CHAPTER I

INTRODUCTION

The professionals in the health care have become more concerned with the psychological, psycho socio aspects of health and illness. The origin of this school of thought dates back to 17th century during which period, it was realized the environment plays a major role in the dynamics of mental well-being. In this accord the term “STRESS” is a common word used and felt by almost all individual in this world. The need to get relieved out of stress is also given due importance by the professionals working under health care ‘Counselling’ is the other common term used world wide. As one of the means to search a way out from stress, it has gained its own value and results in making an individual lead a better life during his life period.

When ‘Stress’, a common factor felt in every individual in this world, the Intensity of Stress faced by the caregivers (i.e) either one of the parent who take care at most of the time of the Intellectually Challenged / Impaired is considerably high due to various factors which distort their paths of life and ambitions. The study on the impact of counselling in altering the stress level among the care givers of the Intellectually Challenged is chosen by the Researcher, to intervene and trace a path and means by which the stress levels could be altered and pave a new way for a better life with the Innocent Angels who are termed as “Intellectually Challenged” who were previously called as Mentally Retarded.

The Intellectually Challenged children are of many types and they are chosen by caregivers in four important criteria for the study they are:

(1) Caregivers of the Cerebral Palsy Children
(2) Caregivers of the Down Syndrome Children
(3) Caregivers of the Autistic Children
(4) Caregivers of the Mentally retarded (who do not fall under the above 3 criteria)

In general terms ‘Intellectually Challenged’ refers to significantly subaverage general intellectual functioning, resulting in or associated concurrent impairment in adaptive behaviour - manifested during the developmental period (Grossman 1983)
AAMR. The children with Intellectual challenge do not form a uniform group the nature, years, severity and the child’s ability to cope with personal problem, all influence how the durability is visible to the observer. However there are some specific signs and symptoms, which can help, in early identification of delayed development (W&S)

- The person does not learn new activities as easily as other people do.
- The child may have difficulty in sitting up, using his or her hands, or moving from place to place.
- The person may be slow to respond to what other say and to what happens around him or her.
- The person may not understand as well as other people what he (or) she sees, hears, touches, smells and tastes.
- The person may not be able to express his or her needs or feeling in a way that other people understand.
- The persons may not be able to think clearly. The person may not be able to compare people or things, or understand the difference between here or there, now or later, or more or less. The person may not know the meaning of where, when, what, how and why.
- The person may remember only for a short time what he or she has been told or what had happened in the past or the person may not remember these tilings at all.
- The person may or may not be able to pay attention to one person or to one activity for long.
- The person may have difficulty in controlling his or her feelings.
- The person may have difficulty in making decision, he or she may not know what to do, what to say, what to think and so on.

In general the children will have problem in

1. Motor co-ordination
(2) Carrying out general activities like toileting, bathing etc.,

(3) Reading, writing and arithmetic

(4) Communication (5) Behaviour and (6) Socialization

Some Intellectually Challenged Children may also have sensory defects such as visual impairment, hearing loss other problems of epilepsy / fits etc.

"Stress" - (Contributing Factors to the caregivers of the Intellectually Challenged)

Stress is the non- specific conventional or mal response of the body to any demand made on it. The basic purpose of which is to prepare the body for the flight or fight. The stress can be physical or psychological whenever we meet with odd situations. The response our body shows is alarming against the dangers. The reactions could be of quickening of pulse rate, increased breathing, sweating, and face acquiring a look of astonishment with the dilation of pupils. This alarm-reaction is followed by a stage of resistance or adoption during which the danger of alarm is slowly diminished, almost to the non- existent levels and the body becomes gradually accustomed to the stressful formulas. If stressful stimulus does not diminish the stage of resistance is followed by the stage of exhaustion, during which the person remains no more adaptable to stressful situation. They break down to illness or death.

*Intellectually Challenged children - Impact on family*

Having a mentally retarded child cause a great amount of stress to the family and calls for life long adjustment on the part of the parents and other family members. It sometimes becomes difficult for the parent to meet the needs of the Intellectually Challenged child and also the needs related to the family functioning as a whole. The entire family including parents, brothers, sisters and extended family members such as grand parents get affected in specific ways because of having an intellectually challenged child in a family.
Birth of Intellectually Challenged

An Intellectually Challenged child does produce greater pressure on the family because of extra demands of childcare, greater financial burden and above all the worry and tension as the child is not normal.

Impact on family as a whole

Every child is unique in this world, and each family has its own strength and awareness to face the challenge from time to time. Most of the parents and other family members naturally do start worrying about the future of the child; feel sad or depressed at various stages of the child’s life. The social life of the family gets affected, they may like to keep themselves aloof from others and indulge less in recreational or leisure activities. Some families face rejection or neglect from the family members, friends or relatives and hence the interpersonal relationships get strained leading to the loss of support. Some mothers may have to give up their jobs that lead to greater financial strains, fathers may seek for jobs or transfers to places where services for such children are available.

The effects vary from family to family depending upon the quality and quantity of emotional, financial and physical support available, the degree of child’s handicap and his age and whether the child has additional problems such as physical disability or behaviour problems.

Emotional reactions the parents undergo

On knowing the fact that their child cannot recover to normally the hopes of the parents get shattered. Some may initially experience shock to learn, that their child is not normal. Some may deny and hope that everything will change after few days. Some parents may get extremely upset, depressed and nothing may seem to be important in life. These reactions may not stay permanently. Through the help of professional guidance, rehabilitation etc., they can slowly get themselves adapted to the conditions necessary in bringing up the child.
Marital problems faced by parents of the Intellectually Challenged

Marital difficulties may arise because of the conflicts between parents on sharing the additional demands for the caring of the child. They may start blaming each other for the birth of such a child. There may be disagreement in treatment. Sexual problem may arise due to fatigue, lack of privacy or fear of producing another disabled child etc.,

The Plight of Non-Disabled sibling

The non-disabled sibling gets affected more and they are expected to share the burden of, caring the affected sibling at their free time, play, recreation or study time. They may feel embarrassed in the midst of their friends when their brother or sister is in socially unacceptable condition way. The parents try to pressurize them to be compatible with the intellectually challenged brother / sister.

Some children develop jealousy / behaviour problem etc. They feel their parent spent more time in caring the disabled than them. Psychologically they may also produce such a child in future.

Other Important Barriers

The major barrier the parents feel is the acceptance of the Intellectually Challenged by their family members, relatives etc.,

- The social life of the parent / caregiver gets affected and they cannot move about freely as before. They meet with a lot of embarrassing situations when they need to handle Intellectually Challenged Children in a group or social occasion.

- The financial strain based on the maintenance of the Intellectually Challenged Child and the extra care needed in medical, para-medical aspects etc.

- The future plan of the whole family gets affected and a lot of compensatory measures are to be taken.
The leisure time and recreational skills all get disturbed. It affects the emotional aspect, and deteriorate the mental health development.

The Grand parents too get worsely affected at their old age seeing the sufferings undergone by their son /daughter having an intellectually challenged child. The care they receive from their son / daughter too shall get affected. They are again placed with more responsibility to care the grand child in case of both parents going to work to earn their livelihood.

On the whole the meaning of life is mostly altered and gets affected by having an intellectually challenged child in our home.

CONCEPTUAL AND OPERATIONAL DEFINITIONS

*Intellectually Challenged* AAMR (Gross Man — 1983)

- Refers to significantly sub-average general intellectual functioning resulting in or associated with concurrent impairment in adaptive behaviour manifested during the developmental period.

- Edger Doll has given a comprehensive definition to describe who is Intellectually Challenged socially incompetent (ie) socially inadequate and occupationally incompetent and unable to manage his own affairs at the adult level, mentally subnormal, retarded intellectually from birth or early age, retarded at maturity deficient as a result of constitutional or disease and essentially incurable.

International classification of the mentally subnormal, accepted in January 1968 is as follows:

<table>
<thead>
<tr>
<th>Class</th>
<th>Range of IQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Border line</td>
<td>70-84</td>
</tr>
<tr>
<td>Mild case (educable)</td>
<td>55-69</td>
</tr>
<tr>
<td>Moderate (Trainable)</td>
<td>40-54</td>
</tr>
<tr>
<td>Severe</td>
<td>25-39</td>
</tr>
<tr>
<td>Very severe</td>
<td>Below 25</td>
</tr>
</tbody>
</table>
**Care Givers**

Caregivers are those who take care of the child in the primary zone. Our study is to participate, to observe, to enhance and facilitate the process of development of the Intellectually Challenged in our study. Mostly the caregivers are parents or either one of them who spent most of their time in taking care of the affected. In some cases it could be Grandparents, aunt or some other employed person who do take care of the child in need.

**Counseling**

Counseling is defined as a form of interviewing in which clients are helped to understand themselves more completely so that they may correct an environment or adjustment difficulty. Counselling aims to help the individual to clear away the entangling tentacle so that he can be what he really is and contribute more both to himself and his fellows.

**Guidance**

It aims to help an individual in the process of his adjustment with himself and his environment. It helps him to develop his strength and abilities to achieve utmost personal and social efficiency. It also aims to stop wastage of human power and physical resources by helping the individual to find their place in society. Thus the guidance is the process of helping an individual to help himself and to develop his potentialities to the fullest by utilizing the maximum opportunities provided by the environment.

**Cerebral Palsy**

Cerebral Palsy (CP) refers to a complex non-progress condition caused by damage to brain within first three years of life that produces a disability because of muscular non-co-ordination and uneasiness. The word ‘cerebral’ refers to brain and palsy with a disorder of movement or posture. The brain damage that causes cerebral palsy may also produce a number of the disorder including mental retardation, seizure, visual and auditory deficits. The brain damaged child has more chances for mental retardation.
**Down Syndrome**

Down Syndrome is a chromosomal disorder that is caused by the presence of an extra chromosome at pair No. 21. They have typical clinical features. Most of the children with Down Syndrome have mild to moderate mental retardation.

**Autism**

Autism is a rare disorder that occurs in one in 1000 children. In a child with Autism, thinking, language and behaviour are all affected. They show strange behaviours, language disorder and social isolation. Autistic characteristics with social withdrawal delayed and deviant language can be seen in some children with mental retardation.

**Disability: Census 2001**

India is one of the few countries that conduct Census every ten years. The irony is that despite this we do not have authentic statistics on the population of disabled people in our country. Comparing official figures of the disabled population in various Asian countries: India 1.9% (Source: NSSO Survey 1991) China 5%, Pakistan 4.9%, Philippines 4.4%, Nepal 5.0% - one would imagine that we have eradicated disability completely from the country!

In the Ninth Five-Year Plan (1997-2002), the Planning Commission had categorically stated that, “to ensure planning for the welfare and development of the disabled more meaningfully, there is an impending need for the office of the Registrar General and Census Commissioner, to revive their practice of 1981 Census to collect the data on the size of the population of persons with various types of disabilities and to make it available through the next population Census of 2001 AD”.

The Census allows statistics on persons with disabilities to be analysed by a wide range of variables such as age, marital status, income, labour force status, family status and then compared with the results for the total population. Further, the Census can give estimates for small areas and small populations, which is usually not possible in Sample Surveys because of size limitations. No doubt the Census may have
problems with under estimation of persons with disabilities, particularly with mild
disability and children and older persons with disabilities. However, while analyzing
the data, this can be taken into account to provide baseline information on frequency
and distribution of disability in the population: essential for policy planning and fond allocation. Data obtained in the Census can then be utilized for the development of representative surveys and studies where more detailed information can be collected on persons with disabilities. The data could be used to reduce the disadvantage inherent in the limited sample size of sample surveys. The ideal approach would be to use the Population Census as a screening device and then use it to improve the efficiency of the sample selection in a Sample Survey.

However, our Census Commission was not even considering the inclusion of disability as a category in the Census 2001. Interestingly, the first Indian Census of 1872 included questions not only on the physically disabled but also on the intellectually disabled! The practice was discontinued in 1931. Thereafter only once in 1981, the International Year for Disabled Persons was an attempt was made to collect information on disabled persons under the Census! This practice was once again discontinued in 1991.

Survey measures of disability

Disability relevant statistics based on Census 2000 data are all derived from long-form sample data. This form asks respondents to answer yes or no to each part of question 16 and 17, for each member of the household:

16. Does this person have any of the following long-lasting conditions?
   a. Blindness, deafness, or a severe vision or hearing impairment?
   b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying.

17. Because of a physical, mental or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities?
   a. Learning, remembering or concentrating?
b. Dressing, bathing or getting around inside the home?

c. (Answer if the person is 16 YEARS OLD OR OVER:) Going out to shop or visit a doctor’s office?

d. (Answer if the person is 16 YEARS OLD OR OVER:) Working at a job or business?

Characteristics of Disability

Socio-demographic characteristics of children with disabilities pertain only to those living in the community and are derived from the 1990 SIPP.

Disabling Conditions

Leading causes of disability include learning disabilities (1,372,200), speech disorders (1,096,000), mental retardation and other developmental disabilities (720,500), mental illness (462,800) and respiratory conditions (362,200) such as asthma.

Age/Gender

Disability increases with age for children - 5.2% are under 3, 14.1% are 3-5, and 80.7% are 6-17. Most children with disabilities are boys (62.6%), whereas most adults with disabilities are women (56%)

Race/Ethnicity

76.9% of children with disabilities were White non-Hispanic (76.9%), 11.8% Black, 7.7% Hispanic and 3.6% were “Other” (ie., American Indian or Asian-American). Disability rates varied by race: 7.5% for White non-Hispanics, 5.6% for Blacks, and 4.6% for Hispanics.

Economic Status

In 1990, 957,600 children with disabilities lived in poverty. Poverty rates were 21.8% for children with disabilities and 20.7% for children without disabilities. The proportion of children on AFDC was similar for children with (9.8%) and without
(9.5%) disabilities. Most AFDC families, along with other low-income families are eligible for Food Stamps. Participation in Food Stamps was higher for children with (15.4%) than for those without disabilities (13.5%).

Health Insurance

Although 782,400 children with and 9,847,000 children without disabilities are uninsured, there is little difference proportionately: 17.6% of uninsured children have disabilities compared to 16.3% who do not. A lower proportion of children with disabilities have private insurance only (69.5%) with and 61.9% without disabilities), whereas a higher proportion of children with disabilities are on Medicaid (by itself or in conjunction with private insurance): 20.5% of those with and 14.2% without disabilities. Medicaid, which pays for the health care of low-income individuals, covers children who are on AFDC, most on SSI, and those who qualify for certain optional State programs covering ill or disabled persons.

Census of India

The Indian Census is the largest single source of a variety of statistical information on different characteristics of the people of India. With a history of more than 130 years, this reliable, time tested exercise has been bringing out a veritable wealth of statistics every 10 years, beginning from 1872 when the first census was conducted in India non-synchronously in different parts. To scholars and researchers in demography, economics, anthropology, sociology, statistics and many other disciplines, the Indian Census has been a fascinating source of data. The rich diversity of the people of India is truly brought out by the decennial census which has become one of the tools to understand and study India.

Census 2001 has revealed that over 21 million people in India as suffering from one or the other kind of disability. This is equivalent to 2.1% of the population. Among the total disabled in the country, 12.6 million are males and 9.3 million are females. Although the number of disabled is more in rural and urban areas, such proportion of the disabled by sex in rural and urban areas. Such proportion has been reported between 57-58 percent for males and 42-43 percent females. The disability
rate (number of disabled per 100,000 populations) for the country as whole works out to 2130. This is 2,369 in the case of males and 1,974 in the case of females.

Among the five types of disabilities on which data has been collected, disability in seeing at 48.5% emerges as the top category. Others in sequence are: In movement (27.9%), Mental (10.3%), in Speech (7.5%), and in hearing (5.8%). The disabled by sex follow a similar pattern except for that the proportion of disabled females is higher in the category in seeing and in hearing.

Across the country, the highest number of disabled has been reported from the state of Uttar Pradesh (3.6 million). Significant numbers of disabled have also been reported from the state like Bihar (1.9 mission), West Bengal (1.8 million), Tamil Nadu and Maharashtra (1.6 million each). Tamil Nadu is the only state, which has a higher number of disabled females than males. Among the states, Arunachal Pradesh has the highest proportion of disabled males (66.6%) and lowest proportion of female disabled.

<table>
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<tr>
<th>Sl.No.</th>
<th>State/UT</th>
<th>Visual</th>
<th>Speech</th>
<th>Hearing</th>
<th>Locomotor</th>
<th>Mental</th>
<th>Total</th>
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<td>Hearing</td>
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NEED FOR THE PRESENT STUDY

‘Stress’ is a common word used today almost daily by million of people world over. It is not possible to provide the exact number or percentage of suffering from ‘stress’ in India when this is a situation in general. The Researcher herself being a Rehabilitation Psychologist working in the field of Rehabilitation for past 15 years felt that the stress experienced by the caregivers is predominantly greater as there are many numbers of factors, which increase stress in them. The intensity of the effect in their children itself lays a stress which is very hard to be accepted and then only the reduction of stress could be focussed. This is the juncture where the need for the present study rooted itself to assess the stress and intervene them with counseling procedures and to see whether their stress could be reduced or atleast kept under control.

There have been very a number of studies in general in this field but yet there was a gap identified in the terms of what intervention could be given to the caregivers of the Intellectually Challenged so that they can live their lives with acceptance, patience and faith, to work with the affected.

Importance of the study

There are many number of individuals/institutions working for the stress management of the individuals. The burden and stress laid on the caregivers of the Intellectually Challenged are those which cannot be curtailed by general men since it can give a temporary solution only.

When a intervention programme in counseling is scheduled as per the need of the parents/caregiver based on the affected child, the result got out of the programme will definitely prove worth while, and this effect is proved by having two important group (ie) (1) group of caregivers under caregivers of Cerebral Palsy, Down Syndrome, Autism and general mental retardation to screen with all the testing material group (2) - with all the above group of parent of varied population is being experimented with counselor package. The variation received shall show the impact of counseling to the caregiver of the Intellectually Challenged. The module worked
can definitely pave a new outlook in counseling parents / caregiver of the Intellectually Challenged.

**Objective of the study**

The objective of the study focuses at

1. To present a profile of the socio-economic status and complete demographic profile of the caregivers of the Intellectually Challenged.

2. To screen the stress level among the caregivers of the Intellectually Challenged on the category studied.

3. To evaluate the factors contributing to increase in stress level to the caregivers of the Intellectually Challenged.

4. To assess the quality of life of the caregivers.

5. To form an intervention counseling module and counsel the parents / caregivers to meet the stress in an effective way.

6. To prove the effectiveness of Intervention / counseling strategies in stress level to the caregivers of the Intellectually Challenged.

**Hypothesis**

The hypothesis tested included the following

1. There is no significant difference in socio-demographic profile of the target population chosen for the study.

2. There is no significant difference in stress level and quality of life of the caregivers of the Intellectually Challenged between the two groups namely experimental and control.

3. There is significant difference in stress level & quality of life of the caregivers who were intervened with counseling procedure.
4. There is significant difference between the control group and experimental group after the counseling procedures.

5. There is no significant difference in stress & quality of life noted in the control group (6 months) after a period of time when revalued.

6. There is significant difference among the caregivers of children affected with Cerebral palsy, Down syndrome, Autism and Mental retardation with respect to stress level and the quality of life.

**Variables of the study**

1. The independent variable of this study includes the socio demographic profile which includes - age, sex, educational status, economic status etc., of the caregivers of the Intellectually Challenged, subjective Independent variable include factors contributing to Stress & Quality of life.

2. The dependent variable include the

   (a) Caregiver of Cerebral Palsy children, Down syndrome, Autism and general Mental retardation.

   (b) The stress level, of the caregivers.

**Limitations of the study**

1. Several biases and limitations in the present study must be acknowledged collecting data from all the parent of the intellectually challenged was not possible. So in few places, where considerable quantity of data could be collected was chosen for the study.

2. There was a high level of resistance shown by caregivers before co-operating for data collection.

3. The post evaluation has its own limitation since most of them felt disinterested in going again through the research programme.
4. Biased and fake answers were delivered in certain cases, which was intervened to work on the real fact rather than giving a false face of well-being.

5. Caregivers natural resistance and fatigue would give a biased coding in some scales.

**Delimitations of the study**

1. With respect to the caregivers of the Intellectually Challenged the major classification category is taken for the study of the parents / caregivers of the Cerebral palsy children, Down syndrome children, Autism children and General Mental Retardation which includes slow learner, Border line case of retardation, Dyslexia etc.,

2. The special educational institutions, intervention clinic and home based training were utilized to collect the data so that the caregivers under all the levels were met.

3. Counseling programme / intervention module were followed in special educational institution to systemize the programme which would give an effective follow-up.