CHAPTER V

SUMMARY OF FINDINGS, SUGGESTIONS and AREAS FOR FURTHER RESEARCH

Summary

The aim of the present study is to find out the result of intervention strategies on the stress levels among the caregivers of the Intellectually Challenged. The parents of Intellectually Challenged children were chosen under four category (ie) caregivers of children affected with Cerebral Palsy, Down Syndrome, Autism and with General Mental retardation.

The study was carried out on the above said population in two groups namely experimental group and control group. Each group consists of 40 in each category ie., 160+160 covering 320 samples. Both the experimental and control group were screened (pre test) with socio demographic profile, stress assessment scale, factors contributing to their stress and the quality of life scale by WHO. Then the caregivers of experimental group were given counselling intervention on the knowledge about the affect, stress undergone by them, handling stress and mental health maintenance.

Assessment on the above said scale is once again (post-test) administered to both the groups (ie) experimental group for whom intervention was given and the control group for whom intervention was not given. The result received from both the pre and post scores of both the group gives the effect of Interventional Strategy on stress level among the caregivers of the Intellectually challenged. The statistical processing yielded significant results which helped in arriving at valuable conclusions in terms of the objectives and hypothesis of the study. The various findings are as follows:

The first analysis of the demographic profile of the respondents was about the sex of the respondent and it was found that male and female were 40% and 60% of the control group and that of experimental group was 43.8% and 56.3%. Female caregivers were more in both the population and there is no significant difference noted. Age of the respondent showed that the number of respondents below 36 yrs
and the age group between 36 to 44 yrs and 45 yrs and above in control group wn 26.3%, 51.9% and 21.9%. In experimental group 26.9%, 43.8% and 29.4%. In both the group number of persons under age group of 36 to 44 were maximum and there was no significant difference noted between both the group.

The Religion and Caste of the respondent when studied shows that the majority of them in both the control and experimental group were Hindus with a percentage score of 87.5% and 82.5% and majority of them belong to the backward community (ie) 69.4% and 74.4%. No significant difference was noted between both the groups on the variable studied.

The educational and occupational status of the control and experimental group showed that majority of the respondents were educated below +2 category (ie) 55.6% and 49.4%, and number of unemployed person were more (ie) 34.4% and 33.1% which indicates that the mothers would be the majority of caregivers for the intellectually challenged children. There was no significant difference noted between both the groups with respect to educational and occupational status.

The type of the family and consanguinity of the respondents when studied shows that No. of persons living as Nuclear family were greater (ie) 83.8% and 79.4% with respect to the control and the experimental group and there is no significant difference noted with respect to consanguinity. In control group, blood related parents were greater that is 57.5% and non blood related parents were greater in experimental group that is 56.5% and there was significant difference noted between both the groups.

The place of living and the total number of persons in the respondents’ family when analysed shows that there was no significant difference noted between both the groups. Majority of them belong to urban setting ie., 91.9% and 95% with respect to the control and experimental groups. Number of members in family was studied and it showed that 4 members in the family were majority with 59.4% 53.8% in both the groups.

On analyzing the factor of working person in the respondents family, their family income and any history of mental illness if exist, it was found that majority of
the respondent in both the control and experimental groups were with single earning member in a family of 65.6% and 63.1% and they belong to middle class income group of people earning between Rs. 81,000 to Rs. 1,72,000 with 50% and 47.5%. There was the history of mental illness traced in both groups with 90% and 91.9%. There was no significant difference noted between both the groups in all the three variable studies.

Age, education and occupational status of the spouse of the respondent showed that there was no significant difference noted between both the groups, the control and experimental. The maximum number of persons were in middle age group 30-44yrs. with 38.8% and 41.9% and their education were below +2 (ie) with 55.6% and 46.3%. Majority of them were employed in private organization (ie) 33.1% and 27.5% with respect to control and experimental group.

The status of the child when analysed on the factors of sex of the child, age of the child and order of the child birth it was found that majority of the respondents children were male in both the control and experimental group with 67.5% and 65.6% and their age were between 10-16 yrs with 48.1% and 46.9%. Majority of children were first born to their parents whose percentage score was 61.9% and 61.3% respectively. There was no significant difference between both the groups on the three variables studied.

RH compatibility of the mother, nature and type of delivery of the mothers of the intellectually challenged when analysed in both the control and experimental group. It was found that the majority of the mother 87.5% and 92.5% showed RH positive and delivery at right time was more by 73.8% and 84.4%. Normal delivery was more in both groups by 64.4% and 61.9%. There was no significant difference noted between both the groups on the variable RH compatibility and nature of delivery. There was significant difference noted in the type of delivery. Though normal delivery was more in both the groups, caesarian delivery when compared with both control and experimental group showed greater percentage (23.8%) than that of the control group (10.6%)
The condition of the child at the time of delivery and Developmental milestone when screened it was found that the maximum number of respondents said that their child did not suffer from Birth Asphyxia (ie) 83.8% and 81.3% in both the control and experimental groups. In the achievement of developmental milestone, majority of the children has shown delayed developmental milestone in both groups (ie) with respect to achievement of head control 75.6% and 65% sitting achieved on delay by 78.1% and 69.4% delayed walking achieved by 83.1% and 80% on the whole there was no significant difference noted on the variable studied (except on the achievement of Head control) in both the control and the experimental groups.

The IQ status of the child, affect of serious illness between 0-2 yrs and affect of seizure disorder when analysed gave a result that the majority of the respondent children taken for the study belong to moderate level of retardation 62.5% and 58.1% and the majority of the children who were affected by any kind of serious illness (0-2yrs.) 60.6% and 55% and no episode of fit was experienced by 62.5% and 66.3% of the control and experimental groups. There was no significant difference noted in both the groups on the variable studied.

The associated problems with retardation such as that of vision, hearing and hands/legs when studied gave a result that there was no significant difference noted between both the control and experimental group. Majority of the respondents’ children reported no associated problem except few and they were mainly that of C.P. children. Percentile value of children not affected in eye sight was 82.5% and 83.1%, hearing problem reported by 90% and 95%. No defect of hand/leg was reported by 61.9% and 71.2%.

The conception period of the mother, the time of identification of the problem and age at which the training was started showed significant difference between the control and experimental groups. The conception period of the mother showed moderate period of conceivement more (ie) 56.9% and 38.1%. The time of identification was responded more in Moderate level (ie) 12-36 months by 55% and 68.1%, maximum number of respondent has started training their child by 25-92 months in moderate period by 50% and 65%.
The special education, previous school experience, type of school and duration of training undertaken shows that maximum number of children in both the group has undertaken special education training (ie) 81.3% and 96.3% and No. of children attended school were 78.8% and 94.4%. Special school is being attended by majority of the children 58.1% and 81.3%. Maximum number of children were attending school between 25-72 months was 48.8% and 46.9%. Except the duration of schooling there was significant difference noted between the groups and this could be due to the maximum response from experimental group and maximum respondents in control group. They chose special school / Rehabilitation clinic and hospital.

The Distribution of the sample between the control and experimental group was distributed evenly (ie) 40 sample in each category (ie) caregivers of cerebral palsy with mental retardation, Down syndrome with Mental retardation, Autism with mental retardation and children affected with General mental retardation. This could facilitate the study effectively to see the impact of the interventional model conducted for the experimental group. The Analysis of Socio demographic profile on the whole for control and experimental group shows homogeneity of the groups which proves to be right base for the study.

The second part of the analysis was to show that the number of stressors of the overall population in control and experimental group in their pre and post test analysis. Here the maximum score scored by the group was taken into consideration and it was found that the majority of the group in the control and experimental group were facing higher level of stress even on holidays and they were uncertain of coming days. The day to day social customs too laid stress on them. They were affected physically and mentally and it affected their sleep. The need to earn more was also stressed by the family. Most of them in both the groups were worried about the marriage of their children and the presence of disabled child prevents them from participating in social activities.

In the majority of statements there was no difference in pre test scores of both the groups whereas in the experimental post test, there were significant difference noted in most of the statement which has evidently issued that the counselling offered to them have brought forth the desired change to some extent.
On analysis, the degree of stress on the various factors found that the majority of the persons taken for the study in both control and experimental showed higher degree in factors like, wish to know more about the condition of the child, the daily chores and maintenance, family bond and relationship affect, the need to know about educational factor felt by both the groups, and the social involvement in the field of Rehabilitation and Recognition of the special child was regretted. Most of them were under monetary pressure and they needed money to meet with the medication, therapy and training process. The physical and mental status of both the groups was highly affected and they were worried about their future. The expectation of Government intervention in the field of intellectually challenged is much desired. Though there are many schemes for disabled the intellectually challenged is still deprived of any such help.

On the analysis, of the result got in pre and post test scores of the control and experimental groups, it was found that the degree of stress on various factors did not show much difference in pre and post test value of the control group. But with respect to the experimental group there was significant difference noted. The counselling offered to the experimental group had imparted enough knowledge regarding the disability of the children and guidance to managing strategy. Counselling was also focused on the Behavioural aspect, mental health maintenance, problem solving technique, Relaxation technique that they could relieve them from the heavy pressure of stress. Attitudinal training imparted has motivated the caregivers to take things positively. Thus the post test of the experimental group showed the lesser degree of stress on various factors taken for the study.

The analysis of the Total number of stress based on the socio demographic variable revealed. That there was significant difference noted with respect to the Total number of stress experienced by the four different categories within themselves. The maximum stress was experienced by the caregiver of the Cerebral Palsy followed by Downs, Autism and then the caregiver of the general mentally retarded children. There was significant difference noted on the factor of education of the spouse of the caregiver of Down Syndrome and the caregiver of the mentally retarded children. And also with respect to occupation of the spouse there was significant difference
noted with the caregivers of Cerebral Palsy children and the caregiver of the Autism children and within the same group. There is significant difference noted during the conception periods of the mothers. In all the other socio demographic variable there was no significant difference noted with respect to the contribution of stress within the categories studied.

The socio-demographic variable in relation to the degree of stress on the factors studied showed that there was significant difference noted within the four categories taken for the study. The degree of stress on factors studied ranked in the order such as caregiver of Cerebral Palsy showed by the degree by 24.30 followed by Down syndrome, Caregivers by 20.38, Autism by 19.43 and 14.85 by general Mental Retardation. The next significant differences are noted in the occupation of the spouse of the caregivers in relation to the degree of stress on various factors studied. The difference was noted within the group of caregivers of Cerebral Palsy children, Down syndrome and the parents of Autism children.

There was significant difference noted in the order of child birth within the three categories such as caregiver of Cerebral Palsy, Down syndrome and the Autism. In all the other socio demographic factors there was no significant difference noted within the category with respect to the Degree of stress on the various factors taken for the study.

The Analysis on the Total Quality of life of the population studied in relation to the socio-demographic variable showed that there is significant difference noted within the four categories studied. The Total Quality of life was high for the caregiver of the mentally retarded children, followed by caregivers of Autism, Down syndrome, and CP Children. There was significant difference noted within the caregiver of Cerebral Palsy and the caregiver of the Down syndrome children with respect to the conception period of the mother. On all the socio demographic variable there was no significant difference noted within the category of study with respect to the Total Quality of life.

Thus the study has reached the objectives taken for the study (ie) to study the socio demographic profile, to screen the stress levels on the category chosen for the
study and assess the factors contributing to the stress and the Quality of life of the caregivers taken for the study, the counseling intervention module to be created to reduce the stress level for the chosen population. The study has proved the hypothesis framed (ie) the homogeneity of the population taken for the study in both the control and experimental with no significant difference in majority of the factors except one or two. The pretest scores of control and experimental group showed no significant difference within each other. The significant difference in stress level and quality of life was seen in experimental group after the counselling procedure.

The post test scores of control and experimental group showed significant difference within both the groups in Total.

The control group post test did not show any significant difference when compared to that of the pre test.

The intervention strategy had proved its impact on reduction in the stress level and improvement in the quality of life. There was significant difference noted within the four categories taken for the study with respect to stress level, Degree of stress on various factors and Quality of life.

The third part of the analysis was to see the difference between the pre-test and post-test score of both the group to find whether the intervention of counselling has altered the stress level of the caregivers of the intellectually challenged children under four categories in both the groups. The result observed showed in six factors, ie.,

(1) Result observed in caregivers of CP children.

(2) Result observed in caregiver of Down syndrome children

(3) Result observed in caregivers of the Autism children

(4) Result observed in caregivers of children affected with mental retardation.

(5) Result observed in pre and post test scores of overall population studied in both control and experimental group.
The mean difference noted in pre and post test scores of all the four categories of the control group did not show significant difference with respect to factors, number of stressors, degree of stress on various factors and quality of life in all the four categories and total general population too, whereas a significant difference was noted in experimental group on all the factors after the intervention of counselling given.

When analyzing the inter relation among the four categories it was found that the caregivers of C.P. children had greater number of stressors than the other three groups (i.e.) 36-95 and 31-40 in the pre and post test evaluation of the control group and 34.56 and 21.60 on the experimental group. The degree of stress on various factors too ranked high for caregivers of the cerebral palsy children (i.e.) 28.20 and 28.47 in pre and post test scores and 26.10 and 24.30 of the experimental group where counselling was offered. The quality of life of the cerebral palsy caregivers were less than the rest of group taken for study in all the five dimension such as physical health, psychological, social relationship, environmental and the total with a mean difference of -1.72, .90, -1.40, -1.35 and 0.89 without significant level.

In experimental group of the C.P. children parents, the quality of life was lesser than that of the rest of the other 3 category but there were significant difference noted in the pre & post scores after counselling intervention. The quality of life under five domains mentioned above showed a mean difference of -12.92, -11.62, -21.90, -17.10 and -15.89.

The second group to undergo maximum number of stressors was the caregivers of the Autism children. The control group pre and post-test score is number of stressors were 33.30 and 33.43 with a mean of .87 and the degree of stress on various factors were 28.22 and 27.62 and that of the experimental group was 35.45 and 13.95 and 27.43 and 19.43 with respect to quality of life. The control group showed a mean difference in five domain such as physical health 1.87, psychological 1.15, social relationship 7.85, environmental -1.10, QOL total 2.44 whereas the experimental group for whom significant difference was noted showed a mean
difference of all the five domain of quality of life was -15.87, -15.97, -8.37, -1.80, -15.51.

The third level of maximum stress and factors contributing to stress was shared by both the groups (ie) caregiver of the Down syndrome children and the caregiver of the general mental retardation affected children.

The analysis of the caregivers Down syndrome children shows the number of stressors in pre & post test is 29.88 and 29.64 with a mean difference of .22. The degree of stress on various factors was 23.88 and 23.90 with a mean difference of 0.02. The quality of life on various factors showed a mean difference of 4.60 in physical health, 1.72 in psychological 2.20 in social relationship, -2.00 in environmental and 1.63 with respect to QOL, Total.

On the whole there was no significant difference noted in maximum number of factors.

With respect to the experimental group of Down syndrome caregivers there was significant difference noted between the pre and post test scores in all the factors studied, where it is evidently proved that the interventional strategy of counselling has remarkably reduced the level of stress and has enriched the caregivers in handling the factors contributing to the stress. The quality of life has also increased to the level of significance. The mean difference noted on all the factors between the pre & post test score are, the number of stressors in pre & post test scores are 83.80 and 18.85 with a mean difference of 14.95. The degree of stress on various factors was 26.48 and 20.38 with a mean difference of 6.10. The quality of life on various domains had a mean difference of -15.47 in physical health, -15.72 in psychological, -16.87 in social relationship, -8.75 in environmental and -14.21 in QOL Total. There was significant difference noted in all the factors.

The caregivers of the mentally retarded children in general category on analysis show that the control group in pre and post test score showed significant difference in certain factor which could be caused due to certain natural factors without separate interventional strategy. The No. of stressor in pre and post test score were 31.85 and 30.85 with a mean difference of 1.35. The degree of stress on various
factors was 22.30 and 23.80 with a mean difference of -1.50. The quality of life on various domains showed a mean difference of physical health -7.02, psychological -1.92, social relationship -3.27, environmental -0.45 and QOL Total -3.17.

The experimental group showed a significant difference in all the factors in pre and post tests score and the number of stressors is 31.23 and 8.95 with a mean difference of 22.27, Degree of stress on various factors such as 23.33 and 14.85 with a mean difference of 8.47. The QOL showed an improvement in all the domains shown with a mean difference such as physical health -15.47, psychological -18.45, social relationship -16.25, environmental -12.00 and total quality of life as -15.54.

As from the above summary it was clearly found that the high level of stress was experienced by the caregivers of the cerebral palsy children and next by the caregivers of the Autism children followed by caregivers of the Downs children and the caregivers of mentally retarded children caregivers. In all the four groups the intervention has shown significant difference in their post test with a reduction in their stress level and an improvement in their quality of life.

The overall population of the study shows that the number of stressors in the pre & post test of control group was 32.99 and 30.99 with a mean difference of 2.00. The degree of stress on various factors was 25.65 and 25.95 with a mean difference of -0.30. And the quality of life on the pre and post test showed no significant difference in all the domains where interventional strategy was not followed. Whereas in experimental group it was found that there was significant difference in the level of stress and the degree of stress on various factor in their pre & post test such as 33.76 and 15.84 with a mean of 17.92 and degree of stress in factors as 25.83 and 19.74 with a mean difference of 6.09 and the quality of life of the experimental group has significantly improved in all the domains such as physical health, psychological, social relationship, environmental and the Total quality of life.

Conclusion

The present study of the impact of counselling on the caregivers of the Intellectually Challenged concludes the vital findings studied under four sectors (ie) (i) the socio demographic Profile studied, (ii) the stress level and the factors
contributing to the stress; (iii) The pre & post test scores of both the control and experimental group on all the factors studied (ie) the stress level, the Degree of stress on factors studied, (iv) The Quality of life in the domains of physical health, psychological, social relationship, environmental and the Total Quality of life, (v) Analysis of Socio demographic profile on the stress level, Degree of stress on factors studied and the Total quality of life of the experimental group.

Analysis of Socio-demographic profile of the caregivers of the Intellectually Challenged showed that the majority of the caregivers in both groups were female and they belong to the age group of 36 to 44 years. With respect to Religion and Caste most of them were Hindus and they belong to the backward community, the education and occupational status reveals that most of them in both groups were educated below +2 level and majority of them were unemployed.

The type of family and consanguinity among the caregivers show that majority of the population studied belong to the Nuclear family and with respect to consanguinity, in control group majority of the caregivers were related by blood and in experimental majority of them were not related by blood.

The place of living and the number of persons in the family shows that majority of the population belong to the urban settings except very few in the rural environment. The number of members in a family ranked high in a family of four members in both the control and experimental groups.

Number of persons working in a family was found to be only one member working in most of the families and the family income was mostly between Rs.81,000 and Rs. 1,72,000. No history of mental illness or defect was observed in the population studied.

The details of the spouse of the caregivers showed that most of the caregivers spouse was under the Age group of 36-44 yrs and they were educated below +2. The occupational status revealed that majority of them was unemployed, working in private organization and self employed in both the control and experimental group.
The details related to the child reveal that the majority of the caregivers had a male child, first born and their age group fall between 10 and 16 yrs., in both the control and the experimental groups.

The RH compatibility, nature of delivery and the type of delivery in which the child was born showed that most of the mothers had a RH positive blood group and they have experienced a delivery at the correct time in a normal mode, in both the control and the experimental groups.

The condition of child being affected by Birth Asphyxia was mostly reported No in both the groups. But the developmental screening showed that the milestone of Head control, sitting and walking were all delayed to maximum number of children whose caregivers were taken for the study.

The physical and mental analysis of the child revealed that the maximum of children whose caregivers were taken for study was affected by moderate level of retardation and there was no episode of any serious physical ailment or fit problem in the majority of the children except few preferably the children affected by cerebral palsy or brain damage showed the affect.

The associated problem of eye sight, hearing and motor (hands/legs) among the children showed that the maximum number of caregivers, children did not show associated affect on the above condition except few identified in motor co-ordination of Hands/legs preferably found in the children affected with the cerebral palsy.

The analysis of conception period of mother, time of identification and age at which the training started showed significant difference in both the group statistically but practical not level of significance noted since majority of the mothers in both a group conceived the child between a period of 7-48 months and identification of the child problem was done during the period of 12-36 months. The training was begun for their child by maximum number caregivers was between 25-72 months in both the control and the experimental groups.

The detail regarding previous special educational training, school experience, type of school and duration of training revealed the maximum number of students
have attended school mainly special school and special education training and the
duration of training experienced by maximum number of children were between
25-72 months.

The sampling distribution is in even order in all the four category studied (ie)
40 in each of caregivers of cerebral palsy children, Down syndrome, Autism and
general mental retardation.

There was no significant difference noted in the study of socio-demographic
profile of the caregivers of the intellectually challenged which indicate the
Homogeneity of the group noted for an effective study. Though there was significant
variation noted statistically in a very few socio-demographic profile there was no
practical level of significance between both the groups.

The second part of analysis shows the stress level of both the control and
experimental group with pre & post test scores and the stress levels was found to be
more or less same in the pre test scores for both the groups whereas remarkable
variation issued in the post test score of the experimental group for whom counselling
intervention was followed with the knowledge input given with attitudinal training
and Rehabilitation support rendered has reduced the stress level of the experimental
group. Whereas there was no significant changes in stress level of the control groups
pre and post test scores for whom no intervention technique introduced.

The analysis of Degree of stress on various factors contributing to the stress
showed that the degree of stress on vital factors was almost the same in pre-test scores
of the control and experimental group. After the intervention of counselling it was
found that the Degree of stress on various factors was reduced. The third part of
analysis was to study stress & degree of stress on various factors along with Quality
of life separately for all the four categories. The study revealed that there was
homogeneity in scores for both the groups in the pre-test for all the four category and
the post test score of experimental group revealed significant variation in the factors
studied for whom the intervention of counselling strategy, has brought forth the
change in lessening of stress level and improvement in the quality of life whereas in
the pre and post test scores of control group there was no significant difference in all
the four groups except significant variation in one or two factors which could be due to natural phenomenon or changes in one's life. But in the majority of the factors there was no significant difference noted between the pre & post scores in all the four category.

The overall population of control & experimental pre & post test scores reveals the fact that there is no significant difference in control pre and post test scores and significant difference was noted in pre & post test score of the experimental group for whom counselling was offered and the stress level has been reduced & the quality of life has been improved. The mean variation found among the pre & post test scores shows the difference in a clear way.

On overall analysis, the higher level of stress was experienced by caregivers of cerebral palsy followed by caregivers of the Autism then Down syndrome and lastly the caregivers of the general mental retardation. In all the four groups interventional strategy applied to the experimental group showed significant difference in pre & post test score which shows that the stress level of the caregivers has been reduced and the quality of life of them have been improved considerably though there were one or two level of statistical significance in the control group. It could have occurred due to the natural process in one’s walk of life.

In the final part, the experimental post test scores were taken for analysis. The relationship between the level of stress and socio-demographic profile show that there is significant relation with respect to the total number of stress within the four category in the order of caregivers of cerebral palsy, followed by Downs syndrome, Autism and general Mental retardation except the educational status of spouse, occupation and coceiving period of the mother. All the socio-demographic factors did not show any significant relationship with respect to the total number of stress.

Analysis of the degree of stress on various factors with socio-demographic too showed a significant difference within the four category chosen for the study, regarding occupation of the spouse and the order of birth of a child. In all the other factors there was no significant difference noted in the total quality of life with that of the socio demographic profile taken for the study.
Thus the study concludes reaching the objectives of the study focusing on the socio-demographic profile of the caregivers of intellectually challenged. Evaluation shows that the total number of stressors, the degree of stressors on various factors and the quality of life, the impact of counselling studied through the post list score, and verified with the hypothesis tested, proved positive as there was no significant difference in the socio-demographic profile of the target population chosen for the study.

> There was no significant difference in stress levels among the caregivers of both the control and experimental group in the pretest (i.e., Initial stage).

> There was significant difference noted between the pre and post test score of the experimental group on all the factors studied after the intervention strategy.

> There is no significant difference noted between pre and post test score of the control group for whom counseling intervention was not given.

> Counselling intervention has proved the reduction in the stress level and improvement of the quality of life of the experimental group.

> There was significant difference noted among the caregivers of children with cerebral palsy, Down syndrome, Autism and Mental retardation with respect to the level of stress, Degree of stress on factors studied and the quality of life.

Thus the study has fulfilled the criteria in proving that the interventional strategy of counselling to the caregivers of the intellectually challenged definitely reduces the stress level and improves the quality of life.
SUGGESTIONS

The possible area requiring intervention as per the present study observations could be split into three levels namely individual, family and the community.

The perception of intellectually challenged children indicated certain levels of impact in their family environment and the quality of life was under affect, the areas of the family environment in which predominant problems persisted were conflict, achievement orientation, intellectual-cultural orientation and control. Regarding the quality of life the pathologies were indicated and included expectation, achievement congruent, confidence in coping, family group support, social support and primary group concern under the category physical, psychological, environmental, social and total quality of life. Thus the negative attitude existing among the caregivers of the intellectually challenged children of their own families and self was evident. Even though the problems perceived at the family environment level may be existing in reality as well, the concern of health professional should be the mode of individual’s reaction to such family level problems. The mode of therapies that could decrease the stress level 15 to improve the quality of life concentrating on awareness, creation to understand the problem, and accept the environmental realities, esteem-building, ego-support, problem solving skills and crisis intervention.

- The Health professional I workers could concentrate on giving reality orientation to the caregivers pertaining to their potentialities and limitations by testing their assets and liabilities in terms of qualities, abilities, resources, supports etc., such an attempt may widen the thinking capacity of the caregivers in relation to his social environment. This is also a basic requirement for motivating the active participation of caregivers in the process of Rehabilitation and further therapeutic procedure of the intellectually challenged.

- The problems in mobility identified by the present study warrant the intervention of health workers. The deficiency in mobility was identified mainly in the areas of education and occupational status of the intellectually challenged. Hence the priority task would be to help the patient force for alternative sources to continue their education and occupation. This could be partially achieved by encouraging
mild and borderline case of affected children to learn further education through extension education, literary drive programme etc., Apart from this the patient can be encouraged to improve their potentialities in expressing the skill like doing small work like embroidery, fragrant stick Making, Weaving, Phenyl making etc., which will boost up their morale.

The present study has observed that the caregivers of intellectually challenged were vulnerable to neurotic illness due to higher stress. This indicates the emotional turmoil within them to feel that their child is away a burden to their families, the declining the family-prestige as well as themselves and furtherance of their other children, the lessor value assigned to them by the society. Hence giving a chance to them to ventilate their feelings in this matter could be a basic step. Next the caregivers will have to be helped to attain awareness pertaining to their own and their family’s potentialities and limitations.

The emotional instability of the caregivers could be handled by ventilating their suppressed thoughts of depression and usually they may symbolize their dejected condition through physical complaints primarily for ventilation. This could be followed by attempts to distract the caregivers’ attention from their own problems. Further they could be helped to locate potentialities available within themselves, their immediate social environment, and the hereditary source levels which may boost up their morale. Wherever required, the patient could be involved in reflecting upon the problems of others which will belittle his own problems by comparison.

Family level

As the caregivers of the intellectually challenged indicated problems at their family level, the following could be the possible areas requiring professional attention.

- The prime task would be to adopt crisis intervention technique and help the family to take a sanguine view of the problems. In this regard the family needs assistance to locate or mobilize potential sources within and outside the family to cope with the crisis. If guidance is required they must meet the appropriate professionals for
assistance. Permanent resources to fight against the stressors in future could also be provided.

* The deficient social support perceived by the family member of the intellectually challenged warrants the prime attention. In this regard the family could be supported to gather the various sources of supports available to the family. This can be done by helping the family to recall various crisis situations in the family during the past and the support sources which come to the help. The family members may be hinted at by this attempt, the possibilities of taking initiatives in widening their contacts by finding new contact by organizing functions, inviting people for tea etc., the support of individual family members network at secondary and tertiary level could be analysed. This may help in the enlistment of new resources of support to the whole family also. The present study-observation of definite support perceived by the caregiver from their own family needs immediate attention. This indicates the lack of confidence among the members regarding their own family and the pathetic condition existing in their family. In addition an attempt to build the strong cohesiveness within the family in order to arouse the feelings of units among members. Ultimately this may boost up the confidence of members in their own family.

Community Level

The problems faced by the caregivers of the Intellectually Challenged require an extensive coverage in the wider communities also. The following are few possible avenues requiring attention.

• The planners and policy makers could be assemble to identify the problems faced by the caregivers of the intellectually challenged and discuss widely keeping in view the limitations to be faced with regard to the affect. Accordingly decision concerning programme and plans could be taken.

• The community resources for the intellectually challenged need to be mobilized widely. They include volunteers, youth services, voluntary organizations, literacy movements, adult education campaign, employment and educational opportunities.
• Frequent visits can be arranged by a multidisciplinary health team to screen the children for their Rehabilitation schedule and physical health problem and periodic counselling and guidance for the caregivers.

• The social work activities can be intensified further in the general hospitals. The government hospitals require the extensive services of the social workers wherein the worst hit population groups of the society like intellectually challenged children present their varied types of problems, of both physical and mental health. The records of the intellectually challenged children on cadre wise to be sorted and needs to be maintained regularly. This will facilitate the identification of cases, so that, proper management can be planned in time.

• The socialization problems identified by the present study requires the immediate attention of all those who are concerned with the welfare of mankind and especially the persons in charge of mobilizing the resources of mankind.

• The problems of caregivers of the intellectually challenged children need to be considered not merely as problem of intellectually disabled rather it should be recognized as a social problem and requires wider coverage by various welfare agencies.

• Special programmes at the government level could be initiated towards the upliftment of the respondents, like providing priorities in the social environmental settings, educational institutions, special educational kits/aids for education, transportation facility, self employment scheme which could be implemented to support in family level and themselves.

• The need for the physical health professionals to consider the socio-economic background of caregivers as etiological phenomena is to be implicated. Especially the general hospitals are the places where the caregivers of intellectually challenged report that the attention paid to the psycho social aspects of the patients are minimum in these hospitals. The study highlights the need for hospital staff to change their concept based exclusively on physiological / psychological approach.
AREAS FOR FURTHER RESEARCH

The findings of the study and explorations of possible solutions, have generated a host of issues that need to be researched and this study is just a beginning, for such issues that can only be addressed further by scientific researchers. The present study on the stress level, of the caregivers of the intellectually challenged has been a genuine plea to the Government and Rehabilitation Council with an appeal that the findings would help them to organize need based programmes.

- Epidemiological studies concerning to the intellectually challenged affect population is the need of the hour. This is a genuine plea to the medical profession and Rehabilitation council of India association through such a study as this would help them to organize suitable programmes for members and caregivers of the intellectually challenged.

- The present study has hinted a variation in the stress levels among the caregivers of cerebral palsy, Down syndrome, Autism with mental retardation and general mental retardation children. Hence further studies could consider the other types of mentally challenged children based on the intelligence, associated problems specifically etc.,

- The population chosen for the study live mainly in Madurai District and only few percentage live outside Madurai. The study on stress level of the caregivers of the Intellectually Challenged can be done in rural setting to see the difference from the caregivers in the urban settings.

- The caregivers chosen showed a Homogeneity in socio-demographic profile in both the groups (ie) control and experimental. The disintegration of the groups could be studied in detail with respect to literacy level of parents.

- The vulnerability of caregivers of the intellectually challenged for mental health problems at different stages / category of affect is an important area requiring research attention.
The criterion of groups taken for the study concentrating on the education sector at different age group may become individualized research.

The family environment has emerged as an important factor as revealed by this study on stress and quality of life. It would be relevant to study the adjustment level of caregivers with the children of affect, family systems like joint family, nuclear family and extended family and also the impact of changes in the family styles based on psycho social condition can be assessed in this context.

The importance of family therapy can also be assessed based on the adjustment level of the caregivers of the intellectually challenged.

Intellectually challenged is a condition that has no cure and as the child with that affect has to cope with disability and caregivers have to accept and live with it. Social work intervention is essential to facilitate this coping process. Therefore studies could be undertaken to assess the efficacy of using specific social work method in different area of intervention such as early identification, learning disability, vocational support etc., etc.,

This study has focused on the stress of the caregivers and the impact of counselling on them, further investigation is required to assess the Rehabilitation potential required for these children so that a suitable rehabilitation model could be evolved based on their rehabilitation potential.

Longitudinal studies may be taken up to assess the role and involvement of the family, during varying stages of development of the intellectually challenged.

This study focuses on the stress level of the intellectually challenged child and the impact after counselling them. This work could be compared with the caregiver of normal children under different age group and the intellectually challenged since the stress faced by parents of normal children too is equally intense and even more vulnerable at times.
A SYSTEM APPROACH IN INTERVENTIONAL STRATEGY TO THE CAREGIVERS
OF THE INTELLECTUALLY CHALLENGED

TARGET SYSTEMS

Individual / Caregiver
Emotional Instability
Low Coping confidence
Low General Well Being
Inadequate Mental Mastery
Perceived Ill-health
Low Physical functioning
Low Mobility
Low Life Satisfaction

Family
High conflict
Poor achievement orientation
Low Organisation
Unsupportive
Low cohesion
Low Expressiveness

Community
Low Awareness
Less organized
Less supportive

RESOURCES SYSTEMS

Natural Systems
Family, Friends,
Co-workers

Formal Systems
Membership Organisation
Association

Societal Systems
School, Hospital, Housing
Therapy Center
Medical Care / Insurance

CHANGE AGENT SYSTEM

Counsellor
Social Worker
Health Professionals

INTERVENTION METHODOLOGY

Crisis Intervention
Multiple Interviewing
Family Counseling
Group Work
Case Work

Employment
Remedial Training
Education

Advocacy
Research
Association formation
Networking

INTERVENTION OUTCOMES

Reality Orientation | Better self-worth | Supportive family | Health care
--- | --- | --- | ---
Participation in appropriate life activities | New Resource Systems | Coping with ambivalent feeling | Better Linkages | Policy Changes
Familial Planning for future | Mobility | Barrier free environment
CHAPTER VI

INTERVENTION MODULE

The researcher has proposed a model for intervention. The objective of this model is to provide a broad framework for intervention action involving human service professionals.

The Need for Intervention

The children affected with Intellectually Challenged may eventually lead total physical dependency on the parents or caregivers throughout their span of life. In this condition the disabled children and the caregivers are called upon to make new and difficult emotional adjustment that frequently require social work / health professional intervention in handling stress. Besides emotional adjustment, the families are confronted with additional problems and limitations inherent to the affect the adjustment the caregivers makes depends to a large extent on his level of social functioning, the nature of affect and it’s meaning, the existence of significant others who rarely around him are available to help, and their access to concrete resources (Lambert 1976). The focus of intervention is mostly related to these factors. The findings of this study have revealed several such factors as individual, family and community levels that may have negative impact on the well being of the caregivers of the Intellectually Challenged children and therefore warrants the immediate attention of health professionals. It is to fulfill this need that the researcher proposes a model for counselling intervention with caregivers of the Intellectually Challenged children.

System Approach

The model draws its inspiration from the model for social work practice developed by Pincus and Minahon (1973). The key element of the model is a classification of the types of system in relation to which the health professional/social worker carries out his role. The professional/social worker can be viewed as a change agent system. The client system is the person (ie) the caregiver, family, group organization or community in which the health professional engages with. The target
system refers to those people (caregivers) the change agent needs to influence in order to accomplish the goals of his change effort (to reduce the stress and improve the quality of life). The client system is not always the system that needs to be changed in order to reach the change goals. Sometimes different people may be considered as target for different goals at different time. The resource system refers to the resources existing under natural, formal and societal groupings.

This approach recognizes the following as the major task of the social worker / health professional

> Helping people enhance and more effectively utilize their own resources.

> Establishing initial linkage between people and resource systems.

> Facilitating interactions and modifying and building new relationship between people and societal resource system.

> Contributing to the development and modification of social policy.

According to these authors the focus of social work practice is on the interaction between people and system in their social environment.

Facilitating this interaction may not be possible through following the traditional methods of social work - case work, group work, and community organization in Isolation (Pincus and Minhan 1973). Hence a system approach in interventional strategy was proposed. The researcher followed this approach as it is comprehensive and versatile enough to provide multicentric application to the problem.

The proposal model consist of four interactive systems (Refer Chart in ------) At any given point of time in the counselling intervention process all these systems are in interaction with each other. This is significant by the bi-directional arrow connecting the systems. The primary role of the health professional is to facilitate this interactive and establish linkage between the caregivers and the various systems.
Client System

The client system consists of the caregivers of the affected child, their family or the whole community. Though the Intellectually Challenged children are the primary clients at different point of time, the family or the community becomes the focus of attention and the change efforts are directed towards these systems. When this happens, the family or the community may be taken as clients.

The finding of this study has revealed several factors in the client system (caregivers) that need to be brought under the focus of change efforts. At the individual level, the caregivers of the Intellectually Challenged children have been found to have low levels of emotional stability, coping confidence and feeling of general well being though there were differences between the different types of the Intellectually Challenged children (Cerebral Palsy, Down Syndrome, Autism, Mentally Retarded) in consistent manner with respect to the characteristics of the affect. When the affected children physical / Intellectual functioning of affected children was low there was high perceived level of stress and factors contributing to the Degree of stress. All these contributed to the low level of quality of life and satisfaction in life which would be the major focus of intervention. The model includes the family as part of the caregivers system who is needed by all means. As the study revealed all but with a difference between the groups, there were several factors in the family that could contribute to the discomfort or stress in the level of the caregivers. But achievement orientation, high conflict, low organization, low cohesion and low expressiveness, were some of the factors. Consequently, the family was not very supportive to a large extent of caregivers. This would also be the focus of the intervention at the family level.

The community is considered as a part of the caregivers system as the community is not yet sufficiently aware of the Intellectually Challenged children and the problems faced by their parents / caregivers. This would also be the focus of intervention at community level in order to organize the community and make it supportive for the caregiver of the Intellectually Challenged.
Change Agent System

The change agent system consists of the health professional, social workers who could relate to Government and non-Government organization. The effort taken is directed towards the client system. As mentioned earlier, the primary role of the change agent system is to facilitate the interaction between various system affecting the required change in the systems and eventually decreases the stress level and improving the quality of life of the caregiver of the Intellectually Challenged children. For this the health professional need to collaborate with all the system around the caregivers to enhance them in all ways by utilizing more effectively their own resources. A role of liaison may be taken to bring forth a linkage between the systems needed for support, like facilitating relationship and building new relationship and the caregivers of Intellectually Challenged.

As it is a non-progressive affect in children, the intervention would be in the form of reality orientation of the affected child, acceptance, enhancing the adaptation skill, morale maintenance, reduction of mental and emotional fatigue and spouse and family member counselling.

Target System

The change agent has to initiate certain changes in the environment which would in turn assist the caregivers of the Intellectually Challenged children in coping with the illness. This environment is termed as the “target system” as it becomes the target of the change efforts of the health professional. There are several target systems and the resource system consists of three types - Natural, formal and societal resource system. The study reveals that caregivers are virtually non-existent of the formal resource system. While societal resource system such as hospital, special school, Rehabilitation centre and recreation centre are available to limited extent, the awareness to get correct form of support is yet to be built with. These resources need to be enlarged to meet the needs. The Researcher would be targeting these resource systems for change as well as establishing linkage between resource system and other systems.
**Intervention** methodology

Apart from facilitating the interaction between the systems and directing change efforts towards the systems, the health professional/social worker has to adopt several methodologies to effect a change in the various systems, as well as to support the facilitation process. The broad areas of the methodology are mentioned in the model. At the primary level, case-work was coupled with multiple interviewing and crisis intervention would be the mainstay of the intervention in handling Intellectually Challenged children. Family counselling and group work with family members would be the methodology at family level intervention that need to be tackled in the intervention process. The caregivers of the Intellectually Challenged themselves become targets when the family or the community is dealt with the client system for intervention purposes.

The caregivers’ ability to cope with can be greatly influenced by the support and encouragement of friends and family. If these supports are lacking, then friends and family become the targets of the change efforts. Similarly employers, co-workers, community members and policy makers can also become the supporters the target system in the intervention-process. Frequently, the resources available with the community for helping the caregivers of the Intellectually Challenged children may be inadequate and inappropriate. In this context the target of intervention would be useful to tap these resources.

**Resource System**

Caregivers of the affected children are dependent on several resource system for help in obtaining the material, emotional or spiritual resources and the services and the opportunities they need to realize their aspirations and help to cope with their life tasks. Intellectually Challenged children would be in direct need of such resource systems to cope with new adjustments they have to make due to the kind of affect they have.

At the secondary level the caregivers were to develop awareness in detail regarding the type and affect the child. All the details regarding that is imparted to improve their knowledge and strengthen confidence in dealing with the children.
With the Rehabilitation strategy available in various sources they are guided and educated.

At the territory level, the stress usually faced was explained to create a supportive environment in the groups and the ways and means to handle them was taught which shall certainly improve the self-worth of the caregivers and contribute to his life satisfaction. Similarly recreation, relaxation and education change the effect of caregivers in the system.

Next level includes the caregivers mobility in engaging themselves in a productive activity along with the health professional/social worker who would involve in advocacy to create an awareness of the problem and influence policy-makers. Formation of caregivers association within District and State level can also greatly contribute to the intervention process.

These associations may provide the following services

☐ Knowledge updatate by calling relevant experts and organize meeting periodically for the caregivers of the Intellectually Challenged.

☐ Guidance and Planning for the rehabilitation of the child.

☐ Therapeutic intervention like occupational, physical, speech etc., could be formulated for the needy in the areas chosen so that the caregivers could be confident of success in giving therapy to the children.

☐ Recreational programs

☐ Personal counselling in families can be arranged periodically

☐ Medical advice

☐ Employment programmes for the abled grown-up children could be planned.

Intervention outcomes

The main outcome of the intervention strategy would be to reduce the stress level and improve the quality of life of caregivers of the Intellectually Challenged.
Intervention would also enhance the caregivers in appropriate life activities such as being a member of a supportive family, participating in decision making, employment, recreation, education etc. This would make them feel confident of self worth and reality orientation could certainly reduce the stress level and improve the quality of life.

The creation of new resource system may provide better supportive hand for the caregivers in the aspects of knowledge development, acceptance of reality in life, recreation, ventilation of feelings etc., etc. Policy level changes regarding the Intellectually Challenged children can bring forth barrier-free-environment for better mobility to reduce the stress and improve the quality of life of the caregivers.

These intervention-outcomes can in turn reinforce the target system and resource systems, whose benefits may then be passed on to the client system through the interactive process.

The strength of the model lies in the fact that the intervention proposed by the model does not follow a linear pattern. It does not work with individual in isolation. Neither does it restrict itself to the institutional services. It does not also advocate a particular methodology.

On the other hand the model facilitates simultaneous intervention procedure to be carried out at various levels. This essentially contributes to the versatility of the intervention model, which the researcher hopes would be instrumental in reducing the stress level and to improving the quality of life of the caregivers of the Intellectually Challenged.