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 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 (Gottleib, 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 abed children’s difficulty such as needing a special setting or difficulties in communication are situations during which parents became pressurized. In addition the demands became 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 Dalé 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 cyclcical 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.