

# Challenges in Providing Reproductive and Gynecologic Care to Women With Intellectual Disabilities: A Review of Existing Literature

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## Abstract

**Objective:** Our review aims to focus on identifying challenges faced by intellectually disabled women (IDW) in receiving gynecological and reproductive care and also highlights evidence based strategies to overcome those challenges.

**Materials and methods:** We conducted a literature review discussing challenges faced by IDW in obtaining healthcare services by thorough search on various electronic databases (PubMed, Google Scholar, and Scopus) starting from 2000 to 28 August 2021 excluding all non-english articles, reviews, editorials and letters to editor. The keywords used for search were “reproductive care”, “gynecologic care”, “intellectual disability”, “mental handicap”, and “mental retardation”.

**Results:** The existing literature review showed that IDW have difficulty maintaining menstrual hygiene and lack knowledge regarding contraception use and sexual health resulting in violations of their reproductive rights. Sexually transmitted diseases and cervical cancer are common among IDW due to their vulnerability to sexual abuse. Nulliparity in IDW increases their susceptibility to even breast cancer. Moreover, they face problems with sexually transmitted infection (STI) and cancer screening due to physical barriers for assessment, low socio-economic status, physician-patient communication issues and deficit in skilled providers. Short acting sedatives such as ketamine or midazolam can be used to overcome challenges faced with gynecological and obstetric examination. Finally forced sterilization and institutionalization has been a habitual practice as menstrual hygiene and pregnancy in IDW raise concerns on psychosocial challenges along with associated obstetric complications.

**Conclusion:** Reproductive and sexual health education including contraception use can be provided by using evidence based strategies involving use of pictures, animations and models by adequately trained healthcare providers including midwives. Further research involving IDW is needed to allow state-wise laws and policies to be created to mitigate the challenges and improve health outcomes in this population.

**Keywords:** Intellectual Disability; Women; Contraception; Reproductive Health

## Introduction

Intellectual disability (ID) is an impairment of an

individual's cognitive functions that has its origin before the age of 18 years (1). The prevalence of ID is estimated at 1-3%, with a male to female ratio of 1.6:1 (2). According to the Diagnostic and Statistical Manual of Mental Disorder (DSM-V) it is classified based on the daily skills rather than on specific IQ

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range of individuals (3). Patients with mild ID can learn practical life skills at a slower pace which allows them to function almost normally in life with only minimal support (3). While patients with moderate ID can learn skills for activity of daily living, they also require moderate support (3). Patients with severe ID on the other hand, have major developmental delays with limited communication skills (3). Although they can manage simple self-care, they strictly require supervision to thrive. As for profound ID, they have extremely limited communication skills and cannot live independently (3). Thus, they require close and complete supervision including help with self-care activities (3). ID could limit an individual's ability to take part in informed consent and pose various challenges in providing medical care (1). However, intellectually disabled women (IDW) are considered competent unless the court has decided otherwise (1).

There are obvious discrepancies in the provision of healthcare facilities to IDW. Increased prevalence of adverse outcomes, insufficient focus on health promotion, and lack of good health care services (4) are mostly reported in these groups (5, 6, 7). Although numerous laws are put in place to ensure the rights, especially the reproductive rights of IDW such as the right to equality, access to reproductive health, and the right to start a family (8), the implementation of these laws is scarce (9,10,11). Yet, other factors that prevent IDW from getting the care that they are entitled to include physical barriers for assessment, caregiver issues, access to health services, transportation difficulties, and a deficit in skilled providers (8). The lack of patient and caregiver education not only hinders providing primary care but also may lead to a higher chance of misdiagnosis of conditions. Often these women also come from low socioeconomic backgrounds that add to the complexities of accessing care (8). The inability of these women to participate in ongoing research has led to limited available data as to how we can improve the health outcomes in these groups (12).

In relation to women's health issues, aspects such as menstrual hygiene, menstrual abnormalities, routine cancer screening and diagnosis, provision of contraception methods (1), as well as both general and reproductive health care education and care (1), need additional focus in these groups. In this review, we aim to discuss the challenges faced by IDW with regards to gynecological and reproductive care and provide evidence-based strategies to overcome those challenges.

## Materials and methods

Multiple electronic databases were searched including PubMed, Google Scholar, and Scopus. Only English articles were considered that were published from 2000 until 28th of August, 2021. Reviews, editorials, and letters-to-editor were excluded. The search strategy involved using the following keywords "reproductive care", "gynecologic care", "intellectual disability", "mental handicap", and "mental retardation". Relevant citations from included articles were also searched for any studies missed by database search. Information in regards to IDW and their challenges undergoing gynecological care were collected and comprehensively analyzed. We also extracted any information that discussed evidence-based solutions to these challenges.

## Results

**Reproductive Care Challenges:** There is physical, mental, and social stigma when it comes to reproductive health in this population with many having to face forced sterilization and institutionalization (12, 13). In case they become pregnant they end up facing psychosocial challenges due to a lack of social support, financial instability, and parenting concerns. Many cases of traumatic interactions with physicians, and child and family services have been documented (14). Additionally, pregnant IDW are at increased risk of threatened preterm abortion and medical disorders like gestational diabetes, gestational hypertension with an increased rate of cesarean section, and postpartum hemorrhage (12, 15). Various comorbid conditions, such as thyroid, musculoskeletal and cardiac problems may lead to a high-risk pregnancy. A cohort study by Hilary K. Brown et al. in 2018 also reported a higher rate of rapid repeat pregnancy within one year among IDW (16).

**Menstrual Hygiene & Family Planning:** IDW may be unable to maintain hygiene during their menstrual cycles and may need to depend on their caregivers. In the past, contraceptive methods have been sought to completely stop menses to deal with concerns of hygiene. IDW are also more likely to use contraception than the general population for various reasons such as preventing sexually transmitted diseases and pregnancy. Though controversial, it is a widely used strategy amid their vulnerability to sexual abuse and concerns on parenting ability (12, 17). Many studies reported that the most

commonly used method of contraception is pharmaceutical drugs like oral contraceptives and injectable hormonal contraceptives, however, sterilization remains a popular option (12, 17). Moreover, disability-related barriers have remained an obstacle in finding the appropriate method of contraception (12). A research survey found 40.8% of the ID population in Brussels were devoid of contraception use and the most widely used contraceptive method in 22.2% of IDW was sterilization followed by other methods (18). The deciding factor for sterilization among them was particularly living facilities where contraceptives are mandatory and sexual intimacy is permitted (18). It was also seen that IQ level had little or no influence on the particular choice of the contraceptive method (18). Another study showed that 50% of IDW showed a restrictive understanding of contraception options (19).

Historically, there was a high prevalence of sterilization among IDW (20). However, nowadays sterilization among IDW as a method for contraception has become a controversial subject and that sterilization should be only used when other methods have failed (20). The shared decision-making trend among physicians and caregivers on behalf of the IDW group has also been criticized stating that this would only suppress their rights to decide-making freedom (20). With a lack of appropriate physician training, it is not uncommon to see physicians struggle with effective communication and the formulation of strategic management plans for these special needs individuals (12). Furthermore, family planning clinics may not be readily available as well (12). Some family members on the other hand show hesitancy in using contraception in a fear that contraception would disguise and encourage continued sexual abuse if the patient is a victim as compared to a lesser chance with the uncertainty of pregnancy in the absence of contraception use (4).

***Sexual Health & Sexually Transmitted Infection (STI) Screening:*** IDW are similar to other women in their desire for sexual satisfaction and the desire to build their own families (21). However, they are often marked as those that lack sexual interest, and/or those who can't control their sexual desires. (21). This common belief has established a system that tries to avoid any talks about sexual health, education, or family planning clinic services to this particular group of people (21). Even if such services are present, they are not user-friendly or easily accessible because they are not designed in a way that would

accommodate the wheelchairs for those that have a comorbid physical disability or extra space for their caregiver (21).

Although IDW have the right to live an ordinary life including experiencing sexual intimacy (22), concerns persist, particularly in their families, about being exploited, contracting sexually transmitted diseases, and getting pregnant (23). IDW often lacks knowledge about normal sexuality, and medical knowledge on sexual health education (24). Healthcare professionals also tend to avoid such conversations as they feel such topics to be inappropriate and unnecessary, as well as most of them, lack the experience in dealing with such topics in a way explainable to IDW (12).

Very little research has been done regarding rates of contracting sexually transmitted infections (STI) like Human Immunodeficiency Virus (HIV) in the IDW population (12). However, it is important to regularly screen for these conditions in this particular group for various noteworthy reasons. Firstly, the fact that IDW are more likely to be abused and less likely to report it (12, 11), they are more prone to contracting and unknowingly spreading it as well. Additionally, there is not much realistic sexual education available for them to have knowledge on how to prevent or test for STI/HIV infections (12).

***Cervical Cancer Screening:*** IDW are considered a low-risk population for cervical cancer as their sexual involvement is less as compared to the general population (9). Many studies have shown that the incidence of cervical dysplasia is much less in institutionalized IDW (1, 26). Most healthcare professionals thus question the use of cervical cancer screening in these patients, (1) given the uncertainties with performing a successful exam, sedation requirements, and unavailability of insurance facilities (27). However, as this population is more prone to abusive circumstances (28), cancer screening is considerably important.

However, Parish SL, et al in 2006 specified that there was a 72% decreased chance of IDW receiving cervical cancer screening compared to the normal population (29). Another study identified that only 31% of IDW had a Papanicolaou test done in the last 3 years (30). As screening with Papanicolaou smear is a seemingly difficult and painful procedure, if patients have had past sexual abuse this could incite fear and anxiety that could hamper the physician-patient relationship, thus the caution by healthcare providers (1). Additionally, general practitioners

performing the test rather than the gynecologist who specializes in women's health and the associated high cost were other limitations that were seen in IDW who resisted Papanicolaou tests (31). Difficulties in traveling to the clinic for the purpose of tests were also considered one of the hindering factors (27).

**Breast Cancer Screening:** Breast cancer is the most frequently diagnosed cancer and the second most common cause of cancer-related death in women. However, with the possibility of early detection through routine screening, the mortality has decreased by 20% with an improved 5-year survival rate (32). The U.S Preventive Services Task Force (USPSTF) guideline recommends "biennial screening mammography for all women aged 50 to 74 years" including IDW (33). However, only 1/3rd of IDW perform self-check or are referred for mammograms (34).

Nulliparity is one of the major risk factors for breast cancer, and IDW, are mostly nulliparous, increasing their chances to develop breast cancer. They are also reported to have high mortality compared to the general population in those diagnosed with breast cancer (35). Hence, breast cancer screening carries immense value to eventually have a better prognosis. Despite this IDW is less likely to screen for breast cancer compared to other general populations or individuals with physical disabilities (32, 36). Even without financial barriers, it was noted that IDW in South Korea, specifically the severe ones, showed decreased participation (32). This could be due to inadequate awareness, negative stigma, and social misconceptions (32). Lack of support system, socio-economic hardship, physical barriers, and associated transportation issues, as well as communication issues, are some additional factors that prevent screening (32). Similar findings were also seen in a United States (U.S.)-based study conducted by Lezzoni et al. which also reported a lower mammogram rate in IDW for similar reasons (36).

## Discussion

The role of primary health care providers is very important regarding the education of IDW. IDW mostly consider social media like TV, newspaper, radio as their source of reproductive and sexual knowledge (12), which creates a gap between practical knowledge and realistic reproductive knowledge (12). This gap can be minimized by providing interpersonal (ID)-centered practical education such as education regarding pubertal changes, menstrual hygiene, proper use of

contraception, pregnancy, and pregnancy-related complications, and their reproductive rights and responsibilities (12) with a focus to improve their decision-making skills. Furthermore, behaviors of the health care workers such as the use of open body language and smiling positively ease the conversation and allow these women to ask questions that they are unsure of (37). The use of pictures, animations, and models can aid in their learning as well as their feelings about sexuality and physical intimacy (37). For instance, Altundag et al reported that appropriate training in changing the pads during menstruation using a dummy significantly improved the skill and implementation of better menstrual hygiene, and thus, this kind of patient education should be encouraged (38). It is also equally important to focus on the mental health aspect of IDW (39). Adequate training to the front-line healthcare providers including obstetricians and midwives can tremendously improve the gynecological and reproductive challenges and the outcomes in these women (39, 40).

If IDW are currently engaged in or are planning to engage in consensual intercourse, management with contraceptives should be considered only as a method of preventing unplanned pregnancy. A number of independently acting factors influence contraceptive choices. Oral contraception can be used to relieve premenstrual symptoms and reduce the amount of menstrual bleeding. However, poor compliance due to the associated psychiatric and behavioral issues has the propensity to considerably reduce their effectiveness (41). The intrauterine device is also contraindicated in IDW who have other disorders with no sensory capability such as stroke, spinal cord injury, multiple sclerosis because of the inability to notice an ectopic pregnancy and pelvic infection. In this case, the barrier method of sterilization itself is a better alternative.

The most critical factor to reduce stress in any interaction with IDW includes proper physician-patient communication, which should be focused on the level of the patient's understanding. Educating the patient not just about the procedure's benefit but also the technical aspect has proved to be beneficial (12, 39). Performing a physical examination can be a stressful entity for IDW patients, both mentally and physically (1). It is performed through devised techniques, especially in high-risk disabled women (1). However, currently, there are no standard methods for the examination of IDW undergoing gynecological examination (1). Adequate preparation

time, along with emotional support are instrumental. Relaxation techniques and deep breathing exercises can be incorporated in the process if possible to facilitate the exam (1, 42).

To overcome the challenges in the gynecological and obstetric examination, with consent, safe short-acting oral sedatives can be used in IDW prior to the procedure (1). The use of ketamine or midazolam alone, or in combination allows for 81% of the success rate of the procedure in IDW who were previously uncooperative (11). Jaffe JS et al. also specified in their study that IDW who were sedated prior to their Papanicolaou smears and endometrial biopsies, were associated with a shorter hospital stay, lower hospital charges, and most importantly had no complications (26). Additionally, less invasive and convenient techniques such as urine samples or even blood samples can be used to replace vaginal culture which may trigger any past traumatic experience (12). Wright TC Jr, et al. identified that a lesser invasive HPV swab test was less invasive and beneficial to IDW that could be used as an alternative method for the diagnosis of high-grade cervical dysplasia compared to invasive tests such as Pap smear (1, 43). However, maintaining confidentiality during examinations is more important in IDW than in the normal group of women (1). Moreover, the decision on getting a pap smear must be individualized depending on factors such as sexual inactivity, prior abusive or traumatic events, and level of IQ (1).

To reduce the rate of unnoticed sexual abuse in IDW, sexual education with topics from basic women physiology to safe and consensual sexual intimacy should be given and policies should revolve around making this approach feasible for all IDW. They also should be educated about the gender disparities and their right to make their own decision (5). With proper and adequate education, these patients feel supported and are better aware enabling them to be less vulnerable to sexual abuse (44). This initiative also increases the likelihood of them disclosing these incidences (45). There should also be frequent appointments with such patients to enhance physician comfort towards caring for these patients, which also provides an opportunity for the physician to engage them in pursuing educational sessions (46). Nevertheless, healthcare providers should always be alert and vigilant to differentiate consensual sexual activity from abuse (24). In the case of true abuse, the physician must report it to the responsible committee.

Overall, to implement the practicality of their

rights, planned individualized care with a goal-oriented scheme needs to be followed not only to strengthen decision-making capacity but also to enhance their self-esteem to make them capable of making those decisions (47). Strong and consistent support along with a respectful approach should be undertaken (47, 48). Moreover, laws and policies should be upgraded towards the betterment of IDW (8). Healthcare providers, on the other hand, should focus on providing education in an understandable way to their IDW patients with regards to their rights as well as available services in the order of less invasive to invasive ones (49, 50). Furthermore, state-wise human right based policy should be strictly implemented to preserve the rights of this population (8). More importantly, adequate training for front-line healthcare providers including obstetricians and midwives can tremendously improve the gynecological and reproductive challenges along with the outcomes in these women. These strategies should be widely considered.

## **Conclusion**

IDW share unique challenges that sets them apart from other women. Menstrual hygiene, family planning, and sexual disease screening are especially important as these are at an increased risk to suffer from sexual abuse. Physicians should be alert to identify any signs and symptoms of sexual abuse in these patients. Physicians should provide an individualized approach to each patient and try to include them in the decision-making process in regard to their reproductive health. Physicians should aim to educate them as the physician-patient relationship plays an important part in IDW's life. Cancer screening should be provided to these women just like the rest of the female population as they are at a similar, if not increased, risk to acquire breast and cervical cancer. Moreover, further research is needed to identify the exact incidence rates of different ailments in these groups as much information is still unknown. This is important as these statistics can help guide future policymakers to ensure that IDW receives the best possible care.

## **Conflict of Interests**

Authors have no conflict of interests.

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