Introduction

“Intellectual disability (mental retardation) is defined as a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e., cognitive, language, motor and social abilities. Retardation can occur with or without any other mental or physical condition” (WHO, 1992)

Some associated disabilities which may lead to intellectual disability are as follows:

- Autism: It is a mental disorder characterized by severely abnormal development of social interaction and verbal and nonverbal communication skills.
- Behaviour Problems: Children with intellectual disability may develop behaviour problems such as tantrums, damage public property, involve in destructive behaviour, may exhibit inappropriate sexual behaviour.
- Cerebral Palsy: Persons with intellectual disability can also have some degree of cerebral palsy which is caused by brain damage and cause permanent physical condition that affects movement.
- Spina Bifida: Some children with spina bifida may also lead to intellectual disability. It means the spinal cord has been damaged prior to birth however the damage or malformation depends on the extent of the damage. It can lead to paralysis in both legs of children,
- Down Syndrome: The Down’s syndrome or mongolism occurs in 1 out of every 700 births. It accounts for about 10 percent of moderate to severe mentally retarded children and commonest identifiable cause of intellectual disability. It is caused by the presence of an extra chromosome 21.

The birth of a child with a disability can have profound effects on the family. No parents want their child to be disabled and it is not an experience anyone expects to have. Rather it is a journey that is unplanned and the terrain that the families have to travel is often rough. When the parents learn that their child has a disability, they begin a journey that takes them into a life that is often filled progression and
pendulum of feelings such as strong emotions, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support. During the upbringing of a child with intellectual disability the caregivers have to face a large number of problems such as financial, emotional, marital, conflict with siblings, problems related to child’s behavior. Social support has been identified as a major protective factor in managing issues related to intellectual disability in the child and is also a contributor to quality life to them. Some of the families are able to find the needed strength within themselves and manage the issues related to their intellectually disabled child. Still there are times when they need outside support which they receive in two forms informal i.e. Family Support which includes awareness and availability of family members to manage the issues related to child with disability, impact on their intra family relations and their reactions to refusal) and formal i.e. State Support which includes services and schemes to protect their rights, awareness among the caregivers, their utilization and reasons if not utilization some of them. These support systems facilitate the families to adapt to and handle the stress and challenges that accompany their child’s disability.

Methodology represents an important part of research as it gives a outline to move towards the anticipated objectives of the study. The methodology adopted for the present study is primarily descriptive, interpretive and evaluative in nature. A sound methodology gives a exact direction to the researcher to find concrete result of the issues under investigation. This chapter gives a fair idea of the adopted research design, procedure adopted for sampling, statistical techniques used for analysis of collected data. It attempts mainly to study the socio-economic profile, support systems available, awareness level and problems of parents having children with intellectual disability in Chandigarh (India) and in Melbourne (Australia).In order to reach out to the given objectives of the study, the whole research was carried out as follows:

1. A structured interview schedule was designed for gathering details of the caregivers by conducting interviews of the parents who have a child with intellectual disability in Chandigarh city and in Melbourne city.
2. Secondary sources related to children with intellectual disability were also consulted to interpret and analysis the data.
3. To get the first hand account of issues related to primary caregivers and the family members of intellectually disabled children through interaction.

4. On the spot observations during field visit were also documented.

5. The data was codified, analyzed and interpreted.

The data for the present study was collected from primary sources through interview schedules. Whereas information on figures and services related to intellectual disability was gathered from secondary sources. In India it was collected from Census on Disability in India, National and International Reports on Disability and Planning Commission reports on Disability, Social Welfare Department, District Disability Rehabilitation Centre. Secondary sources. In Australia it was collected from Australian Bureau of Statistics, national reports and Department of Human Resources.

**Objectives**

The major objective of the study of the problems included socio economic demographic profile, level of awareness of disability and the available support systems among parents who have child with intellectual disability. A list of the specific objectives are:

1. To examine the socio-economic and demographic profile of the caregivers.

2. To study the level of awareness among the caregivers about the intellectual disability, in general and with specific reference to their with intellectually disabled child.

3. To examine the various problems faced by the caregivers having children with intellectual disability. (General problems- marital, social, emotional, financial, school and behavioral problems of the child with intellectual disability.)

4. To study the various Family and State support systems available in Chandigarh and Melbourne for children with intellectual disability. (The Family Support will include: Awareness of the family member on disability related issues of their child and their availability for help and impact of family support on caregivers, their intra family relations and their responses to refusal. The State Support will include: Awareness of state support services among the caregivers, their utilization and reasons if not utilizing some of them).

5. To highlight the scope for social work intervention in dealing with problems.
Universe

It included the primary care givers of the children with intellectual disability in Chandigarh and Melbourne. In order to contact the primary caregivers in both the cities, special schools were contacted through the concerned departments to obtain the lists of the children with intellectual disability and the caregivers contacted thereafter.

Sampling

For the purpose of the present study, a sample of 300 primary caregivers of children with intellectual disabilities, 150 from Melbourne and 150 from Chandigarh was drawn. These primary care givers included either of the spouses. Due to the complexity of nature of problem it was difficult to identify the caregivers. Thus it was thought essential to contact the special schools in both the cities for the purpose of obtaining complete addresses and contact information of the caregivers whose children between the age group of 5-18 years were studying in these special schools. For this purpose multistage simple random sampling method was applied.

In the first stage the lists of special schools in Melbourne (Northern and Western suburbs) and Chandigarh were obtained from the concerned departments i.e. Social Welfare Department, Chandigarh and Department of Education for the Special Schools Melbourne. The total number of schools in Chandigarh was six and the total number of schools in Melbourne (Northern and Western suburbs) was seventeen. Since in Chandigarh there were only six schools, in order to keep equal representation from both cities, in Melbourne too, only six schools were taken i.e. three each from northern and western suburb.

Likewise to draw a sample of 300 caregivers (150 Melbourne and 150 Chandigarh) a separate list of children’s contact information was prepared for each school. This exercise of preparation of list was done separately for each selected school from Melbourne and Chandigarh. Further after preparation of contact lists for each school, 25 children were selected from each selected school e.g. 25 x 6=150 from Chandigarh and 25 x 6 from Melbourne. The first child was drawn by lottery method and this exercise was repeated till the desired sample size from the selected school was not achieved in both the cities.

Once the list of selected sample of children was complete, their addresses and contact numbers were taken and the primary care givers were thus contacted. Some of the primary caregivers eagerly agreed to be a part of the sample, some had to be
persuaded, and there were few who did not want to participate, they were dropped and the next were selected following the same method of simple random sampling.

The findings cited below include socio demographic profile of caregivers of children with intellectual disability. Their reactions to initial diagnosis of their child’s disability, their awareness about issues related to intellectual disability in general and to their child with disability in specific. These also include problems faced by the caregivers due to their child’s disability and the social support in the form of family support (Informal) and state support (Formal)

Findings
Socio Economic and Demographic Profile
Type of Primary Caregiver
The analysis of the data indicated the number of primary caregivers of children with intellectual disability in various categories in Chandigarh and Melbourne. Data showed that in both cities all primary caregivers were mothers. City wise distribution showed that in Melbourne majority of caregivers (90 percent) were mothers and similar results were found in Chandigarh too, where all the responses (100 percent) were given by mothers (Major reason contributing to this response was, the cultural scenario, due to which mothers are considered the home makers and primary caregivers) Apart from this 10 percent fathers in Melbourne were the primary caregivers, since they were single parent families, hence the fathers were the primary caregivers. In both cities majority caregivers were mothers except for Melbourne where 10 percent caregivers were fathers that also being single parents.
Age
An interesting trend was observed in city wise distribution in both cities. In Chandigarh the number of caregivers in the age group of 25-35 years was higher (68 percent) than in Melbourne where it was 23.33 percent. Similarly in the age group of 35-45 years, the number of caregivers from Melbourne was higher (65.33 percent) than in Chandigarh, where it was only 26 percent. Even in the age groups of 45-55 years the number of caregivers in Melbourne was higher (11.33 percent) than Chandigarh (6.67 percent).
**Marital Status**

The analysis of the data on marital status of the primary caregivers showed that in both cities i.e. Melbourne and Chandigarh there were 82.66 percent caregivers living as married couple’s. City wise break up showed that in Chandigarh, the number of caregivers in the above category were higher (95.33 percent) than in Melbourne, where it was 70 percent. On the other side, the total number of caregivers in the category of separated/divorced was 12.33 percent which comprised of 23.33 percent in Melbourne and 1.33 percent in Chandigarh. The number of caregivers in the de-facto was only 3.33 percent in Melbourne. Lastly there were 3.33 percent caregivers each in Melbourne and Chandigarh were living as widow/widower. The trends showed that Chandigarh had higher number of primary caregivers living as married couple.

**Education**

The data on education of the primary caregivers in both cities showed some interesting trends. More than half of the caregivers (56.33 percent) in both cities were undergraduates. Apart from this, the comparison between the two cities in the category of postgraduate and diploma or certificate holders showed differences too. Chandigarh had a higher number (23.33 percent) of caregivers who were postgraduates, as compared to Melbourne, which had only 3.33 percent. Similarly there were 38.67 percent caregivers as diploma or certificate holders category and only 2 percent in Chandigarh. The data further showed that in Chandigarh 11.33 percent caregivers were educated up to matric and 8.67 percent caregivers were educated up to primary, whereas in Melbourne there were none in the above categories. The interesting trend that could be noticed in this was that in Melbourne there were a higher number of caregivers who were either undergraduate or diploma/certificate holder and in Chandigarh a higher number of caregivers were either undergraduate, post graduate and with small number in primary, matric and diploma/certificate.

**Total Family Income (Per Month)**

The analysis showed that in Melbourne nearly half (50 percent) of caregivers had income between $1000-3000, however there were (38 percent) caregivers who had income below $3000-6000 followed by 12 percent caregivers who had income between $6000- 8000. Whereas in Chandigarh nearly 26.66 percent caregivers had a income between Rs.15,000-30,000 and nearly half (50.66 percent) caregivers had
family income between Rs.30,000-45,000 followed by 22.6 percent caregivers who had a family income between Rs.45,000-60,000.

Religion

Analyses of the religion-wise distribution of the caregivers who had children with intellectual disability showed that in Melbourne more than four fifth (81.33 percent) of the caregivers were Christian’s (Census 2011 in Australia showed that in Melbourne, Christianity is the most dominant religious group) whereas in Chandigarh majority of caregivers i.e. 63.33 percent were Hindus (Census of 2011, on religion wise analysis depicts that Hindus are the most dominant religious group living in Chandigarh with a population of nearly 75 percent followed by Sikhs and other religions). Further breakup of the data showed that there was only one respondent in Melbourne who was Sikh, whereas in Chandigarh 27.33 percent caregivers were Sikhs. Some very obvious trends found were that majority of caregivers in Melbourne were Christians and in Chandigarh maximum caregivers belonged to Hindu religion.

Family Type

The distribution of caregivers reflected a higher number of nuclear family setups in both the cities, with 78.67 percent of them living as a nuclear family. City wise distribution showed that Melbourne had a higher number of caregivers (90.67 percent) living as nuclear families as compared to Chandigarh, which had 66.67 percent. The data also revealed that in Chandigarh there were few (27.33 percent) caregivers who were living in a joint family too, whereas in Melbourne, there were only six caregivers who were living together under one roof, as there only few communities such as Vietnamese/Chinese and Indian who still believed in living together. In both the cities there were less than ten percent caregivers who were living with their extended families. Overall all the results showed that in Melbourne majority of caregivers were living in nuclear family set ups where as in Chandigarh though a higher number of caregivers were living as nuclear family but nearly thirty percent were living as joint family too.

Accommodation

Where the type of houses the caregivers were living in is concerned, there were 65.33 percent of caregivers in Chandigarh who were living in the houses, owned by themselves. However there were 34.67 percent caregivers who were living in a rental accommodation. In Melbourne more than half (58 percent) caregivers were living in their own house and more than two fifth (42 percent) caregivers were living
in rented accommodation. The overall distribution of caregivers both in Melbourne and Chandigarh living in their own or rented accommodation was proportionally same.

**Chronological age of special children**

The analysis of the table showed that in both the cities, in total, more than half (52.66 percent) of the caregivers reported that their children were in the age group of 5-10 years. Further break up showed that majority (78.66 percent) of the caregivers in Melbourne reported that their children were in the above age group. Where as in Chandigarh higher number of caregivers reported that their children were in the age group of 10-15(63.33 percent) respectively.

**Intellectual Disability: Reactions and Awareness Among the Caregivers**

**Initial Reactions**

Analysis of initial reactions of the caregivers, when they were told of the disability of their child. In both cities Melbourne and Chandigarh showed that 45.66 percent of the caregivers were shocked when they first came to know of their child’s disability. The city wise distribution of the caregivers was nearly same i.e. 44 percent in Melbourne and 47.33 percent in Chandigarh. Around 23.66 percent caregivers in both cities shared that they were unable to accept the fact that their child was disabled and for a long time they were in a denial mode. City wise distribution showed that caregivers in this category was higher in Chandigarh (30.67 percent) than in Melbourne (16.66 percent) .Other reactions of caregivers included anger, that was found to be higher among the caregivers (10.66 percent) in Melbourne than Chandigarh (2 percent).Some of the caregivers also reported to have been under fear of future of their child, in both cities 7.33 percent caregivers shared the view. Around 3.33 percent caregivers in both cities also shared their feeling of confusion over the sudden news. Self blame was another reaction felt by around 6 percent caregivers in both cities. This was not so in Melbourne.

**Perception of Intellectual Disability**

Highlights of perception of intellectual disability among the caregivers showed that, in Melbourne 92 percent caregivers felt that intellectual disability is a permanent condition and also incurable, this view was shared by 20 percent caregivers in Chandigarh too. Apart from this, more than half (54 percent) of the caregivers in Chandigarh believed that medicines or faith healers could cure intellectual disability, whereas in Melbourne there were none. In Melbourne only 6
percent caregivers considered that intellectual disability is dangerous, on the contrary in Chandigarh there were 13.33 percent who shared the view. Both the cities had less than ten percent (7.33 percent) caregivers who felt that intellectual disability is infectious and were more concerned about their other siblings. This was higher among caregivers in Chandigarh (12.66 percent). The results thus showed that in Melbourne a higher number of caregivers accepted disability of the child as a incurable and permanent condition. In Chandigarh more than half still had misconceptions.

**Awareness of Intellectual Disability**

Early awareness of intellectual disability among the primary caregivers can lead to planning of early intervention for their child. Data analyzed on this issue showed that in Melbourne, nearly two fifth of caregivers (40.67 percent) were familiar with intellectual disability as compared to 34.67 percent in Chandigarh. A closer look at the data showed that there were 62.33 percent caregivers in both cities who had no idea about intellectual disability at all. It can thus be concluded that more than half of the caregivers were not aware in both the cities. Proportionally caregivers in both categories in both cities were almost same.

**Awareness of Testing Method to Diagnose Intellectual Disability**

Analysis on caregiver’s awareness about the methods to test the confirmation the presence of intellectual disability in their children showed that majority of caregivers (73.33 percent ) in Melbourne were aware that IQ test determined the level of intellectual disability followed by 40.67 percent. Apart from this in Chandigarh higher number of caregivers 23.33 percent caregivers had misconceptions that CT scan was the right method. Less ten percent of the caregivers in both cities (7 percent) were aware that genetic counseling test can also be a tool to test intellectual disability in their child. There were 22.33 percent caregivers in total who had no information about the testing methods. Overall more than half of the caregivers were aware of IQ test as the right method in both cities. Citywise distribution showed that this number was higher number in Melbourne.

**Awareness of the Causes of Intellectual Disability**

Analysis of awareness, of the possible causes of intellectual disability among caregivers in both cities showed that, a higher number of caregivers in Melbourne believed that intellectual disability in the child due to chromosomal abnormality (66.67 percent), history of intellectual disability in the family(6.67 percent), extreme prematurity(5.33 percent).Whereas in Chandigarh there were higher number of
caregivers who reported the following were the possible causes of intellectual disability, chromosomal abnormalities (20 percent), past karma (14.67 percent), infection and malnutrition (10.67 percent) each, curse of creator (2.67 percent) and aftermath of evil deeds (5.33 percent). The analysis showed that in both cities higher number of caregivers believed that either chromosomal abnormality or use of drugs by mothers were the possible causes. In Chandigarh some of caregivers had misconceptions that it was caused due to past karma, curse of creator or aftermath of parent evil deeds.

**Awareness of the Medical Terminology Related to Disability**

Highlights of level of awareness among caregivers about medical terminology related to their child’s disability showed that in both cities, in total more than half (63.33 percent ) of the caregivers were familiar with the mental retardation .Similarly 11 percent caregivers in both cities were familiar with cerebral palsy and 13.67 percent had information of down syndrome. There were 7.67 percent in both cities caregivers who knew about learning disorders .The term autism was understood by only by 3.67 percent caregivers in both cities and only 1.33 percent caregivers in Melbourne had knowledge of attention deficit hyperactive disorder. The most common terminology related intellectual disability was found among caregivers in both cities was mental retardation.

**Awareness of Co Morbidity of their Children**

The analysis of data as the co morbidity existing awareness among the children of selected sample included the following. The most common co morbidity in both the cities as reported by caregivers were drooling (24.66 percent) and epilepsy (18.33 percent). Apart from this in Melbourne the following co morbidities were reported by higher number of caregivers were low vision, down syndrome and cerebral palsy. In Chandigarh the co morbidity were reported by a higher number of caregivers were epilepsy, violent behavior. The overall analysis showed that some or the other forms of comorbitities were existing among the child with disability in both cities.

**Age of the Child when Disability was Detected**

Early detection leads to early intervention , the data on this issue indicated in both the that 68.33 percent of the caregivers had detected their child’s disability between the age of 5-10 years .Both cities had almost same number of caregivers in this category. Around 17 percent caregivers in both the cities were able to detect the disability in their child before 5 years of age which comprised of 30 percent in
Melbourne and 4 percent in Chandigarh. Lastly, 14.66 percent in caregivers in both cities identified their child’s disability between the age of 10-15 years.

Melbourne, the formal diagnosis was given at the age of 6 years but before that it was considered as global developmental delay and where caregivers 4.66 percent caregivers in both cities identified their child’s disability between the age of 10-15 years. Analysis indicated caregivers in Chandigarh 66.66 percent caregivers were concerned majority got their child’s diagnosis between the age of 5-10 years.

**Source of Information of Child’s Disability**

Source of information regarding the disability have direct effect on the caregivers attitudes towards disability. The data on this issue reveals that both in Melbourne and Chandigarh majority (90 percent) of caregivers were informed that doctor was the source of their information about their child’s disability, with 92.67 percent in Melbourne and 87.33 percent in Chandigarh. Whereas only 6 percent caregivers in both cities got this Information from psychologist followed by 4 percent from the special educator. Results of both places were almost same. Caregivers in both cities preferred to visit doctors for initial visit for the diagnosis. One of possible reasons could be that both were urban areas with all facilities and caregivers were more aware.

**Early Behavioural Symptoms**

Observation of early behavioral symptoms is helpful in early diagnosis and early intervention. The data analysis showed that 62.66 percent caregivers observed early behavioural symptoms in their child which comprised of 66 percent in Chandigarh and 59.33 percent in Melbourne. Whereas there were 37.33 percent caregivers who did not observe any behavioural symptom at an early age in their child. Proportionately caregivers in both cities in this category were same. The analysis showed that where observation of early behaviour symptoms was concerned, responses of caregivers from both cities was proportionately same.

**Awareness of their Child’s IQ**

Sometime caregivers are unable to decide on how to approach the services required for their child due to lack of awareness of their mental age I Q. It is evident from the analysis that more than half of the caregivers (70.67 percent) in both cities were aware of the IQ of their child. The analysis showed that in Melbourne higher number of caregivers (85.33 percent) were aware, whereas in Chandigarh there were only (44 percent). Apart from this 29.33 percent caregivers in both the cities reported
that they didn’t have any information about their child’s IQ. City wise distribution showed that in Chandigarh (56 percent) were not aware, whereas in Melbourne only 14.67 percent reported the same.

**Sources Approached for Intervention**

Sources approached for treatment and rehabilitation of the child with intellectual disability has direct impact on management of issues related to them. The results in both places clearly show that maximum number of caregivers in both cities visited a social worker/psychologist once they came to know about their child’s disability. In Melbourne it was 94.67 percent and in Chandigarh there were 74 percent caregivers who went to the social worker/psychologist. Around 10.33 percent caregivers in both cities approached special educators for intervention, which comprised of higher number of caregivers from Chandigarh (16.67 percent) than Melbourne, where it was only 4 percent. In Chandigarh 6 percent caregivers preferred to approach pandits/ priests for intervention and 6 percent preferred faith healers. The data thus showed that caregivers in Chandigarh prefer other people about the doctors for intervention. A small number even had misconceptions and preferred pandits/ priests or faith healers. This was not so in, Melbourne.

**Problems Faced by the Caregivers**

**General Problems Faced by Caregivers**

Some of the general problems reported by caregivers included financial, emotional and mental health issues. In both the cities 28.33 percent caregivers reported that they got besieged with their child. Mothers had more emotional issues as compared to fathers. City wise distribution of the data showed that Melbourne had 40 percent caregivers facing emotional problems whereas in Chandigarh there were only 16.66 percent. Next problem that was prominent among the caregivers was the financial problem, which was faced by a higher number of caregivers in Chandigarh (44 percent) than Melbourne where only 10 percent reported the same. Around 19.66 percent caregivers in both complained of physical exhaustion and stress. Challenging behaviours of children with intellectual disabilities was another problem faced by 15.66 percent caregivers in both cities. Lastly around 19.33 percent caregivers who faced more issues related to school activities of the child. The analysis showed that caregivers in Melbourne higher number of caregivers faced emotional problem, physical exhaustion and stress, behaviour related issues (19.33 percent). In Chandigarh higher number of caregivers (44 percent) faced financial problems.
Emotional Problems

Emotional issues of the caregivers indicated that nearly half of the caregivers (48.67 percent) in Melbourne felt aggressiveness in their behaviour as compared to 6.67 percent in Chandigarh. Similarly 28.67 percent caregivers in Melbourne felt they were high on restlessness, where as in Chandigarh there were 22 percent who shared the same. Around 20 percent caregivers in both cities felt the existing pressure in the family due to their child with intellectual disability and their care giving role created lot of anxiety among them. Chandigarh had higher percentage of caregivers among whom feeling of isolation and hopelessness was found. The overall analysis showed that in Melbourne higher number of caregivers reported of emotional problems such as aggressiveness, feeling of restlessness. In Chandigarh higher number of caregivers reported of feeling of isolation and anxiety.

Issues of Marital Conflict

There were some major issues of conflict among the spouses. In Melbourne the main issues were time spent among spouses (25.33 percent) and relative prominence of work between spouses (24 percent). In Chandigarh anger outburst was a common cause of conflict (38 percent) and relative prominence of relatives among spouses (22 percent). In both cities decision of who will bear more child care burden was found to be common cause of conflict (19 percent)

Issues of Conflict Related to Siblings of Child with Disability

Analysis on the issues of conflict related to siblings indicated that in both cities, in total 14.66 percent caregivers felt that they spent less time with siblings of a child with disability. City wise distribution of the data showed that in Melbourne higher number of caregivers (40.66 percent) felt that their normal siblings competing with disabled child whereas in Chandigarh the number is less (20 percent).

Issues of Financial Burden on Caregivers

Individualized services for disabled child call for additional financial burden on the caregivers. Analysis of the data reflected that a 14.66 percent in both cities felt that arrangement for special transport facility for their child with disability created extra burden. Apart from this infrastructural barriers that called for even minor modifications also added to the financial burden. The city wise description showed higher percentage of caregivers (12 percent) in Melbourne were affected on this account as compared to Chandigarh where there were only 5.33 percent. Medical co morbid conditions that forced the caregivers to avail medical services both at
government and private level was an added financial burden, around 19.67 percent of the caregivers in both cities had to undergo this problem. Though it was higher (34 percent) in Chandigarh as compared to Melbourne (5.33 percent). Another area of concern for the caregivers was the miscellaneous (uncalled for or hidden expenditures) expenditures which in both cities was 8.66 percent and at times led to financial crunch. The analysis showed that higher number of caregivers in Melbourne faced financial burden due to following cases high cost of hired caregivers, modifications in the infra structure. In Chandigarh higher number of caregivers reported that they faced financial burden due to the following issues-medical/comorbid conditions. Transport was the common area due to which caregivers from both cities felt added to expenditure.

**School Related Problems**

**Absenteeism**

Absenteeism from school due to erratic behaviour patterns of the children with intellectual disability become an issue of concern for the caregiver. Analysis of the data showed that 43 percent caregivers in both cities faced this issue. When seen individually the number of caregivers in Chandigarh was much higher (62 percent) than in Melbourne (24 percent). On the other hand those who disagreed on this issue was more than half of the caregivers (57 percent) in both cities, city wise distribution showed that the number of caregivers in this category was higher in Melbourne (76 percent) than in Chandigarh where it was 38 percent. Analysis of data showed that a higher number of caregivers in Chandigarh reported that they faced the problem of their child’s absenteeism. On the other hand a higher number of caregivers (76 percent) in Melbourne disagreed on this issue.

**Problem during Admission of Child to Special School**

The responses to the problems faced by caregivers at the time of admission of their child to special schools indicated that, 37 percent of caregivers in both cities faced refusal of admission of their child due to high support needs which meant additional burden on school The number of caregivers in both cities was proportionality same in this category. Apart from this a higher number of caregivers (40.67) in Melbourne reported that their children were forced to drop out as compared to Chandigarh where there were 28 percent who shared this view. In Chandigarh 30.67 percent caregivers even had to visit number of schools before admitting the child. Whereas in Melbourne where there were none. In Melbourne 20 percent
caregivers reported that they don’t have to choose a school as their child as their child gets the admission at the school closer to their home. whereas in Chandigarh there were only 6.67 percent with this issue. The analysis indicated that refusal of admission due to high support needs was one common issues among caregivers of both cities. Apart from this a higher number of caregivers in Melbourne reported lack of choice of school as they had to admit their child in the periphery of their residence and at times there child was not admitted due to challenging behaviour. Whereas caregivers in Chandigarh reported that they had to visit number of schools for admission and were even refused admission due to high support needs.

Problems of Distance of School from Home

Distance to school became an issue of concern due to added behavior problems of the child. The data indicated that in both cities majority (68 percent) of caregivers reported that their children travel 5-10 Km to go to school. Around 22.67 percent in Melbourne and 24 percent caregivers in Chandigarh caregivers reported that their children travelled 10-15 Km.

Problem of Transport Used to Drop Child at Special School

Transport of children as such may not be a problem but when it is for the child with intellectual disability, it certainly is an issue of concern. These children have a number of behavioural problems because of which at times they become unmanageable and have to dropped personally. More than half of the caregivers reported that their children went to school by school bus or auto rickshaw. This service was used more by children (78.67 percent) than in Melbourne which had only 36 percent who availed bus service. Apart from this, 38.67 percent caregivers reported that their children were being dropped by them in car, this comprised of 56 percent caregivers in Melbourne and 21.33 percent in Chandigarh. In Melbourne 5.33 percent caregivers also dropped their children by train and 4 percent by taxi. In Melbourne, majority of children travelled by bus or auto rickshaw and rest by car.

Child’s Inability to Benefit from School Inputs

There are times children are unable to benefit from the school inputs. The caregivers of children with intellectual disabilities sometimes have a set of expectations from the school and their child too, which remains unfulfilled and latter takes form of problem. Analysis showed that more than half of the caregivers (53.33 percent) in both Melbourne and Chandigarh reported that their children had difficulty in reading. Around 33 percent in both the cities caregivers shared that their children
faced difficulties in calculations. Apart from this 6.33 percent caregivers in both cities reported that their children had difficulties in Calculations. Lastly there were only 1.33 percent caregivers whose children had communication problems. The analysis showed that in both cities children with disability had some common problems.

**Social Problems Faced by the Caregivers**

**Social Ridicule through Non Verbal Behaviour at Public Places (restaurant, shops, family picnics)**

Social Ridicule includes, non verbal behaviour at public places (restaurant, shops, family picnics). Awkward reactions faced by the family during their visits to above places is also a part of social ridicule. The data indicated that more than half of the caregivers (52 percent) in both cities who often faced the situation, when people around them stare at them and make them feel uncomfortable. The city wise distribution showed that in Chandigarh 60 percent caregivers faced such situations and in Melbourne there were 44 percent. Around 35.33 percent caregivers in both cities also complained of people pointing fingers at them and their child with disability. This comprised of 53.33 percent of caregivers in Melbourne and 17.33 percent in Chandigarh. Another such non verbal expression faced by 12.67 percent caregivers in both cities was refusal of people to share space with children with disability and their caregivers; there higher number of respondent (22.67 percent) in Chandigarh than in Melbourne which had 2.67 percent caregivers. Analysis indicated that there were two major issues on which a higher number of caregivers in Chandigarh felt uncomfortable and their children were frequently being stared and at times even refuse to share space with their child. Whereas caregivers in Melbourne reported that people often pointed fingers at their children in public places.

**Negative Comments Made at the Child with Intellectual Disability at Public Places**

Negative comments or derogatory vocabulary at public places for their child was often an issue of concern for the caregivers. This may not happen now every now and then but it still has direct effect on their self esteem. Analysis of the data indicated that higher number of caregivers (46.66 percent) in Chandigarh shared that they often had to hear the word crazy and in Melbourne they were 27.33 percent. Similarly around 30.66 percent caregivers revealed that they quiet often had to hear the word abnormal. Apart from this there were 18 percent caregivers reported to have heard the word retarded. Lastly 26.33 percent of the caregivers refused to comment on this issue.
, this number was higher in Melbourne than Chandigarh. The analysis indicated that fifty percent caregivers in Melbourne did not want to talk on this. City wise distribution showed a higher number of caregivers in Chandigarh reported to have heard the words like crazy, abnormal or retarded.

**Problem of Socializing Before and After the Birth of their Child with Intellectual Disability**

It is presumed that socialization pattern of the caregivers does get affected with the birth of a child with intellectual disability. The data indicated that in Melbourne there were 48 percent caregivers who stated that they used to invite or visited people at least once a week before the birth of their child. However there was a significant change found after their child with disability born. Only 20.67 percent reported the same. Similarly there were 30.67 percent caregivers who revealed that they socialized once in fortnight before their child with disability was born as compared to 25.33 percent caregivers who said the same afterward. There were 21.33 percent caregivers were rarely inviting people at their home before the birth of their child however after their child was born more than half of the caregivers (54 percent) indicated that they start socializing or inviting others at their home not most of the time but occasionally i.e. once a month. The trends in Chandigarh were different. There were 64.66 percent caregivers who visited and invited guests once a week but there were only 27.33 who preferred this, after the birth of their child with disability also. There were 31.33 percent caregivers who chose to socialize once in a fortnight and there was increase in the number of caregivers who preferred to do the same after the birth of child with disability. Similar trend were found among the caregivers who socialized at least once a month. There were only 4 percent caregivers who preferred this before their child with disability was born where as there were 23.33 percent who revealed that they socialized at least once a month. The analysis showed that in Melbourne there was increase in number of caregivers who preferred to socialize once a month and decrease in the number of caregivers who preferred to socialize once a weekend once in fortnight. Whereas in Chandigarh the change in the pattern was different. There was decrease in the number of caregivers who preferred to socialize once a week and there was increase in the number of caregivers who preferred to socialize once in fortnight and once a month as they felt it was stress buster for them.
Vacations with Family Before and After the Birth of the Child with Intellectual Disability

Vacations with family helps in unburdening. The responses of the caregivers show the changes that come in the lifestyle of the family when there is a child with intellectual disability. Analysis indicated that in Melbourne half (51.33 percent) of the caregivers stated that they were able to go for short vacation after every six months with their family, before the birth of their child with disability, however after the birth of the child it has been significantly reduced and there were only 22.67 percent caregivers could manage to go on vacations. There were 36.66 percent caregivers who reported that they used to go for family vacations once in a year before the birth of their child with intellectual disability, whereas 62 percent reported the same after the birth of their child with disability, as they felt it had become difficult to go after every six months. Lastly there were only 12 percent caregivers who never had a chance to go out with a family for a vacation before birth of their child disability and afterwards, the number increased to 15.33 percent. In Chandigarh there were only 17.33 percent caregivers who reported that they preferred to go for vacation once in six months, though a short one before the birth of their child, whereas only 4 percent caregivers reported the same after the birth of their child. There were 46.33 percent caregivers who reported going for vacation once a year but there was a decrease in the number of caregivers to after the birth of child with the disability 50.66 percent to 42 percent .Significant difference found among the number of caregivers who never went for vacation before the birth of their child with disability which was 32 percent and after which increased to 54 percent. The analysis showed that in Melbourne there were decrease in the number of caregivers who preferred vacations once in six months and there was increase in the number of caregivers who preferred vacations once in a year. Apart from this there was increase in the caregivers who did not prefer vacations at all. In Chandigarh same pattern was found.

Disruption in Personal Recreation Pattern Before and After the Birth of their Child with Intellectual Disability

Personal recreation helps to release stress and caters to the burn out and also provides some respite from the care giving role. The results indicates that in Melbourne there were 25.33 percent caregivers who took out time for their personal recreation once week but after the birth of their child with disability there were only 12.66 percent caregivers who preferred the same. Around 46.33 percent caregivers
opted for personal recreation once a fortnight, which comprised of 52.67 percent caregivers before the birth and 40 percent which decrease after the birth of the child with disability. There were 22.33 percent caregivers who made a choice for recreation once a month, which included 18 percent before the birth of their child with disability and 26.67 percent afterwards, the reason put forth by the caregivers was that their preference had changed from fortnight to once a month because of their additional responsibilities. Lastly there were 4 percent caregivers who did not prefer personal recreation, before the number of caregivers who shared this view increased to 20.67 percent after the birth, the reason put forth was the additional burden of care giving. Analysis showed changes in the personal recreation pattern too. In Melbourne there was increase in number of caregiver who no longer had time for personal recreation. Those who preferred personal recreation once a week or fortnight decreased and on the other hand preference for once a month personal recreation increased. Similarly in Chandigarh also nearly fifty caregivers could not take out time for personal recreation and no one opted for personal recreation once a week. Those who preferred once in fortnight also decreased. Though there was increase in number of caregivers who preferred personal recreation once a month.

**Life Skills and Behaviour Problems**

**Problems Related to Life Skills of Child with Intellectual Disability**

Children who have intellectual disability have limited development of life skills. Analysis showed that caregivers in Melbourne reported that their child with disability requires assistance in following areas-brushing/bathing (42.66 percent), dressing/undressing (28.67 percent), feeding/eating (17.33 percent), toilet training (3.33 percent) and cooking (6 percent) whereas in Chandigarh child with disability requires assistance in following areas-brushing/bathing (24.66 percent), dressing/undressing (25.33 percent), feeding/eating (28 percent), toilet training (3.33 percent) and cooking (6 percent). Overall analysis showed that in both the cities child with disability requires assistance in life skills.

**Behaviour Problems of their Child with Disability**

Challenging behavior among children with intellectual disability becomes a problem for the caregivers too. It may include display of inappropriate behaviour in public or at home and may be a major source of stress for the caregivers. Analysis of the behavioural problems of the child with disability indicated that in Melbourne
there were higher number of caregivers who reported the following behaviour problems in their children-Absconuling behaviour (16 percent),self injurious behaviour (8.66 percent), avoidant behaviour (1.33 percent). In Chandigarh higher number of caregivers reported following problems such as repetitive behaviour (25.33 percent). In both cities a common problem reported by caregivers (38 percent) was violent behaviour that included kicking, hitting, biting and banging.

Social Support Systems: Family support (Informal) and State Support (Formal)

Family support (Informal): Includes Awareness, Perception and Availability and Reactions to Refusal

Siblings Awareness about Child’s Disability

Awareness among the siblings on the issues related to the child’s disability helps in coping with the problems. In both the cities in total, 33 percent caregivers reported that the disabled child’s siblings were completely aware about the issues related to their brother/sister’s disability. There were (43.67 percent) caregivers in both the cities who were not very confident whether the siblings understood the issues related to the disabled child in their family. Further breakup of the data showed that there were in total more than one fifth (23.33 percent) caregivers stated that their other children do not have any knowledge about disability and they get frustrated when parents give more attention to that child.

Analysis showed that in Melbourne a higher number of number of caregivers felt that the normal siblings did not understand disability related issues, In Chandigarh more than 50 percent felt the normal siblings somewhat understood are 42 percent were fully aware.

Grandparents Awareness of Child’s Disability

Grandparents prove to be significant support system for the families which have a child with disability. Nearly fifty percent of caregivers in both cities felt that the grandparents were fully aware of the child’s disability. The city wise distribution of caregivers showed that Chandigarh had more than fifty percent (57.33 percent) caregivers who felt that the grandparents of their children were fully aware and in Melbourne there were 38.67 percent caregivers who felt the same. Apart from this in both cities nearly 33 percent caregivers felt that the grand parents did not fully understand their child’s disability and 19 percent caregivers felt that their child’s
grandparents did not have any awareness of their disability. City wise distribution showed that Melbourne had higher number (27.33 percent) of caregivers in whose families grandparents were not aware as compared to 10.67 percent caregivers in Chandigarh. Nearly fifty percent caregivers in both cities reported that the grandparents were fully aware. Analysis showed that Chandigarh had higher number of caregivers reported that the grandparents were fully aware. Whereas in Melbourne a higher number of caregivers reported the grandparents were somewhat aware and the caregivers who reported that grandparents were not aware were also higher than Chandigarh.

**Relatives Awareness of Child’s Disability**

Relatives who are almost a part and parcel of a family prove to be a significant support system especially in Indian families. In both the cities more than half (55 percent) caregivers reported that their relatives were aware of their child’s disability and helped the family when required though not on regular basis. City wise distribution showed that Chandigarh had much higher number of caregivers (90 percent) whose relatives were fully aware of the issues related to their child’s disability as compared to 20 percent caregivers in Melbourne. There were 26.67 caregivers in total who were not confident whether their relatives understood the issues related to their child’s disability. This included 44 percent caregivers in Melbourne and 9.33 percent in Chandigarh. This was followed by 18.33 percent respondent who reported that their relatives never turned up for help due to their lack of awareness about disability. The percentage of caregivers in this category was much higher in Melbourne (36 percent) than in Chandigarh where it was only 0.67 percent. Data analysis showed that majority of caregivers in Chandigarh reported that their relatives understood the disability related issues. In Melbourne high number of caregivers reported that their relatives did not understand anything at all.

**Friends Awareness of Child’s Disability**

As reported by the caregivers, close friends were more like family members. It was found in both the cities that in total more than half (52.67 percent) caregivers stated that their friends fully understood their child’s disability and provided emotional support or sometimes babysit their child. City wise distribution showed that Chandigarh had higher number of caregivers (84 percent) who had friends, who were fully aware of the needs of their disabled child as compared to 21.33 percent caregivers in Melbourne. This was followed by 30.33 percent caregivers in both cities
who felt their friends were somewhat aware of the issues related to their child’s disability. The caregivers in this category was much higher (52 percent) in Melbourne as compared to Chandigarh where it was only 8.67 percent. Lastly 17 percent caregivers in both the cities stated that their friends did not understand their child’s disability at all. Many reported that their friend’s have distanced themselves since they came to know of their child’s disability. There were caregivers who reported that their friends preferred to invite them to their places without the child with disability. Awareness among majority of close friends was reported by caregivers in Chandigarh. More than 50 percent felt that they somewhat understood. Caregivers in Chandigarh them to be a great support.

Availability of Family Support to the Caregivers

Sources Available For Emotional Support

Availability of emotional support helps in ventilation as. It gives opportunity to talk about daily hassles the caregiver faces. The caregivers were receiving the emotional support either from child’s grandparents, siblings, friends or relatives. In both the cities 39.33 percent caregivers reported of receiving emotional support from child’s grandparents and felt that it had great impact on their lives and attitudes. Around 31.67 percent caregivers who felt were being emotionally supported by child’s siblings. This included 34 percent caregivers in Melbourne and 29.33 percent caregivers in Chandigarh. Apart from this there were only 17 percent caregivers who reported that support of their relatives catered to their emotionally toned needs. A higher number of caregivers (19.33 percent) in Chandigarh who were receiving emotional support from their relatives as compared to 14.67 percent in Melbourne. Very few (10.33 percent) caregivers were receiving any type of emotional support from their friends. It was interesting to note that 1.67 percent caregivers in both the cities reported that they received emotional support from hired caregiver who were more like a family to them. An interesting trend observed was that grandparents were a common source of emotional support at both places followed by siblings, relatives and friends in both cities.

Sources Available for Financial Support

Grandparents are one of the significant natural emotional support available to families who have a child with disability. A common trend noted in both cities was that in both the cities more than half of the caregivers (60 percent) reported that grandparents provided financial support to them from their pension or otherwise,
which was helpful to buy medicines or for fulfilling other needs. City wise
distribution showed that in Melbourne higher number of the caregivers (66.66
percent) were receiving financial support from the grandparents and in Chandigarh
more than half of the caregivers (53.33 percent) reported the same. There were 6
percent of the caregivers in both the cities who were receiving monetary support from
their relatives, followed by 15.67 percent caregivers whom their other children were
helping them out financially. Approximately, 18.33 percent caregivers in both the
cities were receiving financial help from their friends from time to time. Analysis
showed that in Melbourne majority of caregivers felt they got financial support from
grandparents as and when they needed whereas caregivers in Chandigarh reported
higher support from grandparents and friends.

**Sources of Support Available for Babysitting**

Support for babysitting proves to helpful for caregivers as it gives them some
respite from their role as carer. It is evident from the results that in both cities almost
half (51 percent) of caregivers were getting support from child’s grandparents for
babysitting the child with disability as and when needed. There were 25.33 percent
caregivers in Melbourne and 14 percent in Chandigarh who reported that they turned
to their other children for support. This was followed by only 1.33 percent caregivers
in total who were relying on their relatives. However there were 16.67 caregivers in
Melbourne who reported that their friends babysit their child when needed. Whereas
in Chandigarh it was only 8 percent. Lastly a higher number of caregivers (24.67
percent) in Chandigarh got support from hired caregivers as compared to Melbourne
where hired help was very expensive as reported by caregivers during the interview.
Analysis showed that in both cities grandparents were the major sources available for
babysitting. Apart from that caregivers in Melbourne also depend upon siblings and
friends whereas caregivers in Chandigarh preferred hired caregivers for babysitting.

**Sources of Support Available to Attend Medical Appointments**

Intellectually disabled child especially with high support needs often have to
attend medical appointments and it is difficult for caregivers to take them .In such
situations support from all co- corners is significant .In both cities half of the (50 percent)
caregivers were getting support from grandparents in attending medical appointments.
Nearly one forth (16.67 percent) caregivers were receiving a helping hand from their
relatives followed by 11.33 percent caregivers, whose friends were helping to
transport the child. However there were more than one tenth (13 percent) caregivers
who reported that they could turn to child’s sibling’s for help. Further breakup of the data of both cities showed the higher number of caregivers in Chandigarh were relying on child’s sibling’s. Lastly only 18 percent of the caregivers in Chandigarh took support from hired caregivers whereas in Melbourne there was none. The analysis indicated in both cities that half of caregivers relied on grandparents for support to attend medical appointments. Apart from this caregivers in Chandigarh preferred hired caregivers and relatives for help but in Melbourne caregivers dependent more on siblings and friends as hired help was expensive.

Sources of Support Available for Household Tasks

Caregivers need a helping hand for household chores. Which they may get from siblings or friends or grandparents in the form of physical assistance due to intellectually disabled child’s additional responsibilities. They often look towards family in carrying out everyday domestic tasks such as cooking or cleaning. It is evident that in both the cities majority 44 percent of caregivers were receiving support from child’s grandparents. The data showed that 27.66 percent caregivers in both cities were being helped by the sibling’s of the child with intellectual disability for the household chores. City wise distribution showed there were 30 percent in Melbourne followed by 25.33 percent in Chandigarh. There were 2 percent caregivers who were helped by their relatives to cook or in clean the house when needed in both cities. This was followed by very few (9.33 percent) caregivers in Melbourne who were receiving support from their friends, whereas in Chandigarh there were none. Lastly there were 33.33 percent caregivers in Chandigarh receiving support from hired caregivers whereas in Melbourne there were only 10 percent. Chandigarh. It can be thus concluded that nearly half of the caregivers in both places relied on grandparents for support in household tasks. Apart from this caregivers in Chandigarh also got support from siblings and hired caregivers, whereas caregivers in Melbourne received help from siblings and partially from friends, relatives and hired caregivers, whereas caregivers in Chandigarh had no support from friends and relatives.

Sources of Support Available for Recreation of Child with Disability

Apart from other activities sometimes it becomes difficult to take time out for recreation of child with disability. The data revealed the sources of support available for recreation of child with disability caregivers were receiving. In both the cities nearly half of the caregivers i.e. 49 percent were receiving support from child’s grandparents which comprised of 45.33 percent caregivers from Melbourne and 52.67
percent from Chandigarh. Families reported that grandparents took pride in taking their child with intellectual disability out to the park or play centre and this gave parents respite from their caring role. There were caregivers 23 percent in both cities who were receiving recreation support from the sibling’s of child with disability and city wise distribution showed that number of caregivers in both cities was almost same. There were 26 percent caregivers who were receiving support from their relatives in Melbourne whereas in Chandigarh there were none. It was interesting to know that in Chandigarh 25.33 percent caregivers were taking support from hired caregivers for recreation of their child with disability, whereas in Melbourne there were only 2.66 percent. Lastly there were only 26 percent caregivers who received support from friends that also only in Melbourne. Analysis indicated that nearly half of the caregivers in both cities were given support by the grandparents for recreation of their child with disability. Apart from this caregivers in Chandigarh depended more on hired caregivers and siblings of child with disability but caregivers in Melbourne dependent more on siblings and friends as they felt hired caregivers were expensive.

Sources of Support Available During Counseling Sessions of Caregivers

Support received from family to attend the counseling sessions. The data on this issue indicated that in both the cities grandparents provided maximum support in this respect. Nearly 41.66 percent of caregivers in both the cities reported that they receive support when they had to go for counseling sessions from the child’s grandparents. This comprised of 35.33 percent caregivers in Melbourne and 50 percent caregivers in Chandigarh. Around 25.33 percent caregivers in both the cities received support from siblings of their child with disability. Since there were families who had migrated from other countries who didn’t have any relatives in the same city or in the same country so siblings played a significant role in the family where there is a child with disability. There were 34 percent caregivers in Melbourne and 16.67 percent in Chandigarh who shared this view. In Melbourne 4 percent caregivers received support from relatives and 26.66 percent from friends and there were none from Chandigarh. Lastly around 33.33 percent caregivers from Chandigarh received support from hired care givers whereas there were only 2 percent from Melbourne. Analysis showed that in both the cities maximum number of caregivers received support from grandparents. Apart from this caregivers in Chandigarh depended more on hired care givers and siblings but no support was available from relatives and
friends for this purpose. However caregivers in Melbourne depended more on friends and relatives depending upon the availability.

**Impact of Positive Family Support on the Caregivers**

The city wise distribution showed that in Melbourne there were 71.33 percent caregivers who felt more confident because of family support whereas in Chandigarh there were 62 percent caregivers who shared the view. There were 13.66 percent caregivers in both cities who felt family support during the crisis situation had made them more organized. This included of 22 percent caregivers from Melbourne and 5.33 percent from Chandigarh. Lastly 16.33 percent caregivers in total from both cities felt emotionally and financially secure with 26 percent caregivers in Chandigarh and only 6.67 percent in Melbourne. The analysis revealed that feeling of confidence due to positive family support was found among more than half of the caregivers in both cities. Apart from this, caregivers in Melbourne felt more organized than due to family support, whereas caregivers in Chandigarh felt more emotionally and financially secure.

**Impact of Family Support on the Caregivers Intra Family Relations**

Family support during the crisis has positive effect on familial relations thus facilitating the caregivers to face challenges related to their child with a disability. Perusal of the data showed that more than half of the caregivers (54 percent) felt adequate and positive family support led to better understanding between the spouses. Whereas more than one fifth (27 percent) of the caregivers reported that they were able to spend quality time with their other children. In this category almost equal proportion of caregivers was found in both cities i.e. 28 percent in Chandigarh and 26 percent in Melbourne. Besides this only 15.33 of percent caregivers felt they were able to attend social and recreational activities frequently. City wise examination of data showed that higher number of caregivers in Melbourne i.e. 22.66 percent got opportunity to attend social and recreational activities as compared to 8 percent caregivers in Chandigarh. Lastly only 7.33 percent of the caregivers in Chandigarh complained of strained relations among the family members/relative in Chandigarh due to additional responsibilities related to their child’s disability whereas there was none in Melbourne. The analysis showed that overall in both cities the disability of the child has brought more understanding among the spouses. In both cities proportionally an equal number of caregivers got time to take care of other siblings. Apart from this a higher number of caregivers in Melbourne reported to have got
opportunity to attend social occasions than Chandigarh. Similarly less than 10 percent caregivers reported strained family relations but there was none in Chandigarh.

**Reactions of Caregivers to Refusal of Support by Family**

There are times when the family is unable to extend the needed support which may be monetary or otherwise. Reactions of the caregivers are as follows. The most prominent emotional expression prevalent among the caregivers was anger. Around 25.66 percent felt they tend to become more aggressive in nature when refused of support from family. This included 20.66 percent caregivers from Melbourne and 30.66 percent from Chandigarh. This was followed by feeling of worthlessness expressed by caregivers due to negative responses from their family. In Melbourne there were 28 percent caregivers and in Chandigarh there were 16 percent caregivers who felt this. Another emotional expression common to many caregivers was aloneness, among 20.33 percent in both cities. City wise distribution comprised of 34.66 percent caregivers in Melbourne and 6 percent in Chandigarh. Around 29.33 percent caregivers in both the cities felt pity for themselves which included a higher number (44 percent) of caregivers from Chandigarh, followed by 14.66 percent from Melbourne. A very small percentage (3.66 percent) caregivers in both cities feared that over a period of time their relationships may not able to bear the burden of additional responsibilities and may break. Analysis showed that caregivers in Melbourne reported high on aloneness and feeling of worthlessness, whereas caregivers in Chandigarh reported high on feeling of pity of themselves and anger and fear of breakage of relationships.

**State Support System: Awareness, Perception, Utilization and Reasons if not Availing State Support System**

**Awareness of Special School**

The awareness among caregivers about special schools. In Melbourne majority (96 percent) of caregivers were aware about special schools and the reason quoted by them was, that Australian caregivers do not make decisions about their child’s education in isolation. A variety of specialists are involved in this process. In Chandigarh also most (83.33 percent) of the caregivers were aware about the special school. Some of the caregivers shared that living in the city has given them access to many facilities and added to their knowledge. There were 10.33 percent caregivers who did not have any awareness of special schools; City wise distribution showed the number in Chandigarh was higher (16.67 percent) as compared to Melbourne where it
was 4 percent. The analysis indicated both being urban areas majority of caregivers were aware of special schools and where a lack of awareness among some caregivers was concerned. Chandigarh had higher number of caregivers.

**Awareness of Respite Services/Sheltered Workshop’s/Supported Employment Facility in the Community**

Respite care proves to be a significant service for caregivers in times of crisis. The data showed that in Melbourne majority of caregivers were fully aware of this service and around 33.33 percent were aware to some extent whereas in Chandigarh majority of caregivers (62.67 percent) were not aware at all around 26.67 percent were aware to some extent and only 10 percent were fully aware. Where sheltered workshops are concerned in Melbourne 29.33 percent caregivers were fully aware and majority of caregivers (64 percent) are aware to some extent. In Chandigarh there were only 3.33 percent of caregivers who were fully aware and majority of caregivers i.e. 66 percent were not aware at all. Data on supported employment showed that majority of caregivers 70 percent were aware to some extent. Overall analysis shows that in Melbourne respite care services was availed by maximum number of caregivers and out of the selected sample there were very few who were in the age group of 15-18 years, thus very few caregivers were aware of this service whereas all the above services have been run mostly by special schools.

**Awareness of the Provisions Under Legislations (Persons with Disability Act 1995, National Trust Act 1999 and Rehabilitation Council of India 1992) in India**

The data on awareness of provisions under persons with disabilities act indicated that the provisions about which the caregivers were fully aware included (74 percent), assistance to purchase aids and appliances (58 percent). Same provisions of which the caregivers were aware to some extent only included Medical, vocational and rehabilitation services (60 percent), unemployment allowance(89.33 percent), scholarships (47.33 percent) and information on NGO’S (42.67 percent).The overall analysis showed that the caregivers awareness in the provisions dependent upon the fact that ,which was being availed by them more frequently.

**Awareness About the Schemes for Persons with Disability in India**

Sensitivity and awareness among the caregivers regarding the schemes encourage them to avail them. Above table reveals that 100 percent caregivers were aware about free travel in buses if accompanying child with a disability. Nearly half 48 percent of the caregivers were aware about loans provided by government to the
families having children with disability. There were more than three fifth (67.33 percent) caregivers who were fully aware about government programme for assistance in higher education for children with disabilities. Further analysis showed that there were 43.33 percent caregivers who were aware about reservation in government jobs for children with disabilities followed by 77.33 percent caregivers who were aware about receiving tax rebated in their income tax. Lastly there were 83.33 percent caregivers who were fully aware of health insurance, followed by 16.67 percent caregivers who had awareness to some extent. The analysis indicated that all caregivers were aware of free transport services. Where other schemes such as loan for self help, assistance for higher education, reservation for jobs were more known to caregiver whose children were either nearly 18. Apart from this a higher number of caregivers were aware of income tax rebate scheme and health insurance.

**Awareness of Provisions Under Disability Act 2006 in Australia**

The data showed that a higher number of caregivers were fully aware of following under the legislations. These included carer pension (53.33 percent), local council (79.33 percent). The schemes the caregivers were aware to some extent were, disability pension (56.67 percent), case management services (47.33 percent), assistance to purchase aids and appliances (52.67 percent), accommodation support (30 percent), community health centers (64 percent), neighbourhood services (56 percent), recreation and leisure (62 percent). There were schemes about which a higher number of caregivers were not aware at all included outreach services (92.67 percent), education and vocational support (82 percent), family intervention and support services (68.67 percent), communication aids (52.67 percent), future for young adults (82.67 percent), accommodation support (59.33 percent). The analysis showed that the responses and awareness was as per the need of the caregiver.

**Awareness of the Schemes for Persons with Disability in Melbourne (Australia)**

The analysis of data showed awareness about schemes being run for persons with a disability in Melbourne. It was found that majority (82.67 percent) of caregivers were fully aware about getting discount in public transport when they travel with their child with a disability while small proportion (2.67 percent) were not aware about this scheme. In Melbourne the government also runs half price taxi card scheme for people who have disabilities where the person pays half of the fare when they travel by taxi. There were more than half (55.33 percent) caregivers who were fully aware about this scheme. This was followed by 34 percent who were aware of
this scheme to some extent and 10.67 percent of the caregivers who were not aware at all. Apart from this it was interesting to note that 68.66 percent of the caregivers were not aware of home loans for lower income families followed by 31.33 percent caregivers who were aware to some extent. There were quite a high number of (78.67 percent) the caregivers who didn’t have any awareness about any employment and training schemes existing in the community followed by 16.67 percent caregivers who were aware to some extent and 4.67 percent who were fully aware. The analysis showed that majority of caregivers were aware of discount on public transport and multipurpose taxi programme. Home loan for low income is a service which caregivers can avail only once. Many people are not aware of it and there were few falling in this category in the selected sample Similar was for employment and training schemes, only some caregivers whose child was 18 were aware.

**Perception of the Schemes/Services for Persons with Disability**

Since the governments in all countries provide schemes for empowerment of children with disabilities and their families to avoid exclusion. Similarly India and Australia too have various programmes run by the respective government for the welfare of persons with disability and their families. Still it is not necessary that the caregivers are satisfied with all the services being provided to their child. The analysis of perception of caregivers in both cities about the government programmes for children with disabilities and their families indicated that almost 28.33 percent caregivers believed that the programmes are good and effective. Though city wise distribution of caregivers showed that there were 46 percent in Melbourne and only 10.66 percent in Chandigarh. However 40 percent caregivers in Chandigarh did not have positive perception of the schemes found them satisfactory followed by 17.33 percent in Melbourne. Lastly 39.33 percent caregivers in both the cities were unable to comment on this issue, city wise distribution was proportionately same. One of the reason cited by caregivers in Chandigarh was incomplete information. In Melbourne major reasons cited was too many services, too much paperwork and lot of preliminary tests.

**Utilization of Services/Schemes for Persons with Disability**

Although the governments provides services for intellectually disabled children but at times the families and the children are unable to utilize either due to unawareness of caregivers or the travelling time or paper work involved. The data depicts the utilization of available support services among families who have children
with intellectual disability. In Melbourne 74.67 percent caregivers who reported that they take complete advantage of the support services as and when they need. In Chandigarh there were 32.67 percent caregivers who reported complete utilization. Those who mostly availed the services were around 23 percent in both cities. Apart from this 13.33 percent availed the services only sometimes. This was followed by 16.66 percent caregivers in both cities who rarely availed these services. Lastly in both the cities 6.66 percent of the caregivers never utilized these services, the number of caregivers was higher (26.66 percent) in Chandigarh than Melbourne which was 5.33 percent. Analysis showed that in Melbourne majority of caregivers were completely utilizing the schemes as compared to Chandigarh.

**Reasons for not Availing State Support Services for Persons with Disability**

There is a non exhaustive list of reasons, due to which caregivers are sometimes unable to access the services. The above table also reveals some of the reasons due to which caregivers who have children with disability were unable to avail the support services. In both cities 30 percent caregivers felt exhausted with lengthy paper work involved and stated that they got overwhelmed to see so much paper work. There were 18.33 percent caregivers felt perturbed about putting their name on the long waiting list to reach out to the services. Whereas 12.3 percent caregivers reported that they didn’t have adequate knowledge about disability of their child. Around 6.67 percent reported unawareness of schemes. Childs unmanageable behavioural problems forced some of caregivers (6 percent) not to visit support centers. There were 1.33 percent caregivers in Chandigarh who reported that labeling or stigma as a factor that holds them back from availing support services. Lastly a small number of caregivers 12.33 in both cities who were not aware whom to approach. Analysis showed that in both cities caregivers backed out from taking services due to lot of paper involved. Apart from this in Melbourne major reasons included long waiting lists, child behaviour problems which desuaded them from taking along. Same even felt that there was no need. In Chandigarh caregivers reported the major reasons as lack of knowledge and same did not know whom to approach.

**Suggestions and Recommendation**

- There should be a centralized assessment system for different services so that the caregivers do not have to repeat the child’s history or support needs every time they have to avail a new services.
- Caregivers should get opportunity for direct participation during from level of formation of the scheme to its implementation.
- Caregivers should be updated from time to time regarding their status if they are on waiting list to avail a benefits or services.
- There should be single window system for delivery of services and if possible the services may be provided at the doorstep.
- Caregivers have minimal functional knowledge of the provisions of the Persons with Disabilities Act 1995 and National Trust Act 1999. Thus the utilization of services under this act get affected to some extent. The state must make adequate arrangements in coordination with special schools to contact and organize group meeting of the caregivers to deliver the related information.
- Formation of registered parent groups or associations or self help groups. Since there are common problems among them. They can empathize with each other and share their experiences each other.
- Regular meetings with the state support authorities for improving the efficacy of the implementation of schemes and services.
- State (India) should setup respite care /short stay homes ,at the moment whatever little services in this respect are being provided being provided in Chandigarh are through residential schools for special children. Whereas this issue is related to common problems the caregivers face in their day today life. The results of the present study showed that in both cities the caregivers were living as nuclear families. There are times when they need some relief from their or care giving role they might have to attend some social function or some medical appointment and feel the need to leave their children for few hours to few days. At such times such services prove to be helpful. In Melbourne this service is quite popular but in Chandigarh lot of work needs to be done.
- Addition of issues related to intellectual disabilities in the school curriculum. Since this is the time when impressions are formed. This step in the long run would help in the awareness by creating and accepting attitude towards disabilities among the coming generations.
- Field work component to be added in higher education courses like fine arts, dance. These are two activities which work as therapies and vocation for the children with intellectual indisabilities.
- States to appoint special task forces to keep frequent/regular check that the children with are receiving regular services.

Awareness at **community level** regarding the various issues related to intellectual disability, the legislative frame work, the services and the schemes. Keeping in view the whole social construct of disability, it becomes all the more significant to create sensitivity and awareness in the community at large. This will further help in doing away with the various barriers such as social and architectural, which are also to some extent, affected by the socio cultural milieu. Some methods adopted at the community level may be advocacy and social marketing. Both these methods act as catalyst agents to bring in the needed changes in the thought processes of the community at large towards disability. Some suggestions in this context are as follows:

- Mandatory inclusion of a slot on television for disability related issues. This maybe in the form of daily soaps on the issues related to disability or some shows in which these children can showcase their abilities.
- Inclusion of intellectual disability related issues in the induction or orientation, programs for people working in the service delivery sector such as post office banks, staff of Roadways (buses) whether government or private, railways and health sector.