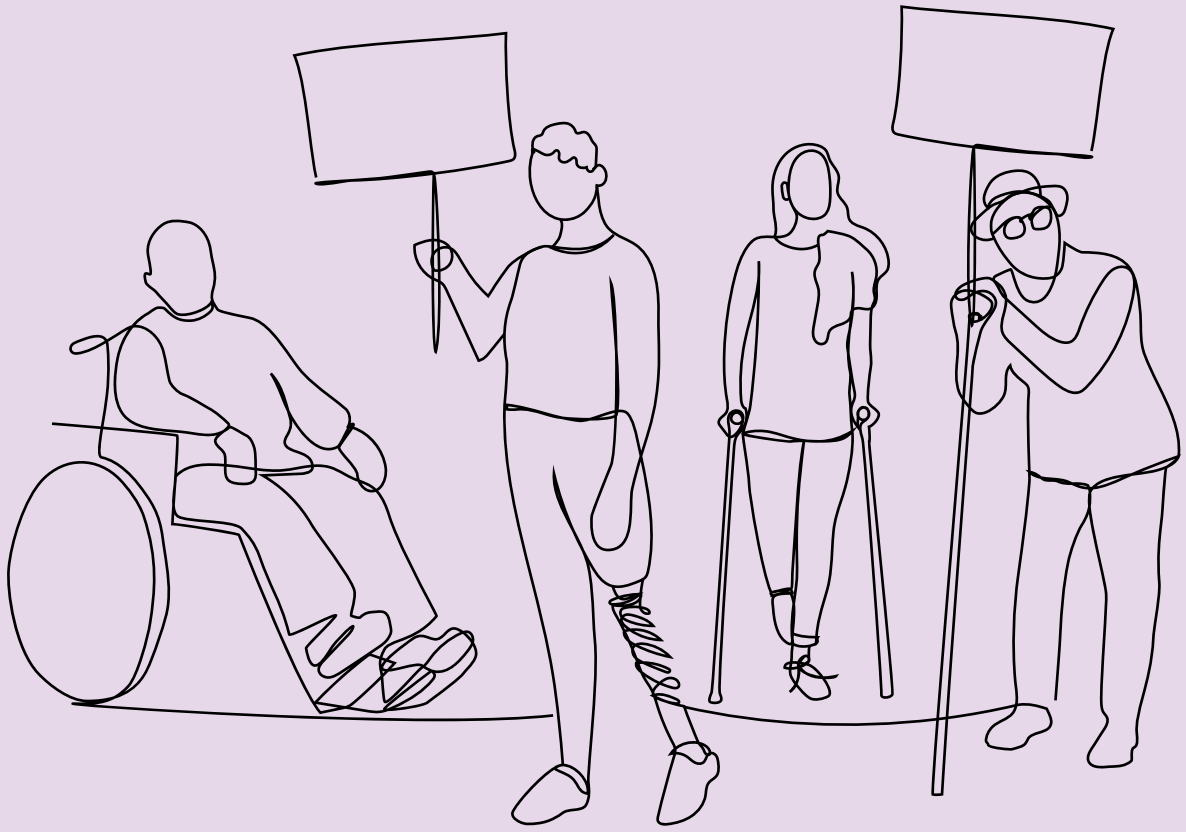
ENFOLD PROACTIVE HEALTH TRUST

DEMYSTIFYING SEXUALITY HANDBOOK

–

FOR STUDENTS AND TEACHERS OF SPECIAL EDUCATION, AND SPECIAL EDUCATORS



For use in conjunction with Demystifying Sexuality Reference Book
Looking at sexuality with a Rights-based, Restorative and Gender Transformative Lens

enfold

Demystifying Sexuality Handbook - for students and teachers of Special Education, and Special Educators

For use in conjunction with

Demystifying Sexuality Reference Book

– Looking at sexuality with a

Rights-based, Restorative and Gender Transformative Lens

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This Handbook is part of a project aimed at preventing gender-based violence by developing and implementing a formal curriculum for teachers and students of undergraduate and graduate studies from nursing, social work, psychology, education, special education and allied disciplines. As envisaged in the project, this curriculum is based on gender equity, personal safety and sexuality education and has been developed using rights-based, restorative and gender transformative approaches. We gratefully thank Ford Foundation for supporting this project.

Introduction

Sexuality in persons with disabilities, like for everyone else, is an essential aspect of their lives and can't be neglected. Though comprehensive sexuality education (CSE) is an important component of educational curriculum, young people with disabilities receive little to no formal education on this, either in school or at home. Sexual health and safety of persons with disabilities is also not prioritized because educators are more focused on other aspects of the students' well-being.

This is where the role of a special educator becomes significant. Special educators are in the unique position of being aware of their student's different abilities as well as learning styles, and are well-positioned to support decisions on when and how much sexuality education a young person may receive. Parents and caregivers of young persons with disabilities may not always be able to provide required and appropriate sexuality education to their children. Special educators can engage such parents or guardians in developing a plan of instruction that is positive, rights-based and gradual, and takes into account the individual young person's developmental and maturity levels. The educator can also engage family members in empowering discussions, especially when their beliefs and values are contrary to the rights of the persons with disabilities.

However, it is possible for special educators to themselves be bewildered by the sexual expression and behaviour of children with disabilities. They may become evasive or silent when it comes to having a dialogue with students on the topic, and have little to no teaching resources on sexuality education for them. It is common for teachers to face difficulties in the classroom regarding discussing aspects of sexuality with students, either due to lack of awareness or beliefs rooted in myths. Although they recognize it as relevant, they may have difficulties in taking on the role of imparting sexuality education to students with disabilities due to lack of personal or academic preparation, or even out of fear of the reaction of the students' families.

Sometimes, the educator's own attitudes or biases towards the subject interfere with them having a discussion with their students and they may not feel comfortable talking about sex and sexuality with young people with disabilities. Unless educators are well-trained to answer questions and provide appropriate sexuality education without hesitation and flinching, students with disabilities are unlikely to learn about how to figure out information on sex and sexuality on their own.

Educators can provide young people with opportunities to learn about the pleasures and responsibilities of exploring and experiencing one's sexuality as well as the socio-cultural and political aspects of it. In order to do this, educators need to have the resources and available support to modify and adapt programs to meet the needs of their students. They can support young people by providing them with scientific information, challenging them to look at their own attitudes and behaviours, and helping them develop the skills they need to adopt healthy behaviours and to stay safe now and in the future.

Enfold Proactive Health Trust has been running its 'Demystifying Sexuality' course since 2007 - the first step in Enfold's multi-level comprehensive sexuality and personal safety educator

training program to empower adults. We have developed the 'Demystifying Sexuality Reference Book' as a basic, theoretical foundational reading material for our trainees - especially teachers and students of undergraduate and postgraduate courses like Social Work, Psychology, Nursing, B.Ed and Special Education. Handbooks customized to the practitioners of each of these disciplines have also been developed.

The 'Demystifying Sexuality Handbook - for students and teachers of Special Education, and Special Educators' has been specially developed for teachers and students of B.Ed/ Diploma in Special Education. This manual is to be used in conjunction with Enfold's above-mentioned 'Demystifying Sexuality Reference Book'. This handbook addresses (1) the sexual and reproductive rights of persons with disabilities in greater detail, (2) discusses the topics covered in the 'Demystifying Sexuality Reference Book' in the context of disability and (3) explains why it is important to provide sexuality education to persons with disabilities.

Objectives of this handbook:

- To inform special educators about concepts and issues related to sexuality, gender, rights, sexual and reproductive health, and life skills, in the context of disability;
- To enable educators to develop greater comfort and ease in discussing sexuality-related issues and relationships;
- To enhance educators' understanding of the sexual needs of persons with disabilities

Structure of the handbook:

Information about the topic in the context of disability is followed by case studies and key messages. The handbook covers basic concepts along with more complex issues combining information on sexuality, sexual and reproductive health and rights to elicit discussion and build clarity and understanding for participants on a variety of subjects and topics like:

- Structure and Function of Sexual and Reproductive Systems
- Diversity in Sex, Gender and Sexuality
- Gender bias
- Sexual and Reproductive Health Issues
- Sexual Development in Children and Adolescents
- Attitudes towards Sexuality, Sexual Preferences and Practices
- Sexuality and Disability
- Sexual Relationships
- Intersectionality
- Sexual Violence
- Life Skills, Body Image and Self-Esteem
- Rights and Laws

While this handbook broadly follows the flow of the chapters in the Demystifying Sexuality Reference Book, the order has been changed for some chapters, additional chapters have been added or extra focus placed on some topics to meet the purpose of this handbook.

Limitation of the work

Topics and issues considered and elaborated upon in this handbook are but a few, and by no means exhaustive. Disabilities are varied and the situation and experience of each individual is unique. Kindly refer to other works to learn more about specific issues.

The **positionality** of the writers and reviewers, as well as the limited field of work that Enfold Team members have been engaged in, are major drawbacks of this work. Though we attempted to bridge this gap by inviting reviewers from diverse fields with different domain knowledge, the work would likely fall short on several counts given that the topic of sexuality is vast and the knowledge and experience of people in this field is constantly expanding.

Language: We have consciously tried to use a gender-neutral language as much as possible, without resorting to discussing various topics in binary terms. For example, instead of girl/boy we have used 'child' and instead of her/him, we have used the pronouns 'they/them'. We have avoided the use of words like 'opposite'/ 'both' in the context of gender and sex, except when quoting or referring to studies that have used such terms.

Terminology used by different groups to describe their experiences and identities and disabilities is varied and changes over time. We remain committed to reflecting this diversity but recognise that terms used in this handbook may vary in their usage or become outdated. Readers might therefore notice that the tone of the content is rarely in absolute or conclusive terms. We have tried to present what is the current thinking around these topics, with the acknowledgement that there may be multiple other perspectives, which may not have been represented. We are happy to receive observations from the readers as we believe these would help us in our future works.

References used in this handbook are from research studies conducted in different parts of the world and relevance may be very different in the Indian context. Due to a dearth of research in the area of disability that currently exists in India, we have had to cite articles, studies, papers etc. from scholars all over the world where there is a significant body of knowledge in this area.

Teaching-learning tools : This handbook does not include material on how to impart sexuality education to adolescents and young persons or the tools that could be used - for that, please refer to the Suvidha Manual and Suvidha toolkit developed by Enfold Proactive Health Trust.

Chapter 1. Structure and Function of Sexual and Reproductive Systems

While there exist a number of misconceptions about our sexual and reproductive systems, especially regarding their structure and function, there is a dearth of awareness about these systems when it comes to people with disabilities. For special educators, this information is crucial in order to fully understand the specific requirements of those with disabilities when it comes to their sexual and reproductive health. In this chapter, we discuss some common issues to show how these deserve special attention and awareness.

Spectrum of experiences with menstruation of women with disabilities

The topic of menstruation is often discussed in secrecy - if at all, and there are a number of misconceptions and myths around it. Rarely are people with disabilities who menstruate included in the little discussion we have on this topic. In this section, we highlight different experiences with menstruation that women and girls with different disabilities have in their lives. Let's take a few examples to elucidate this:

For people with Multiple Sclerosis (MS), certain drugs can cause them to have irregular menstrual cycles, unusually heavy or light flows, spotting in-between cycles or temporary cessation of menstruation (Cheriyedath, 2019). Some women who have MS find it hard to manage their menstrual cycles as they may have mobility issues or tremors, which may affect their ability to use menstrual hygiene products.

Girls with Down Syndrome may have irregular or heavy flow during menstruation (Jeffery et al., 2013). Young girls who have had Spinal Cord Injury (SCI) may have delayed menarche (Rutberg et al., 2007). Most women with SCI will resume normal menstruation within six months post-injury (Sipski, 1991). Emotional and behavioural changes during menstruation are also seen more often in teenagers with disabilities.

Once menarche occurs, girls with developmental disabilities may have physical challenges that may make menstrual hygiene difficult, or they may be unable to deal with menstrual pads. The teen may remove the pads in inappropriate places on account of a heightened sensory awareness of discomfort from the pads. Some may not be physically able to change their own pads, which may interfere with their ability to be independent. This may be seen in girls with cerebral palsy. Some of the girls may also have difficulty communicating about their menstrual cycle. Women with epilepsy often have increased menstrual irregularities (Bosak et al., 2018).

Premenstrual syndrome (PMS) is seen more often in women with intellectual disabilities (Cooper et al., 2019). PMS in adult women may include temper tantrums, crying spells or self-abusive behaviour. The person may require extra support with emotional regulation and management of these symptoms. Medical advice needs to be sought if symptoms warrant such support.

Some girls or women with visual impairments might mistake their period for vaginal discharge, especially if their cycles are irregular. They can predict the beginning of the cycle by recognising bodily symptoms of premenstrual syndrome - such as cramps, breast tenderness or emotional changes. They may have trouble telling if a pad or tampon needs to be changed. Charting and period tracking mobile apps can be useful for them. Girls or women with intellectual disabilities may have difficulty in understanding what is going on in their bodies. So, they may need more support in acquiring required skills.

The first time I got menstruation, it was really tough. I then found it hard to spot when I am bleeding. Slowly I came up with my own ways of finding out the date. Since the menstruation date changes slightly every month, and one cannot be certain about it, I do the following things to organize myself during menstruation:

I have low vision and I cannot spot the blood or stains. So, I always stay vigilant about menstrual cramps and smell. With practice, I now easily find out the difference between a regular stomach-ache and menstrual cramps. When you touch the discharge during or before periods, you get to know what it is by its thickness. Being a person with low vision, I check everything thrice, to be sure about hygiene and cleanliness.

I always have an intuition before I get my periods. I am sure each of us, visually impaired women, has our ways of measuring our dates and identifying its beginning. At the end of the day, everyone has different ways of assessing things and we also do. If you have the misconception that our family members must inform you about it, you need to shun that silly thought.

- Divya Sharma, 27, single, a woman with visual impairment

Challenges in managing menstruation for women with disabilities

Management of menstruation can be a difficult self-care task for girls/women with disabilities. They may face significant hygiene problems due to menstrual irregularities. Inserting and removing a tampon or menstrual cup or even a sanitary pad may not be simple or possible at all for some women with disabilities because of:

- Lack of sensation
- Limited WASH facilities (access to water, sanitation and hygiene) due to inaccessible toilets
- Spasticity
- Strength and dexterity loss

Apart from the above-mentioned issues, women and girls with disabilities may be less likely to gather relevant information themselves. Moreover, existing educational materials don't

necessarily include such information for women and girls with different disabilities or don't cater to their different learning requirements. Women and girls with disabilities also face challenges in accessing sufficient support, especially health services, and are also at the receiving end of discrimination and stigma, which we will discuss in later sections.

Menstrual management strategies for women with disabilities

Menstrual management refers to a range of strategies that women with disabilities can use during menstruation so that they feel comfortable with their menstrual flow and are able to manage their periods with dignity and privacy, as well as hygienically. Providing information in an accessible format is an initial step in effective preparation for menstruation.

Women with disabilities can learn and be supported in menstrual management in the following ways:

- Adjustment to position
- Modification in undergarments, tampons or pads
- Use of aids like mirrors or knee spreaders for changing pads or tampons.

They can also learn to take care of different aspects related to hygiene. Period-proof panties, pads and disposable panties can be considered, especially for those who don't feel sensation below the waist and can't detect leaks. Depending on cognitive ability, tampons and menstrual cups may not be the best collection methods as they require keeping track of time and might be forgotten after insertion. Period-proof underwear, pads and disposable underwear are worth trying.

Sometimes parent(s) or guardian(s) may consider medical procedures (stunting growth, hysterectomy, and/or sterilization). Such treatment is often sought to stop menstruation on the grounds that their menstruation is a hygiene problem. It should be remembered that most women with disabilities can learn to manage their own menstruation with appropriate education and support. Menstrual suppression should only be considered when other options have failed, or if there are significant gynaecological or other medical indications. The exception to this is when the woman herself requests such treatment and can demonstrate that she is capable of making an informed decision. However, it is still important to make sure that the woman and her family members are informed of the choices available, and the advantages and disadvantages of each. It's important to remember that methods of suppression do come with risks, and that these decisions are not made lightly.

Article 25 of the United Nations Convention on Rights of Persons with Disabilities clearly states that free and informed consent should be the basis for providing healthcare to persons with disabilities. The Committee on the Rights of Persons with Disabilities recommends, "the abolition of surgery and treatment without the full and informed consent of the patient" in one

of its first recommendations to a state party. If a person can't consent to an optional medical procedure, it's considered a human rights violation.

Pregnancy in women with disabilities

Due to a lot of stigma around disability, women with disabilities get negative reactions, verbal and non-verbal, from medical personnel, parents and caregivers if they decide to become pregnant as they are considered incapable of taking on the responsibilities of motherhood. However, contrary to popular beliefs, not only can women with disabilities become pregnant, they can also have normal labour and delivery experiences. Many may require advanced planning with the support of their families and health care providers, but it is possible to experience pregnancy.

That said, it is also important to thoroughly plan for conception due to the potential for health issues that may develop later. Provision of genetic counselling is important as many disabilities/disorders can be passed onto the baby from parents. For instance, muscular dystrophy (NHS, 2018). Those who take medication as part of the management of their disabling condition/s must have information about the effect of those medications on the foetus.

Those women who have mobility issues are at high risk for urinary tract infections, impaired balance and gait due to change in their centre of gravity, increased risk for falls, and changes in bowel and bladder management (Mitra et al., 2016). They are at an increased risk for pressure ulcers during pregnancy because of weight gain. Women with spinal cord injuries and Multiple Sclerosis may have potentially severe hypertension (Rabchevsky & Kitzman, 2011).

Women with intellectual disabilities have a high risk of adverse pregnancy outcome and should be considered a high-risk group (Hoglund et al., 2012). Caregivers need to be aware of this and provide tailored pre- and intra-partum care and support. Women with all kind of disabilities should be provided prenatal classes in accessible formats, like sign language interpretation for deaf women, so that their concerns about prenatal care, labour and delivery, and the post-partum period are addressed, including strategies or modifications that may be needed to enable them to care for their infants.

Women who have intellectual or developmental difficulties may have difficulty in understanding and following medical advice. They need longer or more frequent visits, enhanced monitoring and specialised support. The partners and other caregivers of women with disabilities need to be informed about modifications needed and specific childcare equipment that may be helpful for care for their infants.

It is possible that childbirth may pose challenges. In most cases, a vaginal delivery will be possible. Women with neurological disorders, such as Multiple Sclerosis (MS) or spinal cord injury that affect sensation often experience spasm, abdominal pressure and pain or discomfort

associated with contractions. Women with spinal cord injuries or musculoskeletal disabilities (e.g., spina bifida, osteogenesis imperfecta, cerebral palsy etc.) often have specific issues that may require special planning prior to receiving epidural anaesthesia for delivery.

For labour and delivery of a pregnant woman with disability, an integrative team consisting of obstetrician, anaesthetist, support workers and caregivers must be formed. The team would be required to upgrade their knowledge of sign language, use of assistive technology etc.

Breastfeeding with a disability

Individuals with disabilities may feel too weak to breastfeed or be unable to produce milk due to certain medications. Following are some challenges that may be confronted during breastfeeding:

- Positioning and attachment issues – due to fatigue, physical difficulties, overwhelming sensory issues and/or use of wheelchairs, catheters, the most common positions may be impractical and unhelpful.
- Lack of knowledge and information on how medication affects breast milk.

Some suggestions:

- Some women find breastfeeding easier if they sit in a chair or bed where they can lean back a little and also support their arms holding the baby.
- If the woman has limited use of arms and upper body, she may find it easier to lie on their side with the baby lying beside them, supported by pillows or rolled-up cloth.
- A 'nursing bra' made to support the breasts can be tried.
- Support can be sought from other people to enable breastfeeding.
- Milk can be expressed from the breasts manually or with the help of a breast pump and fed to the baby using a bottle or a cup. Animal milk or baby formula can be tried.

Postnatal depression in women with disabilities

Women with disabilities may be more likely to experience symptoms of postpartum depression (PPD) (Mitra et al., 2014). This depends on the health of mothers, severity of disability, level of independence, their relationships with their partners, and their ability to bond with their infants as well as long-term health and well-being of their infants.

Women with disabilities who have difficulty accessing maternity services are at an increased risk of pregnancy-related complications and are at a higher risk for adverse obstetric outcomes (Lipson, 2000; Blackford, Richardson & Grieve, 2000). Thus, the impact of PPD and its symptoms among them and their infants may likely be worse than the impact on the general obstetric population. It is important to screen for PPD symptoms among mothers with disabilities by

healthcare providers and timely referral of those with PPD diagnosis would prove significant in improving the health of both mothers with disabilities and their children**.**

Sexual response in individuals with disabilities

The sexual response cycle refers to the sequence of physical and emotional changes that occur as a person becomes sexually aroused and participates in sexually stimulating activities. Although there is a wide variability in each individual's expression of sexuality, the phases of physiological response to sexual stimuli remain almost similar.

This may not always be the case in the sexual response in individuals with different kinds of disabilities. In persons with spinal cord injury the effect on the sexual response depends on the level and severity of injury, as well as factors such as partnership status, comorbid conditions, sexual experiences and attitudes, and readiness to sexual experimentation. In some, orgasm or lubrication may not be achieved depending upon the level of injury. Audio-visual arousal and/or stimulation of erogenous zones can lead to an orgasm (Otero-Villaverde et al., 2015).

Women with Autism Spectrum Disorder (ASD) are reported to have poorer levels of sexual functioning whereas men with ASD have been found to engage more in solitary sexual activities (Ousley & Mesibov, 1991). There can be loss of genital sensation and orgasmic response in patients with Spinal Cord Injury and Multiple Sclerosis, along with secondary symptoms such as fatigue and cognitive problems, as well as tertiary problems like anxiety, depression and loss of sexual self-confidence (Merghati-Khoei et al., 2013). One may also find it hard to develop or maintain an erection (Hess & Hough, 2012).

In cerebral palsy a person's sexual desire or functioning level may not be affected but cerebral palsy can limit a person's ability to use particular sexual positions and to give themselves or others pleasure in certain specific ways. Erectile Dysfunction may also be the result of certain medication or if someone has problems with body image and low self-esteem due to disability (discussed in detail later). In case of loss of sensation in the genital area, other erogenous zones in the body can be stimulated for pleasure and an orgasm can possibly be experienced.

Orgasms aren't out of the picture for people with disabilities. If there is a lack of sensation, new ways to seek out physical pleasure can be tried. For persons with blindness, body exploration through touch, smell, sound and imagination can help in achieving orgasm. In men with muscular dystrophy the problem of erection can be seen which can be treated with certain medications and rehabilitation interventions (Peric et al., 2012). Ejaculatory dysfunction among disabled people is mostly seen in men with spinal cord injury, multiple sclerosis and spina bifida (Glass & Soni, 1999).

In a study conducted in Poland, the period of adolescent sexual development among people with intellectual disability usually starts later than among people with average pace of development. According to different studies, the first wet dream experience among men with

intellectual disability occurs when they are fifteen (Rowe & Savage, 1987). Wet dreams, also known as nocturnal emissions, are erotic dreams that cause sexual excitement during sleep and lead to an orgasm. In individuals with spinal cord injury there can be loss of nocturnal emission or wet dreams depending on the level of the injury.

For a discussion on masturbation, sex, non-touch orgasm and other common sexual acts, please see chapternumber 6 on Attitudes towards Sexuality, Sexual Preferences and Practices

Key messages

- Disabilities exist on a spectrum and so women with different disabilities will have different needs.
- Management of menstrual hygiene can be a challenge for women with disabilities. Various menstrual management techniques and strategies can be helpful in training them about managing their menstrual cycles and related aspects.
- Individuals with disabilities who are pregnant or are considering pregnancy may experience negative reactions from their partners, family members, healthcare providers, and society as a whole. However, it is possible for them to experience pregnancy and give birth. They need to be supported in their decision to become pregnant and should receive necessary services and expertise required to help them navigate this.
- With proper planning, an integrated team of medical professionals, accessible information and prenatal care, women with disabilities will be able to navigate pregnancy better.
- Childbirth may pose special challenges. In many cases, a vaginal delivery will be possible.
- Persons with disabilities are able to breastfeed as often as other women. They may need physical support, change in positioning and adaptive support to feed the baby.
- Women with disabilities are more prone to postpartum depression. Timely referrals and rehabilitation services can help them.
- Due to certain kinds of disabilities, sexual response may differ from non-disabled individuals but with experimentation of positions, communication skills and partners' support, they can experience sexual pleasure and satisfaction.

Chapter 2. Diversity in Sex, Gender and Sexuality and Persons with Disabilities

Disabled individuals who also belong to the LGBTQI community experience marginalisation for both their disability as well as their sexual and gender identity. Due to them being at the intersection of these mutiple social identities, oppression and discrimination is multilayed. They remain at the risk of losing family support to manage their disabilities and their peers may also distance themselves from them. There can also be a gap in the understanding of their lived experience as disabled indviduals as well as belonging to the queer community. Moreoever, they are often thought of as not having any sexual needs or of being asexual, which further invisiblises their unique identity. There is an important need to include people with disabilities in the discourse around comprehensive sexuality education.

I am a son of a Jaat farmer and grew up in a village. I lost my legs in a tragic train accident in 1996 when I was studying in Agra. Initially I used to get around by walking on my hands. A foundation donated me a hand tricycle. I graduated in Visual Arts.

In 2000, Jaipur Foot were fitted which were heavy, rigid and plastic legs but I was grateful as they gave me dignity. With them, I was able to come to Delhi to explore the art world and try to become part of it. I am gay and the queer community embraced and protected me during my tough times in Delhi. I met the love of my life, Michael Giangrasso at an art fair in September 2012. We kept on meeting and fell in love. Initially we had language problems as he was an American expatriate and my English was not so good but gradually we could understand each other well. I found him to be very understanding and compassionate. First time when I removed my artificial legs and unwrapped bandages baring the stumps of my legs before him he did not let me feel awkward because of my disability.

We promised ourselves to one another. I moved to America. Marriage was a dream we'd kept in our hearts, but India had disallowed same-sex marriage, and it was legal in only a handful of American states. All that changed in June of 2013, when the US Supreme Court struck down discriminatory laws against its gay and lesbians. We were free to marry and we planned our marriage for the following summer in New York.

Balbir Krishan, 47, gay, married, amputee

When they may decide to come out, many LGBTQIA+ with disabilities may have to confront family members and caregivers. They face bullying, segregation, lack of employment opportunities and denial of human rights. Trans-people with disabilities are known to face challenges while accessing healthcare. They are also more likely to experience poverty and financial difficulties (United Nations, 2019).

There also exists a lot of homophobia within the disability community, and ableism within the queer community. There are limited opportunities for self discovery for them and their identities may not be fully recognized. As a result, their unique issues tend to remain invisible within both the communities.

Accessible and inclusive healthcare and community services become challenging for LGBTQIA+ people with disabilities. Moreover, health systems by design don't consider the specific needs of people with disabilities (Nakkeeran & Nakkeeran, 2018). There also remains a greater risk for isolation, increased vulnerability, mental health issues and stigma.

The needs of people with disabilities who belong to the LGBTQIA+ community can be ignored if services are not inclusive. For instance, those with intellectual disabilities living in institutions may find expression of their sexual identity difficult in non-inclusive environments (Noonan & Taylor Gomez, 2010). Lack of sexuality education may put same-sex attracted, gender diverse and intersex people with disabilities at higher risk for compromised sexual health.

If appropriate and accessible information and opportunities are provided, they may be able to express their sexual orientation or gender identity in a healthy and positive way. Other approaches to include LGBTQIA+ persons with disabilities in comprehensive sexuality education can include unprejudiced and healthy conversations, providing related reading and ensuring inclusion in both online and offline spaces.

Key messages

- Persons with disabilities belonging to sexual and gender minority groups face marginalization, bullying and stigma both due to their sexual and gender identity as well as their disability.
- Because of self doubt and lack of awareness, individuals may feel confused.
- Lack of access to education, employment and healthcare may leave them segregated, lonely and neglected.
- Provision of appropriate and inclusive information and opportunities may help them express their intersecting identities in a positive manner.
- Caregivers, family and people in schools/ workplaces can learn to be queer affirming as well as disability affirming.

Chapter 3: Gender Bias and People with Disabilities

Much like everyone else, disabled people also navigate a society that is highly patriarchal, and therefore, extremely gendered. For them, biases based on gender as well as disability affect their well-being and quality of life, as well as their economic opportunities. Heteronormative and ableist attitudes make their experience of living in this world doubly challenging.

There are also different types of gender-based expectations from people with disabilities, depending on the age of onset of disability combined with the type of impairment. Moreover, this is further complicated by the perception of them as people without sexual needs.

Experience of a disabled person's discrimination gets intensified based on not only gender, sexuality and disability, but also due to lower socioeconomic status, caste, tribe, having a refugee status, being indegenous, being old or living with HIV/AIDS. Women are more likely to experience some form of disability during their lives. It has been estimated that approximately 300 million women around the world have mental and physical disabilities (Human Rights Watch, n.d.). Women with disabilities comprise 10% of all women worldwide. According to the 2011 World Report on Disability, female disability prevalence rate is 19.2%, whereas it is 12% for men. In developing countries, especially those where patriarchy is thriving, there are also lesser provisions of medical attention for girls and women in comparison to men.

This greater prevalence of disability in women is often ascribed to women's longer life expectancy, the later onset of dementia in later life and the impact of poor maternal health care, particularly in developing countries. As a result of aging and the longer life expectancy of women, the number of women with disabilities is likely to be higher in many populations than the number of men with disabilities. Many older women who are disabled may lack access to services/support. As life expectancy increases globally, this challenge may surface more across more countries. Lack of accessible support services in these countries may create greater challenges and overall reduction of their quality of life.

However, a gendered analysis suggests that the higher prevalence of disability is not only a matter of being a male or female per se, but also the consequence of social and cultural norms relating to gender, such as ‘systemic exclusion from health care and education, poorer nutrition and gender-based violence’. For example, in conditions which may lead to blindness, such as cataracts which normally occur later in life, women are affected more than men.

Due to social, cultural, financial and religious factors, women with disabilities are less likely than men to make use of existing social services, including residential services as compared to men with disabilities. It is estimated that disabled women worldwide receive only 20 percent of rehabilitation (Human Rights Watch, n.d.). Women with disabilities are found to be more dependent and vulnerable to abuses because of lack of means of livelihood. According to the World Health Organization, “girls with disabilities may be more readily institutionalized than boys” (Economic and Social Council, UN, 2005).

Disabled women and girls also face social isolation. They perform poorly on most indicators of educational, professional, financial and social fronts than their non-disabled female and disabled male counterparts.The global literacy rate is as low as 3% for all adults with disabilities, and 1% for women with disabilities(Helander, 1998). Men with disabilities are twice as likely to be employed as women with disabilities (O'Reilly, 2003).

Women and girls with disabilities experience higher rates of gender-based violence, sexual assault, abandonment, neglect, maltreatment and exploitation than their non-disabled counterparts (United Nations, 2017). Domestic violence, which manifests as physical, sexual, psychological or financial violence, takes place within an intimate or family setting and forms a pattern of coercive and controlling behaviour (Thiara et al., 2011). Disabled people are extremely vulnerable to such forms of violence. They remain at a high risk of violence, both of 'traditional' forms (physical, sexual, emotional) and particular forms related to their disability (withholding medication, denying access to mobility or communication equipment, obstructing personal care and hygiene, or blocking access to medical consultation).

Barriers to seeking help in situations of abuse include increased dependence (physical, emotional, financial) on the perpetrator, lack of information and difficulties in accessing relevant services, fear of institutionalisation, lack of understanding and negative or critical comments by the police or other professionals. Girls with disabilities may also be denied their share of property from their natal and husband's family. Persons with disabilities, including women, have equal rights to inherit or own property as non-disabled persons and have been recognised as having legal capacity, in this regard, under both the Rights of Persons with Disabilities Act, 2016 and the Mental Healthcare Act, 2017. However, the government needs to take steps to create awareness and ensure that persons with disabilities are able to access courts and redress mechanisms to enforce these rights.

According to the UN Flagship Report on Disability and Development (2018), there is an "extremely low" participation and representation of women with disabilities in political leadership roles. The report further says that "[T]he representation of women from organizations of persons with disabilities tends also to be low in national coordination mechanisms on disability matters" and that their representation "in national machinery for gender equality is even lower" (United Nations, 2018).

The impact of gender bias is also felt on disabled men. Socially constructed ideas about masculinity affect all men, and especially those with disability. Most research at the intersection of disability and gender focuses around women with disabilities (Beigi & Cheng, 2010). Because of several stereotypes, a disability can underscore the masculinity of disabled men.

I definitely have faced, and still face issues with the idea of socially appropriate gender roles. Being a male with disability, I have often been judged as a misfit in the traditional ideas of

masculinity. From being denied equal responsibility of work, to getting brushed aside in elite social circles, the association of disability with my masculinity changes people's perception. While I am against the traditional ideas of patriarchy, toxic masculinity, and other forms of discriminatory gender-roles, I have a specific objection to how society develops the idea of a 'perfect male', in which disability is never included. While this puts me to a greater disadvantage amongst the male-dominated circles, it also affects my interactions with non-disabled women, who grapple with the same traditional notions of masculinity. It seems as if there is a certain hierarchy even within the dominant conceptions of males and masculine behavioral practices. This also comes from the idea that masculinity is associated with the character of strength, and disability is usually associated with weakness.

Maitreya Shah, 22, single, man with visual impairment

Many rehabilitation therapies stress on traditional masculine identities, e.g. encouraging disabled men to play wheelchair sports. Parents, peer groups and educators can support boys/men with disabilities by creating an open environment where they can talk about their feelings and emotions without the fear of being judged.

Many LGBTQIA+ individuals with disabilities also often face challenges in accessing health care and social services due to their gender identity and their disability (Kattari et al., 2017). This is especially true people for those with mental health, intellectual, and developmental disabilities (I/DD). People with learning disabilities and/or multiple physical as well as learning disabilities, or those who have socio-emotional disabilities, are seen as most likely to experiencing discrimination in various settings (DREDF, 2018).

Discrimination in health care and social services can have an adverse impact on the quality of care an individual receives. This can prevent individuals from seeking care or support services in the future, both of which have huge impacts on their health and safety.

People with visible disabilities are often assumed to not have sexual needs, and similarly, are assumed to fall within hetro and gender-normative categories, rendering their identities other than what's normative, invisible (Addlakha et al., 2017). Lesbian women with disabilities may experience prejudice more strongly. They are often treated as though their gender or sexual identity is just a phase. If they also belong to an economically poor background, they experience prejudice triply.

When some men with disablities like Multiple Sclerosis are unable to perform normative masculine roles (including being employed), and are unable to cope with their decreasing capacity to be independent, self-sufficient and self-determining, they might explore their sexuality and widen their definition of gender identity to include more feminine and bi-sexual components (Riessman, 2003).

Working towards gender inclusivity

To advance the rights of those with disabilities, it is essential that their perspectives are included in all aspects of work, and that all work on disability incorporates a gendered perspective. Without the meaningful participation of those with disabilities as well as those belong to the LGBTQIA+ community, inclusivity cannot be achieved. Gender equality and empowerment of women can also reduce the prevalence rate of female disability as many women become disabled due to gender discriminatory practices, including early and child marriage, early pregnancy and female genital mutilation. This is seen in low and middle income countries where 75% of all persons with disabilities are women (Human Rights Watch, n.d.).

Strategies solely focusing on the disability don't necessarily result in gender equality among people with disabilities. What we need is much more. To promote gender equality and the empowerment of individuals with disabilities and their human rights, we can focus on:

- Provision of basic education and vocational skills so that they may become financially independent
- Increased economic participation and empowerment by ensuring access to decent work with equitable pay and good working conditions
- Ascertaining equal access to both primary and secondary education
- Providing basic education and employability skills with an objective to make them financially independent
- Promoting economic participation and empowerment by providing decent work and equitable opportunities along with good working conditions
- Generating opportunities for their leadership development, recognition and participation in processes that affect lives
- Stopping all forms of violence against women and girls with disabilities and provision of access to justice/survivor services
- Providing opportunities to participate in peace, security, disaster risk reduction and in humanitarian response.
- Enhancing their capacity to make decisions and ability to choose, including about their sexual and reproductive health and rights
- Challenging social norms that create discrimination and sustain prejudices against LGBTQIA+ and women and girls with disabilities

Key messages

- More women than men are classified as disabled
- While disabled people are much more likely to live in poverty, women are likely to be poorer than men; especially in developing countries where women are often heads of households.

- Younger disabled women achieve lower educational outcomes than men; disabled women are less likely to be in the paid workforce than either men with disabilities for non disabled women, and in general have lower incomes from employment
- Women are less likely to have access to rehabilitation and to employment outcomes when they do receive rehabilitation;
- Type of impairments are different for women and men, with women more likely to experience degenerative conditions, while men are more likely to experience injury-related events
- Disabled women are more likely to remain single or be divorced as compared to and less likely to marry than men with disabilities
- Women are may more likely to face more medical interventions to control their fertility and are at risk to may experience sexual violence in relationships and in institutions.
- Moreover in the developing world, gender patterns in relation to disability indicate that:
- Poverty hits women and girls harder due to patriarchal property ownership structures
- Aid is less likely to reach women and girls; who are less able to compete in situations of scarcity
- Many LGBTQI individuals with disabilities often face lack of health care and social services due to their gender identity and their disability.
- Men with disabilities also face discrimination and issues related to gender roles in society.

Chapter 4. Sexual and Reproductive Health Issues in People with Disabilities

Sexual and reproductive health (SRH) is a crucial component of health and a pillar for sustainable development that deserves special focus, especially in those countries that have limited resources (Barker et al., 2018). Unsafe sex, abortions, HIV (human immunodeficiency virus) and other sexual transmitted infections, sexual and gender-based violence and other pregnancy-related adverse outcomes constitute major risk factors of mortality and morbidity in these regions (Glasier et al., 2006; Ezzati et al., 2002). The needs of people with disabilities in this area, especially, have been ignored for a long time (Kallianes & Rubenfeld, 1997).

People with disabilities also have significant sexual and reproductive health disparities when compared to the general population, as well as higher rates of sexual distress. Because of specific sexual health concerns for individuals with different kinds of disabilities, an integrated approach is required.

Barriers to sexual and reproductive health for people with disabilities

The lack of information on sexual and reproductive health leaves persons with disabilities vulnerable and at a greater risk for preventable health problems. There is a wide range of barriers faced by persons with disabilities in accessing sexual and reproductive health services:

Physical barriers:

- Lack of accessible transportation
- Lack of ramps, elevators or stairs-only spaces
- Lack of scale that accommodates wheelchair
- Narrow corridors difficult for wheelchair, cane, crutches, etc. to navigate
- Small exam rooms, door may not close with wheelchair inside
- Lack of disabled-friendly washrooms
- Tedious processes in accessing services from registration to consultations and medication.
- Inaccessible examination tables and screening machines for individuals with locomotor disabilities
- Lack of tactile flooring and proper signage for visually impaired individuals

Financial barriers:

- Lack of financial independence
- Expensive medical services
- Lack of medical insurance

Patient’s barriers

- Communication difficulties

- Lack of comfort in explaining sexual and reproductive health concerns
- Lack of information in accessible format
- Lack of education

Service provider's barriers

- Lack of training
- Time constraint
- Lack of comfort in dealing with persons with disabilities

Most barriers that prevent people with disabilities from being included in conversations and health promotion efforts around sexual and reproductive health can be addressed by providing sign language interpreters for people who are deaf, providing alternate formats for written materials, using simpler language and ideas that are easy to grasp for those with learning and cognitive disabilities, and providing accommodations to those with physical limitations. An effort needs to be made to understand the access needs of people with different disabilities.

Areas of sexual and reproductive health that need attention

Contraception: Persons with disabilities have the right to decide their own methods of contraception. They may often be denied the information, education and support that is crucial to make informed decisions about contraception. Age-appropriate information on reproductive and family planning education can enable them to exercise their sexual and reproductive rights. Individuals with disability require an understanding of contraception for themselves and their partners.

Contraception was never a real problem to us. We have decided not to have children, though initially I really wanted to conceive and have children. I had slight Polycystic Ovary Disease (PCOD) issues, and to help conceive, the doctor gave me some medication, whose side effects still make me shudder. After experiencing those side effects which included severe drowsiness, suicidal tendencies and severe emotional disturbance, I never dared to wish for a child. Conceiving with gross scoliosis doesn't easily happen unless you plan for it. So we stopped planning. My partner didn't want to have children from the beginning because as a health and wellness professional, he understood the complications of it.

Sai Padma, 45, married, woman with locomotor disability.

Factors to be considered while deciding the method of contraception:

- blood circulation in the lower extremities
- clotting issues associated with their condition
- amount of physical sensation
- manual dexterity

- the stability of condition
- interaction of various contraceptives with their disabling condition or their medications
- presence of depression
- any issue with menstrual hygiene (Family Health International, 1999).

Issues related to different methods of contraception:

- Hormonal contraception can lead to weight gain. For those with mobility limitations this can be quite a disadvantage (Weil et al., 2002).
- If someone is considering hormonal contraception like pills, risk of Deep Vein Thrombosis needs to be assessed for those with mobility issues.
- Anticonvulsant medications, given in certain disabling conditions, may reduce the effectiveness of hormonal contraceptives (Best, 1999).
- Intrauterine devices (IUDs) may increase menstrual flow. In addition, women who have less sensation in the pelvic region may be unable to detect IUD-associated complications like pelvic inflammatory disease (PID).
- Spasticity of the lower extremities can increase difficulty of insertion of an IUD . Partners must be able to assess the presence of the IUD string regularly.
- Barrier methods of contraception require the ability to balance the body, physical dexterity and hand coordination or the willingness of the sexual partner to assume responsibility for its use.
- Those who are at risk for latex allergies need to be cautioned about the use of latex condoms.

A 25 year old young married woman, having hearing impairment, delivered normally at a government hospital. The gynecologist inserted an IUD postpartum without explaining what they had done so the patient did not understand the procedure. Her mother was told that she will not get pregnant for 3 years. Subsequently, the patient suffered heavy bleeding during periods for many months for which she was given various medications. She also became anemic. After one year, when ultrasound was done, she realised that she had an IUD which was subsequently removed giving her relief from her heavy and painful periods.

Received from a practicing gynecologist in Bengaluru

Forced sterilisation and abortions

Persons with disabilities have the right to make their own decisions about their fertility. Forced sterilisation and abortions have been imposed on women with disability due to discriminatory attitudes (Stubbs & Tawake, 2009). There exists a fear that disabled women will produce children with genetic defects or that they can't be good parents. In countries like the US, India and many European countries, it is against the law to force a woman to be sterilised or have an abortion (International Justice Resource Center, 2019).

The United Nations Committee on the Rights of Persons with Disabilities ('UNCRPD') recognises that all PWDs, including children, have the right to exercise legal capacity and "retain their fertility on an equal basis with others," although it does not specifically mention anything about forced sterilisation. However, the rampant violation of the right to legal capacity of women with psychosocial or intellectual disability has been recognised in international law.

The Rights of Persons with Disabilities Act, 2016 specifically protects PWDs from being subjected to medical treatments that impact their fertility without their informed consent, although it also does not specifically refer to forced sterilisation. Further, the Act also does not provide any redressal mechanism for the violation of this right, and only states that a fine of INR 10,000/- may be imposed on anyone violating the provisions in the Act, at large. The Act, under Section 92(f) also criminalises performing, conducting, or directing anyone to conduct any medical procedure that results in, or is likely to result in, the termination of pregnancy of a woman with a disability, without her express consent; an exception is made for emergency situations and cases of women who may have a "severe disability."

The Mental Healthcare Act, 2017 prohibits the sterilisation of men or women, where it is intended as a treatment for mental illness. Section 108 in the Act provides for fine and imprisonment for contravention of the provisions of the Act. However, Mental Health Review Boards (MHRBs) established under the Act for redressal of violations of the Act are yet to be set up in several states(Goyal, 2020). Importantly, the current legal framework, both in Indian statute and in international legal instruments, takes a protectionist view of women with disabilities and frames rights for them in this context, and are yet to be framed in positive terms of entitlements to sexual and reproductive health and rights that women have.

Fertility: Men with spinal cord injury may have difficulties with erections which may result in the inability to ejaculate during sexual intercourse which affects the ability to father children naturally. Men with Down Syndrome have a significantly lower overall fertility rate than that of other men of comparable ages. At least 50% of women with Down Syndrome are fertile. Infertility is also seen in individuals with muscular dystrophy. IVF and Assisted Reproductive Technology can help those who have fertility issues.

Screening and examinations: Individuals living with a disability need sexual health checks, pap smears, testicular checks and prostate checks just like non-disabled people. To prepare individuals for these examinations they may require adequate information about their rights, public and private parts, boundaries, the right to say no, how the examinations need to be carried on in an accessible environment etc.

Breast cancer: Individuals with disabilities need to get examined for breast cancer after 50 years of age. Long-term limitations in activities of daily living are associated with reduced

likelihood of being screened for breast cancer among individuals from age 40 to older than 70 (Schootman & Jeffe, 2003).

Cervical cancer: Individuals with disability have the same need and right to information and services to prevent cancer through vaccination and screening programs. They are as likely to have cervical cancer as non-disabled women, however because healthcare providers believe that they are less sexually active, their need for recommended screening may be ignored. Some sexually transmitted diseases, including Human Papilloma Virus have been associated with increased risk for cervical cancer (Kashyap et al., 2019, p. 308). In India, HPV is given to female children between the age of 10-12 years followed by a second dose in 6 months (Choudhury, 2009). However, vaccination can be administered to women upto 26 years of age. Ideally, the vaccine has to be given before one becomes sexually active. By preventing HPV infection, the vaccine offers protection against cervical cancer in women.

Endometrial cancer: Individuals with disabilities are at the risk of endometrial cancer as non-disabled individuals. Some chronic health conditions or disabilities like Multiple Sclerosis are seen linked with dysfunctional uterine bleeding and oligo-ovulation.

Ovarian cancer: Women with disabilities are not at increased risk for ovarian cancer per se, but pregnancy and use of oral contraceptives are protective factors against ovarian cancer.

Testicular cancer: This is the most common form of cancer in men who are 15 - 44 years old. Men with disabilities may not learn self examination for the presence of lumps in testicles. Persons with learning disabilities (European Association of Urology, 2017) and Down Syndrome (Hafeez et al., 2015) are prone to have testicular cancer due to genetic factors.

Prostate cancer: Starting at age 50, all men, including men with disabilities, should discuss prostate cancer screening with their doctor.

Reproductive tract infections (RTIs): These can be categorized into three types (Wasserheit & Holmes, 1992):

1. Sexually transmitted infections (STIs), such as chlamydia, gonorrhea, and human immunodeficiency virus (HIV);
2. Infections, which are caused by overgrowth of organisms normally present in the genital tract.
3. Infections, which are associated with improperly performed medical procedures such as unsafe abortion or poor delivery practices.

In individuals with congenital syndromes, reproductive anomalies should always be considered.

STIs including HIV: It is often assumed that people with disability are not at risk of HIV and other STIs due to the myth that they do not have sex. While there is a lack of data on STI and HIV rates among people with disability, it is incorrect to assume people with disability are not

sexually active. People with disability face the same sexual risk factors for STIs including HIV as people without disability such as illiteracy, poverty, stigma and marginalisation (Groce, 2005).

High rates of sexual abuse experienced by women and girls with disability also make them more vulnerable to STIs including HIV (Groce, 2003). People with disabilities are often excluded from STI and HIV education which increases their vulnerability (UNAIDS, 2017). Individuals with pelvic sensory impairments or neuropathy may not report pain, burning or other discomforts. Those with vision loss may not be aware of lesions or discharge; they are dependent on a partner or caregiver to notice and describe any abnormalities to them. Healthcare providers and caregivers need to be more vigilant towards manifestations of STIs in persons with disabilities.

Infections due to outgrowth of microbes: Vulvar rashes may be caused by irritation, poor hygiene, urine leakage with subsequent vulvar irritation or due to bacterial infections. These infections may be caused due to urine incontinence, use of catheters or due to sitting on a wheelchair for long hours.

Menopause: Menopause is a stage of life that has been neglected for many women with disabilities. For some this may be a time of physical and emotional change. Many times, behavioural and emotional changes that are caused by the changes during menopause are thought to be part of having a disability. Women with mobility issues face increased risks for conditions that are associated with menopause, including heart disease and osteoporosis. Women with Multiple Sclerosis (MS) may find hot flashes more problematic than other women. Women with disabilities require education and support to understand this stage in their lives and if necessary, receive medical support. An individual's quality of life and ability to live independently can be seriously compromised by secondary disabling conditions. Caregivers and medical service providers would need to look into healthy lifestyles, healthy diet and minimize risks associated with both aging and menopause of individuals with disability.

Key messages

- Persons with disabilities face multiple barriers in accessing sexual and reproductive health services.
- People with disabilities have the right to be treated with dignity and to be provided sexual and reproductive health services and resources in a format or manner that is accessible and works for them.
- Periodical screenings and examinations can prevent many diseases.
- Persons with disabilities have the right to choose methods of contraception and should not be subjected to forced abortions and sterlization
- Individuals with disabilities are equally prone to getting sexually transmitted infections and HIV/AIDs as non-disabled people.

- Menopause may bring additional issues and secondary health conditions may develop. Lifestyle changes can help in maintaining quality of life.

Chapter 5. Sexual Development in Children and Adolescents with Disabilities

Our sexuality doesn't only develop once we reach adulthood, but its foundation is laid in childhood and adolescence. This is why it's important to be aware of the messages we give children about our sexual and reproductive organs and their functions, so they don't develop feelings of shame and guilt around them. This is especially important for children and adolescents with disabilities. To avoid this from happening, we can have age-appropriate conversations with children about our sexual and reproductive organs and their functions so they are able to understand their roles better, and to equip them with enough information so that they feel confident to report perpetrators if they subject them to inappropriate sexual behaviour.

Sexuality is experienced in a variety of ways at different stages and points in the lives of persons with disabilities. Like non-disabled people, sexual feelings, fantasies, and desires occur throughout the lives of persons with disabilities.

Children and adolescents with disabilities

Children and adolescents with developmental disabilities are also sexual beings. However, greater attention is paid to their complex medical and functional issues rather than in addressing the anatomical, physiological, emotional and social aspects of their developing sexuality.

Children with some neurodevelopmental or developmental disabilities are very likely to show premature sexual development or early puberty (Siddiqi et al., 1999). Sexual development, including pubertal changes, is a lifelong process, which presents different emotional challenges at each stage of development. When puberty is premature, however, it concerns parents and caregivers. According to a study, children with Autism and ADHD show delayed puberty (CHADD, 2019).

Like non-disabled children, children with disabilities also need to understand their bodies and relationships. They need to understand how their bodies work, and that they may experience attractions, infatuation, adoration and sexual interests much like anyone else.

As their sexual development continues to progress, they may also start to define their identify as straight, gay, lesbian, bisexual, asexual, pansexual. Some may be in the stage of questioning their sexual orientation. For many people with disabilities who come out as lesbian, gay, bisexual, pansexual, transgender, queer, intersex, asexual, and ally community (LGBTQIA+), forming a romantic/sexual relationship can be very difficult as they may experience social barriers like ableism, homophobia, and heterosexism - all simultaneously (Martino, 2017). Queer people with disabilities confront various challenges while trying to explore their

sexualities, establishing and maintaining relationships, and remaining sexually active (Fraley et al., 2007).

Most young people with an intellectual disability begin puberty at the same age as other young people and experience the same physical and hormonal changes. A young person with an intellectual disability, however, may need more education and support to understand and manage these changes.

Young people with higher care needs may need extra education and support to express their sexuality in positive ways. For example, it may be important to explain the concepts of 'public' and 'private' and to make it clear which behaviours are appropriate in different places.

Like all adolescents, teens with disabilities may express desires and hopes for marriage, children, and normal adult sex lives. In fact, adolescents with physical disabilities are as informed about sexuality as their peers without disabilities. But parents and healthcare professionals may be unsure regarding the potential of these young adults with disabilities to enjoy intimacy and sexuality in their relationships (Berman et al., 1999).

People with disabilities are often infantilized and thought of as in need of constant protection with no sexual needs. Conversely, they may be viewed as inappropriately sexual or as having uncontrollable urges ("hypersexual"). On the contrary many persons with disabilities do take care of their family life and responsibilities. They may take the help of suitable support systems - like people without disability often do.

I could manage the responsibility of my children as I got a lot of support from my husband, in-laws and my mother, brother and sister. Also my friends pitched in whenever they could. I am a very strong willed person so after about one and a half years of injury , I took over as much as I could for the kids relying on others only when I couldn't do certain things like travel or go with them to places which were not accessible. I love being a mother and I never wanted to compromise on that ever.

- Anonymous, 51, married, spinal cord injury.

For families, menstrual hygiene, sexual abuse, pregnancy, and premenstrual syndrome of young girls with disabilities can become concerns. To them, sexual development brings the fear of sexual abuse. The fear is not unfounded. Some people exploit the person's vulnerability and perpetrate sexual abuse. Parents may ask, "How can I stop inappropriate sexual behaviour and sexual urges from developing in my child with an intellectual disability?" However, to attempt to stifle the sexuality of individuals with disability because it is inconvenient for the caregiver or because others may exploit the individual is not a valid reason to suppress their self-expression.

Different concerns may arise for individuals at different ages .

Adulthood

During chronic and acute illness, a major accident or congenital disability can impact sexuality both in terms of interest, and participation in sexual activity; regardless of interest or desire. Whether in a relationship or single, their expression of sexuality might get altered but it never gets diminished, unless the person is asexual. Asexual persons can and often do desire romantic attachment and companionship (McKeever & Brunning, 2019). Masturbation, sexual intercourse and outercourse can bring pleasure and sexual satisfaction.

Old age

The risk for chronic and acute illness increases as we age. Some examples of these illnesses include Parkinson's Disease and Alzheimer's disease. With pain and fatigue, sexual activity can become uncomfortable. Spinal cord injury can cause nerve damage, which can lead to vaginal dryness in women, and erectile difficulties in men. Thus, physical health can change across a life-span and influences what is considered a "normal" or "healthy" sexual life.

For women with disabilities, menopause can affect sexuality in various ways. They may also experience vaginal dryness as the amount of natural secretions in the vagina decreases. This may cause intercourse to be painful. This may result in feeling undesirable. Because hormones play a large role in sexual desire and arousal, their natural decline during the aging process is thought to impact sexual desire and arousal in individuals with disabilities. This is similar to what happens to many non-disabled women who are ageing.

Individuals with disabilities also have the capacity to respond sexually throughout life. With adjustments, modification of immediate environment, acceptance of body and experimentation, persons with disabilities can live fulfilling sexual lives.

Physical changes that take place with ageing affect how people experience their sexuality and its role in their lives. This does not undermine their sexuality.

While disability may or may not have an effect on sexuality, there are also many stereotypes and myths about disability and sexuality.

At any stage in life, sexuality of persons with disabilities mainly remains neglected and even suppressed. Speaking about sexuality is important to every person's health and well-being. But discussing sexuality with persons with disabilities at any age is considered irrelevant, because they are perceived to be sexually inactive, and consequently have no need for such information.

But in reality having a physical or intellectual disability doesn't change the sexual needs of an individual and desire to express it at different stages of life. Though disability may affect the ability to have a regular sex life,one may have to approach sexual activity differently

Key messages

- Sexuality is a natural and healthy part of life.
- All people, regardless of biological sex, gender, orientation, age, disability, and culture, are sexual beings.
- Sexuality is experienced by persons with disabilities in a variety of ways at different stages and points in people's lives.
- Sexuality of a person with disability may be suppressed and prevented from being expressed in a healthy way due to stigma and societal perceptions.
- Sexuality for persons with disabilities can be more satisfying and positive when expressed in a caring, positive, and non exploitative way.

Chapter 6: Attitudes towards Sexuality, Sexual Preferences and Practices

Due to the existing stigma around disability, there is a dearth of research done at the intersection of sexuality and disability (Nagaraja & Aleya, 2018). This perpetuates the notion that sexuality is somehow shameful for disabled individuals and pleasure is out of the question. When we talk about building positive attitudes towards sexuality as well as healthy sexuality for persons with disabilities, we may think of it in terms of:

- an understanding of sexuality as a natural and healthy aspect of human life;
- knowledge of human sexuality and reproductive rights with which to make responsible choices;
- respectful communication and exchange of personal thoughts and feelings between partners; and
- practice of safe and mutually consensual sexual activity.

Barriers in sexual pleasure faced by persons with disabilities

Disability may affect one from experiencing a satisfying sex life to some extent due to a range of issues, including:

- concern about finding a partner
- feeling of fear, guilt or shame
- a lack of arousal
- lack of privacy
- erectile problems
- physical pain from sexual intercourse
- a lack of vaginal lubrication
- difficulty with sexual positioning
- lack of sexual self esteem and negative body image
- negative mental state including anxiety and depression
- problems of incontinence (using catheters)
- certain medications
- fatigue

What can be done?

Sexuality Education

There are many restrictions on the sexual lives of people with disabilities, especially persons with intellectual disabilities. Without access to comprehensive sexuality education and accompanying sex literacy, people with disabilities are excuded frm having essential conversations about sex, sexual expression, and pleasure. The sources from where persons with

disabilities access information are generally not the same as the sources persons without disabilities access.

I got my first period when I was in class 6. Thankfully I knew what was happening to me because I attended a school workshop on it in class 5.

If I talk about managing menstruation as a person with a disability, I will say it's tough. I am almost 100% physically dependent on my parents for all my intimate needs such as using the washroom, going for a bath, and changing clothes. Thus, during my periods, I can't even wear or change a pad on my own. My parents do that for me.

Since I am a college student, I leave my house in the morning and come back by the evening. Because of the nature of my disability, I can't and don't even use the washroom during these hours and it becomes tougher during periods. I keep wearing the same pad from morning to evening - for almost 12 hours. This leads to physical discomfort, feeling of wetness, rashes, bad smell, and leakage. There is always a fear of infection. I usually wear two pads but it still leaks due to my constant sitting position. This also leads to my clothes getting dirty which becomes troublesome both for my parents and me.

Also, my periods never finish on time. My gynecologist says it's because of the added stress of my disability. Therefore, I often have to resort to medication to regulate my menstruation cycle, which has its own side effects. In totality, I would say it's a horrible experience. The lack of independence due to my restricted mobility makes matters worse.

Anonymous, 21, in a relationship, a girl with spinal muscular atrophy

Lack of information or misinformation may make a person with disability feel tempted to avoid sexual activity or limit opportunities to have sex (such as avoiding meeting a partner). People with disabilities are most likely to receive information about sexuality from sources other than families and friends (McCabe & Cummins, 1996). They may also have few lower levels of sexual encounters leading to lower levels of sexual pleasure than people from the general population (McCabe, 1999).

Increasing the sexual literacy of adults with disability by acknowledging and accepting their right to pleasure may be a successful strategy for reducing sexual exploitation and abuse of persons with disabilities (Turner & Crane, 2016).

Ensuring that all people are informed about sex education and have access to resources is of utmost importance. Learning about our own bodies, consent, STIs, contraception, pregnancy, and safety requires to be taught in comprehensive sexuality education.

While learning sexuality education people with disabilities may also get a comfortable environment to talk openly about their experiences. If any complaint is raised, it must be acted upon appropriately by family members, service providers, and the criminal justice system.

Enhancing pleasure

Pleasure cannot be felt if there is discomfort. For people with disabilities, it takes energy to participate in and enjoy sex. From giving and receiving touch in areas of the body like the cheek, the neck, or the back of the hand along with different sounds, scents, and sights can bring erotic pleasure.

If there are times in a day when energy levels are better than others, an individual with a disability may consider engaging in sexual activity then. Or one can take it slow and easy - sex doesn't have to be physically active or demanding. Talking to a counsellor about feelings and seeking help for low self-esteem, anxiety, depression etc. may help.

If certain medicines are affecting sexual interest, thoughts and moods, talking to a doctor about it may be beneficial. Pain can be managed by taking recommended painkillers and certain assistive and supporting aids.

With 100% disability, as in my case, it was difficult to satiate my sexual urge when I was single. However, masturbation was my only way to derive sexual pleasure. After I found a partner and started to live with her, there were initially difficulties in sexual expression and intimacy but gradually with the understanding of my partner, we found our way to express and enjoy ourselves sexually together. While it's not easy for us to have the traditional penetrative sex, we enjoy it our way. While we lay on the bed side by side, my girlfriend turns half to my side, comes over and puts her breasts on my face so that I can suck her nipples. Then she takes my hand and puts it on her vagina where I start fingering her clitoris. She, at the same time, takes my penis in her hand and starts playing with it. While sucking both her nipples one by one, I keep fingering her until she experiences the intense orgasm. Simultaneously she also keeps working on my penis until I've an ejaculation. This is how we enjoy our sexual life to the fullest possible.

Jitendra Kumar Biswal, 48, living with a partner, man with muscular dystrophy.

The important thing is that partners communicate with one another. It is essential to speak about concerns and needs, as well as being honest about what is and isn't working. All partners need to work as a team in dealing with issues that can come up. Taking the time to sort through issues helps the partners feel closer, satisfied and comfortable in their sexual intimacy efforts along with feeling emotionally connected.

Like any other relationship, sexual relationships take time to develop as partners cope with their disability as well as the needs of the partner. All positions may not be possible because of mobility impairment but then there are equally other ways to gratify each other. I learned it over a period of time & did not face any specific problems. Communicating about sexual needs again pertains to mutual trust & verbal & non-verbal cues which we learned over the years.

Anonymous, 45, married, man with locomotor disability

Positions

Whether one partner has a disability or both of the partners do, there are plenty of ways to get creative in the bedroom (Davidson, 2018). For instance, if a person has issues with bowel or urinary functioning, side by side position can be tried to avoid putting pressure on the bladder. Side by side position may also be comfortable for people who have weak or spastic hips.

For people with hip pain or a male wheelchair user with a non-disabled partner, sitting position is more comfortable. For those who have fragile joints and muscles, less bouncy positions are ideal to prevent injury or pain. One can use rolled up towels under one's lower back, in better supporting each other in holding a good sexual position.

Pillows may be helpful for those with hip problems, for example, to have sex when placed between the receiving partner's legs during side-by-side position, where the person is penetrated from behind or at a perpendicular angle. Well-placed mirrors can also help with this kind of strategizing.

Some people with disabilities who use manual and power wheelchairs have found that they enjoy engaging in partnered sexual activity in their chairs. A power chair can recline, allows the person to remain supported, and as such can help in provide greater access for sexual positioning. A Hoyer lift that is usually used to make transfers easier, could also be used as a sex swing, it provides supportive access that is non weight-bearing. Furniture around the house may also prove useful, like the use of a bed or chair as support for a sexual position involving kneeling on pillows.

Sexual practices

Sexuality and sexual preference is a very personal thing. Physical or mental disability may alter the way individuals express their sexuality and may profoundly change feelings about sex. However, disabilities do not necessarily diminish interest in sexual activity, and people with disabilities can frequently both experience and provide sexual pleasure.

Given that I am a person with blindness, sexual attraction for me depends a lot on the non-visual interactions with someone. As the occurrences like 'meeting of eyes', 'verbal gestures', or 'attraction towards the physical appearance of someone' does not really happen with me. My sexual attraction both intentional and otherwise is based on the 'other' qualities of a person. For eg., softer voices of women is a factor that creates such an attraction for me. Both my belief and experience are contrary to the general notion of society which necessitates visual perception as a precursor for sexual attraction. Qualities of a person, personality, mannerisms, or even the proximity of body-temperatures is sufficient to develop the attraction we are referring to. Behavioral changes in a person's identity, or her interaction with me, also forms the string of triggers, if I may call it. Such expressions could easily transform from subtle flow of natural interactions to identifiable, intentional non-visual gestures, forming a stronger exchange. I am

basing the above assertions purely on the tenets of biological and psychological experiences, as opposed to the theories that call sexual attraction as some platonic force.
Maitreya Shah, 22, Single, man with visual impairment

Individuals with disabilities are sexual beings, and should be given deserve equal rights and opportunities to have control over, choices about, and access to their sexuality, sexual expression, and fulfilling relationships throughout their lives. This is important for their overall physical, emotional and social health and well-being. Disabled bodies are mostly regarded as non-normative or even deviant. Their sexuality has mostly been constructed as problematic and remains under the public gaze. There are various barriers to their sexual citizenship.

However, people with disabilities can experience pleasure as they please. Pleasure can be obtained through oral sex if a disability or physical condition of a person doesn't allow penetration. A sensual touch can prove to be a great stimulant. Running different silky fabrics over each other's body, moving a feather over the skin or rubbing an ice cube over intimate places can do wonders.

In the blackness of the bedroom, bias seems to vanish. It almost becomes a sensory deprivation experience for me until I touch the first smooth curve of skin. In darkness, I am completely blind. This, combined with my massage experience and my sense of touch and smell, can make the experience of foreplay and sexual intercourse quite overwhelming. This is especially true when it's the first time with someone. Interestingly, it is that very first touch that locks it all in for me. I use my sense of smell to tell me where to kiss, and the black nothingness turns into the shape of a face.
Edan Chapman is 30-year-old photographer, deaf
(http://archermagazine.com.au/2014/11/deafness-and-sexuality-out-of-the-darkness/)

Masturbation

How someone masturbates varies from person to person. Some may touch erogenous areas of their bodies like the vulva, clitoris, labia inner thigh, anus, nipples, penis, scrotum, lower abdomen etc. Some may do it alone or with a partner. There is no one way to masturbate and everyone has the freedom to feel comfortable exploring their bodies. For people with disabilities, masturbation is often the main sexual expression and means of relief (Eastgate, 2008). It can help them figure out what works to increase sexual arousal or trigger orgasmic release in them.

When I don't have a partner, masturbation becomes the most important tool of self-pleasure. As a disabled person, thinking and focusing on erogenous zones definitely helps me but it's all rooted in my imagination and that's always the key to self-pleasure for me. Sometimes

masturbation is even better than the actual act of sex especially compared to some instances of bad or awkward sex that I have had.

Abhishek Anicca, 33, single man with locomotor disability/chronic illness

If a person with a disability is not able to masturbate alone there can be assisted masturbation. Assisted masturbation is where a toy is placed and turned on, either by the individual with disability or someone else so that stimulation is experienced. There are many kinds of sex toys available in the market that can help an individual with disability to explore sexuality and give and get pleasure. Sex toys can be used by people with disabilities who have difficulty with masturbating on their own. There are also sex toys that are specifically designed for mutual pleasure. Not all toys will be right for everyone, but there are a variety of toys in the market out there to choose from.

I am all for sex toys and masturbation. I try to talk about it as much as possible. My first experience as a desirable person was to masturbate. To explore my body and to see what pleasure looks like for me was to masturbate and to use sex toys. That was definitely my first experience because before that, any encounter with another person wasn't as pleasurable as using a sex toy. So, I am all for it. It's something crucial and is an important part of my life now, to be able to use sex toys and to be able to masturbate even if I have partners or I'm dating. It doesn't matter. What matters is me being able to use these sex toys and to explore my body in terms of not just desirability and pleasure, but also being in touch with my body and to feel like I can do something, that I am good at something, that I can make myself feel good without anyone. A lot of times people will say that eating will make them feel good and yes, I agree completely. Eating makes me feel good - like sushi or something will make me feel pleasure inside myself, but even having access to sex toys, having access to assisted masturbation technology, is very important, I think, as a disabled person. I would encourage anyone, not just people with disabilities, but anyone, to explore their bodies and see what desirability means for them. It doesn't have to be orgasming through your clitoral or through your penile organs, but also through cuddling, through touch. Pleasure can mean different things for eg., masturbation can also be done using a pillow. Like nowadays we have these dolls that can hug and cuddle. Those are also very helpful, I think, and can lead to a lot of pleasure and comfort. So, that's what I would say about sex toys and assisted masturbation.

Shivangi Aggarwal, 28, Single, Queer, congenital disability in hands and legs, uses especially fitted prosthetic shoes to walk.

Those who have some finger or arm movement mobility can use toys with a long handle for self-pleasure. Vibrators are a kind of sex toys which are designed to provide sexual stimulation in the form of intense vibrations that feel pleasurable on various parts of the body. They can be

put inside the clothes, placed on top of an erection, or strapped on to the body or bed, so that someone can lay on the stomach or on the side for better positioning.

A word of caution: Plastic sex toys should be used with a condom over them. Silicon made toys are safer. Sex toys should be cleaned well and stored in a safe and clean place. They should be waterproof. There can be latex allergy in people with Multiple Sclerosis (eHealthMe, 2021) and Spinabifida (Mayo Clinic, 2020).

There are also challenges in everyone's capability to self-pleasure. Those with limited hand functions or those with severe physical disabilities may find it difficult to touch their genitals, remove clothes/incontinence pads and masturbate. There can also be lack of privacy, lack of arousal, erectile issues, physical pain, lack of lubrication and difficulty with positioning.

Some of the challenges that individuals with intellectual disabilities might face while engaging in masturbation include:

1. Understanding social norms around masturbation .
2. Very frequent or prolonged masturbation, often without climax.
3. Practices that may cause injury.

Some individuals with learning disabilities may find their inability to masturbate for long periods challenging (Thompson, n.d.). They also need to be taught the difference between public and private spaces as far as masturbation is concerned. If individuals do not have an understanding of privacy, they may continue to masturbate in public.

Teaching appropriate public behaviour to them is essential. Boundaries of time and place also need to be imposed, which parents and caregivers can help them navigate. Caregivers and educators can play a significant role in helping the person with disability to learn to respect social etiquette so that they can more easily form social relationships and acquire social support.

Sex

The ability of persons with disabilities to engage in sexual activity can be significantly impacted by motor (i.e., movement of limbs), sensory (i.e., touch and temperature sensations), and autonomic (i.e., blood pressure regulation) dysfunctions (Krassioukov & Elliott, 2017). If there is pain, fatigue or discomfort during sexual intercourse, one may have to approach sexual activity differently. Both the partners can try altered positioning. There are no rules to positioning as there are many positions that can be tried. Key concepts are comfort, balance and safety. For those with limited sensation in the genital area, erotic pleasure can be felt by stimulating erogenous zones. Sexual experimentation may be useful depending on the individual's ability to take risks and tolerate feelings of vulnerability.

Deafness may affect the ability of a person to communicate, give and receive informed consent, and take in auditory cues from the partner during sexual activity. Thus, it is better for

individuals who are using hearing aids to not remove them during sex. Otherwise, visual gestures and signals can be used. Senses can be trained to notice different things, to feel different sensations, and to communicate in new ways so that one gets attuned to one's own body and the body of others.

Persons with blindness mostly depend on sense of touch, smell and hearing for achieving sexual pleasure, enjoyment, orgasm, and ecstasy. From the combined stimulation they may be able to know the areas to stimulate, the angles, speeds and rhythms necessary to climax.

Outercourse

Outercourse is an option for people who want to engage in sexual activity without intercourse. It is a sexual activity which can lead to experiencing sexual pleasure that doesn't include any penetration. It may also include activities that do not involve the genitals. For example, body rubbing, kissing, hugging, mutual masturbation, talking about sexual fantasies and similar activities. Communication is key here. It might mean different things to people with different disabilities.

If penetrative sex is not comfortable or possible for both or either of the partners because of physical disability, one can have a fulfilling sex life without penetration, sometimes without even taking their clothes off. It is different from foreplay in the sense that foreplay leads to intercourse whereas in outercourse, orgasm can be achieved even without penetration.

Different sounds, scents, and sights can bring pleasure. Paths to sexual pleasure may not always involve the exchange of bodily fluids. There are many ways to experience sexuality and sexual pleasure. Even those who have lost all physical sensation in their genital regions (for e.g. due to spinal cord injury) can still achieve sexual closeness, pleasure and even orgasm. Outercourse can also be a relatively safer sex. Heterosexual partners need not worry about unintended pregnancy.

Touch and stimulation of erogenous zones is very important. We should all know about how to touch each other properly, about foreplay and different types of sex. It's always good to adapt accordingly and focus on giving pleasure and attaining pleasure rather than participating in the mechanics of a sexual act. Intimacy is the main thing I look for while having sex with a person. It's something that you can never get while masturbating.

- Abhishek Anicca, 33, single man with locomotor disability/chronic illness

Outercourse has many benefits for non-disabled partners as well. It:

- lets partners give each other sexual pleasure without causing pregnancy or spreading STIs
- increases trust and closeness between partners

- prevents pregnancy if you don't have another kind of birth control available
- helps a person understand their partner(s)'s body better
- helps in knowing how one likes to be touched and what feels good

A word of caution: those who practice oral sex can get exposed to STIs if the partner carries them. To prevent theis, condoms or dental dams can be used.

Non-touch orgasm

The concept of using your thoughts to orgasm is not new. In the early 1970s, the Masters and Johnson research team documented the strong connection between sexuality and thought (Weiner & Avery-Clark, 2014). Such orgasms work with the energy of giving and receiving. Those with paraplegia and quadriplegia or with severe disabilities can enjoy erotic pleasure in this way. The brain is the most sexually alive organ in the human body. Pheromones that are responsible for sexual stimulation are processed in the brain. To begin the stimulation, one may have to listen to or imagine deepest fantasies in graphic detail. A person can learn and use techniques, like breathing and conscious control of their thoughts, to facilitate any kind of release that is desired. Along with orgasm, a person can enjoy the feelings of euphoria and pleasure which reduce stress, depression and anxiety levels.

BDSM (bondage & domination, discipline & submission, and sadomasochism)

Alternative sexual practice like BDSM may help in finding paths to arousal that involve different parts of the body. For persons with disabilities who have no or limited use of their genitals, BDSM can be an excellent way to explore and enjoy sexual intimacy. BDSM practices and communication could inspire sexual creativity in persons with disabilities because feelings of pleasure can be enhanced when pain is involved. There's pleasure in reducing pain and in increasing pain. This reconceptualising of 'pain' can be beneficial because "persons with disabilities may feel like a captive of their pain, where they are a victim of and controlled by their pain (Tellier, 2017, p. 488)." So, choosing when and where they receive pain can give them feelings of empowerment, accomplishment, and change. BDSM for people with disabilities can, therefore, help in managing pain, forming a safe place to involve pleasurable pain, and gaining control of their sex lives. Feelings of power and control over one's body can, therefore, create "good pain" for many people with disabilities who may often feel powerless.

BDSM can be physically and mentally demanding so all partners need to communicate about their limitations and modifications needed beforehand. BDSM practices for persons with disabilities need to be safe and consensual.

Fetishes and disability

People with disabilities can also be the object of desire for some people sexually aroused by the disability itself (Limoncin et al., 2013). Sexual attraction to disability (such as missing fingers,

blindness, limb amputation or quadriplegia) is known as *devotism* and those who are specifically interested in and sexually aroused by people with disabilities call themselves *devotees* (Limoncin, 2013). They have two additional subgroups, including people who want to become amputees and refer to themselves as *wannabes* and able-bodied people who act as if they have a disability by using assistive devices (*pretenders*) (Limoncin, 2013).

Sex surrogacy and disability

A sex surrogate is professional who helps individuals with disabilities deal with sexual dysfunction and problems with sexual and physical intimacy. Their role is not simply to help individuals achieve sexual release. Their aim is to nurture a person's sexuality and to help them gain self-esteem, sexual health and confidence. This may involve everything from touching to sexual intercourse. In India, sex surrogates for persons with disabilities are not easily available.

Whenever sex surrogates are hired it must be done with consent of the person with disability.

Key messages

- Having a physical or intellectual disability doesn't affect a person's desire to express themselves sexually.
- Having knowledge and appropriate information about sexuality is very pertinent for persons with disabilities.
- Individuals with disabilities are sexual beings too and experience sexual pleasure. Even if penetrative sex is not possible, orgasm can be achieved by stimulation of erogenous zones. Apart from intercourse, sexual outercourse can also give sexual pleasure.
- A disability may require a person to approach sexual activity differently, and one may have questions and concerns relating to physical or emotional health.
- Modifications and adaptations in positions and postures can reduce physical discomfort and enhance sexual pleasure for all partners.
- Sexual pleasure can be experienced solo or by using various sex toys available in the market or online.
- Alternative sexual practices like BDSM, oral sex and surrogate sex can help persons with disabilities enjoy sexual pleasure and intimacy.

Chapter 7. Sexuality and Disability

Persons with disabilities have been historically discriminated against and this has been further justified to various religions. Religions like Hinduism, Islam, Christianity etc. have segregated and victimized persons with disabilities at different times (Addlakha & Guha, 2011).

In Christanity, disability is regarded as a kind of punishment for those who have sinned. It is seen as a curse for disobedience. The Bible views it as a disease (The Interpreter's Dictionary of the Bible: 1962; Encyclopaedia Judaica: 1972). In some Islamic cultures, disability is seen as an example of the need to be 'fatalistic' in the acceptance of difficulties in life; Islam requires submission to the will of Allah. The presence of disabled child is seen to be a 'test' of faith (Al-Aoufi et al., 2012). Buddhism regards disability as suffering and is seen as a result of bad karma or immoral acts. There has also been emphasis on compassion to build good Karma (Burley, 2012).

Hinduism also believes disability is the result of wrong-doings. Manusmriti[1] mentions that a disabled person reaps in this life the seeds of misdeeds that he had sown in the former life. Any kind of deformity, ugliness, disability, disabled people were thought to be incarnations of something bad or evil. In the Ramayana and Mahabharata the characters having any disability or any deformity were normally associated with something negative or persons having malafide intention (Basham, 2014).

Prior to the twentieth century, social attitudes reflected the view that persons with disabilities were unhealthy, defective and deviant. For centuries, society as a whole treated these people as objects of fear and pity. The prevailing attitude was that such individuals were incapable of participating in or contributing to society and that they must rely on welfare or charitable organizations.

Persons with disability in ancient Greece were not a clearly defined subcategory of human beings (Ojok & Musenze, 2019). Plato talked about persons with disabilities in ancient Greece as inconsequential and invisible and individuals with intellectual and physical disabilities need to be killed because such individuals embody injustice as the lack of order (Jowett, 1986, p. 781) .

Gradually institutions were established where persons with severe disabilities were kept away from families and community programs. These institutions were usually built on the outskirts of town. Societal attitudes fostered this segregating style of management which further stigmatized disabled people.

Before independence colonial rulers paid little attention towards this community. After independence the national government began to pay serious attention towards persons with

[1] traditionally the most authoritative of the books of the Hindu code (Dharma-shastra) in India.

disabilities and took various administrative and legislative measures for the upliftment of their condition. A growing consciousness was emerged to protect the rights of the disabled persons in the international sphere, and India being a signatory to International Covenant on Civil and Political Rights (1966) (OHCHR, n.d.-b) together with the two other human rights documents

Changed Status: The origin of the movement to protect persons with disabilities in India can be traced back to the year 1981. Attempts were being made to rehabilitate the disabled persons. The real movement of persons with disabilities and consciousness for them in India started in the early 1990s.

During the past few decades there have been numerous changes in our society and governmental policies with respect to attitude towards disability and persons with disabilities.

Changed Terminology with changed attitude: In recent years, it has become important to emphasize the individual, not the person's disability; e.g., "individuals with mental retardation" rather than "mentally retarded people." People with disabilities want to be recognized for their abilities, not their disabilities.

Some of the issues that affect the daily lives of people with severe disabilities are:

- independent living
- transportation
- education
- employment
- health care
- sexual and reproductive health and rights

Models of Disability

Models of disability provide significant insight into the attitudes towards disability (Petasis, 2019; Disabled World, 2019). These models show the ways in which our society contributes towards or limits access to gainful employment, provision of goods and services along with, economic and political participation of people with disabilities. They assist us in understanding various perspectives and Models of Disability which show the ways in which our society provides or limits access to work, goods, services, economic influence and political power for people with disabilities. They throw light on the attitudes, conceptions and prejudices of the society towards persons with disabilities.prejudices of society towards persons with disabilities and how these have changed over time

For understanding attitudes about disability it is important to go through the These models reveal the ways in which our society has changed its attitude towards disability and provides or limits access to work, goods, services, economic influence and political power for people with disabilities. Thus models serve a number of important purposes:

- Models of disability help in defining disability.
- Models of disability are based on (perceived) needs.
- Models guide the formulation and implementation of policy.
- Models of disability are not value neutral.
- Models of disability determine which academic disciplines study and learn about PWDs.
- Models of disability shape the self-identity of PWDs.
- Models of disability can cause prejudice and discrimination
- Moral/Religious Model of Disability

Moral/Religious Model - This is the oldest model of disability. Various religious traditions view disability as a punishment given by God for some sin committed by the disabled individual or their family at some point in time. An individual with a disability is held responsible for his condition. Disability, illness and 'suffering' are justified as retribution for their or their families' ill deeds. This can result in their mistreatment and abandonment by society.

Medical Model – Medical Model of Disability appeared around the 19th century. It was during the time when modern medicine began to develop. Since many disabilities have medical reasons, it was thought that medical interventions would benefit persons with disabilities. This model considered that complications in the body impairs a person and if the individual is "cured" then problems would go away. The focus, in this Model, remains only on the individual and society neither has any underlying responsibility nor is bound to provide access and a friendly infrastructure for persons with disabilities.

The medical perspective of disability resulted in the creation of institutions that were developed for people with disabilities where they could be trained and skilled. It focused on supporting and skilling people and seeing them as productive members of the community, rather than a burden, dependent or helpless.

Rehabilitation Model - This model is quite similar to the Medical Model. A person with a disability is taken to be in need of rehabilitation services who can impart training, therapy, counselling or other associated services to lessen the limitations caused by the disability. This model gained importance after WWII when many disabled individuals needed to be integrated into society. The framework of the present day Vocational Rehabilitation system is based on this model.

Tragedy/Charity Model - This model portrays people with disabilities as sufferers who are deserving of our pity. This and the Medical Model are used by non-disabled people to define and explain disability. Because of their circumstances, persons with disabilities are seen as dependent who need care and are unable to manage their own affairs. They need charity in order to survive. This perspective has an adverse impact on the self-esteem of people with disabilities.

The Social Model: Disability, according to this Model, is the result of environmental, social and attitudinal barriers that prevent people with impairments from participating in society. It says that there is a lack of equal opportunities due to physical or social barriers. If cities, structures and built environments were set up in a way that was accessible for people with disabilities, then they would not be excluded or restricted. It also recognises that harmful attitudes towards disabled people create unnecessary barriers to inclusion and requires people to take proactive action to remove these barriers.

The social model distinguishes between impairment and disability. While disability is to do with activities (see below), impairment is described as a characteristic or long-term trait which may or may not result from an injury or health condition that may affect a person's appearance or functioning of their mind or body. For example, information in a document may not be accessible to a person with visual impairment because it is not in an accessible format - say a screen reader compatible format. .

Bio-psycho-social Model: This model forms a non discriminatory and all inclusive concept around disability. It encompasses elements from both the social and the medical model. This model proposes that disabilities are the result of physiological or biological problems that need treatment and intervention by medical professionals. This Model also confers responsibility on the society to take measures to include disabled people in social, economic and political activities by supporting and providing them equal opportunities.

This model is the foundation of the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF). In the ICF, functioning and disability are multifaceted. Here 'functioning' refers to "all body functions, activities and participation" and disability is used as an umbrella term for "impairments, activity limitations and participation restrictions" (WHO, n.d.). The following terms are used in this model:

Impairment: These are "problems in body function or structure such as a significant deviation or loss' - for example leprosy.

Activity limitation: to do with the activities of people (functioning at the level of the individual) and the activity limitations they experience; - for example loss of sensation due to leprosy making it difficult to grasp objects.

Participation restriction: to do with the participation or involvement of people in all areas of life, and the participation restrictions they experience in life situations (functioning of a person as a member of society); - for example, stigma associated with leprosy leads to unemployment or participation in social gatherings.

Inhibitors or enhancers: to do with the environmental factors and personal factors which affect these experiences (and whether these factors are facilitators or barriers) - for example, availability of prosthesis, reconstructive surgeries and the resources to avail these.
In this way, the ICF conceives a person's level of functioning as an effective interplay between their health conditions, environmental factors, and personal factors.

Rights Based Model: According to this approach, people with disabilities are rights holders and the state needs to undertake positive measures to ensure their rights. Social structures and policies that limit or ignore the rights often lead to discrimination and exclusion. This view necessitates the government and its agencies, as well as private establishments to take steps to respect, protect and fulfil human rights. Substantial amounts of structural and procedural modifications would ascertain equal exercising of rights. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2008) aimed to achieve equity for people with disabilities around the world. It outlines the duties that governments around the world must perform to sustain, promote and protect the rights of persons with disabilities.

In India there has been a significant paradigm shift in the way disability is seen i.e. from a charity-based model to a rights-based perspective. The charity or welfare model of disability views “persons with disabilities as complicated and burdensome on others to provide assistance” (Nagaraja & Aleya, 2018). Whereas the rights-based model is of the opinion that all human beings have rights that may not be compromised. This model promotes worthiness, respect, confidence and agency of the individual as a human being, as a possessor of rights, not only the recipient of any resources, services and aid.

Disability and language
(See the note in 'Demystifying Sexuality Reference Book' under the chapter on Sexuality and Disability)

Disability and media stereotypes

Media can deeply influence public opinion and establish societal norms. Persons with disabilities are seldom covered in the media. Images and stories depicted through the media mostly stereotype disabled population. Disabled people are represented as ten commonly recurring stereotypes in the mass media. These include: the disabled person as pitiable and pathetic, as an object of curiosity or violence, as sinister or evil, as the super cripple, as atmosphere, as laughable, as one's own worst enemy, as a burden, as non-sexual, and as being unable to participate in daily life. These stereotypes are particularly seen on television, in the press, and in advertising. The main issue with these images is that they have been designed and produced by non-disabled people.

Persons with disabilities are seldom covered in the media, and when they are featured, they are often negatively stereotyped and not represented in an appropriate way.

“The narratives circulating in popular culture play a significant role in shaping wider understandings of disability’. But popular culture does not only reflect cultural discourses regarding people with disabilities but also influence those discourses”(Cheyne, 2012, p. 121). Stereotypes can be challenged by the inclusion of characters with disabilities in romance novels. In fiction cinema similar the audience would be able to reflect on what they conceptualize about disabilities when they come across characters with disabilities. They can critically think about normative assumptions regarding relationships, sexuality, and disability, and what possibilities a life with a disability might bring (Cheyne, 2013).

The media has the potential to raise awareness, reduce stigma and misinformation. It can be a significant tool to alter societal misconceptions. Persons with disabilities can be represented as individuals that are a part of human diversity. In this way media can actively contribute to an effective and successful integration of persons with disabilities in all aspects of societal life. Since the Convention on the Rights of Persons with Disabilities clearly states that requires States should raise awareness and combat stereotypes related to persons with disabilities, it becomes the media's responsibility to portray persons with disabilities in a manner consistent with a respect for human rights.

Disability Justice

The framework of disability rights emphasises on securing equal opportunities and equal rights for all people with disabilities, while disability justice is a framework that examines disability and ableism as it relates to other forms of oppression and identity. The term ‘Disability Justice’ was coined by black, brown, queer, and trans members of the original Disability Justice Collective, founded in 2005 by Patty Berne, Mia Mingus, Stacey Milbern, Leroy Moore, Eli Clare, and Sebastian Margaret.

Principles on which the concept of Disability Justice is based are:

1. Intersectionality
2. Leadership of those most impacted
3. An anti capitalist politic
4. Commitment to cross movement organising
5. Recognizing wholeness
6. Sustainability
7. Commitment to cross movement solidarity
8. Interdependence
9. Collective access
10. Collective liberation

This approach challenges the idea that the worth of individuals with disabilities has to do with the ability to perform as productive members of society. It insists that their worth is inherent and tied to the liberation of all beings.

Time frames, scripts and disability

There are ableist norms that are related to physical development, sexuality and time. There happens to be a standard pattern of manifestation of child development, adolescence, adulthood, sexual behavior and reproduction. We conceptualize the life scripts in terms of times and phases of a person's development. The transition into normative adulthood is often questioned as people with disabilities are seen as 'unfinished adults' (Kafer 2013). For example, every one must go to school, complete schooling by such and such age, obtain higher education/ vocational/ professional training by a certain age, get a job, get married, have children by such and such age, so on and so forth.

What is required is to reconsider our ideas of what can and should happen in time, and in what sequence, and if these should happen at all!. Normally there are how expectations or assumptions of "how long things take" are based on very particular minds and bodies. Rather than trying to mould disabled bodies and minds to meet the clock, there is a need to bend the clock to meet disabled bodies and minds (Kafer, 2013).

Myths

There are several myths related to disability and sexuality. Many of them have been covered in the 'Demystifying Sexuality Reference Book'.

Way forward

If sexuality of persons with disabilities is not accepted and valued, it can have far-reaching implications. It is important for everyone to consider how to contribute to a culture that upholds and affirms disabled people's right to a sexual life. There is a need to accept the fact that patriarchal heterosexism, cisnormativity, and ableism are both institutionalised and naturalised in educational settings. To change the narrative and by including the voices and perspectives of people with disabilities, scholars, educators and activists can create more inclusive and holistic sexuality education curricula as well as more inclusive educational environments for all students (Campbell et al., 2020).

Key messages

- Since ancients times disability and persons with disabilities are seen as not worthy of social inclusion due to fear, stigma, repulsion, curiosity for persons with disabilities
- During pre pre-modern era disabled people were discriminated against and neglected.
- Gradually changes came in the perceptions of the society and these people were better taken care of
- Media has a great role to play in the portrayal of disabled people so that they are accepted

- Different models of disabilities show change in attitudes to persons with disabilities at both societal and policy making level.
- Disability justice recognizes the intersecting legacies of white supremacy, colonial capitalism, gendered oppression and ableism in understanding how people's bodies and minds are labelled ‘deviant’, ‘unproductive’, ‘disposable’ and/or ‘invalid’.
- Numerous myths present in the society regarding disability and sexuality have also led to their social exclusion

Chapter 8. Life Skills, Body Image and Self-Esteem - in the context of disability

According to the World Health Organization, life skills education is "designed to facilitate the practice and reinforcement of psychosocial skills in a culturally and developmentally appropriate way; it contributes to the promotion of personal and social development, the prevention of health and social problems, and the protection of human rights." (Department of Mental Health, World Health Organization, Geneva, 1999). WHO's department of Mental Health has identified five basic areas of life skills that are relevant across cultures:

- self-awareness and empathy
- coping with emotions and coping with stress
- communication and interpersonal skills
- decision-making and problem-solving
- critical thinking and creative thinking

Developing a healthy attitude to sexuality, and its responsible and rights based expression necessitates development and application of these skills. As in other areas of education and skill development, persons with disabilities have limited access to customized teaching learning materials on this topic. Here we have considered a few personal and interpersonal skills such as decision making, communication, assertiveness, self esteem and body image in the context of disability, and point out why it is important for an educator and caregiver to support persons with disabilities develop the same.

Decision-making

Responsible sexual decision making is crucial as these decisions have an impact not only on individuals involved but others who may be indirectly affected by these decisions. Article 12 of the Convention on the Rights of Persons with Disabilities guarantees individuals the right to legal capacity on an equal basis in all areas of life (OHCHR, n.d.). Like everyone, persons with disabilities also have the right to make their own decisions about their reproductive and sexual health. People with intellectual disability are often incorrectly assumed to lack capacity to make their own decisions and other people, including family members, caregivers and doctors often take decisions *for* them.

Possessing information and knowledge about sex and sexuality is a necessary but not sufficient for sexual consent capacity unless one is able to make decisions for oneself. For instance it is important that a woman with a disability not only needs to have knowledge about contraception, but she must also be allowed to make her own decisions. She must have the opportunity to make her own family planning decisions like starting contraceptive use, method of contraception, duration of use and deciding when to discontinue.

Persons with disabilities may have low sexual esteem which may influence their decisions about their sexual behaviour and choice of partners. Others may pressurize them or exploit their vulnerability.

Individuals with disabilities face difficult decisions about sexuality, which may include:

- whether to have a sexual relationship or not and the limits of the relationship
- whether to disclose disability and issues associated with it (for example urine incontinence or an indwelling catheter
- with whom and how to have sex
- whether a partner can be trusted - what is their motive? What is their attitude towards disability?
- What kind of contraception to use - is it practical for them? any particular side effects that they need to be aware of?
- whether to have children
- in the case of wanting children how and where to get genetic counselling?
- what to do in case of unintended pregnancy
- how to prevent STIs/HIV
- whether to get tested for STI
- where and how to go for screening and sexual health examinations

People with intellectual disabilities may need assistance in making decisions about living arrangements, health care and relationships. They may choose people they know and trust to be part of a support network to help with decision-making. Clinicians, educators and support workers can assist in supported decision making.

A close friend, parent, other family member, educator or counselor can support during the decision-making process. They can assist by:

- Providing up to date and factual information
- Providing opportunities to build and practice skills
- Offering resources
- Discuss doubts
- Giving information in accessible formats

Communication

Communication is important in any type of relationship, but it is especially important in sexual relationships of persons with disabilities. Since there remains complete silence over the issues of sex and sexuality for persons with disabilities, they remain uncomfortable while discussing sexuality in an open manner. Ability to communicate sexual desires, boundaries and physical concerns in the presence of disorders/disabilities, may enhance sexual function. Partners feel connected if they are able to openly discuss their strengths, weaknesses, how they liked to be touched, where and when they feel pain during sexual activity or what they can do or what

they can't. This may lead to sexual and marital satisfaction and a long term bonding irrespective of disability.

It is better to bring such issues up as soon as possible to ensure safety of the partners. Even if there are no specific medical or physical issues to consider simply being able to communicate what feels good and what does not can go a long way towards enhancing pleasure and preventing sex-related injuries, infections, trauma and distress. Effective sexual communication is also likely to encourage and increase the use of contraception, which will minimize the negative outcomes of unprotected sexual activity.

Communication is the key not just for one's sexual life but for the total relationship. As my partner was my friend and colleague at work and knew me quite closely, I could express my fears and apprehensions regarding sex and physical intimacy. I must say, his patience and understanding through knowing me as a person helped us have a harmonious life.

Sai Padma, 45, married, woman with locomotor disability

If one of the partners has mobility issues, spasticity or lack of sensation due to some disability, it would be better if the partner knows and understands about it. This would help in increasing pleasure and reducing pain, discomfort and embarrassment for both the partners.

If both the partners have disabilities, things can be worked out by openly discussing with each other the needs and difficulties. Sometimes doctors and therapists can also provide advice and support. For instance if a certain sexual position or an act increases physical pain, it should be communicated verbally or nonverbally or through body language to the partner to stop.

Communication may be improved by:

- developing the skill of actively listening which helps to connect with the other person cognitively and empathically
- making eye contact
- expressing feelings
- using messages that start with 'I' language to indicate that the person is speaking for themselves and also one's own desires, feelings and goals.
- trying to understand the other person(s)
- offering possible ways to resolve the issues
- Providing nonverbal messages like smiling or touching and asking for clarification.

People with disabilities can be supported by building their communication skills to:

- express themselves
- assert themselves while communicating
- expect to be treated fairly by respecting their sexaul rights
- being able to report intimidation or coercion and manage it

- refuse a request

They can also be supported by building social structures like friends' circle, joining safe internet groups, support groups, that would allow them to feel safe in case they refuse, reject or say no.

Assertiveness

Assertiveness is communicating the feelings and needs while respecting the rights of others. Assertive communication has a significant role to play in healthy sexuality. To be assertive means one feels free to express thoughts, feelings and desires. One is able to initiate and maintain to feel comfortable in relationships. One is able to stand for one's rights. One can be assertive while remaining respectful to others. Sexual assertiveness means that one takes an active role in exploring sexuality, choosing one's partner(s), deciding the duration, frequency and type of sexual activity in conjunction with the partner(s) needs, and also feel comfortable expressing preferences.

During periods of rehabilitation or adjustment to disability, persons with disabilities, along with having difficulties accepting loss of abilities, may experience loss of self confidence along with increased anger and anxiety. This may result in developing a passive personality. Persons with disabilities may become subdued and unable to raise a voice for themselves. They may not give due attention to their own sexual desires and needs. Even if they feel that they deserve sexual gratification they may be too shy to initiate sexual activity, They may want to be agreeable, feel accepted and included and so there is a tendency to focus on their partner's pleasure rather than their own. Being unable to communicate their sexual beliefs and desires therefore may lead to fewer orgasms and lesser sexual intimacy.

Learning the skill of assertiveness can help persons with disabilities to say NO. Being assertive can support communication during sexual activity that is effective for stating one's needs without hurting or overpowering others. For instance being assertive a woman with disability can learn how to negotiate use of condoms/ other contraceptives.

As per a study done in Iran, one who feels weak and is less assertive is not able to openly and freely talk about their mental and physical needs with their partners nor can ask them to satisfy their sexual desires and needs (Sayyadi et al., 2019). Many Indian women still consider sexual activity as a duty (Kakar, 1991). Assertiveness skills may also help in sexual decision making (Widman et al., 2018). Assertiveness skills can be practiced and improved throughout one's life. People with Intellectual/Developmental Disabilities need skills that would support self advocacy so they can communicate what they want from their lives and deal with challenging situations.

Body image

Body Image is the self-perception we have of our body and includes attitudes and feelings about how we look and how we think other people see or perceive us. A positive or negative body image is affected by a combination of factors that may include biological predispositions,

influence of friends and family, influence of media or society, the culture in which an individual lives and broadly their self-esteem. This also influences how we express ourselves in terms of our sexual and gender identity. Violence perpetrated on those marginalised by gender and sexuality also impacts one's self-esteem and sometimes, our body image too.

Persons with disabilities experience negative body image on various levels:

- Appearance - related to the presence of deformities, amputation, scars etc.
- Body functionality - dislike of one's own body due to its reduced functionality after acquiring a disability
- Body disconnection - a physical, emotional and perceptual disconnection with one's body. For instance, one may never want to see their lower body in a full-length mirror after spinal cord injury. There is disconnection between mobile and immobile aspects of the body
- Hygiene - issues like incontinence, being unable to remain hygienic and bad smell make persons with disabilities dislike their bodies.
- Weight-concerns - weight is not only related to appearance but also affects health, function, independence, accessibility, and hygiene

Physical disability can distort body image in many ways due to deformities, spasticity, disfigurement and assistive devices. For instance, a girl with amputation may feel mental stress intensely due to the overfocus on conventional ideas about physical beauty and a "perfect body" by society. When it comes to disability, people can be limited in terms of control and may become overweight. According to a study done in Illinois, those with intellectual disability were documented to weigh, on an average, more than the general population (Rimmer & Yamaki, 2006). Some medicines often lead to weight gain, as does limited movement or limited ability to exercise. The messages received from others imply that this is a personal failing. Individuals who have disabilities are then weighed down with their inability to meet conventional beauty expectations.

Since people with disabilities are largely believed to be non-sexual, their exploration of their own bodies and that of others also becomes limited and stigmatised. This creates an image of a body to be something which only provides functionality, not meant to be pleasured.

"Polio caused a lot of deformities in my body. During my college years, a shortened leg hanging in the air, a highly tilted hip-joint and frequent falling down due to the use of crutches indeed made me conscious of my body image. I, very clearly, felt that girls were not attracted towards me because of my overall looks. Also, a deformed body structure and crutches made things like climbing stairs very difficult for me. So I could not keep up with friends, including girls. I felt uncomfortable in the vicinity of girls as I experienced a marked indifference towards me from their side"
Anonymous, 43, Single, Person with locomotor disability

In case of an acquired disability, one experiences a sudden feeling of loss that can lead to a drop in feeling body positive. The period around which a person acquires the disability is also a significant factor of formation of body image. An adverse body image can bring down the confidence level and make one feel the pain of being disabled.

Those who develop negative body image become can also become vulnerable to developing eating disorder, mental health issues and even to sexual abuse. Poor self-perception and fear of rejection, prevents an individual with a disability from opening up to someone else easily. They themselves may create barriers to forming friendships and intimate romantic relationships, further leading to isolation and loneliness.

Body image also impacts people with visual impairment, since body image is not just the visual physical self, but is multidimensional. Images can be felt by different senses - tactile, audio and kinesthetic. It's a combination of these which help realize one's body image.

Though it may be more difficult for persons with disability to develop a positive body image, it is not impossible. The support system that surrounds the individual, like family, friends, partners, therapists and educators, should reinforce - without sympathy and patronizing attitudes - that the person is beautiful just the way they are. Actively listening to them and showing you care may help in shedding these negative self-perceptions.

Some interventions that can help in improving body image are:

1. Fitness training that may improve mental and physical capacity depending on muscular strength as recommended by medical service providers. This could increase self efficacy of an individual (Cash & Smolak, 2012).
2. Providing media literacy to critically evaluate and challenge the images and messages spread by the media that can lead to negative body image (Grabe et al., 2008; Irving & Berel, 2001). This would educate individuals with disabilities about the biased notion of beauty ideals and teaching strategies to reduce exposure to an appearance-focused media.
3. In order to enhance self esteem identification and appreciation of individual differences, strengths (e.g., sense of humour, intelligence), and talents, and building skills that are necessary for healthy coping and development (e.g., interpersonal skills) (O'Dea, 2004).
4. Providing psychoeducation would give information about the key features of a healthy lifestyle rather than focussing on physical appearance.

Educators, peers and families can help in boosting confidence, inculcating self-acceptance, and encouraging the development of a positive self-regard. Lessons on body positivity may help them reframe their body expectations and feel more positive and accepting of their own body. All this may play a significant role in improving emotional and physical health.

My amputation has affected me physically & mentally. It directly brought a question mark on my body image & self-esteem. As I had lived 21 years of my life on both my legs as a normal being & then suddenly one day got to know that I've to decide to be in the category of 3% of Indian population wherein it completely changed my life. Because of the amputation my walking style changed a bit which shook my confidence level. I had a negative body image. But then within a span of 3-6 months I gained back the confidence and accepted myself the way I'm. I started working on those aspects which were actually in my hands rather than thinking about what can't be undone or blaming god. So I've made myself comfortable with my prosthetic leg that now it hardly matters to me.

Hunny Kapoor, 27, married, below the knee amputee and cancer survivor

For teens with disabilities, parents and caregivers can model positive behaviour related to body image. Focusing more on the functionality of our bodies and the positive things that it can do for us may help support and improve body image (Alleva et al., 2018). Studies have shown that for individuals with autism spectrum disorder, dance and movement therapy may have positive effects on body awareness and well-being, though research in this area is still developing (Barnet-Lopez et al., 2016).

Stereotyping by the media can make integration and recognition of persons with disabilities more difficult. Nuanced perspectives on disability in the media can help the non-disabled population understand the diverse experiences of people with different disabilities..

Self-esteem

Self-esteem plays an important role in matters of general well-being, relationships and our happiness. When we believe in ourselves and accept who we are, it provides us with a belief in our abilities and the motivation to carry them out. We are able to navigate life with a positive outlook. The external, internal and structural factors that make up our self-esteem are complex. Some internal factors are our inner thinking, age, any potential illnesses, disabilities, or physical limitations. External may be our work capabilities, our social image etc. which can also affect our self-esteem.

Because of my disability, I have scoliosis (spinal curve) which has led to an increasing distortion in my back. Earlier, all I wanted was to be able to have a straighter back just like people around me. I was heartbroken when I was rejected for surgery to correct the curve, due to my pre-existing respiratory condition. Another body image issue that I used to face earlier involved an increase in my body weight. Although I have little appetite, I do not lose weight easily due to a lack of physical activity. Because of these issues, I am never able to wear clothes of my choice which used to bother me when I was growing up. I used to make conscious efforts to hide my stomach and back.

However, with time I have come to accept myself more openly. Acceptance began at home with my parents always reinforcing that I am beautiful as I am. My mother always showed utmost enthusiasm while shopping for me. I was encouraged to wear whatever I wanted without worrying about my body. This really boosted my confidence and I never let myself feel judged thereafter. My friends always appreciate me for my dressing sense and the way I carry myself - with grace. This love and acknowledgment by my friends and family helped me in having a more positive body image of myself. Because of this I have embraced my body and am proud of who I am and how I am.

Honestly, it does not affect me now but when I was younger, I always had an ideal body type in mind which I desired. I used to imagine myself standing, walking, running, being able to lift my hand, and doing all those things that require great muscle strength on my part.

Anonymous, 21, in a relationship, a girl with spinal muscular atrophy.

A person with a disability may evaluate their capacity to perform in society. It is characterized by the feeling of inadequacy, guilt, shyness, social inhibition, dependency, helplessness, withdrawal, complaint, tendency to downgrade others, reduced ability, accepting unfavourable assessment as accurate, vulnerability and interpersonal problems (Robson, 1982).

Low self-esteem negatively influences the efficacy, efficiency, learning and creativity of disabled individuals. Common problems caused by low self-esteem in persons with disabilities include:

- Believing that others are better than you
- Finding it difficult to express your needs
- Focusing on weaknesses
- Frequently experiencing feelings such as shame, depression or anxiety
- Having a negative outlook towards life
- Having an intense fear of failure
- Having trouble accepting positive feedback
- Having trouble saying "no"
- Putting other people's needs before your own
- Struggling with confidence

Women with disabilities are more likely to have lower self-esteem, and greater social isolation than those without. They are likely to also receive less education, may be brought up in an overprotected environment, experience poorer quality of intimate relationships, and lower rates of employment (Nosek et al., 2003).

With-self esteem also comes the concept of sexual self-esteem. Sexual self-esteem is defined as how one views their sense of self as a sexual being, or whether one is sexually appealing or sexually "competent". It involves an acceptance of one's own sexuality, and confidence in one's capacity to experience sexuality in a way that is satisfying and enjoyable. If someone has been

physically or emotionally abused, sexually harassed, insulted or embarrassed, then that can impact their sexual self-esteem. Physical disability or some chronic disease may lower or damage the sexual self-esteem of a person.

Sexual esteem is one of the most important factors on which the expression of our sexuality depends. Defined as a “conviction in the worth of one’s sexuality,” sexual esteem involves “an acceptance of one’s own sexuality, and confidence in one’s capacity to experience sexuality in a way that is satisfying and enjoyable” (Maurya, 2016, para 4). With lower sexual esteem a person with a disability is vulnerable to getting into and staying in an abusive relationship for a considerable amount of time. It also affects every sexual choice one makes - who you choose to have sex with and when, whether you limit yourself sexually and how, and whether you choose to use protection or not.

How we present ourselves is related to how we see ourselves. As human beings we can value and cherish our personal strengths and uniqueness. Persons with disabilities can be taught various ways to have healthy self-esteem:

To avoid dwelling on the past negative experiences, what can be done? Special educators, families and friends can play a significant role in providing positive reinforcement of achievement and behavior. This can illustrate a teacher's belief in an individual’s capacity to do better. Thus self defeating patterns of negative thoughts can be reversed. Counselors can also play a crucial role in this and support the person with disability.

- To express their needs
- To feel confident
- To have a positive outlook on life.
- To not hesitate to ask for support, aim for realistic goals, inculcate new interests and focus on abilities.
- To say "no" when they want to

Friends and families can help in boosting the self-esteem of a person with disability. They can support efforts to grow and help cope with feelings of insecurities and self doubt. Self grooming, self care and wellness therapy can also contribute to developing one’s self-esteem and to improving general self-image, self-confidence and relationships with others - all of which support social inclusion.

Persons with disabilities can be supported in developing self compassion (Stuntzner & Hartley, 2015) which comprises the ability to:

- recognize one's own pain and troubles
- treat oneself with kindness and love
- criticize oneself less
- to forgive oneself for not being perfect as expected by others.

A person with healthy self-esteem would:

- Avoid dwelling on the past and negative experiences
- Express their needs
- Feel confident
- Have a positive outlook towards life
- Say "no" and “yes”, according to one’s desires and boundaries

Key messages

- There are personal and interpersonal skills that would help individuals with disabilities to have pleasurable, safe and healthy sexual lives.
- Effective decision-making is essential in developing sexual health and maintaining healthy personal relationships.
- Communication about sexual feelings, desires, and boundaries can improve sexual relationships.
- Communication is necessary to assure consent for a sexual relationship and any sexual act.
- Sexual partners may need to assertively communicate their needs and limits.
- Persons with disabilities may have negative body image
- Self respect and self acceptance are the basic steps to achieve body positivity
- Adverse body image may cause lower sexual esteem
- Identification and development of personal resources is important
- The above mentioned skills can be enhanced by training and practice.

Chapter 9. Sexual Relationships and Persons with Disabilities

Relationships can be challenging. The challenges increase when one partner gets a disability. A disability can impact a partner's lovemaking. For women/girls with disabilities this challenge is much more than men with disabilities.

Individuals with disabilities have the same emotional and physical sexual drives as the people without disabilities. However, issues of sexual intimacy and disability remained unaddressed. Individuals with disabilities seeking intimacy face psychosocial barriers such as a lack of adequate information, negative societal and cultural attitudes regarding sexuality and disability, and often lack the proper education and resources to prepare for intimate relationships.

My disability comes in the way of my sexual expression. It is a big impediment in dating and finding sexual partners. Secondly, I wear a diaper which might turn off/ keep away some partners. Thirdly, sometimes chronic UTI results in lack of arousal and disinterest in sexual intercourse and I might prefer other forms of sexual pleasure during that period.
Abhishek Anicca, 33, Single, man with locomotor disability, chronic illness

They face many barriers to intimacy – not just sex but general relationships. There are many issues that can complicate intimate relationships as disabled people. They aspire to be in a romantic relationship, yet they lack the confidence of building intimate relationships. They are not considered sexually desirable. It is presumed that they will be a "misfit" as a romantic partner. The sense of self-pity is deeply ingrained in their psyche. They remain insecure. Fears of inadequacy hold them back in initiating or approaching someone for a love relationship. People with intellectual disabilities have been thought incapable of understanding and appreciating the value of romantic, sexual, or partner relationships.

There are baseless stereotypes like persons with disabilities, especially women, are dependent, they are unattractive and they are not sexual. Oftentimes it is assumed that for people with disabilities, sexuality is an aspect that is tough or even impossible to experience with them. That's why people with disabilities are often quickly eliminated as potential partners.

Even people who have a disability are unlikely to consider a partner with a disability. But there are also many who have been in a happy relationship for many years and who also had some positive experiences prior to that.

Well, the stereotypical social perception made it very difficult for me to get a life partner. I had to keep trying until the age of 44. But once I found my life partner, we started living together, it wasn't very difficult thereafter. While I've my business and freelance work, she has her own job. So we both earn. However while I take care of the household expenses, she takes care of the daily chores like cooking and shopping etc.

Jitendra Biswal, 48, living with a partner, man with muscular dystrophy

It's important that partners first acknowledge that there's been a big change – and change can be difficult. Some partners face a chronic loss over time due to a disease like Alzheimer's or an accident can suddenly leave a partner quadriplegic. They are no longer as they were before. It is important to understand how they feel about the disability and try to manage the change. The change needs to be acknowledged to ensure the health of the relationship.

Dating and disability

Dating can be quite challenging and formidable for an individual with a disability. People who rely on wheelchairs or who have another form of physical impairment often start dating quite later in life.

One has to be realistic when planning dates together. For individuals with locomotor disabilities the main thing is about picking a location that is wheelchair accessible, with no steps, wide doorways and paths, accessible washrooms, low tables and bars, etc. Most dates can be made accessible if a little research is done ahead of time and pick the right location. Even watching the sunset together or cooking favorite food together can be an exciting date.

I have always been told that love and disability can never go together. Since my childhood, I've been told that I shouldn't perhaps ever think about falling in love because that's something which isn't going to happen to me. I've had a lot of guy friends during school, but I couldn't even think of dating one, because of all the stereotypes and the ableism that I had internalized.

I want a boyfriend who loves me, respects me and accepts me with my disability as my disability is a part of me. I am not looking for a caretaker. I want a person with whom I can enjoy romantic dates, movies, holding hands, hugs and kisses. Why is it so hard for people to understand that I want the same things they want?

I remember once I received a message on Facebook. I rarely receive texts from someone except my close friends. So I was excited when I saw the notification on my phone. It was a senior from school asking if I was in a relationship. I replied with a 'no'. His reply left me stunned. It read, 'Oh! But you're too cute to be on a wheelchair! And you know what? Don't worry! I am willing to date you.' I didn't know what to say so I left the chat instantly. I felt someone was doing a favour to me. It was humiliating.

Srishti, 21, single, a girl with locomotor disability

Being honest and clear about limitations a disability might bring and providing a space for the partner to describe theirs, may allow both to create a more supportive relationship or to step away from relationships that do not work for either partner. LGBTQIA+ people with disability regard body image and personal assistance to be the greatest concerns of dating with disability (Noonan & Taylor Gomez, 2010).

Nowadays, many people look for those connections online. Technology has improved the lives of people with disabilities in many ways. Online dating helps people connect more easily than in the past.

Disclosing disability

In case of online dating or if disability is invisible, one may have to disclose disability early in the relationship. It is up to an individual to decide when and how disclosure is made. Each of the partners needs a certain amount of information about the other to decide whether to commit for the long term.

Disability and marriage

People with disabilities may have to face challenges in finding a life partner as prejudices towards the disabled run deep in our society, a bias that is even more pronounced in villages and small towns.

In a survey done in India in 2010, 59% of women and 48% of men refused to marry someone with a disability. 34% of women and 37% of men said that it depended on the situation and the extent of disability to decide if they would marry a person with disability. Only 7% of women and 15% of men were ready to take a person with disability as their life partner (Sinha, 2011).

Various social and cultural stereotypes and myths prevail regarding marriage of disabled people. Like persons with disabilities are too needy and require more assistance. It is assumed that they are unable to take on the responsibilities of a married life. Some of the stereotypes say that a disabled person should only marry a person with the same disability so that the adjustments are easy.

My partner takes my disability very proudly. Ours is a love marriage. I shared every bit of my story and truth before marriage & she has happily accepted me the way I'm. She is super proud to have me as her partner. Though she has to face a lot of stigma due to society's mindset even after marriage & had faced before marriage too. She has taken a stand for me & especially for us and now we're together. She defines me as the fuel is important for the car the same way I'm important to her.

Hunny Kapoor, 27, married, below the knee amputee and cancer survivor

Many people with disabilities are happily married. To marry someone with or without disability has to be an individual's decision. Role reversals may happen due to disability but love and emotional intimacy with communication skills of the partners can make the marriage a success. Committed partners may mutually decide how to share the roles and responsibilities in their lives.

As far as marriage is concerned I didn't struggle that much as others with physical disabilities. Very lucky to get a receptive partner with whom I am sharing a fulfilling life. Disabled people keep coping up with situations throughout their lives & marriage life has its own share of highs & lows but I have coped up with that successfully till now.

Anonymous, 45, married, man with locomotor disability

Lack of intimacy among partners, difficulty in adjustments due to disability, and inability to emotionally cope up with new and altered situations can cause marital dissatisfaction which may subsequently result in divorces or separation.

As far as my relationship with my husband is concerned , for a few years after the injury I think it was ok but then he started feeling resentful that his physical needs were not met as he didnt want to have a physical relationship with me but felt frustrated. I also felt bad that we were not intimate anymore but it was his decision so I let it go because he was doing other things for us. Gradually he distanced himself emotionally also and last year he told me after his mother died that he wanted to have physical relationships outside marriage and I was not ok with it. I could have left him. I was absolutely shocked and have been trying to come to terms with it. I have decided that we will stay separately on 2 different floors in the new house that we are building so that we are both there for the kids and are in the same house even if on different floors. He has moved on and I am trying to move on too.

Anonymous, 51, separated, spinal cord injury

The Government of India and various state governments offer monetary stimulus to the couple — if one of whom is a disabled person. For instance, the state of Telangana provides one lakh rupees to the couple, the states of Odisha and Maharashtra give fifty thousand rupees.

Key messages

- Persons with disabilities confront barriers in forming romantic relationships.
- Stigma and stereotypes hold them back in having long term relationships.
- Many persons with disabilities are likely to remain single throughout their lives.
- If disability is acquired in later stages in life mutual adjustments can help in managing and forming bonds.
- Lack of knowledge and fear of disabling conditions can lead to broken relationships

Chapter 10. Intersectionality of Sexuality, Gender and Disability

Patterns of power and control are determined by multiple identities that an individual inhabits in this world. For instance, the gendered experiences of people with disabilities cannot be separated from their experiences of disability (McDonald et al., 2007, p. 159). For persons with disabilities, the intersection of identities can sometimes act as obstacles when seeking full inclusion.

For instance, a lesbian woman with disability belonging to a marginalized caste would face multiple challenges, even while making friends. For her there can be domination such as ableism, sexism and casteism, compounded by homophobia.

Men who have acquired disability, like spinal cord injury, limb amputation etc. go through a phase of grief, as they feel that there is a loss of their ability to physically embody certain masculine characteristics such as agility, strength and flexibility (Wilson, 2004). Some men with disabilities strive hard for self-reliance norms, the strain of which may be damaging to their mental health. They might develop symptoms of anxiety, depression or low self confidence.

Patriarchy systemically and systematically oppresses and excludes women, and has negative and unique impacts on other genders as well. Ableism additionally oppresses and excludes those with impairments. These also impact the mental health of women and girls with disabilities for living in disabling environments and within an ableist society.

I faced emotional violence in my marriage of eight years, repeatedly. I was married to a man who I hadn't realized, was controlling and of a passive-aggressive nature. It made me question my choice to be married at all.I was constantly threatened with dire consequences for anything that I did against his expectations, and this led to all kinds of repercussions. I have been left in the middle of the road because my ex-husband thought I wasn't sitting the right way on the bike. Repeated humiliation in public, simply because I wasn't able to hear him properly was a common occurrence. Leaving me in the middle of a conversation just because I have not understood what he was saying the first time has been very much a part of my life. Withholding information, pleasure and opportunities to interact with friends was a common disciplining tool. Isolating me from friends and family was another practice to keep me in line.

It was extremely stressful, and traumatic. It definitely impacted my mental health. It diminished my sense of self, and even after being away from him for almost ten years, there are some things I still hesitate to do- like making a cup of tea for someone else. Being told I was useless and a burden made me see myself as a different person. I had very little support from friends and family. This was because he was always suspicious of my speaking about my life to friends and family, fearing that it will make him look bad. I was afraid to talk with them, and spent time trying to cope by myself. Also, I didn't want to disturb and worry my family and friends. I have cried for those years like never before. Leaving him and my marriage was the only way I could

finally cope. The support given to me then went a long way in re-establishing my sense of self-worth, and I started living again.

Payal Kapoor, 50, separated, totally blind and partially hearing impaired

Some identities create barriers in receiving disability services, while others may further exacerbate exclusion and misidentification of people with disabilities. One-third of the world population lives in poverty and poor women who have disabilities make up some of the most isolated and neglected people in the world. Often, they are excluded from women's movements due to their disability, and from disability movements due to their gender. Due to these intersectional forces, women with disabilities experience different forms of abuse, making them two to four times as prone to violence as their non-disabled peers (Human Rights Watch, 2018).

Even families have isolated and disowned individuals for having a disability, deformity or a chronic disease. This has created an unwelcoming environment with lack of support, access, education, employment, health facilities and barriers to full participation in society for people with disabilities.

We can use the lens of Intersectionality to see how these experiences further impact the formation of the personal identity of an individual with disabilities. One might have experiences of underachievement, inadequacy, powerlessness and inability to develop an independent voice.

Key messages

- Intersectionality is the interconnected nature of social categorization. It is a way our identities intersect and affect our lived experiences.
- People are often discriminated against because of race, culture, ethnicity, language, socioeconomic class, caste, religion, age, and disability.
- People are sometimes discriminated against because of biological sex, appearance, sexual orientation, gender identity, family, and living arrangements.
- Exclusion, discrimination, inequality, powerlessness and non-representation of rights and interests are consequences of intersectional identities of person with disabilities.
- Inequities and prejudices bring about absence of opportunities, and physical and emotional issues and plummeting of self confidence and self esteem.
- With a deep understanding of intersectionality, and support from others, individuals can find their unique voice and agency, helping them, and others, overcome experiences of oppression.

- Respect for the diversity of identities that exist within each of us is essential to building a vibrant, inclusive community for everyone.

Chapter 11. Sexual Violence against Children and Adults with Disabilities

Sexual violence includes any unwanted sexual contact or gestures achieved by force, threats, bribes, manipulation, pressure, tricks, intoxication, or violence. It may be physical or non-physical and includes rape, attempted rape, incest and child molestation, and sexual harassment. It can also involve non-consensual fondling, exhibitionism, oral sex, exposure to sexual materials (pornography), and the use of inappropriate sexual remarks or language.

Persons with different disabilities who face different challenges and have very different needs, remain at higher risk of being at the receiving end of sexual violence. They are often in need of regular assistance or reliance on others. The perpetrator may use this power to threaten, coerce, or force someone into non-consensual sex or sexual activities. An abuser may take away access to the tools a person with a disability uses to communicate, such as a computer or phone. People with disabilities may be less likely to also be taken seriously when they make a report sexual assault or abuse. They may also face challenges in accessing services to make a report in the first place. For example, someone who is Deaf for Deaf-Blind may face challenges accessing communication tools like a phone to report the crime or get help.

"Young people with disabilities, especially girls, are far more vulnerable to violence than their peers without disabilities. Children with disabilities are almost four times more likely to become victims of violence than children without disabilities, and nearly three times more likely to be subjected to sexual violence, with girls at the greatest risk. Children who are deaf, blind, autistic, or living with psychosocial or intellectual disabilities are most vulnerable to violence. Studies have found that these children are five times more likely to be subjected to abuse than others, and are far more susceptible to bullying". (Global Study on Ending Gender-based Violence and Realizing Sexual and Reproductive Health and Rights, UNFPA)

There are also certain misconceptions about sexual abuse of children with disabilities:

- It is often thought that no one would hurt a child with a disability as the disability protects them. However, research from all over the world shows that this is far from the truth - children with disability are 3 times more vulnerable to such abuses.
- It is assumed that children with disabilities are always assisted by some caregiver, and hence, are always protected. However, people do not acknowledge that in most cases of sexual abuse of children with disability, the perpetrators are either caregivers at home or within institutions or some close family member.

- It is wrongly assumed that children with Intellectual and Developmental Disabilities(I/DD)/Autism Spectrum Disorder (ASD) cannot experience or register trauma. That they forget such incidents. This is also a misconception.
- People think children with IDD/ASD do not need to know about sex and sexuality, wheras such infromation can empower them and be extremely helpful.

Lack of knowledge or information about healthy sexuality and the types of touching that are appropriate or inappropriate may lead to sexual abuse of persons with disabilities. This can be challenging if a person's disability requires other people to touch them to provide care. People with disabilities are made to learn to comply.

People with intellectual disabilities experience more violence in general when compared to those without disabilities. They are unable to understand what is happening, nor have a way to communicate the assault to a trusted person. Those with less severe disability may understand that they are being assaulted, but may not be aware that it's illegal. Abusers may also threaten the individual and even the family if they try to report the incident, which may force them to never tell anyone about the abuse. In addition to this, they remain unaware about sexuality issues and may not have been provided assertiveness training. They need to be given accessible information and education about the laws and various legal mechanisms for reporting and how to get medico-legal assistance.

According to a study, 97% - 99% of abusers are known and trusted by the victim who has intellectual disabilities (Davis, n.d.). Abusers can be someone from the residential care staff worker, drivers or transportation providers or even personal care attendants. Therefore, delivery systems established by institutions to meet the specialized care needs of those with intellectual disabilities contributes to the risk of sexual violence (Baladerian, 1991).

Those with locomotor disabilities may not be able to escape from violent situations due to limited mobility. Deaf or hard of hearing women may not be able to send a shout out call for help or easily talk about the abuse, or may remain unprotected from more vulnerable attacks simply due to the lack of ability to hear their surroundings (Gaikwad, 2018).

People with visual impairments are more likely to experience sexual abuse than the sighted population (Blackburn et al., 2014). Sexual harassment incidents among people with visual impairment are very complex to understand. Some might not be able to understand the situation and what exactly is occurring or don't have someone they trust to report the assault (Singh & Sunny, 2017; TNN, 2020).

I faced emotional violence in my marriage of eight years, repeatedly. I was married to a man who I hadn't realized, was controlling and of a passive-aggressive nature. It made me question my choice to be married at all.I was constantly threatened with dire consequences for anything that I did against his expectations, and this could lead to any kind of repercussions. I have been left in the middle of the road because my ex-husband thought I wasn't sitting the right way on

the bike. Repeated humiliation in public, simply because I wasn't able to hear him properly was a common occurrence. Leaving me in the middle of a conversation just because I have not understood what he was saying the first time has been very much a part of my life. Withholding information, pleasure and opportunities to interact with friends was a common disciplining tool. Isolating me from friends and family was another practice to keep me in line.

Payal Kapoor, 50, separated, totally blind and hearing impaired

This poor understanding may be due to lack of access to meaningful sexuality education. There is poor dissemination of information on sexual health for individuals with visual impairments (Krupa & Esmail, 2010) because of:

- inability to acquire information visually
- restriction of tactile learning due to societal norms;
- lack of appropriate information specifically for those with visual impairments in appropriate media forms
- inadequate preparation of families, teachers, and counselors
- the lack of nonverbal communication skills of people with visual impairments.

How to know if sexual abuse has taken place?

Caregivers and families need to be alert and can look for:

Behavioural signs: substance abuse, withdrawal, avoids specific settings/people, sleep or appetite changes, crying spells, self destructive behavior, sexually inappropriate behaviors, severe anxiety/worry, resists physical exam, learning difficulties

Physical signs: bruises or pain in genital areas, tearing of vaginal or anal area, signs of physical abuse, headaches, stomach aches, sexually transmitted diseases. The victim might get pregnant.

Psychological signs: depression, anxiety, panic attacks, low self-esteem, shame and guilt, irrational fear, change in mood, irritability, loss of trust, alienation, sexual dysfunction, obsessive-compulsive disorder and PTSD; and psychosomatic symptoms such as stomach-aches, headaches, seizures and problems with sleeping occur similarly

Challenges after sexual assault

Some examples of barriers that prevent victims with disabilities from reporting and/or seeking help include:

- Lack of accessibility to services (reliance on abusive caregivers to access resources, social isolation, communication barriers, etc.)

- Situational factors (lack of needed services, lack of information about available services, etc.)
- Fear of perceived consequences (retaliation by offenders, loss of independence, negative reactions by family, friends and professionals, etc.)
- Socialization and educational factors (e.g., socialized to be compliant and depend on others for protection, manipulated to feel guilt, blamed, not educated about sexuality)

India ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2007. Under the treaty, states are obligated to "ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages" (Wikipedia contributors, 2021).

According to Rights of Persons with Disabilities Act 2016, the State must ensure protection of all persons with disabilities from abuse, violence and exploitation. The Act articulates specific measures to be taken by appropriate government officials, executive magistrates and the police.

Key provisions of the Criminal Law (Amendment) Act passed in 2013, introduced several procedural, evidentiary and substantive changes in criminal law, aimed at enabling better reporting and prosecution of sexual offences against women, including some provisions that are aimed at enabling women with disabilities to participate in the criminal justice process. For instance, the statement of a woman with permanent or temporary mental or physical disability, against whom a sexual offence has been committed, should be recorded by the police at the woman's residence, or any other place of the woman's convenience and in the presence of an interpreter or special educator. This statement should be videographed as well. Magistrates are required to take the assistance of an interpreter or special educator while recording the statement of a victim of a sexual offence who is temporarily or permanently mentaly or physically disabled. Such a statement will be treated as examination-in-chief in a court and the person will not have to repeat it again. They can be cross-examined based on the statement given to the Magistrate.

The POCSO Act, 2012 also requires that the police, Magistrate and courts take the assistance of a special educator or a person familiar with the manner of communication of the child while recording the statement of a child with disability.

Some relevant provisions of the Indian Penal Code, 1860 ('IPC'), the Protection of Children from Sexual Offences Act, 2012 ('POCSO'), the Juvenile Justice Act, 2015 (JJ Act, 2015') and the Mental Healthcare Act, 2017 ('MH Act') that concern violence against women with disabilities are:

- **Section 376(2)(1), IPC:** Rape of a woman "suffering from mental or physical disability" constitutes aggravated rape
- **Section 376-A, IPC:** Rape or aggravated rape causing a woman to be in a permanant vegitative state is an offence punishable with a minimum term of 20 years imprisonment, which can be extended to life imprisonment
- **Section 5(k), POCSO:** Penetrative sexual assault by "taking advantage of a child's mental or physical disability" constitutes aggravated penetrative sexual assault
- **Section 9(k), POCSO:** Sexual assault by "taking advantage of a child's mental or physical disability" constitutes aggravated sexual assault
- **Section 5(j)(i), POCSO:** If the "penetrative sexual assault" (Section 5(k)) results in mental illness, physical incapacitation, or impairment which permanently or temporarily renders the child unable to perform daily functions, it amounts to aggravated penetrative sexual assault
- **Section 9(j)(i), POCSO:** If the "sexual assault" (Section 9(k)) results in mental illness, physical incapacitation, or impairment which permanently or temporarily renders the child unable to perform daily functions, it amounts to aggravated sexual assault
- **Section 85, JJ Act, 2015:** Disability is considered an aggravating factor for offences committed under the Act, and offences committed against children certified by a medical professional as having a disability attract double the penalty as other offences.
- **Section 20(2)(k), MH Act**: recognises the right of persons with mental illnesses living in mental health establishments "to be protected from all forms of physical, verbal, emotional and sexual abuse." This provision does not specifically apply to women with disabilities/mental illnesses, but to persons of all genders

The Rights of Persons with Disabilities Act, 2016 specifically recognises sexual offences against women with disabilities, which are punishable with a term of imprisonment ranging from six months to five years, with a fine imposed:

- **Section 92(b):** Assault of, or use of force on, a woman with a disability with the intention to "outrage her modesty."
- **Section 92(d):** Sexual exploitation of a woman or child with a disability by a person who is in a position to dominate the will of said child/woman

Section 92(f): Performing, conducting, or directing to conduct any medical procedure that results in, or is likely to result in, the termination of pregnancy of a woman with a disability, without her express consent; with an exception for emergency situations and cases of women who may have a "severe disability"

The National Crime Record Bureau has not compiled data relating to persons with disabilities, and so actual data remains unknown - but most cases of sexual assault of persons with disabilities go unreported due to fear, societal stigma and lack of knowledge about how to report and to whom to report. Even when someone tries to report, they may face obstacles

when making statements to police because they may not be viewed as credible due to having a disability (Keilty & Connelly, 2001). Unfamiliar and stressful court environments may be overwhelming for individuals with disabilities. Lack of information given to them and their families about their legal rights, including the right to legal representation prevents many from advocating for their needs.

V is a 21 year old young person living in rural Bangalore. She lives with her parents and younger brother. She has intellectual disability. In May of 2013, when she was about 14 years of age, V was sexually assaulted by a man who was about 45 years of age, married with a child and living in her village. Despite her intellectual disability, V is quite smart and aware of everything around her. Her speech is impaired, but language is very clear and for those familiar with her, she makes sense. Her mental age was assessed to be of a year old child. She has a good memory for people and places. She attended school for a few years but discontinued after she attained menarche.

V had gone in search of her mother, M, who was working in the field, when she was lured by the accused to an isolated muddy patch. There he undressed and assaulted V sexually. Her mother noticed that her daughter's clothes and undergarments were dirty. V complained that her private parts were hurting, confirming her mother's suspicions. V then went on to tell her mother what had happened, identifying the person who assaulted her as the uncle of her friend.

The family decided against reporting as it would mean going to the police and people in the village getting to know. However, the next morning, the accused came to their home and acted in an intimidating and threatening manner. This and seeing their daughter in pain, completely exhausted and sleeping continuously urged them to report the case to the local police.

Villagers were not supportive and no one was ready to sign as witnesses for the crime scene investigation. The accused threatened V's parents. They decided to go ahead and register the case. Family members of the accused even offered the family money, but V's parents decided to remain committed to the investigation and trial.

V was taken for a medical examination to the District Government Hospital which was about an hour away from their home. V was examined and samples were collected. When the social worker met the attending doctor a few days later, she stated that she was of the opinion that nothing had happened to V, that she was very restless and that she did not cooperate with the doctor for the medical examination. The doctor was very dismissive about the whole incident.

During the recording of the child's statement before the magistrate, V's psychiatrist was present to help interpret. Also during the child's testimony in court a special educator was present.

Case is still under trial.

M feels extremely supported through her engagement with Support Persons, who have, for the past 7 years, remained in touch with the family, assisting them during trial, in obtaining government compensation of Rs. 3.00 Lakhs, along with medical and psychological assistance, follow ups with court authority to bring the trial to a close and other matters that have been coming up from time to time.

*There have been numerous issues that M encountered since the incident in 2013, including financial woes, her own and V's ongoing health issues, long pending trial which included several visits to court for her and V's testimony, extremely delayed reports from the State Forensic Science Laboratory, her husband abandoning her and returning, the list is never ending. But what has been amazing is that M continues to remain positive and committed in her search for justice. She has days when she feels very dejected but sh*e *pulls through. She provides the best possible care for V and treats her very well.*

Source: Enfold RehabilitationTeam

Persons with disabilities may require various kinds of accommodations and procedural support depending on their disabilities. This may include access to sign-language interpretation, the presence of someone to facilitate communication ("special educator"), the use of simple language, and the option to file reports in braille or digitally accessible mediums. Despite the 2013 amendments and the Protection of Children from Sexual Offences Act, 2012, (POCSO) that mandate these provisions, adequate support is rarely given. Most police personnel do not have the training or expert support to handle such cases.

In Delhi, Pooja, an 11-year-old girl with an intellectual disability, was taken to the police station in August 2013 by her father after she was allegedly raped by a neighbor. The police brought in a sign language interpreter to assist the interviewee, but Pooja cannot speak due to a neurological condition; she is not deaf and has no knowledge of sign language. Though the investigating police officer tried to do the right thing by calling a support person, lacking access to proper guidance from a special educator, he misinterpreted Pooja's intellectual disability.

(Source:Sexual Violence Against Girls and Women with Disabilities in India; Human Rights Watch)

Individuals with disabilities often do not receive the facilities they are entitled to and remain devoid of or are excluded from accommodations because they do not have a certificate of disability or because of difficulty in certifying a disability. First Information Report (FIR) is not registered and lack of documentation in police reports precludes them from receiving specific need-based support from the police and judiciary.

Access to medical attention

Medical attention is urgently immediately required in cases of sexual violence to identify tthe need for any medical intervention and facilitate timely evidence collection. In 2014, India's Ministry of Health and Family Welfare issued Guidelines and Protocols for Medico-Legal Care for Victims/Survivors of Sexual Violence, which include requirements for the medical examination of women and girls with disabilities such as providing support accommodations like a special educator to take consent and medical histories. But the failure of many medical professionals to adequately explain medical tests and procedures and ensure that individuals with disabilities are comfortable with the process, may add to the trauma of sexual violence.

Compensation

All state governments need to provide are directed to facilitate compensation to victims of sexual violence, including interim relief in those cases where no trial takes place and because the offender cannot be traced or identified (NALSA, 2018). However, according to a report by Human Rights Watch (2018) even in cases of extreme violence, trauma and economic hardship resulting from childbirth, individuals with disabilities had difficulties in securing compensation from the court or the Criminal Injuries Compensation Board. There is also no set standard, and amounts are often determined arbitrarily, vary between states, and can be driven by media publicity.

Online sexual harassment

Though internet has proved to be a boon for persons with disabilities, there are growing number of cases of cyberbulleying, cyberstalking and online sexual harassment of persons with disabilities.

Online sexual harassment is defined as unwanted sexual conduct on any digital platform and it is recognised as a form of sexual violence. This may include a wide range of behaviours that use digital content (images, videos, posts, messages, pages) on a variety of different platforms (private or public). Persons with disabilities may be harassed or pressured by someone online to share sexual images of themselves or engage in sexual behaviour online (or offline).

There are people who have sexual attraction to disability. They are known as "devotees" (Aguilera, 2007). "Devotees" are individuals, who are sexually attracted to people with disabilities. They are sexually turned on by a person's amputation, paralysis, muscle weakness, muscle spasms, limb difference, etc.There are communities of such people on various social media platforms and they can exploit persons with disabilities online by posting their images in various online platforms.

In case of an emergency or for reporting crimes National police helpline number is 100. The National Women Helpline number is 181. CHILDLINE 1098

Adults with Intellectual Disability and allegations of sexual harassment:

Persons with intellectual disabilities (ID) need special attention to their overall safety. There can be occasions when they unintentionally do some act which are considered inappropriate and harmful or abusive in common parlance. Persons with ID do such acts without understanding the impact of their actions. For example, after puberty begins hormonal change triggers sexual developments in the body of every individual, including a person with ID. This leads to increased feelings and curiosity, increased experimentation, adult-like behaviours and also acts that are sexual in nature such as masturbating in public, body rubbing, fondling or trying to have forced oral/genital contact (Stop It Now!, 2007). In such cases, the persons with ID do not carry any harmful intent, but their actions may result in causing harm to their own self or to the other. Most of them do not also understand that the behaviour is harmful/abusive.

The question arises what immunity does the criminal justice system in the country provide to persons with ID if their act ends up being abusive and thereby unlawful? Do they have any immunity from criminal liability?

According to section 82 of the Indian Penal Code (IPC), a child below 7 years of age gets a complete defence from any kind of criminal liability. It means that a child under the age of 7 cannot be said to have committed an offence. While the Protection of Children from Sexual Offences Act (POCSO), 2012, does not include such a provision, the IPC immunity would apply for any POCSO offences as well.The law imposes an iron-clad presumption that children below the age of 7 years are *doliincapax* (A Latin phrase refers to the presumption in law that a child is incapable of forming the criminal intent to commit an offence).Children between the ages of 7-12 are also presumed to be incapable of committing crimes, but this is a rebuttable presumption. This means that a child between 7-12 years can be found to have committed a crime, if it is proved that the child had the maturity to understand the consequences of their actions.

The only immunity that the criminal law structure in the country provides to any individual with I/IDD is the defence of insanity under section 84 of the IPC. It is based on the assumption that at the time of the crime, the defendant was suffering from severe mental illness and therefore, was incapable of appreciating the nature of the crime and differentiating right from wrong behaviour, hence making them not legally accountable for the crime (Math et al., 2015).

Section 84 IPC can be divided into two broad categories of, major criteria (medical requirement of mental illness) and minor criteria (loss of reasoning requirement). Both major (mental illness) and minor (loss of reasoning) criteria constitute legal insanity. Researchers have pointed out that there is no definition of “unsoundness of mind” in the IPC. The courts have, however, mainly treated this expression as equivalent to insanity. But the term “insanity” itself has no precise definition, carries different meaning in different contexts and describes varying degrees of mental disorders (Math et al., 2015). Moreover, insanity defence is a legal concept, not a clinical one (medical one). This means that just suffering from a mental disorder is not sufficient to prove insanity. The defendant (the person charged with the act of violation) has the burden

of proving the defence of insanity[2]. It is hard to determine legal insanity, and even harder to successfully defend it in court.

Hence, according to most researchers working in this field, with the broader understanding of disability, there arises the need for reform in the way people with ID charged with sexual offences, particularly adolescents, are treated under the criminal justice system. Necessary amendments need to be included to expand section 84 of IPC to include all kinds of disabilities - emphasise on the issue of cognitive disability and refer to estimation of the "mental" or "functional" age of the person charged with abuse/harm/misconduct. Also, the criminal justice system must include Psychiatrists to assist the court in determining psychological disorders. At present, no such system is in place in the Indian Criminal Justice System. Researchers in this field have urged that there is an urgent need to initiate formal training and sensitisation of the judiciary, setup Forensic Psychiatric Training and Clinical Services Providing Centres across the country to increase the necessary human resources to the criminal justice system who would be capable of clarifying psychiatric issues, provide honest and objective opinions based on factual data and sound reasoning. Psychiatrists should also look into behaviours of the defendant before, during, and after the commission of the act that is considered to be an offense, which can give clues toward a person's complete mental status. A standard evaluation procedure of all persons who plead insanity defence is absolutely necessary. It is unfortunate that till date, no such standardized procedure exists in our country. To provide a fair and speedy trial, forensic psychiatry needs to be given utmost importance.

Key messages

- Sexual assault can be verbal, visual, or anything that forces a person to join in unwanted sexual contact or attention
- Persons with disabilities are more likely to be sexually victimized because of their vulnerability and lack of information.
- A person with a disability who has been sexually abused may develop various psychological, physical and behavioural problems. These effects are likely to be more severe and long lasting if the abuse began in childhood.
- The perpetrator is mostly someone who is close to the person with disability
- Online sexual harassment is also increasingly prevalent with the growth of social media and dating sites.
- Persons with disabilities face many barriers while reporting sexual crime, accessing medical treatment and receiving compensation

[2] The accused has to prove by placing material before the court such as expert evidence, oral and other documentary evidence, presumptions, admissions or even the prosecution evidence, satisfying that he was incapable of knowing the nature of the act or of knowing that what he was doing was either wrong or contrary to law. Refer State of Rajasthan v. Shera Ram @ Vishnu Dutta. 2012, 1SCC602, https://indiankanoon.org/doc/624481245/

Consent and Persons with Disabilities

Just because some persons with disabilities are dependent on others for a number of things does not mean that they lose their right to say 'No' to something they don't want or need. Their consent is of utmost importance, especially when it comes to sexual experiences and their right to refuse to engage in any sexual activity with another person.

According to the Section 375 (d) of *Criminal Law Amendment Act 2013*, consent means an "unequivocal voluntary agreement when the woman by words, gestures or any form of verbal or non-verbal communication, communicates willingness to participate in the specific sexual act". This is particularly important for people with disabilities who may find it difficult to give informed consent due to lack of sexuality education and are physically and emotionally more vulnerable.

For consent to be valid it must be voluntary and informed. If a person is under the influence of drugs or alcohol or is under some constant threat or coercion or any other compulsion, the person's ability to give consent may be impaired.

Can a person who is chronologically an adult, but whose mental age is below 18 years, be treated as a "child" for the purpose of trial of a sexual offence?

India's Supreme Court was faced with this question on behalf of a 38-year-old woman with cerebral palsy whose mental age was 6-8 years. She has been allegedly raped. The Supreme Court held that she could not be treated as a "child" under the Protection of Children from Sexual Offences Act, 2012, as age in the law referred to the biological age and could not be stretched to include the mental age of a person.

Consent for sexual activity

Consent is essential when any person engages in sexual activity, and is equally significant when someone has a disability. Overlooking the question of sexual consent for individuals with disabilities, diminishes their agency and dignity.

Sexual consent means both partners agree to the sexual activity and understand what they're agreeing to. It is the foundation of a sexual relationship. Consent must be given for every sexual activity, every time. Sexual activity includes kissing, sexual touching and sexual intercourse (oral, anal, and vaginal). There are as many activities as there are partners with imagination and creativity.

Sexual consent is about a person's right to make their own choice about sexual activity. Consent should be the basis for every sexual encounter. Sex is legal when the participants are above 18 years and they consent to it.

People with disabilities, particularly girls are often treated as being asexual and may also not be given the same education about sexuality and consent that people without disabilities receive. With limited information available they are poorly informed and the society holds largely negative attitudes toward the expression of their sexuality (Nagaraja & Aleya, 2018).

Consent can be given through verbal cues. Those who are not able to give consent verbally may give consent or say no through gestures and non-verbal behaviors or body language (e.g., crying, indicators of fear, pushing the perpetrator away).

Some disabilities may make it difficult to communicate consent to participate in sexual activity, and perpetrators may take advantage of this. In case of sexual violence, the foremost element to be seen is whether the suspect knew the extent of the victim's disability or incapacitation.

Informed consent for medical procedure/abortion/sterilization

For performing medical procedures, therapeutic abortion or sterilization of an individual with disability, informed consent is essential. The term "informed consent" has been defined under Section 2(1)(i) of *Mental Healthcare Act, 2017*, to mean "consent given for a specific intervention, without any force, undue influence, fraud, threat, mistake or misrepresentation, and obtained after disclosing to a person adequate information including risks and benefits of, and alternatives to, the specific intervention in a language and manner understood by the person". It would require a physician or other healthcare professional to provide a patient with sufficient information to allow the patient to understand and give approval for a proposed medical treatment or the performance of a particular medical procedure. Physicians and health care providers need to give adequate explanation to assist persons with disability in making informed decisions.

Under the *Mental Healthcare Act, 2017*, every person other than a minor has the right to make an advance written directive specifying how they wish to be cared for and not cared for and treated or not treated for a mental illness. Under Section 17(a) and (b), they can also specify the individual or individuals who act as a nominated representative and offer support in treatment related decisions and seek information about the diagnosis and treatment. The nomination can be made on a plain paper with the signature or thumb impression of the person making the nomination. The nominated representative is required to consider the "current and past wishes, the life history, values, cultural background and the best interests of the person with mental illness" and "give particular credence to the views of the person with mental illness to the extent that the person understands the nature of the decisions under consideration".

According to Section 2(1)(e) and (za), if no nomination is done, the following order of precedence will be followed in respect of a person with mental illness: nominated representative mentioned in the advance directive; relative; care-giver; or a suitable person appointed by the Mental Health Review Board. If none of them are available, the Director, Department of Social Welfare or their designated representative can be appointed as the nominated representative by the Board. A registered organisation working for persons with mental illness can be temporarily engaged by a mental health professional to discharge the duties of a nominated representative till a representative is appointed by the Board. Care-giver means “a person who resides with a person with mental illness and is responsible for providing care to that person and includes a relative or any other person who performs this function, either free or with remuneration” and “relative” means “any person related to the person with mental illness by blood, marriage or adoption”.

In the case of minors, the legal guardian will act as the nominated representative, unless they are not acting in the best interests of the minor or are not fit to act as one.

Key Messages

- Without consent, any sexual activity is considered as an act of sexual violence
- For a person with disability consent carries equal significance
- Consent once given can be withdrawn any time. It has to be given each time, every time, for sexual acts.
- Consent is also important for medical procedures and carrying out abortion or sterilisation.

Chapter 12. Rights and Laws in the Context of Disability

Laws and policies in the context of disability are constantly evolving globally. The legal landscape has significantly transformed in India and several rights-based laws have been enacted in respect of persons with disabilities, after India ratified the United Nations Convention on the Rights of Persons with Disabilities in 2007. It has shifted from a medical and welfare oriented approach towards persons with disability, to a more rights-based one.

Additionally disability related rights are mentioned in various parts of the Sustainable Developments Goals **(**SDGs), particularly in goals related to providing access to education; achieving full and productive employment; promoting social, economic and political inclusion providing access to safe, affordable, accessible and sustainable transport systems; and increasing availability of high-quality, timely and reliable disaggregated population data.

The domestic and international legal framework on the right of persons with disabilities (hereinafter "PWD") in the specific context of sexual and reproductive rights is briefly outlined in this Chapter.

Domestic Legal Framework

a) The Constitution of India

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 the right to equality and the right not to be discriminated against in any manner, which would include the concept of substantive equality. This would entail positive steps and modifications on the part of the executive and legislature to ensure that persons with disabilities are able to exercise their rights just like any other person. For instance, the concept of "reasonable accommodation" evinces recognition of the substantive notion of equality and the Rights of Persons with Disabilities Act, 2016 states that denial of reasonable accommodation would constitute discrimination.[3] The Supreme Court in Vikash Kumar v. Union Public Service Commission[4] observed:

> "In the specific context of disability, the principle of reasonable accommodation postulates that the conditions which exclude the disabled from full and effective participation as equal members of society have to give way to an accommodative society which accepts difference, respects their needs and facilitates the creation of an environment in which the societal barriers to disability are progressively answered. Accommodation implies a positive obligation to create conditions conducive to the growth and fulfilment of the disabled in every aspect of their existence – whether as

[3] Rights of Persons with Disabilities Act, 2016, Section 2(h).

[4] Civil Appeal No. 273 of 2021 decided on 11.02.21 available at https://main.sci.gov.in/supremecourt/2019/19177/19177_2019_36_1503_26115_Judgement_11-Feb-2021.pdf

students, members of the workplace, participants in governance or, on a personal plane, in realizing the fulfilling privacies of family life."

Article 21 of the Constitution guarantees the right to life to all persons, which has been interpreted by the Supreme Court to include the right to live with dignity, the right to livelihood, and the right to education. In the context of sexual and reproductive health, the Supreme Court in *Sucheta Srivastava v. Chandigarh Administration*[5] held that,

> *"There is no doubt that a woman's right to make reproductive choices is also a dimension of `personal liberty' as understood under Article 21 of the Constitution of India. It is important to recognise that reproductive choices can be exercised to procreate as well as to abstain from procreating. The crucial consideration is that a woman's right to privacy, dignity and bodily integrity should be respected."*[6]

Stating the above, the Court upheld the right of a woman with intellectual disability to continue her pregnancy. Further, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities [7]agreed to provide her assistance with childcare.

Statutory Framework in India

i. Rights of Persons With Disabilities Act, 2016

The Rights of Persons with Disabilities Act [RPD Act] was enacted in 2016 and replaces the Persons With Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995. The primary objective of the RPD Act is to empower persons with disabilities by preventing discrimination against PWDs, safeguarding their dignity, enabling accessibility, and ensuring their full and effective participation and inclusion in society. The RPD Act is a comprehensive legislation that not only provides for the rights and entitlements of PWD but also provides for education; skill development and employment; social security, health, rehabilitation, and recreation; offences against PWD; creation of national and state fund for PWD; the designation of a special court to try offences under the Act; the appointments of Chief Commissioner and State Commissioner for PWD, etc.

The Act in certain key provisions pays special attention to the needs of women and children with disabilities. In particular, section 4 of the Act provides that the State must ensure that women and children with disabilities enjoy their rights equally with others. Section 25(2)(f)

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[5] Sucheta Srivastava v. Chandigarh Administration, Civil Appeal No..5845 OF 2009

[6] Sucheta Srivastava v. Chandigarh Administration, Civil Appeal No..5845 OF 2009, at para 11

[7] Constituted under the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.

mandates States to take measures for prenatal, perinatal and postnatal care of mother and child while Section 25(2)(k) calls for sexual and reproductive healthcare especially for women with disability. Section 10 dealing with reproductive rights of persons with disabilities calls upon the appropriate government to ensure that persons with disabilities have access to appropriate information regarding reproductive and family planning.

The RPD Act also punishes various offences committed against PWD and prescribes punishments for the same.

ii. Mental Healthcare Act, 2017

The Mental Healthcare Act, 2017 is the first legislation that exclusively sets out the legal framework for mental healthcare and rights of persons with mental illness. The Act provides persons with mental illness certain key rights and entitlements, some of which have been listed below:

- right to decision making regarding mental health care and treatment where the person has the ability to:
    - understand the information that is relevant to take a decision on the treatment or admission or personal assistance, or
    - appreciate any reasonably foreseeable consequence of a decision or lack of decision on the treatment or admission or personal assistance, or
    - communicate the decision on treatment or admission or personal assistance by means of speech, expression, gesture or any other means
- right to make an advance directive regarding care and treatment of the mental illness, how the person does not want to be cared for or treated as well as name persons as nominated representative to fulfill certain duties
- Right to access mental healthcare
- Right to community living
- Right to protection from cruel, inhuman and degrading treatment including all forms of sexual abuse
- Right to equality and non-discrimination
- Right to complete information on treatment, side effects, criteria for admission, etc.
- Right to confidentiality
- Right to access medical records
- Right to personal contacts and communication
- Right to legal aid
- Right to make complaints about deficiencies in provision of services

In the context of sexual and reproductive rights, the Mental Healthcare Act prohibits the use of sterilisation procedures on men or women as a treatment for mental illness.[8] Further, it entitles

[8] Section 95(c), The Mental Healthcare Act, 2017.

persons with mental illness to be treated as equal to persons with physical illness in the provision of healthcare and prohibits "discrimination on any basis including gender, sex, sexual orientation, religion, culture, caste, social or political beliefs, class or disability."[9]

iii**. Criminal Offences and Procedures**

Rape of a woman with disability constitutes a ground for aggravated rape that is punishable with a minimum of 10 years imprisonment which could be extended to life imprisonment i.e., till the remainder of the person's natural life and fine. Causing an injury to a woman at the time of committing rape, that causes her to be in a permanent vegetative state is punishment with a minimum term of 20 years rigorous imprisonment, which may extend to life imprisonment, i.e., till the remainder of the person's natural life, or death. The Criminal Law (Amendment) Act, 2013 broadened the scope of rape laws to cover all forms of penetration but also introduced other forms of sexual offences such as harassment, stalking, and voyeurism, as well as enhanced the punishments for the offence of rape.

It also included important modifications to criminal procedures to enhance access to justice of women with disabilities subjected to sexual violence.

For instance, women with temporary or permanent mental or physical disabilities who are victims of sexual violence have the right to have the information recorded by the police in the safety of their home or a place of their choice. The recording should be videographed. When their statement is being recorded by a Magistrate, assistance of a special educator or interpreter can be taken and it should be videographed. Further, such statement can be used during trial and they will not have to repeat it and can be cross-examined based on the statement made to the Magistrate.

iv. **Protection of Children from Sexual Offences (POCSO) Act**

The POCSOAct, 2012 provides for several sexual offences against children. Taking advantage of a child's disability status to commit penetrative sexual assault or sexual assault, amounts to an aggravated offence.[10] It is also an aggravated offence, if the sexual assault results in physical incapacitation of a child or causes the child to become mentally ill.[11] It prescribes several procedures to ensure the equal participation of children with disabilities in legal proceedings. For instance, the police, Magistrate, and Special Courts are required to take the assistance of a qualified and experienced special educator or person familiar with the manner of communication of the child, or an expert.

[9] Section 21(1)(a), The Mental Healthcare Act, 2017.
[10] POCSO Act, Sections 5(k) and 9(k).
[11] POCSO Act, Sections 5(j)(i) and 9(j)(i).

International Legal Framework

United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted in 2006. India ratified the UNCRPD in 2007 and pledged to provide all rights and services as stated in the Convention. This Convention adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. Most significantly, the Convention emphasizes on the non-discriminatory, inclusive, and dignified treatment of persons with disabilities (hereinafter "PWD") in all walks of life. Provisions specific to Sexual and Reproductive Health and Rights (SRHR) are highlighted below:

- Article 8(1)(b) calls upon states to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life.
- Article 16 provides for the freedom from exploitation, violence and abuse and mandates state parties to take appropriate measures to protect persons with disabilities from all forms of violence. The Convention expressly provides that protective, preventive, and recovery & reintegrative measures must be gender-based and gender-sensitive.
- Article 22 mandates respect for privacy and non-interference in any aspect of personal life.
- Article 23 provides for the elimination of discrimination against persons with disabilities in matters relating to marriage, family, parenthood, and relationships. In particular the Convention recognizes the rights of all PWD to marry and found a family on the basis of free and full consent. The Convention emphasizes the right to freely decide on the number of spacing of children, having access to age-appropriate information, and reproductive and family planning education. Lastly, the Convention also calls upon states to ensure that all PWD including children retain their fertility on equal basis with others.
- Article 25 on Health mandates that states must provide PWDs with equal access to free or affordable health care 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. It is regarded 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 Convention aims to address discrimination against women in political, social, economic and cultural spheres.

Although the Convention does not address disability directly, it prohibits discrimination on any basis. In its General Recommendation 18 (1991) by the treaty body of CEDAW, namely the Committee on the Elimination of Discrimination against Women (CEDAW), the Committee 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.

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 considered 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. 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.

International Covenant on Economic, Social and Cultural Rights (ICESCR)

India ratified the International Covenant on Economic, Social and Cultural Rights (CESCR) in 1979. The treaty body under the convention, theCommittee 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 shall not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood’ (United Nations, 2017a). 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]'.

International Covenant on Civil and Political Rights (ICCPR)

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.

Resources

https://www.popcouncil.org/uploads/pdfs/2011PGY_ItsAllOneActivities_en.pdf

https://www.advocatesforyouth.org/wp-content/uploads/storage//advfy/lesson-plans/introduction.pdf

https://www.dsw.org/en/wp-content/uploads/2019/02/SRH-Facilitators-Training-Manual_DSW-2014-1.pdf

https://teachingsexualhealth.ca/teachers/grade/differing-abilities/

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Sexuality in persons with disabilities, like for everyone else, is an essential aspect of their lives and can't be neglected. Though comprehensive sexuality education (CSE) is an important component of the educational curriculum, young people with disabilities receive little to no formal education on this, either in school or at home.

This Demystifying Sexuality Handbook has been specially developed by Enfold Proactive health Trust for teachers and students of B.Ed/ Diploma in Special Education with the following objectives:

- To inform special educators about concepts and issues related to sexuality, gender, rights, sexual and reproductive health, and life skills, in the context of disability;
- To enable educators to develop greater comfort and ease in discussing sexuality-related issues and relationships;
- To enhance educators' understanding of the sexual needs of persons with disabilities

This Handbook is part of a project aimed at preventing gender-based violence by developing and implementing a formal curriculum for teachers and students of undergraduate and graduate studies from nursing, social studies, psychology, education, special education and allied disciplines. It uses a rights-based, restorative and gender transformative approach to meet the aim.