

# **GENDER DISCRIMINATION:** **Equity and Justice**



*Edited by*

**Dr. VANKAYALAPATI VENKATESWARLU**



## CONTENTS

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## CONTENTS

Foreword

Preface

List of Contributors

1. GENDER DISCRIMINATION- SOCIO-LEGAL INITIATIVES FOR GENDER JUSTICE  
-Prof. M. Lakshmi pathi Raju – 1 -
2. MENTAL HEALTH STATUS OF WORKING AND NON-WORKING WOMEN – A STUDY IN KURNOOL DISTRICT OF ANDHRA PRADESH  
-Smt. P. Jayasree, Dr.G.Venkata Ramana – 12 -
3. SEX RATIO AND GENDER INEQUALITY IN INDIA  
-P. Sowjanya Samuel, Prof. Saraswati Raju Iyer – 19 -
4. GENDER INEQUALITY IN INDIA  
-Dr.V.Subhashini, Dr.AVVS Swamy – 30 -
5. GENDER EQUALITY IN INDIA: ISSUES AND CHALLENGES  
-Dr S.Vijayalakshmi – 38 -
6. WOMEN CONSTRUCTION WORKERS AND GENDER DISCRIMINATION OF WAGES  
-Dr. P. ThavithaThulasi – 47 -
7. GENDER DISCRIMINATION OF ADOLESCENT GIRLS WITH DISABILITIES (ASD): EXPERIENCES AND PERCEPTIONS OF PRIMARY CARE GIVERS: IMPACT OF SOCIAL CASE WORK INTERVENTION  
-Dr.R.Madhumathi – 59 -
8. DOMESTIC VIOLENCE AND ITS PREDICTORS AMONG DIFFERENT SOCIAL GROUPS OF WOMEN: AN INVESTIGATION IN SELECTED STATES OF INDIA  
-Dr.A. K. Ravisankar, A. Durga Bhavani – 69 -
9. IMPACT OF MAL-NUTRITION ON TRIBAL WOMEN AND CHILDREN  
-Dr.K.Dhana Lakshmi, Lakshmi Naik .P – 83 -
10. PROMOTION OF EQUALITY OF WOMEN  
-Dr. Srigouri Kosuri, Mr. S. Stanislaus - 88 -
11. GENDER DIFFERENCES IN SUBJECTIVE WELL BEING OF MIDDLE ADULTHOOD STAGE  
-Dr. M.Deepa, Dr.M.Yugandhar Kumar, Dr. M. Ganga Devi, Dr. Ch. Anil Kumar, Dr. Tejasvi. V, Ravinder.M – 94 -

## **GENDER DISCRIMINATION OF ADOLESCENT GIRLS WITH DISABILITIES (ASD): EXPERIENCES AND PERCEPTIONS OF PRIMARY CARE GIVERS: IMPACT OF SOCIAL CASE WORK INTERVENTION**

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### **Introduction**

National data reveals that an overall, 2.21% of Indian population has one or the other kind of disability and approximately 2.68 crore people in India are disabled. Among the disabled population 56% (1.5 Cr) are males and 44% (1.18Cr) are females. In the total population, the male and female populations are 51% and 49% respectively. (Census, 2011 updated 2016).

Evidence from the literature and the field study shows that, due to gender discrimination, the girl child hated even before birth in many cultures. On birth she is either killed or exploited (Sherwani, 1998). A girl child has never been considered an equal to male child and right from her birth she has to face a society which considers her inferior and as a liability. They are treated with contempt and deprived of the love, care and affection (Chatterjee,1980).

The practice of gender discrimination has its roots in the society, and it is reinforced by norms, values, culture, caste, class and religion. Gender discrimination begins early in life, with female infants having a lower chance of survival than male infants, owing largely to the parental neglect of female infants. It is double, when female child has disabilities. The Girl's need for education, food, love, and care is underestimated and many parents consider it a sheer waste of money (Sherwani,1998). Biases started from birth and girls are given secondary status in every stage (Devasia and Devasia,1991). In the study of Parveen (2007) it is mentioned that rural areas thought to be the root cause for gender discrimination. And in the study of Aslam (2007), further elaborates that generally, parents select comparatively better schools, in context of quality, for their sons. Daughters are ignored or enrolled in the schools having lower fees and fewer facilities. Significant gender discrimination is found in health care spending for children while the households face resources scarcity (Asfaw, Klasen, Francesca & Lamanna,2007)

Due to gender discrimination, many social issues crop up like feticide, infanticide, low school enrollment, child marriage, dowry harassment and domestic violence, decrease in sex ratio, kidnapping, Rapes etc. It is more severe, when girl or women who are having disabilities either physical disability or mental disability. This paper tries to explaining about the problems of Adolescent girls with disabilities with special reference to Autism Spectrum

Disorders, and study and explores the experiences and perceptions of primary caregivers of girls with disabilities about gender discrimination and their worries and fears about the future of their children from the community setting of Chittoor district of Andhra Pradesh.

Adolescent Girls with disabilities face many obstacles in their struggle for existence. Many girls and women with disabilities face double discrimination, due to disability and being women. The women with disabilities are typically seen as helpless, dependent, victimized and passive. To date, the situation of girls and women with disabilities in India has not been given the visibility and political importance it deserves and requires. Although on the one hand, problems relating to girls and women and on the other, problems relating to people with disabilities are being addressed separately with increasing attention and urgency, so serious approach has yet been taken to tackle the dual form of discrimination to which girls and women with disabilities are subjected.

There is still an insufficient level of awareness of the existence of this twofold source of discrimination, its effects have been largely unresearched. It remains masked behind each of its constituent parts and any measures taken appear to be based on the idea that the two aspects of the discrimination should be dealt with separately.

Autism Spectrum Disorder is a neurological pervasive developmental growing disorder I in 59 are affected with this disorder.(CDC,2018). They are diagnosed fundamentally based on behaviour and they have core impairments in social interaction, communication as well as restricted and repetition behaviour. Society is treated autism as disease or disability. It does not understand the problems of adolescents with ASD and their families. Stigma is attached to it. There is no cure for ASD, and no global consensus regarding which intervention strategies are most effective. Chronic management, often using multiple treatment approaches may be required to maximize functional independence and quality of life by minimizing the core ASD features, facilitating development and learning, promoting socialization, reducing maladaptive behaviours and educating and supporting families. There are very few support services available for children with Autism. Many services (special Education, Therapies, Vocational Training etc) facilities are accessible at cities than semi urban and rural areas. Though there are support services for individuals with developmental disabilities through Sarva Siksha Abiyan, (SSA) programme, but support from these services are not adequately utilized or meet the challenges of children and families of individual with Autism.

Review of literature traces that less data on therapies for adolescent or young adults exists than for younger children and such research is increasingly important as the prevalence of ASD continues to grow and as children with ASD diagnoses reach adolescence.

The present study is an attempt to explore the case studies of primary care giver's experiences and perceptions about gender discrimination of Adolescent girls with disabilities (Autism Spectrum Disorders) in community settings of Chittoor district of Andhra Pradesh.

**Aim of the Study:**

The aim of the study was to explore the experiences & perceptions of the primary caregivers of adolescent girls with disabilities (ASD)

**Objectives of the study:**

The specific objectives that sought to be addressed were:

1. To understand the psychological issues affecting primary care givers of adolescent girls with Autism Spectrum Disorders (ASD) with reference to gender discrimination.
2. To Know the social and economic encounters of primary care givers of adolescent girls with ASD with reference to gender discrimination.

**Methods and Materials:**

Taking in to consideration of the research objectives, mixed method research design was adopted in which higher weightage was given to qualitative methods. The present study was extracted from the Major Research Project entitled "Efficacy of Social Work Interventions for Children with Autism Spectrum Disorders and their Families" funded by ICSSR, New Delhi, conducted in Nellore and Chittoor districts of Andhra Pradesh.

**Sample:**

The researcher by adopting purposive sampling method only 3 cases were presented based on the severity of gender discrimination faced, from a sample of 40 cases of main study with children with ASD. Out of which 55% of children are 6-11 years and 45% of children are 12-18 years. Among these groups 20% are females and 80% are males with autism. Among 20% of females, 3 cases were extracted for present paper to analyze gender discrimination among girls with disabilities (ASD)

**Tools for Data Collection:**

The following research instruments were used for the present study

S.No.	Tool
1	Intake Form (Socio-demographic Information Schedule)
2	Indian Scale for Assessment of Children with Autism (ISSA)
3	Case studies – recorded and transcribed
4	Functional Assessment Checklist for Programming(FACP)

**Data Collection:**

With the support of Sarva Siksha Abiyan data, cases were identified from the community settings of Chittoor district. The researcher contacted the parents over phone with the support of Inclusive Education Resource Teacher (IERT),

before attending them in home explained about the purpose and nature of study. The interview's were planned according to the convenient time of the primary care giver (mother). Interview method and observation methods were adapted for data collection, where a detailed face to face interview was carried out. Each interview took around 45 minutes to 1 hour to complete. An informal verbal consent was taken from the respondents and assured that the data will be used only for the purpose of research. After 14 sessions data saturation was reached. The researcher and her team (two Research Assistants) visited the homes of adolescent girls with ASD periodically for a period of 9 months. Interventions were given based on assessment by using FACP. Interaction with parents and families of Adolescents with ASD, goals and objectives were selected. (Social case work sessions were conducted with the Primary caregivers of adolescent girls with ASD and pre and post intervention scores explained about the importance of social case work in reducing gender discrimination and involve all the family members in giving training to the adolescent girls with ASD and improvements were noted.

### Case Studies:

#### Case-1

Case 1, Aged 13 years girl with moderate level Autism Spectrum Disorder, residing in Chittoor district of Andhra Pradesh. Born as eldest daughter to rural, middle class (Rs.15,000/- per month), Hindu, nuclear family. She has younger brother studying 3<sup>rd</sup> class. Parents studied up to graduation. Mother revealed that they identified the problem at the age of 30 months. By observing language and interaction difficulties attended Christian Medical College (CMC), Vellore and undergone training for 3 months. After identifying the problem in case 1, there were conflicts in the family. Parents came to Chittoor from their village in the year 2009 for education of their children.

Case 1- mother felt that her husband favoured her son and not shown interest towards daughter and did not treat them equally. In the words of mother *"My husband not at all shows interest towards my daughter. He always likes my son I am getting angry about my family members attitude. My mother-in-law is the main person, and she is residing with my sister-in-law in neighbouring house. She did not like to see my daughter's face. She always tells to my husband your daughter is waste. No use. You have to head down in the society because of your daughter. For all these, your wife is the responsible. At any time son will look after you and the family."*

He thought that it is the responsibility of the mother to look after the girl and has unenthusiastic attitude towards daughter and more interested towards his son. Mother suffered with emotional trauma during her pregnancy due to adjustment problems with her mother-in-law, sister-in-law and her husband.

Mother (42 years) of case -1 also expressed that *"whenever my daughter shows any improvement, when I told to my husband he is not at all shows any interest.*

*He told that you and your daughter enjoy it. For me my son is enough. For him son is the only person living in the home. my daughter and I not shown to his eyes"*

*Further she added that, whenever he bought any food items, he did not share it to his daughter. I only have to share food to my daughter.*

*Mother mentioned that I would like to take my daughter to social gatherings but due to various comments from my family and in-laws, and my husband and other relatives I do not want take my daughter to outings as well as functions"*

*I have planned to commit suicide with my daughter , I was alive because of my father, mother and sister. They told that you have two children one daughter and one son. Son also your child. Do not get aversion to him. As his father told disinterest, he also shows disinterest towards his sister. It is very pricking to me"- Mother of case 1 revealed.*

There is history of medication and changing of schools, and finally they attended Bhavitha centre (Community Centre for Special Education) at Chittoor, but not attending regularly and have dissatisfaction about services available at the centre.

#### **Case-2**

Case 2 – is a 15 years girl with moderate autism, who is youngest daughter of her parents. She has elder brother. Residing in a joint family (6 members), at Renigunta near Tirupati belongs to Hindu religion and monthly income of family is Rs.20,000/-Father doing work in Railways, mother house wife. Both the parents are educated,(degree). Normal delivery, pre-mature baby (one week).Birth weight 3.5.k.g., after delivery 3 days in hospital (incubation). Diagnosed as ASD at the age of 24 months. Case 2 Shows aggression, over activity, language difficulties, feels more appetite.

Mother (40 Years) of case 2 revealed that<sup>1</sup>*"I have lot of pressure to look after household activities. My son is in 10<sup>th</sup> class. My In- laws are more conscious and attentive about my son.Due to my daughter problem I was not able to cope with. No one help me. I was the only person look after the needs of whole family. My husband is relative to me(Consanguous marriage-2<sup>nd</sup> grade ). In my family I have to supply coffee, tiffins, lunch and dinner time to time to my mother-in-law and father-in-law. My daughter has behavioural problems. My mother in law did not allow my daughter to go to SSA, because she is a girl.By sitting and eating in home without activity, my daughter became obese. My family is blaming me for my daughter's behaviour. They did not give me freedom to control my daughter. They over pampered at early age, no schooling, now they are blaming me. Every day morning I worried how the day is going to be and no service help us to overcome this"*

#### **Case-3**

Case 3 – is a 14 years girl with moderate autism, who is youngest daughter of her parents. She has elder sister. Residing in a extended family (5 members), at Juvvala Dinne, K.V.Palli mandal near Piler , belongs to Hindu religion and



monthly income of the family is Rs.6,000/-. Case -3 was a Pre-mature baby born with normal delivery at Government hospital, Madana Palli, after delivery baby and mother was hospitalized for two days.(Incubation). Problem was diagnosed at the age of 8 years. Both parents have no formal education. Eldest daughter is studying 8<sup>th</sup> class at KV Palli. Whole family involved in agricultural works, mother- in -law died, father –in-law look after Sheep rearing (2 in number) Parents have no knowledge about disability. Enrolled at SSA, but not sending the daughter to Bhavitha Centres, irrespective of many remainders.

In the words of Mother (38 years)- *We are very poor. Daily we have to work. For my elder daughter school teachers provide Mid-day meal. Sir (IERT teacher) asked to send my youngest daughter to school. I am the only one look after the needs of the family. My husband goes to the fields morning. I have to prepare food and take it to my husband and father in-law. I became tired with Cleaning, cooking, watering, washing clothes, look after younger daughter and go to the fields. No time for me to send my daughter to Bhavitha school which is 5 kilometre away. Being a girl, and innocent, do not know anything. How can I send? If she were a boy, I would have send. I am worried about abuse and harassment towards my daughter. Days are not good. My daughter is in front of my eyes, It is enough for me.*

From these episodes we can observe the gender discrimination and also disability discrimination in the families of adolescent girls with ASD.

#### **Intervention:**

From the above pieces of episodes with primary care givers of adolescent girl with Disabilities(ASD),It was found that gender discrimination was observed and being a girl, and being women, the primary care givers also struggled with social roles and humiliation, over burdened and stigmatized.

Researcher and her team started the intervention by explained the purpose and need of visit to the primary care givers of adolescent girls with ASD. Explain the importance of training and education, and how it influences the future of their daughters. After 3 to 4 sessions, all the primary care givers agreed and accepted to involve in the training programme of their daughters. Along with visits, phone calls are made both sides to maintain rapport. Confidentiality was maintained. Task analysis, prompts, one-on –one training, reinforcement for every successful attempt, every day training for a period of 3 hours helps the girls with adolescents to improve. After 3 months (1<sup>st</sup>,2<sup>nd</sup> &3<sup>rd</sup> month) they observed the improvement in selected Self Help skills of their children which motivates the family members to show interest in the training programme. In Second phase of time i.e.in 4<sup>th</sup>,5<sup>th</sup> and 6<sup>th</sup> months involved elder and younger siblings in self help skills(Brushing, Grooming, and in academics) except in case-2(Where the elder sibling is studying 10<sup>th</sup> class and not disturb him, instead of it mother in law agreed to look after breakfast to their family members with the support of servant aid, during that time mother of case -2 involved in training programme of their

daughter. By the third phase all the mothers are willing to come to Bhavitha centre and arrange autos to take their daughters to Bhavitha centres initially for two half days in a week and slowly 4 days in a week with the support of other parents of children with disabilities. By the end of 9 months (7<sup>th</sup>, 8<sup>th</sup> and 9<sup>th</sup> Month) there was a tremendous change in the attitude of primary care givers and as well as family members in accepting the child and involve in training programme of the child at their free time or relieve the mother from her household work and make mother to involve in the training programme. Negative comments were reduced. Interactions with other mothers Sharing feelings and knowledge were improved. Now the parents are getting emotional support from each other and also from other parents of Special Needs Children, IERT teacher and other professionals. Evaluation at 3,6,9 months point of time and revealed the findings. Follow up was done for a period of 3 months through phone call. All the primary caregivers are involving in the training programme with the support of family members is continuing.

#### **Major Findings of the study:**

- **The socio-demographic profile of the adolescent girls revealed that**
- Majority 66.6% of children are in the age group of 13 to 15 years.
- 66.66% of parents diagnosed autism in their children at the age 36 months
- 66.6 % of children have born on second birth position.
- 66.6% of children with Autism born with birth weight of 3 k.gs and above.
- 66.6% of mothers suffer with emotional problem during pregnancy
- 33.3% families are belongs to low income group.
- 66.6% of children have language difficulties
- 33.3% of children have temper tantrums and aggression

#### **Demographic details of primary care givers**

- Majority (67%) of parents are in the age group of 40 - 45 years.
- Majority (67%) of parents (Fathers) education levels is Degree.
- Income: Majority (67%) of parents monthly income is between Rs.15,000/- to Rs:20,000/-.
- Majority (100%) of the parents are Hindus in this study.

#### **Improvement in functional skills of Adolescent girls with ASD after intervention:**

After involvement of primary care giver and family members of adolescent girls with ASD in the training programme with social case work intervention for a period of 9 months and the results shows the improvement in functional skills of cases are as follows:

**Case 1** improved in eye to contact while talking with strangers(75%), informing about her toilet need in outside home (100%), washing hands(100%), mixes rice with curry(100%), removes and wears kurtha

(75%), identifying yellow and red color(100%), writes father name, mother name and phone number and address(100%), involved in textile work(75%).

**Case II** improved in brushing skill(100%), Grooming (85%), tying pyjama (90%), selection of dress(100%), Cooperates in walking along with mother and grandparents(80%),Sweeping the floor(60%), sitting in yoga class and practicing asana(75%), involving in gardening, watering plants(80%).

**Case III** improved in her brushing skills(100%), dressing skills (tying pyjama(100%), toileting skills(cleaning self(100%),reducing wondering behaviour and involving in drawing activities(80%), writing name ,mother name, father name and address(100%), Sweeping the floor (70%).

**Suggestions for the wellbeing of caregivers of adolescent girls with ASD:**

- Families of ASD need to ventilate their emotions with the professionals and attend the professionals as early as possible once the parents identified the signs and symptoms of ASD.
- Parents and grandparents of children with Autism need to develop reciprocal relationships with other parents of disabilities.
- Involve all the family members including siblings in the training programmes of persons with disabilities, which reduces burden and fear among primary care givers as siblings are future caregivers for persons with disabilities especially girls and women with disabilities.
- Awareness among the family members help them to develop social net work with close relatives (majority maternal side) and friends, which helps them to overcome the problems of rearing of individuals with disabilities.
- Develop self determination and decision making among parents of ASD by interacting with other parents of special Needs Individuals.
- Specialized knowledge is required to solve the problems and provide appropriate rehabilitation measures to girls and women with disabilities.(ASD)

**Conclusion:**

- The study proved that Social Case work intervention with behaviour principles with 17 sessions (14 Individual Sessions and 3 group sessions) can improve the functional level of adolescent girls and reduces the gender discrimination among the families by creating awareness, knowledge about the disability, teaching of training techniques, and build up the confidence and self esteem among primary care givers and provided opportunities to the adolescent girls with ASD to learn and become independent in some self help skills.

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