

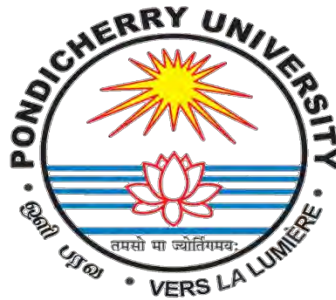
**PARENTAL PROBLEMS, CARE DEMANDS AND
SUPPORT SYSTEMS FOR PARENTS OF
DIFFERENTLY ABLED CHILDREN**

Thesis submitted to
Pondicherry University in fulfillment of the requirement
for the award of the degree of

Doctor of Philosophy
in
SOCIOLOGY

Submitted by
A. BLESSIE RAJAREENA

Under the Guidance of
Dr. C. ARUNA
Assistant Professor



DEPARTMENT OF SOCIOLOGY
SCHOOL OF SOCIAL SCIENCES AND INTERNATIONAL STUDIES
PONDICHERRY UNIVERSITY
PUDUCHERRY - 605 014
INDIA
APRIL 2015



Dr. C. Aruna
Assistant Professor

Pondicherry University
School of Social Science and
International Studies
Department of Sociology

Silver Jubilee Campus
Puducherry-605014
Ph: (O) 0413 – 2654496
(R) 0413 – 2655051
Mobile: +91 9486747787
E-mail: caruna_lect@yahoo.co.in

CERTIFICATE

This is to certify that the thesis entitled “**PARENTAL PROBLEMS, CARE DEMANDS AND SUPPORT SYSTEMS FOR PARENTS OF DIFFERENTLY ABLED CHILDREN**” is a record of original research work done by **A. BLESSIE RAJAREENA** in the **Department of Sociology** as a **full time Ph.D.** Research Scholar during the period of study 2009 – 2015 under my guidance and supervision for the award of the Degree of **Doctor of Philosophy in Sociology**. I further certify that this research work has not previously formed the basis for the award of any other Degree or Diploma or Associateship or Fellowship or other similar title to any candidate of this or any other University.

Counter Signed
Head of the Department

Signature of the Guide



Pondicherry University
School of Social Science and
International Studies
Department of Sociology

A. Blessie Rajareena
Research Scholar

Silver Jubilee Campus,
Puducherry-605014
Mobile: +918870694525
Email: blessree@gmail.com

DECLARATION

I do hereby declare that the thesis entitled “**PARENTAL PROBLEMS, CARE DEMANDS AND SUPPORT SYSTEMS FOR PARENTS OF DIFFERENTLY ABLED CHILDREN**” submitted to Pondicherry University, Puducherry, for the award of the Degree of **Doctor of Philosophy in Sociology**, is a record of original and independent research work done by me during 2009 – 2015 under the supervision and guidance of **Dr. C. ARUNA** and it has not previously formed the basis for the award of any other Degree, Diploma, Associateship, Fellowship or other similar title to any candidate of any other University.

Date:

Signature of the Candidate

A. Blessie Rajareena

ACKNOWLEDGEMENT

*I express my profound gratitude to my research supervisor **Dr. C. Aruna**, Assistant Professor, Department of Sociology, Pondicherry University for her guidance, incredible motivation, cooperation and benevolent care to make all these happen. This quest of my career dedicates itself only to her moral support.*

*I deeply feel obliged to **Dr. G. Ramathirtham**, Head, Department of Sociology, Pondicherry University, for his encouragement and valuable suggestions throughout the course of the study.*

*I am highly indebted to the Doctoral committee members **Dr. B.B. Mohanty**, Professor, Department of Sociology, Pondicherry University and **Dr. B. Rangaiah**, Associate Professor, Department of Psychology, Pondicherry University for their valuable inputs and suggestions in the Doctoral Committee Meetings for the improvement of my work.*

*I extend my sincere gratitude to **Dr. Gulam Dastagir**, **Dr. Sudha Sitharaman**, **Dr. Pradeep Kumar Parida**, **Dr. Imtirenla Longkumer** and **Dr. Mansy M.** for their valuable support rendered throughout my presence in the department.*

*I express my thanks to the support staff **Mr. Mathivanan** and **Mr. Manohar**, Department of Sociology, Pondicherry University, for their support during my study.*

*I owe my thanks to **Dr. N. Ganeshan**, for his statistical assistance for my research work.*

*I thank **Pondicherry University** for providing University Fellowship and **ICSSR** for awarding me Open Doctoral Fellowship for my research work.*

*I am thankful to **District Rehabilitation Centre** for providing me secondary informations regarding school details of differently abled children. I profusely thank **Mrs. Meena** and **Mrs. Reeta**. I am indebted to the respondents of the study and my gratitude to them which cannot be sufficiently conveyed in a brief acknowledgement.*

However, this work would not have been possible without their kind cooperation and their patience in providing valuable information.

*I am greatly thankful to my friends **Dr. C. Balaramalingam, S. Sumithra, Manas Kumar Mallik, Chita Ranjan Das, Manosmita, Hemlatha Bhatt, C. Sathish, Debadatta Pradhan, Bineeta Dash, Deepti, Ankita, Nibedita, Papesh, Balaji** of my Department, who assisted me during the process of my research work and making my stay memorable in this university and also friends of other Departments **Thambi Durai, Manonmani, Panjali, Sathish** and finally all my friends and juniors.*

*Last but not the least, my words are insufficient throughout my life and beyond to acknowledge my parents', sister, brother, sister-in-law **Nancy Sam**, brother-in-law **Prince** and my husband **P. Lawrence** for their patience, inseparable support, prayers and moral boost to let me remain far away. I express my deep sense of gratitude to them. Above all I am grateful to the Almighty for the blessings to complete the work successfully.*

A. BLESSIE RAJAREENA

TABLE OF CONTENTS

CHAPTER NO.	TITLE	PAGE NO.
I	INTRODUCTION	1
II	REVIEW OF LITERATURE	11
III	METHODOLOGY	52
IV	PROFILE OF PARENTS AND FAMILY	61
V	PARENTAL PROBLEMS AND CARE DEMANDS	66
VI	SOCIAL BEHAVIOUR AND SOCIAL SKILLS OF DIFFERENTLY ABLED CHILDREN	83
VII	SUPPORT SYSTEMS	128
VIII	SUMMARY AND DISCUSSION	148

APPENDICES

- I - TABLES - BACKGROUND CHARACTERISTICS, SUPPORT AVAILABILITY
- II - CASE STUDIES
- III - BIBLIOGRAPHY
- IV - INTERVIEW SCHEDULE

LIST OF TABLES AND FIGURES

TABLE NO.	TITLE	PAGE NO.
1	Financial problems of parents	67
2	Employment/work related problems	68
3	Familial responses towards Disability	69
4	Problems in handling of Family responsibilities	70
5	Training of Parents of Differently Abled Children	71
6	Parental Awareness of Child Rights	72
7	Care Demand regarding Dependency of Children	74
8	Care Demand related to Family Issues	75
9	Care Demand related to Emotional Pressures	76
10	Physical and Emotional strain experienced by Parents	77
11	Level of Care Demand by Background factors	78
12	Correlates of level of Care Demand by Background factors	80
13	Regression results of Level of Care Demand by Background factors	81
14	Disruptive Behaviour of Differently Abled Children	84
15	Level of Disruptive Behaviour among Differently Abled Children	85
16	Level of Disruptive Behaviour by Background factors	86
17	Correlates of Disruptive Behaviour by Background factors	87
18	Regression results of Disruptive Behaviour by Background factors	88

19	Self-absorbed behaviour of Differently Abled Children	89
20	Level of Self absorption among Differently Abled Children	90
21	Level of Self absorption among Differently abled children by Background factors	90
22	Correlates of Self absorptive behavior by Background factors	91
23	Regression results of Self absorbed behavior by Background factors	92
24	Communication disturbance behaviour of Differently abled children	93
25	Level of Communication disturbance behaviour among Differently abled children	94
26	Level of Communication disturbance behavior by Background factors	95
27	Correlates of Communication Disturbance behaviour by Background factors	96
28	Regression results of Communication disturbance behaviour by Background factors	97
29	Anxiety behavior of Differently abled children	98
30	Level of Anxiety behaviour among Differently abled children	98
31	Level of Anxiety among Differently abled children by Background factors	99
32	Correlates of Anxiety by Background factors	100
33	Regression Results of Anxiety by Background factors	101
34	Social behaviour of Differently abled children	102
35	Level of Social Behaviour of Children by Background factors	102
36	Correlates of Social Behaviour by Background factors	103

37	Regression results of Social behavior by Background factors	104
38	Self control among Differently abled children	107
39	Level of Self control among Differently abled children	108
40	Level of Self control by Background factors	109
41	Correlates of Self control by Background factors	110
42	Regression results of Self-control by background factors	111
43	Co-operation among differently abled children	112
44	Level of Co-operation among differently abled children	112
45	Level of Co-operation by background factors	113
46	Correlates of Co-operation by background factors	115
47	Regression results of Co-operation by background factors	116
48	Assertive behaviour of differently abled children.	117
49	Level of Assertiveness among differently abled children	117
50	Level of Assertion by background factors	119
51	Correlates of Assertion by background factors	120
52	Regression results of Assertion by background factors	121
53	Level of Social skills among differently abled children	122
54	Level of Social skills by background factors	123
55	Correlates of Social skills by background factors	124
56	Regression results of Social skills by background factors	125
57	Social Behaviour and level of Social skills	126

58	Emotional support received by parents of differently abled children by category of Network.	130
59	Emotional support received by Parents of differently abled children by type of close kin	132
60	Emotional support received outside household by background factors	133
61	Financial support received by parents of differently abled children by Network category	134
62	Financial support received by parents of differently abled children by type of close kin	136
63	Financial support received by outside household by background factors	137
64	Informational support received by parents of differently abled children by Network category	138
65	Informational support received by parents of differently abled children by type of close kin	139
66	Informational support received outside household by background factors	140
67	Service Support received by parents of differently abled children by Network category	141
68	Service support received by parents of differently abled children by type of close kin	142
69	Service support received outside household by background factors	143
70	Companionship support received by parents of differently abled children by Network category	144
71	Companionship support received by parents of differently abled children by type of close kin	145

72	Companionship support received outside household by background factors	146
Figure 1	Map showing geographical location of the Thoothukudi District, study area	57

Significant developments in policy and practice for disabled children and their families have happened. Yet, research indicates that disabled children and their families continue to experience multiple disadvantages in terms of exclusion, unmet needs and physical and social barriers for full participation in society (Beresford, 1994). Hence the family as a unit is in need of support services for successful adaptation and integration in society. Differently abled children become dependent for reasons of being a child and having impairment and these dual reasons make them more vulnerable. In such demanding situations family members are usually the care givers, especially parents. Type of care giving varies across societies, with developed societies having access to more formal or institutional care, while developing societies grapple with inadequate formal support.

Research findings indicate that parents raising a child with disability experience more problems and demand than parents raising a child without disability (Ireys and Silver, 1996). The multiple effects of a single transition of a family member bring in counter transitions. Care giving at familial level is an „unexpected career“ that involves a process and requires adaptation and restructuring of responsibilities over time. Demands associated with lengthy care giving, financial costs, social pressures, other family members demand, physical and mental exhaustion, no alternate care givers etc. weigh heavily on the parents as a care giver. The process of adaptation is a major challenge and the social support from familial and non-familial members are the mechanisms through which they manage their requirement and situation. Therefore it becomes important to understand the problems and demands of parent as care givers and their support system.

Disability is a contextual variable, dynamic over time and is in relation to circumstances (WHO, 2001). In some societies it is viewed as abnormal as proposed by Medical model (Amundson,2000), while in some societies they are well integrated in to society, as in a few agrarian societies (Priestley, 1999), or understood to have special powers such as having an extra ordinary skill (Foucault, 1977). The alternate social model (Barnes, Mercer and Shakespeare, 1999; Oliver, 1996) observes that disability is a consequent on social construction (Levine, 1997), wherein the society imposes

restrictions, through negative social attitudes to institutional discrimination. Marx viewed it as a problem linked to changing mode of production and the disabled are „oppressed“ and treated as underprivileged (Oliver, 1990 and Priestley, 1999). In the process, attempts are more towards repairing the individuals „body parts“ rather than reforming the society to enable the differently abled to have a normal space in the society. As a result of the society“s differential approach, an individual with difficulty, even if it is a child, is looked down, stigmatized and ostracized. Hence the individual faces negative impact on personal growth and social development. It barricades and limits the expression of potentials and also learning skills for their normal day to day living.

According to WHO, „A differently abled child 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). It is estimated that more than a billion people across the world experience disability of which 93million are children in the age group of 0-14 years with moderate disability while 13 million experience severe difficulties. The functioning of a child should be seen not in isolation but in the context of familial and social environment. In developing countries they are exposed to multiple risks, including poverty, malnutrition, poor health and unstimulating home environments, which can further impair them in socio-emotional development (WHO, 2011). It is also observed that women and girls with disability are at a greater risk of abuse (UNICEF, 2011). The number of people with disabilities in India is substantial and likely to grow and disability does not “go away” as countries get richer.

According to the Census 2011, over 26 million people in India are suffering from one or the other kind of disability. This is equivalent to one fourth (22.4 per cent) of the total population. The statistics on adult disability shows more of women than men while among children, such gender difference is not noticed. Approximately 12 million children and 35.29 percent of all people living with disabilities are children. One third of most disabilities are preventable and reports indicate 80 percent of children with

disability do not survive past age forty. Another report by World Bank (2012) noted that children with disability, especially from scheduled castes or scheduled tribes are more likely to be out of school and if they attend rarely progress beyond the primary level which might lead to low employment chances and long-term poverty.

Differing combinations of structural factors such as caste and gender intersect with disability resulting in varied individual experiences, but the broad commonalities is marked by poverty and marginalization from mainstream social processes. Social attitudes and stigma play an important role in limiting the opportunities of disabled people for full participation in social and economic life, often even within their own families. India has one of the progressive disability policy frameworks but huge challenges operate in implementing the policy framework. A policy including family based care giving should be prioritized in addressing differently abled children and their families. Improving the social and economic participation of people with disabilities would have positive effects on everyone and not just the disabled people.

The parents are going through many stages of understanding and accepting their child's disabilities. Before the child's birth the parents may have had several expectations, but after the birth it turns to be an emotional struggle dealing with denial, anger, fear, etc. Families caring for and bringing up the child with disability can create strain in the family or social isolation due to the child's limited and lack of mobility or behavioral problems (McCubbin et al. 1982). However, when a child with a developmental disability also has behavioural problems, this has an added impact upon a parent's ability to undertake the numerous tasks associated with care giving, and thus increases the burden of care for parents.

Parental feelings toward a child with disabilities can include shock, anger, guilt, ambivalence, loneliness and sorrow (Murphy, 1982) and that the typically developing siblings of children with disabilities may experience similar reactions to the child with disabilities. Although individual reactions vary widely, anger, guilt, resentment, and shame are common feelings of the siblings of children with disabilities.

It is generally accepted that caring for a child who has a developmental disability can involve significant and prolonged periods of time and energy, completion of physically demanding and unpleasant tasks, and frequent disruption to family routines and activities.(Seltzer and Heller 1997; Shultz and Quittner 1998). As a result of these increased care-giving demands, it seems reasonable to assume that parents of children with disability are at an increased risk for high levels of care giving burden. It also involves financial strain in providing necessary medical needs, paying special attention to the child along with the psychological strain and burden on parents.

Several unanticipated problems arise for the families such as financial constraint to provide for necessary medical expenditure, special equipment for their easy mobility and independence, admitting in special schools, arranging special transportation, care takers in the absence of the parent, difficulties in entertaining the friends and relatives at their home, marriages for the siblings etc.

Parents go through intense emotional and psychological stress and may have fewer resources of emotional gratification. They may consider mentally handicapped child as a threat to their self esteem and view themselves as a source of disability. They struggle to cope with the financial costs and parents also are confronted with new and unexpected experiences. Parents with differently abled child may have higher levels of stress and lower levels of well being than those with the normal children (Rangaswamy and Bhavani, 2008). In addition, high levels of demand can negatively influence a parent's interaction with other family members and increase the risk of family maladjustment.

The problem also affects parent - child relationships and has important outcomes for the child. Higher levels of parenting problems lead to poorer social and emotional development and higher rates of behavioural problems in both deaf and hearing children. Anxious parents and family members expressed displeasure with doctors or other professionals over the lack of support, and displacement of anger was originally directed at the children with the disability (Pinkerton, 1972, Zuk, 1962). The parental problems

are associated with coercive parent-child interactions, influencing the parent's interaction with other family members and the risk of family adjustment (Thurnbull and Ruef 1996; Featherstone 1981; Friedrich and Friedrich 1981; Krahn 1993; McDonald et al, 1996; Blacher et al. 1997).

Parental problem is also associated with care-giving which includes difficulty of completing tasks involving a lot of time and managing the behavioural problems of children during the tasks based on the level of a child's disability. Chronic conditions of disability make extra demands on parents; resulting in stress (Tew and Laurence, 1975; Breslan et al, 1982; Stein, 1988; Miller et al, 1992). The children with disabilities have special needs that require more attention, greater vigilance and effort in physical, social and psychological aspects (Senel and Akkok, 1996).

Parents of differently abled children face unique situations as they have very less opportunities to explore their own needs and assistance to overcome their difficulties. Lower socio-economic status families are reported to be associated with more problems due to fewer resources (Samer off et al, 1987) and hence the child with a disability is regarded as a burden. Marital intimacy is more impaired when the child with disability is a female. Differently abled girls with intellectual disability are considered to be more burdensome with an increasing chance for neglect and abuse (Loeb, 1979).

Care giving is a crucial service and family is the main provider of long term care. Care giving children with special health care needs enters early into the life course of young parents and may reflect their life course trajectory. Caring for children with special needs can involve parents taking on care giving tasks that are often associated with nurses and other health care professionals. Individuals involved in the care of seriously disabled children are at risk of experiencing health problems (Talley and Crews, 2007). In addition, there is strong evidence that the work of caring for an ill or disabled family member has a substantial impact on health and well-being (MacDonald and Callery, 2007; Singer, et al., 2009). Pavalko and Henderson (2006) cite that caregivers consistently experience higher rates of depression than non-caregivers. Question arises

as to what is the real cause of this depression? Is it due to care work or the emotional impact of having an ill or disabled family member?

Family care is better for the care recipient than the institutional care, as it is consistent with professionals' views on the best provision of care. It is recognized that under conditions where families have an abundance of social, emotional, and material resources, the burden of care giving can be minimized (Cummins, 2001). However, the fact that very few real-life families enjoy such positive conditions, it remains questionable whether home care will provide optimal condition.

Care for children with disabilities within families is quite normal and is delivered often by family. The care of the child is an emotionally charged issue for the family and is considered crucial. The children are in demand of services for physical needs, emotional requirements and participation in society (Cummins, 2001). But family structures are changing in all societies, with smaller size, single parent families, older parents etc. The families also experience complex social circumstance. The seriousness of disability, along with pressure on time, income and physical ability of the care givers influences the stress related to care giving. The nature of care giving today is more complex as additional stressors and life experiences tax families (Chan and Singafoos, 2001; Singer et al, 2009; Talley and Crews, 2007).

Within family care givers are overwhelmingly parents, especially women. Parents also seek respite care, which includes grandparents, friends and other family members who care for a child, which is more often observed in developing societies. Respite care is also sought through the day care centres, special schools and professional providers, but such services are limited in some societies, including India. Several studies indicate the difficulties in care giving as care giver burden and care giver stress and emphasize an adverse effect on the family in terms of financial position, interpersonal relationship within family members and over all familial growth (Singer and Powers, 1993).

While some families despite the problems associated with bringing up differently abled child, adjust quite well (Cunningham, 1982; Fewell, 1986; Turnbull et al., 1986 a). But significant research gap exists in terms of understanding the care demand of care givers and how the families respond, especially in the Indian context. Parents caring for a child with disability problem have a strong likelihood of negatively well-being. If these parents experience high levels of distress and problems in functioning related to the challenge of caring for their child with Physical and mental health problems, they are likely to have more difficulty providing that care. Parents need to be functioning, as well as enhance the well-being of their child and assure their own well-being (Bode et al, 2000; Kazdin and Wassell, 2000).

When a parent feels overwhelmed by the stress associated with caring for their child with a disability, there can be negative implications for the child, the parent and the family as a whole (Gray, 2002). Children with developmental disabilities are often completely dependent upon parents to meet their needs. Parents may therefore find care-giving tasks more burdensome, and as a consequence experience higher levels of stress. Variation in parent stress is associated with care-giving and it also relates to the heterogeneity of childhood disability and especially in the task difficulty, time involved in tasks, difficult child behaviour and level of child disability matters. The view that children's disability induces more parental problem than children without disability has underpinned much research and professional practice but limited in the Indian context. Hence the issues of parenting a differently abled child and understanding their support systems in practice remains to be addressed and the present study will focus on it.

Parents of differently abled children face challenges in everyday living to cope with different stressful events. Parents need support and encouragement in their day to day tasks which changes as the children grow. Care givers with compromised mental and physical health are more likely to provide lower quality care and also at high risk for engaging in harmful behavior toward recipients.

As a result of extra demands of caring for a child with disabilities, caregivers must rely on family support service (Damaini, Rosenbaum, Swinton and Russell, 2004; Freedman and Boyer, 2000). Unlike professionals who provide similar care in institutions, parents may not receive regular breaks from care giving. As a result parents over time, experience health and social consequences related to care giving, a form of relief, such as respite care is an unmet need. Substantial research shows that certain child characteristics (child behavior, time of diagnosis) and indicators of coping (family cohesion, social support) are related to parental health.

Social support is identified to be an important factor in the functioning of families of children with disabilities. Families who have increased levels of support demonstrate less stress. The most effective support network is derived from help received by family and friends. However, the benefits of effective social support may be limited to families who have a less physically disabled, more socially acceptable child. In general, it is important for families to have an effective support system, regardless of the size of the network in order for them to be able to function effectively as a family.

The effectiveness of support networks has been found to be a more important factor for parental self-esteem. Thus a small, actively helpful group of friends or family is more effective at increasing a parent's self-esteem than a larger, less active support group. Social support is able to mediate personal well-being and can improve parental attitudes towards their children (Dunst et al., 1986b). The presence of social support may lead to more positive perceptions of the family environment as it is linked to more stable functioning, a more positive perception of the child, and enhanced parent-child relationship. The magnitude of reaction to disability is considerably less for individuals with good social support from close friends and family members than for individuals with inadequate social support.

Shuval (1981) points out that social support can attenuate one's subjective perception of a problem, and can act as a buffer, once a situation has been defined as disturbing. Social supports are primarily drawn from family members, close friends and

relatives, and other significant persons and are often the most basic, enduring, and immediate sources of social support. A second level of support includes neighbors, more distant friends and relatives, and certain professionals and service providers. Although less intimate, these sources of help are important for emergency and professional need. A third level of support is still less intimate, and is defined by superficial or infrequent contact, often in the context of social institutions (Unger and Powell, 1980).

Although each level of support overlaps with the next, these differing degrees of intimacy require somewhat different interpersonal skills which vary from individual to individual and family to family on a consensual norm. Certain support networks may contain elements of each level of support. Parents of developmentally disabled children have formed many effective self-help and advocacy groups but such organizations are limited in Indian context.

Some families are better able to generate internal support and become part of external social networks (Hirsch, 1981b; McFarlane, Neale, Norman, Roy and Streiner, 1981). A circumstance alone does not define an individual's social support system, but more important is the ability to skillfully interact with others (Gottlieb, 1981; Wrubel, Benner and Lazarus, 1981). The success of families seeking social support, in whatever form, will to a large extent depend on their social competence. Social supports and internal coping mechanisms are closely linked. Social supports can be viewed as complimenting personal coping, or as another form of coping taking over when internal mechanisms fail or subside.

Summing up, it is understood that problems of caregivers of differently abled children, especially parents are important but less studied, especially in Indian context. It is important that both the caregivers „the population at risk“ and also the „care recipients“, the differently abled children should be addressed adequately and the well being of the two groups are highly interlinked. Personal resources of parents, characteristics of the differently abled child and availability of support system impinge on the care demand. How do the care takers, especially parents manage is an important area of social research

that remains unexplored. Hence the present research attempts to describe the problems of care takers. In Indian conditions, the informal support systems are the active and available means, while formal support systems are relatively inadequate. If the informal system is functional, how it is utilized? These are the primary issues to be explored in the present study. In this back drop the research focuses on parental problems, care demand and support systems for the differently abled children.

This study will be one of the descriptive works in Indian context regarding the familial response to children with disability. The study provides scope to understand the vulnerability of children with disability and the care givers, especially the parents, which has a face of feminization in care giving. It also will explore the informal support dynamics and the unmet needs associated with it. Understanding behavior of children and care givers resources will enable the policy makers and people associated with them to deal with the issue of disability and link resources and ties of importance. Several research questions raise in the context of identifying specific parenting problems, demands etc. How does the resource equip the parents in managing their routine as well as in crisis situations? Who do they depend upon largely? How does the society treat them in the larger setup? These questions consolidate and become the rationale for choosing the research topic.

This study specifically aims to describe the parental problems, and focuses on the care demands faced by parents. It also ascertains the support services received by parents. Parenting problems, care demand and support systems are the major conceptual variables which link and direct the study.

A vast number of studies have been conducted to investigate the functioning of families having differently abled children. A good number of studies focused on the stress experienced by these families, particularly whether these families experience more stress than families of children with normal children. However, the effect of social support on families having disabled children are less emphasized in the literature. Social support has shown to have a moderating effect on stress, and much research has been conducted to determine the extent of this effect with families with a disabled child. These problems are largely day to day issues, like the prolonged burden of caring and managing emotional or behavioral problems of children with disability.

Studies pertaining to disabled children have been primarily based on their emotional and adjustment problems as they tend to experience maladjustment and personality disorder due to their disability. In one such study, Kammerer (1940) states a handicap, severe or mild in itself is sufficient to arrest the normal development of the individual and to cause maladjustment and personality disorder, while reported that emotional difficulties such as hostile withdrawal, sense of insecurity, lack of self-confidence and extreme timidity were due to a disabled person's unfortunate experience with siblings and parents. He found that the deformity not only places an individual at social and economic disadvantage but also plays a powerful role in determining the attitude of a disabled person towards oneself. Ringma and Brown (1991) also report that being disabled is not the sole cause of maladjustment, rather it seems dependent upon the number and severity of the problems which a disabled is confronted with.

A major portion of the research work is available on the visually impaired children, their parental care, care demand and support services. But not much of the work has been done on the cognitive, physical, hearing and speech impaired children and their various care demands and services. More so, only few works is available on the motor aspects of life. Besides personality and adjustment studies, a few researchers focus on the mental capabilities of the disabled. The study by Dial and Jack (2009) shows that sighted and blind children did not differ in their ability to think divergently. They also came to a similar conclusion that handicapped and normal children were equally creative in all factors of creativity test measures. Literature related to disability also gives

evidence of the impact of social and environmental forces on the development of intellectual and social competence of the disabled. It is reported that un-stimulating environment, cultural deprivation and poverty are the principal barriers which impede the proper growth and development of disabled persons.

Coming to the literature on specific disabilities, it is noted that with regard to blindness, voluminous work has been done about the cognitive characteristics of the blind. Like-wise several comparative studies have also been made between the congenitally blind and accidentally blind persons. In Indian context, though studies are carried out in this aspect is not very exhaustive, including pertinent areas like, etiology of disability, socio-economic status, educational level, vocational problems, different aspects of prevention and rehabilitation, social adjustment of the disabled, their integration etc. Studies on social adjustment of the blind undertaken by Vasudeva (1979) and Sinha (1982) studied about personality adjustment of the blind children with regard to adjustment with sighted peers, while they reported emotional maladjustment among blind students are to „broken homes“.

Studies related to deaf people pertain mainly to their intelligence level. Vernon (1969) after reviewing a large number of studies concluded that those children, who are deaf and have hearing problem have essentially the same distribution of intelligence as the general population, even though the mean score may be slightly less for the deaf children. Furth (1966) proposed that the deficiencies associated with the linguistic incompetence of the deaf could be overcome if non-verbal method of instruction and communication are more encouraged both at home in the earliest year and in formal school education. Studies further reveal that quality and quantity of the language and education that can be acquired by the deaf do not depend only on the intelligence level of the child but on many other factors such as early recognition of hearing loss, motivation of both the parents and the child towards learning.

In the field of orthopedically disabled empirical studies are much related to ascertain their intelligence and cognitive functioning. Some have even been directed on the effect of disability on personality development. Studies conducted by Kammerer (1940), Wright (1960) and Dembo (1975), among others touch on attitudinal problems of

the orthopedically disabled. In Indian context, Bhatt (1963) has undertaken an earnest effort to present the problem taking into consideration all the relevant facts and figures, reports and returns regarding the physical, psychological, social and vocational rehabilitation of the physically disabled. In the social and psychological fields, the study revealed that the attitudes of the members of the family towards the disabled individual were not in all cases desirable. Almost one-fourth of the total cases were either emotionally rejected or virtually deserted by their families on account of their disablement. Shankar (1976) in his work gives a detail account of different types of child disability, its causes and the need for facilities appropriate to their rehabilitation.

Studies show that birth of disabled child make parents hopeless and negative attitude developed towards their child (Ramaswamy, 1989). Speedwell et al. (2003), in their study, mentioned that parents of sick or disabled children are likely to be more stressed than parents of non-disabled children. They also mentioned that information regarding the welfare of children is beneficial for parents but sources of information have not given much importance in studies.

The birth of a child with disability causes lots of fundamental problems for parents. For some parents, these feelings of failure and loss of self-worth are temporary and for others, these emotions may last for a lifetime. What can be said with certainty is that the process of adjustment for parents is continuous and distinct (Hardman, Drew, Egan and Wolf, 1993). It indicated that parents may react very differently to the child and the mother sometimes took the role of physical protector and guardian for the child's needs, while the father mostly remain reserved in-his role. He may cope by handling the situation carefully by internalizing his feelings.

Mehta (1983) in the book entitled "Handbook of disabled in India" surveyed the problems abroad and in the context of National scenario. The author also covered the categories of the disabled, specifically disabled groups, facilities and concessions available and allied matters in more elaborate way, which helps for the better understanding of disabled children.

Seiquira and associates (1990) marked that more than 50% of the mothers of mentally retarded children were having severe financial burden and also reported 61% of parents faced financial constraints while providing care to these disable children. Many earlier studies on mentally retarded children also reported rising financial burden because of two reasons, one is additional expenditure involved in caring for the mentally retarded children and the other is reduced sources of income because the parents had to spend extra time in parenting severely retarded children. (Mc Andrew, 1976; Seth, 1979; Veena, 1985).

Theoretical Perspectives on Disability

In recent years, the traditional medical model of disability has been challenged and alternative models emerged in various fields of humanities and social sciences, such as anthropology, political science, history, literary and cultural criticism, and disability studies (Barnes, Mercer and Shakespeare, 1999). The critical themes emanating from these arenas have examined the role of social and cultural factors in the development of the category of disability (Ingstad and Reynolds-Whyte, 1995; Priestley, 1999; Stiker, 1982); through the social model of disability. Marxist and political economy perspectives discuss the relationship between disability and the emergence of industrial society (Oliver, 1990, Stiker, 1982); the growing field of disability studies (Linton, 1998); professional domination experienced by people with disabilities (Foucault, 1973, 1977; Sapey and Hewitt, 1991); a critique of the discourse of normalcy (Amundson, 2000; Davis, 1997b) and the discourse of measurement (Cintron, 1997; Witkin, 2001); feminist theories (Garland-Thompson, 1997a; 1997b; Wendell, 1996; 1997); and disability arts and culture (Barnes, 2003; Oliver, 1996). It is noticed that the histories and experiences of people with different disabilities, such as physical disabilities, developmental disabilities, and mental health problems, are not homogeneous. However, once a human condition fits into disabled criteria many similarities emerge that comprise the overall experience of disability.

Social and cultural constructions of disability

Social constructionist framework to disability described constructionism as a theory that seeks to “elucidate the socio historical context and ongoing social dynamic of descriptions, explanations, and accountings of reality”. Rather than taking theory and the dominant forms of understanding as definite conclusions, implicit in social constructionism is the idea that knowledge is not an objective entity, but rather a social creation (Levine, 1997). Constructionism devotes particular attention to the ways in which knowledge is historically situated and embedded in cultural values and assumptions, socio-cultural norms, and language (Patterson, 1997). From the constructionist perspective, language serves as a method for producing meaning and generating knowledge rather than a representation of an objective “truth”. Constructionism as an epistemology, therefore, contributes a liberating quality to the social sciences by way of alteration to the monolithic landscape of positivism and scientific inquiry (Witkin, 1990).

Social constructionism can offer significant insight to contemporary conceptualizations of disability. Most individualistic (personal-tragedy) accounts of disability fail to recognize that even the most objective of disorders, such as visual impairment, do not exist independent of culture and society. The contemporary language of disability, with its individualistic representations of personal tragedy suggests that disability and impairment exist independent of cultural, historical, or other contexts (Brzuzny, 1997). While the emphasis on the influence of society and culture on human behavior has been widely accepted in several academic arenas (anthropology, cultural criticism, sociology etc), and the constructionist perspective asserts that a disability-related impairment comes from the relationship of the person with a disability to the socio-cultural environment; thereby the environment is seen as the primary target of intervention. (Gilson and DePoy, 2002).

Drawing from cultural studies, the cultural construction of disability questions the enlightenment idea of a rational, progressive human actor in society. It scrutinizes knowledge to deconstruct the unstated assumptions about disability and people with disabilities. The subjective experience of disability and both the explicit and implicit

assumptions that shape the disabled experience have been suggested by a large number of ethnographic studies undertaken by anthropologists (Groce and Scheer, 1990; Ingstad and Reynolds-Whyte, 1995; McDermott and Varenne, 1996). How disability is understood in different cultures. How are deficits of the body and mind interpreted and dealt with in different societies? How is an individual's identity as a person affected by the cultural connotations of disability? How do processes of cultural transitions shape the local understanding of disability? Definitions of disability in terms of measurable functional limitations fail to recognize that culture permeates the variations of the human condition with consequences much deeper than the simple ability to perform a given task (Ingstad and Reynolds-Whyte, 1995). Objective criteria of functional limitations do not answer the question of how important is individual ability as a source of social identity in different cultures.

The experience of disability, too, varies across cultures. Edgerton (1985) studies showed societal attitudes toward people with impairments varied greatly in non-Western cultures, from negative discrimination, to acceptance, and to positive attribution of supernatural powers. Disability is, therefore, hardly a unitary concept. Understanding disability as a socially and culturally constructed phenomenon, rather than as an inherent objective "reality" calls into question the presuppositions of the medical model that form the foundation for agenda of human rights/social justice. In this regard, constructionism provides a theoretical framework to rethink disability in liberating and empowering terms.

A Social Model of Disability

The social model of disability was first put forth in the United Kingdom in a 1976 statement by the Union of the Physically Impaired Against Segregation (UPIAS, 1976). It was later discussed in detail by Corker (2000), Finkelstein (1980) and Oliver (1983, 1990, 1996). 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 are fully taken into account 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.

While it is acknowledged that the relationships of people with disabilities to their bodies involve elements of pain and struggle that perhaps cannot be eliminated or mitigated, yet many of the barriers that people with disabilities face are the consequences of having those physical impairments under existing social and economic arrangements, especially the means of industrial production. These social and economic systems could but do not accommodate disabled people's physical conditions or integrate their struggles into the cultural concept of everyday life (Asch and Fine, 1988) and hence viewed as "oppressed"(Pfeiffer, 1996).

The social model of disability says that disability is caused by the way society is organised. The medical model of disability says people are disabled by their impairments or differences. The medical model looks at what is 'wrong' with the person, not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their own lives.

Social Comparison Theory

Social comparison theory is a theoretical orientation that is now considered to have influence in the field of intellectual disabilities (Dagnan and Sandhu, 1999). According to this theory, one's self-concept is largely determined by the ways in which one is treated by significant others. Social comparison research emphasizes that, in situations where the self concept is threatened, there are three possibilities: people may minimize comparisons (Brickman and Bulman, 1977), avoid upward comparisons (Steil and Hay 1997,) or try to self-enhance by making downward comparisons (Crocker, Thompson, McGraw and Ingerman, 1987). In the face of a threat to self-concept people may prefer to compare themselves with others they perceive as „worse off“ than themselves. This can result in an increase in subjective well-being because downward comparisons appear to boost self-concept and reduce anxiety (Gibbons, 1986).

Social comparison theory (Gibbons, 1986; Szivos-Bach, 1993) predicts that comparisons with „normal“ groups and as such their self-concept will decrease because of negative frame of reference effects (Wills, 1991; Buunk, Collins, Taylor, Van Yperen and Dakof, 1990) because participants may view context in different ways (Haslam and Taylor, 1992) and display „selective industry of the mind“ (James, 1890). For example, people may choose to make either upward or downward comparisons and be quite selective as to which groups they use for comparison.

Leary, Tambor, Terdal and Downs (1995) found that rejected people, such as people with disabilities who have been institutionalized, showed greater negative feelings than a comparison group drawn from the normal population. Another study also showed that behaviours or situations associated with exclusion are also linked with decrements in self-concept (Suls and Wheeler, 2000). In a study that examined the relation between social comparison, self-concept and depression for people with intellectual disability, Dagnan and Sandhu (1999) concluded that social comparison self-concept and depression are interacting in the same way as they do for people without an intellectual disability.

Social Approaches to Disability

According to many disability scholars, individualistic approaches (especially the medical model) are biased and lead to practices and social arrangements that oppress disabled people. Interventions are aimed solely at the “abnormal” individual, whereas the surrounding community is left intact. Resources are not directed to changing the environment but to, for example, medical treatments with the aim to “improve” the impaired individual. This leads to a social and moral marginalization of disabled people and restricts them from full participation in society.

This criticism has been presented by a large number of theorists who take a social approach to defining disability. Some of them claim that disability is the result of oppressive material arrangements in society. This position is called the social creationist view of disability. In this perspective, it is essential to grasp the distinction between „physical impairments“ and the social situation, called “disability,” of people with impairments. Impairment is defined as “lacking all or part of a limb, or having a defective

limb, organism, or mechanism of the body,” whereas disability is “the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities”. The core idea of the social creationist view is that disabled people are an oppressed social group. Their inferior status is not a natural effect of their impairment, but it is produced by unjust social arrangements. Disability is seen as the material product of socioeconomic relations developed within a specific historical context. In this approach, the main attention is directed to the disabling barriers and material relations of power.

Parenting Problems

Problems like Stress in families of differently abled children has been well recognized (Dyson, 1993; Krauss, 1993). Raising a child with disability is one of the strenuous jobs that any parents face. Disorders such as Autistic Spectrum Disorder (ASD) or Down syndrome leaves parents with little hope that their child will ever be able to live a normal life. However, Parents of children with ASD have been found to experience more stress and adjustment problems than the parents of children with Down syndrome, who in turn reported more stress and adjustment problems than parents of typically developing children (Sanders and Morgan, 1997). It is reported that, many parents are able to cope well with the demands and requirements of their child, however others will require supportive counseling by a professional who will be able to help them to tackling the problems.

Raising a child with disability a profound impact on the family, firstly as parents come to acknowledge that the abnormality of child. Parents thus have to first deal with the fact that their child is different to other children, and will require special attention throughout their lives. Some of the problems that parents may face are the economic support for providing a disabled child, time demands of intervention therapies, possible social isolation due to a child’s mobility or behavioral problems and strained family relationships (Beckman, 1983).

Duis, Summers and Summers (1997) analyzed Parents versus child stress in diverse family”, and found that parents of children with Down syndrome or with developmental delays experienced more stress than the parents in families who did not have children with disabilities. Tannila et al. (1999) also attempts to clarify the coping mechanism of families with physically and/or intellectually disabled children. The parents of eight children (aged 8-10years) with physical and intellectual disability were interviewed and analysed qualitatively using the grounded theory method. This study found that co-operation and social support as related to the coping strategies are most frequently used. Half of the families seemed to have found successful ways of coping, whereas another half had faced major problems regarding this. There were five main domains in which the high and low coping families differed from each other, such as parent’s initial experiences, personal characteristics, affects of the child disability on family life, acting in everyday life and social support. However the study concluded that development of supportive activities for families with disabled children provides a greater support to the parents. As the role of physicians, nursing staff and other professionals in this process is very important, more attention should be attached to the collaboration between these groups, to enable them to observe the situation from the perspective of the whole family.

Differently Abled Children and its Impact on Relationships among the Family Members

Associated stressors such as the child’s ability, age, and birth order or behavior problems can have an impact on relationships between other members in the family, and can affect the marital relationship. However, the effects may be ameliorated in the presence of certain factors. Firstly, the child’s characteristics can have important effects. Studies have shown that mothers are generally no more stressed than fathers, yet fathers are generally more distressed by their child’s inability to speak, whereas mothers are more distressed by more visible symptoms, such as inappropriate or stereotypical behaviors (Konstantareas and Homatidis, 1989; Ricci and Hodopp, 2003; Frey, K.,Greenberg, M.T., and Fewell, R. R., 1989). Parents of children with less disability may thus experience less emotional distress as there are fewer characteristic or behavioral

factors to influence their coping abilities. Fathers may also be more affected by the gender of their child than mothers, as fathers may be at greater risk of being unable to develop affective ties to their child, particularly if the child with a disability is a son. Main pressure for both mothers and fathers can include having a premature child, and unable to look after the child and their development. In addition, mothers also feel helpless and sometimes derived support from social support networks (Krauss, 1993). While these factors can act as stressors for both mothers and fathers, for maternal employment status can act as a buffer of stress (Warfield, 2001), as mothers have another area to focus their attention and they are not solely spending time being a mother of a disabled child. However, this may also be viewed as a strenuous job, if mothers are working full-time and may be left with little energy to deal with their child at home.

Maclead and Williams (1992) look into factors influencing the functioning of families with mentally retarded person. Results demonstrated that the importance of characteristic of fathers to maternal coping skills in two parent's families and also maternal coping scores were not statistically different between both parents and single parent's households. Single parent's mothers also appeared to be considerably more dissatisfied with family functioning in study on stress in different types of family. In a study examining the relationships between parenting stress and social support, they interviewed 50 caregivers having children with mental handicaps and found that the perceived availability of emotional support from spouses was the most effective way of reducing parenting stress. Nevertheless, all caregivers were recruited by a convenience sampling method that might have resulted in a biased sample. Moreover, the data was collected through self-completed mailed questionnaires so the response rate, understanding and thoroughness in answering the questions could not be controlled.

Singh et al. (2008) focused both positive and negative impact of disability on the parents of disabled children. This study shows that it is not necessary that every family of retarded children will have negative impact but in some families this problem can create a positive impact, like "acceptance of situation realistically", „standing right behind the retarded child and provide support“. The study also highlights that most of the parents of the selected retarded children viewed that they have more "positive impact"

than “negative impact”. To these parents having a mentally challenged child in a family is not a “burden like thing” but they accept the situation more positively and overcome the situation more gracefully. This study concluded that having an intellectually challenged child is not altogether a sign of so-called “bad fate or misfortune” to everyone, but it can also be a challenge which strengthens the parents of these children.

Parish et al. (2008) indicates the material hardship of families raising children with disabilities. Types of hardship include the following; food insecurity, housing instability, health care access. Result shows that families having disabled children experienced greater levels of material hardship. Further, it is also found that hardship declined significantly for families raising children with disabilities when income rose above the poverty level.

Wallander, Pitt, and Mellins (1990) have studied on maternal stress, child independence, and maternal adaptation. 119 mothers were interviewed who have children with cerebral palsy, spina bifida, or hearing impairments between the ages of 2 and 18 years old. Wallander et al. (1990) showed that maternal stress was directly related to maternal mental health, and adaptation was not related to his/her child’s independence.

McDonald, Poertner, and Pierpont (1999) surveyed 259 families having children between the ages of 3 and 14, coping strategies of parents, perceptions of the child, and parenting stress. Findings revealed various patterns of care giving while, child, family, and environmental characteristics as predictors of parenting stress. Child characteristics, such as internalized and externalized behavioral problems contributed to stress, and in particular, the more severe internalized problems were associated with greater level of parenting stress.

Differently Abled Children and Family Resilience

Numerous studies suggest that these challenges may place additional pressure on family relationships. Studies by Dyson (1997) and Cohen (1999) indicate that those mothers and fathers of school-aged children with disabilities experience greater and more frequent stress because of their parenting demands than parents of children without disabilities. Others (Seltzer et al., 2001) found that parents of children with disabilities

report lower rates of social participation than parents of children without disabilities, perhaps due to increased financial problem and more demands for child care. Finally, result shows that having a child with poor health is negatively associated with the parental relationships.

Dyson (1997) found that parents of disabled children [children with mental retardation (13), physical/sensory impairments (11), speech disorder/learning disability (4), and developmental delay (2)] experienced similar levels of stress and that their stress was much higher than that of parents with non-disabled children. Keller and Honig (2004) also looked at stress from a gender standpoint and found that parents have similar level of stress overall but that the expression of that stress differs: fathers rated higher on child temperament, personal relationship and emotional attachment to their disabled child, while mothers experienced more stress in health, role restriction, and their spousal relationship.

Furthermore, the type of stress experienced by parents of a child's disability is not same. Previous research suggests that mothers express more concern than fathers over the daily tasks related to the care of children with disabilities (Pelchat et al., 2003), which help to explain that why fathers are more likely to worry about emotional attachment with their children (Krauss 1993 and Cohen 1999). Compared to mothers, fathers also report financial stress. Gray's (2003) research on gender differences in the parenting of children with autism found that fathers placed a higher level of importance on their „work role“, and their corresponding ability to provide economically for their child's medical care and future independence. Finally, in coping with these stress, it is also suggested that fathers are less likely seek social support for parenting a child with a disability than mothers because many of their male friends do not offer or know how to help them (Chesler and Parry 2001).

Several studies have been conducted on stress in families with differently abled child using the Parenting Stress Index. For example, Smith, Oliver, and Innocenti (2001) studied levels of parenting stress in families with a toddler with a developmental delay. Eight hundred families were assessed with the Parenting Stress Index to measure

perceived stress related to parenting, and the Family Support Scale and the Family Resource Scale to measure perceived support, time, and resources in the family. Smith et al. (2001) found that the more severe the child's disability and little family's resources, the greater the parent stress in the family.

Having a disabled child not only adds stress, but changes the nature of the stress experienced both financially and interpersonally. Part of the stress experienced by these families may be explained by the amount of time parents of disabled children spend in caring for their children and the potential of added financial burden related to their care (Curran et al. (2001) compared the time costs of caring for severely disabled children with that of caring for non-disabled children in the United Kingdom. Sixteen families with physically or mentally disabled children and thirty-one families of non-disabled children participated in the study. It was found that the disabled children required more care than normal children and the intensity of personal care did not decrease with age as it did for normal children. In addition, mothers from 12 of the 16 families with disabled children reported they were unable to return to work due to care of their disabled child, and the financial burden for caring differently abled child was great.

Hartshorne (2002) discussed family resiliency as a strong resource for parents when living with and caring for a severely disabled child. The paper notes that courageousness can be assisted by the parents' social support group and professionals. He suggests that parents will appraise their child's disability through their lifestyle which can have a large effect on how they experience stress. Hartshorne encourages professionals to support family resilience through encouraging parents to find resources that are helpful to them and providing information adequate to their needs without overwhelming them with data, thereby running the risk of discouraging them. Parent networking through formalized support groups and less structured means, such as the internet; help provide emotional support and further access to resources (such as supplies related to their child's care). This study looks at the strength and positive aspects of a parent's courage and resiliency and provides suggestion to professionals in the medical and mental health field, in the interest of educating them as to the best way to assist them.

Gerstein et al. (2009) attempts to study the flexibility and the course of daily parenting stress in families of young children with mentally challenged. The background of the study shows parenting stresses have consistently been found to be higher in parents of children with mental disabilities, yet some families are able to be resilient and thrive in the face of these challenges, despite the considerable research on stress in families of mental disabilities, there is still dearth of research about the stability and compensatory factors associated with everyday parenting stresses.

Problem Faced by the Family

Reichman et al. (2008) review the impact of child disability on the family and suggest several ways to differentiate a child with a disability from parenting a child without a disability. Children with special health care needs often require additional primary care as well as more specialized and long-term medical care. Functional limitations may necessitate structural or technical modifications in the physical home environment. A child's disability may require parents to seek educational and recreational accommodations to ensure that the child has opportunities that are more equal to those of children without disabilities. Finally, as the child grows, specialized rehabilitation programs may be necessary to ensure a positive transition to adulthood. While there are numerous programs and organizations are there to provide parents of children with disabilities with social and financial support, navigating and coordinating these useful programs can be a challenge. Overall, the parents of a child with a disability may encounter a unique set of challenges that are not faced by parents of a child without a disability.

Families with a child of disability experience financial adjustments that make daily living very different from that of families with typically developing children (Parish and Cloud, 2006; Sen and Yurtsever, 2007). Financial stressors include medical insurance, child care, professional services, equipment, transportation, and work disruptions, depending on the severity and type of disability. Mothers of children with a disability reported having inadequate financial support. Additionally, research shows that families with differently abled children are at greater risk of living in poverty when compared to families with a child without a disability.

Social-emotional adjustments related to having disabled child include changes in hopes, dreams, expectations, anxiety, depression, distress, and both familial and non familial relationships. The relationship between the child with a disability and his/her parents has been shown to be associated with behavioural and social-emotional qualities of the child. Children with more severe disabilities also were found to have more social-emotional and behavioural concerns than those with less severe disabilities. Marital strain has been found to be greater in families with disabled children. In one study, approximately 25% of the couples with a child with a disability reported distressed marital relationships (Kersh, Hedvat, Hauser-Cram and Warfield, 2006). In a study of 2,000 families with disabled children, almost half reported that they felt greater marital strain due to the disability. Approximately one-tenth of the couples were separated due to the stress on the family, and one-sixth of the couples had divorced. One factor that reportedly influences marital distress is severity of behaviour associated with a disability.

Research has also shown that mothers are more mostly affected by the challenges of raising differently abled child than are fathers. Research has demonstrated that parents of disable children not only report higher levels of stress, but also lower togetherness and poorer health than parents having normal children (Oelofsen and Richardson, 2006). In a comparison study of 104 families with a preschooler, half of whom had a disability and half of whom did not have any disability, parents completed a variety of questionnaires. Using the Sense of Coherence questionnaire, the Parenting Stress Index, the Health Perceptions Questionnaire, and the Family Support Scale examined coherence, stress, health, and support in families with disabilities including autism, cerebral palsy, muscular dystrophy, Down syndrome and developmental delays. It was revealed that mothers of differently abled children reported poorer health, lower coherence, and higher levels of parenting stress than fathers of children with a disability, but this was not the case parents of children without a disability. Parents of children without a disability reported no significant differences between their ratings of health, coherence, and stress.

Care Giving

Caring for a differently abled child forces a family to adjust, extraordinary physical, financial, and emotional stressors. These Parents often reported lower scores on subjective wellbeing and higher scores on feelings of depression than parents of children without special needs (Oelofsen and Richardson, 2006). A number of studies have shown that much of the stress reported by mothers than fathers because of increasing responsibilities and demands in raising, caring for, and providing for their children due to the disability. Mothers of children with a disability report more psychological distress than others.

The siblings of differently abled children did more extracurricular activities to help and motivate them and are more responsible with regard to financial concern of the parents. Dyson (1988) examined co-existence of siblings of developmentally disabled children and siblings of non-disabled children. Adjustment was measured based on self-concept, behaviour problems, and social competence. Interestingly, brothers of disabled children showed less unusual and isolated behaviour and were less hostile, and had fewer external behaviour problems than siblings in the control group.

Tadema and Vlaskamp (2009) focuses on “The time and effort in taking care for children with profound intellectual and multiple disabilities: which indicate care load and support”. This study examines the type of basic needs caring tasks of parents in the Netherlands on a broad range related to health and basic needs. These perceptions of parents concerning to the care-load are emphasised. Furthermore, the relationship between the actual caring task and the subjective burden of parents is examined related to the child’s age. Twenty five centres for special education throughout the Netherlands were asked to distribute the questionnaire among parents of children from 0-18 years with PIMD and still lived at home, in which Parents of 133 children participated in the study. Their children had a mean age of 8.8 years. The caring task and subjective burden of parents was related to the child’s age, the sample was divided into two age groups. A questionnaire was developed to take into account the care-load, burden and support of parents. However, study focused on both burden and support of parents. Most children are dependent on them for fulfilling all their basic needs and have several health

problems. Significant relationships were found between the number of times parents have to get up at night and the level of burden at night and between the days a child stayed in hospital and the level of parental burden. In this study the results indicate that the caring task places heavy demands on parents in which Professional support is extremely important for parents. The caring task is not necessarily indicative for the subjective burden of parent's experience. Parents of young children express higher levels of burden than parents of older children. In this research both respite care and home support services are valued positively.

Gender differences in Caring of the differently abled children

With regard gender differences, in coping with the stress of parenting a child with a disability, several studies found serious gender differences in parenting behaviour. Co-resident fathers of a child with a disability are less likely to be primary care givers (Green 2003; Foster et al., 2004), have demonstrated greater engagement in social activities such as playing, nurturing, and discipline, as opposed to the instrumental activities of hygiene, teaching, therapy, and feeding (Simmerman and Blacher, 2001). Fathers are also less likely to be involved in a child's treatment, and interact less with health care providers (Hauenstein, 1990). Pelchat et al. (2003) study of parents of children with Down syndrome suggests, this may be because fathers have difficulty in admitting that their child has limitations, and feel greater discomfort from the social stigma generated by their child's disability.

Vidhya and Raju (2006) examined the level of adjustment and attitude of parents of disabled children. Sample consists of 50 parents (either mother or father) of mentally retarded children. Though many factors influence the well-being of a family, one factor is certainly the emotional and physical health of the parents. Parents are definitely the heart of the family. They are the ones who deal with the issues associated with their child's disability and they are also required to maintain the household. Therefore, it is very important as parents to take some time to care for oneself as individuals.

Kersh, Hedvat, Hauser-Cram and Warfield (2006) found that parenting stress and depression for parents of developmentally disabled children was within the range of the normative sample, but that child behaviour problems predicted depressive symptoms in fathers, but not in mothers. Also, marital quality was a predictor of parenting value in mothers, but non-spousal social support was a predictor of parenting value in fathers. Child behaviour problems were linked with parental stress for both mothers and fathers. Both mothers and fathers experience stress, but the way the stress is expressed depends largely on the gender of the parent.

In another examination of psychological functioning in families of children with a disability, 48 mothers and 41 fathers of children with autism between the ages of 2 and 4 were assessed on child characteristics, parenting stress, and parent mental health. Mothers of children with autism had higher ratings of depression than fathers, but also more positive perceptions of their children than fathers of children with autism (Hastings, Kovshoff and Ward, 2005). Within each family, mothers and fathers respond differently to the outcomes associated with having a disabled child, but clearly both are affected in terms of psychological functioning, stress, and coping.

Breslau, Salkever and Staruch (1982) examined the effects of a disabled child's in home residence status on the mothers labour force activity. They found that disabled children increase child care demands on families due to their extraordinary care taking needs and greater dependence on others for care and mobility. Their findings suggested that these increased childcare demands hinder the mother's ability to hold full-time employment at any given time. Realizing that these stressors do not promote, get rid of replace other common every day stressors related to home and work might explain why the caretaker of a newly diagnosed child might report experiencing heightened levels of stress and anxiety.

Parent perceptions, stress, anxiety, and depression were also studied by Hastings (2003) in 18 parent dyads. He assessed stress and mental health in parents with children with autism between the ages of 8 and 17 years. Mothers in the study had higher levels of anxiety than fathers, and mother's stress ratings were related to behavioural challenges

associated with the child's disability. However, mothers and fathers ratings were generally similar with regard to their perceptions of their child.

Keller and Honig (2004) examined child factors and stress in 30 families with a child with a disability between the ages of 7 and 12 years. The children in the study had disabilities including mental retardation, autism, learning disability, multiple disabilities, and sensory/physical conditions. They found higher levels of stress in mothers. The stress levels found in the mothers ratings were related to higher ratings of child demanding and need. Fathers stress was unrelated to child demand and need, but was related to child's acceptability. Fathers had a more difficult time connecting and bonding with their child with a disability, which facilitates stress in the family. Family harmony and use of social support helped alleviate the stress that was found in both mothers and fathers. Positive coping was related to parent satisfaction with the family environment as well as stability of the marital system.

The various studies show that family characteristics, deficient knowledge about mental disability and lack of health care facilities and resources for caring children and adolescents with mental disability. The community and families of children with disability had poor knowledge on mental disability and appropriate care and about availability of resources and quality care. Families were not supported in the care of their children. Some children in consequence did not receive adequate health care. Some suffered from physical problems due to inadequate care; others were being locked in their room during periods when no-one was able to look after them. The factors such as were related to socio-economic characteristics of the families as well as to lacking service facilities. The support of care givers to children with mental disability has to be improved. Community and family based care in the study area would benefit families of children with mental disability.

Respite care is an important factor that acts to reduce parental stress and it lead to improvements in the quality of family life (Factor, Perry and Freeman, 1990). Much voluntary respite care comes from members of the immediate family such as

grandparents, aunts, uncles and siblings who are able to provide emotional or social support (Sharpley, Bitiska and Efremidis, 1997).

Adaptive Social Behavior among the Differently Abled Children

Matson et al. (2003) examine the adaptive and social behaviour of individuals with severe and profound mental retardation which mainly focuses on psychological disorder. These individuals were compared to a group of persons with similar intellectual level but no severe psychopathology. Participants were 36 individuals residing at a large developmental centre of Louisiana. It provides services to approximately 650 individuals, the majority of whom fall in the severe and propound ranges of mental retardation. This study examines with the groups on four factors such as age, gender, level of mental retardation and psychotropic medication. Individuals in the psychiatric disorders group displayed significantly higher levels of some social and many adaptive skills than did individuals in both control groups, with psychiatric disorders and autism/PDD groups.

Levy and Katz (2004) examined the relationship between birth order, attachment style and adjustment in children with a sibling who has mental retardation. Research on the siblings of individuals with disabilities was guided by the assumption that siblings would automatically experience adjustment problems. But this study was referred to as the maladjustment views and focused on pathology in the families of individuals with disabilities without recognition or measurement of potential benefits. Fifty-two children ranging in age from 7-13 with a biological sibling who resided with them in the same household and who was from intact families were chosen for the study. Twenty five participants were in the experimental group with 13 born before and 12 after siblings with a moderate to severe mental retardation. The remaining 27 children had sibling's normal development and they served as a control group. The study results show that the presence of a child with MR in the family does not necessarily negatively affect either attachment style or adjustment of healthy siblings. Besides that it is found that siblings of a child with MR have more severe attachment styles than these in the control group.

Hastings (2003) describes the behavioural adjustment of siblings of children with autism in the United Kingdom and express that siblings of children with autism have more behavioural problems than normative samples and that the psychological stress of their mothers does not predict their behavioural adjustment. Eisenberg and Baker (1998) compared psychological adjustment and behavioural problems among siblings of children with retardation living at home, siblings of children with retardation in residential placement, and siblings of children without psychosocial problems of siblings of children with disabilities. Despite the different situations of these groups, they found that all three groups were highly similar on measures of psychological adjustment, self-esteem, and family environment. However, if the families of children with disabilities live in countries which provide only limited welfare services for disabled persons, and if the burden of care of the child with disabilities is thus left on the families, the pattern of psychosocial relationships among family members may be different from the results reported in their study.

Communication Challenges Observed in Differently Abled Children

In a study, Chan and May (1999) attempts to understand the impact of leisure options on the frequency and spontaneous communication production of a young child with multiple disabilities. The aim of the study was to investigate how the implementation of a multimodal communication system would influence the type and number of communicative attempts across leisure activities. Twelve intervention sessions were carried out over a three month period. The result of this descriptive study showed that with the introduction of leisure options as part of intervention, the child demonstrated increased vocalizations, words and word approximations, communicative gestures and use of signs an increased desire is shown among the communicate. The study findings indicate the usefulness and efficacy of leisure options as a potential intervention procedure in promoting the communication development of children with disabilities.

Communication deficits are seen across a range of verbal and nonverbal skills: gestures, intonation, melody, rhythm of utterance, facial expression and posture (Walenski et al., 2006). These children also face difficulties in using communication to

regulate social relations. Tomanik, Harris and Hawkins (2004) showed that in mothers of children with pervasive developmental disorders (mostly autism) aged 2- 7 years, stress is associated with the child's ability to participate in interactions and communicate. Mostly mothers of children with autism report higher stress when their children have poor communication skills (Konstantareas and Papageorgiu, 2006). It should also be mentioned that communication deficits are usually the primary reason why parents seek professional help (Charman and Baird, 2002).

Repercussions in social behavior of disabled children

Kanner (1943) documented a set of behaviours exhibited by 11 children that differentiated them from having any other psychiatric condition. These behaviours included an inability to develop relationships with people, delay in speech acquisition, lack of communicative use of speech after it was developed, delayed echolalia, pronoun reversal, repetitive and stereotyped play activities, an obsessive insistence on the maintenance of sameness, a lack of imagination, good rote memory, and normal physical appearance. He also recognized that these abnormalities were already present in infancy, which allowed for differentiation from childhood schizophrenia or psychosis. In his paper, he documented multiple reports from parents describing their children's lack of interest in the activities of other adults and children they encountered at home or in their neighbourhoods. It is also found that these types of events focused exclusively on objects, completely ignoring the people in the room. In situations where they were forced to interact with other people, these children displayed annoyance, resentment, and anger.

Among the most important predictors of parent's problems, the changing child's behaviour is one of the important problems. Children with autism present a number of such problems, including aggression and self-injury (Matson and Rivet, 2008). Self-injury, aggressive and otherwise destructive behaviour are the strongest predictors of parental stress (Richman et al., 2009). The child's stereotyped and self-stimulating behaviours are also a source of distress for parents. The actual degree to which specific behaviour problems contribute to parental stress depends on the child's age. Parents of adolescents cite destructive behaviour and withdrawal from contact as the most

significant causes of concern, while self-stimulation and tantrums are mentioned primarily by parents of preschool children (Dunlap and Robbins, 1994).

Baker, Blacher and Olsson (2005) assessed depression, optimism, and behavioural problems in parents of 214 preschool-aged children between the ages of 3 and 5 who were classified as developmentally delayed, borderline, or non delayed. Children were administered the Bayley Scales of Infant Development, and parents completed the Child Behaviour Checklist, the Family Impact Questionnaire, the Center for Epidemiologic Studies Depression Scale, the Dyadic Adjustment Scale, and the Life Orientation Test. A negative relationship was found between child behaviour problems and mother's well-being and optimism.

Social skills of the differently abled children

A number of studies conducted focusing on the parent and teacher expectations converge and diverge. Cai, Kaiser and Hancock (2004) demonstrate that if parents' expectations of children's behaviour converge with teachers', children tend to have fewer behavioural adjustments when entering school for the first time. A longitudinal study of MacMillan (2005) examined differences between teacher and parent views of social skills taking 33 samples of adolescent students previously identified in the elementary grades as at risk for academic or behavioural concerns, or both. This study demonstrates that parents and teachers of adolescents with behavioural problems had different behavioural expectations. Whereas teachers primarily valued cooperation skills, rating skills that display assertion and self-control as less important for success in the classroom, parents valued the self-control, responsibility, and assertion skills. Lane, Stanton- Chapman, Jamison, and Phillips (2007) examined teachers' and parents' expectations of preschoolers' behaviour to determine the extent to which teachers and parents converge and diverge in terms of social skills. Parents and teachers do not always hold similar expectations, and the divergence of behavioural expectations held by teachers and parents may pose difficulties for some young children with disabilities. Therefore, these expectations should be explicit and be compatible at home and school to lead children with disabilities to success in the classroom and to foster strong teacher-parent collaboration for satisfying the educational needs of children with disabilities.

Social Support Services

As the parenting stress of caregivers having children with disability is widely acknowledged, many previous studies tried to explore how the caregivers cope with these stresses. Social support is one of the most important coping factors examined. Social support is defined as information or social environmental conditions that enable an individual to feel loved and cared for, affirmed, or belonging to a group of persons with common goals and beliefs (Schaefer, Coyne and Lazarus, 2002). An individual's perception of support is thought to be a characteristic related not only to the actual availability of support but also to the criteria that individuals use in interpreting behavior as either supportive or non-supportive.

By defining social support, Dunst, Trivette and Cross (1986a) mentioned it is a multidimensional construct that includes physical and instrumental assistance, sharing of information and resources, and as providing emotional and psychological support. The term may also refer to formal services received by professional organisations and less formal organisations, such as social clubs or churches, which the family feel is important to their lifestyle.

Cobb (1976) also defined social support as information belonging to one or more of three classes. Firstly, information which leads the person to believe that they are cared for and loved, secondly, information which leads to person to believe that they are esteemed and valued, and thirdly, information which leads the person to believe that they belong to a network of communication and mutual obligation. These definitions can be summed, to define social support as a network of individuals to provide information, resources, and emotional and psychological support through either formal, professional services, or through less formal mutual involvement within a family, friendship or social group.

Access to social support has been related to positive family and child outcomes in families of children with a disability (Rivers and Stoneman, 2003). Social support can come from various areas of society, for example from a spouse, grandparents, other family members, friends and professional agencies. Mothers tend to first seek support

from other family members, as informal sources of support are believed to be more effective at reducing stress than formal sources (Boyd, 2002). Family assistance can be one of the most useful sources of primary support, as families are more willing and able to provide instrumental and financial assistance. Family respite care and financial supports are some of the most frequently identified services that family support networks are able to provide (Herman and Thompson, 1995).

Informal supports system

Informal supports extend beyond government-sponsored programs and include the natural supports provided by the extended family (e.g., grandparents), friends, and neighbors (McDonnell et al., 1995). Lehman, Ellard and Wortman (1986) suggested that natural supports are the most helpful to families under stress. Natural supports may include in-home assistance, house cleaning, and transportation from extended family members or friends. They suggested that "the nature and type of support will be unique to the individuals involved, and be dependent on a mutual level of comfort in both seeking and providing acceptance".

The parents of children with disabilities, including those with mental retardation, may need a great deal of additional support from society, friends, and other family members to find the happiness that compensates for the frustrations and inconveniences of having a child (Knoll, 1992; Turnbull and Turnbull, 1985). The study focuses on the promotion of positive social environmental factors which may contribute to an increase of self-respect and independence. Informal support was studied by Benson (2006) in 68 parents of an elementary age child with autism spectrum disorder. He found that parent depression and the accumulated effects of stress were reduced with the provision of informal support for parents.

Formal Support System

Bristol and Schopler (1983) defined formal support as "assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or institution". They defined informal support as "a network that may include the immediate and extended family, friends, neighbours, and

other parents". Generally, informal support is the preferred mode of support over formal support (Boyd, 2002). Support from family, friends, and professionals has been shown to reduce stress and responses to stress.

House (1981) differentiated four different types of support such as emotional, instrumental, informational, and appraisal. Emotional support refers to non-tangible assistance, such as listening, sympathy, empathy, encouragement, and praise. Emotional support from extended family and self-esteem were found to be predictive of mother's stress related to parenting (Trute, Worthington, and Hiebert-Murphy, 2008). Instrumental support refers to tangible assistance, such as childcare, housekeeping, transportation, or money. Informational support refers to the provision of information and resources, such as community agencies, professional advice, and online resources. Instrumental and informational support both provide non-emotional assistance and are often grouped together. Thus, across all studies social support is primarily characterized as emotional or instrumental.

Trute (1990) studied family adjustment in households containing young developmentally disabled children". The study examined the importance of marital adjustment as a key predictor of family functioning in household's containing young disabled children. This research selected a cross section survey and random sample of 88 families containing young developmentally disabled children by using in-home interviews of both mothers and fathers. It contains four factors, such as consensus, cohesion, satisfaction and affection. This study focused on the social network of fathers and mothers and included family, friends and human service professionals. Social network members who could be turned to in times of emergency and those who could be identified as confidants. Positive family adjustment is found to have little relationship to specific child attributes (gender, level of disability or temperament). This study concludes that the education level of a disabled child's parents appears to facilitate overall family adjustment.

The Context and Dynamics of Social Support

Dunst et al. (2000) defined social support within the context of family level, in which the family's social network system is instrumental in providing the resources needed for everyday living, in carrying out parenting responsibilities, and in supporting child learning and development. Support is often provided by family members, friends, and community agencies and organizations. These members of the family's social network provided a range of environmental experiences that will ultimately influence the development and behavior of the child and the entire family. It has also been reported that these experiences strengthen the family by instilling feelings of competence and promoting new skills that are instrumental in helping families deal with disable children.

Support group may be a primary source of support for parents of disable children with complex needs. The goals of support group are, is to foster mutual aid, to help members cope with stressful life events, and to revitalise and enhance members, coping disabilities so they can affectively adapt and cope with future stressful events" (Toseland and Rivas 2008).

According to Narramore (2008), the most serious finding from the literature review is that lack of emotional support can affect a parent's mental health. Health professionals need to understand the extent to which parent's emotions are affected when a child is born with a disability and that the emotional stress is likely to increase, not decrease, as parents try to come to terms with a diagnosis and the impact that caring for such child will have on their lives. It is also clear that initially most of the emotional support comes from support groups.

Solomon et al. (2001) discussed the benefits of mutual support groups among parents of disabled children. Fifty-six parents who participated in mutual support groups were surveyed regarding overall helpfulness, satisfaction, group climate, and group impact. Overall, parents reported that the groups provided them with information about their unique problem and possible resources for help. They also valued the information about their child's specific disability; it helped reduce their feelings of insecurity. Parents also expressed the usual feeling of powerlessness in their relationships with professionals, but after being a part of the group and learning new ideas and information, they felt

empowered. Thus, support groups may provide a safe and supportive environment to help parents of children suffering from disabilities.

In another study, Baum (2004) also examined the benefits of parent support group for primary caregivers of a child with special health care needs among a sample of 114 primary caregivers. He found that 93% of caregivers were satisfied with the group and the strongest factors related to satisfaction were getting usable ideas, improved relationship with their child, and finding people to trust.

Horton and Wallander (2001) studied perceptions of hope and social support as resilience factors in 11 families with 5- to 18-year old children with cerebral palsy, spina bifida, or diabetes mellitus. Using a variety of questionnaires, they found no differences in agony among mothers and an inverse relationship with distress was found in mothers with regard to hope, social support, and distress, such that distress occurred with less hope and social support. “Perceptions of hope moderated the relationship between disability-related stress and maladjustment, suggesting a buffering effect when stress is high. However, hope did not appear to be a mediator of the relationship between social support and distress”.

Benson (2006) studied parent depression and the use of parent support, specifically informal and formal parent support, in 68 families with a child with special needs. The children were diagnosed with Autism, Pervasive Developmental Disorder an unspecified autism spectrum disorder, or developmental delay. He found that the use of informal social support was related to significantly fewer symptoms of parent depression, especially in families where the child’s disability symptoms were not severe. This is contradictory to the stress buffering hypothesis that suggests that support will buffer stress in more serious situations where coping resources are strained. That is to say that in the case of a child with a disability, the natural coping resources can sometimes be adequate in buffering the stress related to the disability.

Support Systems

Social support is calculated in a variety of ways, for example, in terms of the structure of support resources, by perceptions of the supportiveness of their relationships, by the number of individuals in the social support network, by the perceived quality of support, and by professional or nonprofessional categorization (Leavy, 1983). The most frequently used measure of social support is perceived quality of support received and satisfaction with it (Osseiran- Waines, Nahid, Elmacian and Sarkis, 1994).

The process by which support alleviates stress is not well understood or studied thoroughly. One theory that attempts to explain how social support alleviates stress is the “stress buffering hypothesis” (Cohen and Wills, 1985). Unlike the main effects hypothesis that states that social support has a positive effect on a family regardless of whether a family is experiencing stress, the buffering hypotheses states that social support has positive effects primarily for persons under stress (Cohen and Wills, 1985; Horton and Wallander, 2001). The stress buffering hypothesis affirms that when a person is in a great deal of stress, the benefits of social support is immense. It is presumed that when stress levels are low, coping skills are independent of social support and stress is thought to be more internally managed (Benson, 2006). Social support alone does not address all of the stressors in a family. It does, however, act as a buffering factor or moderator to the stress in a family. Other buffering factors include the repertoire and number of coping skills, parental or marital relations, stability of support, and problem-solving skill (Keller and Honig, 2004).

Several studies have looked at the relationship between the size of one’s social support network and level of stress in a family. Hodapp, Findler, and Smith (1998) found that the size of the social support network was directly related to the stressors and stress levels in a family with a child with a disability. That is to say that larger support networks were related to lower levels of stress. In a study of use of respite care by mothers of children with disabilities, Salisbury (1990) found that the size of the social support network was negatively correlated with reports of stress. Mothers of children with disabilities who had larger support networks had fewer reports of stress than mothers of children with disabilities who had smaller support networks.

Social support in this context has been studied as a buffering factor for families with a child with a disability (Boyd, 2002; Dunst, Trivette, and Cross, 1986; Troster, 2001). Being the parent of a child with a disability involves stress and disequilibrium in the family system. To cope with the stress and imbalance, a parent must find ways to alleviate the stress and bring about homeostasis. One way to adapt to stress is via social support. While social support can be a great source of coping in some families, mothers tend to use social support as a coping mechanism more so than fathers. Barnett et al. (1987) and Cutrona (1996) studied gender differences in seeking social support and found that mothers are more likely to ask for and receive help from both formal and informal social support networks. Fathers were found to rely on mothers or their internal coping skills to manage stress.

In a study of support as a buffer for stress, Wade, Taylor, Drotar, Stancin, Yeates, and Minich (2004) assessed psychological distress and adjustment in 189 parents of children with a disability. The children in the study had traumatic brain injuries and/or orthopedic impairments and ranged from 6 to 12 years of age. Wade et al. (2004) assessed resources, stressors, and psychological adjustment; they found that greater support and resources and fewer stressors were associated with less psychological distress.

Holahan and Moos (1985) studied factors that buffer the stress-based effect on physical health rather than mental health. They found that the members of the Stress Resistant Group had different stress adaptation skills than the members of the Distressed Group. Those in the Stress Resistant Group used more proactive coping techniques, had more self-confidence, and had better social support networks than those in the Distressed Group, and the members of the Distressed Group used more avoidance coping and had more physical illness than those in the Stress Resistant Group. Therefore, not only was stress related to psychological distress as previously stated, but stress and avoidance coping tactics negatively affected physical health, as well.

While some families have poor or negative coping strategies, many families use positive coping strategies to address stress in their system. Positive coping strategies may include acceptance of the child's disability and feelings toward the child, obtaining help with routine care of the household and children, providing support and education to family members about the disability, maintaining an active social support system, utilizing resources in the community, and having faith (Kuster and Merkle, 2004).

Social Network Theories

A Social Network is defined as the number, frequency and linkages of contacts with other individuals or groups (Worcester, 1990). Social Network theories propose that social interaction between individuals lead to heterogeneous relationships that have different levels of supportiveness (Pierce, Sanason and Sanason, 1991). There are two main Network theories, task-specific theory and hierarchical compensatory theory which relate to care giving.

Task-specific theory categorizes social Network groups as primary, informational and formal groups. According to this theory each social network has different natures and because of these different natures of social networks, each network group can optimally manage different tasks (Litwak, 1985, Messeri, Silverstein and Litwak, 1993). This theory highlights the fact that people dependent on various needs have formal and informal groups to co-operate in most areas of life. In addition, the support provision varies across different relationships even within the primary groups. Hierarchical-Compensatory theory focuses on the importance of care recipients preferences. It relates to an ordered preference based on the primary relationship between care givers and care recipient (Messeri et al., 1993).

Social Support Theories

Uchino conceptualized social support as „the functions that are provided by social relationship“ (Uchino, 2004). Social support theories have linked social support provided by social relationships to health outcomes, although each model emphasizes different processes.

The Functional Impact of Various Social Support Networks

Research shows that people who perceive a strong active social support network are healthier both physically and mentally (Dunst, Trivette and Hamby, 1994; Hodapp, Fidler and Smith, 1998). For example, social support from immediate and extended family, friends and professionals were found to ease the feelings of stress in families with a child with special needs (Hodapp et al., 1998). The most salient predictor of stress levels was the size of the support network of the family, wherein lower stress levels were related to a larger network, particularly the family network.

As shown, informal and formal social support is helpful to families of children with special needs. In a study of stress and coping in 47 families with children with visual impairments between the ages of 8 months and 7 years, Troster (2001) assessed the severity of the visual impairment, additional disabilities/illnesses, functional impairments, daily stress, parenting stress, and perceptions of social support. Social support was found to have a buffering effect on the stress that came from raising a child with a disability. However, parents of children with a disability perceived lower levels of both emotional and instrumental support.

A family's need for support varies over time as they move through different phases of the life cycle. Eventually, a family may move from leaning on support from within the immediate family, to support from the extended family, to support from professional organizations, to support from the larger community, and even strangers (DeMarle and Le Roux, 2001). Two main reasons that mothers of children with autism seek social support are levels of stress and feelings of depression. Mothers stated that they first sought spousal support, then immediate and extended family support. Informal support was perceived as more valuable than formal support with relation to experiences of stress and depression. Of the formal supports assessed, parent support groups were rated most helpful, but were not used by all participants. Generally, mothers who had both informal and formal social support networks had more positive relationships with their children with special needs (Boyd, 2002).

Hassall and McDonald (2005) found that a mother's decision to utilize social support was related to both child characteristics and parent characteristics. Child characteristics that influenced the attainment of social support were challenging behaviours and cognitive limitations. Mothers of children with severe impairments reportedly familiar with more stress than mothers of children with mild to moderate cognitive limitations. While the size of the support network was relatively comparable between groups, the perceived helpfulness of the support from the network directly related to stress levels in the groups. Behavioural challenges can impact the ability to obtain support, in that it may be difficult to find childcare while gaining formal support.

While support is one coping strategy to reduce stress, Taanila, Syrjala, Kokkonen, and Jarvelin (2002) examined the different coping strategies of families with a child with a disability. Eight families of children between 8 and 10 years old with physical and/or intellectual disabilities were interviewed twice. Three main coping strategies emerged from the interviews: gaining knowledge and acceptance, increasing family functioning (cohesion, flexibility, cooperation), and relying on social support from both formal and informal sources. As in previous studies, social support in any form was found to be a strong buffer to stress.

Parenting stress has been inversely associated with social support and cohesive family relationships. Specifically, support and relationships that have open communication and expression of feelings without judgment have been related to better family functioning. Social support in the form of friends, non-relatives, and professionals is also associated with better family functioning, especially for mothers (DeMarle and Le Roux, 2001). Caplan (1974) hypothesized that social support can enhance social-emotional functioning, attainment of information, and physical assistance when needed. Holahan and Moos (1985) found a negative relationship between parent social-emotional well-being and social support.

Seligman, Goodwin, Paschal, Applegate and Lehman (1997) examined perceptions of support from grandparents by mothers of a child with a disability. Seligman et al. (1997) found that grandmothers were rated as more supportive than

grandfathers, and mothers perceived their own mothers to be more helpful than their mother-in-laws. Both maternal and paternal grandparents were reported to provide more emotional support than instrumental support. Therefore, emotional support from maternal grandmothers seemed to be the most helpful of the supports studied.

Support in any form from a grandparent can also impact the parent's psychological wellbeing. Trute (2003) conducted a study to explore parent's perceptions of grandparents support and the impact of grandparent support on parent psychological adjustment in 59 mothers and 38 fathers of children with disabilities between the ages of 5 and 12 years old. The children in the study had a primary diagnosis of developmental delay, and many also had multiple handicaps and/or physical disabilities. He also found that the most important predictor of parenting stress and psychological well-being was perceived levels of emotional support and involvement of their own mothers rather than mothers-in-law. Parents agreed that maternal grandmothers tended to supply more positive support than grandfathers. Unexpectedly, practical or instrumental support from grandparents did not show any relationship with parent psychological health.

Schilmoeller and Baranowski (1998) investigated how helpful and supportive grandparents were to their family with a child with a disability, and how helpful their support was perceived to be. Seventy grandparents (93% grandmothers) of children with Cerebral Palsy between the ages of 1 and 19 were interviewed on their concerns and worries about their grandchild, parent and support group helpfulness, affection solidarity/proximity, and health status. They found that the grandparents in the study reported providing emotional support more frequently, including listening, talking, answering questions, encouraging, and accepting the disability. Grandparents also reported providing instrumental support in the form of financial help, babysitting, and providing respite for the parents.

Role of Mothers and Grandmothers in Social Support

Further research on grandparents as primary supports to families with a child with a disability was conducted by Baranowski and Schilmoeller (1999). One-hundred and five mothers of a child with a disability between the ages of 1 month and 11 years old were assessed on their views of support, helpfulness, and involvement from grandparents in their lives. Disabilities included in the study ranged from developmental delays to physical anomalies. The majority of mothers reported that maternal grandmothers were most supportive, helpful, and responsive to the needs of the mother. Support came in the forms of emotional support and instrumental support. Perceptions of support from paternal grandfathers were rated the least supportive and least involved.

With regard to types of involvement and support, Baranowski and Schilmoeller (1999) found that grandparent's provision of time and emotional support were perceived to be the most helpful types of support reported. Support from grandparents was also related to geographical proximity and emotional closeness to grandparents prior to the child's birth. They stated that "a grandparent was important mainly by virtue of being more than doing". Emotional support was valued more so than instrumental support, even when instrumental support was high. In fact, both maternal and paternal grandfathers reportedly gave more instrumental support, but maternal and paternal grandmother's support, which by nature was more emotional, was perceived as more helpful.

In a study of structural social support (size, range, and interconnectedness of contacts) and functional social support (emotional, instrumental, and informational) in 90 families with a child with Cerebral Palsy, Findler (2000) found that mothers of a child with Cerebral Palsy had higher professional support, but no such differences were found between the groups on measures of nonprofessional support. Maternal grandmothers were rated the most important support in both groups, even above spouse. Mothers perceived receiving more emotional support from either grandparent than instrumental or informational support. Maternal grandparents were also rated more supportive than paternal grandparents, with paternal grandfather least supportive.

Mitchell (2007) outlined grandparent support research in the United Kingdom, and, as in the United States, grandparent support served different functions depending on the presence of a disability. When there is no disability in any child in the family, grandparent support was positive and found in the forms of practical support, such as informal childcare, emotional support, and financial support, especially from grandmothers. Grandparent support was negative when conflict or inappropriate support was provided. In families where a grandchild had a disability, grandparent support had increased practical purposes, including informal childcare, respite care, and domestic help. Emotional support was described in more detail as nonjudgmental advice, listening, and being there. A hierarchy of support was noted wherein maternal grandmother was the most supportive member outside of the nuclear family. All support in families with a child with a disability reported a reduction of stress related to the grandparent support, unless there was a bad relationship between grandparents and their children prior to the birth of the grandchild with a disability.

Scherman and Shutter (1995) studied ways in which grandparents provided support to their grandchildren with a disability and their families. They interviewed 32 grandparents of children with disabilities, 63% of which were grandmothers. The grandchildren ranged in age from 20 months to 13 years and had disabilities such as mental retardation, metabolic /chromosomal disorders, autism, and severe attention deficit disorder. The study focused on assessing grandparent's knowledge of the disability, effect on grandparent's lives, and emotional response in the interview process. They found that "almost all the grandparents perceived their children as needing immediate support", which they provided in several forms. Some grandparents provided direct relief to their children while others directed their support toward their grandchildren. Few grandparents also sought personal support. The majority of grandparents stated that they provided emotional, practical, and financial support, and the minority of grandparents stated that they provided help for the siblings in the family, help through prayer, or information gathering. Emotional support took form as encouragement, calling frequently, and being available. Practical support took form as babysitting, hospital and doctor stays, and chores.

Gardner, Scherman, Mobley and Brown (1994) interviewed 32 grandparents to assess their involvement with their grandchild with a disability. Grandchildren's ages ranged from 20 months to 13 years and the majority of grandchildren had spina bifida. Gardner et al. (1994) looked at involvement, roles, and functions of grandparents, and conducted interviews in five areas: beliefs of role as a grandparent, grandparent/grandchild relationships, specific functions as grandparents, impact of roles on grandparent/grandchild relationship, and help in adjustment for family. Grandparent roles were reported to include twice as much direct contact with the grandchild (games, going for walks, love, encouragement, attention). Direct parent contact also was reported and included babysitting, respite, and financial help. Other roles were transportation to doctor's appointments, school, parties, etc., medical and therapeutic interventions, and diet. The majority of grandparents reported emotional support as the strongest area (love, affection, and encouragement). However, one-fifth of the grandparents felt ineffective in providing support. Half of the grandparents in the study felt no change in the grandparent/grandchild relationship relative to the disability, yet half did feel a change in expectations (lowered) for the grandchild. Some grandparents "expressed concern or frustration that the nature of their grandchild's disability created additional tensions and reduced their patience in interacting with their grandchild".

The effect of various support systems

Majnemer et al. (2002) found in a study of early rehabilitation service utilization patterns of parents with developmentally disabled received occupational therapy, physical therapy was received by 24% of the families, and speech language pathologists provided services to 54% of the families. A small portion of the children saw a psychologist (17%) and then usually only for an evaluation (though the reason for the evaluation is not stated). Approximately half of the referrals for services come from physicians and the other half from other sources. The study found that lack of increased waiting times and lack of outside resources (such as rehabilitation centers) led to over utilization of acute care facility services. It can be inferred then that outside resources can be of help not only to parents, but to the healthcare system as well.

Llewellyn (1995) study on relationships and social support examined experiences of social support related to parenting. Parents reported mixed perceptions of the support they received from spouses/partners, family members. While serving as an important resource, support was also viewed as constraining. Social support has also been found to be an important component in therapeutic processes, as patients who receive special supportive care following an operation require less medication for pain and are able to be discharged earlier than patients who do not receive special care (Cobb, 1976).

The effectiveness of support networks has been found to be a more important factor for parental self-esteem than the size of the network (Seybold et al., 1991), thus a small, actively helpful group of friends or family is more effective at increasing a parent's self-esteem than a larger, less active support group. Social support is able to mediate personal well-being and can improve parental attitudes towards their children (Dunst et al., 1986b). The presence of social support may lead to more positive perceptions of the family environment as it is linked to more stable functioning, a more positive perception of the child, and can enhance the parent-child relationship reported that parents with more supportive social networks were less protective of their child, regardless of the child's diagnosis or severity of the disability, indicating that as levels of social support increase; parents feel less of a necessity to overcompensate by overprotecting their child. This study also found that children were more likely to make more developmental progress if their parents had supportive social networks. These findings suggest that not only does social support relieve some of the stress associated with raising a child with a disability, but it also gives them an opportunity to develop more positive relationships with their child. As parents are less protective they may be more willing to allow their child to experiment with their skills and provide them with more independence, which may explain why these children made greater developmental gains than children whose parents had less supportive social networks. However, the presence of more supportive social networks was related to children who had fewer physical limitations, were more socially acceptable to others, with fewer behaviour problems and with less difficult personality characteristics (Dunst et al., 1986b). This relation of child characteristics to the presence of social support suggests that the benefits

gained through having a supportive network may be limited to those families with a less physically disabled, more socially acceptable child.

While it is acknowledged that social support is an important factor in reducing the stress of parents with children with disabilities, research has found that such families have less social support available to them than families of typically developing children. There are various reasons why social support is often not readily available to families. Firstly, the perceived stigma associated with the child displaying characteristics that deviate from societal norms by displaying stereotypical or unacceptable behaviour may mean that parents are less likely to seek help, or that other people are less likely to be willing to help. Perceived stigma has been found to be consistently related to less perceived support from other family members and more negative interactions with family. The perceived stigma in this study related to the individual's personal feelings about the stressor, for example, embarrassment or shame, and their projections of these feelings onto others, whether or not they accurately reflect support network members or society's feelings about the stressor (Mickelson, 2001). Thus while parents may feel that their child's characteristics will be rebuked by society and fewer people will be willing to help them, this may not actually be the case.

The stress involved in raising a child with a disability can be exacerbated by a lack of social support and can have effects on how the family is able to function and on the psychological adjustment of other children in the family. However, studies have shown that families who report higher levels of social support also report lower levels of stress (Beckman, 1991). This may be because families who have access to higher levels of social support may find that stress levels are ameliorated as the family has other people to turn to for respite care, someone to talk to or just the knowledge that someone else is willing to help. According to family systems theory, social networks and support provided to families both directly and indirectly influence the behaviour, attitudes, expectations and knowledge of parents and their offspring (Dunst, Trivette and Cross, 1986).

Social support has thus been shown to be an important factor in the functioning of families of children with disabilities. Families who have increased levels of support demonstrate less stress. The most effective support network is derived from help received by family and friends. However, the benefits of effective social support networks may be limited to families who have a less physically disabled, more socially acceptable child. In general, it is important for families to have an effective support system, regardless of the size of the network in order for them to be able to function effectively as a family.

In review of literature on the three major areas of parental problems, care demands and social support have indicated the need to conduct further study in this area, in spite of consistent relationships being observed. The line of action suggested that parents of children with disability in various dimensions like stress, care demands and social support factors may be analyzed and the present study makes an earnest attempt in this direction. The methodology adopted to conduct the study is presented in the next chapter.

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 care takers. 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, Co-operation 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 back ground 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 censuses 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

This chapter provides a brief description of socio-demographic and economic details of the differently abled children and their family. The profile includes background characteristics of parents and their differently abled children and their family particulars. Parent related variables include the age, educational qualification, income, occupation, migration, marital status and other socio-economic variables and post natal issues of the parents. The child related details pertain to age, education, type of school, birth order, type of disability, health case history, current health status and various behavioural and social issues faced by them.

A majority of the primary care givers of the children are mothers and they are largely in the age group of 30 to 34 years. The mean age of the respondents is 39 years. Mother's are largely home makers and engage in major care taking activities related to the children.

Two thirds (66.3 percent) of the families are Hindus, followed by the Christians and Muslims. The caste-wise classification shows that one third of the respondents (35.6 percent) belong to Scheduled castes such as Pallar, Thulugan, Chakiliyan etc. and a considerable proportion belong to other Backward castes such as Chettiar, Devar, Nadar, Pillai, Mudaliyar, Naikkar etc. The traditional occupation of Scheduled caste communities is agricultural labor while for the backward dominant communities it is fishing, agriculture and allied activities or family related business activities. Due to educational opportunities, and major changes in society, many head of the household's in these families also involve in modern occupations like factory work, Teaching, and Tailoring etc. More than half (53.1 percent) of the mothers are housewife's, while fathers largely work as coolie or involved in business or clerical work.

Educational attainments of the parents reflect that they are largely educated up to school level with a majority having middle and high school level of education. Eight out of ten (81 percent) of the fathers educated up to primary and middle level, while the remaining (19 percent) of them educated up to higher secondary and above. Educational attainment of the mother reflect that seven out of ten (72 percent) of the respondents educated up to primary and middle level. A greater proportion (88.1 percent) of the respondents is currently married and lives along with their spouses, while the remaining

(11.9 percent) are widowed, separated or divorced. A greater proportion (87.5 percent) of the respondents is in nuclear families, while the remaining (12.5 percent) are living in joint families.

The income of the family is largely earned through daily wages by manual labour and men are the main breadwinners of the family, while some mothers also supplement through beedi making and some are employed as teachers. It indicates that eight out of ten (79.4 percent) respondent's family earnings are less than 10,000 rupees per month, one fifth (20.6 percent) of them earn between Rs. 10,001 to 30,000 while the remaining earn more. The mean monthly income of the head of the household is Rs 9,219. Their socio economic condition of the sample is relatively low but they also make use of the facilities provided by the Government schemes such as ration card, health facility etc.

Two fifths (43.1 percent) are migrants, among them one fifth (20 percent) have migrated due to marriage, especially women. A little less than one fifth (16.2 percent) of families have migrated from rural areas, exclusively for want of education of the differently abled children, and a few had migrated for the purpose of employment. A majority (63.8 percent) of the respondents do not have any savings, while one third (36.2 percent) save for their future needs of differently abled child to spend for medical treatment and emergency. Nearly half (48.1 percent) of the respondents currently have debts and 40 percent of the respondent borrowed money from money lenders and through bank for meeting the regular expenses of family, illness of family members or to start a business.

Profile of the Differently Abled Children

The average age of the differently abled children is 9.53 years and ranges between 5 and 14 years. Of the total, more than two fifth (43.1 percent) are in the age of 11 to 14 years and three out of ten (39.4 percent) are aged 6 to 10 years old. A greater proportion of the children are boys (65.6 percent) compared to girls (34.4 percent).

All the differently abled children of the present study receive various educational supports from the respective school. More than one half (51.9 per cent) of the children are studying in special schools, 33.8 per cent are in normal schools while a small

proportion (14.4 per cent) of children are studying in early intervention centre. The children in normal schools attend school along with peers of their own age in the schools that are located within reasonable distance from their homes. A majority of children received supports such as wheel chair, Hearing Aids, Scholarship for education, free Physiotherapy, speech therapy for Mentally retarded, Cerebral palsy and Autism children, free diagnosis and treatment for Deaf and Dumb, and bus concession is received by all the differently abled children from District Differently abled welfare office, Thoothukudi.

Almost an equal proportion of children are first order (43.8 percent) and second order (40 percent) at birth respectively. One third (33.8 percent) of the children are mentally challenged, followed by a small proportion of the children who are Deaf and Dumb (16.2 percent) and physically Impaired (13.8 percent) and a few are Visually Impaired (7.4 percent) have Multiple disabilities (6.9 percent), while some have Delayed Milestone (5 percent), Down's syndrome (3.8 percent) and Autism (3.1 percent).

Case history of differently abled children family indicates that the average age at marriage of fathers is 26.53 years, and mother's is 21.6 years. A significant proportion (37.5 percent) of the mother's age at marriage was between 16 and 20 years of age, which is quite early. Close to two third (63.8 percent) of the differently abled children's parents were not related by consanguinity before their marriage while the rest (36.2 percent) of the parents were related, especially through maternal side. Eight out of ten (85 percent) parents of the children reported that there was no disability in their families in the last three generations, and a few of those reported indicated polio, physical deformity, and visual impairment. It appears that the prevalence of disability in families is restricted to the current generation.

Gestation and delivery related information indicate that six out of ten (61.2 percent) mothers did not have any problem during pregnancy, while the remaining (38.8 percent) reported problems such as dryness of amniotic fluid, anemic, family problem, took medicine to abort the child during pregnancy etc. The average age of the mother during delivery of the differently abled child was 27.8 years.

Three fourths (75 percent) of the differently abled children were born after complete gestation period of 9 months but one fourth (25 percent) of the children were born before 9 months. Nature of delivery shows that more than half (57.5 percent) of the children were delivered through normal delivery, one third (35 percent) were through caesarean sections and the rest were forceps delivery. Two third (66.9 percent) of the children were born in Government Hospital and others in private hospital while 5 children were delivered at home.

Treatment History of Differently Abled Children

One fourth (25.6 percent) of the parents opined that disability was due to delayed pregnancy, while considerable proportion (20 percent) attribute it to improper care during pregnancy and close consanguine marriage. Nine out of ten (91 percent) children are in the process of taking treatment, while a few are not taking any treatment. Place of treatment shows more than half (56.2 percent) of them take treatment in government hospitals, while a few take treatment in private hospitals. A majority (73.8 percent) take Allopathic form of treatment, while some are treated by alternate therapies such as Physiotherapy, Ayurveda, Sidha and Homeopathy in government and private hospitals. Considerable proportions (14.4 percent) of children have fits regularly and others indicate minor ailments.

Institutional Support for the differently abled children

Institutional support refers to the support provided by the government or other organizations for differently abled children. The study finding shows that six out of ten (65.6 percent) children avail government scholarship through the support of the educational institution where the children are enrolled, while one third (34.4 percent) do not avail government scholarship. Half (50 percent) of the disabled children avail maintenance grant (Rs.1000/-pm), followed by scholarship for education (3.1 percent) and a few received wheel chair and Hearing aid.

Two third (68.8 percent) of the parents are aware about the scholarship through the authorities of school and a small proportion (11.2 percent) of the parents came to know about it through their friends and some through welfare organizations and media.

Half (50 percent) of the children utilize bus concessions. Above one fifth (22.5 percent) of the children receive some assistance such as Aids and Appliances for Rehabilitation from NGO's.

A larger proportion of respondents are mothers who are also the primary care takers. The care takers are relatively young and are mostly Hindus while a significant proportion belong to OBC's and Scheduled castes. Their educational qualification and income level is quite low and many are debted and lesser proportion has savings and significant proportions are migrants. The differently abled children are young and many are boys enrolled in special schools. They utilize many of the support provided by government and schools play an important role as information providers.

Parental Problems

The 'care giving' parents are absorbed in the tasks, concerns and attention to the children in ensuring that the child gets adequate support in all spheres of the needs. But in reality they may or may not be in a position to provide such needs. Families with children of severe disabilities were reported to be severely affected and were more likely to report many unmet needs (John and Howard, 2014). Having a disabled child born into a family and grow into adult is one of the most stressful experiences a family can endure. Parents experience instances of discrimination from society and family towards both the child and the parent. They also experience difficulty in maintaining relations with family members, neighbours and relatives (Davis et al., 2009). In addition the parents are stressed by thinking about future of the child along with their own emotional disturbances (Heaman, 1995). They also have serious financial burden and insufficient support services. Families of disabled children, experience financial constraint due to additional medical expenditure, special equipment, arranging special schools, arranging special transportation, care takers in the absence of the parent, difficulties in entertaining the friends and relatives at their home, marriages for the siblings etc. These lead to mild to severe stress and also emotional disturbances among parents of the disabled children.

They have very less opportunities to explore their own needs and also to overcome their difficulties (Loeb, 1979). The children with disabilities have special needs that require more attention, greater vigilance and effort from parents and also have several physical, social and psychological effects on families who are expected to raise the child with special needs (Senel and Akkok, 1996). The parental problems presented in the chapter focuses on general problems related to parenting and the information is elicited through open ended questions.

Table 1: Financial Problem of Parents

Financial problems	No. of respondents	Percentage
Financial difficulty		
Not experienced	42	26.2
Experienced	118	73.8
Strategies to limit expenditure		
Cut down the basic needs of the family	41	25.6
Limit all kinds of social activities of the family	70	43.8
Reduction in expenses whenever possible	5	3.1
Less expenditure on the education of other children	2	1.2
Management of extra expenses		
Lending through local money lenders	59	36.9
Pawning of gold ornaments	40	25.0
Mortgaging land etc	1	0.6
selling property	6	3.8
Miscellaneous	12	7.5
N = 160		

Financial issues play an important role in managing the child and family. Expenditures include from medical treatment, aids for children to household help. In addition, the families are not in a position to earn more or suffered loss in wages when they had to ‘take off’ during child’s need. Three fourth (73.8 percent) of the respondents experienced financial difficulties and they felt it as an important need as their families were already in middle income or low income category. In addition the differently abled children needed special attention and more expenditure. The parents are not in a position to earn more as the time is diverted to care giving needs, low self-esteem, low motivation and fewer persons in social circles.

About two fifth(43.8 percent) of the parents mentioned limiting all kinds of social activities such as visiting to relatives house, entertainment places such as movies or places where the differently abled child along with family members can enjoy, temples or long distance tours. These limitations are due to both emotional as well as financial stress. A significant proportion have ‘cut down on basic needs of the family such as, not spending more on food, extra educational expenses of other children in families, clothing etc, due to the financial burden. As a result of the expenses in one area, they have cut down expenses in other and for other members in

family or sometimes they have spend very less for the differently abled child itself as they are ‘nonproductive’ children.

To manage the expenses, about one third (36.9 percent) borrowed money from local money lenders for high interest rates. These are usually time bound, gets accumulated and most of the earnings get drowned in settling it. A similar proportion had pawned gold ornaments as it is common in the area to meet emergency expenses, but many times the gold is sold rather than retrieved as they are unable to pay the loan. Some have also sold land and mortgaged properties for the medical expenses of the differently abled child or to manage familial expenses.

Table 2: Employment/work related problems

Compromises in Employment	No. of respondents	Percentage
Take leave		
Take time off or permission very frequently	47	29.4
Sacrifice promotions, training etc.	4	2.5
Arrange someone to take care	1	0.6
Not applicable	11	6.9
	97	60.6
Total	160	100.0

Close to one half of the parents are employed largely fathers and many reported taking leave frequently. Some had to take time off often, some also sacrificed promotion etc, and had to constantly keep arranging for someone to take care of the child.

Table 3: Familial Responses towards Disability

Familiar Responses	No. of Respondents	Percentage
Blame		
Parents not blamed	102	63.8
Parents blamed	58	36.2
Family Members		
Understanding Attitude	57	35.6
Not understanding	103	64.4
Places generally differently abled children are taken		
All places	35	21.9
Some places	94	58.8
Not at all	31	19.4
Total	160	100.0

One third (36.2 percent) of the care takers blame themselves for the situations. It relates to being careless during pregnancy such as being anemic, accidents before delivery, family problem etc., accused for carrying over the genetic problem etc. Usually the mother of the child is generally blamed for transmitting the problem to the child. Two third (64.4 percent) of the parents opine that the kin and family members have an understanding attitude. One fifth (21.9 percent) reported taking their children along with them to all places, while more than one half (58.8 percent) take them only to some places and one fifth (19.4 percent) do not take them to any place along with them. The situation reveals the exclusion of the children, by their own parents for reasons of embarrassment and physical difficulty of the children. It indicates the need for counseling and training for parents regarding their emotional state and need for support of the parents.

Table 4: Problems in Handling of Family Responsibilities

Family responsibilities	No. of respondents	Percentage
Looking after the other children		
Feel guilty	119	74.4
Unable to answer	41	25.6
Looking after the spouse		
Feel guilty	143	89.4
Unable to answer	17	10.6
Supervising the studies of other children		
Feel guilty	121	75.6
Unable to answer	39	24.4
Looking after the needs of family in general		
Feel guilty	158	98.8
Unable to answer	2	1.2
Participating in family functions		
Do not participate	151	94.4
Participate	9	5.6
Experience of Discrimination		
At home	2	1.2
At school	2	1.2
At community	41	25.6
At society	103	64.4
Nil	12	7.5
N = 160		

A majority of parents, especially mother's reported that they felt guilty that they are unable to take care of other children and family. They specifically felt that they are unable to supervise the studies of other children. They also feel that they are unable to attend to spouse as per cultural requirement and in general the needs of family. An overwhelming majority (94.4 percent) report that they do not participate in family functions, as a result of discrimination prevailing in general at the societal and community level. Parents reported that some neighbours and kin made adverse comments about the child and family. Society is also very ignorant of the facts and gives 'loose comments' which hurt the family members. In some situations the same extended family and neighborhood are also very supportive.

Table 5: Training of Parents of Differently Abled Children

Training	No. of respondents	Percentage
Training for parents		
Not availed	134	83.8
Availed	26	16.2
Details of training		
Parents package and Parents counseling	7	4.4
Training for providing proper care	2	1.2
Rehabilitation and counseling(Saiyogi-6months)	17	10.6
Handling of child after training		
Easy to handle the child	10	6.3
Understand children's feelings	13	8.1
Understand children's need	3	1.8

N=160

A majority of parents have not attended training to handle the children while a small proportion have attended training. Only one sixth (16.2 percent) of parents have received training through special schools regarding handling of the children. They have attended ‘Saiyogi’ (6 months course regarding rehabilitation and counseling) program which focuses on counseling while a few others have attended training for providing proper care. Consequent on training, many reported that they are able to understand children’s feelings and needs better and some also reported that it is easier to handle the children.

Parents who attended training are only a small number of those who have children with multiple disabilities or mentally challenged. The remaining parents reported the need but they did not know the significance and were not aware of the program and facility to attend the training.

Table 6: Parental Awareness of Child Rights

Awareness	No. of Respondents	Percentage
Basic Rights		
Not aware	96	60.0
Aware	64	40.0
Right to education		
Not aware	110	68.8
Aware	50	31.2
Right to economic security		
Not aware	135	84.4
Aware	25	15.6
Right to protection from exploitation		
Not aware	142	88.8
Aware	18	11.2

N=160

Awareness regarding child rights by parents is important to access resources for children. They relate to basic rights, right to education, right to economic security and right to protection from exploitation. Three out of ten (31 percent) parents are aware about rights to education of all children. As they are entitled, they know that the differently abled children can avail free education and sometimes in special schools with free boarding and lodging, aids and appliances, tricycles, hearing aids, folding sticks etc.

Only very few (15.6 percent) caretakers know the right to economic security. They report that through this right they get access to various training skills for the differently abled children like chalk piece making, weaving, computer training, and book binding etc. The children through the learning of certain like life skills can earn and it can help them in later life if required. About a tenth (11.2 percent) of parents are aware about the right to protection from exploitation. The person who is disabled has the same basic rights as other citizens of the same country and has a right to proper medical care and physical restoration and educational training. They have the right to economic security and a decent standard of living and also to participate in all aspects of community life and to be provided with appropriate leisure time activities.

Care Demands

Family care giving is described as an ‘unexpected career’ for those involved which requires adaptation and restructuring of responsibilities over time. Parents are the main care givers to the children and they need assistance in coping with care demand, their own emotions and pressures, yet need to adopt a positive approach towards the differently abled children and themselves. Parents of children with disabilities have very high level of demand signifying that they perceived more problems in their role as parents than parents of children without disabilities. The parents are also going through stages of understanding and accepting their child’s disabilities. Before the child’s birth, the parents might have several expectations but after the birth, for many it is an emotional shock and requires time and support to adapt to it. Families caring for and bringing up the child with disability face strain in the family as well as social isolation due to the child’s limited development, lack of mobility or behavioral problems etc. (Cubbin et al., 1982). Having a disabled child born into a family and grow into adult is one of the most stressful experiences a family can endure. Some of the parents perceive their disabled child as an extension of themselves and feel ashamed or experience social rejection, ridicule or embarrassment. Parents’ reactions may be affected due to economic status, level of stress, personality traits, emotional maturity, marital stability and active support system.

To understand the care demand experienced by parents, a set of questions pertinent to care in various domains were used in this study. The questions relate to the service demands, emotional pressure, family strain and ability to mix with society. Several questions were pooled in and later segregated in separate tables. Findings indicate that a significant proportion of parents expressed high care demand owing to ‘worry about child’s future’, ‘taking children out in public’, ‘daily service requirements’, ‘increase in financial responsibilities’, ‘constant care demands of the children’ etc.

Table 7: Care Demand Regarding Dependency of Children

Care demand for dependency of children	No. of respondents (Percentage)
Child cannot take a ride in a bus independently.	155 (96.8)
Have accepted the fact that my child might have to live out his/her life in some special setting.	149 (93.1)
Child can't pay attention very long.	138 (86.2)
Not easy to communicate with my child.	131 (81.8)
Difficult to communicate with my child because he/she has difficulty understanding what is being said to him/her.	126 (78.7)
Feel tense when I take my child out in public.	123 (76.8)
Child cannot remember what he/she says from one moment to the next.	121 (75.6)
Child isn't able to take part in games or sports.	109 (68.1)
Child doesn't communicate with others of his/her age group.	106 (66.2)
Child is not able to express his/her feelings to others.	106 (66.2)
Child is not able to go to the bathroom alone.	93 (58.1)
Child doesn't know his/her address.	90 (56.2)
Confidence is not one of the things I appreciate about my child.	82 (51.2)
Child isn't aware of who he/she is	81 (56.6)
Child can't feed himself/herself.	75 (46.8)
Child cannot walk without help	55 (34.3)
N=160	

Care demand reflects that a majority of parents express having demands and also in varying intensity though the questions limit to knowing whether they experience such problem. The demands relate from emotional pressure of parents to actual needs and services of the differently abled child, along with difficulty to attend to their own needs and requirements. An overwhelming proportion reports constant worry on child's situations, the dependency of the children and their future and the social life of the family. The specific situations relate to the child's inability to lead a normal life, requirement to spend for special needs/aids, or schools, care taking of the children in later life, family upheavals of financial and social pressures. Parents also report anxiety over the overall family development, as other children's development is

effected as they spend less time and money on other children. They also have difficulty in taking care of the regular routine activities as the children are not in a position to recollect their name, address or have difficulty to participate in sports, recreation etc.

It is noticeable that a majority of parent's state that the long term care of the child leads to strain and a significant proportion state that they are too tired to enjoy themselves, indicating strain, exhaustion and poor attention to themselves. The parents are largely pressurized and experience demands as the children are not able to manage their day to day routine activities, or cannot participate in activities that other children normally do. Majority of parents feel acute demand when they feel the children are totally dependent on them. It relates to situation such as need for special setting (93.1 percent) or when the child cannot pay attention very long (86.2 percent), or cannot communicate easily (81.8 percent), when confidence is low (72.5 percent), or when the child cannot express what he/she feels (66.2 percent), or cannot remember what he/she says (58.1 percent), or when they cannot express the need to go to the toilet (58.1 percent), or when they are not aware of who he/she is (56.6 percent) or when they do not know their address (56.2 percent) or cannot walk or feed on their own (34.3 percent). This pressure is felt most by parents who have children with mental disability followed by some type of physical disability. The children's dependency creates physical and mental strain on them.

Table 8: Care Demands Related to Family Issues

Care Demand for Family Issues	No. of respondents (Percentage)
The constant demands for care of my child limit growth and development of someone else in our family.	141(88.1)
Other members of the family have to do without things because of him/ her.	119 (74.3)
Child is unable to fit into the family social group	114 (71.2)
Taking child on vacation spoils the pleasure of the whole family.	79 (49.3)
N=160	

In addition, the care takers responsibility towards other members in family also pressurizes. Women being major care takers, have to carry out multiple roles and shoulder the emotional pressures. They are unable to do things on their own as they

themselves are dependent, do not have a hold over money, are less educated and less aware of formal support available, being blamed, low support available and still has to continue with the activities. This role is crucial and hence can neither shed this role nor can they do to their satisfaction. It relates to issues that the family has to forgo because of the disabled child (74.3 percent) such as a vehicles, better school, outing, good food, clothes etc., considered as limiting the development of other members in the family (88.1 percent), child is unable to fit into the family social group (71.2 percent) etc. Family goes through increased financial difficulties (96.8 percent), and the differently abled child's presence restricts the outing and chances of vacation for the other children (49.3 percent).

Table 9: Care Demand Related to Emotional Pressures

Care Demand for Emotional problems	No. of respondents (Percentage)
Worry about what will be done when the child gets older.	158 (98.7)
Disappointed that the child does not lead a normal life.	154 (96.2)
Feel sad when think about the child.	153 (95.6)
People can't understand what the child tries to say.	152 (95)
Bothers that the child will always be this way.	149 (93.1)
Child is over-protected.	146 (91.2%)
Feel very embarrassed because of the child	144 (90%)
Get upset with the way life is going.	142 (88.7)
Sometimes avoid taking the child out in public.	124 (77.5)
Child will always be a problem.	109 (68.1)
N=160	

In addition, the parents feel the demand to be very high when they face social embarrassment, anxious over the children's position and future, when they feel stressed up and when they cannot relax or cannot meet people with whom they would like to interact with. They simultaneously go through the feeling of guilt and restlessness while they are emotionally and physically exhausted. The feeling of sadness that they go through when they think about the child (95.6 percent), avoid taking the child out in public (99percent), getting too tired to enjoy oneself (98.7

percent), feel that the child is over protected (91.2 percent), disappointment that the child cannot lead a normal life (96 percent), worry about the child’s future when they get older (90 percent), feeling embarrassed because of the child (90 percent), and being upset with the way life is going on (88.7 percent), feeling that the child will always be a problem (68.1 percent), and strain associated with caring (68.1 percent), and unable visit friends whenever they want to (54.3 percent) or emotional issues specific to the care takers. These are important issues which affect their care taking role, and their own emotional state in leading a normal life and carrying out regular activities.

Table 10: Physical and Emotional Strain Experienced by Parents

Details of strain	No. of respondents (Percentage)
It isn't easy for to relax.	144 (90.0)
Caring for the child puts a strain on me.	132 (82.5)
Get almost too tired to enjoy myself.	116 (72.5)
Can't visit friends whenever wanted.	87 (54.3)
N=160	

The demand faced by parents indicates that the children are yet to be adequately trained with regard to the day to day activities which would help them in managing themselves and reduce the care giving burden of parents. The parents also go through a pressure of social embarrassment and are physically drained as they are left with no alternate care either at formal or informal level. In addition the family is pressurized due to financial constraints for which again the parent’s role is important. It is generally perceived that the overall development of the family is effected and other members in the family experience a setback. Parents also constantly go through emotional turmoil of prioritizing the issues.

Table 11: Level of Care Demand by Background Factors

Background factors	Level of Care demand		
	Low	Medium	High
Gender of Respondents			
Male(Father)	8(19.0%)	22(52.4%)	12(28.6%)
Female(Mother)	26(22.0%)	40(33.9%)	52(44.1%)
Age (in years)			
Up to 39	20(23%)	29(33.3%)	38(43.7%)
40 and above	14(19.2%)	33(45.2%)	26(35.6%)
Educational level			
Primary and Middle	22(18.5%)	54(45.4%)	43(36.1%)
High school and above	12(29.3%)	8(19.5%)	21(51.2%)
Occupation			
Employed	16(21.3%)	33(44%)	26(34.7%)
Not employed	18(21.2%)	29(34.1%)	38(44.7%)
Monthly Income of family in Rupees			
Upto 10,000	28(22%)	58(45.7%)	41(32.3%)
10,001 and above	4(12.9%)	4(12.9%)	23(74.2%)
Savings			
Available	7(12.1%)	29(50%)	22(37.9%)
Not available	27(26.5%)	33(32.4%)	42(41.2%)
Debts			
Debted	20(26%)	28(36.4%)	29(37.7%)
Not debted	14(16.9%)	34(41%)	35(42.2%)
Number of children			
Upto Two	19(21.6%)	27(30.7%)	42(47.7%)
Three and above	15(20.8%)	35(48.6%)	22(30.6%)
Type of family			
Nuclear	30(21.4%)	58(41.4%)	52(37.1%)
Joint	4(20%)	4(20%)	12(60%)
Nativity status			
Migrant	17(24.6%)	30(43.5%)	22(31.9%)
Non Migrant	17(18.7%)	32(35.2%)	42(46.2%)
Parental training			
Received	3(11.5%)	13(50%)	10(38.5%)
Not received	31(23.1%)	49(36.6%)	54(40.3%)
Age of the child			
Up to 9 years	20(25.3%)	20(25.3%)	39(49.4%)
10 and above	14(17.3%)	42(51.9%)	25(30.9%)
Sex of the child			
Male	21(20%)	41(39%)	43(41%)
Female	13(23.6%)	21(38.2%)	21(38.2%)
Type of school			
Special school	8(10.3%)	38(48.7%)	32(39%)
Others	26(31.7%)	24(29.3%)	32(41%)
Type of disability			
Mentally challenged	0(0%)	30(37%)	51(63%)
Others	34(43%)	32(40.5%)	13(16.5%)
N 160			

Based on the index scores of various strands in all domains total scores are ascertained at the individual level and later the care demand is categorized into high,

medium and low based on mean and standard deviation. The bivariate distribution of background characteristics with level of care demand depicts that mother's report relatively higher care demand. Similarly younger parents in comparison to older parents, relatively better educated parents, those in joint family, those with higher income, those who do not having savings and debted, non-migrants, those with very young children, and parents with mentally challenged children experience higher care demand. In joint families, the presence of elderly parent's in-law or dependent members impinges on sharing of resources. The personal resources and situational conditions at family pressurizes the care takers which leads to differential care demand.

Several background variables were correlated with care demand (Table 12) and the results indicate that the monthly income of family, type of school, where the children are enrolled either in special school or normal schools and the type of disability of the children has a significant bearing on level of care demand.

Linear regression was carried out to know the bearing of background factors on level of care demand (Table 13). The results indicate that the monthly family income, age of the children, school to which the children attend and the type of disability are significantly related to care demand. Parents having younger children and those having children with mental disability experience higher care demand. Younger children are yet to get accustomed to the routine activities and the dependency is high. Parents are also still in a state of shock as they are yet to come to terms and isolate themselves from the society and exclude themselves which they feel as a personal failure and hence the emotional domains of the demand raises. Parents who have children attending special schools are in need of special care which means there is need for constant care and demand. Similarly parents having mentally challenged children with high dependency also report high care demand.

Table 12: Correlates of Level of Care Demand by Background Factors

Background factors	Level of Care Demand	
	r- value	Sig
Gender of the Respondents Male (Father) Female (Mother)	.072	.363
Age (in years) Up to 39 40 and above	.028	.726
Educational level Primary and Middle High school and above	-.025	.756
Occupational status Employed Not employed	-.067	.400
Monthly Income of family in Rupees Upto 10,000 10,001 and 30,000	.269	.001***
Savings Available Not available	.071	.375
Debts Debted Not debted	-.090	.260
Number of children Up to two Three and above	-.107	.176
Type of family Nuclear Joint	.106	.183
Nativity status Migrant Non Migrant	-.132	.097
Training Received Not received	.047	.552
Age of the child Up to 9 years Above 9 years	-.069	.387
Sex of the child Male Female	-.040	.615
Type of school Special school Others	.154	.051*
Type of disability Mentally challenged Others	-.589	.000***
N=160		

Table 13: Regression Results of Level of Care Demand by Background Factors

Background factors	Level of Care Demand	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.014	.884
Age (in years) Up to 39 40 and above	.068	.395
Educational level Primary and Middle High school and above	.012	.865
Occupational status Employed Not employed	-.138	.128
Monthly Income of family in Rupees Upto 10,000 10,001 and 30,000	.267	.001***
Savings Available Not available	.044	.549
Debts Debted Not debted	-.030	.671
Number of children Upto Two Three and above	-.097	.139
Type of family Nuclear Joint	.041	.561
Nativity status Migrant Non Migrant	.053	.465
Training Received Not received	-.041	.568
Age of the child Upto 9 years Above 9 years	-.124	.098
Sex of the child Male Female	-.039	.611
Type of school Special school Others	-.458	.648
Type of disability Mentally challenged Others	-.656	.000***
N=160		

*P<0.10; **P<0.05; ***P<0.01

To sum this chapter identifies the major problems that care takers face especially in the areas of financial, emotional and work related domains. A specific examination of care demands emphasizes the constant worry about children,

demanding tasks and exhaustion experienced by parents as major causes. The familial income, the type of school which children attend, the type of disability of the child and the age of parents has a significant bearing on care demand.

Disability has a significant effect on the children's interpersonal skills and social interactions with family members and persons outside. The children if not adapted well, have low attachment, do not bond with caretakers, or seek comfort when hurt or upset, and tend to exhibit uncommon use of body gestures. If left unattended it could complicate further development activities as the disorder progresses, or as they grow. Social interaction of differently abled children refers to recognition and understanding of the emotions of other people (Braverman, Fein, Lucci, and Waterhouse, 1989). Many children who have severe disability or have problems with speech and hearing have difficulty in understanding what others communicate to them or have difficulty to make others understand their communications to them. Social and communicative deficiencies are also associated with children experiencing multiple disabilities. Social interaction is necessary to prepare the children better for independent living at least in certain situations when it becomes inevitable.

Their behavior is usually determined by the feeling about themselves, such as self-worth, self-esteem, self-confidence etc. and family, school, peer group and social environment are the main agencies which shape the children's behaviour. In the process, children address their behavior towards the group in the form of attachment to the family, adjustment in school and includes in community (Gnanasundaram, 2009). A child, who has acquired such skills, reflects the successful socialization required for special needs and the child is much happier and interacts with community more freely and has a feeling of inclusion.

According to Dekker's Developmental behavioral checklist scale (2002), the instrument focuses on assessing the social behavior of differently abled children. The scale focuses on children's behavior in terms of Disruption, Self-absorption, Communication disturbance and Anxiety which also includes several social behavior components. These domains explain the basic differences of social, emotional and psychological behavior of differently abled children with respect to others.

The component provides scope to understand the sensitive aspects of interaction and intends to understand the behavioral problems, so as to provide appropriate intervention. Several empirical studies of social behavior (Gillberg, 1990) gives an overview of various behavioural problems, like unmindfulness of words and body language, inability to understand the social relationship etc., experienced by the differently abled children. The Behavioural problems relate to anxiety, shyness, repetitive activity etc, which are normally observed along with disability of children, while it also includes unusual body movements, banging head, being impatient and laughing for no reason etc,

Understanding the social behaviour of children also enables us to know the interactive nature of the child, strain in care demand and specially to know the problematic behaviours which contribute to demanding situations of care givers.

Table 14: Disruptive Behaviour of Differently Abled Children

Disruptive behaviour	Frequency (Percentage)		
	Always	Sometimes	Never
Lies	2(1.2%)	32(20%)	126(78.7%)
Disobedient	7(4.3%)	76(47.5%)	77(48.1%)
Kicks, hits others	20(12%)	64(40%)	76(47.5%)
Impatient	25(15.6%)	72(45%)	63(39.3%)
Jealous	42(26.2%)	59(36.8%)	59(36.8%)
Whines a lot	22(13.7%)	87(54.3%)	51(31.8%)
Says things not capable of	73(45.6%)	42(26.2%)	45(28.1%)
Easily led by others	72(45%)	61(38.1%)	27(16.8%)
Talks too much	29(18.1%)	83(51.8%)	48(30%)
Rapid mood changes	73(45.6%)	51(31.8%)	36(22.5%)
Throws or breaks objects	25(15.6%)	63(39.3%)	72(45%)
Refuses to go to school	47(29.3%)	62(38.7%)	51(31.8%)
Noisy	36(22.5%)	75(46.8%)	49(30.6%)
N=160			

The information elicited is parental perception of the children’s social behaviour. A considerable proportion of the children goes through rapid mood changes, attempt to say things for which they are not capable of and are easily led by others. Some of these behaviours, becomes a chance for others to treat them as an ‘object of entertainment’ or

‘to be exploited’. A significant proportion refuse to co-operate, such as going to school, impatient, disobedient or sometimes they express jealousy or become noisy in certain situations. These are issues which can be handled with ease if the child has been properly understood or if proper training has been given. Other issues relate to talking too much, whining or being impolite, while a few relate to indulging in throwing or breaking objects or kicking or hitting others. These behaviours are stressful for parents and unless parents know to handle them or children are trained, and such behaviours become problematic and troublesome in the long run. This highlights the need for training to the child, the parent or alternate care givers to ensure normal situations and environment.

Based on the summative scores of the strands in the domain of disruptive behaviour, the differently abled children are grouped in to children with high, moderate and low level of disruptive behaviour.

Table 15: Level of Disruptive Behaviour among Differently Abled Children

Disruptive behaviour	No. of respondents	Percentage
Low	38	23.8
Medium	90	56.2
High	32	20.0
Total	160	100.0

About 20 percent of the children have high level of disruptive behaviour, while a little more than one half the children have a medium level of disruptive behaviour while the remaining children have low in disruptive behaviour.

Table 16: Level of Disruptive Behaviour by Background Factors

Background factors	Level of Disruptive behaviour		
	Low	Medium	High
Gender of respondents			
Male (Father)	16(38.1%)	15(35.7%)	11(26.2%)
Female(Mother)	22(18.6%)	75(63.6%)	21(17.8%)
Age (in years)			
Upto 39	18(20.7%)	56(64.4%)	13(14.9%)
40 and above	20(27.4%)	34(46.6%)	19(26%)
Educational level			
Primary and Middle	26(21.7%)	73(61.3%)	20(16.7%)
High school and above	12(30%)	17(41.5%)	12(30%)
Type of family			
Nuclear	32(22.9%)	81(57.9%)	27(19.3%)
Joint	6(30%)	9(45%)	5(25%)
Training			
Received	2 (7.7%)	21(80.8%)	3(11.5%)
Not received	36(26.9%)	69(51.5%)	29(21.6%)
Age of the child			
Upto 9 years	18(22.8%)	41(51.9%)	20(25.3%)
Above 9 years	20(24.7%)	49(60.5%)	12(14.8%)
Sex of the child			
Male	24(22.9%)	62(59%)	19(18.1%)
Female	14(25.5%)	28(50.9%)	13(23.6%)
Type of school			
Special school	6(7.7%)	53(67.9%)	19(24.4%)
Others	32(39%)	37(45.1%)	13(15.9%)
Type of disability			
Mentally challenged	22(27.8%)	46(58.2%)	11(13.9%)
Others	16(19.8%)	44(54.3%)	21(25.9%)
N=160			

The bivariate distribution of background factors with children's level of disruptive behavior shows that fathers, older parents, parents educated up to high school and above, those in joint families report a considerable proportion of children having high as well as low level of disruptive behaviors in comparison to others in the respective category. A significant proportion of younger children (below 9 years) have high disruptive behavior, probably because the training process is not yet completed. More children in special schools are identified with high disruptive behavior. Children with differential ability other than being mentally challenged also exhibit high disruptive behavior, while more of mentally challenged children exhibit low disruptive behavior.

Table 17: Correlates of Disruptive Behaviour by background factors

Background factors	Level of Disruptive behaviour	
	r- value	Sig
Gender of the respondents Male (Father) Female (Mother)	.074	.355
Age (in years) Upto 39 40 years and above	-.033	.679
Educational level Primary and Middle High school and above	-.033	.676
Type of family Nuclear Joint	-.007	.928
Training Received Not received	.051	.525
Age of the child Upto 9 years Above 9 years	-.094	.237
Sex of the child Male Female	.021	.790
Type of school Special school Others	.302	.000***
Type of disability Mentally challenged Others	-.152	.055*
N=160		

*P<0.10, **P<0.05, ***P<0.01

The correlation results show that the type of school in which the children study and the type of disability has a bearing on the level of disruptive behaviour of children. Children are admitted in special schools because of severe disability or need special assistance and hence disruptive behaviour is also high. It is also observed that children other than mentally challenged also report more disruptive social behaviour.

Table 18: Regression Results of Disruptive Behaviour by Background Factors

Background factors	Level of Disruptive behaviour	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	.086	.310
Age (in years) Upto 39 40 years and above	-.121	.201
Educational level Primary and Middle High school and above	.023	.770
Type of family Nuclear Joint	-.072	.379
Training Received Not received	.114	.152
Age of the child Upto 9 years Above 9 years	-.148	.085
Sex of the child Male Female	.136	.099
Type of school Special school Others	.270	.001**
Type of disability Mentally challenged Others	-.108	.189
N=160		

*P<0.10, **P<0.05,***P<0.01

The regression results indicate that the type of school has significant relationship with level of disruptive behavior, indicating that children in special schools have more of disruptive behavior. It reflects the behavioural problems of the children with lesser disability also but training and orientation to the children and family remains unmet. If the children are attended and supported in changing their behavioural problems, their coping, survival and level of dependency can be improved.

Table 19: Self-Absorbed Behaviour of Differently Abled Children

Self-Absorbed behaviour	Frequency		
	Always	Sometimes	Never
Bites others	13(8.1%)	67(41.8%)	80(50%)
Hits or Bites self	16(10%)	48(30%)	96(60%)
Repetitive activity	45(28.1%)	50(31.2%)	65(40.6%)
Bangs head	10(6.2%)	32(20%)	118(73.7%)
Urinate outside toilet	10(6.2%)	54(33.7%)	96(60%)
Laughs for no Reason	37(23.1%)	64(40%)	59(36.8%)
Strips off clothes	27(16.8%)	27(16.8%)	106(66.25%)
Aloof, in own world	24(15%)	46(28.7%)	90(56.2%)
Unusual body movements	42(26.2%)	58(36.2%)	60(37.5%)
N=160			

The table on Self Absorption behavior of children shows that many children engage in repetitive behavior, unusual body movements and laughs for no reason for which they have no control over themselves but are not problematic behaviours. A significant proportion of children also strip of clothes, stay aloof in their own world, hits or bites themselves which is quite problematic and imposes considerable strain on parents, as the children cannot be left alone or with new care takers. A small set of children have important behavioral challenges such as biting others, banging their heads or cannot attend to their natural call. These activities are also stressful and parents become frustrated when they cannot control them and hence parents threaten or punish to control. Later the parents go through the feeling of guilt. Such issues can be handled relatively better if the children and parents had some professional assistance. A considerable proportion of parents go through a majority of these problems either at times or always.

Based on the overall scores of the strands, the children are categorized into high, medium or low absorptive behavior. A significant proportion of parents have observed the children with medium or high absorptive behavior and only a small proportion have children with low absorptive behavior.

Table 20: Level of Self -Absorption among Differently Abled Children

Level of Self-Absorbed behaviour	No. of Respondents	Percentage
Low	45	28.1
Medium	80	50.0
High	35	21.9
Total	160	100

Table 21: Level of Self -Absorption among Differently Abled Children by Background Factors

Background factors	Level of Self -Absorbed Behaviour		
	Low	Medium	High
Gender of the respondents			
Male (Father)	16(38.1%)	18(42.9%)	8(19%)
Female (Mother)	29(24.6%)	62(52.5%)	27(22.9%)
Age (in years)			
Upto 39	21(24.1%)	47(54%)	19(21.8%)
40 and above	24(32.9%)	33(45.2%)	16(21.9%)
Educational level			
Primary and Middle	34(28.3%)	56(47.1%)	29(24.2%)
High school and above	11(27.5%)	24(58.5%)	6(15%)
Type of family			
Nuclear	41(29.3%)	70(50%)	29(20.7%)
Joint	4(20%)	10(10%)	6(30%)
Training for parents			
Received	5(19.2%)	16(61.5%)	5(19.2%)
Not received	40(29.9%)	64(47.8%)	30(22.4%)
Age of the child			
Upto 9 years	16(20.2%)	45(57%)	18(22.8%)
Above 9 years	29(35.8%)	35(43.2%)	17(21%)
Sex of the child			
Male	25(23.8%)	59(56.2%)	21(20%)
Female	20(36.4%)	21(38.2%)	14(25.5%)
Type of school			
Special school	13(16.7%)	50(64.1%)	15(19.2%)
Others	32(39%)	30(36.6%)	20(24.4%)
Type of disability			
Mentally challenged	45(57%)	29(36.7%)	5(6.3%)
Others	0(0%)	51(63%)	30(37%)
N=160			

More mothers tend to report high self- absorptive behaviour of the children in comparison to fathers. Children living in nuclear families have low absorptive behavior, while children in joint family report high self- absorbed behavior. More number of older children have low self -absorbed behavior in comparison to younger children, while female children also exhibit low self -absorbed behavior as well as high self- absorbed behavior. A mixed trend is also noticed for children studying in normal school.

Table 22: Correlates of self -Absorptive behavior by Background Factors

Background factors	Level of Self-Absorption behaviour	
	r- value	Sig
Gender of the respondents		
Male (Father)	.108	.172
Female (Mother)		
Age (in years)		
upto 39	.061	.442
40 and above		
Educational level		
Primary and Middle	.050	.534
High school and above		
Type of family		
Nuclear	.087	.273
Joint		
Training		
Received	.039	.624
Not received		
Age of the child		
Upto 9 years	-.123	.121
Above 9 years		
Sex of the child		
Male	-.048	.548
Female		
Type of school		
Special school	.122	.124
Others		
Type of disability		
Mentally challenged	-.622	.000***
Others		
N=160		

*P<0.10, **P<0.05, ***P<0.01

The correlates of background factors with self- absorbed behavior shows that type of disability has a strong relationship with self -absorptive behavior. It indicates that children other than being mentally challenged also exhibit high self- absorbed behavior which requires intensive care taking and training to manage such situation. Other variables included do not show significant association.

Table 23: Regression Results of Self -Absorbed behavior by Background Factors

Background factors	Self- Absorbed behaviour	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	.103	.083
Age (in years) upto 39 40 and above	.112	.093
Educational level Primary and Middle High school and above	.050	.531
Type of family Nuclear Joint	-.013	.819
Training Received Not received	.057	.473
Age of the child Upto 9 years Above 9 years	-.237	.000***
Sex of the child Male Female	-.007	.905
Type of school Special school Others	-.035	.544
Type of disability Mentally challenged Others	-.749	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

Several theoretically relevant and statistically significant variables are included for the regression analysis. The results indicate that age of the children and type of disability are strongly associated with self-absorptive behavior. Younger children are more in self-absorbed behavior. They are yet to be trained and have no control over their behaviours and hence care takers need to pay greater attention in enabling them to manage self-absorptive behavior. The type of disability relationship indicates that children with disability other than being mentally challenged also need intensive care and training. Assuming moderate disability as manageable and not providing adequate professional care and training may disturb the children's functioning and successful adaptation, while care taking may also be a burden.

Table 24: Communication disturbance behaviour of Differently abled children

Communication disturbance behavior	Frequency		
	Always	Sometimes	Never
Tells to self or imaginary others	50 (31.2%)	73 (45.6%)	37 (23.1%)
Unusual tone or rhythm	18 (11.2%)	103 (64.3%)	39 (34.3%)
Doesn't mix with own age group	16 (10.0%)	71 (44.3%)	73 (45.6%)

N=160

Communication disturbance domain relates to talking to self, repetitive activities and self-isolation by the children. The table indicates that a considerable proportion of children talks to self and has an unusual tone or rhythm while one half do not mix with their peer group. Talking to self and having an unusual tone or rhythm is largely an indication of loneliness and availability of more time with no meaningful work. Similarly some children have difficulty mixing with others largely due to poor self-conception and self-worth or lack of opportunities. It efforts are taken; possibility is high that their communication disturbance can be overcome to a large extent.

The categorization of children by level of communication disturbance shows that a majority of children experience medium or high communication disturbance indicating a difficult care taking.

Table 25: Level of Communication Disturbance Behaviour among Differently Abled Children

Level of Communication disturbance behaviour	No. of respondents	Percentage
Low	25	15.6
Medium	86	53.8
High	49	30.6
Total	160	100

Greater proportion of mothers and those parents with high school level of education and above report both high communication disturbances of their children while they also report low disturbance. More children in joint families have lesser communication problems, while male children tend to exhibit more communication problems, children in special schools and those with disability other than being mentally challenged have communication disturbance problems. As with earlier situation children in special requires special school attention and probably the children are alienated and isolated from the community and hence is forced into low communication behaviour. Children other than being mentally challenged also need support to enable their communication and correct their behaviour.

Table 26: Level of Communication disturbance behavior by background factors

Background factors	Level of Communication disturbance behaviour		
	Low	Medium	High
Gender of the respondents			
Male (Father)	4(9.5%)	28(66.7%)	10(23.8%)
Female (Mother)	21(17.8%)	58(49.2%)	39(33.1%)
Age (in years)			
upto 39	15(17.2%)	47(54%)	25(28.7%)
40 and above	10(13.7%)	39(53.4%)	24(32.9%)
Educational level			
Primary and Middle	13(10.8%)	73(60.8%)	34(28.3%)
High school and above	12(30%)	13(32.5%)	15(37.5%)
Type of family			
Nuclear	19(13.6%)	78(55.7%)	43(30.7%)
Joint	6(30%)	8(40%)	6(30%)
Training			
Received	2(7.7%)	12(46.2%)	12(46.2%)
Not received	23(17.2%)	74(55.2%)	37(27.6%)
Age of the child			
Upto 9 years	13(16.5%)	40(50.6%)	26(32.9%)
Above 9 years	12(14.8%)	46(56.8%)	23(28.4%)
Sex of the child			
Male	17(16.2%)	51(48.6%)	37(35.2%)
Female	8((14.5%)	35(63.6%)	12(21.8%)
Type of school			
Special school	7(9%)	34(43.6%)	37(47.4%)
Others	18(22%)	52(63.4%)	12(14.6%)
Type of disability			
Mentally challenged	21(26.6%)	51(64.6%)	7(8.9%)
Others	4(4.9%)	35(43.2%)	42(51.9%)
N=160			

The correlation table (Table 27) indicates that the type of school in which the children study and the type of disability has a significant association with level of communication disturbance of the children.

Table 27: Correlates of Communication Disturbance behaviour by background factors

Background factors	Level of Communication disturbance behaviour	
	r-value	Sig
Gender of the respondents Male (Father) Female (Mother)	.006	.936
Age(in years) upto 39 40 and above	-.058	.469
Educational level Primary and Middle High school and above	.090	.260
Type of family Nuclear Joint	-.085	.283
Training Received Not received	.156	.049
Age of the child Upto 9 years Above 9 years	-.022	.786
Sex of the child Male Female	-.084	.289
Type of school Special school Others	.345	.000***
Type of disability Mentally challenged Others	-.487	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

The Regression results indicate that the type of family in which the child resides, the school to which the child attends and the type of disability has a significant bearing on communication disturbance. Children in joint family are observed to have higher communication disturbance reflecting that despite having more people at home, they do not spend time with the children to break the monotony and interact with them frequently. The composition of members in the joint family, especially elders does not adequately conducive situations for communication of the child. Children in special schools usually have severe disability issues which might have an impact on

communication problem. It is noticeable that children other than being mentally challenged also have serious communication disturbances. More chances for them to interact and helping them to be occupied will help them to overcome communicative inhibition.

Table 28: Regression Results of Communication Disturbance Behaviour by Background Factors

Background factors	Communication Disturbance	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	.107	.122
Age (in years) upto 39 40 and above	-.145	.061
Educational level Primary and Middle High school and above	.107	.175
Type of family Nuclear Joint	-.215	.002**
Training for parents Received Not received	.168	.034*
child age in years 9 years and less Above 9 years	-.107	.126
child sex Male Female	-.034	.612
Type of school Special school Others	.283	.000***
Type of disability Mentally challenged Others	-.483	.000***
N=160		

*P<0.10, **P<0.05,***P<0.01

Table 29: Anxiety behaviour of Differently abled children

Anxiety Behavior	Frequency		
	Always	Sometimes	Never
Distressed when Separated	43(26.8%)	32(20%)	85(53.1%)
Cries for no Reason	28(17.5%)	86(53.7%)	46(28.7%)
No response to others	20(12.5%)	63(39.3%)	77(48.1%)
Doesn't show affection	23(14.3%)	75(46.8%)	62(38.7%)
Depressed, Unhappy	53(33.1%)	71(44.3%)	36(22.5%)
Plays with Unusual objects	10(6.2%)	59(36.8%)	91(56.8%)

N=160

The anxiety domain shows that a majority of children play with unusual objects like, keys or light switches or even dangerous objects like knife, stick etc, does not respond to others, does not show affection, cries for no reason, becomes distressed when separated and is usually depressed or unhappy. All through the strands indicate the emotional dependency of the children either due to over protection or fear or being insecure. It is noticeable that majorities have high separation anxiety, are also indifferent and are not expressive in affection.

Table 30: Level of Anxiety behaviour among differently abled children

Level of Anxiety	No. of Respondents	Percentage
Low	28	17.4
Medium	102	63.8
High	30	18.8
Total	160	100.0

Nearly two thirds of the children have a medium level of anxiety and close to one fifths have high level of anxiety.

Table 31: Level of Anxiety among Differently Abled Children by Background Factors

Background factors	Level of Anxiety		
	Low	Medium	High
Gender of the respondents			
Male (Father)	4(9.5%)	33(78.6%)	5(11.9%)
Female (Mother)	24(20.3%)	69(58.5%)	25(21.1%)
Age (in years)			
upto 39	15(17.2%)	52(59.8%)	20(23%)
40 and above	13(17.8%)	50(68.5%)	10(13.7%)
Educational level			
Primary and Middle	13(10.9%)	83(69.2%)	23(19.2%)
High school and above	15(36.6%)	19(47.5%)	7(17.5%)
Type of family			
Nuclear	23(16.4%)	92(65.7%)	25(17.9%)
Joint	5(25%)	10(50%)	5(25%)
Training			
Received	8(30.8%)	15(57.7%)	3(11.5%)
Not received	20(14.9%)	87(64.9%)	27(20.1%)
Age of the child			
Upto 9 years	19(24.1%)	43(54.4%)	17(21.5%)
Above 9 years	9(11.1%)	59(72.8%)	13(16%)
Sex of the child			
Male	20(19%)	68(64.8%)	17(16.2%)
Female	8(14.5%)	34(61.8%)	13(23.6%)
Type of school			
Special school	14(17.1%)	47(60%)	17(21.8%)
Others	14(17.9%)	55(67.1%)	13(15.9%)
Type of disability			
Mentally challenged	15(19%)	54(68.4%)	10(12.7%)
Others	13(16%)	48(59.3%)	20(24.7%)
N=160			

A greater proportion of parents in younger age group report higher anxiety of their children, while parents with lower educational attainment also report lower anxiety of children in comparison to better educated parents. Relatively more mothers indicate high as well as low anxiety of the children, while more of fathers report medium level of anxiety by children. Children in joint family experience low anxiety levels as well as high anxiety. Similarly children below 9 years of age have low and high anxiety levels indicating trend in both ways. Relatively more children in special schools have high anxiety and children with disability other than being mentally challenged also have high

anxiety levels. However most of the trends are mixed and do not indicate a clear direction.

The correlation results indicates significant association between parental education, training received by parents and anxiety level of children. Parents with low education report children having high anxiety of children and those with high education report children having low anxiety. Parents with low education may be over protective or not aware, and do not provide chances to be experience new situations and hence higher anxiety level.

Table 32: Correlates of Anxiety by background factors

Background factors	Level of Anxiety	
	r- value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.011	.888
Age (in years) upto 39 40 and above	.082	.305
Educational level Primary and Middle High school and above	.202	.010*
Type of family Nuclear Joint	-.008	.922
Training for parents Received Not received	-.150	.059*
Age of the child Upto 9 years Above 9 years	.062	.436
Sex of the child Male Female	.094	.236
Type of school Special school Others	.042	.597
Type of disability Mentally challenged Others	-.124	.117
N=160		

*P<0.10,**P<0.05,***P<0.01

Table 33: Regression Results of Anxiety by background factors

Background factors	Level of Anxiety	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.090	.297
Age (in years) upto 39 40 and above	.268	.006**
Educational level Primary and Middle High school and above	.154	.051*
Type of family Nuclear Joint	.068	.417
Training Received Not received	-.097	.218
Age of the child Upto 9 years Above 9 years	.053	.545
Sex of the child Male Female	.077	.360
Type of school Special school Others	-.109	.202
Type of disability Mentally challenged Others	-.151	.073
N=160		

*P<0.10, **P<0.05, ***P<0.01

The linear regression results indicate a significant relationship between parent's age, parent's educational attainment and anxiety level of children. Younger parents have children with high anxiety levels. The children also might be younger and probably are yet to come to terms with their situations, behavior and training. Parent's low educational level also affects the anxiety level of children by not providing adequate environment.

Table 34: Level of Overall Social Behaviour of Differently Abled Children

Level of Social Behaviour	No. of respondents	Percentage
Low	22	13.8
Medium	100	62.4
High	38	23.8
Total	160	100.0

The summation of scores on all strands in domain of Social Behaviour shows that a greater proportion of parents have children with medium (62.4 percent) or higher levels (23.8percent) of problematic in Social Behaviour.

Table 35: Level of Social Behaviour of Children by Background Factors

Background factors	Level of Social Behaviour		
	Low	Medium	High
Gender of the respondents			
Male (Father)	12 (28.6%)	19(45.2%)	11(26.2%)
Female (Mother)	10(8.5%)	81(68.6%)	27(22.9%)
Age (in years)			
upyo 39	8(9.2%)	58(66.7%)	21(24.1%)
40 and above	14(19.2%)	42(57.5%)	17(23.3%)
Educational level			
Primary and Middle	18(15.1%)	72(60.5%)	29(24.4%)
High school and above	4(9.8%)	28(68.3%)	9(22%)
Type of family			
Nuclear	20(14.3%)	87(62.1%)	33(23.6%)
Joint	2(10%)	13(65%)	5(25%)
Training			
Received	0(0%)	20(76.9%)	6(23.1%)
Not received	22(16.4%)	80(59.7%)	32(23.9%)
Age of the child			
Upto 9 years	7(8.9%)	50(63.3%)	22(27.8%)
Above 9 years	15(18.5%)	50(61.7%)	16(19.8%)
Sex of the child			
Male	11(10.5%)	68(64.8%)	26(24.8%)
Female	11(20%)	32(58.2%)	12(21.8%)
Type of school			
Special school	4(5.1%)	20(64.1%)	24(30.8%)
Others	18(22%)	50(61%)	14(17.1%)
Type of disability			
Mentally challenged	0	50(61.7%)	31(38.3%)
Others	22(27.8%)	50(63.3%)	7(8.9%)
N=160			

More mothers in comparison to fathers report having children with relatively higher problems of social behavior. Similarly younger parents, parents with high school level of education and above, those in joint living arrangement, parents who received training, parents with younger children and having male children with disability and parents with children attending special schools and children with mentally challenged disability express having children with relatively more difficulties in social behavior.

Table 36: Correlates of Social Behaviour by background factors

Background factors	Level of Social Behaviour	
	r- value	Sig
Gender of the respondents Male (Father) Female (Mother)	.122	.124
Age (in years) upto 39 40 and above	.089	.261
Educational level Primary and Middle High school and above	-.021	.789
Type of family Nuclear Joint	.031	.695
Training for parents Received Not received	.095	.230
Age of the child Upto 9 years Above 9 years	-.147	.064
Sex of the child Male Female	-.098	.218
Type of school Special school Others	.252	.001**
Type of disability Mentally challenged Others	-.474	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

Regarding the overall social behavior, correlation indicates that the type of school which the child attends and the type of disability of the child has a significant association with the social behavior of the child.

Table 37: Regression results of Social behavior by background factors

Background factors	Level of Social Behaviour	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	.136	.081
Age (in years) upto 39 40 and above	.018	.832
Educational level Primary and Middle High school and above	.012	.863
Type of family Nuclear Joint	-.043	.556
Training Received Not received	-.019	.802
Age of the child Upto 9 years Above 9 years	-.207	.008**
Sex of the child Male Female	-.003	.968
Type of school Special school Others	.103	.182
Type of disability Mentally challenged Others	-.489	.000***
N=160		

*P<0.10, **P<0.05,***P<0.01

The regression results indicate that the age of the children and type of disability has a strong influence on their overall social behavior. Parents report older children are better in social behavior indicating that the behavior can be learnt over a period of time but an effective socialization support and grooming can make a major difference in their lives. It is noticeable that parents of children with disabilities other than being mentally

challenged also report problems in social behavior of their children. Hence attention should be given to other differently abled children as they also go through various difficulties and highlights the fact that differently abled children with different challenges should be taken seriously, as they are aware of the situations, also understand happenings around them and experience more problems and hence more attention is needed.

Social Skills of the Differently abled child

The differently abled children are part of the social world which includes relationships at home, school, neighborhood and larger community. Hence, social interaction becomes inevitable and a requirement. Many of the children based on their ability, professional training and parental grooming learn certain social skills and adapt themselves. Social skill is defined in terms of interaction between an individual and his or her environment which enables an individual to adjust and respond appropriately to environmental cues. It provides the children with a means to cope during stressful situations and to avoid interpersonal conflict, (Matson, 1994). Social interactions and relationships with other people are necessary for personal adjustment and integration while social skills are the mediating variables. Social skills also provide an opportunity for the individual to express both positive and negative feelings in interpersonal situations without losing self-composure (Guralnick, 1986). Learning social skills is an important communication tool and reduces the care giver burden to a large extent.

Parents play an important role in enhancing social skills of their children such as teaching strategies for self-control, help them identify appropriate role models and socialize them to adapt to the society. Social skills are the identifiable skills such as Self-control, Co-operation and Assertion which reflect the socially competent behavior of differently abled children (Myoung Sook Kim, 2008). These skills are the fundamental fabric for social interaction of differently abled children with others. The necessity to study social skills arise because, basic skills are required to manage their day to day interaction which are learnt through training from formal institutions or care givers or existing social environment and through it position themselves to face the social world outside. Very often, the differently abled children lose track while communicating, or obsessed with repetitive behavior, lose temper etc. which makes them less sociable and

problematic when compared to other children. Hence it is important to know their level of social skills for professionals to intervene by learning the nuances. It enables the children to navigate their lives for better adaptation, interaction and outcome and also reduces the care giving burden. Many of these skills learnt are important and can be used for effective communication and integration in to the family and society.

Social skills are also defined as the socially acceptable behavioral patterns in which children can achieve social reinforcement and acceptance as well as avoid aversive social situations (Mathur and Rutherford, 1996). Social skills also contribute to long-term positive community participation (Bryan, 1997). A number of researchers have indicated that children's social competence, defined as an aggregate of generalized social skills that strengthen a person's social functioning (Mathur and Rutherford, 1996), has an influence on their school readiness and academic achievement (Gresham, 1983; Hunt, Atwell, Farron-Davis and Goetz, 1996; Vaughn, Elbaum, and Schumm, 1996) through which children become involved, comfortable, and successful in the school environment (Betts & Rotenberg, 2007). How does it operate among the differently abled children and to what extent does it help the child and family to integrate in to the community is probed through this study.

In order to make these differently abled children socially competent, both teachers and parents should establish and communicate their expectations regarding children's behavior. Without clear expectations, children with disabilities may not be aware of parent's expectations or others and thus may have problems in social interaction. When parents and others come together and agree on behavioral expectations, children are more likely to meet those expectations, and thus better adjust to their families, classrooms and outside. Hence these children should be adequately supported at family and school. For the present study, social skills of the differently abled children are understood through several questions related to domains of self-control, Co-operation and Assertion.

Table 38: Self-control among Differently abled children

Self-Control	Frequency		
	Always	Sometimes	Never
Follows instructions	60(37.5%)	65(40.6%)	35(21.8%)
Controls temper with other Children	9(5.65%)	78(48.7%)	73(45.6%)
Controls tempers with parents	16(10%)	80(50%)	64(40%)
Avoids situations that are likely to cause trouble	22(13.7%)	61(38.1%)	77(48.1%)

N=160

The domain of Self-control is the ability to control one's own personal desires and follow directions or instruction of care givers, controlling temper, avoiding risky situations (Table 38). About one third (37.5 percent) of the children follows instruction of their parents or care taker, while a majority of children do not carry out instructions like replacing things or introduce themselves or use a polite language regularly etc. Nearly half (48.7 percent) of the children are not in a position to control temper either with the care givers or other children especially when they do not get things what they want, or when they are not allowed to do things they want to do. Except a small proportion, many are not in a position to avoid situations which would result in trouble regarding their day to day activities such as playing with dangerous objects or doing activities unmindful of its consequences. Strand wise information of each child related to self-control is consolidated to arrive at total scores. Later based on the mean and standard deviation, the children are grouped into high, moderate and low level of social control. On arriving at the scores on children's level of social control, bivariate tables are prepared across several theoretically relevant background variables. The major variables used relate to the children and parental characteristics.

Table 39: Level of Self-Control among Differently Abled Children

Level of Self-control	No. of respondents	Percentage
Low	52	32.5
Medium	76	47.5
High	32	20.0
Total	160	100.0

Close to one third (32.5 percent) of the children are reported to have low self-control while one half (47.5 percent) have medium self-control and the remaining one fifths (20 percent) have high self-control.

Cross tabulation of the back ground factors with level of self-control of children (Table 40) shows that more fathers in comparison to mothers of the disabled children reported that their children had better self-control indicating gender wise difference in reporting and is possible that the children respond differently based on the gender of the parent. There were instances where mothers reported that children are ‘more obedient to father’ as they are generally strict in comparison to mothers. Younger parents reported that the children had low self-control in comparison to older parents. Similarly parents with better educational level also reported that their children had lower self-control. More children in nuclear family have a moderate self-control while those in joint family have lesser self-control indicating the need for children to be groomed and socialized by fewer members but effectively. Younger children had lesser self-control than older children and slightly greater proportion of girl children reported moderate and high self-control in comparison to boys. Children trained in special schools had relatively more self-control in comparison to others. The type of disability is associated with self-control and is observed that the mentally challenged children have greater difficulty in self-control.

Table 40: Level of Self-Control by Background Factors

Background factors	Level of Self-control		
	Low	Medium	High
Gender of the respondents			
Male (Father)	6 (14.3%)	26(61.9%)	10(23.8%)
Female (Mother)	46 (39.0%)	50(42.4%)	22(18.6%)
Age (in years)			
Upto 39 years	39(44.8%)	37(42.5%)	11(12.6%)
40 years and above	13(17.8%)	39(53.4%)	21(28.8%)
Educational level			
Primary and Middle	33(27.7%)	63(52.9%)	23(19.3%)
High school and above	19(46.3%)	13(31.7%)	9(22.0%)
Type of family			
Nuclear	39(27.9%)	74(52.9%)	27(19.3%)
Joint	13(65.0%)	2(10.0%)	5(25.0%)
Training			
Received	5(19.2%)	14(53.8%)	7(26.9%)
Not received	47(35.1%)	62(46.3%)	25(18.7%)
Age of the child			
Upto 9 years	33(41.8%)	33(41.8%)	13(16.5%)
Above 9 years	19(23.5%)	43(53.1%)	19(23.5%)
Sex of the child			
Male	36(34.3%)	47(44.85)	22(21.0%)
Female	16(29.1%)	29(52.7%)	10(18.2%)
Type of school			
Special school	23(29.5%)	44(56.4%)	11(14.1%)
Others	29(34.4%)	32(39.0%)	21(25.6%)
Type of disability			
Mentally challenged	37(45.7%)	37(45.7%)	7(8.6%)
Others	15(19.0%)	39(49.4%)	25(31.6%)
N=160			

An examination of the correlation results of background characteristics with self-control of children (Table 41) shows that there is significant relationship between the Gender of the reporting parents, age of the parent, children's age, type of disability and self-control of the children.

Table 41: Correlates of Self-Control by Background Factors

Background factors	Level of Self control	
	r- value	Sig
Gender of the respondents		
Male (Father)	-.184	.020**
Female (Mother)		
Age (in years)		
upto 39 years	-.301	.000***
40 years and above		
Educational level		
Primary and Middle	.098	.219
High school and above		
Type of family		
Nuclear	-.161	.042**
Joint		
Training		
Received	.125	.116
Not received		
Age of the children		
Upto 9 years	.177	.025**
Above 9 years		
Sex of the child		
Male	.016	.840
Female		
Type of school		
Special school	-.039	.631
Others		
Type of disability		
Mentally challenged	.348	.000***
Others		
N=160		

*P<0.10, **P<0.05, ***P<0.01

The regression results indicate (Table 42) that age of the parents has a strong relationship with the self-control behaviour of the child. It is found that the children exhibit better self-control with father, indicating that if the children perceive the gender of parents differently, they respond differently. Another explanation is that they are scared of fathers and hence behave differently while they are liberal with mother. Similarly the type of school attended by the children also influences self-control. Training of children in the schools also enables the children to acquire the skills. Type of disability also influences self-control, signifying as the ability and problems of children

vary, they also experience difficulty in self-control. All of these affect the level of care giving burden.

Table 42: Regression Results of Self-Control by Background Factors

Background factors	Level of Self control	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.080	.281
Age (in years) upto 39years 40 years and above	-.383	.000***
Educational level Primary and Middle High school and above	.099	.209
Type of family Nuclear Joint	-.134	.063
Training Received Not received	.126	.112
Age of the child Upto 9 years Above 9 years	.132	1.765
Sex of the child Male Female	-.104	.147
Type of school Special school Others	.154	.036*
Type of disability Mentally challenged Others	.449	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

Co-operation is a positive attribute of the children and it is practiced largely by way of maintaining neatness and orderliness at home, peaceful negotiations, and freedom to express. In this context, co-operation mainly refers to the attempts of children to help with household activities like cleaning vessels or house, arranging things in proper place and taking efforts to communicate their problems or needs. A variety of situations are described to understand the co-operative nature of the differently abled children. One

third (32.4 percent) of the children assist or attempts to participate in house hold tasks or maintain themselves and their area regularly. While close to two fifths replace toys and household properties in an orderly way.

Table 43: Co-operation among Differently Abled Children

Co-operation strands	Frequency		
	Always	Sometimes	Never
Helps with household tasks	26(16.2%)	26(16.2%)	108(67.5%)
Keeps clean and neat without being Reminded	50(31.2%)	40(25%)	70(43.7%)
Replaces toys or other household things in place	10(6.2%)	52(32.5%)	98(61.2%)
Communicates problems	70(43.7%)	46(28.7%)	44(27.5%)

N=160

Only two fifths (43.7 percent) are in a position to communicate their problems always, such as wanting to go to washroom, express their needs etc, while others are not in a position to express or communicate. This expression is very important as it is very difficult for the care takers and is a major service requirement.

Sixty percent (60.6 percent) of the children are reported to have low co-operation and only 5 percent have high co-operative skills and the remaining have medium co-operation.

Table 44: Level of Co-operation among Differently Abled Children

Level of Co-operation	No. of respondents	Percentage
Low	97	60.6
Medium	55	34.4
High	8	5.0
Total	160	100.0

Table 45: Level of Co-operation by Background Factors

Background factors	Level of Co-operation		
	Low	Medium	High
Gender of the respondents			
Male (Father)	21(50.0%)	17(40.5%)	4(9.5%)
Female (Mother)	76(64.4%)	38(32.2%)	4(3.4%)
Age (in years)			
upto 39	59(67.8%)	28(32.2%)	0(0.0%)
40 and above	38(52.1%)	27(37.0%)	8(11.0%)
Educational level			
Primary and Middle	62(52.1%)	51(42.9%)	6(5.0%)
High school and above	35(85.4%)	4(10.0%)	2(4.9%)
Type of family			
Nuclear	81(57.9%)	51(36.4%)	8(5.7%)
Joint	16(80.0%)	4(20.0%)	0(0%)
Training			
Received	16(61.5%)	8(30.8%)	2(7.7%)
Not received	81(60.4%)	47(35.1%)	6(4.5%)
Age of the child			
Upto 9 years	62(78.5%)	15(19.0%)	2(2.5%)
Above 9 years	35(43.2%)	40(49.4%)	6(7.4%)
Sex of the child			
Male	69(65.7%)	30(28.6%)	6(5.7%)
Female	28(50.9%)	25(45.5%)	2(3.6%)
Type of school			
Special school	52(66.7%)	24(30.8%)	2(2.6%)
Others	45(54.9%)	31(37.8%)	6(7.3%)
Type of disability			
Mentally challenged	62(76.5%)	17(21.0%)	2(2.5%)
Others	35(44.3%)	38(48.1%)	6(7.6%)
N=160			

As with the domain of self-control, a set of variables are cross tabulated with children's level of cooperation (Table 45). The individual scores of the strands in co-operation domain are summarized and categorized in to High, Medium and Low level of co-operation. The bivariate distribution of background factors with level of co-operation shows that greater proportion of fathers report that their children are co-operative while more mothers report low cooperativeness. Older parents also report higher co-operation by their children. More children in nuclear families and older children are relatively more co-operative. With regard to the gender of the children, females in comparison to

male's are relatively more co-operative and gender difference exist in the co-operative nature of children.

The table on correlates of co-operation with back ground factors (Table 46) shows that a number of factors are associated. It depicts that gender wise reporting of parents, the age of the parents and the educational level of parents are significantly associated with level of co-operation exhibited by children. The type of family, the age of the children and type of disability are also strongly associated with the co-operative behavior of children.

The regression results (Table 47) indicates that educational level of parents, type of family, age of the children and type of disability influences the co-operative behavior exhibited by children. Parents with better educational level are able to train the children and hence better co-operation. Children in nuclear families also have better opportunity to be trained as they are attended and trained largely by parents.

Table 46: Correlates of Co-operation by Background Factors

Background factors	Level of Co-operation	
	r- value	Sig
Gender of the respondents Male (Father) Female (Mother)	- .153	.053**
Age (in years) upto 39years 40 years and above	- .226	.004***
Educational level Primary and Middle school High school and above	.248	.002***
Type of family Nuclear Joint	- .156	.048**
Training Received Not received	.013	.867
Age of the child Upto 9 years Above 9 years	.341	.000***
Sex of the child Male Female	.103	.197
Type of school Special school Others	- .140	.077
Type of disability Mentally challenged Others	.317	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

Table 47: Regression results of Co-operation by background factors

Background factors	Level of Co-operation	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.090	.214
Age (in years) upto 39years 40 years and above	-.149	.070
Educational level Primary and Middle High school and above	.248	.002**
Type of family Nuclear Joint	-.145	.041*
Training for parents Received Not received	.017	.831
Age of the child Upto 9years Above 9 years	.349	.000***
Sex of the child Male Female	-.022	.760
Type of school Special school Others	.018	.802
Type of disability Mentally challenged Others	.372	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

Assertion is a positive act, usually made by children in a particular context, indicates the sociability and interacting skills. This domain strands provides an opportunity to know if the children can articulate their thoughts appropriately to the context and express it verbally or by actions. It also shows the positive inclination of the child to interact and integrate with social activities. The components of this domain largely focus on the interaction skills of the child. A majority of children make friends easily (65.6 percent) and have an interest in a variety of things (53.6 percent) and has an

interest to introduce oneself without being told (50.6 percent). A significant proportion of children is spontaneous in conversation and takes an effort to invite them home.

Table 48: Assertive behaviour of differently abled children

Assertion	Frequency		
	Always	Sometimes	Never
Invites others to home	22(13.7%)	57(35.6%)	81(50.6%)
Makes friends easily	40(25%)	65(40.6%)	55(34.3%)
Introduces herself or himself to new people without being told	32(20%)	49(30.6%)	79(49.3%)
Starts conversation rather than waiting for others to talk first.	15(9.3%)	48(30%)	97(60.6%)
Shows interest in a variety of things	35(21.8%)	51(31.8%)	74(46.2%)

N=160

Table 49: Level of Assertive among differently abled children

Level of Assertion	No. of respondents	Percentage
Low	94	58.8
Medium	30	18.8
High	36	22.5
Total	160	100

Nearly six out of ten (58.8 percent) children have low assertive skills and the remaining have medium (18.8 percent) and high (22.5 percent) Assertive skills.

As with previous domains of social skills, children's level of assertion is ascertained through the scores of the strands in the domain. Cross tabulation of background factors with Assertion (Table 50) shows that more fathers reported that the children have better assertion in comparison to mothers. It is also noticed that children in

nuclear families, older children, female children, children not attending special schools and those with disabilities other than being mentally challenged report higher assertive skills.

Correlation statistics is applied to know the association between several background characteristics and level of children's Assertion (Table 51). Gender of parents reporting, age of parents, children's age, the type of school to which the child attends and the type of disability of the child are identified to be significant variables associated with Assertive skills.

The regression results (Table 52) indicate that the gender of parents, age of the parents, children's age and type of disability of the children influences Assertion. More fathers report Assertive behavior of the child, in comparison to mothers as result of the attitudinal differences and does not report it as a problem as it hurts their esteem. Older parents also have older children, which is a major reason for the assertive skills. The children by themselves over a period of time learn skills by observing others and parents on the other hand overcome the initial period of confinement and take the children out more often and expose them to new situations and new people. Children with disability other than being mentally challenged also exhibit better Assertive behavior.

Table 50: Level of Assertion by background factors

Background factors	Level of Assertion		
	Low	Medium	High
Gender of the respondents			
Male (Father)	19(45.2%)	7(16.7%)	16(38.1%)
Female (Mother)	75(63.6%)	23(19.5%)	20(16.9%)
Age (in years)			
upto 39years	63(72.4%)	16(18.4%)	8(9.2%)
40 years and above	31(42.5%)	14(19.2%)	28(38.4%)
Educational level			
Primary and Middle school	69(58.0%)	22(18.5%)	28(23.5%)
High school and above	25(61.0%)	8(19.5%)	8(19.5%)
Type of family			
Nuclear	81(57.9%)	27(19.3%)	32(22.9%)
Joint	13(65.0%)	3(15.0%)	4(20.0%)
Training for parents			
Received	14(53.8%)	10(38.5%)	2(7.7%)
Not received	80(59.7%)	20(14.9%)	34(25.4%)
Age of the child			
Upto 9years	55(69.6%)	13(16.5%)	11(13.9%)
Above 9 years	39(48.1%)	17(21.0%)	25(30.9%)
Sex of the child			
Male	66(62.9%)	18(17.1%)	21(20.0%)
Female	28(50.9%)	12(21.8%)	15(27.3%)
Type of school			
Special school	51(65.4%)	22(28.2%)	5(6.4%)
Others	43(52.4%)	8(9.8%)	31(37.8%)
Type of disability			
Mentally challenged	61(75.3%)	18(22.2%)	2(2.5%)
Others	33(41.8%)	12(15.2%)	34(43.0%)
N=160			

Table 51: Correlates of Assertion by background factors

Background factors	Level of Assertion	
	r- value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.210	.008***
Age (in years) upto 39years 40years and above	-.357	.000***
Educational level Primary and Middle school High school and above	.037	.642
Type of family Nuclear Joint	-.040	.615
Training Received Not received	-.053	.507
Age of the child Upto 9years Above 9 years	.233	.003***
Sex of the child Male Female	.111	.164
Type of school Special school Others	-.269	.001***
Type of disability Mentally challenged Others	.449	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

Table 52: Regression results of Assertion by background factors

Background factors	Level of Assertion	
	Beta Value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.136	.047*
Age (in years) upto 39years 40 years and above	-.331	.000***
Educational level Primary and Middle High school and above	-.036	.648
Type of family Nuclear Joint	-.012	.854
Training Received Not received	-.052	.512
Age of the child Upto 9 years Above 9 years	.187	.008**
Sex of the child Male Female	-.051	.438
Type of school Special school Others	-.046	.492
Type of disability Mentally challenged Others	.517	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

The overall social skills scores are arrived by summing up scores in all strands of Self-control, Co-operation and Assertion domain and categorized based on the mean scores (Table 53). The table depicts more than half of the children are reported to have moderate level of social skills and a considerable proportion have low skills.

Table 53: Level of Social skills among differently abled children

Level of social skills	No. of respondents	Percentage
Low	44	27.6
Medium	90	56.2
High	26	16.2
Total	160	100.0

Relatively greater proportion of fathers reported that their children have better social skills while mothers have reported moderate and low social skills. Older parents, those in nuclear family, parents who received training, parents with older children, those with female children, children not in special schools and children with disability other than being mentally challenged have better social skills (Table 54).

The correlation table (Table 55) shows that the age of the parents, the age of the children and the gender of the parents reporting has a significant association with social skills.

The regression results (Table 56) also shows that the age of the parents, age of the children, gender of the parents reporting training received by parents and type of disability has a strong relationship with social skills. Fathers report children to have better social skills. Similarly older parents and those with older children and children having disability other than being mentally challenged report better social skills.

Table 54: Level of Social skills by background factors

Background factors	Level of Social skills		
	Low	Medium	High
Gender of the respondents			
Male (Father)	7(16.7%)	21(50%)	14(33.3%)
Female (Mother)	37(31.4%)	69(58.5%)	12(10.2%)
Age (in years)			
upto 39 years	29(33.3%)	56(64.4%)	2(2.3%)
40 years and above	15(20.5%)	34(46.6%)	24(32.9%)
Educational level			
Primary and Middle	31(26.1%)	66(55.5%)	22(18.5%)
High school and above	13(31.7%)	24(58.5%)	4(9.8%)
Type of family			
Nuclear	35(25%)	81(57.9%)	14(17.1%)
Joint	9(45%)	9(45%)	2(10%)
Training			
Received	5(19.2%)	19(73.1%)	2(7.7%)
Not received	39(29.1%)	71(53. %)	24(17.9%)
Age of the child			
Upto 9 years	31(39.2%)	40(50.6%)	8(10.1%)
Above 9 years	13(16%)	50(61.7%)	18(22.2%)
Sex of the child			
Male	30(28.6%)	60(57.1%)	15(14.3%)
Female	14(25.5%)	30(54.5%)	11(20%)
Type of school			
Special school	21(26.9%)	51(65.4%)	6(7.7%)
Others	23(28%)	39(47.6%)	20(24.4%)
Type of disability			
Mentally challenged	33(40.7%)	44(54.3%)	4(4.9%)
Others	11(13.9%)	46(58.2%)	22(27.8%)
N=160			

Table 55: Correlates of Social Skills by Background Factors

Background factors	Level of Social skills	
	r- value	Sig
Gender of the respondents Male (Father) Female (Mother)	-.256	.001***
Age (in years) upto 39years 40years and above	-.331	.000***
Educational level Primary and Middle High school and above	.096	.225
Type of family Nuclear Joint	-.138	.082
Training Received Not received	-.002	.980
Age of the child Upto 9years Above 9 years	.271	.001***
Sex of the child Male Female	.064	.419
Type of school Special school Others	-.119	.134
Type of disability Mentally challenged Others	.381	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

Table 56: Regression results of Social Skills by Background Factors

Background factors	Level of Social skills	
	Beta value	Sig
Gender of the respondents Male (Father) Female (Mother)	-0.210	.003***
Age (in years) upto 39years 40years and above	-0.348	.000***
Educational level Primary and Middle High school and above	.058	.365
Type of family Nuclear Joint	-0.091	.175
Training Received Not received	.163	.020*
Age of the child Upto 9 years Above 9 years	.241	.001***
Sex of the child Male Female	-0.093	.166
Type of school Special school Others	.048	.491
Type of disability Mentally challenged Others	.484	.000***
N=160		

*P<0.10, **P<0.05, ***P<0.01

The overall social behaviour of children is assessed through Marielle C. Decker behavioural scale. It enables us to know the problematic behaviour of children. It is understood through the domains of knowing the disruptive behaviour, self-absorbed behaviour, communication disturbance and anxiety. The overall social behaviour is understood through the domains and categorized into levels enabling us to understand the level of problematic behaviour.

Table 57: Social Behaviour and level of Social skills

Social Behaviour	Social skills		
	Low	Medium	High
Less problematic	2(9.1%)	4(18.2%)	16(72.7%)
Moderate problematic	27(27%)	65(65%)	8(8%)
Highly problematic	15(39.5%)	21(55.3%)	2(5.3%)

N=160

The overall social behaviour of children is cross tabulated with the overall social skills of children. The cross tabulation indicates that children with less problematic behaviour has better social skills and children with highly problematic behaviour have low social skills. The correlation indicates strong association between social behaviour and social skills. Hence children with problematic behaviour or low social skills make the care giving role difficult for parents. Attention to these will enable understanding care giving role, burden and areas to intervene.

To sum up, Social behaviour relates to interpersonal skills and social interactions which involves recognition and understanding of self and others. Implicit understanding is that children's communication ability will enable the children to manage several situations in their day to day interaction. It is assessed through Dekker's behavioural scale (2002) in the domains of disruptive, self-absorption, communication disturbance and anxiety. A majority of parent's reported that the children have difficulty in social behaviour ranging from medium to high problematic behaviours. Social skills are also understood through self-control, co-operation and assertion domains (Kim, 2008). These measures identify the socially acceptable behavioural patterns which has a major link to community participation. Social skills of children are significantly low especially in co-operation and assertion domains. Parental perceptions, age of the parents, age of the children and type of disability has a significant bearing of social behaviour and social skills of differently abled children. There is close interaction between social behaviour and social skills. It signifies the difficulties in care giving task. Hence the parents

experience pressure in the care giving role and needs more research and intervention in the area for both care givers and differently abled children.

Differently abled children and their parents live in a society which stigmatizes and ostracizes them and yet they need to manage their lives. An effort that could make a difference to families of children with disabilities is to help them adapt to the situation, which is largely possible, through the presence of active informal and formal support systems. Social support is the social, economic, moral and psychological support that various institutions provide for the differently abled children and their parents. Support from one's own family enables them to share tasks, in 'demanding times' which is very different from other families. Those who have formal and informal support outside the family are able to cope best (Trivette and Durnst, 1992).

Despite problems every individual and household identifies a set of people with whom they derive and exchange support. The contingent of support received or transacted with a set of persons catering to the social, economic, and psychological needs is identified as support systems. The kind of support varies across culture, kinship and demographic characteristics of support receivers and providers. Social support for this study means the care givers perception that 'there is someone who could give them help when needed'. It also relates to various support actually received from extended family members, neighbors, religious institutions, community members which helps in reinforcing the development of differently abled children and motivation of their parent's contribution towards such children. The effectiveness of support networks has been found to be a more important factor for parental self-esteem rather than the actual size of the network or other structural characteristics. Thus an active helpful group of friends or family is more effective at increasing a parent's self-esteem. Social support is able to provide actual support and mediate personal well-being and can improve parental attitudes towards their differently abled children (Dunst et al., 1986b). The presence of social support leads to more positive perceptions of the family environment as it is linked to more stable functioning, a more positive perception of the child, and can enhance the parent-child relationship. Social support for parents of differently abled children are elicited through various strand and discussed in detail in the present chapter. The support systems are identified through who provides what kind of support. The support is identified through certain common strands of emotional, financial, services or companionship domain. The strands in each domain focus on the general requirement of the families.

Emotional Support

Emotional support varies from the word of appreciation to moral support for these parents as it reduces psychologically the strain of social denial or ostracization. Family members are the major support providers including those in household as well as those outside the household. Apart from the household, children's maternal grandparents, mother's siblings followed by paternal grandparents and father's siblings and their families are the primary support providers.

Table 58: Emotional Support Received by Parents of Differently Abled Children by Network Category

Emotional Support	Family Members	Relatives	Neighbors	Co-workers	Friends	Others
Give assurance whenever uncertain about child's future (EMS 1)	150(93.7%)	2(1.2%)	8(5%)	0	0	0
Help to come out of crisis situations related to child (EMS 2)	134(83.7)	12(7.5%)	12(7.5%)	0	2(1.2%)	0
Console whenever depressed and gripped in various problems of child (EMS 3)	116(72.5%)	10(6.2%)	11(6.8%)	11(6.8%)	12(7.5%)	0
Listen and enquire all personal problems (EMS 4)	113(70.6%)	10(6.2%)	12(7.5%)	14(8.7%)	11(6.8%)	0
Give a word of assurance that he/she will make himself or herself present in child's emergency situations (EMS 5)	118(73.7%)	18(11.2%)	13(8.1%)	4(2.5%)	7(4.3%)	0
Express concern on the child and care taker (EMS 6)	132(82.5%)	16(10%)	6(3.7%)	2(1.2%)	4(2.5%)	0
Provide emotional aid whenever / family problems remain a major one (EMS 7)	106(66.2%)	13(8.1%)	31(19.3%)	3(1.8%)	7(4.3%)	0
Give emotional soothing and enable to feel comfortable with (EMS 8)	97(60.6%)	8(5%)	36(22.5%)	6(3.7%)	13(8.1%)	0
Encourage and enable to take care of the disabled child (EMS 9)	146(91.2%)	4(2.5%)	2(1.2%)	0	8(5%)	0

N=160

A set of strands indicating emotional support were included and information was elicited. A majority of parents received emotional support from their family members like giving assurance when they are uncertain about the children's future, provide emotional aid, and enable them to feel comfortable etc. A majority of respondents receive support in all strands primarily from family members which includes spouse, other children, parents and siblings of the care taker. In addition relatives such as second degree kin, neighbours and friends also play an important role. It is also noticed that greater proportion had to look outside family for emotional support as family members in household also go through a similar situation. They tend to receive external emotional support aid whenever family problems remain a major one, such as strain between spouse, financial pressure at home etc. A greater proportion of parents receive emotional support from family members, followed by neighbours, relatives, friends and co-workers largely. Mothers of children report greater need for emotional support and their needs are currently met through parents and same gender ties (Table 58).

Table 59: Emotional Support Received by Parents of Differently Abled Children by Type of Close Kin

Emotional Support	Spouse	Children		Parents		Father-in-law	Mother-in-law	Sister	Others
		Male	Female	Father	Mother				
Give assurance whenever uncertain about child's future (EMS 1)	80 (49.9%)	0	0	9 (5.6%)	36 (22.5%)	3 (1.8%)	12 (7.5%)	10 (6.2%)	0
Help to come out of crisis situations related to child (EMS 2)	61 (38%)	0	0	19 (11.8%)	29 (18.1%)	4 (2.5%)	14 (8.7%)	3 (1.8%)	4 (2.5%)
Console whenever in depressed and gripped in various problems of child (EMS 3)	96 (59.9%)	0	0	2 (1.2%)	9 (5.6%)	3 (1.8%)	6 (3.7%)	0	0
Who will listen and enquire all personal problems (EMS 4)	93 (58%)	0	0	2 (1.2%)	9 (5.6%)	3 (1.8%)	6 (3.7%)	0	0
Give a word of assurance that he/she will make himself or herself present in child's emergency situations (EMS 5)	72 (44.9%)	0	0	8 (5%)	14 (8.7%)	2 (1.2%)	15 (9.3%)	6 (3.7%)	1 (0.6%)
Express concern on you and your child (EMS 6)	100 (62.4%)	2 (1.2%)	0	6 (3.7%)	13 (8.1%)	3 (1.8%)	7 (4.3%)	1 (0.6%)	0
Provide emotional aid whenever / family problems remain a major one (EMS 7)	90 (56.2%)	0	0	1 (0.6%)	9 (5.6%)	3 (1.8%)	3 (1.8%)	0	0
Give emotional soothing and enable to feel comfortable with (EMS 8)	76 (47.4%)	0	0	2 (1.2%)	9 (5.6%)	3 (1.8%)	7 (4.3%)	0	0
Encourage and enable you to take care of the disabled child (EMS 9)	80 (49.9%)	0	0	9 (5.6%)	36 (22.5%)	3 (1.8%)	12 (7.5%)	6 (3.7%)	0

Table 60: Emotional support received outside household by background factors

Background factors	EMS 1	EMS 2	EMS 3	EMS 4	EMS 5	EMS 6	EMS 7	EMS 8	EMS 9
Gender									
Male (Father)	0	2(4.8%)	23(54.8%)	23(54.7%)	25(59.5%)	12(28.6%)	21(50%)	28(66.7%)	8(19%)
Female (Mother)	10(8.5%)	24(20.4%)	21(17.8%)	24(20.4%)	17(14.4%)	16(13.6%)	33(15%)	85(29.7%)	6(5.1%)
Age (in years)									
upto 39years	4(4.6%)	12(13.8%)	14(16.1%)	20(23%)	19(21.8%)	18(20.7%)	24(27.6%)	32(36.8%)	4(4.6%)
40years and above	6(8.2%)	14(19.2%)	30(41.1%)	27(37%)	23(31.5%)	10(13.7%)	30(41.1%)	31(42.5%)	10(13.7%)
Educational level									
Primary and middle	4(3.4%)	16(13.4%)	34(28.6%)	35(29.4%)	37(31.1%)	26(21.9%)	44(36.9%)	49(41.2%)	12(10.1%)
Higher secondary and above	6(14.6%)	10(24.4%)	10(24.4%)	12(29.3%)	5(12.2%)	2(4.9%)	10(24.4%)	14(34.1%)	2(4.9%)
Occupation									
Employed	2(2.7%)	10(13.4%)	27(36%)	23(30.7%)	29(38.7%)	16(21.3%)	28(37.3%)	37(49.3%)	10(13.3%)
Not employed	8(9.5%)	16(18.9%)	17(20.1%)	24(28.3%)	13(15.3%)	12(14.1%)	26(30.6%)	26(30.6%)	4(4.7%)
Monthly Income in Rupees									
upto 10,000	8(6.3%)	20(15.7%)	35(27.6%)	34(26.8%)	38(29.9%)	24(18.9%)	46(36.2%)	50(39.4%)	10(7.9%)
10,001 to 30,000	0	4(12.9%)	9(29.1%)	13(41.9%)	4(12.9%)	4(12.9%)	8(25.8%)	13(41.9%)	4(12.9%)
Type of family									
Nuclear	10(7.1%)	24(17.1%)	42(30%)	43(30.7%)	42(30.1%)	29(18.6%)	54(38.6%)	61(43.6%)	14(10%)
Joint	0	2(10%)	2(10%)	4(20%)	0	2(10%)	0	2(10%)	0
Nativity status									
Migrant	0	15(21.7%)	16(23.1%)	18(26%)	27(39.1%)	18(26.1%)	21(30.4%)	31(44.9%)	4(5.8%)
Non migrant	10(11%)	11(12.1%)	28(30.8%)	29(31.9%)	15(16.5%)	10(11%)	33(36.3%)	32(35.2%)	10(11%)
No. of children									
Upto Two	3(3.4%)	11(12.5%)	23(26.2%)	28(31.8%)	25(28.4%)	11(12.5%)	30(34.1%)	29(33%)	5(5.7%)
Three and above	7(9.7%)	15(20.8%)	21(29.1%)	19(26.4%)	17(23.6%)	17(23.6%)	24(33.3%)	34(47.2%)	9(12.5%)
Savings									
Available	4(6.9%)	8(13.7%)	18(30.9%)	16(27.5%)	16(27.6%)	16(27.6%)	31(53.4%)	25(43.1%)	9(15.5%)
Not available	8(5.9%)	18(17.7%)	26(25.4%)	31(30.4%)	26(25.5%)	12(11.8%)	23(22.5%)	38(37.3%)	5(4.9%)
Debts									
Debted	6(7.8%)	12(15.6%)	14(18.2%)	11(14.3%)	14(18.2%)	16(20.8%)	25(32.5%)	37(48.1%)	5(6.5%)
Not debted	2(4.8%)	14(16.8%)	30(36.1%)	36(43.4%)	28(33.7%)	12(14.5%)	29(34.9%)	26(31.3%)	9(10.8%)
N=160									

The table regarding outside household by background factors with emotional support shows that fathers, older parents (above 40 years), those with better education, those in nuclear family, employed, non-migrants, those with three and more children, those who have savings and those not debted draw support from outside. It also indicates, contacts of parents, experience, education, smaller families, duration of living arrangement as non-migrant and having the need due to more children and self-sufficient in finance and non debted parents tend to look outside household for support.

Financial Support

The parents often reported spending more during the initial stages of knowing the disability as they thought the problems can be cured. They also shunt between allopathic and alternative care without much benefit. Many who have experienced such difficulty report need for counseling regarding financial management and detailed explanation regarding the disability itself. Economic support is an important support for parents of differently abled children as financial problems increase with medical expenditure, additional services for travel, care etc. Parents of differently abled children largely work in private sectors, fishing, agriculture and allied occupation as daily wage workers and do not have steady income and have to miss out often on income due to sudden need at home for children and have to look up for economic support from immediate family relatives, neighbours and friends.

Table 61: Financial support received by parents of differently abled children by Network category

Financial support	Family Members	Relatives	Neighbours	Co-workers	Friends	Others
To meet the expense of medical treatment (FS 1)	42(26.2%)	98(61.2%)	6(3.7%)	2(1.2%)	4(2.5%)	8(5%)
Petty expenses for family (FS 2)	42(26.2%)	79(49.3%)	18(11.2%)	4(2.5%)	7(4.3%)	10(6.2%)
Facing an unexpected expenditure (FS 3)	49(30.6%)	57(35.6%)	28(17.5%)	4(2.5%)	8(5%)	14(8.7%)

N=160

During times of unexpected medical expenditure the parents borrow from close family members or relatives while support from neighbours and friends are less sought and less available. Major financial needs also arise when they are unable to manage income and expenditure. In addition many are debted and have a major difficulty to meet the regular day to day expenses. Regarding small transactions ranging from Rs.100 to Rs.1000, many neighbours and friends participate. In times of unexpected expenditure, parents of the care takers are the main source of financial support.

In general the family attempts to manage themselves, sometimes older children, especially boys also extend support. The closest dependable members outside the household are the parents, but many of the care takers parent's are themselves old and do not belong to the higher income group. Hence despite the longing to help, the caretaker's parents are unable to extend major financial support (Table 61).

Table 62: Financial support received by parents of differently abled children by type of close to kin

Financial support	Spouse	Children		Parents		Father -in-law	Mother -in-law	Sister	Others
		Male	Female	Father	Mother				
To meet the expense of medical treatment (FS 1)	20 (12.4%)	8 (5%)	0	9 (3.6%)	1 (0.6%)	3 (1.8%)	1 (0.6%)	0	0
Petty expenses for family (FS 2)	20 (12.4%)	6 (3.7%)	0	4 (2.5%)	2 (1.2%)	3 (1.8%)	0	3 (1.8%)	4 (2.5%)
Facing an unexpected expenditure(FS 3)	8 (4.9%)	2 (1.2%)	0	21 (13.1%)	6 (3.7%)	6 (3.7%)	2 (1.2%)	1 (0.6%)	3 (1.8%)

N=160

Table 63: Financial support received by outside household by background factors

Background factors	FS 1	FS 2	FS 3
Gender			
Male (Father)	31(73.8%)	32(76.2%)	10(76.2%)
Female (Mother)	87(73.7%)	86(72.9%)	79(66.9%)
Age (in years)			
upto 39years	64(73.6%)	63(72.4%)	56(64.3%)
40years and above	54(74%)	55(75.3%)	55(75.2%)
Educational level			
Primary and middle	93(78.2%)	96(80.7%)	89(74.8%)
Higher secondary and above	25(61%)	22(53.7%)	22(53.7%)
Occupation			
Employed	56(74.7%)	59(78.7%)	59(78.7%)
Not employed	62(72.9%)	59(69.4%)	52(61.2%)
Monthly Income in Rupees			
upto 10,000	99(77.9%)	92(62.4%)	90(70.9%)
10,001 to 30,000	19(61.3%)	26(83.9%)	21(67.7%)
Type of family			
Nuclear	108(77.2%)	108(77.1%)	101(72.2%)
Joint	10(50%)	10(50%)	10(50%)
Nativity status			
Migrant	52(75.4%)	52(75.4%)	46(66.7%)
Non migrant	66(72.5%)	66(72.5%)	65(71.4%)
No. of children			
Upto Two	59(67%)	60(68.2%)	54(61.4%)
Three and above	59(81.9%)	58(80.6%)	57(79.2%)
Savings			
available	41(70.7%)	38(65.5%)	38(65.5%)
Not available	77(75.5%)	80(78.4%)	73(71.6%)
Debts			
Debted	63(81.8%)	61(79.2%)	49(63.6%)
Not debted	55(66.3%)	57(68.7%)	62(74.7%)
N=160			

With regard to financial support more of male parents, those above 40 years or parents with older children, those with lower level of education and employed parents, those with lesser income, those in nuclear families, migrants, those with more children, those without savings and those having debts are main support receives outside household. Largely low economic position triggers borrowing outside household.

Informational Support

Informational support is essential for the educational needs of the differently abled children. School teachers, social workers and social welfare officers play an important and major role as information providers to the parents of differently abled children.

Table 64: Informational supports received by parents of differently abled children by Network category

Informational Support	Family Members	Relatives	Neighbours	Co-workers	Friends	Others
Providing the information on schooling and other official matters related to differently abled children (IS 1)	12(7.5%)	17(10.6%)	62(38.7%)	7(4.3%)	14(8.7%)	48(30%)
Information regarding child's medical care (IS 2)	13(8.1%)	9(5.9%)	43(26.8%)	0	0	95(59.3%)
Information on govt. aid regarding the disabled child (IS 3)	18(11.2%)	4(2.5%)	15(9.3%)	0	0	123(76.8%)

N=160

General information on school is largely provided by neighbours and other members who are acquainted with them, especially families who also have a differently abled child. Scholarship information and government aids are largely given and facilitated by the formal institutions such as schools, rehabilitation centre etc. Regarding medical care information, many neighbours also provide information but such information relate to alternate care which only lead to additional expenses on family without much benefit (Table 64).

As the differently abled children's families require specialized information, their kin and friends do not have the resource to extend such support rather the formal institutions has a major role. Dissemination of information on facility for the children and training for parents and orientation to community are available to the extent required but the importance towards it is less addressed. Hence there is a gap in utilization of formal facilities due to lack of awareness and practical problems in attending such programs due to lack of time, alternate caregivers at home etc.

Table 65: Informational support received by parents of differently abled children by type of close kin

Informational support	Spouse	Children		Parents		FIL	MIL	SIS	OTH
		B	G	F	M				
Providing the information on schooling and other official matters related to differently abled children (IS 1)	8 (4.9%)	1 (0.6%)	2 (1.2%)	0	1 (0.6%)	0	0	0	0
Information regarding child's medical care (IS 2)	6 (3.7%)	2 (1.2%)	0	3 (1.8%)	0	1 (0.6%)	0	1 (0.6%)	0
Information on govt. assistance regarding the disabled child (IS 3)	8 (4.9%)	4 (2.5%)	1 (0.6%)	3 (1.8%)	0	1 (0.6%)	0	1 (0.6%)	0
N=160									

Table 66: Informational support received outside household by background factors

Background factors	IS 1	IS 2	IS 3
Gender			
Male (Father)	38(90.5%)	42(100%)	37(88.1%)
Female (Mother)	110(93.2%)	115(97.5%)	100(93.2%)
Age (in years)			
upto 39years	83(95.3%)	81(93.1%)	74(85.1%)
40years and above	62(89%)	66(90.4%)	68(93.2%)
Educational level			
Primary and middle	113(95%)	112(94.1%)	104(87.4%)
Higher secondary and above	35(85.4%)	35(85.4%)	38(92.7%)
Occupation			
Employed	71(94.7%)	75(100%)	67(89.3%)
Not employed	77(90.6%)	82(96.5%)	80(94.1%)
Monthly Income in Rupees			
Below 10,000	119(93.7%)	127(100%)	117(92.1%)
10,001 to 30,000	27(87.1%)	28(90.3%)	28(90.3%)
Type of family			
Nuclear	130(92.8%)	130(92.8%)	125(89.3%)
Joint	18(90%)	17(85%)	17(85%)
Nativity status			
Migrant	65(94.2%)	66(95.7%)	69(100%)
Non migrant	83(91.2%)	91(100%)	78(85.7%)
No. of children			
Upto two	82(93.2%)	86(97.7%)	81(92%)
Three and above	66(91.7%)	71(98.6%)	66(91.7%)
Savings			
available	56(96.6%)	55(94.8%)	52(91.4%)
Not available	92(90.2%)	102(100%)	94(92.2%)
Debts			
Debted	69(89.6%)	77(100%)	75(96.1%)
Not debted	79(95.2%)	80(96.4%)	73(88%)
N=160			

Regarding informational support, more males, parents less than 40 years, parents with low level of education, employed parents, those in lesser income group, those in nuclear families and migrants receive more informational support from outside.

Service Support

With regard to actual physical services especially when there is need to stay with differently abled child or self, elderly family members such as father, mother, in-laws etc, are the primary support givers and a small number also draw support from relatives or other

known members from neighborhood such as acquaintances but trust of such acquaintances trust is limited and has to be reciprocated in different form.

Table 67: Service Support received by parents of differently abled children by Network category

Service support	Family Members	Relatives	Neighbours	Co-workers	Friends	Others
Staying with the disabled children during necessity (SS 1)	113(70.6%)	16(10%)	14(8.7%)	0	0	17(10.6%)
Render services when required to take the child out (SS 2)	137(85.6%)	6(3.7%)	15(9.3%)	0	2(1.2%)	0
Help for picking and dropping the child in school (SS 3)	111(69.3%)	4(2.5%)	26(16.2%)	10(6.2%)	9(5.6%)	0
Accompany to take the child to the hospital (SS 4)	111(69.3%)	0	28(17.5%)	2(1.2%)	19(11.8%)	0
N=160						

With regard to accompanying the child and parent when they need to move outside familiar settings, a majority receive support from parents, especially mothers, fathers, mothers-in-law and neighbours. With regard to assistance in picking and dropping the child to school, a variety of networks engage, but primarily support is from family members in household followed by neighbours, co-workers and friends. For hospital visit of children, support is largely provided by family members in household followed by neighbours and friends (Table 67).

Table 68: Service support received by parents of differently abled children by type of close kin

Service support	Spouse	Children		Parents		Father-in-law	Mother-in-law	Sister	Others
		Male	Female	Father	Mother				
Members providing security to disabled children during necessity (SS 1)	93 (58%)	0	0	2 (1.2%)	9 (5.6%)	3 (1.8%)	6 (3.7%)	0	0
Render services when to take the child to all places (SS 2)	61 (38%)	0	0	19 (11.8%)	31 (19.3%)	4 (2.5%)	14 (8.7%)	3 (1.8%)	5 (3.1%)
Help for picking and dropping the child in school (SS 3)	91 (56.8%)	0	0	2 (1.2%)	9 (5.6%)	3 (1.8%)	6 (3.7%)	0	0
Members accompany to take the child to the hospital (SS 4)	91 (56.8%)	0	0	2 (1.2%)	9 (5.6%)	3 (1.8%)	6 (3.7%)	0	0
N=160									

Table 69: Service support received outside household by background factors

Background factors	SS 1	SS 2	SS 3	SS 4
Gender				
Male (Father)	7(16.7%)	5(11.9%)	19(45.2%)	24(57.1%)
Female (Mother)	40(33.9%)	18(15.3%)	30(25.4%)	25(21.2%)
Age (in years)				
upto 39years	24(27.5%)	12(13.8%)	26(29.8%)	22(25.3%)
40years and above	23(31.5%)	11(15%)	23(31.5%)	27(36.9%)
Educational level				
Primary and middle	33(27.8%)	19(15.9%)	37(31.1%)	39(32.8%)
Higher secondary and above	14(34.1%)	4(9.8%)	12(29.3%)	10(24.4%)
Occupation				
Employed	21(28%)	13(17.3%)	33(44%)	32(42.7%)
Not employed	26(30.6%)	10(11.8%)	16(18.8%)	17(20%)
Monthly Income in Rupees				
Below 10,000	41(32.3%)	19(15%)	39(30.7%)	32(25.2%)
10,001 to 30,000	4(12.9%)	4(12.9%)	10(32.3%)	15(48.4%)
Type of family				
Nuclear family	41(29.3%)	23(16.4%)	47(33.5%)	49(35%)
Joint family	6(30%)	0	2(10%)	0
Nativity status				
Migrant	14(20.3%)	12(17.4%)	26(37.7%)	23(33.3%)
Non migrant	33(36.3%)	11(12.1%)	23(25.3%)	26(28.6%)
No. of children				
Upto two	24(27.3%)	9(10.2%)	26(29.5%)	25(28.4%)
Three and above	23(31.9%)	14(19.4%)	23(31.9%)	24(33.3%)
Savings				
available	16(27.6%)	15(25.9%)	22(37.9%)	25(43.1%)
Not available	31(30.4%)	8(7.8%)	27(26.5%)	24(23.5%)
Debts				
debted	32(41.6%)	15(19.5%)	19(24.7%)	16(20.8%)
Not debted	15(18.1%)	8(9.6%)	30(36.1%)	33(39.8%)
N=160				

Older parents, parents with lesser education, employed parents, those with lower income and parents in nuclear families, migrants and those with more children and those having savings report drawing more support from outside household.

Companionship support

Companionship support for the parents of differently abled children and the parents are largely met through the family members at home while, relatives and friends also participate and boost the emotional need of both the children as well as parents. Neighbours are significant in everyday course of life to emergency situations. If families are able to identify and retain supportive neighbours, it provides them an opportunity to relax and break the monotony of care and stress.

Table 70: Companionship support received by parents of differently abled children by Network category

Companionship support	Family Members	Relatives	Neighbours	Co-workers	Friends	Others
Accompany along with child for an outing (CS 1)	111(69.3%)	0	37(23.1%)	0	12(7.5%)	0
Members accompanies child to attend functions and ceremonies (CS 2)	157(98.1%)	3(1.8%)	0	0	0	0
Members accompany to visit various institutions or offices (CS 3)	158(98.7%)	0	2(1.2%)	0	0	0
N=160						

Accompanying along with the child to outing is largely catered by family members in household followed neighbours and friends. The requirement remains an unmet need for the child and parents to relax while other external visits remain a compelling requirement. Respondents and their children rarely attend family functions and even if they attend, it is exclusively with family members and a similar trend is noticed for visiting institution or offices. A majority of the companionship support is largely provided by family members in household which makes their life revolve around the same people or environment which does not provide an opportunity to relieve stress for care givers but pressurizes each other within families (Table 70).

Table 71: Companionship support received by parents of differently abled children by type of close kin

Companionship support	Spouse	Children		Parents		Father-in-law	Mother-in-law	Sister	Others
		Male	Female	Father	Mother				
Accompany along with child outing (CS 1)	91 (56.8%)	0	0	2 (1.2%)	9 (5.6%)	3 (1.8%)	6 (3.7%)	0	0
Members accompanies child to attend functions and ceremonies (CS 2)	80 (49.9%)	4 (2.5%)	3 (1.8%)	9 (5.6%)	36 (22.5%)	3 (1.8%)	12 (7.5%)	10 (6.2%)	0
Members accompany to visit various institutions or offices (CS 3)	81 (50.5%)	4 (2.5%)	3 (1.8%)	9 (5.6%)	36 (22.5%)	3 (1.8%)	12 (7.5%)	10 (6.2%)	0
N=160									

Table 72: Companionship support received outside household by background factors

Background factors	CS 1	CS 2	CS 3
Gender			
Male (Father)	15(35.7%)	3(7.1%)	0
Female (Mother)	34(28.8%)	0	2(1.7%)
Age in years			
Below 39years	22(25.3%)	3(3.4%)	2(2.3%)
40years and above	27(36.9%)	0	0
Educational level			
Primary and middle	32(26.9%)	3(2.5%)	2(1.7%)
Higher secondary and above	17(41.5%)	0	0
Occupation			
Employed	23(30.7%)	3(4%)	0
Not employed	26(30.6%)	0	2(2.4%)
Monthly Income			
Below 10,000	39(30.7%)	0	2(1.6%)
10,001 to 30,000	8(25.8%)	3(9.7%)	0
Type of family			
Nuclear	45(32.2%)	3(2.1%)	2(1.4%)
Joint	4(20%)	20(100%)	0
Nativity status			
Migrant	15(21.7%)	0	2(2.9%)
Non migrant	34(37.4%)	3(3.3%)	0
No. of children			
Two and less	29(33%)	2(2.3%)	2(2.3%)
Three and above	20(27.8%)	1(1.4%)	0
Savings			
available	21(36.2%)	0	0
Not available	28(27.5%)	3(2.9%)	2(2%)
Debts			
Debted	18(23.4%)	0	0
Not debted	31(37.3%)	3(3.6%)	2(2.4%)
N=160			

Excepting taking children for an outing many parents do not receive support from outside household. Fathers, older parents, parents relatively better educated, those with lesser income, those in nuclear families, non-migrant parents, parents with two children or less, those having savings and those not debted receive more support.

To sum up, each family drafts in its own set of people which varies by demographic and background characteristics. Support information was collected through a set of strands in the emotional, financial, information, services and

companionship domains. In majority of the strands in all domain excepting finance and information, family members or close kin were the main support providers. Formal institutions such as schools are very active in facilitating the government support. Mostly younger parents, better educated, those in nuclear family, those with savings and not debted tend to mobilize larger support. Younger age of the children and demands through severity of disability and training received by children has a bearing on the support transacted.

Studies on disability indicate that differently abled children and their families experience multiple disadvantage and barriers in social participation. Children, especially differently abled children are vulnerable and families are the main care givers. 'Care giving' is a challenging task that involves a process and requires adaptation and restructuring of responsibilities of care giver over a period of time. 'Caring' children with special needs enters early into the life course of young parents and places demands on financial costs, social pressures, physical and mental exhaustion etc. The statistical figures of differently abled children across the world and India indicate that a huge number of individuals and families are affected and there is a spiraling effect of disability. It also brings in the need to understand it is as a social issue, as it is a social construction and imposes restriction on the disabled children and their families through negative social attitudes, discrimination, stigmatization and ostracisation. In addition, the problems are intertwined with families experiencing poverty, marginalization and unstimulating home and social environments. India has a progressive disability policy but huge challenges operate in implementation of the policy framework.

Parents and siblings of differently abled children go through many stages of understanding and accepting the child with disability. They also go through a period of shock, anger, guilt, ambivalence, loneliness and sorrow (Murphy, 1982; Goodship, 1987). Caring for children with special needs includes care for a prolonged period of time and requires carrying out physically demanding and unpleasant tasks and frequent disruption of family routines and activities (Seltzer and Heller, 1997; Shultz and Quittner, 1978). Hence it becomes reasonable to assume that parents of children with disability are at an increased risk of care giving burden. Chronic conditions of children make extra demands, which include more attention, greater vigilance and efforts in the physical, psychological and sociological aspects (Senel and Akkok, 1996). Parents of differently abled children face unique situations and have very less opportunities to explore their own needs and largely require assistance in some form to overcome their difficulties. The care giving tasks are usually associated with nurses and health care professionals where in alternate professionally trained members are available for replacement and no personal bonding operates. When family members handle the task with lesser or no training it becomes difficult for the care givers over a period of time. Hence parents as

care takers are less equipped and mentally prepared for it, along with it they are pressurized by demands of other members in the family. In addition the care giving role is largely performed by women, especially in the Indian context. The socio economic background of families, the type and level of disability of children, and their social skills and behavior places differential demands on the care giving role and stress associated with it. In societies where the families have limited resources for alternate care such as kin or formal support, the care givers experience major stress and strain leading to poor quality of care giving, effecting the differently abled child, care giver, family and society at large. Despite all these, some families adjust quite well to the challenges by way of accepting the situations, access formal care, training and device strategies (Cunningham, (1982); Fewel, 1986 and Turnbull et al, 1986a). Parents need to function, as well as enhance the well being of the child and ensure their own well being (Bode et al., 2000, Kazdin and Wassell, 2000).

Social support is identified to be an important factor in the functioning of families of children with disabilities. Families having increased levels of support demonstrate less stress and the most effective support is derived from family and friends. It is also linked to better parental self esteem, more stable functioning and positive perception of the child and enhance the parent child relationship. Generating an active support system, is part of the cultural norm of specific communities, or depends on the ability of families to skillfully interact with others and seek support (Gottlieb, 1981; Wrubel, Bennert and Lazarus, 1981). Social support and internal coping mechanisms are closely linked. In this backdrop the study focuses on describing the parental problems, care demands and support services received by parents. The study is important as care giving by parents and the problem associated with it is less focused in literature, especially in the Indian context. The present study will provide insights for policy framing, centering on the family as a whole and adequately address the care givers needs of the differently abled children.

The specific objectives of the study are (1) to understand the parenting problems and care demands of the parents of differently abled children, (2) to examine the social skills and social behaviour of differently abled children and (3) to examine the social

support for the families. Based on the nature of objectives, a descriptive explanatory research design is adopted for the present study. The nature of data collected is both quantitative and qualitative. To understand care demand, social skills and social behaviour, scales used by Leiser, 2011, Kim, 2008 and Dekker, 2002 are administered in the present study while a social support index is constructed by the researcher to collect information regarding the support needs. A pre-test was conducted among 20 parents and a few modifications related to support questions were incorporated in the final interview schedule.

The study is carried out in Thoothukudi District, Southern part of TamilNadu, India. The district has a population of 17 lakhs and the predominant occupation is fishing and salt making. The area is purposively selected and the district has Rehabilitation centre and child guidance centre's. The district rehabilitation centre provided information about the details of differently abled children enrolled in normal and special schools. 675 children were registered and of these, 620 students were in special schools and 55 in normal schools. A non-probability sample through purposive sampling method was adopted and 160 respondents were identified and included in the sample. Parents who came to drop and pick the children formed the sampling frame. Parents were contacted through referrals from teachers of the school and the parents themselves referred other parents. Non response was low as they were contacted through referrals. 8 respondents were dropped as the information was incomplete. Parents are the study units and target population.

The study is based on primary data and interview schedule was used to collect data which comprised of questions pertaining to background information of parents and children, history of disability of the children, parental problems, care demands, perceived social skills and social behavior of differently abled children and support systems. Data was collected between April 2013 to December 2013. It took about 2 to 3 hours to complete an interview and sometimes required several sittings. The collected data were edited, coded and analyzed through SPSS package. Simple descriptive techniques like percentage and proportions were used to depict basic information and correlation and multiple regression are used to explain care demand, social skills, social behavior and

social support. Children not registered in schools and those at homes were not included which is a limitation of the study.

A brief description of the background characteristics shows that many of primary care givers are mothers of the children. The mean age of the respondents is 39 years and significant proportions are in the age group of 30 to 34 years. A majority of the respondents are Hindus and considerable proportions belong to the scheduled castes and other backward castes. The breadwinners of the family are largely men and engage in traditional occupation such as fishing and agriculture while some are involved in manual labour and a few are employed as teachers, tailors etc. Mothers are largely housewife's due to the care giving role. Most of the parents are educated up to school level especially with middle or high school level of education, with mothers having a relatively low level of education. Most of the children have both parents living with them while a small but significant proportion of care taking mothers are widowed, separated or divorced.

A majority of respondent's family income is less than Rs10, 000/- per month and men are the main breadwinners. A significant proportion of the families are migrants from rural areas, due to marriage, for want of special education of the differently abled children and want of jobs. Nearly half of the families are debted and close to two thirds do not have any savings. The average age of the differently abled children is 9.53 years and ranges between 5 and 14 years. A greater proportion of differently abled children are boys compared to girls and they are either the first born or second born. Regarding the type of disability, around one third of the children in the sample are mentally challenged followed by being deaf and dumb and having a physical impairment. More than half of the children are in special schools while others are in normal schools and early intervention centre. A majority of children receive governmental support such as scholarship and aids such as wheel chair, hearing aid etc.

The father's average age at marriage is 26.5 years and mother's age is 21.6 years. The average age of the mother during delivery of the differently abled child is 27.8 years. About one third of the parents were related as close kin before marriage, while majority revealed that the previous generation of their families did not have any incidence of disability. Most of the children were born after complete gestation period and more than

one half of the mothers had normal delivery and the places of delivery were mostly government hospitals. Many parents reported delayed pregnancy and improper care during pregnancy as major causes of disability of children. Most of the children are under treatment related to the disabilities, especially allopathic treatment. A majority of children receive support from government while educational institutions facilitate to avail the scholarship, aids, bus concessions etc, while the role of NGO's are very minimal.

Parental Problems

The 'care giving' parents are absorbed in tasks, concerns and attention to the children, but in reality there are several unmet needs. It is a stressful experience that a family endures and has less opportunities to explore their own needs and overcome their difficulties. The questions for understanding the problems of parents were open ended and later the information received were categorized. Broadly the parents reported problems related to financial management, employment issues, feeling of guilt and also brought out the gap in inadequate training to parents and lack of awareness regarding the rights of differently abled children.

In the financial domain a majority of the families stated difficulties, owing to medical expenditures for the differently abled child, less earnings, high family expenses etc. The lower income of the parents due to limitations in earning and their already poor socio economic position makes their financial problems acute. As a result, parents restrict expenditure even on basic needs of the family and limit their social participation and cut on any 'extra expenditure'. As a result, some of the differently abled children were also neglected being labeled as 'non productive'. Many were also debted and had to pay high interest rates and hence most of their earnings were used to settle debts and their chance for lifting themselves out of this cycle was very low. Close to one half of the parents were employed and fathers were the main earners. Fathers largely reported difficulty at work as they need to take leave or permission for the sake of children and mothers reported sacrificing jobs and the need to arrange someone to take care of the children during their absence if employed.

A majority of the mothers attributed the blame towards themselves for the child's disability. They reflect on their carelessness during pregnancy, or being carriers of 'curse'. In addition kin such as parent's in-law or sibling's in-law shun the parents for giving birth to such children, especially during familial problems or negotiations. A greater proportion of parents reported an understanding attitude among family members and participated actively in care giving of the child. It was reported that only a small proportion take the differently abled children along with them to all places as they were engulfed with the feeling of social embarrassment.

An overwhelming proportion of parents, especially mothers reported that they felt guilty that they were unable to give adequate attention to other children and family in general. Parents also reported that they generally do not participate in social functions as they feel low in comparison to other parents. They also reported discrimination in the neighborhood and larger society but rarely in family and schools.

A majority of parents reported that have not attended any training for 'care giving' the special children though some parents of children in special schools had opportunity for such training. They reported that no serious importance or awareness regarding the formal training was given and is treated as a familial responsibility both by the institutional authorities and family members. Those who attended training were parents of children who had multiple disabilities, and they reported better understanding towards the children and easier handling of the children after the training. Training is felt as a need by most of the parents irrespective of the type of disability. The social skills and behaviour of children indicate that there are problems even for children who have less severe difficulties. Thus problem persists and gets complicated as a result of limited knowledge of parents in handling the children. Training provides scope for better socialization and grooming of the children. This is largely an unmet need for the parents which will significantly reduce their care giving burden. Regarding awareness of child rights, parents have poor awareness towards all rights and lower awareness regarding the right to economic security and right to protection from exploitation.

Care Demand

Family care giving is an 'unexpected career' for those involved which requires adaptation and restructuring of responsibilities over time. Parents are the main care givers and largely in need of assistance in coping with care demands and other emotional pressures. Care demands are more specific and relate to care giving tasks. It is examined through administration of a scale which relates to assessing demands in various domains. The broad domains relate to dependency of children, financial issues, emotional problems and strain of caretakers. A majority of parents accepted that they constantly worry about the child's situation, their dependency and future and the social life of the family. The specific situations are associated with difficulty in leading a normal life along with high financial expenditure and care taking for a major part of the life.

The anxiety is also due to the impact on overall familial development and lesser time, money and attention given for other children in family. At times other family members forgo their basic needs or comfort. Differently abled children's difficulty such as needing a special setting or difficulties in communication are situations during which parents become pressurized. In addition the demands become harder when the dependent child cannot remember his/her name or address or when they cannot take care of their own physical needs. In addition the responsibility towards other family members also pressurizes them. Women as care givers experience more difficulty as they need to take care of multiple roles. In addition, in the Indian context they themselves are dependent without much power, money or education and are also less aware of formal support and are at the receiving end of the social remarks or stigmatization. They report that neither are they able to do their care giving role to satisfaction nor have assistance in care giving issues. Hence differently abled children are viewed as limiting others development, which is a constant 'prick' for the parents and parents also limit the needs of differently abled child. Either way it becomes a mental agony for parents.

Parents also go through 'social embarrassment', manage their day to day affairs and plan for the future of the children. Hence they experience physical and emotional exhaustion and tend to avoid social participation as much as possible. They are too tired to enjoy, upset with the way the life is going on, and also feel that the child is always a

problem and can never relax. They also report less frequent availability of alternate care and support either at formal or informal level. Parents constantly go through the feeling of guilt and emotional turmoil of prioritizing the issues.

Cross tabulations depict younger parents, parents in joint living arrangement, and those with younger and mentally challenged children to have higher care demand. Correlation findings indicate that the monthly income of family, type of school which the child attends and the type of disability of children has a significant bearing on level of care demand. Regression results further support that the monthly income of family, parents having younger children and those having children with mental disability experience higher care demand. It is understood that younger children are still in the phase of training and hence dependency is high while parents are still in a state of shock and yet to come to terms. The care demand is reported more by parents who have children attending special school as well as those with mental disability. Social behavior and social skills of children in normal schools are also problematic, but parents report experiencing lower care demand for such children. It indicates that parental understanding of the disability and acceptance of it influences care demand faced by parents.

Social Behaviour

Social interaction is important for all children, especially differently abled for participation in social activities. Family, school, peer group, and social environment are agencies which play an important role in grooming them. It also reflects the successful socialization which is usually customized for special needs and the child is happier, on being equipped for better interaction. A child with appropriate social behavior has more chances of inclusion in the community and enables better understanding of the differently abled child in a social circle. Knowledge of child's social behavior also facilitates understanding of the care demand that parents experience and emphasizes the need for such research studies.

Marielle C. Dekkers scale is administered to understand the social behavior of differently abled children and focuses on child's behavior with respect to Disruption, Self

absorption, Communication disturbance and Anxiety of children. In the domain of disruption, it is noticed that many parents report that the children go through rapid mood changes, attempt things for which they not capable of and are easily led by others. A small proportion of children refuse to co-operate, become impatient or disobedient, and a few parents have to deal sometimes with severe problems such as throwing or breaking objects. The behaviours are stressful but can be handled if parents are trained and children are groomed and hence training becomes essential. One fourth of the parents were identified to have the children with low disruptive behavior while the others experience medium or high disruptive behavior. Covariate regression tables show that the type of school and type of disability are significant factors associated with the disruptive behavior.

The self absorptive behavior shows that many children engage in some repetitive behaviours while some children stay aloof or engage in biting themselves or bangs head, and a few also have problematic behavior of biting others or lack toilet training. All of these pressurize the care giving role and parents experiencing such pressures tend to express higher care giving demand and over a period of time become exhausted. These situations, can be handled well if professional assistance is available for training the children as well as parents and availability of residential care for a few days. Three out of ten parents reported low self absorptive behavior of children while many of the parents reported medium and high self absorptive behavior. Correlation and regression results identify children's age and type of disability to be strongly influencing self absorptive behavior. It indicates that as children grow, problems pertaining to the social behavior also reduced.

Communication disturbance domain comprises of indicators related to sociability. A majority of children do not mix with outsiders and it is felt that due to boredom children engage in talking to self or have unusual rhythm in activities which restricts their communication and sociability skills. In comparison to the earlier domains, majority of parents report that their children have issues in communication. This has a direct link with social isolation and efforts are required to make the children more interactive. As with other domains the correlation table indicates that the child's type of disability and

type of school is associated with communication disturbance. Regression results also indicate that the type of living arrangement, the training received by parents, type of disability of the child and the type of school which the children attend also influence the communication of the child.

The anxiety domain shows the significant relationship between anxiety of the children and dependency behaviour. Many children exhibit anxiety when separated, or become distressed or unhappy and sometimes are indifferent to others. A majority of children show medium or high levels of anxiety. Correlation results show that training received by parents has a significant association with the level of anxiety expressed by the children. Regression results indicate parent's age and parent's educational attainment to be important indicators influencing level of anxiety in children. Older parents and parents with better education are able to handle children's anxiety in a better way.

Scores in all strands of various domains in social behavior such as disruption, self-absorption, communicative disturbance and anxiety are summarized. Based on the total scores, the children are categorized into low, medium and high level of anxiety. A majority of children are reported to have medium scores on social behavior and a significant proportion have higher scores indicating higher problematic behavior. Correlation results show that the type of disability and type of school has significant association with the social behavior of children. Regression results depict children's age as an important variable and indicate that as the children grow, the overall social behavior might change and the children may learn to be more sociable. But the intervening period is a very difficult period during which, both the parent and child need counseling and training for better adaptation and to lead a normal life. Learning the appropriate social behavior is more a requirement at the individual level and is a basic necessity for social interaction. Appropriate social behaviour enables the children maneuver the social spaces and link with other individuals in society.

Social Skills

Social skill is defined in terms of interaction between an individual and his or her environment and skills relate to Self control, Co-operation and Assertion which reflects the social competency of differently abled children. Many of the skills learnt enable the

children to adapt, interact and integrate into the family and society. Parents and teachers have an important role in enhancing the children's skills by way of teaching, training and communicating the expectations clearly. Regarding the self control domain, majority of children have difficulty in controlling temper in their interaction with parents and other children, in avoiding situations that might cause trouble and in following parental instructions. Based on the summarized scores of the strands, the scores are converted into high, moderate and low levels of self control. Later the background characteristics are cross tabulated with level of self control. Only about a fifth of children have high self control, while others have medium and low self control. Fathers report that the children have better self control and older parents, parents with older children, those with female children and parents who attended training reported that the children had better self control. But parents with better education, children in joint families, children attending special schools show mixed responses of both high as well as low self control. The correlation results indicate that the gender of parent's reporting, age of the parents, type of living arrangement, age of children and type of disability have significant association with self control. The regression results also show that parent's age, the type of school and type of disability of children has a significant influence on self control. Gender differences are noticed in the social behavior of the children. Training received at school and the type of disability of children impinges on the self control behavior of the differently abled children.

Co-operation is a positive attribute of the children and is understood by way of children's assistance in household maintenance, neatness, personal hygiene and communication. It has a strong relationship with care taking as they relate to routine activities and if children understand and involve it reduces the care burden to a large extent. A majority of the children extend low level of co-operation and one third extend moderate level of co-operation while a small proportion extend a high level of co-operation. The cross tabulations show that father's report more co-operation by children. Children in nuclear families, older children and female children are reported to be more co-operative. The correlation results show that the gender of reporting parents, age of parents, educational level of parents, living arrangement and age of the children are strongly associated with co-operation of children. Regression results point that the

educational level of parents, living arrangement, age of children, and type of disability are significant factors influencing co-operative behavior of children.

Strands in Assertion domain indicate the socializing and interacting skills of differently abled children. It reflects the positive inclination of children to interact and integrate. A considerable proportion of children show interest in a variety of things and express inclination to interact. More children are reported to have low assertive behaviour and a small proportion show high assertiveness. Children of older parents, older children, female children, those not attending special schools and those with challenges other than mental disability show high assertive skills. Correlation statistics indicate that the gender of the reporting parents, age of the parents, children's age, the type of school which the child attends and the type of disability are identified to be important variables associated with assertive skills of children. The regression results indicate that more fathers tend to report higher assertive behavior of the child. Similarly children of older parents and children with disability other than being mentally challenged also exhibit high assertive behavior.

The overall social skills are understood through combining scores of strands in domains of self control, co-operation and assertion. Children of older parents, those in nuclear families, parents who received training, parents with older children, parents of female children, children attending normal schools and children with disability other than being mentally challenged are reported to have better social skills. Parental perceptions, age of the parents and age of the children are variables significantly correlated with social skills. Further the regression results show that, the age of the children, age of the parents and type of disability has a significant influence on social skills. The bivariate tables, correlation and regression results of overall social behavior of children and social skills of children shows a strong association. This reveals the fact that children with less problematic behavior have better social skills and vice versa. Hence efforts should be taken to reduce the problematic behavior of children. These in turn reduce the care demand, care giving burden of parents and enhance the quality of life of the parents and differently abled children.

Support Systems

Social support is the social, economic, moral and psychological support that various institutions provide for the family of differently abled children and their parents. The effectiveness is based on the perception and utilization of resources which may be drawn from formal and informal systems. Despite problems, every individual or household identifies a set of people with whom they derive and exchange support. Its significance is understood through the importance attached to the available help and the actual support drawn. The support enables better care for children, personal well being of care takers and the parent child relationship. The support systems are understood through who provides what kind of support. A few important strands are identified in the domains of emotional, financial, services and companionship through literature, earlier studies and pretest. Support providers include members within household as well as outside and family members are the primary support providers. Parents of care takers and female siblings of caretakers are the major support providers in the emotional domain. They largely provide assurance when required and enable them to feel comfortable. In addition neighbors and friends play an important role. A significant proportion of respondents seek outside household support for emotional needs as family members in household also go through similar situation and there is a tendency to seek same gender ties for such support.

Regarding economic support, many families are in the lower income group and have problems in mobilizing support during financial emergencies. The important financial support perceived is in the form of monetary transactions without interest, which is mainly received from parents of care takers. Smaller financial needs, is sought from neighbors and friends to whom they reciprocate promptly. In general, the family attempts to manage themselves either through mortgaging or selling assets or borrowing for high interest rates. Informational support is essential for the parents, largely for the educational needs of the differently abled children and training of children. School teachers, social workers and social welfare officers play an important role as information providers. Information and motivation in training of parents is an unmet need, which has to be addressed adequately. Kin are relatively less equipped for providing such support.

With regard to service support, there are a number of situations when the care takers are exhausted or their children need additional support. It relates to routine tasks such as household activities or stay with the children whenever required or at times of illness of care takers etc. During such situations elderly family members such as parents or parents-in-law of the care takers extend support. In times of emergency when kin support is not available, neighbours and at times, acquaintances are drawn in. Companionship support is an essential need for care takers and their family as it helps them break the monotony of care giving and stress as well as it helps the differently abled children. Findings indicate that taking children for an outing is a familial responsibility and is confined to family members, especially household, a few times the support or the invitation to join is extended by neighbours and friends. The requirement is an unmet need as the significance is not realized. Fewer family members attend family functions despite being invited by many and also fewer families take children along with them. It becomes exclusively a family affair and is only a choice between attending or not attending. Regarding visiting institutions, it is an official requirement and usually members in household take care of the need but many families postpone the visit if there is a difficulty. The bivariate tables of support with background characteristic show that, many of the families of differently abled children manage their needs within household especially in the emotional and service domain, but with regard to informational and companionship domains, there is a dependency outside while in financial domain there is a need but the financial support is less available outside and hence they manage within household.

In general, the care takers manage with support available within household and a few received supports from outside. There are also specific strands for which more parents seek outside help which largely depends on the nature of support. Among those, who received support from outside household, greater proportions are younger parents, better educated and those in nuclear families. It is observed that personal resources such as availability of savings, not being debted and those with more children mobilized more support in emotional domain. Regarding financial domain, older parents, less educated, employed parents, those with lower income, migrants, those having more children and those without savings tend to mobilize more support from outside. It indicates that the

parents potential to mobilize support and the requirement for support is closely associated with receiving support from outside household. In the informational domain, males, younger parents, those with relatively low education, employed parents, those in lower income group, those in nuclear families and migrants receive more support. Regarding services, older parents, parents with lower education, employed parents, parents in nuclear families, migrants and those having more children and those having savings receive more support from outside household. The companionship support is drawn from outside largely by fathers, older parents, better educated parents, those with lesser income, those having savings and those not debted. Based on the socio-economic background of individuals and care taking being a family responsibility, and hesitation to ask, there is a natural inclination to manage with the available support. This attitude only transpires into a low quality of care and life for the differently abled child and the care takers. The support system approach is a potential analysis to know the areas of support flow and areas which need assistance from external sources. Understanding the nuances of unmet need and flow of support will help formal agencies in facilitating parents to utilize formal and informal systems more effectively.

The result of the study support earlier research findings and observation as well as brings out a few issues of importance. The study findings indicate ‘mothers’ as the major care givers for the differently abled children by way of attending to their routine needs. They ‘opt’ to stay at home, take care of the child and also try to restrict expenditure, by way of doing all manageable physical work and are cautious of not raising expenditure in any ‘unwanted’ expenses. They sacrifice job, leisure, luxury, do not attend to self and also go through a ‘feeling of guilt’. Mothers and fathers respond differently to the outcomes of the differently abled child’s behaviours. Fathers do not express difficulty very explicitly but mothers are more vocal and emotional about the issue. The children’s social behaviours also varies, according to the gender of the parents which is a socialization issue and the present study also supports Hastings (2003) finding that mothers express higher level of anxiety. In the present study perception of children’s ability also varies across gender of parents with fathers reporting less problems of social behaviour and more confidence of the skill of the children in comparison to mothers. But the research also opines that father are not expressive in reporting, or do not want to

share. It is also part of experiencing the process of stressful care taking while a major part of the care giving is usually taken care by mothers.

The study brings out the fact that though behavioural problems and low social skills are noticed even among children of disability other than being mentally challenged, only children with severe disability or those with multiple disabilities are viewed as a cause of high care demand reflecting the attitudinal problems of parents. The findings support Dalf and Robbins, 1994 and Richman et al, 2009 study findings that aggression, self injury and disruptive behaviour are causes of parental stress but the current study findings further report that the severity of disability has a direct influence on care demand.

Financial constraint looms large for families in the study and supports the huge backlog of other studies such as Mc Andrew, 1976, Seth, 1979, Veena, 1985. Along with that, specialized rehabilitation program for children and training for parents are identified to be very important. The knowledge and details of availability of formal support is understood by parents mainly through acquaintances and accidental informers and later through educational institutions such as the school which guides clearly but prior to it, is a process of 'jumping through hoops' and there is a complexity in navigating the system.

Collective experiences reflect the need for more availability, flexibility and coordination of formal support. Baker, Mc Intyre, Crinc, Edelbrock and law, 2003 that report high levels of parenting stress increases child behaviour problems which increased parenting stress in an escalating and cyclical pattern over time. Hence there is need to reduce parenting problems which contribute to stress and there is need to break the cycle. Such situations are narrated by some cases in the study and the study finding also indicate close link between social behaviour, social skill and care demand experienced by parents. Better educated and higher income parents are able to mobilize greater support from outside indicating personal resources also as facilitating factors for drawing in social support.

The qualitative aspects of study findings indicate that availability of social networks and supportive members, reduce the monotony and exhaustion due to care

giving as well as provide information and also influence the behaviour, attitude, expectation, and knowledge of parents. This supports Dutt, Trivette and Cross, 1986 findings that parents also utilize this informal support to a large extent which is a coping strategy. Balancing social interaction, social ties and building up trust worthy neighbours are important for parents and children, as it has a major role in integration with the society. 'Social isolation' of the families is understood to be quite high due to the individual familial withdrawal as well as societal remarks. Parents express 'feeling of embarrassment' to participate in social functions or to take the differently abled child for social functions or even to interact with outside members and hence they avoid such situations to a large extent. Support flow in companionship domain by kin or others is very less indicating confinement. Parents also reported 'strong' remarks by neighbours and kin especially in 'trying' situations during the course of social interaction to have an edge over them and to give an emotional blow.

The study depicts the unique needs and pressurized situation of parents as care givers. Parents negotiate with multiple demands and acceptance of child who is considered as a 'social embarrassment' or 'personal failure'. The situation reflects the 'social construction' and 'societal failure' in providing appropriate support and social environment. Parents are squeezed between membership in society and being a victim of discrimination. Parental background resources are poor, the social behaviour and social skills of differently abled children are to be improved, care demand is high and social support is largely managed within household in the backdrop of self imposed isolation. It reflects the persisting problem and the context of the population especially in the study area. The research highlights the need for preparing and equipping the parents for the care giving role through orientation and training programs for a realistic understanding of the children and issue. Such efforts will enable parents to handle the children appropriately and also enrich knowledge regarding availability of formal resources. Training for the children is also essential to enhance the personal skills and facilitate social participation. Efforts are also required to deconstruct the social construction by sensitizing the communities and ensure social responsibility towards differently abled children and their families.

Amundson, R., 2000. 'Disability, Handicap, and the Environment', *Journal of Social Philosophy*, 23(1): 105–19.

Asch, A., & Fine, M. 1988. Shared dreams: A left perspective on disability rights and reproductive rights. In M. Fine & A. Asch (Eds.), *Women with Disabilities: Essays in Psychology, Culture and Politics* (pp. 297-305). Philadelphia: Temple University Press.

Baranowski, M. D., & Schilmoeller, G. L. 1999. Grandparents in the lives of grandchildren with disabilities: Mothers' perceptions. *Education and Treatment of Children*, 22, 427-446.

Barnes, C., Mercer, G., & Shakespeare, T. 1999. *Exploring Disability: A sociological Introduction*. Malden, MA: Blackwell.

Beckman, P. 1991. 'Comparison of Mothers' and Fathers' Perceptions of the Effect of Young Children with and without Disabilities', *American Journal of Mental Deficiency*, 95, 585 - 595.

Beresford, B. 1994. *Positively Parenting: Caring for a Severely Disabled Child* (London, Social Policy Research Unit, HMSO).

Bhatt, U. 1963. *The Physically Handicapped In India*, Bombay, Popular Book Depot.

Blacher J., Lopez S., Shapiro J. & Fusco J. 1997. 'Contributions to depression in Latina mothers with and without children with retardation: implications for care-giving', *Family Relations*, 46 325-34.

Bode, H., Weidner, K., & Storck, M. 2000. Letter to the editor: Quality of life in families of children with disabilities, *Developmental Medicine and Child Neurology*, 42, 354.

Boyd, B. A. 2002. 'Examining the Relationship between Stress and lack of Social Support in Mothers of Children with Autism', *Focus on Autism and Other Developmental Disabilities*, 17(4), 208-215.

Breslau, N., Staruch, K.S., & Mortimer, E.A. 1982. 'Psychological Distress in Mothers of Disabled Children', *American Journal of Disease of Childhood*, 136: 682-686.

Brickman, P. & Bulman, R. J. 1977. Pleasure and Pain in Social Comparisons. In J. Sullis, R. Miller (Eds), *Social Comparison Processes*, (pp.149-186). London: John Wiley & Sons.

Brzuzy, S. 1997. 'Deconstructing disability: The impact of definition', *Journal of Poverty*, 1(1), 81-91.

Brzuzy, S. 1997. 'Deconstructing Disability: The Impact of Definition', *Journal of Poverty*, 1(1), 81-91.

Buunck, B. P., Collins, R.L. Taylor, S.E. Van Yperen, N.W. & Dakof, G.A. 1990. 'The Affective Consequences of Social Comparison: Either direction has its ups and downs', *Journal of Personality and Social Psychology*, 59, 1238-1249.

Caplan, G. 1976. The Family as a Support System. In G. Caplan & M. Kililea (Eds.), *Support Systems and Mutual Help* (pp 19-36). New York, NY: Grune & Stratton.

Chan, J. B., & Sigafos, J. 2001. Does Respite Care Reduce Parental Stress in Families with Developmentally Disabled Children? *Child & Youth Care Forum*, 5, 253-263.

Chesler and Parry, 2001. Gender roles and/or styles in crisis: an integrative analysis of the experiences of fathers of children with cancer, *Qualitative Health Research*, 11 (3) (2001), pp. 363-384.

Cintron, R. 1997. *Angels' Town: Chero ways, Gang Life, and Rhetorics of the Everyday*. Boston: Beacon Press.

Cobb, S. 1976. 'Social Support as a Moderator of Life Stress', *Psychosomatic Medicine*, 38, 300 - 314.

Cohen MS. 1999. 'Families coping with childhood chronic illness: a research review. *Families, Systems and Health*, 17(2):149-164.

Corker, M. 2000. The U.K. Disability Discrimination Act: Disabling language, justifying inequitable social participation. In L. P. Francis, & Silvers, A. (Eds.), *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (pp. 357-370). New York: Routledge.

Cummins, R. A. 2001. 'The Subjective well-being of People Caring for a Family Member with a Severe Disability at Home'. *Journal of Intellectual & Developmental Disability*, 26(1), 83-100.

Cunningham, C. 1982. Down's syndrome: An introduction for parents, London: Souvenir Press.

Curran, T., Schacter, D. L., Johnson, M. K., and Spinks, R. 2001. Brain potentials reflect behavioral differences in true and false recognition. *Journal of Cognitive Neuroscience*, 13, 201-216.

Dagnan, D., & Sandhu, S. 1999. 'Social Comparison, Self-Esteem and Depression in People with Intellectual Disability', *Journal of Intellectual Disability Research*, 43, 372-379.

Damaini, G., Rosenbaum, P., Swinton, M., & Russell, D. 2004. Frequency and Determinants of Formal Respite Service use Among Caregivers of Children with Cerebral Palsy in Ontario. *CanChild Centre for Childhood Disabilities*. McMaster University, Hamilton, Ontario, Canada.

Davidson, B., & Dossier, D. A., Jr. 1982. 'A Support System for Families with Developmental Disabled Infants', *Family Relations*, 1982, 31, 295-299.

Dembo, Tawara, 1975. 'Adjustment to Misfortune-A problem of Social Psychological Rehabilitates', *Rehabilitation Psychology*, Vol, 22, 1975.

Dial, Jack G., and Catherine L. Dial. 2009. Assessing and intervening with visually impaired children and adolescents, *Best Practices in School Neuropsychology: Guidelines for Effective Practice, Assessment, and Evidence-Based Intervention*.

Duis, S.S., Summers, M., Summers, C.R. 1997. 'Parents versus Child Stress in Diverse Family Types: an Ecological Approach, *Topics in Early Childhood Special Education*, 17:53-73.

Dunst, C. J., Trivette, C. M., & Jenkins, V. 1986. *Family support scale: Reliability and validity*. Asheville, NC: Winterberry Press.

Dunst, C. J., Trivette, C. M., Cross, A. H. 1986. 'Mediating influences of social support: Personal, family, and child outcomes', *American Journal of Mental Deficiency*, 90, 403-417.

Dyson L. L. 1993. 'Families of Young Children with Handicaps: Parental Stress and Family Functioning', *American Journal on Mental Retardation* 95, 623-9.

Edgerton, R. B. 1985. *Rules, Exceptions, and Social Order*, Berkeley: University of California Press.

Featherstone H. 1981. *A Difference in the Family*, Basic Books, New York.

Fewell, R. R. 1986. 'Supports from Religious Organizations and Personal Beliefs', *Families of Handicapped Children: Needs and Supports Across the Lifespan* (pp. 297-316). Austin, TX: PRO-ED.

Finkelstein, V. 1980. *Attitudes and Disabled People*, New York: World Rehabilitation Fund.

Foucault, M. 1977. *Discipline and Punish*, New York: Vintage Books.

Freedman, R. I., & Boyer, N. C. 2000, 'The Power to Choose: SUPPORTS for Families Caring for Individuals with Developmental Disabilities', *Health & Social Work*, 25(1), 59-68.

Frey, K. S., Greenberg, M. T., & Fewell, R. R. 1989. 'Stress and coping among parents of handicapped children: a multidimensional approach', *American Journal on Mental Retardation*, 94(240-249).

Friedrich W. N. & Friedrich W. L. 1981. 'Psychosocial Assets of Parents of Handicapped and Non-Handicapped Children', *American Journal of Mental Deficiency*, 85, 551-3

Furth, H.G. 1966. *Thinking without Language, Psycho Logical Implications of Deafness*, New York: Free Press.

Gardner, E. J., Scherman, A., Mobley, D., Brown, P., & Schutter, M. 1994. 'Grandparents' Beliefs Regarding their Role and Relationship with Special Needs Grandchildren', *Education and Treatment of Children*, 17, 185- 196.

Garland-Thomson, R. 1997b. Feminist Theory, the Body, and the Disabled Figure. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 279-292). New York: Routledge.

Gerschick, Thomas J. 2000. 'Toward a Theory of Disability and Gender', *Signs*, 1263-1268.

Gerstein, E. D., Crnic, K. A., Blacher, J. & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities *Journal of Intellectual Disability Research*, 53 (12), 981-997.

Gibbons, F. X. 1986. 'Social Comparison and Depression: Company's Effect on Misery' *Journal of Personality & Social Psychology*, 51, 140-148.

Gilson, S. F., & DePoy, E. 2002. 'Theoretical Approaches to Disability Content in Social Work Education', *Journal of Social Work Education*, 38(1).

Gottlieb, B. H. 1981. Preventive Interventions Involving Social net-works and Social Support, In B. H. Gottlieb (Ed.), *Social Net-Works and Social Support*. Beverly Hills: Sage Publication.

Gray DE. 2003. 'Gender and coping: the parents of children with high functioning autism', *Social Science and Medicine*. 2003; 56(3):631–642.

Gray, M., Ou, L., Renda, J., deVaus, D. 2003. 'Changes in the Labour Force Statistics of Lone and Couple Mothers', Australian *Institution of Family Studies, Research Paper 33*, Melbourne.

Groce, N., & Scheer, J. 1990. 'Introduction to Social Science and Medicine', 30(8).

Hardman, M. L., Drew, C. J., Egan, M. W., & Wolf, B. 1993. *Human exceptionality: Society, school, and family* (4th ed.). Boston: Allyn and Bacon.

Hartshorne, T.S. 2000. *The relationship between parents and teachers of young children with disabilities: Outcomes for children and families*, North Rocks, NSW, Australia: North Rock Press.

Haslam, S. A., Turner, J.C. 1992. 'Context-dependent Variation in Social Stereotyping 2: The Relationship between Frame of Reference, Self Categorisation and Accentuation', *European Journal of Social Psychology*, 22, 251-277.

Hastings, R. P. 2002. 'Parental Stress and Behaviour Problems of Children with Developmental Disability'. *Journal of Intellectual & Developmental Disability*, 27(3), 149-160.

Hastings, R.P. 2003. 'Child Behaviour Problems and Partner Mental Health as Correlates of Stress in Mothers and Fathers of Children with Autism', *Journal of Intellectual Disability Research*, 1365-2788.

Hirsch, B. J. 1981. b. *Social Networks and the Coping Process: Creating Personal Communities*. In B. H. Gottlieb (Ed.), *Social net-works and social support*, Beverly Hills: Sage Publication.

Ingstad, B., & Reynolds-Whyte, S. 1995. 'Disability and Culture: An Overview', Berkeley: University of California Press. (pp. 3-31).

Ireys H.T, Silver EJ. 1996. 'Perception of the Impact of a Child's Chronic Illness: Does it Predict Maternal Mental Health'? *Developmental and Behavioral Pediatrics*, 17:77– 83.

Kammerer. R.C., 1940. An Exploratory Psychological Study of Crippled Children, *Psychological Record*.

Kazdin, A. E., &Wassel, G. 2000, 'Predictors of Barriers to Treatment and Therapeutic Change in Outpatient Therapy for Antisocial Children and their Families', *Mental Health Services Research*, 2 (1), 27-40.

Keller, D. and Honig, A. S. 2004. 'Maternal and Paternal Stress in Families with School-Aged Children with Disabilities', *American Journal of Orthopsychiatry*, 74: 337–348.

King G. 2002.'A life ness model of pediatric service delivery', *Physical and Occupational Therapy in Pediatrics*, 22, 53-77.

Konstantareas, M., & Homatidis, S. 1989. Assessing Child Symptom Severity and Stress in Parents of Autistic Children', *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 30(3), 459-470.

Krahn G. L. 1993. 'Conceptualizing Social Support in Families of Children with Special Health Needs', *Family Process*, 32, 235-48.

Krauss M. W. 1993. 'Child-related and Parenting Stress: Similarities and Differences between Mothers and Fathers of Children with Disabilities', *American Journal on Mental Retardation*, 97,393–404.

Krauss M.W. 1993. Child-related and parenting stress: similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation*. 97(4):393–404.

Krausz, S. 1988. 'Illness and Loss: Helping Couples Cope', *Clinical Social Work Journal*, 16(1), 52-65.

Leary, M. R., Tambor, E. S., Terdal, S. K., & Downs, D. L. 1995. 'Self-esteem as an Interpersonal Monitor: The Sociometer Hypothesis', *Journal of Personality & Social Psychology*, 68, 518-530.

Levine, J., 1997. 'Re-visioning Attention Deficit Hyperactivity Disorder', *Clinical Social Work Journal*, 25(2), 197-211.

Linton, S. 1998. 'Disability Studies: Not Disability Studies', *Disability and Society*, 13, 525-541.

Loeb, R.C. 1979. Group Therapy for Parents of Mentally Retarded Children. *Health and Development*, 5 (3): 177-188.

MacDonald, H., & Callery, P. 2007. 'Parenting Children Requiring Complex Care: A Journey Through Time', *Blackwell Publishing Ltd.*, 34(2), 207-213.

Macleod, C., and Hagan, R. 1992. 'Individual Differences in the Selective Processing of Threatening Information, and Emotional Responses to a Stressful Life Event', *Behaviour Research and Therapy*, 30, 151-161.

Mc Andrew. I. 1976. Children with a handicap and their families', *Child Care, Health and Development*, 2.

McCubbin, H. I. 1979. 'Integrating Coping Behavior in Family Stress Theory', *Journal of Marriage and the Family*, 41, 237-244.

McDermott, R. P., & Varenne, H. 1996. Culture, Development, Disability. In R. Jessor, A. Colby, & R. A. Shweder (Eds.), *Ethnography and Human Development* (pp. 101-126). Chicago: The University of Chicago Press.

McDonald T. P., Couchonnal G. & Early T. 1996. 'The Impact of Major Events on the Lives of Family Caregivers of Children with Disabilities', *Families in Society: The Journal of Contemporary Human Services*, 10, 502-14.

McDonald, Thomas P., John Poertner, and John Pierpont. 1999. 'Predicting Caregiver Stress: An Ecological Perspective', *American Journal of Orthopsychiatry* 69, (1), 100.

McFarlane, A. H., Neale, K. A., Norman, G. R., Roy, R. G., & Streiner, D. L. 1981. 'Methodological Issues in Developing a Scale to Measure Social Support', *Schizophrenia Bulletin*, 7, 90-100.

Mehta, D.S. 1983. *Handbook of Disabled in India*, Delhi. Allied Publishers.

Marielle C. Dekker 2002. 'Assessing Emotional and Behavioral Problems in Children with Intellectual Disability: Revisiting the Factor Structure of the Developmental Behavior Checklist', *Journal of Autism and Developmental Disorders*, Vol. 32, No. 6.

Mickelson, K. D. 2001. 'Perceived Stigma, Social Support and Depression', *Personality and Social Psychology Bulletin*, 27(8), 1046-1056.

Miller AC, Gordon RM, Daniele RJ, Diller L 1992. 'Stress, Appraisal and Coping in Mothers of Disabled and Non-Disabled Children, *Journal of pediatric psychology*, 17: 587-605.

Mitchell, D. 1985. Guidance needs and Counseling of Parents of Persons with Intellectual Handicaps. In N. Singh & K. M. Wilton (Eds.), *Mental retardation in New Zealand: Provisions, services and research* (pp. 136 - 156). Christchurch: Whitcoulls.

Moos, R. H. 1984. *Family Environment Scale: Children's Edition*. East Aurora: Slosson.

Murphy, M. A. 1982. 'The Family with a Handicapped Child: A Review of the Literature', *J. Dev. Behav. Pediatr.* 3: 73-82.

Myoung Sook Kim, 2008. "Teachers' and Parents expectations of the social behaviour of Preschool children with disabilities", *Master of Science in Special Education*, Oklahoma State University,

Nitza.Lavy-Wasser and Shlomo Katz. 2004. 'The relationship between attachment style, Birth order, and adjustment in children who grow up with a sibling with mental retardation', *The British Journal of Developmental Disabilities*, vol. 50, part 2, No.99, pp.89-98.

Oliver, M. 1983. *Social Work with Disabled People*, Basingstoke: Macmillan.

Oliver, M. 1990. *The Politics of Disablement: A Sociological Approach*, New York: St. Martin's Press.

Oliver, M. 1996. *Understanding Disability: From Theory to Practice*, Basingstoke: Macmillan.

Parish, Susan L., et al. 2008. 'Material Hardship in US Families Raising Children with Disabilities', *Exceptional Children* 75, (1), 71-92.

Patterson, K. A. 1997. Representations of disability in mid twentieth-century southern fiction: From metaphor to social construction (Doctoral dissertation, University of California at Santa Barbara). *Dissertation Abstracts International*, 38, PS 261.

Pavalko, E. K., & Henderson, K. A. 2006. 'Combining Care Work and Paid Work: Do Workplace Policies make a Difference'? *Research on Aging*, 28, 359-374.

Pfeiffer, D. 1996. Understanding Disability Policy: [A review of] Michael Oliver, *Understanding Disability: From Theory to Practice* (New York: St. Martin's Press, 1995). *Policy Studies Journal*, 24, 157-159.

Pinkerton, P. 1972. 'Parental Acceptance of a Handicapped Child', *Developmental Medicine and Child Neurology*, 12, 207-212.

Plachat D, Lefebvre H, Perreault M. Differences and similarities between mothers' and fathers' experiences of parenting child with a disability. *Journal of Health Care*, 2003; 7:231- 247.

Priestley M 1999. Discourse and Identity: Disabled Children in Mainstream High Schools. In: French S; Corker M (eds.) *Disability Discourse*, Buckingham, Open University Press.

Rangaswamy K. 1989. 'Construction of a Scale to Measure Parental Attitude Towards Problem Children', *Child Psychiatry Quarterly*, 22(2/3): 75-80.

Rangaswamy, K. and Bhavani, K., 2008. 'Impact of Disability on the Family and Needs of Families of Disabled Children', *J. Commu.Guid. Res.*, 25(1): 121- 130.

Reichman, N.E., H. Corman and K. Noonan. Impact of child disability on the family. *Maternal and child health journal* 12(6); 569-584, 2008.

Ringma, C., & Brown, C. 1991. 'Hermeneutics and the Social Sciences: An Evaluation of the Function of Hermeneutics in a Consumer Disability Study', *Journal of Sociology and Social Welfare*, 18(3), 57-73.

Sameroff, A., Seifer, R., Bartocas, B., Zax, M., Greenspan, S. 1987. 'IQ Scores of four year old Children: Socio-Environmental Risk Factors', *Pediatrics*, 79: 343-350.

Sanders, J. L., & Morgan, S. B. 1997. 'Family Stress and Management as Perceived by Parents of Children with Autism or Down syndrome: Implications for Intervention', *Child and Family Behavior Therapy*, 19, 15-32.

Scherman, A., Gardner, E. J., Brown, P., & Schutter, M. 1995. 'Grandparents' Adjustment to Grandchildren with Disabilities', *Educational Gerontology*, 21, 261-273.

Schilmoeller, G. L., & Baranowski, M. D. 1998. 'Intergenerational Support in Families with Disabilities: Grandparents' Perspectives Families in Society', *The Journal of Contemporary Human Services*, 2, 465-475.

Seiquira, E.M., Rao, P.M., Subbu Krishna, D.K. & Prabhu G.G. 1990. 'Perceived Burden and Coping Styles of the Mothers of Mentally Handicapped', *NIMHANS journal*, 8(1).

- Seligman, M. 1987. 'Adaptation of children to a chronically ill or mentally handicapped sibling', *Can. Med. Assoc. J.* 136: 1249–1252.
- Seligman, M., & Darling, R. B. 1997. *Ordinary Families Special children: A Systems Approach to Childhood Disability* (2nd ed.). New York, NY: The Guilford Press.
- Seltzer M.M. & Heller T. 1997. Families and Caregiving Across the Life Course: Research Advances on the Influence of Context', *Family Relations*, 46, 395–405.
- Seth, S., 1979. Mental attitude Towards Mentally Retarded Children. In E.G. Parameswaran and S. Bhogle (Ed.), *Developmental Psychology*, New Delhi, Light and Life Publishers.
- Seybold, J., Fritz, J., & McPhee, D. 1991. 'Relation of Social Support to the Self-Perceptions of Mothers with Delayed Children', *Journal of Community Psychology*, 19(1), 29-36.
- Shankar, Uday. 1976. *Exceptional Children*, New Delhi: Sterling Publications, 1976.
- Shultz R. & Quittner A.L. 1998. 'Caregiving for Children and Adults with Chronic Conditions: Introduction to the Special Issue', *Health Psychology*, 17, 107–111.
- Shuval, J. T. 1981. 'The Contribution of Psychological and Social Phenomena to an Understanding of the Etiology of Disease and Illness', *Social Science and Medicine*, 15-A, 337-342.
- Singer, G. H. S. and Powers, L. E. 1993. Contributing to Resilience in Families: An Overview. In: G. H. S. Singer and L. E. Powers (Eds.). *Families, Disability and Empowerment* (pp. 1-25). Baltimore: Paul H. Brookes Publishing Co.
- Singer, G. H., Biegel, D. E., & Ethridge, B. L. 2009. 'Toward a cross disability view of family support for caregiving families', *Journal of Family Social Work*, 12(2), 97-118.

- Singh, T.K., Indla, V. & Indla, R.R. 2008. 'Impact of disability of mentally retarded persons on their parents', *Indian Journal of Psychological Medicine*, 30(2), 98-104.
- Sinha, S.P. 1982. 'Personality Adjustment of the Blind Students', *Indian journal of Psychometry and Education*, Vol.13.
- Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. 2001. Parenting Stress in Families of Children with Disabilities. *American Journal of Orthopsychiatry*, 71, 257-261.
- Speedwell, L., Stanton, F., & Nischal, K. K. 2003. 'Informing Parents of Visually Impaired Children: Who Should Do It and When'? *Child: Care, Health and Development*, 29 (3), 219-24.
- Steil, J. M., & Hay, J. L. 1997. 'Social comparison in the workplace: A study of 60 dual-career couples', *Personality & Social Psychology Bulletin*, 23, 427-438.
- Stein. R.E.K. 1988. *Caring for Children with Chronic Illness: Issues and Strategies*, New York: Springer Publishing Company.
- Stiker, H. 1982. *A history of Disability*, Paris: Aubier Montaigne.
- Suls, J., Wheeler, L. 2000. *Handbook of Social Comparison: Theory and Research*. New York: Kluwer Academic/ Plenum Publisher.
- Szivos-Bach, S. E. 1993. 'Social Comparisons, Stigma and Mainstreaming: The Self-Esteem of Young Adults with a Mild Mental Handicap', *Mental Handicap Research*, 6, 217-236.
- Talley, R. C., & Crews, J. E. 2007. 'Framing the Public Health of Caregiving', *American Journal of Public Health*, 97(2), 224-228.
- Tannila, A., Kokkonen, J., & Jaervelin, M. R. 1996. The Long-Term Effects of Children's Early-Onset Disability on Marital Relationships', *Developmental Medicine & Child Neurology*, 38(7), 567-577.

Tew, B, Laurence. K. 1975. 'Some Sources of Stress Found in Mothers of Children with Spina Bifida', *British Journal of Preventive and Social Medicine*, 29:27-30.

ThiyamKiran Singh et.al. Impact of Disability of Mentally Retarded Persons on their Parents. *Indian Journal of Psychological Medicine*. July Dec 2008, vol 30.

Toseland, R., & Rivas, R. 2008. *An introduction to group work practice* (6th ed.).

Trute, B. &Heiburt-Murphy, D. 2002. 'Family Adjustment to Childhood Developmental Disability: A Measure of Parental Appraisal of Family Impact', *Journal of Pediatric Psychology*, 23,271-280.

Turnbull A.P. &Ruef M. 1996. 'Family perspectives on problem behavior', *Mental Retardation*, 34, 280-93.

Uchino, Bert N. "Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support." *Perspectives on Psychological Science* 4.3 (2009): 236-255.

Unger, D. G., & Powell, D. R. 1980.'Supporting Families under Stress: The Role of Social Networks', *Family Relations*, 29, 566-574.

United Nations Children's Fund (UNICEF) and UNESCO Institute for Statistics (UIS), 2011. Global Initiative on Out-of-school Children: Conceptual and Methodological Framework (CMF), UNICEF and UIS, New York and Montreal.

Vasudev, V., 1979. *Social Adjustment of the Blind*, Abstracts of Research Studies on the Handicapped in India, Bombay: Tata Institute of Social Sciences.

Veena, S.G. 1985. 'Management Problems and Practices of Homemakers with a Disabled Member in the Family', *The Indian Journal of Social Work*, 65, 4.

Vernon, M. 1967. 'Relation of Language to the Thinking Process, *Archives of Genetic Psychiatry*', vol.16.

Vidhya Ravindranadan and Raju, S. 2007. 'Adjustment and Attitude of parents of Children with mental retardness', *Journal of the Indian Academy of Applied Psychology*, 33, (1), 137-141.

Wallander, Jan L., Lisa C. Pitt, and Claude A. Mellins. 1990. 'Child Functional Independence and Maternal Psychosocial Stress as Risk Factors Threatening Adaptation in Mothers of Physically or Sensorial Handicapped Children', *Journal of Consulting and Clinical Psychology* 58,(6), 818.

Warfield, M. E. 2001. 'Employment, Parenting and well-being among Mothers of Children with Disabilities', *Mental Retardation*, 39(4), 297-309.

Wills, T. A. 1981. 'Downward Comparison Principles in Social Psychology', *Psychological Bulletin*, 90, 245-271.

Witkin, S. L. 2001. 'The Measure of Things', *Social Work*, 46(2), 101-104.

Woolfson, L. 2004. 'Family well-being and Disabled Children: a Psychosocial Model of Disability related Child Behaviour Problems', *British Journal of Health Psychology*, 9(1), 1-13.

World Bank, 2012. Gender Equality and Development, World Development Report, World Bank, Washington D.C.

World Health Organization 2001. 'International Classification of Functioning', *Disability and Health (ICF)*, Geneva: World Health Organization.

Wright, B.A. 1960. *Physical Disability: A Psychological Approach*, New York: Harper and Row.

Wrubel, J., Benner, P., & Lazarus, R. S. 1981. Social Competence from the Perspective of Stress and Coping. In J. D. Wine & M. D. Smye (Eds.), *Social Competence*, New York: Guilford Press.

Zeisler, Laurel, 2011. Association between Stress and Decisional Procrastination in Parents of Children with Down syndrome during Their Developmental Transitions, Dissertations. Paper 1361.

Zuk. G.K. 1962. The Cultural Dilemma and Spiritual Crises of the Family with a Handicapped Child, Exceptional Children.

Table 1: Personal profile of the Respondent

Particulars	No. of respondents	Percentage
Gender of the respondents		
Male (Father)	44	27.5
Female (Mother)	116	72.5
Age (in years)		
25-29	16	10.0
30-34	44	27.5
35-39	27	16.8
40-44	32	20.0
45-49	21	13.1
50-54	10	6.3
55 and above	10	6.3
Mean		39.0
S.D		8.2
Religion		
Hindu	106	66.2
Christian	52	32.5
Muslim	2	1.3
Caste		
Forward Caste(FC)	14	8.7
Backward Caste(BC)	13	8.3
Most Backward Caste(MBC)	27	16.8
Other Backward Caste(OBC)	49	30.6
Scheduled community(SC)	57	35.6
Educational Level		
Illiterate	10	6.2
Literate	16	10.0
Primary	24	15.0
Middle	42	26.2
High school	27	16.9
Higher Secondary	23	14.4
Diploma	6	3.8
Graduation	12	7.5
Marital Status		
Married	141	88.1
Others(W/D/S)	19	11.9
Total	160	100

Table 2: Socio Economic Status

Socio Economic Status	No. of respondents	Percentage
Monthly Income		
Below 10,000	127	79.4
10,001-30,000	31	19.6
Above 30,001	2	1.2
Mean		9.219
Ownership of House		
Own	105	65.6
Rental	53	33.1
Lease	2	1.2
Type of House		
Thatched	86	53.8
Tiled	45	28.1
Terrace	29	18.1
Type of family		
Nuclear family	140	87.5
Joint family	20	12.5
Migration		
No	91	56.9
Yes	69	43.1
Reason for Migration		
For marriage	32	20
For getting a job	9	5.6
For education	26	16.2
Husband service	2	1.2
Savings for disabled child		
Not available	91	56.9
Available	69	43.1
Purpose of Savings		
For medical treatment	10	6.2
For emergency	5	3.1
For future	43	26.9
Total	160	100

Table 3: Profile of the Disabled child

Profile of the Disabled child	No. of respondents	Percentage
Gender		
Male	105	65.6
Female	55	34.4
Age (in years)		
Below 5	28	17.5
6-10	63	39.4
11-14	69	43.1
Mean		9.53
S.D		3.8
Type of School		
Normal School	54	33.8
Special School	83	51.9
Early Intervention Centre	23	14.1
Birth Order		
One	70	43.8
Two	64	40.0
Three	18	11.2
Four	4	2.5
Five	4	2.5
Type of Disability		
Physically Impaired	22	13.8
Visually Impaired	12	7.4
Mentally Challenged	54	33.8
Deaf & Dumb	26	16.2
Cerebral Palsy	16	10.0
Down syndrome	6	3.8
Autism	5	3.1
Multiple Disabilities	11	6.9
Delayed milestones	8	5.0
Total	160	100

Table 4: Case History of differently abled child

Case History of differently abled child	No. of respondents	Percentage
Father's age at marriage		
Below 20	11	6.9
21-30	133	83.1
31-40	16	10.0
Mean	26.53	
S.D	3.5	
Mother's age at marriage		
16-20	60	37.5
21-25	81	50.6
26-30	19	11.9
Mean	21.6	
S.D	3.0	
Spouse Relationship		
No	102	63.8
Yes	58	36.2
Exact Relationship		
Mother side	27	16.9
Father side	16	10.0
Both	15	9.4
History of disability in last three generations		
No	136	85.0
Yes	24	15.0
Generations details		
Having Polio	2	1.2
Handicapped	4	2.5
Others	18	11.2
Total	160	100

Table 5: Gestation and delivery

Gestation and delivery	No. of respondents	Percentage
Problem during pregnancy		
No	98	61.2
Yes	62	38.8
Age of the Mother during disabled child delivery		
Below 20	4	2.5
21-30	104	65.0
31-40	52	32.5
Mean		27.8
S.D		5.2
Completion of full term		
No	40	25.0
Yes	120	75.0
Nature of delivery		
Normal	92	57.5
Caesarean	56	35.0
Forceps	12	7.5
Place of delivery		
Home delivery	5	3.1
Private hospital	48	30.0
Govt. hospital	107	66.9
Total	160	100

Table 6: Treatment History

Treatment History	No. of respondents	Percentage
Causes for child's disability		
Delayed pregnancy	41	25.6
Consanguine marriage	27	16.9
Improper care during pregnancy time	32	20.0
Delayed delivery	11	6.9
Early marriage	6	3.8
Genetics problem	8	5.0
Mother's physical problem	22	13.8
Family problem	4	2.5
pre matured birth	9	5.6
Taking treatment		
No	13	8.1
Yes	147	91.9
Place of treatment		
Govt hospital	90	56.2
Private hospital	57	35.6
System of treatment		
Allopathic	118	73.8
Ayurvedic	2	1.2
Sidha	2	1.2
Homeopathy	2	1.2
Other	23	14.4
Common diseases		
Severe cold	8	5.0
Fever	18	11.2
Fits	23	14.4
Other	3	1.9
Total	160	100

Table 7: Institutional support for differently abled children

Institutional support	No. of respondents	Percentage
Avail Govt Scholarship		
Not avail	55	34.4
Avail	105	65.6
Nature of Scholarship		
Maintenance grant(1000/-pm)	80	50.0
For education	20	12.5
Wheel chair	1	0.6
Hearing aid	4	2.5
Know about scholarship		
Through media	2	1.2
Through the authorities of school	110	68.8
Through friends	18	11.2
Welfare organisation	8	5.0
any other	22	13.8
Bus concession		
Not avail	80	50.0
Avail	80	50.0
Railway concession		
Not avail	78	48.8
Avail	82	51.2
Assistance from NGO's		
Not avail	124	77.5
Avail	36	22.5
Total	160	100

Table 9: Financial support received within household by background factors

Background factors	FS 1	FS 2	FS 3
Gender			
Male	11(26.2%)	10(23.8%)	10(23.8%)
Female	31(26.3%)	32(27.1%)	39(33.1%)
Parents Age (in years)			
upto 39years	23(26.4%)	24(27.6%)	31(35.6%)
40years and above	19(26%)	18(24.7%)	18(24.7%)
Parents educational level			
Primary and middle	26(21.8%)	23(19.3%)	30(25.2%)
Higher secondary and above	16(39%)	19(46.3%)	19(46.3%)
Parents occupation			
Employed	19(25.3%)	16(21.3%)	16(21.3%)
Not employed	23(27.1%)	26(30.6%)	33(38.3%)
Monthly Income in Rupees			
Below 10,000	28(22%)	35(37.6%)	37(29.1%)
10,001 to 30,000	12(38.7%)	5(16.1%)	10(32.3%)
Type of family			
Nuclear	32(22.9%)	32(22.9%)	39(27.9%)
Joint	10(50%)	10(50%)	10(50%)
Nativity status			
Migrant	17(24.6%)	17(24.6%)	23(33.3%)
Non migrant	25(27.5%)	25(27.5%)	26(28.6%)
No. of children			
Upto Two	29(33%)	28(31.8%)	34(38.6%)
Three and above	13(18.1%)	14(19.4%)	15(20.8%)
Savings			
Available	17(29.3%)	20(34.5%)	20(34.5%)
Not available	25(24.5%)	22(21.6%)	29(28.4%)
Debts			
Debted	14(18.2%)	16(20.8%)	28(36.4%)
Not debted	28(33.7%)	26(31.3%)	21(25.3%)

N=160

Table 10: Informational support received within household by background factors

Background factors	IS 1	IS 2	IS 3
Gender of caretakers			
Male	4(9.5%)	0	5(11.9%)
Female	8(6.8%)	3(2.5%)	8(6.8%)
Parents Age			
39years (in years)	4(4.6%)	6(6.9%)	13(14.9%)
40years and above	8(11%)	7(9.6%)	5(6.8%)
Parents educational level			
Primary and middle	6(5%)	7(5.9%)	15(12.6%)
Higher secondary and above	5(14.6%)	6(14.6%)	38(92.7%)
Parents occupation			
Employed	4(5.3%)	0	8(10.7%)
Not employed	8(9.4%)	3(3.5%)	5(5.9%)
Monthly Income in Rupees			
upto 10,000	8(6.3%)	0	10(7.9%)
10,001 to 30,000	4(12.9%)	3(9.7%)	3(9.7%)
Type of family			
Nuclear	10(7.1%)	10(7.1%)	15(10.7%)
Joint	2(10%)	3(15%)	3(15%)
Nativity status			
Migrant	4(5.8%)	3(4.3%)	5(8.6%)
Non migrant	8(8.8%)	0	8(7.8%)
No. of children			
Upto Two	6(6.8%)	2(2.3%)	7(8%)
Three and above	6(8.3%)	1(1.4%)	6(8.3%)
Savings			
available	2(3.4%)	3(5.2%)	5(8.6%)
Not available	10(9.8%)	0	8(7.8%)
Debts			
Debted	8(10.4%)	0	3(3.9%)
Not debted	4(4.8%)	3(3.6%)	10(12%)

N=160

Table 11: Service support received within household by background factors

Background factors	SER 1	SER 2	SER 3	SER 4
Gender				
Male	35(83.3%)	37(88.1%)	23(54.8%)	18(42.9%)
Female	78(66.1%)	100(87.7%)	88(74.6%)	93(78.8%)
Parents Age (in year)				
upto 39years	63(72.4%)	75(86.2%)	61(70.1%)	65(74.7%)
40years and above	50(68.5%)	62(84.9%)	50(68.5%)	46(63%)
Parents educational level				
Primary and middle	86(72.3%)	100(84%)	82(68.9%)	80(67.2%)
Higher secondary and above	27(65.9%)	37(90.2%)	29(70.7%)	31(75.6%)
Parents occupation				
Employed	54(72%)	62(82.7%)	42(56%)	43(57.3%)
Not employed	59(69.4%)	75(88.2%)	69(81.2%)	68(80%)
Monthly Income in Rupees				
Below 10,000	86(67.7%)	108(85%)	88(69.3%)	95(74.8%)
10,001 to 30,000	27(87.1%)	27(87.1%)	21(67.7%)	16(51.6%)
Type of family				
Nuclear	99(70.7%)	117(83.6%)	93(66.4%)	91(65%)
Joint	19(70%)	20(100%)	18(90%)	20(100%)
Nativity status				
Migrant	55(79.7%)	57(82.6%)	43(62.3%)	46(66.7%)
Non migrant	58(63.7%)	80(87.9%)	68(74.7%)	65(71.4%)
No. of children				
Upto two	64(72.7%)	79(89.8%)	62(70.5%)	63(71.6%)
Three and above	49(68.1%)	58(80.6%)	49(68.1%)	48(66.7%)
Savings				
available	42(72.4%)	43(74.1%)	36(62.1%)	33(56.9%)
Not available	71(69.6%)	94(92.2%)	75(73.5%)	78(76.5%)
Debts				
debted	45(58.4%)	62(80.5%)	58(75.3%)	61(79.2%)
Not debted	68(81.9%)	75(90.4%)	53(63.9%)	50(60.2%)
N=160				

Table 12: Companionship support received within household by background factors

Background factors	Com 1	Com 2	Com 3
Gender			
Male	27(64.3%)	39(92.9%)	42(100%)
Female	84(71.2%)	118(100%)	116(98.3%)
Parents Age (in years)			
upto 39years	65(74.7%)	84(96.6%)	85(97.7%)
40years and above	46(63%)	73(100%)	73(100%)
Parents educational level			
Primary and middle	87(73.1%)	116(97.5%)	117(98.3%)
Higher secondary and above	24(58.5%)	4(100%)	41(100%)
Parents occupation			
Employed	52(69.3%)	72(96%)	75(100%)
Not employed	59(69.4%)	85(100%)	83(97.6%)
Monthly Income in Rupees			
Below 10,000	88(69.3%)	127(100%)	125(98.4%)
10,001 to 30,000	23(74.2%)	28(90.3%)	31(100%)
Type of family			
Nuclear	95(67.9%)	13(97.9%)	138(98.6%)
Joint	16(80%)	20(100%)	20(100%)
Nativity status			
Migrant	54(78.3%)	69(100%)	67(97.1%)
Non migrant	57(62.6%)	88(96.7%)	91(100%)
No. of children			
Upto two	59(67%)	86(97.7%)	86(97.7%)
Three and above	52(72.2%)	71(98.6%)	72(100%)
Savings			
Available	37(63.8%)	58(100%)	58(100%)
Not available	74(72.5%)	99(97.1%)	100(98%)
Debts			
Debted	59(76.6%)	77(100%)	77(100%)
Not debted	52(62.7%)	80(96.4%)	81(97.6%)
N=160			

Case studies

Case: 1

In case A, the mother is handicapped due to polio but that hampers her household work. She gave birth to two sons and both of them have disability. The elder son has physical disability and younger son has physical disability along with slight mental disability. The spouse is an auto driver and her mother in law always curses the mother and her sons and also insists her husband to leave his children and wife and get married to another person. But the auto driver gives special attention to his wife and children. The father states that “everybody in my extended family blames me for marrying a polio affected woman. They do not understand my sacrifices in terms of money and time spent for my two sons and ridicules my love for my sons. They keep pestering me to abandon my wife, sons and remarry another girl. Since I am engaged in driving auto, I have to go for work whenever I am called. It is very difficult and sometimes unmanageable for me to do all the household errands like buying the necessary stuffs for the house and also do all the basic things for my two sons like giving them bath, making them eat etc. Hence I am under tremendous physical, mental and financial pressure which my extended family members and my mother do not understand”. One day when he was in an auto stand he saw a lady carrying a disabled child. He asked the lady where she wanted to go. She told that she wanted to go to the „Early Intervention Centre“. And while she was travelling the auto driver asked her the reason why she was carrying the child and where she is taking the child. The lady told that child has „Locomotor disability“ and that she is taking the child to the school specially meant for it. Then he enquired all details about the school and observed the children at school taking treatment. The auto driver later discussed it with his wife and decided to admit his younger son. The very next day his younger son was taken in to the school and necessary treatment and care was given. Now the auto driver is able to see a lot of changes in his son. Now he is happy to see his son’s improvement and also the benefits that the government has given him.

Case: 2

In case B, the father is a coolie aged 38 years and mother is a home maker aged 35 years with 3 children. The third among the children is mentally affected. The mother reported that it happened because of their mistake. After giving birth to first two children, they did not take precautionary steps and later the lady was pregnant. Due to their economic situation, they wanted to abort the child, and hence went for an undesirable kit. But it was no use and she gave birth to a mentally abled child. Now the child is 8 years old and is kept at home. The child often says that he is not able to play with their neighbour for they ignore him because of his illness. They also keep calling him „mental“. When they put him into the normal school he was kept aside by both the teachers as well as his friends. He was in such school only for 3 months and then they came to know about that special school through collector office. Then he was put in special school. Now he is comfortable and also there is improvement in his behaviour. He adheres to the instruction of parents and teachers. Further, the behavioral change is attributed predominantly to the teachers by the parents. As a result, he learnt the social skills such as values, norms and ethics through which he controls the self. He is also benefitted by the government support. The mother also feels that she is not able to take care of the other two children properly both regarding their health and studies. Because the child is totally dependent, the mother also has fear about the child future and does not take him out anywhere, fearing about the society. The boy is also supported through bus and train concession which he uses to travel to school.

The child's mother narrates that „when my son was admitted in normal school, his class mates observed that he was not only a slow learner but also abnormal mentally. My heart throbbed with pain when my son's class mates called him „mental“. Since my son was not able to cope to the normal school environment, he was shifted to the special school. We admitted our son to that school and now I feel that slowly and steadily he is able to adjust to the environment and is learning to read, write and do arithmetic with enthusiasm.

Case: 3

In this case, the boy is of multiple disorders. He is 5 years old; he has this problem right from his birth. His mother is 26 years old and his father passed away in a fatal accident after 3 days of his birth. The child's mother has passed higher secondary level of education not employed. The child's maternal uncle is a degree holder and is the only earning member of the family. There is no support from the side of her husband's family, for they think that the child is the cause for his father's death. They also think that the child is the curse for their family. On the other side, her relatives force her to leave the child in any of the orphanage, and ask her to get wedded to another person. But she is determined to live only for her child. But the child's mother states that "I live only for my child. I have accepted the fact that my child might have to live out his life in a special setting. He is totally immobile. If I get married and go away, who will take the responsibility of him? Therefore I cannot think of remarriage". Further the child's mother said that "Although I usually avoid taking my child out because of his health condition. Once I had to take him to a doctor and get medicines, on the way, I met one of my school friend who explained to me about the special school and the benefits given to disabled children and I had admitted my son after enquiring in my place". Now she is safe and secure about their child's life and also that she is able to see some improvement in his health such as fixing direct eye contact, growth of bones and improvement muscular motion. They also give training for providing proper care. This training helps her to take better care about the child at home. After seeing the improvement in the child, now the mother is able to take the child happily outside without any hesitation. Now she is getting financial support both from the government and her brother. Now she is able to face the challenges in bringing up the child.

Case: 4

Revathi is a 8 years old girl affected by mental disorder, who is the third child. The mother is aged 42 years and father aged 49 years. Father works as a manager in one of company. The child parents are close relatives and the child has two siblings, one sister and one brother. Both of them were physically handicapped. Her sister used wheel chair while her brother just used a walking stick. But at the age of 18 both of them passed away suddenly. After many years, this girl was born. Both their parents were happy with the child. But in the beginning they were not aware of the disorder. In due course of time, the parents found that their child was not active when compared to other children. Once they came to know about the disability of the child they went for medical treatment. But it was of no use. Then the doctor suggested them to take their child to the special school. The child's mother spends most of the time only with girl for she fears losing this child also she never spends time either with her husband or in any functions. The child's mother states that "My child doesn't know her address, she is not aware of whom she is, what is her name, and she cannot even talk properly. I am getting old and I don't know how I am going to manage with her. She is just 8years old and she has a long way to go. She is a girl child and after me and my husband, I don't know who will take care of her. A girl child needs more care, protection and financial support. We have no problems with our financial abilities, but our only problem is that we are growing old and she is quite young". Now after getting in to the school the parents are able to see the changes in the girl. They also feel that the teachers are very supportive and co-operative with them and the child. Those they do not get financial support from their family members, they support the child in an emotional way. This is because they think that it is their mistake of getting them married among blood relations.

Case: 5

Nisha is 9 years old. She has a disease that has made her bones very weak and hence is not physically grown like other children. She is very short for her age and cannot walk or stand on her own. She cannot go to the toilet on her own either. However she is very clever. She has good coordination in her hands and she has a lively personality. Nisha has just started school. She lives near the local school and every day her grandmother or her sister carries her on their backs to school. In class Nisha sits at the front so that she can see the board easily. She is too small to sit at the usual desks, she also needs some support for her back, so she sits in a special chair and table which. The school provided Nisha is very good at maths and all her schoolwork is neat. She loves to learn. If she wants to go to the toilet she asks her teacher to help. In the breaks between the lessons Nisha's friends carry her outside the classroom. She can't run about like them but they usually include her in their games. Before Nisha started school, the teachers were apprehensive. They were worried how the other children would treat Nisha, so they spoke to the whole school and told all the children about Nisha. After that no one teased her. She is dependent on others for her work and she is supported by her family members. Nisha's grandmother narrates her everyday experiences "She is very bright child. Although she is totally paralyzed from neck to toes and she needs help to eat, drink and go to toilet. Her grasping power and understanding maths is remarkable. She is just 9years old but she solves the basic arithmetic problems as quick as her classmates. Her classmates and teacher are a real gift to her. They encourage, motivate and help her emotionally and physically. They are the reason for her the development of her academic and social skills. I take Nisha with her sister to school every day and bring her back. She is a very cooperative child" reports her grandmother.

Case: 6

Kandhan aged 15 years old studying in 8th standard has weakness in both Legs and has a minor M.R. (Mental Retardation). He is the last child for his parents. He has 3 elder sisters and two brothers. The brothers are engaged in fishing. Before enrolling in rehabilitation centre he was not able to communicate himself verbally and cannot walk properly. He used to get assistance from his brother whenever he went to school. In the school the peers teased him and he said he was hurt very much. This made him to be away from class for several days. His parents thought that he should be cured so they took him to private and Government hospitals a number of times but he was not cured despite spending much money. Therefore his parents lost interest and left him as he was. The district rehabilitation centre visited his village and identified him. Seeing his physical and mental disorder they took him to the Psychiatrist and the Physician for physio therapy and detected the level of mental disorder. The parents of the child stated that “He is the last son for us and all his elder siblings do not care for kandhan emotionally and financially. They think he is „not worth spending”. We somehow pooled in money for his nervous weakness treatment and took him to various government hospitals many times, but all those efforts was of no use. We were completely dejected emotionally and financially. But finally we got a ray of hope when the district rehabilitation centre visited our village and assured us that he can be cured. The financial support that we get from government of Tamilnadu to take care of his educational and medical needs is a boon to us. After getting him admitted to special school, his reading, writing and communication skills have improved and we are happy about it.

Case: 7

Kavitha, an 11 year old girl with cerebral palsy from birth, lives with her parents and siblings in rural area. The family's economic and social condition is very poor. Her father is an alcoholic and spends all his money on alcohol and it is impossible for her mother to maintain her family all alone as they are not financially well off. Her older brother tried to help the family through agricultural work, but this was not enough for meeting family expenses, especially Kavitha's special needs and the situation left her joyless and her only entertainment was TV. Through rehabilitation centre Kavitha and her family were assessed by teacher and an occupational therapist. Kavitha received simple treatment for mental and physical development like pencils, crayons, sticks for learning mathematics and colorful geometric toys and also books. The teacher and therapist worked intensively with the child, as a result, she has made great progress in reading and understanding and is even able to tell time. Her sensory motor and soft motor skills are improved. She is motivated for education and does her homework. She is creative with her clay and drawing. Kavitha's overall mental development shows a positive sign for her family members. With the support of the rehabilitation now her family receives subsistence allowance and free healthcare. Her socialization skills have improved significantly and she has made a lot of friends in school.

Case: 8

Ramesh is 9 years old. He is in his first year at a primary school. He is the best student in his class even though he is blind. He lost his sight in an accident at home when he was 7 years old. Before the accident he went to primary school and was one of the cleverest students. After the accident he stayed at home, his parents didn't know how to help him. They heard about the special school through another blind children parent. They took Ramesh to the school and he started studying there. At the special school, Ramesh learned Braille a system where letters are represented by bumps made in paper using a simple slate. Ramesh learned Braille quickly, and because he was clever he could remember nearly everything he had learned before his accident. In class Ramesh sits in the front so he can clearly hear the teacher. Ramesh has developed an excellent memory to compensate for his lack of sight. Another boy, Ramesh's friend helps him. The school textbooks have not been translated into Braille so his friend reads clearly to Ramesh. The teachers also adapt teaching aids to help Ramesh. Outside of class, the other children help Ramesh to make sure he doesn't fall down when moving around the school. They have also learned that it is important for them to touch him gently when they start to speak to him and to say their name. If they do this, Ramesh knows who is talking to him and he can look at them. When Ramesh finishes school he wants to be a teacher, so he can help other blind children. His mother narrates that "Ramesh was not born blind. He just lost his vision in an accident unfortunately. Since he is a normal child with just visual impairment, his learning process in school is as same as other children. He has learnt the Braille script and manages his schools quite well without my help. His friends are quite helpful and help to escort him to some place within school or other places. With his incredible memory Ramesh learns his lessons by rote.

**PARENTAL PROBLEMS, CARE DEMANDS AND SUPPORT
SYSTEMS FOR PARENTS OF DIFFERENTLY ABLED
CHILDREN**

Interview Schedule

NAME OF THE RESPONDENT:

I. Personal Profile of the Parent

1. Respondent Id :
2. Relationship of the respondent to the disabled child :
3. Age :
4. Religion : Hindu/Christian/Muslim/Others
5. Caste :
6. Educational Qualification :
7. Occupation :
8. Marital Status :

II. Household Particulars

Relationship to the Respondent	Age	Sex	Marital Status	Education	Occupation	Income (per month)

9. Details of family members staying outside-----

III. Socio-Economic Details

1. Ownership of house : Own/Rental/Lease
 - 2.1 No of rooms in your house?
 - 2.2 Do you have any separate room for your disabled child?
2. What type of house are you staying now:
Hut/Thatched/Tiled/Terrace/Other specify
3. Place of Birth/Native place :
4. Did your family migrate to this place : Yes/No
 - 4.1 If yes, Reason for migration :
 - 4.2 Duration of staying-----
5. Do you have any savings for you? Yes/No
 - 5.1 If yes, a) purpose of savings-----
6. Do you have any savings for your disabled children? Yes/No
 - 6.1 if yes, how much-----
 - 6.2 purpose of savings-----
7. Do you currently have any debts? Yes/No
 - 7.1 If yes, source of money borrowed from: Money lender/relations/others
Specify
 - 7.2 If yes, how much?
 - 7.3 If yes, for what purpose?

IV. Case History of Differently Abled Children

Family History

- 1 Age of the Father and Mother at marriage:
Father's age:
Mother's age:
- 2 Is your spouse related to you? Yes/No

2.1 If Yes exact relationships-----

(Also mention the details of relationship)

3 Whether the family had history of disability in the last 3 generations?

Yes/No

3.1 If yes, give details-----

Gestation and Delivery

4 Age of the mother during the first delivery-----

5 Was the child delivered on completion of full term? Yes/No

5.1 If No, when?

6 Nature of delivery: Normal/Caesarean/Forceps

7 Place of birth: Home delivery/Private/Govt

8 Did the mother of disabled child have any problem during pregnancy?

Yes/No

8.1 If yes, give the details-----

9 What was the age of mother when the disabled child was delivered?

10 Did the child undergo any treatment soon after birth? Yes/No

10.1 If yes, when?

10.2 If yes how long?

10.3 If yes why?

11 Type of disability:

12 Was the condition known to you at birth? Yes/No

12.1 If yes, how the disability detected?

12.2 If yes, who first told you about your child's condition?

12.3 If no, how old was your child when you realised he/she had a disability?

13 Nature of disability: congenital/acquired/accidental/others

14 What is the birth order of the disabled child?

Treatment History

15 What are the causes, according to you, of your child's disability?

16 On identification that the child was disabled, did the child undergo any special type of treatment? Yes/No

16.1 If yes, Place of treatment : Govt/Private

17 Which system of treatment?

Allopathic/Ayurveda/Sidha/Homeopathy/Other -----

18 Does your child have any other common diseases?

V. Social Skills of the Child

Social Skills	Always	Some Times	Never
<p>Self-Control</p> <ol style="list-style-type: none">1. Follows your instructions2. Controls temper with other Children3. Controls temper with parents4. Avoids situations that are likely to results in Trouble <p>Co-operation</p> <ol style="list-style-type: none">5. Helps you with household tasks without being Asked6. Keeps clean and neat without being Reminded7. Replaces toys or other household things in place8. Communicates problems <p>Assertion</p> <ol style="list-style-type: none">9. Invites others to your home10. Makes friends easily11. Receives criticism well12. Introduces herself or himself to new people without being told13. Starts conversation rather than waiting for others to talk first.14. Shows interest in a variety of things			

VI. Social Behaviour of the Child

Social Behaviur	Always	Sometimes	Never
<p>I. Disruptive</p> <p>Lies</p> <p>Disobedient</p> <p>Kicks, hits others</p> <p>Impatient</p> <p>Jealous</p> <p>Whines a lot</p> <p>Says things not capable of</p> <p>Easily led by others</p> <p>Talks too much</p> <p>Rapid mood changes</p> <p>Throws or breaks objects</p> <p>Refuses to go to school</p> <p>Noisy</p> <p>II. Self-Absorbed</p> <p>Bites others</p> <p>Hits or bites self</p> <p>Repetitive activity</p> <p>Bangs head</p> <p>Urinates outside toilet</p> <p>Laughs for no reason</p> <p>Strips off clothes</p>			

<p>Aloof, in own world</p> <p>Unusual body movements</p> <p>III. Communication Disturbance</p> <p>Talks to self or imaginary others</p> <p>Unusual tone or rhythm</p> <p>Doesn't mix with own age-group</p> <p>Preoccupied with one or two</p> <p>IV. Anxiety</p> <p>Distressed when separated</p> <p>Cries for no reason</p> <p>No response to others</p> <p>Doesn't show affection</p> <p>Depressed, unhappy</p> <p>Plays with Unusual objects</p>			
--	--	--	--

VII. CARE DEMANDS

CARE DEMANDS	YES	NO
<ol style="list-style-type: none"> 1. My child cannot take a ride in a bus independently. 2. I have accepted the fact that my child might have to live out his/her life in some special setting. 3. My child can't pay attention very long. 4. It is not easy to communicate with my child. 5. It is difficult to communicate with my child because he/she has difficulty understanding what is being said to him/her. 6. I feel tense when I take my child out in public. 7. My child cannot remember what he/she says from one moment to the next. 8. My child isn't able to take part in games or sports. 9. My child doesn't communicate with others of his/her age group. 10. My child is not able to express his/her feelings to others. 11. My child is not able to go to the bathroom alone. 12. My child doesn't know his/her address. 13. His/ Her confidence is not one of the things I appreciate about my child. 14. My child isn't aware of who he/she 15. My child can't feed himself/herself. 16. My child cannot walk without help. 17. The constant demands for care of my child limit growth and development of someone else in our family. 18. Other members of the family have to do without things because of him/ her. 19. My child is unable to fit into the family social group. 		

<p>20. Taking my child on vacation spoils the pleasure for the whole family.</p> <p>21. I worry about what will be done with my child when he/she gets older.</p> <p>22. I am disappointed that my child does not lead a normal life.</p> <p>23. I feel sad when I think about my child.</p> <p>24. People can't understand what my child tries to say.</p> <p>25. It bothers me that my child will always be this way.</p> <p>26. My child is over-protected.</p> <p>27. Sometimes I feel very embarrassed because of my child.</p> <p>28. I get upset with the way my life is going.</p> <p>29. Sometimes I avoid taking my child out in public.</p> <p>30. My child will always be a problem to us.</p> <p>31. It isn't easy for me to relax.</p> <p>32. Caring for my child puts a strain on me.</p> <p>33. I get almost too tired to enjoy myself.</p> <p>34. I can't go visit friends whenever I want.</p>		
--	--	--

VIII. Parental Problems

1. Do you feel inferior to others since you have a disabled child? Yes/No/
2. Did you have any financial difficulty due to your disabled child? Yes/No/
3. What are the main problems you had to face because of financial limitations?
 1. Cut down the basic needs of the family
 2. Forgot the education of other children
 3. Limit all kinds of social activities of the family
 4. Any other
 5. Not applicable

4. What are the ways you opted for meeting the extra expenses?
 1. Lending through local money lenders
 2. Pawning gold ornaments
 3. Selling property
 4. Mortgaging land, etc
 5. Any other
 6. Not applicable

5. When you had to stay with the child, in the hospital for treatment who took charge of your family?
 1. Your parents
 2. Your in-laws
 3. Spouse and elder children
 4. Other relatives
 5. Neighbour
 6. Any other
 7. Not applicable

6. If you are a employee how often do you
 1. Take leave
 2. Take time off/Permission
 3. Sacrifice promotions, training etc
 4. Arrange someone to take care
 5. Any other
 6. Not applicable

7. Did you have to resign your job due to your child's disability? Yes/No

8. Do others blame you for your child's disability? Yes/No
 - 8.1 If yes why?-----

9. Do you feel guilty that you are not able to do your other duties like	Agree 1	Disagree 2	N.A 3
1. Looking after the other children 2. Looking after the spouse 3. Supervising the studies of other children 4. Looking after the needs of family in general 5. Participating in family functions			

10 Do you feel your family has an understanding attitude towards the disabled child?
Yes/No

11 Where will you take this child along with you?

All places/some places/Not at all

11.1 If All places-----

11.2 If some places a) where?

b) Why?

12 Did you ever receive any training on management of the child?

Yes/No

a. If yes, give details of the training-----

b. How are you able to manage after the training?

13 How did the family members treat the child?

As others/Not taking so much
care/Neglected

Specify-----

14 Where do you think your child is discriminated?

At home/at school/at play/at community/at
society

Specify-----

IX. Support Services

Support Services	Family members	Relatives	Neighbors	Co-workers	Friends	Others
<p>Emotional support</p> <p>Who give assurance whenever you are uncertain about your child's future?</p> <p>Who help you to come out of crisis situations related to your</p>						

<p>child?</p> <p>Who console you whenever you are in depressed and gripped in various problems of your child?</p> <p>Who will listen and enquire all your personal problems?</p> <p>Who give a word of assurance that he/she will make himself or herself present in your child's emergency situations?</p> <p>Who express concern on you and your child?</p> <p>Who provide emotional aid whenever your personal/ family problems remain a major one?</p> <p>Who give emotional soothing and enable you to feel comfortable with?</p> <p>Who encourage and enable you to take care of the disabled child?</p> <p>Financial support</p> <p>Whenever you are in need of large amount of money for your child's medical expense/related expense/edu/Aid/Recreation whom you will seek the help?</p> <p>Whenever you are in need of petty expenses regarding your child, whom will you seek for help?</p> <p>If you are facing an unexpected expenditure who helps you financially?</p> <p>Informational support& Services</p> <p>Who provides the information on schooling and other official matters regarding your child?</p> <p>Who helps you to get the information on your child's medical care?</p>						
---	--	--	--	--	--	--

Who gives the information on govt aid regarding the disabled child?						
Who come and stay with you for security whenever there is necessity for your disabled child?						
Who render services when you take your child to all places you go?						
If there is a need to pick & drop your child at school who provides help?						
When you need to take your child to the hospital who accompanies you?						
Companionship support						
Who accompanies when you take your child to outing?						
Who accompanies when you take your child to attend functions and ceremonies?						
Who accompany with you and your child when you visit various institutions or offices?						

Institutional support for differently abled children

1. Do you get any government scholarship or assistance? Yes/No
 - 1.1. If yes, what scholarship?
 - 1.1. If yes, how much?
 - 1.1. Whether it is sufficient?
 - 1.2. If no, what was the reason?
 - 1.2.1 Not aware of the facility
 - 1.2.2 High income limit
 - 1.2.3 Nobody to take initiative
 - 1.2.4 Any other

2. How regular is the scholarship?
 - 2.1 Have been getting every year
 - 2.2 Not getting it for the last two years
 - 2.3 Gets intermittently
 - 2.4 Others

3. How did you come to know about the government scholarship?
 - 3.1 Through media
 - 3.2 through the authorities of school
 - 3.3 through friends
 - 3.4 Welfare organization
 - 3.5 Any other

4. How did you purchase the required aid in the absence of financial assistance?
 - 4.1 through money lender
 - 4.2 Bank loan
 - 4.3 Raised money through friends and relatives
 - 4.4 Any other

5. Is your child getting bus concession for travelling locally? Yes/No
 - 5.1 If yes, amount-----
 - 5.2 If no why?
 - 5.2.1 Disability is minimum
 - 5.2.2 Difficulty in getting the formalities done
 - 5.2.3 Not aware of the facility
 - 5.2.1 Any other

6. Is your child getting railway concession for travelling long distances?
Yes/No
 - 6.1 If yes, amount-----
 - 6.2 If no, what is the reason?
 - 6.2.1 Do not travel long distance
 - 6.2.2 Not aware of the facility
 - 6.2.3 Nobody to escort

6.2.4 Any other

7. Do you avail any assistance from NGO's? Yes/No

7.1 If Yes, what and how?

7.2 If No, why?

Awareness of Child Rights

1. Are you aware of the disabled basic rights as other citizens? Yes/No

2. Are you aware of the right to Education for disabled? Yes/No

- For ex Government is providing free special education, free boarding and lodging for the disabled and also providing aids and appliances for the disabled, such as tricycles, hearing aids, folding sticks, goggles etc.

3. Are you aware of the right to economic security for disabled? Yes/No

- For ex Government is providing various training for the disabled like chalk piece making, weaving, computer training, book binding etc.

- If yes, what? Have they utilized?

4. Are you aware of the right to protection from exploitation for disabled?
Yes/No