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 93 million 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, Rosenauum, 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.