

Menstrual Health to Ensure No One is Left Behind with Emphasis on Persons with Disabilities

Technical Brief



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The contents were produced by KPMG, led by Anise Gold-Watts, PhD. Technical leadership was provided by UNFPA ESARO mainly Tamisayi Chinhengo, Meron Negussie, Yousuf Alrawi, Maria Bakaroudis, Cleopatra Okumu, Frankline Echerue, Mathias GAKWERERE, Felicia Jones, Isabelle Jost, Willis Odek and Angela Baschieri (PhD). In addition, the Leadership of the Africa Coalition on Menstrual Health (ACMH), Diana Nelson, Halima Lila, Dr. Shela Mogaila Mokgabudi, Jennifer Rubli, Mathato Nkuatsana, Nontsikelelo Manzini-Matebula, Mags Beksinska, Neville Okwaro, Renjini Devaki, Grace Sanday, Mandi Tembo and Sophia Grinvalds have provided technical support in reviewing and ensuring accuracy. The assessment was developed under the auspices of the Safeguard Young People Programme with the generous support of UNFPA, the Global Joint Programme on Ending Child Marriage, the Swiss Agency for Development and Cooperation and the Embassy of the Kingdom of the Netherlands.

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Key messages



- Overall, individuals with disabilities and marginalized populations are frequently overlooked in the development, research, design, execution, surveillance, and monitoring and evaluation of menstrual health policies and programmes.
- Limited evidence and understanding exist regarding the menstrual health situation, resources, strategies, perspectives, concerns, and needs of individuals with disabilities in the African context.
- The evidence base is even more limited with regards to other marginalized groups (e.g. racial and ethnic minorities, women, LGBTQ+ individuals, people with disabilities, indigenous populations, refugees and migrants, religious minorities and individuals from low-income backgrounds) in relation to their menstrual health.
- The research that exists within the African context rarely goes beyond identifying barriers for effective menstrual health of persons with disabilities and their caregivers.
- Persons with disabilities and marginalized groups face multiple layers of discrimination, negative sentiments and stigma, where their status as people who menstruates can exacerbate existing exclusion and discriminatory practices. These experiences are often due to barriers within society faced by persons with disability or marginalized persons (including access to appropriate facilities, products and support). Individuals who possess multiple marginalized identities, such as being a person with a disability, a sexual minority, or residing in a rural area, may encounter heightened levels of exclusion that intersect and compound their marginalization and experiences of human rights violations.

Introduction and background



Globally, 1 billion people (approximately 15 per cent of the global population) experience disability and are, therefore, a focus of the Leave No One Behind agenda (WHO, 2011). Women with disabilities account for almost one-fifth of women worldwide. Globally, over 180 million persons 10 to 24 years of age live with mental, intellectual, physical or sensory disability, and around 80 per cent of them live in low-income countries (UNFPA, 2018).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006) provides a definition of disability in its Article 1: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' The United Nations

convention definition is chosen for the purpose of this brief, while recognizing that other terms such as 'people with disability' or 'disabled people' are often preferred by persons with disabilities themselves (WHO, 2020).

Menstrual health is widely recognized as a human rights issue, and that CRPD calls on states to provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including the area of sexual and reproductive health and population-based public health programmes.

Persons with disabilities have a higher risk of experiencing a wide range of challenges such as exclusion, limited access to quality care and facilities, to education and/or to other opportunities

(WHO, 2011). The layered disadvantages faced by persons with disabilities also causes a higher risk of developing secondary conditions or health problems, which may in turn negatively impact their wellbeing (WHO, 2023). Furthermore, persons with disabilities still encounter barriers of accessibility (e.g. time, distance, affordability and accommodation at sanitation facilities) to menstrual health-related products, information, safety, facilities and services. Persons with disabilities may experience intersectional discrimination and may be more vulnerable to various forms of rights violations due to one or more intersecting factors, including gender, age, economic status, ethnicity, sexual orientation, religion, indigeneity, migration status, race and nationality.

As articulated by Hennegan et al. (2021), menstrual health is defined as 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. It includes the ability to manage menstrual hygiene effectively, access to safe and affordable menstrual products and facilities to dispose of used menstrual materials. Additionally, menstrual health involves access to accurate information and education on menstruation and related topics, as well as the ability to participate fully in all aspects of society, free from the stigma and discrimination associated with menstruation.

Furthermore, people with disabilities often face more social and structural obstacles, which can lead to their exclusion from everyday social and cultural activities.

To explore this and other, interrelated topics with menstrual health, the UNFPA East and Southern Regional Office (ESARO) and the African Coalition for Menstrual Health Management convened menstrual health symposia in May 2021 and May 2023. These symposia have generated a breadth of knowledge about the status of menstrual health in the African context, which have informed the findings and recommendations in this technical brief (UNFPA, 2021;

UNFPA, 2023). During the 2023 symposium, although there was no dedicated session on persons with disabilities or marginalized groups, the importance of inclusive menstrual health programmes, interventions, policies and ensuring access to affordable products of choice for these groups was echoed in multiple sessions (UNFPA, 2023).

Purpose and scope

At the 2023 Africa Menstrual Health Symposium, stakeholders came together to make substantial strides in understanding and planning for comprehensive, multi-sectoral menstrual health interventions of the future. This technical brief provides an up-to-date summary of key evidence related to menstrual health with the main aim of presenting available information on persons with disabilities and other marginalized populations in relation to menstrual health in Africa.

This technical brief also builds upon and serves as an update of key literature on menstrual health focused on the region namely, Siri Tellier and Maria Hyttel's 2018 Menstrual Health Management in East and Southern Africa: Review Paper (Tellier, Hyttel, 2018), the Technical Brief on the Integration of Menstrual Health into Sexual and Reproductive Health and Rights Policies and Programmes (UNFPA ESARO, 2021) and the 2021 Report of the Africa Symposium on Improving Menstrual Health Management (ACMHM, UNFPA, 2021).

Additionally, the brief provides a summary of existing evidence on the topic of menstrual health among persons with disabilities and marginalized groups in Africa, guided by a 'leave no one behind' lens. Placing rights in the centre, and focusing on inclusion of persons with disabilities and marginalized groups, is in line with the Sustainable Development Goals, which are underpinned by the principle of 'leave no one behind' and reaching the furthest behind (UNFPA, 2021).

Methodology

This technical brief presents the findings of a rapid literature review of academic and grey literature using a scoping review methodology, with a focus on the period from 2018 to 2023. To conduct a rapid literature search, search terms were used through relevant websites, databases, or search engines such

as PubMed and Google Scholar. Relevant studies and/or programmes conducted in the African region¹ were included in the search and inclusion/exclusion criteria applied. Information extracted from the rapid review was analysed and grouped thematically and key findings are presented below.

While this methodology has limitations, given the general scope and limited resources, it provides an overview of recent literature, gaps in existing evidence and recommendations for future implementation derived from existing literature. Moreover, the rapid review does not approximate an academic systematic review, or an attempt to assign quality to sources. Additionally, in instances where there was limited literature from African countries, relevant global literature was included. The brief highlights the recent evidence on persons with disabilities with regards to menstrual health

throughout Africa, and aims to provide an overview of the same for other marginalized groups.

This brief can also be read in relation to the technical brief on human rights and gender transformative approaches, which details findings on marginalization and menstrual health through a human rights lens.

For the purpose of this brief, 'marginalized groups' refers to other groups of persons which, as is the case for persons with disabilities, may be hindered from full and effective participation in society on an equal basis with others due to physical, mental, psychological, social, cultural, economic, or other barriers that society creates. Furthermore, the term 'women, girls and people who menstruate' has been used to be inclusive of all individuals who do not identify as female, but still experience menstruation.

Overview of the current evidence



Menstrual health and intersectionality

Findings revealed that limited research has been conducted on persons with disabilities and other marginalized groups and menstruation within the African context. However, among the articles identified, multiple documents highlight the existence of double or layered discrimination faced by persons who are disabled or marginalized, and who also menstruate (Wilbur et al., 2019; Grimes et al., 2023; Moodley et al., 2022). This draws upon the theoretical concept of intersectionality, initially introduced by Crenshaw (1991) in feminist writings, which examines how race and gender intersect to create processes of marginalization and exclusion. Over time, intersectionality has evolved to acknowledge that individuals possess multiple identities that can impact experiences of discrimination, oppression and marginalization. These identities may stem from

various biological, social and cultural categories like gender, ethnicity, socioeconomic status, or disability. Furthermore, intersectionality demonstrates how different forms of oppression, such as racism, sexism, ageism and disability biases, often overlap or intersect.

Intersectionality plays a crucial role in determining how marginalized an individual member of a particular group becomes in society. Experiencing menstruation and the possible stigma that follows, is layered with other experiences of exclusion, as per the socioecological framework, adapted by Wilbur et al. (2019) to persons with disability and menstruation. Taking a 'leave no one behind lens' can provide the analytical tools to assess whether policies, programmes, projects and interventions are inclusive of marginalized groups in all stages, from planning and formulation to analysis of the root causes of problems, to designing interventions, monitoring, providing feedback and lessons learnt, assessing their success.

¹ Countries of relevance included the 54 African countries covered by UNFPA regional offices at the time of review.

In many African societies, menstruation is considered unclean or impure, which can overlap with existing discrimination or stigma related to disability or other experiences of marginalization.

This multifaceted discrimination has by Wilbur et al. (2019) been described as a 'layer' of discrimination, which will 'vary for people with different impairment types.'

Other marginalized groups that face barriers to fully exercising their right to a complete state of menstrual health, include incarcerated persons (in prisons that hold majority women or majority men populations), sexual and gender minorities, such as non-binary persons, gender non-conforming persons, and trans persons, sex workers, persons with mental health and below average intelligence conditions, individuals struggling with addiction, socioeconomically disadvantaged groups, ethnic minorities, persons living in rural and hard to reach areas, single-person households, child-headed families, people living with HIV and other groups that are marginalized due to context-specific structures and norms.

Best practice

Providing training to health workers on the realities of gender and sexual minorities and societal stigmatization they face helps reduce provider stigma and discrimination in health care settings. This in turn improves access to, and the quality of, services for marginalized groups.

(Mwangazi et al., 2023)

External factors that influence persons with disabilities menstrual health: Caregivers

Women, girls and persons with disabilities who menstruate may be hindered from effectively managing their menstruation depending on whether they have either physical, mental, intellectual or sensory impairments. Furthermore, challenges experienced by women, girls and persons with disabilities in managing their menstruation may also be influenced by the views, needs and socioeconomic characteristics of their caregivers, thereby impacting their menstrual health. Expectations of society and carers may range from considering women, girls and persons with disabilities to be asexual and incapable of menstruation, and thus being surprised when menarche occurs, to wishing to suppress menstruation medically, or even going as far as choosing sterilization and hysterectomies for some women, girls and persons with disabilities (Steele & Goldblatt, 2020).

Wilbur et al. (2019) have conducted a systematic review of the literature on women, girls and persons with disabilities and menstrual health. Although the review does not provide exclusive evidence in the African context, it includes articles from Africa as a basis for the conclusions derived. Among the findings, Wilbur et al. (2019) identified that the main concerns of carers of people with intellectual impairments are related to communication about premenstrual symptoms, and that carers report that persons with intellectual impairments can express an aversion to wearing a menstrual product, or go against cultural norms by discussing periods with others or changing products in front of others. This lack of adherence to cultural codes and norms regarding menstruation can in turn lead to the restriction of the person's freedom of movement or freedom of association.

A compounding challenge occurs if the caregivers do not have a close relationship with the woman, girl and person with disability or marginalized person, hindering disclosure of challenges that come with menstrual health due to mistrust and fear. Persons with below average intelligence and those who are bedridden may not have the opportunity to learn selfcare due to lack of national training of home based caregivers who are the first points of contact, especially in rural or hard to reach areas, as a cultural norm or societal requirement, women, girls and menstruating persons

may not achieve efficient care as they live a solitary life in a secluded room or out of public view. The severe practice of shackling people with psychosocial disabilities has been documented by Human Rights Watch as a reoccurring practice in many African countries, which may in turn have a significant impact on the menstrual health of such persons (HRW, 2020).

Lack of training, customized information and general knowledge about menstrual health among persons with disabilities

Wilbur et al. also discusses the level of knowledge about the experiences of persons with intellectual impairments with pre-menstrual symptoms and communication difficulties surrounding these symptoms (2019). Providing adequate menstrual health training and support for people with intellectual impairments, and for carers of women, girls and persons with disabilities that require the assistance of others, is essential for achieving good menstrual health.

There is a need for customized and user-friendly menstrual health information that are presented in a slow pace to ensure accessibility, especially to women, girls and menstruating persons who have no opportunity to access general education. To address this gap, UNFPA has taken an inclusive approach to comprehensive sexuality education, which includes menstrual health education, and is tailored to, among others, out-of-school young people with disabilities (UNFPA, 2020).

Challenges relating to accessibility and user-friendly facilities

A systematic review of the inclusion of disability within efforts to address menstrual health during humanitarian emergencies, found that hygiene kits provided in emergencies were not always appropriate for women, girls and people with disabilities (Wilbur et al., 2022). Although the majority of the emergencies identified in the review were natural hazards in the Asia-Pacific region, these lessons can be translated to the African context. Importantly, Calderón-Villarreal et al. (2022), found that within refugee camps in among others Kenya, Uganda, South Sudan and Zimbabwe, households that included a person with disabilities

had poorer water, sanitation and hygiene (WASH) access than other households. The humanitarian innovation organizations Elrha and CARE have piloted menstrual underwear (period panties)/conventional underwear and menstrual cups in menstrual hygiene kits in refugee settlements in Uganda for women, girls and menstruating persons and their caregivers. As has been pointed to by Wilbur et al. (2022), such piloting should include persons with disabilities that have different types of impairments, and their carers, to provide much-needed information on the comfort and acceptability of different products among different groups.

There are hardly any WASH facilities that meet the needs of women, girls and persons with disabilities or marginalized groups in emergency contexts, especially in rural/hard-to-reach areas.

This leads to compromised safety and potential menstrual health related infections due to lack of sufficient and safe water supply (Tellier et al., 2020).

When WASH facilities are not accessible for people with physical or visual impairments, it can complicate their ability to manage menstruation effectively. A study conducted in a school in Ghana, found that girls that were deaf and hard of hearing cited lack of access to proper sanitary pads as the primary menstrual health challenge (Mprah et al., 2022). Additionally, a recent UNICEF report from Tanzania states that menstruation reduces the academic performance of girls with disabilities through reduced attendance and reduced attentiveness (2021). Another UNICEF study in the Comoros, Eswatini, Kenya, Lesotho, Madagascar, South Sudan, Uganda and Zimbabwe found that “menstrual health and hygiene in WASH programming are contributing to the participation of girls with and without disabilities in education in various countries” (Grimes et al., 2023).

Standards for menstrual health programmes

The UNFPA's 'Guidelines on Disability Inclusion in UNFPA's programmes' provides standards for disability-inclusive programming, which can be adapted to menstrual health programmes. It lays out UNFPA's key principles to ensuring disability inclusion in programmes:

- **Data and evidence:** emphasis is placed on the need for more research, and the need for disaggregating data by disability.
- **Mainstreaming:** making programming disability-inclusive does not require standalone programmes, but mainstreaming disability inclusion into ongoing work through target indicators is a best practice.
- **Participation:** partnership with disabled peoples' organizations, and ensuring meaningful and active participation at all stages of programming is a key for sustainable results.
- **Multi sectoral response:** to create enabling environments to achieve sexual and reproductive health rights of persons with disabilities, it is necessary to engage with different actors including the health sector at multiple levels.

(UNFPA, 2023)



Gaps in the existing evidence



Gaps that were identified throughout the literature review are presented below.

- Although there is a vast amount of literature and research on people living with disabilities in Africa, the intersection of people living with disabilities and marginalized groups and menstrual health in the African context are under-researched. The specific and various menstrual-related needs of persons with disabilities and marginalized groups to improve menstrual health and wellbeing are still not well understood within the African context (Wilbur et al., 2019).
- Menstrual health organizations often lack significant engagement with marginalized and disabled communities, including incarcerated individuals, asylum seekers, and women in uniform, neglecting their unique menstrual and mental health needs.
- Global research is lacking on the training, perspectives, situation and needs of caregivers for people with physical and intellectual disabilities, as well as access to products, especially in relation to comprehensive care and training for menstruating individuals, with even fewer studies conducted in Africa.
- WASH programmes need to heighten integration of customized and user-friendly facilities for person with disabilities and marginalization to build confidence and safety.
- Wilbur et al. (2019) discovered that the preparation stage of reviews on menstrual health of people with disabilities often neglect to consult those affected, and their caregivers' insights are not adequately integrated into related guidelines, policies and strategies.
- In a qualitative review of policy documents and interviews with relevant stakeholders in Kenya, Senegal, among other countries, Alhelou et al. (2022), described an emerging awareness of the intersection of menstrual injustice with marginalization. The review analyses how dynamics of inclusion and exclusion are part of the menstrual health policy sphere. Alhelou et al. (2022) also suggest that policies and advocacy platforms concerning menstruation showed very little, to no attention, towards trans and non-binary individuals who experience menstruation, who were largely overlooked and excluded from the policies, both when policies were being formulated, and in the final documents.
- Qualitative interviews with formerly incarcerated women in South African correctional facilities, have, among others, found that access to sanitary towels or other methods for managing periods is limited in prisons, and that experiences of period poverty while incarcerated are commonplace (Moodley et al., 2022). However, there is little research and knowledge about the menstrual health of incarcerated women and other marginalized groups within the African context. Moodley et al. (2022) highlighted that neglecting menstrual health research and policies for imprisoned women in South Africa could worsen period poverty.

Conclusion and recommendations



Although there was limited documentation on persons with disabilities and marginalized groups and menstrual health in the African context, this technical brief highlights that experiences of marginalization and exclusion are layered and intersectional. Additionally, other challenges experienced by persons with disabilities and marginalized groups relating to accessibility, limited knowledge about menstruation

and the influence of caregivers on menstrual practices and management within the African context were identified. However, the urgent need to address the significant lack of research and integration concerning menstrual health for individuals with disabilities and marginalized groups must be emphasized. Furthermore, it is recommended to:

- Use an adapted socioecological framework for addressing the menstrual health of disabled persons and their caregivers, to address gaps in understanding around the development of standardized measurements of menstrual health-related outcomes for disabled persons and their caregivers, as recommended by Wilbur et al. (2019).
- Conduct further research on whether menstrual products are accessible, available, affordable and acceptable with an explicit focus on persons with disabilities and marginalized groups to develop an in-depth understanding regarding the product needs of these persons (Wilbur et al., 2019).
- Expand efforts to explore the premenstrual syndrome and pain management experiences of persons with disabilities, including consciousness raising and communication on pain and pain management for persons with disabilities who require close care (Wilbur et al., 2019).
- Advance and strengthen interventions that target higher-level stigma within the structural and policy levels in programme and policy efforts, as this in turn can help influence interpersonal stigma and the marginalization experienced by persons with disabilities and marginalized groups (Mwanguzi et al., 2023).
- Engage persons with disabilities, caregivers, and other marginalized groups at the lower levels and NGOs that give service to the groups in the programmatic and policy, design and development processes so they can actively share their expertise, wisdom and insights to tackle their menstrual-related needs that will contribute to more useful and tailored interventions, policies, or guidelines.
- Advocate for the consideration of person with disability and marginalization in national budgets and private sector funding be increased and given specific consideration.
- Further in-depth research studies are necessary, particularly from an intersectional standpoint, in order to gain a comprehensive understanding of country and culture-specific issues related to menstrual health. As part of this initiative, it is crucial to have a fundamental understanding of the assumptions, stigma, and diverse cultural and societal norms faced by girls, women and individuals with disabilities who menstruate. This knowledge should be utilized and encouraged as a starting point for the development of policies.
- For many young persons with disabilities, there is a need for tailored comprehensive sexuality education, which includes learning about menstruation, products available, and learning to manage their menstrual health, or learning about bodily autonomy in relation to menstrual health.
- Inclusion of menstrual health education for young persons with disabilities, through comprehensive sexuality education and/or other standalone initiatives so that they learn about menstruation, products, menstrual health on a personal level.

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