

SOCIAL EXCLUSION OF WOMEN WITH DISABILITIES

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INTRODUCTION

Women with disabilities have a right to good health. Good health depends on enough nutritious food to eat, regular physical activity, and access to information and services to prevent and treat health problems, especially problems of reproductive health. Millions of women are living with disabilities, varying conditions that make their already burdened roles even more challenging because of physical or mental limitations. Various diseases and conditions produce some form of disability, and a number of them disproportionately affect women. In general, the severity of a disability is described in terms of how much that disability limits one's daily activities. Women are more likely than men to be limited in the amount or kind of major activity they can perform, and more stigmatized owing to the huge demands that the activity makes on their time and energy. Some of the challenges faced by women with disabilities include: physical barriers, such as architectural barriers and lack of adequate transportation and support services to keep appointments, run errands, or receive medical care; financial restraints; and lack of reliable health information and services that address their needs.

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According to United Nations Development Programme (UNDP), 8 percent of the world population suffers from different forms of physical, mental and sensor disorders. WHO estimates that 10 percent of the world's population experience some form of disability or impairment. There is growing evidence that women with special needs comprise between 4 and 8 percent of the Indian population (around 40-90 million individuals). The National Sample Survey Organisation 2011 indicates 73 percent persons with special needs are from rural areas. Disabled women are women who have one or more impairments and experience barriers in society. Women with special needs are multiply disadvantaged through their status as women, as persons with special needs, and majority numbers as persons living in poverty. Much of the discrimination experienced by differently abled women is based on an implicit notion that they are not the same as other women and so cannot be expected to share the same rights and aspirations. The isolation and exclusion of disabled women even extends to mainstream women and women's movements, which deny them their rights and identity. Isolation and confinement based on culture and traditions, attitudes and prejudices often affect disabled women more than men. This isolation of disabled women leads to low self-esteem and negative feelings. Lack of appropriate support services and lack of adequate education result in low economic status, which, in turn, creates dependency on families or care-givers. Some societies go so far as to assign fault to a mother who gives birth to a disabled child, especially so if the mother is a disabled woman. Differently abled women and men can experience different kinds of attitudes based on gender discrimination. While men are still seen as the major bread-winners and leaders of society, a disabled man, considered "less of a man", won't conform to that stereotype.

This is the aspiration of every disabled woman - to be able to have friends, to go to school, to have the qualifications and skills for a good job and then do the job well, to be independent, to be respected, to give and receive love. In other words, they want to have a life like other women. But most women with disabilities cannot live like others. They are more likely to be extremely poor have little or no schooling, be without vocational skills, be unemployed, have less access to public services, be unmarried or childless, be physically, sexually, or psychologically abused. They make up, without doubt, one of the most excluded and isolated groups of people in every society, being **triply disadvantaged by their disabilities, by their sex, and by poverty**. Like all other disabled people, women with disabilities are often treated as if their particular disability has affected all their other abilities. In society's eyes they are not capable of earning an income and let alone of living independently. Excluded from opportunities, disabled women are on the whole desperately poor. While poverty is a result of

discrimination, it is also a cause of further discrimination. Poverty is the lack of resources: not just money, but also skills, knowledge, and social connections. Without those resources, disabled women have very limited access to institutions, services, markets, and employment. The extensive discrimination against women with disabilities violates the principle of equality of rights and their human dignity. They are denied equal opportunities in social, economic, and political life. The difficult situation of women with disabilities has been recognized nationally and internationally. However, there is as yet not enough action or results. Where disabled women have been given opportunities for training and work, they have shown that they can be loyal and reliable workers. They are highly motivated because, while for most people work is a means of gaining financial independence, for women with disabilities having a job also means becoming part of society - something others take for granted.

Women with disabilities tend to be more vulnerable to exploitation of various kinds. According to the 2010 UNDP Human Development Report, women with special needs are twice as prone to divorce, separation and violence. Disabled women also tend to be relatively easy targets of sexual exploitation. In general, differently abled women tend to be in a state of physical, social and economic dependency. This can lead to increased vulnerability to exploitation and violence. Because of the relative isolation and anonymity in which women with special needs live, the potential for physical and emotional abuse is high. It is estimated that having a disability doubles an individual's likelihood of being assaulted.

Women with disabilities are multiply disadvantaged through their status as women and are living in **poverty**. Around the world, women make up just over 51 percent of the population. The problems of women with disabilities become very complex with other factors such as social stigma and poverty. Forming part of two disadvantaged and minority groups (disabled people, and within these "women"), they find themselves up against a **double discrimination**, as well as various barriers which make accomplishing objectives essential in everyday life very difficult.

Women with different kinds of disabilities have different requirements and problems, which need to be addressed accordingly through specific interventions in areas like education, accessibility, training & employment, social security and protection and the like. No single stakeholder can bring positive changes in the situation and status of women with special needs. A combined effort – more sensitivity, awareness, willingness, initiative - of women with special needs themselves, the government and non government organizations, common people, media personnel, law-makers and law-protectors, teachers, educators and trainers, can

empower women with special needs in true sense and ensure their societal mainstreaming. This research study would be helpful to policy makers, government and Non-governmental organization for framing an appropriate policy to improve the quality of life and retention of women with special needs into mainstream stream of social life.

This study was interested to concentrate on to identify the status and social inclusion of women with special needs in Tiruchirappalli district. The project director also focused to analyze the impact of disability on their marital status, emotional disturbance, social attitude, Abuse & violence against women with special needs, family adjustment and quality of life of women with special needs. This study would great helpful to the Disabled Rehabilitation centers, Organizations and policy makers for improving and preparing appropriate policies & welfare programmes to improve the social inclusion and quality of life of women with special needs.

METHODS AND MATERIALS

The aims of the study are to identify the status and social inclusion of women with special needs in Tiruchirappalli district. The study also indents to analyse the impact of disability on their marital status, emotional disturbance, empowerment of women with special needs social attitude, Abuse & violence against women with special needs, family adjustment and quality of life of women with special needs. The present descriptive study would be conducted in 16 blocks of Tiruchirappalli district. The universe consists of 1249 WWD in Tiruchirappalli District. The researcher select 20 women with disabilities as a sample from each block of Tiruchirappalli District (N=320) through stratified disproportionate random sampling method. This study is taken with a view to understand the socio-demographic characteristics of the respondents and to examine their empowerment on decision making and social inclusion, and quality of life of women with disabilities in the study areas. The study also indents to analyse the impact of disability on their marital status, emotional disturbance, Abuse & violence against women with special needs.

The purpose of the study was to identify the status and social inclusion of women with special needs in Tiruchirappalli district. The study also indents to analyse the impact of disability on their marital status, emotional disturbance, empowerment of women with disabilities social attitude, Abuse & violence against women with disabilities, family adjustment and quality of life of women with disabilities. The participants for this study were drawn from women with special needs in Tiruchirappalli district. The universe consists of 1249 women with special needs in Tiruchirappalli district. Out of which the researchers

selected 20 women with special needs in from each block (n=320) through stratified disproportionate random sampling technique. The researcher would use primary method of data collection. The research would use interview schedule for data collection, which includes three phases.

In the first phase, the researcher would administer interview schedule, which focuses on demographic characteristics of the women with special needs through semi-structured and open ended individual questionnaire. It also includes questions on the empowerment of women with special needs on decision making and social inclusions and to find out the level of awareness on their rights, policies and welfare programmes. The unique features of this research also constitute Ethnography, which is a qualitative research method used to describe the impact of disability on marital status, emotional disturbance and changes in social attitude.

In the second phase the researcher would employ the technique of structured focus groups to discussion on the issue of their rights, policies and welfare programmes available for them. The focus group approach was selected as an appropriate method to explore sensitive discussion areas with women with special needs. The introduction given by the researcher was designed to make people comfortable in sharing their views. It is the researchers' intention to do research in this area and to explore their problems through one-on-one interviews, problem tree analysis and participatory rural appraisal analysis with the respondents. The purpose of these techniques was to explore the issue of abuse related to emotional and psychological domain of the respondents. All focus group sessions would be audiotape recorded with the permission of participants and tapes were transcribed. A content analysis of the major themes in the transcripts was then undertaken using a computer that helps the process of coding long narratives for themes. Once coded, the findings can be sorted by theme. A group of initial codes were created based on major themes found in the literature and then supplemented with additional themes drawn from reading the transcripts. The coding completed by a research assistant was then compared with coding done by the Deputy Director of this project to assure agreement in the application of codes and differences were discussed and resolved. Based on a reading of the transcripts, types of abuse were coded as physical, emotional, sexual, neglect, denial of rights, isolation and other. In the third phase the researcher would also use structured scales to find out the impact of disability on quality of life and psycho-social problems of women with disabilities.

Table No: 1
Distribution of the respondents according to their Decision making in house hold

| S. No. | Decision making in house hold | No. of Respondents (n = 320) | Percentage |
|--------|---|------------------------------|------------|
| 1 | Decision making in household | | |
| | Yes | 125 | 39.1 |
| 2 | No | 195 | 60.9 |
| | Consulted for decision regarding her life | | |
| 3 | Yes | 151 | 47.2 |
| | No | 169 | 52.8 |
| 3 | Consulted for decision regarding her medical needs | | |
| | Yes | 144 | 45.0 |
| | No | 176 | 55.0 |

Table 1 indicates that 68.4 percent of WWD are consulted by other members in the family while taking important financial decisions in the household. Percentage of WWDs who are consulted while taking decisions concerning their own life is 47.2 percent and 45 percent WWDs are consulted for making vital decisions regarding their medical needs. It was concluded from the table ours being a patriarchal society, household decisions are usually taken by the (male) head of the family. Women in general are either considered insignificant or even if their views are taken into account, the final decision is always made by the male members. Among the blocks that were covered in the survey, the percentage of WWDs consulted while taking household-decision is found to be the highest in urban and west block of Tiruchirappalli District and lowest in Musiri block.

Table No: 2
Distribution of the respondents according to their Social Mobility and Inclusion

| S. No. | Social Mobility and Inclusion | No. of Respondents (n = 320) | Percentage |
|--------|---|------------------------------|------------|
| 1 | Participation in other social gatherings | | |
| | Yes | 57 | 17.9 |
| | No | 263 | 82.1 |
| 2 | Reasons for not joining other social gatherings | (n=263) | |
| | Deprived due to impairment | 190 | 72.2 |
| | Guardians do not permit | 30 | 11.4 |
| | Social insecurity | 16 | 6.0 |
| | To avoid any embarrassing moment | 12 | 4.6 |
| | Due to some bad experiences | 15 | 5.8 |
| 3 | Discrimination in enjoying social status compared to other women | | |
| | Yes | 242 | 75.7 |
| | No | 78 | 24.3 |
| 4 | Types of discrimination | n=242 | |
| | Due to impairment | 190 | 78.5 |
| | Get no benefit from panchayat/local government body | 52 | 21.5 |

The table 2 explains that majority 82.1 percent of the women with disabilities not participate in the social gatherings and 17.9 percent only joining social gatherings outside home. This indicates mobility of WWDs within and outside home is very low. Out of the 82.1 percent WWDs who do not participate in functions outside home, 72.2 percent said that disability is the main reason behind it. Lack of guardians' permission is also an important reason (11.4 percent). A majority (75.7 percent) of the WWDs said that they face discrimination compared to others (non-disabled women) in enjoying social status. A large majority of WWDs face discrimination within family, among friends and in the community at large in terms of social behaviour. It was concluded from the table that the factor of 'independent' accessibility and mobility is very crucial for WWDs to be a part of mainstream society. Surprisingly, a large percentage of WWDs in all the block of study areas said that their homes are accessible and have good mobility in terms of attending social gatherings outside home. But most of their homes have not been modified according to their needs. This seems to be a little

contradictory. May be the WWDs interpreted accessibility and mobility in a different way, where they can move around within and outside home with the help of family members.

The qualitative findings highlight that the participation of persons with disabilities in activities within the community was limited. In our study area 47 per cent of persons with disabilities attended both social and religious functions, of which 53 per cent attended only religious functions. Persons with disabilities are discouraged from attending social functions like a marriage, while most of them take part in religious functions. The group discussion revealed that there were cases where friends have stopped visiting the persons with disabilities and since mobility is limited they find it difficult to visit others. Relatives usually take them to temples and mosques during religious celebrations. This could also be due to the fact that most villages (65 per cent) had at least one temple and many had 5-6 temples and some (6 per cent) had mosques also. They do not visit religious places outside their communities because of the physical hurdles (staircase leading to temple) they have to face. Sometime the non-disabled carried the persons with disabilities to the temple but this did not happen in the case of other social occasions. Women with disabilities are found to be socially insecure. The study highlighted several situations in which women were abused and exploited. To protect them, girls are not sent outside the village and in homes for the mentally retarded; women are sterilized to avoid pregnancies.

Results from the similar study of Thomas and Thomas (2007) Although there is a world-wide trend towards women with disabilities emerging from their isolation to establish their own self help groups and rights groups, the situation in developing countries remains quite different. In the available literature on women with disabilities in developing countries, it is often stated that these women face a triple handicap and discrimination due to their disability, gender and developing world status. In the South Asian context, gender equity is an issue for a large majority of women, given the socio-cultural practices and traditional attitudes of society. This paper discusses some of these unique disadvantages that disabled women in developing countries face in comparison with disabled men, and suggests possible strategies to overcome these disadvantages in a community based rehabilitation setting. World-wide, women with disabilities are emerging from their secluded state to organize themselves, and to form their own self help and rights groups to address their concerns. Some countries in South Asia have formulated policies relating to health care, education and rehabilitation to include women with disabilities. However, women with disabilities continue to face problems related to access to opportunities, negative attitudes and environmental barriers, which are problems that all disabled persons face. These barriers, coupled with some of the unique disadvantages

that women with disabilities face in traditional societies in developing countries, have contributed to keeping them marginalized, preventing them from taking their rightful places in these societies. However, it is possible to bring about a change in their situation through specially planned community based rehabilitation programmes to overcome the disadvantages that they face and to make them integrated, contributing members of their societies, with the same opportunities and choices as anyone else.

Table 3

Distribution of the respondents according to their Abuse and Harassment

| S. No. | Abuse and Harassment | No. of Respondents (n = 320) | Percentage |
|--------|---|---------------------------------|------------|
| 1 | Awareness about abuse and sexual harassment | | |
| | Yes | 210 | 65.7 |
| | No | 110 | 34.3 |
| 2 | Personal experience of sexual harassment | | |
| | Yes | 189 | 59.0 |
| | No | 131 | 41.0 |
| 3 | Place of experience of harassment | N= 189 | |
| | Home | 25 | 13.2 |
| | Work place | 84 | 44.5 |
| | Public Place | 20 | 10.6 |
| | Rehabilitation centers | 50 | 26.5 |
| | Medical institutions | 10 | 5.2 |
| 4 | Possible action to overcome/protect such situation | N=189 | |
| | Will Protest | 60 | 31.8 |
| | Will shout | 10 | 5.2 |
| | Will inform the family member | 60 | 31.8 |
| | Can't protest due to my impairment | 10 | 5.2 |
| | Will try to escape | 35 | 18.6 |
| | The culprit should be punished | 14 | 7.4 |
| 5 | Possible action in future if she faces harassment | (n=131) | |
| | Will Protest | 37 | 28.2 |
| | Will shout | 12 | 9.1 |
| | Will inform the family member | 30 | 23.0 |
| | Can't protest due to my impairment | 12 | 9.1 |
| | Will try to escape | 20 | 15.3 |
| | The culprit should be punished | 20 | 15.3 |

The table 3 experienced that it is quite surprising to find that 34.3 percent WWDs do not know what is meant by sexual harassment. The awareness level is very low. The level of

knowledge regarding abuse and sexual harassment is high among WWDs (almost 65.7 percent). Out of 59 percent WWDs are experienced sexual abuse and harassment, 44.5 percent faced it at work place and 26.5 percent in rehabilitation centers. The percentage of WWDs who said that they would protest if they face sexual harassment in future (28.2 percent) which is followed by 23 percent will inform the family members regarding their abuse and harassment. A very few percent of the women with disabilities opined that cannot protest due to their disability. The rate of crime and violence against women in general is increasing in India every year. National Crime Records Bureau and several research studies and surveys have records of such cases, but there are hardly any data on abuse/sexual harassment faced by girls and women with disabilities in India. However, the data in the above table reveals that majority of the WWDs have personal experience of sexual harassment or any form of abuse. It is a known fact that women usually do not disclose their experience of sexual abuse at home/public place/work place out of social stigma, a sense of fear and lack of support from within the family. In case of WWDs, the situation is understandably much worse as most of such cases go unreported/undisclosed by the victims.

Table 4

Distribution of the respondents according to their Awareness about Acts/Policies & Rights

| S. No. | Awareness about Acts/Policies & Rights | No. of Respondents (n = 320) | Percentage |
|--|--|------------------------------|------------|
| 1 | Awareness about policy/act | | |
| | Yes | 120 | 37.5 |
| 2 | No | 200 | 62.5 |
| | Awareness about acts/ laws / polices related to women's right | | |
| 3 | Yes | 110 | 34.3 |
| | No | 210 | 65.7 |
| 4 | Awareness about CEDAW | | |
| | Yes | 100 | 31.2 |
| 4 | No | 220 | 68.8 |
| | Awareness about Special provisions for disabled women through law | | |
| | Treatment rehabilitation | 50 | 15.6 |
| | Education | 250 | 78.1 |
| | Training | 40 | 12.5 |
| | Employment | 240 | 75 |
| | Independent living | 30 | 9.3 |
| | Safety and social security | 100 | 31.2 |
| Access to social services & information | 80 | 25 | |
| Abuse: Physical, Social, Mental and Sexual | 50 | 15.6 | |

Table 4 indicates that a miserable situation is being revealed by the above table. A Majority of the WWDs not aware about policy and law related persons with disabilities (62.5 percent), awareness about acts/ laws / polices related to women's right (65.7 percent) and awareness about CEDAW (68.8 percent). However, majority of the women with disabilities not aware about various special provisions for disabled women through law such as treatment rehabilitation, education, training, employment, independent living, safety and social security, access to social services and information and abuse: physical, social, mental and sexual. It was understand from the focus group discussion among the 60 women with disabilities in Tiruchirappalli district. A large majority of women with disabilities not having knowledge about act/laws for securing equal rights and opportunities for WWDs, along with

state/national policies for WWDs. Around 68 percent feel that these policies are gender sensitive. But those who think otherwise had views on what to be added /amended:

- The policies should be reviewed in totality.
- The sections of employment and development should be gender sensitive.

79 percent of the respondents feel that there is a need of provisions for WWDs in the acts/policies. Thirty (50 percent) WWDs did not have any knowledge and Fifty (83.3 percent) WWDs had some knowledge regarding laws that lay out special provisions for WWDs in terms of: treatment and rehabilitation, education, training, employment, independent living, safety and social security and all forms of abuse. Others had a mixed response. The other respondent has knowledge about laws regarding all the aspects, except education, training and independent living.

The following provisions were suggested if laws were drafted for WWDs:

- a) Treatment/rehabilitation: access to psychiatric treatment
- b) Education, training and employment: provision for special quota/incentive
- c) Independent living: awareness in the community
- d) Access to services and information: awareness about mental disability
- e) Penal provision for all forms of abuse: stringent policing and welfare initiative

50 percent of the respondents are aware of CEDAW but do not think that it has enough provisions for realization and protection of WWDs' rights. Much lesser percentage of respondents is aware of UN MDGs.

It is also observed from the participation of focused group discussion the first critical factor that has an impact on the effectiveness of any Act is the level of awareness about its existence amongst the target group. The level of awareness about these initiatives was not found to be high. A little less than half the respondents (47%) are aware about the Persons with Disabilities Act,(1995) while, 53% are unaware about the Persons with Disabilities Act, (1995). A majority (80 percent) of the respondents was aware of Persons with Disabilities Act. The respondents were asked to identify the most important legislation for empowering the persons with disabilities, especially the women with disabilities. Various responses/legislation Acts were given like Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995, Rehabilitation Council of India Act of 1992, National Trust for Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act of 1999, Mental Health Act of 1987, etc.

77.2 % of the women respondents could not specifically name any Legislation/act for empowering the persons with disabilities, especially the women with disabilities. Of those who could refer to some act, identified Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 (20.76%). The government has ensured the 3% reservation in poverty alleviation schemes to women with disabilities, as stipulated under the Act. The women respondents who were in some way or the other were disabled/handicapped were given the list of legislations and were asked to indicate that which of the legislations provides for 3 percent reservation quota for the persons with disabilities in government jobs. 22% of the women referred to Persons with Disabilities Act 1995 as legislation, which provides for 3 percent reservation quota for the persons with disabilities in government jobs. A Majority, 76.4% of the respondents named various centrally sponsored poverty alleviation schemes, which have 3% reservations. These respondents did not name any legislation/Act, but various schemes and programmes whose guidelines states 3 percent reservations for the disabled.

SUGGESTIONS

Issue of discriminations and denial of rights faced by Women with disabilities remain mostly hidden from the civil society. There is a lack of serious discourse among the GOs, NGOs and civil society around rights of disabled girls and women. This study unveils the utterly poor status of Women with Disabilities in all important areas of development and the need of focused attention to improve the same.

- Women with disabilities must be involved in all policy and decision making processes, and at every level of the projects: as staff, volunteers, participants, and evaluators.
- Education, vocational training and rehabilitation programs must include women with disabilities, to prepare women and girls for careers and gainful employment.
- The Governments should ensure anti-discrimination measures by forming special task forces to protect women with disabilities.
- The self-help organizations adopt policies to promote full representation of women with disabilities.
- The women with disabilities should be included in all the policy making bodies from panchayat to parliament levels.

- Set up state wise task force to prepare white paper on the quality of services available for girls/women with disabilities and all the institutions managed or supported by the government and other donors.
- Long term campaign is needed to stop abuse & violence against disabled girls & women, raising awareness about their rights and families to take proactive role to encourage and allow the disabled girls to take part in education and all other important activities.
- Bringing a change in the situation calls for accountability and will force of the stakeholders. The role of state, GOs and NGOs working for rights of women & girls and civil society in general is very important.
- In order to improve the quality of life of women with disabilities in the rural and urban India, district CBR Societies for women with disabilities should function in cooperation with CBR.
- All organizations working for women with disabilities and all organizations of women with disabilities and Self-Help Groups of Parents of adolescent girls with disabilities should become members of the society.
- Mainstream organizations must support and work in partnership with organizations led by women with disabilities.
- Education, vocational training and rehabilitation programs must include women with disabilities, to prepare women and girls for careers and gainful employment.
- Finally the following assistance for women with disabilities in India can be undertaken by:
 - 1) Providing them with advocacy and leadership training.
 - 2) Conducting a needs assessments and skills training in the area of information and communications technology (ICT).
 - 3) Assisting them in obtaining loans and implementing initiatives under a government micro-credit program that includes health micro-insurance.
 - 4) Integrating the women with disabilities into community structures through their participation in village self-help groups.
 - 5) Creating a virtual network in each state among women with disabilities to exchange information on health issues; and
 - 6) Promoting access to the government's reproductive health care program through inclusion in health awareness programs.

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