**Title:** Reproductive Rights of Women with Intellectual Disability in India.

Authors

1. Sundarnag Ganjekar

Associate Professor of Psychiatry

Department of Psychiatry

National Institute of Mental Health and Neuro Sciences

Hosur Road

Bengaluru 560029

INDIA

Email: [sundarnag@nimhans.ac.in](mailto:sundarnag@nimhans.ac.in)

1. Sydney Moirangthem

Additional Professor of Psychiatry

Department of Psychiatry

National Institute of Mental Health and Neuro Sciences

Hosur Road

Bengaluru 560029

INDIA

Email: [sydmoir@gmail.com](mailto:sydmoir@gmail.com)

1. Channaveerachari Naveen Kumar

Professor of Psychiatry

Head, Community Psychiatry Services

Department of Psychiatry

National Institute of Mental Health and Neuro Sciences

Hosur Road

Bengaluru 560029

INDIA

Email: [cnkumar1974@gmail.com](mailto:cnkumar1974@gmail.com)

1. Geetha Desai

Professor of Psychiatry

Department of Psychiatry

National Institute of Mental Health and Neuro Sciences

Hosur Road

Bengaluru 560029

INDIA

Email: [desaigeetha@nimhans.ac.in](mailto:desaigeetha@nimhans.ac.in)

1. Suresh Bada Math

Professor of Psychiatry

Head, Forensic Psychiatry Services and Tele Medicine Center

Department of Psychiatry

National Institute of Mental Health and Neuro Sciences

Hosur Road

Bengaluru 560029

INDIA

Email: [nimhans@gmail.com](mailto:nimhans@gmail.com)

Corresponding author

Sundarnag Ganjekar

Associate Professor of Psychiatry

Department of Psychiatry

National Institute of Mental Health and Neuro Sciences

Hosur Road

Bengaluru 560029

INDIA

Email: [sundarnag@nimhans.ac.in](mailto:sundarnag@nimhans.ac.in)

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**Main Article**

**Abstract**

Reproductive rights of Women with Intellectual Disability (WID) is a matter of concern for all stakeholders including woman herself, caregivers, guardians, and her treating physicians. Psychiatrists are often called by the judicial system to give opinion regarding her capacity to consent for procedures such as medical termination of pregnancy and permanent sterilization. Apart from her physical and obstetric examination, assessment of mental status and intelligence quotient (IQ) are also carried out to facilitate the above issue. The Rights of Persons with Disability Act, 2016 (RPwD) and the Mental Health Care Act, 2017 talk about the free and informed consent and assessment of capacity respectively. However, the methods by which these goals can be achieved are important and can serve as a guide to the clinicians. Before assessing the capacity, the treating physicians should try and educate WID with appropriate information on proposed procedure, its risk and benefits through various means of communication and then assess the capacity to consent for the procedure. This article summarizes the existing legislation on the reproductive rights of WID and comes up with guidance notes on approaching the issue clinically.

**Keywords:** Women with Intellectual disability, Informed consent, Capacity assessment, Reproductive rights, Pregnancy, Medical Termination of Pregnancy, Menstrual hygiene

**Introduction**

Women with intellectual disability (WID) in India face dual challenges, one being a woman in a patriarchal society and other intellectual disability itself. Intellectual disability by definition is a condition characterised by significant limitation both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviour which covers range of every day, social and practical skills (1). WID are often perceived as women devoid of identity, femininity, sexuality, companionship and are deprived of opportunities of motherhood (2). The challenges encountered by them or their caregivers include; a) training and care for menstrual hygiene, (3), b) sex education (4), c) marriage and procreation (5) d) contraception and pregnancy planning, e) antenatal care and f) roles and responsibilities of a mother (6). The above challenges often pose barriers in planning rehabilitation for WID.

Article 21 of Indian Constitution- Right to Life and Liberty, states that it is a right of a woman to make a reproductive choice and it is a dimension of “personal liberty” (7). Women can choose to procreate or abstain from procreation. The reproductive rights of women with intellectual disability have been discussed on several occasions and each time Supreme Court of India has upheld their “personal liberty” (8).

The United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) marks a paradigm shift in attitudes and approaches to persons with disabilities. The persons with disabilities are no longer an ‘objects’ of charity, medical treatment and social protection, rather as ‘subjects’ of rights with choices as to how he or she wants to live and what treatments, if any, he or she wishes to use. Keeping UNCRPD as yardstick, India signed and ratified the same on 1st October 2007. The Rights of PWD Act, 2016 (RPWD Act 2016) replaced the PWD Act 1995 to protect the rights and dignity of persons with disabilities which is complaint to the UNCRPD. It defines persons with disability (PwD) as any person with long-term physical, mental, intellectual, or sensory impairments which on interacting with barriers hinder effective and equal growth in the society.

Among PwD, women are one of the most vulnerable population. Among them women with intellectual disability have been reported to be at risk for sexual abuse, human right violation both at their homes as well as sheltered homes (9). Caregivers of women with intellectual disability face a dilemma about procreation and motherhood rights, irrespective of whether she is in a state-run special home or staying with her parents/guardian (6). There have been instances where WID are forced to undergo hysterectomy to avoid menstruation in the state-run women shelter homes (10).

Menstruation and its care is another perceived challenge by the caregivers. The reproductive hormones play a role in menstruation, development of secondary sexual characteristics, and libido in WID as they do for normal women. These physiological changes might be challenging for WID in understanding and interpreting the same and may pose risk for sexual exploitation and for unwanted, unplanned pregnancies. Caregivers often find it challenging to train them in menstrual hygiene, more so for those with moderate-severe intellectual disability. In many instances’ parents might seek hysterectomy as a means of protecting WID. Procedures like this requested by the guardian or sheltered home authorities results in violation of reproductive rights, right to autonomy, & right to life (5). Unplanned/unwanted pregnancies and its medical termination are additional challenges a caregiver or the individual face.

Often the role of a psychiatrist is to certify the mental health status, intellectual ability and capacity to consent for any medical procedure. Certification of the severity or the extent of intellectual disability (as measured through Intelligence Quotient) is not difficult. However, whether numerical value of IQ enable or limits the WID to take certain important decisions is a different discussion. This issue of decision making becomes pertinent over challenging situations such as medical termination of pregnancy, tubectomy, oophorectomy, hysterectomy & contraception, which might be against the constitutional rights of the woman.

The questions that arise in these contexts are: can WID provide informed consent? can she consent to bear and rear the child? can she consent to terminate the pregnancy or opt for temporary or permanent sterilization? This article discusses the reproductive rights of WID using a case scenario. .

Case vignette

A 26-year-old WID is brought to the obstetrician by her parents for termination of pregnancy. On examination, she is found to be 19 weeks pregnant with possible low intelligence, and the woman is unaware of her pregnancy status. The obstetrician seeks psychiatrist opinion regarding her ability to give consent for the MTP. Detailed assessment by the psychiatrist revealed that she has moderate intellectual disability. She needs assistance in her activities of daily living. On enquiring about her pregnancy, she reports that she likes babies and she can play with them. She is unable to reveal details about the father of the baby. She expressed happiness after she found herself to be pregnant. However, she is unable to comprehend the roles and responsibilities of being a mother. Parents report that they also want her to undergo hysterectomy along with MTP as it is difficult for them to provide care during as well as protect their daughter from any unwanted pregnancies. She has poor understanding about selfcare, menstruation, and sexual knowledge.

In the above case scenario, following challenges arise in the clinical contexts:

1. How to assess the “capacity” to give informed consent for termination of pregnancy and or temporary/permanent sterilization in an adult WID?
2. Who will be responsible for the care of her baby if the mother is unable to look after the baby?
3. Can parents or legal guardian give consent for termination of pregnancy and/or permanent / temporary sterilization for WID?
4. What are the roles and responsibilities of the psychiatrist in this scenario?

Before we address the above, let us summarize the relevant Acts, Rules and Regulations concerned with reproductive rights of WID in India (Table 1).

It is clear from the above Table 1 that to be a mother is the personal liberty of a woman and no one can curtail it unless it is deemed to cause grave injury to the physical or mental health of a woman. Even for a WID, the Constitution of India (and the laws thereof) does not support termination of pregnancy and provide limited guardianship. In a landmark Supreme Court Judgement regarding termination of pregnancy in a woman with intellectual disability (8), the apex court observed that persons with borderline, mild or moderate mental retardation are capable of being good parents. The judgement had also said the possibility that a person with a low IQ can possess social and emotional capacities that enable woman to be a good mother. Further, the apex court mentioned that it could not order a termination without consent of adult WID (8). The above case and its judgement by the Supreme Court illustrates an example of protection of the reproductive rights of the women with intellectual disability.

Capacity to consent

“Capacity” can be equated to the subjective standard of the informed consent. This is also individual’s mental capacity to understand task in hand. It is a challenging task for the mental health professionals to assess mental capacity of WID to give consent for termination of pregnancy and/or temporary/permanent sterilization. How much do WID can understand the medical procedures and its consequences? Whether such procedure will benefit her or cause harm? Is the procedure reversible?

IQ level might indirectly reflect the capacity of WID to make reasonable decision regarding the procedure. To summarize, capacity to consent revolves around four important concepts a) comprehension b) retention of the information c) weighing the risks and benefits of the purported procedure d) communication of choice. However, the RPWD Act is silent about the issue of ‘capacity to consent’. Hence it reasonable to borrow the concept of ‘capacity’ under section 4 of MHCA. Once the capacity is assessed, the psychiatrist has multiple options to choose. A) complete capacity to consent B) limited capacity to consent C) absent capacity to consent.

The RPwD Act clearly mentions that “No person with disability shall be subject to any medical procedure which leads to infertility without her free and informed consent”.

The RPwD 2016 in its section 10 (2) mentions about the *free and informed consent. H*owever, it does not define *informed consent.* Mental Healthcare Act, 2017 defines informed consent as “consent given for a specific intervention, without any force, undue influence, fraud, threat, mistake or misrepresentation, and is obtained after disclosing to a person adequate information including risks and benefits of, and alternatives to, the specific intervention in a language and manner understood by the person”. This definition although applies for person with mental illness but the court can borrow this definition at its liberty in any given case. Hence, informed consent is both an ethical and legal obligation for medical practitioners.

Figure 1 shows the workflow diagram for the capacity to consent for medical procedures among WID

Capacity present

If capacity is present, the choice of the WID will prevail. The informed consent obtained will be valid under the law (see figure 1).

Capacity doubtful

In a real life scenario, psychiatrists often find themselves in a dilemma about the presence or absence of capacity despite thorough evaluation. In such a scenario, it is advisable for the psychiatrist to engage and empower WID by training to achieve required level of capacity. This can be done through various means and methods such as providing appropriate information, education and communication material, role plays, vicarious learning, virtual aids and provision of other relevant material. This could help them achieve the desired level of capacity (to consent). It is recommended that the capacity be reassessed after the above training has been completed.

Capacity absent

In the absence of capacity to consent for the medical procedures such as MTP or permanent / temporary sterilization, the clinician can consult rules and regulation as per RPwD Act. The RPwD Act has provision of “limited guardian” in the absence of capacity. “limited guardianship” means a system of joint decision which operates on mutual understanding and trust between the guardian and the person with disability, which shall be limited to a specific period and for specific decision and situation and shall operate in accordance to the will of the person with disability. The act also notifies that every guardian appointed to person with disability can function as limited guardian. On and from the date of commencement of RPwD Act, every guardian appointed under any provision of any other law for the time being in force, for a person with disability shall be deemed to function as a limited guardian.

The intellectual quotient (IQ) is not a sole measure to assess capacity for providing informed consent. However, capacity to consent can vary depending on the level of IQ. The informed consent is a process and should be facilitated in all possible means of communication in WID. Table 2 shows the minimum documentation required for the for the ‘capacity to consent’ for the medical procedures among WID

Capacity to give consent is inversely related to the severity of the intellectual disability. There is no established cut off IQ value below which a woman can be deemed to have no capacity. A woman with moderate to severe intellectual disability may express her wish but her actual capacity (eg: for physical care of the infant) might be poor. The logical reasoning capacity of the individual can be assessed through the IQ. The value of an IQ does not per se give an understanding of whether the mother can bear and rear the child. However, intellectual disability of severe and profound nature cannot be enabled and empowered to make complex decisions such as consent for medical and surgical procedures.

If the capacity to consent is absent, RPwD Act, 2016, Section 14, describes the provision of guardianship, limited/total guardianship in case to take legally binding decisions. In this scenario, the guardian ship obtained under RPwD Act, 2016 from the District Court will enable the guardians to take appropriate decisions regarding the WID.

In a landmark Supreme Court judgement (2009) of Suchita Srivastava and Anr vs Chandigarh administration, the bench ordered for the clarification of the role and responsibilities of a nominated guardian under the NTA 1999. In this case, the guardian (chairman of the NTA) went with the wishes of the WID and hence the apex court instructed the state government to provide all the support to guardian, WID and her unborn baby. As per RPDW Act it is the responsibility of the parents/legal guardian to provide adequate and appropriate support for WID. It iterates that the guardianship will extend to the child of WID also till it attains age of majority.

Law provides provision for termination of pregnancy in WID with loss of capacity and with the opinion of registered medical practitioner and with the consent of guardian of the women with disability (Section 92, RPWD Act).

It the duty of the health professionals to follow the existing law than being influenced by the care givers of WID

Grounds for sterilization procedures

It may be essential for women to maintain menstrual hygiene to prevent herself from infections. It might be possible to train WID in menstrual hygiene. However, intellectual disability of the profound, severe and to some extent moderate degree might be difficult to train or might need repeated instruction and support. However, this cannot be, the grounds for hysterectomy. Similarly, the apprehensions of the caregivers that WID may conceive or subjected to sexual abuse or be involved in sexual activities is also not a ground for neither permanent or temporary sterilization.

**Guidelines for Assessment of WID for medical and surgical procedure**

1. Documentation of the reason for the referral and retain a copy of the referral note in the patient’s record
2. Detailed evaluation of the clinical status (Physical Examination, Mental status examination and cognitive functions)
3. Formal Intelligence Quotient assessment
4. If the evaluating psychiatrist is able to arrive at the diagnosis and considering the task in hand he/she can
   1. Prepare the certificate stating that referred patient has capacity to give consent for the proposed procedure.
5. If the evaluating psychiatrist unable to arrive at the reasonable diagnosis then
   1. Inpatient care can be considered (at the discretion of treating psychiatrist) for further evaluation of capacity to consent for procedures.
   2. Before the capacity assessment following steps is advised
      1. Psychoeducation about risk and benefits of the procedure
      2. Alternative treatment and associated risk and benefits
   3. Capacity assessment
      1. Comprehension
      2. Assessment of risk
      3. Communication of decision
6. The certificate should focus only on diagnosis and capacity to consent for planned procedure.
7. Issue the certificate through the medical board

**Conclusion**

According to the Indian constitution, irrespective of their intellectual capacity every woman has reproductive rights to choose or refrain from procreation. Psychiatrist giving expert opinion regarding women’s capacity to undergo temporary/ permanent sterilization or termination of pregnancy should be aware of all the relevant constitutional laws. In the absence of clear wording for WID it is at most important for the treating psychiatrist to be aware of the major judgements given by the supreme court of India. Rather than prejudiced by their own perception on the WID or by their well-wishers it is important to go through the prevailing rules, regulations and provisions that are provided in the Indian legal system to safeguard their clinical practice as well as upholding the reproductive rights of WID.

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Table 1: The current Indian Acts, Rules and Regulations concerned about women’s reproductive rights focusing on WID

|  |  |  |
| --- | --- | --- |
| Acts / Rules / Regulation | Relevant sections | Phrasing within the Act / Rules / Regulation |
| The Constitution of India (7) | Section 21 | No person shall be deprived of his/her life or personal liberty except according to procedure established by law. |
| Rights of Persons with Disabilities (RPWD 2016) (11) | Section 10. | (1) The appropriate Government shall ensure that persons with disabilities have access to appropriate information regarding reproductive and family planning.  (2) No person with disability shall be subject to any medical procedure which leads to infertility without his or her free and informed consent. |
| Section 13 | (2) The appropriate Government shall ensure that the persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law. |
| Section 13 | (5) Any person providing support to the person with disability shall not exercise undue influence and shall respect his or her autonomy, dignity and privacy |
| Section 14. | Provision for guardianship: a district court or any designated authority, as notified by the State Government, finds that a person with disability, who had been provided adequate and appropriate support but is unable to take legally binding decisions, may be provided further support of a limited guardian to take legally binding decisions on his behalf in consultation with such person, in such manner, as may be prescribed by the State Government: |
| Section 92. | (f) whoever, performs, conducts or directs any medical procedure to be performed on a woman with disability which leads to or is likely to lead to termination of pregnancy with her express consent except in cases where medical procedure for termination of pregnancy is done in severe cases of disability and with the opinion of a registered medical practitioner and also with the consent of the guardian of the women with disability. *Shall be punishable with imprisonment for a term which shall not be less than six months, but which may extend to five years and with fine.* |
| Medical Termination of Pregnancy (MTP) Act, 1971 Amendment 2020 (12,13) | Section 3 | abortion is allowed if continuation of the pregnancy could involve a risk to the life of the pregnant woman or cause grave injury to her physical or mental health, or there is a substantial risk that if the child were born, it would suffer from such physical or mental abnormalities as to be seriously handicapped |
| Section 3 | 4 (a) No pregnancy of a woman, who has not attained the age of eighteen years, or, who, having attained the age of eighteen years, is a [mentally ill person], shall be terminated except with the consent in writing of her guardian. |
| Mental Healthcare Act, 2017 (14) | Section 20 | (*h*) to have adequate provision for wholesome food, sanitation, space and access to articles of personal hygiene women’s personal hygiene be adequately addressed by providing access to items that may be required during menstruation; |
| Section 95  Prohibited procedures | (c) sterilisation of women when such sterilisation is intended as a treatment for mental illness. |
| The National Trust for the Welfare of Persons with Autism, Cerebral palsy, Mental retardation and Multiple disabilities Act, 1999 (15) |  | *Reproductive rights of WID are not adequately addressed* |
| Women’s commission act, 1990 (16) |  | *Reproductive rights of WID are not adequately addressed* |
| The protection of human rights Act, 1993 (Amendment 2019) (17,18) |  | *Reproductive rights of WID are not adequately addressed* |
| MCI codes of conduct regulations 2002 (19) |  | Chapter 1 Point No. 1.9 Evasion of Legal Restrictions: The physician shall observe the laws of the country in regulating the practice of medicine and shall also not assist others to evade such laws. He should be cooperative in observance and enforcement of laws and regulations in the interest of public health. A physician should observe the provisions of the Mental Health Care Act, 2017; Persons with Disabilities (Equal Opportunities and Full Participation) Act, 1995 such other Acts, Rules, Regulations made by the Central/State Governments or local Administrative Bodies or any other relevant Act relating to the protection and promotion of public health.  Chapter 6 Point 6 Human Rights: The physician shall not aid or abet torture nor shall he be a party to either infliction of mental or physical trauma or concealment of torture inflicted by some other person or agency in clear violation of human rights. |

Table 2: Minimum documentation required for the ‘capacity to consent’ for the medical procedures among WID

|  |  |
| --- | --- |
| Procedure | Documentation required |
| Clinical Examination | Complete Physical Examination  Mental Status Examination |
| Assessments | Intelligence Quotient (IQ)  Capacity Assessment as per MHCA 2017 |
| Information about medical procedure provided to the WID | 1. Nature of procedure 2. Risk and Benefit of procedure 3. Reasonable alternatives 4. Risk and benefits of alternatives |
| Patient’s understanding on medical procedure | Clinical assessment on the patient’s understanding of elements 1 through 4 |