Disability Inclusion in the Health System

A Handbook to Promote Equity for Persons with Disabilities in the Health System in India

Renu Addlakha
Ritu Singh
Neha Naryanan

Centre for Women's Development Studies
An autonomous research institute supported by the
Indian Council of Social Science Research (ICSSR)
25 Bhai Vir Singh Marg(Gole Market), New Delhi - 110001

Disability Inclusion in the Health System

A Handbook to Promote Equity for Persons with Disabilities in the Health System in India

Renu Addlakha

Ritu Singh

Neha Naryanan

2024

Centre for Women's Development Studies
An autonomous research institute supported by the
Indian Council of Social Science Research (ICSSR)
25 Bhai Vir Singh Marg (Gole Market), New Delhi – 110001.

Contents

Acknowledgments

Several individuals and organisations have contributed to providing the material and moral support to make this Handbook a reality. Several researchers worked at different times on the project of which this Handbook is a part. Our gratitude to Tejaswi Chhatwal, Shantanu Nevrekar, Radhika Kannan, Swapnil Gedam, Tejaswi Vasant Raste, Komal, Nitin Pagare in the fieldwork.

We would also like to thank the unstinting co-operation of the staff at the Centre for Women's Development Studies in providing all necessary logistical and other assistance.

Last but not the least, our heartfelt gratitude goes to all the persons with disabilities who agreed to be part of the study.

June 2024

Renu Addlakha

Ritu Singh

Neha Naryanan

List of Tables

List of Images

1. INTRODUCTION

Health is the foundation of life. That is why all societies since time immemorial have developed elaborate systems of managing any threat to this fundamental basis of life long before modern medicine became the dominant system. The right to life is inextricably bound to the right to health, which is the first of the fundamental rights of any human being. This is such a self-evident fact, and yet, in the face of increasing inequities and inequalities across the world, it needs to be periodically and vehemently reiterated.

At the 74th World Health Assembly in May 2021, Member States adopted resolution WHA74.8, according to which "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (World Health Organization 2021). Persons with disabilities have an equal right to the highest attainable standard of health as any other human being. This right is inherent, universal, and inalienable, and is enshrined in international law through human rights treaties, and in domestic legal frameworks, including national constitutions and disability legislations.

The passage of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 fostered a new era on human rights, disability rights, and the participation of persons with disabilities in society on an equal basis with others.

This core treaty provides an international framework that protects and promotes, among other rights, the right of persons with disabilities to enjoy their highest attainable standard of health by making decisions about their bodies and their health care without being discriminated against because of disability (UNCRPD Article 25). In addition, Article, 9 (Accessibility), Article 10 (Right to Life), Article 19 (Living Independently and being Included in the Community), Article 17 (Protecting the Integrity of the Person), Article 20 (Personal Mobility Including Availability of Assistive Devices), Article 21 (Freedom of Expression and Opinion, and Access to information in Accessible Formats), Article 22 (Respect for Privacy Including Protection of Personal Health and Rehabilitation Information), Article 23 (Respect for Home and the Family Including Reproductive and Family Planning Education and Services, Retention of Fertility), Article 26 (Habilitation and Rehabilitation Iincluding the Multidisciplinary Assessment of Individual Needs and Strengths; Training for Professionals and Staff Working in habilitation and Rehabilitation Services and Availability, Knowledge and Use of Assistive Devices and Technologies), Article 27 (Work and Employment Including Safe and Healthy Working Conditions) of the UNCRPD also elaborate on the right to health of persons with disabilities from different perspectives (United Nations, 2006). In addition to the UNCRPD, various global development, health and national legal frameworks have recognized and promoted the right to health for persons with disabilities.

Persons with disabilities continue to experience a wide range of health inequities, to which the contributing factors have not changed over time. As a result, many persons with disabilities die prematurely, have poorer health, incur higher costs and experience more limitations in functioning than those without disabilities. Many of these health inequities are not connected to their impairments[1], but arise out of the structural inequities

---

[1] Impairment is the biological limitation that a person with disability experiences, which is due to a departure from an established norm for a 'normal' person based on medical criteria. Disability, on the other hand, refers, to the social, economic and other disadvantages that a person with disabilities experiences, which are the result of the

and discriminatory attitudes towards all kinds of impairments in society. The COVID-19 pandemic dramatically exposed the disadvantaged position of persons with disabilities within and beyond the health sector, and the need to act upon this urgently to improve their life situation in the area of health.

It needs to be noted that underling the health systems across the world is a pervasive medical ableism. Even though ideals of beneficence, objectivity and non-malevolence are assumed to be basic to medical work, we know that health professionals are not immune to the influence of dominant societal understandings of and attitudes toward their patients. In other words, they may be just as much victims of ableism as anyone else, when ableism is understood as "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human." (Campbell 2001). Just because biomedicine has ben central in defining, treatment and management of disabilities does not mean that health professionals, by definition, have a comprehensive understanding of and an unbiased attitude towards patients with disabilities. People with anomalous bodies and deviant minds may be regarded as less competent and less worthy than people who appear and behave more conventionally: their quality of life may be considered poorer even by health professionals. Suffering, pain and affliction may be used by health professionals to qualify their quality of life. Assuming that people with disabilities do not have capacity for autonomous decision-making and are in need of protection are core characteristics of ableist oppression in the health system.

When discussing health inequities for persons with disabilities in the context of pervasive ableism, it needs to be reiterated that they do not only need accessible infrastructure and a humane approach with regard to specific health problems, but they also require ongoing care due to the multiple inequities they experience in different domains of their lives like education,

---

social stereotypes and discriminatory behaviour towards disability in society. Module I of this Handbook discusses in detail the differences between impairment and disability.

employment, recreation and even within their own families. Recognizing that persons with disabilities require not only treatment but comprehensive care, and then devising approaches to guarantee such comprehensive care will address the multiple interlocking inequities that they experience in their lives. The aim of this Handbook is to give a blue-print for creating such a caring ambience within the health system.

It is against this backdrop of the gross inequities experienced by persons with disabilities in the health system that this HANDBOOK TO PROMOTE EQUITY FOR PERSONS WITH DISABILITIES IN THE HEALTH SYSTEM IN INDIA has been written with a view to helping the health workforce, particularly clinicians, hospital administrators and other service providers in the health system to develop a holistic understanding of the life situation of persons with disabilities; and on the basis of such an understanding, to create and use appropriate diagnostic, intervention and preventive strategies to address their multiple needs.

The main objectives of this Handbook are:

- To help the health workforce develop a holistic understanding of the life situation of persons with disabilities from a gender-sensitive perspective.
- To generate awareness about the barriers faced by persons with disabilities, particularly women and sexual minorities with disabilities in accessing the health system.
- To help health care providers develop skills and strategies to communicate directly with clients with disabilities.
- To enable the health workforce, develop appropriate diagnostic, intervention and preventive strategies to address the multiple needs of persons with disabilities, particularly women and sexual minorities with disabilities.
- To make health facilities accessible to people with disabilities in a non-discriminatory manner.

The Handbook is primarily designed to help health care providers and managers understand the inequities experienced by persons with disabilities in their search for health care, and develop appropriate strategies to overcome the obstacles that persons with disabilities, particularly women and sexual minorities with disabilities face in this connection. Consequently, the target groups of this Handbook are clinicians, hospital administrators, paramedical pprofessionals and other service providers in the health system.

1.1 Disability: Meaning

The roots of definitions of disability lie within medicine. As specialists in the understanding and working of the body in both health and illness, doctors and other health professionals acquire knowledge and skills which make them experts. In fact, the process of certifying a person as disabled in the legal sense is entirely the domain of medical experts.

Like everyone else, health professionals also experience illness and disability in the course of their own lives; for is not everyone 'temporarily able-bodied? Then, why is it that statistics across the globe consistently show multiple inequities that people with disabilities face making their experiences of the health system more often than not traumatic?

International estimates place the extent of all kinds of disabilities at around 15%-20% of the total world population over the age of five years. Globally that comes to over 1 billion people, of whom 110-190 million people have very significant difficulties in functioning. (World Health Organisation 2022). These figures broadly correlate with the definition of disability found in Article

1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which states that:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others
(https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities).

BOX 1

ARTICLE I OF THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES DEFINES PERSONS WITH DISABILITIES AS THOSE WHO HAVE LONG-TERM PHYSICAL, MENTAL, INTELLECTUAL OR SENSORY IMPAIRMENTS WHICH IN INTERACTION WITH VARIOUS BARRIERS MAY HINDER THEIR FULL AND EFFECTIVE PARTICIPATION IN SOCIETY ON AN EQUAL BASIS WITH OTHERS https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities.

This all-encompassing perspective provides the framework within which medical definitions of impairment and legal definitions of disability intersect in their operationalization in clinical contexts. Onset, duration type and degree of impairments set the stage for definitions of disability. For instance, an impairment must be of a level and of a time duration to adversely impact the capacity of an individual to carry out daily life activities in order to be identified as a disability for accessing the legally mandated benefits available to persons with disabilities. Not only do disabilities vary in terms of their extent or degree (mild, moderate, severe) and mode of onset (congenital or acquired), but also in terms of their heterogeneity containing a vast range of physical, sensory, emotional, cognitive, developmental, communication limitations among others. In other words, disability is an umbrella term encompassing impairments, activity limitations, and participation restrictions (UNCRPD 2006). Disabilities also vary in terms of their visibility from being very visible (amputation) to partially visible (Deafness) to invisible schizophrenia). Advancements in medicine, wider availability of health services, decline in child mortality, increased life expectancy, greater number of individuals with chronic and life-style related illnesses, higher number of traffic accidents, conflict and wars, natural and human disasters and climate change are all contributing to an increase in the number of persons in the population with disabilities across the globe. Furthermore, the majority of persons with disabilities are from the lower-socio-economic strata trapping them in a vicious cycle of poverty, disability and ill-health.

1.2 Disability and Health

Disability is a global public health issue as people with disabilities, face widespread barriers in accessing health and related services, such as rehabilitation, and have worse health outcomes than people without disabilities. Depending upon the definition and perspective adopted towards disability by different governments, people with disabilities represent between 10% and 20% of the world’s population, which comes to over 1 billion persons (World Health Organisation and World Bank 2011). They are disproportionately poor, and have historically experienced various forms of social exclusion and oppression. They experience major health disparities, since there are major gaps in the health system in addressing their needs. It needs to be emphasized that persons with disabilities have the right to and can achieve the highest attainable standard of health as those who do not have disabilities.

As the World Report on Promoting Health Equity for People with Disabilities (World Health Organization 2022) points out, reducing health inequities experienced by persons with disabilities can contribute to universality, people-centeredness, and non-discrimination in health services and public health promotion. Within the goal of universal health care for all, this benefits everyone, particularly other marginalized populations: older people, persons with non-communicable diseases, migrants and refugees, people from lower socioeconomic backgrounds, or those with limited literacy skills. All these groups can benefit from approaches that are disability-inclusive targeting persistent barriers in the health sector. Addressing these barriers will also benefit the families and the wider support networks of persons with disabilities, particularly women and girls who disproportionately assume caregiving and support roles within families.

Before the enactment of the United Nations Convention on Rights of Persons with Disabilities in 2006, definitions of disability and the benchmark level enabling a person to access benefits on account of being disabled varied across nations. For instance, when the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act was passed by the Indian Parliament in 1995, only 7 disabilities (namely blindness and low vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation and mental illness) were recognised entitling a person to benefits like reservation in education and employment. This number has been subsequently increased to 21 disabilities in the Rights of Persons with Disabilities Act, which replaced the earlier Act in 2016. The moot point is that who is labelled as disabled, what type of disability a person (physical, mental, sensory, developmental, psychosocial, communication) has and what is the extent (mild, moderate, severe) of the disability are all determined by doctors highlighting the embryonic relationship between disability and medicine. The purpose of this Handbook is to help health care providers respectfully engage with and effectively treat this large pool of the population that they service in their routine practice.

BOX 2

ADDRESSING HEALTH INEQUITIES FOR PERSONS WITH DISABILITIES BENEFITS EVERYONE.

People with disabilities have greater engagement with the health system throughout their lives on account of their impairments and associated secondary conditions than those without disabilities. Most disabilities have health-related complications. Furthermore, health inequities that are driven by unjust or unfair conditions and factors lead to worse health outcomes for persons with disabilities. For example, compared with the general population, persons with disabilities die prematurely. There is evidence that those with intellectual disabilities are 8 times more likely to die from COVID 19 (Gleason et al. 2021) and that persons with psychosocial disabilities have up to a 20-year mortality gap (Fiorillo and Sartorius 2021). Differences in health outcomes and everyday functioning can be attributed to the complex interactions of biological risk factors and the unfair conditions in which persons with disabilities are born, grow, live, work and age. For example, persons with disabilities experience higher rates of chronic health conditions often driven by reduced access to health care. Data from the World Health Organisation and World Bank (2011) Model Disability Survey reveals that environmental factors such as inaccessible physical environments and transportation, lack of social support and assistive devices, and negative attitudes and barriers in accessing health care, increase the limitations in the functioning of persons with disabilities than people without disabilities. An inaccessible health system is one of the major factors contributing to health inequities for persons with disabilities.

BOX 3

- AN ESTIMATED 1.3 BILLION PEOPLE EXPERIENCE SIGNIFICANT DISABILITY. THIS REPRESENTS 16% OF THE WORLD'S POPULATION, OR 1 IN 6 OF US.
- PERSONS WITH DISABILITIES FACE MANY HEALTH INEQUITIES.
- SOME PERSONS WITH DISABILITIES DIE UP TO 20 YEARS EARLIER THAN THOSE WITHOUT DISABILITIES.
- PERSONS WITH DISABILITIES HAVE TWICE THE RISK OF DEVELOPING CONDITIONS SUCH AS DEPRESSION, ASTHMA, DIABETES, STROKE, OBESITY OR POOR ORAL HEALTH.
- PERSONS WITH DISABILITIES FIND INACCESSIBLE AND UNAFFORDABLE TRANSPORTATION 15 TIMES MORE DIFFICULT THAN FOR THOSE WITHOUT DISABILITIES.
- HEALTH INEQUITIES ARISE FROM UNFAIR CONDITIONS FACED BY PERSONS WITH DISABILITIES, INCLUDING STIGMA, DISCRIMINATION, AND POVERTY, EXCLUSION FROM EDUCATION AND EMPLOYMENT, AND BARRIERS FACED IN THE HEALTH SYSTEM ITSELF.
- https://www.who.int/news-room/fact-sheets/detail/disability-and-health

BOX 4

PEOPLE WITH DISABILITIES FACE HIGHER RATES OF PRE-TERM BIRTHS, LOW WEIGHT BABIES, STILLBIRTHS, MALNUTRITION), SEVERE DIAHORROEA AND SERIOUS ILLNESSES (SHIN ET AL 2020). SEXUAL AND REPRODUCTIVE HEALTH SERVICES ARE INACCESSIBLE. IN ADDITION TO REDUCED ACCESS TO HEALTH CARE SERVICES, INADEQUATE PROVIDER SKILLS, FINANCIAL CONSTRAINTS AND INCREASED SUSCEPTIBILITY TO CATASTROPHIC HEALTH EXPENDITURES EXACERBATE THEIR PLIGHT (LEE ET AL. 2016).

1.3 Disability Health and the Environment

Inaccessible health facilities adversely affect the functioning levels of persons with disabilities than those without disabilities. Promoting health equity for persons with disabilities has a ripple effect on their total life situation, since good health is the non-sine quo of life itself. As the Global Report on Health Equity for Persons with Disabilities (2022) points out, advancing health equity is a prerequisite for their wider participation in society. Good health and well-being are essential to living a decent and meaningful life. Not benefiting from necessary health care hinders the realization of other fundamental rights, such as the right to education or employment. By not receiving the required health services, such as rehabilitation and assistive technology, persons with disabilities may not be able to attend school, access livelihood opportunities, go to work or participate in community life and society. For example, a study conducted in Nepal revealed that a major reason why children with disabilities do not go to school is because of poor health (Zuurmond et al. 2014). In another study conducted in the Maldives, Banks et al. (2022) found that people with disabilities had poorer health and had greater difficulties in accessing health care than their non-disabled counterparts. Hence, advancing health equity for persons with disabilities will lead to larger societal equities for them as a whole.

BOX 5

ENVIRONMENTAL FACTORS CONTRIBUTING TO HEALTH INEQUITIES FOR PERSONS WITH DISABILITIES INCLUDE: I) STRUCTURAL FACTORS SUCH AS CULTURE AND SOCIAL VALUES, GOVERNANCE MECHANISMS; II) SOCIAL DETERMINANTS, INCLUDING POVERTY, EDUCATION,EMPLOYMENT, TRANSPORTATION; III) RISK FACTORS SUCH AS SMOKING, ALCOHOL CONSUMPTION AND DRUG USE, AND PHYSICAL INACTIVITY; AND IV) THE HEALTH SYSTEM (WHO 2022).

https://iris.who.int/bitstream/handle/10665/364833/9789240063624-eng.pdf?sequence=1

From a macro-level, increasing privatisation of the health system creates its own set of barriers and enablers. Persons with disabilities from the higher echelons of society can benefit from the specialised medical and support services of high quality available to those with paying power. However, the public health system, which is the resort for the majority of the population with disabilities, has to make do with the lower standard of health care services available in most such institutions. Neo-liberal reform with a focus on free market rather than the right to health disadvantages people with disabilities due to their increased health care needs and lower socioeconomic status (Sakellariou and Rotarou 2017). Marketization overrides social justice (Mladenov et al. 2015). This inequity within neoliberal health system plays a major role in exacerbating the health inequities for persons with disabilities (Hiranandani and Sonpal 2010).

BOX 6

WITH ITS FOCUS ON FREE MARKET, PRIVITISATION UNDERMINES THE RIGHT TO HEALTH. ITS ADVERSE IMPACT ON THE HEALTH STATUS OF THE MAJORITY OF PERSONS WITH DISABILITIES CANNOT BE OVER-STATED.

1.4 People with Disabilities' Experiences of the Health System

People with disabilities are forced to engage with the health system more than non-disabled persons throughout their lives. Not only is the medical system a necessary resort for the primary disability. Secondary conditions cause adverse outcomes in health, wellness, community participation, and quality of life (Hough 1999). Depression and social isolation are perhaps, the most common secondary psychosocial conditions affecting all persons with disabilities. Then, there are more specific health conditions associated with specific disabilities like urinary tract infections with wheelchair users; osteoporosis and fractures are also more associated with movement disabilities. Early and continuous screening can reduce the risk of secondary conditions and improve health outcomes for persons with disabilities.

In the process of engaging with the health system, people with disabilities face many barriers going beyond accessibility issues. Negative encounters with doctors, nurses and other health care providers are a routine occurrence leading to ineffective and negative communication, even miscommunication. In addition to the general societal prejudicial attitudes and paternalism towards disability to which health providers are not exempt, the underlying communication barriers reported by persons with disabilities are the health care providers' perceptions arising from the medical discourse itself. For instance, health professionals may assume that patients with disabilities cannot be healthy or sexual, or that all their health problems are linked to their disability. They may (perhaps subconsciously) believe that such patients are of lower intelligence who cannot articulate their health problems or comprehend treatment protocols. But perhaps, the most damaging aspect of such interactions is the providers' non-recognition or negation of the experiences, knowledge and expertise of persons with disabilities about their health and disability. Of course, this state of affairs is a manifestation of the larger power differential in the doctor-patient relationship, but it has particular deleterious consequences for patients with disabilities, especially women, transgender and non-binary persons, wherein gender and disability combine leading to a double oppression. Professional expertise, patriarchy and ableism frame the provider-patient relationship in this scenario

The relationship between people with disabilities and the health system is paradoxical: on the one hand, the labelling process that categorises a person as disabled sets the stage for a lifelong and life-altering lifespan is initiated by medicine. It is noticed that the contact with the health system is maximum following the onset of disability in a frenetic search for cure. Then, depending on the course of the disability, when it is accepted that cure is not an option, contact may diminish until the onset of other (secondary) illness conditions. On the other hand, the nature of the disability itself may require constant contact with the health system, i.e. glaucoma resulting in visual impairment. The course of the disability intersects with other variables, such as socio-economic class, place of residence, gender of the affected person, family dynamics, etc. to constitute the relationship of the person with disabilities with the health system.

While it stands to reason that persons with disabilities are less likely to report being in excellent or very good health in comparison to their non-disabled counterparts, it is also true that like everyone else, they need the health system to be able to lead long healthy and productive lives within the limitations imposed by the disability and a constantly ageing body.

Several reports on health and disability have reiterated the need for special measures to address the multiple health care needs of the disabled population (Institute of Medicine US 2008; National Council on Disability Report 2009; World Health Organization 2011).

BOX 7

HEALTH CARE ACCESS FOR PERSONS WITH DISABILITIES NEEDS TO BE IMPROVED, INCLUDING AVAILABILITY OF FACILITIES, EQUIPMENT, TRANSPORTATION AND INSURANCE

HEALTH CARE WORKFORCE NEEDS TO BE SENSITISED TO THE FACT THAT PEOPLE WITH DISABILITIES CAN LIVE LONG, HEALTHY AND PRODUCTIVE LIVES;

STIGMA AND DISCRIMINATION AGAINST PERSONS WITH DISABILITIES NEEDS TO BE REDUCED WITHIN THE HEALTH SYSTEM

THE KNOWLEDGE, SKILLS AND ATTITUDES OF HEALTH CARE PROVIDERS TO WORK WITH PATIENTS WITH DISABILITIES NEED TO BE IMPROVED

PROCEDURES FOR ONGOING COLLECTION AND DISSEMINATION OF DATA ON HEALTH AND DISABILITY, PARTICULARLY DISABILITY-RELATED HEALTH DISPARITIES AND INTERVENTIONS NEED TO BE ESTABLISHED

1.5 Gender, Violence and Eugenics

Disability is not the only factor that impacts persons' with disabilities' perceptions of, access to, and experiences of the health system. Among the other socio-demographic variables, such as caste/class, education, occupation, place of residence, etc. gender is a key category. The research on the basis of which this Handbook is written, focussed on the differential experiences of men and women with disabilities in this regard. Men and women with disabilities experience different barriers in life: While men with disabilities experience more marginalisation in the areas of education, sport, professional achievement and other domains connected with traditional roles of manhood, women with disabilities' access to even the most traditional female roles of wife and mother is very challenging. Compared to men with disabilities and non-disabled women, women with disabilities are more likely to never marry, marry later, and be divorced, if they do get married (Asch & Fine, 1988). According to the 2011 Census of India, more men (62%) than women with disabilities (54%) are married. More women with disability fall within the divorced/separated and widowed categories (13%) than their male counterparts (6%).

Violence and disability are integrally linked. Many people become disabled through acts of violence, and people with disabilities are more frequently the objects of violence than people without disabilities (Sobsey 1994; Waxman 1991). Again, the gender variable complicates the picture, as more women are globally the victims of sexual and domestic violence. So, a woman with disability will be less able to defend herself in a risky situation because she may not be able to run or scream for help. Then, persons with developmental disabilities may be too trusting of others and hence may be easier to trick, bribe or coerce. They may not understand the differences between sexual and non-sexual tactile behaviour. Persons with speech and hearing difficulties may have limited communication skills to report abuse. Furthermore, since persons with disabilities are often taught to be obedient, passive and control their behaviour, this will render them easy victims. Being powerless, isolated and anonymous, women with disabilities are even more vulnerable to an abuse and violence. Violence against women, children and sexual minorities with disabilities is an area that has received less attention (Lund 2020; Plummer and Findley 2012; Stalker and McArthur 2012). Much of the literature in this area is based on the studies which show that women with disabilities are at a much greater risk of being sexually abused than other women. Women with disabilities in institutions are at a much greater risk of being sexually abused than their counterparts outside (Crossmaker 1991). A similar picture is painted on the situation of women with disabilities in the Indian context (Dawn 2014; Mohapatra and Mohanty 2005).

Since women with disabilities are seen as dependent and in need of being taken care of, stereotypical notions present them as incapable of filling the caring and nurturing mothering role (Shaul, Dowling, and Laden 1985). The widespread belief that women with disabilities cannot and should not bear and raise children has made it difficult for pregnant women with disabilities to find doctors who will accept them as clients. They have also found it hard to gain access to the information and services related to their special needs (Finger 1985). Not only have women with disabilities reported difficulties in becoming biological mothers and keeping custody of their own children, they also encounter discrimination if they have attempt to adopt children or become foster mothers.

Society’s fears that women with disabilities will produce defective children are for the most part groundless, because the vast majority of disabilities are not hereditary. These fears have resulted in severe discrimination against women with disabilities in general, and women with intellectual and psychosocial disabilities in particular. More importantly, these women are thought to lack moral restraints concerning sexual activities and it is believed that as a consequence they would produce a large number of illegitimate and deficient children. The preventative measures taken against this perceived threat in the past included large scale forced sterilization (Nielson 2013) and institutions for "feeble minded women of child-bearing age" (Massachusetts Society for the Prevention of Cruelty to Children 1913) were established. Till 1960, 26 states of the United States still had sterilization laws; and as late as 1980, 33 states still had laws that prohibited people with intellectual disabilities from marrying (Scheerenberger 1987). No other group of women with disabilities has been as severely discriminated against in terms of their reproductive rights, and some of the myths surrounding women with intellectual disabilities, such as the myth of their uncontrollable sexuality, are still, very much alive today.

It is widely documented that women with disabilities are typically seen as non-sexual (Fine and Asch 1988). This is true of society in general as well as of most professionals with whom women with disabilities come into contact. Because women with disabilities are seen as non-sexual, they are not seen as in need of information about birth control or what is possible in terms of having a sex life and children, but like other women, they do menstruate and undergo menopause for which they need to be provided information which they can understand. This misconception is not only an incorrect representation of the actual lives of persons with disabilities, but also a violation of their sexual and reproductive health rights. It is no wonder that many people with disabilities consider sexuality to be the area of greatest oppression.

It is in the light of the multiple oppressions experienced by people with disabilities vis-a-vis the health system that this Handbook has been developed.

BOX 8

VIOLENCE GENDER AND DISABILITY HAVE BEEN INEXTRICABLY LINKED. BEYOND PHYSICAL, SEXUAL AND PSYCHOLOGICAL VIOLENCE, THE DOCTRINE OF EUGENICS HAS LED TO REPRODUCTIVE VIOLENCE AGAINT WOMEN WITH DISABILITIES.

1.6 Overview of Handbook to Promote Equity for Persons with Disabilities in the Health System in India

Some of the negative perceptions that inhibit good communication by health providers with their patients with disabilities include under-estimation of the abilities and quality of life of persons with disabilities, their capacities for self-care embedded in their own understanding and expertise on their disability as a lived reality. It is hoped that this Handbook will help to sensitise, create awareness and motivate among health care professionals about the life situations of persons with disabilities, and current thinking on disability in international human rights law and policy, which may be applied in clinical practice. While some categories of health care staff, like rehabilitation professionals, social workers and other allied professionals may have varying degrees of familiarity with the disability discourse, other categories of the health care workforce may not. The target group of the Handbook is health personnel in general, and those engaged in clinical practice in particular.

This Handbook comprises 6 modules in addition to the Introduction. The first Module elaborates on the contemporary perspectives on disability going beyond medical notions of impairment to its socio-cultural and politico-economic dimensions. Apart from different definitions, classifications and models of disability, the module discusses the different forms of discrimination experienced by people with disabilities contributing to their marginalisation. The concluding section of Module I presents an overview of disability in India in terms of prevalence, laws and policies.

Given the importance of gender and sexuality in the constructions of identity, the second module presents a broad understanding of these concepts in their intersections with disability. While the focus of the Handbook is on the inequities experienced by persons with disabilities vis-a-vis the health system, it needs to be borne in mind that the concept of gender goes beyond the binary, encompassing the whole range of LGBTQIA+ (lesbian, Gay, Bisexual, Transgender, Queer, Persons with intersex variations and Non-sexual) configuration, each of which may intersect with disability. However, a detailed analysis of the complexity of the whole gender spectrum and its intersections with disability are beyond the scope of the present Handbook.

The strong stereotypes of non-sexuality and hypersexuality, with which persons with disabilities are saddled, result in a total neglect of their sexual and reproductive rights by the health system. This has major consequences for women with disabilities due to the biological nature of their bodies like menstruation, and the reproductive events of pregnancy and motherhood in their lives. The third module looks at the concepts of sexual health and rights, reproductive health and rights in the context of the challenges faced by persons with disabilities in socio-cultural contexts, wherein disability, sexuality and reproduction are enveloped in varying degrees of taboo.

The fourth module moves the lens of analysis directly on the interface between people with disabilities and the health system upon which they are dependant to be identified as disabled and to be rehabilitated enabling them to adjust to the world in the context of the limitation of the disability. However, the health system, by virtue of being part of the wider society, does not protect them from the stigma and discrimination that they experience in other domains of their lives. This module discusses the concept of rehabilitation and the barriers that people with disabilities face in their engagement with the health system. It also puts forth some of the major myths and misconceptions held by health care personnel on disability and people with disabilities, which needs to be debunked to make the health care environment disable-friendly.

While infrastructural barriers are a major obstacle to people with disabilities in accessing the health system, the clinical interface between a patient with disabilities and the health care practitioner can be equally oppressive. The fifth module looks at the attitudinal and contextual barriers that create bottlenecks in the communication process. It discusses both established clinical processes and routines which disadvantage patients with disabilities, especially in terms of the human relational factors.

The final module delineates the features of an ideal disability inclusive health system that addresses the general and specific needs of people with disabilities. The sixth module discusses the concept of inclusion highlighting that an inclusive health system benefits all stakeholders and not just persons with disabilities. It offers some solutions to remove the bottlenecks to facilitate a congenial health care environment, wherein patients with disabilities do not feel discriminated against by health providers. Disability inclusion reduces the barriers that various vulnerable groups like the elderly, pregnant women, illiterate and economically disempowered experience in accessing health care, thus providing the highest standard of health care to all users.

BOX - 9

MODULES IN HANDBOOK

- DISABILLITY
- DISABILITY, GENDER AND SEXUALITY
- SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS: SSUES AND CONCERNS FOR PEOPLE WITH DISABILITIES
- PATIENTS WITH DIABILITIES AND THE HEALTH SYSTEM
- COMMUNICATION BARRIERS FOR PATIENTS WITH DISABILITIES AND THEIR HEALTH CARE PROVIDERS
- CREATING A DISABILITY INCLUSIVE HEALTH SYSTEM

2. DISABILITY

Objectives

After going through this Module, you will be able to:

- *Understand Disability from a Multi-Dimensional Perspective: Definitions and Classifications*

- *Understand the Different Models of Disability*

- *Become Aware of the Different Forms of Discrimination Faced by Persons with Disabilities*

- *Get an Overview of Disability in India: Prevalence, Laws and Policies*

2.1 Disability: Multi-Dimensional Concept

Defining disability is not an easy task. It is a dynamic, complex, and multi-dimensional concept. Disability is a word used in daily conversations, which holds different meanings for different people. In commonplace parlance, it is generally used to refer to visible deficits like lack of vision, impaired hearing or a limb deformity. Often people think that 'disability' only refers to people who use a wheelchair or walker. But disability cannot be determined solely on the basis of whether a person uses an assistive aid or not. For people with disabilities, the experience is unique to every individual. Two people with the same type of disability can be affected in very different ways. In medicine, disability is defined in terms of measurable impairments taking account of the biological deficit. Thus disability is a complex phenomenon, having physical, psychological, social and cultural aspects.

According to the World Health Organisation and World Bank Report on Disability (WHO 2011) about 15% of the world's population have some form of disability which constitutes over 1.3 billion people. With the worldwide increase in chronic health diseases such as cardiovascular diseases, diabetes, cancer, accidents due to car crashes, injuries due to falls, violence and mental health disorders, largely related to the increase in ageing population due to increased life expectancy, the pervasiveness of disability is expected to increase exponentially in the near future, as it is inextricably linked with non-communicable diseases. In fact, the relationship between disability and non-communicable diseases is bidirectional because these conditions are accompanied by impairments, and people with disabilities are more vulnerable to non-communicable diseases (Prynn and Kuper 2019).

BOX 10

DISABILITY IS A DYNAMIC, COMPLEX, AND MULTIDIMENSIONAL CONCEPT HAVING PHYSICAL, PSYCHOLOGICAL, SOCIAL AND CULTURAL ASPECTS.

2.2 Classifications of Disabilities

There are different ways to classify disabilities which are often overlapping, and distinguished more for heuristic purposes than concrete identifiable characteristics. Disabilities may be simultaneously categorised on the basis of origin, cause, symptoms or manifestations, course and outcome.

2.2.1 Classification of Disabilities by Aetiology and Manifestations

Physical Disabilities are condition that limit one or more basic physical activities, like movement, seeing, hearing etc. Examples of physical disabilities include: spinal cord injuries, paraplegia[2], amputation, muscular dystrophy[3], arthritis[4], visual and hearing impairments. The latter are also

---

[2] Paraplegia is a type of paralysis that affects one's ability to move the lower half of the body. It occurs when an illness or injury impacts the part of the nervous system which controls the lower half of the body.https://www.healthline.com/health/chronic-illness/paraplegia

[3] Muscular dystrophy refers to a group of genetic diseases that cause progressive weakness and degeneration of skeletal muscles. These disorders (of which there are more than 30) vary in age of onset, severity, and the pattern of the affected muscles. In due course of time, muscles progressively degenerate and weaken. Many people with MD eventually lose the ability to walk. Some types of muscular dystrophy also affect the heart, lungs, gastrointestinal system, endocrine glands, spine, eyes, brain, or other organs.. Muscular dystrophy is not caused by injury or activity. https://www.ninds.nih.gov/health-information/disorders/muscular-dystrophy

[4] Arthritis is the swelling and tenderness of one or more joints. The main symptoms of arthritis are joint pain and stiffness, which typically worsen with age. The most common types of arthritis are osteoarthritis and rheumatoid arthritis.

classified as sensory disabilities, since they affect the sense organs like the eyes and ears.

Developmental Disabilities are a group of conditions resulting from impairments in physical, learning, language or behaviour, which begin during the developmental period of the life cycle, often adversely impact daily functioning and usually last throughout the lifespan (Rubin and Crocker 1989). Examples of developmental disabilities include Down syndrome[5], Fragile X syndrome[6], Autism Spectrum Disorder[7], intellectual disabilities and Cerebral Palsy[8].

---

https://www.mayoclinic.org/diseases-conditions/arthritis/symptoms-causes/syc-20350772

[5] Down syndrome is a genetic disorder caused by abnormal cell division resulting in an extra full or partial copy of chromosome 21. It varies in severity among individuals, causing lifelong intellectual disability and developmental delays. It is the cause of learning disabilities in children and other medical abnormalities, including heart and gastrointestinal disorders. https://www.mayoclinic.org/diseases-conditions/down-syndrome/symptoms-causes/syc-20355977

[6] Fragile X syndrome is a genetic disorder caused by changes in a gene called Fragile X Messenger Rib nucleoprotein 1 (FMR1) that usually makes a protein called FMRP, which is required for normal brain development. People who have this condition do not make this protein resulting in developmental delays, intellectual disabilities, behavioural issues, physical abnormalities, anxiety, and attention-deficit/ among other problems. It's the most common form of inherited intellectual and developmental disability.it affects both males and females with the latter having milder symptoms.
https://my.clevelandclinic.org/health/diseases/5476-fragile-x-syndrome

[7] Autism spectrum disorder is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. It is described as a "developmental disorder" because symptoms generally appear in the first 2 years of life. Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience. People of all genders, races, ethnicities, and economic backgrounds can be diagnosed with this condition. Although it can be a lifelong disorder, treatments and services can improve a person's symptoms and daily functioning.
https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd

[8] Cerebral palsy is a group of conditions that affect movement and posture. It's caused by damage that occurs to the developing brain, most often before birth. Symptoms appear during infancy or preschool years and vary from very mild to serious. People with cerebral palsy may have stiff muscles, known as spasticity. Symptoms also can include irregular posture, movements that can't be controlled, a walk that's not steady or some combination of these. There is no cure, but treatments can help improve function.

Intellectual Disabilities are conditions that result in significant limitations in cognitive capacities which have a ripple effect on social and practical skills. These are specific cognitive difficulties that may create a low intelligence quotient (IQ) score and pose difficulties in adapting to life situations. Understanding and applying information is hard for such persons. Intellectual disabilities such as Down syndrome and Fragile X Syndrome, can happen due to genetic factors. It may be noted that although developmental and intellectual disabilities are distinct categories, they often overlap in the individuals in whom they are identified.

Cognitive Disabilities are a group of conditions that affect mental processes of awareness, perception, reasoning, memory and judgement. This category includes a wide range of conditions with different causes like brain injury, altered brain chemistry and hormonal issues, such as Alzheimer's[9] or Parkinson's[10] diseases, deficiency of certain vitamins, psychiatric illness and substance abuse. A person with this type of problem experiences difficulties in such mental functions as perceiving, recognizing, choosing, understanding, remembering etc. The person may have difficulties in processing, quantification and/or visualization of information.

---

https://www.mayoclinic.org/diseases-conditions/cerebral-palsy/symptoms-causes/syc-20353999

[9] Alzheimer's disease causes a decline in memory, thinking, learning and organizing skills over time. It's the most common cause of dementia and usually affects people over the age of 65. There's no cure for Alzheimer's, but certain medications and therapies can help manage symptoms temporarily. https://my.clevelandclinic.org/health/diseases/9164-alzheimers-disease

[10] Parkinson's disease is an age-related degenerative brain condition, It's best known for causing slowed movements, tremors, balance problems and more. Most cases happen for unknown reasons, but some are inherited. The condition isn't curable, but there are many different treatment options. https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview

Psychiatric Disabilities are characterized by emotional, cognitive, and/or behavioural dysfunction. For example, depression, substance abuse, different types of mental illnesses like bipolar disorder[11], and schizophrenia[12]. Other terms like mental disabilities and psychosocial disabilities are also used interchangeably with psychiatric disabilities in order to shift the focus of attention from medical to social, cultural and economic aspects.

2.2.2 Classification of Disabilities by Onset

Disabilities may occur at birth due to genetic or environmental factors or they may occur later in life.

Congenital Disabilities are structural or functional anomalies that occur in the womb or during delivery and manifest either at birth or later in life. Examples include Down syndrome, cleft palate[13], spina bifida[14] among

---

[11] Bipolar disorder (formerly called manic-depressive illness) is a mental illness that causes unusual shifts in a person's mood, energy, activity levels, and concentration. These shifts can make it difficult to carry out day-to-day tasks. The mood changes range from periods of extremely "up," elated, irritable, or energized behaviour (known as manic episodes) to very "down," sad, indifferent, or hopeless periods (known as depressive episodes).
https://www.nimh.nih.gov/health/topics/bipolar-disorder#part_2264

[12] Schizophrenia is characterised by significant impairments in the way reality is perceived. Delusions, hallucinations, disorganised thinking and behaviour are the critical manifestations of this complex disease. People with schizophrenia often also experience persistent difficulties with their cognitive or thinking skills, such as memory, attention, and problem-solving.
https://www.who.int/news-room/fact-sheets/detail/schizophrenia

[13] Cleft palate or cleft lip are openings or splits in the upper lip, the roof of the mouth (palate) or both. Cleft lip and cleft palate result when facial structures that are developing in an unborn baby don't close completely. They are among the most common birth defects. These defects can be corrected through surgeries.
https://www.mayoclinic.org/diseases-conditions/cleft-palate/symptoms-causes/syc-20370985

[14] Spina bifida is a condition that occurs when the spine and spinal cord don't form properly in the developing foetus. In babies with spina bifida, a portion of the neural tube doesn't close all the way. This affects the spinal cord and bones of the spine. . When necessary, early treatment for spina bifida involves surgery. However, surgery

many others. Genetic disorders also occur in the intra-uterine state of foetal development. However, it is to be noted that not all congenital disorders are genetic disorders. For example, congenital defects or malformations may be caused by intrauterine infection (like rubella) or maternal consumption of drugs that are harmful to the developing foetus. All genetic disorders do not necessarily manifest at birth or in early infancy. For example, colour blindness, Duchene Muscular Dystrophy[15].

<u>Acquired Disabilities</u> occur at any time after birth in the course of a person's life. Examples include spinal cord injury caused by a road accident, Alzheimer's disease occurring in the elderly.

2.2.3 Classification of Disabilities by Visibility

<u>Visible Disabilities</u> are disabilities that are evident from appearance with the naked eye, can be observed and measured by other people through the extent of hindrance caused to daily life activities. These conditions often result in stigma, social marginalization, and the development of negative stereotypes of the persons having the disability. Some examples are polio, amputation, cerebral palsy, acid attack among others.

<u>Invisible Disabilities</u> are disabilities that are not evidently visible but they have visible or invisible symptoms such as mental disorders, hearing and vision impairments. These conditions are not always obvious to the observer, but they interfere in the daily activities of the affected person, ranging from mild challenges to severe limitations. Examples of invisible

---

doesn't always completely restore lost function.https://www.mayoclinic.org/diseases-conditions/spina-bifida/symptoms-causes/syc-20377860

[15] Duchene Muscular Dystrophy is a severe, genetic disorder that causes muscles to gradually weaken, primarily affecting boys. It's the most common form of muscular dystrophy, affecting one in 3,500 to 5,000 new-borns. It is caused by a lack of production of dystrophic, a protein that muscles need to work properly. https://www.mda.org/disease/duchenne-muscular-dystrophy

disabilities include depression, attention deficit hyperactivity disorder[16], and schizophrenia. Many chronic illnesses such as renal failure, diabetes, and sleep disorders also have disabling consequences, i.e. vision loss in diabetes.

2.2.4 Classification of Disabilities by Course

Static Disabilities are disabilities that are more or less permanent. Examples of static disabilities include loss of limb, total blindness and deafness.

Progressive Disabilities are disabilities or health conditions that get worse over time resulting in a general decline in functioning. Osteoarthritis, Parkinson's disease, cystic fibrosis[17] are examples of progressive conditions that generally follow a downward course.

Intermittent/Episodic Disabilities are characterised by periods and degrees of wellness and disability that fluctuate over time. Examples include diabetes, cancer, HIV and AIDS and multiple sclerosis[18], bipolar disorder

---

[16] Attention-deficit/hyperactivity disorder is one of the most common mental disorders affecting children. Symptoms of ADHD include inattention (not being able to keep focus), hyperactivity (excess movement that is not fitting to the setting) and impulsivity (hasty acts that occur in the moment without thought). ADHD is considered a chronic and debilitating disorder and is known to impact the individual in many aspects of their life including academic and professional achievements, interpersonal relationships, and daily functioning (Harpin 2005).

[17] Cystic fibrosis) is an inherited disorder that causes severe damage to the lungs, digestive system and other organs in the body. It affects the cells that produce mucus, sweat and digestive juices. These secreted fluids are normally thin and slippery. But in people with this condition, a defective gene causes the secretions to become sticky and thick. Instead of acting as lubricants, the secretions plug up tubes, ducts and passageways, especially in the lungs and pancreas. Cystic fibrosis is progressive and requires regular care. https://www.mayoclinic.org/diseases-conditions/cystic-fibrosis/symptoms-causes/syc-20353700

[18] Multiple sclerosis is the most common disabling neurological disease of young adults with symptom onset generally occurring between the ages of 20 to 40 years.
The immune system cells s mistakenly attack myelin in the central nervous system (brain, optic nerves, and spinal cord). Myelin is a substance that makes up the protective sheath (myelin sheath) that coats nerve fibres (axons). Multiple sclerosis is a chronic disease that affects people differently. A small number of people will have a mild course

among others. People living with such disabilities experience periods of fluctuating good and ill health and have to rely on proper care, monitoring and treatment to manage the condition. Periods of remission alternate with upswing in symptoms.

BOX - 11

DISABILITIES MAY BE CLASSIFED ON THE BASIS OF AETIOLOGY, ONSET, SYMPTOMS, MANIFESTATIONS, VISIBILITY, CAND COURSE

2.3 Historical Overview of the Idea of Disability

Since time immemorial, what is today referred to as disability has been a feature of the human condition (Stiker 1999). Every society has experienced and labelled departures from so-called normal functioning of human beings, be it in sensory modalities, appearance, cognition or affect. Socio-cultural, religious and moral ideas have been used to account for such departures. For example, attributing mental disorders to demonic possession and explaining physical differences in terms of the outcome of bad *karma* are commonplace explanations even today. It is only with the rise of modern science and medicine in Europe and the United States from the 18th century onwards that such beliefs have been challenged. The social understanding of disability is a very recent development, which is slowly being incorporated into the health care system.

---

with little to no disability, whereas others will have a steadily worsening course that leads to increased disability over time.. The disease is rarely fatal and most patients have a normal life expectancy.https://www.ninds.nih.gov/health-information/disorders/multiple-sclerosis

Looking at the development of the disability concept over the past three centuries, one can see the gradual transformation in its conceptualisation. By the 1800s in Europe and the United States impairment began to be viewed not only as an individual problem but as a public health issue with social and policy implications. During this period disability and impairment were used interchangeably. At that time, disability was seen as a purely medical problem caused by disease, trauma, or other health condition giving rise to the medical model of disability which views disability as an individual problem. Since the definition of what constitutes an impairment/ disability is derived from the medical model, this model has been the most important model in the understanding, treatment and management of disabling conditions and individuals with disabilities. According to the medical model, disability is an abnormality or pathology residing in the body or mind of the affected individual. The medical field works towards the cure/care of the disabling conditions through therapies and treatments or alterations of behaviour of the individual with disabilities, so that she can be rehabilitated. This model views physicians as the 'experts' who know what is best for those with disabilities. Since persons with disabilities are not given a voice in the treatment and management of their condition apart from following the instructions of the experts, medical professionals have historically come to wield immense power over the persons with disabilities and their families. This has created a stark power imbalance between people with disabilities and medical professionals.

More recently since the 1960s, the disabled people's movement in the West, academics and researchers from the fields of social and health sciences, have identified the critical role of physical, social and cultural factors in the understanding and management of disabilities. Disability has come to be viewed more as a consequence of environmental and societal factors creating barriers to the abilities of people with impairments to lead fulfilling lives and to participate fully in their communities. While impairment continues to be an important factor in the definition of disability, the burden of blame has shifted from the individual and/or family to the wider society. Individuals with disabilities, their families, and advocacy groups the world over now view disability more as a consequence of an inaccessible environment full of different kinds of barriers that obstruct the optimum functioning of persons with disabilities. The solution lies in social and political inclusion of persons with disabilities and their full participation in society. This is not to underplay the important role of the health system in the treatment and management of the impairment, but to highlight the need to adopt an intersectional approach that combines biological and environmental factors.

The movement from a 'medical model' to a 'social model', is described as one in which people are viewed as being disabled by society rather than by their bodies (Oliver 1990). While the medical model emphasises the 'impairment' – 'lacking all or part of a limb; having a defective limb, organ or mechanism of the body – which is a biological condition, the social model focuses on 'disability' – a condition created by the society on account of denying human rights to a person with impairment(s). The two models are often presented as dichotomous, but disability_should neither be viewed as a purely medical condition nor as only a socially constituted situation.

In 1980, the World Health Organisation prepared The International Classification of Functioning, Disability and Health (ICF), developed with the help of academics, clinicians and persons with disabilities to advance the understanding and measurement of disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental. This is the 'bio-psychosocial model' which emphasizes the interaction of biology and environment in the development of disability.

According to the WHO, "Disability is the umbrella term for impairments, activity limitations_and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition or impairment) and that individual's contextual factors (environmental and personal factors)" (World Health Organization 2011: 4).

According to the ICF, problems with human functioning are categorized in three interconnected areas:

- Impairments: problems in body function or alterations in body structure – for example, paralysis or blindness;
- Activity limitations: difficulties in performing and executing activities – for example, walking or eating;
- Participation restrictions: difficulties with involvement in any area of life – for example, facing discrimination in employment or transportation.
- According to the bio-psychosocial model, disability refers to difficulties encountered in any or all three areas of functioning mentioned above. The ICF goes on to define ‘activity’ as the execution of a task or action by an individual and ‘participation’ as a person’s involvement in a life situation. Activity limitations and participation restrictions can be described as the obstructions an individual with disabilities experiences in performing tasks and engaging in social roles. Activities and participation can be hindered or facilitated depending on environmental factors, such as social support and relationships, technology, social services, policies, or the beliefs and ideologies of others.
- More specifically, the ICF includes the following in the categories of activities and participation:
- Learning and applying knowledge
- Managing tasks and demands
- Mobility (moving and maintaining body positions, handling and moving objects, moving around in the environment, moving around using transportation)
- Managing self-care tasks (eating, sleeping bathing)
- Managing domestic life (household tasks like cooking, cleaning, shopping)
- Establishing and managing interpersonal relationships and interactions
- Engaging in major life areas (education, employment, managing money or finances)
- Engaging in community, social, and civic life.

The ICF can also be used to understand and measure the positive aspects of functioning, such as body functions, activities, participation and environmental facilitation. It adopts neutral language and does not distinguish between the type and cause of disability – for instance, between 'physical' and 'mental' health. 'Health conditions' are 'diseases, injuries, and disorders, while 'impairments' are specific decrements in body functions and structures, often identified as symptoms or signs of health conditions. Disability arises from the interaction of health conditions with contextual factors – environmental and personal factors.

The ICF contains a classification of environmental factors describing the world in which people with different levels of functioning must live and act. These factors can be either facilitators or barriers. Environmental factors include: products and technology; the natural and built environment; support and relationships; attitudes; and services, systems, and policies. It further distinguishes between a person's capacities to perform actions and the actual performance of those actions in real life, a subtle difference that helps illuminate the effects of environment and how performance might be improved by modifying the environment. The ICF also recognizes personal factors, such as motivation and self-esteem, which can influence how much a person participates in society. However, these factors are not yet conceptualized or classified.

The ICF is universal because it covers all human functioning and treats disability as a continuum rather than categorizing people with disabilities as a separate group: disability is a matter of more or less, not yes or no. However, policy-making and service delivery protocols might require thresholds to be set for impairment severity, activity limitations, or participation restrictions. The ICF classification is useful for a range of purposes – research, surveillance, and reporting – related to describing and measuring health and disability, including: assessing individual functioning, goal-setting, treatment, and monitoring; measuring outcomes and evaluating services; determining eligibility for welfare benefits; and developing health and disability surveys.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), adopted in 2006, states in its Preamble that disability is the outcome of the "..the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" Thus, defining disability as an interaction implies that it is not an attribute of the person or family alone: rather society is held accountable and hence improvement in social participation of people with disabilities can be advanced by tackling the barriers which hinder them in their social and personal lives. It is very important to improve the conditions in communities by providing accommodations that decrease or eliminate activity limitations and participation restrictions for people with disabilities, so they can participate in the roles and activities of everyday life.

BOX 12

A HISTORICAL OVERVIEW OF DISABILITY SHOWS THE DOMINANCE OF MEDICINE IN ITS DEFINITION AND MANAGEMENT. THE WORLD HEALTH ORGANISATION'S APPROACH COMBINES MEDICAL KNOWLEDGE WITH A CONTEXTUAL APPROACH THAT ENGAGES SCIENCE, SOCIETY AND CULTURE IN THE BIO-PSYCHOSOCIAL MODEL. IT PROPOSES A TRIPARTITE STRUCTURE OF IMPAIRMENT, ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS TO CONCEPTUALISE DISABILITY.

2.4 Models of Disability

Contemporary scholarship on disability has identified certain overarching frameworks that look at disability from distinctive perspectives, highlighting different dimensions of the disability concept. In this section these models are briefly described. It may be noted that all these models are today still prevalent to varying degrees.

2.4.1 Moral and/or Religious Model: Disability as an Act of God

The moral/religious model of disability is perhaps the oldest model of disability and is found in most religious traditions. According to one of the primary forms of this model, disability is regarded as a punishment from God for a particular sin or sins that may have been committed by the person with disability in this life or in previous lives. This model tries to morally justify the negative experiences of the person with disabilities, implying that the person somehow 'deserves' it. Sometimes it is not only the individual's sin that is regarded as a possible cause of the disability, but any sin that may have been committed by her parents and/or ancestors. This can lead to entire families being blamed for the disability of one member and, subsequently, being excluded from social participation in their community.

Evidence of the moral/religious model of disability can be seen in Hindu mythology, wherein people with disabilities are almost always represented as negative characters: Shakuni and Manthara from the Scriptures are two such figures that create the impression in the minds of readers and listeners that people with disabilities are generally villainous. Other religious traditions have also constructed disability as a curse, leading to feelings of guilt and shame among affected individuals and their families.

A more positive viewpoint arising from this model looks at disability as a challenge or opportunity given by the grace of God for character development. This viewpoint regards the development and deepening of certain positive character traits like endurance as God's plan for the persons with disabilities. Consequently, persons with disabilities may be regarded as 'blessed', as they have the opportunity to learn important life lessons that people without such conditions, who do not necessarily have the opportunity to learn.

Although the moral and/or religious model of disability is no longer as widespread as it was in pre-modern times, the basic philosophy underlying the model is still frequently encountered in the way people reason when confronted with illness or disability. This way of looking at disability cuts across classes and communities particularly in societies like India, where religion is a very important aspect of people's lives.

2.4.2 Tragedy and/or Charity Model of Disability: Disability as Victimhood

The tragedy and/or charity model is closely connected with the religious/ moral model. It looks at people with disabilities as victims of their impairment – 'their situation is 'tragic', and they are 'suffering'. This model depicts people with disabilities as victims of circumstance who should be pitied. The model emphasises that able-bodied people should take responsibility in assisting persons with disabilities as 'they need special services, special institutions, etc., because they are different' (Duyan 2007: 71).

Although the charity model seeks to act in the interest of persons with disabilities, encouraging humane treatment, it depicts them as helpless, depressed and dependent on others people for care and protection, contributing to the preservation of negative stereotypes and misconceptions about persons with disabilities.

2.4.3 Medical Model: Disability as a Disorder/Disease

From the mid-1800s onwards, the medical (or biomedical) model of disability began to gradually substitute the moral and/or religious model in the West as a result of major advances in the field of medical sciences. The medical model of disability views disability as a problem of the individual, directly caused by disease, trauma, or other adverse health conditions. The person with disabilities is assigned the role of a patient to be given sustained medical attention by trained professionals in the form of individual treatment and rehabilitation (Creamer 2009; Olkin 1999). The goals of medical intervention are cure, improvement of the physical condition to the extent possible, and rehabilitation (adjustment of the person with the disability to the conditions of life that she lives in).

According to the medical model, persons with disabilities digress from what is considered normal. Terms like 'invalid', 'cripple', 'spastic', 'handicapped' and 'retarded' came to be used to identify them. In addition to negative language, this model also advances the idea that people without disabilities are somehow better than or superior to people with disabilities.

Till recently medical professionals without exception only accepted the medical model approach to the diagnosis and treatment of persons with disabilities, failing to look at the persons' lives beyond the immediate impairments. However, even though it has been severely criticised, particularly by the disability rights movement, the medical model continues to hold sway, since medical criteria are still used to identify people with disabilities by the state for provision of social services and entitlements.

2.4.4 Social Model of Disability: Disability as a Socially Constructed Phenomenon

Through the activism of people with disabilities in the United Kingdom after the Second World War, the social model of disability emerged in the 1970s as a sharp critique of the medical model of disability with its emphasis on biology. According to the social model, disability is viewed as a problem created by the organisation of the society and hence any significant solution must be directed at societal change rather than individual adjustment and rehabilitation. The model shifts the burden of change from the individual with disabilities (and her family) to the collective responsibility of the society calling for social actions and environmental modifications to enable participation of people with disabilities in all areas of social life (Barnes, Mercer, and Shakespeare 2010; Oliver 1981).

The minority model of disability, also known as the socio-political model of disability, is the nomenclature adopted for the social model in the United States in the spirit of the Civil Rights Movement spear-headed by Martin Luther in the 1960s. It suggests that people with disabilities constitute a distinct social group that shares in common the experience of disability oppression. The minority model normalizes the experience of disability as a minority experience no more or less aberrant or deviant than other minority groups' experiences (sex, race, sexual orientation, etc.). Accordingly, people with disabilities are, in part, disabled not by what's going on with their bodies *per se*, but by the manner in which the able-bodied majority of society views them (Drum 2009; Hahn 1988; Longmore 2003).

Although the social model of disability has been the most powerful in challenging the medical understanding of disability, it is not without criticism. Firstly, this model ignores the realities of impairment in its single-minded focus on society as the source of oppression of persons with disabilities. A related criticism is that it ignores the subjective accounts of the 'pain' of both impairment and disability, since it is more concerned with barriers that obstruct the functioning of persons with disabilities. The third criticism states that it is unable to adequately incorporate other social divisions, e.g. 'race', gender, ageing, sexuality and so on. A fourth criticism centres on the issue of 'otherness' i.e., it is not just the physical and environmental barriers *per se* but the way cultural values position disabled people as 'other' that marginalises people with disabilities (Oliver 2004; Shakespeare and Watson 2001).

2.4.5 Bio-Psychosocial Model: Integration of Perspectives

The bio-psychosocial model of disability seeks to integrate both biomedical and social perspectives in understanding a person's medical condition. Initially proposed by George Engel in 1977, it emphasizes that comprehending an individual's health entails considering not only biological factors but also psychological and social influences. Breaking down the model, 'Bio' refers to physiological pathology, 'psycho' encompasses thoughts, emotions, and behaviours such as psychological distress, fear/avoidance beliefs, coping mechanisms, and attribution, while ‘social’ includes socio-economic, socio-environmental, and cultural factors including work dynamics, family circumstances, and economic factors.

Traditionally, in the medical model, doctors focus primarily on pathology and impairment, while health and social care professionals address activity limitations and participation restrictions. However, within the bio-psychosocial model, rehabilitation teams are encouraged to adopt a comprehensive, multi-disciplinary approach, taking into account the entirety of the individual's circumstances, and ensuring a personalized and holistic approach to rehabilitation.

As already, discussed, the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) is grounded in this model. Some controversy surrounds the inclusion of health aspects within a disability model, particularly from proponents of the social model of disability, who argue that disability stems solely from society's failure to accommodate individual needs. The comprehensive ICF acknowledges the importance of describing an individual's functioning (including her health status) within its social context, offering a detailed framework for understanding disability

2.4.6 Identity Model: Disability as an Identity

The identity model (or affirmation model) of disability proposed by John Swain and Sally French (2000), is “essentially a non-tragic view of disability and impairment, which encompasses positive social identities, both individual and collective. This model shares the social model’s understanding that the experiences of disability is socially constructed, but differs to the extent that it asserts that disability is a positive identity. It begins with an unconditional acceptance of disability, i.e. people with impairments are different but there is nothing wrong with them that needs to be fixed. This model enables persons with disabilities to adopt a positive self-image. The salient features of the identity model are motivating persons with disabilities to engage in activism with others with disabilities in the development of a collective identity, the collective expression of ‘frustration and anger’, and a realisation that there is nothing wrong with them embracing an identity as ‘outsiders’, but they should have the right to be ‘insiders’ if they so wish. The identity model has influenced many in the disability community, inspiring them to adopt a positive self-image that celebrates ‘disability pride’ (Darling and Heckert 2010).

2.4.7 Human Rights Model of Disability

The human rights model incorporates different sets of human rights, namely, civil and political as well as economic, social and cultural rights (Degener 2017). Human rights model is very similar to the social model of disability, but there are some differences between the two. It provides a theoretical framework for disability policy that emphasizes the intrinsic dignity of people with disabilities (*ibid.*), while the social model emphasizes underlying social factors like stigma and discrimination that shape understandings of disability. Secondly, the human rights model acknowledges the fact that some people with disabilities are indeed confronted by challenging life situations and argues that such factors should be taken into account in the development of relevant social justice theories. The social model, on the other hand, does not give adequate recognition to the reality of pain and suffering in their lives, as its focus is more on infrastructural and social barriers. Then, the human rights model offers more room for minority and cultural identifications, while the social model does not focus on identity politics. The human rights model accepts the importance of disability prevention policies, as such policies are an example of human rights protection for persons against adverse health conditions, while the social model is mostly critical of public health policies for prevention of impairments.

2.4.8 Economic Model of Disability: Disability as a Challenge to Productivity

The economic model of disability focuses on 'the various *disabling effects* of an impairment on a person's capabilities, and in particular on labour and employment capabilities' (Armstrong, Noble and Rosenbaum 2006). It defines disability in terms of a person's inability/ability to participate in work. In addition to assessing the persons with disabilities capacities to be productive, it also assesses the economic impact of the disability on the family and state. Hence, the economic model is often utilised by governments for formulating disability policy.

The economic model of disability has been criticised for approaching disability solely in terms of a cost-benefit analysis, overlooking other important factors. Such an economic focus can lead to the dehumanisation of the person with disabilities as someone who is useless because she is not able to be as economically productive as someone else, who does not have the same impairment.

2.4.9 The Nagi Disablement Model

This the first disablement model introduced in 1965 by Saad Nagi, an American sociologist, who identified conceptual confusion among some interrelated terms like pathology, pathophysiology, impairment, functional limitation and disability. He recognised the importance of social economic, family and community factors in influencing disability. He recommended a multi-dimensional analysis of diseases and injuries because two people with the same injury have the potential for very different treatment, performance, and disability outcomes due to their different life situations. The importance of the Nagi model lies in the fact that there is a reconfiguration of the perception of disability away from physical limitations by defining it more broadly as the product of a change in the expected interactions between the individual and the environment. Thus, disability is a relational concept which must factor in the perspectives of the affected individual and the interpersonal environment in which she lives (Nagi 1965).

2.4.10 Capability Model of Disability

The capability approach developed by Amartya Sen is a useful framework for defining disability and understanding its economic causes and consequences. Sen developed the capability approach as a set of interrelated themes in welfare economics, viz. personal well-being, poverty, and inequality. In Commodities and Capabilities (1985), Sen talks about focusing on a person's capability to function, that is, what the person can do or can be versus the more standard concentration on opulence (the person's real income) or utility (as in traditional welfare economics). According to Sen, capability does not constitute the presence of a physical or a mental ability; rather, it is understood as a practical opportunity. Functioning is the actual achievement of the individual, what she can actually achieves through being or doing. Here, disability can be understood as a deprivation in terms of capabilities or functioning that results from the interaction of an individual's (a) personal characteristics (e.g., age, impairment) and (b) basket of available goods (assets, income) and (c) environments (social, economic, political, cultural). This approach helps to explain the importance of the economic causes and consequences of disability and is closely related to the International Classification of Functioning, Disability and Health of the World Health Organization (World Health Organization 2001). The capability approach allows disability to be differentiated at two levels: at the capability level, or as a potential disability, and at the functioning level, or as an actual disability. Second, there is considerable interpersonal variation in the link between a given impairment and disability resulting from a variety of factors. The capability approach accounts for these factors at the individual level through the resources available, the environment in which she lives, and her personal characteristics. The capability approach clearly accounts for human diversity (Sen 1992) through the inclusion of personal characteristics (e.g., race, gender, residence), which the social model and the Nagi model do not address as explicitly.

Although the capability approach has been used in international development to analyse the link between disability, gender discrimination, and poverty (Welch 2002), its usefulness in defining disability and formulating disability policies has not been adequately considered.

2.4.11 Feminist Disability Model

Feminist Disability Studies interprets disability in terms of the power relations within a patriarchal society wherein women are subordinate to men. Regarding disability as largely a social construction, the feminist perspective, like the social model, questions the biological basis of definitions of normality and disability. Feminist Disability Studies Chesler 1972; Davis 1984; Fine and Asch 1988; Garland-Thomson 2002 and 2008; Morris 1993; Thomas 1999; and Wendell 1996) question the disability labelling process when it comes to women, particularly the labelling of women as mentally ill. The prevailing medical systems of classification and management of disabilities do not factor in the distinct realties of women’s bodies and lives. Medical assessments, labelling and rehabilitation of disabilities have to be more gender-sensitive. The major work of Feminist Disability Studies seeks to highlight how gender and disability are intertwined exclusionary and oppressive systems rather than the natural and appropriate order of things.

BOX 13

THERE ARE MANY MODELS OF DISABILITY THAT HIGHLIGHT THE HETEROGENEITY OF THE DISABILITY CONCEPT. MAJOR MODELS OF DISABILITY ARE

1. MORAL/RELGIOUS MODEL
2. TRAGEDY/CHARITY MODEL
3. MEDICAL MODEL
4. SOCIAL MODEL
5 BIOPSYCHOSOCIAL MODEL
6. IDENTITY MODEL
7. HUMAN RIGHTS MODEL
8. ECONOMIC MODEL
9. NAGI MODEL
10. CAPABILITY APPROACH
11. FEMINIST DISABILITY PERSPECTIVE

2.5 Disability and Discrimination

The rise of the global disability rights movement, the establishment of disability discrimination legislation in many countries, and the advent of the United Nations Convention on the Rights of Persons with Disabilities have together contributed to a revolutionary change in viewing disability ushering in major efforts for removal of barriers to enhance participation of people with disabilities in all domains of life. However, people with disabilities still continue to experience many forms of overt and covert discrimination. For instance, if a health care provider assumes that people with disabilities are not sexually active, she may withhold information or exclude them from screening for conditions like sexually transmitted infections, cervical cancer, or HIV and AIDS that non-disabled people receive as a matter of course. Such assumptions can have dangerous, if not fatal, consequences for persons with disabilities.

Multiple forms of discrimination are commonplace in the lives of people with disabilities. The examples below drive home the point:

> Direct Discrimination is when a person with disabilities is treated worse in comparison to another person in a similar situation only because of being disabled. There are many forms of direct discrimination with varying degrees of harm. For instance, bullying and harassment are more violent forms of direct discrimination. Harassment is when someone treats you in a way that makes you feel humiliated, offended or degraded. People with disabilities are regularly called names and laughed at by friends, family and the society in general due to the disability. However, direct discrimination may also take on other less violent forms. For example: during an interview for a job, a candidate tells the potential employer that she has a diagnosis of attention deficit hyperactivity disorder and has recently recovered from depression. The employer decides not to appoint her even though she is the best candidate interviewed, because it is assumed she might take a lot of time off owing to her impairment, or feel that the recurrence of depression might affect her productivity.
>
> Indirect Discrimination happens when an organisation has a particular policy or way of working that has a more negative impact on people with disabilities compared to others who are not disabled. For example: a job advertisement states that all applicants must have a driving licence. This puts some people with disabilities at a disadvantage because they may not be eligible for obtaining a driving licence due to having epilepsy. If the advertisement is for the job of a driver, the requirement would be justified. If it is, however, for a teacher to work across two schools, it is more difficult to justify.

People with disabilities experience discrimination, if the employer or organisation doesn't make reasonable infrastructural and other adjustments to accommodate them. For example: an employee with mobility impairment needs a cabin/cubicle or workspace on the ground floor. If the office does not have an elevator, the employer is bound to comply with this requirement, if she has employed a person with mobility impairment. What is considered reasonable, however, depends on a number of factors, including the resources available to the organisation for making the adjustment. If an organisation has an office space on the ground floor, it would be reasonable for it to designate one room on the ground floor for the employee with mobility impairment.

BOX 14

PEOPLE WITH DISABILITIES FACE DISABILITY-BASED DISCRIMINATION IN ALL AREAS OF THEIR LIVES. SUCH DISCRIMINATION MAY BE DIRECT OR INDIRECT. BULLYING AND HARASSMENT ARE FORMS OF DIRECT DISCRIMINATION. WHILE NOT PROVIDING REASONABLE ACCOMMODATION AT THE WORKPLACE MAY BE A FORM OF INDIRECT DISCRIMINATION

The following narratives provide a graphic description of disability-based discrimination:

Personal Story 1: Disability-Based Direct Discrimination

Smriti is a 42-year-old unmarried Hindu woman, who lives with her 75- year old mother in a lower middle class area of Delhi. She has polio in her lower limbs, which gives her a disability score of 81%, according to her disability certificate. She contracted polio when she was 6 months old. She has undergone two surgeries on her left leg at a private hospital, which worsened her condition as her leg became thinner and weaker than before the operations. She also underwent long-term treatment at a government hospital. Initially, she used callipers but later stopped using them after she found it uncomfortable and inconvenient. Instead, she used to crawl on the floor for mobility. Currently, she uses a wheelchair. She can also drive a scooter and a car and uses these modes of transportation.

Smriti completed her school education from a government school near her home. She has done her graduation in Hindi Honours from a college of Delhi University and a masters in Political Science through distance education. She started working right after completing her education as she was determined to become economically self-reliant and overcome the disadvantages of her disability. She had five jobs at which she worked for a year each, and at least seven more jobs where she worked for shorter periods of time on contractual basis. She had to leave at least four of these jobs due to accessibility issues. Currently, she is a government employee, working as a lower division clerk at a state university in Delhi for the past 12 years.

Smriti is a paraplegic athlete. She plays basketball, rugby, table tennis, and has participate in several national-level competitions in the categories of shot put and discus throw.

The following was Smriti’s experience at a job interview where she faced discrimination due to her disability. She had gone for a job interview at a central government ministry in response to an advertisement for a clerical position on contract. After qualifying the preliminary test, she took the typing test and got the maximum score. She was told that she had got the job. She was standing all the while waiting for the results. She said that those conducting the test were not even decent enough to offer her a place to sit. When she got to know that she got the job, she went and sat on a chair. When they saw this, they asked her, “Madam, how will you do your job” implying that she was incapable of doing the job, for which she had qualified, as she had to sit and work. To this, she replied that it was a typing job, which can be performed while seated. But they told her that at their workplace, some clerical staff have to move the files to different tables, which she would not be able to do. She said that she told them that since she had qualified for a typing job, she would only do the typing work, she would not walk around and do the other work. After this, they rejected her. Smriti said that she felt very bad that she couldn’t get the job even after qualifying the interview and topping the typing test.

This is a case of direct discrimination that Smriti had to face at a job interview. The job description did not mention that the applicant would also be required to move around carrying files as part of her work. However, the employer organization decided not to appoint her even though she topped the test because the potential employee was expected to do other work beyond the job description.

This illustration also points to the ableist assumption that the employer organization had that any person who could be a typist, would also be able to move around and could be utilized for carrying files or other clerical work that required movement. If the employer organization had mentioned in the advertisement that the job responsibilities entail the potential employee to perform activities that require them to move around, a person with mobility impairment like Smriti could have applied for the job keeping in mind the requirements, and avoided the humiliation and rejection after qualifying for and even being selected for the job.

2.6 Disability in India

2.6.1 Prevalence of Disability in India: Census 2011

The most comprehensive and recent macro-level enumeration of the population with disabilities in India is the 2011 Census. Although the figures are outdated, yet they provide an approximate understanding of the number of persons with disabilities in the population in the country. According to the 2011 Census, 2.21% of the total population, i.e., 26.8 million people have disabilities. Eight broad categories of disabilities were included in the Census survey to arrive at this figure, namely disability in seeing, hearing, speech, movement, mental retardation, mental illness, any other and multiple disabilities. The figure is undoubtedly an underestimation due to the limited number of disabilities included and underreporting of even the limited number of conditions covered on account of the stigma associated with disability in general. Lack of awareness about disabilities and absence of sensitivity to the issue are also contributing factors for the underreporting.

According to the 2011 Census, majority (69%) of the disabled population lived in rural areas (1.86 Cr), while the remaining 31% lived in urban areas (0.81 Cr). While 55.9% of the total disabled population comprised males, 44.1% comprised females. Among the males with disabilities, 62% were married, while for females with disabilities, the corresponding figure was 54%. The proportion of different types of disabilities reported were: mobility disability recorded the highest prevalence at 20.3%, followed by hearing at 18.9%, seeing at 18.8%, multiple disabilities at 7.9%, mental retardation at 7.6%, speech at 7.5%, and mental illness at 2.7%. The category of 'any other'[19] constituted 18.4%. While disabilities in seeing,

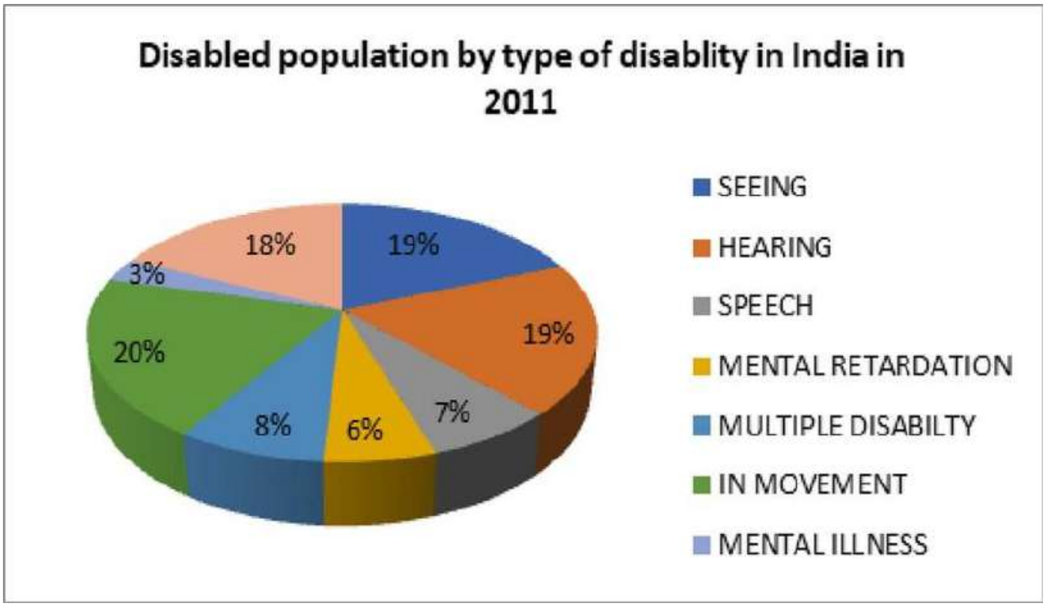
---

[19] This was a new category introduced in the 2011 Census to ensure complete coverage. This option enabled respondents to report those disabilities which were not listed in the question. In such cases, where informant was not sure about the type of disability the option of reporting disability as 'Any Other' was available.

hearing, multiple disability and any other showed higher numbers among females, other categories of disabilities showed a higher prevalence among males. Furthermore, it was found that disability in speech and hearing was more prevalent in urban areas, whereas disability in movement and multiple disabilities were higher in rural areas. Of the total disabled population, literacy rate was 55%, while 45% were reported to be illiterate. Literacy by sex was 62% for males and 45% for females with disabilities. As expected, there were more literate persons with disabilities in urban areas in comparison to rural areas. At all India level, 36% of the total persons with disabilities were workers. Among the males, 47% were working and among females, only 23% were reported to be working. In rural India, 25% of the females with disabilities were working, while in urban India, the corresponding figure was 16%. The higher proportion of persons with disabilities across all categories of analysis in rural areas is due to the higher population concentration in rural India.

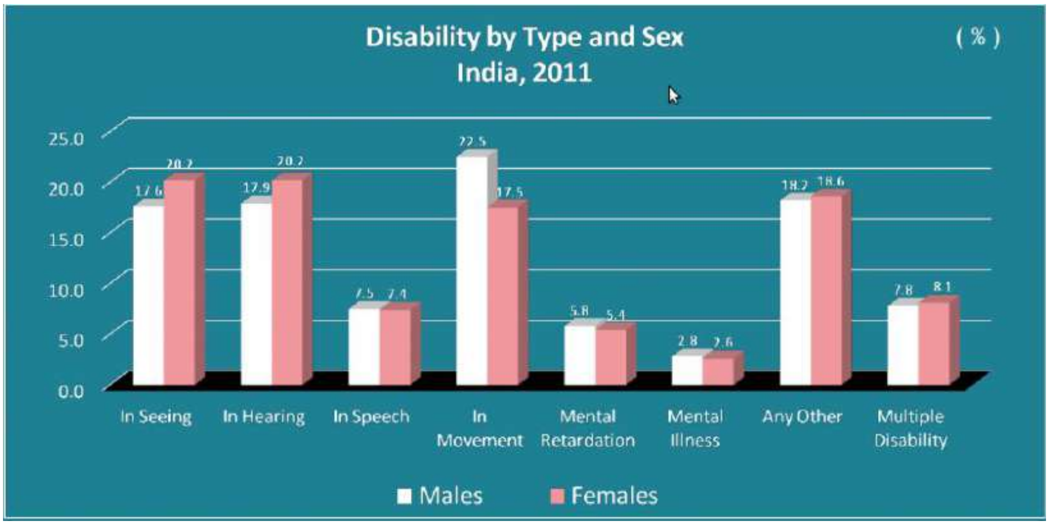
The following tables depict the prevalence of disabilities in India on the basis of 2011 Census:

Table No. 1



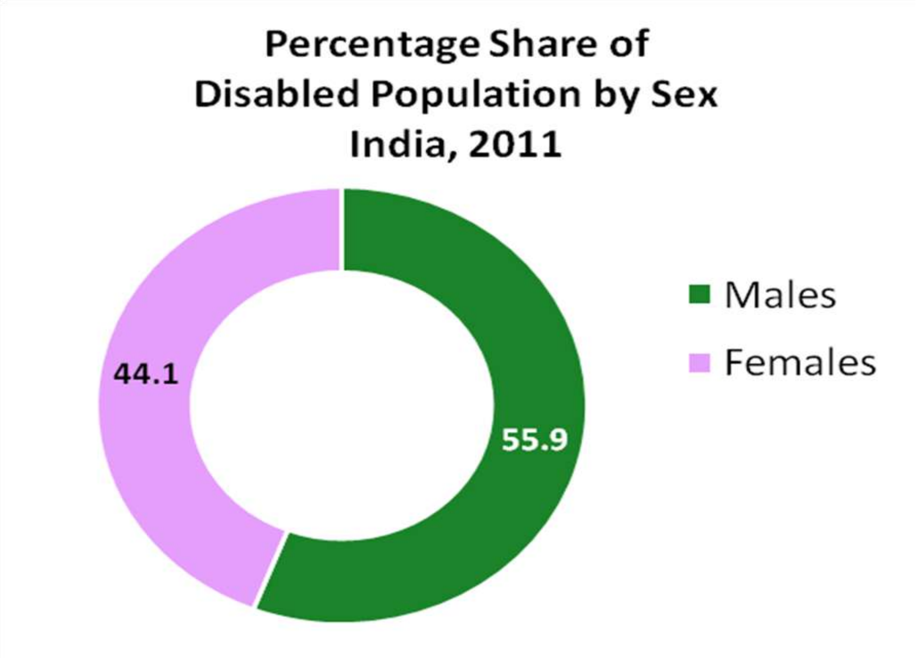
Source: https://www.researchgate.net/figure/Percentage-of-disabled-persons-in-India-census-2011-15_fig1_360604788

Table No. 2



Source: https://enabled.in/wp/census-of-india-2011-disabled-population/

Table No. 3

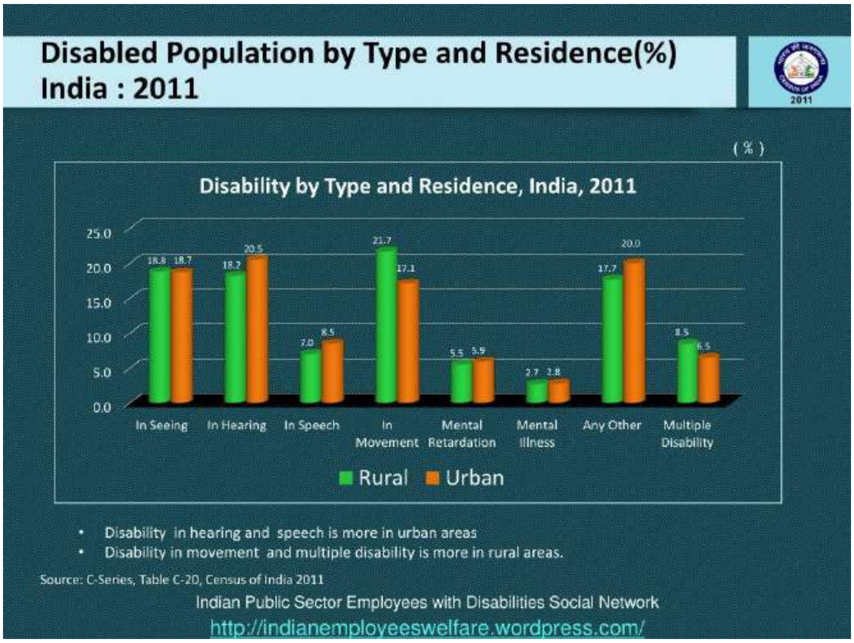


Source: https://enabled.in/wp/census-of-india-2011-disabled-population/

Table No. 4

Source:https://unstats.un.org/unsd/demographic-social/meetings/2016/bangkok--disability-measurement-and-statistics/Session-6/India.pdf

Table No. 5



Disabled Population by Type and Residence(%)
India : 2011

Disability by Type and Residence, India, 2011

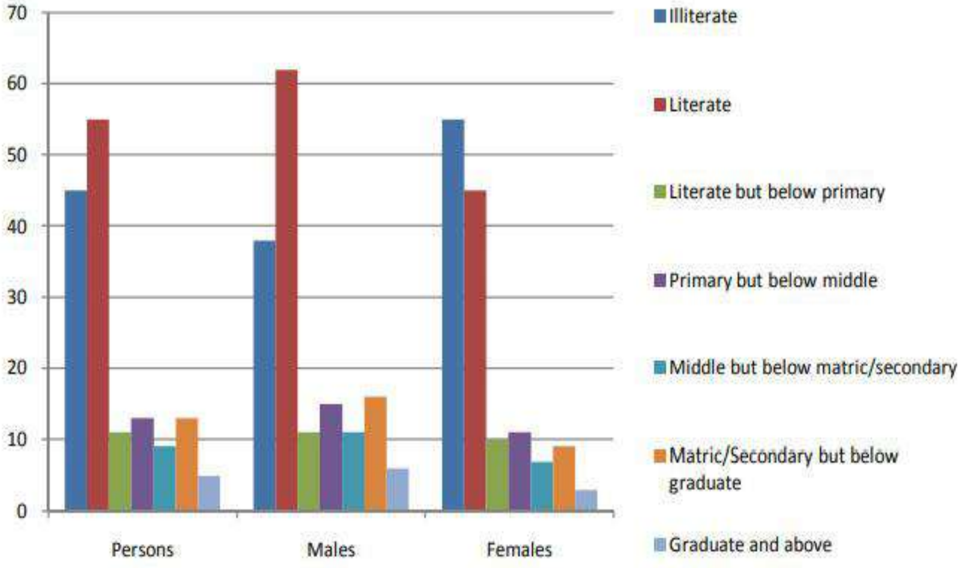
- Disability in hearing and speech is more in urban areas
- Disability in movement and multiple disability is more in rural areas.

Source: C-Series, Table C-20, Census of India 2011

Indian Public Sector Employees with Disabilities Social Network
http://indianemployeeswelfare.wordpress.com/

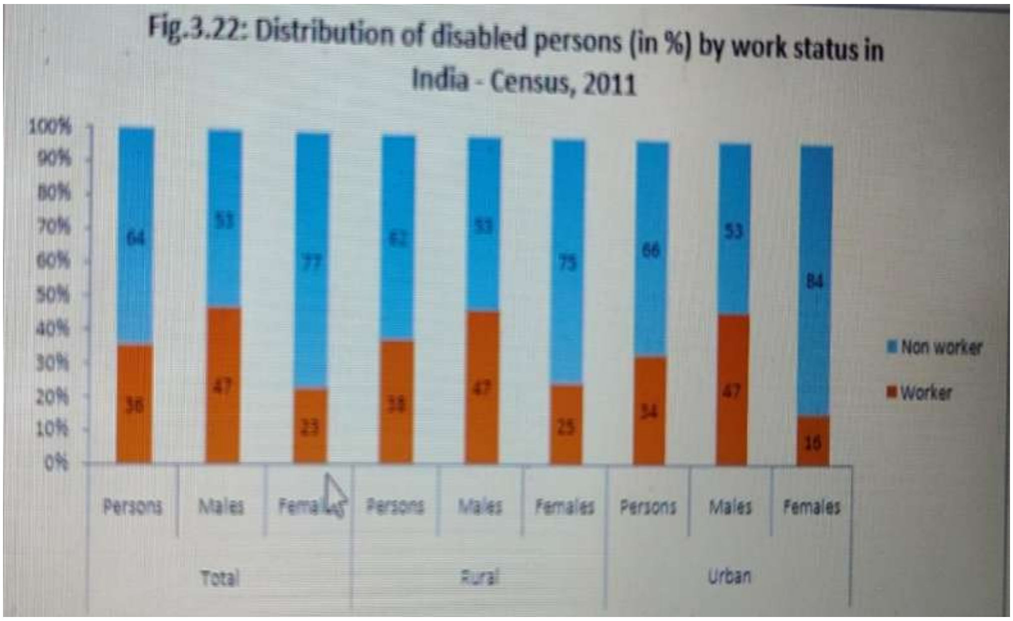
Source:https://www.slideserve.com/hasad/census-of-india-2011-data-on-disability

Table No. 6 Disabled Population by Literacy Rate in India in 2011 (%)



Source: https://wecapable.com/disabled-population-india-data/

Table No. 7



Source: https://ruralindiaonline.org/en/library/resource/disabled-persons-in-india-a-statistical-profile-2016/

2.6.2 Incidence of Disability: National Sample Survey 2018

The most recent estimation of the disabled population in India was carried out by the National Sample Survey Office (NSSO 76th Round) undertaken during July-December 2018 by National Statistical Office (NSO), Ministry of Statistics and Programme Implementation), Government of India. Prior to this, a survey on the same subject was carried out by NSSO during the 58th round (July-December 2002). The main objective of the Survey of Persons with Disability was to estimate indicators of incidence and prevalence of disabilities, cause of disability, age at onset of disability, facilities available, difficulties faced by persons with disabilities in accessing/using public building/public transport, arrangement of regular caregivers, out of pocket expenditure relating to disability, etc. In the National Sample 76th round survey, all the 21 specified disabilities as stated in The Rights of Persons with Disabilities Act, 2016 were included.

In this survey, total number of persons with disability surveyed was 1, 06,894 (74,946 in rural areas and 31,948 in urban areas). Some of the key findings obtained from this survey are stated below:

Prevalence and Incidence of Disability: In India prevalence of disability (percentage of persons with disabilities in the total population) was 2.2%. It was 2.3% in rural areas and 2.0% in urban areas. Prevalence of disability was higher among males than females. Among males, prevalence of disability was 2.4% of total male population, while it was 1.9 among females of total female population. Incidence of disability in the population (onset of disability in the previous one year, per 1, 00,000 persons) was 86.

Education Level: Among persons with disabilities of age 7 years and above, 52.2% were literate.

Living Arrangement, Caregiver and Receipt of Aid/Help Disability Certificate: Percentage of persons with disability who were living alone was 3.7%. 62.1% had caregivers: for 0.3% of the persons with disabilities a caregiver was required but not available. For remaining 37.7% no caregiver was required. Percentage of persons with disability who received aid/help from the government was 21.8%, 1.8% received aid/help from organisations other than the government, and another 76.4% did not receive any aid/help outside the family. Only 28.8% of the persons with disabilities survey had disability certificates.

Labour Force Participation and Unemployment Rate among persons of age 15 years and above with disabilities: Labour force participation rate in the population survey was 23.8%

BOX 15

NATIONAL-LEVEL AND AREA-SPECIFIC SURVEYS OF PREVALENCE AND INCIDENCE OF DISABILITY IN INDIA UNDERTAKEN BY THE GOVERNMENT ESTIMATE THE RATE OF DISABILITY AT 2.1% OF THE POPULATION. WHILE THE WORLD HEALTH ORGANISATION'S ESTIMATES PUT IT AT 15%-20% HIGHLIGHTING THE NEED TO REVIST THE STATISTICAL PROFILE OF THIS GROUP IN THE POPULATION.

2.7 State Mandate on Disability: Constitutional Provisions, Laws and Policies on Disability in India

2.7.1 Constitutional Provisions

The Constitution of India guarantees fundamental rights, such as right to justice, right to liberty of thought, expression, belief, faith and worship, equality of status and opportunity etc. to all its citizens, including persons with disabilities (although they are not specifically mentioned). Article 41 of the Constitution states that the State shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement and in other cases of undeserved want. Article 46 lays down an obligation on the state to promote with special care the educational and economic interests of the weaker sections (which includes persons with disabilities) and protect them from social injustice and all forms of exploitation.

The subject of 'relief of the disabled and unemployable' is specified in the state list of the Seventh Schedule of the constitution. This means that state governments, and not the Central Government, are responsible for programmes and policies in the disability sector.

Despite this positive orientation, there are a number of extant constitutional provisions which are directly discriminatory towards persons with disabilities. For instance, Articles 102 and 191 disqualify a person from being a Member of Parliament or Legislative Assembly of States "if he is of unsound mind and stands so declared by a competent court". Then, stigmatising terms like "handicapped', 'person of unsound mind' and 'mentally retarded' persons still exist in the Constitution.

BOX 16

ARTICLES 41, 46, 102 AND 191 OF THE CONSTITUTION OF INDIA DEAL WITH DISABILITY AND UNSOUNDNESS OF MIND RESPECTIVELY

2.7.2 Disability Laws

At present there are a number of disability-specific laws in India, which are briefly discussed below:

2.7.2.1 The Rehabilitation Council of India Act, 1992

The Rehabilitation Council of India was set up under the Rehabilitation Council of India Act, 1992. The Council regulates and monitors the training of rehabilitation professionals and promotes research in rehabilitation and special education. The main functions of the Council are:

- Determining minimum standards of special education;
- Establishing standardized qualifications and subsequent registration for rehabilitation professionals and other personnel in the disability sector;
- Establishing standardized procedures for registration of the institutes in the disability sector:

- Regulating professional conduct of rehabilitation professionals and institutions.

Interestingly although the Rehabilitation Council of India recognises 16 categories of rehabilitation professionals in the disability sector, it does not cover physiotherapists and occupational therapists, who are the main professionals working with people with disabilities in the health system.

2.7.2.2 The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

The Government of India established the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities in 1999. The objectives of the Trust are:

- To enable and empower persons with disabilities to live as independently and as fully as possible within and as close to the community to which they belong;
- To strengthen facilities to provide support to persons with disabilities to live within their own families;
- To extend support to registered organizations to provide need- based services during periods of crisis in the family of persons with disabilities;
- To deal with problems of persons with disabilities who do not have family support;
- To promote measures for the care and protection of persons with disabilities in the event of death of their parent or guardian;
- To evolve procedures for the appointment of guardians and trustees for persons with disabilities requiring such protection.

2.7.2.3 The Rights of Persons with Disabilities (RPwD) Act, 2016

The RPwD Act replaced the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. Its definition and provisions are more in keeping with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2006) which India signed in 2007. A Person with Disability in the RPwD Act is defined as a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others. This definition is identical to the definition of disability given by the UNCRPD).

One of the major achievements of this Act is the expansion of the number of conditions legally recognized as disabilities from seven to twenty-one:

Additional benefits have been provided for persons with benchmark disabilities (40 percent or more disability) and those with high support needs. Furthermore, every child with benchmark disability between the age group of 6 and 18 years shall have the right to free education. There is five percent reservation in seats in government and government-aided higher educational institutions for persons with benchmark disabilities. Four percent reservation is provided in government jobs for persons with benchmark disability.

In addition to ensuring physical accessibility and provision of financial support to persons with disabilities, a new provision of the Act is provision of penalties for offences committed against persons with disabilities.

BOX 17

21 Disabilities Recognized in the Rights of Persons with Disabilities Act 2016

1. BLINDNESS
2. LOW-VISION
3. LEPROSY-CURED PERSONS
4. HEARING IMPAIRMENT (DEAF AND HARD OF HEARING)
5. LOCOMOTOR DISABILITY
6. DWARFISM
7. INTELLECTUAL DISABILITY
8. MENTAL ILLNESS
9. AUTISM SPECTRUM DISORDER
10. CEREBRAL PALSY
11. MUSCULAR DYSTROPHY
12. CHRONIC NEUROLOGICAL CONDITIONS
13. SPECIFIC LEARNING DISABILITIES
14. MULTIPLE SCLEROSIS
15. SPEECH AND LANGUAGE DISABILITY
16. THALASSEMIA
17. HEMOPHILIA
18. SICKLE CELL DISEASE
19. MULTIPLE DISABILITIES INCLUDING DEAFBLINDNESS
20. ACID ATTACK VICTIM
21. PARKINSON'S DISEASE
    http://www.ccdisabilities.nic.in/sites/default/files/2021-09/THE%20RIGHTS%20OF%20PERSONS%20WITH%20DISABILITIES%20ACT%2C%202016%20%28English%29.pdf

2.7.2.4 The Mental Health Care (MHCA) Act, 2017

According to a survey by the Indian Council of Medical Research (ICMR) 7.5% of the Indian population is affected by mental illness (Birla 2019). The covid 19 pandemic and its aftermath have increased the burden of mental morbidity The Mental Health Care Act replaced the Mental Health Act of 1987. It is a comprehensive mental health legislation rooted in human rights law that has tried to prioritise the interests of the mentally ill persons so that they can live a life of dignity. According to Article 2 of the Act, mental illness indicates a substantial disorder of thinking, mood, perception, orientation or thought that grossly damages judgment, behaviour, capacity to recognise reality or the ability to meet the usual requirements of life, mental conditions associated with the degradation of alcohol and drugs, but does not constitute mental barrier which is a condition of arrested or inadequate development of mind of a person, particularly characterised by sub-normality of knowledge. The Act forbids discrimination of any kind on the basis of sex, gender, sexual orientation, religion, culture, caste, social, class, disability and political beliefs against mentally ill people. It guarantees right to confidentiality to mentally ill people with regard to their diagnosis, treatment and rehabilitation. The Act decriminalises attempt to suicide which is even now punishable under section 309 of the Indian Penal Code. Instead of imprisonment, the person who attempts suicide is entitled to humane treatment in the form of care and support. The Act abolishes such barbaric practice as chaining, administration of ECT without muscle relaxant and administration of ECT to minors., But perhaps the most revolutionary feature of the Act is the provision of a patient making an advance directive or living will on how she wants to be treated and who would be her nominated representative, when she is no longer in a position to make decisions regarding her welfare.

2.7.2.5 Disability in Other Laws

There are a number of other laws in which disability emerges as a determinant with implications for health. For instance, Section 3 (subsection 2) of the Medical Termination of Pregnancy (MTP) Act, 1971 allows for termination of pregnancy, if there is indication of significant risk to the physical or mental health of the mother, or there is substantial risk to indicate that if the child is born, it would suffer serious physical or mental abnormality. Similarly, the Pre-Natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act, 1994 allows for conducting pre-natal diagnostic procedures for detection of genetic or metabolic disorders chromosomal abnormalities, congenital anomalies, haemoglobinopathies or sex-linked diseases. Depending on the medical expert opinion regarding prognosis of the disabled foetus and/or its impact on the health of the mother, termination may be permitted by the court. More recent legislations like The Protection of Children from Sexual Offences Act, 2012 and the Criminal Law Amendment Act, 2013 regard sexual offences against children with disabilities and women with disabilities respectively as cases of aggravated sexual assault entailing harsher punishment. These laws also mandate communication accessibility be ensured, so that disabled victims may give their testimonies in their own words at a place and time of their choosing. Assistance of sign language interpreters and special educators are recommended.

While on the one hand, India has progressive disability laws like the Rights of Persons with Disabilities Act and the Mental Health Care Act outlined above, other regressive extant legal provisions have not been removed. For example, Section 84 of Indian Penal Code (IPC) deals with the "act of a person of unsound mind." "Nothing is an offence which is done by a person who, at the time of doing it, by reason of unsoundness of mind, is incapable of knowing the nature of the act, or that he is doing what is either wrong or contrary to law." Section 13 of the Hindu Marriage Act, 1955 allows for divorce on grounds of unsoundness of mind. Similarly, according to the Indian Contract Act, 1872 a person of unsound mind is not capable of entering into any contract including transfer of property. According to section 16 (B) of the Representation of the People Act, 1950 a person can be disqualified as a voter if she is of unsound mind. Thus it can be seen that there are many existing legal provisions which work against the interests of people with disabilities in general and mental illness in particular.

BOX 18

INDIAN LEGISLATION ON DISABILITY IS A FULL OF CONTRADICTIONS. WHILE ON THE ONE HAND, INDIA HAS PROGRESSIVE DISABILITY LAWS LIKE THE RIGHTS OF PERSONS WITH DISABILITIES ACT 2016 AND THE MENTAL HEALTH CARE ACT 2017, OTHER REGRESSIVE EXTANT LEGAL PROVISIONS LIKE SECTION 13 OF THE HINDU MARRIAGE ACT, 1955 ALLOWS FOR DIVORCE ON GROUNDS OF UNSOUNDNESS OF MIND HAVE NOT BEEN REMOVED.

2.7.3 Policy Framework on Disability in India

In the same year that the United Nations General Assembly ratified the UN Convention on the Rights of Persons with Disabilities**,** the Government of India formulated the National Policy for Persons with Disabilities (2006), a short statement which dealt with physical, educational and economic rehabilitation, with a special focus on rehabilitation of women and children with disabilities, barrier-free environment, social security, research etc.

Disability is a cross-cutting issue across several central ministries like Health, Education, Social Justice and Empowerment, Labour among others. However, the Department of Empowerment of Persons with Disabilities (DEPWD), which falls under the central Ministry of Social Justice and Empowerment, is the nodal department whose function is to mainstream disability issues in the development agenda of the country, and to facilitate well-being and inclusion of all legally recognised categories of persons with disabilities in all aspects of life. The Government of India has changed the terminology in the disability debate from *viklangjan* (disabled people) to *divyangjan* (loosely translated as divine or gifted people) with a view to destigmatizing persons with disabilities. Divyangjan is now the term officially used by the government in all matters related to disability.

Apart from reservation in education and employment in the public sector, there are a number of government schemes for the welfare and empowerment of people with disabilities at the centre and state levels like, assistance for purchase/ fitting of aids and appliances (ADIP), including cochlear implants, unique disability identity cards, concessions for travel in public transportation like the Railways, national scholarships, disability pensions unemployment allowances, loans at concessional rates for self-employment, grants in aid to NGOs in the disability sector among others.

The Government of India has also established 7 national institutes specializing in different types of disabilities and 8 composite regional centres to promote research and conduct training for service delivery to persons with disabilities. Indian Sign Language and Training Centre has also been established to promote training, research and standardization of sign language in India.

BOX 19

THERE ARE A NUMBER OF GOVERNMENT-SUPPORTED SCHEMES TO HELP PERSONS WITH DISABILITIES TO OVERCOME SOCIAL, ECONOMIC, EDUCATIONAL AND OTHER BARRIERS IN THEIR LIVES. FINANCIAL ASSISTANCE, IN THE FORM OF SCHOLARSHIPS, ALLOWANCES AND PENSIONS, CONCESSIONS IN TRAVEL AFFIRMATIVE ACTION AND PROVISION OF PROSTHESIS AND OTHER ASSISTIVE AIDS ARE SOME EXAMPLES OF SUCH SCHEMES.

Photo No. 1

This photo shows an elderly woman wrapped in a shawl sitting on a wheelchair being accompanied by a young male relative. The female patient is being examined by a male health care professional in a government hospital in North Delhi.

Photo No. 2

Woman on Wheelchair being escorted by her male relative to the Outpatient Department after registering at the Registration Counter in a government hospital in east Delhi.

QUESTIONS FOR REFLECTION AND DISCUSSION

- ✓ *What is the relationship between impairment and disability in medical practice?*
- ✓ *What models of disability do you think play out in your professional set up? Discuss with examples how these are harmful or beneficial for patients with disabilities.*
- ✓ *How can laws and policies on disability in India be helpful in your work with patients with disabilities?*
- ✓ *How does bringing in the concept of disability impact your routine work?*
- ✓ *Can and should disability be eradicated?*

3. DISABILITY, GENDER AND SEXUALITY

Objectives

After going through this Module, you will be able to:

- *Understand the Concept of Gender and some Important Associated Terms*
- *Become Familiar with the Concept of Patriarchy as the Deep-rooted Cause of Gender Inequality and Inequity*
- *See the Relationship between Sexuality and Gender and Definitions of Some Associated Terms*
- *Understand Sex and Gender Beyond the Binary of Male and Female.*
- *Understand the Concept of Intersectionality*
- *Appreciate the Intersections between Disability, Gender and Sexuality*

3.1 Overview of Sex and Gender

As we go about our daily lives, we assume that every person is either a boy or a girl, man or a woman. The dichotomy of male and female is the ground upon which individual identity is built up from the moment of birth. The early linguistic act of declaring a baby's sex after birth, sets up the baby for life, launching a gradual process of learning to be a boy or a girl, a man or a woman, and to see all others as boys or girls, men or women. The sense of being male or female is so deeply embedded in our sense of who we are, our desires, our actions, our beliefs and our institutions that it is the first social identity that the brain registers, often subconsciously, when meeting someone for the first time. It is ever-present in our interactions with others as also in our perceptions about ourselves. Indeed, it is imputed to explain everything from driving styles to food preferences. Simply put, while sex refers to the biological features with which we are born based on the reproductive system, gender is something that we acquire as we grow. It is something we think, or we do (West and Zimmerman 1987), or something we enact or perform (Butler 1990). So, gender refers to the economic, social, political, and cultural attributes and opportunities associated with being male or female (United Nations Population Fund [UNFPA] 2005). Gender refers to the social definitions of what it means to be a woman or a man. Gender is a dynamic concept referring to the socio-cultural characteristics and roles that are associated with persons with reference to their sex.

While sex and gender are often used interchangeably, there are critical differences between the two. Sex refers to biologically defined and genetically acquired differences between males and females, according to their physiology and reproductive capabilities or potentialities. It is universal and mostly unchanging.[20] Thus, while sex is based on biology, gender is embedded in socio-cultural factors. However, the sharp distinction between

---

[20] However, it is to be noted that sexual features may be altered through hormonal or surgical procedures. Gender re-assignment surgery is an accepted medical procedure for altering gender identity.

sex and gender may get blurred. There is no single objective biological measure for male or female sex. Sex is based on a combination of anatomical, endocrinal and chromosomal features, and the selection among these criteria for sex assignment is based heavily on cultural beliefs about what actually makes someone male or female. Thus, the very definitions of the biological categories male and female, and people's understanding of themselves and others as male or female, are ultimately social. As Anne Fausto-Sterling argues,

> "…labelling someone a man or a woman is a social decision. We may use scientific knowledge to help us make the decision, but only our beliefs about gender – not science – can define our sex. Furthermore, our beliefs about gender affect what kinds of knowledge scientists produce about sex in the first place." (2000: 3).

While the initial research on sex and gender framed the biology-society-culture continuum in terms of the binary of male and female, there is now a clear recognition of sexual and gender diversity positing other identities like lesbian, gay, transgender, queer, intersex and non-sexual. It is within this diversity framework of sex and gender that this discussion is framed.

For purposes of this Handbook, there are certain important concepts related to gender given below to understand the nuanced nature of the concepts of sex and gender:

<u>Gender Identity</u> is each person's internal and individual experience of gender. It is a person's sense of being a woman, a man, both, neither, or anywhere along the gender spectrum. A person's gender identity may be the same as or different from their birth-assigned sex.

<u>Gender Equity</u> is the process of being fair to women, men and persons with other sexual and gender identities. To ensure fairness, measures must be taken to compensate for the historical and social disadvantages that prevent

persons located at different points within the sexual and gender diversity spectrum from operating on a level playing field. https://www.unfpa.org/resources/frequently-asked-questions-about-gender-equality.

Gender Equality refers to equal enjoyment by women, men and sexual and gender-diverse individuals' of socially-valued goods, opportunities, and resources and rewards (*ibid*.).

Gender Stereotypes are ideas that people have on masculinity and femininity: what men and women of all generations should be like and are capable of doing. (e.g., girls should be obedient and cute; they may be allowed to cry. Boys, are, however, expected to be brave and not cry; women are better housekeepers and men are better with machines, or boys are better at mathematics and girls are more suited for nursing (United Nations Human Rights Office 2014).

Gender-Based Violence is violence based on gender roles and norms as well as due to unequal power relations between women, men and other sexual and gender diverse individuals. This kind of violence is specifically targeted against a person because of their gender, and it disproportionately affects women and persons having marginal sexual and gender identities like transgender persons. Hence, gender-based violence is a form of discrimination that seriously inhibits persons' (other than heterosexual men) ability to enjoy rights and freedoms on a basis of equality. It includes, but is not limited to, physical, sexual, and psychological harm (including intimidation, coercion, and/or deprivation of liberty within the family or the community). It also includes violence perpetuated by the state or institutions on individuals based on their gender. https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-elimination-all-forms-discrimination-against-women

Gender Mainstreaming is the process of incorporating a gender perspective into policies, strategies, programmes, project activities, and administrative functions, as well as into the institutional culture of an organization. https://www.unfpa.org/resources/frequently-asked-questions-about-gender-equality

Gender and Health**:** Gender has a strong impact on health in a variety of ways. For instance, unequal access to resources in the household, such as food, education, and medical care disadvantages women throughout the world, particularly in developing countries adversely affecting their health. Gender inequity and lack of control over their bodies are responsible for much of the exposure to HIV and AIDS among women. Risk taking behaviour is the norm amongst males throughout the world, as it is positively associated with masculinity. Higher rates of tobacco consumption among males result in a host of diseases like lung cancer, cardiovascular disease and stroke among men.

Thus, gender plays a critical role in the onset, prevalence and treatment of health conditions among men and women. Socially defined traits often stereotype men and women as having fixed and opposite characteristics, such as active (male) vs. passive (female), and rational (male) vs. emotional (female). The language of medicine and its underlying philosophy have, and may still equate male with 'normal', leaving female to be considered as 'other' and the non-normative bodies and identities being regarded as 'abnormal'. General health is often defined in terms of the functioning of the male body, while female bodies are almost exclusively configured in terms of reproduction, and trans-bodies as simply not normal.

BOX 20

GENDER AND SEX ARE OFTEN USED INTERCHANGEABLY, BUT THERE ARE DIFFERENCES. WHILE SEX IS PRIMARILY BASED ON BIOLOGY, GENDER IS MORE ROOTED IN SOCIETY AND CULTURE. BOTH SEX AND GENDER PLAY A CRITICAL ROLE IN HEALTH.

3.2 Patriarchy

Patriarchy (literally meaning the rule by the father) is the underlying ideology responsible for prevailing gender relations in society, wherein women, transgender and non-binary people are subordinated to men resulting in gender inequality and inequity. Patriarchy has dominated human society since time immemorial. It is a system wherein men exercise control over women's labour power, mobility and resources, sexuality and reproductive capacities. It is believed that this system of domination came into existence with settled agriculture and onset of private property, wherein women were critical for establishing male-based kinship to facilitate hoarding of resources within family networks through their reproductive and productive labour.

The feminist historian Gerda Lerner pioneered the task of exploring the connections between patriarchy and other social structures within a historical context. Male dominance over women is a product of historical developments which began in the second millennium BCE in the Ancient Near East, and not is 'natural' or biologically determined as argued within the logic of patriarchy that 'women are weak'. She defines patriarchy as "The manifestation and institutionalisation of male dominance over the children in the family and the extension of male dominance over women in society in general." Men hold power in all the key institutions of society and women are denied access to such power. Lerner also adds that "women are a party to their own subjugation because they have been taught to internalise that they are inferior" (Lerner 1986: 239).

Patrilineality and patrilocality are key pillars of patriarchy, which structurally place women in an inferior position vis-a-vis men. Inheritance of property and the family name are passed on through the male line; thus increasing women's subordination by denying them access to key resources. In most societies after marriage, women move from their natal to their husbands' homes. This change of residence disadvantages them as they are forced to leave their familiar surroundings and adjust to new environments where they have very little agency.

Caste and gender hierarchies are the organising principles of the *brahminical* social order in India. Patriarchy in India cannot be discussed without bringing caste into the discussion. For instance, there is greater control over upper caste women's mobility and sexuality. This is because the preservation of the caste system is realised by the upper caste males through restraining and regulating the movement and sexuality of women of their caste. Women are regarded as gateways into the caste system. The lower caste male, whose sexuality is a threat to upper caste purity, has to be institutionally restricted from having sexual access to upper caste women. To ensure this, the sexuality of women of the higher caste order must be carefully controlled. Hence, the subordination of upper caste women is done through sexual control over them to maintain both patrilineal succession and caste purity (Chakravarti 2010). The practice of Sati and the prescription of an austere life for widows and the ban on their remarriage in Hindu society were all aimed at controlling their sexuality. Lower caste women have had greater mobility because patriarchy functions differently within the *Dalit, Bahujan* and *Adivasi* societies, where women's productive labouring roles outside the home enable them to have greater agency over their bodies and decision-making power in other areas of life. However, greater mobility does not always ensure a dignified life to lower caste women because patriarchy, albeit different, exists within the lower caste societies as well.

In India, motherhood is glorified in all customs and traditions, and it finds expression in most socio-cultural media of expression like myths and legends, folk songs, stories and movies. However, motherhood in an unmarried woman is unacceptable in society, because the child has to bear the family name of the male parent, who must belong to the same or a specific caste and religion. Similarly, women, who are mothers of only daughters, are also stigmatized. Motherhood is equated with being the mother of a son, which is deemed to be the ultimate purpose of a woman's life or what makes a complete 'woman'. Not being able to bear any children is the ultimate curse for a married woman.

The intersections of gender and caste with ableism results in creating further fissures within the disability community. Persons of higher caste are able to access more resources, and hence their life situation is better than their lower caste counterparts due to their more advantageous location within the social order. On the other hand, due to greater poverty, lack of education and access to health care, the incidence of disabilities has been found to be higher among persons belonging to the lower caste groups like *Dalits* (Pal 2010)

BOX 21

PATRIARCHY IS THE SOCIAL SYSTEM THAT INVESTS ALL POWER IN MALES AND ULTIMATELY DISADVANTAGES WOMEN IN ALL SPHERES OF LIFE

3.3 Gender and Sexuality: Conflations and Distinctions

As already seen, the terms sex and gender are often conflated on both theoretical and linguistic levels[21]. In English, physiological/bodily aspects are often referred to as *sex,* which include genitalia, chromosomes, and

---

[21] The sex-gender discussion arises out of Western theory because languages like Hindi lack terms to make the distinction between sex and gender.

physical features, while social aspects are called *gender,* including cultural meanings associated with behaviour, personality and expressions typically branded as feminine or masculine. Despite this interchangeability of terms, sex seems to be a poor substitute for gender, because it is incorrect to assume that sex precedes and determines gender. Instead, the interchangeability is normative and excludes many individuals with other experiences and/or sexual and gender identities. Consequently, some scholars like Gayle Rubin (1975:165) suggest using the terms "gender/sex" together to move away from the idea that sex is an objective category or a distinct biological phenomenon.

A growing literature on the social determinants of health suggests that many population and individual level-health conditions are not solely attributable to biology. Levels of income, income inequalities, educational levels, and social networks have all been associated with different dimensions of health and illness. Distinguishing between sex and gender is a common practice in the social sciences, which has now begun to percolate into the language of prevention, causation, and outcomes within medicine as well. While it is true that genetic makeup and hormone profiles tend to be the same across societies, environmental variables play a critical role in shaping the way these biological characteristics get manifested in individual bodies. Gender, on the other hand, is a social, rather than a biological construct, and varies with the roles, norms and values of a given society or era. For instance, being able to give birth is primarily a function of biology, whereas the norm of giving birth as essential to be recognised as a woman, the nature of parenting done, or the status associated with being a mother are more closely linked to gender roles and expectations that vary across societies.

In the Indian context, sexuality (the concept as distinct from sex the adjective as in 'being male or female' and the verb as n 'having sex') is largely addressed publicly in cases of abuse, violence and negative consequences of unsafe sex such as infections and unwanted pregnancies. While these are important issues and concerns to be addressed, sexuality, in its widest sense is not limited to abuse or infections. The full scope of sexuality as being vast, and connecting deeply to human life and human rights, at multiple points such as intimacy, relationships, self-expression, self-worth, pleasure and eroticism, is only beginning to be explored. There is no single agreed upon definition of sexuality. However, the World Health Organisation (WHO) offers a working definition that is broadly accepted:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (WHO 2006). https://www.ohchr.org/en/instruments-mechanisms/ instruments/convention-elimination-all-forms-discrimination-against-women

The biological indicators of sex as a 'male' are presence of penis and scrotum, testosterone and XY chromosomes, while that of a 'female' are presence of vagina and vulva, oestrogen and progesterone and XX chromosomes. However, this combination of attributes may not be present in the same arrangement in all individuals. Before the twentieth century, only male and female sex were considered valid, and those who did not adhere to the binary had to pick one and behave as per the associated gender norms and standards. Babies born with ambiguous genitalia were regarded as "abnormal". Doctors could decide the sex and gender of such babies and use surgical techniques to correct them. Such 'persons with intersex variations had to undergo repeated medical procedures to align with the sexual identity conferred upon them at birth, leading to much trauma in life (Fausto-Sterling 2000). The recognition and legitimation of a multiplicity of sexual and gender identities beyond the male-female binary is a relatively recent phenomenon, and it has spawned a new vocabulary that is gradually gaining public currency.

While concepts of equality and equity are associated with gender, there are a number of concepts associated with sexuality which are given below:

Sexual orientation refers to an individual’s psychological, emotional and/or sexual attraction towards another person. It refers to a person’s sexual or romantic attractions. It also includes sexual identity, sexual behaviours and desires. There are a number of sexual orientations that people may have beyond heterosexuality which is the most prevalent in a population.

Heterosexuality is the quality or characteristic of being sexually or romantically attracted exclusively to persons of the opposite sex. https://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/policies-politiques/e/713.pdf

Homosexuality is sexual interest in and attraction to members of one’s own sex. Gay and lesbian are examples of homosexuality.

https://www.britannica.com/topic/homosexuality

Bisexuality is sexual desire or behaviour directed towards people of more than one gender, sometimes understood to include attraction to one's own sex or gender and at least one other sex or gender.
https://www.dictionary.com/browse/bisexuality
Pan Sexuality is sexual, emotional, and/or romantic attraction towards others regardless of their sex or gender identity. https://www.britannica.com/topic/pansexuality

Persons with Intersex variations refers to individuals born with one or more sexual characteristics including chromosome patterns, gonads, genitals that do not distinctly identify the person as either female or male at birth. Intersexuality is an overarching term that refers to human bodies that fall outside the strict male and female binary. https://www.verywellmind.com/what-is-intersex-5092841#:~:text=Intersexuality%20is%20an%20overarching%20term%20that%20refers%20to,may%20involve%20ge

Transgender is an umbrella term referring to individuals who do not identify with the sex category assigned to them at birth, or whose identity falls outside of stereotypical gender norms. The term "transgender" encompasses a diverse variety of gender identities and expressions, including identities that fit within a female or male classification and those that do not (for example *hijra* or the third sex). https://www.dictionary.com/ browse/transgender

Homophobia is the prejudice against homosexuals or homosexual behaviour. Aversion towards or irrational fear of homosexuality also comes under homophobia. https://www.britannica.com/topic/homophobia
Cisgender refers to a person whose gender identity corresponds with the sex assigned to them at birth. There is a correspondence between their sexual and gender identities.
https://www2.gnb.ca/content/dam/gnb/Departments/ed/pdf/K12/policies-politiques/e/713.pdf

Non-binary gender refers to an individual whose gender identity is neither exclusively male nor female or is in between or beyond both gender. https://www2.gnb.ca/content/dam/gnb/ Departments/ed/pdf/K12/policies-politiques/e/713.pdf

Queer sexuality is sexual politics that rejects normative definitions of appropriate feminine and masculine sexual behaviour. A queer community may be made up of people who identify as cisgender, lesbian, gay, bisexual, transgender, persons with intersex variations or even non-sexual. People embracing a queer sexual identity are referred to as being non-binary or gender fluid. They may self-identify as both, neither or some combination of male and female. Their gender identify may vary over time in the course of their lives.

3.3.1 Examples of Diversity of Sexual and Gender identities

The sporting field is the space where the gender binary of male and female is most visible. It is also the space where this binary comes into question as seen in the cases of sportspersons like Santhi Soundarajan and Dutee Chand, whose bodies challenge the very existence of the gender binary. These Indian sportswomen were made to undergo sex determination tests to affirm their sex to determine whether they would participate as female or male athlete. One of the most controversial aspects of sex determination tests is that it is assumed that only two combinations of chromosomes – XX for females and XY for males- are possible in a body. This, however, is not true. There can be multiple chromosome variations/ combinations present in one body. For instance, a woman, can have the Y chromosome cohabiting with the X chromosome. Santhi Soundarajan failed the sex determination test conducted on her. It was found that she had partial androgen insensitivity syndrome (PAIS), in which a partial unresponsiveness of the cell to the presence of androgenic hormones impairs the development of male genitalia in a developing foetus. In some cases of PAIS, a person can have underdeveloped male genitalia and in other cases, a person can have male genitals and breasts. However, the very foundation on which sex determination tests have been built disregards and excludes all kinds of differences, limiting itself to a chromosome binary and gender ambiguity arising out of a patriarchal understanding of sex and gender. In the case of Dutee Chand, she was barred from competing in an international women's competitions when tests showed that she had hyperandrogenism, meaning that her testosterone levels were higher than that of an average woman athlete as per the guidelines of International Association of Athletics Federation (IAAF). Her case poses the fundamental question: does an increase in testosterone level make one less of a woman? It may be noted that sportspersons may use substances like steroids to enhance their capacities even though this practice is banned. Steroids may alter the sexual hormonal profile of users.

BOX 22

WHILE SEX AND GENDER MAY BE HEURISTICALLY DISTINGUISHED, IN ACTUAL PRACTICE THEY CONFLATE AND OFTEN OVERLAP. THE SPORTING ARENA OFFERS EXAMPLES THAT BOTH AFFIRMS THE BINARY AND QUESTION THE SEPARATION BETWEEN THE TWO

3.4 Intersections of Gender, Sexuality and Disability

Our experiences are shaped by different aspects of our identity. It is important to recognise each element individually and its relation to other elements of identity in order to make sense of our experiences. The term "intersectionality" was coined by Kimberle Crenshaw, an American feminist in 1989 to argue against the idea that race discrimination is what happens to all black people and sex discrimination is what happened to all women. She argues that "because the intersectional experience is greater than the sum of racism and sexism, any analysis that does not take intersectionality into account cannot sufficiently address the particular manner in which Black women are subordinated." (1989: 140). Corresponding to sexism and racism is the equally powerful category of ableist society, constituted in favour of the majority, namely the 'non-disabled' or 'able-bodied', results in discrimination against those whose bodies and minds do not conform to those of the dominant group.

Disability is a cross-cutting minority identity. Intersectionality is especially useful in understanding the experiences of people with multiple minority identities. In India, caste, gender, sexuality, class, ability/disability, age, region and religion among others, determine the location of persons in the society. A woman is considered inferior in comparison to a man. However, there exists a hierarchy in privileges enjoyed among women. A woman with disabilities is more likely to be discriminated against as compared to a non-disabled woman. As Nasa Begum puts it "the dual oppression of sexism and handicapism places disabled women in an extremely marginalized position" (1992: 70). Understanding disability through an intersectional lens is important for insights into the multiplicity of oppressions a person with disabilities has to face. Although disability may be the predominant characteristic by which a person with disabilities is labelled, it is important to remember that gender influences play a crucial role in determining how that person's disability is perceived and reacted to. Both disability and gender are understood as socially constructed classifications, the impact of each may be alleviated or impaired according to which group the individual is predominantly identified with. Men with disabilities might be perceived as inferior on account of their disability, but being of the male gender helps them retain their social status due to patriarchy, which is not possible for a woman with disabilities. Furthermore, being engulfed within the myriad identities of class/caste, class and religion, people with disabilities are further pushed to the margins of society. Renu Addlakha (2008) argues that disability is both the cause and effect of poverty. They reinforce each other, leading to increased marginalisation. The opportunities available to a person with disabilities are decreased because of poverty. For example, a poor family may not be able to provide proper treatment, assistive aids and equipment or even education to their daughter with disabilities, whereas a family from an upper caste and class location will be able to provide such amenities, thus increasing her chances of getting educated, employed and empowered. On the other hand, a person who acquires a disability due to an automobile accident in adult life may have to lose her job and hence be reduced to poverty due to the onset of disability.

Bodies are pivotal to being recognised as 'properly' sexual and gendered beings. Bodies operate socially as canvases on which sexuality and gender are displayed, the devices through which such identifies are expressed in tangible form. Therefore, the bodies of people with disabilities make them vulnerable to being denied recognition as women or men. The extent to which the body of a person with disabilities is deemed socially compromised is based on the type of disability, its visibility, its severity, and whether it is physical or mental in nature. Such a person's body is assessed in comparison with the body of an 'ideal able-bodied' person as it is popularly represented in media, especially in films. This often pushes persons with disabilities to feel inferior in comparison to the able-bodied people with respect to their bodies. The "perfect body" image of a woman in the Indian context is that of an upper caste, young, tall, slim, fair, agile and non-disabled female. This is evident from the matrimonial advertisements in newspapers that search for "attractive, tall, slim, fair, homely" women. Consequently, older women, short women, fat women, dark-skinned women, lower caste women and women with disabilities are not considered attractive because they do not conform to the dominant body-image of a 'perfect' woman.

Disability affects the gendering process in different ways. Often, the gender roles assigned to a person without disabilities are not expected from a person with disabilities of the same gender. For instance, women are assigned gender roles like managing the household, cooking, procreation and caregiving. However, women with disabilities are assumed to be unfit to take on familial responsibilities as a wife and mother because of their non-normative bodies. This is described by Adrienne Asch and Michele Fine (1988) as 'rolelessness' which implies invisibilisation and cancellation of femininity. So, women with disabilities aspire to pursue the feminine identity epitomised by the society, they may be denied access to it on account of their disability. This situation makes women with disabilities feel a great sense of achievement in performing the stereotypical gendered roles of wife and mother, not only because she wants to essay these roles but because she wants to prove herself 'capable' of performing the gender roles of a 'normal' woman. The pressure to fulfil conventional gender-role expectations on women with disabilities by their families may push some women to either decide not to aspire to conventional gender roles for political or personal reasons, or compel other women with disabilities to struggle to conform to the roles and associated norms of being 'real women'. Alternatively, facing rejections from society and realizing that the socially sanctioned roles of gender and sexuality are forbidden to them, such women may experience feelings of worthlessness and low self-esteem, even leading to serious mental health problems. (Begum 1992).

While many issues faced by persons with disabilities may equally apply to men with disabilities and even other sexual minorities, some issues are specific to women with disabilities. Among the special issues more often faced by women with disabilities are forced marriage, domestic violence, and other types of physical, emotional, and sexual abuse, the burdens of household responsibilities, and issues concerning pregnancy, labour, delivery, and childrearing.

The sexual and reproductive health and rights (SRHR) of people with disabilities continue to be contested, there are particular concerns in relation to women with disabilities. For women, disability often means exclusion from a life of femininity, partnership, active sexuality and denial of opportunities for motherhood (Fine and Asch 1988). The following are the stark realities of the lives of women with disabilities:

<u>Survival Rates</u>: In many societies, the survival rate for women with disabilities is lower than that for men with disabilities. For example, (Helander 1999) reports that in Nepal the long-term survival rate of women, who were disabled by polio, is only half that of men who had polio.

<u>Unstable Relationships</u>: Considered in some societies as less eligible marriage partners, women with disabilities are more likely to live in a series of unstable relationships, and thus have fewer legal, social and economic options should these relationships become abusive.

<u>Maternal Morbidity and Mortality</u>: Women with disabilities are not only less likely to receive general information on sexual and reproductive health and have access to family planning services. If they become pregnant, they are also less likely than their non-disabled counterparts to have access to

prenatal, labour, delivery and post-natal services. Physical, attitudinal and information blocks frequently exist. Often, community-level mid-wifery staff will not see women with disabilities, arguing that the birthing process needs the help of a specialist or will necessarily require a Caesarean section – which is not necessarily the case. Of equal concern is the fact that in many places, women with disabilities are routinely turned away from such services should they seek help, often being told that they should not be pregnant, or scolded because they have decided to have a child (Maxwell, Belser and David 2007).

Non-Disabled Women in Households with Family Member(s) with Disabilities: Parents and siblings of children with disabilities often find themselves socially isolated. Stigma, poverty, and lack of support systems take a toll on such families. The caregiving burden often falls disproportionately on women in such households. Thus, support systems for care providers, as well as for persons with disabilities, are crucial – both formal systems, such as social security and health insurance, and informal social networks, such as community support groups are required. Furthermore, in a number of societies, if a child is born with a disability, it is assumed that the mother has been unfaithful or has otherwise sinned. She suffers significantly as a result of this assumption. Even without such stigma, the physical, mental and financial stresses, coupled with social isolation, result in rates of divorce and desertion often twice as high among mothers of children with disabilities as among their peers who do not have children with disabilities (Andersson 1997; Aughinbaugh et al. 2013 Namkung et al. 2015). There are a number of ramifications of this – most striking, a cycle of increasing poverty.

In India, men with disabilities have greater access to health, education and employment opportunities as compared to women with disabilities. It is also easier for such men to find sexual partners, both with and without disabilities (Addlakha 2007: 112). However, a gender sensitive approach shows that men with disabilities also have to confront a whole range of gendered discrimination as disability is assumed to challenge both self-perceived and other-perceived notions of manhood and masculinity. Dependency and vulnerability are perceived as "weak" or feminine attributes. The conservative ideas about the qualities that make-up a normal man are being physically strong, aggressive, self-reliant and providing financial security and social status to the family. This is often in conflict with being a man with disabilities in need of support. This can have extremely distressing outcomes on sexual/gender identity and overall self-concept of men with disabilities (*ibid.*113).

Men with disabilities also face gender-related issues:
Information on Sexuality and Reproduction: In many societies, while women receive instruction about sexual and reproductive health either at home or in school, young men are left to pick up such information "on the streets" – casually, through other men's comments, jokes and innuendoes. Young men with disabilities are often shielded from even this information, unreliable and incomplete as it may be. Young men with mental and intellectual impairments are particularly likely to be deprived of sexual and reproductive health information.

Sexual exploitation: It is widely believed that men are not sexually abused. This is not true. In particular, men with disabilities are susceptible to sexual abuse, from both male and female perpetrators. Indeed, men with disabilities are at a heightened risk for lifetime and current sexual violence victimization (Mitra 2011). Accessible abuse reporting and effective intervention programmes are as important for men with disabilities as they are for women with disabilities.

All people have the right to sexual well-being, but more often than not, people with disabilities are regarded not only as non-sexual but also often not even as people. The non-disabled world has found it challenging to grapple with the idea that disabled bodies can have sexual feelings, the mere thought that people with disabilities may engage in sexual behaviour and activities is considered 'unwholesome, repulsive and comical'

(Greengross 1976). Such stigma leads to people with disabilities, particularly women with disabilities, being labelled as non-sexual beings.

Similarly, queer people with disability may also be marginalized as a result of existing notions of sexuality. Alison Kafer (2003) states that in case of queer women with disabilities, their sexual preferences are seen as signs of their confusion related to their disability and body. It is opined that women with disabilities resort to a lesbian lifestyle as they are unable to find a male partner on account of being disabled. It is perceived as a compulsion and not their sexual choice. The stigmatisation of being non-sexual may also lead to same-sex relationships of queer women with disabilities being viewed as platonic. Indeed, not only does the queer disabled community face oppression from the broader mainstream society on account of its non-heteronormative sexual orientation, but also within the disability community from the heterosexual disabled people. Queerness has been historically medicalised as perverted, corrupt, and pathological, while disability has also been associated with deviance, perverseness, and tragedy. Both pose a threat to the boundaries of heterosexuality and vice versa, as they challenge the supposed normality of able-bloodedness and heterosexuality (Clare 2001; McRuer 2003).

BOX 23

DISABLED BODIES ARE OFTEN DENIED LGEITMATE SEXUAL AND GENDER IDENTITIES DUE TO NEGATIVE STEREOTYPING. SUCH BODIES ARE CONSIDERED EITHER NON-SEXUAL OR HYPERSEXUAL RESULTING IN FURTHER DISENFRANCHISEMENT OF PEOPLE WITH DISABILITIES, PARTICUARLY WOMEN AND QUEER PEOPLE WITH DISABILITIES. THE INTERSECTIONS OF SEX, GENDER AND DISABILITY PRODUCE PARTICULAR FORMS OF STIGMA AND DISCRIMINATION FOR PEOPLE WITH DISABILITIES, PARTICUARLY IN THE HEALTH SYSTEM.

Personal Story 2: Denial of Sexual Expression

Sameeksha is a 20-year-old unmarried Hindu woman. She is a person with locomotor disability, which she acquired in an accident when she was 13-years-old. She uses an electric wheelchair for mobility. She was born and brought up in Punjab, but moved to Delhi for her graduation in Delhi University. Her family consists of her father, mother and brother. She is in a heterosexual relationship with a man, who is non-disabled man.

Sameeksha recounted an incident when she was wearing a short skirt while walking on the road. A female stranger passed a comment on her appearance and said, "You are wearing such clothes even after being disabled". Sameeksha said that she has had several experiences of strangers questioning her desire to be attractive. Such experiences are not always verbal. She said that whenever she is out with her boyfriend, and they hold hands or kiss in public, people stare at them. The comment of the woman on Sameeksha's attire tells us that a woman with disabilities should not wear short skirts or look sexy. The underlying assumption is that women with disabilities are not supposed to have sexual desires or want to look attractive. The stares she gets from strangers for expressing her desire towards her boyfriend in public point towards the society's bias towards women with disabilities, and the belief that they should not/ cannot engage in sexual or intimate activities.

Personal Story 3: Failing the Marriage Test Due to Disability

Priya is a 30-year-old unmarried Hindu woman working as a Human Resource Associate in a private company in Gurugram. She has a post graduate degree. She was diagnosed to be having cerebral palsy and is a wheelchair user. However, according to her, she suffered from hip dislocation and certain symptoms of cerebral palsy. She met a man online and they started dating. After a few months, the man came to meet her along with his family. The first question that his mother asked Priya was if her menstrual cycle was normal. She was further questioned on how she would manage the wedding rituals and puja that would require her to sit on the floor. She was also asked by the potential mother-in-law if she could wear a *sari* and manage the kitchen work on her own. Priya said, she knew the questions were asked with the full knowledge that she cannot do the said activities in order to humiliate her. During marriage negotiations women with disabilities, like other women, are also expected to be able to perform housework, take care of the husband and his family and bear and rear children.

To challenge patriarchy and protest against the sexual objectification of women by men, the women's movement has demanded the right for women to define their sexuality and to end all discrimination against queer people. Women with disabilities are entitled to the same rights as other women; however, their sexuality has not been a dominant topic of discussion. They are considered non-sexual on account of the society’s inability to perceive anything beyond able-bodied heterosexuality. Women with disabilities concerns regarding sexual pleasure, pregnancy and childbirth, and body image are often disregarded by health care professionals and personal care assistants. Such avoidance has a detrimental effect on sexual health and well-being. In some cases, forced sterilization, abortions, and hysterectomies may be performed to prevent unwanted pregnancies (Waxman-Fiduccia 1999). In India, the practice of forced hysterectomies came in public limelight in 1994, when fourteen mentally challenged women between the ages of 18 and 35 were forced to undergo hysterectomy at Shirur Home for Mentally Challenged Women in Pune (Maharashtra).

People with disabilities are constantly failed by the society, state and institutions, which refuse to acknowledge their autonomy and integrity as sexual beings. They are perceived to be sexually undesirable and therefore incapable of being in sexual, intimate or romantic relationships. Consequently, it is mistakenly assumed that people with disabilities do not get sexually assaulted or abused, as people don’t find them attractive or desirable. This leads to accounts of women with disabilities experiences of sexual harassment and abuse being disbelieved. The fact that even non-disabled women’s experiences of sexual abuse are looked at with suspicion by society explains why women with disabilities are hesitant to talk about such experiences of violence. Furthermore, they may be gas-lighted into believing that their experiences are not real. However, we know that vulnerability is a major contributing factor to sexual violence from studies across the world (Alemu et al. 2023; Anyango et al. 2023; Daruwalla et al. 2013; Riley et al. 2022), and no one can deny that women with disabilities are vulnerable.

QUESTIONS FOR REFLECTION AND DISCUSSION

- ✓ *Can you identify instances of patriarchy in your work?*
- ✓ *What is the relationship between sex and gender?*
- ✓ *How can the understanding of gender and sexuality help you in your work?*
- ✓ *How does a gendered approach contribute to our understanding of disability? Give examples.*

4. SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS: ISSUES AND CONCERNS FOR PEOPLE WITH DISABILITIES

Objectives

After going through this Module, you will be able to:

- *Know important terms and concepts pertaining to sexual health, sexual well-being and sexual rights*

- *Understand the meaning of reproductive health and rights*

- *Appreciate the challenges faced by people with disabilities in the areas of sexual and reproductive health and rights.*

4.1 International Mandate to Guarantee Right to Health for Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities has several articles addressing the health of people with disabilities directly or indirectly. The two main articles in this regard are Article 25 and Article 26, which are given below:

Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

In particular, States Parties shall:

A. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

B. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

C. Provide these health services as close as possible to people's own communities, including in rural areas;

D. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

E. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

F. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

Article 26 - Habilitation and Rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.
2. To that end,
3. States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

2. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

3. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

4. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

5. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.
6. Within the hierarchy of health needs, sexual and reproductive issues receive the least attention when it comes to people with disabilities due to underlying misconceptions of non-sexuality. This desexualisation has particularly deleterious consequences for women with disabilities, which are invisible in the health system. It is the purpose of this module o highlight this hidden aspect of the lives of people with disabilities, so that professionals do not succumb to social stereotypes and misconception.

https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

4.2 Sexual Health, Sexual Well-Being and Sexual Rights

Terms like sexual health. Sexual well-being and sexual rights are relatively new terms that have been introduced into public discourse by international human rights law and through the activism of human rights movements for empowerment of marginalised groups like women, the Afro-Americans and other ethnic minorities, indigenous peoples, sexual minorities and persons with disabilities. The United Nations has played a pivotal role in promoting their dissemination and adoption among its 193 member states.

Renu Addlakha (2007) notes that anecdotal evidence and personal communication with different stakeholders in the disability sector in India suggest that the rights of persons with disabilities to relationships, a family and children have been completely side-lined. While theoretically endorsing the need to address the sexual and reproductive concerns of persons with disabilities, interviews with policy-makers, special educators, and rehabilitation professionals among others reveal that they assign them a secondary status, arguing that they can be taken up after basic needs of health, education and employment have been addressed. It is the purpose of this module to show that sexual and reproductive health issues are as important in the lives of persons with disabilities as other health issues, education and employment.

4.2.1 Sexual Health and Well Being

The first reference to sexual health as an intrinsic aspect of total health was in the International Conference on Population and Development (ICPD) Programme for Action (Cairo, 1994), which stated that reproductive health, "also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases." (UN WOMEN 1995). It was further stated that it is important that "People are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so." (https://www.un.org/womenwatch/daw/ beijing/platform/health.htm) Implicit in these statements are the rights of men and women to be informed about and to have access to safe, effective, affordable and acceptable methods of family planning of their choice…"(*ibid.*)

In 1995 at the Fourth World Conference on Women in Beijing, sexual health found mention as a part of sexuality, over which women's autonomy was recognised as: "The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence" (Beijing Declaration and Platform of Action 1995). These early articulations established that sexual health is related to sexuality, sexual relations (including but not limited to reproduction) and disease prevention; that it entails the 'availability, accessibility, acceptability and quality' of information, knowledge and services, to enable women making informed choices for a satisfying and safe sex life. Notably, sexual health was accepted as an aspect of women's inalienable rights and gender equality.

The Committee on Economic, Social, and Cultural Rights (CESCR) General Comment 14 (2000) elaborates on the state obligations in relation to sexual and reproductive health. Affirming that these are an aspect of the right to the highest attainable standard of health (Article 12), it notes the "need to develop and implement a comprehensive national strategy for promoting women's right to health throughout their life span ... [to] include interventions aimed at the prevention and treatment of diseases affecting women … including sexual and reproductive health services." It furthers says that State obligations in this context are "to ensure that harmful social or traditional practices do not interfere with access to pre- and post-natal care and family planning; to prevent third parties from coercing women to undergo traditional practices, e.g. female genital mutilation; and to take measures to protect … in particular women, children, adolescents and older persons, in the light of gender-based expressions of violence." (https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmlBEDzFEovLCuW1AVC1NkPsgUedPlF1vfPMJ2c7ey6PAz2qaojTzDJmC0y%2B9t%2BsAtGDNzdEqA6SuP2r0w%2F6sVBGTpvTSCbiOr4XVFTqhQY65auTFbQRPWNDxL Additionally, it calls upon States to refrain from limiting access to contraceptives and other means of maintaining sexual and reproductive health, from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information.

The World Health Organisation (2006) defines sexual health as:

> "*…*a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled."

(https://www.cesas.lu/perch/resources/whodefiningsexualhealth.pdf

Consensus on the definition of sexual health by the WHO has been growing, and the right to sexual health and wellbeing is now understood to include within its scope linkages with positive sexuality, sexual relationships and sexual rights.

BOX 24

SEXUAL HEALTH IS DEFINED AS:

"…A STATE OF PHYSICAL, EMOTIONAL, MENTAL AND SOCIAL WELL-BEING IN RELATION TO SEXUALITY; IT IS NOT MERELY THE ABSENCE OF DISEASE, DYSFUNCTION OR INFIRMITY. SEXUAL HEALTH REQUIRES A POSITIVE AND RESPECTFUL APPROACH TO SEXUALITY AND SEXUAL RELATIONSHIPS, AS WELL AS THE POSSIBILITY OF HAVING PLEASURABLE AND SAFE SEXUAL EXPERIENCES, FREE OF COERCION, DISCRIMINATION AND VIOLENCE. FOR SEXUAL HEALTH TO BE ATTAINED AND MAINTAINED, THE SEXUAL RIGHTS OF ALL PERSONS MUST BE RESPECTED, PROTECTED AND FULFILLED." (https://www.cesas.lu/perch/resources/whodefiningsexualhealth.pdf)

Sexual health and well-being are both recognised as an inseparable aspect of human rights coming under the ambit of the right to health. Initially, sexual health and well-being were recognised in association with reproductive health. However, over a period of two decades, sexual health has evolved into a separate thematic area that includes physical, social, psychological, and epidemiological attributes with respect to sexuality; and the linkages of each of these dimensions with material and social conditions that inform access, experiences and health outcomes of diverse population groups. Thus, it can be said that sexual health is directly linked to the right to health, the enjoyment of which is inter-dependent on and inseparably associated with the fulfilment of other human rights. The term 'well-being' is used in association with or as an adjunct to sexual health, as it is not limited to disease prevention and treatment, but includes other aspects like enjoyment, pleasure and autonomy with reference to sexuality. Society also displays a pervasive discomfort with the idea of sexual pleasure, which is reflected in punitive regulation and policing of adolescent sexuality. Expressions, and perceived expressions of sexuality, including choice in clothing, partners, digital access, etc. are strictly monitored by families, and other state and non-state actors.

4.2.2 Sexual Rights

The World Health Organisation (2006) defines sexual rights as follows:
"Sexual rights embrace human rights that are already recognised in national laws, international human rights documents and other consensus documents. They rest on the recognition that all individuals have the right — free of coercion, violence and discrimination of any kind — to the highest attainable standard of sexual health; to pursue a satisfying, safe and pleasurable sexual life; to have control over and decide freely, and with due regard for the rights of others, on matters related to their sexuality, reproduction, sexual orientation, bodily integrity, choice of partner and gender identity; and to the services, education and information, including comprehensive sexuality education, necessary to do so.
https://www.cesas.lu/perch/resources/whodefiningsexualhealth.pdf

According to the WHO (2006), sexual rights include the rights of all persons, free of coercion, discrimination and violence, to:

- The highest attainable standard of sexual health, including access to sexual and reproductive health care services
- Seek, receive and impart information related to sexuality

- Sexuality education
- Respect for bodily integrity
- Choose their partner
- Decide to be sexually active or not
- Consensual sexual relations
- Consensual marriage
- Decide whether or not, and when, to have children, and
- Pursue a satisfying, safe and pleasurable sexual life.
  https://www.cesas.lu/perch/resources/whodefiningsexualhealth.pdf

Fundamental to ensuring sexual rights is the availability of scientific and unbiased information around sexual health and well-being for making informed sexual choices, engaging in safe sex practices, and preventing diseases. Age-appropriate Comprehensive Sexuality Education (CSE), that comprises issues such as gender relations, roles, identities, body and relationship of the self with the body, positive and negative sexual contact, harm and pleasure, disease prevention, amongst others, is widely recognised as the way for enabling children and young persons in schools to become aware about their bodies, personal hygiene, gender identities as well as safe sex practices. However, CSE as per international standards has not yet been implemented anywhere in India. It has faced considerable resistance from certain areas like religious groups.

Security from sexual violence and freedom from the control and regulation of one's sexual autonomy have also been recognised as fundamental to sexual health and rights. However legal reforms notwithstanding, the law in India is still not consistent in distinguishing consensual sex from non-consensual sex. It does not uphold sexual autonomy of adults, since it neither criminalises all forms of non-consensual sexual contact, nor does it de-criminalise all consensual sex. For example, based on a moralistic understanding of good and bad sex, the law obstructs legal redress from sexual violence to persons with non-normative sexual orientations and gender identities, sex workers, and to women in relation to marital rape.

Apart from limiting legal redressal, the quality of redressal has also been called into question.

There is increasing acceptance that besides women, other victims of gender-based violence include children, persons with non-normative sexual orientations or gender identities, and that vulnerability to violence is aggravated by disabilities, social and economic status, marital status, and conflict situations.

The inter-dependant web of sexual health rights includes the availability of age- and stage-differentiated, and scientifically accurate sexuality education, information and health services, disease prevention and treatment such as for HIV and AIDs and sexually transmitted infections (STIs). Sexual rights also include protection from gender-based violence, respect for the evolving capacities of adolescents, and attentiveness to the needs of persons with disabilities.

Without directly mentioning it, the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD 2006) enumerates several rights that relate to sexuality but overall they are less explicit and affirmative than expected. The articles dealing with sexuality include Article 25 (Right to Health), Article 26 (Habilitation and Rehabilitation).

BOX 25

SEXUAL RIGHTS INCLUDE THE RIGHTS OF ALL PERSONS, FREE OF COERCION, DISCRIMINATION AND VIOLENCE, TO:

- THE HIGHEST ATTAINABLE STANDARD OF SEXUAL HEALTH, INCLUDING ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH CARE SERVICES
- SEEK, RECEIVE AND IMPART INFORMATION RELATED TO SEXUALITY
- SEXUALITY EDUCATION
- RESPECT FOR BODILY INTEGRITY
- CHOOSE THEIR PARTNER
- DECIDE TO BE SEXUALLY ACTIVE OR NOT
- CONSENSUAL SEXUAL RELATIONS
- CONSENSUAL MARRIAGE
- DECIDE WHETHER OR NOT, AND WHEN, TO HAVE CHILDREN, AND
- PURSUE A SATISFYING, SAFE AND PLEASURABLE SEXUAL LIFE
  https://www.cesas.lu/perch/resources/whodefiningsexualhealth.pdf

Article 14 (Right to Liberty and Security of Person), Article 16 (Freedom from Exploitation, Violence and Abuse) and Article 23 (Respect for Home and the Family). Article 6 of the Convention is specific to Women with Disabilities.

The Indian Rights of Persons with Disabilities Act (2016) does not use the term, ‘sexual rights’. It indirectly incorporates sexuality within other sections like Protection against Violence, Abuse and Exploitation (chapter 2 section 7). Accessing sexual and reproductive rights in India is a major challenge and those with disabilities face more barriers.

4.3 Reproductive Health and Rights

Complementary to and intertwined with sexual health and rights are reproductive health and rights.

4.3.1 Reproductive Health

As already mentioned, sexual health was included under the overarching rubric of reproductive health, which encompasses all matters related to the male and female reproductive systems, with the primary focus being on facilitating procreation. Discussions on reproductive health are still gender-biased as the focus continues to be on the female reproductive system due to women's child bearing and rearing roles**.** However, a truly holistic perspective on the issue involves focusing on all dimensions of the gender spectrum, and remembering that sexual health and rights are only one important component of reproductive health.

Reproductive Health as stated in the Programme of Action of the International Conference on Population and Development in 1994 is defined as:

"…a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capacity to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are: the rights of men and women to be informed, have access to safe, effective, affordable and acceptable methods of family planning including methods for regulation of fertility, which are not against the law; and the right of access to appropriate health care services to enable women to have a safe pregnancy and childbirth and provide couples with the best chance of having a healthy infant." https://www.cesas.lu/perch/resources/whodefining sexualhealth.pdf

BOX 26

REPRODUCTIVE HEALTH IS DEFINED AS "…A STATE OF COMPLETE PHYSICAL, MENTAL AND SOCIAL WELL-BEING, AND NOT MERELY THE ABSENCE OF DISEASE OR INFIRMITY, IN ALL MATTERS RELATING TO THE REPRODUCTIVE SYSTEM AND TO ITS FUNCTIONS AND PROCESSES. REPRODUCTIVE HEALTH THEREFORE IMPLIES THAT PEOPLE ARE ABLE TO HAVE A SATISFYING AND SAFE SEX LIFE AND THAT THEY HAVE THE CAPACITY TO REPRODUCE AND THE FREEDOM TO DECIDE IF, WHEN AND HOW OFTEN TO DO SO. IMPLICIT IN THIS LAST CONDITION ARE: THE RIGHTS OF MEN AND WOMEN TO BE INFORMED, HAVE ACCESS TO SAFE, EFFECTIVE, AFFORDABLE AND ACCEPTABLE METHODS OF FAMILY PLANNING INCLUDING METHODS FOR REGULATION OF FERTILITY, WHICH ARE NOT AGAINST THE LAW; AND THE RIGHT OF ACCESS TO APPROPRIATE HEALTH CARE SERVICES TO ENABLE WOMEN TO HAVE A SAFE PREGNANCY AND CHILDBIRTH AND PROVIDE COUPLES WITH THE BEST CHANCE OF HAVING A HEALTHY INFANT."
https://www.cesas.lu/perch/resources/whodefiningsexualhealth.pdf

4.3.2 Reproductive Rights

Reproductive rights primarily focus on the issues related to reproductive processes and procreation. Reproductive rights as stated in the Programme of Action of the International Conference on Population and Development in 1994:

"… Embrace certain human rights that are already recognized in national laws, international laws and international human rights documents and other consensus documents. These rights rest on the recognition of the basic rights of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes the right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents. (https://www.un.org/womenwatch/daw/beijing/platform/health.htm)

Both men and women have reproductive rights. They include:

- Right to access to good quality reproductive health care
- Right to make free and informed decisions
- Right to menstrual health
- Right to access contraception
- Right to abortion
- Freedom from coerced sterilization
- Right to receive information about sexually transmitted infections.

BOX 27

BOTH MEN AND WOMEN HAVE REPRODUCTIVE RIGHTS, WHICH INCLUDE RIGHT TO ACCESS TO GOOD QUALITY REPRODUCTIVE HEALTH CARE

- RIGHT TO MAKE FREE AND INFORMED DECISIONS
- RIGHT TO MENSTRUAL HEALTH
- RIGHT TO ACCESS CONTRACEPTION
- RIGHT TO ABORTION
- FREEDOM FROM COERCED STERILIZATION
- RIGHT TO RECEIVE INFORMATION ABOUT SEXUALLY TRANSMITTED INFECTIONS
- PROTECTION FROM SUCH HARMFUL PRACTICES AS FEMALE GENITAL MUTILATION (WHO 2006).

It may be noted that there is considerable overlap between sexual and reproductive health and rights, particularly in relation to information and services relating to contraceptives, abortion and sexually transmitted infections.

As already mentioned, in addition to the International Conference on Human Rights Declaration in 1968 and the International Conference on Population and Development in 1994. Reproductive health and rights have been recognized in the International Covenant on Economic, Social and Cultural Rights, 1996 (ICESCR) (Article nos. 10 and 12)[22] and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), 1979 (Article no. 16)[23] (also fore-ground the focus on reproductive rights as necessary in realising the human rights of women. The Sustainable Development Goals (SDGs)[24] and the preceding Millennium Development Goals (MDGs)[25] also encompass several goals that directly and indirectly recognise reproductive rights.

---

[22] Article 10 of ICESCR states that: The States Parties to the present Covenant recognize that: Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits. https://www.ohchr.org/sites/default/files/Documents/ProfessionalInterest/cescr.pdf

Article 12 of ICESCR states that: 1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child https://www.ohchr.org/sites/default/files/Documents/ProfessionalInterest/cescr.pdf

[23] Article 16 of CEDAW guarantees women equal rights in deciding "freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.
https://www.ohchr.org/en/women/sexual-and-reproductive-health-and-rights#:~:text=CEDAW%20(article%2016)%20guarantees%20women,them%20to%20exercise%20these%20rights.%22 Accessed February 19, 2024

[24] Targets 3.7 of the Sustainable Development Goals (SDGs) calls on countries “by 2030, to ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes”.
https://www.un.org/en/development/desa/population/publications/pdf/family/familyPlanning_DataBooklet_2019.pdf Accessed February 19, 2024.

[25] MDG 5 The only goal related to sexual and reproductive health, which is related to improvement in maternal health.

India, being a signatory to these covenants and conventions, is obligated to ensure that these goals are fulfilled in its laws and policies. Looking at national laws and policies relevant to reproductive health and rights presents a mixed picture of compliance as well as huge gaps. India was the first country in the world to have a national level Family Planning Programme after Independence in 1952 (https://mainmohfw.gov.in/sites/defaults/files/06Chpater.pdf) While the aim was primarily fertility regulation, it has evolved over the years in keeping with international trends and moved from a clinical to a reproductive health and rights approach. India was also one of the first countries to legalise abortion through the Medical Termination of Pregnancy Act (MTP) 1971. With the aim of curbing the rampant practice of female abortion on grounds of sex selective due to the cultural preference for male children, India passed the Pre-conception and Pre-National Diagnostic Techniques (PCNDT) Act in 1994. Unfortunately, both these laws make disability selective abortion legal. Anita Ghai and Rachana Johri (2008) note that "A careful reading of it shows that while selection on the grounds of sex is unambiguously banned, there is a positive sanctioning of selection on the basis of disability. Consequently, this results in the legitimisation of one kind of selection, that is, on the basis of disability, while prohibiting it on grounds of sex". This has the eugenic potential to sanction the elimination of 'un-fit' or 'inferior' people, which must be challenged.

However, the focus still continues to be on maternal and child health to the exclusion of other dimensions of reproductive health and rights like the neglect of reproductive morbidities and easy access to safe abortion services for all categories of women. At the policy level, sterilisation still dominates the reproductive health landscape.

---

https://www.who.int/news-room/fact-sheets/detail/millennium-development-goals-(mdgs) Accessed February 19, 2024.

International human rights standards require that sexual and reproductive health services should be available, accessible, acceptable and of good quality (AAAQ). Stigma around sexuality, criminalisation of same-sex marriage and adolescent sexual expression, and legal ambiguity around sex work renders\ specific population groups such as queer persons, adolescents, persons with disabilities, and sex workers more exposed to threat, further alienating them from sexual and reproductive health services, while augmenting the risk and occurrence of abuse and violence in their lives. When the few who do access these services, they often have to face humiliating treatment. Dominant negative stereotypes about the sexuality of such marginalised groups, lack of knowledge and sensitivity among health care providers act as barriers not only to information and interventions in the areas of contraception and abortion, but also to getting such simple services like blood tests for HIV and AIDS and other sexually transmitted infections by members of these groups.

4.3.2.1 Right to Safe, Hygienic and Dignified Menstruation

According to the United Nations Children's Emergency Fund (UNICEF), access to safe and dignified menstruation is a fundamental need and a basic human right (https://www.unicef.org/mongolia/stories/access-safe-and-dignified-menstruation-fundamental-need-and-human-right). The World Health Organisation (2022) also recognizes that menstrual health should be addressed as a health and human rights issue, not as a hygiene issue. It calls for three actions to achieve this end. Firstly, to recognize and frame menstruation as a health issue implies understanding and managing its physical, psychological, and social dimensions in the perspective of the life course – from before menarche to after menopause. Secondly, to recognize that menstrual health means that women and girls and other people who also menstruate, have access to information and education about it, and access to necessary menstrual products like water, sanitation, and disposal facilities; to competent and empathic care when needed; to live, study and work in an environment in which menstruation is seen as positive and healthy, and not something to be ashamed of; and to fully participate in work and social activities during periods.https://www.unicef.org/mongolia/stories/access-safe-and-dignified-menstruation-fundamental-need-and-human-right

The issues and concerns regarding menstruation and its management are the same for persons with disabilities and non-disabled persons, except for those with severe/ multiple disabilities and intellectual disabilities. The latter may require additional support from care providers for management of menstrual hygiene. As in the case of non-disabled girls, lack of support to manage menstruation may also lead to dropping out of school of girls with disabilities upon reaching puberty.

4.3.2.2 Right to Safe, Accessible and Effective Contraception

Every women and adolescent girl has the right to access contraception and family planning services, Access to family planning and contraception services, free of coercion or impediment, is a component of the right to health that is central to women's autonomy in the realization of their rights to equality and non-discrimination. Contraceptives enable women and adolescent girls to exercise their right to decide whether to be pregnant, the number and spacing of their children and to have pleasurable and safe sexual experiences without the risk of unintended pregnancies. https://www.ohchr.org/en/ statements/2021/09/world-contraception-day-26-september-2021

People with disabilities are often regarded as non-sexual and unable to bear and rear children and be good parents. In either case, contraception is often considered 'unwanted' or 'unnecessary' for them. Hence, they are often deprived of the knowledge, information and resources to access contraceptive services. But, disability in no way affects a woman's fertility as ovulation and menstruation are regulated by hormones and are rarely impacted by impairment. In some cases, medication may interfere with contraceptive efficacy. Apart from physiological factors, the main barriers to contraception for people with disabilities is the discrimination which deprives them of essential information and access to suitable methods of fertility regulation. People with disabilities suffer from lack of information on contraceptive choices, availability of contraception and how to use them. They do not have space to express concerns, fears and challenges with respect to various contraceptive methods and safe sex practices. Most often, contraceptives or contraceptive-dispensing services are not designed keeping people with disabilities in mind. These services and products are considered to be 'not useful' for or 'not required' by people with disabilities based on the misconception of them being non-sexual.

4.3.2.3 Right to Decide If, When and How to get Pregnant

According to the International Covenant on Civil and Political Rights 1966 (ICCPR), the right of a woman or girl to make autonomous decisions about her own body and reproductive functions is at the very core of her fundamental right to equality and privacy, concerning intimate matters of physical and psychological integrity (Articles 3 and 17 of ICCPR)[26] . Every woman has the fundamental right to choose to or not to get pregnant but also to have a safe pregnancy and childbirth experience.

For women with disabilities, prejudice and discrimination often make pregnancy and childcare a challenging proposition, as there is a perception in society that a disabled woman's child will also be disabled. In addition, people with disabilities are also considered a burden, both physically and financially, hence the idea of them having children is thought of as adding

---

[26] Article 3 of ICCP states that: The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all civil and political rights set forth in the present Covenant.
https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WG/WGDAW_HRC_GC36_submission.pdf
Article 17 of ICCPR states that: 1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.
2. Everyone has the right to the protection of the law against such interference or attacks.
https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WG/WGDAW_HRC_GC36_submission.pdf

to that burden. However, a large number of women with disabilities do have children, most of whom are not disabled. Once a woman with disabilities decides to have a child, she has to face the unfavourable and often hostile attitudes and behaviours of health care professionals and the health care system in general. Basic equipment like low-height examination tables, portable floor lifts, and adjustable radiological and diagnostic equipment for various tests like mammography and commodes and shower transfer benches are simply not available in most hospitals.

In a 2014 report of the South India Disability Evidence (SIDE) Study of 2012, researchers concluded that:

> "Women with disability have a significantly lower pregnancy rate compared to women without a disability. Women with disability have significantly higher risk of co-morbidities like diabetes and depression. Contrary to what has been reported from many countries, parameters related to antenatal and natal care were similar for women with and without a disability." (Murthy, John, and Sagar 2014).

Most of the procedures or services that pregnant women with disabilities require are similar to those required by non-disabled pregnant women. Hence, some modifications and general sensitivity towards the specific needs of pregnant women with disabilities would make the services accessible to them. Caregivers and health care providers' attitudes towards the sexuality of persons with disabilities have to be changed. A woman with disabilities has equal rights as any other woman to bear and/or rear a child as per her choice.

Due to greater number injuries in men on account of automobile accidents, engagement in risky occupations like mining and participation in combat, issues around sexuality and fertility have received considerably more attention. Physical disabilities due to severe spinal cord injuries impact the fertility of man with disabilities. There are many articles on this issue, particularly in the journal *Sexuality and Disability* published by Springer.

However, this may be more due to erectile dysfunction and an inability to ejaculate than due to diminished sperm production. Assistive devices to help men with spinal cord injury to have and/or maintain an erection are available.

4.3.2.4 Right to Safe Abortion Services

According to the World Health Organisation (2024), ensuring that women and girls have access to safe, respectful and non-discriminatory abortion services as and when they choose to use them is a fundamental human right. https://www.who.int/_health-topics/abortion#tab=tab_1 According to Human Rights Watch (2022), access to safe and legal abortion is a matter of human rights, and its availability is the best way to protect autonomy and reduce maternal mortality and morbidity.
https://www.hrw.org/news/2022/06/24/qa-access-abortion-human-right

According to the Convention on the Rights of Persons with Disabilities, women with disabilities must have access to safe abortion services. According to article 25 (a) States Parties must provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.
https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

However, abortion is a complicated matter in India. While it is legally permissible in the country since 1971, many women continue to avail of backstreet (illegal) abortion services due to the stigma associated with voluntary abortion, particularly among unmarried women. Furthermore, the issue of female foeticide forces many women to undergo sex-selective abortions, when they get to know that the foetus they are carrying, is a female. Numbers are naturally hard to come by though in 2006 a study in the medical journal, The Lancet reported that around ten million female foetuses had been aborted in the preceding twenty years in India (Sheth 2006).

Additionally, doctors and other health care professionals should be aware that women with disabilities have the same rights as other women to seek abortion and/or to be pregnant: and therefore there should be no discrimination in the services provided to them. It is important to sensitise medical staff to the reproductive rights and needs of people in general and people with disabilities in particular.

4.4. Barriers and Challenges to Sexual and Reproductive Health for Persons with Disabilities

Persons with disabilities face many barriers to information and services about sexual and reproductive health, gender-based violence and abuse. First is the assumption that they are not sexually active and therefore do not need such information and services. Research shows, however, that persons with disabilities are as sexually active as persons without disabilities (WHO/UNPFA 2009). Despite this, their sexuality has been ignored and their reproductive rights, denied. At best, most existing policies and programmes concentrate on the prevention of pregnancy but ignore their desires to conceive and have children. At worst, forced abortion and sterilization abortion have often been imposed on them.

Furthermore, sexual and reproductive health services are often inaccessible to persons with disabilities for many reasons, including physical barriers, the lack of disability-related clinical services, and stigma and discrimination. All efforts to include persons with disabilities, their needs, and their concerns in health policy and programmes must confront multiple challenges. People’s impairments are not the source of these challenges. Instead, these challenges are imposed by society on persons with disabilities. Some such barriers are:

- Lack of physical access, including transportation and/or distance to clinics, and within clinics lack of ramps, adapted examination tables, and the like;
- Lack of information and communication about sexual and reproductive health services in accessible formats like simple language, pictures, Braille, large print and sign language interpretation;
- Health care providers' and policymakers' lack of awareness, knowledge, and understanding about persons with disabilities;
- Health care providers often lack awareness about and comprehensive understanding of the human rights paradigm;
- Invisibilisation due to underestimation of the actual number of persons with disabilities in the population leading to them being given low priority among groups requiring attention. Moreover, the widespread incorrect assumption that persons with disabilities are non-sexual or not sexually active and hence do not require sexual and reproductive health services;
- Majority of persons with disabilities face prejudice and stigma in their daily lives. This prejudice triggers the deprivation of a long array of human rights, from freedom of movement and association to health and education and pursuit of a livelihood.
- While most of the documents on sexual and reproductive health and rights are available in English, only around 30% of the population speaks and understands English in India;
- Lack of funding, including absence of health-care insurance for persons with disabilities;
- Often, even programmes with the best intentions treat persons with disabilities as a "target" or passive recipients of services. In fact, persons with disabilities constitute a significant stakeholder group that should have a prominent role in decision-making, whenever

health programmes are planned. Their involvement is the most effective way to ensure that programmes are disability-inclusive.

BOX 28

PEOPLE WITH DISABILITIES FACE PHYSICAL, ATTITUDINAL, LINGUISTIC AND OTHER BARRIERS TO ACCESSING HEALTH CARE IN THE AREAS OF SEXUAL AND REPRODUCTIVE HEALTH. THEIR INCLUSION IN DECISION-MAKING PROCESS IS CRTUCIAL

The above discussion would not be complete without highlighting how lack of awareness about their own bodies combines with poor body image, low self-esteem, general absence of privacy and comfort make it extremely difficult for persons with disabilities to deal with issues around sexuality and reproduction. The general fear and apprehension associated with taboo issues further exacerbate their life situation rendering them more vulnerable to stress, depression and trauma.

4.5 Sexual Violence and Abuse of Persons with Disabilities

Persons with disabilities are up to three times more likely than non-disabled persons to be victims of physical and sexual abuse and rape. Persons with intellectual and mental disabilities are the most vulnerable (Sobsey 1994; Waxman 1991). Persons with disabilities placed in institutions, group homes, hospitals, and other group living situations routinely face violations of their sexual and reproductive rights apart from facing an increased risk of abuse and violence (WHO/UNPFA 2009). Violence in such cases is compounded by the fact that the victims may be physically and financially dependent on those who abuse them. Furthermore, when they come forward to report such abuse, the medical, legal, and social service systems are often inaccessible and tedious, if not totally unresponsive.

Influenced by eugenic thinking, sterilization on grounds of disability has been legally sanctioned and historically prevalent particularly in the case of persons with intellectual disabilities all over the world (Rowlands and Amy 2019), even though a majority of disabilities are not congenital. Hysterectomy in women with disabilities, especially intellectual disabilities or women with disabilities who are confined to bed and cannot take care of themselves, is viewed as a solution to the 'problem' of menstruation and unwanted pregnancy and, by extension sexual abuse. When girls with disabilities reach puberty, parents may seek advice on how to protect their daughters from sexual abuse and consequent unwanted pregnancies. Hysterectomy may be opted for as a possible solution to this problem. However, this does not protect such girls and women from sexual abuse and violence but only stops the process of menstruation and the possibility of pregnancy. Furthermore, studies show that hysterectomy or the removal of the uterus has negative health consequences for women and should be undertaken only under exceptional circumstances (Madueke-Laveaux et al. 2021). In addition to being a major surgery, the removal of an organ that plays an important role in the optimal functioning of the female body has adverse consequences for overall health. Section 10 of the Rights of Persons with Disabilities Act, 2016 in India protects the rights of women with disabilities from medical procedures that may lead to infertility, without informed consent.

BOX 29

CONTRARY TO POPULAR THINKING RATES OF SEXUAL VIOLENCE AND ABUSE ARE HIGHER AMONG PERSONS WITH DISABILLITIES IN COMPRISOON TO THE GENERAL POPULATION LARGELY DUE TO THE MULTIPLE VULNERABILITIES THEY FACE AS A GROUP. QUESTIONABLE PRACTICES LIKE FORCED ABORTION AND STERILISATION HAVE BEEN ROUTINELY USED TO ADDRESS THE ISSUE IN CONNECTION WITH WOMEN WITH DISABILITIES

4.6 Sexuality, Reproductive Health and Rights in A Life-Cycle Perspective

Like everyone else, persons with disabilities have sexual and reproductive health needs throughout their lives, and these needs change over a lifetime. Different age groups face different challenges. For example, adolescents go through puberty and require information about the changes in their bodies and emotions, and about the choices they face concerning sexual and reproductive health related issues. Informing young persons with disabilities about this topic is often difficult because parents, educators, and counsellors often do not know how to talk about the subject as it is hedged in by social taboos. As a result, many young people with disabilities do not receive even basic information about how their bodies develop and change as they mature. Most often, they are unaware of the basic vocabulary about their bodies and sexuality, and so they are not able to recognise and/or describe what is happening to them or whether someone is taking advantage of them. During an interview conducted for this project, Preeti, a 21-year-old female student of Delhi University with visual impairment, informed that she had never heard the words contraception or masturbation in her life. Women with disabilities are taught to be compliant and to trust others, instead of providing them with the knowledge and information to make informed decisions. So, they do not have experience-setting limits with others regarding physical contact. Adolescents with disabilities like their non-disabled peers need to know all about sexual and reproductive health, but they may also need special preparation concerning sexual abuse and violence and the means to protect themselves against it. It is also important to ensure that services are tailored to their specific needs. On reaching the age for having a family, women and couples with disabilities, like everyone else, have the right to decide whether and when to have children and a right to sound and unbiased information on how to make decisions regarding contraception, timing of pregnancy, antenatal and postnatal care. Due to popular ideas about eugenics, such couples may be dissuaded from starting a family. Therefore, they need unbiased scientific counselling to make informed choices about parenting options available to them.

Reproductive and mental health are intertwined. Perinatal and postpartum depression, psychological consequences of gender-based violence or HIV and AIDS, feelings of loss and guilt after unsafe abortions, miscarriage and stillbirth are explicit examples of this connection. For persons with disabilities, physical, social and attitudinal barriers may increase mental health difficulties in these circumstances. It is crucial to pay close attention to the mental health or psychological well-being of persons with disabilities, their families, and other care providers.

Sexual and reproductive health concerns of individuals who become disabled through accident or illness during adulthood are often overlooked. These individuals often do not see themselves as members of a disability community, and they lack the social supports that many people who have grown up with a disability rely on. Indeed, these adults acquiring disabilities later in life hold the same prejudices and misperceptions about disability as those without disabilities. For instance, 47-years old, Ritu Batra, didn’t consider herself to be a disabled person. She had her first attack of multiple sclerosis at 35 years of age after she had had two children. At the time of the interview, she couldn’t walk without support, faced bladder control and memory problems. During the interview, she referred to people with the disabilities using the pronouns “they/them” and non-disabled people as “we/us”. Persons disabled later in life may be more likely to face depression than those disabled from birth or in childhood. Thus, the role of professionals who provide mental health and psychosocial care is particularly important in such cases.

To sum up, people with disabilities have the same sexual and reproductive health needs as other people, but they face more obstacles than non-disabled people to obtaining information and services in this regard. Usually, it is the ignorance and negative attitudes of society, including health-care providers, that create most of these obstacles, and not the disabilities *per se*. This echoes the absence of social attention, legal protection, understanding and support for persons with disabilities. Hence, they often remain unaware about basic facts about themselves, their bodies, and their rights to define what they want. Sexual and reproductive health and rights of persons with disabilities have been unheeded by both the disability community and the medical profession. Yet, they may actually have greater needs for sexual and reproductive health and rights education, services and care than persons without disabilities owing to their increased vulnerability to abuse. For instance, persons with disabilities fit the common pattern of structural risks for HIV and AIDS and other sexually transmitted infections – e.g. high rates of poverty, high rates of illiteracy, lack of access to health resources, and lack of power when negotiating safer sex. In most cases, the already existing services and facilities can be adapted easily to accommodate persons with disabilities. Therefore, increasing awareness of both persons with disabilities, their parents, teachers and different service providers is the first and biggest step towards achieving the goal of universal health care for persons with disabilities.

QUESTIONS FOR REFLECTION AND DISCUSSION

- ✓ *Distinguish between sexual and reproductive health in the context of human rights.*
- ✓ *How are the needs of sexual and reproductive health of persons with disabilities different from the general population?*
- ✓ *From your experience, how do you look at the issue of disability and reproduction?*
- ✓ *How does a gendered approach contribute to our understanding of disability? Give examples*

5. PATIENTS WITH DISABILITIES AND THE HEALTH SYSTEM

Objectives

After going through this module, you will be able to:

- *Understand the Meaning of Rehabilitation for People with Disabilities*
- *Appreciate the Different Barriers Faced by People with Disabilities in Accessing the Health System*
- *Be Introduced to the Major Myths and Misconceptions about Persons/Patients with Disabilities in the Health System.*

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being including persons with disabilities. This is an inalienable right enshrined in human rights treatise. The UNCRPD article 25 guarantees the rights of persons with disabilities to enjoy the highest attainable standards of health by making decisions about their bodies and health care choices without discrimination on the basis of disability. Even though the concept of disability is embedded within the medical discourse, persons with disabilities experience many inequities when they access the health system. Stigma and discrimination are stark realities for them in their health-seeking behaviour. They have to confront the same physical, social, cultural and attitudinal barriers in accessing health care for disability-related and other health conditions that they face in life in general. Disability is an extremely diverse phenomenon with multiple sources, manifestations and outcomes. While some disabilities like haemophilia and thalassemia require extensive health care intervention, others like visual and hearing disabilities may not. However, all people with disabilities have the same general health care needs as everyone else, and therefore need to regularly access mainstream health care services.

5.1 Rehabilitation Medicine

The World Report on Disabilities (2011) defines rehabilitation as
"….a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments". https://iris.who.int/handle/10665/44575

Rehabilitation is a global approach to 'rehabilitate' a person with disabilities in the context of her living environment, which includes a range of services going beyond health care. Rehabilitation focuses on improving an individual's total functioning. For instance, improving a person's ability to eat, drink and move independently. Rehabilitation also includes making changes to the individual's environment, for example by installing toilet handrails. However, barrier removal initiatives at societal level, such as fitting a ramp to a public building, are not considered rehabilitation.

The rehabilitation process begins with identifying a patient's problems and needs, relating the problems to relevant factors of the person's life and her environment, defining rehabilitation goals, planning and implementing the measures, and assessing the effects of the intervention. Educating people with disabilities is essential for developing knowledge and skills for self-care, management and decision-making. People with disabilities and their families experience better health and functioning when they are partners in rehabilitation.

Rehabilitation medicine is concerned with improving functioning through the diagnosis and treatment of health conditions, reducing impairments, and preventing or treating complications (WHO 2011). Doctors with specific expertise in medical rehabilitation are referred to as physiatrists, rehabilitation doctors, or physical and rehabilitation specialists (Gutenbrunner et al. 2007). Medical specialists, such as psychiatrists, paediatricians, geriatricians, ophthalmologists, neurosurgeons, and orthopaedic surgeons, can be involved in rehabilitation medicine, as can a broad range of therapists like physiotherapists, occupational therapists, orthotists, prosthetists, speech and language therapists, social workers, psychologists among others. In many parts of the world where specialists in rehabilitation medicine are not available, services may be provided by doctors and various therapists.

Rehabilitation therapy, in its broadest sense, is aimed at restoring and compensating for the loss of functioning and preventing or slowing down deterioration in functioning in every area of a person's life. Therapy measures may include:

- Training, exercises, and compensatory strategies
- Education
- Support and counselling
- Modifications to the environment

- Provision of Resources and Assistive Technologies https://iris.who.int/handle/10665/44575

BOX 30

REHABILITATION MEDICINE IS A SET OF MEASURES THAT ASSIST INDIVIDUALS WHO EXPERIENCE, OR ARE LIKELY TO EXPERIENCE, DISABILITY TO ACHIEVE AND MAINTAIN OPTIMAL FUNCTIONING IN INTERACTION WITH THEIR ENVIRONMENTS". MODALITIES OF REHABILITATION MEDICINE INCLUDE: TRAINING, EXERCISES, AND COMPENSATORY STRATEGIES, EDUCATION, SUPPORT AND COUNSELLING, MODIFICATIONS TO THE ENVIRONMENT. PROVISION OF RESOURCES AND ASSISTIVE TECHNOLOGIES (WHO 2011)

One of the important methods of rehabilitation is the use of assistive or adaptive technologies, of which there are quite a number. An assistive technology device is defined by the WHO (2011) as "any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities". https://iris.who.int/handle/10665/44575 Assistive technologies enable people to live healthy, productive and independent lives, but they are far from available to all. It is estimated, for example, that 360 million people, globally, have moderate to profound hearing loss, yet hearing aid production meets less than 10 percent of the need (WHO 2013).

Common examples of assistive devices are:

- Crutches, Prostheses, Orthoses, Wheelchairs, and Tricycles for People with Mobility Impairments;

- Hearing Aids and Cochlear Implants for those with Hearing Impairments;
- White Canes, Magnifiers, Ocular Devices, Talking Books, and Software for Screen Magnification and Reading for People with Visual Impairments;
- Communication Boards and Speech Synthesizers for People with Speech Impairments;
- Devices such as Day Calendars with Symbol Pictures for People with Cognitive Impairment.

Assistive technologies, when appropriate to the user and the user’s environment, have been shown to be powerful tools to increase independence and improve social participation.

The availability of rehabilitation services in different settings varies within and across nations and regions. Medical rehabilitation and therapy are typically provided in acute care hospitals for conditions with acute onset. Follow-up medical rehabilitation, therapy, and assistive devices could be provided in a wide range of settings, including specialized rehabilitation wards or hospitals; rehabilitation centres; institutions such as residential mental and nursing homes, respite care centres, hospices, prisons, residential educational institutions, and military residential settings; or single or multi-professional practices (offices or clinics). Longer-term rehabilitation may be provided within community settings and facilities such as primary health care centres, schools, workplaces, or home-care therapy services.

BOX 31

ASSISTIVE TECHNOLOGY IS DEFINED AS ANY ITEM, PIECE OF EQUIPMENT, OR PRODUCT, WHETHER IT IS ACQUIRED COMMERCIALLY, MODIFIED, OR CUSTOMIZED, THAT IS USED TO INCREASE, MAINTAIN, OR IMPROVE THE FUNCTIONAL CAPABILITIES OF INDIVIDUALS WITH DISABILITIES (WHO 2011). COMMON ASITIVE TECHNOLOGIES INCLUDE CRUTCHES, PROSTHESES, ORTHOSES, WHEELCHAIRS, AND TRICYCLES, HEARING AIDS AND COCKLEAR IMPLANTS, WHITE CANES, MAGNIFIERS, OCULAR DEVICES, TALKING BOOKS, COMMUNICATION BOARDS AND SPEECH SYNTHESIZERS.

The cost of rehabilitation can be a barrier for people with disabilities. Even where funding from governments, insurers, or NGOs is available, it may not cover the total costs to make rehabilitation affordable (Bigelow et al. 2004). Most people with disabilities may be unemployed, have lower incomes, may be less likely to be covered by employer-sponsored health plans or private voluntary health insurance. If they have limited finances and inadequate public health coverage, access to rehabilitation may also be limited, compromising activity and participation in society. Lack of financial resources for assistive technologies is a significant barrier for many (Zongjie et al. 2007). People with disabilities and their families purchase more than half of all assistive devices directly (Albrecht et al. 2003). In a national survey in India, two thirds of the assistive technology users reported having paid for their devices themselves (The World Bank 2009). A 2007 national study on rehabilitation needs in China found that about 40% of people with disabilities who needed services and assistance received no help. The unmet need for rehabilitation services was particularly high for aids and equipment, rehabilitation therapy and financial support for poor people with disabilities (WHO 2011).

Spending on rehabilitation services is difficult to determine because it generally is not disaggregated from other health care expenditure. Limited information is available on expenditure for the full range of rehabilitation measures (WHO 2011). Governments in 41 of 114 countries did not provide funding for assistive devices in 2005. Even in the 79 countries where insurance schemes fully or partially covered assistive devices, 16 did not cover poor people with disabilities, and 28 did not cover all geographical locations (*ibid.*). In some cases, existing programmes did not cover maintenance and repairs for assistive devices, which can leave individuals with defective equipment and limit its use (The World Bank 2009). One third of the 114 countries providing data to the 2005 global study did not allocate specific budgets for rehabilitation services (South-North Centre for Dialogue and Development 2006). Countries of the organisation of Economic Cooperation and Development (OECD) largely comprising countries from Western Europe appear to be investing more in rehabilitation than in the past, but the spending is still low (OECD 2008). Policy actions require a budget matching the scope and priorities of the plan. The budget for rehabilitation services should be part of the regular budgets of relevant ministries – notably health – and should consider ongoing needs. Ideally, the budget line for rehabilitation services should be separated to identify and monitor spending.

BOX 32

REHABILIATION COSTS ARE A MAJOR BARRIER BOTH FROM USER AND PROVIDER SIDES. PEOPLE WITH DISABILITIES MAY FIND REHABILITATION SERVICES TO BE BYOND THEIR FINANCIAL CAPACITIES, WHILE COUNTRY BUDGETS MAY NOT EVEN HAVE SEPARATE BUDGET LINES FOR REHABILITATION.

5.1. 1 Rehabilitation in India

Rehabilitation education in India is governed by the Rehabilitation Council of India (RCI), a statutory body established by an Act of Parliament in 1992, known as the Rehabilitation Council of India Act, 1992. The main objective of RCI is to regulate and standardize the training of professionals working in the fields of rehabilitation and special education, and to ensure that high-quality services are provided to people with disabilities. Additionally, RCI is responsible for maintaining the central rehabilitation register (CRR) and promoting research in this domain. In its regulatory role, RCI is responsible for standardization of curriculum, research, training and manpower development, recognition of institutions offering various courses on rehabilitation and registration of rehabilitation professionals. The RCI through its recognized institutions offers certificate, diploma, degree and refresher courses in various aspects of rehabilitation.

The main objectives of RCI are:

- To regulate the training policies and programmes in the field of rehabilitation of persons with disabilities
- To bring about standardization of training courses for professionals dealing with persons with disabilities

- To prescribe minimum standards of education and training of various categories of professionals/ personnel dealing with people with disabilities
- To regulate these standards in all training institutions uniformly throughout the country
- To recognize institutions/ organizations/ universities running master's degree/ bachelor's degree/ P.G. Diploma/ Diploma/ Certificate courses in the field of rehabilitation of persons with disabilities
- To recognize degree/diploma/certificate awarded by foreign universities/ institutions on reciprocal basis
- To promote research in Rehabilitation and Special Education
- To maintain Central Rehabilitation Register for registration of professionals/ personnel
- To collect information on a regular basis on education and training in the field of rehabilitation of people with disabilities from institutions in India and abroad
- To encourage continuing education in the field of rehabilitation and special education by way of collaboration with organizations working in the field of disability.
- To recognize Vocational Rehabilitation Centres as manpower development centres
- To register vocational instructors and other personnel working in the Vocational Rehabilitation Centres
- To recognize the national institutes and apex institutions on disability as manpower development centres

To register personnel working in national institutes and apex institutions on disability under the Ministry of Social Justice & Empowerment (Rehabilitation Council of India 2024). GIVE LINK https://rehabcouncil.nic.in/objective accessed 5th June 2024

The Council prescribes minimum standards of education and training for 16 categories of professionals and personnel allocated to RCI

- Audiologists and Speech Therapists
- Clinical Psychologists
- Hearing and Ear Mould Technicians
- Rehabilitation Engineers and Technicians
- Special Teachers for Educating and Training the Handicapped
- Vocational Counsellors, Employment Officers and Placement Officers
- Multi-purpose Rehabilitation Therapists, Technicians
- Speech Pathologists
- Rehabilitation Psychologists
- Rehabilitation Social Workers
- Rehabilitation Practitioners in Mental Retardation
- Orientation and Mobility Specialists
- Community Based Rehabilitation Professionals
- Rehabilitation Counsellors, Administrators
- Prosthetists and Orthotists
- Rehabilitation Workshop Managers

https://rehabcouncil.nic.in/categories-us accessed 5th June 2024

However, professionals like physiotherapists and occupational therapists are not covered under the RCI Act as they are regulated by other paramedical bodies.

It is to be noted that RCI does not offer any direct benefit, financial or material help, to individual persons with disabilities.

BOX 33

THE REHABILITATION COUNCIL OF INIDA IS THE NODAL BODY RESPONSIBLE FOR ALL ASPECTS OF REHABILITATION IN INDIA, INCLUDING RECOGNITION OF REHABILITATION PROFESSIONALS AND INSTITUTIONS, TRAINING AND PEDAGOGY, RESEARCH AND HUMAN RESOURCE DEVELOPMENT IN THE DISABILITY SECTOR. HOWEVER, IT DOES NOT PROVIDE ANY DIRECT BENEFITS TO PERSONS WITH DISABILITIES.

5.2 Barriers to Accessing the Health System by Persons with Disabilities

There are multiple types and levels of challenges people with disabilities facie in accessing the health system (Hashemi et al. 2020; Kuper and Heydt 2019; Srisuppaphon et al. 2016). From the demand side, they are unwilling to voluntarily approach the medical system due to previous unpleasant experiences, perceived rejection by health staff, limited availability of health care facilities especially in far flung geographically difficult terrain (Chiluba and Muke 2019; Dassah et al. 2022; Mwangi et al. 2021), lack of accessible transport, high cost of consultation and treatments. They also have to face informational inaccessibility, attitudinal barriers, high costs poor quality of care (Mitra et al. 2017) On the supply side, there are inaccessible physical infrastructure, inadequate information and knowledge and negative attitudes of health care workers (Hashemi et al. 2020). Systemic gaps in the health system are a major contributing factor to the disability gap; Hashemi et al. 2020; Kuper and Heydt 2019). Lack of laws and policies, absence of collaboration with people with disabilities and their absence in leadership roles, inadequate health financing and lack of routine disaggregated health data contribute to the persistence of accessibility challenges for persons with disabilities.

Accessibility is a general term used to describe the degree to which a product, device, service, or environment is available to be used by all intended audiences. People with disability encounter a range of barriers when they attempt to access health care, such as:

- Physical or Infrastructural Barriers
- Attitudinal Barriers
- Organizational or systemic Barriers

5.2.1 Physical or infrastructural Barriers; Inaccessible Transportation

Perhaps the most straight-forward barrier to consider arises from limited physical access to health care services. From the moment a person with disabilities steps out of the home, she must deal with many obstacles – from coming down or climbing up the stairs at the place of residence to walking on the pavement. Reaching the health care facility is an arduous task in itself due to the absence of affordable accessible public transportation. Indeed, most health services are often located far away from where most people live or in areas not serviced by accessible transport systems. The 'travel chain' refers to all elements that make up a journey, from starting point to destination, including pedestrian access, vehicles, and transfer points. If any link is inaccessible, the entire journey becomes difficult (Maynard 2009). Footpaths for walking are not suitable for wheelchair users or for people using a stick to walk; sidewalks to reach the bus stop or metro station may be encroached upon by hawkers; subways are not disable-friendly as they do not have elevators everywhere; road signage and boards on public transport are not made to cater to the needs of people with disabilities. The public transport system in India does not always provide wheelchair access in buses or railways.

Without sufficient technical and financial resources and user involvement in decision making, the best intentions can do more harm than good. In Kuala Lumpur (Malaysia), for instance, bollards were installed on curb ramps to prevent two-wheel vehicles from accessing the pedestrian pavements. This, however, also blocked access for other users including wheelchair and crutch users and people with prams. Similarly, Indian Railways have provided wheelchair-accessible 'Coaches for the Disabled'. These have adapted seats, manoeuvring space and accessible toilets for people with mobility impairments. However, there is no accessible boarding device to bridge the vertical and horizontal gap between the coach and the platform, eliminating the value gained from having an accessible coach. These are examples of how with the best of intentions, a lack of proper planning can actually lead to more barriers in an attempt to overcome them. The transport accessibility goal is for people with disabilities to have access to all vehicles and the full service area, as well as the pedestrian environment that will enable them to complete their journey to the health care centre seamlessly.

5.2.2 Physical or infrastructural Barriers within Health Facilities

Upon arrival at the health facility, another set of physical barriers have to be surmounted to even enter the premises of the clinic, hospital or testing centre. Some of these barriers are:

- Stairs at the entrance to buildings, absence of ramps, location of health services and activities on floors, which do not have elevator access.
- Inaccessible toilets, doorways and rooms that do not accommodate wheelchair users, or are difficult to navigate for people with other impairments.
- Standard furniture, including examination tables, beds and chairs that can be difficult for people with disabilities to mount or even be placed on.

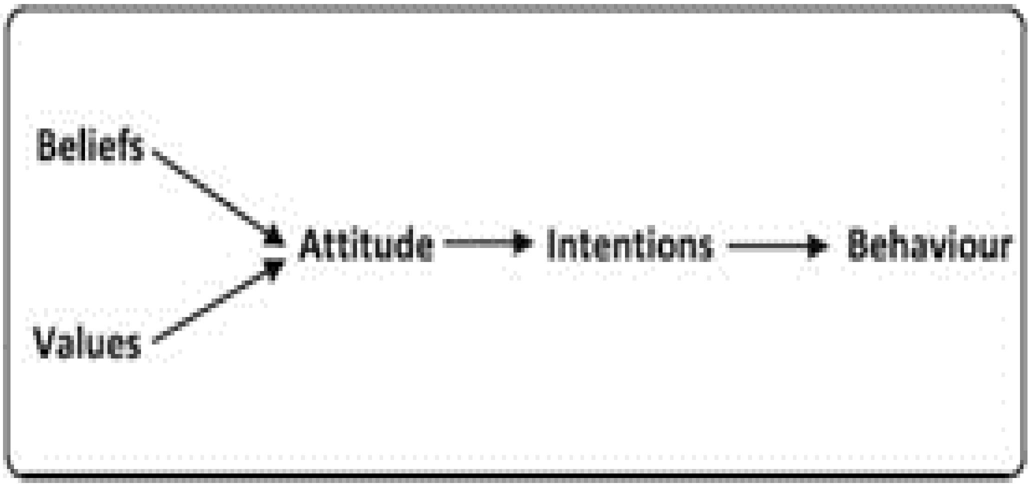
- Door Knobs that are difficult to grasp for a person with arthritis or multiple sclerosis.
- Health facilities are often poorly lit, do not have clear signage, and are laid out in a confusing way that makes it hard for people to find their way around.
- Mammography equipment that requires standing poses a barrier to the examination of women with disabilities who cannot maintain an erect posture.
- Absence of weighing scales that can accommodate wheelchairs or be accessible to persons with other kinds of disabilities.
- Inaccessible medical diagnostic equipment contributes to health disparities among people with disabilities. Indeed, the inability to access basic preventive health care screenings because of inaccessible examination tables and screening equipment can lead to delayed detection of serious health conditions (e.g., breast or prostate cancer) (Pendo 2010).

The above accessibility features are not disability-specific, as persons having other health conditions would greatly benefit by such simple and relatively inexpensive infrastructural modifications making the experiences of all health care users more comfortable.

5.2.3 Attitudinal Barriers

Attitude is defined as the combination of beliefs and feelings held by an individual that predisposes the person to behave in a certain way. It comprises affective, cognitive and behavioural components. Fishbein and Ajzen (1975) describes attitude in the diagram below, which shows the relationship between people’s attitude, knowledge and behaviour.

FIGURE 1



Source: Fishbein and Ajzen 1975

https://www.researchgate.net/publication/233897090_Belief_attitude_intention_and_behaviour_An_introduction_to_theory_and_research

Attitudes are influenced by an individual's experiences combined with positive or negative reinforcements. Although attitudes and behaviour are linked, attitude is only one element as social norms and group pressure also influence individual behaviour. Negative attitudes and behaviour come from people not having adequate knowledge as well as negative social norms and group pressures. Negative attitudes towards people with disabilities, such as being patronising and paternalistic, are the source of many barriers that people with disabilities face (Aguerre et al. 2019; Munthali et al. 2019; Opuku et al. 2017; Vergunst et al. 2015; Yee and Breslin 2010). They relate to stereotyping and prejudice. Many people regard a disability as a tragic shortcoming of an individual, instead of proactively seeing the issue. Being proactive means considering a disability as a social responsibility to proactively accommodate people with disabilities to live productive and fulfilling lives.

Attitudinal barriers are behaviours, perceptions, and assumptions that discriminate against persons with disabilities. These barriers often emerge from a lack of understanding, which can lead people to ignore, judge, or have misconceptions about a person with disabilities. Examples of attitudinal barriers include:

- Assuming a person with disabilities is inferior;
- Stereotyping people with disabilities by assuming their quality of life is poor or that they are unhealthy because of their impairments;
- Perceiving disability as only a personal tragedy, as something that needs to be cured or prevented, as a punishment for wrong-doing, or as an indication of the lack of ability to behave as expected in society;
- Assuming that someone with a speech impairment cannot understand;
- Making a person feel as though a "special favour" is being done for her by providing her some accommodations.

Persons with disabilities face social barriers in health care that hinder their access to services or and prevent them from enjoying their rights to diagnosis and treatment. Stigma and discrimination touch nearly all aspects of the lives of persons with disabilities. They are present at interpersonal and institutional levels, through laws and customs that systematically marginalize them and can prevent them from obtaining and accessing services.

The negative attitudinal barriers have real time consequences on the health of persons with disabilities. Some of these consequences experienced by persons with disabilities in health care settings are given below:

- Most health centres do not have policies in place to accommodate the needs of people with disabilities. Insufficient time is not set aside for medical examination and other procedures in connection with patients with disabilities. Such policies could include allowing longer and flexible appointments, providing outreach services and reducing costs.

- People with disabilities commonly report experiences of overt prejudice, stigma and discrimination by health service providers and other staff at health facilities. This is partly due to the fact most service providers have limited knowledge and understanding of the rights of people with disabilities and their health needs: and have inadequate training and professional development about disability. For instance, neither health professionals nor ppersons with disabilities are well informed about various secondary health problems like hypertension, obesity, cholesterol etc. which the latter might develop because of their disabilities or forced sedentary lifestyle. Thus, these ssecondary health conditions of persons with disabilities are neglected resulting in lack of routine screening for dental health issues, diabetes, reproductive tract infections, and sexually transmitted infections among other health problems.
- Another barrier faced by people with disabilities in the health system is little or no communication with patients by the health care providers due to assumptions of incompetence and stigma. People with disabilities are rarely asked for their opinion or involved in decision-making about the provision of health services to them. Health care professionals are often uncomfortable with the disability and fear such things as autonomic dysreflexia during screening exams. Negative attitudes or preconceptions of health care providers can also mean people with disabilities may be excluded from universal health care programmes, such as sexual and reproductive education, if health care professionals mistakenly assume that they will not need these services.
- Girls and women with disabilities face particular barriers to sexual and reproductive health services and information on menstruation, contraception and abortion. For instance, rehabilitation centres do not prepare girls with disabilities to manage menstruation. They need truthful and complete information about sanitary products to make informed decisions. Health workers often make the inaccurate assumption that these women are non-sexual or are unfit to be

mothers. Such an assumption puts them at higher risk for Human Papilloma Virus (HPV) infection associated with cervical cancer as they are not considered eligible for screening. Due to barriers in obtaining accurate information on choice of contraception, women with disabilities are more likely to use permanent contraception or no contraception at all than the general population of women (Nosek et al. 1998). Then, access to genetic counseling should be a fundamental health right of all persons with disabilities, but there are hardly any genetic counselling centers for them.

- Mental health issues of persons with disabilities get neglected. Iindividuals with disabilities and mental health challenges frequently encounter gaps in the support system. They may seek assistance from a disability-specific health service, only to be denied that due to their mental health condition. Conversely, they might approach a mental health service and face rejection due to their disability status.
- Being victims of stigma and discrimination in a health care setting may discourage people with disabilities and their families from attending health care services altogether, leading to high treatment dropout and exacerbation of illnesses.

BOX 34

PEOPLE WITH DISABILITIES EXPERIENCE PHYSICAL /INFRASTRUCTURAL AND ATTITUDINAL BARRIERS IN ACCESSING HEALTH CARE. PHYSICAL OBSTACLES CONFRONT THEM IN REACHING THE HEALTH CARE FACILITY IN THE FORM OF INACCESSIBLE TRANSPORTATION AND THE BUILT ENVIRONMENT. WITHIN THE HEALTH FACILITY, MORE PHYSICAL BARRIERS HAVE TO BE OVERCOME INCLUDING INACCESSIBLE MEDICAL SPACES AND EQUIPMENT. BUT PERHAPS THE MOST HARMFUL ARE THE ATTITUDINAL BARRIERS THAT THEY FACE IN THEIR INTERACTIONS WITH HEALTH CARE PROVIDERS DUE TO THE LATTER’S LACK OF KNOWLEDGE AND NEGATIVE STEREOTYPES ABOUT PEOPLE WITH DISABILITIES.

Personal Story 4: Confronting Attitudinal Barriers in the Health System

Priya is a 33-year-old married Hindu woman with two children. She has polio in both legs. Although she did not want to get married at the age of 22 years, she succumbed to family pressure and agreed to an arranged marriage. Her husband has polio in one leg. After her marriage, Priya was not treated with love by her mother-in-law who thought she would not be able to do household chores. She had to work hard in order to prove to her mother-in-law that she was a capable homemaker and mother. Recounting an experience of seeking health care, Priya said she had gone to visit a governmental hospital during her pregnancy and found the behaviour of the health care staff to be very objectionable. They addressed her disrespectfully by using the familiar form tu. She was extremely upset by the rude behaviour and did not want to continue visiting the hospital. However, her husband complained to higher authorities at the hospital about the rude behaviour. The next time when she visited the hospital, the medical staff treated her with respect addressing her as "ma'am". When she faced some complications during her second pregnancy, she was taken to the government hospital with high blood pressure and was admitted but refused to give her a bed. They asked her to sit on a chair. She was supposed to be lying down and taking rest but she was sitting on a chair and crying. Her husband complained again to the head of the nursing department, and she was given a bed after that.

This example illustrates that that Priya faced attitudinal barriers by health care providers, who treated her shabbily due to her being a woman with disabilities.

Personal Story 5: Medical Neglect in Health Care

Anjali is a 26-year-old married Hindu woman who suffers from polio. Her husband is also orthopedically disabled. Theirs was a love marriage. Her husband is eight years older than her. They have a son. Her husband belongs to the Scheduled Caste category. Anjali's in-laws wanted a non-disabled bride for their son. As in the case of Priya, they thought that as a woman with disabilities, Anjali would not be able to do household chores. But now that they see her doing all the work, their attitude towards her has been changing. Anjali was taken to a government hospital in Delhi for her delivery. She had fever and was admitted to the hospital due to pregnancy-related complications. However, she did not receive any attention from the medical staff for one whole day. She was made to lie on a bed and nobody came to check on her fever. She had not eaten anything the whole day either. In the evening, she told her husband about the situation. He called some acquaintances from their neighbourhood and demanded the hospital authorities to give them permission to shift her to another hospital for better care. However, the hospital authorities did not agree to this initially, and after much altercations, they finally gave in to the demand. The family took her to another government hospital. According to Anjali, the behaviour of doctors there was very good but the nurses were rude.

Apart from the lack of medical attention upon admission, both Priya and Anjali reiterated their displeasure at the negative and disrespectful behaviour of the health staff in the government hospitals.

5.2.4 Organizational or Systemic Barriers

Organisational or systemic barriers refer to lack of awareness on the part of stakeholders like administrators and/or health care providers of implementation of existing laws and regulations for people with disabilities. Zuurmond et al. (2019) has documented the system-level factors imposing barriers to access health services for people with disabilities, such as the limited availability of specialist health and rehabilitation services, assistive devices, physiotherapy, and the weakness of referral systems and coordination of care.

The first systemic challenge is being able to adequately identifying people with disabilities. The algorithm for prioritizing registrants for triage does not flag those with disabilities, even though they often have many complex health needs. They may 'fall through the cracks in the system'. The staff governing the regular intake checklists are not necessarily health professionals, and so perhaps do not pick up the subtle nuances or interpret the patients' needs.

Examples of such organisational or systemic barriers directly connected with institutional governance include:

- Eligible persons with disabilities are denied the opportunity to participate in or benefit from legally available services. For instance, every person with a benchmark disability is entitled to obtain a disability certificate in India, which will enable her to access other benefits and services like reservation in education and employment. This document can only be provided by a pre-designated government health facility after a medical evaluation. However, the process of obtaining such an important document is very arduous for people with disabilities and their families, as it involves multiple visits. Then, the validity of the certificate is not only time0bound but varies across states and regions within the country.
- Lack of sensitisation, supervisor and monitoring of health staff in their interactions with patients with disabilities to ensure that all

available services are accessible and reasonable accommodations are being provided to them, so that they receive optimum medical care.

There are several challenges related to the implementation and enforcement of pro-disability policy and legislation including in the health sector. At the centre of lack of enforcement is wide-spread lack of awareness and training on disability issues among professionals of existing laws and policies focussing on the rights of people with disabilities. This implementation gap is illustrated by inaccessible services and infrastructures. At a structural level, one of the most important barriers is the lack of disability data collection and monitoring of service delivery (Mac-Seing et al. 2022).

Thus policy, programme development and implementation lack a disability perspective resulting in the neglect of this critical group of users. The way to overcome such systemic obstacles is to ensure involvement of people with disabilities right from conceptualisation of policies and programmes to their implementation, monitoring and evaluation.

BOX 35

THERE ARE MANY SYSTEMIC AND ORGANISATIONAL BARRIERS LARGELY DUE TO LACK OF DISABILITY KNOWLEDGE AND COMPETENCIES AMONG HEALTH STAFF

5.2.5 Informational, Communication and Technological Barriers

Attitudinal barriers contribute to information and communication barriers. The pre-conceived notions of health care providers often lead to little or no communication with patients with disabilities. A study with deaf people indicated negative attitudes were a result of frustration, as health care staff and deaf people were not able to communicate with each other, since staff did not give deaf people enough time to explain their situation (Pereira and Fortes 2010). Communication barriers further intensified for this group during the covid 19 pandemic due to face masks that hinder lip reading and lack of sign language interpreters (Naylor et al. 2020). Other studies mention that health care providers would ignore patients with disabilities and give priority to other patients in anticipation of communication problems (Kritzinger et al. 2014; Mprah 2013). People with intellectual, sensory or communication impairments may require adjustments in the way information is given and received in the health care system. Some examples of barriers to communication faced by people with disabilities using health care services are as follows:

Absence of Health information in accessible formats: Limited availability of written material or sign language interpreters in health care settings for people with hearing disabilities. Auditory health messages may be inaccessible to people with hearing impairments, including videos that do not include captioning, and oral communications without accompanying Handbook interpretation. Absence of health information in large print, Braille or in electronic documents that are not properly formatted and cannot be read by a screen reader pose communication barrier for persons with visual impairments.

Presentation of Health Information using a lot of Medical Jargon. The use of technical language, long sentences, and words with many syllables may be significant barriers to understanding for people with cognitive impairments. Making health information available in easy-to-follow formats – including plain language and pictures or other visual cues – can make it easier for all people.

Challenges of the Digital Space for Persons with Disabilities. Digital technologies can break down traditional barriers to communication and information. The acceleration of digitisation during the pandemic poses significant challenges for persons with disabilities. Evidence suggests that the level of use of information and communications technology (ICT) by persons with disabilities is significantly lower than among persons without a disability. In some cases, they may be unable to obtain access to even basic products and services, such as telephones, television and the Internet (The World Bank 2022).

Accessible ICT has three distinct features: accessible design, availability and affordability. The starting point is content; the information itself needs to be accessible, understandable and useful. If a person does not understand the system, or what they are being told, for whatever reason, it makes that service inaccessible, irrespective of her abilities or capabilities. However, the issue can be that much worse for people with disabilities. A survey commissioned by the Zimbabwe Parents of Handicapped Children's Association found that people with hearing and visual impairments were excluded from general HIV and AIDS services, as counselling and testing were not offered in sign language and educational and communication materials were not offered in Braille (Hanass-Hancock 2009). Just having the infrastructure will not fix the problem; many places, including the UK, provide the facilities to enable communication with people with disabilities, but it is unused as the core issue behind communication has not been addressed. Communication is not achieved unless the recipient has understood the message. The delivery of the message should be the basis for any decision when considering technological solutions to communication. In many cases, the most important component is the patience and empathy of the person providing the information. The National Accessibility Portal initiative of South Africa was a state project to address the needs of approximately 4 million persons with disabilities, where less than one percent is economically independent. It recognised that effective communication and access to information and services empower people with disabilities, using innovative, cost-effective and appropriate ICT-based technologies for support. It aimed to empower and uplift them economically to enable them to play a full, participatory role in society. The portal served as a one-stop shop for information, services and communications for people with disabilities, caregivers, the medical profession, and others providing disability services. The research and development phase of the Portal was completed in March 2009, but was then closed down due to a lack of funding (Agarwal and Steele 2016). Communication, Information and Technological (ICT) barriers are interlinked. Technology can enhance the user experience, but it can also create unintentional barriers for some users. Technology barriers occur when a device or technological platform is not accessible to its intended audience and cannot be used with an assistive device.

BOX 36

ICT CAN BE A MAJOR FACILITATING FACTOR FOR ENHANCING THE USER EXPERIENCES OF PATIENTS WITH DISABILITIES IN HEALTH CARE

5.3 Myths and Misconceptions about Patients with Disabilities in the Health System

Everybody's fighting some kind of stereotype, and people with disabilities are no exception. The difference is that the barriers people with disabilities face begin with people's attitudes — attitudes often rooted in misinformation and misunderstandings about what it's like to live with a disability. Some of these misconceptions with implications for health care are highlighted below:

Myth 1: All persons who use wheelchairs are chronically ill or sick.

Fact: The association between wheelchair use and illness may have evolved through hospitals using wheelchairs to transport sick people. A person may use a wheelchair for a variety of reasons, none of which may have anything to do with lingering illness.

Myth 2: Wheelchair use is confining; people who use wheelchairs are 'wheelchair-bound'.

Fact: A wheelchair, like a bicycle or an automobile, is a personal assistive device that enables someone to get around.

Myth 3: Accessible toilets are just for wheelchair users.

Fact: People who don't use wheelchairs might need accessible toilets for various reasons. For example, they could have a colostomy bag (where bowel motions are collected in a disposable bag) and need the extra space and running water. Elderly patients having bodily stiffness balancing problems may need to use handrails.

Myth 4: All persons with hearing disabilities can read lips.

Fact: Lip-reading skills vary among people who use them and are never entirely reliable.

Myth 5: People who are blind acquire a 'sixth sense'.

Fact: Although most people who are blind develop their remaining senses more fully, they do not have a 'sixth sense'.

Myth 6: People with disabilities are a one-dimensional group.

Fact: People with disabilities reflect the same diversity that exists in the rest of society, including varying social, economic, cultural, family and educational characteristics. The viewpoints expressed by an individual with disabilities are not representative of those of all people with disabilities.

Myth 7: The lives of people with disabilities are totally different than the lives of people without disabilities.

Fact: People with disabilities go to school, get married, work, have families, do laundry, grocery shop, laugh, cry, pay taxes, get angry, have prejudices, vote, plan and dream like everyone else.

Myth 8: People with disabilities cannot understand or need not be provided information about their own body.

Fact: Everyone, irrespective of their disability or any other discriminating factor, has a right to information about their own body.

Myth 9: Parents or relatives of people with disabilities can make decisions for people with disabilities with respect to the kind of medical treatment they should get.

Fact: People with disabilities should have autonomy over their own body and right to make decisions about the same.

Myth 10: People with disabilities are non-sexual.

Fact: Like everyone else, people with disabilities can be sexual or non-sexual and can have any sexual orientation.

Myth 11: Most people with disabilities cannot have sexual relationships.

Fact: Anyone can have a sexual relationship by participating in sexual activity. People with disabilities can have children naturally or through adoption. People with disabilities, like other people, are sexual beings.

Myth 12: Women with disabilities cannot get pregnant or give birth.

Fact: Like other women, women with disabilities can get pregnant and give birth.

Myth 13: Women with disabilities, who have one child, should not try for more children as it is risky.

Fact: Women with disabilities can have as many children as they want; and the risk should be assessed by a doctor based on the capabilities and conditions of the body and not on the disability.

Myth 14: Women with disabilities do not require sexual health screening exams.

Fact: Women with disabilities are equally at risk of contracting sexually transmitted diseases and require the same screenings and exams at the same intervals as everyone else.

Myth 15: People with disabilities always need help.

Fact: Many people with disabilities are independent and capable of giving help. If you would like to help someone with a disability, ask if she needs it before you act.

Myth 16: There is nothing one person can do to help eliminate the barriers confronting people with disabilities.

Fact: Everyone can contribute to creating a barrier-free world.

(Dyess Air Force Base, https://www.dyess.af.mil/Fact-Sheets/Display/Article/267598/myths-and-facts/

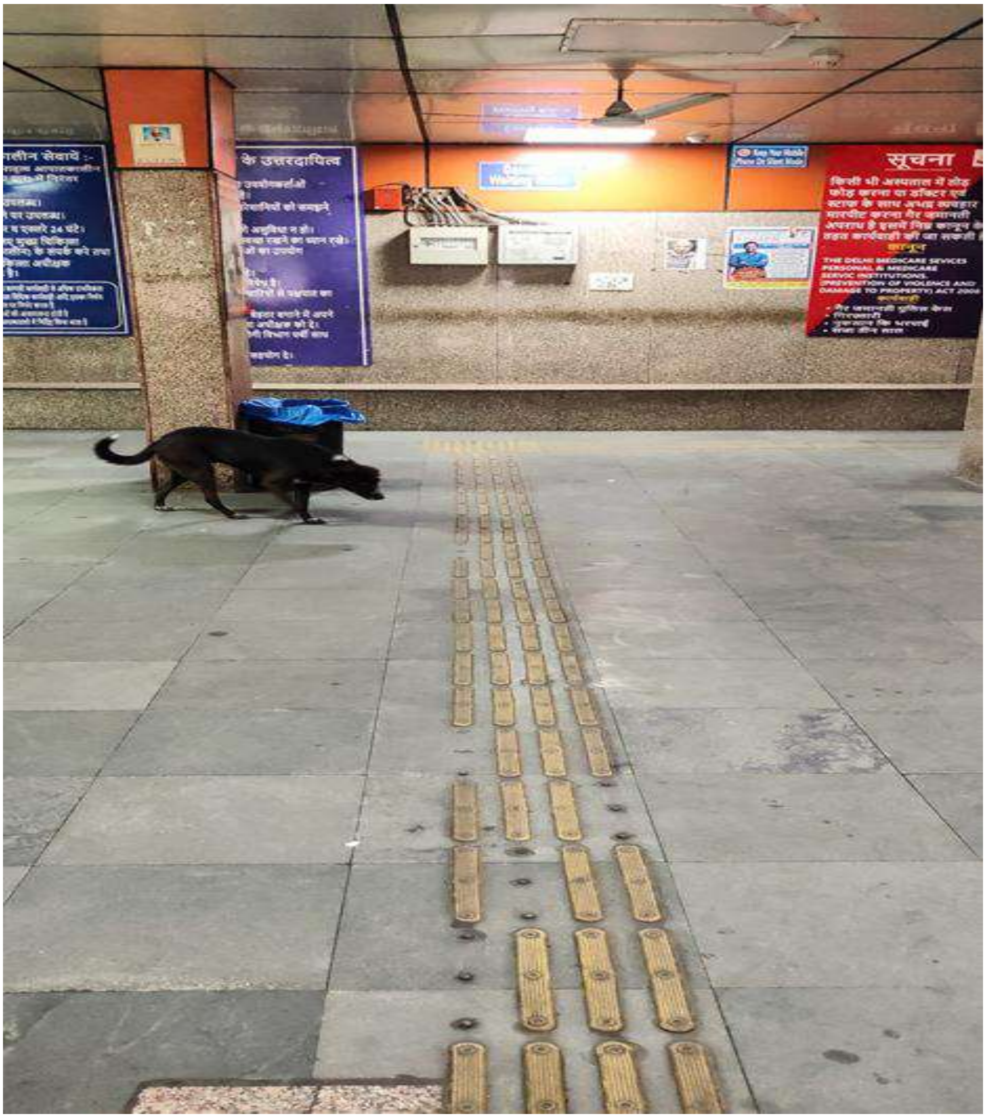
Photo No. 3

Verandah connecting Outpatient Department Corridors in a Public Hospital in East Delhi

Photo No. 4

Accessible-Cum-Transgender Toilet in a Public Hospital in South Delhi

Photo No. 5



Tactile Paving in the Outpatient Department of a Public Hospital in North Delhi

Photo No. 6

Accessible Parking outside a Public Hospital in South Delhi

Photo No. 7

Inaccessible Outpatient Counter for People with Disabilities in a Public Hospital in East Delhi

QUESTIONS FOR REFLECTION AND DISCUSSION

- ✓ *Discuss the status of rehabilitation medicine within clinical practice, particularly its limitations in delivery of optimum care for persons with disabilities.*

- ✓ *What, according to you, are the main barriers experienced by patients in your practice area?*

- ✓ *How can your organisation overcome the barriers you have cited above?*

- ✓ *Can you give other myths and misconceptions about disability and people with disabilities apart from the ones given in this Module?*

6. COMMUNICATION BARRIERS FOR PATIENTS WITH DISABILITIES AND THEIR HEALTH CARE PROVIDERS

Objectives

After this module, you will be able to:

- *Understand the Multiple Barriers Faced by Patients with Disabilities in Communicating with Health Care Providers*

- *Understand the Barriers Faced by Health Care Staff in Communicating with Patients with Disabilities*

6. 1 Communication Barriers in the Provider-User Relationship

As already, mentioned people with disabilities need to engage with the health care system due to their impairments and other health issues at different points in their lives. Even though the medical model is the basis for defining and managing impairments and disabilities, yet the health care system is often neither competent nor sensitive to the specific needs of such patients. In the preceding module, we looked at some of the major barriers encountered by patients with disabilities as they access the health system. Lack of communication and miscommunication are major obstacles in the provider-user relationship, which require a particular focus in the context of this Handbook. Therefore, in this Module we will examine this web of communication from both sides, namely the communication barriers that persons with disabilities experience in the health system as also the barriers faced by health care providers in their engagement with people with disabilities.

BOX 37

PATIENTS WITH DISABILITIES AND HEALTH PROFESSIONALS BOTH CONFRONT BARRIERS IN COMMUNICATION IN HEALTH SETTINGS

6.1.1 Physical Barriers in Clinical Communication

The physical environment is an important barrier obstructing effective communication between health workers and people with disabilities. For example, noisy spaces like crowded outpatient departments can make it difficult for people with hearing impairment, aphasia and cognitive communication impairments to communicate with health care providers and vice versa. The relative absence of separate consulting rooms acts as an obstacle in clinical communication. Other institutional factors, such as complex administrative procedures, long queues, and extended waiting periods can also be hindrances in effective communication between health care workers and people with disabilities. For example, complicated registration formalities, location of various examination procedures in different parts of the hospital complex, lack of adequate staff to guide patients and their families etc. are stressful for patients with disabilities. Of course, funding to make health facilities more affordable to persons with disabilities, particularly in connection with providing them assistive aids and appliances, is a major barrier.

6.1.2 Lack of Medical Information in Accessible Formats

Health care settings do not provide important information in formats accessible to people with different kinds of disabilities. For example, audio signage is not available for visually impaired patients nor are there sign language interpretation facilities for people with hearing and speech impairments. Furthermore, prescription labels and other important medical information is more often than not handwritten and/or in very small print, which is not legible even to a majority of non-disabled persons. The inability of the health care system to provide such basic reasonable accommodation is a serious concern, which needs to be addressed on a priority bases (Ali et al. 2013; O'Halloran et al. 2015). This does not only result in difficulties for communication with and by patients with disabilities, but it may also adversely affect diagnosis and treatment. For example, if the doctor's instructions are not available in an accessible form to the patients, it is likely to adversely affect the treatment process.

6.1.3 Obstacles in Doctor-Patient Interaction: Perceptions, Attitudes and Assumptions

Health care providers often lack the understanding of how to communicate with people with disabilities, and they may also lack the required skills on deciding what information and how much should be given to people with different disabilities (Mencap 2018; O'Halloran et al.

2015; Salvador-Carulla and Saxena 2009). Sometimes, even family members emerge as a barrier to communication by health care providers as they are seen to be speaking on behalf of patients with disabilities; yet health care providers also tend to rely more on family members to provide information on the patients with disabilities because they lack the skills to communicate directly with them.

Doctors and other health professionals carry the same misconceptions and assumptions about disability as other members of society, which stem from the underlying stigma and discrimination towards this group. Such assumptions and negative attitudes may be detrimental and life-threatening (Shakespeare et al. 2009). For instance, not testing women with disabilities for human papilloma virus (HPV), and hence making the HPV vaccine unavailable to this population group under the false assumption that people with disabilities do not have a sexual life shows how the health system can do harm to persons with disabilities. Persons with disabilities are often ignored in the clinical context (Becker et al. 1997). They may have trouble expressing themselves clearly and coherently because of the nature of the impairment (Muskat et al. 2014). Therefore, health providers may actively avoid engaging certain categories of patients like those with psychosocial disabilities or prefer communicating with the family and caregivers. People with disabilities reported being ignored (Ali et al. 2013), treated harshly and even regarded as 'less than human' (Schneider et al. 2004). Schneider et al. (2004), in fact, found that people living with schizophrenia were not treated more as non-persons. Diagnosis and treatment are often discussed, side-lining the patient with disabilities altogether (Ali et al. 2013; O'Halloran et al. 2015; Ward et al. 2010; Ziviani et al. 2004). Often health care workers communicate with people with disabilities in a derogatory manner, suggesting that they do not respect them nor take seriously the questions and information that the latter put forward. This attitude of the health care providers makes people with disabilities feel uncared for and unsupported (O'Halloran 2015). This is a violation of informed consent and other medical ethics principle (Ali et al. 2013).

Lack of knowledge/awareness and sensitivity on disability issues, ignoring the views of people with disabilities and infantilizing such patients may contribute to misdiagnosis and faulty treatment. Lack of compliance with the treatment plan and absence of trust of the patients with disabilities may lead to poor follow-up and adverse treatment outcomes (Lennox and Chaplin 1997).

6.1.4 Time Constraints in Effective Clinical Communication

Time, as a constraint to effective communication about complex medical problems, has been identified as a significant variable (Bachman et al. 2006; Kirschner and Curry 2009; Yee, 2011). Extra time is required for history-taking and examination for patients with disabilities because understanding and obtaining information from such patients is a more drawn out process (Lennox et al. 1997). For instance, patients with multiple sclerosis have reported on the neglectful role of health care providers towards them as they were always in a hurry and were inattentive to their needs (Kroll et al. 2006; Morrison et al. 2008). If the consultation is rushed, the patients' medical history will be unclear and the consequent quality of health care poor.

Time constrain is a general problem in the health system, particularly in the public sector which has more adverse impact on patients with disabilities. Shortage of health care staff, such as doctors and nurses, results in long waiting periods. This can further discourage people with disabilities from accessing health care services (Tesfaye et al. 2021). Research has documented insufficient time in the medical consultation as a barrier in making informed decisions (Bradbury-Jones et al. 2015; Malouf et al. 2017). Additionally, tight working hours is one of the reasons cited by health care providers that hinders hands-on training on disability in clinical communication (Murphy 2006). From the patients' sides, long waiting periods to secure medical appointments (daSilva et al. 2022; Voillemont et al. 2022) and short consultation times (McBain et al. 2016) further compromises the quality of health delivered and received by users.

6.1.5 Absence of Capacity Building on Disability in the Medical Curriculum

Medical training fails to provide adequate information on disability in general and how to relate to people with disabilities in clinical work. Medicalising disability without looking at health in a holistic manner may adversely affect the work of clinical diagnosis and treatment. Furthermore, not having a structured approach to developing the quality of empathy in medical practitioners may also result in the violation of the human rights of people with disabilities. The virtual absence of peers living with disabilities in medical schools is another barrier to developing the understanding of and skills to relate to patients with disabilities.

For instance, many health care providers have limited understanding of communication needs and preferences of individuals with hearing disabilities, and tend to make erroneous assumptions about lip-reading, the efficacy of written notes and the literacy skills required in health settings. Another difficulty is the health care providers' inability to appropriately modify communication practices, such as the tendency to speak too fast, asking multiple questions without waiting for or not attentively listening to patients' responses, giving too much information, and not allowing enough time for people with disabilities to absorb the information particularly with regard to medication and other medical instructions. Difficulties in communication for such patients may include lack of understanding and/or lack of confidence to ask questions and voice their concerns. There are incidents of health staff being rude, insensitive, behaving in an unfriendly manner and using an unwelcoming tone or appearing uninterested (Ali et al. 2013; Becker et al. 1997; Reeves and Kokoruwe 2005; Schneider et el. 2004). Health care providers are not provided training on how to figure out the communication needs of persons with disabilities like initiating the communication process, speaking slowly, cultivating an open attitude etc. (Becker et al. 1997; Warfield et al. 2015).

Lack of up-to-date knowledge about disability (Flynn et al. 2016), lack of skills of working with people with disabilities that should be inculcated during medical training and residency have a direct impact on communication with patients with disabilities (McColl et al. 2008; Warfield et al. 2015). Furthermore, medical training does not provide health care providers with information about assistive technologies that could be helpful for patients with disabilities in the interaction between their impairments and other health conditions (Bowers et al. 1996).

It can be seen from the above that in the medical curriculum, disability education has received less attention. Medical schools are supposed to produce doctors who are knowledgeable about the needs of patients with disabilities, yet only very few medical schools across the world provide formal content about disability, thus depriving a broad cross section of medical students with the knowledge and skills to understand and effectively treat patients with disabilities. In order to achieve better health outcomes for such patients, doctors need to be equipped with comprehensive medical school curricula about disability. Prior to 2019, medical curriculum provided by the Medical Council of India (MCI) treated disability as a purely medical issue firmly grounded in the medical model. Even the new competency-based medical education curriculum implemented by the Medical Council of India in August 2019 is overly reliant on the medical model of disability and does not involve all the stakeholders. The revised medical curricula is an outcome-based approach to medical education which strives to cultivate proficiency through training learners for assessing them with regard to the acquisition of observable abilities and attributes that are essential to effective health care delivery. Competences are the abilities and attributes that are crucial to effective health care delivery. Disability competencies, refer to the skills and the attributes necessary for providing quality health care to patients with disabilities. https://www.nmc.org.in/information-desk/for-colleges/ug-curriculum/

BOX 38

SOME OF THE IMPEDIMENTS WHICH BOTH USERS WITH DISABILITIES AND PROVIDERS HAVE TO DEAL WITH ARE ABSENCE OF DISABILITY ISSUES IN THE MEDICAL CURRICULUM, ABSENCE OF MEDICAL INFORMATION IN ACCESSIBLE FORMATS AND BOTTLENECKS IN PATIENT PROVIDER-INTERACTION

QUESTIONS FOR REFLECTION AND DISCUSSION

- ✓ *Discuss the communication barriers you have experienced when engaging with patients with disabilities, and how you overcame them.*
- ✓ *What role can organisations like hospitals play in overcoming the communication barriers between service providers and patients with disabilities?*

7. CREATING A DISABILITY INCLUSIVE HEALTH SYSTEM

Objectives

After this module, you will be able to:

- *Understanding the Meaning of Inclusion with Respect to Disability and the Health Sector*
- *Understand how Medical Pedagogy can help in Overcoming Provider-Based Barriers to the Creation of a Disability-Inclusive Health System.*
- *Learn how to Overcome Physical and Infrastructure Barriers*
- *Learn how to Overcome Attitudinal Barriers*
- *Learn how to Overcome Communication Barriers*

7.1 Disability Inclusive Health System

Article 1 of the Convention on the Rights of Persons with Disabilities requires States to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, which includes their right to health, and to promote respect for their inherent dignity. As we have already seen, people with disabilities like everyone else have to engage with the health system in the course of their lives for both-disability-related and other health issues. In the course of this engagement with different types of health providers and institutions, they face many barriers, which have been highlighted in this Handbook. The concluding module focusses on what can be done to overcome the multiple barriers (physical/infrastructural, attitudinal, organisational/systemic and informational, /communication) to make the health system in general and health care providers in particular be more responsive to the needs of people with disabilities.

Disability inclusion in the health system involves

- Providing fair and equal treatment to all users
- Eradicating the belief that people with disabilities are unhealthy or less capable of doing things (stigma, stereotypes).
- Making products, communication, and the physical environment more usable by as many people as possible (universal design); and
- Modifying items, procedures, or systems to enable a person with a disability to use them to the maximum extent possible (reasonable accommodations).
- Incorporating disability competence in medical pedagogy

In keeping with the slogan "nothing about us-without us" of the disability rights movement, disability inclusion primarily involves the active participation of people with disabilities and their organizations in programme planning and design, implementation, monitoring, and evaluation. Until that utopia is reached, some concrete measures can be undertaken to overcome the barriers faced by people with disabilities in the health system are discussed in the following paragraphs.

Box 38

THE HALLMARIKS OF A DISABILITY INCLUSIVE HEALTH SYSTEM ARE OVERCOMING BARRIERS TO GUARANTEE ACCESSIBILITY, UNIVERSAL DESIGN, REASONABLE ACCOMMODATION, AND INVOLVEMENT OF PERSONS WITH DISABILITIES IN DECISION-MAKING

7.2 Recommendations for a Disability Inclusive Health Ecosystem

LEGAL PROVISION OF UNIVERSAL HEALTH CARE FOR PERSONS WITH DISABILITY

A comprehensive approach towards facilitating a disabled-friendly health ecosystem requires social, economic, legal and policy mandates and incentives going beyond the health system. For instance, there should be enactment of a comprehensive legislation relating to the right of persons with disabilities to accessible and non-discriminatory health care in conformity with Article 25 of the United Convention on the Rights of Persons with Disabilities. This should be translated into universal availability of schemes and programmes devised to realize health care rights, entitlements and benefits to all persons with disabilities with due consideration accorded to gender, age and socio-economic status in intersection with disability. Domiciliary services should be made available wherever required to attain universal coverage. One of the ongoing demands of the disability rights movement has been provision of medical and life insurance to persons with disabilities in the public and private sectors on an equal basis with others.

UNIVERSAL ACCESSIBILITY OF THE HEALTH SYSTEM

Health care facilities should be accessible to people with disabilities through availability of accessible transport. Within health care settings, there should be an accessible environment through accessible procedures and equipment with reasonable accommodation for all persons with disabilities. Accessibility in the built environment should be complemented by a disability-sensitive and proactive health care workforce that has disability competencies to interact with and treat patients with different disabilities belonging to different socio-economic, ethnic and caste groups. Disability-friendly ethical guidelines should be framed to guarantee confidentiality and informed consent, enable autonomous decision making and ensure beneficence for persons with disabilities.

DIABILITY-COMPETENCIES IN MEDICAL EDUCATION

In India, for the first time the medical curriculum was updated in 2019 by incorporating a component on disability rights and the dignity of people with disabilities at the undergraduate level with a view to creating-0isability sensitivity among medical students. This is an outcome- based approach to medical education which strives to ensure proficiency through training learners for the acquisition of observable abilities and attributes that are essential to effective health care delivery. More than 550 medical schools in India follow this new medical curriculum. The aim is to ensure that doctors understand disability as per the United Nations Convention on the Rights of Persons with Disabilities, and respect diversity among the community of people with disabilities. They should also be familiar with India's Rights of Persons with Disabilities Act, 2016. In addition to a short orientation on the disability concept through a lecture, disability etiquette and cultivating a non-discriminatory attitude to people with disabilities and their caregivers will be inculcated through use of patient narratives, case histories and clinical profiles. Through this, medical students would develop the competence (skills and attributes) essential to provide quality health care to patients with disabilities.

Since this curriculum still appears to be heavily influenced by the medical model and focuses mainly on the prevention and management Implying that what people with disabilities need is the cure, doctors with disabilities[27]s disability rights activists, and health educators came together to develop a framework of 27 disability competencies for health professions that based on the lived experiences of people with disabilities, human rights and on social accountability (Singh et al. 2020). A revision of the competency-based medical curriculum by a group of disability rights activists, patients with disabilities and other critical stakeholders would contribute to overcoming any deficiencies in existing medical pedagogy.

PROMOTE USE OF AND RESEARCH ON ASSISTIVE/ADAPTIVE TECHNOLOGIES IN THE HEALTH SYSTEM

Technological advancement, particularly in the areas of assistive and adaptive technologies, can contribute hugely to a disabled-friendly health ecosystem. Scientific research and development should be encouraged by providing funding to develop innovative, cost-effective and appropriate technologies to support people with disabilities. Stephen Hawking was one of the most prominent people in history to use a high-tech communication aid known as augmentative and alternative communication (AAC)[28]. With his recognizable wheelchair and computer-generated voice, he demonstrated the value of technological solutions in liberating the voice of those with physical and communication disabilities. However, such technologies need to be made cost-effective before they can be available for wider use.

---

[27] It may be noted that the Medical Council off India bars those with 80% locomotor disability from even attempting the MBBS exam,

[28] AAC is a set of tools and strategies that an individual uses to solve every day communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices, etc. Everyone uses multiple forms of communication, based upon the context and our communication partner. Effective communication occurs when the intent and meaning of one individual is understood by another person. The form is less important than the successful understanding of the message.

Image 1: Adjustable Height Examination Table

https://chaoyangmedical.en.made-in-china.com/product/yZmfDIxuHtkO/China-Hospital-Medical-Clinic-Patient-Electric-Adjustable-Examination-Table-Examination-Bed.html

Image 2: Wheelchair Accessible Scales

https://www.detecto.com/product/product-category/WheelChair-Scales

Image 3: Height Adjustable Mammography Chair

https://heltisdiffusion.com/en/mammography-tables-and-chairs/12247-mobile-height-adjustable-mammography-chair

Image 4: Hospital Bed with Commode

https://www.flipkart.com/furniture/furniture-accessories/hospital-beds/pr?sid=wwe,q7b,i7g

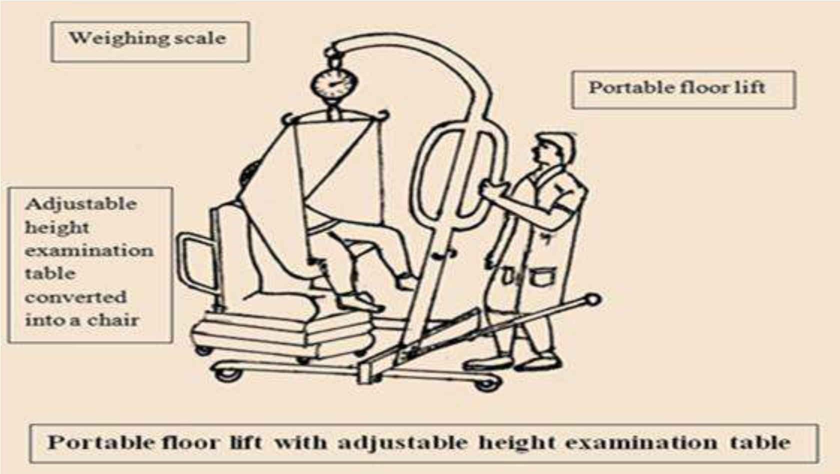
Image 5: Adjustable Gynaecological Examination Tables with Padded Leg Supports

https://www.medicalexpo.com/prod/jiangsu-saikang-medical-equipment/product-76520-998041.html

Image 6: Hoyer Lift

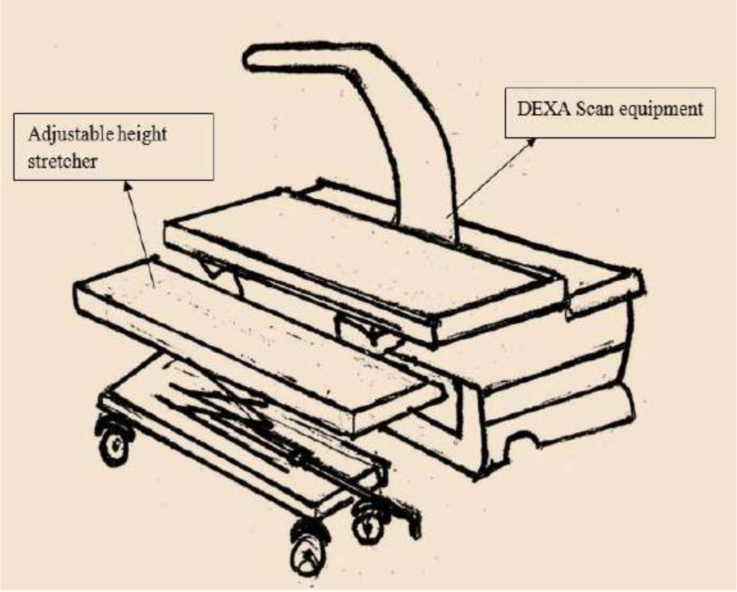
https://www.hoyerlift.com/

Image 7: Portable Floor Lift



https://vikaspedia.in/health/health-campaigns/accessibility-standards-for-healthcare/accessible-medical-equipment-and-furniture

Image 8: Adjustable Height Stretcher for Radiological Examination



https://vikaspedia.in/health/health-campaigns/accessibility-standards-for-healthcare/accessible-medical-equipment-and-furniture

Image 9: Bathing Aids

https://callbeforeyoufall.com/aids-for-getting-in-and-out-of-the-bath/

Image 10: Grab bars

https://callbeforeyoufall.com/aids-for-getting-in-and-out-of-the-bath/

Image 11: Bath Tub Transfer Chairs

https://homeability.com/bathtub-transfer-chairs-lifts-benches/

Image 12: Sliding Bath Tub Chairs with wheels

https://homeability.com/bathtub-transfer-chairs-lifts-benches/

Image 13: Commode Transport Chair with wheels and Padded Seat

https://www.amazon.in/Rolling-Transport-Handicap-Disabled-Capacity/dp/B08C513GXW

Image 14: Toilet Frame

https://www.ubuy.co.in/product/4NV3ZQ-oasisspace-stand-alone-toilet-safety-rail-heavy-duty-medical-toilet-safety-frame-for-elderly-handicap-and-disabled-adjustable-bathroom-toilet-handrail

Image 15: Walking frame

https://www.amazon.in/Dyna-Rehaid-Walking-Frame-Wheels/dp/B01CVA1HBC

Image 16: Gurneys or Wheeled Stretcher

https://www.medik-medical.com/ambulance-stretchers/gurney-ambulance-stretcher.html

Image 17: Bed Levers

https://multifit.co.nz/wp-content/uploads/2018/06/bed-Lever-2.jpg

INVOLVEMENT OF PEOPLE WITH DISABILITIES AT ALL LEVELS TO PROMOTE DISABILITY INCLUSION

“Nothing about us, without us”, a slogan of the disability rights movement, should also inform solutions to improve health care accessibility (Lord et al. 2010). Instead of imposing well-meaning ideas upon persons with disabilities or inviting them to the table as an after-thought, solutions should be developed together with them (*ibid.*). This demonstrates respect for the lived experiences of persons with disabilities as experts in navigating a world that was not designed with them in mind (Lewis 2019). There should be involvement of persons with disabilities at all levels to ensure that the principal stakeholders have a role in all matters relating to them. For instance, medical students should have designed exposure to patients with disabilities, and there should be ongoing mentorship of practitioners by experts with disabilities, so that patients with disabilities are treated according to the highest standards of health care. Becker et al. (1997) in their qualitative study on reproductive health care experiences of women with physical disabilities suggested that disability awareness training for health care providers be conducted involving women with disabilities, so that providers become sensitive to issues from their lived reality. Providers need to be prepared to spend more time with these patients, establishing rapport, providing information and individualizing care to their special needs, and giving the women-- particularly those who experience spasticity--more time to relax before initiating the physical examination. Providers must also recognize that many women with disabilities bring to the examination a history of negative health care experiences. One woman their study stated, "I had a lot of operations growing up .... I was always being poked and prodded so that really brought a whole lot of baggage into any kind of exam, like a pelvic, because it's so like being prodded." Since positioning during a pelvic examination is difficult for many women with physical disabilities, providers should be prepared to help them find positions that are most comfortable for (*ibid.*).

Improvement in knowledge about specific disabilities among health care providers should be undertaken, for example, in mandatory training on intellectual disability during undergraduate and postgraduate training (Ali et al. 2013; Muskat et al. 2014). Competence training in caring for patients with disabilities through professional development opportunities is of huge significance (Lee et al. 2023; Muskat et al. 2014). Additionally, cultural competency training on how to interact with people with disabilities need, to be offered in medical and nursing schools, or in "continuing medical education" programmes (Crossley 2015). Collaboration between medical professionals and the disability movement can be productive. For example, doctors could be encouraged to collaborate with members of the Deaf community to develop mobile apps and toolkits. Basic sign language classes can also be offered during these sessions. Another example is, facilitating access to audio and visual information in health care settings for the Deaf and blind (Chua 2019). Evidence-based curricula, protocols and other resources need to be developed medical sign language interpretation (ibid.).

BOX 39

RECOMMEDNDATIONS FOR A DISABILITY INCLUSIVE ECOSYSTEM

ACCESSIBLE TRANSPORT TO REACH THE HEALTH SYSTEM

ACCESSIBLE BUILT ENVIRONMENT AND INFRASTRCTURE OF HEALTH CARE BUILDINGS

DISABILITY-ACCOMMODATIVE MEDICAL EQUIPMENT AND PROCEDURES FOR DIAGNOSIS AND TREATMENT

DISABILITY SPECIFIC DIAGNOSTIC PROCEDURES LIKE PHYSICAL ASSESSMENT SKILLS

PSYCHOSOCIAL CARE AND SUPPORT TO PATIENTS WITH DISABILITIES AT EVERY STAGE OF THE MEDICAL PROCESS BE IT INVESTIGATION, EVALUATION, DIAGNOSIS, TREATMENT, INTERVENTION AND FOLLOWUP

GENERIC AND JOB-SPECIFIC DISABILITY SENSITISATION AND TRAINING OF DIFFERENT CATEGORIES OF HEALTH PERSONNEL INCLUDING DOCTORS, NURSES, LABORATORY STAFF, HOSPITAL ADMINISTRATORS ETC.

PROVISION FOR APPOINTMENT OF DISABILITY LIASON OFFICERS TO GUIDE PATIENTS WITH DISABILITIES AND THEIR FAMILIES

REGULAR AND PERIODIC TRAINING OFF HEALTH STAFF ESPECIALLY DOCTORS ON DIRECT COMMUNICATION WITH PATIENTS WITH DISABILITIES

FOCUS ON SEXUAL AND REPRODUCTIVE HEALTH OF WOMEN AND MEN WITH DISABILITIES

COLLABORATION WITH DISABILITY RIGHTS MOVEMENT

DISABILITY COMPETENCY IN MEDICAL EDUCATION

8. CITED REFERENCES

Addlakha, Renu. 2007. “How Young People with Disabilities Conceptualize the Body, Sex and Marriage in Urban India: Four Case Studies.” *Sexuality and Disability* 25, no. 3: 111–23. https://doi.org/10.1007/s11195-007-9045-9. Accessed March 4, 2024.

Addlakha, Renu. 2008. "Disability, gender and society." *Indian Journal of Gender Studies* 15, no. 2: 191–207. https://doi.org/10.1177/097152150801500201. Accessed March 4, 2024.

Agarwal, Anjlee, and Andre Steele. 2016. “Disability considerations for Infrastructure Programmes.” GOV. UK. https://assets.publishing.service.gov.uk/media/57a08954ed915d3cfd0001c4/EoD_HDYr3_21_40_March_2016_Disability_Infrastructure.pdf Accessed March 4, 2024.

Aguerre Ines M, Amy R. Riley-Powell, Caroline T. Weldon, Monica Pajuelo, Rosa A. Celis Nacimento, Anité Puente-Arnao, Lilia Cabrera, Richard A. Oberhelman, and Valerie A. Paz-Soldan. 2019. “Knocking on Doors that Don’t Open”: Experiences of Caregivers of Children Living with Disabilities in Iquitos and Lima, Peru.” *Disabil Rehabil.* 41, no. 21: 2538-2547. https://doi.org/10.1080/09638288.2018.1471741. Accessed March 4, 2024.

Albrecht, Gary L., Katherine D. Seelman, and Michael Bury. 2003. *Handbook of Disability Studies.* London: Sage Publications.

Alemu, Nahom Eyasu, Morolake Josephine Adeagbo, and Bekele Melese Eshete. (2023). “The risk of interpersonal violence against women with disabilities in low-and middle-income countries: A systematic literature review.” *International Journal of African Nursing Sciences* 18, 100554. https://doi.org/10.1016/j.ijans.2023.100554

Ali, Afia, Katrina Scior, Victoria Ratti, Andre Strydom, Michael King, and Angela Hassiotis. 2013. "Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers." *Plus One* 8, no. 8: e70855. https://doi.org// 10.1371/journal.pone.0070855. Accessed March 4, 2024.

Anderson, Eric. 2024. "Homophobia." Encyclopaedia Britannica. https://www.britannica.com/topic/homophobia Accessed March 4, 2024.

Andersson, Gunnar. 1997. "The Impact of Children on Divorce Risks of Swedish Women." *European Journal of Population* 13: 109–145. https://doi.org/10.1023/A:1005803001129 Accessed March 4, 2024.

Anyango, Cartrine, Isabel Goicolea, and Fredinah Namatovu. 2023. "Women with disabilities' experiences of intimate partner violence: a qualitative study from Sweden." *BMC Women's Health* 23, no. 381. https://doi.org/10.1186/ s12905-023-02524-8 Accessed March 4, 2024.

Armstrong, Sarah, Mindy Noble, and Pauline Rosenbaum. 2006. "Deconstructing barriers: The promise of socio-economic rights for people with disabilities in Canada." In *Economic Rights in Canada and the United States,* edited by Rhoda E. Howard-Hassmann and Claude E. Welch, 49-68. University of Pennsylvania Press.

Aughinbaugh, Alison, Omar Robles, and Hugette Sun. 2013. "Marriage and divorce: patterns by gender, race, and educational attainment." Monthly Labour Review. U.S. Bureau of Labour Statistics. https://www.bls.gov/opub/ mlr/2013/article/marriage-and-divorce-patterns-by-gender-race-and-educational-attainment.htm# Accessed March 4, 2024.

Bachman, Sara S., Mark Vedrani, Mari-Lynn Drainoni, Carol Tobias, and Lisa Maisels. 2006. "Provider Perceptions of Their Capacity to Offer

Accessible Health Care for People with Disabilities.” J*ournal of Disability Policy Studies* 17, no. 3: 130-136. https://doi.org/10.1177/10442073060170030101. Accessed March 4, 2024.

Banks, Lena Morgon, Timothy O'Fallon, Shaffa Hameed, Sofoora Kawsar Usman, Sarah Polack, and Hannah Kuper. 2022. “Disability and the achievement of Universal Health Coverage in the Maldives.” *PLoS One* 17, no. 12: e0278292. https://doi.org/10.1371/journal.pone.0278292 Accessed March 4, 2024.

Barnes, Colin, Geof Mercer, and Tom Shakespeare. 2010. “The social model of disability.” In *Sociology: Introductory readings,* edited by Anthony Giddens and Philip W. Sutton, 161–166. Cambridge: Polity Press.

Becker, H, A Stuifbergen, and M Tinkle. 1997. “Reproductive health care experiences of women with physical disabilities: a qualitative study.” *Arch Phys Med Rehabil.* 78, no. 12 Suppl 5: S26-33. https://doi.org//10.1016/s0003-9993(97)90218-5. Accessed March 4, 2024.

Begum, Nasa. 1992. "Disabled Women and the Feminist Agenda." *Feminist Review* 40, no. 1: 70–84. https://doi.org/10.1057/fr.1992.6. Accessed March 4, 2024.

Bigelow, Jeffrey, M Korth, J Jacobs, and Narelle Anger. 2004. “A picture of amputees and the prosthetic situation in Haiti.” *Disability and Rehabilitation* 26, no. 4: 246–252. https://doi.org/10.1080/09638280310001644915 Accessed March 4, 2024.

Birla, Neerja. “Mental Health in India: 7.5% of Country Affected; Less than 4,000 Experts Available.” The Economic Times Panache October 10, 2019. https://economictimes.indiatimes.com/magazines/panache/mental-health-in-india-7-5-of-country-affected-less-than-4000-experts-available/articleshow/71500130.cms?from=mkj Accessed March 4, 2024.

Bowers, B., Joyce, M., & Esmond, S. 1996. *Quality Care: The perspectives of individuals with physical disabilities and their caregivers.* An introductory report to the Partnership Program based on interviews with individuals with physical disabilities and their caregivers. University of Wisconsin-Madison. http://www.dhs.wi.gov/WIpartnership/ pdfwpp/Quality-PhysDis.pdf Accessed March 4, 2024.

Bradbury-Jones, Caroline, Jenna P. Breckenridge, John Devaney, Thilo Kroll, Anne Lazenbatt, and Julie Taylor. 2015. "Disabled women's experiences of accessing and utilising maternity services when they are affected by domestic abuse: a critical incident technique study." *BMC Pregnancy and Childbirth* 15, 181.

https://doi.org/10.1186/s12884- 015-0616-y. Accessed March 4, 2024

Britannica, T. 2023. "Homosexuality." Encyclopedia Britannica. Accessed February 19, 2024. https://www.britannica.com/ topic/homosexuality. Accessed March 4, 2024.

Butler, Judith. 1990. *Gender trouble and the subversion of identity*. Routledge.

Campbell Fiona Kumari. 2001. Inciting legal fictions: Disability's date with ontology and the ableist body of the law. Griffith Law Rev 10. 42–62.

Chakravarti, Uma. 2010. "Conceptualising Brahmanical Patriarchy in Early India: Gender, Caste, Class and State." *Economic and Political Weekly* 28, no. 14: 579–585.

Chesler, Phyllis. 1972. *Women and Madness.* Garden City, New York: Doubleday & Company.

Chiluba, Brian Chanda and Nalukui Muke. 2019. "Barriers to Health Care for Disabled People: A Review of the Literature from Low Income Countries." *Indonesian Journal of Disability Studies* 6, no. 2: 210-214. https://doi.org/10.21776/ub.IJDS.2019.006.02.11 Accessed March 4, 2024.

Chua, Hillary. 2019. "Healthcare Access for the deaf in Singapore: Overcoming communication barriers." *Asian Bioethics Review* 11, no. 4: 377–390. https://doi.org/ 10.1007/s41649-019-00104-3. Accessed March 4, 2024.

Clare, Eli. 2001. "Stolen Bodies, Reclaimed Bodies: Disability and Queerness." *Public Culture*, 13 no. 3: 359–365. https://doi.org/10.1215/08992363-13-3-359. Accessed March 4, 2024.

Creamer, Deborah B. 2009. *Disability and Christian theology: Embodied limits and constructive possibilities.* Oxford University Press.

Crenshaw, Kimberle. 1989. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics." *University of Chicago Legal Forum* 1, no. 8: 139–167.

Crossley, Mary. 2015. "Disability Cultural Competence in the Medical Profession." *St. Louis Journal of Health and Policy.* https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2650092. Accessed March 4, 2024.

Crossmaker, Maureen. 1991. "Behind locked doors-Institutional sexual abuse." Sexuality and Disability, 9, no. 3: 201-219. https://doi.org/10.1007/BF01102393 Accessed March 4, 2024.

da Silva, Veronica Andrade, Adson Renato Rodrigues Busnello, Renata Cristina Cavassin, Paula Cunha Loureiro, Auristela Duarte de Lima Moser, Deborah Ribeiro Carvalho. 2020. "Physiotherapy access for children and adolescents with physical disabilities in public institutions." *Cien Saude Colet.* 25, no. 7: 2859-2870. https://go.gale.com/ps/i.do?id=GALE%7CA635201250&sid=sitemap&v=2.1&it=r&p=AONE&sw=w&userGroupName=anon%7E2d2a39cc&aty=open-web-entry Accessed June 7, 2024.

Darling, Rosalyn B., and Alex D. Heckert. 2010. "Orientations Towards Disability: Differences Over the Lifecourse." *International Journal of Disability Development and Education* 57, no. 2: 131–143. https://doi.org/10.1080/ 10349121003750489. Accessed March 4, 2024

Daruwalla, Nayreen,Shruti Chakravarty, Sangeeta Chatterji, Neena Shah More, Glyn Alcock, Sarah Hawkes, and David Osrin. 2013. "Violence Against Women With Disability in Mumbai, India A Qualitative Study." *Sage Open* 3, no. 3. https://doi.org//10.1177/2158244013499144 Accessed March 4, 2024.

Dassah, Ebenezer, Heather M. Aldersey, Mary Ann McColl, and Colleen Davison. 2022. "Health care providers and persons with disabilities' recommendations for improving access to primary health care services in rural northern Ghana: A qualitative study." *PloS one* 17, no.9: e0274163. https://doi.org/10.1371/journal.pone.0274163 Accessed March 4, 2024.

Davis, Hillyer Barbara. 1984. "Women, Disability and Feminism: Notes towards a New Theory." *Frontiers: Journal of Women's Studies* 8, no. 1: 1-5. https://doi.org/10.2307/3346081. Accessed March 4, 2024.

Dawn, Ranjita. 2014. "Our lives, our identity": women with disabilities in India. *Disability and rehabilitation* 36, no. 21: 1768–1773. https://doi.org/10.3109/09638288.2013.870237. Accessed March 4, 2024.

Degener, Theresia. 2017. "A new human rights model of disability." In T*he United Nations convention on the rights of persons with disabilities: A* *commentary,* edited by Rachele Cera, V. Della Fina, and G. Palmisano, 41-60. Cham, Switzerland: Springer.

Department of Education and Early Childhood Development. 2020. "Policy 713 - Sexual Orientation and Gender Identity". Accessed February 19, 2024. https://www2.gnb.ca/content/ dam/gnb/Departments/ ed/pdf/K12/policies-politiques/e/713.pdf Accessed March 4, 2024.

Dictionary. com. "Transgender". Accessed June 3, 2024. https://www.dictionary.com/browse/transgender

Dictionary.com. 2005. "bisexuality". Accessed February 19, 2024. https://www.dictionary.com/browse/bisexuality Accessed March 4, 2024

Drum, Charles E. 2009. "Models and Approaches to Disability." *Disability and Public Health.* https://doi.org/10.2105/ 9780875531915ch03. Accessed March 4, 2024.

Duyan, Veli. 2007. The community effects of disabled sports. In *Amputee sports for victims of terrorism,* edited by Centre of Excellence Defence against Terrorism, 70–77. Amsterdam: IOS Press.

Dyess Air Force Base. n.d. "Myths and Facts." DYESS AIR FORCE BASE. https://www.dyess.af.mil/Fact-Sheets/Display/ Article/267598/myths-and-facts/ Accessed March 4, 2024.

Eldridge, A. 2024. "Pansexuality." Encyclopedia Britannica. Accessed February 19, 2024. https://www.britannica.com/ topic/pansexuality. Accessed March 4, 2024.

Engel. George. 1977. "The need for a new medical model: a challenge for biomedicine." *Science* 196 (4286):129-136. https://doi.org/10.1126/ science.847460 Accessed March 4, 2024.

Fausto-Sterling, Anne. 2000. *Sexing the body: Gender politics and the construction of sexuality*. New York: Basic Books.

Fine, Michelle, and Adrienne, Asch. 1988. Introduction: Beyond pedestals. In *Women with Disabilities: Essays in Psychology, Culture and Politics,* edited by Michelle Fine and Adrienne Asch: 1-38. Philadelphia: Temple University Press.

Finger, A. 1985. "Claiming all of our bodies: Reproductive rights and disability." In With the power of each breath: A disabled women's anthology edited by Susan E. Browne, Debra Connors, and Nanci Stren. Cleis Press.

Fiorillo, Andrea, and Norman Sartorius. 2021. Mortality gap and physical comorbidity of people with severe mental disorders: the public health scandal. *Annals of General Psychiatry* 20, 52. https://doi.org/10.1186/s12991-021-00374-y Accessed March 4, 2024.

Fishbein, M. and Icek Ajzen. 1975. Belief, attitude, intention and behaviour: An introduction to theory and research. Reading MA: Addison Wesley. https://www.researchgate.net/publication/233897090_Belief_attitude_intention_and_behaviour_An_introduction_to_theory_and_research Accessed February 26, 2024.

Flynn, Samantha, Nicholas J. Hulbert-Williams, Lee Hulbert-Williams, and Ros Bramwell. 2016. "You don't know what's wrong with you": An exploration of cancer-related experiences in people with an intellectual disability." *Psycho-Oncology* 25, no. 10: 1198–1205. https://doi.org/10.10/pon.4211. Accessed February 26, 2024.

Garland-Thomson, Rosemarie. 2002. "Integrating Disability, Transforming Feminist Theory." *NWSA Journal* 14, no. 3: 1–32. http://www.jstor.org/stable/4316922.

Ghai, Anita, and Rachana Johri. 2008. "Prenatal Diagnosis : Where Do We Draw the Line ?" *Indian Journal of Gender Studies* 15, no.2: 291–316. https://doi.org/10.1177/ 097152150801500205V Accessed March 4, 2024.

Gleason, Johnathan, Wendy Ross, Alexander Fossi, Heather Blonsky, Jane Tobias, and Mary Stephens. (2021). "The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States." NEJM Catalyst. https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051 Accessed March 4, 2024.

Government of India. 1860. The Indian Penal Code. Accessed May 29, 2024. https://lddashboard.legislative.gov.in/sites/default/files/A1860-45.pdf Accessed March 4, 2024.

Government of India. 1872. "The Indian Contract Act, 1872." Accessed February 16, 2024. Available at https://www.indiacode.nic.in/bitstream/123456789/2187/2/A187209.pdf Accessed March 4, 2024.

Government of India. 1950. Constitution of India. Accessed May 29, 2024. Accessed May 29, 2024. Available at https://lddashboard.legislative.gov.in/sites/default/files/COI...pdf Accessed March 4, 2024.

Government of India. 1950. "The Representation of the People Act, 1950." Accessed 16 February, 2024. Available at https://www.indiacode.nic.in/handle/123456789/1663?locale=en#:~:text=An%20Act%20to%20provide%20the,Council%20of%20States%20to%20be Accessed February 26, 2024.

Government of India. 1952. "Chapter -6 Family Planning." Accessed February 26, 2024. https://main.mohfw.gov.in/sites/default/files/06Chapter.pdf Accessed March 4, 2024.

Government of India. 1955. "The Hindu Marriage Act, 1955." India Code Digital Repository of Laws: A System of Laws for Communication. https://www.indiacode.nic.in/handle/123456789/1560?locale=en Accessed March 4, 2024.

Government of India. 1971. "MTP ACT, 1971." https://main.mohfw.gov.in/?q=acts-rules-and-standards-health-sector/acts/mtp-act-1971 Accessed February 26, 2024

Government of India. 1992. "The Rehabilitation Council of India Act, 1992." https://www.indiacode.nic.in/bitstream/123456789/19048/1/rehabilitation_council_of_india_act_1992.pdf Accessed March 18, 2024

Government of India. 1994. "Pre-Conception Pre-Natal Diagnostic Techniques Act, 1994." Accessed February 26, 2024. Available at https://www.indiacode.nic.in/bitstream/123456789/8399/1/pre-conception-pre-natal-diagnostic-techniques-act-1994.pdf Accessed March 4, 2024.

Government of India. 1995. "The Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995." Accessed May 24, 2024. https://thenationaltrust.gov.in/upload/uploadfiles/files/Persons%20with%20Disability%20Act%201995.pdf Accessed March 4, 2024.

Government of India. 1999. "THE NATIONAL TRUST FOR WELFARE OF PERSONS WITH AUTISM, CEREBRAL PALSY, MENTAL RETARDATION AND MULTIPLE DISABILITIES ACT, 1999." Accessed February 16, 2024. Available at https://niepid.nic.in/THE%20NATIONAL%20trust.pdf Accessed March 4, 2024.

Government of India. 2006. "The National Policy for Persons with Disabilities." Accessed February 16, 2024. https://www.mospi.gov.in/sites/default/files/reports_and_publication/statistical_publication/social_statistics/Chapter%208%20-National%20redressal.pdf Accessed March 4, 2024.

Government of India. 2011. "Census of India 2011." Accessed February 14, 2024. http://www.ccdisabilities.nic.in/resources/disability-india Accessed February 27, 2024.

Government of India. 2012. THE PROTECTION OF CHILDREN FROM SEXUAL OFFENCES ACT, 2012. Accessed May 29, 2024. https://www.indiacode.nic.in/bitstream/123456789/2079/1/AA2012-32.pdf Accessed March 4, 2024.

Government of India. 2013. The Criminal Law (Amendment) Act. Accessed May 29, 2024. https://districts.ecourts.gov.in/sites/default/files/CRIMINA-LAW%28AMENDMENT%29%20ACT-2013.pdf Accessed March 4, 2024.

Government of India. 2016. "The Rights of Persons with Disabilities Act 2016." Accessed February 20, 2024. Available at http://www.ccdisabilities.nic.in/sites/default/files/2021-09/THE%20RIGHTS%20OF%20PERSONS%20WITH%20DISABILITIES%20ACT%2C%202016%20%28English%29.pdf Accessed March 4, 2024.

Government of India. 2017. The Mental Healthcare Act. https://main.mohfw.gov.in/sites/default/files/Mental%20Healthcare%20Act%2C%202017_0.pdf Accessed May 29, 2024.

Government of India. 2019. Persons with Disabilities in India, NSS 76 th round (July-December 2018). (NSS Report No 583 (76/26/1). Ministry of Statistics and Programme Implementation. https://www.mospi.gov.in/sites/default/files/publication_reports/Report_583_Final_0.pdf Accessed March 4, 2024.

Greengross, Wendy. 1976. "Entitled to Love : The sexual and emotional needs of the handicapped." Malaby Press [for] National Fund for Research into Crippling Diseases.

Gutenbrunner Christoph, A. B. Ward, M Anne Chamberlain, and A. Bardot. 2007. "White book on Physical and Rehabilitation Medicine in Europe." *Journal of Rehabilitation Medicine* 2007 39, no. 45: 1-48. https://doi.org/10.2340/16501977-0028. Accessed March 4, 2024.

Hahn, Harlan. 1988. "The Politics of Physical Differences: Disability and

Discrimination." *Journal of Social Issues* 44, no. 1: 39–47. https://doi.org/10.1111/j.1540-4560.1988.tb02047.x. Accessed March 18, 2024.

Hanass-Hancock, Jill. 2009. "Disability and HIV/AIDS - A systematic review of literature on Africa." *Journal of the International AIDS Society* 12, no. 1: 1–.11. https://doi.org/10.1186/1758-2652-12-34. Accessed March 4, 2024. Accessed March 4, 2024.

Harpin, V. N. 2005. "The effect of ADHD on the life of an individual, their family, and community from preschool to adult life." *Archives of Disease in Childhood* 90, no. Suppl 1: i2-7. https://doi.org//10.1136/adc.2004.059006 Accessed March 4, 2024.

Hashemi, Goli, Mary Wickenden, Tess Bright, and Hannah Kuper. 2020. "Barriers to accessing primary health care services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies." *Disability and Rehabilitation* 44, no. 8: 1207–1220. https://doi.org/ 10.1080/09638288.2020.1817984. Accessed March 18, 2024.

Helander, Einar. 1999. *Prejudice and dignity: an introduction to community-based rehabilitation,* 2nd edn. New York, United Nations Development Programme.

Hiranandani, Vanmala, and Deepa Sonpal. 2010. "Disability, Economic Globalization and Privatization: A Case Study of India." *Disability Studies Quarterly* 30 no. 3/4. https://doi.org/10.18061/dsq.v30i3/4.1272 Accessed March 4, 2024.

Hough, J. 1999. Disability and Health: A National Public Health Agenda. In R.J. Simeonsson, and L. N. McDevitt (Eds.), *Issues in Disability and Health: The Role of Secondary Conditions and Quality of Life* (pp. 161-203). University of North Carolina Press.

Human Rights Watch. 2022. "Q & A: Access to Abortion is a Human Right." https://www.hrw.org/news/202.2/06/24/qa-access-abortion-human-right Accessed March 18, 2024

Institute of Medicine (US). 2008. *Evidence-Based Medicine and the Changing Nature of Healthcare: 2007 IOM Annual Meeting Summary.* National Academies Press (US).

Kafer, Alison. 2003. "Compulsory bodies: Reflections on heterosexuality and able-bodiedness." *Journal of Women's History*, 15, no. 3: 77–89. https://doi.org/10.1353/jowh.2003.0071 Accessed March 18, 2024.

Kirschner, Kristy L, and Raymond H Curry. 2009. "Educating Health Care Professionals to Care for Patients with Disabilities." *JAMA* 302, no. 12: 1334–1335. https://doi.org/10.1001/jama.2009.1398 Accessed March 18, 2024.

Kritzinger, Janis, Marguerite Schneider, Leslie Swartz, and Stine Hellum Braathen. 2014. "I just answer 'yes' to everything they say": Access to health care for deaf people in Worcester, South Africa and the politics of exclusion." *Patient Education and Counseling* 94, no.3: 379–383. https://doi.org/10.1016/j.pec.2013.12.006 Accessed March 18, 2024.

Kroll, Thilo, Gwyn C Jones, Matthew Kehn, and Melinda T Neri. 2006. "Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: a qualitative inquiry." *Health Soc Care* 14, no. 4: 284-93. https://doi.org//10.1111/j.1365-2524.2006.00613.x Accessed March 4, 2024.

Kuper, Hannah, and Phyllis Heydt. 2019. The Missing Billion: Access to Health Services for 1 Billion People with Disabilities. https://www.lshtm.ac.uk/TheMissingBillion Accessed March 18, 2024.

Lee, Danbi, Samantha W. Pollack, Tracy Mroz, Bianca K. Frogner, and Susan M. Skillman. 2023. "Disability competency training in medical education." *Med Educ Online* 28, no.1: 2207773. https://doi.org//10.1080/10872981.2023.2207773 Accessed March 18, 2024.

Lee, Jeong-Eun, Hyung-Ik Shin, Young Kyung Do, and Eun Joo Yang 2016. "Catastrophic Health Expenditures for Households with Disabled Members: Evidence from the Korean Health Panel." *Journal of Korean medical science* 31, no. 3: 336–344. https://doi.org/10.3346/jkms.2016. 31.3.336

Lennox, Nicholas, and Robert Chaplin. 1996. "The psychiatric care of people with intellectual disabilities: The perceptions of consultant psychiatrists in Victoria." *Australian & New Zealand Journal of Psychiatry* 30, no. 6: 774–780. https://doi.org/10.3109/00048679609065044 Accessed March 18, 2024.

Lerner, Gerda. 1986. *The Creation of Patriarchy*. New York: Oxford University Press.

Lewis, Catherine. 2019. "Talking about disability: why the words we choose matter." *Classical.* https://www.classical915.org/post/talking-about-disability-why-words- Accessed March 4, 2024.

Longmore, Paul, K. 2003. *Why I Burned My Book and Other Essays on Disability.* Temple University Press.

Lord, Janet E., David Suozzi, and Allyn L. Taylor. 2010. "Lessons from the experience of U.N. Convention on the rights of persons with disabilities: Addressing the Democratic deficit in Global Health Governance." *Journal of Law, Medicine & Ethics* 38, no. 3: 564–579. https://doi.org/10.1111/j.1748-720x.2010.00512.x. Accessed March 18, 2024.

Lund, Emily M. 2021. "Interpersonal Violence Against Sexual and Gender Minority Individuals with Disabilities." In *Violence Against LGBTQ+ Persons* edited by Emily M. Lund, Claire Burgess, Andy J. Johnson. Springer. https://doi.org/10.1007/978-3-030-52612-2_15 Accessed March 4, 2024.

Mac-Seing, Muriel, Emmanuel Ochola, Martin Ogwang, Kate Zinszer, and Christina Zarowsky. 2022. "Policy Implementation Challenges and Barriers to Access Sexual and Reproductive Health Services Faced By People with Disabilities: An Intersectional Analysis of Policy Actors' Perspectives in Post-Conflict Northern Uganda." *International Journal of Health Policy and Management* 11, no. 7: 1187-1196. https://doi.org//10.34172/ijhpm.2021.28 Accessed March 18, 2024.

Madueke-Laveaux,Obianuju Sandra, Amro Elsharoud, and Ayman Al-Hendy. 2021. "What We Know about the Long-Term Risks of Hysterectomy for Benign Indication-A Systematic Review." *Journal of Clinical Medicine* 10, no. 22: 5335. https://doi.org/10.3390/jcm10225335 Accessed March 18, 2024.

Malouf, Reem, Jenny McLeish, Sara Ryan, Ron Gray, and Maggie, Redshaw. 2017. "We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability." *BMJ Open* 7, no. 6. https://doi.org/10.1136/bmjopen-2016-015526 Accessed March 18, 2024.

Massachusetts Society for the Prevention of Cruelty to Children. 1913. *The Menace of the Feeble-Minded in Massachusetts.* Griffith-Stillings Press.

Maxwell, Jane, Julia Watts Belser, Darlena David. 2007. *A Health Handbook for Women with Disabilities.* Oakland, CA: Hesperian Foundation. https://store.hesperian.org/prod/A_Health_Handbook_for_Women_with_Disabilities.html Accessed March 4, 2024.

Maynard, Alice. 2009. "Can measuring the benefits of accessible transport enable a seamless journey?" *Journal of Transport and Land Use* 2, no. 2: 21–30. https://www.jstor.org/ stable/26201629 Accessed March 18, 2024.

McBain, Hayley,Kathleen Mulligan, Frederique Lamontagne-Godwin, Julia Jones, Mark Haddad, Chris Flood, David Thomas & Alan Simpson. 2016. "Implementation of recommended type 2 diabetes care for people with severe mental illness – a qualitative exploration with healthcare professionals." *BMC Psychiatry* 16, no. 222 https://doi.org/10.1186/s12888-016-0942-2 Accessed March 18, 2024.

McColl, Mary Ann, Donna Forster, S. E. Shortt, Duncan Hunter, John Dorland, Marshall Godwin, and Walter Rosser. 2008. "Physician experiences providing primary care to people with disabilities." *Healthcare policy/Politiques de sante* 4, no. 1: e129–e147. https://doi.org/10.12927/hcpol. 2008.19989 Accessed March 18, 2024.

McRuer, Robert. 2003. "As good as it gets: Queer Theory and critical disability." *GLQ: A Journal of Lesbian and Gay Studies* 9, no. 1–2: 79–105. https://muse.jhu.edu/article/40800/pdf. Accessed March 4, 2024.

Mencap. 2018. "Treat Me Well: Simple Adjustments Make a Big Difference. https://www.mencap.org.uk/sites/default/files/2018-07/2017.005.01%20Campaign%20report%20digital.pdf. Accessed March 18, 2024.

Mitra, Monika, Vera Mouradian, and Marci Diamon. 2011. Sexual Violence Victimisation against Men with Disabilities. *American Journal of Preventive Medicine* 41, no. 5: 494-497. https://doi.org//10.1016/j.amepre.2011.07.014 Accessed March 4, 2024.

Mitra, Spohie, Michael Palmer, Hoolda Kim, Daniel Mont, and Nora Groce. 2017. Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal* 10, no. 4: 475–484. https://doi.org/10.1016/j.dhjo.2017.04.007. Accessed March 18, 2024.

Mladenov, Teodor, John Owens, and Alan Cribb. 2015. "Personalisation in disability services and healthcare: A critical comparative analysis." *Critical Social Policy* 2015 35, no. 3: 307–326. https://doi.org//10.1177/0261018315587071 Accessed March 4, 2024.

Mohapatra S, and M. Mohanty M. 2005. *Abuse and activity limitation - a study on domestic violence against disabled women in Orissa, India*. Oxfam, India.

Morris, Jenny. 1993. "Feminism and Disability." *Feminist Review* 43, no.1: 57- 70.

Morrison, Elizabeth H, Valerie George, and Laura Mosqueda. 2008. "Primary care for adults with physical disabilities: perceptions from consumer and provider focus groups." *Family medicine* 40, no. 9: 645–651. https://pubmed.ncbi. nlm.nih.gov/18830840/ Accessed March 18, 2024.

Mprah, Wisdom Kwadwo. 2013. Perceptions about Barriers to Sexual and Reproductive Health Information and Services among Deaf People in Ghana. *Disability CBR & Inclusive Development* 24, no. 3: 21–36. https://doi.org/http://doi.org/10.5463/dcid.v24i3.234 Accessed March 18, 2024.

Munthali Alister C, Leslie Swartz, Hasheem Mannan, Malcolm MacLachlan, Charles Chilimampunga, and Cecilia Makupe. 2019. "This one will delay us": barriers to accessing health care services among persons with disabilities in Malawi." *Disability and Rehabilitation* 41, no. 6: 683-690. https://doi.org/10.1080/09638288.2017.1404148 Accessed March 18, 2024.

Murphy, Joan. 2006. "Perceptions of communication between people with communication disability and general practice staff." *Health Expect.* 9, no.1: 49-59. https://doi.org/ 10.1111/j.1369-7625.2006.00366.x Accessed March 18, 2024.

Murthy, Gudlavalleti Venkata S, Neena John, Jayanthi Sagar, and South India Disability Evidence Study Group. 2014. "Reproductive health of women with and without disabilities in South India, the SIDE study (South India Disability Evidence) study: a case control study." *BMC Womens Health* 14, no. 146. https://doi.org.10.1186/s12905-014-0146-1. Accessed March 18, 2024.

Muskat, Barbara, Priscilla Burnham Riosa, David B Nicholas, Wendy Roberts, Kevin P Stoddart, and Lonie Zwaigenbaum. 2014. "Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian Paediatric Hospitals." *Autism* 19, no. 4: 482–490. https://doi.org/10.1177/ 1362361314531341 Accessed March 18, 2024.

Mwangi, Luci, W., Jonathan A. Abuga, Emma Cottrell, Symon M. Kariuki, Samson M. Kinyanjui, and Charles RJC. Newton. 2021. "Barriers to access and utilization of healthcare by children with neurological impairments and disability in low-and middle-income countries: a systematic review." *Wellcome Open Research* 6, no. 61. https://doi.org/ 10.12688/wellcomeopenres.16593.2

Nagi, Saad Z. 1965. Some conceptual issues in disability and rehabilitation. In *Sociology and Rehabilitation* edited by Marvin B. Sussman, 100–113. American Sociological Association.

Namkung, Eun Ha, Jieun Song, Jan S. Greenberg, Marsha R. Mailick, and Frank J. Floyd. 2015. "The Relative Risk of Divorce in Parents of Children with Developmental Disabilities: Impacts of Lifelong Parenting." *American journal on intellectual and developmental disabilities* 120, no. 6: 514-526. https://doi.org//10.1352/1944-7558-120.6.514 Accessed March 4, 2024.

National Council on Disability. 2009. "The Current State of Health Care for People with Disabilities." Accessed March 15, 2024. https://www.ncd.gov/report/the-current-state-of-health-care-for-people-with-disabilities/Accessed March 4, 2024.

Naylor, Graham, Burke Louise A, Holman Jack A. 2020. "Covid-19 Lockdown Affects Hearing Disability and Handicap in Diverse Ways: A Rapid Online Survey Study." Ear and Hearing. *The Official Journal of the American Auditory Society* 41, no. 6: 1442-1449. https://doi.org//10.1097/ AUD.0000000000000948 Accessed March 18, 2024.

Nielson, Kim E. 2013. *A Disability History of the United States.* Beacon

O'Halloran, Robyn, Brooke Grohn, and Linda Worrall. 2012. "Environmental factors that influence communication for patients with a communication disability in acute hospital stroke units: a qualitative metasynthesis." *Arch Phys Med Rehabil.* 93, (1 Suppl): S77-85. https://doi.org//10.1016/j.apmr.2011.06.039 Accessed March 4, 2024.

Nosek, Margaret A., Lisa-Ann Wuermser, and Laurie J. Walter. 1998. Differences in contraceptive methods used by women with physical disabilities compared to women without disabilities. *Prim Care Update Ob Gyns* 5, no. 4: 172–173. https://doi.org/10.1016/s1068-607x(98)00076-6 Accessed March 4, 2024.

OHCHR. International Covenant on Economic, Social and Cultural Rights Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966 entry into force 3 January 1976, in accordance with article 27. https://www.ohchr.org/sites/default/files/Documents/ProfessionalInterest/cescr.pdf Accessed March 4, 2024.

Oliver, Mike. 1981. A new model of the social work role in relation to disability. In *The handicapped person: A new perspective for social workers,* edited by Jo Campling, 19–32. University of Illinois: RADAR

Oliver, Mike. 1990. *The Politics of Disablement.* Basingstoke: Macmillan and St. Martin's Press.

Oliver, Mike. 2004. The Social Model in Action: if I had a hammer. In *Implementing the Social Model of Disability: Theory and Research,* edited by Colin Barnes, and Geof Mercer, 18-31. The Disability Press.

Olkin, Rhoda. 1999. *What psychotherapists should know about disability New York:* Guilford Press.

Opoku Peprah Maxwell, Wisdom Kwadwo Mprah, Judith Mckenzie, Bernard Nsaidzedze Sakah, and Eric Badu. 2017. "Lives of persons with disabilities in Cameroon after CRPD: voices of persons with disabilities in the Buea Municipality in Cameroon." *Int J Disabil Hum Dev.* https://doi.org/ 10.1515/ijdhd-2016-0009 Accessed February 19, 2024.

Organisation for Economic Co-operation and Development. 2008. *Modernizing sickness and disability policy: OECD thematic review on sickness, disability and work issues paper and progress report.* Paris.

Pal, Gobinda C. 2010. "Dalits with Disabilities: The Neglected Dimension of Social Exclusion." *Working Paper Series* 4, no: 3. https://idsn.org/wp-content/uploads/user_folder/pdf/New_files/India/Dalits_with_disabilities__IIDS_working_paper_.pdf Accessed March 4, 2024.

Pendo, Elizabeth. 2010. "Reducing Disparities Through Health Care Reform: Disability and Accessible Medical Equipment." *Saint Louis University School of Law.* https://scholarship.law.slu.edu/cgi/viewcontent.cgi?article=1369 context=faculty Accessed February 19, 2024.

Pereira, Patricia Christina Andrade, and Paulo Antonio de Carvalho Fortes. 2010. "Communication and information barriers to health assistance for deaf patients." *American Annals of the Deaf* 155, no. 1: 31–37. https://doi.org// 10.1353/aad.0.0128 Accessed February 19, 2024.

Plummer, Sara-Beth, and Patricia A. Findley. 2012. "Women with Disabilities' Experience with Physical and Sexual Abuse: A Review of the Literature and Implications for the Field." *TRAUMA, VIOLENCE, & ABUSE* 13, no. 1: 15-29. https://doi.org// 10.1177/1524838011426014 Accessed March 4, 2024.

Prynn, Jospehine E., and Hannah Kuper. 2019. "Perspectives on Disability and Non-Communicable Diseases in Low- and Middle-Income Countries, with a Focus on Stroke and Dementia*." International journal of environmental research and public health* 16, no. 18: 3488. https://doi.org/10.3390/ijerph16183488 Accessed March 4, 2024.

Reeves, David, and Brian Kokoruwe. 2005. "Communication and communication support in primary care: A survey of Deaf Patients." *Audiological Medicine* 3, no. 2: 95–107. https://doi.org/10.1080/16513860510033747 Accessed February 19, 2024.

Rehabilitation Council of India. 2024. "Categories US 19." https://rehabcouncil.nic.in/categories-us. Accessed June 5, 2024.

Rehabilitation Council of India. 2024. "Objectives." Rehabilitation Council of India. https://rehabcouncil.nic.in/about-us/objective#:~:text=To%20encourage%20continuing%20education%20in,in%20the%20field%20of%20disability. Accessed June 5, 2024.

Riley, Andrew, Nayreen Daruwalla, Suman Kanougiya, Apoorwa Gupta, Mary Wickenden, and David Osrin. 2022. "Intimate partner violence against women with disability and associated mental health concerns: a cross-sectional survey in Mumbai, India." *BMJ open* 12, no. 4. e056475. https://doi.org/10.1136/bmjopen-2021-056475 Accessed March 4, 2024.

Rowlands, Sam, and Jean-Jacques Amy. 2019. "Sterilization of those with intellectual disability: Evolution from non-consensual interventions to strict safeguards." *Journal of Intellectual Disabilities* 23, no.2: 233-249. https://doi.org/10.1177/1744629517747162 Accessed February 19, 2024.

Rubin, Gayle. 1975. "The traffic in women: Notes on the 'political economy' of sex". In *Toward an Anthropology of Women,* edited by Rayna R, Reiter, 157-210. New York and London: Monthly Review Press.

Rubin, Isadore Leslie, and Allen C. Crocker. 1989. *Developmental disabilities: Delivery of medical care for children and adults.* Lippincott Williams and Wilkins.

Sakellariou, Dikaios, and Elena S. Rotarou. 2017. "The effects of neoliberal policies on access to healthcare for people with disabilities." *International Journal for Equity in Health* 16, no. 199. https://doi.org/10.1186/s12939-017-0699-3 Accessed March 4, 2024.

Salvador-Carulla, Luis, and Shekhar Saxena. 2009. "Intellectual disability: Between disability and clinical nosology." *The Lancet* 374, no. 9704: 1798–1799. https://doi.org/10.1016/s0140-6736(09)62034-1 Accessed February 19, 2024.

Schneider, Barbara, Hannah Scissons, Laurie Arney, George Benson, Jeff Derry, Ken Lucas, Michelle Misurelli, Dana Nickerson, and Mark Sunderland. 2004. "Communication between people with schizophrenia and their medical professionals: A participatory research project." *Qualitative Health Research* 14, no. 4: 562–577.

https://doi.org/ 10.1177/1049732303262423 Accessed February 19, 2024.

Sen, Amartya K. 1985. *Commodities and capabilities.* Volume 7 of Professor Dr. P. Hennipman lectures in economics, theory, institutions, policy. Amsterdam: Elsevier.

Sen, Amartya K. 1992. *Inequality re-examined.* Cambridge: Harvard University Press.

Shakespeare, Tom, Lisa I Iezzoni, and Nora E Groce. 2009. "Disability and the training of Health Professionals." *The Lancet* 374, no. 9704: 1815–1816. https://doi.org/10.1016/s0140-6736(09)62050-x Accessed February 19, 2024.

Sheth, S. S. 2006. "Missing female births in India." *The Lancet* 367, no. 506: 185–186. https://doi.org/10.1016/S0140-6736(06)67931-2. Accessed March 4, 2024.

Shin, Jae Eun, Geum Joon Cho, Seongeun Bak, Sang Eun Won, Sung Won Han, Soo Bin Lee, Min-Jeong Oh, and Sa Jin Kim. 2020. "Pregnancy and neonatal outcomes of women with disabilities: a nationwide population-based study in South Korea." *Scientific reports,* 1O, no. 1: 9200. https://doi.org/10.1038/s41598-020-66181-9 Accessed March 4, 2024.

Singh, Satendra, Kamala Gullapalli Cotts, Khan Amir Maroof, Upreet Dhaliwal, Navjeevan Singh, and Tao Xie. 2020. "Disability-inclusive compassionate care: Disability competencies for an Indian Medical Graduate." *Journal of Family Medicine and Primary Care* 9, no. 3: 1719-1727. https://doi.org/10.4103/jfmpc.jfmpc_1211_19 Accessed April 1, 2024.

Sobsey, Richard. 1994. *Violence and abuse in the lives of people with disabilities: The end of silent acceptance. Baltimore:* Paul H Brookes Publishing.

South-North Centre for Dialogue and Development. 2006. "Global survey of government actions on the implementation of the standard rules of the equalisation of opportunities for persons with disabilities." Amman: Office of the UN Special Rapporteur on Disabilities. https://www.un.org Accessed February 19, 2024.

Srisuppaphon, Donruedee, Wachara Riewpaiboon, Apakorn Supanya, and Viroj Tangcharoensathien. 2016. "Development of a disability-inclusive healthcare service: review of the Healthcare Accreditation Programme in Thailand." *Knowledge Management for Development Journal* 12, no. 1: Disability Inclusive Development Part 1.https://www.km4djournal.org/index.php/km4dj/article/view/298 Accessed March 4, 2024.

Stalker, Kirsten and Katherine McArthur. 2012. Child Abuse, Child Protection and Disabled Children: A review of recent research. Available at https://pure.strath.ac.uk/ws/portalfiles/portal/120573965/strathprints027452.pdf Accessed March 4, 2024.

Stiker, Henri-Jacques. 1999. *A history of Disability.* University of Michigan Press.

Swain, John, and Sally French. 2000. "Towards an Affirmation Model of Disability." *Disability & Society* 15, no. 4: 569–82. https://doi.org/10.1080/09687590050058189 Accessed February 19, 2024.

Tesfaye, Tagel, Endrias Markos Woldesemayat, Nana Chea, Demelash Wachamo. 2021. "Accessing Healthcare Services for People with Physical Disabilities in Hawassa City Administration, Ethiopia: A Cross-Sectional Study." *Risk Manag Healthc Policy,* 14: 3993-4002. https://doi.org/10.2147/RMHP.S317849 Accessed February 19, 2024.

The World Bank. 2009. *People with Disabilities in India: From Commitments to Outcomes.* Washington. https://documents1.worldbank.org/

curated/en/577801468259486686/pdf/502090WP0Peopl1Box0342042B01PUBLIC1.pdf Accessed February 19, 2024.

Thomas, Carol. 1999. *Female Forms: Experiencing and Understanding*

Disability. Buckingham, U.K: Open University Press.

Shakespeare, Tom, and Nicholas, Watson. 2001. The Social Model of Disability: An outdated ideology? In *Exploring Theories and Expanding Methodologies: Where we are and where we need to go* (*Research in Social Science and Disability, Vol. 2*), edited by Sharon, N. Barnartt, and Barbara Mandell Altman. Emerald Group Publishing Limited, Leeds, pp. 9-28. https://doi.org/10.1016/S1479-3547(01)80018-X Accessed March 4, 2024.

UN WOMEN. 1995. "The United Nations Fourth World Conference on Women Beijing, China - September 1995 Action for Equality, Development and Peace PLATFORM FOR ACTION." United Nations Entity for Gender Equality and the Empowerment of Women. https://www.un.org/ womenwatch/daw/beijing/platform/health.htm Accessed February 19, 2024.

UNICEF. 2022. "Access to safe and dignified menstruation is a fundamental need and a human right (Nomin Lkhagvasuren)." https://www.unicef.org/mongolia/stories/access-safe-and-dignified-menstruation-fundamental-need-and-human-right Accessed February 19, 2024.

United Nations Department of Economic and Social Affairs. 2019. "Family Planning and the 2030 Agenda for Sustainable Development Data Booklet." https://www.un.org/en/development/desa/population/publications/pdf/family/familyPlanning_DataBooklet_2019.pdf Accessed February 19, 2024.

United Nations Economic and Social Council. 2000. "COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS Twenty-second session Geneva, 25 April-12 May 2000. Agenda item 3 Substantive Issues Arising In the Implementation Of The International Covenant On Economic, Social And Cultural Rights." https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmlBEDzFEovLCuW1AVC1NkPsgUedPlF1vfPMJ2c7ey6PAz2qaojTzDJmC0y%2B9t%2BsAtGDNzdEqA6SuP2r0w%2F6sVBGTpvTSCbiOr4XVFTqhQY65auTFbQRPWNDxL Accessed February 19, 2024.

United Nations Human Rights Office of the High Commissioner. 2014. "Gender Stereotypes and stereotyping and Women's rights." Accessed https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WRGS/OnePagers/Gender_stereotyping.pdf Accessed February 19, 2024.

United Nations Human Rights Office of the High Commissioner. 2017. "Mandate of the Working Group on the issue of discrimination against women in law and in practice. Inputs on the Human Rights Committee draft general comment No. 36 on article 6 of the International Covenant on Civil and Political Right, on the right to life (October 2017 https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WG/WGDAW_HRC_GC36_submission.pdf Accessed February 19, 2024.

United Nations Human Rights Office of the High Commissioner. 2021. "World Contraception Day, 26 September 2021." https://www.ohchr.org/en/statements/2021/09/world-contraception-day-26-september-2021 Accessed February 19, 2024.

United Nations Human Rights Office of the High Commissioner. 2024. "Sexual and reproductive health and rights OHCHR and women's human rights and gender equality." https://www.ohchr.org/en/women/sexual-and-reproductive-health-and-rights#:~:text=CEDAW%20(article%2016)%20guarantees%20women,them%20to%20exercise%20these%20rights.%22 Accessed February 19, 2024.

United Nations Population Fund. 1994. International Conference on Population and Development (ICPD) 05 September 1994 Cairo, Egypt. https://www.unfpa.org/events/international-conference-population-and-development-icpd Accessed March 4, 2024.

United Nations Population Fund. 2005. "Frequently asked questions about gender equality. https://www.unfpa.org/resources/frequently-asked-questions-about-gender-equality Accessed February 19, 2024.

United Nations. 1968. "International Conference on Human Rights 22 April-13 May 1968, Teheran." https://www.un.org/en/conferences/human-rights/teheran1968 Accessed June 4, 2024.

United Nations. 1979. "Convention on the Elimination of All Forms of Discrimination Against Women New York, 18 December 1979." https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-elimination-all-forms-discrimination-against-women Accessed February 19, 2024.

United Nations. 2006. "United Nations Convention on the Rights of Persons with Disabilities." https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf Accessed March 4, 2024.

Vergunst Richard, Leslie Swartz, Gubela Mji, Malcolm MacLachlan, and Hasheem Mannan. 2015. "'You must carry your wheelchair' – barriers to accessing healthcare in a South African rural area." *Global Health Action* 8, no. 1. https://doi.org/10.3402/gha.v8.29003 Accessed February 19, 2024.

Voillemont, Cyrielle, Eric Imbault, Marie Schoenberger, and Paolo Di Patrizio. 2022. "Care and management of adults with autism spectrum disorder in family practice: difficulties experienced by general practitioners." *Family Practice* 39, no. 3: 464-470. https://doi.org/10.1093/fampra/cmab126 Accessed February 19, 2024.

Ward, Rolanda L, Amnada D Nichols, and Ruth I Freedman. 2010. "Uncovering health care inequalities among adults with intellectual and developmental disabilities." *Health & Social Work* 35, no. 4: 280–290. https://doi.org/ 10.1093/hsw/35.4.280 Accessed February 19, 2024.

Warfield, Marji Erickson, Morgan K Crossman, Jennifer Delahaye, Emma Der Weerd, and Karen K Kuhlthau. 2015. "Physician perspectives on providing primary medical care to adults with autism spectrum disorders (ASD)." *Journal of Autism and Developmental Disorders* 45, no. 7: 2209–2217. https://doi.org/10.1007/s10803-015-2386-9 Accessed February 19, 2024.

Waxman, Barbara Faye. 1991. "Hatred: The unacknowledged dimension in violence against disabled people." *Sexuality and Disability* 9: 185–199. https://doi.org/10.1007/BF01102392 Accessed March 4, 2024.

Waxman-Fiduccia, B. F. 1999. "Sexual Imagery of Physically Disabled Women: Erotic? Perverse? Sexist?" *Sexuality and Disability* 17, no. 3: 277–282. https://doi.org /10.1023/a:1022189224533 Accessed February 19, 2024.

Welch, Patricia. 2002. "Applying the capabilities approach in examining disability, poverty, and gender." Conference Proceedings- Promoting Women's Capabilities: Examining Nussbaum's Capabilities Approach, September 9-10, 2002. Cambridge: Von Hugel Institute of St. Edmund's College.

Wendell, Susan. 1996. *The Reflected Body; Feminist Philosophical Reflections on Disability.* London and NY: Routledge & Kegan Paul.

West, Candance, and Zimmerman Don H. 1987. "Doing Gender." *Gender and Society* 1, no.2: 125–151. http://links.jstor.org/sici?sici=0891-2432%28198706%291%3A2%3C125%3ADG%3E2.0.CO%3B2-Whttps:// Accessed February 19, 2024.

World Bank. 2022. Approach Paper Universal Digital Inclusion and Usage July 20, 2022. https://ieg.worldbankgroup.org/ sites/default/files/Data/reports/ap_universaldigitalinclusion.pdf Accessed June 7, 2024.

World Health Organization (WHO). 1980. *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relation to the Consequences of Disease.* Geneva, Switzerland: World Health Organization.

WHO. 2001. "International Classification of Functioning, Disability and Health. Geneva: World Health Organization." Available: https://iris.who.int/bitstream/handle/10665/42407/9241545429-eng.pdf Accessed May 29, 2024.

WHO. 2006. "Defining sexual health Report of a technical consultation on sexual health 28–31 January 2002, Geneva." cesas.lu. fgoAccessed February 19, 2024.

World Health Organization & World Bank. 2011. "World report on disability 2011. World Health Organization." https://iris.who.int/handle/10665/44575. Accessed May 22, 2024.

WHO. 2013. "Millions have hearing loss that can be improved or prevented. https://www.who.int/news/item/27-02-2013-millions-have-hearing-loss-that-can-be-improved-or-prevented Accessed February 19, 2024.

WHO. 2018. "Millennium Development Goals (MDGs). https://www.who.int/news-room/fact-sheets/detail/millennium-development-goals-(mdgs) Accessed February 19, 2024.

WHO. 2021. "SEVENTY-FOURTH WORLD HEALTH ASSEMBLY WHA74.8 Agenda item 26.4. The highest attainable standard of health for persons with disabilities." https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf Accessed February 19, 2024.

WHO. 2022. "Global Report on health equity for persons with disabilities." https://www.who.int/publications/i/item/9789240063600 Accessed February 19, 2024.

WHO. 2022. "WHO statement on menstrual health and rights 50th session of the Human Rights Council Panel discussion on menstrual hygiene management, human rights and gender equality." https://www.who.int/news/item/22-06-2022-who-statement-on-menstrual-health-and-rights Accessed June 4, 2024.

WHO. 2024. "Abortion." https://www.who.int/health-topics/abortion#tab=tab_1 Accessed February 19, 2024.

WHO/UNFPA. 2009. "Promoting sexual and reproductive health for persons with disabilities WHO/UNFPA guidance note." https://www.unfpa.org/sites/default/files/pub-pdf/srh_for_disabilities.pdf Accessed February 19, 2024.

Yee, Silvia, and Mary Lou Breslin. 2010. "Achieving accessible health care for people with disabilities: why the ADA is only part of the solution." *Disability Health J.* 3, no. 4: 253-261. https://doi.org//10.1016/j.dhjo.2010.07.006 Accessed February 19, 2024.

Yee, Silvia. 2011, August. "Health and Health Care Disparities Among People with Disabilities." Disability Rights Education & Defense Fund. https://dredf.org/public-policy/health-access-to-care-old/health-and-health-care-disparities-among-people-with-disabilities/ Accessed February 19, 2024.

Ziviani, Jenny, Lennox, Nicholas, Heather Allison, Micahle Lyons, and Chris Del Mar. 2004. "Meeting in the middle: Improving communication in primary health care consultations with people with an intellectual disability." *Journal of Intellectual & Developmental Disability* 29, no. 3: 211–225. https://doi.org/10.1080/13668250412331285163 Accessed February 19, 2024.

Zongjie, Yin, Dai Hong, Xiao Zhongxin, and Xue Hui. 2007. A research study into the requirements of disabled residents for rehabilitation services in Beijing. *Disability and Rehabilitation* 29, no. 10: 825–833. https://doi.org/ 10.1080/09638280600919657 Accessed February 19, 2024.

Zuurmond, Maria, Lena Morgon Banks, Prem Aryal, Sushil Joshi, Jacqueline Gallinetti, Adrienne Monteath-Van Dok, Aidan Leavy, Linda Campbell, Silje Vold, and Gillian Quinn. 2014. "Include us in education! A qualitative research study on barriers and enablers to education for children with disabilities in Nepal." Full report. https://plan-international.org/uploads/2022/01/include_us_in_education-eng-full_report.pdf Accessed May 22, 2024.

Zuurmond, Maria, Islay Mactaggart, Nanda Kannuri, Gudlavalleti Murthy, Joseph Enyegue Oye, and Sarah Polack. 2019. "Barriers and Facilitators to Accessing Health Services: A Qualitative Study Amongst People with Disabilities in Cameroon and India." *Int J Environ Res Public Health* 16, no. 7: 1126. https://doi.org//10.3390/ijerph16071126. Accessed February 19, 2024.

Centre for Women's Development Studies
An autonomous research institute supported by the
Indian Council of Social Science Research (ICSSR)
25 Bhai Vir Singh Marg(Gole Market), New Delhi - 110001