



# Menstrual Health and Hygiene Management for Persons with Disability



Insights and Good Practices from India

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### **Executive Summary**

Persons with disabilities (PwD) constitute 2.2% of the total Indian population, corresponding to 26.8 million people (Registrar General of India, 2011). The Rights of Persons with Disabilities (RPwD) Act, 2016 specifies that a person with disabilities has "long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others" (Government of India, 2016). Among PwDs, girls and women with impairments are particularly stigmatized, facing the double burden of being female and having a disability. Their rights, dignity and autonomy are often disregarded and violated. While efforts are ongoing to facilitate inclusive education and employment, the health and reproductive rights of PwDs are starkly neglected. Menstruation, a basic physiological aspect of sexual and reproductive health (SRH), is deeply affected for girls and women with disabilities.

Menstrual health, which is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in relation to the menstrual cycle, is relevant for all people who experience menstruation, irrespective of their socio-economic status and abilities. For PwDs who menstruate, their menstrual health needs are poorly understood and addressed, placing them at risk of adverse health outcomes and compromising their wellbeing.

Given the increased attention to and investment in menstrual health and hygiene globally and in India, the limited discourse around the intersection of menstruation and disability is striking and needs attention and action. Attempting to fill these lacunae to the extent possible, this white paper outlines the key challenges and constraints faced by PwDs with regard to menstrual health and hygiene, and presents simple and potentially scalable solutions. The paper draws on the experiences and solutions shared by individuals and organizations working closely with persons with varied disabilities across India. Salient areas for action to promote good menstrual health of PwDs include:

- Information, Education and Communication (IEC) on menstrual health and hygiene in accessible formats that are appropriate for PwD with differential needs and functioning capacities
- An enabling socio-cultural environment for menstrual health and hygiene
- Appropriate and safe menstrual absorbents, and hygiene promotion
- Responsive and inclusive WASH facilities, including disposal solutions in different settings (home, school, place of work) and humanitarian contexts

Solutions for PwDs across the domains noted above must recognize the heterogeneity of needs and experiences of persons with different disabilities, and among persons with similar disabilities living in diverse socio-economic contexts. Caregivers, both family caregivers and institutional carers, are vital in disability-focused interventions, and need to be included both as participants and as partners. Underlying all interventions is a rights-based approach that highlights the importance of placing the diverse needs and experiences of persons with disabilities at the centre and understanding and responding to them in a respectful and responsive manner.

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# **Acronyms**

BCC Behavior Change Communication

CRPD Convention on Rights of Persons with Disability

DPO(s) Disabled People's Organization

FLW Frontline Worker

IEC Information, Education and Communication

IPC Interpersonal Communication

ISL Indian Sign Language

IVRS Interactive Voice Response System

KII Key informant interview

MHH Menstrual Health and Hygiene

MHHM Menstrual Health and Hygiene Management

MoSPI Ministry of Statistics and Programme Implementation

NGO Non-Governmental Organization

NPCB National Programme for Control of Blindness

PMS Premenstrual Syndrome

OLS Open Learning School

PwD Persons with Disability

SBM Swachh Bharat Mission

SOP Standard Operating Procedure

SRHR Sexual and Reproductive Health and Rights

SSA Sarva Shiksha Abhiyan

ToT Training of Trainers

UNFPA United Nations Population Fund

NID National Institute of Design

RPwD (Act) The Rights of Persons with Disabilities Act, 2006

ILO Act International Labour Organization

WASH Water, Sanitation and Hygiene

WHO World Health Organization

# **Glossary of terms**

Braille	Braille is a tactile method of communication that enables people with visual impairment to read. Each Braille character or cell is made up of six dots, arranged in a rectangle, containing two columns of three dots each. Braille can be adapted to several languages including Hindi.
Caregivers	Caregivers provide care to persons who need assistance with everyday self-care activities. There are two broad types of caregivers: 1) Home-based caregivers are often family members who care for persons with disabilities. Home-based caregiving is often gendered work, with women (most often mothers) taking on the bulk of responsibilities (Thapa & Sivakami, 2017). 2) Institutional caregivers work in an organization, health care facility or hospital, receive some level of training, and are monetarily compensated for their work.
Disabled People's Organization	A <b>Disabled People's Organization</b> is a representative organization or group of persons with disabilities, where persons with disabilities constitute most of the overall staff, board, and volunteers in all levels of the organization. It includes organizations of relatives of persons with disabilities (only those representing groups without legal capacity to form organizations, such as children with disabilities and persons with intellectual disabilities) where the primary aim of these organizations is empowerment and the growth of self-advocacy of persons with disabilities.
Indian Sign Language and Indian Sign Language Interpreters	<b>Indian Sign Language</b> (ISL) is used by and to communicate with people with hearing impairment. Indian Sign Language Interpreters translate verbal information into Indian Sign Language to communicate with persons with hearing impairments.
Menstrual Health	Menstrual health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in relation to the menstrual cycle. This definition is applicable to all menstruators, including those with disabilities.

Multiple Disabilities	According to the <b>Rights of Persons with Disabilities (RPwD) Act, 2016</b> , a person who has more than one disability recognized under the Act is identified as having multiple disabilities.
Person with Disability	The <b>RPwD Act, 2016</b> defines 'person with disability" 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".
People with Hearing Impairment	As per the <b>World Health Organization</b> , a person who is not able to hear as well as someone with normal hearing – hearing thresholds of 25 decibel or better in both ears – is said to have hearing impairment. Hearing loss may be mild, moderate, severe, or profound. It can affect one ear or both ears, and leads to difficulty in hearing conversational speech or loud sounds. Hearing Impairment can be hard of hearing (HOH) or deaf.  The <b>RPwD Act, (2016)</b> , specifies "deaf" as persons having 70 DB hearing loss in speech frequencies in both ears. "Hard of hearing" means person having 60 DB to 70 DB hearing loss in speech frequencies in both ears.
People with Intellectual Disability	As per the RPwD Act, (2016), intellectual disability is defined as a condition characterized by significant limitation in both intellectual functioning (reasoning, learning, problem solving) and adaptive behavior, which covers a range of everyday social and practical skills including – specific learning disabilities (a heterogeneous group of conditions where there is a deficit in processing language, spoken or written, that may manifest itself as a difficulty to comprehend, speak, write, spell, do mathematical calculations. This category includes conditions as perceptual disabilities, dyslexia, dysgraphia, dyscalculia, dyspraxia and development aphasia. In addition, autism spectrum disorder is also included and refers to a neurodevelopmental condition typically appearing in the first three years of life that significantly affects a person's ability to communicate, understand relationships and relate to others, and is frequently associated with unusual or stereotypical rituals or behaviours.
People with locomotor disability	The <b>RPwD Act (2016)</b> specifies locomotor disability as a person's inability to execute distinctive activities associated with movement of self and objects resulting from affliction of musculoskeletal or nervous system or both. Locomotor disability includes cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular

dystrophy.

People with Visual Impairment	<b>Visual impairment</b> is when a person has sight loss that cannot be fully corrected using glasses or contact lenses. Blindness as defined by the National Programme for Control of Blindness (NPCB) as – a) Inability of a person to count fingers from a distance of 6 meters or 20 feet (technical definition), b) Vision 6/60 or less with the best possible spectacle correction, c) Diminution of field vision to 20 feet or less in better eye. There are two main categories of visual impairment: 1) Being partially sighted or sight impaired, where the level of sight loss is moderate, and; 2) Severe sight impairment (blindness), where the level of sight loss is so severe that activities that rely on eyesight become impossible.
Reproductive Health	Reproductive health is 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 implies that people can 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 (WHO, 2006).
Sexual Health	According to the World Health Organization(2006), sexual health is a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, and infirmity.
Special Schools	A special school is a school for children with disabilities who have special needs (in terms of education or learning). In these schools, the curriculum and learning approach is tailored to meet the needs of children with disabilities.

#### **Introduction**

# 1.1 Status of persons with disability in India and implications for their sexual and reproductive health and wellbeing

Persons with disabilities (PwD) constitute 2.2% of the total Indian population, corresponding to 26.8 million people (Registrar General of India, 2011). The Rights of Persons with Disabilities (RPwD) Act, 2016 specifies that a person with disabilities has "long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others" (Government of India, 2016). The RPwD Act,

2016 recognizes several disabilities including physical disabilities (locomotor disabilities, visual impairment, hearing impairment, speech and language disability); intellectual disabilities (learning disabilities, autism spectrum disorders); mental illnesses and disabilities caused by chronic neurological conditions (multiple sclerosis, Parkinson's disease) and blood disorders (such as haemophilia, thalassemia), and multiple disabilities¹.Disabilities differ in terms of their severity, that is the extent to which they affect the person's daily functioning and their support needs, and can be broadly categorized as mild, moderate, and severe (TARSHI, 2018). Some PwDs have "high support" needs in terms of intensive physical, psychological



<sup>&</sup>lt;sup>1</sup> A full list of Disability recognized under the RPwD Act, 2016 can be found in Annexure 1.

and/or cognitive support, to carry out daily activities, take independent and informed decisions to access services and participate in various areas of daily life including education, employment, family and community life, and treatment and therapy (Government of India, 2016).

Stemming partly from their impairments and partly from socio-cultural attitudes towards disabilities, PwDs may not be able to fully participate in many areas of daily life or be excluded from doing so. In response to these hurdles, the RPwD Act, 2016 stipulates the rights and entitlements of PwDs, emphasizing equality and non-discrimination, protection from cruelty, inhumane treatment, abuse, violence and exploitation; the right to participate in community life, protection and safety; as well as equal opportunities for education, skill development, employment, social security, health, rehabilitation and recreation. The RPwD Act, 2016 importantly recognizes that certain groups among PwDs are particularly vulnerable, such as women and children, and that certain rights that may be more neglected or disregarded than others, such as reproductive rights. Despite these provisions, the realization of rights and entitlements of PwDs is poor, and grossly undermined, especially for those from socially and economically vulnerable groups. Together, stigmatization, discrimination and inequalities undermine and violate the rights, dignity and autonomy of PwDs (WHO, 2013).

Among PwDs, girls and women with impairments are particularly vulnerable, facing the double burden of being female and having a disability. Efforts to facilitate inclusive education and employment are ongoing, yet the health and reproductive rights of this population are starkly neglected (Thapa & Sivakami, 2017). The RPwD Act, 2016, recognizes reproductive rights, stipulating that, "Government shall ensure that persons with disabilities have access to appropriate information regarding reproductive and family planning" and that "no person with disability shall be subject to any medical procedure which leads to infertility without his or her free and informed consent" (Government of India, 2016). The chasm lies in the operationalization of these important provisions through inclusive educational and health services for PwDs, particularly for girls and women.

Deeply embedded prejudices and misconceptions about the reproductive anatomy and abilities of PwDs exist (Cuskelly & Bryde, 2004; Galea et al., 2004), and manifest in them being considered asexual, unsuitable for marriage and unable to manage their fertility or raise children (UNFPA, 2013). Access to sexual and reproductive health (SRH) information and services is compromised by these social and physical barriers. PwDs are markedly more likely to be denied information on SRH, including menstrual health and hygiene compared to their counterparts without any impairments (Wilbur et al., 2019). Several studies stress the critical need for comprehensive SRH information for PwD (e.g., Wong 2000; Vaughn et al. 2015; Wilbur et al., 2019), with lack of information identified as a key factor in increasing their vulnerability to SRH problems, including the inability to negotiate safe sexual relationships (TARSHI, 2010). The consequences are dire - women and girls with disabilities are three times more likely to be victims of physical and sexual abuse (UNFPA, 2013). The risks faced by girls and women with disabilities to poor health, including poor SRH, are heightened during public health emergencies and humanitarian crises. A survey with women, nonbinary and transgender persons with disabilities during the early days of the COVID-19 pandemic highlighted the fear among this marginalized group that their already constrained access to support and services will be further compromised. The survey report called for emergency response to include attention to gender and disabilities (Women Enabled International, 2020).

Menstruation, a basic physiological aspect of SRH, is deeply affected for girls and women with disabilities. Field insights suggest compromised menstrual health of persons with disability, resulting from a complex interplay of factors that affect menstrual health for all in general, compounded by the physical and psycho-social vulnerabilities of having one or more disabilities.

# 1.2 Menstrual health of persons with disability

In early 2021, the newly conceptualized definition of menstrual health was proposed - menstrual health is a **state of complete physical, mental, and social**  well-being and not merely the absence of disease or infirmity, in relation to the menstrual cycle (Hennegan et al, 2021). The landmark paper proposing this definition marked a significant shift from the narrow focus on menstrual hygiene to elucidate key aspects of menstrual health, for all people who experience a menstrual cycle, throughout their life-course:

- Access to accurate, timely, age-appropriate information about menstrual cycles, menstruation, and changes experienced throughout the life-course, as well as related self-care and hygiene practices
- Care for their bodies during menstruation such that their preferences, hygiene, comfort, privacy, and safety are supported. This includes accessing and using effective and affordable menstrual materials and having supportive facilities and services (including water, sanitation and hygiene (WASH) services), changing menstrual materials, and cleaning and/or disposing of used materials
- Access to timely diagnosis, treatment and care for menstrual cycle-related discomforts and disorders, including access to appropriate health services and resources, pain relief, and strategies for self-care
- Experience a positive and respectful environment in relation to the menstrual cycle, free from stigma and psychological distress, including the resources and support they need to confidently care for their bodies and make informed decisions about self-care throughout their menstrual cycle
- Decide whether and how to participate in all spheres of life, including civil, cultural, economic, social, and political, during all phases of the menstrual cycle, free from menstruationrelated exclusion, restriction, discrimination, coercion, and/or violence

The above conceptualization of menstrual health is relevant for all people who experience the menstrual cycle, irrespective of their gender identity, socioeconomic status, and physical and cognitive abilities. The purpose and strength of this conceptualization is to engender supportive and inclusive actions for all menstruators, incorporate the nuances of lived realities and differing contexts in the delivery of interventions, and subtly draw the linkage between menstrual health and sexual and reproductive health

and rights. These aspects are critical considerations for policy makers and implementers to operationalize the definition and its components through policies and programs on menstrual health and hygiene (MHH).

For a vast majority of women, girls, and persons with gender diverse identities, menstruation is more than just a physiological process; the experience of menses is couched in socio-cultural norms (that perceive menstrual blood as impure or dirty, and menstruators as impure), and economic and structural factors that present several hurdles to hygienic management, good health, help and health-seeking behaviours. Adolescents and adults with disabilities face greater challenges to achieving good menstrual health, compounded by constraints imposed by limited mobility, cognitive capacities and self-care, and the socio-cultural implications of being female with a disability. Stemming from the complex interplay of factors related to gender, female reproductive processes, and disability, the menstrual needs and experiences of PwD who menstruate are poorly acknowledged and supressed, and consequently, remain unaddressed on several fronts.

The definition of menstrual health clearly highlights the need for information, social supports, access to safe menstrual materials, WASH facilities, health services, and a conducive environment for those who menstruate. For PwDs, these needs must be interpreted and addressed in the context of their disability (or disabilities) and their socio-economic Mainstream information, education, realities. communication (IEC) on MHH may not be relevant for PwDs as these materials are not responsive to their physical and cognitive capacities, and social realities. Moreover, intervention needs may differ for persons experiencing similar disabilities. For example, interventions with girls and women with visual impairments may develop MHH focused IEC materials in Braille, and in Indian Sign Language (ISL) for those with hearing impairments. However, persons with visual impairments and hearing impairments who do not know Braille or ISL respectively, will be excluded from receiving this essential information. In the similar vein, PwDs experiencing multiple impairments need MHH interventions that respond to their specific

information and social support needs and constraints. MHH interventions for PwDs call for nuanced and responsive adaptation of MHH components to meaningfully improve menstrual health for this heterogeneous group.

The role and capacities of caregivers must be considered when framing and implementing any intervention for PwDs. Institutional care facilities and special schools do exist in India, yet these institutions are not widely available for or accessible to all those in need, and are often cost prohibitive. PwDs living in rural areas and non-metro cities, and those from low-income families are at a particular disadvantage in accessing such services. Existing institutions may specialize in certain types of disabilities, and therefore lack the capacities to meet the requirements of all persons with disabilities. For several PwDs, a bulk of support and care needs lie with the family, usually mothers and sisters (Alur, 2001). However, the avenues for information and support to primary caregivers are grossly limited; family caregivers often find themselves ill-equipped to handle the special needs of their children, and, are overwhelmed by yet another responsibility as their daughters enter puberty (Wikler, 1981). A study from urban India found that managing menses and maintaining menstrual hygiene placed considerable demands on mothers as these tasks required periodic attention and additional support, and were reported as the least preferred responsibilities (Thapa & Sivakami, 2017). The study further noted that caregivers devised their own methods to support menstrual management. Depending on the level of disability, some mothers trained their daughters to manage menstruation and menstrual hygiene independently. In other instances, mothers turned to long-term solutions like surgical procedures (e.g., hysterectomy), that eliminated the need for menstrual management and removed the risk of unwanted pregnancy. This study starkly found that families considered hysterectomy as an option even before the girl attained menarche (Thapa & Sivakami, 2017).

Given the increased attention to and investment in menstrual health and hygiene globally and in India, the limited discourse around the intersection of menstruation and disability is striking and must be addressed. In an attempt to fill these lacunae, this white paper outlines the menstrual health and hygiene needs of PwDs, as well as the role of their caregivers in India, and pools together potential solutions to enable these girls and women to experience and manage menses in a safe, dignified and healthy manner. Central to the paper is an inclusive, responsive and rights-based approach to all solutions.

2

## Methodology

#### 2.1 Goal and objectives of the paper

This document aims to capture the needs and experiences, solutions and innovations to improve menstrual health and hygiene management among persons with disability, and to enable their

caregivers at home and in institutions to provide adequate support. This is intended to be a *living document*, that should be reviewed and updated every two years to capture further insights, effective and new solutions.



- Identify and present the menstrual health and hygiene needs of persons with disabilities as well as their caregivers who care for and support them
- Identify specific considerations for menstrual health and hygiene interventions for persons with disabilities
- Outline considerations for solutions and highlight interventions implemented to improve menstrual health and hygiene for PwDs

#### 2.2 Methodology

The paper has been developed based on insights from:

- Desk review of global and India literature on MHH among persons with disabilities
- Key informant interviews (KII) with individual experts and organizations working with persons with disabilities. KIIs were conducted with 21 experts and organizations
- Focus group discussions with special educators and parent groups to understand the unique perspectives of home-based and institutional caregivers. Three focus group discussions were conducted with institutional caregivers, and one focus group discussion with parents of children with disabilities

The desk review, key informant interviews and focus group discussions explored the following:

- The menstrual health and hygiene of girls and women with the following disabilities: visual, hearing (and speech), locomotor, intellectual, and multiple impairments (co-morbid conditions)
- Menstrual health and hygiene needs in relation to: awareness and education, social norms related to menstruation, access to and hygienic use of menstrual hygiene materials, access to and use of WASH facilities, and caregiver needs
- Solutions and interventions to address menstrual health and hygiene needs with a focus on: education and awareness, addressing social norms, improving product access and facilitating hygienic use, enabling access to and use of water, sanitation and hygiene services, and addressing caregiver needs
- Resources and guidance documents on: Information, education, communication (IEC) and behavior change communication (BCC) resources on the areas noted above

#### 2.3 Framework guiding the paper

This document is guided by a framework that incorporates the following components:

#### 1. Type of disabilities

The needs, implications and solutions highlighted in this paper are relevant for people with visual impairment, hearing impairment<sup>2</sup>, locomotor impairment, select intellectual and developmental disabilities, and multiple disabilities<sup>3</sup>. The paper acknowledges that certain disabilities and impairments are not addressed. For instance, specific considerations for persons with autism spectrum disorders and other mental health conditions are not included in this version of the paper, and should be addressed in future versions.

Needs and solutions are highlighted keeping domains of functioning central. The paper explicitly notes that information and support needs, menstrual hygiene materials, WASH infrastructure and access, capacity building of caregivers will differ across type and degree of disability, and proposes considerations and solutions accordingly.

#### 2. Key stakeholders

This paper primarily focuses on actions to improve the menstrual health and hygiene management among persons with disabilities who experience menstruation, and their caregivers who support them at home and in institutional settings<sup>4</sup>.

People with disability who menstruate: Girls, women and persons with gender diverse identities who have a disability (or disabilities) and who experience menstruation have the right to good menstrual health. The paper acknowledges that girls and women of reproductive age constitute the majority of those who experience menstruation, and uses the term persons with disabilities to ensure that all those who experience a menstrual cycle are represented.

Caregivers: Caregivers include both family caregivers and institutional carers who look after and support PwDs. Caregivers often lack information and support to address physical and psychosocial menstrual hygiene needs of their children with disabilities. Orientation and training/

<sup>&</sup>lt;sup>2</sup> This paper recognizes that persons with hearing impairments also have speech impairments.

<sup>&</sup>lt;sup>3</sup> In the context of this paper, a person with multiple disabilities has two or more co-occurring disabilities that interact with each other, and may cause greater vulnerabilities. For example, a person with locomotor disability may also have intellectual impairment.

<sup>&</sup>lt;sup>4</sup> Information on menstrual health and hygiene management should be a component of sexual and reproductive health and rights education and services provided to all persons with disabilities, irrespective of their gender and experience of the menstrual cycle.

capacity building of primary caregivers, and continued support to them is imperative for good menstrual health of PwDs.

Other stakeholders: Other stakeholders who need to be sensitized on the needs of PwDs and potential solutions. include:

- Health care providers (doctors and nurses):
   Health care providers offer treatment to PwDs
   for their specific disabilities, and yet may not
   necessarily address the range of SRH needs,
   including menstrual health
- Policy makers and program implementers:
   While India has seen tremendous policy and
   programmatic action on menstrual hygiene
   management, the challenges and solutions for
   PwDs has been less explored and incorporated
   into policy and programmatic guidance. This
   holds true for Government decision makers
   and implementers, as well as civil society

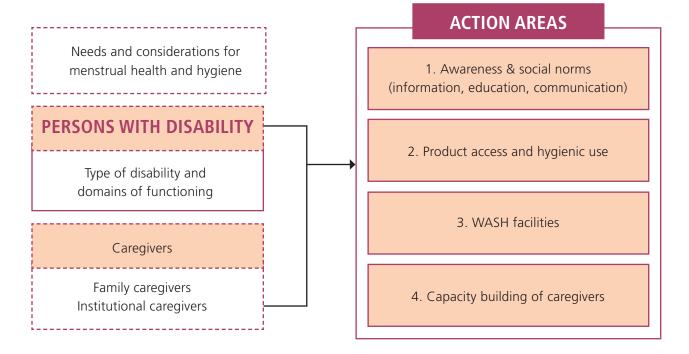
organizations that deliver menstrual hygiene management interventions in rural and urban settings across the country

# 3. Menstrual health needs of and solutions for PwD and their caregivers related to:

The paper focuses on the following action areas, identified by KIIs and through the review of literature:

- Information, education and communication on menstrual health and hygiene in accessible formats that are appropriate for PwD with differential needs and functioning capacities
- Social norms relevant for menstrual health and hygiene
- Appropriate and safe menstrual absorbents, and their hygienic use
- Water, sanitation and hygiene (WASH) facilities, including disposal solutions in different settings (home, school, place of work)

Figure 1: Framework for inclusive MHHM programming for people with disabilities



#### 2.4 Structure of the paper

The paper has three broad sections, corresponding to the main areas of intervention for menstrual health and hygiene for PwDs and caregivers, namely awareness and social norms; product access and hygienic use, and inclusive WASH

facilities, and concludes with a discussion on how MHH interventions for PwDs can be integrated within policy and programmatic dialogues. Within each of the three action areas, the paper outlines the needs and challenges faced, considerations for each type of disability, and solutions deployed by organizations.



#### **ACTION AREA 1:**

Information, education, communication and positive social norms related to menstrual health and hygiene for persons with disabilities

# 3.1 The need for comprehensive information and positive social norms on menstruation and menstrual hygiene

Persons with disabilities have the right to comprehensive SRH (Vaughn et al. 2015; Wong 2000; TARSHI, 2010). While girls and women in India face significant challenges to responsive and accessible SRH information, support and services (beyond family planning and maternal health services), these challenges are magnified for those with disabilities. This information and service barrier and gap increases their vulnerability to SRH problems, undermines their ability to negotiate safe sexual relationships (TARSHI,

2010), and increases their risk of physical and sexual abuse three fold (UNFPA, 2013).

Article 9 of the Convention on the Rights of Persons with Disabilities, 2006 (CRPD) necessitates that appropriate, comprehensive, high-quality information in accessible formats should be made available to PwDs. Information and awareness on menstrual health and hygiene are essential to enable girls and women to manage menstruation healthily, with dignity, and as independently as feasible. This, in turn, will engender bodily autonomy, self-confidence, and agency, and contribute towards the realization of reproductive health and rights for PwDs across their lifespan.



# 3.2 Implications of disability in accessing information, education and training on MHH

Several factors shape whether and the extent to which PwDs who menstruate, and their caregivers can access and receive comprehensive information on menstrual health and hygiene.

Misconceptions and stigma as barriers to information access: Misconceptions and assumptions regarding the reproductive abilities and sexuality of PwDs undermines their SRH rights, including the right to information and essential services. PwDs are perceived as being sexually inactive and even asexual, and as unsuitable for marriage, unable to manage their fertility or raise children (UNFPA, 2013). Consequently, PwDs are denied information and education on SRH including menstrual health and hygiene management (Wilbur et al., 2019). Studies further note that since PwDs are assumed to be asexual, they are not included in routine MHH related awareness and outreach efforts (Murthy et al., 2014; Groce, 2005; Groce et al., 2006a; Groce et al., 2006b; Moll, 2007). Discussions with key informants highlighted that information provided to PwDs is often restricted to how to change menstrual hygiene materials, and that too only after they attain menarche. The physiological aspects on menstruation and the menstrual cycle are rarely discussed.

Unavailability of information in accessible formats:

According to Census 2011, overall literacy rate among PwDs is 54.5% as compared to 74% among people without a disability (Office of the Registrar General & Census Commissioner, Government of India). Urban-rural differences are also apparent, as 68% PwDs in urban areas are literate in contrast with just 49% PwDs in rural India (MoSPI, 2016). Low literacy levels among PwDs adds an additional barrier in accessing information on MHH as they cannot read written communication. A vast majority of mainstream resource materials on MHH are text heavy, with limited and poorly represented visual imagery, and are rarely adapted to reflect the realities and meet the requirements of marginalized groups (Becker et al., 1997; Wong, 2000; Anderson & Kitchin, 2000; WHO & UNFPA, 2009). Persons who face challenges in comprehending mainstream materials are at considerable disadvantage. Persons with intellectual or cognitive impairments face significant hurdles in comprehending information shared in such formats. Greater information sharing through digital media brings to light the issue of digital access. Girls and women's interaction with digital media are limited, and those with disabilities experience far greater hurdles to such digital access.

Of all information barriers faced by PwDs, the most significant is the paucity of such materials in disability-specific and accessible formats. For instance, mainstream information on MHM are in the form of visual posters, pocket books, and other textual and pictorial IEC, and not available in Braille, large print, audio or experiential formats, as needed by persons with visual impairments. Braille is most often taught in special schools; as a result, students with visual impairment attending regular or mainstream schools (Government, Government-aided, and private) are unlikely to be introduced to Braille. Textbooks in regular schools cater to students without impairments, and the process of translating educational and extracurricular content into suitable formats for children with disabilities is challenging and overlooked. Children with visual impairments who are not in special schools or mainstream schools are further disadvantaged, lacking exposure to any educational content.



For people with hearing impairments, pictorial representation and experiential formats rare. Few educators and persons with hearing impairments are taught Indian Sign Language (ISL). Furthermore, the use of ISL is complex for several reasons. First, few ISL interpreters and users exist; second, girls and women who do not know ISL are not able to communicate; third, terms for certain aspects of menstruation may not exist in ISL; and fourth, ISL interpreters are not trained on sensitive issues such as MHH and SRH and are unable to provide all the necessary information in a transparent and unbiased manner. A key informant brought to light the fact that ISL interpreters have their own prejudices and sometime filter information on MHH being provided to people with hearing impairments. In Nepal, Wilbur et al. (2019) found that Nepalese sign language does not have an expression for menstruation.

Information withheld by a range of stakeholders: PwD are denied SRH and MHH information by a range of stakeholders including their family members, teachers and special educators, healthcare providers, and frontline workers (FLW) (TARSHI, 2010; WHO & UNFPA; 2009). These stakeholders perceive PwDs to be childlike and dependent, and not suited for marriage and parenthood, and therefore not in need of such information and education (Thapa & Sivakami, 2017).

Research insights and KIIs revealed that as girls with disabilities attain puberty, parents are likely to restrict their movement and interactions to a greater extent. Due to stigma, PwDs are kept hidden inside the home, denied the freedom of mobility, education and employment (Sharma & Sivakami, 2018). The physical journey to school is difficult, compounded by fear that girls with disabilities are vulnerable to abuse, especially sexual abuse in schools. As a result, many children and adolescents with disabilities discontinue their education or are never educated. They then lack exposure to school based channels of information on SRH and MHH, peer support, and existing adolescent health services. Even if children with disabilities are in school, they may be left out of extra-curricular activities and sessions. A stark study across 57 countries found that school going children with disabilities were much more likely to be excluded from receiving general information on health in educational institutions (World Bank, 2011).

Lack of information and training for caregivers (at home and at institutions) and medical professional to communicate with PwDs: Often times, primary carers (mostly mothers), teachers and special educators, health care providers and FLWs struggle to communicate essential health information in appropriate formats to PwDs, particularly on sensitive SRH issues. A representative from a Disabled Person's Organization (DPO) reported that mothers or family members of persons with hearing impairments do not know ISL, resulting in a "lifetime of communication gaps" between the family and PwD. Key informants shared that special educators trained in ISL are few, with those trained often bringing their biases into interactions with PwDs. Such preconceptions result in filtering of information and communicating partial or incomplete information to persons with hearing impairments. Mothers of persons with intellectual disabilities were found to be ill-equipped to deal with pre-menstrual symptoms and felt "frustrated and overwhelmed". Studies have also shown decreased quality of life, increased risk of illness and difficult family and social relationships for family caregivers, especially mothers (UNPFA, 2009). Strikingly, health care providers, including gynaecologists, are ill equipped to address the specific SRH needs of PwD (Sharma & Sivakami, 2018).

# 3.3 Information, education and communication on menstrual health and hygiene for PwDs

Two important considerations exist for MHH education and awareness interventions for PwDs. First, MHH information and education must reach both PwDs and their primary caregivers – at homes and in institutions. Second, formats for information sharing and support must be responsive to their disabilities and to their domains of functioning.

#### **Stakeholder groups**

Table 1 highlights the primary, secondary, and tertiary groups to be reached with information and education on MHM.

Table 1: Stakeholder groups for MHM information, education and communication on MHH for PwD

Stakeholder groups for c	communication	Rationale	
Primary (those to provide education and impart skills to manage menstruation)	<ul> <li>PwD of reproductive age</li> <li>Family caregivers</li> <li>Institutional caregivers</li> </ul>	PwD of reproductive age are the focus of communication efforts to create awareness about the body and basic physiological processes such as menstruation, and teach skills to manage menstruation independently and in a healthy manner.  Caregivers, both home-based and institutional, are primary sources of support for PwDs.  Persons with high support needs are dependent on caregivers for management of daily tasks including menstrual hygiene management.	
Secondary (those who impart information to PwD)	<ul> <li>Family caregivers</li> <li>Institutional caregivers</li> <li>Special educators and Indian Sign Language (ISL) Interpreters</li> <li>DPOs and NGOs working with PwDs</li> </ul>	Family caregivers, institutional caregivers, special educators, ISL interpreters, and organizations working with PwDs may have misconceptions about PwDs and their menstrual needs, and are influenced by societal norms related to menstruation.  These critical stakeholders require training to provide comprehensive information and support, ideate context specific solutions, and engage with PwDs in a respectful and non-judgmental manner to improve their health and menstrual hygiene practices.	
Tertiary (those who create a conducive environment for changing existing norms/prejudices	<ul> <li>Brothers and fathers</li> <li>Health care providers</li> <li>Regular schools (attended by children with disabilities)</li> <li>Community leaders</li> <li>Local Government (Gram Panchayat, Gram Pradhan/Sarpanch), district administration</li> </ul>	Male family members (fathers and brothers), are often decision makers in the family, and may control the financial resources. As seen in some routine MHH interventions, men and boys need to be sensitized to MHH and how PwDs in their families may require additional support for good menstrual health.  The tertiary audience can support efforts to improve MHH (e.g., inclusive toilets at home, at the community level and in institutions), and facilitate access to community based services and facilities.	

## Information needs on MHH and addressing social norms

The information, education, and communication

areas for PwD and their caregivers on MHHM are presented in Table 2.

Table 2: Details on information needs of PwDs and their caregivers

Information and behavior change communication on:	Details	Considerations for a certain type of disability	Relevance for caregivers
Menstruation and menstrual hygiene	<ul> <li>Puberty (pubertal changes in girls and boys)</li> <li>The female reproductive system (and male reproductive system as appropriate)</li> <li>Menstruation and tracking of menstrual cycle</li> <li>Menstrual hygiene management (changing menstrual hygiene materials, daily bathing and genital washing)</li> <li>Basic information on pre-menstrual syndrome, common menstrual problems and disorders (e.g., dysmenorrhea, amenorrhea)</li> </ul>	<ul> <li>PwDs without and with mild intellectual impairment can be provided all information in suitable formats that are responsive to their needs</li> <li>People with visual impairment need skills to identify when menses start and to determine the difference between discharge of menstrual blood and vaginal discharge.</li> <li>Essential information on pubertal changes, menstruation, menstrual cycle and hygiene must be provided to people with severe or profound intellectual disability (this is also relevant for people who have intellectual disability in addition any other disability).</li> </ul>	In-depth information relevant for all caregivers. Additional efforts required to customize this information to meet specific needs of each type of disability
Types of menstrual materials available  Hygienic and safe use of menstrual hygiene materials	<ul> <li>Description of the types of menstrual hygiene materials, including:</li> <li>Cloth pads (stitched and unstitched)</li> <li>Disposable sanitary pads</li> <li>Menstrual cups</li> <li>Menstrual underwear</li> <li>Underwear</li> </ul>	• PwDs without and with mild intellectual impairment can be provided all information in suitable formats that are responsive to their needs. Emphasis should be on tactile interactions with menstrual materials and understanding of hygienic use.	

Information and behavior change communication on:	Details	Considerations for a certain type of disability	Relevance for caregivers
	<ul> <li>Advantages and disadvantages of each type of menstrual hygiene material, and considerations for use (In annexure 2)</li> <li>Instructions to use different menstrual hygiene materials</li> <li>Suitability of menstrual hygiene materials according to the type of disability and adapting menstrual hygiene materials to meet specific needs</li> <li>Duration of use (3-6 hours) and frequency of changing menstrual materials (3-6 times a day)</li> <li>Washing of genitals with water and daily bathing</li> <li>Risks associated with poor menstrual hygiene and the use of unsafe materials</li> <li>Where to buy or access menstrual hygiene materials</li> <li>How to keep menstrual materials safely/ hygienically in schools, institutions and at home</li> </ul>	<ul> <li>Demonstration of how to use cloth and disposable sanitary pads to be carried out, with support to practice how materials will be used (e.g., demonstration sessions on placing pads in the underwear)</li> <li>For people with severe or profound intellectual disabilities, choosing between a number products can be confusing and overwhelming. Discussion with the girl/woman and her primary caregiver will determine the most appropriate product(s) to introduce. Use of menstrual materials can be demonstrated as illustrated by the Bishesta intervention (Nepal)</li> </ul>	<ul> <li>Caregivers need information on the range of menstrual hygiene materials, considerations of each product for different disabilities, and on promoting and supporting hygienic use of materials (details on modifications to products outlined in next section on menstrual hygiene materials)</li> <li>Caregivers also need skills to engage with PwDs to identify their preference for and comfort with different menstrual hygiene materials</li> <li>Caregivers of persons with severe intellectual disability and/or severe mobility restrictions need information on how to support them for menstrual hygiene (illustration in next section on menstrual hygiene materials)</li> </ul>

Information and behavior change communication on:	Details	Considerations for a certain type of disability	Relevance for caregivers
Hygienic maintenance of menstrual hygiene materials	<ul> <li>Reusable menstrual materials:</li> <li>How and where to wash with soap and water, especially when water is in limited supply</li> <li>Guidance on soaking cloth pads for 15-30 mins prior to washing, for ease of washing</li> <li>How and where to sun dry washed cloth pads properly</li> <li>How and where to store cleaned materials safely</li> <li>Disposable menstrual materials</li> <li>Guidance on not washing disposable sanitary pads after use</li> </ul>	Based on the degree of disability and the ability to perform washing tasks, information on washing, drying, and safe storage to be given to all.	<ul> <li>Caregivers need information on hygienic maintenance of reusable materials and one time use of disposable materials, and how they can support PwDs to engage in hygienic management of these materials.</li> <li>Caregivers of those with severe/profound intellectual disabilities, visual impairments, and severe locomotor disabilities who cannot wash, dry and store materials themselves, need training on performing these tasks</li> </ul>
Safe disposal of menstrual hygiene materials	<ul> <li>Instructions to discard used materials by wrapping them in paper and throwing in dustbin.</li> <li>Unsafe disposal (what not to do) – discard in the open, throw in toilet.</li> </ul>	Information can be provided to all those with disabilities, along with guidance on how to place dustbins for ease of access.	<ul> <li>Information can be provided to all caregivers, along with guidance on how to place dustbins for ease of access</li> <li>Administrators of disability institutions require standard protocols for regular disposal and management of MH waste products and ensuring hygiene in sanitation facilities</li> </ul>

Information and behavior change communication on:	Details	Considerations for a certain type of disability	Relevance for caregivers
Management of pre- menstrual syndrome and addressing menstrual problems and disorders	<ul> <li>Pre-menstrual symptoms and menstrual problems</li> <li>Management of emotional changes / behaviour changes associated with premenstrual phase</li> <li>Communicating pain or discomfort (for PwD)</li> <li>Identifying whether PwD is in pain or distress and what can be done to manage it (for caregivers)</li> </ul>	<ul> <li>Information on these topics to be shared with all PwDs, with an emphasis on how to manage pre-menstrual symptoms and menstrual pain</li> <li>For those with severe/ profound intellectual disabilities, interactive dolls may have to be used to identify discomfort and pain</li> </ul>	• Caregivers of people with intellectual disability need support to identify premenstrual symptoms, pain, discomfort, emotional changes, especially when the PwD cannot verbally express their experiences
Addressing restrictive gender and social norms related to menstruation	<ul> <li>Identifying social norms related to food, social interactions, religious worship, and mobility and how they affect menstrual hygiene practices related to access to information, support and menstrual hygiene materials, hygienic use of materials, safe disposal of used materials</li> <li>Discussing which restrictive social norms can be changed, and how this can be done, providing examples of how adolescents and adults have fostered favourable attitudes related to menstruation</li> <li>Engaging key community influencers (e.g., mothers, men and boys, community leaders, teachers) to foster positive attitudes and social norms</li> </ul>	<ul> <li>Relevant for all persons disabilities, with communication tailored to cognitive capacities</li> <li>For persons with severe/ profound intellectual disabilities, taboos and restrictions need to be communicated in a manner that they can understand using stories and adequate repetition</li> </ul>	<ul> <li>Relevant for all caregivers, with facilitated sessions to help them address restrictive social norms practiced in their home and institutions</li> <li>Caregivers need skills to create a culture of openness to discuss sensitive issues and proactively address and mitigate taboos</li> </ul>

Information and behavior change communication on:	Details	Considerations for a certain type of disability	Relevance for caregivers
Information on sexual reproductive rights	<ul> <li>Information on bodily autonomy, safe sex, right to provide and withhold consent for any sexual activity</li> <li>Possible health implications of sterilization, including hysterectomy</li> <li>Sexual and gender-based violence - information on what qualifies as harassment (verbal, visual, and physical), and good touch, bad touch</li> <li>Information on where counselling services for SRHR, mental health and psychosocial support can be accessed</li> </ul>	<ul> <li>Information on SRH, gender-based violence should be provided in an age appropriate and sensitive manner</li> <li>Privacy and confidentiality must be ensured, and appropriate linkages with referral services must be facilitated</li> <li>For girls and women with severe/profound intellectual disabilities, information must be provided in a manner that can be comprehended. For instance, use of dolls and stories can facilitate understanding and expression of negative experiences</li> </ul>	<ul> <li>Caregivers need information on SRH, how to communicate information to girls and women with disabilities, and engage them in discussions in a sensitive manner</li> <li>Caregivers need additional guidance on how to identify signs of harassment and abuse, especially for those girls and women who are unable to express themselves and their experiences.</li> <li>Instructions to caregivers to decide appropriate person to look after PwD in case of absence and emergencies</li> </ul>

# 3.4 Communication approaches for information on MHH

Educational institutions for PwDs (regular day school, special school, specialized residential facility for PwD) are important platforms to communicate information on MHH, supported by special educators

and teachers. Home based outreach efforts by NGOs, DPOs, health care providers and frontline workers are needed for PwDs who are not in an educational institution, and their caregivers.

Table 3 presets the communication approaches needed for relevant stakeholders.

Table 3: Communication approaches for providing information, education, and communication on MHH

Strategy	Stakeholders and suitability of approach for types of disabilities
Interpersonal communication (IPC) in small groups or through one on one sessions	<ul> <li>Persons with visual impairment (partial and full) and their caregivers</li> <li>Persons with hearing impairment (partial and full) and their caregivers</li> <li>Persons with locomotor impairment (partial and full) and their caregivers</li> <li>Persons with intellectual impairment and their caregivers will require specialized IPC depending on the severity of the impairment (described later)</li> </ul>
Individual plan and training/education	<ul> <li>Depending on the type(s), severity of disability, understanding capacity, need for support or assistance, an individual training plan<sup>5</sup> should be made for:</li> <li>All persons with disabilities</li> <li>People with intellectual disability and their caregivers (especially those who have moderate-severe intellectual disabilities)</li> <li>People with locomotor disability and their caregivers (particularly those who have restricted mobility and those who are immobile without assistance)</li> <li>People with multiple disabilities and their caregivers (for instance, hearing and visual impairment, visual and intellectual impairment)</li> </ul>
Home visits	<ul> <li>Home visits by DPOs and NGOs allow for direct support to PwDs and their home-based/family caregivers, especially when mobility outside the home is challenging or discouraged (due to social stigma). This is particularly needed for:</li> <li>People with visual impairment, hearing impairment and/or locomotor impairment who are not enrolled or engaged in any institution</li> <li>People with intellectual disability</li> <li>Home visits are required to elicit support from fathers and brothers, and other influential family members</li> </ul>
IEC and behavior change communication materials (BCC)	<ul> <li>IEC materials tailored to different abilities (details on IEC/BCC materials discussed later in this section)</li> <li>FAQs booklets for PwDs and caregivers can help answer MHH related questions, including specific considerations for PwD.</li> <li>Information on taboos and myths related to menstruation should be conducted with their primary caregivers, and family members</li> </ul>

<sup>&</sup>lt;sup>5</sup> A training plan is a customized systematic plan of action to provide the necessary information and support in line with their needs and context.

Strategy	Stakeholders and suitability of approach for types of disabilities
Capacity building	The following stakeholders need to be trained to deliver information and support on MHH:  Home based/family caregivers  Indian Sign Language (ISL) Interpreters  Institutional caregivers  Peer educators  Special educators  DPOs and NGOs  Health care providers (doctors and nurses at the sub-center, PHC or health and wellness center. Private clinics may also be reached)  Frontline workers who conduct outreach to PwDs and their families, and those who implement routine MHH interventions in the community  Nodal teachers in regular schools conducting MHH sessions
Community dialogue to foster greater support for PwDs	<ul> <li>Community leaders</li> <li>Local Government (Gram Panchayat, Gram Pradhan/Sarpanch), district administration</li> </ul>

#### Key consideration for IEC and BCC for PwD

Accessible IEC and BCC materials are needed in relevant formats, of good quality covering necessary age- appropriate information in requisite detail. Key considerations for IEC and BCC materials are outlined as follows:

#### Regular communication on puberty and menarche before the first menses:

- Communicate information on puberty and menstruation to caregivers and PwDs before puberty. Such prior information will enable greater support to children when they attain puberty and experience their first menses. The depth of information shared will depend on the abilities of PwD to comprehend this information
- Provide information that is age-appropriate, relevant, and responsive to experiences and needs

**Developing IEC materials according to the type of disability:** Existing mainstream IEC/BCC materials should be reviewed for their suitability for people with a range of disabilities, and should be tailored to meet their specific requirements. Examples of disability-specific considerations include:

 Persons with visual impairments: IEC/BCC materials in Braille (where applicable), large texts, audio formats (e.g., radio or voice-overs),

- and experiential formats (e.g., three dimensional models, dolls). Digital information needs to be in PDF format to facilitate use of text to speech software
- Persons with hearing impairments: IEC/BCC in ISL, pictorial format, and audio subtitles in appropriate language (for those who can understand written language)
- Persons with intellectual disabilities: IEC/BCC in pictorial and experiential/tactile format, at the level of understanding and learning patterns of these individuals (e.g., materials from the Bishesta campaign)
- IEC materials should be made available in multiple formats to facilitate adequate repetition of essential information
- For persons having multiple disabilities, tailor materials to meet the needs of the predominant disability keeping in mind the severity and limitation imposed by co-occurring conditions

While IEC materials can also be developed in digital formats, they should be fully accessible for PwDs and their caregivers.

Clear and appropriate language with pictorial representation: 45% of PwDs in India are illiterate (MoSPI, 2016), while others may have had only a few years of formal schooling. Family caregivers



Kaniz and Sumaiya currently live in the girls hostel at PHT Center. They are both visually impaired students. Recently Local NGO Nabolok with the help of Water Aid Bangladesh has improved the health situation at the school by creating ease of access to pure water and sanitation facilities. The inclusive design of the facilities has changed the life of vision and hearing disabled students. Boalkhali, Khulna, Bangladesh. 28 November, 2021

Photo credit: WaterAid/DRIK/ Habibul Haque

may be illiterate or have limited education as well. In response to literacy constraints of PwDs and their caregivers, all IEC and BCC materials to keep the following in mind:

- Clear pictorial representation
- Use of models and dolls to explain menstruation and menstrual hygiene practices
- Where images and models are used:
  - Visual representation must be inclusive of bodies and experiences of PwD (e.g., IEC/ BCC for a person with mobility restrictions should depict a girl in a wheelchair or with supportive crutches or in bed)
  - Images to be positive, reinforce positive behaviors, bodily autonomy, and respect
- Textual information must be in the appropriate language with clear and large font size, accompanied by images (best to limit detailed textual information)
- Words and sentences (in text or audio) to be simple and clear, and locally relevant. Technical language should be avoided. For instance, using the local word for menstruation (e.g., mahina, masik pali, MC) and not the scientific term

**Information to be repeated and reinforced:** Repetition of information is necessary to sustain interest, overcome varying levels of understanding and different (often new) formats in which the information is provided. For instance, for persons with hearing impairment, if the information was

first presented via a sign language interpreter, the next session can be conducted using picture stories, reiterating key messages. Similarly, if information is provided to girls/women with intellectual disabilities using a doll, the subsequent session can use stories and song to reinforce key messages.

**Demonstration:** Demonstration using dolls and models must accompany the provision of information, particularly in relation with the reproductive system, menstrual cycle, and use of menstrual materials. Models can be effectively used to demonstrate how to wear menstrual hygiene materials, placement of menstrual hygiene material on underwear. During demonstrations:

- Impart information slowly, with repetition to ensure comprehension by all
- Use simple, clear language, without technical terms and jargon
- Use experiential and interactive materials, engaging PwD in activities, and encouraging them to touch the models and dolls, and menstrual materials

# 3.5 Additional consideration for IEC and BCC for persons with visual impairment

- Use three tactile dimensional (3D) models to explain the reproductive system and process of menstruation (using touch)
- Present information in audio formats, including digital audio formats (e.g., podcasts, WhatsApp audio), and radio campaigns
- Use materials with textual information in large fonts for persons with partial visual impairment.
   Avoid detailed pictures that require greater visual attention
- Provide only the most relevant information via Braille, as too much information communicated in Braille may be challenging to comprehend

Klls suggested training to develop tactile sense and sense of smell at a young age for those born with visual impairment (congenitally blind). People who become blind later in life (due to medical conditions) have to be trained to develop their other senses. The development of alternate senses is important even for MHM as the sense of smell and touch is often used to identify menstrual blood and vaginal discharge.

#### Examples from organizations on IEC and BCC for people with visual impairment<sup>6</sup>

#### **SAMARTHYAM**

Samarthyam has prepared a handbook for parents on home based education covering MHM for adolescent girls with severe and multiple disabilities. The handbook is a pictorial guide with 'easy to read' text for training parents with little to no literacy requirement to further train their daughter on MHM and self-care.

## THE SANITATION AND HYGIENE FUND – DEVELOPMENT OF TACTILE BOOKS "AS WE GROW UP"

The Sanitation and Hygiene Fund, formerly known as WSSCC, in collaboration with IIT Cell – the Centre for Excellence in Tactile Graphics, and Saksham Trust developed a tactile book in Hindi and English on menstrual hygiene management helping people with visual impairment to understand pubertal changes in their bodies.

## DIGITALIZATION OF BOOK "AS WE GROW UP" – SANITATION AND HYGIENE FUND IN COLLABORATION WITH SAKSHAM TRUST

Electronic and audio version of the book "As we Grow Up" was also developed for people with visual impairment who cannot use Braille. The digital book is available in the digital library created by Saksham Trust.

## NATIONAL FEDERATION OF BLIND – THREE DIMENSIONAL REPRODUCTIVE MODELS

A three-dimensional model of the female reproductive system is used to explain the process of menstruation through touch. Pictures of these models are shown here.



<sup>&</sup>lt;sup>6</sup> Please see annexure for contact details of organizations for resources. Many of these materials are not in the public domain.

#### THE SANITATION AND HYGIENE FUND – TACTILE MENSTRUAL APRON

A tactile menstrual apron allows for persons with disability to understand the position of the female reproductive system and its various organs.

### SAKSHAM TRUST – TAILORED INTERVENTION FOR GIRLS WITH VISUAL AND HEARING IMPAIRMENT

Special educators and caregivers provide information on pubertal changes and reproductive system by leveraging and developing the tactile sense. Sand or clay models to indicate differences in a male and female body.

#### TARSHI - INFOLINE

TARSHI's Interactive Voice Response System (IVRS) could be an important resource for some who cannot read or do not have access to the internet. The Infoline provides callers (both persons with and without disability) with information on a range of topics related to sexual and reproductive health, HIV, contraceptive choices, sexual and gender identities, violence, safety and pleasure in a pre-recorded format. Currently, information is provided in English and Hindi on these topics.

#### HELLO SAHELI, SUKHIBHAVA/UNINHIBITED

Sukhibhava/Unlimited launched the <u>Hello Saheli</u> helpline in 2020 to provide information and support on MHHM. This free helpline service provides interactive voice response menstrual, sexual, and reproductive health education and free tele-gynecological services.

#### <u>SAMARTHYAM - INFOLINE</u>

Samarthyam partnered with CREA to empower women and girls with disabilities to make informed decisions about their bodies and sexuality by providing them information on various issues related to their SRHR through "Kahi Ankahi Baatein".

#### **AAINA – RED TALK, MOBILE BASED APPLICATION**

The Red Talk App developed for the benefit of all looking for information about growing up and menstruation specifically for girls and women with visual and hearing impairment in a pictorial (visual) and storytelling (audio) format that engages the reader in a simple interactive way and can connect key messages well. It was developed for adolescent girls, including girls with disabilities, their parents, care givers, associates and others with interest to understand adolescence with the focus on menstruation, hygiene practices, use and disposal of absorbents, and myths and facts about menstruation.

# 3.6 Additional consideration for IEC and BCC for persons with hearing impairment

- Engage a fluent ISL interpreter when conducting training with those who are well versed with ISL:
  - Train and sensitize the ISL interpreters to the specific MHH needs
  - Situate ISL interpreters in a place with maximum visibility during in-person group sessions
  - Engage two ISL interpreters where possible, especially for long training sessions, to facilitate effective delivery of sessions
  - Provide adequate time for interpretation by the ISL interpreter and communicate slowly
- Use ISL with clear visual/pictorial materials to

- reiterate key messages. Persons with hearing impairment are often adept at understanding visual cues, and assimilate visual information well
- Use poster images of people with hearing impairment using ISL with each other (positioning sign language as a powerful way to communicate needs and solutions)
- Consider using train-the-trainer technique while conducting training, whereby those with hearing impairment conduct sessions or communicate essential information to their peers
- Distribute pictorial pamphlets to give information on MHH. For instance, visual/ pictorial information on different types of menstrual hygiene product available in the market, how to use menstrual hygiene materials hygienically, and appropriate disposal

## Examples from organizations on IEC and BCC for people with hearing impairment and visual impairment<sup>7</sup>

#### NOIDA DEAF SOCIETY – TRAINING OF TRAINERS AND GROUP TRAINING SESSIONS

Noida Deaf Society follows the training of trainers (ToT) technique to deliver MHHM awareness sessions to persons with hearing impairment. The trainings are conducted by persons who have hearing impairment themselves and are fluent in ISL. The trainings have proven to be effective as the trainers are sensitized to and aware of the unique needs and MHHM requirements of people with hearing impairment.

## THE SANITATION HYGIENE FUND – VIDEOS IN INDIAN SIGN LANGUAGE ACCOMPANYING AUDIO CAPTIONS

The Sanitation and Hygiene Fund (formerly WSSCC) in collaboration with Noida Deaf Society developed the "As we Grow Up" book into a video form containing information on pubertal changes and menstrual health and hygiene management in ISL (<u>English</u> and <u>Hindi</u>) with subtitles. A <u>video</u> of people with hearing impairment sharing experience of their first period was also developed.

# 3.7 Additional consideration for IEC and BCC for persons with intellectual impairment

The nature and degree of intellectual impairment will determine the type of IEC and BCC materials developed for use with this group. Attention to the follow can help tailor appropriate interventions:

- Conduct a needs assessment (with parents/ caregivers) to understand which formats the person with intellectual disability responds to and prefers
- Use IEC/BCC materials that contain visual/pictorial elements (with limited or no textual content) keeping in mind persons who have difficulty in comprehension, have little understanding and limited ability to learn new concepts
- Develop individualized training plan (collaboratively with special educators, trainers, and caregivers and persons with intellectual disability) to accompany IEC/BCC materials (further demonstrated in the illustrations)
- Develop experiential and interactive training sessions

- Repeat information frequently and in different formats - visual, audios, songs, experiential, dance
- Develop activities and booklets that the person with intellectual disability and their caregivers can go through together. As an example, the Bishesta campaign developed a story booklet for persons with intellectual disability and their caregivers to "read" together.



Meena Bogati, 22, and her mother Kanchhi Bogati, holding tools from the 'Bishesta' campaign, outisde Banepa Muncipality office, Kavre, Nepal, December 2018.

Photo Credit: WaterAid/Shruti Shrestha

#### Examples from organizations on IEC and BCC for people with intellectual impairment<sup>7</sup>

# LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE & WATERAID UK – BISHESTA CAMPAIGN

Bishesta campaign is an intervention designed to improve understanding of menstrual health and hygiene for people with intellectual disability and their caregivers. The campaign centres around two characters named "Bishesta" and "Prerana" - Nepalese names that mean 'extraordinary' and 'motivation'. The campaign employs experiential learning technique using dolls to explain the basics of menstruation and maintenance of hygiene. The campaign has a strong and prominent visual and tactile component that is used in all materials, including the Bishesta doll. The goal is to help girls with intellectual impairments to identify with the character of the doll. The training guide is available here.



#### AAINA – DEVELOPMENT OF INDIVIDUALIZED PLAN

<u>Aaina</u> in Odisha, works with special educators, persons with intellectual disability and family members to create an individualized MHHM plan. A yearly plan for each child is developed based on the severity of disability, their understanding and learning pace. The development of the plan and training with both PwD and their caregivers starts before the PwD attains menarche. These plans are divided in quarterly and monthly goals to be met. At the end of the plan period, indicators are used to assess whether the PwD is able to fulfil the identified goals, and the support required to meet them. Along with the individual plan, a register is maintained to track the menstrual cycle of girls. Other strategies tried and recommended by Aaina include:

- Repeat trainings on where to get sanitary pads, how to put on the pads, where to change pads and dispose starts, how to put pads on underwear. Training starts before menarche
- How to maintain hygiene (training provided on attaining menarche)
- Training and support to enable girls to communicate needs and experiences (e.g., experiencing discomfort or pain)
- The individualized plan is communicated in detail to the special educator and parents who support the girl. They are taught to track the girl's menstrual cycle, and support her to prepare for menses a week before her menses. They also teach the girls to distinguish between vaginal discharge and menstrual blood

# INDIVIDUALIZED PLAN EMPLOYING PARTICIPATORY METHODOLOGY FOR EMERGENCY PREPAREDNESS (INPUT FROM SAKSHAM)

The city of Oikado in Japan is prone to tsunamis and earthquakes. One intervention worked with persons with intellectual disabilities to develop a manual with step-wise actions to take in response to warning signals for impending disasters. Persons with intellectual disabilities were involved in creating a multimedia textbook called the Daisy Book with solutions suited to their individual needs. These efforts culminated into a Standard Operating Procedure (SOP) to facilitate replication at scale. Training on the SOP was repeated daily to become an integral part of the daily routine for persons with intellectual disabilities.

This approach can be replicated for routine training for MHH, beyond emergencies. An SOP can be developed by identifying expected behaviour (from persons with intellectual disability and their caregivers) during the menstrual cycle, and rehearsed until the drill is becomes a habit. The SOP will identify which steps or processes during the menstrual cycle is being done by whom, and facilitate assignment of responsibilities and completion of tasks (e.g., person in charge of purchasing and stocking sanitary pads). The SOP will also identify locations for specific activities (e.g., place to store and change menstrual materials, where to discard used materials).

## 3.8 Additional consideration for IEC and BCC for persons with physical impairment

- Developing of information in different formats is not necessary for persons with locomotor disability who do not have any additional hearing, visual and/or intellectual impairment. Mainstream IEC/BCC materials should be adapted for use with them, with visual representation that is reflective of their unique needs and mobility constraints (e.g., pictorial representation of a girl with crutches or in a wheelchair accessing a toilet)
- Conduct sessions in an accessible, disabledfriendly location
- Conduct home visits for persons with locomotor impairment who have limited or no mobility

## 3.9 IEC and BCC for home-based caregivers

Home-based care givers require support to provide information to their family members on menstruation and menstrual hygiene. Below are examples of how organizations have facilitated this support:

#### SAMARTHYAM – HOME BASED TRAINING GUIDE FOR CAREGIVERS<sup>7</sup>

Samarthyam has prepared a home-based training manual that engenders positive attitudes towards menstruation. The module proposes the following:

- All female family members including the primary caregivers are provided with home-based training.
  Mothers can demonstrate good menstrual hygiene behaviors. For instance, the mother can place
  a red bindi on the calendar when she starts her menses. She can demonstrate how pads or cloth
  should be used with underwear, and note each time the materials are changed.
- The home-based training manual specifies the role of brother and father, including:
  - Moving the wheelchair near the toilet, or assisting the girl up to the toilet
  - Purchasing sanitary pads from the market
  - Supporting consumption of nutritious food and timely medication (as needed)
  - Supporting health care access (as needed)

#### SANCHAAR, TRAINING OF PWD AND CAREGIVERS

Sanchaar has develop modules for different age groups imparting appropriate information to PwDs. Within their larger Adult Daily Living Training (ADLT), Sanchaar provides age-appropriate information on SRH including good touch and bad touch to PwDs from the age of nine years. Between the ages of 9-13 years, training is conducted with mothers and daughters in the same group. After the PwD turns 13 years, the trainings are conducted separately to address their SRHR comprehensively, and to focus on their overall mental and emotional well-being. At the end of each training session, the trainer leaves the room and provides an opportunity for all PwDs to discuss and ask guestions to each other for 30 minutes.

<sup>&</sup>lt;sup>7</sup> This resource is not yet in the public domain. Samarthyam and UNICEF can be contacted for more information.

## 3.10 Fostering social support for PwDs who experience menstruation

Social stigma and discrimination related to disability and menstruation are prevalent and must be addressed. While this is a very challenging area, potential interventions are:

- Community based MHH campaigns on addressing taboos, breaking the silence to include institutions for PwDs and families of PwDs. For instance, an MH Day campaign in a community can include a component of addressing MHM for all, including persons with disabilities and gender diverse identifies
- Routine MHH outreach activities to reach out of school girls and women who have disabilities, as well as their home-based caregivers
- Training of frontline workers and community mobilizers (who deliver routine MHH interventions) to be sensitive to PwDs and their care givers, and to include them in their outreach efforts
- Engage boys, men, community stakeholders and influencers to counter stereotypes associated with menstruation and disability

#### 3.11 Linkages with SRH services

MHH related education should be linked with SRH information and services, especially since several SRH issues have implications for MHH, including information on issues of bodily autonomy, safe sex and use of contraception, consent, and harmful effects of hysterectomy (that are not medically recommended). MHH may also serve as an entry point to discuss relevant SRH issues with PwDs and their caregivers. Details on how these two issues are linked/can be linked are lacking, and requires concerted action.

# 3.12 Gaps in Information, education, and communication for PwD and their caregivers to be addressed

Key informants highlighted important lacunae to be addressed with regard to MHH education and addressing social norms. First, IEC and BCC resources are often found only with specialized institutions, and select DPOs and NGOs. Comprehensive MHH educational package with adequate detailing for different disabilities does not exist in India. Few, if any resources, exist for girls and women with disabilities who are not a part of formal institutions. Further resources for homebased caregivers are scarce, and training content for institutional caregivers, special educators, and frontline workers on SRH and MHH are limited.

Second, information gaps on certain topics of menstrual health and hygiene management are prevalent. Experts highlighted specific content related gaps to be addressed:

- IEC for PwDs and primary caregivers on premenstrual syndrome, menstrual problems and disorders, and how these can be addressed. For instance, persons with intellectual disability may experience symptoms of PMS in a heightened manner. They tend to become aggressive, withdrawing from their caregivers and people around, stop eating food. Caregivers, hence, must be equipped with information on coping mechanisms required to manage these symptoms
- Persons with intellectual impairments are unable to verbally express their uneasiness and pain. Advice for caregivers to identify signs to understand when the person is experiencing discomfort, distress and menstrual abnormalities
- Information on medical management of menstruation and factors to be considered.
   For instance, families require information on the benefits and risks of hysterectomies performed on adolescents and young women with disabilities, as well as on the use of oral contraceptive pills to regulate menses
- IEC/BCC materials to tackle taboos and myths related to menstruation and disability

Third, the limited resources available may not be shared with other organizations, resulting in constrained access to existing materials, and duplication of efforts by developing new materials. To facilitate wider sharing of resources and to avoid replication of efforts, DPOs and NGOs working at the intersection of disability and MHHM can consider co-developing missing materials and creating or leveraging platforms to access open source materials.



### **ACTION AREA 2:**

Menstrual hygiene products: Implications and solutions

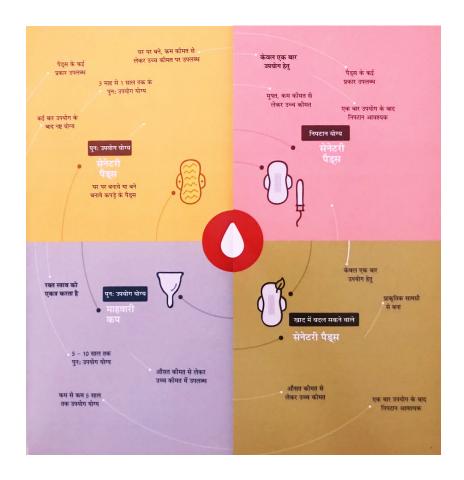
66

There is no one period product that works for everybody (or every body)

Ashe Grey, Disability Rights Activist

## 4.1 Rationale for action area 2

Sanitary pads are the most widely available commercial products in the Indian market. Simultaneously, research and development on menstrual hygiene products have evolved to include a range of disposable and reusable products globally and in India8. Despite this rich landscape of menstrual hygiene materials, popular products such as sanitary pads may not necessarily be available to all PwDs, nor cater to their unique needs for protection. Alternative products such as menstrual underwear, (readymade) reusable cloth pads and menstrual cups are not well known in general, and not promoted for use by PwDs. The menstrual hygiene product needs of PwDs is a strikingly neglected are of intervention.



<sup>&</sup>lt;sup>8</sup> Refer to Annexure II for details on the landscape of menstrual hygiene products in India.

## 4.2 Implications of disability for product access and use

People with physical, visual and intellectual disabilities face a number of constraints while using commercial sanitary pads as well as homemade materials.

Persons with locomotor disabilities: Persons with locomotor disabilities (e.g., paraplegia, cerebral palsy) find sanitary pads uncomfortable. Charlifue et al's study (1992) on women with quadriplegia and paraplegia using wheelchairs (in the United States of America), reported that pads scrunch easily and are not adhesive enough to remain in place. Researchers noted that wheelchair users experienced discomfort due to increased perspiration in the genital area especially during summer months. Further, people with locomotor disabilities had trouble determining the correct positioning of the pads, and when worn incorrectly, complained of extreme irritation, discomfort and leakage. The same study also highlighted that women with spinal cord injuries used more than one sanitary pad at a time for greater protection from leakage and stains (Charlifue et al., 1992). These study findings, while dating back 30 years, continue to resonate as evidenced from discussions with key informants in India, who raised pertinent issues of product appropriateness, comfort, coverage, adhesiveness, and absorptive capacity to meet the needs of PwDs. Key informants further emphasized that caregivers of PwDs requiring extensive physical support faced difficulties in correctly positioning sanitary pads for maximum absorption and leakage prevention. PwDs experienced challenges in regularly changing menstrual materials, and preferred long duration use pads.

Persons with visual impairments: Persons with total visual impairment may struggle to place sanitary pads on the underwear, stick the wings to the underwear, and determine correct positionality of pads for maximum protection. They may also have difficulty in determining the start and end of the period. A study conducted in Turkey with visual impaired women reported that 40.7% shared that they menstruated for between 6-10 days. Researchers concluded that this finding may reflect low awareness of when the period had ended rather than an indication of longer menses (Dündar & Özsoy, 2020).

Persons with intellectual impairments: People with intellectual disabilities find sanitary pads and cloth pads unfamiliar, uncomfortable, and may reject their use. Key informants emphasized that people with intellectual disabilities have increased sensitivity that leads to this discomfort. Thapa and Sivakami's study in New Delhi (2017) found that people with intellectual disabilities could not accept sanitary pads, and caregivers (most often mothers) used positive reinforcements and coercive measures to make them wear sanitary pads. Physical discomfort often manifested in removal and throwing of sanitary pads when alone or in the presence of others (Thapa & Sivakami, 2017; Wilbur et al., 2019). Caregivers felt overwhelmed and exasperated that they had to use forceful methods during every menstrual cycle and for every pad change (Thapa & Sivakami, 2017).

Product preference, convenience and Undermining product use is poor knowledge of product options that may be better suited to meet requirements arising from different disabilities, and how different products may be accessed (IFMSA, 2021). Sanitary pads are the preferred menstrual absorbent (among PwDs and their caregivers) as they are easier to use and dispose. PwDs and caregivers prefer long duration products so that they have to change fewer times during the day. A study with 75 women with disabilities from Karnataka reported that 54.67% used sanitary napkins and 38.67% used cloth pads (Patache et al., 2015). However, sanitary pads are expensive, are not easily available to all those who need them, and may not always be suitable to meet menstrual needs of persons with certain types of disability. In Odisha 59% of caregivers of PwDs wanted their children to use sanitary pads, and were hindered by high expenditure (Aaina, 2015). Although many State Governments (e.g., Rajasthan, Odisha) have provisions for free or subsidized distribution of sanitary pads in schools and in communities via ASHA and anganwadi workers, special schools and families with PwDs are not able to avail of these services.

**Hygienic use of menstrual hygiene materials:** Many people with physical disabilities are dependent on caregivers for daily personal hygiene tasks like bathing, dressing, and menstrual hygiene management (wearing and changing of sanitary pads, and genital cleansing). Menstrual hygiene management tasks are complicated

when social norms related to menstruation are expected to be followed by caregivers and PwDs. A key informant shared that in some homes, caregivers are considered impure when looking after a menstruating family member with a disability. She added that the caregiver needs to bathe and change clothes each time she changes a pad for her menstruating daughter; without this, she cannot undertake other household chores. Beliefs about purity and menstruation and related social norms hinder menstrual hygiene practices - caregivers may change pads for PwDs less frequently than required, and may not wash genitals or assist PwD with genital washing.

The extent of impairment adversely impacts hygiene practices. A study found that persons with complete visual impairment are less likely to follow menstrual hygiene practices compared to persons with partial visual impairment (Dündar & Özsoy; 2020). Lack of hygiene and low frequency of changing pads was also found among persons with intellectual disability, as who have difficulty tracking their menstrual cycle, time (for changing pads), and maintaining hygiene habits. Girls and women with intellectual impairments may use sanitary pads for longer duration and have to be reminded, and at times, coerced by their caregivers to change their sanitary pads (Thapa & Sivakami; 2017).

Market place accessibility of menstrual hygiene products: Persons with total visual impairment, locomotor and intellectual impairments face physical and social hurdles to independently purchase menstrual hygiene products. Many PwD are completely dependent on their caregivers and/or institutions to provide them with menstrual hygiene materials or assist them to markets.

School absenteeism: PwDs miss about an average one week of school during their menses. A key informant from Odisha noted that some girls may miss up to 14 days of school (one week in anticipation of periods and one week of menstruation). In Odisha, a study with 100 girls with disabilities found that 35% of girls enrolled in schools remained absent during menstruation (Aaina, 2015). An important determinant of school absenteeism among PwDs is the absence of assistance required from their caregivers to wear and change sanitary pads, in addition to poor WASH facilities that are inaccessible

for PwDs. Key informants shared that PwDs who menstruate are likely to discontinue education on reaching puberty because of the assistance required from caregivers and partly because parents were unwilling to send their child to school because of fear of sexual abuse and exploitation.

## 4.3 Supporting access to and hygienic use of menstrual hygiene materials

### Key considerations for access to and use of menstrual hygiene materials

Key informants shared practical considerations to improve access to and use of menstrual materials, responding to the unique needs and circumstances of PwDs and their caregivers:

- Disposable sanitary pads are preferred due to easy access and use, and limited knowledge of other products that may be more comfortable or suitable. Some experts suggested that cotton cloth pads (stitched pads with wings) may be used if caregivers and PwDs are taught and supported to use them hygienically. One key informant suggested introducing menstrual cups with PwDs who have the physical capacity to insert and remove cups independently
- PwDs and caregivers should be presented with information on the product range - disposable sanitary pads, reusable cloth pads and menstrual underwear, and menstrual cups. Benefits of each product (by disability) should be discussed. PwDs and caregivers can select the most appropriate product based on such discussions
- Desirable product qualities include longer duration materials that are more absorbent; products with a soft top layer that prevent genital irritation; sturdy products with adequate adhesive or buttons to keep the pads intact on underwear
- Underwear may be modified with added layer(s) for leakage protection or a stitched inner lining to insert the pad (making it difficult for PwD to remove)
- Sessions in institutions and home visits should include demonstration/modelling of how to wear menstrual hygiene materials with underwear for PwD and their caregivers. Home-based and institutional carers need to be trained to uphold the dignity and to respect bodily autonomy of PwD when assisting them to change their menstrual materials and underwear, and washing genitals

## Role of caregivers in supporting access to products and hygienic use

Caregivers play a vital role in ensuring menstrual hygiene for persons with disabilities. Training of caregivers on menstrual products should be conducted before the children with disabilities attain puberty. Caregiver training will incorporate many of the aspects addressed earlier, with additional inputs on the following:

- Importance of hygienic use of appropriate menstrual materials such that dignity of the PwD is maintained
- Supporting PwDs to use the product appropriately, ensuring their privacy and dignity
- Establishing a fixed and convenient storage place for menstrual materials and changing space that is accessible for PwD. Caregivers should consult the PwD to identify the storage space and changing place
- Identifying menstrual irregularities and problems (e.g., tracking menstrual cycle, signs of heavy bleeding)
- Selecting (or assisting the PwD in selecting, as appropriate) the most suitable menstrual material from the range of materials based on PwD needs

- If sanitary pads are used, the quantities to be purchased to enable hygienic use(i.e., changing between 3-6 times a day based on menstrual flow)
- Making good quality, comfortable cloth pads of required quantity, and maintaining these products (thorough washing, sun drying and safe storage). Cloth should be pre-folded or stitched in the appropriate shape and length for ease of use. The carer may place the pad in the underwear before giving it to the girl to use
- Informing girls when her clothes are stained, and assisting her to change. Caregivers can pack an additional set of clothes for the girl to take to school during menstruation. Extra underwear with sanitary pad/cloth pad attached can be sent as well

In institutional settings, administrator, special educators and caregivers need to work together to mainstream attention to MHH in their training plans; maintain and monitor menstrual hygiene product stock, establish an area within the toilet facility for changing materials in privacy, establish waste disposal solutions, and ensure that sanitation facilities are clean and safe to use.

#### Good practices for all types of disabilities<sup>7</sup>

#### **VIDYASAGAR – TRAINING TO DRESS AND UNDRESS**

- 1. Vidyasagar trains parents of children with locomotor disability and severe and profound intellectual disability to dress, undress and change sanitary pads. Parents are taught different positions, postures and movements to facilitate changing of clothes and pads with the least discomfort to the child. Such trainings are conducted with parents when their children are young (before puberty) to build their abilities and confidence. Parents can then adapt the solutions to their specific home contexts.
- 2. Suggestions are given to the caretakers and parents on adaptive clothing during the time of menstruation. Adaptive clothing refers to clothing that is easier to remove, to facilitate easy changing of menstrual products.

## SANCHAAR – INCORPORATING CLOTH PAD USE IN ACTIVITIES OF DAILY LIVING TRAINING

Sanchaar works with girls and women from low-income and marginalized communities, and supports their use of cloth pads. Though activities of daily living training (ADLT), girls and women are trained to fold cloth pads and about the correct placement of pads. Sanchaar does regular home-visits to check the whether the cloth pads are washed thoroughly and dried in direct sunlight, how girls and women are managing their menses, and if they require any additional information or support.

#### **USE OF ADULT DIAPERS**

In many cases of people with locomotor or intellectual disability, caregivers use incontinence materials like adult diapers as they offer more protection than regular sanitary pads (adult diapers are larger, offer greater coverage and absorptive capacity, and stay in place).

## OPEN LEARNING SCHOOL (OLS) – SCHOOL CHILDREN SENT WITH EXTRA SETS OF UNDERWEAR WITH ATTACHED SANITARY PADS

Open Learning School (OLS) requests parents to send 2-3 extra underwear with attached sanitary napkins, and a plastic bag. When assisting the child to change in the institution, the OLS caregiver removes the used pad from the underwear and discards it, and places the used underwear in the plastic bag to be taken home. The caregiver then assists the girl to wear the clean set of underwear and fresh pads sent from home.

#### OPERATIONALIZING INFORMED PRODUCT CHOICE FOR PWDs

Sadhvi Thukral, a post graduate student at the National Institute of Design (NID), Ahmedabad developed the 'Kahani Her Mahine Ki" kit, containing a tactile model and booklet that helps PwDs learn about their bodies and menstruation. The kit also contains information and samples of various kinds of disposable menstrual hygiene products available in the Indian market.

Figure 2: "Kahani har mahine ki" kit; taken from womensweb.in



## 4.4 Orientation and training on menstrual hygiene materials for persons with disabilities

Sessions, trainings, home visits, and individualized plans for PwDs and their caregivers (at home and in institutions) must include information on the following to enable hygiene management of menses:

• Simple steps to track the menstrual cycle, and

prepare for menses (e.g., purchase sanitary pads, wash and dry cloth pads, store products in identified storage space, remind PwD that she will menstruate and what to do, practice wearing pads)

 The types of menstrual hygiene materials available, their benefits and challenges and suitability of each category of material in relation to the specific disability. PwDs to be encouraged

- to interact with sample materials to build their familiarity with the products
- Information on where to purchase or access menstrual hygiene absorbents, and how to purchase them (e.g., using communication cards). Information on Government schemes for free or subsidized distribution to be shared
- Orientation to V-shaped underwear<sup>9</sup> and to wearing sanitary pads and cloth pads with underwear, emphasizing appropriate positioning to ensure absorption and prevent leakage
- Orientation to cloth pads, how to use stitched cloth pads (for those who may use this material), and details on how to wash, dry and store cloth pads hygienically
- Storage of menstrual hygiene materials at home and institutions in a safe, accessible and private place
- Frequency of changing materials, and the need for regular changing by highlighting the discomfort caused by wetness or a pad used for longer duration

- How to clean genitals after changing materials
- Repeat training before each menstruation to remind PwDs on important practices, and to support habit formation
- Development of individualized plans for managing periods, including use, maintenance and disposal of materials

## 4.5 Additional training needs for persons with specific disabilities

#### For persons with visual impairments:

- Correct positioning of the adhesive sanitary pad and wings onto the underwear
- Additional support and hand holding for use of insertion products such as tampons or menstrual cups
- Support to familiarize self with place to change and discard menstrual hygiene materials, particularly in institutional setting and public settings



<sup>&</sup>lt;sup>9</sup> V-shaped underwear give shape to the waist and hold it tight. Due to the V-shape it also makes it easier to insert menstrual hygiene absorbents with wings (like readymade cloth pads and sanitary pads) to be tightly held on either side of the base of underwear.

## Interventions from organizations working with persons with visual impairment are presented here<sup>7</sup>:

#### **SAKSHAM TRUST**

1. Preparing girls with visual impairment to manage menstruation independently at home

At home, girls are assigned fixed storage space for their menstrual materials, and are oriented to the storage space and the surrounding area through touch-based recognition. The storage space should be equipped with underwear, menstrual hygiene materials, newspaper. The changing area should have a dustbin for easy disposal. The allocated storage space and changing place should not be changed without consulting the girl to avoid anxiety when the period starts.

2. Orientation of caregivers and family members

During the orientation session, trainers work with female family members to share solutions to help girls with visual impairment to manage menstruation independently:

- Instructions to not move any menstrual hygiene item or change storage place without consulting the PwD
- Tracking the menstrual cycle of PwD
- Supporting girls to purchase menstrual hygiene materials
- 3. Cue cards with name of product for ease of purchase in markets

For people with visual impairment who are familiar with Braille, a communication card in Braille is made with the name and quantity of menstrual hygiene product to be purchased.

For persons with visual impairment who do not know Braille, a communication card with the name of the sanitary pad brand, quantity needed can be made, to share with shopkeepers at the time of purchase.

These options are most appropriate for persons with visual impairments who are independent and mobile. Those who require assistance and are accompanied by a family or institutional caregiver will not require such communication cards.

4. Training to identify blood stains and time to change menstrual materials

Given that girls with visual impairment may not be able to easily identify blood stained clothes or bedsheets, Saksham counsellors support girls to use the sense of touch to identify if their clothes and underwear have become "kadak" (crisp) as a result of dried blood, and use their sense of smell to identify if their underwear/discharge smells of blood.

## NATIONAL FEDERATION OF BLIND, MAHARASHTRA – MENSTRUAL HYGIENE PRODUCT KIT AND VENDING MACHINES

1. In its training on menstrual health and hygiene, the trainers use a kit containing all types of menstrual hygiene materials that girls touch and gain familiarity with.

Additionally, vending machines are installed to facilitate ease of access at a minimal cost.

- 2. Girls are equipped in the following ways to enable to manage menstruation:
- Use of cue cards with name of menstrual hygiene material (works for persons with visual and speech impairment)
- Allotment of a specific place in the house to store menstrual hygiene materials
- Maintenance of registration by the caregivers and ayahs to track periods
- Using the sense of smell to distinguish between blood discharge and white discharge

#### For persons with intellectual disability:

Depending on severity of the intellectual disability, their level of dependence, cognition capacity, individuals with intellectual disability can be trained and assisted to manage their periods as independently as possible. Their caregivers need training as well, and the intensity of training and support will differ by the nature and extent of support needed by PwDs. Sessions with girls and women with intellectual impairments and their caregivers should incorporate the additional details:

• Identifying when to change pads

- Assisting for genital cleaning with dignity and respect
- Addressing the discomfort caused by sanitary pads (e.g., stitching a soft cotton layer insider the underwear to serve as a pouch within which the pad is placed. This prevents direct contact between the pad and genitals, and may be more comfortable)
- Placing pad in underwear beforehand

Promising practices from organizations working with girls and women with intellectual disabilities are listed here<sup>7</sup>.

#### SAKSHAM TRUST – ENHANCING COMFORT WITH SANITARY PADS

Saksham trains caregivers to make girls wear sanitary pads for 15 days of a month to get them comfortable with the sensation of a sanitary pad. According to them, it takes six months to one year for girls to get used to the feeling of wearing a sanitary. Although time consuming, this experiential process was effective to enhance acceptance of these products.

#### SAMARTHYAM – DEMONSTRATING PAD USE

Samarthyam has proposed home-based training with pre-pubertal girls (prior to their first menstruation) to familiarize them with menstruation, how to use sanitary pads (or other materials of choice) and the expected hygiene behaviors during menstruation.

Samarthyam proposes trainings with mothers and all other female members of the household on mensuration and menstrual hygiene management for female family members who have a disability. Mothers and other female family members are asked to demonstrate or model menstrual hygiene behaviors that are expected from the girl herself. For instance, when mother starts menstruating, she will show her daughter to put red bindi on the calendar to signify the start of periods. She will show her daughter how to place the sanitary pad on the underwear.

Samarthyam emphasizes that demonstrations should be done every month to reinforce the learnings, and make menstrual hygiene practices a habit.

## AAINA – ESTABLISHING AND PRACTICING THE DRILL BEFORE EVERY PERIOD

Family and institutional caregivers are taught to track a girl's menstrual cycle. Based on the cycle, a drill is initiated 3-4 days prior to menstruation, to prepare a girl for the period. During this drill, the girls are asked where she will take the pad from, where she will change the pad, how the pad will be used, and how it will be wrapped and discarded. This process is repeated for each day of the drill until she starts her period. Aaina's experience suggests that this drill fosters independent management of menses.

#### ELHRA - WORKING WITH PWDS IN HUMANITARIAN CONTEXTS

<u>Elhra</u> is working with people with intellectual impairment and their caregivers displaced by natural disasters (in Vanuatu) and the Syrian crisis (in Lebanon). As a part of their innovation and project aims, Elhra is developing menstrual underwear taking into consideration the unique challenges and requirements of people with intellectual disability.

#### For persons with locomotor disabilities

Given the type and severity of locomotor impairment, PwDs and caregivers need additional training on how to dress, undress and use menstrual materials given their mobility constraints. Caregivers of individuals with severe locomotor disabilities must be oriented on the most convenient and safe positions for changing clothes and menstrual materials, while respecting the dignity of the girl or woman, and preventing physical discomfort and pain.

Some persons with locomotor disability may require some additional modification in their menstrual material, as they remain seated or are immobile for longer durations, and experience leakage as a result. To prevent this, modifications to menstrual hygiene materials may include the following:

- Thick pads and/or longer pads with higher absorption capacity
- Firm fitting underwear, underwear with a soft inner pouch, or menstrual underwear (that has additional layers can be considered to prevent leakage)

#### 4.6 Market innovations for menstrual hygiene products

Menstrual underwear: Menstrual underwear by companies such as <u>Soch Green</u>, offer greater

coverage and protection from leakage during menses. These can be used with and without a sanitary pad or cloth pad.

Reusable cloth pads: Stitched reusable cloth pads can be considered, if PwD or their caregivers are able to thoroughly wash, sun dry and safely store such materials. Type of reusable cloth pads can be found at <a href="Soch">Soch</a>, <a href="EcoFemme">EcoFemme</a>, FabPads</a>, and <a href="Uger">Uger</a>. Some pads such as the Uger pad and FabPad designs can be made at home.

Menstrual cup: Some Companies adhere to *universal design*<sup>10</sup> principles to make their menstrual hygiene products inclusive, to meet the needs of diverse users. Keela Cup and Flex have engineered a modified menstrual cup that makes insertion and removal easier for those with physical disabilities that might affect their grip and vaginal reach.

Figure 3: Keela Cup (left) and Flex cup (right)





<sup>&</sup>lt;sup>10</sup> Universal design means "the design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design, and this should include bathroom facilities, shelters and other facilities

## 4.7 Future actions to enhance product access

- Further research is needed to identify comfortable, appropriate and affordable menstrual products for all people with disabilities, particularly for those with locomotor disabilities and intellectual impairments
- Document designs and adaptations of cloth pads and menstrual underwear need to be developed and shared.
- IEC/BCC materials in accessible formats to support thorough washing, drying in sunlight and safe storage of reusable cloth pads, menstrual underwear and menstrual cups
- Government initiatives (at the national and state levels) may consider extending existing free or subsidized supply of sanitary pads to girls and women with disability at home via ASHAs and/ or Anganwadi workers. Such schemes may consider supplying special packs of extra-long pads for girls and women with disabilities, free of cost or at subsidized rates. States such as Bihar have vibrant SHG production of sanitary pads. These SHGs can manufacture extra-long pads or engage in the production of stitched

- cloth pads for girls and women with disabilities
- Leading manufacturers and social enterprises can create a separate line of menstrual materials for those with disabilities in response to specific needs. These companies can work with experts and DPOs to design responsive and inclusive menstrual hygiene products. These materials can then be supplied to institutions working with PwDs, as well as through Government channels
- DPOs and institutions working directly with PwDs can consider establishing and operating sanitary pad and cloth pad manufacturing units.
   Staff and students can be trained to operate the units and sell/distribute the products to PwDs (both who are served by the institution and those who are not)
- Companies manufacturing sanitary pad machines can be consulted on how machines may be adapted to make products to meet the requirements of greater length, absorbency and stability
- Organizations making cloth pads can be engaged to develop training materials and provide training on customizing these materials for use with persons with different disabilities



### **ACTION AREA 3:**

Inclusive and gender-responsive water, sanitation and hygiene (WASH) facilities and disposal

## 5.1 Rationale for responsive WASH facilities and disposal for PwD

Inclusive WASH infrastructure and facilities are integral to realize the rights of PwDs. Both the CRPD, 2006 and the RPwD Act, 2016 stipulate that efforts should enable PwDs to live independently and participate fully in all aspects of life. The CRPD, 2006 also defines accessibility to public facilities, services and information as a human right (CRPD, 2006 Article 9), and the right to clean water services as a component of adequate standard of living (CRPD, 2006 Article 28). Additionally, the Human Rights Council adopted a resolution in 2010 affirming that access to safe drinking water and sanitation is a human right for all people, including those with disabilities. Accessible toilets have a

positive influence on self-esteem among PwD, as well as household and community attitudes towards them(WaterAid, 2008).

PwDs experience substantial barriers to accessing WASH facilities in their homes, institutions and in public spaces; these hurdles are intensified for individuals who experience menstruation. Menstrual hygiene management for PwDs requires WASH facilities in homes, institutions, and in community and public toilets that are responsive to both gender and disability specific considerations. The Swachh Bharat Mission (SBM) (Rural and Urban) envisages equitable and inclusive access to sanitation facilities for all, and has addressed sanitation needs for persons with disabilities, girls/women, and transgender persons during the first phase from 2014-2019. States such as Chhattisgarh



have demonstrated inclusive community sanitation complexes (for women, men and transgender persons), and several schools in Odisha have established inclusive WASH facilities in schools attended by children with disabilities. The need, now, is to widely disseminate inclusive WASH designs, and scale up such efforts to provide access for all those in need.

## 5.2 Implications of lack of responsive WASH facilities for PwD and their caregivers

Lack of privacy and dignity: Specific challenges for PwDs include the lack of autonomy, dignity and privacy when using facilities, contact with unclean surfaces and dirty water, fear of abuse, and increased discomfort (White et al., 2016; Kuper et al., 2018). Closely linked with lack of privacy, many studies note low self-esteem and disrespect experienced by those who are dependent on family members to assist them in using sanitation facilities (Hannan 2005; Tesfu & Magrath 2006; Flowers 2009). PwDs reported feeling uncomfortable and having low morale when they required assistance when urinating, defecating, bathing, and changing and disposing menstrual hygiene materials (Banks et al., 2019).

Impact on physical and mental health: Women and girls with disabilities are at a higher risk of experiencing sexual and physical abuse when using WASH facilities or fetching water, especially at night (Groce et al., 2011). They also have an added risk of contracting urinary tract infections (UTI) (Groce et al., 2011). PwDs who require assistance to use sanitation facilities may limit their food and water intake and wait until evening for a family member to assist them in toileting needs (Groce et al., 2011). Some key informants interviewed for this paper shared that family members may restrict food and fluid consumption for PwDs to delay the need to use a toilet. A key informant also highlighted that due to inaccessible household toilets and the presence of male family members, the female caregiver of a girl with muscular dystrophy let her urinate once a day and defecate once a week by letting her lower body hang from the side of the bed. As a result, the child was sickly with bed sores, and developed skin and urogenital infections. Such actions increase susceptibility to ill health (both physical and mental) and poor quality of life.

**Implications on school attendance:** Studies find that children with disabilities are often prevented from attending schools due to lack of accessible toilets and limited physical support to use toilets (Menya & Safu, 2005; Bah, 2010). This can lead them to miss school days during their periods.

Implications for caregivers: While a functional toilet may exist at home and in institutions, PwDs frequently require physical assistance to use toilet facilities (Mactaggart et al., 2018). Assistive technologies for PwDs are absent, due to high costs associated with these technologies, and lack of information on low-cost assistive technology that can be fashioned for use at home and in schools for PwDs. Limited access to responsive WASH facilities for female PwDs affects their caregivers as well, leaving them limited time to engage in other tasks at home and outside the home (Hannan, 2005; Jones & Reed, 2005; Groce et al., 2011).

**Access barriers:** Physical access barriers to toilets at home, in schools and public spaces include<sup>11</sup>:

- Slippery, rough, steep pathway to toilet
- Unavailability of tactile pathways for persons with visual impairment leading to toilets
- Muddy ground
- Poor or no lighting inside and around toilet/ toilet complex
- High steps leading to toilet (inaccessible steps with excess height of riser, and shorter width of the tread in steps)
- Narrow entrance of toilet
- Narrow toilet cubicle or stall, and insufficient space inside toilet stall (for wheelchair users, people using crutches and walkers, and for those who require additional assistance)
- Distance between the toilet from the home or institution
- Handrails (on ramps, stairs) and grab bars (inside toilet facilities) are either non-existent, or inadequate in terms of height
- Doors are inconvenient to close (too heavy, do not have an accessible handle to operate)

<sup>11</sup> Adapted from The Handbook on Accessible Household Sanitation for Persons with Disabilities (2015) developed by the Ministry of Drinking Water and Sanitation (SBM – Gramin) and Making Sustainable Sanitation Inclusive for people with disabilities developed by Susana (2011)

- Inaccessible water for toilet flushing in the case of pour-flush toilets, and for bathing, washing, and hand washing
- Uneven, slippery, dirty toilet floors

These access barriers are relevant for all persons with disabilities and not specific to those who experience menstruation. These access barriers however intensify challenges faced for menstrual hygiene management, and compromise healthy practices.

#### 5.3 Inclusive, accessible, and genderresponsive sanitation facilities to facilitate safe and dignified menstrual hygiene practices

Access to appropriate assistive technology is critical for disability inclusion. Assistive technology enables persons with disabilities to access critical services, participate equally in the community and live with dignity.

Gopal Mitra, Senior Social Affairs Officer, Executive Office of the Secretary-General, United Nations

This section outlines features of inclusive WASH facilities and gender responsive sanitation facilities are outlined.

## Global and India guidance for disability inclusive sanitation

Global and India specific guidance on inclusive and gender-responsive sanitation facilities exist, and can be operationalized and reinforced to enable all PwDs who menstruate to practice menstrual hygiene at home, in schools and in public spaces in a safe and dignified manner.

The Compendium of Accessible WASH Technologies is a global resource that provides technical and

visual guidance on low cost technologies to make water, sanitation, hygiene, (including bathing and washing) facilities responsive to the needs of persons with disabilities, addressing many of the access barriers listed earlier in this section. The technologies illustrated in the compendium aim to provide as much 'independent access' as possible, enabling PwDs to use WASH facilities independently or with minimal assistance. The solutions in the book are applicable to household settings, though some technologies may be implemented in schools, and community toilets.

The Government of India, under the Swachh Bharat Mission-Grameen, has catalysed action on accessible sanitation for all, with a focus on rural India. This resource, called the Handbook on Accessible Household Sanitation for Persons with Disabilities (2015) (Ministry of Jal Shakti) emphasizes that accessible and inclusive toilets will<sup>12</sup>:

- Address barriers to sanitation, including barriers in reaching the sanitation facility, in entering and getting out of the facility, and in using the facility.
- Ensure safety of users at all times.



<sup>&</sup>lt;sup>12</sup> Source: Adapted from The Handbook on Accessible Household Sanitation for Persons with Disabilities (2015) developed by the Ministry of Drinking Water and Sanitation (SBM – Gramin)

- Ensure privacy of users at all times.
- Ensure dignity of users at all times.

## Features of disability inclusive and gender responsive sanitation facilities

Inclusive sanitation facilities need to respond to disability specific needs. Table 4 highlights these

considerations drawing upon the Government of Chhattisgarh's initiative. The Rajya Swachh Bharat – Chhattisgarh envisages equitable and inclusive access to sanitation facilities for all and developed a handbook for the same (with the understanding that some individuals will have multiple or co-morbid conditions and will have additional requirements).

Table 4: Inclusive toilet considerations by type of disability

Type of disability	Identified difficulties faced in accessing/using toilets	Examples of design considerations/solutions being envisaged
All		<ul> <li>Smooth and barrier free pathways to the toilets</li> <li>Handrail along path for support</li> <li>Ramps with adequate and appropriate gradient, anti-skid flooring, and railing for support</li> <li>Floor made of non-slippery material (consideration for anti-skid flooring)</li> <li>Well-lit area outside the toilet and inside the toilet</li> </ul>
Physical disability/ significant mobility impairments, such as: Cerebral Palsy Locomotor Disability Muscular Dystrophy Multiple Sclerosis Haemophilia Parkinson's disease Thalassemia Dwarfism Sickle cell disease	<ul> <li>Difficulties in maintaining balance</li> <li>Difficulties in squatting, getting up and/or turning</li> <li>Difficulty in finding and/or holding objects such as doorknob, water container etc.</li> <li>Extreme pain in movement</li> </ul>	<ul> <li>Toilet entrance adequate for a wheelchair to enter</li> <li>Toilet cubicle space adequate for a person with a wheelchair, crutches, walker to move and close door comfortably</li> <li>Grab bar at appropriate height inside the toilet cubicle</li> <li>Raised seat</li> <li>Height/level of fixtures adjusted as per requirement to ease access</li> <li>Modifications in the door to ensure privacy and ease of use</li> </ul>
<ul> <li>Total blindness</li> <li>Low vision (partial impairment)</li> </ul>	<ul> <li>Difficulty in finding path</li> <li>Difficulty in maintaining balance</li> <li>Difficulty in finding and/ or holding objects such as doorknob, water container, dustbin.</li> </ul>	Adequate colour/tonal contrast between walls, floor and fixtures
<ul><li>Intellectual disabilities</li><li>Autism spectrum disorders</li></ul>	<ul><li>Sensitivity to sight/smell</li><li>Fear in dark/closed space</li></ul>	<ul> <li>Adequate space and ventilation in toilets</li> <li>Toilet and area outside the toilet well illuminated</li> </ul>

Source: Rajya Swachh Bharat Mission – Gramin, Development of Panchayat and Rural Development, Government of Chhattisgarh

Specific design features for inclusive and gender responsive sanitation facilities in institutions,

community and public toilets are shown in Table 5; gender responsive features are highlighted.

Table 5: Features of disability inclusive and gender responsive sanitation facilities (institutions, community and public toilets)

Features	Essential	Context-specific
Reasonable distance	<ul> <li>Community toilets are close enough to the homes they serve</li> <li>Public toilets are within or close to the intended activity area or users</li> </ul>	<ul> <li>The recommended distance depends on local standards, needs and available resources. For community toilets in India, walking distance is suggested up to 200–350m in India; for public toilets, distances increase up to 1km in India.</li> <li>Layout and terrain need consideration to enable ease of access</li> </ul>
Accessible cubicle	<ul> <li>At least one toilet cubicle in each section (male and female) is accessible for people with disabilities and meets national or international accessibility guidelines, including:</li> <li>A wide, outward-opening door (80 cm is a recommended minimum width), with a railing or rope on the inside to assist with closing the door.</li> <li>Space for a wheelchair to manoeuvre or for an accompanying carer. The recommended minimum cubicle size is 1.5 m wide and 2.2 m deep for the whole length.</li> <li>Raised toilet seat and sturdy handrails designed to support body weight extending the whole inside of the cubicle. A galvanised iron pipe of 25–55 mm in diameter is robust and suitable for heavy use by many users.</li> <li>Large bolt lock which is easier to grip.</li> <li>All features (sink, hooks, means for anal cleansing and mirror) are positioned at a lower height and menstrual hygiene management facilities such as buckets, taps with running water, soap at suitable height and distances.</li> </ul>	Caretakers/attendants are aware of and trained on how to understand and support people with different types of disabilities

Features	Essential	Context-specific
Accessible path	<ul> <li>Path to the toilet block and accessible cubicle is well lit and wide enough, at least 1.2 m and ideally 1.8 m.</li> <li>Path is flat where possible, even, unobstructed and non-slippery Where ramps are used, the gradient should ideally be 1:12 slope ratio (not less). Handrails to support use of ramp</li> </ul>	Tactile paving and/or guiding posts for visually impaired people.
Menstrual hygiene provision	<ul> <li>Accessible shelf for storing of menstrual hygiene products and cut newspapers</li> <li>Dustbin (wide rimmed, and easily accessible)</li> </ul>	<ul> <li>Girls and women with disabilities using toilets must be consulted before installing foot operated or pedal operated dustbins, and dustbins with lids. These features, while allowing for discrete disposal may not be convenient for those with disabilities.</li> </ul>
Female friendly features	<ul> <li>Lighting inside and outside the facilities for night time</li> <li>Separate entrance for female toilets that are clearly labelled. Inclusive toilet facility for females with well-placed signage that can be understood by all</li> <li>Walls and doors made of solid materials. The toilet should be covered with solid materials from all 4 sides</li> <li>All cubicles to have doors and locking measures</li> <li>Mug for genital and anal washing</li> <li>Water availability in/near toilet facilities</li> </ul>	Locking mechanisms to be suitable for PwD, at accessible height and design for ease of use

Source: WaterAid, 2015; Female Friendly Public and Community Toilets, 2018

Annexure 3 presents additional design features, and Annex 4 presents resources for inclusive WASH.

## Illustrations of inclusive toilet designs for LMIC contexts

UNICEF<sup>13</sup> developed an add-on modular component in consultation with PwDs in Angola and Bangladesh that fits into traditional toilets to make them more accessible. These toilet designs can also be used in emergencies by people with or without a disability.

Figure 4: Two toilet on-add modular designs developed by UNICEF



<sup>&</sup>lt;sup>13</sup> For design specification and further information on On-add modular toilets please refer to the <u>UNICEF website</u>.

#### **Orienting PwDs to toilets**

The construction of inclusive facilities must be accompanied by orientations to PwDs and caregivers on toilet access and use, while ensuring privacy and safety, and considering abilities of PwD. Some insightful solutions proposed by key informants are presented here<sup>7</sup>.

#### SAKSHAM TRUST – ORIENTATION TO TOILET FACILITIES

Saksham Trust orients their students to the toilet, focusing on the identification of the commode, water tap, dustbin, jet spray or mug. During the initial months in the institution, an assistant accompanies the children to provide any support. They are also taught to clean the toilet seat rim in a half-circular manner, keeping one hand at the end of the rim for support.

## NATIONAL FEDERATION OF BLIND, PUNE (NFBP) – ASSESSING CLEANLINESS OF TOILETS AND REDUCING RISK OF INFECTION

NFBP instructs girls with visual impairment not to sit on the toilet rim and advises them to assume a squatting position when using public toilets. Girls with visual impairments are also taught to use their olfactory senses to sense if the toilet is dirty.

For the toilets inside the institution, girls and staff are oriented on the placement of the commode, mug, flush, and dustbin. NFBP plans to have one model toilet solely for training girls with visual impairment. The training will help them use toilets comfortably and reduce risks of infections.

#### **VIDYASAGAR - CHANGING STATION**

Vidyasagar has adapted the toilet complex design to meet the support requirements of people who need assistance in changing clothes. A concrete slab is placed inside the toilet complex where the child can be positioned for easy and comfortable removal and changing of clothes and menstrual hygiene materials.

#### **OLS - TIMELY USE OF SANITATION FACILITIES**

In addition to orienting the child to the toilet, OLS support staff are trained and instructed to take children to the toilets at short intervals so they do not restrict their food or liquid intake.

#### 5.4 Menstrual waste disposal for PwD

Considerations to facilitate immediate disposal of menstrual waste by PwDs are presented below<sup>14</sup>:

 Type of dustbin: While foot operated dustbins, dustbins with lids are often preferred to aid discrete disposal of menstrual waste, such solutions may not be convenient for those with disabilities. Girls and women should be consulted to identify the type of dustbins they prefer and will find convenient to use. Key informants suggested that wide rimmed

<sup>&</sup>lt;sup>14</sup> Downstream stream management of menstrual waste calls for larger set of actions beyond the user.

- dustbins be made available in an easily accessible part of the toilet stall, to facilitate easy disposal of used materials. Paper to wrap used materials also needs to be easily accessible, and replenished routinely. Dustbins in institutional settings should be cleaned regularly.
- Placement of dustbin: A dustbin must be available in each toilet cubicle. The height and the placement of dustbin must be in accordance with requirements of people with locomotor impairments and visual impairments. In institutional settings, persons with visual impairments and locomotor impairments must be consulted to identify the most suitable place for dustbins, and the placement should be changed only after further discussion with PwDs.
- Availability of paper to wrap sanitary pads before disposal: Pre-cut old paper (newspaper or old paper) or paper bags made from old newspapers should be kept in a shelf or placed on a nail in the toilet, that can be easily reached. Pictorial and verbal cues to wrap the pad in paper before discarding in dustbin should be placed in the toilet stall (in institutional settings, community and public toilets).

Downstream menstrual waste management solutions such as incinerators, burning pits, and waste disposal pits need to be placed carefully in or near the toilet complex in institutions and public toilets so as to not hinder the movement of PwDs or cause potential harm. Incinerators in schools should be operated by trained caretakers or cleaners, and not by students.

### On ground practices by DPOs (Disabled People's Organization) on menstrual waste solutions<sup>7</sup>

#### SAKSHAM TRUST AND NATIONAL FEDERATION OF BLIND, PUNE

People with visual impairment are consulted and oriented on the placement of dustbins. The placement of the dustbin is not changed without informing the students.

During training with parents, Saksham orients and instructs the parents and family members to not change the position of the dustbin, soap, water facility without informing the PwD.

## WATERAID AND LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINES, BISHESTA CAMPAIGN

To make people with intellectual disability aware of menstrual health and hygiene, Bishesta campaign provided dustbin which is kept near the young woman's bed.

#### **VIDYASAGAR**

The support staff at Vidyasagar ensure waste segregation of solid waste, food waste, and menstrual waste, and its proper collection.

## 5.5 Water for personal hygiene in toilets/toilet facilities

Adequate quantities of clean water are needed to meet basic needs like bathing and defecating, and to meet their menstrual hygiene needs (washing genitals, washing cloth pads and stained clothes). Key considerations for water requirement for menstrual hygiene needs of PwDs are:

 Accessibility of water points: Water (ideally running water) should be available inside the toilet facility. If running water is not available, a bucket (or container) with adequate water needs to be easily accessible within the toilet stall and bathing space.

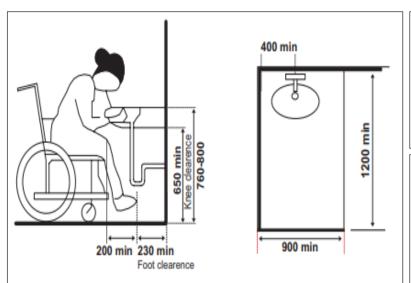
Design and structure of water points<sup>15</sup>: Height, placement and type of water tap in toilets, bathing stall, and handwashing stations should be examined from an accessibility and ease of use perspective. For instance, a person with mobility restriction and/ or a person with limited hand movement will face challenges with a screw top (or traditional washer) tap, and prefer a monobloc or disc tap that can be used easily with push movements. Further, taps must be at a height that can be accessed by persons with locomotor impairments.

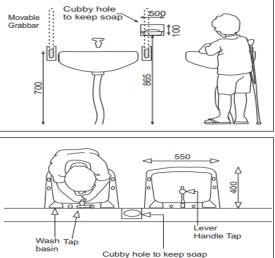
### 5.6 Hygiene and handwashing station consideration for PwD

Samarthyam<sup>16</sup> proposes the following design features for accessible handwashing stations:

- Washbasin should be of dimensions 520 mm and 419 mm, and mounted in a manner that the top edge is between 700mm – 800 mm from the floor
- Washbasin design should provide for knee and toe clearance for wheelchair users of at least 760 mm wide, 200 mm deep, 650 mm-680 mm high
- Installation of lever handle taps
- A cubby hole to keep soap at the height of 865 mm. Ideally, washbasins at two levels are proposed in a toilet, one for people without a disability at normal height and another for people with disabilities (and children)
- The bottom edge of the mirror to be one meter from the floor
- The area space specification will differ if handwashing station is inside the toilet, and if it is outside the toilet<sup>17</sup>

Figure 5: Inclusive hand washing facility for PwDs<sup>16</sup>





<sup>&</sup>lt;sup>15</sup> Source: <u>Practitioners manual</u>: <u>Making Water, Sanitation and Hygiene Accessible and Safe through improved Planning and DesignSamarthyam</u> (2016)

<sup>&</sup>lt;sup>16</sup> Source: <u>Practitioners manual: Making Water, Sanitation and Hygiene Accessible and Safe through improved Planning and Design Samarthyam</u> (2016). These design features are taken from the <u>CPWD Guidelines</u>.

<sup>&</sup>lt;sup>17</sup> For reference to dimensions of a toilet with and without handwashing station for PwD, refer to: The Handbook on Accessible Household Sanitation for Persons with Disabilities (2015) developed by the Ministry of Drinking Water and Sanitation (SBM – Gramin)

# 5.7 Engagement of relevant stakeholders when designing and constructing inclusive and gender-responsive WASH facilities

Gender and disability inclusive WASH facilities should be designed, implemented and scaled with the following considerations<sup>18</sup>:

- Formulate and/or adapt global and national standards for inclusive sanitation facilities, specifying standards for WASH facilities in market places, community and public toilets, and toilets in institutions (schools, Anganwadis, health care facilities, and worksites) and homes
  - Consulting persons with disability, caregivers and DPOs in the process of formulation and adaptation, as well as during construction
  - These stakeholders must be engaged in conducting social audits of these facilities, and in making facility improvement plans
- Provide assistive devices to individuals to enable them to access existing facilities
- Train local masons, civil engineers, district officials, and DPOs in inclusive and genderresponsive sanitation designs, and guidance on how to access materials and equipment (from vendors)
- Train PwDs, home-based and institutional caregivers, DPOs and local Government representatives to conduct accessibility audits

of public, community and institutional toilet complexes to assess their responsiveness to the needs of PwDs, and female PwDs in particular.



<sup>&</sup>lt;sup>18</sup> Adapted from "The Handbook on Accessible Household Sanitation for Persons with Disabilities (2015)" developed by the Ministry of Drinking Water and Sanitation (SBM – Grameen).

6

## Capacity building of stakeholders to address MHH needs of PwDs

Several stakeholders are engaged in working with and supporting PwDs, and require additional capacity building or training to provide MHH specific information, support and care. Organizations and individuals who work on MHH in India may lack understanding of, and experience with PwDs, and require training to expand the scope of their ongoing interventions to be inclusive and responsive to the needs of neglected groups, such as PwDs. Frontline workers who implement Government health and nutrition interventions directly with communities, often require orientation to both MHH and PwDs, and how their specific interventions and outreach services can support PwDs in the communities they serve.

The type and depth of training will differ across groups. For instance, organizations working with PwDs having a nuanced understanding of their needs, may require more inputs on the information and key messages to be communicated to PwDs and their caregivers on MHH, and the menstrual products they can use to provide necessary protection. For organizations working on MHH, training may centre more on creating awareness about MHH needs of PwDs, how their program can reach such individuals and adapt to provide requisite support, and the need to collaborate with DPOs or organizations focusing on PwDs to provide comprehensive support. At the very minimum, capacity building efforts of organizations and frontline workers providing direct



support to communities must include information on the reproductive system, menstruation and the menstrual cycle, menstrual hygiene practices, safe and effective menstrual products, menstrual problems and disorders, and disposal solutions. For those who are implementing MHH interventions with PwDs, in-depth training will be required to support these efforts alongside relevant IEC/BCC materials. The table below outlines the essential training components for relevant stakeholders engaged in outreach and interventions with PwDs and/or on MHH.

Table 6: Essential training components for stakeholders engaged at the community level

Essential training components	PwD focused organizations	MHH focused organizations	Frontline functionaries and healthcare providers	Engineers, masons
The female reproductive system, menstruation and the menstrual cycle				
Menstrual products and their hygienic use and maintenance				
PMS and menstrual problems and disorders				
Gender and social norms, and their effect on menstrual health and hygiene				
Safe and appropriate disposal				
Role of caregivers at home and in institutions in supporting menstrual health and hygiene practices				
Effectively communicating information (on the above) to PwDs and their caregivers				
Consideration for inclusive design of WASH and disposal infrastructure				

7

# **Conclusion and way forward**

Every person who experiences menstruation has the right to menstrual health, irrespective of their gender-identity, abilities and socio-economic status. Persons with disabilities face significant challenges in navigating their daily lives; and those who menstruate face additional hurdles arising from the triple burden of having a disability (or disabilities), being female, and the socio-cultural aspects of Menstrual health interventions in menstruation. India have evolved since 2010 into a comprehensive form that encapsulates information and education, menstrual hygiene product access and hygienic use, and menstrual hygiene responsive WASH facilities. These actions have been bolstered through enabling policies and interventions by Government, development focused organizations and civil society, and the private sector. Given this progress, MHH focused dialogues and interventions must advance to encompass a disability-inclusive and rights-based approach.

This paper outlined the key challenges and constraints faced by PwDs with regard to MHH, and presented simple and potentially scalable solutions, drawing upon the insights from individuals and organizations working closely with persons with varied disabilities across India. Salient areas for action to promote good menstrual health of PwDs include: 1) information, education and communication on menstrual health and hygiene in accessible formats that are appropriate for PwD with differential needs and functioning capacities, and an enabling socio-cultural environment for menstrual health and hygiene; 2) appropriate and safe menstrual absorbents, and hygiene promotion; and 3) responsive and inclusive WASH facilities, including disposal solutions in different settings (home,

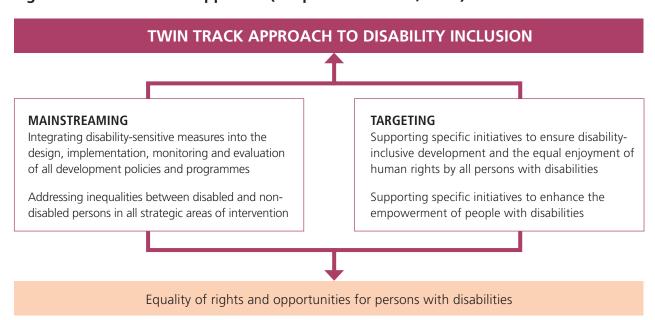


school, place of work). Solutions for PwDs across these domains must recognize the heterogeneity of needs and experiences of persons with different disabilities, and among persons with similar disabilities living in diverse socio-economic contexts. Caregivers, both family caregivers and institutional carers, are vital in disability-focused interventions, and need to be included both as participants and as partners. At their core, interventions for and with PwDs must engender a rights-based approach that highlights the importance of placing the diverse needs and experiences of persons with disabilities at the centre and understanding and responding to them in a respectful and responsive manner.

The United Nations promotes the integration or mainstreaming of disability-inclusive measures into the "design, implementation, monitoring and evaluation of all development policies and programmes" (United Nations Division for Social Policy and Development, Division of Economic and Social Affairs). While integration is the goal, disability-specific policies, programmes and initiatives are often needed to facilitate the inclusion of and participation by PwDs (especially where their inclusion has been lacking). This approach of mainstreaming disability while also undertaking focused or targeted measures to engender inclusion is known as the "twin-track approach" to advancing disabilityinclusive development (Department for International Development, 2000). Mainstreaming and targeted efforts are both driven to actualize the rights and inclusion of persons with disabilities in all aspects of development, to counter discrimination and stigma faced by PwDs in various aspects of their lives.

The twin-track approach is applicable for menstrual health and hygiene management among PwDs, though little is written about how this can be operationalized. Discussions with experts interviewed for this paper suggest that the approach may vary across action areas to improve MHH for PwDs. For instance, the information needs on menstrual health and hygiene may have to be tackled taking a disability-specific approach given that these needs have been overlooked in traditional MHH interventions and require significant format modifications. A disability-specific approach can guide policy makers and program implementers to develop and deliver comprehensive MHH communication packages that are relevant for persons with different and multiple disabilities, tailored to meet their unique needs, and in accessible formats. Access to menstrual hygiene products, on the other hand, may be addressed from a mainstreaming perspective, ensuring that all interventions that facilitate product access (e.g., Government schemes, NGO interventions), include PwDs in their outreach, and menstrual materials are designed to meet these varied needs. Inclusive WASH facilities in households, institutions, public spaces, in both development and humanitarian situations are another area for a disability-inclusive mainstreaming approach.

Figure 6: the Twin Track approach (adapted from DfID, 2000)



The MHH policy and programmatic narrative in India can progress to incorporate a disability-inclusive approach, and simultaneously, implement disability-focused interventions to facilitate responsive and inclusive activities. Such assimilative actions will require additional supportive measures to implement and later to scale. Some short-term and mid-term actions include:

- Analysis of existing MHH policies and interventions to identify opportunities to integrate disability-inclusive strategies, and outline steps to facilitate integration within policy and programs, with appropriate budgetary allocations
- Orientation and capacity enhancement of health, education and WASH sector stakeholders engaged in the planning, delivery, and monitoring of mainstream MHH interventions to incorporate disability-inclusive approaches
- Capacity building of frontline workers directly implementing routine MHH interventions to reach and support PwDs and their caregivers in a responsive and sensitive manner

- Review and adaptation of sector standards for WASH in schools, WASH in anganwadis and WASH in health care facilities to incorporate provisions for gender and disabilities
- Support for collation, sharing, and adaptation of MHH intervention resources relevant for PwD (IEC and BCC materials, support for menstrual hygiene materials and inclusive WASH facilities) across sector stakeholders, and exploration of support for organizations with limited resources to access and use these resources (e.g., open source platforms)
- Identification of platforms to share innovations and solutions more widely, and facilitation of periodic collaborative review of policies, programmatic approaches to incorporate new and promising inclusive approaches
- Incorporation of needs, experiences of PwD in evidence generation and learning around MHH
- Representation of DPOs and agencies working with girls and women with disabilities in MHH related groups (programmatic and advocacy) to ensure representation of their voices and experiences

# 8 Annexures

#### **Annexure 1: Types of disabilities**

As per the Rights of PwDs Act, 2016, a person with disability is defined as "a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders full and effective participation in society equally with others". The following types of disabilities are listed under the act:

- 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. Haemophilia
- 18. Sickle Cell disease
- 19. Multiple Disabilities including deaf blindness
- 20. Acid Attack victim
- 21. Parkinson's disease

#### Annexure 2: Landscape of menstrual hygiene products in India

#### Disposable sanitary pads

The disposable sanitary pad market is estimated to be valued at more than INR 2800 crores, despite the market having shrunk by about 10-12% during 2020 due to COVID-19 pandemic. The Government procurement market is estimated to add another INR 250 crore worth of product procurement. While 85-89% consumer market share is held by the large multi-national companies or MNCs (such as Johnson and Johnson, Procter & Gamble, and Unicharm), there are more than 50 mid-tier manufacturers, as well as many more branded and unbranded resellers who account for the remaining 10-15%. There are over 50 brands of disposable sanitary pads operating at scale and many unbranded products that are being manufactured and sold by small enterprises or sold for rebranding and repacking. Price has been standardized or regularized for the market by the large MNCs. Quality assurance of disposable sanitary pads is of concern. The erstwhile BIS standard for disposable sanitary pads and the revised IS 5405:2019 provide clear quality control requirements for these products. However, only 64% of manufacturers in this study stated that they were aware of the standards and their components and only 36% complied with the revised BIS standards published in 2019. A review of manufacturers on India Mart found that a majority do not provide any information on quality standards for their products.

## Reusable sanitary pads and period panties

Reusable products include fabric-based pads, and menstrual underwear. Innovations exists in types of fabrics used to make pads, placement of layers, chemical and mechanical anti-microbial treatment (by at least three manufacturers in India) and some design innovations like labia pads. Period underwear is also an enhancement of the same product which uses the same materials but is designed as a standalone wearable product with either a belted option or in the form of a traditional underwear.

The reusable sanitary pads market is characterized by approximately 15-18 small to mid-sized players with monthly production in the range of 4000-35,00,000 per month. Most of these players either manufacture their own products or through contract manufacturers for wearable textile products. 88% percent of organizations interviewed manufactured their own product through women's groups or more organized production units. The remaining entities procure their product from a contract manufacturer who also produces for a national underwear brand and have better quality control procedures than others. This allows them to cut production costs in a business characterized by high consumer acquisition costs. Production lead time is typically high (around 3-4 weeks).

Close to 40% of organizations interviewed have a decentralized production model with limited production capacity. In this model, procurement of raw material, first round of quality checks and cutting is done at a central location. Women employees take this material to their homes and stitch the pad. Finally packing and dispatching of finished product takes place at the central facility. 63% percent respondents have a centralized production model with higher production capacities (more than 10 lakh units per month).

The BIS has provided guidance on materials and sizes for both reusable sanitary pads and period underwear through the IS 17514:2021 and UNGM procurement specifications also provide guidance. However, compliance with these standards is low.

#### Menstrual cups

The modern menstrual cup has existed in its current form and shape since the 1930s in the developed world and earlier versions have existed since the 1860s. While the menstrual cup is new to India, the structure and form of the product has not changed considerably. It is a bell-shaped receptacle intended for insertion in the vagina for collecting menstrual blood.

The menstrual cup market in India is characterized by products manufactured locally and imported from contract manufacturers who are equipped to manufacture a molded silicone product, with over 25 brands of menstrual cups retailed in India. Two of seven respondents included in the study have their own menstrual cup brands that are manufactured through contract partners in India, and the rest are imported from China, Australia, US and Europe. While products imported from Europe, Australia and the United States are typically made in ISO 13485 compliant facilities, the same is not necessarily true for those manufactured in India. Little data is available on products imported from China and information is typically sensitive to suppliers and buyers. Some respondents are also re-sellers for international brands in India. Manufacturing processes and raw material grades also vary. Production capacity is in the range of a few lakh units per month with lead

times as low as one week. Production capacity for startups may be lower if they do not have exclusive contracts with their suppliers.

The BIS does not have any standards for menstrual cups and will not be developed until clinical data on the safety of menstrual cups is available from the local context. The US FDA classifies menstrual cups as a class 2 medical device while the European Union classifies them as a personal hygiene device with minimal regulations. Due to variance in classifications and lack of clarity of quality control procedures, different manufacturers meet different specifications.

#### **Product considerations**

Product Category	Disposabl	e pads	Reusable	e pads
	Regular disposable pads	Compostable	Readymade reusable sanitary pads (stitched)	Homemade cloth pads (stitched/ unstitched)
Description	Disposable sanitary pads	Disposable sanitary pads made from natural fibers and bio-plastics that can be composted (decompose into organic matter).	Sanitary pads made of fabric (cotton, micro- fiber, antimicrobial treated) that can be washed, dried, stored and reused during the next menstrual cycle	Sanitary pads made from old clothing
Manufacturer	Proctor & Gamble (Whisper) Johnson & Johnson (Stayfree, Carefree) Niine Whole sale manufactures (non-branded) Small scale and self-help group production (branded and non-branded)	Aakar Innovations (Anandi pad) Saathi Pads	Real Relief (SafePad ) Goonj (MyPads ) Jatan Sansthan (Uger pad) Soch pad  Falalin cloth available in local markets (unbranded)	
Duration of use	Pad must be changed every 3-6 hours	Pad must be changed every 3-6 hours	Pad must be changed every 3-6 hours	Must be changed every 3-6 hours

Product Category	Disposable	e pads	Reusable	e pads
	Regular disposable pads	Compostable	Readymade reusable sanitary pads (stitched)	Homemade cloth pads (stitched/ unstitched)
Life-cycle of the product (Reusable)	One-time use	One-time use	Reusable cloth pad may be used for 12-18 months	Unstitched cloth may last 4-12 months (depending on quality of cloth)
Cost	Several cost variants available. Sanitary pads made available at subsidized rates or given for free through Government schemes	Cost variants available. Some compostable products more expensive than others	Several cost variants exist. Cost partially dependent on the nature of fabric used (e.g., organic cotton) and whether that fabric has been treated in some way (e.g., anti- microbial fabric)	Variation among the products.
Market availability of local manufacturers for procurement	Product varieties available in local (kirana) shops, medical shops, SHGs, schools, anganwadis and health centers	Contact Contac	Limited  Often has to be procured/ purchased directly from manufacturer	High – made from cloth that exists at home
Supportive supplies	<ul><li>Soap for handwashin</li><li>Underwear</li><li>Lidded waste disposate female sanitary facilit</li></ul>	al bins inside the	<ul> <li>Underwear</li> <li>Soap for handwas</li> <li>Laundry detergent</li> <li>Bucket for washing</li> <li>Pegs and ropes</li> <li>Non-transparent st</li> </ul>	g
Supportive environment	<ul> <li>Sanitation facility for</li> <li>Water for washing, behandwashing</li> <li>Demonstration on the</li> </ul>	pathing and	<ul> <li>Sufficient water for sanitary pad, cloth</li> <li>Washing and dryin</li> <li>Solid waste disposs after 12 months</li> <li>Demonstration on and disposal</li> </ul>	es and body ng space al mechanism

Product Category	Disposab	le pads	Reusabl	e pads
	Regular disposable pads	Compostable	Readymade reusable sanitary pads (stitched)	Homemade cloth pads (stitched/ unstitched)
Benefits (general)	<ul> <li>Easier to access</li> <li>Several varieties         exist at different         price points</li> </ul>	• Environment friendly (decomposes within 6-12 months)	<ul> <li>Can be made at he clean, soft cotton</li> <li>Can be designed needs (e.g., longer pads)</li> <li>Several varieties er available cloth pade underwear can be different price point</li> </ul>	cloth to address specific r and/or thicker  xist; commercially ds and menstrual e purchased at
Specific advantages for PwD	<ul> <li>Easy to use and can be discarded after single use</li> <li>Extra-long and more absorbent variations exist (though at higher cost)</li> </ul>		<ul> <li>Can be designed needs of PwDs (exponents)</li> <li>Can be designed needs of PwDs (exponents)</li> <li>Cloth layer story</li> <li>Cloth pads and more and be made at low income families</li> <li>Caregivers (home-institutional carers to make cloth page)</li> </ul>	ctra-long, with eater absorption, itched into odified underwear w cost for lowbased and s) can be trained
Constraints	<ul> <li>Environmental implication of disposable pads</li> <li>Necessitates disposal facilities</li> <li>Can be costly</li> <li>Free distribution may be halted during emergencies, abruptly cutting off access</li> <li>One-time use only</li> <li>Requires frequent re-distribution</li> <li>PwDs may require assistance to discard sanitary pads</li> </ul>	<ul> <li>Necessitates disposal facilities</li> <li>Not widely available</li> <li>Costly</li> <li>One-time use only</li> <li>Requires frequent redistribution</li> </ul>	<ul> <li>Requires water av washing of pads, to wash thorough space to wash and</li> <li>Socio-cultural nor washing and dryir may require assist and dry cloth pad underwear</li> </ul>	soap/detergent ly, and a private d dry materials ms surrounding ng practices PwDs ance to wash

## Annexure 3: Design considerations for accessible sanitation for persons with disabilities<sup>19</sup>

## Technical design adjustment for accessible household toilet design principles<sup>20</sup>

The Handbook on Accessible Household Sanitation

for Persons with Disabilities (2015) has specified household design features for inclusive toilets (Table 6).

Table 7: Features of inclusive household toilets

Design	Specifications <sup>21</sup>	Disability specific requirement
Proximity/location and distance of toilet is safe	<ul> <li>Indoor installations and those attached to houses are easier and safer to reach and preferable</li> <li>It should not be more than 15m from the house</li> </ul>	
Level and marked paths	• Path should be 120-180 cm wide	<ul> <li>For persons with visual impairment - Guideposts with tactile cues to guide from home to toilet</li> <li>For persons with partial visual impairment – guideposts with tactile cues painted in bright colours</li> <li>Suitable for people with physical impairment including wheelchair users</li> </ul>
Ramps or low steps with	<ul> <li>Gradient of the ramp should be 1:12 or more/ maximum 5% of slope so PwDs can reach destination without any assistance from anyone</li> <li>Ramp should be smooth, non-slippery, firm and stable and materials unlikely to wear off quickly. For e.g.: concrete as it prevents the path from becoming slippery and muddy</li> </ul>	Painted it in bright colours to increase visibility for all
Handrails to the path leading up to the entrance of the toilet	<ul> <li>Hand rails should be fixed at least 45mm from the adjacent wall/surface it is fixed</li> <li>Handrails at 70-90 cm height and curbs on both sides</li> <li>Handrails should be circular in section with 40 to 45mm diameter</li> </ul>	<ul> <li>For person with visual impairment - tactile cues on hand rails</li> </ul>

<sup>&</sup>lt;sup>19</sup> Source: <u>Susana</u> (2011)

<sup>&</sup>lt;sup>20</sup> To reduce cost, low materials like bamboo, wood or steel can be used to create hand rails, grab bars, ramps.

<sup>&</sup>lt;sup>21</sup> For detailed floor design and dimensions that have water closet, for wheelchair users, people who crutches refer to the Handbook on Accessible Household Sanitation for Persons with Disabilities (2015) developed by the Ministry of Drinking Water and Sanitation (SBM – Gramin)

Design	Specifications <sup>21</sup>	Disability specific requirement
Wide entrance to toilets	<ul> <li>90cm for persons using wheelchair or any assistance to get inside the latrine</li> <li>Highlight the edge of a step or entrance</li> <li>The threshold of the toilet should have no trip hazard – for e.g.: door seal</li> <li>A level platform or 'landing' with a minimal length of 120 cm is needed in front of the toilet.</li> </ul>	<ul> <li>For a wheelchair user -         entrance area should be flat         so wheelchair users can leave         the chair before entering the         toilet</li> </ul>
Door	<ul> <li>The width of the door should be at least 90cm</li> <li>Door should not be heavy which is hard to open</li> <li>Doors should ideally open outside</li> </ul>	
Door handles locking measures	<ul> <li>Door handle must be fixed outside and inside the door of 150mm for easy grabbing and opening</li> <li>Grab bars instead of door knobs so can be easily opened by a person who uses wheelchairs or has reduced strength</li> <li>Door handles must be fixed 650 to 1100 mm above the floor level</li> <li>Where possible, handles must be lever shaped or D type handles</li> </ul>	• Strings, or door handles should be provided at 650mm to 1100 mm height and 150mm long handle fixed on the outside so that it is accessible to a wheelchair user
Floors <sup>22</sup>	<ul> <li>Should have smooth and easy to clean surfaces for people with mobility impairment and require assistive devices like crutches</li> </ul>	
Spacious enough inside the toilet	<ul> <li>A distance of 450mm to 600mm beside and beyond the leading edge of the door and a safe landing space of 1200mm X 1200mm in front for a wheelchair user to manoeuvre</li> </ul>	
Grab bars inside the toilet	<ul> <li>40 to 45mm in diameter</li> <li>Ideally it should be adjusted on both sides of wall</li> <li>The height should be at 450mm to 750mm</li> </ul>	<ul> <li>For wheelchair users – movable grab bars (U type) to be provided on transfer side</li> </ul>
Commode	<ul> <li>480mm height of commode (or adjustable according to individual requirement)</li> <li>Sitting can be fixed or movable – depending on the individual requirement</li> </ul>	<ul> <li>Movable toilet seats raised Indian commode for persons who have difficulty squatting</li> </ul>
Water	<ul> <li>Water inside the toilet – it can be stored in a bucket or the water can be supplied through tap</li> <li>The water container not be kept on the floor, it must be kept at a height that is convenient for all (adjustable according</li> </ul>	<ul> <li>Visual impaired must be oriented with the placement of water tap or water container (whichever is available in the toilet)</li> </ul>

<sup>&</sup>lt;sup>22</sup> For detailed floor design and dimensions that have water closet, for wheelchair users, people who crutches refer to the Handbook on Accessible Household Sanitation for Persons with Disabilities (2015) developed by the Ministry of Drinking Water and Sanitation (SBM – Gramin)

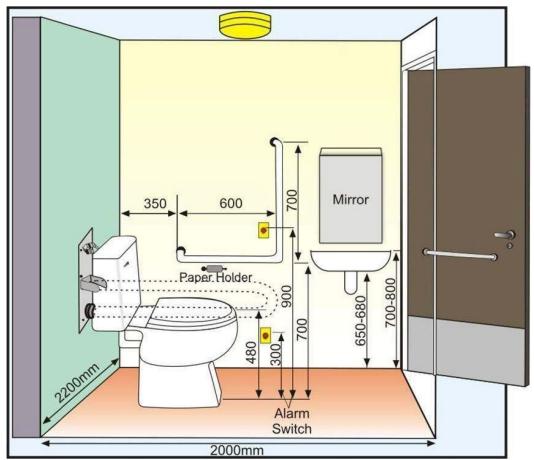
Design	Specifications <sup>21</sup>	Disability specific requirement
	<ul> <li>If water is supplied via tap – screw tap should be replaced with elbow taps, of foot lever on 'tippy taps' for people with weak legs and restricted hand movements</li> </ul>	<ul> <li>Orientation of persons with visual impairment</li> </ul>
Menstrual hygiene provision	<ul> <li>Accessible Shelf (placed at a location and height that is accessible) for storing of menstrual hygiene products and pre-cut newspapers for disposal</li> <li>Dustbin that is accessible. Dustbins should be wide mouthed and kept in a set location</li> <li>Hook at lower level to enable hanging of bags and clothes</li> </ul>	

Source: The Handbook on Accessible Household Sanitation for Persons with Disabilities (2015) developed by the Ministry of Drinking Water and Sanitation (SBM – Gramin)

Samarthyam has proposed a visual design for a toilet stall (with some of the features noted

in Table 6) with appropriate measurements (Figure 7).

Figure 7: Internal layout of accessible toilet<sup>23</sup>



<sup>&</sup>lt;sup>23</sup> Source: Practitioners manual: Making Water, Sanitation and Hygiene Accessible and Safe through improved Planning and Design; Samarthyam (2016)

#### **Annexure 4: Resources**

Theme	Information and education	
Suitability for the type of disability	Organization	Resource link
People with hearing impairment	The Sanitation and Hygiene Fund in collaboration with the Noida Deaf Society  www.noidadeafsociety. org	https://www.youtube.com/watch?v=0uk3wqtcgKs&ab_channel=TheSanitationandHygieneFund  https://youtu.be/hJNRw98ugJl_  https://youtu.be/bW-rl4V8xCU_  https://youtu.be/Ouk3wqtcgKs  For more information, please reach out to:  Ruma Roka: ruma_roka@hotmail.com
All disabilities (existing materials developed by the organization can easily be modified to suit varying needs)	Thoughtshop	https://thoughtshopfoundation.org/project_summaries/ Adolescent.html
People with visual impairment	National Federation of Blind, Maharashtra	https://www.mozaweb.com/Extra-3D_scenes-Female_reproductive_system_intermediate-139737  For more information, please reach out to: Sakina Bedi: <a href="mailto:sakinaiam@gmail.com">sakinaiam@gmail.com</a> Aarti Takawane: <a href="mailto:aarti.takawane@gmail.com">aarti.takawane@gmail.com</a>
People with visual impairment	National Federation of Blind, Maharashtra	PDF version only, not available online

Material can be adapted according to disability	Mangla Godoble, Dr Vaijyanti Khanvilkar	https://halfpricebooks.in/products/vayat-yetana- by-mangala-godbole-dr-vaijayanti-khanvilkar- 1?variant=32205059358773
Material can be adapted according to disability	Dr Smita Dharap	https://www.bookganga.com/eBooks/Books/details/ 5118707027226652788?BookName=%e0%a4%95% e0%a4%b3%e0%a5%80%20%e0%a4%89%e0% a4%ae%e0%a4%b2%e0%a4%a4%e0%a4%be% e0%a4%a8%e0%a4%be
Theme	Menstrual hygiene material:	5
Suitability for the type of disability	Organization	Resource link
All	Aaina	https://aaina.org.in/Resources/Publications/Aaina- viability-low-cost.pdf
		For more information, please reach out to: Sneha Mishra: <u>secretary@aaina.org.in</u>
	Deepshikha Ranchi	https://www.youtube.com/watch?v=uQbY wcHdBk&ab_channel=eiLabs
Theme	WASH and Disposal	
Suitability for		
the type of disability	Organization	Resource link
the type of	Samarthyam, developed for Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment, Government of India	https://enabled.in/wp/wp-content/uploads/2015/11/ WASH-Practitioners-Manual-Samarthy.pdf  For more resources on accessibility standards, design specifications of public WASH facilities: please write to Samarthyam (samarthyamindia@gmail.com)

People with physical disabilities, visual impairment and multiple disabilities	WEDC, WaterAid, and Sanitation and Applied Research for Equity (SHARE)	https://washmatters.wateraid.org/sites/g/files/ jkxoof256/files/Compendium%20of%20accessible%20 WASH%20technologies 3.pdf
Theme	SRHR and gender based violence	
All	UNFPA and Women Enabled International	https://womenenabled.org/wei-unfpa-guidelines.html
Theme	Disability Toolkit	
Suitability for the type of disability	Organization	Resource link
All	WHO – West Pacific Region	https://iris.wpro.who.int/bitstream/hand le/10665.1/14639/9789290618928-eng.pdf
All	Christian Blind Mission & DID	https://www.cbm.org/fileadmin/user_upload/ Publications/CBM-DID-TOOLKIT-accessible.pdf
All	United Nations – Division for Social Policy Development (DSPD), Department of Economic and Social Affairs (DESA)	https://www.un.org/development/desa/dspd/2016/11/ toolkit-on-disability-for-africa-2/
All	Source: International Online resource center on disability and inclusion	https://asksource.info/resources/asia-disability-toolkit
Theme	Advocacy	
All	UNICEF	https://www.unicef.org/media/98881/file/MHH- Disabilities-Guidance-Note-ENG.pdf

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