STATEMENT OF THE PROBLEM

Disability is increasingly on the development agenda and is one of the major challenges to be focused for the overall development of the society. Disability is one of the major causes for dependency and deprivations throughout the world. However, causes leading to it and its magnitude vary across different cultural setups. The WHO (2001) defines disability as a contextual variable, dynamic over time and in relation to circumstances. According to the social model, disability is the result of interaction between people living with impairments and an environment filled with physical, attitudinal and communication barriers.

Social model theory offers significant insight to contemporary conceptualizations of disability. The social model perspective asserts that a disability-related impairment comes from the relationship of the person with a disability to the socio-cultural environment and thereby the environment is seen as the primary target of intervention (Gilson and DePoy, 2002). Instead of a narrow focus on functional limitations, the problem, according to the social model, is “society’s failure to provide appropriate services and adequately ensure the needs of disabled people in its social organization” (Oliver, 1996). Disability, according to the social model, encompasses all factors that impose restrictions on people with disabilities, ranging from negative social attitudes to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to exclusion in work arrangements, and so on. Families of children with disabilities face unique challenges associated with their child’s condition which may affect the entire family as an interactive unit; that is, if something affects or influences one member in the family all members of the family are affected as a whole. Parents of differently abled children have different or an additional set of responsibilities compared to the parents of other normal children and thus may endure an additional level of stress related to their child’s disability. They undergo unique problems associated with raising the differently abled children along with other children in the family and also to integrate with the society. Parenting problems and care demand is a particularly salient variable when working with families that include children who have developmental disabilities. Multiple demands on family resources are prevalent in such
families, and stress levels tend to be elevated and adversely affect the family functioning (Dyson, 1997).

Several studies (Beresford, 1994; Tunali and Power, 1993) have focused on the problems and care demands of the disabled and their behaviour towards peers, family and society, while fewer studies have focused on care takers, especially parents. Several strategies are identified to support the parents to provide care and to take care of themselves. Despite these, the informal support by way of familial, kin and neighborhood support etc. help them to manage their day to day affairs and help them integrate into the community living. Studies indicate positive outcome, subsequent on dependable active support. Hence there is a vital need to understand the parents and their problem, for better care of the differently abled children, other children in family, their own health and family wellbeing.

The parents of disabled children also face inferior status and discrimination in society and have to deal with the problems associated in their daily life where adaptation and coping are major issues. In addition, most parents desire to raise their children with special health care needs at home, though for some, individual circumstances and societal factors limit the family's ability to provide for their child's special needs. In developing societies especially, India family care is still the predominant system and formal support system are few and has limited reachability. Few studies (McDonald, Poertner and Pierpont, 1999) indicate that some parents make a smooth transition to what has happened and become their child’s most important support, yet in the process, the parents face various problems which are to be addressed. Mothers continue to carry the disproportionate burden in raising a disabled child, thereby being more prone to experience stress related to child care and often demonstrate depression, anxiety, health concerns, social isolation and low self-esteem. Social support provides scope for a range of experiences that will ultimately influence the development and behavior of the child and the entire family, (Dunst et al., 2000). In this back drop social support theory is significant to understand the problems and adaptation of the differently abled children and their family.
An overview of literature indicate problems of parental anxiety, care demands and stress but only a few studies (Frank, Floyd and Gallagher, 1997) linked the relationship between parental problems, care demands and support services for the parents. Questions arise why some parents adjust better and others do not. Hence in this backdrop the present study examines the parental problem, care demands and support services of the parents of differently abled children in Indian context. The study also examines the social behavior of differently abled children as they interact in society and utilization of support services intended for the differently abled. Understanding factors that can explain different patterns of parenting problems and how it relates to support services is a necessary step to design interventions to help parents adjust and manage situations and research is needed to examine the complex interrelationships.

OBJECTIVES
With a view to understand the issues related to children with disability, problems faced by the parents of differently abled children and the social support received by them, the following specific objectives are framed.

- To understand the parenting problems and care demands of the parents of differently abled children.
- To examine the social behaviour and social skills of differently abled children.
- To examine the social support to parents of differently abled children.

OPERATIONAL DEFINITIONS

Disability
Disability is one who is unable to ensure by himself, entirely or partially the necessities of a normal individual or social life including work as a result of deficiency, either congenital or not in his physical or mental capabilities (WHO, 2001).

Parental Problems
The daily hassles or difficulties arising due to the disability of children and perceived as problematic by parents are considered as parental problems.
**Care Demand**

The stressful care giving tasks and associated care of differently abled children, perceived as very demanding by parents is defined as care demand. Behavioral problems of the differently abled children, extra time to be spent by the parents in care giving, education and grooming of the differently abled children are important domains of care demand.

**Social Support**

The perception of parents that there is someone who could help them when needed in the domains of social, economic, moral and psychological needs is termed as social support.

- Emotional support relates to having someone who can listen sympathetically when encountering problems, express concern, care and acceptance.
- Companionship support relates to having someone for companionship to participate in formal, social and leisure activities.
- Service support is the availability of practical help in day-to-day routine tasks.
- Financial support is the provision of material aid in form cash or kind when needed.
- Informational support relates to providing information or linking persons or institutions providing information.

**Support Systems**

Support systems are the sources of support such as formal or informal systems (family, kin, friends, neighbours etc.) which provide support in the common and uncommon strands of support needs. It is reckoned through specific sources involved in emotional, financial, services, companionship and informational domains.
Social Skill

Social skill is defined in terms of an interaction between an individual and his or her environment and the skill acquired which enables an individual to adjust and respond appropriately to environmental cues.

Social Behaviour

Social behaviour of differently abled children relates to attachment behavior, ability to bond with caretakers, expressing normality when hurt or upset, and maintaining normal bodily gestures during social interactions.

RESEARCH DESIGN

The purpose of the research is to describe the social world of differently abled children, the problems faced by parents of differently abled children and examine care demand and social support. Hence a Descriptive-Explanatory research design is applied for the present study. The study is largely quantitative in nature supplemented by qualitative information.

MEASURES

To understand the care demand of parents, an organized and comprehensive framework proposed by Zeisler (2011) is used. It relates to strands associated with child related and family related issues, emotional problems and strain experienced by caretakers. Further a scale developed by Kim (2008) was applied to measure the social skills of the differently abled children. It comprises of items related to Self-control, Cooperation and Assertion. To assess the social behavior of the differently abled children, a comprehensive tool used by Dekker (2002) was adopted for the present study. It consists of domains such as Disruptive behaviour, Self-absorbed behaviour, Communication aspects and Anxiety level. The type of support and sources of support received by parents is ascertained through an index of strands, comprising of emotional, financial, informational, service and companionship domains.
Figure: 1 Map showing geographical location of the Thoothukudi District (Study Area)
RESEARCH SETTING

The research is carried out in Thoothukudi District which is situated in the southern part of Tamil Nadu, South India. The total area of the district is 4621 square kilometers. The district has eight taluks, twelve blocks, two municipalities, twenty town panchayats and four hundred and sixty eight revenue villages. Marine fishing, pearl and chunk fishing are the major occupations in the district. The total population of this district as per 2011 Census is about 17 lakhs. Many Government organizations like District Disability Rehabilitation Centre, Child Guidance Centre of Medical Department exists and Early Intervention Centre and Non-Governmental Organizations are available in Thoothukudi District. The District Disability Rehabilitation Centre (DDRC) was established by the National Institute for the Mentally Handicapped, Secunderabad during November 2000. Contact details and secondary information pertaining to differently abled children were elicited from this organization. The objectives of DDRC is to facilitate the provision of disability certificate, assessment on need of assistive devices, therapeutically services, to provide supportive and complimentary services to promote education, vocational training and employment for person with disabilities, providing orientation training to teachers and families, providing training to persons with disabilities for early motivation and early stimulation for education. Keeping in view of the local resources, it helps the differently abled to identify suitable jobs, so as to make the differently abled children economically independent and provide referral services for existing educational, training and vocational institutions.

STUDY POPULATION AND SAMPLING

The focus of the study is on the parents of differently abled children in Thoothukudi District. There are eighteen special schools for differently abled children in Thoothukudi district. The total strength of all differently abled children registered is 675 children in schools of which 620 students were in special schools and 55 were in normal schools. Among them, parents of 160 differently abled children were included and the parents were the sample for the study. Parents of differently abled children in the age group of 5 to 14 years are the study units and the target population. Respondents were identified from Special schools, Normal schools and other Government Organizations
where the disabled children are enrolled. Parents who came to these schools to drop and pick the children framed the sample. Parents were approached through the teachers and some parents were approached through other parents and those who agreed to participate were included for the study. Through this, the details regarding the parent’s problems, care demands and social support received by the parents of disabled children were collected. Hence, a purposive non-probability sample of 160 respondents, identified through referrals and snowball sampling technique has been included for the present study.

TOOLS OF DATA COLLECTION

The study is based on primary data and the information is collected from parents of differently abled children. Interview schedule was used to collect data and it consists of questions related to background factors of parents and their children, history of disability of the children, parental problems and care demands, social skills and social behavior of differently abled children and social support services. With the constructed schedule, a pre-test was carried out among 20 parents of disabled children to decide upon the appropriate measurement. The pre-test helped in defining the parental problems, care demands and social support services in finalizing the questions to be adopted to elicit information. Based on the experience gained from pre-test, the interview schedule was reframed and a few additional questions related to social support and care demands have been incorporated for the study. Later, the schedule was translated into Tamil, the local language and information was elicited from parents. Supplementary information is collected through case studies, which form a subset of the sample. Pertinent information relevant to the present study was collected between April 2013 and December 2013. In many cases several sittings were required to complete the interview.

STATISTICAL TECHNIQUE

The collected data were edited, coded and analyzed through SPSS package. Simple descriptive techniques like percentages, proportion and mean were used to portray the basic information and bivariate tables were used to examine the association. Correlation and Regression are used to understand and explain social skills, social behavior and social support.
FIELD ENCOUNTERS

A comprehensive study of parents and their problems led the researcher to have an understanding of their current situation. But still, it was not easy for the researcher to get the required information from the parents as they had difficulty in spending time since they were fully engaged with demands related to their differently abled children at home as well as at school. Since they need to take care of their children’s activities, several sittings were required to collect information. Comparatively mothers were ready to share the problems of their children than fathers, as in most cases only mothers were spending more time with their children in schools as well as in home. Similarly, it was difficult to interact with teachers as they were also stressed with time and only during break hours, the researcher was able to receive the required information. Regarding the secondary data the researcher approached the District Collector Office and, District Disability Rehabilitation Centre to collect information on Schools and censes on disability. But adequate data was not available within the government departments to lead the research and so the researcher relied on other supportive sources. Overall, the researcher was able to get the necessary information with the co-operation of the parents, teachers and the institutions (i.e. schools) where the primary data has been collected.

CHAPTERIZATION SCHEME

Chapter I: Introduction

Chapter II: Review of Literature

Chapter III: Methodology

Chapter IV: Profile of Parents and family

Chapter V: Parental problems and care demands

Chapter VI: Social behavior and Social skills of differently abled children

Chapter VII: Support systems

Chapter VIII: Summary and Discussion