Manual on Sexual and Reproductive Health & Rights of Women with Disabilities

Developed by Abha Khetarpal

Manual on

Sexual and Reproductive Health

&

Rights of Women with Disabilities

Abha Khetarpal

President Cross the Hurdles

(Project supported by Women's Fund Asia)

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'National Icon Endoscopic Surgeon' of India
"India's No 1 Gynaecologist"
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A special thanks to all the 50 women with disabilities who took part in the needs assessment study.

Forewords

“This manual on the issues in reproductive health of disabled women is excellent, timely, and much needed. I recommend it to all health providers, especially to the doctors. We doctors only occasionally, if at all, come across disabled women patients and thus have little or no experience of handling their problems. This manual can be very handy in such situations. I recommend that health professionals keep this booklet by their elbow when treating disabled women.”

Dr (Prof) Sadhana Kala
‘National Icon Endoscopic Surgeon’ of India
“India’s No 1 Gynaecologist”
Honorary Consultant Gynaecologist to Army, Navy, Air Force (Emeritus)

“Appreciations for the comprehensive and elaborate document, with every detail covered. It will definitely serve as a good guide for medical practitioners, apart from information dissemination to stakeholders.”

Smitha Sadasivan
Member
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“It is well compiled and very informative”.

Dr Indu Aggarwal
MBBS, DGO, PGDHHM
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Acronyms and Abbreviations

UNCRPD- United Nations Convention of Rights of Persons with Disabilities
ICF-International Classification of Functioning
CESCR-Covenant on Economic, Social and Cultural Rights
CCPR-International Covenant on Civil and Political Rights
CVD-Cardio Vascular Dystrophy
MS-Multiple Sclerosis
CP-Cerebral Palsy
OI-Osteogenesis Imperfecta
ID-Intellectual Disability
DD-Developmental Disability
DS-Down Syndrome
SCI-Spinal Cord Injury
SB-Spina bifida
AD-Autonomic Dysreflexia
PMS-Premenstrual Syndrome
UTI-Urinary Tract Infection
IUD-Intra Uterine Device
PMDD-Pre Menstrual Dysphoric Disorder
CEDAW- Convention on the Elimination of All Forms of Discrimination against Women
SRH-Sexual and Reproductive Health
SRHR-Sexual and Reproductive Health and Rights
STI-Sexually Transmitted Infection
WwDs-Women with Disabilities
WASH- Access to water, sanitation and hygiene
DVT- Deep Vein Thrombosis
LARC-Long-acting reversible contraception
CS-Caesarean section
GA-General anaesthetic
PID-Pelvic Inflammatory Disease
HSV-Herpes Simplex Virus
HPV- human Papillomavirus
HIV-Human Immunodeficiency Virus
HBV-Hepatitis B Virus
TBI-Traumatic Brain Injury

PPS-Post Polio Syndrome

HRT-Hormonal Replacement Therapy

UNFPA –United Nations Population Fund

SDG-Sustainable Development Goal

AIDS-Acquired Immuno Deficiency Syndrome

Introduction

Though the importance of sexual and reproductive health has been acknowledged in international agreements, many countries still do not consider sexual health as a legitimate health issue. All women have a right to reproductive care regardless of disability.

According to 2011 Census in India among the disabled population 56% (1.5 Cr) are males and 44% (1.18 Cr) are females. Girls and women with disabilities are ignorant regarding their sexual and reproductive health and often don't know how to protect themselves against abuse, pregnancy and diseases. They lack information as parents and educators often do not know how to take up the subject. They lack comprehensive sexuality education and even are not taught basic vocabulary about their bodies. Thus they are unable to describe whether someone is taking their advantage. Many are taught to be compliant and to trust others, and so they do not have experience setting limits with others regarding physical contact.

Often, women with disabilities are considered to be non sexual. They are just as likely to be sexually active as women without disabilities. Unfortunately they face major obstacles in realizing their Sexual and Reproductive Health and Rights (SRHR) due to the barriers they face in reaching out to the healthcare professionals.

To enjoy their rights women with disabilities need certain measures to be put in place. These include awareness on SRH and disability, improving physical access to medical facilities, staff development among medical personnel, and adapting materials to fit persons with disabilities. The Manual thus deals with the specific issues relating to different kinds of disabilities, their unmet needs regarding maintenance of Sexual and Reproductive Health and Rights and what all can be done to remove different kinds of barriers faced by them.

This manual would be useful for its most important stakeholders i.e. women with disabilities as it provides them with necessary information. They should be knowledgeable about their own disability which in turn will foster effective provider-patient relationships and more active participation in self-care and health promotion.

This manual is also designed for clinicians to improve their knowledge and practice in providing care to women with physical disabilities and chronic health conditions. It reviews strategies for management as well as specialized approaches. Different sections cover the pelvic exam, cancer screening, contraception, pregnancy, menopause, aging, health promotion, as well as other critical components of comprehensive reproductive health care.

Caregivers going through this manual would understand the SRH needs of women with disabilities. They can observe and monitor their conditions well. NGOs, Disabled People's Organizations (DPOs), women's organizations and policy makers would become more knowledgeable about SRH requirements of women with disabilities so that appropriate measures can be taken in this regard.

What is Disability?

Concept and Meaning

According to World Health Organization disability is an umbrella term, covering impairments, activity limitations, and participation restrictions.

Impairment is disturbance altering body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is an issue experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon and multidimensional experience of the person involved. It reflects the interaction between features of a person's body and features of the society in which he or she lives. Reducing the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) recognises that 'disability is an evolving concept'[i]. '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 effective participation in society on an equal basis with others'[ii]. UNCRPD reiterates that disability is an evolving concept which results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

Thus disability is part of the human diversity. Everyone is likely to experience it, either permanently or temporarily, at some point in their life[iii].

Three dimensions of disability are recognized in International Classification of Functions (ICF)[1]: body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions).

Classification of Disability

Categorizing disabilities helps the government identify needs and allocate necessary resources to various populations of people with similar disabilities. These classifications provide a basis around which individuals with disabilities can organize their legal, social, and advocacy efforts.

[1] The International Classification of Functioning, Disability and Health, also known as ICF, is a classification of the health components of functioning and disability. Created in 2001, it provides a unifying framework for classifying the health components of functioning and disability.

There are many different ways to classify disabilities, but no one way has been deemed the standard. The most general way to categorize disabilities is to categorize them into one of the following categories.

- *Visible Disabilities* – disabilities that can be objectively observed and measured by others. These disabilities often lead to marginalization or to the development of stereotypes of the person having the disability.
- *Invisible Disabilities* – disabilities that are not immediately apparent. Some **examples** are depression, attention deficit disorder, schizophrenia and many chronic illnesses such as renal failure, diabetes, and sleep disorders.

Disability has also been categorized by symptoms and manifestations, not cause or source. In this system, disabilities fall into one of four broad categories.

- *Physical Disability* – a condition that puts a limit on one or more basic physical activity, including mobility and sensory activities. Examples include: spinal cord injuries, paraplegia, quadriplegia, amputations, cerebral palsy, seizure disorders, muscular dystrophy, arthritis, visual impairments and hearing impairments.
- *Intellectual Disability* – Intelligence may be defined as the ability to obtain and use knowledge in an adaptive condition. This situation is characterized by significant limitations in conceptual, social, and practical adaptive skills. These are specific cognitive difficulties that create a low intelligence quotient (IQ) score and pose number issues to adapt to new situations. For instance in socializing or taking a test. Understanding and applying new information is harder. Intellectual disability—such as Down syndrome, Fragile X syndrome can happen due to genetic conditions, complications during pregnancy, infections or toxic exposure.
- *Cognitive Disability*- cognition means awareness in general and the ability to learn in particular. It can be caused due to brain injury, severe, hormonal issues, and alternate chemical levels as in Alzheimer or Parkinson, deficiency of certain vitamins, psychiatric illness and substance abuse. It is an obstacle to learning. A person with this type of problem experiences difficulty in perceiving, recognizing, choosing, understanding, etc. It might be a problem processing printed text or defective short-term memory. It could be problems with the idea of number quantities or imagining shapes. It is an impairment that affects an individual's ability to access, process, or remember information, for example in dyslexia, attention deficit disorder. Those with these disabilities can adjust and compensate for the cognitive deficiency by adapting a testing or learning method.

- *Psychiatric Disability* – a disability characterized by emotional, cognitive, and/or behavioural dysfunction, for example, depression, substance abuse, different types of mental illnesses like bipolar disorder, schizophrenia.

In the Rights of Persons with Disabilities Act 2016[iv], in India, disability has been defined based on an evolving and dynamic concept. The types of disabilities have been increased from 7 to 21 which are given below:-

1. Blindness\Low-vision
2. Leprosy Cured persons
3. Hearing Impairment (deaf and hard of hearing)
4. Locomotor Disability
5. Dwarfism
6. Intellectual Disability
7. Mental Illness
8. Autism Spectrum Disorder
9. Cerebral Palsy
10. Muscular Dystrophy
11. Chronic Neurological conditions
12. Specific Learning Disabilities
13. Multiple Sclerosis
14. Speech and Language disability
15. Thalassemia
16. Hemophilia
17. Sickle Cell disease
18. Multiple Disabilities including deaf blindness
19. Acid Attack victim
20. Parkinson's disease

Speech and Language Disability and Specific Learning Disability have been added for the first time. Acid Attack Victims have been included. Dwarfism, muscular dystrophy have has been indicated as separate class of specified disability. The New categories of disabilities also included three blood disorders, MS, Parkinson Disease, Thalassemia, Hemophilia and Sickle Cell disease.

Models of disability

Various models of disability shape people's perceptions and ideas about persons with disabilities.

The Moral/Religious model

This is the oldest model of disability and is found in a number of religious traditions. Disability is regarded as a punishment from God for a particular sin or sins that may have been committed by the person with disability. Sometimes it is not only the individual's sin that is regarded as a possible cause of their disability, but also any sin that may have been committed by their parents and/or ancestors.

Charity Model

People with disabilities are often treated as objects of charity and pity. People assume that a person with disability is always dependent and considered as a burden for the society. The individual is an object of pity[v].

Medical Model

It is sometimes described as 'personal tragedy' model. Here people with disabilities were treated as sick and needing to be cured, fixed and cared for through medical intervention and therapy. Under the medical model, the experts on disability were considered medical professionals, such as doctors, nurses, therapists[vi]. Disability is considered as sickness. Most services are focused on curing the person's disability or making him appear non-disabled, instead of making the environment more accessible.

Social and Human Rights Models

Based on a human rights paradigm, these models stress that disability-related challenges arise from an inaccessible social structure. These models focus on environmental and attitudinal barriers that prevent people with disabilities from having equal opportunities in their societies[vii]. Many disability rights activists today embrace social and/or human rights models. UNCRPD is based on this model of disability.

According to this if a person with a disability is able to attend a school, go to work, participate in community activities alongside non-disabled people, perhaps using disability-related accommodations or modifications that make the environment more accessible to them, and then there is no disability.

Sexual and Reproductive Health and Rights

Women's sexual and reproductive health is related to multiple human rights, including the right to life, the right to be free from torture, abuse and coercion, the right to health, right to nutrition, the right to privacy, the right to education, right to accessible information, right to informed decision and consent and the prohibition of discrimination.

What is sexual and reproductive health?

Sexual and Reproductive health is the ability to have a safe and satisfying sex life and the ability to reproduce. It is associated with the freedom for all to decide if, when, how often and with whom one has sex and their freedom to decide if, when and how often to reproduce.

The definition suggests that reproductive health encompasses:

- the potential to reproduce
- freedom to control reproduction
- the ability to go through pregnancy and childbirth safely, with successful maternal and infant survival and outcomes
- the capacity to obtain information about and access to safe, effective and affordable methods of family planning
- the ability to have a satisfying, safe sex life, without fear of pregnancy and disease
- the ability to reduce gynaecologic disease and risk throughout all stages of life

Reproductive health extends into the years before and beyond the years of reproduction, not just the time of reproduction. It also recognizes gender roles, and the respect and protection of human rights.

The reproductive years are usually thought of as the years spanning from menarche, with onset usually between ages 12 to 14, to menopause at around age 50. For demographic purposes, reproductive age is usually defined as 15 through 49.

Importance of Reproductive Health

- Reproductive health is a human right stated in international law.
- Reproductive health plays an important role in morbidity, mortality and life expectancy.
- Reproductive health problems are the leading cause of women's ill health and mortality worldwide.

Key Characteristics

What should be the key characteristics of Sexual and Reproductive Health in various programs and policies?

User-centered and Participatory

Programs and services that are developed must be based on the needs of the user. The user should be included in every step of program planning, implementation, and evaluation.

Respect

Services provided should be free from judgement and stigma. Utmost care has to be taken about the user's privacy and consent.

Informed Choice

User should have easy and accurate access to information about available services and options.

Freedom from Coercion

Services are delivered should be free of any kind of pressure, constraint or harassment.

Equal Access

Irrespective of race, class age, gender, sexuality, HIV status, profession and disability services should be affordable, offered in appropriate languages, accessible and available to everyone at all times.

Quality of Care

Services must be provided by trained personnel, with accurate and proper monitoring and evaluation performed regularly.

Integration of Care

Family planning, sexual health, and maternal health services should be offered in one location or even available at neighbourhood or doorstep, through a smooth referral process which should be linked to services for survivors of gender-based violence.

Core SRH services

Sexual and Reproductive Health should include:

- Contraceptive services and supplies including male and female condoms, with full range of temporary and long lasting methods and emergency contraception according to the needs of women with disabilities. Audio and video descriptions of how to use them.
- Counselling services and proper guidance.
- Safe and accessible abortion and treatment of complications arising from unsafe abortions.
- Maternal care, including pre natal and postnatal care of mother and the new born by skilled medical professionals at delivery and emergency care centre.
- Prevention, diagnosis and treatment of sexually transmitted infections including HIV AIDS and human papilloma virus (HPV) as well as cancers of reproductive systems, infertility and various sexual dysfunctions.
- Integrated services at the same time and same place and even doorstep services for women with disabilities.

Components of sexual and reproductive health

Various components are:

- *Safe Motherhood* Reproductive health includes facilities and services for safe motherhood. This component is meant to keep a track of the pregnancy itself all the way to delivering a baby, as well as neonatal, pre natal and postnatal periods, and breastfeeding.

- *Family Planning* People get help in decision making regarding how many children they want to have, what are the best ways of achieving it and spacing between two pregnancies, or choose to become permanently infertile.

- *Dealing with sexual dysfunction and infertility* Reproductive health care supports people that want to become parents by providing them with required information, medicine, treatment and alternative ways of reproduction.

- *Dealing with Sexually Transmitted Infections, HIV and AIDS* Sexually active woman, whether disabled or non disabled can get STIs. Most of STIs are relatively short and reproductive health centres are equipped with dealing with them. However, some diseases are more severe and untreatable like HIV/AIDS. The centres can provide information on how to deal with them on a daily basis. This includes taking the prescribed medicines in time, learning how to deal with positive status and fighting the stigma around the disease. Apart from the STIs, various non-transmittable diseases can damage the reproductive system. These include various types of cancers and other illnesses that might negatively affect the reproduction. Reproductive health centres deal with them as well.

- *Dealing with Gender-Based Violence*. Gender-based violence is associated with a variety of negative health outcomes for women. There are reproductive and maternal health consequences. Victims of an unwanted pregnancy resulting from rape are more likely to choose to terminate that pregnancy. In the developing countries many abortions are performed by individuals who lack proper training or in facilities that do not meet medical standards. This may result in complications, internal injuries and even death. Violence and abuse can be major obstacles in accessing healthcare. Women with disabilities may be limited in their ability to independently travel to health centres, make personal decisions about their care, and pay for services. Stigma and fear can also obstruct them from seeking information or help.

- *Services for providing safe abortions*. There can be many reasons for getting an abortion. For example, unplanned pregnancy, health complications, pregnancy from a sexual assault (rape), etc. Proper services should be available that could facilitate the process of pregnancy termination. In the absence of legal and safe abortion services, illegal abortions happen, leading to harmful consequences. Reproductive health concerns itself with not only abortions, but also their aftermath.

- *Sexuality education.* Girls and women with disabilities who have reached the age of sexual maturity should know about puberty, pregnancy 'what is reproduction', 'what is safe sex', 'why contraception is important', HIV/AIDS, STIs and gender based violence. Basic sexuality education is essential for reproductive health.

- *Dealing with harmful practices.* Discouraging harmful practices, such as female genital mutilation, child marriage and sexual violence. Reproductive health is meant to prevent such practices from happening and to remedy the damage that has already been done through mental and physical therapy.

- *Functional and accessible referral*. Reproductive health is an important part of general health. It is essential for social, economic and human development. The highest attainable level of health is not only a fundamental human right.

Programmes dealing with various components of reproductive health exist in some form almost everywhere. Women with disabilities should also be involved in programmes that are related to their overall health and wellbeing. Reproductive health should be concerned with issues revolving around harmful practices, unwanted pregnancy, unsafe abortion, reproductive tract infections, sexually transmitted infections and HIV/AIDS, gender-based violence, infertility, malnutrition and anaemia, and reproductive tract cancers.

Appropriate services must be accessible and include information, education, counselling, prevention, detection and management of health problems, care and rehabilitation. Reproductive health services must assume their responsibility to offer accessible and quality care, while ensuring dignity, freedom of choice, informed consent, confidentiality and privacy in all reproductive matters.

Many countries prohibit abortions, mostly on religious grounds. However, illegal abortions are often harmful for the pregnant person, and they lead to many unnecessary complications. Even in countries where abortions are legal, some might cause unexpected health problems.

Relationship between Sexual and Reproductive Health and Rights

Sexual health is closely linked to reproductive health. Reproductive health is a lifetime concern for every individual, from infancy to old age.

Though there is a link between sexual and reproductive rights but they are not interchangeable terms. This distinction is important because “sexual rights” involve recognizing that sexuality is an integral part of who we all are throughout our whole lives, can be expressed in various ways, and goes beyond our reproductive biology, roles and capabilities. Sexual rights include:

- The right to choose whether, with whom, and how one engages in sexual relations
- The right to privacy, freedom of expression, bodily autonomy and integrity

- The right to comprehensive sexual and reproductive health information and services to make safer, consensual and fulfilling choices around sex and relationships
- The right to make free and informed choices in relation to one's sexuality, sexual orientation, and gender identity, and live free from discrimination, coercion and violence.

Sexual health and reproductive health are also different and distinct dimensions of human well-being.

Determinants

Sexual and reproductive health (SRH) is directly related to the survival of the human race involves complex community and social taboos. Sexual and reproductive behaviours are unique in being regulated by society.

Determinants of SRH include:

(I) Law, policies and human rights,

(ii) Education,

(iii) Society and culture

(iv) Economics

(v) Health systems

Sexual and reproductive health requires knowledge of normal physiology and development, healthy expressions of sexuality, an understanding of the consequences of sexual and reproductive behaviours, as well as communication skills that assist people in making informed and responsible choices. Access to services that provide contraception, safe abortion, pregnancy care, and diagnosis and treatment of sexually transmitted infections is critical.

"Honestly with schizophrenia-we don't get to sexual health firstly :) We're stereotyped at the basic level of comprehension, articulation and the fact that I have an enormous insight of myself. Learning to not disclose my schizophrenia where my sexual health is concerned has been my way - as my family and I have never seen the need or connection to disclose it to a gyneac or any other doctor owing to the numerous stigma we have faced with my other medical conditions. Interns, trainees, and young doctors look at me with awe, and keep asking all kinds of irrelevant questions when they find out I have schizophrenia. Curiosity is acceptable but they tire me out entirely by these questions taking a whole hour to certify that I am of sound capable mind before asking me questions pertaining to my actual condition (which in my case was my follow up post a brain tumour surgery)"

Reshma Valliappan aka Val Resh

Founder-Director, The Red Door India

Ashoka - Ink fellow 2014

Barriers in way of accessible SRHR

Physical barriers

- Lack of accessible transportation
- Lack of ramps or and presence of stairs-only
- Lack of tactile marking
- Small hallways, difficult for wheelchair, cane, crutches, etc. to navigate
- Small exam rooms and inaccessible doors
- Lack of accessible washrooms
- Lack of adapted examination tables and medical equipments
- Lack of wheelchair accessible weighing machines
- Lack of prescriptions in accessible format
- Lack of sign language interpreters
- Lack of easy to understand and delay in providing appropriate information

Patients' barriers to care

- Poverty and lack of medical insurance
- Lack of education and awareness
- Lack of comfort
- Issues of communication
- Lack of privacy
- Fear and apprehensions

Barriers faced by medical health providers

- Lack of knowledge
- Lack of training to handle diverse kinds of disabilities
- Societal stereotypes regarding disability
- Lack of comfort
- Time constraint

Barriers imposed by society

- Stigma of disability
- Negative attitude towards disability and sexuality (assuming that disabled are non sexual)
- Marginalization of women with disabilities
- Absence of comprehensive sexuality education for women with disabilities

Factors complicating gynaecologic care for women with disabilities

- Increased prevalence of orthopaedic disorders (e.g., kyphoscoliosis[2])
- Increased prevalence of joint complications (e.g., contractures, spasticity)
- Possible difficulty with communication (with patient, caregiver, or clinician)
- Lack of knowledge of caregiver
- Caregiver or provider's refusal to provide care
- Refusal of patients to accept care
- Increased prevalence of autonomic dysreflexia[3] in women with SCI
- Possible coexistence of neurological problems (e.g., Tourette Syndrome, epilepsy)
- Increased prevalence of nutritional problems (e.g., gastroesophageal reflux, feeding tube complications)
- Possible skin problems such as pressure ulcers that may limit positioning

[2] Kyphoscoliosis is a deformity of the spine characterized by abnormal curvature of the vertebral column in two planes

[3] Autonomic dysreflexia is a syndrome in which there is a sudden onset of excessively high blood pressure. It is more common in people with spinal cord injuries that involve the thoracic nerves of the spine or above (T6 or above)

Myths about sexuality and disability

Various myths about sexuality and disability prevail in our society, with the result that the sexual well-being of disabled women is often neglected. These myths include the following:

- disabled women are non sexual
- only independently functioning women can handle sexual relationships
- disabled women are single are celibate
- disabled women cannot be mothers
- all disabled women are heterosexual
- disabled women should be grateful for sexual relationships
- disabled women are different
- Youth and beauty are essential to sexuality.

Physicians can reject these myths and attempt to understand the possible impact of disability on their patients' sexuality.

Menstrual Management; Health and Hygiene

What is menstruation?

Menstruation is the monthly flow of blood from the uterus through the vagina in girls and women from puberty to menopause. The cycle is usually around 28 days but can vary from 21 to 35 days. Each cycle involves the release of an egg (ovulation) that moves into the uterus through the fallopian tubes. The body's tissues and blood start to line the walls of the girl's uterus for fertilization. If the egg is not fertilized, the lining of uterus is shed through the vagina along with blood. The bleeding usually lasts between two to seven days each month, with some lighter flow and some heavier flow days. Menstrual cycle during the first year or two is often irregular.

Menarche The medical word for the age or date of someone's first period (menstruation) is menarche. The average age of onset of menarche is 12.4 years. Menarche is the result of complex interactions between the hypothalamic, pituitary, and ovarian hormones. It also can be affected by thyroid, adrenal, and pancreatic hormones. Thyroid hormones are necessary for normal menses, and their deficiency or excess can inhibit menarche or lead to abnormalities in existing menstrual patterns. Menarche generally is considered early if it occurs before 9 years of age and late if it occurs at or after 15 years of age. It is associated with the ability to ovulate and reproduce.

Menarche signals reproductive maturity and concerns around menstrual management of girls with disabilities may become linked with concerns around vulnerability to sexual abuse and pregnancy.

Stages of menstruation

- Follicular (before release of the egg)
- Ovulatory (egg release)
- Luteal (after egg release)

Common menstrual problems

Girls with physical and learning disabilities are more likely to suffer from period problems than their peers without disabilities. Some of the more common menstrual problems include:

Premenstrual syndrome (PMS) – Anything that occurs right before periods - such as cramps, breast tenderness, regarded as pre-menstrual syndrome. Mood issues can include anything from mild to moderate depression, melancholia, sensitivity, even full-blown anger and self-hatred. Hormones can trigger a range of side effects, including fluid retention, nausea,

bloating, vomiting, headaches, fatigue and irritability. Some women may even experience diarrhoea and constipation.

One may need to urinate frequently. Some may have severe pain in the lowest part of the pelvis a few days before, during, or after a menstrual period. Symptoms tend to be more severe if:

- Menstrual periods started at an early age.
- Periods are long or heavy.

PMS in Down syndrome is troublesome.

General Self-care Steps during PMS See Appendix 1

Dysmenorrhoea – or painful periods. It is thought that the uterus is prompted by certain hormones to squeeze harder than necessary to dislodge its lining. Treatment options include pain-relieving medication and the oral contraceptive pill.

Heavy menstrual bleeding (previously known as menorrhagia) – if left untreated, this can cause anaemia. Treatment options include oral contraceptives and a hormonal intrauterine device (IUD) to regulate the flow.

Amenorrhoea – or absence of menstrual periods. This is considered abnormal, except during pre-puberty, pregnancy, lactation and post menopause. Possible causes include low or high body weight and excessive exercise.

Pre Menstrual Dysphoric Disorder (PMDD)- It is an extension of PMS. In both PMDD and PMS, symptoms are seen seven to 10 days before periods and last for the first few days of periods. PMDD may also cause bloating, breast tenderness, fatigue, and changes in sleep and eating habits. In PMDD, however, at least one of these emotional and behavioural symptoms like sadness, anxiety, moodiness and irritability are more.

Menstruation and Disability

All teenagers may have irregular cycles during the first 2–5 years after menarche, but adolescents with disabilities may have additional reasons to experience menstrual irregularities in teenagers with Down Syndrome who are on mood stabilizing medication, and teenagers with seizure disorders. Thyroid disease, that is more prevalent in women with Down syndrome, can cause disturbance in menstrual cycle in girls/women with Down Syndrome[viii].

The prevalence of epilepsy is approximately 20–40% in people with intellectual disability[ix]. In catamenial epilepsy (a gender-specific type of epilepsy), there is greater frequency of

seizures during certain phases of the menstrual cycle[x]. Approximately half the women of childbearing age who have epilepsy report an increase in seizures around the time of their monthly menstrual period. Women with epilepsy have an increased incidence of reproductive endocrine disorders, including irregular menstrual cycles, *anovulatory cycles* (absence of ovulation), *amenorrhea* (abnormal absence of menstruation) and *oligomenorrhea* (infrequent or very light menstruation)[xi].

Some neurological conditions are linked with irregular menses. Women with MS and other neurological diseases may encounter a spurt in disease-related symptoms at the time of premenstrual or menstrual phases[xii].

Patients with spina bifida have shown to have early sexual maturation. The average age of menarche for females with spina bifida ranges from 10.9 to 11.4 years where the average age in females without spina bifida is 12.7 years[xiii].

Young girls who have had traumatic brain injury (TBI) or SCI may have delayed menarche or even an early puberty[xiv]. Most women with SCI will resume normal menstruation within six months after injury. A study shows that roughly 25% of women with SCI have *perimenstrual dysautonomia* i.e. gooseflesh, headaches, flushing, and sweating[xv].

Women with rheumatoid arthritis have later onset of menarche and increased rates of ovulatory dysfunction[xvi]. Greater frequency of hyperprolactinemia is seen in women with SCI, Traumatic Brain Injury and Multiple Sclerosis i.e. is stopping of menstrual periods or decreased menstrual flow[xvii]. Many women with disability may have risk of osteoporosis.

There is a range of medical conditions are associated with abnormalities of reproductive function and menstrual cycle. Prader-Willi syndrome[4] and Laurence-Moon syndrome[5], for example, are both associated with intellectual disability and hypogonadism[xviii] (sex glands don't produce hormones). Being underweight from any cause may result in amenorrhoea, while one may have heavy periods if one is obese. Those who take drugs anticonvulsants and antipsychotics may have menstrual irregularities.

Girls with OI can expect to begin menstruating at the same age as women who do not have OI. Menstrual periods usually occur at the customary time and cycles are generally regular. There may be heavy bleeding in women with a history of easy bruising or bleeding tendencies.

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[4] A complex genetic condition that affects many parts of the body. This condition is characterized by weak muscle tone (hypotonia), feeding difficulties, poor growth, and delayed development.

[5] A rare autosomal recessive genetic disorder associated with retinitis pigmentosa, spastic paraplegia, and mental disabilities.

Teens with swallowing problems or feeding tubes may have such a low weight that they experience either absence of menstruation or a very light and infrequent one.

Barriers for menstrual hygiene for women/girls with disabilities

Menstruation restricts the mobility and behaviour of a woman because of myths, misconceptions and taboos in our country.

Menstruation causes hygiene problems and increases the need for attendant care in women with mobility disorders.

Some of the girls may even have difficulty communicating about the menstrual cycle.

Some difficulties that are specific to both having a cycle and a disability are: handling tampons, pads, or menstrual cups (collection methods), menstrual awareness and managing menstrual-related pain. All this is because of various hurdles faced by them. Like:

Lack of sensation

Due to weakness or nerve damage some women may have problems with perineal (area around vagina) sensation. She may not know that menstruation has started, or when she needs a change. She may have problem in finding the vulva and in knowing if the tampon is inserted correctly or if the sanitary pad is at proper place. She may not even be aware if she is sitting uncomfortably on a pad, with the possibility of causing a pressure area.

Limited accessibility

WASH facilities (access to water, sanitation and hygiene) that provide privacy for women to wash their bodies, stained clothing and any cloths used for menstrual hygiene management are not available to them in underdeveloped regions or villages in India. A woman with disability may have difficulty in finding an accessible toilet, especially in rural areas. She may not be able to reach her perineum (area between vagina and anus), as in women with short stature or dwarfism, when seated on an ordinary unraised toilet.

Spasticity

Women affected by involuntary jerky muscular contractions may have trouble in spreading legs so that she can place a pad. Inserting a tampon may increase her spasticity.

Strength and dexterity loss

Women with paraplegia, quadriplegia or multiple sclerosis who are wheelchair users or those with upper extremity strength or dexterity loss caused by cerebral palsy, multiple sclerosis or quadriplegia, bilateral upper extremity amputation, or rheumatoid arthritis are likely to face problems of management depending upon the severity of their disability. A woman who has lack of strength in hands may have trouble getting her pants down, transferring to the toilet,

or standing. She may also have difficulty opening the packaging of the pads or tampons. A woman may have particular difficulty in handling tampons and may bend or distort them.

When to see a doctor about regarding menstrual health?

One should see a doctor if:

- Menstruation doesn't start by the age of fifteen.
- Menstruation doesn't start within three years after breast growth began, or if breasts haven't started to grow by age of thirteen.
- Periods suddenly stop for more than ninety days.
- Periods become very irregular after having had regular, monthly cycles.
- If periods occur more often than every twenty one days or less often than every thirty five days.
- Bleeding happens for more than seven days.
- Bleeding happens more heavily than usual or using more than one pad or tampon every two hours.
- Bleeding between periods.
- One has severe pain during period.
- One suddenly gets a fever and feels sick after using tampons.

For doctors and medical professionals

Rehabilitation centres do not prepare women with disabilities to manage menstruation. They need truthful and complete information about sanitary products to make informed decisions. Health care providers need to discuss with women who have limited mobility the benefits of hormonal reduction of menstruation frequency versus the risk of a slightly increased risk of deep vein thrombosis[6] (DVT) or stroke. Hypercoagulability[7] tests can be done to investigate a woman's risk for DVT.

Many times functional and accessible referral "options to suppress menstruation whether via an Intra Uterine Device or oral contraceptives" are considered to simplify life and personal care needs

Many times parents or caregivers of girl/women with intellectually disability consider medical procedures hysterectomy to manage periods. They may be concerned about the girl's inability to cope with menstrual hygiene due to lack of mobility, physical flexibility or

[6] Blood clot in the veins

[7] Hypercoagulability can be defined as the tendency to have thrombosis as a result of certain inherited and/or acquired molecular defects.

understanding. Distressing symptoms of pain, heavy flow, irregular bleeding, mood changes or cyclical disturbances in seizure control may seem problematic. There can be concerns regarding pregnancy, vulnerability to sexual abuse or sexualised behaviour. It should be kept in mind that suppressing menstruation doesn't resolve issues like sexual violence**.** The obstetrician–gynaecologist need to evaluate underlying causes before initiating a suppressive treatment. The evaluation for abnormal bleeding is the same for adolescents with disabilities as it is for other adolescents.

According to international ethical guidelines suggest that non-therapeutic hysterectomy in women with ID should not and ought not to be recommended as a solution to manage menstrual hygiene even if it is technically safe. What needs to b done is to investigate the options available, supports and resources along with the education and training for the women concerned, their parents and their caregivers, followed by training of all professionals involved[xix]. This will provide more justice for the women and this means better and fairer choices for everyone in the society. Low-and middle-income countries need to develop and enact policies and statutes in this area of public health and clinical practice.

Goals could be to:

- decrease flow
- relieve pain or symptoms
- Provide contraception, or obtain amenorrhea.

While using various methods of sanitation women with disabilities can confront many issues. These difficulties can be lessened by changes in positions.

See Appendix 2 for Changes in positions to change sanitary pad/tampon.

Good menstrual hygiene for WwDs requires:

- Access to accurate and pragmatic information
- Access to affordable menstrual hygiene materials
- Access to facilities that provide privacy for changing and washing
- Access to water and soap
- Access to disposal facilities

During menstruation the blood tends to enter tiny spaces like the skin around the opening of the vagina. This excess blood should be washed away before the pad is changed. This would beat bad odour from the region. This can be difficult for

wheelchair users. If they are unable to wash they can wipe off with tissues or toilet paper

The region around groin and underside of thighs must be kept dry in order to prevent from fungal and bacterial infections.

Appendix 3: Tips to remain hygienic during menstruation.

Charting

Charting is important to remember that every cycle is different. Some women have four day periods while other will have seven. Some may experience irritability and cramping, while others, menstrual migraines or both. Tracking menstrual cycle doesn't require much. Simply record the symptoms and after a few months you will notice some common trends.

Kinds of charts

Caters to individual needs. For example, for a woman who currently needs assistance while eating, or while using the toilet, try rubber or self-inking stamp and a large calendar; for a woman with very poor vision, a method which relies more on touch and less on visual information may be more helpful (e.g. A wall chart with Velcro-attached objects or shapes); for the most dependent women, for whom charting will be done by others, the whole-year chart at the end of this chapter is the most suitable. The woman should still be present during charting and receive basic explanations of the process.

Chart every day. Regular charting will help people to be aware of both physical and psychological changes which accompany menstrual cycles. Patterns will probably emerge. The women and those assisting them will become more able to predict and respond appropriately.

Establish a routine. Choose a time of day which seems suitable to chart. Some people like to chart towards the end of the day or night. Others do it twice-daily: this applies particularly to settings where women are assisted by different people at different times of the day, such as in residential services.

Record relevant information. Women experience different kind of changes during her menstrual cycle. Like sore breasts, abdominal swelling, irritability, and fatigue, depression or some women may experience positive changes such as increased energy and enthusiasm. Each woman may have 3-4 types of information recorded. For some women, it will be important to record changes in mood and behaviour. The personal meaning of "happy" and "sad" stamps for each woman can be noted- either on her calendar or in her chart. Heaviness of flow may be an issue for some women. Using an Estimation of Menstrual Flow

chart for several months will be helpful to clarify the type of flow a woman is experiencing. Women's involvement in their own pad management can also be charted, to record achievements and progress.

For Parents/ Caregivers

Attitudes of family members, care givers and friends towards menstruation can influence the reactions of a young woman who has a disability. Care givers of young women with the need of menstrual management may not know how to explain menstruation to her and how to train her in pad changing. The young woman may have grown and her weight may have increased. All this can add to difficulties for the people who assist her with bathing, toileting and changing menstrual pads. It is absolutely significant that those who provide personal assistance have a positive and supportive outlook towards menstruation. An individual plan would be required to take the needs, abilities and conditions of a young woman into consideration. For young women who are very dependent for self care, reassurance and acceptance of menstruation must be the main aim, rather than teaching of skills.

See Appendix: 4 Tips for mothers and caregivers for menstrual management of girls/women with disabilities

Contraception

What is Contraception?

Birth control, also known as contraception, is designed to prevent pregnancy. “Any device or act whose purpose is to prevent a woman from becoming pregnant can be considered as a contraceptive”. Some barrier methods, like male and female condoms, also provide twin advantage of protection from sexually transmitted infections (STIs). Contraceptive methods may work in a number of different ways:

- Preventing sperm from getting to the eggs. Types include condoms, diaphragms, cervical caps, and contraceptive sponges.
- Keeping the woman's ovaries from releasing eggs that could be fertilized. Types include birth control pills, patches, shots, vaginal rings, and emergency contraceptive pills.
- IUDs, devices which are implanted into the uterus. They can be kept in place for several years.
- Sterilization, which permanently prevents a woman from getting pregnant or a man from being able to get a woman pregnant.

Contraceptives reduce the risk of STI transmission. The use of a condom with every sexual act reduces the risk of several STIs, including gonorrhoea, Chlamydia, herpes and other ulcerating viruses, bacterial vaginosis, and pelvic inflammatory disease. Latex is the best material, but polyurethane is effective in the case of latex allergy as in the case of women with Spina bifida. Dental dams also reduce the risk of STIs. Diaphragms and cervical caps prevent cervical and upper genital tract infection but not vaginal and external genital infection.

Contraception and Disability

Reproductive health services, particularly contraceptive information and services remain mostly unavailable to individuals with disabilities due to barriers to physical access, lack of disability-related technical and human support, stigma, and discrimination. Misconceptions prevail that women with disabilities are non sexual. Discriminatory views augment barriers to accessing contraceptive information and services. WwDs may also be subjected to coercive or forced contraceptive policies, such as sterilization.

The Convention on the Rights of Persons with Disabilities explicitly recognizes that individuals with disabilities have the right to “decide freely and responsibly on the number and spacing of their children, and to have access to age-appropriate information, reproductive and family planning education”. Article 23(1) States Parties shall . . . ensure . . .

[t]he rights of persons with disabilities . . . to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.
Contraceptive information and services must be available, accessible, affordable, acceptable, and of good quality in order for states to meet their obligations to respect, protect, and fulfil this right.

Disability is a spectrum, and there is no one-size-fits-all solution for contraception. There are specific considerations for the use of different contraceptive methods in women with movement limitations, sensory impairments, seizure disorders, developmental disability, and emotional and psychiatric disorders.

Barriers in accessing knowledge about contraception

- Lack of dialogue about contraceptive needs of women with disabilities.
- Family planning practitioners are not well trained to handle reproductive health needs of women with disabilities. Having a disability may make it more difficult to access certain kinds of birth control.
- Disabled women are not taken for routine gynaecologic examinations because of false assumptions that women with disabilities will not have children.
- Physical/infrastructural/communication/informational barriers to access healthcare facilities.
- Women with paralysis, impaired motor function, and other obvious physical disabilities are rarely offered counselling on sexuality or contraception for making informed decisions.
- For women with disabilities it is difficult to choose the right option for contraception. The health care provider has to be taken into confidence in order to figure out what method works best with the given conditions.

Factors affecting selection of contraceptive method

The selection of a contraceptive method for a disabled woman depends on consideration of factors such as:

- Quality of blood circulation
- Abnormal clotting
- Degree of physical sensation
- Manual dexterity
- Possible interactions with other medications
- Effect of contraceptives on the disease process

- Problems with menstrual hygiene
- Depression and state of mental health

Because of barriers in obtaining accurate information on choice of contraception, women with disabilities are more likely to use permanent contraception or no contraception at all than the general population of women[xx].

Different Methods of Contraception

Hormonal contraceptives

Hormonal contraceptives contain a small amount of man-made oestrogen and progestin hormones. These hormones work to inhibit the body's natural cyclical hormones to prevent pregnancy. The effectiveness of hormonal contraceptives depends on medications already being used by the woman such as antibiotics, anti psychotics, blood-pressure-lowering or cholesterol-lowering drugs, antifungal drugs or certain herbal products. Hormonal contraceptives include the pills, patches, vaginal rings and injections.

Contraindications

Pills that contain oestrogen are contraindicated in women with impaired circulation[xxi], a history of cerebrovascular accident, and immobility of the extremities. Due to this women with mobility issues may have a higher risk of blood clots. Therefore hormonal birth control that contains oestrogen might not be the best option. The combination of increased risk from lack of mobility plus increased risk from oestrogen may mean that the risk of blood clots with these methods is too high.

Some physical disabilities also affect bone density, such as cerebral palsy, anorexia, and congenital conditions where osteoporosis (low bone density) is a concern. Contraceptives that contain progesterone decreases bone density are not the best option. For example DMPA[8] (Depot medroxyprogesterone acetate) or Depo-Provera can impact bone mineral density[xxii].

Some cognitive and neurological disabilities (like Attention Deficit Disorder) make taking a daily medication difficult to remember. Some people have disabilities that make it difficult to swallow a pill or to open packets that contain pills. For psychosocial disabilities, health care provider must be aware if the woman is prone to depression, anxiety, panic attacks, or mood swings as birth control options that have synthetic hormones may magnify conditions of depression, anxiety, panic attacks, or mood swings[xxiii].

Women with psychologic disturbances of depression, anxiety, or thought disorganization require the full range of contraceptive options and protection from sexually transmitted diseases. If compliance is assured, oral contraceptives are the preferred method otherwise progestin implants or injections may be prescribed. But progestin-only contraceptives come with many side effects, including worsening of mood in depressive patients.

[8] Depot medroxyprogesterone acetate (DMPA, also known as Depo-Provera) is an injectable progestin-only contraceptive.

Some women may gain weight after using hormonal contraceptives. Weight gain is of particular concern in women with locomotor disability, as the added body weight may make mobility and transfers more difficult.

Women with DD will find the presence of the patch bothersome, and may attempt to remove it. Placing the patch on the lower part of the back may solve that problem. Women who have developmental disabilities (DD) are at increased risk of fractures due to low Bone Mass Density [xxiv]and incidence of falls and other trauma may increase[xxv] .
Hormonal contraceptive management in women with epilepsy is very important as there are maternal and foetal risks if contraception or seizure management fails. Oral contraceptive pills may increase the frequency of epileptic seizures and there is possibility of neural damage in brain[xxvi].

Progestin only contraceptives may also increase the severity and/or frequency of fractures, bone density loss[xxvii] in women with developmental disabilities.

Patch

A transdermal patch is available which contains oestrogen and progesterone. The patch is useful for women who have difficulty remembering to take daily pills or have difficulty in swallowing. Higher oestrogen levels in the patch may lead to an increase in DVT. In addition, women may find the patch irritating and try to remove it. If the patch is placed on the lower back the problem may be resolved.

Vaginal ring

The vaginal ring is a soft, flexible, transparent ring that contains both oestrogen and progesterone. The ring is placed inside the vagina. The ring stays in place for twenty one days and is then removed for seven days when menstruation occurs. New ring is inserted after seven days. Women must be comfortable with their bodies and the insertion and removal process. They get freedom from taking a pill daily. The vaginal ring is usually not used in women with disabilities because of issues concerning placement and removal, which would need to be done by caregivers. A woman may feel vaginal discomfort, foreign body sensation, and vaginitis. Additional side effects are similar to those of Oral Contraceptive Pills. Due to hormonal contraceptives vaginal bleeding or spotting that occurs between menstrual periods can cause hygiene issues in women with locomotor disabilities.

Barrier Methods

Barrier methods stop sperm from entering the vagina. Barrier methods include condoms (male and female), diaphragms, cervical caps, and contraceptive sponges.

A barrier method may be difficult for women with poor coordination or upper-extremity disabilities. This method of contraception requires intact balance, physical dexterity and hand coordination or the willingness of the woman's sexual partner to assume responsibility for its use. Latex condoms may not be suitable for women with spinabifida as they may have latex allergy[xxviii]. Polyurethane condoms can be used instead.

For women with learning and intellectual disabilities barrier method may be difficult to learn. Communication with partner may also be difficult. Moreover a woman may need her partner's assistance while trying to insert it.

Long lasting reversible contraception

Long-acting reversible contraception (LARC) is a contraceptive that lasts for a long time.

There are two types of LARC:

- the intra uterine device (IUD) that lasts for five to ten years
- The implant that lasts for three or five years.

They are sometimes called "fit and forget" contraception because you don't need to remember it every day or every month. LARCs are the most effective types of contraception. They are more than 99% effective at preventing pregnancy.

Intrauterine Devices

The IUD is also a long-acting reversible contraceptive method. It is a T-shaped device which is placed in the uterus by a trained professional. It is also used to decrease menstrual flow in women with heavy periods. Intrauterine devices should be recommended to women who have less sensation only after careful evaluation. With a decreased level of sensation they may not feel the symptoms of complications, such as perforation, pelvic infection, or ectopic pregnancy.[26,39] Insertion for women with disabilities may need to be done under anaesthesia due to unpredictable cooperation and a potentially small uterus

A woman or her partner should be able to check the string to assure correct placement. Clinicians must work individually with each woman to assess her ability to manage common side effects.

IUDs can increase menstrual bleeding and can cause hygiene problems for women with compromised manual dexterity.

Implants

The contraceptive implant is a small, flexible rod about the size of a match stick. The implant is put under the skin of the upper arm. It can stay there for up to 3 years. The implant slowly releases a progestogen hormone into the blood stream. This can prevent pregnancy for up to 3 years. Women with disabilities, particularly cognitive disabilities, may not tolerate the procedure and sedation may be necessary. Women with upper arm amputation need to take implantation on their leg. Heavy bleeding can cause hygiene issues in women with mobility impairment. Anticonvulsant medicines would not act properly if these implants are done.

Emergency contraception

There are two options for emergency contraception: the emergency contraceptive pill (ECP) or a copper IUD. The ECP is approved to be taken up three days after unprotected sex. For women of an average weight, the ECP is 98% effective. For women who weigh more than 70kg, the ECP is less effective and a copper IUD is recommended. Women, who weigh more than 70kg and choose to take ECP, should ask if taking a double dose is the right option for them. The copper IUD can be inserted up to five days after unprotected sex, and is more than 99% effective at preventing pregnancy. Emergency contraception can be used to prevent pregnancy if:

- haven't used protection
- normal contraception fails e.g. condom splits
- have missed more than one contraceptive pill
- you have been vomiting or had diarrhoea while on the pill
- missed injection
- you have been forced to have sex without contraception

Fertility awareness

Fertility awareness is learning the signs of fertility in menstrual cycle to help a woman plan or avoid a pregnancy.

Permanent contraception/ Sterilization

Gynaecological procedures, such as hysterectomy with bilateral oophorectomy (surgical removal of ovaries), are associated with higher risk of CVD[xxix], cognitive impairments, Parkinsonism, dementia and depression.

Permanent contraception prevents all future pregnancies. It is very difficult or impossible to reverse. For females it is tubal ligation.

Caregivers or family members, after consulting the woman with disability may request sterilization. There is a mistaken belief that surgical sterilization will diminish the chances of sexual abuse or acquiring STIs. But sterilization cannot protect from sexual abuse, or cure sexual acting out, abusive or inappropriate behaviour. It has no effect on menstruation. Sterilization is the preferred birth control for couples who have had all the children they wish, and for a few people who do not want children. Some people with disabilities do choose sterilization. Making a permanent decision such as this may be difficult for a person with a cognitive disability. Some people cannot learn to give informed consent. It is almost always better to explore other birth control options.

Women find that sexual lubricants help them to safely have sex. There are some lubricants that are specifically designed for procreation. These lubricants help sperm move more efficiently, increasing the chances of a successful pregnancy

Infertility

The majority of women with physical disabilities have unaffected fertility potential and clinicians should avoid assuming that the male partner need not be evaluated.

Fertility in women with spinal cord injuries may be affected only in rare cases. It may happen that women may stop ovulating for some period of time after an injury[xxx]. If a woman is able to have intercourse, she can get pregnant. Even if they are not sexually aroused or don't have sexual sensation still they can get pregnant but this can have adverse impact on desire to get sexually involved, decreasing the chances of conceiving.

Muscular dystrophy in women may cause irregular periods and infertility[xxxi]. Some may have difficulty having sexual intercourse due to physical disability such as spinal deformity or contracture. There are greater chances of complications like increased risk of miscarriage, increased fluid around the baby which may cause premature labour, heavy bleeding either before or following delivery and retained placenta or afterbirth[xxxii]. The incidence of diabetes is slightly more in myotonic dystrophy and the bodily changes as a result of pregnancy may precipitate diabetes during pregnancy. All this can lead to further complications in women with myotonic dystrophy.

Muscle weakness may cause physical difficulty in assuming the appropriate position, or maintaining the physical exertion required for the sexual act. These types of problems may result in incomplete penetration or maintenance of the sexual act.

Reproductive abnormalities and infertility are two to three times more common in epileptic females than in the general population. Rise in the serum prolactin level and increase in the luteinizing hormone (LH)[9] and follicle stimulating hormone (FSH)[10] can be caused due to seizures[xxxiii]. Epileptic women have a higher rate of reproductive and endocrine disorders[xxxiv]. Women with certain disabilities are prone to ovulatory dysfunction. Disabilities such as SCI, TBI, and MS may be associated with hyperprolactinemia[11],[xxxv]. Practitioners should not neglect to obtain a pituitary evaluation. Similarly, chronic disease states such as

[9] LH causes the egg to be released from the ovary

[10] FSH stimulates the ovarian follicle, causing an egg to grow. It also triggers the production of oestrogen in the follicle.

[11] Hyperprolactinemia is a condition in which a person has higher-than-normal levels of the hormone prolactin in the blood. The main function of prolactin is to stimulate breast milk production after childbirth. Higher prolactin level may cause infertility both in men and women.

diabetes mellitus, and myasthenia gravis[12] may experience altered thyroid function or other the disorders of endocrine glands result in oligo-ovulation[13].

There can be adverse effect on ovulation due to drugs commonly used by women with different kinds of disabilities, such as corticosteroids, nonsteroidal anti-inflammatory agents, immunosuppressant and antidepressants[xxxvi].

Fertility Treatment

Although the evaluation and treatment of infertility is the same in disabled and nondisabled women, women with disabilities may require special consideration in a variety of circumstances.

Women with pelvic contractures, such as is caused by CP, may have difficulty attaining adequate positioning for many required procedures. Women with visual disabilities and mobility limitation may require help in comprehending basal body temperature or other ovulation testing. AD can set in women with SCI who have injury above the level of T6 during procedures to induce ovulation like endometrial biopsy[14], hysterosalgpingography[15], or hyperstimulation[xxxvii].

It is estimated that 50% of women with Down syndrome are fertile. They may use any method of contraception without much medical risk[16]. Even Tubal ligation (permanent birth control through surgery) can also be performed without risk for women with Down syndrome who are in stable medical condition

[12] Myasthenia gravis is a long-term neuromuscular disease that leads to varying degrees of skeletal muscle weakness.

[13] Oligo-ovulation is a disorder in which ovulation doesn't occur on a regular basis and your menstrual cycle may be longer than the normal cycle of 21 to 35 days.

[14] A procedure performed to obtain a small tissue sample from the lining of the uterus

[15] An x-ray examination of a woman's uterus and fallopian tubes that uses a special form of x-ray

[16] https://www.ndss.org/resources/sexuality/

Pregnancy

Poor health, medical complications and adverse birth outcomes are more common in pregnant women with disabilities as compared to women without disabilities. There can be difficulty while scanning due to posture, anaesthetic challenges for both airways/spines, positioning at delivery, bladder care, difficulty in looking after baby and also psychological adaptation for some women[xxxviii].

Preconception Care

Preconception counselling and planning are essential to minimise risks for mother and newborn and maximise social and environmental support for women with disabilities. They are able to make informed reproductive decisions and achieve optimal reproductive outcomes.

Preconception risk mediation is required to be integrated into primary and specialty care to assist a woman with disability so that she may proactively manage her reproductive health.

While every women has the right to have a healthy child, differently abled are reluctant to think over if this could lead to a genetic disorder. Even while consulting one of the best specialised doctors they precisely come up with the statements… "Its 50-50 that you will have healthy child, however we have seen people with same challenges having healthy child" …Moreover they not sure that shall we proceed with progeny or not. Hence it's really hard to make decision having all this in my mind.

Sheetal Malhotra (A woman with dwarfism)

Assistant Vice President

US Bank

Genetic Counselling

Women with disabilities whose disability has genetic component should be provided genetic counselling before and after conceiving. The following issues that need to be addressed with the disabled woman who is planning a pregnancy:

- The effects of her disability on pregnancy, labor, and delivery
- The effects of pregnancy, labor, and delivery on her disability
- A list of the effects of medications on the foetus
- Improvement in health that could enhance childbearing
- Preparations for adjustments by the family for child care
- Different facilities available to the disabled pregnant woman and her family.

For instance women with muscular dystrophy may wish to have their babies tested for the disease while in the womb. They have right to accurate information about the required genetic testing. If the women know that they are at risk for a genetic condition, they may use this information in deciding whether or not to become pregnant and–depending on the condition– have more options to choose from and avoid passing the condition to the offspring. It is imperative to handle referral for genetic counselling with sensitivity as it may sometimes raise difficult psychosocial issues for women with disabilities.
In case of genetic blindness, there is the probability of transmitting the responsible gene and the possibility of repeated blindness. In this case, genetic counselling is recommended.

When either parent is affected with OI, the foetus is at risk of being born with OI as well. In this circumstance, there is, in fact, in each pregnancy a 50% chance that the foetus will also have OI[xxxix]. So couples at risk should be seen for counselling prior to conception. Couples should be made aware of various complications that can be associated with OI and pregnancy. Discussion would include the availability of various prenatal diagnosis techniques or second trimester antenatal ultrasound for the detection of OI. Weekly ultrasounds after 36 weeks gestation may be beneficial in detecting skeletal changes that may preclude vaginal delivery.

Women with disabilities, who are on certain medication meant to manage their disabling condition, must be aware of the effect of those medications on the unborn baby. If a woman is on teratogenic[17] medications, preconception counselling educates her about the use of

[17] A teratogen is an agent that can disturb the development of the embryo or foetus. Teratogens stop pregnancy or produce a congenital malformation (a birth defect). Classes of teratogens include radiation, maternal infections, chemicals, and drugs.

these medications and plan with providers the best way to balance her medical treatment with a desire for a healthy pregnancy and infant.

Screening for various infectious diseases is also mandatory during this period.

Providers should understand that women with disabilities can have healthy pregnancies and that disabilities can coexist with wellness. After assessing the medical, social, and psychological issues linked to pregnancy and the disability, the woman and her family have to be counselled on them. Those with mental health issues like anxiety and depression also decide to get screened before they conceive.

Women with disabilities need to be informed of contraceptive choices that are feasible and appropriate for their medical and personal conditions. For women with developmental disabilities informed consent and supported decision making need to be addressed while deciding about contraception.

Many women with multiple sclerosis (MS) may approach their primary healthcare provider, neurologist, or obstetrician for advice before thinking about pregnancy. Issues of concern may include risk of relapse and progression of ailment, analgesia during delivery, interventions to reduce the chance of relapse in the peripartum period and the potential effect, if any, on their child.

Pre Natal Care

All pregnant women require prenatal care. As compared to the non disabled women, women with a disability may require more frequent visits throughout their pregnancy

Women with physical disabilities may have higher risk for poor birth outcomes such as low birth weight and premature birth compared to non disabled women.

For prenatal care of a pregnant woman with disability, an integrative team consisting of obstetrician, anaesthetist, support workers and care givers must be formed.

Prenatal visits involve

- Monitoring the health status of the woman and her foetus
- Monitoring intrauterine growth
- Monitoring and managing symptoms related to pregnancy or to the woman's disability
- Assessing the woman and her partner's ability to adapt to changes associated with pregnancy and to anticipate needs after delivery
- Preparing the woman for labor and delivery, postpartum and parenting
- Providing the woman and her partner with the opportunity to discuss any issues related to pregnancy, labor and delivery and postpartum.
- Disability of a woman can also be impacted by the normal effects of pregnancy. Bodily changes due to pregnancy depend on the type of disability and the individual woman. For example, the weight gain and altered body structure linked with pregnancy can adversely affect her mobility, ability to transfer, and her overall independence.

Issues in prenatal care

1. Responses received by women with disabilities during their pregnancy are mostly negative**.** Although preconception care is recommended for many women with disabilities, many women do not seek preconception care and some even forgo prenatal care as many times health care providers' initial reactions to the idea of pregnancy is to try to discourage them from considering pregnancy. They assume that they are seeking termination of their pregnancy or even go to the extent of making negative comments about them being irresponsible in considering pregnancy and motherhood.

2. Women with disabilities have difficulty finding health care providers and hospitals who could manage their pregnancy and childbirth considering complications faced by them due to their disability.

3. Those with mobility constraints have reported inaccessible physician offices and clinics, not being weighed even once during their pregnancy, and receiving no help in transferring to a high, non-adjustable exam table in the absence of an adjustable table.

4. Midwives, nurses and hospital staff often lack knowledge on how to meet the care and communication needs of women with intellectual disabilities.

5. No reliable information is available to guide women with physical disabilities who are considering pregnancy and motherhood. Women with disabilities often find prenatal classes uninformative and not helpful because the class instructors are not knowledgeable about their disabilities and possible effects on pregnancy, labor and delivery. For example, antenatal information may be distributed in a manner inappropriate and insufficient for women with visual impairment.[xl] [xli] There is some evidence that women with hearing impairment receive fewer antenatal visits and have limited access to maternity information.[10] [11]

Providers may many times become nervous because disabled pregnant women are not in any of their medical textbooks.

Issues specific to different disabilities

Women with Epilepsy

Getting and keeping good seizure control during pregnancy is crucial. Risks from seizures in the mother during pregnancy are greater than the risks from seizure medications. These risks include trauma from falls or burns, increased risk of premature labor, miscarriages, and lowering of the foetal heart rate.

Women with Muscular Dystrophy

For instance in women with muscular dystrophy, when it comes to pregnancy, there are chances of several complications. Because of muscle weakness in areas of abdomen, back, and uterus-women with muscular dystrophy may require a Caesarean section. If muscular dystrophy has affected the heart, then pregnancy is not advised. In all the cases, it's important to have a team of doctors who are familiar with treating women with muscular dystrophy. Some women with disabilities have experiences that require some thought and advanced planning on the part of the women, their families, and their health care providers. In women with muscular dystrophy, the extra weight associated with being pregnant is generally the main problem for women who have weakness, especially if they are at the stage where they have difficulty walking and frequently trip or fall. Occasionally women may find that they need to use a wheelchair most of the time at the end stage of their pregnancy and this may further aggravate their weakness.

Women with myotonic dystrophy are at risk of a number of complications which include increased risk of miscarriage, increased fluid around the baby which may cause premature labour, heavy bleeding either before or following delivery and retained placenta or afterbirth. Many of these complications are particularly evident when the baby has congenital myotonic dystrophy. The incidence of diabetes is slightly increased in myotonic dystrophy and the bodily changes associated with pregnancy may precipitate diabetes during pregnancy, which will bring its own complications.

Women with Learning Disabilities

The babies of mothers with learning disabilities are at increased risk of poor birth outcomes, including[xlii]:

- Premature birth
- Low birth weight

1. Woman with a learning disability may have severe levels of stress, anxiety and depression.

2. Women with learning disabilities may face opposition to their desire to be a parent. It is assumed that they cannot take care of their children. So they may even face pressure for an abortion.

Women with intellectual disability

They have a higher risk of adverse pregnancy outcome and should be considered a risk group. Caregivers need to be aware of this and provide better planned pre- and intrapartum care and support. Women with ID more often had preterm births and CS[xliii]. Reasons for shorter gestation length could be that women with ID have more difficulty in understanding and interpreting signs and symptoms of pregnancy complications such as premature contractions. Other medical reasons include preeclampsia, which is more prevalent during pregnancy among women with ID than among women without ID[xliv]. A shorter gestational length may pose different problems for women with ID. Women who have Down syndrome are able to have children; they have a 35-50% chance that their baby will have Down syndrome.

Women with intellectual and developmental disabilities have nearly double the rate of having another baby within a year of delivering compared to women without such disabilities[xlv]. Rapid repeat pregnancy within one year of a previous live birth is associated with smaller babies, preterm birth, neonatal death and other adverse effects. It also indicates a lack of access to reproductive health care, such as pregnancy planning and contraception.

In some cases, pregnant women with disabilities are advised to end the pregnancy and to have a tubal ligation (i.e., "have her tubes tied") or have a hysterectomy to prevent future pregnancies.

Women with different physical disabilities

- Frequent infections due to bladder function in women with SCI and MS can lead to spontaneous abortion and miscarriage, pre-term labor, and low birth weight babies.
- Skin problems increase with physical disabilities during pregnancy. These can range from more pressure ulcers with spinal cord injury to skin hardening with scleroderma[18],[xlvi].

[18] Scleroderma (sklair-oh-DUR-muh) is a group of rare diseases that involve the hardening and tightening of the skin and connective tissues.

- The risk of blood clots increases as the pregnancy progresses for women who use wheelchairs.
- There may be a higher risk of developing anaemia during pregnancy in women with SCI.
- Women who have cervical or higher thoracic injuries may be prone to respiratory and pulmonary problems[xlvii]. As the baby grows it pushes up the diaphragm so the health providers need to monitor respiratory functions.
- Breathing difficulties and risk of pneumonia increase as the pregnancy progresses for women who already have respiratory impairment.
- Pre-existing bowel problems may increase during pregnancy, particularly constipation and risk for bowel impaction.
- Women who have disabilities due to neurologic conditions, like MS, SCI or CP, may experience more spasticity during pregnancy[xlviii].
- Women who have gait difficulties may find these get worse during late pregnancy as they become heavier and their centre of gravity shifts.
- Women with MS may also be more subject to fatigue.
- Risk for gestational diabetes.
- Risk of autonomic dysreflexia, a life-threatening sudden rise in blood pressure, increases for women with high-level spinal cord injuries, and may be misdiagnosed and incorrectly treated as pre-eclampsia.
- Possibility of increase in oedema (swelling) in legs, and some risk for Deep Vein Thrombosis (blood clots).
- There is typically a decrease in blood pressure by the second trimester.
- The frequency of seizures tends to increase during pregnancy for women who have already have seizures with their brain injury.

Internists and obstetricians may have gaps in knowledge about possible disability-related complications of pregnancy with spinal cord injury. This has might be the cause that doctors to communicate unwarranted negative expectations about pregnancy outcomes to women with disabilities who become pregnant or who express the desire to have children.

Women with Schizophrenia

Increased risk of adverse pregnancy outcomes has been noted in women with schizophrenia[xlix]. For example, a higher proportion of low birth weight babies have been reported for offspring of mothers with schizophrenia compared with other mothers[l].

Women with schizophrenia may not receive appropriate care[li]. Lack of satisfaction and lack of trust among these women have been found to be the main barriers in seeking help during pregnancy[lii].

Women with schizophrenia are two times more prone to experience pre-eclampsia[19], pre-term birth and other serious pregnancy and delivery complications as women without the condition[liii]. They are more likely to experience placental abruption[20] and septic shock[21] during pregnancy.

Women with spinabifida

The shape of a woman's uterus can be significant when a woman is trying to conceive, as well as during her pregnancy. Women with spina bifida may have bicornuate uterus[liv]. A woman with a bicornuate uterus may find that her baby lies in an irregular position, which can affect childbirth. This increases the risk of a woman having a miscarriage in the later stages of pregnancy, and of her baby being delivered early. These problems are thought to be due to irregular uterine contractions or reduced uterine capacity caused by the irregular shape of the uterus. A woman with a bicornuate uterus also has a higher chance of giving birth to a baby with birth abnormalities compared to a woman with a regular-shaped uterus[lv].

If a woman with a bicornuate uterus becomes pregnant, her condition would be considered high-risk[lvi]. This means the pregnancy would be monitored more often with increased check-ups on the health and progress of the baby to identify any problems early on and minimize risks. If a baby ends up in a breech position before birth, it may be that a caesarean section is necessary.

Women with osteogenesis imperfecta (OI)

In one study, it was reported that the risks of birth abnormalities in babies born to a woman with a bicornuate uterus were four times higher than to a woman without the condition.

While there are obviously increased maternal and foetal risks for women with OI, the majority of women with OI or brittle bone disease who successfully conceive seem to go

[19] Preeclampsia is a condition during pregnancy where there is a sudden rise in blood pressure and swelling, mostly in the face, hands, and feet
[20] When the placenta separates early from the uterus before childbirth
[21] Septic shock is a potentially fatal medical condition that occurs when sepsis, which is organ injury or damage in response to infection, leads to dangerously low blood pressure and abnormalities in cellular metabolism

through pregnancy quite well. A woman with osteogenesis imperfecta (OI) who becomes pregnant may experience an uneventful pregnancy or one that is laden with difficulties. Similarly, a developing foetus that is found to have OI may be born with few complications, or it may not survive beyond a few hours.

It is estimated that a woman with OI who becomes pregnant represents only 1 in 25,000 pregnancies that occur.

Pregnancy does not appear to have a significant adverse effect on the milder forms of the disorder. Women with OI Types I and IV may experience loose joints, reduced mobility, increased bone pain and dental problems during pregnancy.
Individuals with the more severe and debilitating forms of OI who have short stature and curvature of the spine may be at increased risk for both medical and obstetrical complications. If the level of curvature of the spine is great, the likelihood of heart and lung difficulties is increased. It is possible that these women will require early hospitalization due to increasing breathlessness.

OI is rare, and a pregnant woman with OI is even rarer, most obstetricians and other medical care providers will not have had experience in managing such cases.

All disabled women are at a higher risk for delivering preterm compared with non-disabled women, particularly those with physical disability, mental health problems, learning disability and women with multiple disabilities.

Some chronic conditions, such as multiple sclerosis and rheumatoid arthritis improve during pregnancy; while others, such as lupus tends to worsen.

For Service Providers

Women with disabilities can explore various adaptive tools and strategies to cope with their pregnancy and parenting if they have a team of health care providers who are willing to collaborate to manage both disability and pregnancy related issues.

- Women with a higher risk for respiratory and pulmonary dysfunction may require monitoring ventilatory status and adjusting positioning and/or abdominal binders.
- It may be necessary to stop spasm medications during pregnancy, which can be a problem if increased spasticity affects mobility and function.
- Risk of pressure ulcers which would require evaluation of seating and cushions during pregnancy.
- For oedema (swelling) in legs, and risk for Deep Vein Thrombosis (blood clots), rehab physician should be consulted.
- Mobility, equipment needs, and functional capabilities may change.
- In order to optimize blood flow to the uterus and maintain optimal foetal cardiac output, bed positioning must generally be adjusted to create a lateral tilt (head raised).
- If blood pressure is low, it should be discussed in advance with your OB or rehab physician.
- Women with disabilities need assistance from others, physical and occupational therapy, or upgraded equipment to help with mobility and daily activities.
- Because of bladder spasms and leakage, and catheter usage. They may require a change in the bladder management program.
- Obstetricians need to refer women with disabilities to the anaesthesia team during the last month or so of pregnancy to ensure that any issues that might affect anaesthesia, labor and delivery are considered prior to delivery. For example, women with spinal cord injuries or musculoskeletal disabilities (e.g., spina bifida, osteogenesis imperfecta, cerebral palsy) often have specific issues that may require planning before receiving epidural anaesthesia for delivery. For instance it is matter of concern that spinal or epidural analgesia may cause further injury to spinal cord in women with SCI.

- Nurses and others providing prenatal care need to make special efforts to identify the questions and concerns of women with disabilities about prenatal care, labor and delivery, and the post-partum period, including strategies or modifications that may be needed to enable them to care for their infants.
- Efforts to anticipate challenges that may occur during labor and delivery should be undertaken to minimize women's concerns and risk for negative outcomes.
- In addition, attention should be given early in pregnancy to identify modifications and to acquire specific childcare equipment that may be helpful to women with disabilities to care for their infants.
- To increase access to healthcare for this vulnerable group, improved provider knowledge and awareness of a human rights approach to disability and health is required.
- To be inclusive, antenatal classes should:

  - ✓ Be enabling and empowering
  - ✓ Focus on ensuring that each person has the opportunity to gain confidence, develop skills and make meaningful relationships
  - ✓ Be facilitated by someone with a positive attitude to people with learning disabilities
  - ✓ Present information in accessible format. It should be in a format learning disabled people can understand and relate to. Resources should be highly visual and words should be in plain English. There should be opportunities to try out practical skills more than once. here should be example role play and modelling promote the transfer of skills learnt to new and different situations, which is a key challenge for people with learning disabilities.

''I am on my 35th week of pregnancy: 36th week is about to start from this Sunday, and the Dr who was handling my case from the very 1st month had planned my C section on the 36th week. But now the major problem has arrived and that is the unavailability of a proper anaesthetist for me in our locality. The reason is that I have a spinal Injury background (C6-C7level) I am a quadriplegic wheelchair bound person who decided to go ahead with this pregnancy after discussing the matter with few neuro and my gynaecologist. They gave me a green signal and now I am almost towards the completion of the term. But now no anaesthetist is available to give me conventional intubation as my neck curvature is limited due to vertebral fixation (with titanium plates) they said they need a special device called optic fibre for this purpose which is unavailable in our local hospital.''

Moupee Prashant (A woman with spinal cord Injury)

Ichapur 24 pragnas North West Bengal

Labor & Delivery Issues

If labor and childbirth are properly planned and managed most women with disabilities have labor and delivery experiences similar to those of other pregnant women. Most women with disabilities prefer to have a vaginal delivery but more receive CS as compared to non disabled women. It is important to realize that even women with neurological disorders, such as multiple sclerosis or spinal cord injury, that affect sensation often experience spasm, abdominal pressure and pain or discomfort associated with contractions.

In women with muscular dystrophy muscle weakness may make it harder for the woman to push with contractions. Forceps or ventouse (suction applied to babies head) may be used under local anaesthesia to pull out the baby. If the baby is very distressed or the mother is a long time in labour, the mother may have an emergency caesarean section. If problems are anticipated this may be the planned form of delivery.

Caesarean section (CS) is either performed under epidural (when the mother is awake) or under general anaesthetic (GA). This is a major operation and it may take additional time for women with muscle weakness to recover their strength fully.

Particular care needs to be taken for patients with myotonic dystrophy having GA, as they have an increased risk of complications with the use of certain drugs. Women with muscular dystrophy are at increased risk of developing chest infection following GA, this risk is more for smokers. Those with heart involvement from their muscular dystrophy may find that pregnancy precipitates or brings on additional problems. Pregnancy causes the body to increase the amount of fluid. This, together with the extra weight from the developing baby may increase the work the heart needs to perform. Delivery may put additional strain on the heart.

In women with spinal cord injury diagnosis of labour in women with above T10 of the spinal cord injury can be difficult. Women with SCI may opt for a vaginal delivery. Ability to detect the onset of labour and contractions will depend on level of injury. Sign of beginning of labour is mucous “show”. Most of the women with SCI above T10 come to know of uterine contractions in the form of abdominal discomfort. Extra vigilance is required to prevent the woman being in labour without knowing. One may experience other sensations such as abdominal tightening, backache, an increase in spasticity, autonomic dysreflexia (AD), bladder spasms, pain above the level of injury, or changes in breathing. A foetal/contraction monitor may be helpful, along with regular monitoring.

In women with OI if there is trauma during pregnancy or obstetrical manipulation at the time of vaginal delivery, fractures may happen. It has been suggested that because a risk

does exist for a woman with OI to fracture during delivery and because there is potential for other complications, elective caesarean section (a planned c-section) may be the delivery method of choice for most women with OI. Some of the reported complications during delivery include:

1. a birth canal that is too small to permit birth
2. uterine rupture
3. haemorrhaging

Some physicians might consider a caesarean section advisable if there is a history of previous pelvic fractures or contracted pelvis, or if the woman has a severe form of OI. However, in women with OI who have normal pelvic dimensions, there does not appear to be a compelling reason to avoid labor or vaginal delivery. These anaesthesia procedures, which involve injection of medication near the spine, may be difficult in some women with deformity from vertebral compression fractures.

In women with intellectual disabilities (ID) Labor may start suddenly. Women with ID may not have received sufficient or appropriate information. They are likely to be unprepared. This can cause more anxiety and stress during delivery, and lead to more CSs being performed on medical as well as humanitarian grounds[lvii].

What else can be done?

Despite legitimate obstetric concerns, physicians must reassure their disabled patients that together they can anticipate and overcome most obstetric problems through common-sense preventive measures.

Many strategies exist to help patients with SCI, MS, or other neurologic impairments, as well as their care givers, recognize the onset of labor. A private tour of delivering facilities allows the visually impaired patient the opportunity to examine physical boundaries, and the neurologically impaired patient the ability to resolve access issues before labor's onset. Similarly, the hearing-impaired patient can identify her interpreter before delivery or meet with labor and delivery staff, who can assure the patient that they have access to transparent masks and that they know not to speak too quickly or exaggeratedly if she lip reads. Regardless of the disability, the disabled patient needs extra reassurance from all obstetric staff that her pregnancy will most likely result in the normal, term delivery of a normal, healthy infant.

Postpartum

Many women with disability find themselves on postpartum nursing units in inaccessible rooms, making their recovery and self-care difficult. Depending on the type of delivery they had (vaginal delivery vs. caesarean section) and the nature of their disability, they may have difficulty managing an episiotomy incision[22] following a vaginal delivery.

Breast Feeding

Many women with disabilities plan to breastfeed their babies although some women need modifications in breastfeeding positions and strategies to hold their baby for breastfeeding. Nurses who are knowledgeable and sensitive to the needs of women with disabilities and their preferences for breastfeeding can be very helpful in assisting women in breastfeeding.

Across all groups, babies born to disabled were significantly less likely to be breast fed at the time of hospital discharge compared with non-disabled women.

Breast feeding can cause an increase in spasticity. Women with a spinal cord injury below at or above T6 may have decreased milk production after six weeks. The reason behind this can be lack of nipple stimulation which is essential for milk ejection reflex occur. These women may also experience problems related to autonomic dysreflexia. They can also face difficulties with positioning and handling the baby for breast feeding[lviii].

Upper arm impairment and spasticity may make it difficult to hold the baby for feeding.

Tips for breastfeeding: Appendix 6

Nursing may cause AD. Watch for symptoms and stop nursing immediately if AD occurs. It is uncertain if women with quadriplegia[23] can experience the "let-down" response (the physiological response to suckling that sends milk from the mammary gland into the nipple). According to a recent case mental imaging, relaxation, and/or oxytocin nasal spray enabled women with SCI at T4 and above to nurse successfully[lix]

Some medications may need to be stopped during breast-feeding and should be reviewed with your provider.

[22] Episiotomy is usually performed during second stage of labor to quickly enlarge the opening for the baby to pass through.

[23] paralysis of all four limbs; tetraplegia.

If a woman's activity level decreases substantially during pregnancy, she may become quite debilitated and need physical therapy or other rehab after the baby is born.

Childcare

After delivery women with disabilities need to be prepared to ask for additional assistance.

There has not been very much research on parenting with SCI. A 1994 survey of 26 families with mothers who had SCI (47 children total) found no differences in terms of parenting roles, responsibilities, participation or burden, compared with controls (families in which the mother did not have SCI)[lx]. One woman in this survey reported that having children gave her extra motivation to stay healthy.

Most women with disabilities, including those with severe disabilities, are very resourceful and find ways to do an excellent job in taking care of their infants. Some modifications may be needed, such as a side-opening crib that open like a door and can be opened by a mother from her wheelchair.

Postpartum depression is a concern for all populations; there are no data suggesting it is worse or more in women with disabilities.

“Having more understanding from doctors and them being more approachable is very important. Not just being approachable but for disabled people, what is the conversation after there has been unprotected sex, how to address STIs and STDs, how to address pregnancy. For example, I do have an experience when I went for a gynaecological test and at that time, the doctor made me feel like there was something severely wrong with me, that I wouldn't be able to do things in a way which is considered normal in society. I had a very bad experience and reaction to what the doctor had to say. I actually came out crying from that visit. It was very traumatising and even now when I talk about it”. It feels like it was such an unnecessary thing I had to go through because after having a second consultation, everything turned out to be perfectly okay. Even if it wasn't perfectly okay, there is a way to approach something which is abnormal.

Doctors do not see past your disability. For example, if you had an unprotected sex and you want to go get a test for STI, it's very difficult for disabled people to just cross in that medical model. It's very difficult to let that disability thing pass and get the test done. Another time when I went to a dermatologist and the first thing he asked me was whether I am married. That completely put me off and I walked out of the office. It's something that really triggers and puts off people with disabilities and it's very difficult to approach health officials. So, I think talking to friends and just doing online research is an option when it comes to sexual health, for me as a disabled woman”.

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STIs and HIV

Sexually transmitted infections

Sexually transmitted infections (STIs) are infections that can be caught or transmitted by unprotected sex, or close sexual contact, with another person who already has an STI. Symptoms vary from person to person. Only a doctor can diagnose an STI. An STI is also known as venereal disease. Symptoms in women include:

- pain or discomfort during sex or urination
- sores, bumps, or rashes on or around the vagina, anus, buttocks, thighs, or mouth
- unusual discharge or bleeding from the vagina
- itchiness in or around the vagina

Need for Protection against Sexually Transmitted Diseases

The transmissibility of several STIs and HIV/AIDS is greater from infected man to uninfected woman than the reverse. The vagina has a large mucosal surface which is open to a man's sexual secretions and there are greater chances for microbial growth than the penile surface in men. Moreover the infected semen stays in the vagina for some time and also contains higher percentage of virus than the woman's sexual secretions. Thus, men are twice more effective as transmitters of STIs than women[lxi].

Sexually transmitted infection (STI) prevention is especially important for women with pelvic sensory impairments that could allow STI symptoms to go unrecognized.

There is a need to address issues of STIs regarding the treatment of women with disabilities and to suggest ways in which the patient and the provider can work together for a positive outcome.

Health care providers and care givers view disabled women as non sexual. A disabled woman finds it awkward to share her intimate needs with health care providers and family. She may also be unable to self-detect signs of sexually transmitted infection (STI). An STI can also be the sign of an abusive relationship. Thus, anyone caring for the disabled patient

must become knowledgeable about the particular problems that STIs can cause in women with disabilities.

Signs and symptoms of STIs used by physicians to diagnose infection in nondisabled patients may prove less reliable in disabled women. Women who have less sensation in pelvic area may not feel pain or cramping as much as nondisabled women with Chlamydia, gonorrhoea, or pelvic inflammatory disease would feel.[33] Increased spasticity may be the only warning signs voiced during the examination. In the same way visually impaired women may not detect or accurately describe a lesion that could represent syphilis, herpes, or human papillomavirus infection.

STIs in women with disabilities may go unnoticed and therefore undiagnosed because of access barriers, misconceptions and lack of awareness of their risk status.

Pelvic Inflammatory Disease (PID)

Pelvic Inflammatory Disease is an infection in uterus, fallopian tubes, and/or ovaries. PID happens when bacteria moves from your vagina and cervix to other parts of the body. It can lead to chronic pain and other serious health problems, like infertility.

PID is usually caused by two sexually transmitted infections: Chlamydia or gonorrhoea. These STIs can be cured easily with antibiotics, but many people don't know they have them because they usually don't have symptoms — that's why getting tested for STIs is important.

PID symptoms may include:

- longer, heavier or more painful periods
- pain in your belly
- being very tired
- fever or chills
- bad-smelling vaginal discharge
- pain during sex

If not treated, Chlamydia and gonorrhoea can result in PID. PID can also be caused by other untreated infections, like bacterial vaginosis[24]. A pelvic exam is needed to find out PID. One needs to be tested for Chlamydia, gonorrhoea, and other infections as they cause PID. Examination of urine, blood, and/or fluids from vagina and cervix is required for its diagnosis.

[24] A type of vaginal inflammation caused by the overgrowth of bacteria naturally found in the vagina, which upsets the natural balance.

Other tests include ultrasound; endometrial biopsy (taking a small sample of tissue from the lining of your uterus); and laparoscopy (inserting a tiny camera through a small cut in belly button to look at reproductive organs).

Preventive measures include having safer sex and using condoms. Remember that douching (spraying or showering with water) may lead to PID as it pushes bacteria deeper into body and can cause irritation and infections. So douching should be avoided.

Syphilis

Syphilis is a sexually transmitted infection (STI) caused by a type of bacteria. There are four stages of syphilis are:

Primary it begins with a small, round sore, which is painless. It can appear on the sexual organs, rectum, or inside the mouth.

Secondary Skin rashes and a sore throat may develop during the second stage of syphilis. The rash won't itch and is usually found on the palms and soles, but it may occur anywhere on the body. Other symptoms of secondary syphilis may include:

- headaches
- swollen lymph nodes
- fatigue
- fever
- weight loss
- hair loss
- aching joints

Latent-This stage could last for years before progressing to tertiary syphilis.

Tertiary-Some potential outcomes of tertiary syphilis include:

- blindness
- deafness
- mental illness
- memory loss
- destruction of soft tissue and bone
- neurological disorders, such as stroke or meningitis
- heart disease

- Neurosyphilis, which is an infection of the brain or spinal cord

Syphilis in a woman with disability may go unnoticed by partner, attendant, or practitioner or mistaken for consequences of her disability.

Women with visual or sensory impairment may not detect the ulcer or chances of primary syphilis before its spontaneous regression 3–12 weeks after infection. As with nondisabled patients, physicians should maintain a high index of suspicion when considering a diagnosis of syphilis, and not hesitate to perform serum screening tests, which generally detect infection 4–6 weeks after exposure.

Some women whose disabilities take multiple medications so they may mistake skin rashes for yet another medication reaction and secondary syphilis may go unnoticed. Tertiary syphilis includes optic atrophy[25], locomotor ataxia[26], and even paresis[27]. MS patients also develop this constellation of findings. Thus, a physician treating a woman with MS, who develops visual disturbance and sensory or balance abnormalities, may falsely attribute these findings to MS rather than going for testing for syphilis. Patients with symptoms of neurosyphilis[28] may exhibit a change of mental status or the beginning of a new physical disability. This may confuse the patient, the patient's family, and her care givers, who may have overlooked infectious disease, such as syphilis.

Herpes

Herpes is an infection caused by HSV (herpes simplex virus). This virus affects the external genitalia, anal region, mucosal surfaces, and skin in other parts of the body. Symptoms include blisters, ulcers, pain when urinating, cold sores, and vaginal discharge

Both primary and recurrent lesions present problems for the disabled, infected patient.

Patients with primary HSV have painful genital ulcerations and flu-like symptoms. Women with sensory impairment may fail to see the infection. They may complain about uneasiness or increased spasticity.

Healing of blisters may improve with adequate ventilation of involved areas. But immobilized patients may have difficulty attaining or maintaining positions that allow ventilation.

[25] A condition that affects the optic nerve, which carries impulses from the eye to the brain.

[26] Loss of coordination of movement, especially as a result of syphilitic infection of the spinal cord.

[27] A condition of muscular weakness caused by nerve damage or disease.

[28] Neurosyphilis is a bacterial infection of the brain or spinal cord.

Recurrent genital herpes may also go undetected by the disabled patient. Many times clinicians falsely assume the lesions on weight bearing areas as pressure ulcers but clinicians and care givers must monitor women with sensory impairment and a known history of HSV infection for skin lesions consistent with HSV.

Hepatitis A, B and C Viruses

Hepatitis A (also known as hep A or HAV), causes inflammation of the liver i.e. liver becomes swollen and painful. Hepatitis A virus can transmit from any sexual activity with an infected person and is not limited to faecal-oral contact. Measures that are mainly used to prevent the transmission of other STIs (e.g., use of condoms) do not prevent hepatitis A transmission. Vaccination is the most effective means of preventing Hepatitis A transmission among persons at risk for infection. Having an STI, including hepatitis A increases your risk of getting HIV as most STIs cause sores that make it easier for HIV to enter the body. Some people may be infected both by hepatitis A and HIV.

Hepatitis B transmits among unvaccinated adults with risk behaviours for hepatitis B transmission, including among those who have multiple sex partners and sex partners of people with chronic hepatitis B infection. Hepatitis B is easily transmitted through sexual activity.

Hepatitis C can be transmitted through sexual activity. Having a sexually transmitted disease or HIV, sex with multiple partners, or rough sex (sex that may incorporate things like physical domination, spanking, or name-calling) appears to increase a person's risk for hepatitis C. There is no vaccine for hepatitis C. The best way to prevent hepatitis C is by avoiding behaviours that can spread the disease, especially sharing needles or other equipment to inject drugs.

People with intellectual disability are a well-known high-risk group for hepatitis B virus (HBV) infection.

Many disabled women may get into risk-taking behaviours, or require transfusion after traumatic injury before routine screening of blood for HBV or HIV viruses, and yet never undergo testing during their rehabilitation.

Many times doctors may confuse symptoms such as fatigue, malaise, arthritis, and flu-like symptoms with worsening of certain disabilities, such as MS or rheumatologic diseases, and not screen for blood borne infections.

Patients who continue to engage in high-risk behaviour after the onset of a disability should undergo vaccination, just as is recommended for all nondisabled patients. Vaccination may also be warranted in patients with a history of TBI, who may have impaired judgment.

Human Papillomavirus

HPV is the name for a group of viruses that includes more than 100 types. More than 40 types of HPV can be passed through sexual contact. The types that infect the genital area are called genital HPV. (Between 10% and 60% of the population demonstrate DNA evidence of exposure to human papillomavirus (HPV)[34]

HPV is spread through:

- Vaginal, oral, or anal sex. HPV can be spread even if there are no symptoms. This means you can get HPV from someone who has no signs or symptoms.
- Genital touching. A man does not need to ejaculate (come) for HPV to spread. HPV can also be passed between women who have sex with women.
- Childbirth from a woman to her baby

Some types of HPV can cause illnesses such as genital warts or cervical cancer. There is a vaccine to help you prevent HPV. HPV usually goes away on its own and does not cause any health problems. But when HPV does not go away, it can cause health problems including:

- Cervical cancer
- Other genital cancers (such as cancers of the vulva, vagina, or anus)
- Cancer of the back of the throat, including the base of the tongue and tonsils
- Genital warts

In women with mobility problems HPV lesions are not detected properly. They do not undergo regular screening because of access issues, and therefore these women are at increased risk for premalignant and malignant cervical diseases caused due to HPV infection. If a woman's disability is severe, she is less likely she is to receive either PAP smears or mammograms.

Chlamydia is the most commonly reported STI, caused by a type of bacteria, which can be passed from person to person during vaginal sex, oral sex, or anal sex. Infections can occur in the mouth, reproductive organs, urethra, and rectum. In women, the most common place for infection is the cervix (the opening of the uterus). Chlamydia usually does not cause symptoms. When they occur, they may show up between a few days and several weeks as mild infection of vagina or urinary tract:

- A yellow discharge from the vagina or urethra
- Painful or frequent urination
- Vaginal bleeding between periods
- Rectal bleeding, discharge, or pain

Gonorrhoea is also very common STI. Gonorrhoea and Chlamydia often occur together. Gonorrhoea also is caused by bacteria that can be passed to a partner during vaginal, anal, or oral sex. Symptoms include the following:

- A yellow vaginal discharge
- Painful or frequent urination
- Vaginal bleeding between periods
- Rectal bleeding, discharge, or pain

Testing for Chlamydia and Gonorrhoea

Urine sample is taken or a swab is taken from vagina to test both of these STIs.

Human Immunodeficiency Virus (HIV)

Women with disabilities are more vulnerable to HIV. Gender equality is amplifies this problem. Since women with disabilities are more likely to remain uneducated, unemployed and poor than both women without disabilities and men with disabilities, they face greater discrimination.

Stigma and discrimination increases the risk of sexual violence or abuse against women with disabilities while at the same time preventing them to report about such violence.

Factors that lead to increase in risk of acquiring HIV in women with disabilities are:

- Social marginalization
- HIV prevention messages and communication are often inaccessible to people who are blind or deaf, and health service facilities are often not accessible to people with physical disabilities.

- Sexual violence or rape
- Inability to negotiate barrier use during sex.
- Risk taking sexual behaviour is seen after disabling injury – the so called "promiscuous phase".
- Histories of transfusion after traumatic injuries.

As with other infectious diseases, care givers may mistakenly attribute signs and symptoms of HIV infection to other afflictions encountered by disabled patients. Women using wheelchairs are prone to infections like candidal vaginitis[29] and vulvitis[30]. They may not be aware that such stubborn infections may represent a more serious problem. Mucocutaneous ulcerations[31] due to HIV may disguise as pressure ulcers of the perineum and buttocks.

Clinicians may less commonly test disabled women for HIV than their nondisabled counterparts, buying into the false notion that HIV is not a disease of women and that disabled women are not sexually active or vulnerable to abuse.

HIV test and other sexually transmitted infection tests

All sexually active women and their partners should be tested for HIV and other STIs before starting sexual activity. Prevention education and risk assessment for HIV should continue annually, with additional screening based on risk. All pregnant women should be screened for HIV at the start of pregnancy, with retesting during pregnancy based on risk factors. Helps prevent spread of HIV and other STIs, many of which can only be detected through testing.

There's no cure for HIV/AIDS and many sexually transmitted infections, such as HPV and genital herpes. The best way to stay healthy is to practice safer sex.

Suggestion for the providers

Many medical practitioners find colposcopic[32] examination of the disabled woman difficult and uncomfortable for the patient. Wall-mounted colposcopy units and examination tables that allow support of altered leg adduction (movement of a limb towards the midline of the body or towards another part) will help both patient and physician. Women with SCI lesions above T6 risk development of AD during any cervical manipulation necessary to diagnose or

[29] Candidal vaginitis is a vaginal yeast infection.

[30] Vulvitis is an inflammation of the vulva, the soft folds of skin outside the vagina.

[31] Ulcers of oral, genital and anal areas in HIV

[32] Colposcopy is a procedure to closely examine your cervix, vagina and vulva for signs of disease. It's often done if cervical screening finds abnormal cells in cervix.

treat any abnormal development of tumour or abrasion. Careful monitoring of blood pressure is needed. Antihypertensive medicines should be easily available. Professionals who are trained to handle AD should be present.

Reproductive tract infections (RTI)

The term RTI refers to any infection of the reproductive tract. In women, this includes infections of the outer genitals, vagina, cervix, uterus, tubes, or ovaries.

Vaginitis

Women who use wheelchairs who sit for long hours on wheelchairs can get vaginitis because of moisture and irritation of the labial area. Women who are on chronic corticosteroid33 therapy or have disabilities related to diabetes may also develop recurrent Candida vaginitis.

Vaginal calculi are extremely rare in literature, doctors should consider them while treating women with incontinence and associated disabilities, paraplegia, or prolonged immobilization in lying position.

Vaginitis is as irritation and/or inflammation of the vagina. The three most common vaginal infections are bacterial vaginosis (BV), Candida vaginitis (yeast infection) and trichomonas vaginitis (trich). As with Candida vaginitis, bacterial vaginosis also emerges. Vaginal infections can produce a variety of symptoms, such as abnormal or increased discharge, itching, fishy odour, irritation, painful urination or vaginal bleeding. Noninfectious vaginitis may be due to allergic reaction or irritation from vaginal sprays, douches, spermicides, perfumed soaps, detergents or fabric softeners; from atrophic changes (wasting away of a body organ or nerve damage) because of menopause; or from irritation by vaginal secretions[lxii]

Wet Viginal Mount test for vaginitis

A vaginal wet mount (or vaginal smear or wet prep) is a gynaecologic test wherein a sample of vaginal discharge is observed by wet mount microscopy by placing the specimen on a glass slide and mixing with a salt solution. It is used to find the cause of vaginitis and vulvitis.

Antifungal medications are given in Candida. Bacterial vaginosis require antibacterial medications. Vaginitis can be caused by various sexually transmitted organisms. Noninfectious vaginitis is managed by removal of the cause.

Prevention strategies: avoid douching, careful and immediate drying after washing or bathing, exclusive use of cotton underwear or panty, front to back wiping after bowel movement, and avoidance of all scented bath or perineal products.

[33] Corticosteroids, often known as steroids, are an anti-inflammatory medicine prescribed for a wide range of conditions. They're a man-made version of hormones normally produced by the adrenal glands.

Other infections

Pressure ulcers

Pressure ulcers are a type of injury that breaks down the skin and underlying tissue when an area of skin is placed under constant pressure for certain period causing tissue ischaemia, cessation of nutrition and oxygen supply to the tissues and eventually tissue necrosis.. Pressure ulcers are largely preventable in nature, and their management depends on their severity. Pressure ulcers are largely preventable in nature, and their management depends on their severity. They are also known as 'bedsores', 'decubitus ulcers'. Women who are at risk for skin breakdown, including women are unable to change their positions frequently or those who have less sensation in the lower parts of their body, are more susceptible to pressure ulcers and infections. There are three predisposing factors for pressure ulcers:

- Loss of movement
- Failure of reactive hyperaemia
- Loss of sensation.

These infections can lead to sepsis[34]. Sepsis can even be life threatening. Because of pressure ulcers may impact women's ability to use a wheelchair. Severe pressure ulcers may even require surgical treatment and skin grafts. Women and their health care providers need to know about the early signs of skin breakdown.

Preventive strategies include:

- changing positions,
- Keeping skin clean and dry
- use of cushions,
- proper fitting of prosthetics or orthotics
- good nutrition
- Women, their partners, caregivers, or family members need to inspect the woman's skin daily.

Mental health conditions - people with severe mental health conditions such as schizophrenia or severe depression have an increased risk of pressure ulcers for a number of reasons[lxiii]:

[34] A potentially life-threatening condition caused by the body's response to an infection

- Their diet tends to be poor, resulting in hypoproteinemia (extremely low level of protein).
- They often have other physical health conditions, such as diabetes or incontinence.
- They may neglect their personal hygiene, making their skin more vulnerable to injury and infection that help an ulcer to form.

Urinary tract infections

In this infection occurs when bacteria grow in the bladder. UTI's are more common in women. Risk factors include:

- Wheelchair use/immobility
- Kidney problems
- Diabetes
- Prior history of UTI infections
- Kidney stones
- Dehydration
- Being sexually active
- Having urinary tract abnormalities
- Use of incontinence undergarments or catheter
- Improper perineal cleaning technique

Signs and symptoms:

- Frequent trips to the bathroom or avoiding urinating,
- increased touching or itching of the genital area
- crying during or immediately following urination,
- Onset of incontinence in someone who uses the bathroom independently,
- decrease in appetite,
- fever
- Sudden changes in behaviour, such as an increase or an onset of irritable or aggressive behaviours.
- Sudden confusion, for example, not being able to do tasks that the person could easily do a day or two before.

UTI's can make dementias temporarily worse for people who have Parkinson's, Alzheimer's, or other dementia.

Women with SCI, MS and Parkinson's Disease are at a greater risk of developing urinary tract infection. Urinary tract infection (UTI) is responsible for major morbidity and mortality in spinal cord injury (SCI) patients. This can be due to:

- Neurogenic bladder (Neurogenic bladder is bladder dysfunction caused by neurologic damage. Symptoms can include overflow incontinence, frequency, urgency, urge incontinence, and retention)
- Incomplete voiding
- Elevated intravesical pressure
- Catheter use
- Frequent exposure to antibiotics increases the risk of infection by resistant organisms.

UTIs interfere with rehabilitation, and may lead to secondary urologic complications. The classic symptoms of UTI are unreliable indicators in SCI patients with neurogenic bladder.

How to reduce the risk of infection:

- Avoid getting dehydrated by drinking plenty of water. If you don't like drinking plain water, add a small amount of cordial or fruit juice. Cranberry juice is particularly good.
- Go to the toilet as soon as you feel the need, and try to make sure you empty your bladder completely.
- Wipe from front to back after going to the toilet
- Keep yourself clean. Even if you're not able to take bath or shower easily, try to keep yourself clean 'down below' by gentle washing every day with a mild unscented soap and warm water, being sure to rinse and dry well.
- Avoid perfumed soaps or scrubbing hard as this can cause irritation
- If you're sexually active, try to empty your bladder before and after sex, and wash your genitals afterwards
- If you use incontinence pads or diapers, these should be changed regularly to prevent bacteria from growing on them

- If you have a catheter (a tube inserted in your bladder to drain urine), make sure that the tube doesn't become blocked or twisted, and change the bag regularly (or get someone to do this for you).
- Methodologies other than urethral catheters (like handy urine bottles) should be used for urine drainage assistance whenever possible. These include condom catheterization and IC

Menopause

Menopause is defined as the absence of menstrual periods for 12 months. It is the time in a woman's life when the function of the ovaries ceases.

Stages of Menopause

The process of menopause is a gradual one. There are three stages:

Perimenopause is the interval in which a woman's body begins making the natural shift from more-or-less regular cycles of ovulation and menstruation toward permanent infertility, or menopause.

Periods may become irregular — longer, shorter, heavier or lighter, sometimes more and sometimes less than 28 days apart. One may experience hot flashes, sleep problems and vaginal dryness.

Menopause

When the woman goes through twelve consecutive months without menstrual period.

Post menopause

The years following menopause are called postmenopause. As a result of a lower level of oestrogen, postmenopausal women have an increased risk for a number of health conditions, such as osteoporosis, heart disease, and changes in the vagina and bladder.

There is no reliable lab test to predict when a woman will experience menopause. The age at which a woman starts having menstrual periods is not related to the age of menopause onset.

The average age of menopause is 51 years old, but it may happen in early in 30s or as late as in the 60s. In Indian women, menopause takes place a little earlier, the average age ranging from 40 to 49 years.

Symptoms of menopause

- abnormal vaginal bleeding
- hot flashes[35]
- urinary symptoms
- Erratic and fluctuating hormone level

[35] Hot flashes are feelings of warmth that spread over the body and last from 30 seconds to a few minutes

- calcium depletion
- sudden mood swings
- nights sweats
- sleepless and disturbed nights

Complications that women may develop after menopause include:

- osteoporosis and heart disease
- joint and muscle pain
- bladder incontinence
- fatigue
- loss of energy
- heart palpitations
- tingling of the skin
- numbness of hands and feet
- weight gain
- headaches
- loss of memory
- feeling generally unwell

Disability and Menopause

Menopause may be triggered by circulatory, endocrine, immunological or neurological changes in women with disabilities. Cardiovascular, respiratory, metabolic, muscular, skeletal, skin and connective tissue, endocrine, and sexual functions may get affected due to aging. Decrease in oestrogen impacts various systems.

Women with mobility limitations

These women face greater risks associated with menopause, including heart disease and osteoporosis. Women who already have bowel and bladder issues may have increased genitourinary problems including urinary tract infections, kidney and bladder stones and poorer renal function. Women with autoimmune diseases have complex and varied responses to changes in their oestrogen levels. Women who have issues with skin integrity (whole, intact and undamaged skin) such as women with SB, SCI, or MS, may have increased difficulty with pressure ulcers after menopause. Skin integrity plays a major role in quality of life and health. These women are more sensitive than other women to thermal and vasomotor[36] changes[lxiv]. There can also be an increase fatigue and muscle weakness.

Women with visual problems

Problems of eyes like Macular Degeneration and Glaucoma are also associated with menopause. Women in menopause have higher intraocular pressure[37]. Chances of glaucoma increase when there is early menopause i.e. before the age of 45. Women are more prone to get this disease because of falling oestrogen level and aging and have a higher rate of visual impairment than males with glaucoma.

Investigations into the sex-specific mechanisms of glaucoma are needed to develop new preventive and therapeutic interventions.

The optic nerve, which is a large nerve in the back of eye, sends vision to the brain. It shrinks with age -- about 0.2 percent per year and low oestrogen contributes to this. Age related macular degeneration is a main cause of blindness in elderly people. Oestrogen becomes deficient in women after menopause and this deficiency makes women more likely to suffer from macular degeneration.

[36] Relating to the constriction or dilatation of blood vessels.

[37] Intraocular pressure (IOP) is the fluid pressure inside the eye

A blood test can check levels of oestrogen and other hormones to confirm starting of menopause.

Women with MS

Some women find their MS gets worse once their menstrual cycles end. In women with multiple sclerosis (MS) may find hot flashes more enfeebling than other women because of their sensitivity to thermal fluctuation (frequent changes in temperature). There can be overlapping of symptoms. It may be hard to tell the difference between symptoms of MS and signs of menopause. Symptoms of the two conditions can look very similar. Women with MS may find the increased mood, sleep and memory changes associated with menopause to be particularly troublesome.

Women with Polio

According to research women who are disabled by polio have more trouble with the menopause than the non-disabled ones. Women who have post-polio syndrome may very likely experience menopause differently than their peers physiologically, physically, and psychologically. Severity of post-polio symptoms is also significantly related to severity of menopause symptoms. Severity of menopausal symptoms depends on the severity of post polio symptoms. Menopause might happen at the time when post polio sequel is worsening. All this can lead to new or progressive muscle weakness, joint and muscle pain and fatigue. All this can occur years after stability of initial polio infection. There are many problems that are common between both PPS and menopause:

- Sleeplessness
- Fatigue
- Joint pains
- Greater emotional stress
- Feeling of dissatisfaction
- Moodiness and depression
- Sensory feelings like numbness, tingling, loss of feeling
- constipation
- dryness of eyes increase

Women with epilepsy

They may reach menopause at an earlier age than women in the general population. In some women due to change in hormonal levels, patterns of seizure change at the time of menopause.

Women with Down's syndrome

They reach the menopause earlier than the general population. The average age for women to reach the menopause in the general population is 51 years old. For women with Down's syndrome the average age to reach the menopause is 46 years old but it can happen up to ten years earlier than in the general population. Women with Down's syndrome face difficulty in explaining their symptoms. For instance they do not know about a "hot flushes"; and might not be able to distinguish between a hot flushes and feeling hot due to the weather. With an early onset of menopause these women also appear to suffer from dementia[38] at an early age. Women with cognitive and mood changes may find the increased mood swings, sleep and memory changes.

Women with learning disabilities

They often have the menopause earlier than other women but do not have proper information about its nature. They may face emotional disturbances during this period.

Women with Spinal Cord Injury

Perimenopause presents a unique challenge for women with SCI because the symptoms may be similar to other conditions associated with SCI, such as autonomic dysreflexia, skin dryness, infections, bladder changes impaired temperature regulation, and spinal cord cysts.

According to a study women with incomplete injuries have more severe night sweats than those with complete injuries. Women with paraplegia had greater complaints of palpitations and reported more changes in the amount of bleeding with menstruation cycles than those with tetraplegia[lxv].

Another example is frequent headaches during menopause usually caused by reduced oestrogen and a subsequent constriction of blood vessels in the brain. But headaches may also be a symptom of AD if the woman's injury is above T6. Failure to manage blood pressure adequately could make AD difficult to differentiate and lead to a hypertensive crisis. Women with SCI may have depression during menopause. It can be due to poor sleep patterns, irritability, fluctuating hormone levels, and a general sense of losing control.
Due to masking and overlapping of symptoms treatments for SCI-related conditions might be delayed.

[38] A chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning.

It is imperative that women monitor their bodies and be alert to changes that may signal underlying problems.

What could be done?

For women with disabilities menopause may pose unique challenges that non disabled women do not experience. Basic health maintenance issues may also be adversely affected in women with disabilities by environmental factors. Physical barriers can be additional obstacles with preventive health screening that is essential in aging populations.

A comprehensive evaluation and the development of a suitable management plan, which takes into account the multifactorial nature of aging as a disabled woman, are essential in delivering optimal care to this population.

Provision of correct and accessible information: Women with disabilities typically have not received information about the nature menopause. It is important to inform women about menopause and arrange for periodic evaluations by a health care professional with expertise in women's health. Medical and psychological literature does not have anything substantial and specific on this issue which can be made available for women with disabilities. Women with disabilities need to be aware of long-term health issues following menopause, including risk of osteoporosis and cardiovascular disease.

Support staff who work with women with disabilities should have knowledge and resources to enable them to support women through this important transition.

Health care professionals should not assume that women with disabilities already know key things about the menopause.

Women with disabilities are very likely to want to be supported through the menopause by female staff.

Treatment options might need to be tailored to the individual.

Care providers, and women with disabilities, should carefully monitor their symptoms during perimenopause and the treatment plan should reflect a joint decision between the woman and her provider.

Women must coordinate gynaecological appointments with ongoing treatment. Avoiding routine gynaecological care is potentially dangerous and unsafe.

Healthcare providers must educate women regarding menopause and the symptoms often associated with this phase of life.

Doctors may choose to use supplemental hormonal agents or low-dose oral contraceptives for cycle control and regulation of fluctuating oestrogen levels. But it should be kept in mind that women with alterations in mobility are at an increased risk for DVT associated with oral contraceptives[lxvi]. Hormonal therapies can lead to weight gain which can have adverse impact on women with mobility limitations.

A shorter duration of reproductive life span is associated with a higher risk of Cardio Vascular Disease, which is likely driven by the timing of menopause induced either naturally or surgically. Extremely early age at menarche is also associated with a higher risk of Cardio Vascular Disease.

Women may have specific concerns about the interactions among the medications they use to manage their disability and medications available for menopause-related problems. HRT use has been linked to increased seizure activity among women with seizure disorders[lxvii]. On the other hand MS may respond positively to oestrogen and negatively to dropping oestrogen levels, and women may experience improvement in MS-related symptoms when they use HRT.

Alternatives to HRT can also be thought for treating women with disabilities in order to avoid adverse side effects. Those who are interested in alternative products or nutritional supplementation are advised to work with health care providers who are knowledge.

I wanted to get my mammogram done so called up various super speciality hospitals in Delhi, the national capital of the country. Not a single hospital has a wheelchair accessible mammogram machine. I won't like to take the name of the hospital, but at one hospital a person on the other side of phone told me madam aap ajayiye hum apko utha kar apka mammogram kar denge. Koi pareshani nahi hogi….(Madam you come and will carry you to get your mammogram done. There is will be no problem).

Abha Khetarpal (Woman with locomotor disability)

President, Cross the Hurdles

Screenings

Women with physical disabilities have traditionally been referred to specialists, mainly physical medicine and rehabilitation specialists to coordinate and manage their disability. But these specialists do not provide routine reproductive health care. This has led to gaps in women with physical disabilities routine health maintenance.

Basic screening and the pelvic examination

Pelvic examinations are performed to evaluate pain, bleeding, and vaginal discharge and to screen for cervical cancer and sexually transmitted infections. A very little is given to the procedure of pelvic examination technique as far as women with disabilities are concerned. They can find these examinations uncomfortable and intrusive.

Pelvic examination in women with cognitive, sensory, or mobility impairments can be difficult but it should not be avoided. Sexually transmitted infection rates the same as in women with no disability.[61]

Woman with visual impairment must be given opportunity to feel the speculum[39] and articulate each step of the exam before proceeding. If three-dimensional genital models are available, they would be useful to educate the woman with her anatomy and to show the steps of the exam process. During the exam, explain what is happening and about to happen. Practitioners should remember to identify themselves upon entering the exam room and inform the woman if it is necessary for them to leave. Patient should be asked verbally about the kind of assistance she would need during the time of examination.

Woman with deafness should be able to choose which form of communication she wishes to use during her exam: a sign language interpreter, lip reading or writing. If she wants sign language interpreter should be allowed to remain in the room. The providers need to negotiate where the interpreter will stand, so the patient can continue to communicate readily, yet the clinician can move about without hindrance. Some patients may wish to view the exam with a mirror while it is happening.

With mobility impairments (e.g., stroke, spina bifida, multiple sclerosis, cerebral palsy, some orthopaedic injuries), spasticity may result in pain and limit range of motion of the legs. For a woman who cannot flex her knees, abduct her hips, or use stirrups (foot support) for another reason, alternative positions can be attempted.

[39] A metal instrument that is used to dilate a canal in the body to allow inspection

Women with intellectual impairment are many times unable to cooperate during pelvic examination when the procedure is carefully explained. In that case sedation may be given. The ethics of this practice must always be carefully considered.[67]

Women with spinal cord injury During the pelvic examination of women with spinal cord injuries at or above T5-6 doctors have to be very careful. Perineal manipulation can result in autonomic dysreflexia. The process might result in hypertension, nausea, headache, nasal congestion, flushing, sweating, and muscle spasms. Proactive management, of the urologic and gastrointestinal tracts, including emptying the bladder prior to examination and maintaining an effective bowel regimen, is required.

If autonomic dysreflexia happens:

- Immediately stop the examination
- Repositioning the patient in a more upright posture
- Loosen the clothing
- Bladder catheterization to remove urine
- Checking for faecal impaction[40] using lidocaine jelly
- Short-acting anti-hypertensive if hypertension is severe and does not resolve promptly.
- Use of beta blockers[41] should be avoided.

Things to consider

Materials need to be developed to enhance clinician sensitivity regarding the experience of having a disability and provide general guidance with respect to scheduling a realistic gynaecological appointment length, installing appropriate office equipment, learning safe transfer techniques, and maintaining respectful etiquette when working with patients who present with a service animal, personal care assistant, or sign language interpreter.[62,63]

1. Physicians caring for disabled women must perform pelvic examinations in a way that assures patient access, safety, comfort and privacy.
2. Patients should meet the clinician alone to ensure privacy for discussion of intimate topics, such as contraception, safer sex, and interpersonal violence[64] .

[40] Faecal impaction is a severe bowel condition in which a hard, dry mass of stool becomes stuck in the colon or rectum.

[41] Certain medicines used to control heart rhythm, treat angina, and reduce high blood pressure.

3. An assistant may be needed during examination to manually support lower extremities for women with spinal cord injury (SCI), stroke, cerebral palsy (CP), orthopaedic injury, multiple sclerosis (MS), and even obesity. For women with CP side lying, or heel-to-heel positions are suitable since they have a problem in straightening their knees.
4. Last but not the least physicians must allow more time to examine the woman with disability.[lxviii]
5. It is better to advise the patients to empty their bladders before the examination and to perform standard bowel programs the night before to minimize the risk of triggering AD and bowel accidents during examination. In some conditions like MS, women may not be able to empty bladder voluntarily. For such women, alternate arrangements during examination may be allowed / done.
6. In order to adjust leg positioning rapid pulling movements should be avoided to avoid muscle spasticity.
7. Liberal application of lidocaine gel[42] to the perineum before insertion of the speculum can lessen the likelihood of developing AD. This can also be useful to decrease discomfort during examination.
8. Blood pressure should be monitored periodically during the pelvic examination. Exam positions may need to be altered in order to complete a pelvic exam based on the woman's disability. For example, females with spina bifida may have kyphoscoliosis, hip dislocation, and lower extremity contractures which would make a traditional gynaecologic exam difficult.

For different positions see Appendix 5

[42] medication is used to prevent and control pain during certain medical procedures such as inserting a tube into the mouth, nose, throat, or urinary tract.

As you know I have cerebral palsy (CP). So whenever I have to visit a gynaecologist for issues regarding sexual and reproductive health the first and major most problem is accessibility. If somehow I am able to reach to the clinic of a gynaecologist, I am first asked which doctor I was seeing earlier. I am mostly turned away when they look at me and my disability asking me to visit my 'own' doctor. For issues regarding CP I go to a neurologist but how can I go to a neurologist if I need treatment relating to sexual and reproductive health? Few days back I developed urine infection and went to a local physician. His wife who was a gynaecologist, attended me. After talking to me she said she won't prescribe me any medicine for urine infection and suggested me too visit the doctor who I usually visit. If everyone avoids and shrug off what we need, where would we go?

Once I had developed a severe pain which radiated from back towards my right breast…I went to a gynaecologist but she declined. Then I contacted the organization AADI. They connected me to a doctor who agreed to examine me and that too because her own child had CP and she knew what CP is. Does this mean that the doctors who have someone with disability in their homes would only understand what we actually go through? Then only we would get treated? I was recommended mammogram. As the machine could not come to level of my wheelchair I was shifted on to a revolving chair which had wheels but with no arms. I am unable to sit on a chair without arms as there is a risk of falling down without side support. My clothes were removed and four female staff held me with great difficulty in different positions to get me screened. They literally carried me to get the screening done. I was crying all the time because of physical pain as well as embarrassment that I was facing. The whole process was not only uncomfortable but my dignity was also compromised with.

Meenu Mani (A woman with Cerebral Palsy)

President, Yes We Can

Other complications

Allergy

Latex allergy is common in patients with spina bifida (23% of women with spina bifida have latex allergy). Medical and surgical interventions may also put the patient at risk for latex allergy. Therefore latex-free gloves and equipment should be readily available for all exams.

Hypersensitivity

Before the exam, the patient may want to inform the provider of any hypersensitive areas of her body to help prevent possible discomfort or spasms during the exam. Some women may experience variable responses to ordinary tactile stimulation such as spasms or pain. Others experience generalized discomfort and agitation that makes medical care difficult. Sensitive areas can be avoided or an extra amount of lubricating jelly can be used to decrease friction or pressure.

Spasticity

Spasms may be a common aspect of a woman's disability. There can be slight tremors (involuntary movements) to quick or violent contractions. Spasms may occur during a transfer, while assuming an awkward or uncomfortable position, or from stimulation of the skin with the speculum.

If spasm occurs during the pelvic exam, the assistant should gently support the spasming area (usually a leg or abdominal region) to avoid any injury to the patient. Spasms should be allowed to resolve before continuing with the exam.

A woman who experiences spasms should never be left alone on the exam table where a spasm could pose a serious danger to her. An assistant should stand near the exam table and maintain physical contact with the patient to ensure both safety and a feeling of security.

Catheterization

If a woman is using catheters, it is not necessary to remove the catheter, as it will not interfere with the pelvic exam in any way. Urine bag, usually attached to a woman's leg by a strap, should be empty at the start of the exam so it will not need to be drained later. Tactile stimulation in her pelvic area during the exam could cause her bladder sphincter (muscle that allows urine to pass through) to open, with resulting incontinence.

Breast cancer screening

Breast cancer is the most common gynaecologic malignancy, Breast cancer clinical examination is recommended about every 3 years for women in their 20s and 30s, and every year for women 40 and about. A good clinical breast exam may help identify breast cancer relatively early.

Breast cancer risk assessment is particularly important since women with disabilities have a higher risk for developing breast cancer compared to heterosexual women due to higher prevalence of nulliparity[43] and HRT in conditions like MS. In addition to delayed diagnosis because of access barriers, women with disabilities may harbor an increased risk for developing breast cancer. These women, because of decreased physical activity and limited food choices are statistically heavier than other women, with obesity being one of the risk factors linked with breast cancer.[7] Early exposure to x-rays to the spine, a common occurrence in girls with cerebral palsy, scoliosis, and other conditions has also been linked to an increased risk for the development of breast cancer[lxix].

Women with disabilities may be at increased risk for under detection of breast pathology as a result of a variety of factors. Some clinicians and patients, for example, wrongly believe that mammography can be performed only when a woman is standing, neglecting to offer this essential screening tool to women in wheelchairs. Some women with disabilities have restrictions in upper body movements, making it difficult for them to perform breast self-examination.

Physical limitations may impact the quality of the mammography image, limiting both back and front views and restricting the ability to obtain lateral views.

Access barriers such as high examination tables and absence of wheelchair accessible mammogram machines may limit a woman's ability to obtain regular clinical breast examination.

Clinicians need to work and educate with women, families and care providers to overcome obstacles in breast health care and improve access to mammography.[5, 6]

[43] A condition in a woman of never having given birth

Pap test and HPV test (human papillomavirus)

A Pap test or Pap smear is a preventive screening exam a doctor uses to test for cervical cancer in women. It can also reveal changes in cervical cells that may turn into cancer later. Pap test to be done every 3 years for women ages 21-29; for women 30-65, Pap test and HPV test needs to be done every 5 years or Pap test alone to be done in every 3 years. Women at average risk should not be screened more than once every 3 years. Testing may be stopped at age 65 or 70 for women who have 3 or more normal Pap tests in a row and no abnormal test results in 10 years.

An HPV test is usually done at the same time as a Pap test. Pap test collects cells from cervix to check for abnormalities or the presence of cancer. An HPV test can be done using the same sample from the Pap test or by collecting a second sample from the cervical canal.

Women with disabilities—both mobility limitations and others—are less to receive Pap smears mainly due to infrastructural barriers like inaccessible examination tables, lack of hoist for transfers and assumptions of sexual inactivity of women with disabilities. Moreover women with disabilities are devoid of health insurance and so are not able to afford such examinations. Lack of education and awareness are also responsible for not getting this preventive screening done leaving them undiagnosed and at a greater risk of getting cervical cancer. The rate of screening for cervical cancer is low among women with both disability and various other medical issues. Policymakers should note these results as they work toward improving cancer screening rates for an aging population with complex medical needs.

People with intellectual disabilities experience substantially more obstacles in health promotion and cancer prevention activities compared to the general population. Obstacles include:

- Communication difficulties between patients and paramedics
- Patients' poor compliance with management plans
- Inspection difficulties
- An insufficient understanding of available resources

Ovarian cancer

Women with disabilities are not at increased risk for ovarian cancer per se, but they are more likely to have predisposing characteristics including nulliparity[44] and less frequent use of oral contraception. Ovarian cancer can be a silent disease until late in its progression. Annual pelvic examinations are important for identification of any lump as early as possible[lxx].

[44] The condition in a woman of never having given birth

Endometrial cancer

Endometrial cancer is another one of the obesity-linked cancers and women with disabilities who lack physical activity or are wheelchair users may tend to gain weight especially during middle age[lxxi],[lxxii].

There is dysfunctional uterine bleeding and oligo-ovulation in women with multiple sclerosis (MS), myasthenia gravis[45] (MG) and Sjögren's syndrome[46]. These women may be at increased risk for getting endometrial cancer. This calls for regular evaluation of irregular vaginal bleeding.

Colon cancer

It is estimated that 394,000 deaths from colorectal cancer still occur worldwide annually Colon cancer is the fourth most common cause of cancer. Women with disabilities are at equal risk of getting colon cancer as their non disabled counterparts. There are different cancer screening techniques for example faecal occult blood testing (FOBT) and colonoscopy. Since the procedure of screening is difficult, women with disabilities may not get screened. Testing of stool for blood during a rectal exam should be part of every gynae-cologic exam for women above the age of 50 on yearly basis.

Recommendation for accessibility for screening

Service providers need to make reasonable adjustments so that people with disabilities are not disadvantaged compared to people without disabilities.

To provide an accessible gynaecological examination or cancer screening women with different kinds of disabilities, healthcare establishments must be equipped with following facilities:

1. An accessible height exam table with adjustable level
2. Padded leg supports instead of typical stirrups. Using padded, soft, adjustable boot-type stirrups can make positioning more comfortable and easier and can reduce spasticity.
3. Hoist for transfers from wheelchair to bed or examination table.
4. Accessible mammogram machines.
5. Elements to stabilize and support a person such as rails, straps, stabilization cushions, wedges, or rolled up towels those with chronic pain and spasticity.

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[45] Myasthenia gravis (MG) is a long-term neuromuscular disease that leads to varying degrees of skeletal muscle weakness. The most commonly affected muscles are those of the eyes, face, and swallowing. It can result in double vision, drooping eyelids, trouble talking, and trouble walking

[46] Sjogren's (SHOW-grins) syndrome is a disorder of your immune system identified by its two most common symptoms — dry eyes and a dry mouth. The condition often accompanies other immune system disorders, such as rheumatoid arthritis and lupus

6. Hydraulic stirrups can be used to facilitate examination in the lithotomy[47] position.
7. Complete removal of physical, administrative, and attitudinal barriers to the care of disabled women.

[47] a supine position of the body with the legs separated, flexed, and supported in raised stirrups, originally used for lithotomy and later also for childbirth.

Vaccines

HPV is difficult to spot because an infected person might show no symptoms. One could develop one's own symptoms years after having sex with someone who is carrying it. While not every strain can be prevented by vaccinations, some can. So it is better to get vaccinated.

Hepatitis A is a type of liver disease. It is most commonly contracted due to dirty food or water. It can also be contracted from certain sexual activities. Hepatitis A is totally preventable after getting the vaccine, which consists of two shots administered six months apart.

The Hepatitis B Vaccine

Like hepatitis A, hepatitis B is also a liver disease, contracted through the exchange of infected bodily fluids. One can also contract hepatitis B by sharing drug paraphernalia, and getting a tattoo with equipment that wasn't properly cleaned. This vaccine can be received in a series of two, three, or four injections.

Some STIs including gonorrhoea, Chlamydia, and syphilis, do not yet have a vaccine.

Sexual violence and abuse and women with disabilities

When there is violence against a woman her body integrity is violated. Religion, traditions and societal perceptions do not provide a woman with disability, the right to control her body, including her sexuality and reproduction. Failure to recognize this basic human right leads to harmful practices against women with disabilities. Women with disabilities remain devoid of:

- The fundamental rights to physical autonomy and self determination
- The enjoyment of the highest standard of physical and mental health
- Access to healthcare services
- The right to determine the number, timing, and spacing of children;
- The right to exercise her sexuality free from discrimination, coercion, and violence
- The right to decision making

The Problem

It has been a well established fact that women with disabilities are more likely to experience domestic violence, emotional abuse, and sexual assault than women without disabilities[lxxiii]. They may also feel more isolated and feel they are unable to report the abuse, or they may be dependent on the abuser for their care. The perpetrator can also be partner or even a family member.

Those with physical disabilities may find it more difficult to escape from violent situations due to limited mobility.

Deaf or hard of hearing women may not be able to call for help or easily communicate abuse, or may be more vulnerable to attacks simply due to the lack of ability to hear their surroundings.

Women and girls with intellectual or psychosocial disabilities may not know that non consensual sexual acts are a crime and should be reported because of the lack of accessible information.

Women with psychosocial disability are at a greater risk of violence. They remain dependent on their caregivers, service providers and families. Many times they are unable to communicate their experiences[lxxiv]. Many times they are not given an opportunity to be heard. Their statements may be dismissed as imaginary due to assumed lack of legal capacity.

Under section 7(2) of Rights of Persons with Disabilities Act, any person or registered organization, who or which has reason to believe that an act of abuse, violence, or exploitation has been, is being or likely to be committed against any PWD, may give information to the local Executive Magistrate who shall take immediate steps to stop or prevent its occurrence and pass appropriate order to protect the PWD. Police officers, who receive a complaint or otherwise come to know of violence, abuse, or exploitation, shall inform the aggrieved PWD of his right to approach the Executive Magistrate. The police officer shall also inform about particulars of nearest organization working for the rehabilitation of the PWD, right to free legal aid, and right to file complaint under the provisions of this Act or any other law dealing with such offence.

Suggestions

Relatives must be strong advocates for their loved ones with disabilities. If you have a relative with a disability, learn the signs of abuse, especially if your relative has trouble communicating.

Report abuse to adult protective services if you notice any of the following with a loved one who has a disability:

- Suddenly being unable to meet essential day-to-day living needs that affect health, safety, or well-being
- Lack of contact with friends or family
- Visible handprints or bruising on the face, neck, arms, or wrists
- Burns, cuts, or puncture wounds
- Unexplained sprains, fractures, or dislocations
- Signs of injuries to internal organs, such as vomiting
- Wearing torn, stained, soiled, or bloody clothing
- Appearing hungry, malnourished, disoriented, or confused

Access to justice is a major challenge for women and girls with disabilities mainly due to the stigma associated with their sexuality and disability. They are often not able to get the support they need at every stage of the justice process: reporting the abuse to police, well sensitized and trained police personnel, getting appropriate medical care, accessing rehabilitation programs and navigating the court system.

Women and girls with disabilities who survived sexual violence continue to face high barriers to the justice system. The challenges many women and girls with disabilities face throughout the justice process are filing a police report, obtaining appropriate medical care, having complaints investigated, navigating the court system, and getting adequate

compensation. They lack appropriate information as they face social isolation[lxxv]. Women and girls with disabilities may require accommodations—different kinds of support depending on their disabilities—that are procedural and age-appropriate such as access to sign-language interpretation, the presence of someone who can help in communication, the use of simple language, and the option to file reports in Braille.

Women with disabilities have right to participate in the investigative and judicial processes. They have the right to record their statement with police in their home or a place of their choice, and the right to assistance by an interpreter or support person when the complaint is recorded and during trial. Protections should be given to those who are seriously physically hurt or who have a temporary disability. These women should no longer remain the invisible victims of sexual violence.

Key provisions of the Criminal Law Amendments, 2013 aimed at enabling the participation of women and girls with disabilities in the criminal justice process include:

The right to record their statement with police in the safety of their home or a place of their choice;

The right to have their police statements videotaped;

The right to assistance by a "special educator" or interpreter when the complaint is recorded and during trial; and

Exemption from having to repeat their videotaped statement at trial, subject to cross-examination.

A global study from UNFPA reveals that girls and young women with disabilities face up to 10 times more gender-based violence than those without disabilities. Girls with intellectual disabilities are particularly vulnerable to sexual violence.

Some facts about disability, gender and discrimination

- Female infants born with disabilities are victims of infanticide than male infants with disabilities. They may never be legally registered, which cuts them off from publicly provided health care, education and social services. It also renders them more vulnerable to violence and abuse.

- Girls with disabilities are less likely to receive basic needs and care including food, healthcare, assistive devices, education and employment.

- Girls and young women with disabilities are at the greatest risk of sexual violence.

- Young girls with disabilities are more vulnerable to violence than their peers without disabilities.

- Violence against girls with disabilities can take many forms including bullying, physical discipline at the hands of caregivers, the forced sterilization of girls, or violence in the guise of treatment, such as electric shock 'aversion therapy' to control behaviour.

- Neighbours and family members who know they are alone can use the opportunity to sexually abuse them, with little risk of being caught or punished. They may even be subjected to trafficking by their own families. They experienced abuse most commonly from their husband or intimate partner, followed by a person in a position of authority in their community (e.g., house owner, village chief, teacher, religious leader, employer), or a relative other than their husband (e.g., uncle, brother-in-law).

- Research has found the incidence of intimate partner violence experienced by people with disabilities to be high[lxxvi].

- Young women with disabilities are denied the right to make decisions about their reproductive and sexual health.

- These young women are not seen as needing information about their sexual and reproductive health and rights – or as being capable of making their own decisions. As a result, girls with disabilities have even less knowledge about sexual and reproductive rights than their male peers. Low levels of sexual education, including education about HIV transmission and prevention, often translate to risky sexual behaviours.

- Young women with disabilities are routinely denied access to family planning and other sexual and reproductive health services. As a result these women are the most likely to experience forced abortions, forced sterilizations, STIs and sexual violence.

- Researchers have found disabled people to have poor mental health. Violence against women is prominent among women with psychosocial disabilities. In a study in India it was revealed that 30% of the women with psychiatric disabilities reported some form of sexual coercion[lxxvii]. Women with physical disabilities are more likely to have anxiety disorders, depression, obsessive-compulsive disorder, dementia and behavioural disorders[lxxviii].

- Myths and stigma contribute to the vulnerability of young people with disabilities. One of the most significant myths for young people with disabilities is the belief that people who have an STI can cure the infection by having sexual intercourse with a virgin. Young women with disabilities are at particular risk of rape by infected individuals because they are often incorrectly believed to be asexual – and thus virgins.

In interviews conducted for the 2004 Global Survey on HIV/AIDS and Disability, disability advocates and service providers reported virgin rapes of people with disabilities in 14 of 21 countries reviewed.

Disabled Women of Sexual Minority Group

Disabled women belonging to sexual minority group like lesbian, bisexual women, face the brunt of stigma more than anyone else. Because of the fear of being judged and complete exclusion, there can be a withholding of relevant personal information when dealing with the health care providers which can have an adverse effect on the care provided.

Numerous hurdles are seen while talking about love and coming out. There is discrimination, social isolation and lack of support.

They are at risk of acquiring various sexually transmitted infections[lxxix]. STIs such as human papillomavirus (HPV), bacterial vaginosis and trichomoniasis can spread between women. Oral sex and sexual behaviour involving digital-vaginal or digital-anal contact can spread the infection, specifically when penetrative sex toys are shared. Disabled women of sexual minority group with pre-existing or acquired physical, intellectual, sensory or mental health disabilities are at risk of HIV. Unfortunately this group of population is largely been excluded from HIV prevention campaigns, clinical outreach efforts and social and economic support schemes. Apart from STIs and HIV other health conditions such as arthritis, obesity and asthma are quite prevalent among them. There are risky behaviours such as smoking or a lack of exercise. Women may have poor physical health and mental distress significantly increased the odds of disability. Women who identify as lesbian or bisexual encounter barriers to health care that include concerns about confidentiality and disclosure, discriminatory attitudes and treatment, limited access to health care and health insurance, and often a limited understanding as to what their health risks may be. Infections, including bacterial vaginosis, candidiasis, herpes, and human papillomavirus infections, can be contracted by lesbians[lxxx],[lxxxi] .

There is prevalence of negative attitudes among health professionals. Lack of sexuality education that addresses a range of sexual identities is missing. All this places LGBT people with learning disabilities at and increased risk of HIV. Different hostilities are directed towards disabled and LGBT people because of hidden anxieties about the ‘undecidability’ of the body and the nature and purpose of human existence. There is limited access to LGBT-inclusive and fully accessible services. Accessing affordable, accessible, and inclusive health care, community services, and more is challenging for LGBT people with disabilities. This is particularly true for people in rural communities. Because of this they remain at a greater risk for isolation and increased discrimination.

Some important points for disabled women with different sexual orientation See Appendix 7.

Some facts

- Sexual minority women, lesbians, bisexual, women who have sex with women [WSW], experience health disparities and few interventions have been focused on this underserved group of women.
- There is limited research on the health status and health needs of the lesbian, gay, bisexual and transgender (LGBT) population and this research has primarily focused on sexually transmitted infection among men who have sex with men with very little focus on sexual minority women (lesbians, bisexual women and women who have sex with women).
- Compared to their heterosexual counterparts, sexual minority women are more likely to report poorer mental and physical health and less access to and utilization of health care services.
- There is a need for cultural sensitivity training for health care providers and health care facility staff to reduce homophobia (dislike of or prejudice against homosexual people) and heterosexism (attitudes, bias, and discrimination in favor of opposite-sex sexuality) which may be harmful/ non-inclusive of sexual minority women
- When one comes out as disabled and LGBTQ+, one may experience more isolation, outside of the LGBTQ+ community, and within it.

A few studies in India indicate that several mental health professionals continue to use different methods to cure homosexuality such as masturbatory reconditioning, aversion treatments including mild shock and hormonal treatments[lxxxii]

Sexual dysfunction

Sexual dysfunction refers to a problem occurring during any phase of the sexual response cycle that prevents the individual or couple from experiencing satisfaction from the sexual activity. In other words it is persistent, recurrent problem with sexual response, desire, orgasm or pain during sexual intercourse.

Symptoms in women

- Low sexual desire. This involves a lack of sexual interest and willingness to be sexual.
- Sexual arousal disorder. Desire for sex might be intact, but one has difficulty with arousal or are unable to become aroused or maintain arousal during sexual activity.
- Orgasmic disorder. There is persistent or recurrent difficulty in achieving orgasm after sufficient sexual arousal and ongoing stimulation.
- Sexual pain disorder. There is pain associated with sexual stimulation or vaginal contact.

Physicians and family members often forget that disabled women are sexual beings and may experience sexual response as their nondisabled counterparts.

Sometimes excitement and sexual desire that arises out of erotic stimuli may get suppressed due to disability, pain or fatigue. Some women with SCI experience spasticity in the lower extremities, causing discomfort and difficulty in adjusting positions.

Women with CP often have internal spasms. This can lead to painful intercourse or vaginismus. There can be balance issues that can limit comfortable positions. Women with CP may face problems while developing a positive relationship with their bodies and physical limitations. They might be too hesitant to discuss their needs with partners.[lxxxiii] All this can lead to avoidance of sexual activities or there can be lack of sexual arousal or libido.

Cognitive limitations, mental disorders (such as depression), medications, and certain medical problems may also lead to sexual dysfunction.

Psychological and psychosocial challenges including body image issues, anxiety and depression following limb loss may lead to sexual dysfunction in amputees[lxxxiv].

Sexual health is also influenced by environmental and emotional factors. Sexual self-concept or how we ourselves as a sexual creature, is an important part of sexual health and the core of sexuality. Sexual self-concept predicts our sexual behaviour and thus plays a significant

role in boosting mental and sexual health. Physical disability or mental health problems like schizophrenia can have adverse impact on sexual self concept of women. Lower the sexual self concept greater are the chances of sexual dysfunction.

Women with joint difficulties such as rheumatoid arthritis and osteoporosis may find sexual positioning painful and so may avoid sexual activity. Vaginal pain symptoms, poorer body image, and fatigue may cause sexual dysfunction[lxxxv]. And sexual interest is inversely related to vaginal pain symptoms, body image, and weight problems.

In multiple sclerosis there is demyelination of the nerve which may affect arousal and orgasm[lxxxvi]. There may be problems with other organ systems as well as fatigue, anxiety, depression, and, indeed, altered desire.

One of the side effects of long-term psychiatric medication is sexual dysfunction in the form of loss or diminished sexual desire[lxxxvii]. Women with disabilities may not be able to discuss these issues with their doctors (especially if they are not married). In the absence of this information, the person is unable to make informed decisions and may not recognise sexual dysfunction as a side effect of medicines.
Similar issues arise about other kinds of side effects, such as weight gain, decreased fertility, and so on afraid or embarrassed about an odour whereas women with arthritis may be in physical pain. Medical conditions such as diabetes mellitus, hypertension, and obesity may begin in adolescence and persist into adulthood are also associated with sexual dysfunction. The earlier these conditions are managed, the better the prognosis for the improvement or correction of the dysfunction. Women with spinal cord lesions are at risk for autonomic dysreflexia. This is a condition that is triggered by sexual stimulation, constipation, genital examination or other actions. Women with spinal cord lesions may also have painful bed sores.

Sexual dysfunction because of congenital or acquired disability

Congenital or birth impairments affect sexual development due to lack of privacy and independence in daily living. Social interaction is less and sexual confidence is missing. If there is an acquired disability the acceptance of situation is less and there is greater anxiety relating to altered body image. Process of adjustment is completely different.

Hidden impairment

Women with an impairment that is hidden from others but which affects continence or sexual function often find the situation unbearable. People with spina bifida and perineal paraplegia often walk without apparent difficulty but experience problems with sexual function and with controlling their bladder and bowel. The unpredictability of control often leads them to avoid

social mixing, therefore increasing their isolation. People with disabilities often present with low self confidence and a poor body image, and so clinicians should not confuse the severity of a condition with the severity of its impact on the patient[lxxxviii].

What can be done?

When evaluating sexual dysfunction, clinicians should consider the range of cognitive as well as physical influences on sexual expression.

Sexual counselling can help in improving sexual self concept.

Soft touch of areas that have preserved sensation, erotic videos, and sensual music can help stimulate sexual desire. Couples may find gentle touching of all areas arousing, sharing in the knowledge that they are being touched by each other.

Altering analgesic regimens to permit sexual activity during periods of maximum pain relief can help. Women with some chronic conditions experience increasing fatigue at different times of day and it would be recommended to avoid attempting sexual activity during these periods.

Slow and gentle muscle stretching can help relieve spasticity and can become an important part of foreplay.

It is important for health care providers to be sensitive and ask about such topics as sexual expression is a normal part of the lives of all human beings.

Sexuality must be taken seriously as a part of standard rehabilitation care and that professionals bring up the issue of sexuality during the rehabilitation process.

Disability services and general practitioners must address the sexual needs of not only the patients but also their partners at times of need.

Legal Framework, National and International Treaties, Declarations and Strategies

There are many international and regional human rights treaties that try to protect the sexual and reproductive health and rights of girls and women with disabilities. These include the rights to:

- Life
- Health, including sexual and reproductive health
- Privacy, liberty and security of the person, and to decide the number and spacing of children
- Information and education, including information and education on sexual and reproductive health
- Equality and non-discrimination
- Accessibility
- Enjoy the benefit of scientific progress
- Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Right to informed consent

Constitution of India

The Constitution of India under Chapter III guarantees fundamental human rights to all persons. The right to equality is enshrined in Article 14 of the Constitution and recognizes that all persons are equal before the law. Persons with disabilities are entitled to this guarantee to not be discriminated against in any manner and to be treated equally which includes the requirement for special treatment where required.

UNCRPD

On May 3, 2008, the U.N. Convention on the Rights of Persons with Disabilities entered into force and in the same year India ratified the Convention. The Convention enumerates many rights that relate directly to sexuality, including the right to health; the right to liberty and security of person; freedom from exploitation, violence, and abuse; and respect for home and the family. It also contains an article specific to women with disabilities and an article mandating awareness-raising to combat stigma (UNITED NATIONS, 2006a).

Article 2 - Definitions

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the

recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

“Reasonable accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

“Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Article 3 –General Principles

Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.

Article 9 –Accessibility

To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia: (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces; (b) Information, communications and other services, including electronic services and emergency services.

Article 12 -Equal Recognition before law

States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. States Parties shall take appropriate measures to

provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Article 16 – Freedom from exploitation, violence and abuse.

States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. 4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

Article 22 – Respect for privacy.

States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 23 – Respect for home and the family.

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized; (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided; c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

Article 25 – Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States

Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

CEDAW

The Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) is an international treaty adopted in 1979 by the United Nations General Assembly. Described as an international bill of rights for women, it was instituted on 3 September 1981 and has been ratified by 189 states. India ratified CEDAW Treaty in 1994.

The Preamble of the Convention on the Elimination of All Forms of Discrimination against Women states that "…discrimination against women violates the principles of equality of rights and respect for human dignity, is an obstacle to the participation of women, on equal terms with men, in the political, social, economic, and cultural life of their countries, hampers the growth of the prosperity of society and the family and makes more difficult the full development of the potentialities of women in the service of their countries and of humanity." The Convention is also concerned that women in poverty have the least access to food, health, education, training, and opportunities for employment and other needs.

Article 1 gives a definition of discrimination against women: "the term "discrimination against women" shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field".

Article 2 (a) provides that States Parties undertake to "…embody the principle of equality of men and women in their national constitutions or other appropriate legislation if not yet incorporated therein and to ensure, through law and other appropriate means, the practical realisation of this principle." Article 2 (b) states that States Parties undertake "…to adopt appropriate legislative and other measures, including sanctions where appropriate, prohibiting all discrimination against women."

CEDAW 12(1) States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health services, including those related to family planning.

About disabled women in its General Recommendation 18 (1991) of the Committee on the Elimination of Discrimination against Women (CEDAW) recommends that States parties provide information on disabled women in their periodic reports, and on measures taken to deal with their particular situation, including special measures to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life.

The Committee also asks CEDAW state parties to report on "measures they have taken to ensure that disabled women have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life."

Disability organizations also have written shadow reports for the Committee that focus on the situation of women and girls with disabilities in their countries. The Committee can use these shadow reports to evaluate the overall implementation of CEDAW in the country. **Writing a shadow report for the CEDAW committee can be one way to bring wider public attention to the unique human rights challenges confronting women and girls with disabilities of the country.**

Convention on the Elimination of All Forms of Discrimination Against Women and its Optional Protocol: A Handbook for Parliamentarians can help parliamentarians to learn how to create laws that protect the human rights of women. When focusing on the legislation needs of women and girls with disabilities, it may be best to use this handbook in conjunction with *Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities.*

Intersection of UNCRPD and CEDAW

In 2018 the UN Committee on the Rights of Persons with Disabilities (CRPD) and the Committee on the Elimination of All Forms of Discrimination against Women (CEDAW) released a joint statement on the need for all states parties to guarantee sexual and reproductive health and rights for all women, in particular women with disabilities. It was

recalled that gender equality and disability rights are mutually reinforcing concepts and States parties should guarantee the human rights of all women, including women with disabilities. As such, States parties have an obligation to respect, protect and fulfil the rights of women, including women with disabilities, in relation to their sexual and reproductive health and rights[lxxxix]. States must ensure the enjoyment of their sexual and reproductive health and rights without any form of discrimination. Women with disabilities should also have access to safe and legal abortion, as well as related services and information for their sexual and reproductive health maintenance. All this is a precondition for safeguarding their human rights to life, health, and equality before the law and equal protection of the law, non-discrimination, information, privacy, bodily integrity and freedom from torture and ill treatment.

Covenant on Economic, Social and Cultural Rights (CESCR)

India ratified the International Covenant on Economic, Social and Cultural Rights (CESCR) in 1979. The Committee on Economic, Social and Cultural Rights in its 1994 General Comment No.5 on Persons with Disabilities referred to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly on 20 December 1993, stating that 'persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood'. The Committee stressed that 'both the sterilisation of, and the performance of an abortion on, a woman with disabilities without her prior consent are serious violations of article 10 (2) [of the International Covenant on Economic, Social and Cultural Rights]'.

Covenant on Civil and Political Rights (CCPR)

India ratified the International Covenant on Civil and Political Rights (CCPR) in 1979. In its General Comment No. 28 [Equality of rights between men and women], the Human Rights Committee which monitors compliance with the CCPR clarified to States parties that forced sterilisation is considered to be in contravention of CCPR Articles 7, 17 and 24. The Committee stated in part that ….. 'To assess compliance with article 7 of the Covenant, as well as with article 24…. States parties should [also] provide the Committee with information on measures to prevent forced abortion or forced sterilization……The information provided by States parties on all these issues should include measures of protection, including legal remedies, for women whose rights under article 7 have been violated.' The Committee further stated: 'States parties must provide information to enable the Committee to assess the effect of any laws and practices that may interfere with women's right to enjoy privacy and other rights protected by article 17. Areas where States may fail to respect women's

privacy relates to their reproductive functions, for example where general requirements are imposed for the sterilization of women.

Incheon Strategy

Goal 6 of Incheon Strategy mentions about gender equality and women's empowerment. Target 6.C calls for the state parties to ensure that all girls and women with disabilities (WwDs) have access to sexual and reproductive health services on an equitable basis with girls and women without disabilities and Target 6.D calls for increase in measures to protect girls and women with disabilities from all forms of violence and abuse[xc].

The Beijing Declaration and Platform for Action

The Beijing Declaration promotes fundamental human rights for women.

Article 9 provides that the Parties are committed to: "…ensure the full implementation of the human rights of women and of the girl child as an alienable, integral and indivisible part of all human rights and fundamental freedoms."

Article 13 speaks of the full participation of women in all spheres of society. Article 14 provides that women's rights are human rights. Article 17 is of significant importance in that it recognises a woman's right to control all aspects of her health. Article 26 addresses the problem of women and poverty. It states that the Parties are determined to "…eradicate the persistent and increasing burden of poverty on women…". Article 29 focuses on preventing and eliminating all forms of violence against women and girls. Article 32 provides that Parties commit to "…intensifying efforts to ensure equal enjoyment of all human rights and fundamental freedoms for *all women and girls* who face multiple barriers to their empowerment and advancement because of factors such as (…) *disability*."

Article 2 of the Beijing Platform for Action states that: "…the human rights of women and of the girl child are an inalienable, integral and indivisible part of universal rights (…) the Platform seeks to promote and protect the full enjoyment of all human rights and the fundamental freedoms of all women throughout their life cycle." Chapter IV, article 46 recognises that women "…face barriers to full equality and advancement because of factors such as their (…) *disability*."

RPWD ACT 2016

Chapter V Section 25. (1) of RPWD Act 2016 clearly states that the appropriate Government and the local authorities shall take necessary measures for the persons with disabilities to

provide (a) free healthcare in the vicinity specially in rural area subject to such family income as may be notified; (b) barrier-free access in all parts of Government and private hospitals and other healthcare institutions and centres. Section 25 2(f) mandates states to take measures for pre-natal, perinatal and post-natal care of mother and child and 25 2(k) calls for sexual and reproductive healthcare especially for women with disability.[xci]. Sec 7 of RPWD ACT 2016 instructs the Government to take appropriate measures in order to protect persons with disability from any sort of abuse, violence or exploitation

Sustainable Development Goals and SRHR

There are several targets that relate directly to SRHR, as well as those that have aspects of SRHR demonstrating the cross-cutting nature and importance of SRHR to achieving sustainable development for all. Women with disabilities cannot be excluded from this.

The specific targets that relate directly to SRHR are:

Goal 3. Ensure healthy lives and promote well-being for all at all ages
Targets:
3.1 By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births
3.3 By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, waterborne diseases and other communicable diseases
3.7 By 2030, ensure universal access to sexual and reproductive healthcare services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes.
3.8 Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all
Goal 5. Achieve gender equality and empower all women and girls
Targets:
5.1 End all forms of discrimination against all women and girls everywhere
5.2 Eliminate all forms of violence against all women and girls in the public and private spheres, including trafficking and sexual and other types of exploitation
5.3 Eliminate all harmful practices, such as child, early and forced marriage and female genital mutilation
5.6 Ensure universal access to sexual and reproductive health and reproductive rights as agreed in accordance with the Programme of Action of the International Conference on Population and Development and the Beijing
Platform for Action and the outcome documents of their review conferences.

Components of SRHR can also be found in other goals. SRHR cuts across all areas of sustainable development and is of utmost importance to achieve 2030 Agenda. Many targets of the Agenda are necessary for establishing a conducive environment where SRHR could be realized. This includes, for example, the following:
Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all
Targets:

4.1 By 2030, ensure that all girls and boys complete free, equitable and quality primary and secondary education leading to relevant and effective learning outcomes

4.5 By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations

4.7 By 2030, ensure that all learners acquire the knowledge and skills needed to promote sustainable development, including, among others, through education for sustainable development and sustainable lifestyles, human rights, gender equality, promotion of a culture of peace and nonviolence, global citizenship and appreciation of cultural diversity and of culture's contribution to sustainable development

Goal 6. Ensure availability and sustainable management of water and sanitation for all

Target:

6.2 By 2030, achieve access to adequate and equitable sanitation and hygiene for all and end open defecation, paying special attention to the needs of women and girls and those in vulnerable situations

Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all

Target:

8.5 By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value.

Goal 10. Reduce inequality within and among countries

Targets:

10.2 By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status

10.3 Ensure equal opportunity and reduce inequalities of outcome, including by eliminating discriminatory laws, policies and practices and promoting appropriate legislation, policies and action in this regard

10.4 Adopt policies, especially fiscal, wage and social protection policies, and progressively achieve greater equality.

Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels

Targets:

6.1 Significantly reduce all forms of violence and related death rates everywhere

16.2 End abuse, exploitation, trafficking and all forms of violence against and torture of children

16.3 Promote the rule of law at the national and international levels and ensure equal access to justice for all

Recommendations

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Within the renewed commitment of primary health care, we need to look at the intersection with sexual and reproductive health and rights and bring it in an integrated way to help increase access to comprehensive services, and also integrate with other sectors to achieve the SDGs.

In order to achieve three pillars of sustainable development: social, economic, and environmental issues countries around the world need to address the issues concerning 4.3 billion people of the world at reproductive age, otherwise, we will not be successful. In a lot of places, access to sexual and reproductive health services is very limited. There may be access to a single component, such as family planning or adolescent services, abortion services or maternal health services, without having all the components of sexual and reproductive health.

Government agencies, non profit organizations, healthcare establishments and the community need to work together or in partnerships with all the stakeholders to integrate sexual and reproductive health and rights of women with disabilities in the broader health systems of the country.

General recommendations

- Commitment of universal access of sexual and reproductive health services.
- Physical infrastructure must be improved according to the needs of people with disabilities. This may sometimes require working on modifying the design of the hospitals facilities.
- Providing accessible transportation to persons with disabilities.
- Ensuring appropriate accessibility while constructing new clinics and hospitals.
- The whole issue of public-private partnerships is very important. Even though in primary health care, the government should take responsibility to ensure the basic rights of the people, public-private partnerships are another way resources can be mobilized. Non-government, private hospitals and profit-making organisations should join hands with government in funding health requirements for women with disabilities.
- Consultation fees need to be lowered to allow women with disabilities to reach health facilities.
- Provision of healthcare insurance for persons with disabilities
- More information platforms for women with disabilities should be established.

- Political participation of women with disabilities must be encouraged so that they can better voice the issues that affect them.
- Undertake an intersectional development programme on the reproductive and sexual health needs of young women, girls and disabled students
- Create national standards for reproductive health and sexual policy that explicitly meet the needs of disabled women and girls.

Procedural changes

There is need for process optimisation where some processes can be made easier for persons with disabilities like having a one stop where persons with disabilities can get all services at once from registration to treatment and prescriptions. This can reduce the movement and number of processes that a person with disability has to access within the facility. Viable separate facilities can be provided for women with disabilities where they get the one-stop care and/or services.

Provision of Comprehensive Sexuality Education

Materials on SRH and other health related information should be adapted in order to ease access since most of the materials for information are geared towards people who can see or hear like audio and pamphlets. The main issues can be translated to Braille while audio more and advanced visual aid can be used for women who are deaf and hard of hearing. Introduce mandatory, age-appropriate, and inclusive sexuality education in school curricula, using resources designed in collaboration with disabled women and girls

Specific recommendations to provide SRHR to WwDs

- Government, health and social care bodies should work together to:
- Ensure capacity building of health and social care professionals about disabled women's sexual and reproductive health needs through development of continuing professional development resources.
- Create a disabled women's reference group to advice on the planning of reproductive, sexual and maternal health services, infrastructure, and new and improved accessible resources.
- Ensure that reproductive, sexual, maternal and perinatal health services are resourced with specialist equipment and accessible signage.
- Introduce Routine Enquiry forms along with removing procedural hassles for users at every appointment/care plan/review or informal chat.
- Create a pool of sign language interpreters to work with disabled women accessing reproductive, sexual, maternal and perinatal health services.
- Develop clear protocols to eliminate harmful forced practices regarding disabled women and girls' reproductive rights and health across health, care and legal

sectors. In India, while there are Ministry of Health guidelines for the sterilisation of men and women, there are no explicit and clear provisions against forced sterilisation of girls and women with disabilities.[xcii]

- Create and implement checks and accessible consent processes to guarantee free, prior and informed consent and shared decision making in all reproductive and sexual health operations and treatments
- Update relevant strategies, policy frameworks and service standards to reflect the reproductive, sexual and maternal health needs of disabled women and girls
- Undertake research to fill substantial knowledge gaps regarding disabled women's reproductive, sexual and maternal health to inform future policy and practice.

Recommendation to tackle violence against disabled women

- Government, non profit organizations and health bodies need to work together to:
- Ensure that disabled women and girls' specific experiences are reflected in health care plans.
- Develop resources for medical professionals around the needs of disabled women who report sexual violence and abuse.
- Disabled people's or disabled women's organisations and rape crisis centres and women's aid groups need to improve working relationships among themselves.
- Improve physical and infrastructural accessibility of police stations and courts.
- Improve provision of appropriate equipment, procedures and accessible information within healthcare services regarding violence against disabled women.
- Impart focussed trainings to police and judicial staff including lawyers and judges on the issues faced by women with disabilities and the remedial measures.

Conclusion

Sexual and reproductive health is a critical component of any woman's health. It is widely acknowledged that reproductive health is a concern for all and more so for women with disabilities, with a rise in cases of reproductive health issues. This include rising cases of breast, cervical, ovarian and other forms of cancers, that can be prevented or treated if detected on time. This would require women with disabilities having the knowledge on these services and having friendly health facilities to seek the services.

The importance of validating a disabled patient's sexual identity must be stressed. The physician can provide this validation by initiating discussion of the woman's sexual function and of safer sexual practices. Unfortunately, many physicians fail to initiate such discussion and respond to concerns voiced by the patient herself by suggesting that she consult another health professional (e.g., a psychologist).

For women with cognitive disabilities the challenge is enormous, particularly if insight and self-awareness are impaired. An awareness of social subtleties such as eye contact and a sense of personal space may be inadequate, and behaviours that promote acceptance by other people may have to be learned. This can be difficult for women with attention deficits that prevent them from screening out distractions. Physicians referring a patient with a cognitive disability to other health care providers can point out that the patient may well have sexual needs and may need help in establishing appropriate relationships.

The sexuality of people with disabilities, many of whom require varying degrees of assistance to lead fulfilling sex lives, continues to be overlooked, avoided or even dismissed as a component of holistic care because of a longstanding stigma that shrouds disability and sex. A dearth of resources, training and infrastructure to guide caregivers and patients in addressing sexual needs contributes to the problem

Appendices

Appendix 1: General Self-care Steps during PMS

- Take a pain killer (as advised by your physician) if you have headaches, backaches, cramps, or breast tenderness.
- Limit salt and drink plenty of fluids.
- Avoid caffeine and alcohol.
- Try eating smaller, more frequent meals to reduce bloating.
- Try to exercise (only those which your body can tolerate or your doctor recommends you)
- Try to move around in fresh air
- Try to socialise and discuss common experience
- Get enough sleep.
- Look for ways to manage your stress.
- Eat plenty of fruits, vegetables, pasta, and whole-grain breads and cereals.
- Take a daily multivitamin that includes 400 mcg of folic acid.
- Choose low-fat or non fat dairy products

Appendix 2: Changes in positions for changing sanitary pads/ tampons

1. A women sitting on a wheelchair may be able to use tampons independently if she can pull her pants down. She then must sit right on the front edge of her seat. Good practice is required to manage tampons in this position.
2. Pads must be placed well underneath because the menstrual flow is inclined to run to the back both in a standing and a seated woman, especially in a wheelchair with its backward tilt.
3. A woman, who cannot lean over to reach her perineum, may need a raised toilet seat so that she can place a pad or a tampon. If she lacks sensation, she may also require a mirror angled so that she can see underneath, and if she has spasticity, she may require a knee spreader to keep her legs abducted. She can be taught to lean sideways using a raised toilet seat.
4. If a woman's balance is poor and she is unable to reach forwards, or if she is unable to get up again if she rests her trunk on her knees, she may need to lean sideways, and perhaps hold on to a bar or her wheelchair at the side. Both of these positions allow tampons to be used. Both of these positions also require transfers from wheelchair to toilet, and of course the problem remains of pulling down pants, and pulling them up again.
5. Some women cannot balance well enough on a toilet, and may require use of both the hands due to problems in dexterity. For such women it would be easier to transfer to a bed to change pads or tampons rather than doing it on wheelchair or toilet seat.
6. Women who have problems of coordination such as those with cerebral palsy can kneel so that they can stabilize themselves sufficiently to cope. This position can be two-point or three-point kneeling since one hand must be free. But if public facilities are used, this can be very unpleasant if they are unclean or littered. This may also be very embarrassing if the cubicles have wide gaps underneath.
7. A woman with spasticity or loss of balance may be able to stand with the help of a grab bar, and if she can hold on with one hand only, she would be able to manage pads or tampons. Some method of retrieving pants may be required, unless the woman can reach down for them. Skirts can be equally difficult because they have to be held up, usually with the teeth, and also obscure vision.
8. Women with cerebral palsy, multiple sclerosis, or spinal cord injury with spasticity may be able to raise their buttocks from the wheelchair, but since this usually requires two hands, it is convenient to take help.

Appendix 3: Tips to remain hygienic during menstruation

1. The vagina has its own cleaning mechanism and it has a very fine balance of good and bad bacteria. Washing it with soap can kill the good bacteria.
2. Always wash or clean the area in a motion that is from the vagina to the anus.
3. It is necessary to discard used napkins or tampons properly because they can spread infections.
4. Try to stay dry during periods. Change pads regularly and stay dry. Apply an antiseptic ointment, after a bath and before bed. Visit a doctor in case of severe rashes.
5. Those who have heavy flow during their periods do not use two sanitary pads or a tampon and sanitary pad or a sanitary pad along with a piece of cloth.
6. Bathing not only cleanses the body but also gives a chance to clean the private parts well. It also relieves menstrual cramps, backaches, helps improve the mood and makes one feel less bloated.

Appendix 4: Tips for parents and caregivers for menstrual management of girls/women with disabilities

One needs to consider the following points:

1. While talking about menstruation, the tone of voice, as well as the words used, should be very influential.
2. Television and magazine advertisements may help to illustrate some of this information.
3. Try to use “anatomically correct” dolls when providing explanations for some young women.
4. Personalised books can be another useful approach.
5. Never reinforce negative reactions to the sight of blood.
6. Encourage modest behaviour while bathing, dressing and toileting.
7. Encourage interactions with the young woman of same age.
8. Encourage appropriate (that is, in private) masturbation behaviour if it is occurring.
9. Ensure consistency of approach in menstrual management.
10. If your daughter has visual disability then you must try covering your eyes and do the things you're teaching your daughter.
11. Teach her to ask a friend or her teacher if she's unsure whether or not she has a stain that's visible to others.
12. A visually impaired girl may need some more detailed explanations if she can't see the pictures and diagrams.
13. For girls with autism carers might need to tell her whom to go to at school if her periods start there. It’s a good idea to start talking about it early. Teaching simple phrases like *'You will bleed every month' and 'Blood is not dirty or ‘It is clean'* can be an effective way to break down more complicated ideas.
14. If your child uses visual supports, a visual schedule that shows the steps involved in changing a reusable cloth, pad or tampon can be useful. It will also help if you show your child where to attach the cloth or sanitary pad – you could mark her underwear to show where it goes.
15. Once your child’s periods have started, you could teach how to use a calendar or an app to plan when her period is due.
16. Self care is the most important thing to focus on at this age. One lesson plan must focus on preparing the girl for menstruation by teaching her how to change her own sanitary napkin. This must be started when she is still small because rate of acquisition is very slow in developmental and intellectual disabilities.

17. Keep a list of activities or objects which each woman enjoys. Some of these can be planned for when the woman has her period. This may help her to associate periods with pleasant experiences.
18. Enjoyable activities may also direct attention away from discomfort, or inappropriate menstrual behaviours.
19. It may be appropriate to assist the woman to start using pads a few days before her period is due. This may help to communicate to some women that menstruation will soon begin.
20. Changes to the environment can signal to a woman that her period is due. Playing distinctive soothing music, burning a relaxing essential oil, giving her a daily massage in the days before and during a woman's period, may communicate to her in a pleasant way that her period is due.
21. Before you change her pad, tell her what you are going to do and give her the object or tangible symbol that has been chosen to symbolise "change of pad" for her. Try to do so in a similar private place.
22. Show her a full packet of pads at the start of her period. Each time that her pad is changed, show her how to packet is becoming less full. On the last day of her period, show the woman the almost-empty packet. When the packet is empty, she may be able to help dispose of it in the bin.
23. Every step of the process has to broken down into its simplest elements. This can be done many times a day for practice. Try that she is not scared. For e.g.

    - ✓ Putting the sanitary napkin in a purse
    - ✓ bringing the purse to the bathroom,
    - ✓ sitting on the toilet
    - ✓ removing the paper from the back of the pad

24. Use positive language around menstruation. Never use negative connotations like "the curse". Your own attitudes around menstruation can influence how your girl feels about it too.
25. Children with ASD often fear change and unpredictability so it is important to make menstruation part of our dialogue with your children. Preparation process is key to reduce anxiety
26. Introduce the 28-day cycle calendar after menstruation starts to build in awareness and predictability of when menstruation will happen.
27. Help your daughter to manage the emotional symptoms of PMS by letting her know how she might feel. Pictures to illustrate these feelings might be useful.

28. If your daughter understands the reasons of these symptoms and their length it may be useful for her to be in control of her changing body. For example, *'You are looking uncomfortable today. I wonder if your period is coming soon'*.
29. Shaving pubic hair is not necessary for hygiene reasons.
30. It's fine to talk about menstruation, but teach her that there is a time and place.

Appendix 5: Different Positions for pelvic examination[xciii]

The Stirrups Position

Obstetrical stirrups provide more support than the traditionally used stirrups. This position allows a woman who has difficulty using the foot stirrups to assume the traditional pelvic exam position. The woman may need help in putting her legs into the stirrups. The stirrups can be padded to increase comfort and reduce irritation. A strap can be attached to each stirrup to hold a woman's legs securely in place if the woman needs more support or has spasticity.

The M·Shaped Position

The patient lies with her entire body supported by the table. The woman lies on her back; knees bent and apart, fee t resting on the exam table close to her buttocks.

If the woman's legs are not completely stable on the exam table, an assistant may support her feet or knees. If a woman has two leg amputations, an assistant may elevate her legs to simulate this position. Women who have trouble with their hips may find this position easier. In women with cerebral palsy and spinal cord injury muscles can suddenly get stiff during the exam. Caregivers and assistants can try to hold the legs during the exam and help the women to relax her muscles.

The V-Shaped Position

The patient must lie comfortably on her back with her straightened legs spread out wide to either side of the table, or she can hold one leg out straight and keep one foot in a stirrup. One or two assistants are needed to support each straightened leg at the knee and ankle. The patient may be more comfortable if her legs are slightly elevated or if a pillow or rolled up towel is used under her back or tailbone.

The Diamond-Shaped Position

The woman lies on her back with her knees bent so that both legs are spread flat and her heels meet at the foot of the table. The assistant may help the patient support herself on the table and hold her feet together in alignment with her spine to maintain this position. A

woman may be more comfortable using pillows or an assistant to elevate her thighs and / or use a pillow under the small of the back.

The Knee-Chest Position

This position is good for a woman who feels comfortable and balanced lying on her side. The patient lies on her side with both knees bent, her top leg brought closer to her chest; or her bottom leg can be straightened while the top leg is still bent close to her chest. After speculum is removed, the woman will need to roll onto her back. The assistant may provide support for the patient while she is on the exam table, help the woman straighten her bottom leg if necessary, or support the patient in rolling onto her back. If the patient cannot spread her legs, the assistant may help her elevate one leg.

Appendix 6: Tips for breastfeeding

Support staff, nurses and doctors can educate women with disabilities to breastfeed the newborn baby.

A woman who is unable to hold her baby may feel better control over the baby and breastfeeding when lying down as opposed to sitting up.

Pillows can be used to support arms and/or upper body. If woman's breasts are large, pillows or rolled up towels can be used underneath her breast for support.

Make sure the baby, especially the baby's head, is well supported and that you sit or lie in a position that is comfortable for you.

If a woman cannot use her arms and upper body, she can breastfeed with help from family members or friends. Some can be asked to hold the baby in position, especially the baby's head.

A 'nursing bra' made to support the breasts and with a way to cover and uncover the nipple for breastfeeding should be used.

If the woman is unable to breastfeed her baby, she should be taught to remove milk from her breasts by hand and feed it to her baby using a bottle or a cup. If she is unable to remove the milk by herself, she may someone to help her.

Appendix 7: Some important points for disabled women of sexual minority group

- Lesbian and bisexual women with disabilities don’t have proper information in the absence of accessible sexuality education. They need to be informed not to have unprotected sex unless they are certain about themselves and their partners.
- Testing is important because many people don't know they're infected, and others might not be honest about their health.
- During oral sex a small piece of latex (dental dam) or a barrier must be used.
- Sex toys must be washed properly with hot soapy water between uses or cover them with a fresh condom. During digital vaginal or anal penetration, a glove should be used.
- Another reliable way to avoid sexually transmitted infections is to stay in a long-term mutually monogamous relationship with a partner who isn't infected.
- Alcohol and drugs should be avoided. Needles should not shared while using injectable drugs
- Vaccinations can protect from hepatitis A and hepatitis B. The HPV vaccine is available to women up to age 26.

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