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“GENDER ANALYSIS OF CHILDREN WITH INTELLECTUAL DISABILITY: CHALLENGES AND COPING STRATEGIES AMONG PARENTS IN CHITTOOR DISTRICT, ANDHRA PRADESH”.

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INTRODUCTION

“Disability wasn't my wish or choice but yet I'm dealing with it each and every day.... It has given me more scars on my heart than any other wound on my body...!” Harsh Ganjoo.

- ✓ All parents wish for a healthy baby, but some parents though not by their option are gifted with a child having disorder
- ✓ The birth of a baby is usually predicted with great excitement and expectation of a future filled with joy, happy and success.
- ✓ In India, disability is still viewed in terms of a “tragedy” with a “better dead than disabled” approach, the idea being that it is not possible for disabled people to be happy or enjoy a good quality of life
- ✓ One such instance is the belief in the theory of karma, which is often involved to explain major life events, including the occurrence of disability
- ✓ Intellectual disability is a long-standing disability. It is a pressure that requires a continuing coping response by the father and mother.
- ✓ Some are able to cope up with such a circumstances and some experience psychological tension
- ✓ Parenting a child with disability is not an easy job.

CAUSES OF INTELLECTUAL DISABILITY

- ✓ Genetic factors
- ✓ Environmental factors

PREVENTIVE MEASURES

As per the etiology, let us see how they can be prohibited, prohibition can be broadly grouped into three stages.

1. Antenatal period
2. Intra natal period
3. Puerperal period

MANAGEMENT OF INTELLECTUAL DISABILITY

- ✓ There are number of management strategies that can help people with intellectual disability to lead a better quality of life
- ✓ Management of ID includes cognitive stimulation, special educational support, and vocational training
- ✓ Parenting counseling
- ✓ The ultimate aim of education and training of the persons with intellectual disability is a social and occupational adjustment in adult life
- ✓ Vocational Training.

CHAPTERIZATION OF THE THESIS

The Thesis Comprises of Five Chapters

Chapter I: Introduction

Chapter II: Review of Literature

Chapter III: Methodology

Chapter IV: Results and Discussion

Chapter V: Summary, Conclusions, Implications and Recommendations

NEED FOR THE STUDY

Some studies supported that;

- ✓ First challenge faced by the parent's of intellectual disability is absence of meaningful relationships with the society
- ✓ Second challenge is stigma – In the public's have low acceptance behavior towards these families
- ✓ Third challenge is most of the parents have been experienced with anxiety regarding stabilizing the needs of affected children.
- ✓ Intellectual disabled children parents have to face more economical and financial burden
- ✓ Approximately 6.5 million people in the United States have an intellectual disability
- ✓ Approximately 1-3 percent of the global population has an intellectual disability-as many as 200 million people

- ✓ Intellectual disability is significantly more common in low-income countries -16.41 in every 1,000 people. (WHO–2011).
- ✓ Prevalence rates of ID children in India is 10.5/1000
- ✓ Percentage of Male children is 0.2% and Female children is 0.1% of the total population in India
- ✓ In Andhra Pradesh both male and female children rates are equal number 0.2%
- ✓ In Chittoor district total 4500 children names registered in SarvaSikshaAbayan. Boys are 2750 and Girls are 1750 (2018)
- ✓ NGOs Schools (7) – Number of students 500, boys -300, girls 200 (2018).

CENTRAL GOVERNMENT SCHEMES FOR THE REHABILITATION OF DISABLED

- ✓ Detection, intervention of primary nature, prevention of disability
- ✓ Education and training
- ✓ Rehabilitation-physical, psychological, social and economically
- ✓ Three percent reservation seats in government and government aided educational institutes.

State Government Schemes

- ✓ The SSA framework provides Rs. 3,000/- month for mild and moderate challenged children and Rs. 5,000/- month for severe and profound challenged child and transport charges Rs. 300/- month for all the affected children, additional escort charges Rs. 250/- month for disabled children

REVIEW OF LITERATURE

Moreover, for a logical presentation, the brief review of studies has been presented in three following sub-sections;

- ✓ Gender aspects of parents with intellectual disabled children
- ✓ Challenges of parents with Intellectual disabled children
- ✓ Coping strategies of parents with intellectual disabled children.

THEORETICAL BACKGROUND

- ✓ Orem's Self-care framework focuses on the actions taken by parents who are considered to meet their own and their dependent needs
- ✓ Care is defined as actions taken by individual who is able to identify his or her self – care requisites
- ✓ Dependent care is defined as actions taken by parents for dependent family members
- ✓ The first and foremost problem that the family faces in dealing with physical problems of the child is helping him with activities of daily living.

CONCEPTUAL FRAMEWORK

- ✓ It is system with connected conceptualization that are constructing a logical plan of action by righteousness of its applicability to usual topic
- ✓ A conceptual framework describes each of the concepts and their relatedness to one another
- ✓ A framework is the abstract logical structure of meaning that guides the development of the study and enables the researcher to link the findings to the body of knowledge.

HYPOTHESIS OF THE STUDY

- ✓ Ha1: Parental demographic and the socio-economic variables of their families would exert significant impact on the successful or otherwise performance of parents in dealing with their intellectually disabled children
- ✓ Ha2: There is a remarkable connection between parental gender, surroundings and adaptability in facing challenges of dealing with intellectually disabled children and coping strategies they designed and execute in solving the problems.

PROFILE OF THE STUDY AREA

- ✓ The study area for the present research is Chittoor District of Andhra Pradesh was selected purposively with large number of affected children and more number of Bavitha schools (i.e., 66 mandals) for the present study by the researcher
- ✓ Total mandals in Chittoor District are 66 in which the researcher has selected 20 mandals and from each mandal 10 affected children's total – 200 were selected for the present study by Lottery method.
- ✓ Five schools run by NGOs were also selected by the researcher those are; Thapovanma Trust – Chittoor, Velugu Special School – Madanapalli, Rimers Special School – Palamaner, Deaf Special School – Puttur and RASS – Tirupati
- ✓ From each school 10 children were selected total 50 children. Both the parents: fathers 250 and mothers 250 and total 500 samples were selected by lottery method (During the year 2017 – 2018).

SAMPLE FRAME AND SIZE

- ✓ The baseline survey by using both qualitative and quantitative techniques were used in the study
- ✓ Adapting simple random sampling technique a sample of 500 parents of ID children is selected from the specified Bavitha Schools
- ✓ The sample parents are identified with reference to children names enrolled and registered in head office of the Bavitha schools, i.e., SarvaSikshaAbhayan (SSA) and NGO run schools.

Research Design: Descriptive Research Design

Tool for Data Collection:

- ✓ Semi-structured interview scheduled for gathering data on relevant variables of the study
- ✓ Data was collected from July 2018 to June 2019
- ✓ For the collection of data from the respondents, an interview schedule was prepared after review of related literature from the various books and journals.

The tool has the subsequent parts

SECTION– A: Deals with socio- demographic variables of both the parents of intellectual disabled children

SECTION – B: Deals with contributing factors of Intellectual Disabled individuals

SECTION – C: Scale linked to gender aspects

SECTION - D: Scale to related challenges

SECTION -E: Scale interconnected to coping strategies.

ANALYSIS OF DATA

- ✓ Coded and Entered Data into Excel Spreadsheets

- ✓ Frequency Tables and Cross-Tabulations
- ✓ Chi-square test of Significance/ Statistical Analysis done with IBM, SPSS (version 20.0) Soft ware

MAJOR FINDINGS OF THE STUDY

Section – I: Back ground characteristics of Respondents

- ✓ It is amply evident from the study that 45.20% male parent respondents are in the age cohort of 31-35 years.
- ✓ With regard to frequency distribution of female mother respondents 41.60%, are in the age groups of 26-30 years
- ✓ When the data was analyzed father's (64.80%) monthly income was 5000 – 7000 and Half of the mother's (52.80%) monthly income was 5000-7000 rupees
- ✓ When the parents were enquired about their type of family, more than three fourth (80.10 %) respondents belongs to nuclear family.
- ✓ Maximum number of parents have got consanguineous marriage (54.40%) in that (26.00%) parents were of first degree consanguinity
- ✓ Out of 250 mothers (75.20%) had normal delivery and half of the mothers had (50.80%) birth asphyxiated children

SECTION - II: Description of demographic variables of affected children

- ✓ It is evident that majority of the affected ID children (46.00%) comes under 6- 10 years of age group

SECTION – III Association between Gender Aspects and Selected Variable of Parent's

- ✓ Identified major gender differences
- ✓ Father's (34.40%) and mother's (30.80%) are agreed to say that father does not have patience to take care of his affected children
- ✓ Fathers (30.00%) and mothers (39.20 %) are agreed and fathers felt that the mother is responsible person to take care of the affected child
- ✓ Fathers (41.60%) and mothers (43.20%) are strongly agreed that the mother has to sacrifice her total life for her disabled children.

SECTION – IV: Association between challenges and Selected Variables of Parent's

- ✓ It indicates that the mothers and their boy and girl children have no relationship between challenges and selected variables
- ✓ The study results accepts the alternative hypothesis hence, it is inferred that there is a relationship between gender and fathers' challenging aspects but there is no relationship between gender and mothers challenging aspects.

SECTION – V : Association between Coping Strategies and Selected Variables of Parents

- ✓ Chi-square test was administered to know whether there is relationship between parents and their coping strategies on ID
- ✓ Results were revealed that there is a positive relationship between parents and their coping aspects on intellectual disability
- ✓ It denotes that there is a positive relationship between parents and their coping aspects on intellectual disability. Hence the researcher accepts the alternative hypothesis.

GENDER ASPECTS, CHALLENGES AND COPING STRATEGIES OF BOTH PARENTS

GENDER ASPECTS

- ✓ Father Aspects Correlation is significant at 0.05 level of age of the fathers, education of the father, area of living and occupation of father
- ✓ The study results accepts the alternative hypothesis
- ✓ Mother Aspects Correlation is significant at 0.05 level of age of the mother, education and consanguinity marriage of mother
- ✓ Correlation is significant at the 0.01 level of gender of the mother, income of the mother
- ✓ The study results accepts the alternative hypothesis.

CHALLENGES

- ✓ Father challenges Correlation is significant at 0.05 level of education, area of living and income
- ✓ The study results accepts the alternative hypothesis
- ✓ Mother Challenges Correlation is significant at 0.05 level of age, education, consanguinity marriage
- ✓ The investigator accepts the alternative hypothesis.

COPING ASPECTS

- ✓ Father Coping Strategies: Correlation is significant at 0.05 level of area of living and family type.
- ✓ Correlation is significant at the 0.01 level of income, suggestions to reduce this disability
- ✓ The investigator accepts the alternative hypothesis
- ✓ Mother Coping Strategies: Correlation is significant at 0.05 level of area of living, occupation, income, marriage and type of relation
- ✓ Correlation is significant at the 0.01 level of education, suggestions to reduce this disability
- ✓ The investigator accepts the alternative hypothesis

RECOMMENDATIONS:**PARENTS ASPECTS**

- ✓ To ensure the full awareness of the parents regarding governmental programmes
- ✓ There is a proper demarcation of rolls between male and female parents in the home environment
- ✓ Counseling services shall we provide to the parents
- ✓ Parental adjustment or satisfaction in taking care of mentally disabled children

POTENTIAL VISTAS OF FUTURE RESEARCH

- ✓ Comparative studies shall also be conducted across religious groups, rural – urban populations and economic status groups
- ✓ Studies can be conducted covering different segments of the parents of children suffering from various disabilities
- ✓ Longitudinal studies can also be taken up so as to assess the changing needs of intellectually affected children as the progress along the evolutionary continuum of their life spans.

POLICY MAKERS

- ✓ Experimental studies shall be conducted on dietary supplementation with folic acid
- ✓ Special studies shall be initiated on pregnant women
- ✓ The study shall also aim at development of awareness materials and methods, keeping the parents of developmental disabilities as target groups.

STRUCTURED TEACHING PROGRAMME ON FAMILY INTERVENTIONS AND COUNSELLING ASPECTS

- ✓ Parenting an Intellectual disability child is not an easy task
- ✓ Parents having an Intellectual disability child experience a variety of “Psychological Stress” related to the child’s disability
- ✓ Parents especially mother’s need every possible help and encouragement possible in their difficult task.
- ✓ **AIMS AND OBJECTIVES OF FAMILY INTERVENTIONS ARE TWO FOLDS**
- ✓ To ensure optimal care for the child with intellectual disability in terms of the needs for his/her development
- ✓ Health and wellbeing, and to become a respectful citizen of society [normalization]
- ✓ To ensure a successful family adaptation.

PARENTAL REACTIONS

- ✓ Shock – Stunned by the news
- ✓ Denial – Refuse to believe the news that the child has any disability
- ✓ Depression
- ✓ Acceptance- gradually accepts the child with his real abilities.

MANAGEMENT

- ✓ Home based family care approach with parents and other family members as partners in care
- ✓ Early detection and intervention
- ✓ Normalization and integration
- ✓ Individualization of intervention
- ✓ Medical measures to treat underlying or associated problems
- ✓ Appropriate optimum habilitation to a give child and family in a given environment
- ✓ Family empowerment.

FAMILY INTERVENTIONS

- ✓ Parent Training
- ✓ Parental Motivation
- ✓ Parental counseling

INITIAL COUNSELLING

- ✓ Pre orientation
- ✓ Involvement of the parents
- ✓ Parents should be given proper information about the capability and incapability of the child.

Identification Schedule

- ✓ Counselors should create awareness through educating the parents regarding their role

Suggestions for the Parents

- ✓ Your attention to the child's wants and feelings
- ✓ Avoid labeling children either positively or negatively
- ✓ Praise your child often.

BARRIERS IN COUNSELLING

- ✓ Emotional disturbance of the parents
- ✓ Anxiety
- ✓ Religious and cultural beliefs of the parents
- ✓ Misconceptions and false beliefs of the disorder
- ✓ Changes personality characteristics of the parents
- ✓ These barriers need to be minimized in counseling.

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