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Challenges of Persons with Disability and their Reproductive Rights

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Abstract: It is the fact that people with disability have same rights including reproductive rights as everyone else and these have been clearly mentioned in the United Nations Convention on the Rights of Persons with Disabilities which was adopted in 2006. About 650 million people in the world or 10 percent of the world's population live with disabilities and frequently encounter a myriad of physical and social obstacles. According to Census-2001, there are 93.01 lakh women with disabilities, which constitute 42. 46 percent of total disabled population. The person with disabilities requires protection against their rights including their reproductive rights ¹. The largest minority group in the world as said by the World Health Organization requires the same health care needs and protection in terms of health facilities as others. They are among the most vulnerable group in the society mostly lacks equal opportunities and advancement in the mainstream of population because of their gender, cultural, ethical and religious fragments. The presence of various disabilities especially to women and girls makes them even more victim of discrimination. Girls and women of all ages with any form of disability are among the most vulnerable and marginalized section of the society. There is therefore, need to protect such girls and women with legal framework. This article aims to highlight on the reproductive rights of a person with disability. Especially, the situation of women with disabilities is that they are even denying the traditional roles of marriage and child bearing. It is important to have comprehensive law to consider and address the challenges of person with disabilities in attaining their reproductive rights.

Keywords: women, disabilities, reproductive rights and legal framework

1. Introduction

People with disability are frequently excluded with the topic of discussion whenever there is any discussion on reproductive rights. The disabled communities consist of a diverse group of individuals with various types of disabilities. So, including them in such issue is very important in order to achieve complete health care service to everyone. Their ability to reproduce is often undermine because of their disability².

The individuals with disability are often not included due to a smaller number of people having disability and also reproductive rights. The term "disability" encompasses all type of disabilities such as- physical, sensory, and neuro divergent abilities. The rights of disabled persons also include reproductive rights where the people of such communities also have the same inherent rights like any other individuals to their bodily autonomy, self-determination, parenthood, and accessible affordable health care including contraception and abortion, that is free from discrimination and social stigma.

However, there has always been hurdles to attain reproductive rights by the persons with disability. It is often seen that they right to reproduce has been undermined by the societal pressure. The health care programme also fails to address their issues holistically. There re cultural and social barriers to acquire comprehensive health care.

There are various reasons that the disabled people are denied of their right to bodily autonomy such as their inability to represent their issues. There is a need to represent the experiences of disabled people while exercising their ability to reproduce what are the challenges they are facing. Then only policy -makers will include them and their problems in the framing of laws.

Persons with Disability and Reproductive Rights

In India, where patriarchy is the part of the culture and way of life of almost all the communities. In a developing country, like India being born as women itself is considered as curse in the society or family and when such girl child born with certain disabilities; we can imagine their life. They will have to lead a miserable and pathetic life. They are treated as useless and burden to the family. Women with disability are socially invisible category. It is not just the attitude of the people towards them that is disheartening but also the problem of social inclusion barriers that they come across is the bigger challenge in the society.

Sometimes those who are lucky may get supportive family but it is found that they are denied various rights including the freedom to live as an individual. They remain untreated, uneducated and untrained to live their life. This makes them even more dependent on their family members. That may lead to lifelong burden to the family and relatives. They are being excluded from religious and social events in the communities as well as in the families as the family feels insecure to bring them out because of the stigma that surrounds them. All these leads to disabled women experiencing extreme neglect, isolation and unawareness of their options for participation in a more vocational life. The study in India also found that the experience of women with disabilities relates their problem with gender. They have a lesser autonomy and decision-

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¹ A Multi State Socio- Economic Study of Women with Disabilities in India Report (UNDP-Government of India- SMRC Study) Bhubaneshwar 2007. National Interactive Web Portal on Disability.

² Jordan Fletcher, Halina Yee, Bonnie Ong, and Rosemary Claire Roden "Centring Disability visibility in reproductive health care: Dismantling Barriers to achieve Reproductive Equity" September 2023 London Women's Health.

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making power with regards to their own lives as compared to their male counterparts with disabilities.³

In India, women are socially, economically and culturally backward and their life becomes even more miserable when they have disability. When women with disability comes, they have very limited opportunities in terms of employment also. Disability is often another reason to cause violence to these people as they lack intellectual capacity to understand and communicate about such abuse. Moreover, they are often abused either by the family members or by the care taker. They are already been felt and treated as a burden to the family. So, they could not share their problems with the family members freely. Inappropriate touch, and sexual misbehaviour usually by the family members is reported frequently.

There is many research done by the governmental and nongovernmental organization which have reports suggesting that women with disabilities are being treated even worse than animals. They are forced into mental hospitals and institutions where they are kept in unhygienic condition. They are subjected to physical violence and abuse and involuntary treatment such as electric shocks. A report from Human Rights Watch found that women forcibly admitted to the government institutions and the hospitals and they suffer grave abuse and violence.4 They are dumped by the family members to these institutions. It is true that women are marginalized, stigmatized and discriminated in the society. The life of women is very difficult and it is even worse if it is disabled women. The stigma of disability is everywhere in the world and more so if it is women thus it is necessary that their rights should be protected by the law.

The typical stereotype perceives that disabled women are not capable of becoming responsible mother. They are not even considered as fit to be a mother. So, these women have to face many challenges even to carry on their traditional roles and responsibilities. They are subjected to cruel treatment and they are discriminated more because of their disability. Their medical condition is ignored and their mental and physical health is not considered as priority by the government or by the family members. There is lack of attention given by the policy makers towards their needs whether it is- medical facilities, trasportation and support- system to these people. They have been treated with inequality leaving lifelong scar, trauma and hardship in their life.⁵ As a result of which they are not been able to exercise their rights properly like any other human being. The society is not sensitive towards their needs and treat them with inequality making them feel weak, incomplete, inadequate and disabled.

Law relating to persons with disabilities

There have been few legislations for the protection of the rights of disabled persons in India. There are some declarations at the international level such as- the International Year of Disabled Persons in 1981 and the

International Decade of Disabled Persons from 1983 – 1992. Before 1981, disability was a peripheral issue, confined to the domains of social welfare in state policies and programmes and service delivery in the civil society sector. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 provides the legal protection to the disabled persons in the society. But these are not sufficient to bring the problems of disabled persons in national arena. In 2016, the Rights of Persons with Disabilities Act replaced the Persons with Disability Act, 1995.

There has been a struggle to establish safe environment for disabled persons where they feel more accepted and loved. But sadly, like many issues in the society, this issue has not drawn the attention of policy- makers and is still remained unheard. Moreover, women with disability have to deal with issues relating to gender discrimination. Socially, gender and disability are related as it stress upon how society makes their norms for the people depending upon their ability. The status of people and their treatment depends upon how much they are capable in the society. If a person is unfit by any chance according to their norms they will be neglected. Gender has been thought to determine the behaviour on the part of both men and women. Their role in the society is fixed by the society depending upon their gender. In case of disability, it is added factor to determine their inferiority. Thus, the social relation of gender and the social relation of disability is closely connected. It has to be addresses together as they have been exploited and abused physically and mentally not just because they are women but also because they are disabled. Therefore, the rights of disabled women have to deal with many issues including issues relating to reproduction. It was found that women with disability have more issues relating to the reproductive rights and health. It is noticed from various research work that women with disability faces more difficulties especially in terms of their right over their body including the circumstances where they are forcefully sterilized in a state-run home. The state institutions justify their action as best in the interest of the disabled women.

It is also found that the disabled women based in urban areas have more facilities than that of disabled women in rural areas. They are more educated and have more facilities to avail in urban areas than in the rural areas. However, the life of disabled women is still more miserable whether they are in urban and the rural areas. Their right as a woman has been denied and their capacity to reproduce has been overlooked with regard to their reproductive capacity.

As per the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD,2006) persons with disabilities include those "who have long- term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and

³ www.ijcrt.org

⁴www. hrw.org India: Women with Disabilities Locked away and

⁵ www.ucpress.org

⁶ Renu Addlakha "Slow Progress for Women with Disabilities in India" 129-134 April 1 2022 www.ucpress.org

⁷ Helen Meekosha "Gender and Disability" Centre for Disability Studies disability-studies.leeds.ac.uk 2004.

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effective participation in society on an equal basis with others".8

According to WHO, the International Classification of functioning, Disability (UNCRPD2006) persons with disabilities includes the negative aspects of the interaction between an individual (with a health condition) and the individuals' contextual factors (environmental and personal factors).

In India there has been transformation in society with the enactment of Rights of Persons with Disabilities Act,2016 (RPD ACT). This Act addresses discrimination, violence and torture that has been dealt by people with disabilities. It also recognizes civil, political, social and cultural rights of these persons and also provides the provision to constitute monitoring authority and a special court to try offence against persons with disabilities. ¹⁰

In India, "a person with benchmark disability" means a person suffering from not less than 40% of any specific disability, as certified by a medical authority. ¹¹ The Act of 2016 provides 21categories of disabilities. We all know that disabilities are an impairment that restricts or limits the functional abilities of a person.

Rights of women with disabilities under International Law

Earlier, under international law there was no mention of disability as a protected right. The only issue that used to be addressed under various Convention was a disability as a health issue. The Convention on the Rights of Persons with Disabilities (UNCRPD) contains the rights of disabled persons comprehensively. Article 6 of UNCRPD provides that the State parties must recognize that women and girls with disabilities face multiple discrimination and must take all appropriate measures to ensure their full development, advancement and the enjoyment of all human rights and fundamental freedom.

Rights of women with disabilities under Indian law

In India, the Constitution is the guardian of its people and therefore the law must be made according to the provisions of the Constitution of India. The fundamental rights available under Article 14, 15 and 16 do not have a specific mention of physically/ mentally handicapped or disabled person, but they do have provision for the protection of marginalized section including women so obviously women with disability also comes under it. These provisions include a positive role of the state to uplift the status of disadvantaged groups.

Talking about specific legislation, there is special law for the protection of the rights of disabled person, i.e., the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

The following rights are guaranteed to the person with disabilities: 12

- The right to equality, dignity and respect for integrity.
- Ensures the rights of women and children with disability
- The right to live in the community
- It provides protection from being subjected to torture, cruel, inhuman or degrading treatment.
- The protection from abuse, violence and exploitation.
- Persons with disabilities are entitled to equal protection and safety in situations of risk, armed conflict, humanitarian emergencies and natural disasters.
- Children with disabilities not to be separated from their parents
- The Act recognizes the reproductive rights of persons with disabilities.
- The Election Commissions to ensure that persons with disabilities can cast their vote
- The Act states challenges faced by persons with disabilities in accessing the justice system
- Legal rights of persons with disabilities
- Appointment of limited Guardian
- Persons with disabilities require high support
- Responsibilities of mainstream schools to ensure inclusive education
- Protection against discrimination in employment

Interventions to support women and girls in conflict and crises have found that it is important to:

- Have organizational commitment to translate policies that integrate both disability and gender discrimination
- Support staff to identify skills and capacities when working with girls and women with disability rather than just focusing on their risks and vulnerabilities.
- Carry out activities which strengthen protective peer networks. Set targets for inclusion in existing programmers, including economic strengthening programmers.
- Recruit women with disabilities as volunteers and staff.
- Partner with, and support, women's disabled people's organizations.¹³

It was found that though policies and programmes are being framed to recognize the rights of women and girls with disabilities but still there is a gap in legal framework which needs immediate response. It includes the strengthening the capacity of networks of women with disability on humanitarian ground and addressing gender-based violence especially targeting women with disability. It also includes providing opportunities to such girls and women by training them life skills so that they become independent economically.

Reproductive rights of women with disabilities

Section 10 states that the appropriate government shall ensure that persons with disabilities have access to appropriate information regarding the reproduction and family planning and that no person with any disability is subjected to any

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 $^{^{\}rm 8}$ Sahiba Chahal "Women with disabilities in India 2 $\it IJCRT$ vol.L.9 Issue3 March 2021

⁹ WHO, 2001.

¹⁰ Swagata Raha & Shampa Sengupta "Rights of Women with Disabilities under Indian Legislations" vol.14 Social-Legal Review 2018 www.manupatra.com

¹¹ Rights of Persons with Disabilities, 2016

¹² https://nhrc.nic.in

¹³ Dr. Amrapali Mahadev Jogdand Major Dr. H. j. Narke "Inclusion of Women with Disability in India" *The International Journal of Indian Psychology* 1075 vol.10 issue1 jan – March 2022

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medical procedure which leads to infertility without his or her free and informed consent.

The reproductive rights of women with disabilities are a matter of great concern for all including law makers, care givers, guardians and woman herself. The most crucial question is regarding "her capacity to give consent" with regard to procedure such as medical termination of pregnancy and permanent sterilization. Sometime from physical and obstetric examinations, assessment of mental quotient is also carried out to facilitate an understanding of the informed consent.¹⁴

The Rights of Persons with Disabilities Act, 2016 and the Mental Healthcare Act,2017 explains the term "Informed Consent". The assessment process of informed consent and capacity to consent require an adequate information to the person so that they can exercise their reproductive rights properly. They are to be informed about the procedure, risks and benefits through various means of communication. The present Act also provides the guidance to the clinical physician how to address such issues. There is also an issue when it comes to freedom to make choices in matters relating to reproduction especially with respect to women with disability. Women and girls always experience discrimination in healthcare sector especially during abortion or sterilization.

Health:

The health of women is of very important not just for women but for the whole country also. As she bears the responsibilities to have future generations. It also indicated the empowerment of women in a country. However, there is alarming concern when talking about the maternal health of women with disability.¹⁵

There is also high mortality rate in women due to lack of nutrition and concern towards the health of women. Their health is never a priority for them nor for their family. This has been more with the women with disabilities. There is neglect in the health of women especially maternal health of women. Therefore, unless these areas will not be addressed and health of all women including women with disabilities will not be considered as prime area to improve, there will not be any change.

If we compare women with no disability with women with disability, it is always women with disability who have greater risk of gestational problems and adverse maternal health. Maternal mortality is preventable health issue but it is a public health concern in India. Women with disabilities have more health complications relating to pregnancy such as pre-term birth, hypertension disorders during pregnancy, gestational diabetes etc.¹⁶

Shortcomings to combat barriers

In a country like India there are various social, cultural, political and legal barriers existed in a country to realize and recognize the reproductive rights of disabled women. Women with disability have to face many barriers when accessing reproductive health services including maternal health care, physical inaccessibility, transportation, and the societal belief that they are non- reproductive and incapable of becoming parent. It includes so Some of the most important barriers are as follows:

Maternal health care: Maternal health care use for India is reported in the National Family Health Survey. It was found that only38.5% of women of these women attending four ANC visit as recommended by WHO as recorded in Rajasthan in 2015-2016. It is also found that economic development, healthcare infrastructure and gender empowerment can have an impact on maternal healthcare use and accessibility.¹⁷

1) Gender Discrimination

Women with disabilities could not enjoy their reproductive rights like that of the normal women. At first gender-discrimination in the society mostly lacks equal opportunities and advancement in the mainstream of population because of their gender, cultural, ethical and religious fragments. The presence of various disabilities of women and girls makes them even more vulnerable.

The situation of women with disabilities is that they are even denying the traditional roles of marriage and child bearing. It is necessary to address these issues of women with disabilities to attain their reproductive rights like any other normal women.

2) Physical and mental abuse

Many reports suggests that women with disabilities are being treated even worse than animals. They are forced into mental hospitals and institutions where they are kept in unhygienic condition. They are subjected to physical violence and abuse and involuntary treatment such as electric shocks. A report from Human Rights Watch found that women forcibly admitted to governmental institutions and hospitals suffers grave abuse and violence. They are dumped by the family members.

Like any other women, women with disabilities have a right to be protected from various violences and to live with dignity, maintain good health, to have environment free from any violence.

Lack of awareness on reproductive and sexual rights and health

Women with disabilities have to go through various physical, psychological and sexual violence. They are neglected and

www.nebi.nlm.nih.gov

¹⁴ Sundarnag Ganjekar "Reproductive Rights of Women with Intellectual disability in India" *Indian Journal of Medical Ethics* Jan-Mar 1 2023.

¹⁵ Vani Maradi "women Empowerment in India: Issues and Challenges 242 vol.49(1) *Indian Bar Review* 2022

¹⁶ Jessica L. Gleason Jagteshwar GrewalZhen ChenAlison N. Cernich and Katherine L. Grantz "Risk of Adverse Maternal Outcomes in Pregnant Women with Disabilities" JAMA Network Open Dec 2021 e2138910.

¹⁷ M. Tara Casebolt, Kavita Singh, IIene S. Speizerand Carolyn T. Haslpern "Maternal Healthcare use by Women with Disabilities in Rajasthan, India; A secondary analysis of the Annual Health Survey" *PMC website* October 2024.

Impact Factor 2024: 7.101

isolated, detained and denies with health care facilities. They are forced to sterilization and forced psychiatric treatment. They are at high risk of gender- based and other forms of violence because of the age-old patriarchal system and social stereotypes that existed in our society.

They may not have physical and intellectual capacity to know about their physical needs and desires. The Act recognizes the right to privacy to such persons. This protection includes the privacy in family, have correspondence, honor, reputation, rehabilitation and all the information about their reproductive capacity and procedure related to it. All these rights are necessary to attain their bodily and sexual privacy.

They are deprived of their right to marry and right to choose partner as society thinks that they are non- sexual and nonsuitable for marriage and having family. Moreover, they are forced to undergo permanent sterilization procedures violating their right to reproduce.

This violates their reproductive rights depriving them of having normal life and family. This led to extreme isolation and lifelong grief. Article 23 of UNCRPD provides the state parties to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationship on equal basis with others. But in reality, they do not enjoy such rights.

4) Lack of intellectual capacity

The women face disparities in sexual and reproductive rights and health care service because of the lack of their intellectual capacity. The underlying factor of disability tend to stigmatized women in the society. Their needs are unmet in pregnancy and childbirth. They also have to face lack of prenatal care and post-natal care. They are at the greatest risks of experiencing barriers to their reproductive rights.

5) Lack of financial assistance

Women with disabilities could not enjoy their reproductive rights. They are mostly unemployed or under employed. So, it is difficult for them to stand on their own. Right to employment and opportunity of persons with disabilities has been recognized under Article 27 of UNCRPD. But very few are given opportunity even after reservation in employment.

2. Conclusion and Suggestions

To conclude, the person with disabilities causes various discriminations. It makes the life of people with disabilities very difficult and if such person is women than it will be even worse. There are laws but they are not enough to provide safe and caring environment for women with disabilities.

There is a need to include "disability" term under Article 15 of the Constitution by the amendment. In 2019, this demand was reaffirmed by the UN Committees. In the state of Sikkim, first time a polling booth was allotted for the disabled people. So that they can exercise their political right freely and easily. This is also a welcome step as this may draw an attention of the law maker towards the rights of disabled people including

There is a need to make a gender – sensitive laws and to make people in the society including care-giver, institutional care taker, guardians and family members about the needs of such people. Their reproductive rights can be attained only when their other rights will be protected. There are various steps through which reproductive health of such people can be

- a) Accessible health care facilities and resources: -The inaccessible and unaccommodating health infrastructure is one of the disadvantages for a woman with disability to exercise her reproductive rights. The government must ensure that there is infrastructure in the government or private hospitals for disabled women.
- Accessible transportation: Even if reproductive health care is available and also covered by the health insurance, physically accessing such facilities also poses challenges to the people with disabilities. The problem is worse in rural areas where a lack of physical infrastructure- such as sidewalks and a limited accessible public transit system make transportation to health care appointment incredibly challenging.
- c) Access to abortion service: They have no access to proper accurate information about the procedure of abortion to the disabled women. Besides, forced sterilization is always there in every part of the country including India on disabled persons.
- d) Access to contraceptives: Access to contraceptives, management of menstruation and even precautionary measures are not available to these people. These needs are overlooked by the health care providers.
- Access to screening etc.: There is no facilities to access preventative screenings, pap smears and mammograms as they are an essential part of preventive reproductive health screenings. These are barriers to the reproductive health of the disabled women.
- Access to maternal health services: -In recent study, it is found pregnancy rates among women with disabilities have neared those of non- disabled women. Yet, women with disabilities experience much higher rates of pregnancy- related complications. The number of barriers when accessing maternal health care includes lack of provider, training and knowledge about how to meet their maternal health care needs, inaccessible health care needs, facilities and equipment.

In accessibility to health services experienced by persons with disabilities a qualitative data is required. 18 The above issues need to be addressed with clear law for the protection of rights by facilitating to accessibility to infrastructure to women with disability. Disabled -friendly health care services in every nook and corner of the country. Use of technology to make accessibility to service to such people such as mobile application to provide service. There should be more research to understand disability people's emotions and feelings so that they can also enjoy their life like any other human being. The

¹⁸ Shamyr Sulyvan Castro Fernando Lefevre Ana Maria Lefevre Chester Luiz Galvao Ceasar "Accessibility to health services by persons with disabilities" Oct 2010 researchgate .net

Impact Factor 2024: 7.101

law should be made taking into consideration the best interest of the disabled person. The issues like right to procreation, menstruation, economics barriers and attitudinal barriers. The model of disability should cover medical disability and social disability.

The Mental Health Care Act, 2017 should be taken into consideration while highlighting the issues of disabled women. The operation of sterilization is exception and not a permanent solution to the problem of disabled women. They need to be sensitized about the menstrual management and hygiene. There should be support system build around disabled women so that they will not be abused by anyone. Reaching out to the issue of reproductive rights of disabled women from grass root level is necessary to attain it. The society should be sensitive about these people and must involve in the pursuance of their well- being. The question that they may always ask themselves must be are we treated at par with other persons. We need to remove disability of mind of the society rather than the disabled persons. Our literature should be rich enough to narrate their sufferings to the society. We must conduct awareness programmes from the community level. Another most important issue to deal with while dealing with issues of reproductive rights are to remove taboo of sexuality in the society. It is even a taboo in the society to talk freely about the subject like sex or sexuality. Unless we are not open to discuss this topic without hesitation there will be more women who suffers in silence more so with disabled women who have no intellectual and physical capacity to understand the subject.

Health of women is of paramount importance for the wellbeing of the country and an important factor in gaining empowerment in national and international arena. Therefore, taking into consideration the health of all women including health of disabled women it is necessary that law makers should make law with holistic approach including all types of women whether based on physical capabilities and mental capabilities.

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