It also presents the status of disability in India.

Chapter three presents the overview of SERP, the state initiative for the PWDs through a description of its functioning while chapter four presents a detail note on the functioning of RDT. In these two chapters emphasis has been laid on understanding the functioning, strategies adopted by both the organizations in approaching the PWDs in the villages, launching of various programmes and their mobilization into groups. Chapter five presents the socio-economic profile of the respondents and makes a comparative analysis of both the state and non-state initiatives. Chapter six brings out the comparative assessment of the functioning of both the state and non-state initiatives along certain social categories like, group, identity, participation, etc. Chapter seven draws conclusion based on the findings of the study.

CHAPTER-II

THEORISING DISABILITY

2.1 Introduction

The present chapter introduces disability as understood and treated by the society in different time periods such as early civilization, middle age, era of Enlightenment and Victorian era and also deals with disability in 20th and 21st centuries. It presents a brief history of disability in India and analyzes disability studies by providing a sociological understanding of disability.

The history of disability takes us back to the ancient civilizations where there is evidence of 'atypical body' or 'a typical human being'. Though the term 'disability' was not used to refer to the impaired or atypical body, different cultures throughout the history had varied reaction towards the people with atypical body, behavior and appearance. In early civilizations, the Ancient Greeks had antipathy towards those with bodies that were atypical, which today is referred as impaired bodies. From the analyses of the classic myths, texts and symbols, it appears that those who were mildly atypical experienced a range of support and inclusion in community life. However, in many areas, extreme deviation from the typical body were considered inhuman, particularly in newborns (Braddock and Parish, 2001; Galvin, 2003).

On the other hand, in Ancient Greek civilization, there is a significant disagreement among scholars regarding the interpretation of legitimate responses to atypical bodies. Greeks were viewed as murderers of deformed neonates who were allegedly labeled as monstrosities and were left to die. Galvin (2003) claims that, such practices were very limited across the Greeks. Rather, analysis of myths and symbols reveals the historical common denominator of multiple explanations and responses to atypical bodies and minds on the basis of why the atypical had occurred, its frequency and whether it could be cured (Galvin, 2003; Thiher, 2002). Thus, in ancient civilizations, human condition was identified. Variations of the condition were explained rather than categorizing all into atypical. Accordingly, there were legitimate acceptance and supportive responses for some type of impairment. For example, when atypical performance resulted from war injury and where the explanation was known, it was considered to be heroic and some cities maintained a pension fund to be made available to such persons (Gilson and Depoy, 2004).

Though, there is limited knowledge of disability in the middle ages, a majority of the literature focuses on Western civilizations. According to Metzler (2006), the negative stigma currently held about the middle ages limited scholarly investigation of disability in this era and influenced the analysis with pejorative and inaccurate assertions of disability by linking disability to sin and punishment. A significant disagreement on the extent to which supernatural and divine explanations were ascribed to impairment was noted in middle ages too. Metzler, quoted by Gilson and Depoy (2011) suggests that as the middle ages unfolded, the emergence of medicalisation started to unseat sin and divinity as the major legitimate explanations for and responses to disabling conditions. There were evidences of the importance of the church in the middle ages. In this age, there was the growth of institutional and charity approaches for individuals who were atypical, particularly for those who were not embedded within strong kinship systems of their own (Farmer, 2002; Green, 2006). There was an observable emergence of faith-based hospitals and the role of faith in healing also had its root in the middle ages. Charity in the form of services was considered as service to God.

In the era of Enlightenment, similar to the middle ages, the majority of analyses of disability were through a Western European lens. The belief in the supernatural was slowly being dethroned by science by the end of the middle ages, the views of difference were being drastically altered (Gilson and Depoy, 2011). Advances in scientific knowledge about the anatomy and physiology of the human body contributed to the growing sense that illness and differences in human activity could be explained by observations in the physical world.

The distinction between atypical birth-based and acquired human characteristics was developed during this time. Some birth-based failures in activities necessary for atypical growth were explained as 'monstrosities' while injuries to an individual were regarded as natural (Stiker, 2000). This era brought increasingly complex explanations for all human activities, appearances, experiences and the impaired. Particularly in westernized developed countries, as religious hegemonic explanations gave way to philosophical and systematic intellectual rationales (McClellan and Dorn, 2006), the interplay of economic and social factors in influencing the analysis of all human experience emerged and influenced explanations of the impairment as well.

The Victorian era was marked by the growth in medicine and science. But, despite the appearance of medicine and medical explanations, morality and social circumstances were still dominant explanation for unusual behavior, experience and appearance. Houses for the poor of all ages, asylums for the sick and intellectually impaired, mentally-ill were built in towns and cities. These categories were believed to be dependent as they lack capabilities to employ in income generating activities. Circumstances within the poor house were particularly and intentionally harsh to encourage families to support their members at all costs rather than abandon them to care (Gilson and Depoy, 2011).

2.2 Disability in 20th and 21st Centuries

The dawn of the 20th century brought the advancement of science and technology, which was a crucial factor in reshaping conceptualizations of disability and responses to it across the globe (Warschauer, 2004). The increasing sophistication in knowledge and technology not only shaped disability as primarily medical but also ensconced the medical and health professions as guardians and gatekeepers in many aspects of the lives of people with legitimate diagnosis. Medicine along with technology further reified disability as an embodied medical condition which needs pharmaceutical corporations, diagnostic entities, profitable treatment techniques, manufacturers and retailers of durable medical equipment, assistive technology and proprietary training etc. Thus, the advancement of scientific knowledge was important in life saving and enhancing strategies as well as in the creation of an elite group of health professionals and physicians who exchanged specialized knowledge and skill for status and economic benefits (Seldon, Bartholomew and Myddleton, 2007).

The rise of industrialization, standardization and the advancing of a global market economy in the 20th century had a notable impact on disability, impairment or impaired body. Physical work remained the dominant paradigm in defining a person's worth as a contributor to the market economy. Thus, the capacity to work has been a primary marker of one's social value as a result of which the impaired were lagging behind in the race of earning. In addition, the small private nursing homes that provided safety and care for disabled family members were replaced with larger institutions with tripartite concern for releasing family caregivers to economic production removing the atypical from public view and maximizing the profit potential of institutional care. It was the emergence of disability industry during this time where, increasing costs of technology and insurance also paved the way for the proliferation of global provider corporations whose focus was on maximizing profits (Gilson and Depoy, 2011).

The meanings attached to impairment have varied from time to time and from one society to another. The traditional Indian society treated impairment as a result of wrong deeds in one's past life. But, with the dawn of the 20th century, those superstitious beliefs were replaced by rational and secular ideas deriving from new medical findings through which all types of impairments began to acquire a medical meaning and this medical approach towards disability led to the emergence of the medical model of disability as described by the present disability scholars.

The disability rights movement originated and gained momentum in the United Kingdom in the 1970s. This movement was primarily led by the disabled people themselves who waged a struggle for their rights based on the philosophy of self-advocacy through organizations in different parts of the country. These included groups like Centre for Independent Living (CIL) founded by Ed. Roberts in Berkeley, California and Disabled In Action founded by Judy Heumann in New York in 1971 (Scotch, 2001; Shapiro, 1993).

The impairment/disability binary was first proposed in the United Kingdom during this time (1970s). Impairment was viewed as embodied deficit and disability as the concomitant responses to this condition. According to Henderson, as quoted by Gilson and Depoy (2011), impairment is a corporeal condition which leaves a body aesthetically or functionally different and to a great extent inferior to the typical unimpaired body. Disability is distinguished from impairment as a social condition in which impaired bodies are met with discrimination and exclusion. In this nomenclature, terms such as physically or cognitively disabled do not make sense and should be supplemented by physical or cognitive impairment. From this distinction, the social model of disability emerged. Through this modular lens, the body is not indicated as locus of disability at all. Disability is simply a discriminatory social response to an atypical body (Gilson and Depoy, 2011).

2.3 History of Disability in India

The history of disability in Western societies differs from the history of other South Asian countries. Thus, one cannot use the histories of disability in Europe and America as a blueprint in studying disability in Indian history. Disability in Indian context differs from its Western counterparts with regard to the culture, religion and moral behavior towards impaired body. The existing scholarship on the history of disability in India takes us back to Usha Bhatt's discussion on development of social attitude towards persons with disabilities (1963). There were both positive and negative attitudes towards impaired during the 'pre-historic' time where many tribes killed off people who were deemed physically unfit to survive in the world. On the other hand Todas, an Indian tribe was respectful towards adults and children with disabilities (Bhatt, 1963).

Indian epics such as the 'Mahabharata' and 'Manusmiti' are considered to be important sources for the history of disability. The story of Mahabharata portrays people with different kinds of disabilities in a sympathetic manner. The belief in 'Karma' among Hindus considers ones past life responsible for the condition of present life. They believe that according to 'Karma' of an individual in his/her past life, the present life is decided by God. Thus, any kind of disability is accepted as the person's ill deeds in his/her past life. In Mahabharata and Ramayana, many characters with disabilities are presented in a negative light. For example, Dhritarastra, the blind king in Mahabharata, being deprived of the throne and the portrayal of Shakuni who had orthopedic disability and Manthara (a dwarf woman in Ramayana) as characters with evil intent (Ghai, 2003).

However, later on Buddhism promoted a more tolerant attitude towards disabled by emphasizing the virtues of mercy, charity, truth, purity, kindness, goodness and non-violence (Bhatt, 1963). Gradually the colonial intervention in the form of schools, hospitals and institutions provided formal care and rehabilitation to the disabled people. However, Shilpaa Anand (2013) argues that texts such as Mahabharata and Manu's laws cannot be treated as equivalent to the Bible and other remitic theological texts within Western history. She argues that epics such as the Mahabharata are not governed by doctrinal authority as the Bible is, while Manu's laws only offer prescriptions that are sensitive to context and cannot be applied in a generic manner. Referring to Anita Ghai, Anand (2013) suggests that characters in ancient discourses such as 'Surdas', a blind poet-singer and 'Ashtavakra', known for his eight deformities, are representative of those who fought disability oppression.

2.3.1 Disability in India in the post 1980s

The rights based approach came to influence the activists of the advocacy movement of the blind in India in the 1970s with the founding of the National Federation of the Blind Graduates in 1970, which was renamed as the National Federation of the Blind (NFB) in 1972 (Chander, 2008). The NFB waged a struggle for the rights of the blind during that decade through a moderate form of advocacy. Other organizations like the National Blind Youth Association joined the struggle and changed its course from moderate to radical by the early 1980s (ibid). There was a sustained and radical movement carried out by the NFB and certain other advocacy organizations of the blind since the early 1980s, which paved the path for the implementation of the disability law in India.

During the early and mid 1980s, this movement focused on the implementation of the Office Memorandum of 1977. This Office Memorandum was the first government measure for providing one percent reservation for three categories of the disabled, i.e. the blind, deaf and physically impaired in certain selected categories of jobs under the central government services and public undertakings (Mani, 1988; Pandey and Advani, 1995). The blind activists achieved several successes in terms of employment of the blind through the movement by the later part of the 1980s, most important being the recruitment of 239 qualified blind persons in 1987 in Delhi. Thereafter, this movement focused on the demand for the enactment of a comprehensive disability rights law, resulting in the passing of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full participation) Act (Government of India, 1996) (Chander, 2013).

2.4 Disability Studies

The meaning of disability, generally forwarded by the dictionaries, describes it as a disadvantage, deficiency, especially a physical or mental impairment that restricts normal achievements; something that hinders or incapacitates or disqualifies. Disability was viewed as a problem to the individual life or at the most a family’s problem. Thus, for long, disability studies have not had the visibility as that of race, class, gender or caste, primarily on account of the general pervasiveness of discrimination and prejudice against persons with disabilities across cultures (Davis, 2006). Impairment, though as old as the origin of *Homo sapiens*, has been passed off without attracting the critical social inquiry until recently (Reddy, 2011).

Almost all the approaches developed to define disability presented the notion of impairment as a deficit or abnormality. They had a blueprint of a so called normal body and if a person does not fit into that framework, then s/he is considered as ‘abnormal’, ‘handicapped’, ‘sick or ill’. Thus, medical intervention comes forward to treat such illness or disease. It was treated as an isolable phenomenon and it relates only to the person who is under such condition and thus the general solution to that was therapeutic treatment or any other individualized effort to get rid of the condition.

The assignment of medical meanings to disability has had many and varied consequences for disabled people for a long time. The medical definitions of disability, though still continue to influence conventional understanding were the only dominant modes of explaining disability for a greater period. Abberley (1998), points out that disabled people are only relevant as a problem, and are thus excluded from making of cultural, political and intellectual world. It was the predominant medical paradigm, prior to the 1980s, which objectified and categorized people as sick or healthy.

The impaired have been marginalized from the academia and the activists' agenda for a long time. Davis (2006) maintains that while race, gender and caste have achieved more than an acceptable modality in theory, discourse, critique and political struggle, disability has continued to be relegated to hospital hallways, physical therapy tables and remedial classrooms (*ibid.:* xv). Disability studies, forcefully grounded by those affected who formed the largest physical minority group in the United States, began to emphasize the invisibility of the impaired from the mainstream social sphere and raise questions on the social constructions about impairment, mobility, and accessibility.

Moving beyond the traditional curriculum of graduate and undergraduate programmes which confined to the training of health care workers and counsellors, disability studies started looking outward, setting up of a 'socio-political-cultural examination of disability' (Linton, 1998). Colin Barnes (1998) points out that since psychological and physical impairments are presented as the cause of disability or handicap, they should be cured by psychological or medical intervention. People with impairments become objects to be treated, changed, improved and made 'normal'. As a result of the way disability was defined and the way it was interpreted earlier, disability studies was dominated by a kind of issue or condition confined to the physical object and needed only the attention of physicians, medical surgeons and therapeutic rehabilitative institutions. Thus, it lacked sufficient and necessary attention of the theorists and scholars as a minority group. It also failed to address the cultural, political and intellectual understanding of such conditions (Reddy, 2011).

2.5 Sociological Understanding of Disability

The sociological terrain of disability studies can be understood in terms of paradigm shifts from the view of disability as the product of an individual's mental functioning and behaviour (functionalism) to an engagement with the structures and institutions of society that disable (radical structuralism). Along the way, researchers have highlighted the primacy of the experiences of disabled people to an understanding of the social world (interpretivism) while others have contested ideologies of disablism (radical humanism) (Goodley, 2011).

2.5.1 Functionalism

The functionalist view of the world sees society as regulated and ordered, promotes objective measures of (dys) functional mental states and behaviors and inevitably, views disabled persons as adherents of 'sick role' (Barnes, 1998). From this view, disabled persons have inherited pathological conditions that can be objectively diagnosed, treated and in some cases ameliorated (Gabel and Peters, 2004). Functionalism sets impairment and disability as synonymous concepts. It views disability as a product of a deficient material body that struggles to escape the pitfalls of essentialism and biological determinism (Donaldson, 2002). Functionalism starts and ends with individuals and the maintenance of social order. This view has promulgated a pathological condition wherein the victim must place herself/himself in the hands of medical authorities to follow 'illness management regimes' (*ibid*). The consensual understandings of this theory focus on the ways in which disabled people are managed to maintain the social order even if this involves them being therapeutically treated by professionals allied to medicine, social work (Oliver, 1983) and psychology (Goodley and Lawthom, 2005). Functionalism reduces sociological phenomenon to the level of the individual living in a consensual world. Many disability studies until 1990s followed this methodological individualism (Rioux, 1994) empowering the traditional and moral model.

2.5.2 Interpretivism

An interpretivist stance understands the social world as an emergent social process created by individuals and their shared subjective understandings. Disabling or enabling identities and attitudes are made by and between voluntaristic individuals in a coherent regulated world (Ferguson et al., 1992). This approach understands disability as the product of voluntaristic individuals engaged in the active creation of identities. Interpretivists are interested less in people and their moments and more in moments and their people (Charmaz, 2004).

This recognizes the importance of subjective interpretations of social actors in a social world. Goffman's 'stigma' and 'spoiled identity' are rooted in this conception. It explores the meaning of impairment and disability as they are constructed through interpretation and action of individuals. It understands disability as the product of voluntaristic individuals engaged in the active creation of identities (Goodley, 2004).

A related theoretical position to the interpretivism is phenomenology, which places the dilemmas and possibilities of disability at the level of embodiment (Hughes and Paterson, 1997). Phenomenologists attend to the capacities of the body as the place where self and society interact (Shilling, 2005; Langdridge, 2007). Embodiment refers to how the body operates in the world at the intersection of the corporal and institutional (Sherry, 2006).

2.5.3 Radical Humanism

Radical humanism saturates knowledge production in the illusive shared subjective creation of dominant disability discourses, hegemonies and social meaning marking processes of wider society. Meanings are imprisoned within ideological processes, but also produced by resistant counter-hegemonic cultural practices and emergent community identities (Marks, 1999). It views disability and impairment as cultural signifiers constructed through culture and ideology. It tackles the contradictions and asymmetries of culture and ideology.

A radical humanist stance is interested in the politics of appearance (Thomson, 2002), the cultural dislocation of desire (Mitchell and Snyder, 2006), the marking of normalcy (Corbett, 1991, Davis, 1995), the socio-cultural production of bodies (Donaldson, 2002), the fiction of an idealized body politics (Price, 2007), ideological representation of disability (Hevey, 1992; Barnes, 1993; Shakespeare, 1997) and disability as a sight for the production for social ideologies of perversion, victimization and fetish (McRuer and Wilkerson, 2003).

2.5.4 Radical Structuralism

Radical structuralism sees the social world as constantly in conflict where economic and political structures can be objectively observed and in which certain social groupings are always at risk of alienation, oppression and false consciousness. It views disability or more properly disabilism as the socio-political, economic and structural exclusion of people with impairments. This perspective is the foundational principle of the social model reflecting the influence of Marxist Sociologists in 1970s, through which issues such as illness and disability were understood as products of capitalism. Radical structuralists seek to resurrect militant democratic socialism as a basis for imagining a life beyond the dream world of capitalism (Giroux, 2004).

Materialistic analysis views the categories of disability/impairment as essential to a capitalist system's exclusion of certain social groups from participating in economic activities (Erevelles, 2005). Disabled people become even more excluded by capitalism as it develops modes of production that makes labor a commodity to be bought and sold in the market. Radical structuralism politicizes disability by shifting the problem from the interiority of the functionalist body to the exteriority of capitalist structures and modes of domination. The institutions of family, education, care and welfare are viewed as organizationally structured and tuned to the purposes of international capitalism. Radical structuralism excludes the individuals, their subjective accounts and the body in favor of a macro-sociological focus on the social system (Turner, 2008).

2.6 Theorists on Disability

Although disability studies are more than 30 years old, it had different dimensions for different theorists. One can go back to Durkheim who conceived 'the disabled' as an object of sociological inquiry or even further to the time of enlightenment where 'the disabled' first became an interpretive category, bureaucratically tracked, counted, managed and subsequently evocative of a peculiar fascination for thinkers of the time (Davis, 1997). But, in spite of the presence of the concept in the academic history, it had very little influence upon the day-to-day decision making processes of the academic departments, conference organizers and journal editorial boards. Thus, disability has just recently become a sight of critical inquiry (Titchkosky, 2002). May it be Parson's 'sickness behavior' or Goffman's 'stigma'; it was always confined to the individual condition rather addressing the social imposition or intervention in making people disabled. Colin Barnes (1998) suggests that, three roles, namely the 'sick role', 'impaired role', and 'rehabilitation role' dominated the traditional sociological account of disability. Parsonian paradigm has been responsible for two approaches, one is the 'sick role' in relation to disability and its association with the social deviance and the other one is the notion of health as adaptation.

The Parson's model has differentiated between 'normal role' and 'sick role'. It suggests that, at the onset of illness, 'sick' people should adopt the sick role. The assumption of this model is that illness and disease impede both physiological and psychological abilities; 'sick' individuals are automatically relieved of all normal expectations and responsibilities. Moreover, they are not expected to recover through their own volition rather they are encouraged to view their present situation as 'abhorrent and undesirable' and in order to regain their former status, they are expected to seek help from a professional medical expert.

Parson's model assumes that regardless of the nature of the condition or the socio/economic factors involved, everyone will behave in exactly the same way (Barnes 1998). It plays little heed to subjective interpretation and articulates only the views of the representatives of society credited with the responsibility for recovery, i.e. the medical profession. Sieglar and Osmond (1974) as coated by Barnes (1998) argue that same assumption as mentioned above in case of 'sick role' applies to the people with impairments. The ‘impaired role’ is ascribed to an individual whose condition is unlikely to change and who is unable or unwilling to meet the first prerequisite of sick role to get well as quickly as possible. Occupants of this construct are said to have abandoned the idea of recovery altogether and accepted dependency. Signifying a loss of ‘full human status’ the impaired role does not require the exertions of co-operation with medical treatment in trying to regain one’s health, but the price for this is the kind of second class citizenship.

Another model, ‘rehabilitation’ model, as articulated by Safilio-Rothschild (1970), suggests that once a person with impairment becomes aware of his/her condition s/he must accept it and learn how to live with it. Within this framework of reference, individuals with impairments are obligated to assume as many ‘normal’ functions as quickly as possible. They are not exempt from social expectations or responsibilities, but must adapt accordingly. Additionally, they should co-operate with professional and innovate and ameliorate new methods of rehabilitation.

But, gradually the social constructivist account gained momentum which claims that the members of the society are responsible for the undesired situation for the disabled in the society. They highlighted that the barriers to participation of people with impairments are socially originated. Thomas (2004), points out that problem is in the definition of the situation of disability. The understanding on disability does not arise simply because the impaired body gives trouble, rather it is presented to the people through interaction with the social and physical environment and through social production of knowledge.

The social constructivist theorists attempted to draw a distinction between impairment and disability. The social model defines impairment as the lack of a limb or part thereof, or a defect of a limb or the mechanism of the body and disability as a form of disadvantage which is imposed on top of one’s impairment, i.e., the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments (UPIAS, 1976).

Dealing with the semantics of disability, Linton (2006) maintains that the usage of the word 'disability' in disability studies is radically different from the general understanding of the term disability. She notes that the prefix, *dis*, in the word disability connotes separation, taking apart. The prefix *dis* separates ability and its absence. Accordingly, a person is described as disabled if s/he lacks ability. Notably, the term disability here does not refer to the biological condition located within the individual, but refers to the act of repudiation of ability by the society (Reddy, 2011). Thus, *dis* connotes a particular social arrangement that signifies the act of exclusion perpetrated by the society on the individual. This argument has systematically shifted the presumptions associated with the term disability from the impaired onto the society. On this ground, Paul Hunt (1966) argues that the problem of disability lies not only in the impairment of function but also, more importantly, in the areas of our relationship with 'normal' people. Extent of participation of disabled people in social, religious and political functions is an important indicator of inclusion and exclusion.

It is important to discuss Goffman's 'stigma' in explaining how the society establishes the means of categorizing persons as disabled or able. He maintains that social identity is an outcome of anticipation on the part of the social actors. The anticipation transforms the normative expectations to demands. The demands made, in effect, of the opposite person may be referred to as virtual social identity and the attribute actually possessed by the person may be referred to as the actual social identity. Goffman (1963) suggests that, based on the virtual social identity norms, the social actors classify the identity of others. But, Goffman's notion of stigmas was criticized for the normative assumptions of categorizing differences. It overlooked the fact that stigma represents value judgments of the dominant group (Coleman, 1986).

Tanya Titchkosky (2002), points out that 'stigma' is a social phenomenon for Goffman where, the meaning of a mark of difference (attributes) is generated between people. The mark becomes a stigma through interaction, thus, marks of difference are not treated by Goffman as *ipso facto* leading to stigma. Potentially stigmatized people interact with others who can potentially stigmatize them. The others who possess the potential to stigmatize people are referred as 'normals'. Normals are those who have many different attributes, but who do not, in the interactional situation in question, have attributes of difference. Normals are those who, at least in the face of some individuals and within some interactional situations do not represent ‘undesired differences’. In Goffman’s delineation of the social construction of stigma, ‘normalcy’ is the standpoint which does not obtrude but rather allows for the recognition of who or what is stigmatized. Normalcy is the unmarked sight from which people view the stigma of disability.

Goffman (1963) anticipates that both reader and researcher are normals. Normals are ‘we’ that include Goffman, his imagined readers, and all others who do not depart negatively from normalcy. It is the interference of so called normal’s sense of the normal body. It is the conception of those normals who consider some body as abnormal. Thus, it is the normals who present the physically challenged people as disabled in the society. But, what if it is looked from the eyes of the person with impairment himself or herself. It is again a problem with the traditional way of theorizing disability which lacks the active participation of the impaired researcher, reader, academician and even a member of the society in the process of construction of the term. It is due to the lack of voice from the impaired people about their experiences that they are put to the category of disabled by the society. Is it their pathological condition or the regularly encountered stigma or discrimination that leads to their social isolation? (Titchkosky, 2002)

Nick Watson (2002) presents data from the informant’s accounts about their own sense of identity, who think what they are and their image of themselves. He observes that, many of the respondents rejected physicality as an essential biological determination of the self or identity. For them, self and identity is not about the differences but it is about what they can do. Some respondents even questioned the whole notion of normality challenging the social construction of what is to be normal and what is a normal body. If a person with disability is able to do all his/her daily activities as an abled bodied person does, then why and on what basis they are called or addressed as disabled. Amartya Sen’s capability approach also points out the difference between potential and actual disability (Mitra, 2006).

Throughout the time, disability studies have been shifted from being represented as a social problem of deviance to the socio-cultural and political meaning of the concept and interrelationship. The way disability was understood and interpreted by the society has changed over recent years. Disability is now considered as a social issue rather than a personal condition of individuals. The social explanation of disability has started considering the barriers, discrimination and the interference of normals in interacting processes. But, an active participation and involvement of the persons with disabilities in policy making and planning agendas is needed. Besides, there are some methodological and analytical pitfalls that hinder the effective empirical verification of disability studies.

Bynder and Kong-Ming (1976), through a research study on 100 sociologists and psychologists engaged in research in disability attempted to examine two basic questions viz. what sociological notions have been used to tackle the various problems that are present in disability? And, have sociologists been able to solve any of these problems? They observed that sociologists seemed to be mired in a number of limited concepts (even though they claim and indeed are working within broader frameworks) and this prevents them from viewing and making statements regarding the context of disability including the social conditions which contribute to disability. The researchers discussed the shortcomings of current conceptual frameworks used in disability research. They argue for the need for a change in conceptualizing the term disability and its revaluation for a significant research in the sociology of disability and its practical application.

2.7 Disability Studies in India

Configuring disability studies in the Indian context where a web of social, economic, political and scientific (medical) factors have bearings on marking the body is one such challenge for the researchers. The specificities of disability in India overwhelmingly vary from that of the West. If for the disabled in the West, the matters of identity, dignity, access and inclusion are of critical importance, in a developing country like India persons with disabilities are still struggling for their survival rather than identity. They need access to their basic rights such as health, shelter and nutrition rather than independent living (Reddy, 2011). They claim to be called by their names and not by their type of disabilities. In the words of Anita Ghai (2002), most of the time, an agenda borrowed from the Western counterparts lacks the reflexivity to analyze the Indian context in which disability is not a singular marker.

While disability advocates in the developed world have progressed from issues of service delivery and rehabilitation to an engagement with the multiple nuances/meanings of disability existence, the developing world continues to agonize over securing the very basic elements that disabled people need to survive. At the same time, with a large section of the Indian population living below the poverty line, families in crises have historically used the services of philanthropic and charitable institutions. Similarly, the successive governments of the country have relied heavily on charitable non-governmental organizations to secure basic rights such as education, shelter, health and nutrition for persons with disabilities. One of the specific ways Indian disability studies vary from that of the global North is that it needs to take cognizance of the reality of millions of disabled who live with poverty in rural areas and negotiate with the near inaccessible health, education, and employment sectors. In such cases, the way in which society reacts towards the persons with disabilities determines the inclusion. It is quite embarrassing to note that there has been an observable exclusion of the impaired in social life. This is not because of the physical barriers to the mobility of the impaired, but the attitude of others in the family who discourage the persons with disabilities from moving out. In some cases, the wheelchairs provided by the state or other non-governmental organizations, though helped the orthopedically challenged to move independently in a much better manner but it could not bring many changes in the larger society which is evident in the perception of the so called ‘normal’ social beings.

The attitude of the family members and neighbours towards the persons with disabilities is important in providing support in their daily life. A positive attitude towards the impaired can change the social stigma attached to disability from denial to approval. Therefore, disability scholars not only focus on discriminatory attitudes and social barriers, but also on disability as a development issue where an intersectional approach is required (Mehrotra, 2012).

Among the very few early studies on disability in Indian context, Usha Bhatt's (1963) work on an in-depth analysis of social attitudes towards disability is important. She examines the changing social attitudes towards disability in different historical periods through an analysis of the religious scriptures and main currents in Western philosophy. She elaborates the *karma* model (sections of past life, exerting an influence on the present life) and explains the reasons for the lack of development of rehabilitation services for the disabled in India. Bhatt argues that while the break-up of the institution of the extended family and two World Wars have had a tremendous impact on the social attitudes towards disability in the West, India remained relatively unaffected by such events. The disabled segment of the society did not get the due attention of policy makers and planners. As a result, social attitudes towards disability continue to be highly influenced by the moral and charitable approaches arising out of the traditional Hindu notions of *karma* and *dharma* (religious duty). Thus, Usha Bhatt's study was a pioneering work at the time when there was hardly any focus on disability as a subject of academic pursuit. But, on the other hand, it must be admitted that Bhatt's sociological understanding is based more on a moral rendition than a disability studies perspective (Chander, 2013).

It is only during 1990s, that books on disability accorded some recognition to the importance of the disability studies approach acknowledging the advocacy potential of the disabled activists. Three publications in 1990s deserve special mention. The book by Ali Baquer (1994), which was more embedded in a disability studies perspective and emphasized on the argument that the government should take serious account of the demands of the disabled for comprehensive disability rights legislation. Books by R.S.Pandey and Lal Advani (1995) and by Ali Baquer and Anjali Sharma (1997), discuss the issues relating to the disability law. The authors, however, take the line of the traditional medical model of disability as they basically present status reports on disability related issues in India.

Lately, more works have started reflecting a clear disability studies approach. For instance, Asha Hans and Annie Patri (2003) and Anitha Ghai (2003) have incorporated the disability studies perspective in their analysis. Interestingly, both of the works are grounded in a strong feminist perspective. Hans and Patri's edited volume (2003) is significant as it adopts a disability studies perspective in the discourse on identity of disabled women by including contributors who either happen to be disabled themselves, siblings or parents of the disabled or women scholars working on theorizing the academic discourse on disabled women's identity. Drawing upon the marginalization of women with disabilities in Western feminist discourse, Ghai (2003) develops the argument of marginalization of women with disabilities by feminist theorists in India and discusses the multiple forms of oppression disabled women face in the Indian society (Chander, 2013).

Bringing out the issues of rural disabled, Insa Klasing (2007), in an empirical study of persons with disabilities in rural areas in two states, Andhra Pradesh and Rajasthan, reports that persons with disabilities in India face much more varied and severe problems that even threaten their survival when compared to their counterparts in the West. Acknowledging the inadequacies associated with the data on the number of disabled in the country, coupled with the inferior social position of the disabled people in the villages, Klasing (2007) reports that even these highly participatory and intensive surveys could not identify all disabled people in the villages. The findings of the study foreground the peculiarities of the disabled in India by revealing the strong nexus between poverty, low educational levels and impairment. The study reports that access to medical facilities in rural areas has a direct and indirect bearing on disability in India. Presenting the status of state health assistance, it points out that, while about 80 percent of disabled in India live in rural areas, the rehabilitative services are concentrated in urban areas. The study suggests for a review of the rural public health system in the light of its empirical observation that the medical needs of the impaired persons in rural areas are grossly neglected. It maintains that though pregnant mothers and infants are the primary targets to prevent the occurrence of impairment (through vaccination and medical assistance), the impaired are bypassed (Reddy, 2011).

On the patterns of exclusion from educational sphere, Klasing reports high incidence of illiteracy among the disabled not just because of poor economic status but due to oppressive socio-cultural stereotypes that prevail in the Indian society. The study finds that, even those who had access to school reportedly dropped out because of humiliation in public, in school and on the way to school. The repeated confrontation with jeering and ridicule evokes a sense of shame and disgrace in disabled children and deters them to pursue their educational aspirations. Klasing's study finds that most of the schools are physically inaccessible and not equipped with trained teachers to teach the disabled children. Even those parents who could afford to send their children to school had to stop due to the normative practices enforced by the school authorities. Children with disabilities were deregistered by the school authorities on the ground that they cannot be taught along with other children or would distract the attention of other students in the class (ibid).

Women with disabilities live with discrimination of greater magnitude when compared to their male counterparts in India. Mehrotra (2006), in a study of disabled women in rural Haryana observes that disability becomes an additional burden on the gendered position demanding them to cope with twin identities of women and impaired. Anita Ghai (2001), while highlighting the deep rooted social discrimination against the impaired women observes that, 'for poor families with a hand-to-mouth existence, the birth of a disabled child or the onset of significant impairment in childhood is a fate worse than death'. Attempting to expose the social stereotypes that operate against the disabled women, Ghai presents the anguish of a mother of a disabled girl in her own words '*wasn't it enough that we are poor and helpless. Why did God have to add to our burden by giving me a daughter and that too blind?* (Ghai, 2001).

It is important to note that cultural stereotypes play a greater role in the marital prospects of persons with impairment in India. Interestingly, Klasing's (2007) study while reporting a high incidence of marriage among disabled women respondents states that, traditional norms in villages impel the parents of the disabled girls to get their daughter married. A girl's life is perceived as ruined or incomplete in the Indian society if she remains a spinster all her life. The 'societal perception of marriage as the final responsibility of the parents towards their daughters leads some parents to resort to any means, fair or foul, to find them husbands' (Hema N. S cited in Klasing 2007). In the process, parents make many compromises ranging from marrying their daughter to an older person, widower or as a second wife to offering exorbitant amounts of dowry. Even if disabled women do get married, however, the study finds that the marriage always remains precarious. The rate of marriage among disabled men, however, is reported to be low because the same cultural norms work against the prospects of marriage for men with disabilities. Klasing's (2007) study quotes a male disabled respondent saying 'parents of girls are generally reluctant to accept a disabled son-in-law as they feel that the disabled man cannot provide financial security for their daughters'.

In a study in rural Haryana, Mehrotra (2006) found that the most professed support a woman with disability can get is the sharing of her responsibilities with her sisters. For this, the disabled girl is often married into the same household as her sister, usually with a consecutive brother and sometimes to the same man as her sister. This type of marriage practice often comes to the aid of a disabled woman. Other characteristics associated with the marriage of a disabled woman is that she is usually married to a disabled man, a widower, in a household whose economic condition is lower than her natal home, or to a man who cannot find a spouse for whatever reason. There were also reports of heavy dowries paid by parents of disabled girls (Mehrotra, 2006).

Dependency among the disabled on the family members is overwhelming in rural India. Besides impairment, the vicious circle of poverty leading to lack of education, lack of employment and above this, the disabling social settings result in complete dependency of the disabled on the family members. To overcome the extent of dependency of the disabled people on the family members, the state policies promote collectivization through Self-Help Groups (SHGs). It is claimed that the formation of SHGs has not only raised hopes of income generation, training in vocational skills for the disabled, but also to fight discrimination by institutions like schools, hospitals and employers collectively. Klasing (2007) reports that in a village, a SHG of the disabled had even enforced the delivery of state services like aids and appliances or disability certificates by staging a demonstration in front of the disability commissioner's office at district headquarters.

In addition to the above mentioned works on disability, Nilika Mehrotra's recent work 'Disability, Gender & State Policy: Exploring Margins' (2013), foregrounds disability from an anthropological perspective. It contributes to the studies in marginalization and social inequalities in India. Covering a wide range of issues from international and national contexts, the book critically examines the role of disability rights movements, as well as the regional policies and practices. It explores the cultural perceptions of disability, the construction of gender and personhood in rural and urban contexts, and the issues in social support and care work. Moreover, it highlights the implications of globalization and psycho-social disabilities among poor urban women and analyzes disabled persons' access to resources like education and employment opportunities in diverse sectors, providing a comprehensive account of the disabled, embedded in India's communities, citizenry, and democracy.

Renu Addlakha's work 'Disability and Society: A Reader' (2009) and 'Contemporary Perspectives of Disability in India: Exploring the linkage between Law, Gender and Experience' (2011), provide important input to the conceptualization of disability and various approaches towards it. Her recent volume 'Disability Studies in India: Global Discourses, Local Realities' (2013) seek to engage with the concept of disability from a variety of disciplinary positions, socio-cultural contexts and subjective experiences within the overreaching framework of the Indian reality. The volume is a compilation of existing and ongoing research with a particular focus on the intersections with other socio-demographic variables such as gender, class, caste, ethnicity, age, rural-urban residence etc. in the diverse areas of law, policy, medicine, family and culture. It discusses various disability issues like historicising disability in India, the disability rights movement in India, the need for care, gender issues, identity construction and formation, inclusion of disabled and their participation in the larger society etc.

In historicising disability, Shilpaa Anand (2013) argues that historicising disablement in non-Western cultural contexts using the Western paradigm is problematic. She claims that through a re-evaluation of the historical methods the disability researcher would really contribute to the history of disability in Indian context. Jagdish Chander (2013) presents the disability rights movement in India in a chronological sequence along with the disability studies by various authors at that time.

Upali Chakravarti (2013) finds that families shoulder a greater responsibility in care-giving. Moreover, the mother of the person with disability is assigned with the caring duty. In the absence of mother, it is either the wife or sister to take over the responsibility. Chakravarti contends that families require not only material resources, but also continual psychological support. Amit Upadhyay (2013) brings an important dimension to disability through narratives of orthopedically impaired persons engaged in gainful employment. He highlights the difficulties faced by orthopedically handicapped persons, both at the workplace and in getting jobs. Upadhyay also discusses the difficulties faced by them in negotiating the built environment at the workplace and the need for further research in this area.

Sandhya Limaye (2013) presents detailed case studies of hearing impaired adolescent girls in Mumbai. According to her, ‘adolescence is one of the critical developmental stages of life cycle involving a distinct set of tasks which include awareness and acceptance of the changing body, development of peer relationships, internalization of gender role expectations and the development of a personal identity in addition to exercising autonomy, training for acquiring work for economic independence and entering marriage and family life’.

Towards issues of disability and feminism, Nandini Ghosh, Renu Addlakha, Michel Friender and Sandhya Limaye reveal how women with disabilities are often subjected to multiple discriminations due to the patriarchal notions of sexuality which considers them incapable of taking on sexual, reproductive and maternal roles. Friender (2013) in her findings on identity formation and transnational discourses concludes that culture plays a crucial role in the construction of self-hood and identity. She also explores how culture and gender modify the experiences and articulations of deaf identity in a non-Western setting.

Another group of authors offer concrete proposals to ameliorate the life conditions of persons with disabilities through micro and macro level approaches. Suggestions are made to replicate strategies of the women's movement for empowerment of persons with disabilities. Bhargavai V. Davar (2013) delineates the tensions between the feminist politics empowerment that seeks social transformation in gender relations and the personal experiences of distress of individual women in search of healing. Her article follows other feminist disability scholars in their critique of the allegiance of the mainstream women's movement to a homogenous notion of womanhood that does not adequately valorise how disability creates fundamental differences among women.

On the other hand, Asha Hans, Amrita Patel and S. B. Agnihotri (2013) show that allocating resources is not enough when the social, political and cultural realities block access of persons with disabilities, particularly women with disabilities to such resources. Using the paradigm of gender budgeting to analyze allocations and expenditure in the disability sector in four of the poorest states in India, they highlight the yawning gap between policy rhetoric of rights and empowerment and inadequate resource allocations to match it. The authors found steadily diminishing utilization of resources in the disability sector. Bad governance, structural adjustment programmes and lack of awareness about such programmes by persons with disabilities and their families are major reasons for this under utilization. They strongly recommend the need for a concentrated national campaign of awareness building on the englightment available to persons with disabilities in the country and suggest that there should be a specific allocation of budget in skill and capacity building program/schemes for the women with disabilities.

Reddy (2012), in an empirical study of the state initiatives towards the disabled in rural areas in three regions of Andhra Pradesh namely, Telangana, Rayalaseema and Costal Andhra observes that the state initiative through the Society for Elimination of Rural Poverty (SERP) work on mobilizing the PWDs into SHGs. The study suggests that the SHGs provided the disabled a platform to share their experiences and feelings. Thus, social interaction attained prime focus through the SHGs. As SERP approach is based on the rights mode, the group members feel that it is their right to claim the benefits provided by the government to the PWDs and society's attention towards their needs and interest. Thus, discussion over rights was observed to be the key motivating aspect in the increased participation of the PWDs in various socio-economic activities.

Based on the findings of the above said research, the paper by Chand and Reddy (2012), finds that the change in formal institutional approach may not echo similar change in the customary or informal institutional milieu in which the impaired participates as a social entity. The paper suggests that the initiatives taken up by SERP brought significant changes in the identity of impaired by increasing their participation in social, political and economic activities. The study, however also finds that inclusive measures of state institutions though enhanced participation, failed to break the barriers of participations located in socio-cultural contexts. For example, lack of participation in private social life such as attending weddings, having non-disabled friends and getting married. On the other hand, it was also observed that the participation of the disabled people is more economic rather that social by nature.

2.8 Dimensions of Disability in India

The sheer magnitude of disability in India is enormous. India is home to the largest population of disabled in the world. Kishor Bhanushali in his work on 'Dimensions of Disability in India' illustrates the efforts of the state in recording the number of disabled in the country. He reports that the Census of India began collecting information on disability since its inception in 1872. The questionnaire of the 1872 Census, called the 'House Register' included questions on the physically disabled, the mentally disabled and persons affected by leprosy.

Data collection on infirmities was continued in the censuses from 1881 to 1931. However, due to the problems of authenticity and quality of data collected on disabled population, the enumeration of physically disabled persons was discontinued during the 1941 Census. It was felt that the question on disabled population did not lend themselves to a census inquiry since these did not seem to provide accurate data due to a variety of reasons particularly due to the social stigma attached with this characteristic.

After a gap of 50 years or four decennial Censuses since 1931, a question on disability was again canvassed at the 1981 Census (Bhanushali, 2011). In 1981, which was declared as the 'International Year for the Disabled', there was the inclusion of a question on disability during censuses all over the world. However, the exercise was limited to the extent that data on only three broad categories of physical disabilities viz. totally blind, totally dumb and totally crippled was ascertained. The 1981 Census data reported considerable under enumeration of physically handicapped persons. Thus, it was felt that simple census enumeration exercise does not help in identifying people with disabilities. Based on the assumption that the complexity of the definition of disability and inherent reservations of the population to share the information with the enumerator, it was felt that the enumeration of disability lies beyond the scope and capacity of Census operations (*ibid)*. Thus, the census enumeration in 1991 did not focus on disability. However, as the disability rights movement started gaining ground across the globe and with the obligation under Persons with Disabilities (Equal Opportunities, protection of Rights and Full Participation) Act, 1995, the question on disability was again incorporated in the Census of India 2001 (Reddy, 2012).

2.9 Defining Disability

Census of India 2011 observes that defining and measuring disability is a complex issue and it is not easy to communicate these concepts during the Census enumeration process in which only a limited amount of questioning time is possible to be spent with a household for obtaining detailed information on every individual (Census of India, 2011). With regard to definitions adopted by PWD Act, Census of India states that the concepts and definitions of disabilities coupled with measuring its extent and its types contained in the PWD Act, 1995 were found to be extremely difficult to canvass even in normal circumstances, assuming people had time, were willing and forthcoming to share this information and there was an expert investigator to elicit this information. Census, therefore, uses its own definitions of disabilities.

Census of India classified disability into eight types viz. seeing, speech, hearing, movement, mental retardation, mental illness, any other and multiple disability. Seeing disability includes a person who cannot see at all (has no perception of light) or has blurred vision even with the help of spectacles. A person with no vision in one eye but full vision in the other eye (one-eyed persons) was not considered as having a disability in seeing. Similarly, persons having night blindness alone and color blindness alone were considered as disabled in seeing. A person was considered to be having a disability in hearing if s/he cannot hear at all and has difficulty in hearing day-to-day conversational speech (hard of hearing) or if s/he uses a hearing aid. Persons having problem in only one ear were not treated to have hearing disability Similarly, a person was considered to have disability in speech, if s/he is above the age of 3 years and cannot speak at all or s/he is unable to speak normally on account of certain difficulties linked to speech disorder. However, persons who stammer but whose speech is comprehensible were not treated as disabled in speech. Further, persons born with hearing disability and are unable to speak (deaf and mute) were treated as having a multiple disability.

Persons having a disability of bones, joints or muscles of the limbs leading to substantial restriction of movement were considered to be having movement disability. Absence of a part of a limb like a finger or a toe was not considered as a disability. However, absence of all the fingers or toes or a thumb would make a person disabled by movement. If any part of the body is deformed, the person was also treated as disabled and covered under this category. A person, who cannot move her/himself without the aid of another person or without the aid of stick etc., was also treated as disabled.

Mental Retardation was defined in the census as a condition of arrested or incomplete development of mind of a person which is specially characterized by sub-normality of intelligence. The onset of mental retardation is usually from birth or in some cases before the age of 18 years. A person who lacks comprehension appropriate to her/his age was considered as mentally disabled. This would mean that if a person is not able to comprehend her/his studies appropriate to her/his age and is failing to qualify her/his examination is mentally disabled. Mentally retarded and insane persons would be treated as mentally disabled.

A person having a psychological or behavioral pattern associated with distress or disability that is not a part of normal development was treated to be mentally ill. The affected person is generally not able to cope with the problem. As per medical literature, there are different types of mental illnesses like Anxiety Disorders (phobia, panic disorder, social anxiety disorder etc.), Mood disorders (intense and sustained sadness, manic depression etc.), Perception disorders (delusions, hallucinations, schizophrenia) and Personality disorders (eccentricity, paranoia etc.). The disabilities that were not covered under any of the above said categories were listed as any other category of disability. This category includes disabilities like Autism etc. Multiple disabilities mean a combination of two or more disabilities. For instance, persons with both speech and hearing disabilities were considered as persons with multiple disabilities.

Though the first official data on disability specific information was available from the survey conducted through the National Sample Survey Organization (NSSO) in 1991 by the Department of Statistics of the Ministry of Planning and Program Implementation, it was contradictory to the estimates of the World Bank. The sample survey concluded that only 1.9% incidence of disability existed in India, further indicating that other measures would need to be taken to produce reliable information on the status of disability in India. The Census data of 2011 on the number of persons with disabilities presents a picture of higher magnitude. Nearly 2.68 crores of people in India have been recorded as disabled.

Table 2.1: Distribution of Population of Disabled in India

Gender	Total	Rural	%	Urban	%
	26,810,557	18,631,921	69.49	8,178,636	30.51
Male	14,986,202 (55.90%)	10,408,168	69.45	4,578,034	30.55
Female	11,824,355 (44.10%)	8,223,753	69.55	3,600,602	24.03

Source: Census of India - 2011

Table 2.2: Distribution of Population of Disabled in Andhra Pradesh

Gender	Total	Rural	%	Urban	%
	22,66,607	15,12,961	66.75	7,53,646	33.25
Male	12,244,59 (54.02%)	8,12,882	66.39	4,11,577	33.61
Female	10,421,48 (45.98%)	7,00,079	67.18	3,42,069	32.82

Source: Census of India – 2011

An observation of Census data reveals that disability is a predominant phenomenon in rural areas (accounting for nearly 70 percent of disabled people) in comparison to urban areas (see Table 2.1). In the case of Andhra Pradesh, disabled persons living in rural areas account for nearly 67 percent of the total disabled population in the state (see Table 2.2). It may be said that at all India level and in Andhra Pradesh, women constitute nearly 45 percent of the total disabled population.

Table 2.3: Distribution of Population of Disabled in India by Types of Disabilities

Types of disabilities	Number of Disabled	Percentage
Seeing	50,32,463	18.77
Hearing	50,71,007	18.91
Speech	19,98,535	7.45
Movement	54,36,604	20.28
Mental Retardation	15,05,624	5.62
Mental Illness	7,22,826	2.70
Any Other	49,27,011	18.38
Multiple Disability	21,16,487	7.89
Total No. of Disabled	26,810,557	100.00

Source: Census of India, 2011

Census of India 2011 collected data on eight types of disabilities. Table 2.3 suggests that those having disabilities in movement constitute a major percentage of disability i.e. 20.28 per cent. Those with seeing, hearing and any other impairment constitute almost equal percentage of the disabled population. Further, 7.89 percent of the disabled population is reported to be having multiple disabilities. However, it may be observed that only 2.70 percent of the disabled population is suffering from mental illness.

2.10 Disabled Population in Anantapur District

The census 2011 data suggests that there are a total of 1, 21,908 persons with disabilities in Anantapur district, out of which 65,939 are men (54.08%) and 55,969 (45.91%) are women. Out of the total 1, 21,908 disabled people, 95,961 (78.71%) are residing in rural areas while the remaining 25,947 (21.28%) in urban areas.

Table 2.4: Distribution of Population of Disabled in Anantapur district by Types of Disabilities

S.NO.	Type of disabilities	Sex-composition		Total	%
		Male	Female		
1	In Seeing	9,111	9,309	18,420	15.11
2	In Hearing	7,899	8,104	16,003	13.13
3	In Speech	8,393	6,464	14,857	12.19
4	In Movement	18,655	12,029	30,684	25.17
5	Mental Retardation	4,100	3,729	7,829	6.42
6	Mental Illness	1,116	1,091	2,207	1.81
7	Any Other	11,383	10,552	21,935	17.99
8	Multiple Disability	5,282	4,691	9,973	8.18
Total Disabled Persons		65,939	55,969	1,21,908	100

Source: Census of India, 2011

It may be observed from Table 2.4 that 30,684 persons constituting 25.17 percent of the total disabled have physical disability followed by 21,935 persons (17.99 percent) with any other disabilities including Autism, etc. Further, Table 2.4 suggests that 18,420 persons constituting 15.11 percent are visually impaired followed by 16,003 (13.13percent) with hearing impairment and 14,857 (12.19 percent) with speech impairment. Persons affected by psychological and behavioral disorders such as anxiety, personality disorders, perception disorders etc. falling under mental illness constitute 1.81 percent of the total disabled persons and persons with multiple constitute 8.18 percent of the total disabled population.

The chapter presented an overview of theoretical discourse on the concept of disability and highlighted the research in the area of disability. It also dwelt on the disability scholarship in India and on the sociological insights on disability. It presented a cursory view of the extent of disability in India by presenting data on disability. The next chapter discusses the functioning of SERP a State initiative functioning in Anantapur district for the welfare of the PWDs.

CHAPTER-III

THE SOCIETY FOR ELIMINATION OF RURAL POVERTY (SERP): AN OVERVIEW

3.1 Introduction

Disability has been attracting greater attention from the development planners, academia and researchers due to the increased activities by the disability rights groups. Approaches on disability moved beyond the traditional medical intervention and welfarism to rights mode. Critical understanding of cultural representation, charity based initiatives put the disabling environment and society in forefront. India as a developing country, though lags behind the Western counterparts, has witnessed certain developmental initiatives for a better living of the persons with disabilities. One such initiative is the Andhra Pradesh Rural Poverty Reduction Project (APRPRP) which has taken up disability development initiative under its poverty eradication programmes. A quasi-government body by name Society for Elimination of Rural Poverty (SERP), an autonomous society set up under Societies Act, works on five major components of development which includes a component on disability. This chapter attempts at describing the functioning of the SERP on disability. It explores the emergence of SERP and discusses the strategies adopted by SERP for the disabled in the state. As mobilization of the PWDs into self-help groups is the basic approach of SERP, an intense discussion is provided on the strategies adopted in the formation as well as sustenance of SHGs in the state of Andhra Pradesh.

Poverty has been the thrust area for successive governments in India since independence. Defined as the inability to secure the minimum consumption requirements for life, health and efficiency on account of insufficient income or assets, poverty attracted the attention of policy makers and thus, several governments initiated a number of poverty elimination programmes over the decades. Provision of necessary requirements to meet minimum human needs of food, clothing, shelter, education and health have been the focus of many development approaches of the state.

The common objective adopted in this direction is to enable the poor to have access to incomes which could earn a person below poverty level to meet the needs of food, clothing, shelter etc. The minimum needs of a person to rise above the poverty line are calculated in terms of calorie intake of 2100 in urban areas and 2400 in rural areas. A person is considered poor if his/her consumption or income level falls below these minimum levels necessary to meet the basic needs. Thus, poverty in rural areas where a large number of people are concentrated has been the special focus of various state initiatives. Andhra Pradesh, in this context, offers no different picture of poverty to that of elsewhere in the country. Beyond the notions of basic food needs, rural poverty has been viewed as a multi-dimensional phenomenon encompassing the inability of individuals and groups to satisfy basic needs, lack of control over resources, lack of education and skills, poor health and malnutrition, lack of shelter and poor access to water and sanitation. The scope of state initiatives on poverty take into cognizance of varied and complex issues deeply embedded in the social, institutional, and cultural contexts (www.serp.ap.gov.in)[3].

3.2 The Andhra Pradesh Rural Poverty Reduction Project (APRPRP)

As envisioned in the Andhra Pradesh vision 2020 document, the state of Andhra Pradesh embarked on a long-term rural poverty reduction programme to enable the poor and the marginal to overcome poverty. The Andhra Pradesh Rural Poverty Reduction Project (APRPRP) is one such programme on rural poverty started with the financial assistance of the International Development Association (IDA) in 2003. The implementing and coordinating agency is the Society for Elimination of Rural Poverty (SERP).

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[3] A large part of this chapter is sourced from the report titled "Enabling the differently abled: a sociological understanding of the development initiatives of the state and the community towards the disabled in rural Andhra Pradesh" submitted to the University Grants Commission, New Delhi in 2012. The project was funded by the UGC under Major Research Project Scheme and the researcher was associated with the project as Project Fellow.

The objectives of APRPRP are:

- to ensure that the poor, particularly the poorest of the poor, sustain self-reliant empowered organizations to take advantage of their new opportunities,
- to facilitate them to convert their secure asset base into an economically viable, improved and sustainable living,
- to achieve higher educational level particularly among girl children,
- to integrate bottom-up participatory development of the target groups with well-coordinated and transparent delivery of public services at the local level.

There are five major components of APRPRP, viz. Institution Building, Community Investment Fund (CIF), Social Risk Management and Social Protection, Girl Child Labour Elimination and Disabled people. The Institution Building component includes social assessment for identification of individuals and groups and their specific needs, social mobilization of the target groups and setting up of organizational machinery for coordination of Community Based Organizations (CBOs) and Panchayat Raj Institutions (PRIs) through joint planning and sharing of responsibilities and monitoring the outcomes through a baseline assessment. The project aims at providing support to the line departments working in health, nutrition, education, agriculture and rural development at the grass root level and strengthens them.

The second component of APRPRP is the Community Investment Fund (CIF) which facilitates funding for livelihood opportunities that the poor as a group may want to pursue, livelihood for small and marginal farmers, infrastructure development, land and water conservation/management interventions, development of pilots for enhancing livelihood opportunities such as producers' co-operatives. The third component of APRPRP relates to Social Risk Management and Social Protection. This component incorporates awareness and capacity building regarding risk management alternatives including government safety net programmes for the poor. It also aims at creating a social fund i.e. a revolving fund managed by the Mandal Samakhyas (MS) to meet the needs of the members of the group who are in dire need of money, facilitating and administering formal insurance services of life, health, accident, livestock to the group members etc.

The fourth component of the project focuses on Girl Child Labor Elimination and putting them back in schools. The project undertakes campaigns to wean away girl children from work and put them into schools, mobilize the parents against child labor practices, establish Bridge Schools for girl children for training them so as to send them to regular schools.

The fifth component of the project is aimed at disabled persons. The specific activities under this component are:

- social mobilization and capacity building of the disabled persons in rural areas,
- campaign for sensitizing the disabled, members of the family and the community on issues relating to the disabled,
- promotion of livelihood opportunities for the disabled,
- setting up of special training centers, educational support to children with disabilities,
- helping the disabled to secure their entitlements under government programmes and prevention of disability,
- creating a barrier free environment in schools like providing special toilets for disabled girl children, training of the school teachers on special education skills required to deal with children with disabilities and generation of awareness amongst the other students about the need to treat disabled children with respect and care.
- building linkages with institutions providing institutional support to disabled for specialized services like corrective surgery and obtaining aids and appliances.

3.3 Society for Elimination of Rural Poverty (SERP)

APRPRP is implemented through the Society for Elimination of Rural Poverty (SERP), which is an independent, autonomous society registered under the Andhra Pradesh Societies Registration Act. It is supported by a State Project Management Unit (SPMU) located at Hyderabad and by the District Project Management Units (DPMU) of each district. The organization functions with the objectives of evolving strategies for empowerment of poor through social mobilization and institution building, promoting institutions at the village level, building up of capacities of local bodies so as to enable them to address the needs of the rural poor, serving as a resource centre for research and analysis, training on social and economic conditions of the poor and implementing anti-poverty programmes of the state. SERP as an autonomous organization combines the authority and accountability of the government and operational flexibility of an NGO. Its structure is designed to expedite the implementation of the programmes to reach the target poor quickly and facilitate transfer of control of all the project initiatives to the community.

3.4 Organizational structure of Society for Elimination of Rural Poverty

The organization has a General Body and an Executive Council for guiding and taking forward the objectives of the project. The Chief Minister of Andhra Pradesh state is the Chairperson for the general body. A retired Indian Administrative Officer is the Vice-Chairperson of the general body and the President of the executive council. Eminent individuals belonging to government and NGOs having a proven track record of commitment and concern for the poor constitute the general body and the executive council. The Chief Executive Officer (CEO) is the head of the organization and oversees the day-to-day administration of all activities of the organization. The CEO is a senior person from the Indian administrative services of the state.

3.4.1 State Project Management Unit (SPMU)

SERP consists of SPMU (State Project Management Unit) and several DPMUs (District Project Management Unit) implementing the project. The SPMU is headed by the CEO/SPD (State Project Director) who oversees the operationalization of different projects of SERP. The roles and responsibilities of the SPMUs are as follows:

- positioning and capacity building of the Project Directors.
- develop strategic planning and operational plan.
- provide an interface with government and donor agencies.
- linkage with state level offices of development departments, development agencies and other corporate offices.
- recruitment of District Project Managers (DPMs) for DPMUs.
- capacity building of the DPMs.

- initiate special studies on emerging issues in the implementation of the project.
- work for policy advocacy on pro-poor issues, take up policy issues with government and line departments.
- constitute the state level committee to guide, steer and coordinate the project.
- take overall responsibilities to implement the project for the realization of the objectives and expected outcomes of the project.
- develop required material for training and capacity building such as training modules, video films etc.

The SPMU collectively takes the responsibility of accomplishing the above responsibilities under the overall guidance of the Chief Executive Officer and the State Project Coordinator.

3.4.2 District Project Management Unit (DPMU)

There are several administrative units responsible for the overall functioning of DPMUs. The Head of a DPMU is the Project Director who is from a civil service cadre of the state and is assisted by administrative personnel (Assistant Project Manager) and some functional specialists (District Project Managers). The roles and responsibilities of DPMU are to:

- recruit persons with commitment to various organizational positions at the district level.
- facilitate the mandal samakhyas to recruit persons at mandal level.
- capacity building of organizational staff at the district level.
- capacity building of grass root activists, members of the groups and other important stakeholders.
- sensitization and orientation of elected representatives of panchayat raj institutions.
- sensitization and orientation of the line departments at the district and mandal level.
- develop linkage with all line departments, commercial banks, micro finance institutions, non-government organizations and other development institutions.

- interface between the District Administration and SPMU for coordinating the project activities.

3.4.3 Role of District Collector

The District Collector plays an important role in the functioning of SERP at the district level. The Project Director of SERP works in close coordination with the District Collector. The Project Director apprises the District Collector once in a fortnight on the progress and activities of the projects. The District Collector plays the roles of chairing the District Coordination Committee (DCC) set up for the implementation of the project. Recruitments of the project take place under the guidance of the District Collector. The District Collector provides overall guidance to the project in the district by reviewing and coordinating with all the line departments.

3.4.4 Functions of the Project Director

The Project Director (PD) of District Rural Development Agency (DRDA) anchors all the poverty elimination programmes of SERP at the district level. Being a state funded project and as a responsible executive of the state machinery, it is the duty of the PD to apprise of the activities of SERP to the local public representatives. Hence, the PD attends all the general body meetings of the Zilla Praja Parishad (ZPP) and apprises the members, who include the elected representatives, on the strategies, activities and progress of the project.

3.4.5 Organization at the Mandal level

At the mandal level, there is a Mandal Community Support Cell (MCSC) with functionaries like Assistant Project Manager (APM), Community Coordinators (CCs) and Mahila Mandal Samakhyas (Mandal Forum/Mandal Federation). The MCSC takes up the following project activities at mandal level

- organize all the target poor households into self-help groups.
- organize all the self-help groups into village federation.
- capacity building of Mandal Forum/Mandal Samakhya.
- capacity building of the self-help groups and village organizations.

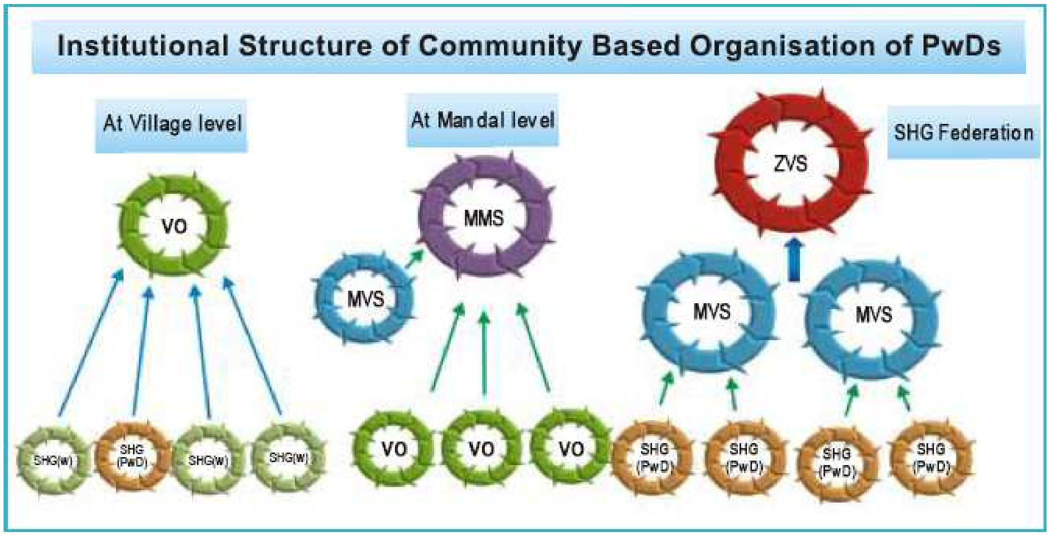
- facilitate the Community Based Organizations (CBOs) to prepare the sub-project proposals and send to DPMUs for approvals.
- help CBOs to implement the sub-projects effectively to benefit the target poor.
- help CBOs to develop linkage with banks, line departments and other development agencies.
- promote a cadre of community activists, social activists and para professionals in social mobilization, training, health, livestock, marketing, livelihoods, sanitation, agriculture, education and social issues.
- interface with the panchayat raj institutions at the mandal and village level.
- sensitize, orient and apprise all the stakeholders at mandal level on project activities and progress.
- develop Management Information System (MIS) and furnish monthly reports to DPMU.

3.5 Strategy for the Differently Abled

Andhra Pradesh ranks fourth in the incidence of disability in the country (Census, 2011). Moreover, around 70 percent of the disabled in the state reside in rural areas who face problems of nutritional deficiency, poor living conditions, marginalized identity, confinement to homes, lack of education, employment etc. The social apathy towards the disabled adds to the invisibility of the disabled in the rural areas.

Recognizing that the persons with disabilities are among the poorest and the most vulnerable of the poor, the SERP had initiated disability interventions as a pilot project in 138 project mandals in the state (by 2012 the programme was extended to all the 1,128 mandals of the state). So far, 2,23,081 disabled have been mobilized into 22,329 self help groups (SHGs) by forming 138 Mandala Vikalangula Samakhyas (MVSs) and 3 Zilla Vikalangula Samakhyas (ZVSs). These SHGs, MVSs and ZVSs were envisioned to evolve as a model of institutional relationship between Community Based Organizations (CBOs) of disabled and various government and non-government stakeholders and make them as resource centers in addressing the problems of the disabled. The long-term objective of this component is to help disabled persons and their caregivers to improve their livelihood opportunities and quality of life.

Figure 3.1: Organization of SHGs for the disabled from village to the district level



Source: http://www.serp.ap.gov.in

VO= Village organization

SHG (W)= Self Help Group (Women)

SHG (PWD)= Self Help Group (Persons with Disabilities)

MVS= Mandala Vikalangula Samakhya

MMS= Mandala Mahila Samakhya

ZVS= Zilla Vikalangula Samakhya

3.5.1 Strategy

Given the high degree of marginalization faced by the disabled people, the primary strategy of the SERP has been to empower persons with disabilities within their communities and build mechanisms for effective linkages with local public and administrative institutions. The project has been operating through social mobilization and building people's institutions focused on the needs of disabled persons and the community. Work is undertaken within the broader social mobilization activities of the project to ensure that the support for disabled persons is fully mainstreamed into support mechanisms for the rural poor. The SERP mainly focuses on improving the livelihood opportunities for disabled persons across the state. The disability project of the SERP strives to promote community interventions, including Community Based Rehabilitation (CBR). In addition to these activities, the other components of the

SERP have been aimed at the convergence of interventions in the health, nutrition and education sectors to support disability prevention and inclusive education for the rural poor.

The major approaches of SERP towards the disabled in the rural areas are through social mobilization and capacity building of disabled persons. SERP engages the services of Community Coordinators (CCs) and Community Development Workers (CDWs) to coordinate the activities at the mandal level. In its effort to strengthen the existing community based rehabilitation approach, the SERP has set up Training Resource Centers (TRC) in the districts. The CDWs and CCs are trained to focus on social mobilization, identifying persons with disabilities, creating awareness of rights and entitlements for disabled persons, inclusive education and community based rehabilitation. They are also provided with basic skills in counseling, street theater and training. Through this training, it aims at addressing the social stereotypes in the villages towards the impaired, overcoming those stereotypes and taking up awareness activities on preventive measures, inclusive education and removal of environmental barriers which hinder the participation of the disabled.

The project also aims at ensuring the efficient delivery of state services to the disabled like issue of certificates by the Medical, Health and Family Welfare department of the state. Besides this, the other the priority activities of the SERP include creation of barrier-free environments like ramps, special toilets etc. in community buildings such as schools, Panchayat offices etc. and supply of aids and appliances. The disability unit of SERP also aims at facilitating close collaboration between various state functionaries such as health, education, credit institutions so as to enable the participation of the disabled in rural development. Close linkages between the Community Based Organizations (CBOs) and the state educational institutions have been focused on to facilitate and promote education among the disabled children. It envisages for setting up bridge and residential schools for the disabled children and teacher training in inclusive education. It aims at bringing change in the attitude of the state educational staff regarding persons with disabilities and to improve understanding of disability prevention and treatments. In its attempts it involves the Health and ICDS functionaries working in the villages to prevent the occurrence of impairment by focusing on safe drinking water, salt iodization, ante-natal care, environmental and personal hygiene.

SERP initiated efforts to reach out to disabled persons and motivate them to form self-help groups (SHGs). The idea of working with groups for the benefit of disabled evolved with the successful functioning of women SHGs in rural Andhra Pradesh. Persons with disabilities are encouraged to form SHGs. It also aims at involving the family members or parents in order to make them aware of the benefits of groups. SERP works for providing education to the children with disabilities and provide training for employment including self-employment. As part of its strategy, the SERP has been promoting livelihood opportunities for the disabled by recruiting livelihoods specialists to train the disabled members of the SHGs in livelihood opportunities. A livelihood analysis is conducted for disabled SHG members and the members are trained for engaging in productive employment and self-employment. The project made provisions for financing support for new livelihood opportunities in the form of self employment for the disabled. Medical treatment and corrective surgeries are also part of the activities of the project. These services are provided in close collaboration with the Medical and Health Department through the state as well as district level hospitals. It is emphasized that the CDWs and CCs take an active role in identifying the needs and liaison with the service providers.

3.6 Formation of Self-Help Groups (SHGs)

It is strongly believed in the circles of government of Andhra Pradesh that successful strategies for poverty reduction lie in the concept of SHGs. Thus, starting from organizing the poor into SHGs to the self managed and self sustainable, SHG approach has become a model worth emulating in development projects (Reddy, 2012). The SERP in its efforts to form SHGs adopted the Community Resource Person's (CRP) strategy. SHGs are formed by identifying the poor/poorest of the poor (PoP) through the process of Participatory Identification of Poor (PIP) which involves social mapping, resource mapping, door to door interaction, wealth ranking etc.

It is slightly revised in the case of disabled, as the disabled are identified based on social mapping and medical examination. In the disabled SHGs all the disabled of the village, irrespective of caste, community, religion, gender, age and class are encouraged to form groups. The identified disabled are counseled on the importance of SHG as a tool for socio-economic upliftment, identity formation, rights assertion and participation.

3.6.1 Norms of SHG

After the group is formed, the group is expected to follow certain practices which make them eligible to take part in wider activities of SERP.

The group norms are:

- every SHG should have a name.
- meetings are mandatory. Place of meeting (at each member's house on rotation basis), frequency of meeting (weekly), day of meeting in the week are decided by the members of the SHG facilitated by the CDWs.
- training to the members of the SHG is imparted on leadership, roles and responsibilities, book keeping etc.
- members are advised to decide on leadership modalities like rotation basis or selection through consensus or voting, tenure, roles and responsibilities etc.

SHGs follow a protocol for group meetings as provided by the SERP. The protocol includes a standard agenda as meeting starts with a prayer followed by a self introduction of the members. The members select the presiding officer for the weekly meeting and also follow an attendance record of the members. They review previous meeting resolution's implementation, discuss on savings, repayments, internal lending and external loans (Bank Linkage/Community Investment Fund). Apart from that, the persons with disabilities in the group also engage themselves in other issues such as identity, problems with certificates, pensions, health and hygiene, education, employment etc.

SHGs are encouraged to follow the Panchasutras religiously. Panchasutras are the five important principles for the SHG to mature into an advanced SHG which derive certain additional economic and social benefits from the SERP.

The Panchasutras are:

- Weekly meetings: The SHG which meets weekly once is strong and viable. The needs of the members are met promptly. The level of uncertainty in the lives of the disabled comes down significantly.
- Weekly savings: In a SHG where savings are pooled once a month, the needy members have to wait for 30 days to access small loans for addressing urgent domestic needs. In a SHG where savings are pooled once a week, the needy members get loans instantly.
- Regular internal lending: Members access loans through internal lending from the group corpus with sources from bank interest, savings and interest accruing from repayments. This practice helps to address the needs of all members to some extent.
- Regular repayments: Regular repayment of loans ensures rotation of money among members and also enhances the credit worthiness of the SHG with the bankers or financial institutions.
- Healthy bookkeeping: Every SHG should have a regular bookkeeper to maintain the records of the SHG viz. meeting minute book, cash book, loan ledger (small loans and big loans) and savings register. The bookkeeper should be well mannered and selected from the same village. S/he should be paid an honorarium from the SHG corpus. The bookkeeper should be very obedient to SHG members.

The SERP provides the following advices to the SHGs for better functioning.

- corpus to be built by practicing the Panchasutras without fail.
- leadership qualities will be developed on the basis of leadership rotation and selection of presiding officer for weekly meeting in which every member in the SHG would get opportunity to perform as a leader.
- day to day needs of the members are discussed.
- the SERP advices the SHGs to be best practicing groups as the SHGs are graded into performing and non-performing ones.
- a performing SHG will be preferred by the bankers or other credit institutions in lending loans.

- a performing SHG will qualify to be a member of the Village Organization (VO) after three months of strict adherence to recognized norms.
- after six months the performing SHG will qualify for Critical Rating Index (CRI) of NABARD in terms of Bank Linkages for loans.
- The SHG is also supported by the project through the Community Investment Fund (CIF) for utilization as a food security measure or for livelihoods or urgent domestic needs (ex. housing, health, daughter's marriage and similar needs).

3.6.2 Formation of Village Organizations (VOs)

The SHGs of every village form into Village Organization (VO) around a common interest and solve problems concerning all. The disabled SHGs are linked to VO for the sake of convenience and also because of the fact that the goals of the two concur. VO helps to revive the defunct and dormant groups in the village. It provides a platform for uniting the poor, disabled and their households and acts as an intermediary between the community and other rural state institutions like the gram panchayat, ICDS centre, primary schools, banks, PHCs etc. VO provides support and guidance to SHGs through constant and close monitoring by acting as a facilitator. It generates a pool of social capital for the development of poor households, disabled, and their SHGs.

It also mobilizes resources and links the SHGs to various service providing agencies like banks, veterinary services, agriculture sector services, health etc. Convergence with gram panchayat is enabled by the VO for addressing the problems of the poor and the disabled. The SERP on its part strives to strengthen the VOs through capacity building to all SHG members on the need and importance of the VO. The SERP provides training to the Executive Committee and office bearers on VO management and financial management and on VO agenda, meeting process and meeting norms. It develops a VO level participatory system of the SHGs through monthly reports, i.e. Maasa Nivedikas and works on issues like gram panchayat, anganwadi centre, primary school, public health centers etc.

The SERP provides training to VO members on need and importance of registration of the VO, provisions of the Andhra Pradesh Mutually Aided Cooperative Society (APMACS) Act and legal compliance. The VOs are helped in the process by the external CRP teams, mandal samakhya staff (Community Coordinator, Master Bookkeeper) Project Staff (Assistant Project Manager, Area Coordinator) government staff for convergence issues (Veterinary doctors, PHC Medical Officer, ICDS staff).

3.6.3 Formation of Mandala Vikalangula Samakhya (MVS)

In the case of women SHGs, all the VOs of villages in the mandal are federated into Mandala Samakhya (MS) at the mandal level with the objective of solving problems which require the collective action of the SHGs of the mandal by mobilizing the resources and services from various state agencies and functionaries in the mandal. In the case of the disabled, all the SHGs of the villages in the mandal are federated into Mandala Vikalangula Samakhya (MVS). The point to be noted here is that at the village level, the disabled SHGs join the VO along with women SHGs whereas at the mandal level, the disabled SHGs federate into MVS exclusively. MVS is a body at the mandal level meant only for the disabled which functions along with the women federations at the mandal.

The main objectives of the Mandala Vikalangula Samakhya are:

- to bring all the poor disabled families in the mandal out of poverty.
- to ensure development of social capital of the SHGs through training.
- to strengthen SHGs through continuous monitoring.
- mobilizing resources from the state and other agencies and linking them to the SHGs and VOs.
- convergence with mandal level line departments of the state.
- facilitate market linkages of locally manufactured products, e.g. pickles, bamboo products etc. and other innovative products of the SHG members.

The MVSs are strengthened through

- monthly general body meeting with two representatives from each SHG and EC meeting with fifteen representatives nominated by MVS as RGB members.
- establishing norms for conducting monthly meetings.
- setting up of an office for conducting meetings, trainings and other programmes and also to secure its books/records/other material.
- identifying the training needs of its members and preparing a monthly training calendar and implementing the action plan.
- ensuring the representation (apart from the disabled) of the poorest and poor, educated and service minded persons as office bearers in the MVS.
- reviewing the functioning of the staff (CCs/CVs/MVTCs/MBKs) in the RGB meeting and ascertain duties and responsibilities to the staff.
- reviewing the SHGs functioning based on the monthly reports and provide support to SHGs.
- obtaining financial support through the Community Investment Fund and provide financial assistance to SHGs through VOs during the MVS meetings.
- maintaining transparency in MVS financial transactions, book keeping etc.
- establishing norms for implementing various activities.
- discussing the proposals of SHGs for development.
- providing financial assistance to SHGs through VOs with a range of 100 to 120 installments.
- forming sub-committees for monitoring the proper utilization of various services by MVS like social sub-committee, asset verification sub-committee, bank linkage sub-committee, training and monitoring sub-committee, marketing sub-committee etc.
- coordinating with government departments, officials and public representatives, inviting them for attending MVS meetings for ascertaining information about various governmental and non-governmental programmes/schemes for the benefit of the disabled SHG members.
- enabling bank linkage to the SHGs.
- reviewing monthly reports of SHGs and to support in resolving the issues concerning the SHGs.
- auditing of its records.

- taking up social issues in the villages for the betterment of its members. For example, issues like better health and education facilities, sanitation, anganwadi centers, employment guarantee scheme, houses for the disabled, pensions, barrier free facilities in the village, bus passes, certificates etc.

These activities at the MVS are carried out by the EC members with the help of the project staff (Area Coordinator/District Project Manager), external senior CRP teams, line department staff (for convergence) and Zilla Vikalangula Samakhya (ZVS) members. The ZVS is the federation of all the MVS at district level, which is formed by the representatives of the MVS. ZVS works for the welfare of the members at the district level.

3.6.4 Community Resource Person (CRP)

The CRPs are those disabled members of mature SHGs and Mandal Samakhya (MS) who have been actively participating in the group meetings regularly and who take up issues and come forward to help the functionaries of the SERP in motivating, mobilizing the disabled in the villages. The CRPs are paid a nominal honorarium when they go to other villages as part of motivating campaign. SERP defines the CRPs as those disabled members, both men and women who have come out of isolation, poverty with the active support, guidance and assistance provided by the SHGs and MS. They are recognized as role models in their SHGs. The CRP strategy is based on community centered and community learning approach.

The CRPs have good articulation and communication skills. They are those disabled who once had bitter experience of disability in the past. And once they joined the SHG as members of the groups how they gained good knowledge and experience on SHG concept, group management norms, SHG meeting process, clarity on the need of Bookkeepers and the role of Bookkeeper, agenda fixation, various functions of SHGs, clarity on the role and function of Community Animator with SHGs are explained to others. They have the ability and skills to conduct trainings to the community, particularly for the disabled by drawing lessons from their personal experience and the best practices of their SHGs and MS. They have the ability to use their folklore in the trainings and facilitation for motivating the poor women. They document their SHGs and MS profiles, institutional maturity progress, best practices nurtured and adopted, members' case studies along with their achievements and use them as training material in the trainings and facilitation.

3.7 Community Investment Fund (CIF)

The Community Investment Fund is an important component of the efforts of the SERP in mobilizing the disabled into SHGs. Recognizing the fact that each individual has separate needs and distinct capabilities which have to be harnessed in proper manner in order to come out of poverty, a community-owned and managed loan fund named CIF has been evolved to help members meet part of their credit needs, gain experience in fund management and demonstrate credit worthiness that will help leverage funds from other sources and develop new financial products that are suited to their unique needs. The CIF is provided from the project to the SHG of the disabled and is expected to revolve among the members who take and repay loans from this fund. Different types of loans for business, agriculture, housing, education and other needs as per the wishes of the members are given to the group members. CIF is a grant from project to MVSs and loan from MVSs to SHG level for implementing micro plans of SHGs. The CIF is essentially designed to reach the disabled only. Thus, the CIF is hoped to act as a catalyst to help the poor disabled to meet their demand for improved access to credit for investment needs.

The specific objectives of the CIF are to:

- act as a catalytic fund for addressing livelihood and household needs of members of SHGs,
- demonstrate credit worthiness and investment worthiness of poor SHG members,
- capacity building and initial support for SHG federations,
- financial product development suited to the rural poor,
- broaden and deepen the range of financial services,

Under the CIF funding, provision is available through the Micro Credit Plan (MCP) that incorporates the household needs and livelihood activities for income enhancement. It includes plans for investment in asset creation for income generation and household need investments. The process of MCP preparation is an integral part of the financial management process of the SHG. Since MCP is envisaged as a comprehensive tool to improve the levels of income and quality of life of members of SHGs and the overall functioning of SHGs and their federations, the members of the SHG are sensitized about the MCP process and helped to prepare the investment plan. The preparation of MCP involves all the SHG members and joint analysis of the planned investment plans. Members do self-assessment of their SHG based on regularity in savings and internal lending of funds, book keeping and regular meetings before further planning. Based on the MCPs, the project releases certain portion of the CIF entitlement to VOs based on the performance of the SHG. The CIF is released to the VOs in two installments.

CHAPTER-IV

THE RURAL DEVELOPMENT TRUST (RDT): AN OVERVIEW

4.1 Introduction

This chapter describes the non-state initiative towards the persons with disabilities. The organization chosen for the purpose is Rural Development Trust, popularly known as RDT. The chapter presents the origin of RDT and its various initiatives taken up over several decades in Anantapur district of Andhra Pradesh. It discusses the efforts of RDT towards PWDs in detail.

The Rural Development Trust was established by Father Vincent Ferrer and Anne Ferrer in 1969 as a non-government organization registered under the Indian Registrations Act, 1908 in Anantapur town located in the Rayalaseema region of Andhra Pradesh. Its main office is located in Anantapur town, on the way to Bengaluru. Currently, Anne Ferrer, wife of Father Vincent Ferrer is the Executive Director while Moncho Ferrer, son of Mr. and Mrs. Ferrer is the Program Director of RDT. A management team called Core Team sets the direction and strategy for the organization. It also guides the various program interventions of RDT apart from sustaining the motivation of various cadre staff to work in accordance with its guiding principles.

Since its inception, RDT has been carrying out various needs based welfare oriented integrated programs of development to improve the quality of life of rural poor, especially the marginalized and the underprivileged sections namely Scheduled Castes (SC), Scheduled Tribes (ST), Backward classes and Persons with Disabilities (PWDs) in the district. In continuation of its efforts for resource mobilization for the cause of poor and needy, RDT has set up its first Resource Mobilization Centre (RMC) in Mumbai in September 2012 with a view to sensitizing the like-minded persons in India to participate in the struggle of RDT against poverty.

4.2 Mission of RDT

RDT's goal is to reduce the sufferings of vulnerable sections of rural areas viz., scheduled castes, tribes, backward castes, women and persons with disabilities by contributing towards their self-reliance. It aims at their emancipation and empowerment and thereby ensuring their peaceful co-existence with other privileged sections in the society.

RDT works with the following mission:

- to reach as many poor as possible and facilitate them to have strength and capacity both individually and collectively to be the leaders in their own development.
- to transform the semi-desert[4] land through a holistic approach covering land, water, vegetation and livestock development and to ensure that people live in harmony with natural resources contributing for ecological regeneration, environmental development and sustainable livelihood enhancement.
- to sensitize both men and women on the inherent discrimination and violence against women both in the family and in society and developing appropriate support systems and networks to fight against such discrimination.
- to facilitate persons with disabilities to avail equal rights and opportunities in every sphere of development and to have an access to all the resources and services covering health, education, livelihood and rehabilitation to lead a dignified life.
- to be a dynamic and creative organization that always strives to participate in development efforts with the characteristics of being spiritual in its motivation based on knowledge and skills, sharing the aspirations and struggles of the poor.
- to sensitize the general public about the living conditions of rural and urban poor and to promote a 'caring and just society'.

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[4] Anantapur is a drought prone district.

At a broader level, RDT has been implementing its program activities across various sectors in 3,152 villages spread over 101 Revenue mandals in 5 districts of Andhra Pradesh. It includes 63 mandals of Ananthapur district, 22 in Kurnool, 7 in Prakasam, 7 in Mahabubnagar and 2 in Nalgonda district. These villages include 224 villages of Chenchu tribes of Nallamala forest area spread across 29 mandals in 4 districts of Srisailam region. The Project area of RDT is administratively divided into seven regions namely Bukkarayasaumdram, Bhathalapalli, Kadiri, Srisailam, Kalyandurg, Uravakonda and Madakasira. However, most of its programmes are concentrated in Anantapur district. RDT works in all the 63 mandals of the district.

4.3 Sources of Funding

The sources of RDT funding include both international and national. A large amount of funds is received from foreign sources through Fundación Vincent Ferrer (FVF) located in Spain. It was established in 1996 by Father Vincent Ferrer, who belongs to Spain. Apart from this, individuals located in various countries donate funds to RDT through FVF. Besides, RDT receives funds from both the central government and state governments also. It collaborates with the state government and district administration for providing services to the poor. For example, residential special training centers are funded by Rajiv Vidya Mission under the Sarva Sikha Abhiyan programme of Anantapur district. The housing programs for the poor and the persons with disabilities are co-funded by Andhra Pradesh State Housing Corporation Limited (APSHC), Hyderabad and the Rehabilitation and Resettlement Commissionerate, Government of Andhra Pradesh.

Non-Conventional Energy Development Corporation Limited (NEDCAP), Ananthapur supports RDT initiative on ecology programs by supplying biogas plants and smoke chulas on subsidy. The District Medical and Health Office (DM&HO), Anantapur offers services of the government doctors, medicines and other treatment equipments to RDT. Diagnostic material and medicines for TB control programme are funded under the Revised National TB Control Programme (RNTCP), Direct Observation Treatments (DOTs) by the government of Andhra Pradesh.

Moreover, the Antiretroviral Therapy (ART) Centre has been providing treatment free of cost to persons living with HIV/AIDS who access the services of ART Centre situated at RDT referral hospital complex at Bathalapalli. Medicines, provided free of cost by Andhra Pradesh State Aids Control Society (APSACS) through National Aids Control Organization (NACO), are supplied by RDT through its network of medical professionals which include doctors, nurses, pharmacists, counselors. RDT works in close coordination with NACO. It may be said that RDT has been taking up development initiatives on its own with the funds received from donors (both national and international). Apart from that, it has also been actively participating in the state interventions towards poor in various sectors of development.

4.4 Major interventions of RDT

The development interventions of RDT cover the following major sectors viz. education, empowerment of women, Community-Based Rehabilitation (CBR), rural hospitals, community health, community habitat, ecology and sports and cultural activities. The initiatives of RDT are discussed below to highlight its approach and functioning.

4.4.1 Education Sector

RDT strives to promote literacy in rural areas by emphasizing on cent percent enrollment and retention of students, especially girls, up to the secondary level. It encourages children belonging to marginalized sections to study beyond secondary level and facilitates their admission in different schools. RDT introduced the ‘Education Special Scholarship’ scheme in 2004 to support higher education among poor children. This scheme helps meritorious poor students to pursue intermediate course in corporate colleges and further continue various professional/technical courses such as medicine, engineering, pharmacy, nursing etc. RDT has started a professional school in April, 2012 to give intensive training to rural based university graduates and post graduates in foreign languages, basic computer skills and communication skills in English.

4.4.2 Empowerment of Women

RDT has been working to empower women belonging to poor, marginalized rural communities since 1982-83 with the objective of making them main actors in their own development. Programmes dealing with the issues of violence against women and girls were initiated to raise awareness and to support women facing various types of maltreatment and harassment. There are also mobile counseling centers to deal with cases of human trafficking, sexual harassment, domestic violence, health problems including Sexually Transmitted Diseases (STDs) and other problems such as misunderstanding between husband and wife, dispute between women and family members etc.

4.4.3 Rural Hospitals

Under this scheme, RDT aims at providing quality professional health care services to people at affordable rates supplementing the government health infrastructure. RDT runs two general hospitals and a care and support centre for HIV/AIDS patients. The services of basic specialties viz. medicine, surgery, gynecology and obstetrics, pediatrics, anesthesia and traumatology are offered at affordable cost to the rural people. Basic supportive departments such as pathology, microbiology and radiology extend services under one roof to the needy at reasonable rates. It also offers services to persons with disabilities through its specialized centers dealing with issues of locomotor, vision, hearing and speech impairment and mental retardation. It actively advocates for the immunization of newly born children and concentrates on the nutritional and medical needs of pregnant women in order to reduce the occurrence of impairment.

4.4.4 Community Health

The basic objective of RDT under the community health program is to enable the rural poor to have access to health care (government or private) with a special emphasis on safe delivery, child care, nutrition and HIV/AIDS. RDT, in fact, helped state health services by training local women as community health workers. It concentrates on the prevention and treatment of common and serious health problems in women and children. RDT also has a team of doctors who treat health problems through alternative systems of medicine. Its medical staff, including doctors and paramedics are working in 2,409 villages.

4.4.5 Community Habitat

RDT has also been providing assistance in constructing permanent houses to the people from disadvantaged groups (scheduled castes, scheduled tribes, other backward class communities and those with disabilities) by creating assets, both individual as well as community based, and also works towards improving the facilities at rural level especially for education, health and other necessary infrastructure.

4.4.6 Ecology

RDT through this initiative intends to transform the semi-desert land into land capable of sustaining its population and also sensitizes people to live in harmony with natural resources contributing for sustainable livelihoods, ecological regeneration and environment development. Anantapur district being located in the rain shadow region doesn’t fully benefit from the monsoons. Rainfall is not only erratic, but is also unevenly distributed causing a negative effect on crop productivity. Larger areas in the district have coarse soil-surface texture which is poor in water and nutrient retention, and is highly prone to wind and water erosion. Mostly rain fed farming is prevailing since there are no perennial rivers providing canal irrigation. Recurring droughts and decline in pasture lands have led to dwindling livestock population. RDT through this scheme, has undertaken contour bunding for soil and moisture conservation, introduced solar irrigation for tapping underground water resources and promoted modern micro irrigation systems namely drip, sprinklers and micro sprinklers as part of conserving underground water resources and ensuring its optimum and scientific utilization.

4.4.7 Sports and Cultural Activities

RDT through this initiative aims at bringing out hidden talents among children belonging to scheduled castes, scheduled tribes and children with disabilities in sports and cultural aspects. It works for enhancing their self-confidence and self-esteem by enabling them to equally compete with other children at district, state, national and international levels.

4.4.8 Human Resource Development (HRD)

Since its inception in 2010, the HRD wing has been focusing on capacity building of its staff at senior and middle level management, grass-root and others working in institutions like hospitals and disability rehabilitation or training centers. Capacity building focuses on community organization, leadership development, sensitizing its staff on issues of gender, disability etc. It also identifies its own personnel who have the potential, knowledge and aptitude to train them as trainers.

4.4.9 Persons with Disabilities

Persons with disabilities are the most vulnerable people who face discrimination both in the family and society. They are subjected to social exclusion irrespective of their gender, community and financial background. They lack equal opportunities and face a number of barriers that include the stigma of disability, little understanding of their abilities, lack of appropriate rehabilitation services and inputs. Though they are entitled to share the same rights like any other human being, they are denied the opportunities and responsibilities that should rightfully be theirs. However, the situation of disabled persons is improving gradually due to global level attention on disability over the past one and half decade. Though it is the primary responsibility of the government, both at the central and state to provide development, rehabilitation and social security measures to the disabled persons, voluntary and philanthropic organizations do have a social responsibility to complement the efforts of the government.

In this direction, RDT has been working with people with disabilities since 1987 with the objective of enabling them to have equal opportunities and rights and the capacity to access all the existing resources and services to lead a life with identity, dignity, respect and justice in the family, community and society.

4.5 Evolution of CBR/Disability Programme in RDT

In 1985, the Government of India in collaboration with UNICEF had initiated Universal Immunization Program (UIP). Anantapur was one of the districts selected by the Government of India for the implementation of UIP. Thus, UNICEF was instrumental in promoting cooperation between RDT and the District Medical and Health office. During the implementation of UIP, the organization found a number of polio affected children in its project area. There was a suggestion from UNICEF to go in for the rehabilitation of polio affected children. This marked the beginning of RDT's work with persons with disabilities.

A household survey in 20 contiguous villages covering approximately 20,000 people in Uravakonda mandal was initiated by RDT in 1985. The survey had covered only physically challenged, visually challenged and speech and hearing impaired persons excluding persons with mental retardation. There were about 226 persons with disabilities in 20 villages in the age group of below 45 years. RDT started working with persons affected by polio and children with speech and hearing impairment. However, the staff working in the field of community health and community organization had no conceptual clarity and understanding about the problems/issues of persons with various types of disabilities. This was one of the biggest challenges in RDT's work with persons with disabilities. There was little scope for training the staff in the overall understanding of various types of disabilities and the method of working with persons with disabilities, especially those living in rural areas. One of the senior medical professionals working with RDT was sent to London to get trained in community based rehabilitation as the organization couldn't find a course that encompassed knowledge about all types of disabilities in India.

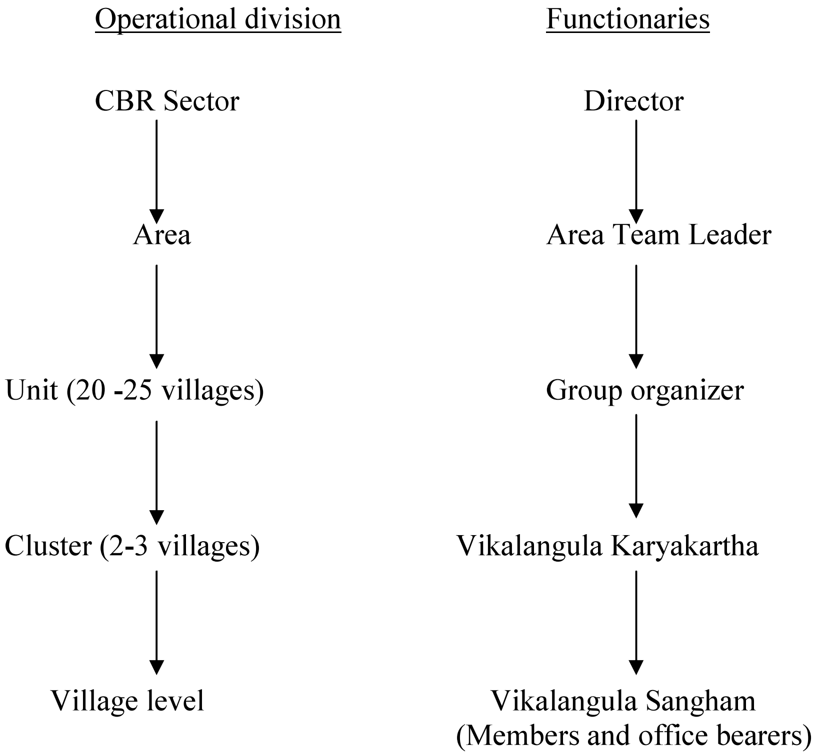
In the process, RDT met a person called Venkatesh, a visually challenged representative of Action on Disability Development (ADD) India, an NGO involved in the development of persons with disabilities. He shared his experience of organizing adult disabled persons in Tamil Nadu into self-help groups as one of the ways to bring them into the fold of development. He desired to work with adult disabled persons in 20 villages where RDT had conducted a household survey and initiated preliminary work with them. Persons with disabilities were facilitated to form into 10 self-help groups hailing from two contiguous villages. Venkatesh enacted the role of an animator and motivated PWDs to organize themselves for their own development. It was a challenging task to ensure the get together of persons with different types and intensities of disabilities.

With this background, RDT had initiated the program for persons with disabilities from 1988-89 onwards. In the year 1998, it emerged as an independent programme headed by a team comprising of Director, Sector Team Leaders, Group organizers, technicians, special educators and support staff.

4.6 Present Structure of the Programme towards PWDs

The community based rehabilitation sector of RDT deals with the programmes aimed at persons with disabilities. It covers 300 villages for the programme implementation. All the villages covered under the programme are collectively referred to as the area. Further, each area is divided into units. Each unit comprises of 20 to 25 villages depending upon the population of the village. Units are further segregated into clusters where there are 2 to 3 villages per cluster. The CBR sector is headed by the Sector Director. S/he co-ordinates the sector activities and provides necessary guidance and directions to Area Team Leaders (ATLs)/Group Organizers/Institutions' staff.

Figure 4.1: Functional division of programmes for PWDs



4.6.1 Area Level

The Area Team Leaders (ATLs) are responsible for programme implementation at the area level which consists of more than 300 villages. They receive guidance and directions from the Director of CBR wing in RDT. They coordinate the work and activities and provide necessary guidance to the Group Organizers in the respective operational units. They also monitor the special institutions for children with various disabilities and are accountable to the Sector Director.

4.6.2 Unit Level

Each Unit comprises of 20-25 villages. Each Unit is headed by Group Organizers (GOs) who coordinate the activities in the villages under their operational jurisdiction. The Group organizers provide guidance to the volunteers of disabled called Vikalangula Karyakarthalu[5] (VK). The Group Organizers are accountable to the concerned Area Team Leader. The ATLs provide necessary guidance to the Group Organizers and provide technical support. The Group Organizers conduct household surveys, organize the PWDs into groups named as Vikalangula Sanghams (VS). They also provide awareness and leadership training on effective management of mini-bank to the group leaders. Moreover, GOs keep a track of the functioning of Vikalangula Sanghams and encourage the sanghams to take up various issues which have a bearing on their life. Implementation of various income generating programs for the PWDs at the village and group level is closely monitored by the GOs.

4.6.3 Cluster Level

The Vikalangula Karyakarthalu are the volunteers of the RDT at the cluster level. Their work involves identification of PWDs in the villages under the cluster. Each Vikalangula Karyakartha covers a cluster of 2 to 3 villages. They provide effective facilitation to the Vikalangula Sanghams in all aspects. They belong to one of the villages of the cluster and are not necessarily disabled. They provide essential guidance to the groups of disabled in the villages and monitor the functioning of the groups.

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[5] Telugu name for the volunteers of disabled. They are appointed by RDT. Vikalangula Karyakarthalu is a plural form while Vikalangula Karyakartha is singular form

4.6.4 Village Level

All those persons who are identified by the Vikalangula Karyakarthalu as disabled (those suffering from impairment - both physical and mental) in each village are encouraged to form a group of their own. Caste, age, religion and gender do not matter in the formation of the group. Since it is difficult for the disabled in the village themselves to form a group on their own, the role of the Vikalangula Karyakartha becomes important. Once formed, each group elects a member as their leader who works as a bridge between RDT and the disabled members of the group. The group, known as Sangham (Telugu word), meets twice a month. The members discuss issues or problems concerning the disabled members which include economic, social, cultural and political and also conduct mini-bank transactions related to savings and loan disbursement and utilization.

4.7 Objectives of Community Based Rehabilitation (CBR) of RDT

The goal of the CBR sector is to facilitate the persons with disabilities to fight for equal rights and claim their legitimate opportunities in all fields of development and to overcome the barriers caused due to discrimination, stigma and economic and physical dependency. The focus is on the inclusive development of disabled persons and building up of their full capacities and extending support to them to live with identity and dignity combating discrimination prevailing in all spheres of their lives. The following are the six specific objectives of the CBR sector of RDT.

4.7.1 Social objectives

The social objective of the CBR sector is to promote social cohesion among persons with disabilities and make them assertive by means of resisting discrimination, claiming constitutional rights, accessing the prevailing services and mobilizing resources of government and non-governmental organizations which have a bearing on the quality of their life. The CBR sector is involved in the following activities for the betterment of living conditions of the persons with disabilities in rural Anantapur.

- survey for identification of persons with disabilities.

- facilitating the process of organizing persons with disabilities in its operational villages into SHGs called Vikalangula Sanghams and initiating the formation of federation of persons with disabilities at mandal/district level.

- conducting awareness workshops on various issues of disability, including programs for early identification of disability, prevention of disability, timely induction of therapeutic interventions and education.

- conducting capacity building training programmes for the leaders of SHGs and leaders of federation both at mandal and district levels so as to:

    - consolidate their strength to deal with the issues of discrimination, including physical abuse.

    - claim for their genuine rights guaranteed by the Indian Constitution.

    - ensure that every single disabled person avails the existing services and resources from government and voluntary organizations meant for their development.

    - insist for a barrier free environment at the places frequently used by persons with disabilities (e.g. educational institutions, bus station, railway station, banks etc.)

- conducting rallies and organizing special functions on the eve of World disabled day, International disabled day, International Braille day etc. to infuse confidence among persons with disabilities and to sensitize family, community and society.

4.7.2 Educational objectives

The educational objectives are aimed at providing access to special education and rehabilitation training from pre-school to high school for the mentally challenged, children with cerebral palsy, visually challenged and hearing impaired children apart from extending financial help to students with disabilities for pursuing their normal education from primary to higher/professional/technical level.

The following are some of the activities of the CBR sector towards providing education and rehabilitation for the disabled children**:**

- sensitizing parents, family members, government teachers and general public towards the issues of children with disabilities and soliciting them to show empathy to bring change in the quality of their life.
- running residential schools/centers providing special education and rehabilitation training, including vocational education to children with disabilities.
- imparting skills in co-curricular activities such as singing, dancing, miming and arts as well as games and sports to bring out hidden talents among children with disabilities.
- encouraging children with disabilities to compete among themselves as well as competing with able-bodied children in various competitions organized both within and outside RDT.

4.7.3 Economic objectives

These objectives are aimed at facilitating persons with disabilities to improve their socio-economic status by means of imparting vocational/skills in handicrafts, upgrading their existing skills and providing them access to capital apart from encouraging them to mobilize institutional finance to start feasible income generating schemes.

The economic activities include:

- promoting thrift and saving by facilitating SHGs to run a mini bank with their monthly savings.
- providing access to revolving fund called Disability Sangham Development Fund (DSDF) for income generation schemes such as rearing of rams, milch cattle, starting a petty business and any other service trades identified by the group members.
- imparting skills in various handicrafts such as book binding, jute making, embroidery, tailoring, jewelry making, paper-mache, making of incense sticks etc. leading to their self-employment with a provision for marketing support.

4.7.4 Physical objectives

The CBR sector provides aids and appliances including physiotherapy for improved mobility which reduces the extent of dependence of persons with disabilities on others apart from carrying out their daily routines and livelihoods. The physical activities of RDT include:

- running low cost aids and orthopedic workshops, fabricating/supplying mobility aids and appliances including prostheses at subsidized prices.
- conducting screening camps for identification of persons needing aids and appliances and therapeutic interventions including physiotherapy, occupational therapy and speech therapy.
- training of parents/family members in daily living skills /life skills and other therapeutic interventions as suggested by the medical professionals.

4.7.5 Medical objectives

The CBR sector of RDT **e**xtends referral services covering both medical and surgical intervention with a view to reducing the intensity of disability and morbidity among persons with disabilities. The medical activities include:

- referring persons with disabilities to specialist doctors or to medical institutions where specialized services are available for either surgical or medical intervention.
- undertaking orthopedic surgeries at RDT hospital located at Bhathalapalli with the help of internal and external orthopedic doctors.

4.7.6 Organizational objectives

The organizational objectives facilitate the CBR sector in networking with other like minded voluntary organizations, social institutions and research institutions including experts in the field of disability across the country to have a mutual sharing of expertise and experiences as well as to be in tune with the latest developments which contribute for improved quality of life among persons with disabilities.

4.8 Extent of coverage

Along with the above mentioned objectives, RDT works for the integrated development of persons with disabilities. By 2010, 17,951 persons with disabilities comprising of 10,578 men and 7,373 women were organized into 1,347 SHGs. The SHGs are spread across 1,705 project villages in Anantapur district (RDT-CBR Sector Annual Report, 2010). Those villages having only less than 5 disabled persons are merged into the SHG of adjoining village. There are however, regular follow up visits to such villages.

Table 4.1: Details of CBR initiative of RDT by 2010

No. of villages having CBR pragramme	1,705
No. of self-help groups constituted	1,347
No. of PWDs covered in SHGs	17,951
Gender composition:	
Men	10,578
Women	7,373

Source: RDT-CBR Sector Annual Report, 2010

According to the Census 2011, the number of PWDs in Anantapur is 1,21,908. However, Table 4.1 suggests that only 17,951 PWDs are covered by RDT leaving 1,03,957 out of the programme. As there are limitations in its spread in terms of financial, organizational and manpower, RDT has been confined to a part of Anantapur district. With the launching of SERP, the coverage of the disabled in the district has increased significantly.

4.9 Initiatives of RDT towards PWDs

RDT has taken up the cause of PWDs much before the state realized the need. It started mobilizing the PWDs in the project villages into SHGs. It began motivating them to start thrift and savings and then slowly encouraged them to fight for their legitimate rights. It developed confidence among the members through collectivization. Apart from the group activities, RDT has taken up several initiatives affecting the lives of the PWDs. These initiatives are discussed below.

4.9.1 Access to Education

RDT has been providing incentives and extending need based support with a view to ensuring enrollment and retention of disabled children pursuing primary as well as secondary education in local government schools or special institutions run by RDT and other organizations. The type of incentives and support includes the supply of school uniform, supply of school materials and stationery, children saving grants and supply of hearing aids and mobility appliances. Apart from this, RDT also extends financial support to disabled children pursuing their higher, professional and technical courses. The efforts of the organization are reflected in the number of disabled children pursuing education (from primary to higher levels including professional/technical courses). Some of the figures concerning the academic year 2010-11 are presented below.

- 1,117 disabled students comprising of 691 boys and 498 girls are in government primary schools as against 1,158 consisting of 681 boys and 471 girls in government high schools.
- 356 students are in intermediate (+2),which includes 203 boys and 153 girls
- 299 students consisting of 195 boys and 104 girls are pursuing graduation as against 46 students consisting of 31 boys and 15 girls doing post-graduation.
- A total of 227 students are pursuing technical/professional education, out of which 157 are boys and 70 are girls.
- In all, 680 students comprising of 435 boys and 245 girls pursuing higher/professional/technical education were given educational grants during 2010.

The parents of the children with disabilities are encouraged to send their wards to schools. The RDT functionaries at the village level take the responsibility of enrolling the children in the schools. Despite stiff resistance from the school authorities, in the name of difficulty in teaching children with disabilities, the RDT volunteers see to it that the children are enrolled. It may be said that the first level of resistance in sending a child with disabilities to school comes from the parents. If the parents are convinced, then the school authorities deny the opportunity. However, because of persistence of different levels of functionaries of RDT, many children in its operational villages have been enrolled into schools and colleges. The RDT functionaries who have been working for more than two decades in the field suggest that once the child gets accustomed to the school environment, in spite of resistance of discrimination, s/he prefers to pursue further studies. RDT has also been identifying those children with good performance and encouraging them to pursue higher education by providing financial assistance. Thus, the efforts of RDT have yielded rich results as far as the educational needs of children with disabilities are concerned.

4.9.2 Special Education and Rehabilitation

With a view of providing equal opportunities in education to children with disabilities, RDT started residential schools in selected area headquarters. These institutions have been providing special education to the children with disabilities. Apart from education, the schools also encourage disabled children to participate in co-curricular activities such as quiz, dancing, singing, drama and various cultural events including sports and games. In addition to curricular and co-curricular activities, the schools provide rehabilitation training such as mobility skills, daily living skills and vocational skills by specially trained teachers or professionals.

A total of 17 residential schools have been established by RDT by December 2010. They provide special education and training to 1,325 disabled children at various levels of schooling which includes 465 students of high school and 860 students of primary school. Out of the 17 residential schools, four schools are meant for hearing impaired, six for intellectually disabled, four for visually challenged, one for children with cerebral palsy, one high school for inclusive education and one high school for hearing impaired children. These schools are located at nine places in the district, viz. Kalyandurg, Kadiri, Kanekal, Kuderu, Bukkarayasamudram, Uravakonda, Udegolam, Anantapur and Bathalapalli. All the residential schools catering to special education and rehabilitation needs of children with various disabilities have a teacher-student ratio of 1:5 and have good infrastructure, including spacious classrooms and dormitories, modern teaching aids, hygienic dining and kitchen, play materials, recreation facilities etc. coupled with trained instructors and support staff (RDT-CBR Annual Report, 2010).

Table 4.2: Residential Schools for children with disabilities operated by RDT

S. No.	Category of Residential Schools Providing Special Education & Rehabilitation Training	Boys	Girls	Total
1	Primary schools for Visually Challenged Children			
	No. of Schools	-	-	4
	No. of children	81	75	156
	Totally Visually Impaired:	31	20	51
	Partially Visually Impaired:	50	55	105
2	Primary schools for Speech & Hearing Impaired Children			
	No. of Schools	-	-	4
	No. of children	147	119	266
	Mild hearing loss	1	1	2
	Moderate hearing loss	7	4	11
	Profound hearing loss	139	114	253
3	Centers for Intellectually Disabled Children			
	No. of Centers	-	-	6
	No. of children	197	210	407
	Mild	5	21	26
	Moderate	88	114	202
	Severe	104	75	179
4	Centers for children with Cerebral Palsy			
	No. of Centers	-	-	1
	No. of children	26	19	45
	Mild:	0	3	3
	Moderate	9	12	21
	Severe	17	14	31
5	Total Primary schools providing special education	-	-	15
	Total children in primary schools	451	423	874
High Schools				
6	High school for inclusive education			
	No. of Schools	-	-	1
	No. of children	119	80	199
	Totally Visually Impaired	45	20	65
	Partially Visually Impaired	36	20	56
	Physically Challenged	2	4	6
	Orphan children	36	36	72
7	High School for Hearing Impaired Children			
	No. of Schools	-	-	1
	No. of children	156	110	266
	Mild hearing loss	4	4	8
	Moderate hearing loss	14	12	26
	Profound hearing loss	139	97	236
	Total High Schools	-	-	2
	Total Children in High School	275	190	465

Source: RDT-CBR Sector Annual Report, 2010

4.9.3 Promotion of Thrift and Savings

RDT emphasizes on thrift and savings among PWDs in the villages and facilitates access to banks. RDT believes that thrifts and savings are essential means of economic empowerment. Members of SHGs are trained to manage and monitor their thrift and savings, popularly called as mini-bank, independently. Each member contributes a minimum saving ranging from Rs.10/- to Rs.15/- per month and their cumulative savings are rotated as credit among themselves for their various needs. The interest, thus accrued is shared by the members. This has enabled the PWDs to source funds for their various needs without depending on others. Each group has identified a literate person among them to record the transactions and update their mini-bank ledgers. The person is also responsible for writing minutes of meetings of the SHG.

Table 4.3 shows the number of groups operating mini-banks, number of members and their cumulative savings (individual savings, grants given by RDT and revolving funds provided by government).

Table 4.3: Status of mini banks, 2010

S.No.	Details	Total
1.	No. of groups running their mini bank	1,298
2.	No. of disabled persons having membership in mini bank	17,281
3.	Cumulative Savings (Amount in Rs.)	
a.	Individual savings	3,19,30,849
b.	RDT Matching Grants	50,20,362
c.	Revolving fund from Govt.	60,61,752
	Total Amount (in Rs.)	4,30,12,963

Source: RDT-CBR Sector Annual Report, 2010

It is evident from Table 4.3 that a total of 1,298 SHGs having a membership of 17,281 persons with disabilities are running their mini-banks with a total cumulative saving of Rs. 4,30,12,963/-. The total saving includes savings by the members (Rs. 3,19,30,849/-) followed by grants given by RDT (Rs.50,20,362/-) and revolving funds provided by the government (Rs.60,61,752/-).

4.9.4 Socio-economic Security Measures

RDT has been extending certain socio-economic security measures for disabled persons having membership in self-help groups. These include children saving schemes for promotion of literacy and creation of an asset for future security and construction of disabled friendly permanent houses. It also ensures covering of needy persons under a pension scheme of its own and of the government and provides access to permanent drought fund for either agricultural needs or income generating activities.

Table 4.4: Distribution of PWDs availing pensions and other services

S.No.	Pensions and services as on 2010	No. of PWDs
1.	Pensions	15,289
2.	Medical Certificates	17,405
3.	Travel Concession	9,937
4.	Ration Card:	14,949
5.	Voter Identity Card	9,465
6.	Marriage Incentives	489
7.	Scholarships	1,285
8.	House sites from Government	4,727
9.	Government houses	3,008

Source: RDT-CBR Sector Annual Report, 2010

4.9.5 Housing for Disabled Persons

RDT has been focusing on constructing permanent houses to the persons with disabilities who have their own house sites as part of its socio-economic security incentives. The total number of houses built for the disabled persons by RDT is summarized in Table 4.5.

Table 4.5: Houses built for the disabled by RDT

Period	Number of houses built
By the end of 2009	1,736
During 2010	189
Total houses built for disabled persons	1,925

Source: RDT-CBR Sector Annual Report, 2010

4.9.6 Occupational Mobility through Income Generating Activities

Disabled women are victims of discrimination based on gender on and above the discrimination they face as disabled. Women with disabilities are marginalized, socially unaccepted and neglected both at family and community levels. RDT, aimed at empowering disabled women by engaging them in income generating activities, has set-up a handicraft centre as part of CBR in 2001. It aims at enabling disabled women to make use of their skills in handicrafts so as to earn some money. The objective of the handicrafts unit is to facilitate the process of social integration of persons with disabilities, especially women by imparting and upgrading their skills in various handicrafts that fetches not only sustainable income but also enables them to have self-respect and identity in the society. It aims at creating awareness among disabled women and providing them managerial and leadership skills through trainings and counseling. RDT helps in providing access to raw materials and marketing network so as to ensure continuity of production and earn sustainable incomes. Through this initiative, RDT encourages disabled women to save their earnings for their future needs and also extends support for the creation of assets by means of creating fixed deposit bonds for their future security.

A total of 237 disabled young women have been trained so far in different handicraft skills. Out of this, 160 disabled women still continue to work in handicrafts while the rest have opted out due to personal, medical and family reasons. The trained women with disabilities are engaged in production of handicrafts such as jute, jewelry, embroidery and tailoring, paper mache, crockery items (RDT-CBR sector Annual report, 2010). Table 4.6 presents the details of the number of women with disabilities trained in different types of handicrafts.

Table 4.6: Handicrafts training to the women with disabilities

S.No.	Type of handicrafts training	No. of women with disabilities trained		
		Centre based Training	Home based Training	Total
1.	Jute Making	22	10	32
2.	Embroidery	13	13	26
3.	Paper Mache	10	18	28
4.	Crockery	8	3	11
5.	Jewelry	10	13	23
6.	Tailoring	5	6	11
7.	Book binding	29	0	29
	Total	97	63	160

Source: RDT-CBR Sector Annual Report, 2010

The disabled women working in the handicraft workshops are paid every month based on the number of pieces made by them. The products are sold in the RDT stall and other shops located in Anantapur. These handicrafts have also been exported and it was revealed that the handicrafts made by the disabled women gained popularity in Spain. The total sale of handicrafts products amounted to Rs.5,38,80,408/- by the end of 2010 (RDT-CBR sector Annual report, 2010).

4.9.7 Medical and Physical Rehabilitation Services

Under this initiative, RDT has been providing referral services to persons with disabilities requiring orthotic, prosthetic, medical and surgical intervention at RDT hospitals or other hospitals located in Anantapur and elsewhere in Andhra Pradesh. RDT aims at reducing the dependency, morbidity, mortality and deformities to the extent possible among persons with disabilities. One of the most important programs which contributed to restoring or improving mobility status of persons with disabilities was the orthopedic surgeries done by Spanish Traumatalogists at RDT Hospital at Bhathalapalli.

Table 4.7: Medical and rehabilitation services provided to the PWDs by RDT

S.No.	Medical and rehabilitative services	Total No. of PWDs availed the services
1.	No. of cases referred to hospitals and doctors at Anantapur	151
2.	No. of cases referred to higher institutions of specialist doctors outside Anantapur District	18
3.	Orthopedic Surgeries	1,317
4.	Harelip and Cleft Palate surgeries	27
5.	Other surgeries	102

Source: RDT-CBR Sector Annual Report, 2010

It may be observed from Table 4.7 that about 1,317 orthopedic surgeries and 102 other surgeries were done to the PWDs by the end of 2010. During the interaction with the beneficiaries, it was found that surgeries coupled with the use of appropriate aids and appliances improved their mobility to a great extent. There is an improved self-confidence and self-respect due to their improved mobility, reduced dependency on others for schooling and increased involvement in domestic and livelihood activities.

4.9.8 Supply of Aids and Appliances

Prior to 1992, there were no rehabilitation services in Anantapur. The disabled were neither aware nor had access to aids and appliances. Thus, only less than five percent of disabled persons in the entire district were availing some of the rehabilitation services available in Anantapur. As a result, many children were deprived of education due to their inability to cope with the mobility problems and adult disabled remained confined to their houses without being involved in any of the livelihood activities. All these barriers made disabled persons dependent on their families.

Recognizing the situation of disabled persons, RDT felt the need for starting orthotic and prosthetic workshops. Towards this, RDT had sent some of its staff members for multi-purpose rehabilitation technician training in specialized institutes. The first workshop at Kalyandurg was set up in 1992, followed by Kuderu in 1993, Bhathalapalli and Kadiri in 2003. The workshops are equipped with needed infrastructures such as oven, moulds and other accessories and are located in spacious buildings with barrier free environment. Maintenance of machinery and equipment is of high standards. Care is taken to buy the required material in bulk quantities for fabricating the appliances at low price. These workshops fabricate low cost aids and appliances such as calipers and crutches. A total of 31,186 aids and appliances were distributed to persons with disabilities in the year 2010. An average of 150 to 200 disabled persons avail the services of each workshop and the type of cases that come to workshops include post-polio paralytic cases, clubfoot, spinal cord injuries, cerebral palsy, amputation cases etc. Table 4.8 summarizes the appliances fabricated, repaired and issued to needy persons from the workshops of RDT by the end of 2010.

Table 4.8: Supply of Aids and Appliances to the PWDs by RDT

New Appliances fabricated and issued to needy persons from all 4 Ortho Workshops of RDT		
S.No.	Details	Quantity
1	Total registrations	15868
2	No. of visits by the beneficiaries	50070
3	Aids & Appliances: Orthosis	
3.1	Calipers	5230
3.2	Crutches	3261
3.3	Splints	3193
3.4	Sandles	2956
3.5	Walker	79
4	Prosthesis	
4.1	Above Knee Prosthesis	317
4.2	Below Knee Prosthesis	921
4.3	Above Elbow Prosthesis	5
4.4	Below Elbow Prosthesis	11
4.5	Syms	4
5	Special Appliances	
5.1	Special Seat	66
5.2	Sandling Board	13
6	Plaster of Paris	5282
7	Tri-cycles	1561
8	Wheel Chairs	565
9	Cots	55
10	Mattresses and water beds	59
11	Physiotherapy	5343
12	Others	2265

Source: RDT-CBR Sector Annual Report, 2010.

CHAPTER-V

SERP AND RDT: AN ANALYTICAL OVERVIEW

5.1 Introduction

The objective of this chapter is to analyze the data collected from the field during 2010-2011 as part of the research work. It presents the profile of the study area and describes the socio-economic profile of the respondents of both SERP and RDT. Data is presented in a comparative manner so as to understand the nature and intensity of efforts of both the state and non-state organizations towards persons with disabilities.

5.2 Profile of Andhra Pradesh

Andhra Pradesh[6] is one of the 29 states of India, situated on the country's southeastern coast. According to the 2011 census, the state is the tenth largest by population. The state has the second longest coastline among all the states of India. There are two regions in the state namely Coastal Andhra and Rayalaseema and hence, the two regions are more often referred as Seemandhra. There are 13 districts with 9 in Coastal Andhra and 4 in Rayalaseema. It is endowed with a variety of physiographic features ranging from Eastern Ghats, Nallamala forest, coastal plains to Deltas of two major rivers of Krishna and Godavari. The state is the largest producer of rice in India. The Andhra Pradesh Reorganization Act, 2014 bill was passed by the Parliament of India for the bifurcation of Andhra Pradesh and formation of Telangana state comprising ten districts. The study was conducted in Anantapur district of erstwhile Andhra Pradesh. This district is a part of Andhra Pradesh even after the bifurcation of the state.

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[6] The details of Andhra Pradesh presented here pertain to its status post-bifurcation i.e. after June 2014

Anantapur

It is believed that Anantapur got its name from Anaatasagaram, a big tank, which means Endless Ocean. Anantapur district was formed in the year 1882. The district has 63 mandals. As per census 2011, Anantapur has a population of 40,83,315 comprising of 20,64,928 male and 20,18,387 female population. Total literates in the district are 23,50,294 of which male and female are 13,65,701 and 9,84,593 respectively. The total geographical area of the district is 19.13 lakh hectares out of which the net area sown is 9.23 lakh hectares. The total cropped area is 9.75 lakh hectares.

5.3 Profile of the Respondents

Data for the study was collected from two groups of respondents comprising of:

i. Persons with disabilities supported by the state initiative, i.e. SERP[7] and

ii. Persons with disabilities supported by non-state initiative, i.e. Rural Development Trust (RDT).

A total of 30 respondents from nine villages across three mandals namely Parigi, Lepakshi and Somandepalli of Anantapur where the SERP programme is functional were selected for the study. The villages where the study was conducted are Parigi town, Peddireddypalli, Kodiganahalli of Parigi mandal, Lepakshi town, Vibhoothipalli and Ketaganicherugu of Lepakshi mandal and Brahmanpalli, Suddakuntapalli, Somandepalli town, Eedulaballapuram of Somandepalli mandal.

On the other hand, 42 respondents from nine villages across three mandals namely Kadiri, Bukkarayasamudram and Uravakonda of Anantapur where RDT operates were selected under the non-state initiative. The villages are Kummaravaudlapalli, Nadimipalli, Balappagaripalli of Kadiri mandal, Korrapadu, Reddypally, Rotaripuram of Bukkarayasamudram mandal and Y.Ramapuram, Amidyala and Peddakonkuntla of

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[7] Data used in the thesis under SERP were collected as part of the UGC funded Major Research Project (2008-2011) titled "Enabling the differently abled: a sociological understanding of the development initiatives of the state and the community towards the disabled in rural Andhra Pradesh" for which the researcher worked as Project Fellow. Data on RDT respondents were collected by the researcher independently.

Uravakonda mandal. The respondents were met and interacted in their natural habitat for the study.

It may be important to mention that SERP, the state initiative has not been operating in the mandals where RDT has been functioning for a long time. The decision was made by the district level authorities to reduce the scope for overlapping in the efforts of rural development. The list of respondents in each village and the number of villages in each mandal where SERP has been operational was collected from the district level functionaries of SERP. With the help of them, the villages and also the respondents were identified. On most of the occasions, the SERP functionaries accompanied the researcher to the field and introduced to the respondents.

They also took the lead in organizing the meetings initially, thereby helping the researcher in getting familiar with the respondents. The details of the SHGs were collected from the group and the SHG members were approached directly by the researcher due to greater familiarity. On the other hand, in the case of RDT, general information on the initiatives taken up by RDT was gathered from its office. The Director of the CBR/Disability unit provided all the required information on the work carried out by RDT towards PWDs. The researcher along with the given information then proceeded to conduct an intensive study in the field. The village level workers, popularly known as Vikalangula Karyakarthalu helped the researcher in identifying the beneficiaries and the SHGs. Non-availability of the respondents and unwillingness on the part of the respondents were some of the field level issues which the researcher had to negotiate with. The respondents who were willing and accessible were interviewed at their respective residences itself. Nevertheless, proper care was taken by the researcher to include persons with all types of disabilities.

The findings of the study are presented in two parts; first part provides an overview of the socio-economic profile of the respondents, while the second part analyses impairment from a sociological perspective by focusing on the issues of social construction of disability in rural areas and the impact of state and non-state initiatives. Three important parameters, namely group, identity and participation are used to make the sociological interpretation. The following part discusses the socio-economic profile of the respondents.

5.4 Socio-economic Profile of the Respondents

Table 5.1 shows the type of disabilities and the number of respondents of SERP and RDT. It may be observed that about 43 percent and around 47 percent of the respondents of SERP and RDT respectively, are orthopedically challenged and constitute a major part of the total respondents. There are respondents who were identified with disabilities like speech and hearing impairment and visually challenged and mentally retarded though their number is meager in comparison to the total number of respondents. The respondents with speech, hearing impairment, and mental retardation were approached through their family members and the functionaries of SERP and RDT accordingly. However, care was taken to make the objective assessment as regards the issues concerning identity, participation etc. with the formation of SHGs and state and non-state initiatives. The orthopedically challenged, visually challenged and dwarf were interacted directly by the researcher as there was no need for any interpretation. During the interaction with respondents of other categories, the researcher used non-verbal gestures to communicate and understood their responses as interpreted by their family members. At the time of interaction with the children, who are also the respondents, parents helped the researcher in providing the data.

Table 5.1: Type of Disabilities

Type of Disabilities	No. of Respondents	
	SERP	RDT
Orthopedically Challenged	13 (43.3%)	20 (47.6%)
Visually Challenged	4 (13.3%)	8 (19.0%)
Mentally Retarded	5 (16.7%)	9 (21.4%)
Dwarf	2 (6.7%)	0
Orthopedically Challenged and Mentally retarded	1 (3.3%)	2 (4.7%)
Speech and Hearing Impaired	4 (13.3%)	3 (7.1%)
Speech Impaired	1 (3.3%)	0
Total	30	42

Figure 5.1: Type of disabilities, SERP and RDT

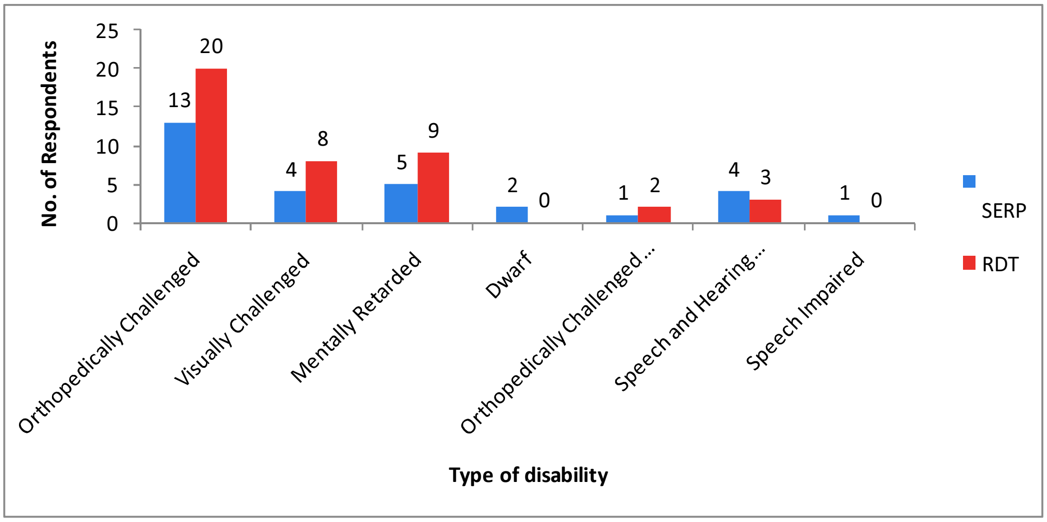


Figure 5.1 presents the comparative picture of respondents according to the type of disabilities. A majority of the respondents are orthopedically challenged in both the cases of SERP and RDT. It may also be observed that mentally retarded respondents are more in the case of RDT than SERP. In the case of RDT, there are no respondents under the category of dwarf and speech impaired, while speech and hearing impaired respondents constitute to around 3 percent of the total respondents of RDT.

5.4.1 Gender

It may be seen from Table 5.2 that among 30 respondents of SERP, 14 are women and 16 are men. On the other hand, out of the total 42 respondents of RDT, there are equal numbers of men and women respondents. Although, it was not consciously attempted at, the proportionate representation of respondents along gender lines enriched the data. The presence of equal number of women in RDT and almost equal number of respondents in SERP in a way reflects the prevalence of disability equally across men and women. It also suggests that the state and non-state initiatives do not discriminate on the basis of gender. Men and women respondents are aware about the importance of groups and the potential of the non-state and state programmes to impact their lives.

Table 5.2: Gender profile of the respondents

Gender	SERP	RDT
Women	14	21
Men	16	21
Total	30	42

It was observed that most of the disabled women are active participants in their groups and in some cases their participation is more than their male counterparts. Although the type and extent of impairment impose limitations on participation, it was however observed that, woman as a member of the group tends to take an active role than as an individual in the family.

Table 5.3 and 5.4 present the distribution of respondents across gender and types of disabilities for both SERP and RDT.

Table 5.3: Type of disabilities and gender, SERP

Type of disabilities	Women	Men	Total
Orthopedically Challenged	4	9	13
Visually Challenged	1	3	4
Mentally Retarded	4	1	5
Dwarf	2	-	2
Speech and Hearing Impairment	1	3	4
Orthopedically Challenged and Mentally retarded	1	-	1
Speech Impaired	1	-	1
Total	14	16	30

It may be observed from Table 5.3 that a majority of the respondents, among both men and women are orthopedically challenged i.e. 56.25 and 28.57 percent respectively. However, the number of visually challenged men, and speech and hearing impaired men respondents are equal in number which is higher than that of the number of women respondents of the similar category. On the other hand, it may be observed that mentally retarded women respondents are more when compared to men respondents. Further, it may be observed that all the dwarf, orthopedically challenged and mentally retarded and speech impaired respondents are women.

Table 5.4: Type of disabilities and gender, RDT

Type of disabilities	Women	Men	Total
Orthopedically Challenged	11	9	20
Visually Challenged	3	5	8
Mentally Retarded	4	5	9
Dwarf	-	-	-
Speech and Hearing Impairment	1	2	3
Orthopedically Challenged and Mentally retarded	2	-	2
Speech Impaired	-	-	-
Total	21	21	42

Table 5.4 also shows that, as in the case of SERP, majority of the respondents of RDT i.e. 20, (11 women and 9 men) belong to orthopedically challenged category followed by mentally retarded respondents. It may be observed that all the 3 respondents of SERP and RDT (SERP:1 and RDT:2) with multiple disabilities (orthopedically challenged and mentally retarded) are women. In both the cases of SERP and RDT, visually challenged men respondents are more than women respondents in the category. Further, there are no respondents in the categories of dwarf and speech impaired among RDT respondents.

5.4.2 Age and Type of Disabilities

Unlike other SHGs, the membership into disabled SHG is not limited to young and adult women. Any person, both men and women with impairment, including children of one year could be enrolled as a member of the disabled SHG. Thus, respondents included in the study belong to different age groups ranging from 7 years to 75 years. Table 5.5 shows the age of the respondents of SERP and RDT.

Table 5.5: Age of the respondents

Age Group	No. of Respondents	
	SERP	RDT
< 14 years	3	6
15 to 25 years	5	14
26 to 35 years	9	13
36 to 50 years	10	7
50 years >	3	2
Total	30	42

It may be observed that a majority of the respondents of RDT belong to the age group of 15 to 25 years, whereas in case of SERP majority of the respondents belong to the age group of 36 to 50 years. It may also be observed that children below 14 years of age are more in RDT than SERP. There are only 3 respondents below 14 years of age in SERP where as there are 6 respondents in the case of RDT in the same age group. The number of respondents above 50 years of age is more in SERP than RDT.

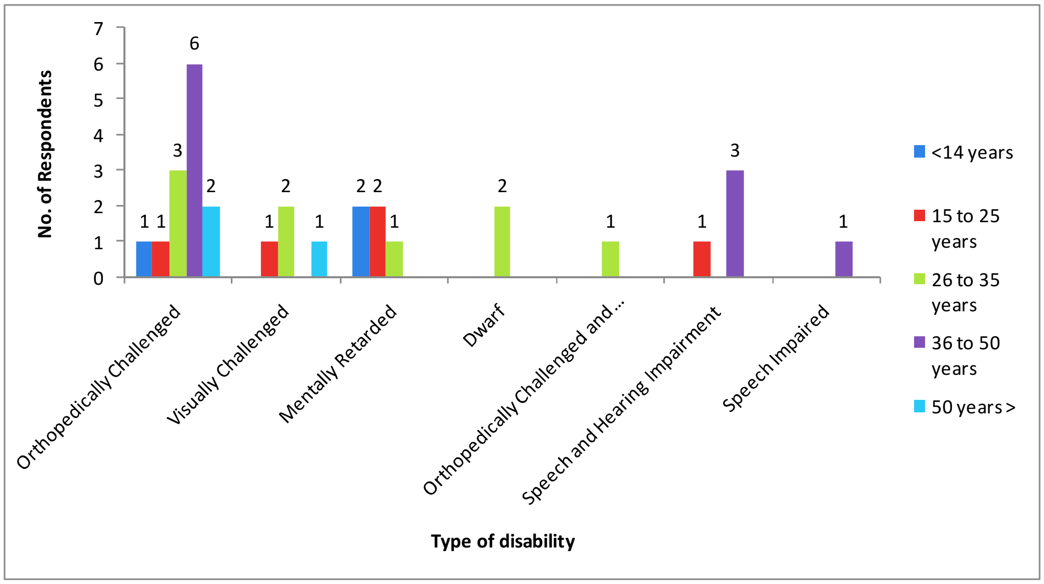
5.4.2(a) Type of Disabilities and Age of the Respondents of SERP

Table 5.6 shows that, a majority of the orthopedically challenged respondents belong to the age group of 36 to 50 years. In case of mentally retarded category, all the respondents are below 35 years of age. The only orthopedically challenged and mentally retarded respondent belongs to 26 to 35 years age group. Similarly, the lone respondent who has speech impairment belongs to 36 to 50 years age group. Significantly, there is only 1 orthopedically challenged respondent in the below 14 years age group category.

Table 5.6: Type of disabilities and age, SERP

Type of disabilities	Age group					Total
	<14 years	15 to 25 years	26 to 35 years	36 to 50 years	50 years >	
Orthopedically Challenged	1	1	3	6	2	13
Visually Challenged	-	1	2	-	1	4
Mentally Retarded	2	2	1	-	-	5
Dwarf	-	-	2	-	-	2
Orthopedically Challenged and Mentally retarded	-	-	1	-	-	1
Speech and Hearing Impairment	-	1	-	3	-	4
Speech Impaired	-	-	-	1	-	1
Total	3	5	9	10	3	30

Figure 5.2: Type of disabilities and age, SERP



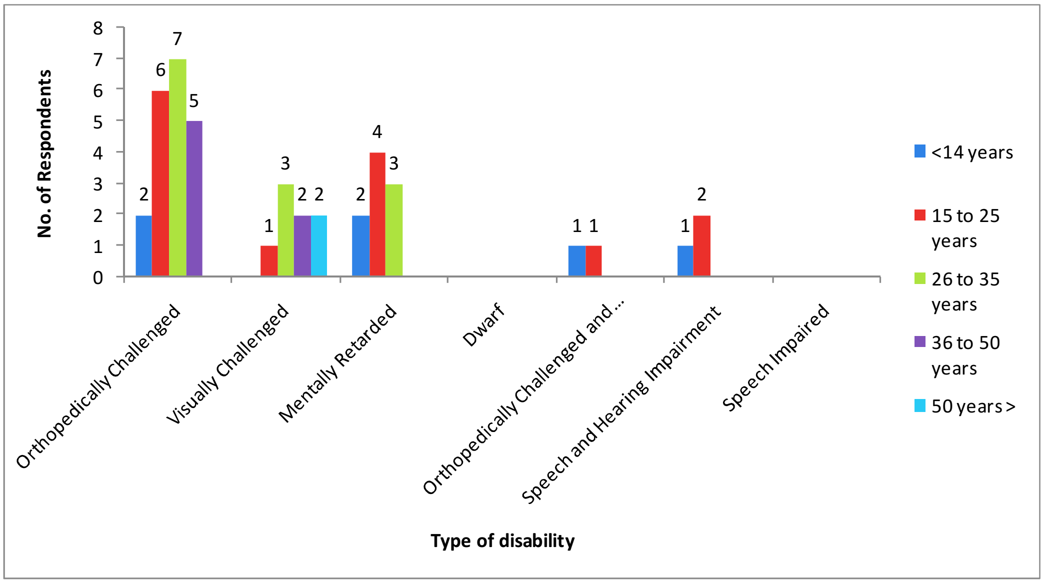
5.4.2(b) Type of Disabilities and Age of the Respondents of RDT

Table 5.7 shows the type of disabilities and age of respondents belonging to RDT. It may be seen that, a majority of the respondents belong to the age group of 15 to 35 years. There are 14 respondents in the age group of 15 to 25 age and 13 in the age group of 26 to 35 years followed by mentally retarded and visually challenged.

Table 5.7: Type of disabilities and age, RDT

Type of disabilities	Age group					Total
	<14 years	15 to 25 years	26 to 35 years	36 to 50 years	50 years >	
Orthopedically Challenged	2	6	7	5	-	20
Visually Challenged	-	1	3	2	2	8
Mentally Retarded	2	4	3	-	-	9
Dwarf	-	-	-	-	-	-
Orthopedically Challenged and Mentally retarded	1	1	-	-	-	2
Speech and Hearing Impairment	1	2	-	-	-	3
Speech Impaired	-	-	-	-	-	-
Total	6	14	13	7	2	42

Figure 5.3: Type of disabilities and age, RDT



5.4.3 Age and Gender

Table 5.8 shows the distribution of respondents along age and gender. Along gender lines, the data of SERP presents that 7 women respondents are in the age group of 26 to 35 years while 9 men respondents are in the age group of 36 to 50 years. On the other hand, in case of RDT, 9 women respondents are in the age group of 15 to 25 years, whereas an equal number of men respondents belong to the age group of 26 to 35 years.

It may be inferred from the data that in case of SERP majority of women respondents belong to the age group of 26 to 35 years, whereas in the case of RDT majority, i.e. 9 out of 21 of the women respondents belong to the age group of 15 to 25 years while 9 men respondents out of 21 belong to the age group of 26 to 35 years. The number of young respondents (below 25 years age) is higher in case of RDT i.e. (20) when compared to SERP (8) respondents. The respondents belonging to the age group of above 50 years are all men respondents in both the cases of SERP and RDT. However, among the respondents of SERP who are below 14 years of age, a majority are girls whereas in case of RDT, both girls and boys are equal in number in this category.

Table 5.8: Age and gender

Age group	SERP		RDT	
	Women	Men	Women	Men
< 14 Years	2	1	3	3
15 to 25 Years	4	1	9	5
26 to 35 Years	7	2	4	9
36 to 50 Years	1	9	5	2
50 Years >	-	3	-	2
Total	14	16	21	21

5.4.4 Education

A number of studies on disabled in India have found that education among the disabled is less when compared to others (Klasing, 2007). Low education levels among the disabled are attributed to the lack of facilities in rural areas for special training to the speech impaired, hearing impaired, visually challenged and mentally retarded. The disability activists argue that it is not just the infrastructural and institutional factors that contribute to the dismal educational levels among PWDs, the social barriers also play a dominant role in deterring the disabled from accessing education.

Table 5.9 shows the educational levels of the respondents belonging to the SERP and RDT. The first category i.e. up to 5th class, includes the respondents having no formal education and those having primary education up to 5 years of schooling. Data presented here refers to those respondents who are above five years of age. A large majority of the respondents from SERP and RDT (60 percent and 47.61 percent) belong to this category.

Table 5.9: Education, SERP and RDT

Education level	No. of Respondents		Total
	SERP	RDT	
Upto 5th class	18	20	38
6th to 10th class	7	8	15
+2 (inter)	3	7	10
Undergraduate	1	5	6
Post-graduate	1	2	3
Total	30	42	72

The number of respondents having post graduation is only 1 in case of SERP and 2 in the case of RDT. In the case of RDT, the number of respondents who have intermediate as their qualification is more when compared to SERP.

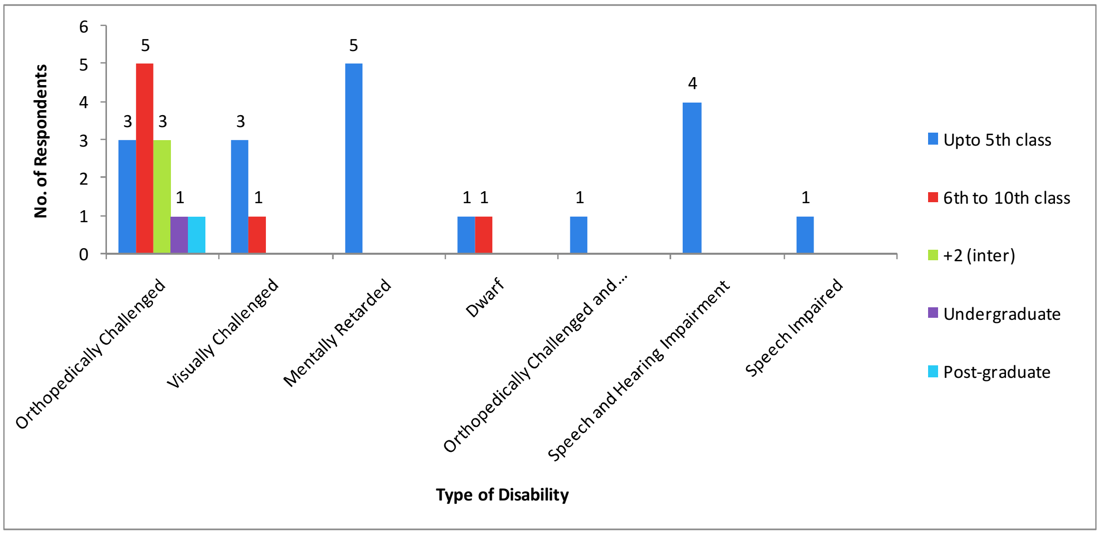
5.4.4 (a) Type of Disabilities and Educational level of the Respondents of SERP

Table 5.10 shows the type disabilities and educational level of the respondents of SERP. It may be observed that 18 out of 30 respondents (60 percent) have less than five years of formal education, i.e. those who studied up to 5th class, followed by 7 respondents who studied up to 10th class. It may be pointed out that very few respondents i.e. only 5 out of 30 have gone for education beyond 10th class.

Table 5.10: Type of disabilities and educational level of the respondents, SERP

Type of disabilities	Education level and no. of respondents					
	Up to 5th class	6th to 10th class	+2 (inter)	Under-graduate	Post-graduate	Total
Orthopedically Challenged	3	5	3	1	1	13
Visually Challenged	3	1	-	-	-	4
Mentally Retarded	5	-	-	-	-	5
Dwarf	1	1	-	-	-	2
Orthopedically Challenged and Mentally retarded	1	-	-	-	-	1
Speech and Hearing Impairment	4	-	-	-	-	4
Speech Impaired	1	-	-	-	-	1
Total	18	7	3	1	1	30

Figure 5.4: Type of disabilities and educational level of the respondents of SERP



Data on education along the lines of the type of disabilities presents that it is only the orthopedically challenged who have reported education beyond 10th class with the exception of one visually challenged and one dwarf. Out of the 13 orthopedically challenged respondents, 5 are educated beyond 10th class. All the mentally retarded respondents, speech impaired and speech and hearing impaired have either no formal education or have primary education up to 5th class.

All the visually challenged respondents have stopped their studies with 10th class. The deterring factors appear to be social, cultural and institutional barriers which prevent them from pursuing higher studies. Among those orthopedically challenged who had access to appliances like wheelchairs and support from family members, could move out of the village to pursue higher education. It may be inferred that more than the mobility factors, the pedagogy and curriculum prevent a majority of respondents with disabilities like visual impairment, speech and hearing impairment to access higher education.

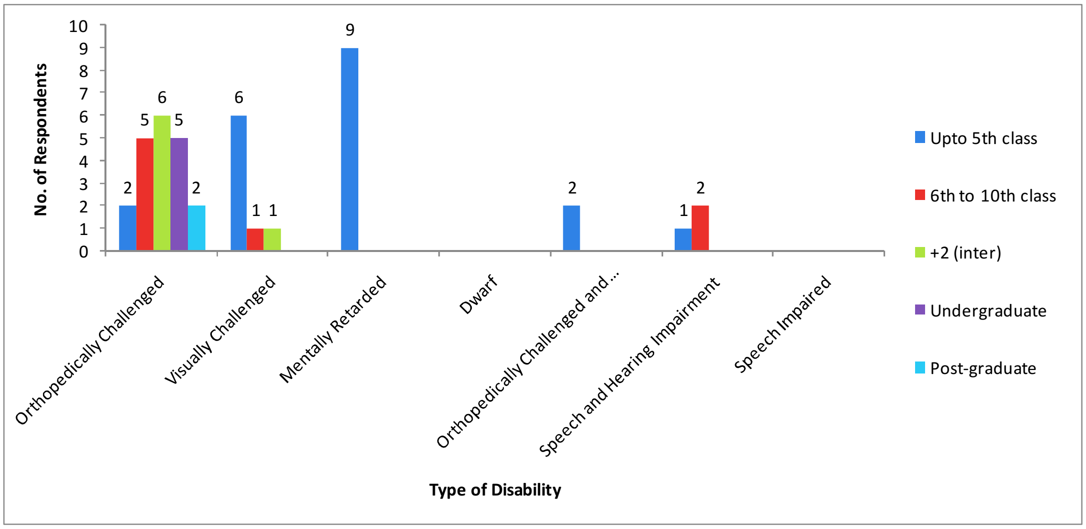
5.4.4 (b) Type of Disabilities and Educational level of the Respondents of RDT

Table 5.11 shows the type of disabilities and educational level of the respondents of RDT. It may be observed that 20 out of 42 respondents have less than primary education followed by 8 respondents having studied up to 10th class. Only 14 respondents have pursued education beyond 10th class.

Table 5.11: Type of disabilities and educational level of the respondents, RDT

Type of disabilities	Education level and no. of respondents					
	Up to 5th class	6th to 10th class	+2 (inter)	Under-graduate	Post-graduate	Total
Orthopedically Challenged	2	5	6	5	2	20
Visually Challenged	6	1	1	-	-	8
Mentally Retarded	9	-	-	-	-	9
Dwarf	-	-	-	-	-	-
Orthopedically Challenged and Mentally retarded	2	-	-	-	-	2
Speech and Hearing Impairment	1	2	-	-	-	3
Speech Impaired	-	-	-	-	-	-
Total	20	8	7	5	2	42

Figure 5.5: Type of disabilities and educational level of the respondents of RDT



Orthopedically challenged have reported education beyond 10th class with the exception of one visually impaired in the case of respondents of RDT. In the case of SERP, the visually challenged respondents were found to have stopped their studies with 10th class, whereas one visually challenged respondent of RDT was found to be pursuing his intermediate education. Further, all the mentally retarded respondents under the category have primary education. In contrast to SERP, two speech and hearing impaired respondents have more than five years of formal education.

5.4.5 Marriage

Marriage among the PWDs, particularity among women, is an important sociological issue for the scholars of disability studies. Marriage as a social institution is deeply embedded in the religious and cultural beliefs and value system. As a result of the importance attached to marriage of women, parents prefer to get their daughters married at any cost. Often, they do not mind getting their impaired daughters married to an unsuitable partner as well.

Marriage seems to be the main social support for women with disabilities. Demographers have consistently suggested that marriage, parenthood and social support networks are associated with better health for men and women. They further argue in favor of considering the association between marriage, gender and physical impairments. Marriage is seen as having a positive correlation with disability managements (Mehrotra, 2013).

Data were collected on the grounds of marital status of the respondents in order to analyze the concerns of marriage among disabled. Data presented here pertains to those respondents who have attained the marriageable age, i.e. 18 years for girls and 21 years for boys. Table 5.12 shows the marital status of the respondents of SERP and RDT.

Table 5.12: Marital status of the respondents

Marital Status	No. of Respondents	
	SERP	RDT
Married	13	17
Unmarried	13	16
Total	26	33

It is to be noted that 4 respondents of SERP and 9 respondents of RDT have not attained the marriageable age. Therefore, out of the total 30 respondents of SERP, 26 are in the marriageable age. Similarly, out of the total 42 respondents of RDT, 33 respondents belong to the marriageable age. It may be observed that in the case of SERP, the number of the married and unmarried respondents is equal, whereas in case of RDT majority of the respondents are married.

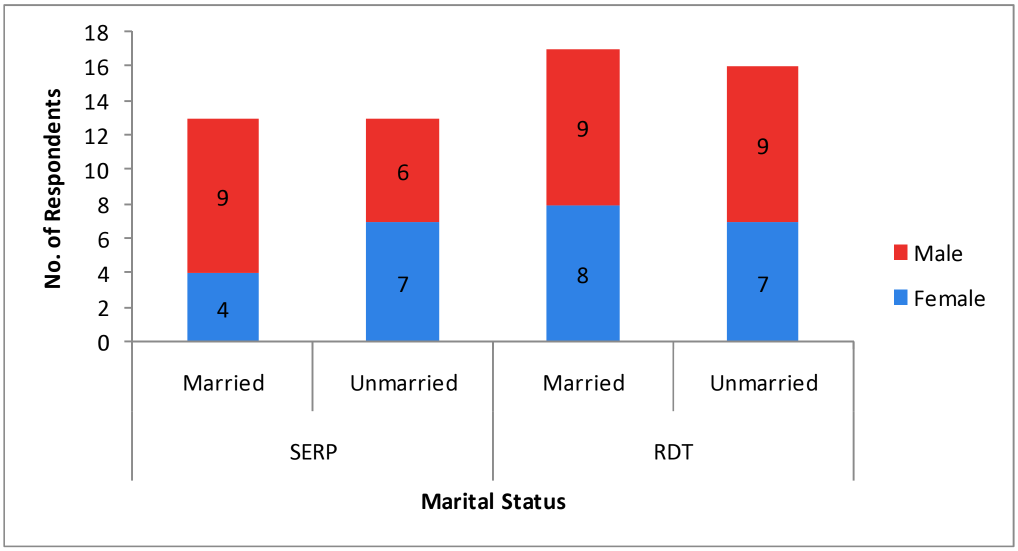
5.4.5 (a) Gender and Marital Status of the Respondents of SERP and RDT

In order to understand discrimination in marriage with respect to issues concerning the disabled women, data were analyzed along gender lines. Table 5.13 shows the gender and marital status of the respondents of SERP and RDT.

Table 5.13: Gender and marital status

Gender	No. of Respondents			
	SERP		RDT	
	Married	Unmarried	Married	Unmarried
Female	4	7	8	7
Male	9	6	9	9
Total	13	13	17	16

Figure 5.6: Gender and marital status



Data present that, out of the total 11 women respondents of SERP who have attained the marriageable age, majority of them i.e. 7 are unmarried and only 4 are married. On the other hand, out of the 15 women respondents of RDT falling in the marriageable age, 8 are married and 7 are unmarried. It may be observed that 6 male respondents of SERP were found to be unmarried even after having attained the marriageable age. However, it may be seen that the number of married and unmarried male respondents of RDT is equal in number i.e. 9.

5.4.5 (b) Type of Disabilities and Marital Status of the Respondents of SERP and RDT

Table 5.14 shows the type of disabilities and marital status of the respondents of SERP and RDT in the marriageable age. It may be observed that a majority of the married respondents (7 out of 13 in case of SERP and 11 out of 17 in case of RDT) are orthopedically challenged. All the mentally retarded respondents of SERP and RDT were found to be unmarried even though they are in their marriageable age. The four visually challenged respondents of SERP are unmarried whereas, out of 8 visually challenged respondents of RDT, 6 are married and only 2 are unmarried. In both the cases of SERP and RDT, respondents having both orthopedic impairment and mental retardation were found to be unmarried. On the other hand, all the speech and hearing impaired respondents of SERP are married in contrast to RDT where all the respondents of the same category are found to be unmarried.

Table 5.14: Type of disabilities and marital status, SERP and RDT

Type of disabilities	SERP			RDT		
	Married	Unmarried	Total	Married	Unmarried	Total
Orthopedically Challenged	7	5	12	11	6	17
Visually Challenged	-	4	4	6	2	8
Mentally Retarded	-	2	2	-	5	5
Speech Impaired	1	-	1	-	-	-
Dwarf	1	1	2	-	-	-
Speech and Hearing Impairment	4	-	4	-	2	2
Orthopedically Challenged and Mentally retarded	-	1	1	-	1	1
Total	13	13	26	17	16	33

5.4.6 Age group and Dependency

Independent living connotes individual's social and economic status. Individual as a member of the family integrates into the collective as a source or contributor to the family's economic, social and cultural life. As a member of the family, an individual is dependent, yet shows signs of independence in terms of control over resources, decision making etc. Considering this as an important parameter in assessing the living conditions of the impaired, data were collected on issues of dependency. The respondents below 14 years of age were considered as dependents. Thus, the data on dependency pertains to those respondents who belong to the age group of 15 years and above. An attempt was made to analyze age group and dependency through a complex set of questions ranging from respondents' income, employment, savings, land holdings, etc.

Table 5.15 shows the age group and dependency status of the respondents of SERP and RDT.

Table 5.15: Age group and dependency, SERP and RDT

Age Group	Dependency					
	SERP			RDT		
	Dependent	Independent	Total	Dependent	Independent	Total
15 to 25 years	3	2	5	9	5	14
26 to 35 years	2	7	9	4	9	13
36 to 50 years	2	8	10	1	6	7
50 years >	1	2	3	1	1	2
Total	8	19	27	15	21	36

Table 5.15 shows that about 70.3 and 58.3 percent of the respondents of SERP and RDT respectively lead an independent life by engaging themselves in various income generating activities. It may be noted that 3 respondents of SERP and 6 respondents of RDT who are below 14 years of age were treated as dependents. However, 8 respondents of SERP and 15 respondents of RDT in the age group of 15 years and above were still found to be dependent on their family members for their livelihoods. Among those who claim to be independent, in the case of SERP, majority of them i.e. (8 out of 19) are in the age group of 36 to 50 years followed by 7 respondents in the

age group of 26 to 35 years. On the other hand, in the case of RDT, majority of the independent respondents (9 out of 21) are in the age group of 26 to 35 years.

5.4.7 Gender and Dependency

Table 5.16 shows the gender and dependency among the respondents of SERP and RDT.

Table 5.16: Gender and dependency, SERP and RDT

Gender	Dependency					
	SERP			RDT		
	Dependent	Independent	Total	Dependent	Independent	Total
Female	6	6	12	10	8	18
Male	2	13	15	5	13	18
Total	8	19	27	15	21	36

It may be observed from Table 5.16 that among 19 independent respondents of SERP, 13 are men and 6 are women. It may also be seen that an equal number of male respondents (13 each) are independent in both SERP and RDT. The respondents below 14 years of age are considered as dependents. Thus, it may be observed that out of 8 dependent respondents of SERP, 2 are men and 6 are women. Similarly, out of 15 dependent respondents of RDT, 5 are men and 10 women. It may be inferred from the above table that majority of the women in both the cases of SERP and RDT were found to be dependent in contrast to their men counterparts.

5.4.8 Gender, Dependency and Marital Status

Independent living is a factor of gender and marital status. Table 5.17 shows the gender, dependency and status of marriage of the respondents of SERP and RDT. Married women are categorized as independent in a narrow sense that they no longer depend on their parents and/or siblings. After marriage, they raise a family of their own as marriage provides them an independent identity from that of their natal home. However, it may be seen that, out of the total 10 unmarried women respondents of RDT, majority of them i.e. 8 are dependent and only 2 are independent. It is also observed that only 1 married male respondent in both the cases of SERP and RDT is dependent on his family members.

Similarly, in the case of SERP, 4 unmarried women respondents are dependent on their parents and other family members. It may also be observed that the married independent women respondents are more in case of RDT whereas in case of SERP the dependent and independent women married respondents are equal in number.

Table 5.17: Gender, dependency and marital status, SERP and RDT

Status of Marriage	Gender	Dependency					
		SERP			RDT		
		Dependent	Independent	Total	Dependent	Independent	Total
Married	Female	2	2	4	2	6	8
	Male	1	8	9	1	8	9
	Total	3	10	13	3	14	17
Unmarried	Female	4	4	8	8	2	10
	Male	1	5	6	4	5	9
	Total	5	9	14	12	7	19

In this chapter, data collected on the state and non-state organizations was analyzed. Data reveals that the participation of men and women in the SHGs is equal. With reference to the women respondents of the group, in case of SERP, it was found that orthopedically challenged and mentally retarded women are equal in number and constitute a majority. On the other hand, in case of RDT, majority of women respondents are orthopedically challenged. Presence of respondents below 14 years and above 50 years proves the ‘age no bar’ norm of the group. Though majority of the respondents were found to have less than 5 years of formal education, they belong to the older age group. The younger generation between the age group of 15 to 25 was found to be either pursuing their studies or having better educational qualifications.

Next chapter presents a discussion on the findings of the study. The discussion is based on the data presented so far and observations made by the researcher in the field. Apart from this, data collected through in-depth interviews with the respondents and functionaries is used in the discussion.

CHAPTER-VI

FINDINGS AND DISCUSSION

6.1 Introduction

This chapter attempts at a critical examination of state and non-state initiatives towards PWDs based on the data collected from the field. Using the data collected through observation, in-depth interviews with the respondents, it analyses the social organization of SHGs and other initiatives of state[8] and non-state and the influence of these initiatives on identity, participation and independent living of the PWDs in the society. The chapter presents the findings juxtaposing the theoretical arguments located in disability studies.

The state and non-state initiatives towards the disabled through SERP and RDT are modeled on the lines of SHGs. The popularity of Grameen Bank of Bangladesh has resulted in the proliferation of SHGs for savings and credit across the developing world. SHGs are widely viewed as instruments of development through micro-finance, including savings, credit, lending and borrowing (Karmakar, 1999; Bouman, 1995; Premchander, 2003). The term self-help group is generally used in India to refer to a small, registered or unregistered group of 10 to 20 members involved primarily in savings and credit activities. Members save periodically as a group and use their group savings to get bank loans which are then lent out to members who require loans at a fixed rate of interest. NGOs and various governmental organizations, especially the banks, have played a significant role in India in strengthening SHGs by establishing institutional linkages for better financial and organizational resources (Nair, 2005). Based on the Grameen Bank scheme, India has pioneered the institutional linkage model of SHGs which is now widely replicated across the developing world (Karmakar, 1999).

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[8] Discussion on the state initiative i.e. SERP is benefitted from the Project report titled “Enabling the differently abled: a sociological understanding of the development initiatives of the state and the community towards the disabled in rural Andhra Pradesh” submitted to the University Grants Commission, New Delhi in 2012. The project was funded by the UGC under Major Research Project Scheme and the researcher was associated with project as Project Fellow.

NGOs in India have been at the forefront of organizing SHGs since the 1980s for savings and credit among the low income groups. However, the phenomenal growth in SHGs began once the National Bank for Agriculture and Rural Development (NABARD), an apex development bank was established by the Reserve Bank of India in 1992. The NABARD, with its mandate of agricultural and rural development started promoting the SHG system in the mid 1990s to enable the rural poor, especially women to have access to external financial resources (Selvam, 2005). Micro-finance activities in India are now dominated by women's self-help groups (Rahman, 1999). There are over one million SHGs operating in rural India (Selvam, 2005) and some statistics indicate that over 90 percent of the members of these groups are women (Nair, 2005). Over the years, institutions in India have developed a sound organizational structure of SHGs, especially in the rural areas where the majority of SHGs exist. Self-help groups are now federated at village, block and district levels (the three-tier rural governance structure) in order to maximize their potential (Chaudhry, 2012).

In the last eight to ten years, especially in the southern states of India, Disability and Justice, a non-governmental organization has been organizing SHGs of disabled people and mobilizing them to form collectives e.g. self-help groups at the village level and federations at the district level (Ramachandran, 2003). These collectives are meant to provide a platform to raise awareness, to advocate, to enable self-representation and to monitor proper implementation of the provisions of the Disability Act in their area (Chaudhry, 2012).

With the objective to form groups which eventually work for the welfare of the impaired, the state embarked on mobilizing the disabled to form groups which are termed as Vikalangula Sangham (group of disabled). The motto behind the formation of self help groups for the disabled, evolves from The Biwako[9] Millennium[10]

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[9] Lake "Biwa" is the largest freshwater lake in Japan, in the City of Otsu. It is in this city that the High-level Intergovernmental Meeting to conclude the Asian and Pacific Decade of Disabled Persons was held. Hence, the name of the framework is "Biwako" ("ko" means a lake).

[10] The word "Millennium" indicates that the Framework is adopted at the beginning of the new millennium and that it is also structured to supplement the UN Millennium Development Goals and targets.

Framework for Action towards an inclusive barrier free and rights based society for persons with disabilities in Asia and Pacific. The Biwako Millennium Framework (BMF) for Action[11] recommended by the UN to member countries as part of the 2nd Asian Pacific decade of disabled persons 2003-2012, adopted in October 2003, mandated the following seven areas to mainstream the disabled:

- Self-help organizations of persons with disabilities and related family and parent associations,
- Women with disabilities,
- Early detection, early intervention and education,
- Training and employment, including self-employment,
- Access to built environment and public transport,
- Access to information and communication,
- Poverty alleviation through social security and livelihood programs.

6.2 Mobilization of PWDs into SHGs

The task of forming the group is entrusted to the Community Coordinator (CC) and the Community Development Worker (CDW). Once the families which include disabled member(s) are identified, the CDW goes to the house and explains about the state initiatives and its advantages to the members of the family. Community Resource Persons (CRPs) help in motivating the disabled members and their families through cultural shows, success stories, advantages and positive changes of joining the group. Along with this, the village level functionaries of SERP constantly hold consultations with the disabled members as well as their family members till they join the group.

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[11] In May 2002, ESCAP adopted the resolution Promoting an inclusive, barrier-free and rights-based society for people with disabilities in the Asian and Pacific region in the twenty-first century. The resolution also proclaimed the extension of the Asian and Pacific Decade of Disabled Persons, 1993-2002, for another decade, 2003-2012.

Murthy, a partially blind member of Gandhi Vekalangula Sangham who works as a CDW narrates the difficulties faced by him in mobilizing the PWDs into the group. In his words, *'I struggled a lot when I started mobilizing them into groups. I visited each and every house having disabled member and approached them personally and requested them to join the group. It took four months to convince the disabled persons and their parents to join the group. At last, they joined our group'*.

Many respondents also appreciated the effort of CCs and CDWs in influencing them to join the group. Jia, a 23 year old partially blind respondent of Babaiah Vikalangula Sangham of Lepaskhi mandal says that *'Radha madam (CDW) and Ramana sir (CC) really changed my life. I was suffering from my disability and was confined alone at home without doing anything. My family members used to treat me as a burden. When Ramana sir came to me and asked to join the SHG, I was not ready in the beginning, but, when Radha madam told me the benefits of joining the group, I was interested and thus, Ramana sir helped me in joining the group and now I am an independent person and also able to contribute to the family income. Thanks to sir and madam'*.

Besides the continuous effort of CCs and CWDs in mobilizing the PWDs into SHGs, in many cases it was found that the improvement in both social and economic lives of the members influenced the neighbors to join the group. Moreover, the attention of the state functionaries on the disabled members and the activities of the Vikalangula Sangham influenced others who stayed away to join the group. Thus, more disabled members joined the group subsequently. Cultural programmes on the rights of the PWDs also encouraged the disabled members to join the group and to be united.

Mallanna, aged 38 years, having an orthopedic impairment, belonging to Anjeneluswami Vikalangula Sangham of Ketaganicherugu village, Somandepalli mandal says that, *'I am a weaver and make sarees. I used to sell my products to a cloth trader named Dharmavaram. I did not have enough money to buy a handicraft machine. I was not a member of Vikalangula Sangham earlier, but two of my neighbors who were members of the disabled group had developed a lot in their business through the financial help (in the form of loan) received from the group. I was influenced by them and joined the group and took a loan and brought maggamu (handloom)'*.

In the interaction with the researcher, the SERP functionaries stated that, in a majority of the cases, initially the family members were reluctant to allow their impaired member to join the group as they were apprehensive of the benefits of the group. They also felt that this (taking the disabled member to the group meetings in the village and outside the village etc.) would add extra burden to the care giving work already provided to the impaired person by the family without much benefit. The family members reportedly told the SERP functionaries that taking care of the dependent impaired person itself was time consuming. With such mindset, many families did not allow their disabled members to join the group initially. However, there are few cases where family members were enthusiastic to take membership for their impaired member. It was mentioned by the SERP functionaries that the lure of loans (access to credit through CIF or bank) motivated most of the family members to allow their impaired members of the family to join the group. Nevertheless, it may be suggested that the State is considered as a key player in the lives of the rural poor as they look at the State for any financial benefit through schemes. They also feel that it is their right to use the benefits of the State.

RDT follows the similar strategy of identifying and mobilizing the disabled into groups. Vikalangula Karyakarthalu (VK) are entrusted with the task of identifying the persons with disabilities in the village. Vikalangula Karyakarthalu are the volunteers of disabled people in the village and work under the guidance of Group Organizers. On mobilization of persons with disabilities in the villages, it was told by the VK that as RDT and Father Vincent Ferrer, founder of RDT, are well known among the rural poor of Anantapur district, it was easy on the part of the VK to motivate the persons with disabilities to join the group. When approached by the VK the members of the disabled family were more than willing to take membership for their disabled member in the group. Further, the awareness about the facilities available at various special schools run by RDT encouraged some parents to join the group.

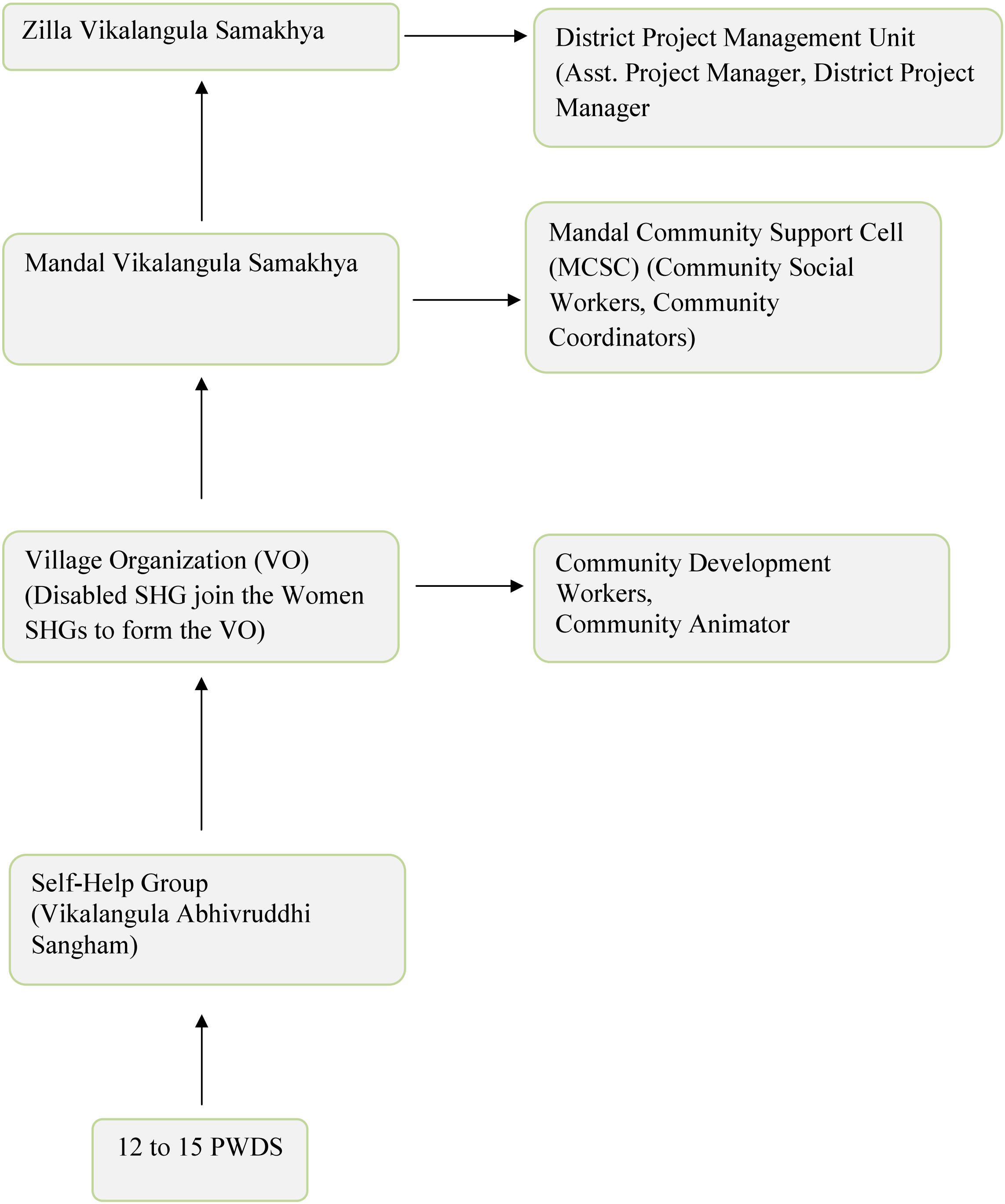
6.2.1 Group Structure

The number of disabled in a group formed by SERP is 12-15 members. Groups are formed irrespective of age, caste, class, type of disability and gender. Children as young as 4 years to a person of 60 years of age were found to be members of the group. In some cases, one of the family members is allowed to operate the membership on behalf of the disabled member. Every group has a name.

Generally, the names having religious significance, such as Manikantha Vikalangula Abhivrudhi Sangham, Vinayaka Vikalangula Abhivrudhi Sangham, Saraswati Vikalangula Abhivrudhi Sangham are given. Other secular names like Nakshatra Vikalangula Abhivrudhi Sangham, Nehru Vikalangula Abhivrudhi Sangham etc. are some common names found in the study. Name not only gives identity to each group when it federates into a larger body at the mandal level, but is also a pre-requisite to operate financial transactions with the SERP and credit institutions like banks. Every group elects its president and secretary and appoints a bookkeeper to record accounts and maintain minutes. These elected representatives are referred to as First leader and Second leader. The term of these office bearers is two years and on the expiry of the term, a new body constituting newly elected members is formed.

In case of SERP, the role of the Community Coordinator (CC) is immense and strongly felt in the affairs of the group. It may be mentioned that all groups were found to be relying heavily on the advices and suggestions of the CC. The role of CC is felt in the selection of office bearers of the group, giving day to day guidance and in other group matters. The group members maintain a close contact with the CC.

Figure: 6.1: Organization of SHGs, SERP

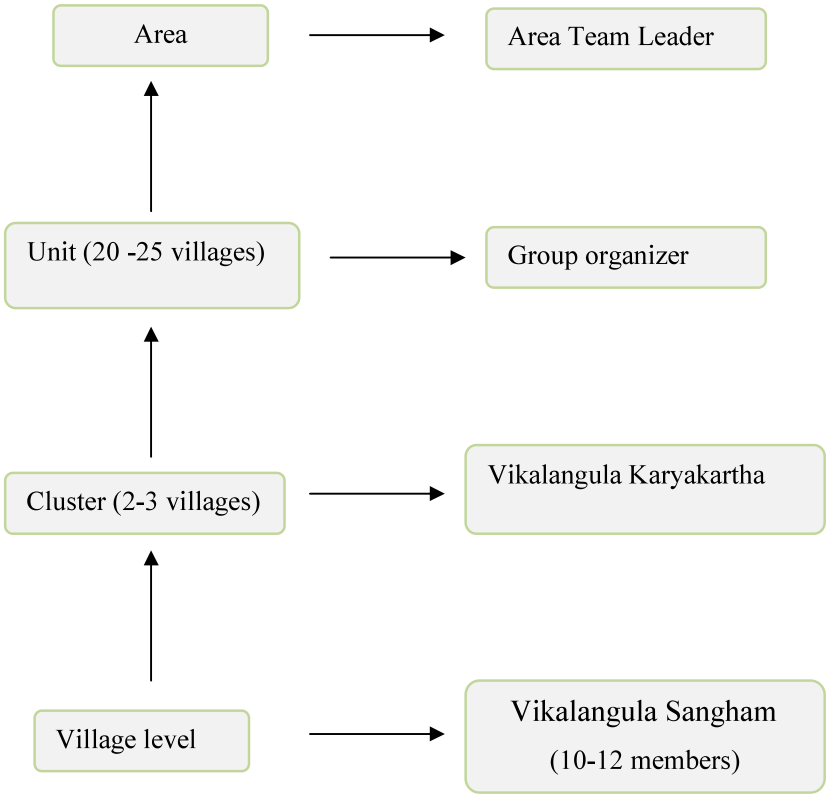


The functionary of SERP at the village level is a Community Development Worker (CDW). There are 4 to 5 CDWs and 1 Community Animator (CA) in each village. At the mandal level, there are 1 to 2 Community Coordinators (CC) and 2 Community Social Workers (CSW) to coordinate with the village level workers. District Project Manager and Assistant Project Managers are located at the district headquarters. In addition, there are two resource groups per district. Each resource group looks after 10 to 15 mandals in the implementation of the programmes for the disabled (Chand and Reddy, 2012).

On the other hand, the groups formed by RDT generally constitute 10 to 12 members. As in the case of SERP, there is no discrimination based on age, sex, caste, class and types of disabilities in becoming a member of the group. Every group has a name. Some names like Sri Ganesha Vikalangula Sangham, Yarrithatha Vikalangula Sangham, Sri Bapuji Vikalangula Sangham, Sri Venkateswara Vikalangula Sangham, Sri Sai Vikalangula Sangham, Appaswami Vikalangula Sangham, Yamuna Vikalangula Sangham, Avyudaya Vikalangula Sangham, Sri Anjaneya swami Vikalangula Sangham, Laksmi Narasimhaswami Vikalangula Sangham, Sri Shiridi Sai Vikalangula Sangham, Sree Nethajee Vikalangula Sangham, Sree Ganga Gowri Vikalangula Sangham were found in the study.

Every group elects their leaders who are referred as group leaders. One group leader heads one Sangham. The Vikalangula Karyakarthalu work towards the formation of group and are responsible to the Group Organizers of the Unit. The Group Organizers are accountable to the Area Team Leaders. The main tasks of the Group Organizers are to conduct household surveys, to guide the group in effective management of their savings and to provide leadership training to the group leaders. They also keep a track on the processing and follow up of income generating programmes.

Figure: 6.2: Organization of SHGs, RDT



6.2.2 Group Activities

Generally, every group meeting starts with the prayer. Every group member knows the prayer which calls for self belief, self help and cooperation. It is a motivational song and the ritual of singing at the start of the group meeting provides them an identity of serious participation and focused approach about their group affairs. Every group meets at least twice a month. Some groups also meet once a week. The days of meetings are fixed in most cases. The regular meetings are held on any of the weekdays during evenings in the house of one of the members. Meetings are generally held in the house of the member of the SHG which is centrally located. Parents of the disabled children attend on their behalf. On special occasions, parents bring their disabled children also. Otherwise, parents or other family members take decisions on their behalf. It was reported that all the parents do inform the proceedings of the meetings to their children or the disabled family member and take their consent. This is ensured by the group members and functionaries. The functionaries rather encourage the participation of impaired who cannot move on their own and insist on their family members to bring them expecting that the members would learn certain skills in group interaction. However, mentally retarded and children with severe impairments are exempted from the meetings.

It was reported that group meetings also act as forums to identify promising individuals who can voice their views and SERP functionaries would identify their abilities and select them to participate at the mandal, district and state level meetings. Many have travelled on such occasions and it was reported to be a great experience as they suggest that they would have never crossed the boundaries of the village without the group. The frequency of interaction with officials, bank personnel, other members of the village and people other than family members has increased with the setting up of the group. This has generated a lot of interest among the group members as it created a positive identity to them.

The members of PWD groups always compare the performance of their group with other SHGs including women SHGs operating in the village or mandal level. One respondent, who is also the President of a group mentions that ‘our Vikalangula Sangham is performing better than the women SHGs in terms of repayment of loans, attendance to meetings, raising issues at the village and mandal forums’. Such kind of comparison is always made from the normal point of view and slightest achievement by the disabled is celebrated not only by the group members themselves, but also by the functionaries of SERP. However, on the whole it was an unanimous opinion of all the group members as well as SERP functionaries that the SHGs of disabled perform better than the women SHGs.

In case of RDT, the group members attend cultural programmes by students of various special schools on occasions such as the International Deaf Day celebration on 24th September, 2010 when Mrs. Anne Ferrer, Executive Director, RDT flagged off the cycle rally in Anantapur. About 50 students from BKS High school located at Bukkarayasamudram along with teachers, officials from CBR sector and Spanish volunteers took part in it. The rally was led by a Spanish cyclist Jose Luis Garcia Ginard, who travelled all over India to raise funds and creating awareness about deafness and deaf people. The group members also attended theater and poetry workshops during July and August, 2010. A deaf Spanish volunteer conducted a series of dramas, plays and mime shows in the primary school for hearing impaired children. Some of these plays were on making PWDs aware of their rights. In some cases, it was reported that the group members take part in the awareness campaign in their respective villages.

6.2.3 Group Discussions

The general issues discussed in the group meetings are thrift, proceedings of the meetings held at the mandal and district headquarters, needs like certificates, admissions in schools etc. Often personal issues like harassment or ill treatment by family members or spouses are also taken up in the group meetings. They also share their feelings on personal issues related to their families, neighbors and village in general. Group members were observed to be very particular about their rights, which they had come to know through the meetings. Generally, the SERP functionaries also discuss the rights of the disabled and the constitutional safeguards. The ways and means of achieving these rights are also discussed in the group meetings.

The issues raised by the disabled in various forums range from official apathy in issuing impairment certificates for bus pass, school and college fee reimbursement, admission to schools, medical care, ration cards, pensions etc. By raising these issues in the common platforms, it is hoped that others in the village would be aware of their problems and change would take place in their attitude over a period. However, the issues related to physical and architectural barriers which need to be addressed by the village members and functionaries receive less attention or are never raised by the disabled themselves. This is a significant aspect of the disabled programme because it lays much emphasis on the disabled and very little on the broader social context.

The social model specifically points this out and tries to problematize the social factors that contribute to the disabling environment and suggest for bringing changes in the society and institutional approaches towards the disabled. It may be suggested that the disability movement in India and in Andhra Pradesh is still in its nascent stages and it is hoped that in the due course the programme would change its course as recommended by the social model.

The disabled groups of RDT meet at least twice a month. The dates of at least two meetings are fixed. The meetings are generally held on 3rd and 15th of every month. Along with the savings and loan sanction from the bank, they also avail grants from RDT which is equal to the amount of their savings. Thus, there is an additional requirement of contacting the Area Team Leader for getting the loans. Moreover, the group members have a discussion on the requirement of equipments such as artificial limbs, Jaipur foot etc. from the orthopedic workshop run by RDT for the needy members of their group. The parents of the disabled children seek suggestions from the group organizers and team leaders regarding the admission of their children into various special schools run by RDT.

6.2.4 Federation of SHGs

Every group member saves on biweekly or monthly basis. The savings received are recorded and the amount is given to the responsible members of the women SHGs who, while depositing their savings in the mandal headquarters would also deposit the savings of the disabled SHGs. It is interesting to note that some women who are impaired and are members of women SHGs also take membership in the disabled SHGs. The dual membership has not attracted any contempt from the functionaries and the other members of the SHGs because they believe that a disabled women member has the right to be a member of the women SHG and the disabled SHG. All the SHGs including women and disabled of the village meet together once a month and discuss the issues pertaining to them. The office bearers, either the President or Secretary or any one of their members attend the group meetings. This is an extended meeting where the state level functionaries of SERP also take part.

All the women and disabled SHGs federate at mandal level. While the disabled SHGs at the village level are associated with women SHGs because of a small number of disabled SHGs in each village (in most of the villages only one SHG for the disabled was found), at the mandal level the disabled SHGs have their own federation named Mandal Vikalangula Samakhya (MVS). Generally, the number of SHGs in the MVS is more than fifteen. There are office bearers for every MVS who represent the views of the disabled of the mandal. They take part in decisions pertaining to credit, repayment, medical needs and rights issues. Every month there is an extended meeting of all the SHGs including women and disabled where the 5th item of the agenda pertains to the disabled. It was suggested that, earlier, though disabled members were also attending the mandal level monthly meetings, their issues would never come up for discussion as the issues of women SHGs used to take all the time. When the disabled members protested, the SERP functionaries, now, made it mandatory to have the 5th item of the agenda, which is expected to come early for discussion, on the issues pertaining to the disabled.

6.2.5 Group as a Marker of Unity and Strength

Empirical data collected from both SERP and RDT suggest a significant change in the identity of the impaired. The PWD members of the group identify themselves as a group and have developed a strong 'we-feeling' among them. They value themselves as 'we' rather than 'I'. In a way, the group provides them a platform to vent their feelings. It provides them a platform to share their sorrows and pleasures which helps them develop bondage with each other. One of the respondents of SERP maintains that *'though there were many impaired persons like blind, orthopedically challenged, deaf etc. in the village, but we never knew each other before. Even though we knew each other, there was no common ground to interact and share. Sometimes caste and class differences also hinder our communication as upper caste members do not feel like interacting with the lower caste members'.* The same respondent maintains that *'but as disabled, we cross all the social boundaries like caste and class as disability is common and equal to all. Our family members also don't object, thinking that we are also engaged in doing some economic activity like thrift or taking loans'.*

Another respondent of RDT shares that, *'we were subjected to discrimination in every sphere of life, but we had no voice to resist it as we were not organized. Our situation now looks better and progressive because we are organized into SHG'.*

In one instance, a group member told the researcher that when they heard about the harassment of a member by her husband, all the group members went to her house and spoke to the husband and other family members about the ill treatment. From that day, the member did not report any hardship and now they feel that there is someone in the village who would speak out for them. In another case, Ramachandra, an orthopedically challenged from Karidikonda village of RDT, was cheated by the Post master of the village by drawing his MNREGA wage using his job card to the tune of Rs. 25,000/-. After knowing this, all the Vikalangula Sangham members made a complaint to the local authorities. This unified and courageous action of the disabled members of the SHGs woke up the higher officers who made the Post master pay all the money to Ramachandra.

In another instance, one disabled member of the RDT group purchased an agricultural land from a person in Bramhanapalli village. The seller and his family were exploiting the disabled member by using his personal land to go to their fields on tractors and bullock carts with the support of the local politicians even when the crop was sown. The disabled member sought the help of the Mandal Samakhya who approached the local Village Revenue Officer, Surveyor and the Mandal Revenue Officer. The officers personally visited the land and warned the person of strict action against the practice and he stopped using the land of the disabled for his personal needs thereafter.

Within the village, the disabled were left out from socio-political as well as economic participation. It was only after the formation of disabled SHGs which made the PWDs united and provided them a platform to voice their demands through groups. Thus, it was found that the formation of groups is more rights based approach rather than rehabilitation. The group members suggested that after starting their groups, the attitude of the officials in the state government offices like Mandal Revenue office, Mandal Development office, Gram Panchayat office and even banks has changed drastically.

A respondent mentions that *'earlier we had to make many trips to the Mandal Revenue office for our certificates, but, now whenever we go, our work is attended immediately and even they offer us seats to sit. When we go as a group, they also start feeling the pressure and act on our requests immediately. The group has given us strength'.* In another instance, another respondent says that *'earlier banks never used to entertain us and never considered us as worth having a bank account thinking that we do not have any source of income. Now, they have changed their attitude and even appreciate our repayment'.* Apart from a reactive mechanism of collective hitting back, some groups had also adopted pro-active initiatives to fight discrimination such as holding a public meeting in the village explaining the hurtful consequences of prejudiced behavior by employers, school teachers and neighbors towards the disabled.

6.3 Changing Attitudes of the Society towards the Disabled

The very visit of the functionaries including APM, CC, CDW, CRP etc. to the homes of the disabled itself was a big factor that influenced the attitude of the people. It was reported by the disabled that prior to the formation of the group nobody used to bother about them either in the village or in the family. A respondent observed that *'in such a situation, a state functionary coming in search of us was a surprise to all of us. When we heard that a programme was launched for the benefit of the disabled we felt happy. But, initially there were many apprehensions because the family members were of the opinion that nothing would come out. However, the repeated visits of the functionaries and the conversations of neighbors forced our family members to join the group'.*

The groups which started with two or three members initially soon attracted other disabled members of the village. The poor who are more vulnerable would come forward to join the group. The upper caste and the economically well off did not join the group in the initial stages. However, with the group functioning gaining momentum in terms of savings, group meetings on various issues of the disabled, interactions with the functionaries and visits to mandal and district meetings attracted even those who stayed indoors.

On the other hand, RDT has been creating awareness through various modes of communication such as wall paintings, cultural shows, distribution of pamphlets, organizing rallies, group meetings and workshops. It also sensitizes the disabled about the causes of certain kinds of disabilities such as polio and guides them in prevention through vaccine and proper care of pregnant women. The stage shows by the disabled children of various special schools portray the situation of persons with disabilities in present day society, along with the importance of SHGs, income generating schemes, rights and privileges of persons with disabilities including the provisions incorporated in the Rehabilitation Act of 1995 and access to government services and resources etc.

Workshops and trainings are organized for improving the leadership and managerial skills of the leaders of the village level self-help groups as well as members representing network groups at mandal level. Many Spanish volunteers take up the charge of conducting these workshops. It was reported that on the eve of the International Disability Day, the International Deaf Day and the Annual Day of RDT such programmes are organized in the premises of RDT. Through the process of capacity building of persons with disabilities, RDT trains them not only to identify the issues/problems that obstruct their growth, but take up income generating activities to enhance their living standards.

All these efforts helped in changing the attitude of the PWDs about themselves and other villagers towards the disabled. In the words of a respondent of RDT, *'we were confined to our homes, unnoticed and uncounted. When RDT initiated the awareness programmes, our neighbors and other village members started recognizing us. Prior to that, we were not even allowed to take part in any kind of cultural programmes in our village. But, when there was some programme for us, we felt special in the society'.*

6.4 Identity

Village as a microcosm manifests the social and cultural constructions of society in social interactions in its true form (Reddy, 2012). Social relations embedded in a hierarchical social order have been well recorded by sociologists and anthropologists for a long time. Caste and class relations deciphered using various sociological methods have been debated and revisited by many scholars several times. Rigorous intellectual discourse in fact, led to movements of rights, equality and justice as witnessed in feminist, anti-apartheid movements etc. Anchoring the body, the disability rights movement initiated by the disabled in the United Kingdom and United States of America led to the recognition of the disabled rights world over. This marked the beginning of the identity and rights of the disabled and facilitated rights discourse in the circles of academia for the disabled.

The body politics though took a new shift with the disability rights approach, however, never disappeared from social interaction, particularly in the primary group relations like family, neighborhood, village etc. Village as a primary unit of social relations in the Indian context presents a historical socio-cultural construction of human body and impairment. Stemming from the normal discourse, the assumptions of the human body and impairment determined the social space for the impaired for a long time. Hierarchisation of human bodies on the lines of psychosomatic impairments led to constructions of abilities. Nevertheless, it may be suggested that production relations or relations to the means of production greatly influenced the constructions of body and impairment. Thus, the impaired bodies have been marked as less able and thus disabled. The social constructions emanating from economic relations transcend to social and cultural spheres creating barriers to participation, access and inclusion (Reddy, 2012).

Such social constructions of human body impinge upon the relations between PWD's and their family members, neighbors and villagers. These notions often reverberate even in the institutional circles, thus leading to deep levels of exclusion of PWDs. Disabled identity overtly figures in the manner the impaired is referred to in social interactions. Often, the impaired are referred to by the type of disability such as kuntodu (crippled), goddodu (blind), pichodu (mentally retarded), moogodu/eddodu (dumb).

In general conversations, these nicknames are used by others either to refer to the impaired person or called by these nicknames directly. A respondent maintains that *'we are always called by our nicknames based on our impairment. We, therefore, feel shy to interact with others'.* The impact of such feeling is not only felt by the impaired, but also by their family members. In fact, family members feel frustrated to hear these names, but over a period get adjusted by ignoring such kind of references. This also results in attempts to isolate the impaired from interacting with others. The fear of stigmatization often forces the impaired and her/his family members to maintain distance from others.

While the methods of overcoming the ridicule range from isolation to rebellion, some respondents suggested that their family members, particularly their mother or father, would quarrel with those who call them by their nicknames. Others who cannot fight back suffer silently and often take respite in their fate. However, such overwhelming influence of social identity has a devastating effect on the individual as the family members always try either to protect or maintain distance from the impaired person in the family. These result in restrictions on physical movements in the village, accessing school, peer group, medical care and even state benefits. On the other hand, in the case of poor families, particularly in the case of wage laborer families, the impaired children are left free to make their own way of negotiating with social stigma. As the parents are busy earning their livelihood, no proper care is given to the impaired children. The children are either left in the streets or at their homes alone. Other constraints such as ridicule and branding the impaired and their families also restrict their participation in celebrations, rituals, family get-togethers etc. (Reddy, 2012).

6.4.1 Social Identity

Apart from the economic benefits, the members also narrate the invisible social benefits of the SHGs. They feel good about being noticed by others on their way to attend meetings and back from the meetings. Neighbors and other villagers notice the PWDs going to the meetings and any casual inquiry about the purpose is proudly answered by them as something important. Others also ask them about what transpires in the meetings. The disabled persons have something to share with others. They share their activities, announcements, programmes etc. with neighbors and others in the village.

It was mentioned by many respondents that as a result of greater awareness about the activities of the SHGs of the disabled on their rights, now the villagers and neighbors stopped calling them by nicknames. *'We are all called by our names now'* said many respondents. This has created a positive identity to the disabled in the villages. Moreover, many respondents said that they did not even know the other disabled in their village. After joining the group, they came to know each other which helped in developing a social relationship. When they share their experiences with the group members, they feel that other disabled will empathize as all of them face similar experiences.

6.4.2 Political Identity

At the mandal and district level, the Mandala Vikalangula Samakhya gained its political identity. Every political party recognizes the strength of the PWDs and offers ready help. As these SHGs along with the women SHGs emerged as a strong vote bank, their participation in government activities is sought by the administration and political parties. At the time of launching of any programme, the group members are informed. The members of the group hold a preliminary meeting on the eve of the public meeting and deliberate their strategy. For example, in Andhra Pradesh, the state government launched a programme called 'rachchabanda'. It was mentioned by the respondents that all the members of the group attended these meetings and highlighted their issues.

The courage to voice their views on the issues of PWDs in public, government forums is something unthinkable earlier, said one of the respondents.

> *'We were always at the receiving end. Now, we are in a position to place our demands publicly and ask the officials to look into the issues directly. For example, we have demanded ration cards, voter identification cards, bus passes and health cards on par with the poor. Although some of us belong to higher castes, our economic condition is even worse than the poor. On the majority of our demands, we received a positive response. Even in the case of National Rural Employment Guarantee Scheme (NREGS), we have placed our request through the group to the district officials to give us employment cards. For this the district administration responded positively'.*

RDT, unlike other NGOs does not confine its services to rehabilitation only. Rather, it has initiated the capacity building programmes for the disabled through SHGs. It was told by the functionaries of RDT that the state of Andhra Pradesh also took a clue from the successful functioning of SHGs for the disabled. Through the SHGs, the PWDs started meeting people other than their family members, neighbors and relatives which enhanced their self confidence. The disabled and their family members now feel that they are doing something on their own for the family and they have a weekly task of attending the meetings. A sense of worthiness motivates them to attend and participate in the meetings. They feel that they have the scope to discuss, decide and execute. It is a sense of empowerment which no other programme provided them before. Though the modern assistive technologies and other rehabilitative services from various charity organizations could have improved their physical ability, but the group provided them the strength to face the onslaught of the society. The group also helped them to bring change in the attitude of others towards disabled.

6.5 Participation

The way in which society reacts towards persons with disabilities determines the exclusion. This is not just because of their inability to move out on their own, but also because of the barriers imposed on them by the society. Extent of participation of disabled persons in social, religious and political functions is an important indicator of inclusion and exclusion. The study observes that the participation of the disabled in social functions is varied on the lines of impairment. In general, there has been an observable exclusion of the impaired in the social life emanating from the social construction of impairment. They rarely come out of their houses because of the physical barriers to the mobility of the impaired along with the attitude of others in the family who discourage them from moving out claiming that their presence is not needed.

Social life for persons with disabilities is marked by overwhelming presence of the family members. In cases of severe impairments which require constant attention and support, the life of the impaired is one of dependence. For people with severe locomotive impairments, visually challenged, mentally retarded and multiple impairment support of others are highly required for carrying out their day to day chores. For such persons, social interaction beyond the family members is negligible. They are largely confined to their homes or at the most to their neighborhood.

Physical mobility, which is important for participation, has been observed to be varying across age, type of impairment and gender. The architectural barriers at public places such as absence of ramps and lifts hinder the mobility of orthopedically challenged and visually challenged people’s participation. Moreover, the family members who take care of the impaired person assume that it is unnecessary for the disabled member of the family to go out and talk to others. They also feel overburdened and a waste of time in taking care of the needs of the impaired persons. This is more in the case of the poor who eke out living on daily wages. The impaired needs for mobility are generally turned down by the members of the family and so is the case with women.

Women have greater restrictions on their movement compared to their men counterparts. As a result of the attitude of others towards the impaired, persons with impairment hesitate in participating in community activities. As a result of these stereotypes on the part of the family members about the need for social interaction beyond the family, the impaired have often been confined to the homes. The children were neither sent to schools nor allowed to play with others.

It is important to note that, women are always entrusted with the care giving work of the impaired person in the house. Generally, mother, sister or grandmother is always responsible for care giving. As a result, even the impaired person depends on mother or other women members in the house for care and support to meet their daily chores including cleaning, bathing, feeding, clothing and other activities of hygiene. It was observed in the study that those children, irrespective of their age, who face severe impairments, were always found to be closely associated with women members of the family. As the impaired man attains maturity, parents look for marriage alliances not aiming to give him the family of his own, but to delegate or shift the burden to the wife. In the cases where a person with multiple impairments cannot be married, the mother is entrusted with the responsibility of care giving.

However, with the starting of self-help groups for the disabled, the issue of social interaction attained prime focus. Though, the primary purpose of the groups was not to give them scope for increased social interaction, but the group meetings have provided the impaired a platform for sharing and interaction. This also, in a way, forced the family members to bring their dependent impaired member to the meetings. The functionaries insist on their presence and hence, the parents are often compelled to bring them to the group meetings. This has opened up a window of opportunity for the impaired persons to interact with other disabled in the village, to know their rights through the interactive sessions with other disabled members organized as part of motivational programmes and participating in the discussions meant for them.

The group has also provided the parents of the disabled a platform to share their experiences and feelings, to which one respondent explains that:

'otherwise, it would not have been possible because, we did not know the other disabled in the village. Even if we knew, we used to hesitate or shy away from interacting. Caste and other economic aspects would have disallowed our interaction with others. In this way, the group brought us onto a common platform where now as parents, we feel that we are not alone and there are others like us and there is someone (group) to take care of us and our impaired children'. With the group generating a lot of interest among the other members of the village, the disabled are frequently enquired about the happenings in the group. '*They keep asking us about what is happening in the group and what we do in the group,* said a respondent. *This was unimaginable before, as every conversation with members outside the family always centered on our impairment'.*

Both SERP and RDT work on overcoming the architectural barriers by providing assistive technologies such as wheelchairs, Jaipur foot and other prosthetics to the physically impaired. SERP provided wheelchairs and prosthetics to the orthopedically challenged members of the group. The ground level functionaries of SERP (i.e. Community Animator) arrange the visits of the medical practitioners to the village for preliminary check ups. Once the problem is diagnosed, the CA motivates the disabled members and families to approach the specialists of the nearby towns. It was found in the study, in one instance, that the CA of a village taking the disabled member to the nearby town bearing all the expenses on his own. In the absence of support of the family members, the SERP functionaries take the lead in providing medical services. Coordination with the specialists and the disabled in the villages is taken up by the CA. In case of requirement of advanced medical treatment like surgeries, special artificial limbs etc; the disabled members are taken to the places wherever such treatment is available. It was told that in many instances, the SERP paid for the travel expenses as well as food and accommodation charges for the disabled.

RDT started an orthotic and prosthetic workshop for manufacturing artificial limbs and other required equipments to enhance the mobility of disabled. Accordingly, it had sent a couple of its staff in ‘multi-purpose rehabilitation technician training’ in various institutes. It started its first workshop at Kalyandurg in 1992 followed by Kuderu in 1993, Bhathalapalli and Kadiri in 2003. The workshops are located at barrier free buildings. Workshops are provided with proper ramps and railings for easy access to the disabled. It was reported by the technicians at the workshops that the conventional metal calipers are not user friendly because they are very heavy in weight and are worn with a typical black high ankle orthopedic boot. Moreover, they are cosmetically not appealing and are not suitable for local rural conditions. Hence, the rejection rate of such calipers is very high especially among children. The polymer appliances are preferred because they are light in weight and facilitate mobility and ensure comfort as they can be worn for a longer duration of time.

However, the affordability towards these advanced appliances is a matter of concern. SERP provides all the appliances at free of cost whereas RDT charges a nominal price for the advanced appliances. Although the supply of mobility aids and appliances helped the orthopedically challenged to move independently in a much better manner than before, it has not brought much change in the larger society which is evident in the absence of ramps to use a wheelchair.

Political participation is another important indicator of major change. As mentioned, the PWDs who are members of the SHG meet regularly once a week where the discussion is centered on their savings and loans. Discussions over rights have been observed to be motivating them to take up various socio-economic developmental activities. The SERP approach has always been based on the rights mode and the group members feel that it is their right to claim certain things like government benefits, and society’s attention towards their needs and interests.

The members of the group are greatly influenced by the talks and interactions of the SERP functionaries. They are motivated because they see and experience how a disabled person who was considered as incapable of anything before, is now actively engaged in the activities of SERP either as Community Development Worker or Community Coordinator (almost all the CDWs and CCs and other functionaries are disabled, both men and women). Though most of them belong to orthopedically challenged category, few of them also include visually challenged, dwarf, and hearing impaired. SERP arranges lectures by the senior CDWs, CCs and office bearers of SHGs of the same district or from other districts of the state to the SHG members of the villages. The SHG members observed that these lectures have been a great source of inspiration to them. *'After seeing a person who was like us before, now achieving so many things is a great source of inspiration to us. Also, the SERP functionaries keep mentioning the achievements in different meetings which motivate us to achieve something and show to the society'.* Knowledge about the possibilities, opportunities enabled by the SERP is believed to have changed the attitude of the PWDs and their family members in the rural areas.

The impaired and their parents have begun to believe that education is the key in getting a decent work. It is important to mention that SERP has recruited a good number of PWDs at the local level to work with the disabled members and their families in the village. Those PWDs having minimum educational qualifications are recruited at the village and mandal levels. Also, the villagers feel that though SERP is a quasi-government organization, working in SERP is like holding a government job. When the SERP disability project was launched, it preferred the local disabled with necessary educational qualification to work as CDWs. Those with impairments like orthopedically challenged, visually challenged or hearing impaired with the required educational qualification were selected as CDWs. Many women were also selected.

There are evidences of individuals with impairment who were active members in the political affairs (as a member of the Gram Sabha). However, their role was more as a person with disability, representing the issues of the disabled. On the other hand, RDT encourages PWDs to take part in various cultural activities such as dramas and other performances on stage organized by RDT.

Father Vincent Ferrer, founder Director of RDT is considered as God by the persons with disabilities in Anantapur district. There is a statue of Father in front of the office of the Mandal Revenue Officer (MRO) at Bukkarayasamudram of Anantapur district. Mandal Samakhya members discussed the installation of Father Vincent's statue at the MRO office with all the 26 SHG members of Bukkarayasamudram mandal and took their opinion and suggestions on the matter. It was reported by the members that the proposal was sent to the District Collector. After getting permission, the group members collected donations from their fellow members for installing the statue. Anne Ferrer, the Executive Director of RDT unveiled the statue on the occasion of the International Day of Persons with Disabilities.

All the PWDs and Mandal Samakhya members, Sector Directors, Regional Director and other staff members of RDT along with Spanish volunteers and government officials and local people were present on the occasion. In the words of one respondent, *'it is because of the effort of late Father Vincent Ferrer that we the disabled people are getting some recognition in the society today. Thus, we wanted Father's statue in front of the MRO office at Bukkarayasamudram to remind all the PWDs to fight for their rights'.*

Members of SHGs manage and monitor their savings popularly called mini-bank independently. Each member contributes a minimum saving of Rs.10 to 15 per month and the savings of all the group members is rotated as loans among themselves for their various needs. Each group has appointed a disabled member of their group to take care of the mini-bank activities, like updating the ledgers, writing the minutes of the meeting of SHG, etc. It was found from the study that, the PWDs draw the loan amount ranging from Rs. 1,000/- to 1,00,000/-. With the financial help thus received from SERP, disabled persons are engaged in agriculture, milch cattle rearing, sheep rearing, and in other family owned petty businesses.

Respondents observe that *'we were considered worse than beggars before. Earning even one rupee was considered a great thing for us'.* In the SHGs, the parents of the disabled were motivated to save on behalf of their disabled children. Mini-bank encouraged the habit of thrift and credit and it reduced our dependency on others for our basic needs. It developed mutual trust on one another and is quite useful in emergency needs.

It was reported by the respondents that, RDT works towards the disabled SHGs with the aim of reducing economic dependency of disabled on others for basic and emergency needs. It encourages the members to save and take loans from mini-banks of the SHG. Towards this, RDT has constituted an exclusive revolving fund so as to enable disabled persons having membership in self-help groups to avail credit for taking up income generating activities either independently or with the support of their family members. Loans to the tune of Rs.10,000/- is given to the disabled members.

The members take loans to start various income generation activities either independently or with the support of their family members. RDT facilitates SHGs to mobilize the existing resources to improve their living conditions. RDT also provides matching grants to those self-help groups which are successfully managing their mini-bank for a period of not less than one year. In addition to the support from RDT, the state also provides revolving fund, which is credited into the mini bank account of the SHG so as to enable the members of SHG to use the fund for their various needs. The income generating activities taken up by the PWDs include rearing of livestock (milch cattle and rams), setting up of petty shops, supporting the family occupation based services like, barber shop, carpentry etc.

However, it is interesting to note that RDT follows a very peculiar strategy with regard to the repayment of loans. Two members of the group act as guarantees to the member who avails the loan and if the person fails to repay the loan on time, the amount is recovered from the saving account of the guarantors. This strategy works successfully as the guarantors put continuous pressure on the member to repay the loan as soon as possible. Apart from various awareness and capacity building programmes, RDT also emphasizes on promotion of skills and income generation programs that not only improve the socio-economic status but also self-confidence and willpower of the disabled.

Many of the persons with disabilities do not possess permanent houses. A majority of them live in dilapidated mud houses or thatched huts with little or no ability for maintenance. They lack even minimum financial resources for their subsistence living and it is an impossible task for them even to think of undertaking minor repairs to the huts in which they live. It was found from the study that, many respondents even use the loan amount from the SHG either for constructing a new house or for repairing the existing one. RDT has been constructing permanent houses to the disabled who own a house site, whether sanctioned by the government, or inherited from parents or purchased from others. Both the SERP and RDT have been in the forefront in the construction of houses. The houses built by SERP and RDT have the logos of the respective organization by which it was funded.

RDT has initiated a programme for economic emancipation of disabled women. It started a handicraft centre in 2001 for occupational mobility through handicrafts by which the disabled women can make use of their skills. The handicrafts thus, improve their socio-economic conditions that in turn would pave the way for their emancipation and empowerment. In the words of Lakshmi (32 years old), a member of Yamuna Vikalangula Sangham of RDT, located at Amidyala village, Uravakonda mandal:

> *'I have a physical disability and my left leg got affected by polio. I studied up to class V. I am married and have two children. However, my husband revealed later that he married me unwillingly. Hence, I was ill treated by my in-laws and even my husband sometimes. On knowing the RDT initiative for the disabled, I joined the SHG. Since then, my Sangham has been my strength. The members of the SHG also tried to convince my husband and in-laws. They even threatened my husband about the possibility of filing a police case if he and his parents don't change their attitude. At a later stage, he deserted me. He had married another woman and set up a separate family. He is an auto driver, but drinks liquor and wastes his income. I have to rely upon my income to feed my children. I am a skilled tailor and I stitch ladies dresses every day. I earn not less than Rs.1,800/- per month'.*

Umapati, aged 28 years, a physically challenged respondent of RDT belongs to Sri Sai Vikalangula Sangham of Korrapadu village, Bukkarayasamudram mandal narrates that:

'I am staying with my parents, elder brother and his wife and their two children. But I am always ill treated by my brother and his wife. They treat me as a burden along with my aged parents. My brother is the only earning member to feed the whole family. I'm also unmarried because of my impairment. I came to know about the group from the RDT VK and decided to join the group. After joining the group I took a loan of Rs.30,000/- and setup a clothes shop at Bukkarayasamudram (nearby town). Gradually, my business picked up I've started earning Rs.6,000/- to 8,000/- per month. This income has changed my life altogether. My position in the family improved and later, I got an alliance and married. Now I live with my wife and we have a child.

Eshwaramma, 35 years old physically challenged respondent of RDT belonging to Neelareddypalli village of Bukkarayasamudram mandal is a member of Sree Ganga Gawri Vikalangula Sangham. She is the first child of Errappa Reddy and Laxmidevi. Her right leg was affected due to polio when she was 3 years old. But, she completed Diploma in Electronics. She has two younger sisters and a younger brother. She had to give up her studies due to financial problems in the family. Seventeen disabled persons of her village came forward to form the Sangham in the year 2002 with the facilitation of RDT and Eshwaramma was one of them. She was an active member of the sangham and became Treasurer in the Mandal Samakhya in the year 2006. She used to participate actively in various group activities and her advises were sought by the Sangham members as and when required. She took a loan of Rs. 10,000/- from RDT and started a flour mill. Later, she also took a bank loan and set up a clothes business. To support this, she also took a loan under the income generating programme (IGP) and set up a small candle making unit. She was supported by her family members along with the Sangham members. However, all this was not sufficient to support her family financially.

She then approached the Andhra Pradesh Dairy Development Co-op. Federation Ltd. and got a loan to set up a dairy unit in her village. She underwent training for a week arranged by the government. She established a good rapport with the government officials and even helped others in the village in getting loans, including the disabled to buy jersey cows at a cost of Rs. 25,000/- each. The disabled members are given a subsidy of Rs.10,000/- and the cattle insurance and fodder were provided free of cost. All these acts of her gave her recognition and respect in the village. In the month of December 2010, she got an IGP loan of Rs.35,000/- and she contributed Rs.15,000/- and started a saree shop along with one more dairy at Bukkarayasamudram. Now, she is able to support her family very well. One of her sisters is studying MCA (Master of Computer Applications) and both her younger brother and sister are pursuing B. Tech.

The Sangham is perceived as a source of strength not just to the impaired person, but also for the family members of the disabled. It was found during the study on groups of SERP that the members take the benefits of the group loans to the family. As a result the position of the impaired individual has improved in the family. This is because of the changed identity of the disabled in the family as other family members feel that the impaired person is also worth procuring a loan from the State. Many respondents reported that, the loans taken by them are given to their family for various purposes ranging from buying cattle, spending on agriculture, setting up of petty shops, contributing to the family business, paying school or college fee of their family members, etc.

Madhava Kumar, aged 30 years, an orthopedically challenged respondent of Sree Bapuji vikalangula sangham of RDT belonging to Balappagaripalli village of Kadiri mandal observes that, *'I have helped my brother in setting up of a petty shop by contributing a major share in the business. Now, my position in the family has changed as my sister-in-law appreciates my worth and started behaving in a positive way. Even my niece and nephew started treating me well'.* In families whose access to institutional credit (which is the cheapest in terms of interest) is limited by various factors, disabled members have become their major source of accessing credit. It is not just about supporting the family in terms of getting loans but, the feeling that they too are contributing to the family made them confident. They have reported that the parents and siblings have started involving them in decision-making.

Another orthopedically challenged respondent of RDT named Kamalamma, aged 39 years has a college going son. Her husband deserted her. She is now staying with her father. She states that, *'I have used the loan amount for my son's college fee. I feel that I can pay back the amount as I run a small shop. I have also received a wheelchair from the government after joining the group. It gives me great pleasure in moving out without much difficulty, pain and inconvenience to others'.*

On the other hand, there are also dark spots in the loan utilization. In one instance, Rajamma, the mother of Shankar (18 years), a mentally retarded respondent of Anjaneya Vikalangula Sangham of Ketaganicherugu village, Somandepalli mandal took a loan from the group through SERP. However, the condition of the boy has not improved at all as she has been leaving the boy to beg for himself and loiter around in the village. She took a loan on his behalf and utilized it for other personal purposes. On knowing this, the group members went and counseled her against this.

It may be important to mention here that Andhra Pradesh stands out from other states on the disability front because there has been a remarkable political initiative to mobilize the impaired across the state by an outfit named Madiga Reservation Porata Samithi headed by Mr. Manda Krishna Madiga. It is basically working for classification of scheduled castes. On the sidelines of this struggle, he organized the impaired from the village to the state level and led a prolonged agitation for their rights, including reservations and pensions. This has led to forming a strong political vote bank and no political party now affords to ignore the strength of the impaired persons. The struggle, in fact, forced the government to announce the enhancement of pensions to the impaired from Rs. 200/- to Rs. 500/- a month and implement it successfully. On the first of every month, all the disabled receive Rs. 500/- as pension. The amount though appears to be little, in real terms, it has brought a change in the lives of the disabled and their families. This amount has become a great contributor to the family's income, particularly for the poor families.

6.6 Medical care and Corrective surgeries in enhancing Socio-economic Status

Another aspect of the group that helped increased participation was the medical care and support of both the state and non-state organizations. As an effort to tackle the problems of impairment through medical corrective surgeries, SERP provides medical care to the group members. Individuals, whose impairments could be corrected through surgeries, were identified and referred to specialists. The services of specialist doctors were made available through medical camps organized at mandal or district level. Those identified for major surgeries and treatments were sent to the state level referral hospital located at Tirupati. The response to the medical care is quite enthusiastic. The SERP has been conducting several camps for identification and diagnosis at the mandal and district levels by taking the services of government doctors.

The impaired individuals who require medical treatment are mobilized by the CDWs from each group. The CDWs and other functionaries help the group members and their accompanying person in reaching the camp, interacting with the doctor and reaching back home. In fact, CDWs are also entrusted with the responsibility of taking the impaired for regular checkups where medicines are also provided. In the cases of mental retardants, who require continuous treatment for a long time, the role of CDWs is well appreciated. One of the CDWs reports that sometimes the group member who is to meet the doctor for a checkup is left to us by their parents. As the parents go to work and do not want to lose a day’s wage for taking the impaired person to the doctor in the nearby town, they leave the work to us.

In the case of RDT, the Vikalangula Karyakarthalu take the responsibility of getting the required treatment to the needy members of the group. It was reported by the RDT personnel that the hospital at Bathalapalli serves as the centre for treatment of orthopedically challenged persons. It was reported that many orthopedic surgeries were conducted by Spanish traumatalogists. RDT, through its global linkages ropes in specialist doctors from abroad to conduct surgeries on the disabled.

It also conducts medical champs on the occasions of the visit by the doctors from abroad. RDT also encourages and guides the members to avail government facilities in this regard. Along with this, the aids and appliances are provided by RDT to help the persons with disabilities to improve their mobility. Moreover, the orthopedic workshops run by RDT provide improved and advanced appliances for the disabled at low cost. Five respondents were interviewed at the workshops who had come to get their appliances fabricated. All the respondents were found to be economically sound in comparison to their counterparts at the village. They preferred to pay for the advanced prosthetics than the wheel chairs provided by RDT. They were getting the under-knee prosthetics fabricated for easy movement.

On the other hand, during the process of interaction with the respondents at their village, a respondent using wheel chair was asked about the low cost appliances, he replied saying, *'I am a poor person and my income is only sufficient to meet my basic needs of food and cannot afford even the low cost appliances. Thus, I am happy with the wheelchair provided by the government'.*

The Vikalangula Karyakarthalu also identify the impairment in its early stages and provide necessary guidance to the parents in treatment for the improvement of affected children. The newborn babies with symptoms of impairment like dumb and deaf, cerebral palsy are identified by the Vikalangula Karyakarthalu and the parents are guided to the special rehabilitation centers for the newborn babies. While visiting special centers the researcher observed that, RDT categorized the mentally and intellectually impaired children to various sections depending on their possibility of improvement. The special centers provide the required training and treatment for the impaired children. Similarly, children showing signs of orthopedic impairment in their early age are provided with necessary physiotherapy by the experts. These centers have teachers, ayahs, cooks and other workers.

The number is decided by the Field Director and Assistant Director of the disability unit. There are school in-charges for every school and centers to keep track of the training programmes. RDT made provision for accommodation for the mother of the babies who undergo treatment. The mothers are taught the requisite skills in handling and treating their babies. RDT also appoints trained 'ayahs' to look after the babies during the treatment. The mothers are allowed during the process of physiotherapy for children with polio and locomotor disabilities. Mothers are also trained in giving the physiotherapy sessions at home. This is done under the guidance of the specialist doctors and trained paramedical staff.

RDT lays great emphasis on the medical treatment through physiotherapy and corrective surgeries. A number of orthopedically challenged have availed the facility and have expressed the feeling of gratitude to RDT in their conversation with the researcher. Particularly, in the case of young boys and girls, medical corrective surgeries resulted in the reduction in the extent of limping or the use of aids and appliances. This, the beneficiaries said opened up opportunities for getting a better marriage alliance. Parents of girls expressed their happiness because of increased prospects of getting a good bridegroom. They said prior to the group this was unthinkable as we were neither aware of such facility nor could afford it.

The SERP has also been taking up the medical corrective surgeries which have helped the participation of PWDs in general social and economic life. Moreover, the group members were provided with appliances like crutches, wheel chairs, hearing aids, spectacles etc. which helped them in handling daily chores. As a result of improved mobility, the disabled are now more active in their social life. They started going out of their homes, attend social functions in their villages and started interacting with their neighbors. The respondents observed that all this is possible because the aids and appliances provided by SERP and RDT helped them in leading an independent and dignified life.

It may be mentioned that most of the impairments in rural areas occur due to lack of timely medical care and attention. This is due to ignorance, poverty and lack of advice and access. It was suggested by the SERP functionaries that most of the orthopedically challenged, mental retardants, speech and hearing impaired could have avoided impairment had there been timely medical attention. In the case of a boy, who is now about 15 years old, was detected with hearing impairment at four years of age. But, he was not given proper treatment because he was living with his grandparents as both his parents passed away when he was 4 years old. His grandmother expressed that, *'had my grandson was given correct medical treatment at that time when he was* *a child, he wouldn't have become speech impaired'.* It was observed that the boy cannot speak and as result after primary education, he was asked not to come to the school as his presence would distract others. However, the SERP functionaries intervened and spoke to the school Head master who now allows the boy to come to the school. The boy also goes to the school whenever he wishes as the school didn't impose any restriction on performance.

The SHGs brought the issues of disability to the critical glare of the villagers who otherwise never bothered to address or acknowledge the issue thinking that it is the problem of the family of the disabled and not of the community. The SHGs have succeeded in highlighting the rights of the disabled and the social responsibility of the members of the village towards them. Moreover, the economic independence facilitated by the SHGs of the disabled has helped a lot in their recognition in the mainstream society at large.

The researcher has come across many instances wherein the disabled member of the family has become the major source of external credit. The loans with low rates of interest have attracted the attention of many parents. Gangulamma, (aged 30 years) a dwarf respondent of Manikanta Vikalangula Sangham of Peddiredipalli village, Parigi mandal shares that:

'after joining the group, I have availed a loan provided by the state as part of the Community Investment Fund (CIF) and another round of loan with bank tie-up. I helped my brother to buy an auto with the help of which he is making his living. He stays with his wife and children. I stay with my parents. Now literally, I have become an important source of help for them'. The same respondent also observes that the group activity has given her enough confidence and courage to speak to others. *'Earlier, I never used to travel through the main road of the village, fearing ridicule. Now, I go through the village with my head high, as everyone started to feel that I am an important part of my family. Even my sister-in-law treats me well now'.*

A little financial independence gives greater strength to the disabled not just for becoming the sole earning member of the family, but because they have some money at their disposal over which they have control. In addition to the group activities, the state supports the disabled through monthly pensions. A sum of Rs. 500/- is paid as pensions to the disabled which is considered as a big amount in the lives of the disabled and their families[12]. Many families of the disabled have been able to clear the loans taken from the group with the help of the pensions.

6.7 Special Schools and Centers for PWDs by RDT

Apart from the interaction with the members of SHGs, the researcher also visited the RDT run orthopedic workshops, special schools for visually challenged, speech and hearing impaired, intellectual disability children and inclusive schools. In addition, handicrafts and book binding units were also visited. Interacting with the speech and hearing impaired students through sign language, cheering visually challenged children in a cricket match, participating in the process of book binding by the children with mental retardation and a keen observation of handicrafts made by the disabled women were some unforgettable experiences of the researcher throughout the study.

A combination of structural forces such as caste, gender, religion, poverty etc. intersect with disability resulting in varied individual experiences and the broad commonalities that shape the lives of people with disabilities in India. Their lives are largely marked by poverty and marginalization from mainstream social processes. A study by the World Bank (2007), for example, notes that children with disabilities are five times more likely to be out of the school than children belonging to scheduled castes or scheduled tribes. Moreover, when children with disabilities attend school they rarely progress beyond the primary level leading ultimately to lower employment chances and long-term poverty. Thus, education is a key aspect in the empowerment of disabled persons, but a sizeable number of disabled persons are not literate.

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[12] Both the states of Telangana and Andhra Pradesh have announced a hike of monthly pension to the PWDs from Rs. 500/- to 1,500/- as part of their election manifesto. At the time of writing the thesis, in Telangana, the government has launched the pension scheme ‘Aasara’ which covered the PWD also.

Children with various disabilities have equal right to pursue education and enjoy equal opportunities like able-bodied children.

6.7.1 Special Schools

RDT aims at promoting literacy among the disabled children by providing access to education through special schools and inclusive schools. It claims that, its aim is to see the disabled children requiring either normal or special education should not be left out irrespective of their family background. It also creates awareness by sensitizing parents of disabled children as well as teachers of the general schools in the village to enroll all the eligible disabled children requiring either normal education or special education. RDT conducts special awareness workshop for parents of disabled children which includes organizing exposure visits to the institutions run by the RDT and counseling of parents of disabled children through group meetings and individual family visits. It also motivates government school teachers for the admission of eligible disabled children into the local government schools.

RDT provides incentives and extends need based support such as school uniform, textbooks, notebooks and stationery, hearing aids and mobility appliances with a view to ensuring enrollment and also retention of disabled children pursuing primary as well as secondary education in local government schools or special institutions run by RDT are other initiatives of RDT. It also supports the higher/technical/professional education by sponsoring meritorious disabled children to pursue their two year pre-university course in reputed corporate colleges in the nearby towns and extends financial and other forms of educational assistance to the disabled students pursuing professional/technical education.

6.7.2 Centers for Mentally Challenged Children

The centre for children with mental retardation was started in 1994 at Kalyandurg. The centre, started with just 5 children in 1994, now has strength of about 20 children. The children are categorized into groups depending on the possibility of improvement. Children as young as one to two years are treated by the doctors of RDT for improvement of their condition. The children with serious ailments are kept under the watch of the trained staff. Other children are taught basic daily activities, literacy, vocational and cultural skills. The children remain in the centre for three weeks and are trained to be independent in their day to day living. The parents of the mentally challenged children visit the centre once a week and follow the progress of their children. After every three weeks, the children are sent to their homes for one week. The parents are instructed to observe the improvement in their children during the one week stay with them. This is aimed at helping in the socialization of disabled children and getting them acclimatized to the social environment at home. RDT claims that the condition of several children with mild mental retardation has been improved and later on, the same children were admitted into the government schools in their villages for formal education.

6.7.3 Special School for Children with Visual Impairment

RDT started a pre-school for children with visual impairment at Kuderu mandal on an experimental basis in 1997. A teacher trained in Braille teaches the visually impaired children in Braille for a period of 3 to 4 years after which they are admitted into local government schools or special schools/vocational centers meant for visually impaired children located outside the project area. Another centre was started at Kalyandurg in 1998 to enable parents in Kalyandurg Block to admit their visually impaired children into the centre. The visually challenged children are enrolled into the residential schools run by RDT where they undergo special education and rehabilitation training. RDT runs both primary and secondary residential schools for visually impaired children.

Braille press run by RDT produces all text books in Braille script for primary as well as secondary school going children in Anantapur district. It enables them to have access to children's magazines and other reading materials. The teachers of these schools use tactile maps and other learning materials such as types of soil, flora and fauna that can be felt with hand for a better understanding. In the words of Balaji, a visually impaired respondent aged 16 years, studying in 9th standard reports that, *'we are now set to join the inclusive high school run by RDT at Anantapur. We earlier studied in residential primary school for visually challenged children run by RDT. We are trained in Braille script, but in class X and above, we need to rely upon scribes to write our examinations. We lose a lot if the helpers or scribes are not efficient enough to reproduce what we share orally'.*

6.7.4 Centre for Children with Speech and Hearing Impairment

RDT started a special school for children with speech and hearing impairment at Uravakonda mandal in the year 1998. It provides hearing aids for the needy children pursuing special education. It developed sign language manuals to improve the quality of teaching as well as effective communication. In 2010, sign language unit of CBR sector of RDT organized a number of workshops/events/activities. A two week long workshop was organized for students pursuing higher education in RDT run centers and other government institutions/schools.

Another workshop on awareness and sensitization of the deaf community was also held along with the supplementary sessions. RDT claims that conducting regular workshops is important for enhancing the skills of the teachers in making classroom interaction more participatory along with a special training in sign language. The children are then integrated with non-disabled children in the government schools in their respective villages.

6.7.5 Centre for Children with Cerebral Palsy

The centre was established in 2002 at Kuderu and it is the only centre in Anantapur district catering to the rehabilitation needs of about 45 children with cerebral palsy. There are trained ayahs (nursemaid) and teachers for children with cerebral palsy in this centre. The centre provides access to need based rehabilitation training for cerebral palsy children who suffer from various multiple physical and health problems such as stiff joints, difficulty in communication, behavioral problems, feeding difficulties, difficulties in performing daily activities, daily living skills, frequent epilepsy, etc. that require special care and attention. The ayahs take care of the children. They feed them and give toilet training. They also help the children in their mobility inside the centre. The teachers teach the children basic activities, daily living skills and basic communication skills so as to make them independent. Depending on their condition, children are also trained in basic education like alphabets, numbers and words. They are also taught about the objects and things of daily uses. The teachers are provided accommodation in the premises of the centre run by RDT.

6.7.6 High School for 'Inclusive Education'

Inclusive education strives to address the learning needs of children with special needs with a particular focus on those who have been subjected to isolation and exclusion. The philosophy behind inclusive education is to promote opportunities for all children to participate, learn and have equal treatment irrespective of their mental or physical abilities. Inclusive education is a key initiative for integrating a special child with the mainstream. In this direction, RDT has established an inclusive school wherein children with special needs are combined with the mainstream children to encourage overall improved learning. The school has developed a need-based curriculum focusing on special students to allow them to discover their own skills and work on them to catch up with their peers. The main objective of setting up such a school by RDT is to ensure the participation of children with special needs in all mainstream activities to the best of their abilities. This includes a balanced curriculum that is appropriate for all categories of children, teachers who have the ability to handle the individual needs within the classroom to promote personality development, social skills and participation among the children with disabilities.

RDT has provided special infrastructural facilities for the convenience of disabled children. It was observed that a specially designed ramp was built to enable and guide the blind students from the main entrance of the school itself. The visually challenged students while walking on the ramp can make out the distance they walked, location where they are standing and direction to reach the intended place through sensual experience by touch of the feet. The classrooms, staff room, computer labs and even the toilets have sign boards in Braille to facilitate a hassle-free access to the blind students. RDT also encourages the visually challenged students in sports by providing special sports gear.

The classrooms are equipped with special study materials for visual, speech and hearing impaired students. For example, in Geography class the teacher provides the tactile maps to the visually impaired children to help them in understanding the subject with sensory experience. Along with the course teacher, there are sign language experts in the classroom to translate all the lessons in sign language for the benefit of speech and hearing impaired students. The partially blind and partially hearing impaired students are provided special aids and appliances for their learning. The inclusive school has labs with computers that facilitate the learning process of the children with special needs.

6.7.7 Book Binding Unit

RDT runs a book binding unit of its own where they produce notebooks. The notebooks prepared by this unit are distributed among the children studying in schools run by RDT. In addition to this, other institutes outside RDT also place orders for theses notebooks. It was observed that a total of seventeen mentally retarded or intellectually disabled were actively engaged in the book binding work. They were doing the work independently. The training is provided by the RDT staff of the unit. All of them are below 25 years of age and are categorized into small groups of 2 to 3 members each. Each group is assigned with particular work, for example, cutting papers, arranging them in order, putting gum on the cover, stitching the books and stacking them. They are paid for their work which makes them economically independent. Thus, RDT has successfully changed the notion of inefficiency attached to the persons with mental retardation by engaging them in some productive work.

6.8 Participation of Children with Disabilities in Annual events of RDT

Besides the special schools and centers run by RDT for the children with disabilities, it also encourages participation of the students with disabilities in various competitions along with other training programmes. Quiz festival is an annual event of the education wing of RDT. Till 2001, it was only for the non-disabled children. But, from 2001, children with visual impairment have started taking part in it. Moreover, the participation of the disabled children in the art festival held on the eve of annual day celebrations of RDT in 2010 was reported to be significant as five first prizes, three second prizes and two third prizes were bagged by the children with disabilities.

A two week long workshop for the students with disabilities pursuing higher education outside RDT institutions/schools was organized during September, 2010. It was reported that forty five students attended the workshop where they were trained in communication skills in english, basic commuter application skills and sign language. RDT also provides support for hearing impaired children in computer labs to learn skills in computer education. During February-August, 2010, the sign language unit staff with the help of a Spanish deaf computer technician and computer teachers experimented the methodological adaptations (visual adaptations - proper lighting, light alarms, practical demonstration while conducting theoretical as well as practical classes, use of sign language in computer class) in the computer labs.

Enable India Foundation (EIF) celebrated the International Deaf Day in Hyderabad on 2nd October, 2010. It was reported by RDT personnel that, children with hearing impairments of special schools of RDT were invited to participate in the cultural program and 14 boys from Kuderu centre and 10 girls from Bukkarayasamudram centre participated in the program. The boys presented group Kuchipudi dance and the girls performed a folk song.

Children with intellectual disabilities and cerebral palsy were also found to be active in various activities. Six girls (3 from Bukkarayasamudram, two from Kalyangurg and one from the Bathalpalli centre for children with intellectual disabilities) represented the state team in the Special Olympics Bharat[13] Winter Games in Floor Hockey held in December, 2010 at Shimla, Himachal Pradesh. It was also reported that three children with intellectual disability belonging to the school run by RDT were selected to represent India in the 100 meters running in the World Summer Games held in Athens in June, 2011.

This chapter discussed the state and non-state initiatives taken up by the government of Andhra Pradesh and RDT respectively towards the persons with disabilities. The discussion highlighted the operational aspects of the initiatives and also brought out the influence of SHGs in the lives of the disabled. It also delineated the changing attitude of the society towards the persons with disabilities. The socio-political and economic participation of the PWDs has been explained in detail. Situating disability within the domain of rehabilitation, the chapter also explored the facilities and services provided by RDT to the children and persons with disabilities.

Grounding the discussion on identity and participation, the chapter highlighted the importance of SHGs which provided the disabled the opportunity to come on to a common platform, share and develop a common identity as a group. The persons with disabilities in the village now know each other, share their feelings and address their needs through group. Moreover, the economic independence in terms of contributing to the family income has enhanced their status in their family.

It was observed that, although RDT and SERP work towards mobilizing the PWDs into SHGs, their approaches are different. The involvement of government through SERP plays an important role in the minds of the PWDs and their family members. There is a feeling that being the member of SHGs of SERP, the PWDs would have direct relation with the government which would pave way to their rights. On the other hand, members of the SHGs by RDT are grateful to the founder of RDT. RDT is

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[13] The goal of Special Olympic Bharat is to improve the quality of life of persons with Intellectual Impairment and their inclusion in sports. Special Olympic Bharat (SOB) is an accredited program of Special Olympics International Organization set up for this purpose.

well known among the poor of Anantapur for its charity. Thus, when RDT started its disability unit, persons with disabilities were more enthusiastic to avail the aids and appliances. But, gradually the concept of SHG and its income generating activities gained wider acceptance among the PWDs. This approach of organizing the PWDs into SHGs by RDT became successful and was also followed by the state government.

CHAPTER-VII

CONCLUSION

The notions associated with impairment vary across cultures and languages (Barnes, Mercer and Shakespeare, 1999). The history of disability suggests that civilizations responded to embodied differences in different ways. An investigation of the diverse notions on and approaches to impairment reveals that the social and cultural dimensions shape the way in which impairment is perceived, say, 'abnormality', 'disability' or 'handicap'.

The cultural characteristics of society have been instrumental in shaping the concept of disability. The notions of the body located in the Enlightenment period popularized 'medical' or 'individual' model which explains disability as caused by a disease or bodily disorder. This marked a person as disabled when s/he is ill or is suffering from a trauma. Criticizing this model for reducing disability to the individual level, the social model of disability emerged. This model argued that disability is created by the social, cultural, architectural and economic barriers set up by the society designed for non-disabled people. It defines disability as a social problem resulting in an oppressive relationship between the disabled and non-disabled.

Disability studies, denouncing the individualization of impairment, argue for separation of impairment and disability. It looks at impairment as a personal problem which the individual has to negotiate while, disability as a social construct. Hence, it argues for working with the larger social context which contributes to the disabling conditions. This suggests for acting on the people in general and not the impaired alone to do something with regard to the disabled. However, critical disability studies warn against the fallacy of separation of individual and impairment. It suggests that impairment is to be negotiated in such a way that the individual's chances of participation increase.

Critical disability studies recommend medical interventions to the persons suffering from severe disabilities along with tackling social and structural barriers. Thus, it does not denounce medical intervention as proposed by the disability studies. Until the emergence of disability studies, policy measures focussed on the impaired bodies subjecting them to correction, segregation and normalization. With the disability activism, there has been a perceptible change in the agendas and planning for the disabled.

Non-government organizations, also known as private, not-for-profit, voluntary or civil society organizations have taken up the development of PWDs as a charity or welfare. From 18th and 19th century onwards, the main framework for formal services was to provide support by placing PWDs in institutions for medical corrections. In the developed countries context, till the 1960s, people with intellectual impairments, poor mental health conditions and physical and sensory impairments were segregated and placed in residential institutions called 'asylums' or hospitals. In developing countries, similar institutions were initiated by the international NGOs. However, the presence of the sector remained minimal compared to the developed countries. In India, CBR programmes have become the sources of assistance and support for many persons with disabilities and their families. The CBR policy of India also placed emphasis on the NGOs in taking the lead in the delivery of services to the PWDs. Several NGOs were funded by the central government to take up the welfare of the disabled.

Rural Development Trust (RDT), an NGO, has been working for the betterment of the lives of the most deprived sections of the society since 1969 in Anantapur district of Andhra Pradesh. RDT has been carrying out several need-based welfare and integrated programs of development to improve the quality of life of rural poor, especially the marginalized and the underprivileged sections including PWDs. It has been offering special education and rehabilitation training from pre-school to high school for the mentally challenged, children with cerebral palsy, visually challenged and the hearing impaired. It has also been providing financial help to the students with disabilities to pursue their normal education from primary to higher professional and technical levels.

The main emphasis of RDT has been to facilitate the economic empowerment of PWDs as it believed that economic improvement results in higher social status. It has been working to improve the socio-economic status by imparting vocational skills in handicrafts, upgrading their existing skills and providing them access to capital, apart from encouraging them to mobilize institutional finance to start feasible income generating activities. Also, RDT has been providing aids and appliances including physiotherapy for improved physical movement for the persons with locomotor disabilities. These services cover both medical and surgical interventions taken up to reduce the intensity of disability and morbidity among persons with locomotor disabilities.

On the other hand, a number of state initiatives towards the marginal sections of society have been launched by the successive governments in the country. Echoing the basic principles of humanity, justice and equality, the governments evolved policies to reach out to the poor, oppressed and the vulnerable. Notwithstanding the progress made, the issues of poverty and equity still continue to dominate the policies of the state. Programmes aimed at specific sections of the population are often directed by the evolving global concerns towards universal laws for living. One such concern has been the issue of disability. As a member of the United Nations, India shared the concerns of global forums for the disabled and enacted several legislations in this regard. The state machinery always assumed that the problems of impaired were to be addressed by medical and psychology professionals instead of social development programmes. The social forces contributing to disability were never addressed by the state in the empowerment of the disabled. In view of the above, the government of Andhra Pradesh incorporated disability in its rural poverty eradication programme through SERP for addressing the problems of the disabled.

The present study was carried out in Anantapur district of Andhra Pradesh during 2010-11. Anantapur was selected as the field site because both SERP (sate initiative) and RDT (non-state initiative) work for the disabled persons in the district. The present research is a comparative study aimed at examining the initiatives of the state and non-state organizations towards the PWDs. The study attempted to provide an assessment of the approaches of state and non-state organization towards PWDs. It explored the social organization of PWDs into SHGs and critically examined the impact of such efforts on the PWDs themselves and society at large. The study problematized the issues of identity, participation and inclusion through collectivization by locating the observations and arguments in the sociology of disability perspective. It analyzed the perceptions of the PWDs towards the roles of the family, neighborhood, community and other rural institutions such as panchayat raj, co-operatives, banks, educational and religious institutions on the issues concerning the integration and mainstreaming the disabled.

The study finds that SERP has adopted the community based rehabilitation approach to empower the PWDs. It also adopted the rights based approach through mobilization of PWDs into Self Help Groups (SHGs). Although the functioning strategy has been to empower the PWDs economically, the SERP initiative observed to have provided an identity to the PWDs in the operational villages which is inclusive. It was found that the functionaries of SERP work in a hierarchical structure where authority and guidance flows from top to the village level functionaries. It was also observed that a majority of the village and mandal level functionaries of SERP were PWDs belonging to the villages of the programme implemented mandals.

On the other hand, RDT had evolved the community based rehabilitation services towards the disabled much before the launching of the state initiative. Unlike SERP, RDT functions in a non-hierarchical manner, which is typical of a flat organization. Moreover, the functionaries of RDT are not always disabled persons. The process of identification and mobilization of the PWDs into group was found to be easier in case of RDT than that of SERP as RDT had developed enormous goodwill among people from the deprived sections of the villages where it has been functioning for a long time. It may also be said that while the key strategy of SERP was SHGs, RDT placed emphasis on education along with mobilization of PWDs into SHGs.

It was reported by the RDT functionaries that the parents of the children with disabilities were more interested in sending their children to the special schools run by RDT rather than joining the SHGs. In the initial phase of its working, RDT adopted a multi-pronged strategy to bring awareness and mobilize PWDs of the villages. It was reported by the RDT functionaries that cultural programmes like stage shows, dramas, and also distribution of pamphlets, pasting of posters and drawing wall paintings depicting the benefits of SHGs were carried out. The SERP, being a state initiative, used the government machinery at the village, mandal and district level along with its functionaries in mobilizing the PWDs into SHGs.

The findings of the study are discussed along three important parameters viz. the impact of group, participation and identity. The self help groups have played an important role in the lives of the disabled. The SHGs have not only provided a platform to share, exchange, feel and discuss the issues of their concern, but gave them much needed strength to face the onslaught of the oppressive majority over them. It enabled their participation, gave them identity and brought hopes in their lives. For an impaired person in the village, interaction with neighbors and others is always laced with discrimination and derogatory remarks. Usually, their mark of identification is their impairment. However, after the formation of SHGs, they are called by their names instead of their impairment. Adding to this identity in the village, the importance of the PWDs in their families increased as they are able to support the family financially.

Seeley (2001) argues that the greatest obstacle to participation and equity is the prevalence of deep rooted negative attitude on the part of non-disabled people in the family and community. Bhambani (2003) suggests that the ability to contribute to the family income enhances the worth of an individual in the eyes of other family members as well as the members of the community. It was found from the study that the PWDs of the group draw loans ranging from Rs. 1,000/- to 1,00,000/. With the financial help thus received, they were observed to be engaged in income generating activities related to agriculture and allied activities like goat, milch cattle rearing, family occupations etc. thus, contributing to the family income.

Misuse of loan also has been reported during the study. This was witnessed in the case of SERP beneficiaries where family members (mother in the specific case) misused the loan for other purposes instead of providing proper medical care to the disabled. The SERP has evolved mechanisms to address such issues. It was reported that group members, on knowing such cases, go to the house of the particular member and counsel the family members. Thus, group acts collectively to safeguard the interests of the members of the SHG. This action, of course, is based on the training and awareness provided by the SERP functionaries to the members of the SHGs. The CDWs also play an important role in counselling the family members against the misuse of the loans.

In the case of RDT, it emphasizes on thrift and savings by the members of the SHGs. Loans are given strictly for income generating activities. Moreover, it keeps a strict vigil on the use of the loan amount and its repayment through the members of the same group. It was observed during the study that RDT keeps a detailed record of the loans availed by the members and their usage. RDT provides a matching grant to the members of the group working successfully for a period of not less than one year. Successful functioning is assessed based on the regular thrifts and savings and repayments by the members of the SHGs. The matching grant (equal to the amount saved by the group) by RDT is the important motivating factor that encourages the members of the group for proper utilization of the loan amount and timely repayment. Moreover, RDT insists on a guarantor to stand as a surety to avail loan. The guarantor, one of the group members, is accountable for proper repayment of the loan by the person who avails the loan.

Another crucial aspect of identity in rural areas is marriage. Most of the respondents of the study, both from RDT and SERP, were found to be married to their cross-cousins. In the case of both men and women, the mental or physical conditions of their partners are well known to each other before their marriage. There are also evidences of surrogate marriages where the disabled sister is married to the husband of her sister. When probed about the reasons, parents of the respondents suggested that once a girl is married, irrespective of the outcome or suitability, she attains her full social status and also after their (parents) death, there will be someone to look after her.

However, it was observed that, the other reason for the impaired women getting married to her sister's husband was to avoid parting with property or money to a person outside the family. The fear of parting with property is due to the fact that in many previous instances (in other villages, at other points of time) the person who got married to an impaired woman had deserted her after enjoying the money/property given at the time of marriage. They, particularly the married sisters of the impaired girls feel that an impaired woman has no life outside the family, is always confined to house, looks after the family members and takes care of daily chores of the family. Also, they believe that she would not have any economic interest and thus would not demand a share in the property of the husband. However, marriage among the mentally retarded was low when compared to orthopedically challenged and visually challenged. Due to the social compulsions attached to marriage, parents of disabled daughters perform the marriage of their daughter by paying a higher dowry or get them married to another impaired person or to a cross cousin.

Empirical data suggest that a significant change in the identity of the impaired has occurred after the initiation of SHGs. Empirical observation and interaction with the group members reveal that the disabled of the village have developed a strong 'we-feeling' after forming the group. They have developed a strong bondage as the feeling of neglect or discrimination is common to all the members. Capacity building programmes by the functionaries of SERP and RDT have enabled them to know the opportunities available for development. In their conversations with the researcher, it was clearly evident that the disabled value themselves in 'we' rather than 'I'. They started putting up a collective voice whenever and wherever required. Thus, it may be said that the underlying intention of forming SHGs on rights mode approach rather than rehabilitation approach has been realized to a certain extent. Apart from a reactive mechanism of collectively hitting back, some groups had also adopted pro-active initiatives to fight discrimination, such as holding public meetings in the village explaining the consequences of prejudiced behavior by employers, school teachers and neighbors.

Another important finding from the study is the role of special schools in the lives of mentally challenged children. As part of the present research, the special schools were visited and the researcher interacted with the children, their caregivers and family members. It was reported that the mentally challenged children are learning basic normal behavioral skills in the special schools. Apart from learning the basic skills of maintaining oneself, parents reported that the schools also provided relief as the children are in the safe custody during the day. As a majority of the parents of the mentally retarded children belong to wage labourer families, taking care of the child at home was nothing but losing a day's wage. After setting up of the special schools parents go to work once the child is sent to the school.

As far the educational achievement is concerned, it was reported by the SERP and RDT functionaries that the children who have acquired certain skills in maintaining themselves and behaving with others are admitted in the regular schools in the villages. It was reported that the functionaries of SERP and RDT visit the school and convince the school administration about the child's abilities to continue education along with other children.

RDT has established a number of special schools for disabled children. It provides aids and appliances to enhance understanding. The researcher visited the advanced computer labs set up for the partially visually challenged students and the Braille press which produces special study material for the visually challenged students. The speech and hearing impaired students are taught by the teachers who are trained in sign language. The visually challenged children learn reading and writing Braille in these schools. As the text books are available in Braille, the children appear to be at ease in learning. However, in the case of SERP such facilities (books in Braille, Braille teaching, teachers trained in sign language) are missing. It is being run with the sole aim of bringing changes in the behaviour of the mentally retarded children rather than imparting education.

It was reported in the study that the functionaries of RDT keep a regular watch on the new born babies in the villages for an early identification of the impairment. When identified with some kind of abnormality, both the children and mother are taken to professionals for treatment. According to the prescribed treatment by the doctors, the trained experts start working on the children. It is important to note that the special centers for the mentally challenged children work with the objective of mainstreaming them. Thus, the strategy follows a planned treatment process wherein the children are provided training on various daily living activities and basic skills for a period of one week or ten days and then they are sent back to their respective villages to stay with their parents. During the stay in their habitat, the activity or improvement is judged and accordingly further treatment is provided.

Unlike the special schools of the government where leaving the mentally challenged children makes the parents feel free from the responsibilities of taking care of them for the whole day, RDT works on both parents and children. The mentally challenged children are trained and treated in the presence of their parents so that they can follow the instructions by the professionals. The initiative of RDT for an inclusive school is a remarkable one. It exemplifies the possibility of teaching every student irrespective of impairment. Children with special needs have a distinctive experience undergoing inclusive education along with non-disabled classmates. There are several barriers for providing education to special children in a regular classroom. This can be overcome by creating more awareness on inclusive education, by re-structuring the curriculum to cater to all types of students, by recruiting teachers who are specially trained etc.

It was found from the study that RDT invites Spanish professionals like deaf computer technicians and orthopedic surgeons apart from volunteers for conducting workshops and cultural programmes for the disabled children. In this context, RDT brings in the international expertise in its functioning. As the founder director hails from Spain, a number of professionals in medicine and community work visit RDT and take part in its activities. They bring new ideas along with their expertise. At the same time, it also involves government functionaries in its initiatives.

Persons with disabilities are stigmatized and marginalized resulting in backwardness. It calls for sensitization, which would result in considering disabled persons as human beings whose creativity, abundant intrinsic abilities and skills remained dormant due to the discriminatory attitudes, behavior and values. Thus, it may be suggested that any initiative towards the empowerment of the PWDs should focus on improving the condition of persons with disabilities so that they gain access to opportunities and enhance their living standards. This is possible by providing necessary aids and appliances to overcome their difficulties due to impairment. Moreover, identification of hidden skills, abilities and talents by providing them a right platform would definitely improve their participation in various spheres of life.

RDT was found to be giving importance to education to the impaired children more than any other rehabilitation. The special schools for children with special needs increased the literacy rate among the PWDs. RDT's initiative towards starting inclusive schools proves to be a step forward to overcome such barriers. However, questions of assimilation of those children in mainstream society still linger. Even if they are provided with equal opportunities in education, they are still discriminated and are confined to the margins. Disability scholars argue that impairment is an individual problem, whereas disability is a social problem. In such context, the initiatives towards the PWDs should also focus on working on the society to eradicate the deep rooted notions of disability. This can be successful by changing the attitude of the non-disabled towards the PWDs.

The study suggests that the SHG provides credit assistance, creates awareness on the rights of PWDs and guides its members to avail aids and appliances along with corrective surgeries. The economic independence of the disabled gained them an identity in their family and in the society. But, a critical look reveals that the effort of making the disabled persons economically independent is nothing but normalizing. Though the researcher had not come across the instances of lapses on the part of the functionaries in the programme, there were complaints about the external credit sources like banks that would not come forward to lend loans to the groups through bank linkages despite their SHG being regular and fulfilling all the pre-requisites. The group members suggest that banks still treat the disabled SHGs as not worthy of availing of loans as the bank officials doubt the repaying capacity of the disabled. The strategy of organizing PWDs into SHGs works only with the disabled instead of changing the attitude of the society towards them. The interventions by both the state and non-state organizations don't seem to work on the social issues.

Although the identity of the disabled among the family members, neighbors and other villagers has changed, but again such notions of identity place body at the centre. However, the efforts of both the state and non-state rely on the commonly held notions of disabled identity. Similarly, participation of impaired individuals has not been facilitated by bringing changes in the wider society which is evident in the absence of architectural alterations to the buildings of community institutions in the villages, like panchayat office, school or bank. Absence of ramps to these buildings is visible in the villages where the study was conducted. The absence was more prominent where the SERP was functioning. The villages where RDT is working also have similar problems. However, RDT's own buildings are inclusive and accessible to the orthopedically challenged and the visually challenged. On the other hand, it was observed that the SERP offices were not completely disabled friendly. These observations lend credence to the statement that the state and non-state initiatives still focus on the impaired rather on the wider society.

The study finds that inclusive measures of state though enhanced participation, failed to break the barriers of participation which are located in the wider socio-cultural context. For example, in the case of political participation, the SERP initiative of the group has not resulted in significant changes in the larger society. It was revealed in the study that some group members though act as leaders of their group, they never had a chance to participate actively in the political affairs of their respective villages. There are evidences of a very few respondents who were active members in the political affairs. However, even in the cases of active participation, their participation was limited to represent the State's successful efforts towards the disabled and celebrate the achievements of that particular impaired person rather than treating the person as a leader. The disabled members are asked to give suggestions or grievances related to the disabled only but their concern for other general issues is not taken seriously. This reflects the assumption that a disabled person should talk only about the issues of disabled while others will talk about the issues in general.

Though, RDT started mobilizing the disabled into SHGs since three decades, the group activities are still confined to the process of savings and availing the financial support for various income generating activities. The identity of the PWDs has changed because of economic independence. The society started recognizing the persons with disabilities as efficient to earn and contribute to the family. The efforts of RDT towards working on the larger society for changing their attitude and making them aware about the ability of an impaired have been met with limited success. RDT organizes many cultural programmes to encourage the disabled to form groups, but very few programmes highlight the need for change in the wider social context so as to make the society inclusive.

It may be said that the prime responsibility of development, empowerment and providing barrier free environment for the disabled has been the responsibility of the state. Supplementing the state efforts, NGOs also have been working on the same issues. However, the approaches of these two players have significantly been different owing to institutional, cultural and political reasons. State initiatives are bogged down with bureaucratic problems while the non-state initiatives are plagued with operational issues related to finance, personnel etc. A collaborative effort of state with voluntary organizations would definitely provide fillip to the welfare of the disabled. The development, implementation, and monitoring strategies towards the disabled should bring together all the stakeholders including state functionaries, non-governmental organizations, professional groups and disabled rights groups along with the general public. Involving the disabled groups in such policies and programmes is a must as persons with disabilities often have unique insights about their disability and their situation.

The present study on the development initiatives of the state and non-state organizations focused on the approaches, strategies and facilities for the PWDs in detail. A comparative observation helped the researcher in meeting the objectives of the study. Though it was found that community based rehabilitation is the basic and primary strategy of SERP and RDT, there are differences in the approaches followed by both the organizations. It was observed that the PWDs associate more with the state through the SHGs formed by the SERP when compared to the RDT SHGs. The members of the SERP SHGs were found to be considering themselves as legitimate partners in the development process. They consider that it is mandatory on the state to take up their issues. The PWDs see development as their right, as a citizen of the country, rather than a charity. Thus, the PWDs were found to be associating more closely with the state through SERP SHGs rather than RDT SHGs. It was also noticed that the approach of the SHGs of SERP was found to be more rights based than rehabilitation based. In case of SERP, the name of the 'government' as such plays an important role in motivating the PWDs to take part in the developmental programmes. By making the PWDs aware of their constitutional rights, the state has made them politically influential.

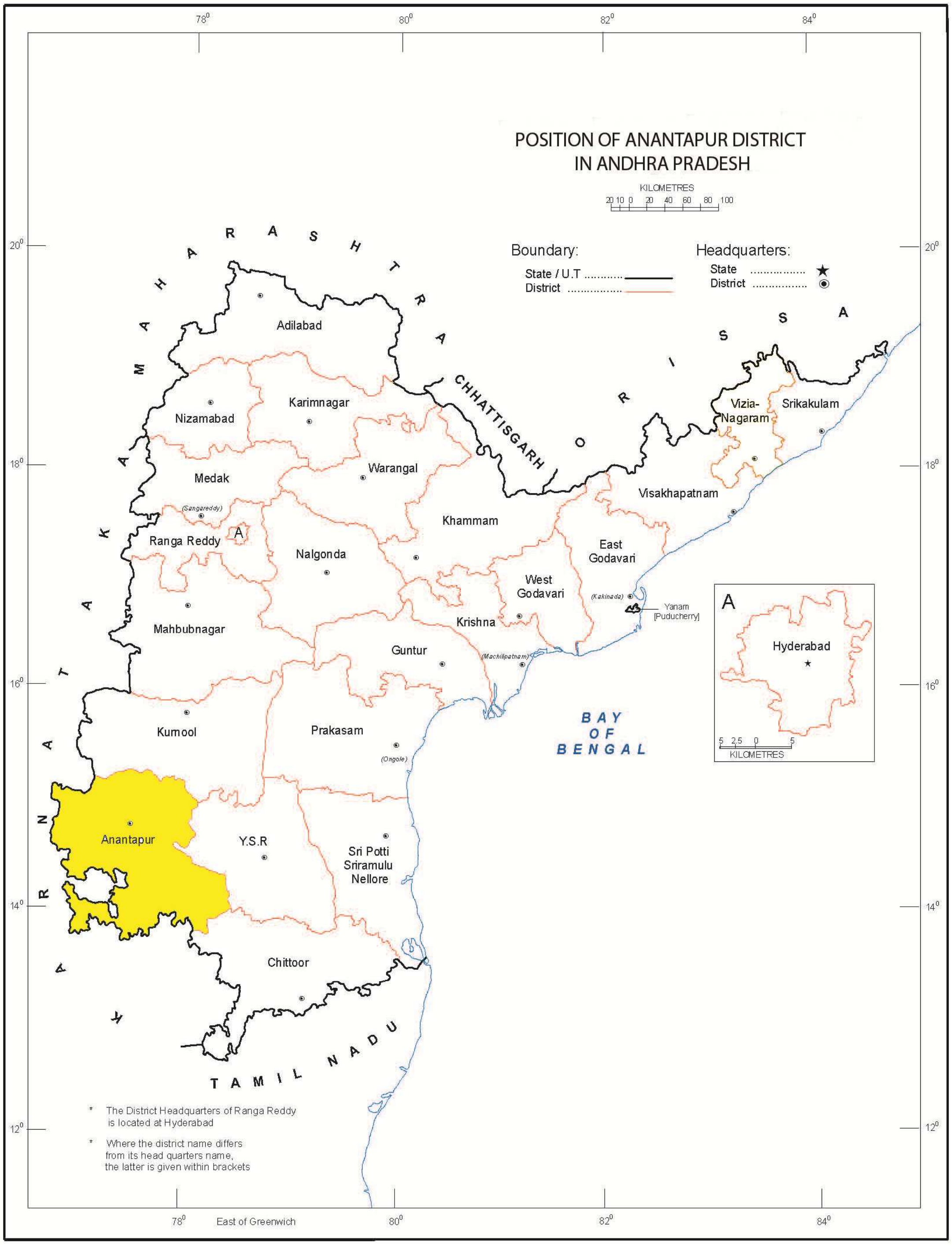
Siebers, as quoted by Mehrotra (2013), argues that without some sense of collective identity, claiming rights under federal and state protections will be difficult. The SHGs of SERP have been federated into state level bodies, thus forming an influential political pressure group. Any benefit to the PWDs doesn't just influence a single vote, but the entire family and to some extent the community. Realizing this, various political parties recognize the potential of PWDs' SHGs and thus seek votes promising special financial and other programmes. Apart from this, with sustained efforts of the state SHGs, the officials of banks, educational institutions and other government departments were found to be giving due importance to the demands of the PWDs.

The rights mode approach of the SERP towards PWDs has resulted in creating a positive identity to PWDs. The message of PWDs as the equal citizens of the country has reached the people in general and officials loud and clear. It was observed by a villager in one of the study villages that people now stopped calling PWDs by their short names associated with impairment. They have realized that calling by such names would attract legal provisions. Moreover, the continuous efforts of the government officials in the form of regular visits to the houses of the PWDs, SHG meetings and federation of the SHGs at the mandal level helped in changing the attitude of the society towards the PWDs. But, this has to be seen in the limited context of identity. Larger and wider changes required in the society have not yet taken place. Stigma associated with impairment still continues in the spheres of cultural and social aspects. Participation in economic, cultural and social aspects has not changed much, although on political front there is a perceptible change. However, what is important to note is that there is a significant difference in the approach of the society towards PWDs with the state initiative. The same may not be told about the non-state initiative. SERP with its functioning for the past decade has significantly altered the views of people what RDT couldn’t do in more than two decades. The argument the study raises is that a state initiative carries a certain amount of obligatory influence on the part of people in general and other institutions of the state as well. Such obligatory element is not found when a similar initiative is taken up by a non-state actor. Thus, the thesis observes that non-state initiatives can supplement the efforts to a certain extent, but cannot deliver the results as a state initiative does.

As far as the deliverables related to development and empowerment are concerned, a less bureaucratic and participatory style of functioning yields positive results. Local specific programmes, external resources, access to the latest medical and assistive technologies have been the hallmark of the functioning of the RDT. The person behind RDT, Father Vincent Ferrer, who relentlessly worked on poverty, illiteracy and education carries enormous goodwill in the villages of Anantapur. The goodwill of the organization appears to have mattered a lot in mobilizing the PWDs into the SHGs. Personalities and programmes do influence the outcomes of the non-state initiatives. A positive opinion on the RDT created a conducive atmosphere for the successful implementation of programmes for the PWDs. The improved assistive technologies provided by RDT helped the PWDs in active participation in the broader society. The initiative of RDT was found to be set up in a less bureaucratic manner when compared to SERP. It was observed that SERP follows a more standardized approach by covering the PWDs throughout the state whereas RDT was found to be adopting a localized approach towards the PWDs of a specific district i.e. Anantapur with greater success.

However, RDT works towards the disabled with a goal of overall development of PWDs in all spheres of life. Thus, it focuses on development in a long term basis. Unlike SERP, for which meeting the target of the government is important, RDT focuses on personality development through inclusive programmes. SERP concentrates on following the rules and regulations during the project implementation. It keeps a track on the numbers of groups formed, number of meetings conducted and distribution of appliances to the PWDs etc. On the other hand, RDT gives importance to mainstreaming the PWDs through efforts like inclusive schools, cultural participation of the PWDs of the SHGs and making them comfortable in their natural habitat irrespective of their impairments. The feedback mechanism/channel of RDT was found to be very strong. A transparent and continuous involvement of the functionaries with the PWDs helps in improvising the developmental plans of the organization.

Anantapur district in Andhra Pradesh



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Appendix - 1

The Rights of Persons with Disabilities Draft Bill, 2014

The Rights of Persons with Disabilities Bill, 2014 was introduced in the Parliament on 7th February, 2013. The Bill repeals the Persons with Disabilities (Equal Opportunities Protection of Rights and Full Participation) Act, 1995. The highlights of the Bill are as follows:

- **Definition of disability:** The Bill seeks to broaden the definition of disability which includes 19 conditions such as autism, low vision and blindness, cerebral palsy, deaf blindness, haemophilia, hearing impairment, leprosy, intellectual disability, mental illness, muscular dystrophy, multiple sclerosis, learning disability, speech and language disability, sickle cell disease, thalassemia, chronic neurological conditions and multiple disabilities. Persons with benchmark disabilities are defined as those with at least 40 per cent of any of the above specified disabilities.
- **Rights of persons with disabilities:** The Bill states that persons with disabilities shall have the right to equality and shall not be discriminated against on grounds of their disability. Rights of disabled persons include protection from inhuman treatment and equal protection and safety in situations of risk, armed conflict, humanitarian emergencies and natural disasters. All existing public buildings shall be made accessible for disabled persons within five years of the regulations being formulated by the National Commission for Persons with Disabilities. No establishment will be granted permission to build any structure, issued a completion certification or allowed to occupy a building, if the building does not adhere to the regulations formulated by the Commission.
- **Education, skill development and employment:** The Bill provides for the access to inclusive education, vocational training and self-employment of disabled persons. All government institutions of higher education and those getting aid from the government are required to reserve at least five percent of seats for persons with benchmark disabilities.

- **Employment and Posting:** The central and state governments have to identify posts in establishments under them to be reserved for persons with benchmark disabilities. At least five percent of the vacancies are to be filled by persons or class of persons with at least 40 percent of any of the disabilities. Of this, one per cent shall be reserved for persons with (i) blindness and low vision, (ii) hearing and speech impairment, (iii) locomotor disability, (iv) autism, intellectual disability and mental illness and (v) multiple disabilities. The Bill provides that the reservation has to be computed on the basis of total number of vacancies in the strength of a cadre. The government may exempt any establishment from this provision.
- **Legal Capacity:** Disabled persons have the right, equally with others, to own and inherit movable and immovable property, as well as control their financial affairs.
- **Guardianship:** The Bill provides that if a district court finds that a mentally ill person is not capable of taking care of himself or of taking legally binding decisions, it may order guardianship to the person. The nature of such guardianship is also specified.
- **National and State Commissions for persons with disabilities:** The central and state governments are required to establish a National and State Commissions for Persons with Disabilities, respectively. The Commissions will be composed of experts and be required to (i) identify any laws, policies or programmes that are inconsistent with the Act; (ii) inquire into matters relating to deprivation of rights and safeguards available to disabled persons, (iv) monitor implementation of the Act and utilization of funds disbursed by governments for the benefit of disabled persons.
- **Central and state advisory boards:** The central government and state governments shall constitute Central and State Advisory Boards on Disability. The boards shall advise governments on policies and programmes on disability and review the activities of organizations dealing with disabled persons.

PERSONS WITH DISABILITIES IN RURAL ANDHRA PRADESH: A COMPARATIVE STUDY OF DEVELOPMENT INITIATIVES OF THE STATE AND NON-STATE ORGANIZATIONS

Synopsis

Of

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Synopsis

Introduction

Disability is a relative term in so far as different cultures define their norms of ‘being’ and ‘doing’ differently. Disability has been subjected to many definitions in different disciplines and for different purposes. It has been described from medical, sociological and political perspectives and definitions of disability have been developed and used in different contexts. Medicalisation of impairment pre-supposed a normal body that is free from challenges. Standards of body and mind pronounced by medical scientific knowledge marked body as ‘physiological-pathological’ object and the defective ones were associated with ‘degeneracy’. The bio-socialist notion that guided the medical paradigm objectified and categorized people as sick or healthy, mad or sane and justified the hierarchical standard for treating some bodies as abnormal and inferior (Reddy, 2011). Correspondingly, the involvement of the medical profession in disability has added to the process of objectification and correction and in a way, medicalisation emerged as a key aspect in the social policies for persons with disabilities (Chand and Reddy, 2012).

The Disability Rights activists in North America and Europe began to oppose considerations which placed body at the center of explanation. Taking roots during 1980s, the social construction model referred to as 'social model' argued for looking at the social barriers that disable the impaired body rather than impairment. They believed that impairment-based constraints of an individual could be overcome not by subjecting the impaired body to correction, but by changing the way social environment was built and construed. Paul Hunt (1966) argued that ‘the problem of disability lies not only in the impairment of function... but also, more importantly, in the areas of our relationship with ‘normal’ people’ (Paul Hunt cited in Barnes and Mercer, 2003). The manifesto of the Union of Physically Impaired Against Segregation (UPIAS) maintains that it is the society which disables physically impaired people and disability as a social construct is something external and imposed on the impaired, leading to isolation and exclusion of the impaired from full participation in the society. (Barnes and Mercer, 2003).

The critics of the social model, argue that impairment cannot be treated as something *a*social or pre-social. Disallowing theoretical analysis of the body and the accompanying pain, suffering and emotional trauma, as proclaimed in the social model, only adds to the oppression (Galvin, 2003).

Recognizing these limitations in both the medical and the social model, the World Health Organization (WHO) developed the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980s. It provides a conceptual framework for disability which is described in three dimensions: Impairment, Disability and Handicap. This, however, received considerable criticism for its reliance on bio-physiological definitions of normality and for ignoring the social, economic, political, and cultural barriers in the environment. Considering the criticism about the deficiencies in the ICIDH model, the WHO revised and renamed it as the International Classification of Functioning, Disability and Health (ICF). In the ICF model, problems with human functioning are categorized in three interconnected areas viz. Impairment is considered as a problem in the functioning of the body or alterations in the structure of the body, for example, paralysis or blindness. Activity limitation is the difficulties in executing activities, for example, walking or eating. Participation restrictions are problems with involvement in any area of life, for example, facing discrimination in employment or transportation.

In India and South Asia, disability is largely seen as a product of cultural impediments such as beliefs and stereotypes as well as structural impediments like poverty, underdevelopment, illiteracy, unemployment and caste, class and gender barriers etc. PWDs are marginalized in education, employment, mobility and other significant areas of life. The meaning of disability in India is embedded in this basic struggle for survival and cultural understanding. Prevention and rehabilitation models continue to be relevant in such circumstances (Mehrotra, 2012).

As service providers, almost all the traditional organizations work with the idea of rehabilitation. However, during the 1980s, there was a shift in the policy frame from welfare to development where the disabled have now figured not as recipients, but as participants in the development process. This period witnessed the greater interest and participation of international Non-Government Organizations (NGOs) and the emergence of local NGOs in partnership with the government working at community level. In India, this phase saw groups being formed by disabled activists for claiming their political, legal and social goals by adopting a rights-based approach.

State initiatives towards persons with disabilities in Andhra Pradesh

In the light of increased activism on disability rights, there has been a perceptual change in the approach of the state towards the PWDs. For implementing the rural development project in a professional and accelerated manner, the Government of Andhra Pradesh has established the ‘Society for Elimination of Rural Poverty’ (SERP) in the year 2000 as an autonomous society under the Societies Act. The Society for Elimination of Rural Poverty works on six major components, one of which is disability.

Non-state initiatives towards Persons with Disabilities in Andhra Pradesh

NGOs have made a significant contribution in the area of disability through the activities of early intervention, assessment, therapeutic services, parents’ education, formation of self-help groups, etc. The Rural Development Trust (RDT) is one such non-government organization located in Andhra Pradesh carrying out need based welfare and integrated programs of development for rural poor and needy, especially those belonging to marginalized and underprivileged sections, namely Scheduled Castes (SC), Scheduled Tribes (ST), Backward Class communities (BC) and Persons with Disabilities (PWDs) for the past 44 years.

Objectives of the Study

Given the background, the study aims at understanding the state and non-state initiatives towards the PWDs in rural Andhra Pradesh. The study attempts at describing the methods adopted and approaches evolved in the delivery of services to the PWDs. In its attempt, it draws comparisons between the state and non-state initiatives from the point of view of the target group i.e. persons with disabilities.

The specific objectives of the study are:

- To describe the functioning of state and non-state organizations in approaching and mobilizing PWDs in rural areas.
- To critically examine the impact of such initiatives from the point of view of the PWDs. This aspect explores the issues of identity, access and participation through an understanding of relations of persons with disabilities with their family members, neighbors, institutions at the village level and above after the initiation of the programme for the disabled.
- To discuss the differential approaches of the state and non-state towards PWDs and bring out the emerging concerns pertaining to the issues of development of the marginalized.

Research Strategy

The study aimed at understanding the state and non-state initiatives for the persons with disabilities selected the Society for Elimination of Rural Poverty (SERP) as the state initiative and the Rural Development Trust (RDT), a non-government organization as the non-state initiative, both of which work for mainstreaming and empowering the persons with disabilities. The study was conducted in Anantapur district where both the programmes of development, i.e. of the SERP and RDT are implemented for a comparative understanding between the state and non-state development initiatives towards persons with disabilities.

Sample Selection

The basic unit of study is village to which persons with disabilities belong. From those mandals[1] of Anantapur district where SERP has been functioning, three mandals were selected. From these three mandals, three villages from each mandal were selected for the study. Thus, under the state initiative nine villages were selected. The selection of the villages was random adopting the criteria of successful functioning of SHGs. The sample for the study on RDT was identified from the data given by the Disability unit of RDT. Villages were identified based on the inputs provided by the functionaries of RDT. The criterion adopted in the selection of RDT initiated villages was similar to that of the selection of villages under SERP.

Data were collected from a total of 72 respondents comprising of 30 respondents of SERP and 42 respondents of RDT. Family members and functionaries formed part of additional data, with whom the researcher interacted and discussed the issues related to the PWDs. The respondents were also met in their group setting. As the PWDs of every village selected for the study are members of SHGs, data were collected using focused group discussions with the SHGs. The interviews were recorded using a voice recorder after taking consent from the respondents or their family members. The voice recordings were transcribed and analyzed. Data from the functionaries was collected during the travel to the villages, in their offices or in the villages.

Primary Sources

Data from the field were collected using semi-structured questionnaire, interview and focus group discussions. Socio-economic profile of the respondents was collected using the semi-structured questionnaire. In-depth interviews were carried out to collect data on roles, social relations, perceptions of the persons with disabilities with regard to the issues of impairment and ways to cope with it.

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[1] Mandal is the administrative unit for about 10 to 15 villages. Mandals were carved out of Blocks in Andhra Pradesh.

Secondary Sources

The necessary data were collected through secondary sources like government records on the persons with disabilities, functioning of the groups in terms of savings, conduct of meetings, participation, etc.

Findings and Discussions

The study finds that SERP has adopted the community based rehabilitation approach to empower the PWDs. It also adopted the rights based approach through mobilization of PWDs into Self Help Groups (SHGs). Although the functioning strategy has been to empower the PWDs economically, the SERP initiative observed to have provided an identity to the PWDs in the operational villages which is inclusive. It was found that the functionaries of SERP work in a hierarchical structure where authority and guidance flows from top to the village level functionaries. It was also observed that a majority of the village and mandal level functionaries of SERP were PWDs belonging to the villages of the programme implemented mandals.

On the other hand, RDT had evolved the community based rehabilitation services towards the disabled much before the launching of the state initiative. Unlike SERP, RDT functions in a non-hierarchical manner, which is typical of a flat organization. Moreover, the functionaries of RDT are not always disabled persons. The process of identification and mobilization of the PWDs into group was found to be easier in case of RDT than that of SERP as RDT had developed enormous goodwill among people from the deprived sections of the villages where it has been functioning for a long time. It may also be said that while the key strategy of SERP was SHGs, RDT placed emphasis on education along with mobilization of PWDs into SHGs.

It was reported by the RDT functionaries that the parents of the children with disabilities were more interested in sending their children to the special schools run by RDT rather than joining the SHGs. In the initial phase of its working, RDT adopted a multi-pronged strategy to bring awareness and mobilize PWDs of the villages. It was reported by the

RDT functionaries that cultural programmes like stage shows, dramas, and also distribution of pamphlets, pasting of posters and drawing wall paintings depicting the benefits of SHGs were carried out. The SERP, being a state initiative, used the government machinery at the village, mandal and district level along with its functionaries in mobilizing the PWDs into SHGs.

The findings of the study are discussed along three important parameters viz. the impact of group, participation and identity. The self help groups have played an important role in the lives of the disabled. The SHGs have not only provided a platform to share, exchange, feel and discuss the issues of their concern, but gave them much needed strength to face the onslaught of the oppressive majority over them. It enabled their participation, gave them identity and brought hopes in their lives. For an impaired person in the village, interaction with neighbors and others is always laced with discrimination and derogatory remarks. Usually, their mark of identification is their impairment. However, after the formation of SHGs, they are called by their names instead of their impairment. Adding to this identity in the village, the importance of the PWDs in their families increased as they are able to support the family financially.

Seeley (2001) argues that the greatest obstacle to participation and equity is the prevalence of deep rooted negative attitude on the part of non-disabled people in the family and community. Bhambani (2003) suggests that the ability to contribute to the family income enhances the worth of an individual in the eyes of other family members as well as the members of the community. It was found from the study that the PWDs of the group draw loans ranging from Rs. 1,000/- to 1,00,000/. With the financial help thus received, they were observed to be engaged in income generating activities related to agriculture and allied activities like goat, milch cattle rearing, family occupations etc. thus, contributing to the family income.

Misuse of loan also has been reported during the study. This was witnessed in the case of SERP beneficiaries where family members (mother in the specific case) misused the loan for other purposes instead of providing proper medical care to the disabled. The SERP has evolved mechanisms to address such issues. It was reported that group members, on knowing such cases, go to the house of the particular member and counsel the family members. Thus, group acts collectively to safeguard the interests of the members of the SHG. This action, of course, is based on the training and awareness provided by the SERP functionaries to the members of the SHGs. The CDWs also play an important role in counselling the family members against the misuse of the loans.

In the case of RDT, it emphasizes on thrift and savings by the members of the SHGs. Loans are given strictly for income generating activities. Moreover, it keeps a strict vigil on the use of the loan amount and its repayment through the members of the same group. It was observed during the study that RDT keeps a detailed record of the loans availed by the members and their usage. RDT provides a matching grant to the members of the group working successfully for a period of not less than one year. Successful functioning is assessed based on the regular thrifts and savings and repayments by the members of the SHGs. The matching grant (equal to the amount saved by the group) by RDT is the important motivating factor that encourages the members of the group for proper utilization of the loan amount and timely repayment. Moreover, RDT insists on a guarantor to stand as a surety to avail loan. The guarantor, one of the group members, is accountable for proper repayment of the loan by the person who avails the loan.

Another crucial aspect of identity in rural areas is marriage. Most of the respondents of the study, both from RDT and SERP, were found to be married to their cross-cousins. In the case of both men and women, the mental or physical conditions of their partners are well known to each other before their marriage. There are also evidences of surrogate marriages where the disabled sister is married to the husband of her sister. When probed about the reasons, parents of the respondents suggested that once a girl is married, irrespective of the outcome or suitability, she attains her full social status and also after their (parents) death, there will be someone to look after her.

The study suggests that the SHG provides credit assistance, creates awareness on the rights of PWDs and guides its members to avail aids and appliances along with corrective surgeries. The economic independence of the disabled gained them an identity in their family and in the society. But, a critical look reveals that the effort of making the disabled persons economically independent is nothing but normalizing. Though the researcher had not come across the instances of lapses on the part of the functionaries in the programme, there were complaints about the external credit sources like banks that would not come forward to lend loans to the groups through bank linkages despite their SHG being regular and fulfilling all the pre-requisites. The group members suggest that banks still treat the disabled SHGs as not worthy of availing of loans as the bank officials doubt the repaying capacity of the disabled. The strategy of organizing PWDs into SHGs works only with the disabled instead of changing the attitude of the society towards them. The interventions by both the state and non-state organizations don't seem to work on the social issues.

Although the identity of the disabled among the family members, neighbors and other villagers has changed, but again such notions of identity place body at the centre. However, the efforts of both the state and non-state rely on the commonly held notions of disabled identity. Similarly, participation of impaired individuals has not been facilitated by bringing changes in the wider society which is evident in the absence of architectural alterations to the buildings of community institutions in the villages, like panchayat office, school or bank. Absence of ramps to these buildings is visible in the villages where the study was conducted. The absence was more prominent where the SERP was functioning. The villages where RDT is working also have similar problems. However, RDT's own buildings are inclusive and accessible to the orthopedically challenged and the visually challenged. On the other hand, it was observed that the SERP offices were not completely disabled friendly. These observations lend credence to the statement that the state and non-state initiatives still focus on the impaired rather on the wider society.

The study finds that inclusive measures of state though enhanced participation, failed to break the barriers of participation which are located in the wider socio-cultural context. For example, in the case of political participation, the SERP initiative of the group has not resulted in significant changes in the larger society. It was revealed in the study that some group members though act as leaders of their group, they never had a chance to participate actively in the political affairs of their respective villages. There are evidences of a very few respondents who were active members in the political affairs. However, even in the cases of active participation, their participation was limited to represent the State's successful efforts towards the disabled and celebrate the achievements of that particular impaired person rather than treating the person as a leader. The disabled members are asked to give suggestions or grievances related to the disabled only but their concern for other general issues is not taken seriously. This reflects the assumption that a disabled person should talk only about the issues of disabled while others will talk about the issues in general.

The present study on the development initiatives of the state and non-state organizations focused on the approaches, strategies and facilities for the PWDs in detail. A comparative observation helped the researcher in meeting the objectives of the study. Though it was found that community based rehabilitation is the basic and primary strategy of SERP and RDT, there are differences in the approaches followed by both the organizations. It was observed that the PWDs associate more with the state through the SHGs formed by the SERP when compared to the RDT SHGs. The members of the SERP SHGs were found to be considering themselves as legitimate partners in the development process. They consider that it is mandatory on the state to take up their issues. The PWDs see development as their right, as a citizen of the country, rather than a charity. Thus, the PWDs were found to be associating more closely with the state through SERP SHGs rather than RDT SHGs. It was also noticed that the approach of the SHGs of SERP was found to be more rights based than rehabilitation based. In case of SERP, the name of the ‘government’ as such plays an important role in motivating the PWDs to take part in the developmental programmes. By making the PWDs aware of their constitutional rights, the state has made them politically influential.

As far as the deliverables related to development and empowerment are concerned, a less bureaucratic and participatory style of functioning yields positive results. Local specific programmes, external resources, access to the latest medical and assistive technologies have been the hallmark of the functioning of the RDT. The person behind RDT, Father Vincent Ferrer, who relentlessly worked on poverty, illiteracy and education carries enormous goodwill in the villages of Anantapur. The goodwill of the organization appears to have mattered a lot in mobilizing the PWDs into the SHGs. Personalities and programmes do influence the outcomes of the non-state initiatives. A positive opinion on the RDT created a conducive atmosphere for the successful implementation of programmes for the PWDs. The improved assistive technologies provided by RDT helped the PWDs in active participation in the broader society. The initiative of RDT was found to be set up in a less bureaucratic manner when compared to SERP. It was observed that SERP follows a more standardized approach by covering the PWDs throughout the state whereas RDT was found to be adopting a localized approach towards the PWDs of a specific district i.e. Anantapur with greater success.

However, RDT works towards the disabled with a goal of overall development of PWDs in all spheres of life. Thus, it focuses on development in a long term basis. Unlike SERP, for which meeting the target of the government is important, RDT focuses on personality development through inclusive programmes. SERP concentrates on following the rules and regulations during the project implementation. It keeps a track on the numbers of groups formed, number of meetings conducted and distribution of appliances to the PWDs etc. On the other hand, RDT gives importance to mainstreaming the PWDs through efforts like inclusive schools, cultural participation of the PWDs of the SHGs and making them comfortable in their natural habitat irrespective of their impairments. The feedback mechanism/channel of RDT was found to be very strong. A transparent and continuous involvement of the functionaries with the PWDs helps in improvising the developmental plans of the organization.

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