

CHAPTER V

SUMMARY CONCLUSIONS RECOMMENDATIONS

The fundamental purpose of management is to bring about change in an orderly manner. The change may be the result of freely chosen goals or of adjustments to the forces beyond the control of the individual or family, such as is in the case of a person born with some physical disability or affected by it sometime during the life.

The adjustments have to be made by the disabled persons themselves but the extent to which they succeed in achieving proper adjustments is very much dependent upon the family in which they live. At no time in the history of human race, there has been so much national and international interest in finding a solution to this problem. The year 1981 had been declared by United Nations as the International Year of Disabled Person. The research activities and the welfare programmes gained impetus during this year.

A lot has been done to identify the problems that beset the disabled person and their families, both in India and abroad. The investigator, however, did not come across a single study on the management problems and practices of the families with disabled family member, carried out in India. However, research studies have been conducted abroad on some of the aspects of management problems and practices of disabled homemaker specially, and impact on management of families with disabled family member in general.

Statement of Problem

The topic under consideration is to identify the management problems and resulting practices of the families with a disabled member in the family. Disability of a family member is a major crisis in the family which leads to a number of psycho-social and managerial problems. The attitude of the homemakers towards disability may reduce or aggravate the extent of problems experienced by them. The problem situation thus created may either motivate the family to set forth the goals for the rehabilitation of the disabled member or neglect him in despair. The goals set and the resources available form the inputs to the managerial system and give direction to the plans and organization of action to be taken. The plans need to be implemented to bring about the output in form of extent of rehabilitation of the disabled person and the adjustment made by the family. Thus the focus of the study is on identification of the managerial behaviour of the homemaker in meeting her problems.

The findings of the study aim to draw attention of the planners at both the central and state government level and the social welfare institutions towards the need felt by the families to cope up with the disabled persons. The results can therefore be used to stimulate the creation of new services for the welfare of the disabled and their families and extension of those which already exist.

Objectives of the Study

The specific objectives of the study were :

- 1) To identify the management problems faced and practices followed by the homemakers with the

disabled family member.

- 2) To determine the factors which influence the management problems and practices of the homemakers with disabled family member.
- 3) To analyze the attitudes of homemakers towards disability.
- 4) To study the interrelationship among the extent of problems faced by the homemakers, adjustments made and the attitude of homemaker towards disability.
- 5) To evolve suggestions :
 - a) for homemakers to cope up with the problems they face.
 - b) for social welfare agencies to improve their services.

Method of Procedure

The population of the study comprised of the families of disabled person in the city of Vadodara. A pilot study of 50 families was made to assess the extent of disability of the disabled in order to select the sample and to establish the validity and reliability of instruments prepared for the final study. A stratified purposive random sampling method was used to select a sample of 50 families keeping in mind the disability and age of the disabled person. On the basis of the results of the pilot study, non-probability purposive, quota sample of 25 families was chosen keeping in mind nature and extent of disability and age of the disabled family member. The sample consisted of five orthopaedically handicapped, five blind, five deaf-mute, five mentally retarded and five people suffering from cerebral palsy.

Data were collected by personal interview and observations of the selected household in order to develop case studies. The research tools used to collect data were: an extent of disability scoring sheet, a descriptive rating scale, a Likert type attitude scale and a guided interview schedule. The data were analyzed with the help of descriptive as well as relational statistics. Frequencies, means and percentages were used to describe nature, cause and extent of disability, problems faced by the homemakers, practices followed by them and their attitude towards disability. Relational statistics was used to study the relationship between selected variables. The tests used were, t-test, chi-square, Pearson's product moment correlation and partial correlation.

Major Findings of the Study

On the whole the deaf-mute group had lowest disability scores and the cerebral palsy group had the highest. The extent of disability of the disabled person affected the problems faced by the family although the relationship was not significant. The practices followed to solve the problems arising due to disability increased with the extent of handicap.

Problems Faced by the Homemaker.

The main problem which worried most of the respondents was "care and attention of the disabled person in future". Most of the respondents found it difficult to cope with the demands of the disabled person but it was more so in the case of families who had completely dependent disabled person. Nearly three-fourth of the families experienced frustration in reducing the disability of their family members. The fear created by having

one disabled child was the psychological block in having more children in some of the families.

The social contacts of the homemaker were restricted due to the constraints imposed by the dependence of the disabled member. The father and the siblings showed tendency to over protect rather than neglect the disabled member in most of the families. The inadequacy of facility for day-care of disabled person was also felt by the parents of the families. Some families also felt that provision for college education should be made for deaf and dumb persons also. Need for more vocational training centres for the disabled was also felt by majority of the families. To find a suitable marriage partner was the problem faced by most of the families and to find a physically fit one was even greater.

The families found it difficult to save money in most of the cases. Lack of funds came in the way of securing special training, special medical treatment, buying special equipment and investing in self-employment of the disabled person in some of the families. The expenditure on hospitalization varied from Rs.400 - 3000. The special treatment of disabled person was discontinued in majority of the cases due to heavy expenses involved in transporting the disabled person to and fro. The time costs involved were also the cause of discouragement. The families who had to keep constant watch on the disabled person found it difficult to work without interruption.

Practices Followed by the Homemaker.

Self-reliance of the disabled person in his day-to-day activities was one of the most common goals for rehabilitation of the disabled person in the family. Self-employment for the

financial independence of the disabled person was also the goal set by majority of the families. Education and vocational training for the disabled person were also among the goals set by families with younger children.

The joint pattern of decision-making was prevalent in most of the cases. With regards to treatment and education, parents ~~made~~ the decision, while the decision regarding employment and marriage were ~~made~~ by parents in consultation with the disabled person. The disabled family member had a say in making all decisions if he was an adult. The mothers in some cases were very much committed to the progress of their children and were able to achieve success in reducing the problems to certain degree.

The families used their savings as well as borrowed money from relatives or employers for the treatment of the disabled family member. Some mortgaged the jewellery of the homemaker to finance the expenses, while siblings took up employment or the father did overtime work to meet the financial crisis. Measures taken by family for the financial security of the disabled person were in form of provident fund, insurance, investment in property and business.

Homemaker did not get enough rest, sleep and leisure in cases of severely disabled person. The rest and sleep varied from 6-8 hours while leisure time varied from 1-5 hours per day. The help received by the homemaker for the care of the disabled person was from grown up daughters, husband, sons, neighbours, friends and relatives. Hired help was used by only two families in care of the disabled person. The hired help was used by majority of the families in household work although family members and relatives too helped.

All families tried to acquire information regarding better care of the disabled family member. All families tried to treat the disabled person equally and normally. Aggressive behaviour of young disabled children was checked by most of the families.

More than half of the families tried to give some education or vocational training to the disabled persons. A few of the disabled persons were self-employed, few of them had jobs, while some did not get any job even after qualifying and repeatedly trying to secure job.

All except one made special provision for disabled person in the family budget. Families tried to have simpler meals to reduce household work in some of the cases. Standards of the household work were adjusted to suit the amount of time and energy at the disposal of the housewife. Disabled persons were also helping in household work in some cases. Two of the disabled persons were housewives and carried out majority of the household work. Four families made alterations in the toilet facilities to suit the disabled person. Special chair and proper work-heights were designed to meet the disabled person's requirements.

Attitude of Homemaker.

On the whole it was found that the respondents viewed disability with a congenial attitude but were more positive on their reaction to psychological and social aspects rather than education, marriage and special treatment of the disabled person.

Relationship Among Variables.

The attitude of the homemaker had negative relationship with the problems faced by the homemakers and positive relationship

with the adjustments made. It therefore indicated that if the attitude of homemaker was positive, the extent of problems faced by her were less but she made more attempts in order to solve the problems.

The nature of disability on the whole did not have any significant effect on the extent of problems faced but it had significant relationship with extent of psychological, social, educational and employment problems. The age of the disabled person was negatively correlated with the extent of problems faced by homemakers, therefore younger the disabled person, greater the problems faced by the homemaker.

The more specific the goals set by the homemaker for rehabilitation of the disabled person, the less were the problems faced by them. The income of the family was negatively correlated with the extent of economic problems faced by the homemakers. It was also negatively correlated with the problems faced in management of household work. The higher the income the ~~fewer~~ the problems.

The sex of the disabled person did not have significant effect on the extent of problems faced by the homemaker. The homemakers in the joint families faced ~~fewer~~ problems on the whole and specially in the management of household work. The role of the disabled person in the family did not affect the extent of problems faced by the family. The more efforts homemakers made to rehabilitate the disabled person the less was the extent of dependence. There was inter-relationship among problems faced, adjustments made and attitudes of the homemaker.

Suggestions Evolved.

In majority of the cases the ~~homemakers~~ needed help in dealing with the psychological problems they faced and means which they could use to improve their managerial behaviour. Some also needed guidance in finding places and knowing about the opportunities for rehabilitation of the disabled family member.

In majority of the cases suggestions given were found to be helpful and the homemaker improved their management.

Conclusions

The purpose of the study was to identify management problems faced and practices followed by the homemakers, the factors influencing them and the attitude of homemakers towards disability. The conclusions are therefore centered around these three major areas.

- 1) Problems faced by the homemakers.
- 2) Practices followed by them.
- 3) Attitude of the homemaker.

Problems Faced by the Homemakers.

The conclusions drawn in this respect are as follows:

- 1) Lack of awareness about preventive measures on the part of family was the cause given by majority of the homemakers for the disability of their family member.
- 2) All of the homemakers experienced significant effect on the problems faced in adjusting and coping with the extent of disability of their family member in day-to-day activities.
- 3) All homemakers experienced psycho-social problems. The main problems were worry, anxiety, fear, frustration, embarrassment, unhappiness and lack of

understanding. The mixed socio-economic group of children was the cause of worry for some parents.

- 4) The dependence of the disabled person imposed restrictions on the extent of social contacts of the respondents. Those who had severely disabled person and did not have help from relatives and in form of servants were facing this problem to a greater extent.
- 5) The homemakers experienced increased demands on their time and energy as the care of disabled person took up extra time and the problem was more so with disabled person who needed constant attention.
- 6) A need was felt for increasing educational and vocational training centre for the disabled. Provision for higher education facilities for deaf-mute was also felt.
- 7) Unemployment of disabled person was a source of anxiety for the family. The families felt the need of providing better job opportunities for the disabled.
- 8) The nature of disability also affects the problems faced by them. The extent of disability was found lowest in deaf-mute and highest in cerebral palsy group. The extent of problems are more if the child is young but not as a function of sex or role of the disabled person.
- 9) The income and type of the family also affected the problems. As the income increased the extent of problems faced were less. High income families whether single or joint did not have much of problems. Middle and low income single families especially experienced more problems. Joint families face less problems than the nuclear families. In single families if the extent of disability was more, and the child was young the family experienced more problems.
- 10) All families faced financial problems to a certain extent. The problems were severe in lower income families than higher income.
- 11) The problems faced in management of household work too were less in higher income and joint families when compared to lower income and single families.
- 12) The attitude of the homemaker towards disability greatly affects the problems she faces. The more positive the attitude, the less the problems.
- 13) The families who were not aware of the facilities and opportunities for the disabled persons were facing more problems.

- 14) The families felt need of day-care and/or residential centres for disabled children. The families with cerebral palsied children felt the need more acutely than others.

Practices Followed by the Homemakers.

- 1) Families who had set realistic and specific goals made better adjustments.
- 2) Joint decision-making was more prevalent in the families. The adult disabled person also participated in decisions concerning their needs.
- 3) The extent to which the families were able to accept the disability as challenge varied from one family to another.
- 4) Family members, friends and neighbours extended help to the homemaker in most cases for care of disabled person and/or for household work.
- 5) Families tried to provide formal education and vocational training to the disabled family member in order to make him/her financially independent and for those who could not be trained or educated the family made attempt to invest in securities for the benefit of the disabled family member in future.
- 6) Families resorted to credit, supplement income and cutting expenses on some essential as well as luxury items in order to meet the expenditures. Some took help of social welfare agencies to meet cost of treatment.
- 7) Families tried to have simpler meals to reduce housework and made adjustments in their standards of work when pressed for time.
- 8) The need was felt for social institutions with better facilities and care for families who could afford to pay for it.
- 9) The disabled family member was made to feel as useful member of the family by allowing him/her to help in simple household tasks.
- 10) Families provided physical facilities to suit needs of the disabled person.

Attitude of Homemaker.

- 1) Most of them had positive attitude in viewing the disability although some of them had more positive attitudes.
- 2) The attitude of the homemaker plays a vital role in rehabilitation of disabled person as it affected the problems experienced and adjustments made. Therefore development of positive attitude towards disability was found to be very important for optimum rehabilitation of the disabled person.

The homemakers were given suggestions to solve some of their problems and were asked whether the suggestions were helpful to them or not. It was found that in majority of cases they proved to be helpful in improving their management.

The results of the follow up study revealed that the families can tackle the problem of rehabilitation of the disabled person when they become aware of where to seek advice, ways to reduce work, ways to seek financial help and improve their resource management in general.

Recommendations

The recommendations of the present study fall under following major categories :

For Educators in the Field of Home Management.

Educators in the field of Home Management should **emphasize** following competences in order to help families with disabled family member and for disabled homemakers themselves.

Competences to be developed by the families should be as follows:

- 1) Positive attitude of family and society towards disability helps to reduce psycho-social problems.
- 2) Acceptance of disability as a challenge by family helps disabled to develop his residual physical resource to the optimum level.
- 3) Encourage him to move, dress, feed and carry out all daily routine activities with minimum help.
- 4) Mobilize resources to secure physical aids which can make disabled person self-reliant.
- 5) families should take interest and find necessary information in order to educate, train and help disabled person to become financially independent.
- 6) Families should take interest in establishing the emotional security of the disabled family member.
- 7) Families should become aware and take maximum advantage of benefits and facilities provided by the community, and government to help the disabled financially, educate him, train him, provide recreation and care for him, and save family resources for other goals.
- 8) Homemakers should improve their time and work patterns in order to meet the increased demands and not feel pressures of time.
- 9) Homemakers should be made to realize the importance of investment of funds in, and maximum utilization of time and labour saving equipments, in reducing the time and energy problems of the homemaker.
- 10) Homemaker should seek help of family members, friends, relatives and neighbours to utilize the human resources at her disposal.
- 11) Homemaker should learn to substitute other resources to save money wherever possible. Families should find ways to supplement family income.
- 12) Families should set forth realistic goals.
- 13) Families should seek guidance and help from professional persons rather than waste money on misleading guidance of well wishers.
- 14) Homemakers should seek professional guidance in understanding the disability and develop coping skills to help the disabled person.

Competences to be developed by the disabled homemakers should be as follows :

- 1) Disabled homemakers should be made aware of better ways to adjust their work and work methods to suit their limitations.
- 2) Homemaker should be encouraged to use correct work height.
- 3) Homemakers should be advised about special tools they can use.
- 4) Homemakers should be encouraged to utilize time and labour saving devices which suit their limitations.
- 5) They can use special clothes which help dressing and undressing without much effort.
- 6) Homemakers should be trained for carrying out household tasks even with their limited physical capacity.
- 7) Simplifying work becomes more important for disabled homemakers.

For Social Welfare Agencies.

The needs felt by the families centred around increasing the number of institutions and organizations as well as improving the existing ones for the disabled people. The need was felt :

- 1) To start a special institution for cerebral palsied children.
- 2) To provide speech therapy in English as well as regional language.
- 3) To give opportunity to deaf-mute people for higher studies.
- 4) To extend the facilities and benefits to the deaf-mute which are extended to blind and orthopaedically handicapped such as travel concession.
- 5) Pre-natal clinics to provide proper guidance to pregnant women in order to prevent disability.
- 6) More day-care facilities should be provided for all types of handicaps so that the homemaker can have help in the care of disabled family member.

- 7) Guidance and counselling facilities for the parents of the disabled so that the home environment can be improved.
- 8) Help should be extended to the disabled as well as his children for education and employment.
- 9) Preventive measures should be intensified to stop disability caused by infections and sickness.
- 10) Social welfare agencies should intensify membership drive so that more and more people can be benefitted by their guidance and help.
- 11) While planning services for the disabled one should keep in mind that they are normal part of society and do not exist as a group apart with separate lives.
- 12) The disabled also have same right and needs as any other person and their problems should be considered as a part of the society.
- 13) The services planned should have a holistic approach and regard handicapped person as a whole, physically, mentally, socially and emotionally rather than confined to his physical handicap only.
- 14) Plans should be made with and for the disabled person on the basis of abilities not disabilities and of capabilities not limitations to develop his assets to optimum level.
- 15) Care and treatment services should be a teamwork of highest order. Professional personnel in medical therapeutic, educational, social and vocational adjustment fields should form the team.
- 16) The Home scientist as a team also can help to design and manage services for families of the disabled to augment their own resources and make their unique contribution to the society. They could provide :
 - 1) Care for the handicapped to allow families to get away for vacations or even an evening out.
 - 2) Counselling to help families cope with their own emotional expectation, resentments, fear, love, guilt and shame.
 - 3) Educational programs to help families develop long-range financial plans to accomodate disabled family member.
 - 4) Emergency help for families of the handicapped when there are unusual circumstances, such as illness, surgery or absence of the caretaker.

- 5) Develop programs which are not just custodial but offer recreational and life skill programmes.
- 6) The area of suitable clothing, housing and household equipments for the disabled should also be incorporated in guidance services.
- 7) Home scientists can serve as go between for community services and organizations by learning about the services each offer and disseminating information to families who need it.

For Further Research

The research in various aspects of management problems and practices can be carried out in order to develop conclusive results.

- 1) A detailed study of problems of each type of handicaps and the factors affecting them.
- 2) A study of time and activity pattern of families with cerebral palsied children.
- 3) A study of time and activity pattern of families with young disabled child.
- 4) A study of money management problems and practices of families with disabled person especially in low and middle income groups.
- 5) A study of family's awareness and utilization of the services being provided for the disabled people.
- 6) A study of problems of disabled person according to their role and position in the family.
- 7) A comparative study of problems and practices of joint and nuclear families with disabled family member.
- 8) A study of extent of participation of different family members in care and attention of disabled family member.
- 9) The study on organization process used by the homemakers in distributing tasks in the families with disabled person.
- 10) The study of nature and extent of disability on extent of problems faced by the family.

- 11) A study of certain personal characteristics of the disabled such as age, sex, role, period after onset of disability, his education and employment status and the extent of problems faced by the families.
- 12) A study of attitude of people in different walks of life towards disability.