**After Me Who Will Care!**

Circa 2033, Ajay is 49 Years old. Unfortunately his mother expired six months back. His father who was 80 years old and was in reasonably good health expired suddenly nine months back. His brother Gaurav, settled in Australia, had come down for the last rites of mother. However he had to return back after 14 days due to personal contingencies. Gaurav has not been able to get Australian visa for Ajay who is intellectually challenged. Gaurav had anticipating this situation and was in constant discussion with mother trying to evolve a solution.

Ajay suffers from moderate to severe mental disability but was trained well from early childhood on activities of daily living (ADL) by his mother. With age Ajay also faces physical challenges, can barely walk and has weakened muscles due to entropy and declining nuro signals. However he is a very cheerful person who loves TV, Music, social company and non veg food. He generally goes to a neighboring restaurant for non vegetarian food accompanied by care taker (Milind) at least once a week. He also enjoys participating in religious bhajan-kirtan. Above all he is fond of company of his cousins and their children and other residents of society where he lives.

Ajay’s parents kept planning to make some arrangement for his after care (when they will be no more). But two reasons played in their mind, deterring them to take a final decision. Firstly, they thought that since home is the best environment they would have Ajay stay at home as long as their own health allows them to take care of him. Second reason was about providing Ajay the standard of facilities that he was used to at home – they were unable to find such institution. Since both parents expired in a span of three months their plan (what ever parents had in mind) was never implemented. Gaurav discussed Ajay’s resettlement issue with cousins (who had assembled for last rites of his mother) and together they decided to leave Ajay in company of care taker Milind. Milind had developed caring attitude towards Ajay in the last three years association. He was asked to take care of Ajay staying in Ajay’s home. Milind was authorized to withdraw money from Ajay’s bank using ATM card for the salary and common living expenses. Gaurav and one of Ajay’s cousins are monitoring bank a/c through net banking and top it up periodically. The decision on shifting Ajay to a suitable residential care facility was postponed to future.

This arrangement worked well for four months. One day Milind asked Ajays cousin whether he can bring his wife and daughter from his village to Pune and stay in Ajay’s house. While this arrangement was still being discussed and finer details debated among Gaurav and cousins. While this arrangement was still being discussed and finer details debated among Gaurav and cousins, Milind received sad news from his village. His father died in an auto accident. Milind rushed back to his village living Ajay in the care of his local cousin. Few days later he called up Ajay’s cousin to inform that since he has to take care of his ailing mother and sister and also the agricultural land it will be difficult for him to return to his job in Pune. He was the only male member left in his family. Ajay and his cousin’s family are not comfortable to live together on long term basis.

**So what happens to Ajay now!!**

The above is a typical case study that most parents/ families may go thru in the life cycle of persons with “Special Needs”.

The above happens in spite of the fact that there are many residential care facilities available for Special persons. The better among them are set up mostly by parents / sibling of Special Person. The provide facilities for Special Persons to live independently with assistance from care takers, in an atmosphere of care and dignity. These are called Assisted Living Centers (ALC) for special Persons. To name a few, that are located in and around 200 km of Pune, there is Nirdhar Pratishthan, Nav Kshitij, Sadhna village, Savali, Adhar etc. Still more are being built by parents associations like Umed Parivar.

**Today’s Assisted Living Centers (ALCs)**

Most private ALCs are managed by trustees consisting of parents/siblings of Special Persons and run as public charitable trusts/societies. The ALCs generally support vocational training center apart from assisted living arrangement to provide gainful vocation to resident Special Persons. The level of living comfort varies from twin shared room to 10 bed dormitory and would compare with living standard of family of middle income group to low income group standard, respectively. The degrees of household facilities provided to residents vary from institution to institution based on the monthly living expenses charged to guardians. The resident special persons seem to be happy living there. Most of these ALCs charge monthly fee to guardians of Special Persons and run on no profit basis. They rely on public donations for capital expenditure and at times to cover losses in operating expenditure. They tend not to rely on government grants.

With such Assisted Living Centers (ALC) available, Why is then that parent continue to live thru the uncertainty about the future of their Special Person son / daughter?

Parents ‘Thinking & Concerns

The thoughts that go thru the minds of parents are somewhat akin to the thoughts the parents undergo while selecting a suitable home/match for their daughter. The prime concern is that Special Person – son / daughter should get comparable living standard & comforts as he /she is used to at home and should not get ill treated or exploited. There is also a monthly fee payable to ALC which some parents / guardians think as unnecessary drain on their resources. Hence there is a tendency to postpone the rehabilitation till the mother can look after the Special Person. The issue comes to fore when they themselves (parents) require care during old age, and after their death. The siblings may generally tend to look after their Special Person brother / sister. But whether similar care is possible after they are employed in a job/ business and married with responsibility of own family is a moot question. In a survey it has emerged that over 42% of old aged parents are not getting the desired care while living with their married son in old age. Therefore logically such percentage of Special Persons could be much higher. Besides the Special Persons may not be able to communicate about their dissatisfaction as effectively as their parents. These issues are not unknown to the parents and are upper most in their mind when ever the thought about future care of their Special Person crosses their mind. Then what are the concerns that deter the parents from taking timely decision?

CONCERN 1: Till we are alive, let us take care of him/her as best as we can. It is well known that Special Person is best taken care in an integrated environment. Therefore home would be the best.

Factors:

1. Financial; affordability of ALC

2. Level of care required; perception of Special Person over dependence on them (parents)

3. Level of physical comforts; TV, Music, own room, food.

4. Integration opportunity; with parents, siblings, relatives, family friends, friendly neighbors etc.

5. Love & Affection; attachment, Opposition from siblings

6. Risk of sexual exploitation (for women Special Person)

7. Not trained in ADL

8. Disability not adaptable to most ALCs

CONCERN 2: Disability / health / behavioral condition

Factors:

1. Type of disability; multiple disabilities, disability requiring specialized care

2. Behavioral issues; violent, unsocial, petty criminal

3. Extent of disability; Severe, profound, immobile, multiple

4. Not trained in ADL

CONCERN 3: General concerns

Factors:

1. How the Special Person will be looked after in old age

2. Emergency medical facilities

3. Redressal of grievances of Special Person

4. Safety

CONCERN 4: Financial constrains (due to lack of planning)

Factors:

1. Perceived incapacity to pay monthly maintenance charges.

2. Uneven distribution of immovable property among siblings resulting in lack of adequate resources for maintenance of Special Person.

3. Ambiguous distribution of wealth / movable property / business assets.

Overcoming Parents’ Concerns

All the above mentioned reasons are justified and based on practical considerations. The underlying reason is attachment (affection) & need for integration, uncertainty of future and sometimes financial considerations. Some models of Special Person care that would address this requirement are:

a) Maximize employment of parents / siblings in the ALCs. The preference is given to below poverty line Special Person’s Parent / sibling / relatives.

b) In case land / FSI are available, build few flats where Special Person stays with parents as a family. ALC looks after Special Person as well as the parents. The parents pitch in the capital cost of flat and all running expanses for self and Special Person. After the death of both parents the flat can be given to another Special Person & parent with condition that first Special Person continues to share the flat. Else other Special Persons are accommodated in the flat leaving at least one room for original Special Person occupant.

c) Some of the large parent trusts build technical and administrative capacity to provide care to smaller group of parents of Special Person who may form a mini ALC (mALC) in one of their houses. The responsibility of managing the mini ALC is outsourced to management team of larger ALCs. Therefore larger ALC conduct on job training for care takers who are later employed in mini ALCs.

Such large ALC trusts can provide care taker, technical and administrative support from their pool of staff. In an unforeseen eventuality where a mini ALC is required to be closed, the affected Special Person have to be accommodated in trust’s larger ALC. The author can suggest broad outlines of terms of agreement and fiduciary arrangement.

The parental concerns also point to two contradictory issues. First there are some parents / guardians who are unable to afford monthly fee. Second there is a segment of high income, parents (HNIs) who are ready to pay for the facilities but existing ALCs do not cater for such facilities such as single room (studio type) occupancy, TV etc.

d) Here some exclusive lodging facilities may be provided at 3 to 5 times the capital & operative cost. The additional fee can cross subsidize common facilities and poorer Special Persons. On the face it may look controversial but such cross subsidy / exclusivity are practiced in all spheres of our life. Resultant beneficiaries will be to both wealthy and poor category of Special Persons.

If such facility existed Ajay’s parents would have made a timely decision!!

e) The suggestions at Serial (b) above also would also address the income disparity issue.

Addressing General Concerns

The general concerns’ arising in the mind of caring parents of Special Person is understandable. However most of these concerns are taken care by ALUs managed by professionally managed trusts run by conscientious parents. Generally ALUs have tie up with local doctor and nursing home for emergency care. They also tie up with philanthropic specialists and hospitals for regular check up. But to ensure that the local manager and care takers are well aware of policies and procedures it is desirable to have documented procedures. These procedures in the form of booklet should be available to parents for their reference and satisfaction, and would define minimum service levels. The trustees have to ensure that the staff is formally trained on these procedures. The special residents are also apprised of these procedures to the extent possible. Some of the procedures that must be documented for staff training are:

1. Behavior management policy
2. Residents’ IN/OUT and guardian visit register
3. Medical checkup and history of each resident
4. Base line assessment and periodic update
5. Housekeeping services & area hygiene
6. Nutrition diet & food tasting
7. Emergency evacuation procedure
8. Emergency treatment procedure
9. Record of Trustees meeting with Special Persons to address grievances (one to one, and group meeting)
10. Succession pipeline of Trustees who are parent of special person.

Senior Citizen Parents Counseling Services

Last set of issues mainly arise from the ignorance, lack of awareness and sometimes irrational actions on the part of parents of Special Person. For example there are many cases of old mother being ill treated by own son/daughter after the father unwisely bequeathed all property to sons/daughters during her (mother’s) life time.

The author has come across financially well off guardians unwilling to pay meager fee increase for the Special Person residing in an ALC. The Special Person is deprived of the rightful share of parent’s wealth that could easily pay for her monthly ALC expenditure.

We are well aware of early intervention counseling for young parents. In the context of fiduciary issues there is requirement of ‘Later’ age counseling of parents of Special Persons. The scope of counseling services should cover following subjects:

1. Guardianship
2. Fiduciary responsibility
3. Justified distribution or cash in lieu of share of unmovable property & mother’s stree-dhan.
4. Family pension provisions for retired government employees.
5. Importance of readying the statutory documents / certificates for Special Person during parents’ life time.
6. State government pension applicable for below poverty line Special Persons etc.
7. Medical policy initiated by National Trust.

Parent associations that have members experienced in the field of legal, finance, social welfare should step in to fill this much needed counseling requirement of senior citizen parents. For larger coverage typical formats covering the specific interests of Special Persons can be shared on the internet.

The present generations of parents have less luxury of relying on joint family ties to take care of Special persons after their death. The concern of parents, rich or poor, about the upkeep (after them) of their Special Person son/daughter has to be addressed by today’s parent associations. Therefore building capacity of parent bodies to undertake management of mini ALCs and large ALCs is essential. The documentation of standard procedures followed in good ALCs and training will improve standard of care in other ALCs. The parent bodies also need to generate and share knowledge with individual parents to enable them to handle fiduciary matters and make informed choice while bequeathing their wealth.

***After Me Who Will Care!***

*Answer: Well managed parent bodies bequeathed with fair share of my assets.*

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